What do we mean by support? The receipt of disability services and compensation for people with a Spinal Cord Injury (SCI) in Victoria.

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Abstract

The provision of support for people with a permanent impairment of spinal cord injury (SCI) in Victoria in recent decades has been characterised by complexity and variation. Up until the late 1970s and mid 1980s, the dominant model of support for any person with a SCI and impairment in the state, and across Australia, was medical intervention. Support was strongly focused on the treatment and correction of any impairment, and where correction of impairment was not achievable, ongoing support needs of an individual were either provided informally by friends and family (while the individual often endured significant levels of social discrimination in terms of physical and attitudinal barriers), or individuals were segregated away from society and placed within an institutional facility. Support within these institutional facilities was characterised by control, poor living standards, enclosure, over-crowding and abuse, and in many cases offered little more than survival.

The development of international theories and political movements, such as the Principles of Normalisation, Social Role Valorisation, the Disability Rights Movement and Independent Living Movements during the 1960s and 1970s however radically transformed understanding about the social positioning of people with impairment, such as individuals with SCI, and how support could be provided. Strongly influenced by these movements, the Victorian government (and Australian Government) set about developing new models of support for people with impairment based on concepts of social inclusion and community-based living. The transition to these new models of support involved wide-scale deinstitutionalisation of people with impairment and the establishment of an in-home, community-based support framework. The transition to these new models of support during the 1970s and 1980s marked a new era in support for all people with impairment in Victoria and Australia. It marked the beginning of the
social advancement of people with impairments in the state and began work on the new goals of full social inclusion and equality for all people with impairment.

The shift towards a community-based model of support for people with a permanent impairment of SCI in Victoria however was particularly complex. The transition from deinstitutionalisation required the state’s Department of Human Services (DHS), the overseeing government department for the provision of disability support in the state, to develop an entirely new policy framework around the model of community-based support. This required the establishment of in-home attendant care service structures, development of related legislation and disability service standards and development of medical and equipment programs. In addition, at a community level, much of the state’s built environment and public transport systems were inaccessible to anyone with a mobility impairment such as SCI. Further, this new model of community-based living needed to address significant community attitudinal discrimination towards people with impairment, in particular in relation to opportunities for education and employment. Significant policy reform and works were thus required before the state could begin to work towards achieving its goal of full social inclusion of all people with impairment.

To add to these complexities, two insurance-based statutory authorities in Victoria - the Victorian Transport Accident Commission (TAC) and the Victorian WorkCover Authority (VWA) had also, since the 1980s, been funding in-home community-based support for people who had acquired any permanent impairment as a result of a transport or workplace accident respectively. As with the DHS, these statutory authorities were still developing structures for the provision of in-home, community based services and equipment programs, however unlike the DHS, the TAC and VWA had already established funding mechanisms for community-based accommodation modifications, medical and allied health services and vehicle modifications. In addition, both the TAC and VWA had established loss-of-earning payment structures to compensate for loss-of-income as a result of acquiring a permanent impairment such as SCI, and opportunity to
claim for compensation through the Common Law where fault could be attributed to how the impairment had been acquired. The TAC and VWA however operated through separate policy and legislative frameworks, and parameters and guidelines around the provision of support, loss-of-income and compensation mechanisms varied for each authority.

Due to these historical developments, individuals in Victoria today that acquire a permanent impairment of SCI are uniquely propelled into this complex framework of contrasting disability service, support and compensation structures. Unlike support for purely medical-based impairments such as multiple sclerosis, spina bifida or cerebral palsy which are funded entirely by DHS, support for individuals acquiring a SCI can be funded by either of the state’s major support funders - the DHS, TAC or VWA - based solely on how their SCI was acquired. As such, the DHS, TAC and VWA all operate as parallel and separate funders of SCI support within the state, each with differing guidelines and parameters. Individuals that acquire a SCI are placed under the jurisdiction of one of these funders based on how they acquired their SCI. Support for individuals that acquire a SCI in Victoria thus uniquely spans the complex framework of disability services available across the state.

The diverse array of disability service and compensation structures now existing in Victoria for people who acquire a SCI thus provides a unique landscape to examine what we mean by support for people with impairment in our community. The provision of a multiplicity of disability services and financial support, all with distinctly differing parameters and limitations and funded by various government or state-based statutory authorities, together allow for a thorough examination of how the concept of support for individuals with SCI, and more broadly people with impairment in Victoria, has evolved since the 1970s. It allows us to examine what constitutes support and how support in a community-based setting is experienced by individuals having acquired a SCI. In a wider context, it allows us to ask ‘what do we mean by support?’.
This qualitative study thus examines the experiences of 11 individuals who have acquired a SCI in Victoria and explores what it means for these individuals to feel supported within this complex funding landscape. I examine what support means for these individuals who have all received some form of state funded disability service and/or compensation support in Victoria from between the mid 1980s (during the initial establishment of community-based disability service framework) through to the recent implementation of Individualised Support Packages (ISPs) during the mid 2000s. In examining a concept of support for these participants and more broadly, all people with impairment in Victoria, I examine firstly the complex policy development of support services in Victoria and Australia - from historical and theoretical viewpoints, including major inquiries and policy formulations, to medical and social movements at national and international levels that have impacted the provision of disability services and compensation in Victoria. Secondly, I discuss the varying attributes of support as defined by individuals with SCI themselves sitting within this complex policy landscape such as attendant care support, equipment support, financial/compensatory support, support from legal frameworks, access to infrastructure and informal support. I examine how participants navigated obtaining and maintaining funded supports, the impact of work-relationships in utilising funded support, the impact of receipt or non-receipt of financial support from compensation, the impact of policy and disability movements on how support was understood and conceptualised and how these factors together impacted on the life-course of these individuals. I suggest that a platform of support for each individual is required at a policy level to address and identify the various aspects of support required, for not just individuals acquiring a SCI, but for all people with impairment in Victoria, to ensure all individuals are adequately supported in seeking to achieve the community goals of social inclusion, quality of life and opportunity to advance individual capabilities.
In this study, I utilised a relativist ontological approach that acknowledged the individual experience and reality of each of the study’s participants, while acknowledging that the study participants to some degree shared similar social realities and common experiences from receipt of support through common structures. I utilised a constructivist epistemology that supported the generation of theory and obtainment of knowledge through inductive approaches, and which supported the subjective viewpoints of each participant experience. The constructivist epistemology allowed for knowledge and concepts to be generated based on effective exploration of the inter-relationships, shared social realities and impacts of service policy structures.

For the study methodology, I drew on Charmaz’s Constructivist Grounded Theory approach, a form of Grounded Theory that furthers the original Grounded Theory approaches of Glaser and Strauss (1967) and Strauss and Corbin (1990). The utilisation of a Constructivist Grounded Theory methodology allowed me to acknowledge pre-existing theories and concepts in relation to the topic, while supporting the construction of new social realities and the creation of knowledge from the interaction with the participants. Drawing on a Constructivist Grounded Theory allowed me to effectively utilise interpretative processes to generate concepts and drive the generation of knowledge. The approach also allowed for flexibility within data collection and analysis processes.

I believe my dual position as a researcher and as a person with SCI myself added depth and insight to the study. I believe it provided opportunity for closer, shared understandings of experiences and was an advantage in gaining insight and understanding about support for people with impairment and specifically support for individuals with acquired SCI.
Declaration

This is to certify that:

(i) the thesis comprises only my original work towards the PhD except where indicated in the Preface,

(ii) due acknowledgement has been made in the text to all other material used,

(iii) the thesis is fewer than 100,000 words in length, exclusive of tables, maps, bibliographies and appendices
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<th>Description</th>
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<tbody>
<tr>
<td>ABS</td>
<td>Australian Bureau of Statistics</td>
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<tr>
<td>A&amp;EP</td>
<td>Aids and Equipments Program (Vic Govt)</td>
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<tr>
<td>AIHW</td>
<td>Australian Institute of Health and Welfare</td>
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<tr>
<td>CAAS</td>
<td>Continence Aids Assistance Scheme (Fed Govt)</td>
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<tr>
<td>CDS</td>
<td>Commonwealth Disability Strategy</td>
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<td>CRS</td>
<td>Commonwealth Rehabilitation Service</td>
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<tr>
<td>CSDA</td>
<td>Commonwealth State Disability Agreement</td>
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<tr>
<td>CSTDA</td>
<td>Commonwealth State Territory Disability Agreement</td>
</tr>
<tr>
<td>CRPD</td>
<td>United Nations Convention of Rights People with Disability</td>
</tr>
<tr>
<td>DDA</td>
<td>Disability Discrimination Act 1992 (Cmwlth)</td>
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<tr>
<td>DHS</td>
<td>Victorian Department of Human Services</td>
</tr>
<tr>
<td>DSA</td>
<td>Victorian Disability Services Act</td>
</tr>
<tr>
<td>DSP</td>
<td>Disability Support Pension (Fed)</td>
</tr>
<tr>
<td>FaHCSIA</td>
<td>Dept of Family, Housing, Community Services and Indigenous Affairs</td>
</tr>
<tr>
<td>HACC</td>
<td>Home and Community Care (Local Govt)</td>
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<tr>
<td>IHAS</td>
<td>In-Home Accommodation Support (Vic Govt)</td>
</tr>
<tr>
<td>HRC</td>
<td>Human Rights Commission (Cmwlth)</td>
</tr>
<tr>
<td>ILM</td>
<td>Independent Living Movement</td>
</tr>
<tr>
<td>IYDP</td>
<td>United Nations of International Year of Disabled Persons</td>
</tr>
<tr>
<td>MAB</td>
<td>Motor Accidents Board</td>
</tr>
<tr>
<td>NDA</td>
<td>National Disability Agreement (Cmwlth)</td>
</tr>
<tr>
<td>RDNS</td>
<td>Royal District Nursing Service</td>
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<tr>
<td>SCI</td>
<td>Spinal Cord Injury</td>
</tr>
<tr>
<td>SRV</td>
<td>Social Role Valorisation</td>
</tr>
<tr>
<td>TAC</td>
<td>Victorian Transport Accident Commission</td>
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<tr>
<td>UDHR</td>
<td>United Nations Universal Declaration of Human Rights</td>
</tr>
<tr>
<td>VEOHRC</td>
<td>Victorian Equal Opportunity and Human Rights Commission</td>
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<tr>
<td>VWA</td>
<td>Victorian WorkCover Authority</td>
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Chapter 1: Introduction

That is one thing with spinal cord injury you can’t escape and the general public can - every decision you make impacts and falls onto you. If you are able bodied and you crap someone off or cut your leg or something like that, at the end of the day, it is not going to matter. But if you have a spinal cord injury, and you do something the carers don’t like, you are going to have trouble with the carers. Same with your body, it will breakdown and you are stuck in bed. I find it a great leveller with decisions you make, it has consequences on your health, your body and everything [David]

Approximately 300-400 people in Australia and 100-120 people in Victoria acquire a spinal cord injury (SCI) each year. At any one time, a population of 9000 people in Australia and 2500 people in Victoria live with a permanent impairment of SCI (Cripps 2006).

The experience of receiving support following a SCI is unique to each individual. Following the acquirement of a serious and permanent injury such as SCI, dramatic changes are often required at a day-to-day level to complete even the most basic living tasks such as showering, dressing, eating, washing one’s teeth or making a cup of tea. Support to complete these and other daily living tasks can vary for each individual depending on their level of injury and function, the level of informal support available, individual agency and the availability of formal disability service allocations available. Support is also often required to modify a home for accessibility, to purchase mobility equipment, to fund the purchase of private accessible vehicles and to purchase required medical/healthcare provisions.

The ability to obtain financial support following the acquirement of a SCI is also a critical factor in relation to wellbeing and the life-course of an individual. The sudden loss of income following the acquirement of a SCI can propel individuals into sudden financial
hardship and create difficulties for family and children dependent on this income, further increasing levels of stress during SCI rehabilitation. Access to welfare benefits such as the Disability Support Pensions (DSP), loss-of-earning payments or claims for compensation are heavily impacted by how the SCI was acquired and the subsequent funding pathway an individual finds themselves on over their life-course. The extent of financial support available can strongly impact on how supported an individual may feel following the acquirement of their SCI and dramatically impact on the life-course of the individual.

Individuals in Victoria today that acquire a permanent impairment of SCI are uniquely propelled into a complex framework of contrasting disability service, support and compensation structures. Unlike support for purely medical-based impairments such as multiple sclerosis, spina bifida or cerebral palsy, which are funded entirely by the Department of Human Services (DHS), support for individuals acquiring a SCI can be funded by either of the state’s major support funders - the Department of Human Services (DHS), the Transport Accident Commission (TAC) or the Victorian WorkCover Authority (VWA) - based solely on how their SCI was acquired. As such, the DHS, TAC and VWA all operate as parallel and separate. Support for individuals that acquire a SCI in Victoria thus uniquely spans a complex framework of disability services available across the state.

Only a handful of studies at international and national levels have sought to examine the experiences of people with SCI in relation to funding of support services. These studies focused on issues around case management, sources of double disadvantage for people living in remote and rural areas, comparisons between paid and unpaid care, and the care-market. Further studies have examined Quality of Life, predictors of life satisfaction, barriers to healthcare, coping strategies, interventions and psychosocial adjustment of people following the acquirement of a SCI. Only one international study (Young et al. 2004) has contrasted people with SCI receiving services from various
funding bodies, while at a local level only Harris (2009) has explored the impact of variously funded medical-health services on a trauma cohort in the state of Victoria.

In this study, I explore the concept of support for individuals acquiring a SCI in Victoria in relation to this complex disability funding framework. I contrast and compare the experiences of individuals acquiring a SCI in Victoria that receive funding for disability support services from three of the major disability funders in the state - the Department of Human Services (DHS), the Transport Accident Commission (TAC) and the Victorian WorkCover Authority (VWA). I examine the structures within each of these funding bodies related to the provision funded disability support services and specifically, the function and role of compensation as support within this complex disability support services framework.

The objectives of the study were:

- to examine the structure of the current disability support service framework in Victoria
- to examine the contrasting experiences of individuals who acquire a spinal cord injury (SCI) in relation to receipt of funded disability support services in Victoria
- to examine the role of compensation for individuals who acquire a spinal cord injury (SCI) in Victoria

In examining this complex disability support services framework and exploring a concept of support for people with impairment, specifically SCI, I firstly introduce each of the study’s participants through use of individual biographies. Chapter two provides a summary of the life-course of each of the 11 participants involved in the study in relation to their SCI. Each participant biography includes events associated with how they acquired their SCI, their level of injury, their previous and current employment status, what each participant has been doing since acquiring their SCI, formal services utilised by each participant and their position in relation to receipt of compensation.
In Chapter three, I begin a detailed document analysis that firstly examines the major international movements and theoretical discourses in relation to social responses to impairment and ‘disability’ in western society during the twentieth century. I examine how each of these movements and theories in their various ways, have influenced the construction of the disability support service framework in Victoria that exists today, and how in turn, these influences have impacted on the day-to-day life of individuals acquiring a SCI in Victoria such as the study participants. I explore the varying theoretical, political and material standpoints of discourses such as the Medical Model, the Principles of Normalisation, Social Role Valorisation and the Social Model. I also explore major international movements that sought to promote social inclusion and reduce impairment-based discrimination of people with impairment such as the Disability Rights Movement and the Independent Living Movement. I then examine more recent discourses associated with impairment and ‘disability’ such as the biomedical critiques of the Social Model and Capability Approaches that seek to further advance the status of people with impairment.

In chapter four, I continue the document analysis and examine the policy development associated with the establishment of the current disability support service framework for people with impairment in Victoria, based on more broader Australian policy development. I examine firstly medicalised social responses to disability at a federal level that dominated policy decisions and models of support for people with disabilities up until the 1970s. I then examine key policy developments beginning in the 1970s, that initiated processes of deinstitutionalisation and supported the development of a model of community-based support for people with impairment, such as individuals acquiring a SCI. This includes the Royal Commission into Human Relationships (1977), the New Directions Report (1985), the Disability Services Act (1986), the Commonwealth State Territory Disability Agreements (CSTDAs) funding agreements and the Disability Discrimination Act (1992).
In chapter five, I examine the specific policy attributes related to the development of the disability support service framework in Victoria. I examine key policy documents and implementation of legislation related to the establishment of the state’s three major disability funders - the Department of Human Services (DHS) the Victorian Transport Accident Commission (TAC) and Victorian WorkCover Authority (VWA), and analyse the role and parameters of each funder in relation to their funding of disability services for people with SCI in Victoria. Following on from this, in chapter six, I examine the policy and legislative development of compensation as a form of support in the state. I examine the historical development of compensation in Victoria through to the use of compensation in the modern legal system and the role of Common Law in seeking to obtain a compensation claim after having acquired a SCI. I explore the particular advantages and disadvantages of the role of the Common Law in claiming compensation, and examine the varying structures in which compensation is administered through within the state, such as automated payment structures and ongoing payment systems.

In chapter seven, I present the study’s methodology. I provide in depth detail of the study design and methodology, including explanation of the study’s ontological and epistemological approaches and Constructivist Grounded Theory analysis approaches. I then discuss strategies that were utilised to ensure the study was methodologically rigourous, and present the ethics review, data collection, recruitment methods, sampling strategies and data management processes.

In chapter eight I discuss participant experiences related to utilisation of funded disability support services and the impact of the disability support service framework based on in-depth interviews conducted with each participant. I explore various themes that emerged during interviews, including knowledge and adequacy of support services, navigation of the support service framework and administrative burden related to
utilisation of support services. Chapter nine continues on with participant experience of work-relationships in relation to utilisation of support services. I explore three key work-relationships identified by participant responses in relation to utilisation of support services: work-relationships between participants and their funders/insurers, work-relationships between participants and their service providers and work-relationships between participants and their attendant carers in the home.

In chapter ten I examine participant understanding and experience of compensation. I utilise three distinct discussion areas to examine receipt of compensation: identification and characterisation of compensation pathways, key themes associated with compensation communicated by participants in receipt of compensation and key themes associated with compensation communicated by participants not in receipt of any compensation.

In chapter eleven of the thesis, the main discussion chapter, I discuss a concept of support in relation to participants, and more broadly, people with impairment across the state. I examine the development of a substantive theory of support specific to people with SCI and examine how participants understand and define support. I examine how participant’s utilisation of various forms of support (including financial support from compensation) helped ensure firstly survival and wellbeing, and secondly, social inclusion and advanced individual capability. I examine the concept of support for all people with impairment as a multifactorial construct, where support can be viewed as both objective and subjective, micro and macro and formal and informal. I then discuss the construct of support as fluid and individualised, and the impact of factors such as knowledge, adequacy, navigation, administrative burden and support service parameters on support. Further, I examine a concept of support through the lens of national and international theoretical movements and discourses on disability and impairment. I examine the conceptualisation of a ‘platform of support’ for people with impairment based on the utilisation of various structures of support, that seeks to incorporate the
array of support required by people with SCI to enable them to live inclusively in the community, such as formal attendant care, financial support, legal support and support from accessible physical infrastructure. I examine how a platform of support could be utilised to examine areas of risk, identify where support may be missing/reduced, where particular support structures may need to be increased, and how a support platform may be utilised to assist in determining which combination of support structures work to maintain social inclusion and wellbeing for people with an impairment of SCI.
Chapter 2 : Participant Biographies

2.1 Introduction

This chapter introduces each of the study participants through the use of individual biographies. The biographies summarise the living situation of each participant in relation to their SCI - their life situation before their SCI, how each participant acquired their SCI injury and the level of bodily motor function remaining following the SCI. The biographies then summarise each participant’s transition home from spinal rehabilitation, the support services utilised once they were home, their situation in relation to compensation, employment status, informal support and lifestyle choices that have been a part of their SCI life-course.

2.2 Participant Biographies

Ben

Ben is a 45 year old man who acquired a SCI as a result of a transport accident in Victoria approximately 9 years ago. No substantial fault to anyone or anything could be attributed to the accident. Ben acquired a SCI at the C6 level, which categorises him as a low level quadriplegic. As this level of injury effects bodily motor function from the mid-chest level down and reduces hand function, Ben requires assistance with most day-to-day living tasks such as personal care, preparing food, home duties and transportation. Although having a high level SCI, Ben has chosen to use a push wheelchair only and thus requires considerable assistance with his mobility.

When Ben acquired his SCI, he was employed full time. He had been in the same field of employment for 15-20 years and was well established in his career. He had completed further tertiary qualifications in relation to his employment area and was actively seeking a career promotion. Ben was married with children when he acquired his SCI and lived in a home he owned in a suburban setting.
Despite acquiring his SCI as a result of a transport accident, costs associated with Ben’s SCI were provided by his employer’s private insurer through the VWA. This was because of a then existing policy structure in Victoria that placed cover for transport accidents occurring during employment hours and while directly engaged in a employment activity under the jurisdiction of VWA and not the TAC as is the present situation. Ben thus received funding provisions associated with his SCI, in full, from his employer’s private insurer through the VWA.

As per the guidelines of the VWA, the day after Ben acquired his SCI, he began receiving fortnightly, ongoing loss-of-earning payments from his employer’s private insurer. These payments supported Ben while he was hospitalised and in spinal rehabilitation. Payments to compensate for his loss-of-earnings were approximately 80% of his previous full time wage. A number of months into his spinal rehabilitation, Ben was notified by the private insurer that they were beginning proceedings to assess compensation for a pain-and-suffering incurred as a result of the SCI.

A private assessment panel established by the private insurer conducted the proceedings associated with the awarding of Ben’s compensation. Ben had no opportunity to be involved in the negotiations related to the awarding of compensation, except for being required to complete a number of medical assessments to substantiate the accuracy of his level of injuries. Ben was not given opportunity to have legal representation, negotiate the compensation settlement amount or make any claim for compensation through Common Law. During this time, Ben continued to receive his ongoing, fortnightly compensation payments for loss-of-earnings.

Approximately eight months after having acquired his SCI, and while still in spinal rehabilitation, Ben received a lump-sum compensation payment from his employer’s private insurer to compensate him for the pain-and-suffering he had endured in relation to acquiring his SCI injury. This payment was in the range of approximately A$150,000 –
250,000 and Ben was not given any opportunity to appeal the amount of the compensation payment he had been awarded.

Before transitioning home from spinal rehabilitation, Ben met with a number of attendant care agencies to begin establishing his home-based attendant care program. He was also involved in discussions with his employers’ private insurer and VWA to determine allocations of funding that would be required for equipment, vehicle modifications and housing modifications.

When Ben returned home from spinal rehabilitation, he and his wife lived in temporary accommodation for a number of months while they continued the construction of their new home (now redesigned with full access modifications funded by the private insurer through VWA). Ben also began utilising a number of support services such as attendant care, gardening, home cleaning and physiotherapy to assist him with his day-to-day living tasks, parenting tasks and in managing his home. These were all funded by his private insurer through VWA. Ben utilised a high allocation of attendant care that included up to 65 hours active hours per week and non-active sleepovers on some nights.

Nine years after his accident, Ben now lives in their redesigned home with his wife. He continues to utilise a substantial amount of support services, including a high allocation of attendant care support hours and gardening services that his private insurer through VWA continue to fund. All equipment utilised by Ben in association with his SCI is funded by VWA, including replacement and servicing of equipment. Ben also continues to receive his ongoing, fortnightly compensation payments for loss-of-earnings. He has not returned to full time employment but is actively involved in community consultations, committees, education and awareness programs and advocacy roles.
Stefan

Stefan is a 59 year old man who acquired a SCI as a result of a transport accident while in South America approximately nine years ago. Stefan was employed as a full time consultant with an international corporation and was involved in a transport accident while undertaking an employment related task. Initially no fault was applied to anyone in relation to the transport accident, however a number of years later, a class action was undertaken by a collective against the manufacturer of the vehicle in relation to a particular type of fault with that vehicle model. Stefan believes this manufacturing fault was the cause of the car accident. As this class action was being conducted overseas however, Stefan chose not to become involved in the action despite the fact that he may have received compensation if he was involved in the class action. Stefan was also married with children at the time he acquired his SCI and in between work-related travel, lived with his family in a home he owned in an inner-suburban setting.

Stefan acquired his SCI at a C4-C5 level, which categorises him as a mid level quadriplegic. As this level of injury effects bodily motor function from the upper-chest level down and reduces all hand function, Stefan needs assistance with virtually all day-to-day living tasks including personal care, preparing food, home duties and transportation. Stefan chooses to use a motorised wheelchair and, once assisted into the chair, is very mobile.

Because Stefan acquired his SCI in a transport accident in an overseas setting, Stefan was not eligible for local transport accident insurance cover. As with Ben, Stefan came under the jurisdiction of his employer’s private insurer through VWA and received funding for support services and equipment associated with his SCI in full from the private insurer through VWA.

Stefan began receiving fortnightly, ongoing loss-of-earning payments from the private insurer immediately after acquiring his SCI, which were 100% of his previous full time
wage. Stefan noted that these payments had been crucial in providing him with income to pay the household bills and support his family during this time. Stefan was then awarded a lump-sum compensation payment for pain-and-suffering from his private insurer, sometime ‘early on’ in the first year or two after having acquired his SCI. No reference was made of being given any opportunity to negotiate his compensation payment, make any claim for compensation through Common Law, negotiate the compensation payment provided or obtain legal representation to settle his claim. No reference was made as to the amount of compensation that was obtained although we can presume from known VWA cases such as these it was substantial (at least $A400,000).

While in spinal rehabilitation, Stefan consulted with a number of attendant care agencies to begin the process of setting-up his home-based attendant care program. He was also involved in discussions with the private insurer and VWA in relation to funding for equipment, vehicle modifications and housing modifications that he would require as a result of having acquired his SCI.

When Stefan returned home from spinal rehabilitation, he and his wife lived in the house they had previously lived in, which had undergone considerable access modifications funded by his private insurer. Ben began utilising an extensive amount of support services funded by the private insurer. These included attendant care, gardening, home cleaning, counselling, occupational therapy, podiatry and physiotherapy to assist him with his day-to-day living tasks, parenting tasks and managing his home. Stefan utilised a high allocation of attendant care - up to sixteen hours per day of active attendant care hours plus an eight hour non-active sleepover each night. Stefan and his private insurer also jointly purchased a new van, with the vehicle modifications funded by the private insurer.
Nine years after his accident, Stefan lives in the same home with his wife and children. He still utilises an extensive level of support services that continue to be funded by the private insurer. His private insurer also funds the replacement and servicing of any equipment Stefan requires associated with his SCI.

Stefan continues to receive ongoing, fortnightly compensation payments from the private insurer for loss-of-earnings, however the amount of payment was reduced a number of years after having acquired his SCI to just on 50% of his then full time wage. Stefan has not returned to full time employment, but is involved in completing further qualifications to return to employment as a consultant in his area of a speciality.

Jim

Jim is a 44 year old man who acquired a SCI as a result of a transport accident in Victoria approximately four years ago. Fault for the transport accident was attributed to another driver. Jim acquired his SCI at a T10 level, which categorises him as a mid level paraplegic. This level of injury affects the motor function of the legs and lower trunk only, and he retained full function of his arms, hands and upper body. Jim is independent with virtually all day-to-day tasks, such as personal care, preparing food and driving, and is fully mobile in a push wheelchair. Jim requires only a minimal level of attendant carer and gardening services for assistance with heavier lifting tasks or where there is reduced wheelchair access in completing a task.

When Jim acquired his SCI, he had just completed a professional business employment role and was in the development and start-up phase of his own business venture. His employment career had spanned 20 years and had included a variety of full time, high level professional business roles. Jim described himself as a highly motivated career person who was actively involved in seeking to improve his professional status. He described his pre-SCI life as being lived to the full with various work roles, committee
roles and travel. Jim was married with children at the time he acquired his SCI, and lived in a home he owned in an inner-suburban setting.

Although Jim acquired his SCI as a result of a transport accident in the state, he was not able to obtain any fortnightly, ongoing compensation payments for loss-of-earnings of significance from TAC as he was not technically fully employed when he acquired his SCI. Jim did however have a private life-and-disability income protection insurance policy, and he was therefore qualified to receive fortnightly, ongoing loss-of-earnings payments through this income-protection policy. Jim was able to receive these payments for nearly 4 years after his SCI, which provided crucial income for him to cover living expenses and household bills.

While still in spinal rehabilitation, Jim obtained legal representation and advice associated with initiating a Common Law claim for compensation against TAC for anticipated loss-of-career earnings and pain-and-suffering. Jim was also involved in negotiations with the TAC in obtaining funding for equipment, vehicle modifications and housing modifications now required as a result of having acquired his SCI.

Jim returned home from spinal rehabilitation after ten months. He lived with his wife and children in the house they had previously lived in, which had since undergone renovations to improve access. These modifications were fully funded by the TAC. Jim initially began utilising only a very moderate level of support services. This included only 2 to 3 hours of attendant care, physiotherapy, counselling, gardening and home cleaning support services. Jim returned to part time employment during this time, but noted that the minimal amount of fortnightly loss-of-earnings payments he was receiving from the TAC were then reduced because of his employment earnings capabilities.

Approximately a year and a half after he acquired his SCI, Jim and his legal team began formal proceedings in claiming for compensation through the Common Law system. In
line with state policy, any Common Law claim for compensation from a transport accident in the state is made against the TAC. In this sense, Jim [or any TAC client making a Common Law claim] was receiving services funded by TAC while taking on legal action against the TAC in claiming for compensation.

Jim described his claim for compensation as involving numerous legal meetings and negotiations which he described as a ‘legal dance’. He recalled being extensively involved in the pre-court negotiations, which included him attending meetings, presenting details of his claim and contributing to negotiation processes. Jim also recalled having to attend five or six medical assessments as a part of the Common Law proceedings, to substantiate the accuracy of his level of injuries for the courts. Jim described these medical assessments as very legalistic in style and recalled that he had been very uncomfortable with the testing and probing aspects of the assessments.

After a further year and a half of negotiations, Jim’s claim for compensation through Common Law was settled out of court just before court proceedings were due to begin. Jim described the final meeting of negotiations as being particularly adversarial, with the barristers in attendance contesting many of the claim details. He recalled that at that time, he had been preparing himself to go on the stand and defend his claim if needed and continue on with the court proceedings if the specific amount of compensation he had been seeking was not reached in these negotiations. Jim received a considerably large compensation payment, which included the maximum amount available for pain-and-suffering (approximately A$300,000) and a considerable loss-of-earnings payment (approximately A$600,000). Jim’s fortnightly, ongoing loss-of-earning payments from his private income insurance ceased soon after his claim for compensation had been settled. Overall, Jim’s claim for compensation took just on three years from when he acquired his SCI.
Four years after his accident, Jim now lives in the same home and is continuing with his parenting role. Financially, Jim is fully independent from the TAC and manages his own financial portfolio. Over the four years Jim has gradually reduced his utilisation of support services and now only utilises physiotherapy, home cleaning and gardening services. Jim continues to be employed in a part time capacity and is involved in voluntary work.

**Lawrie**

Lawrie is a 60 year old man who acquired a SCI as a result of a mining accident in the state of New South Wales approximately 25 years ago. The mining company or Lawrie did not specifically attribute fault for the mining accident to any adverse circumstances, however the assignment of fault was later heavily contested in the courts. Lawrie acquired his SCI at a T12 - L1 level, which categorises him as a mid level paraplegic. This level of injury affects the motor function of the legs only, with no effect on upper body function and he thus retained full function of both his arms and hands. Lawrie is independent in conducting virtually all day-to-day tasks such as personal care, preparing food and driving, and is fully mobile in a push wheelchair.

When Lawrie acquired his SCI, he was working full time as a miner. He had previously worked with a number of mining organizations, both in New South Wales and interstate, and had once moved states in seeking to find higher paid work. Lawrie was living in a regional centre near the mining site, in a rented house, at the time he acquired his SCI. Lawrie was single at the time of the accident.

As Lawrie acquired his SCI as a result of a mining accident in New South Wales, he received fortnightly, ongoing loss-of-earnings payments through his employer’s private insurer of 80% of his previous full time wage. Lawrie noted that these compensation payments however were not a true indication of his wage earnings, as the amount he was receiving was calculated on his base wage only and did not include the high-earning
bonus ‘peak work’ payments for overtime and heavier work rates (which is generally 25% higher than the base award earnings). Lawrie thus viewed his loss-of-earnings compensation payments as not a true representation of his earning capacity as a miner at the time he acquired his SCI. He did note that the ongoing loss-of-earning payments had provided him with needed income for living expenses and accommodation costs at the time.

While still in spinal rehabilitation, Lawrie obtained legal representation and received legal advice associated with initiating a Common Law claim for compensation for anticipated career loss-of-earnings and pain-and-suffering. Lawrie was also involved in negotiations with the private insurer in obtaining funding for his wheelchair, related equipment, vehicle and housing modifications that were required.

Lawrie completed his spinal rehabilitation after 5 months. When seeking to transition from spinal rehabilitation back into the community, Lawrie recalled there had been considerable difficulties in finding accessible accommodation to rent. After considerable effort he had been able to find a unit within his rental price range where the owner had agreed that minor access modifications could be completed. Once settled in his new accommodation, Lawrie was mostly independent and began utilising only a very minimal level of support services, such as visits from the community spinal nurse and home cleaning once a week.

Lawrie returned very briefly to employment at the mine in an administrative role, however he soon enrolled in a course at a local technical college in a related business area and then transferred into a University degree. He completed his University degree 4 years after having acquired his SCI. While studying, Lawrie continued to receive fortnightly, ongoing loss-of-earnings payments from his private insurer.
A short time after transitioning to his rented accommodation, formal proceedings to claim for compensation through Common Law were initiated by Lawrie’s legal team. Lawrie noted the legal action overall was quite an extended process. Difficulties with legal representation resulted in him utilising three sets of legal teams over the duration of the claim. In one instance, he had been unsatisfied with the legal team’s approach to his claim, and in another, had felt that he had not been advised adequately in relation to negotiating a settlement. Lawrie described having been satisfied with the representation from his third legal team, which he felt had represented him successfully in the courts and in later reaching a settlement.

Following extended negotiations, the court case to resolve Lawrie’s claim for compensation began 6 years after he had acquired his SCI. Ten days were set aside by the courts to resolve the claim, however the claim was settled in the courts before the full 10 days were required. Lawrie’s recollection of the court case was that he felt very overwhelmed and intimidated being in the courts surrounded by barristers and undergoing examinations. Lawrie recalled that the court case had been very adversarial, contested and stressful, and that once the predetermined amount of compensation he had been seeking had been offered, he had ‘taken the money and ran’. Lawrie noted that there was no breakdown in the settlement amount between compensation for loss-of-earnings or for pain-and-suffering (as the case had been settled not awarded) and this seemed to be of some issue to Lawrie in terms of expected entitlement. The settlement amount Lawrie received was not disclosed, but it could be readily assumed that in the least, it was in medium to high hundreds of thousands of dollar. Lawrie’s fortnightly ongoing loss-of-earning payments ceased once the compensation claim had been settled.

Lawrie also recalled that at the time of the legal proceedings, he was unsure as to whether he was liable for legal costs of the claim for compensation if the case was
unsuccessful, and that he was unsure as to if he would have access to government funded services associated with his SCI if a settlement of the claim was made.

After the compensation settlement had been reached and as a result of his University degree, Lawrie obtained full time employment with a large private corporation. This employment required him to move to Victoria where he has lived since then. During this time, Lawrie married and had children, and moved into a home that they had purchased. They privately paid for the extensive access modifications required to make the house fully accessible for him. Lawrie has remained in the same house and been employed full time with the same corporation for the last 20 years.

Twenty five years after his accident, Lawrie is still employed and married and is continuing with his parenting role. Financially, he is fully independent with income received from his full time employment and compensation interest. In terms of support services, Lawrie began receiving home cleaning services funded through the local council for a short period of time, but after experiencing staffing difficulties, now privately funds his own house cleaning. Lawrie also noted that on many occasions he has privately funded the purchase of his own equipment and medical procedures to avoid dealing with waiting lists and the restricted parameters of the DHS equipment program. Despite a minimal level of usage of services, Lawrie is still somewhat unsure now as to what services he may be eligible for through DHS. In hindsight, Lawrie views himself as not having received a ‘proper’ settlement because his claim for compensation was settled and was not allocated by the courts per se.

Annie

Annie is a 57 year old lady who acquired a SCI as a result of a transport accident in Victoria approximately 23 years ago. Fault for the transport accident was attributed to Annie as, while driving the vehicle, she lost concentration and crashed the vehicle. Annie communicated that the passengers travelling in the vehicle at the time of the accident
'all got out okay’ so she was happy about that. Annie acquired her SCI at a C6-C7 complete level, which categorises her as a mid level quadriplegic. As this level of injury affects bodily motor function from the mid-chest level down and reduces hand function, Annie needs assistance with most day-to-day living tasks including personal care, preparing food, home duties and transportation. Annie chooses to use a semi-motorised wheelchair, and with this level of function, requires only some assistance with mobility.

When Annie acquired her SCI, she had been working full time as a trained therapy support worker, and had worked both in Australia and overseas. Due to a number of immediate family issues, Annie had stopped working in this field and was working part-time in a non-related area at the time of her accident. Annie had also been married and had a young child, and was living in a rented apartment on the second level of an apartment block in a large regional town at the time she acquired her SCI.

As Annie acquired her SCI as a result of a transport accident in Victoria in the early 1980s, she initially received funding for services from the Victorian Motor Accident Board (MAB) but was then transferred onto the TAC system in 1986 when the TAC was commissioned. During her spinal rehabilitation, Annie was involved in extensive consultation with MAB about setting-up an attendant care program for when she returned home, and in obtaining funding for her wheelchair and required equipment.

Annie was not entitled to a large compensation payment because of the level of fault contributed to how she had acquired her SCI. Annie also noted that she would have been nervous about financially managing a large compensation payment and was glad she just had the reliable ‘support’ rather than ‘compensation’. The automated compensation Annie was awarded by the MAB was approximately A$25,000 (calculated as loss-of-earnings for one full year of employment). The compensation payment she received was fully automated, and she noted that she did not have to fight to obtain it and she was not given any opportunity to negotiate or appeal the amount. Annie qualified for the
Disability Support Pension (DSP) and began receiving fortnightly income pension payments that paid for living and household expenses.

Annie completed her spinal rehabilitation after 10 months. In transitioning home, her previous second floor apartment was not accessible so Annie was keen to purchase a new, accessible home that she would live in with her daughter with the assistance of attendant carers. She recalled that she would not even consider the option of institutional care when it was presented at the time. After a lengthy search, Annie found a suitable home close to her daughter’s school, and with some financial assistance from her father and with funds from her compensation payment, was able to purchase this house. The MAB then paid for the access modifications required to make the house accessible, and while the new accommodation was being purchased and fitted-out, Annie was able to rent an accessible unit attached to the spinal rehabilitation unit.

When Annie moved into her new home, she began utilising a number of services funded by the MAB, such as attendant care, gardening and physiotherapy to assist her with her day-to-day living, parenting tasks and in managing her home. Annie utilised a moderately high allocation of attendant care hours, utilising 65 hours of attendant care support per week plus non-active sleepovers each night. As the MAB did not fund provisions for home cleaning, Annie sourced her home cleaning through the Local Council through the Home and Community Care (HACC) program.

In 1986, now funded through the TAC, Annie began an internship in journalism supported by the TAC. After then completing a higher research University degree, Annie then started her own small business, and continued to receive the DSP to supplement her income.

Twenty three years after acquiring her SCI, Annie is still in the same home and feels secure in knowing she owns her own home. She is not employed per se, but continues to
operate her small business and receives the DSP to supplement this income. Annie is also actively involved in committees and busy with her private art work. Annie continues to utilise a moderate amount of services funded by TAC, including 65 hours of attendant care per week, non-active sleepovers each night, physiotherapy and gardening. Annie still utilises the HACC program funded through the Local Council for home cleaning. The TAC also continues to fund required replacement and servicing of equipment. Annie views her TAC support as her back up, and feels that a compensation payment would not have given her the support she feels she now has from the TAC. She described being content with her current lifestyle.

**Tom**

Tom is a 43 year old male who acquired a SCI as a result of a sporting accident in Victoria approximately 12 years ago. Fault for the accident was not attributed to anyone or anything. Tom acquired his SCI at a C5-C6 complete level, which categorises him as a mid level quadriplegic. As this level of injury affects bodily motor function from the mid-chest level down and reduces most hand function, Tom needs assistance with most day-to-day living tasks such as personal care, preparing food, home duties and transportation. Tom chooses to use a push wheelchair and with this level of function, requires considerable assistance with mobility.

When Tom acquired his SCI, he was employed full time in the media and entertainment sector. Tom noted he was on a pretty good amount of money and enjoyed the fast pace and social aspects of his work. Tom had recently married and was living in an inner city apartment.

During his spinal rehabilitation, Tom’s wife was trained to do his full personal care. No formal funding for attendant care was made available, and no attendant carers were trained up to complete Tom’s personal care. Tom consulted with an Occupational
Therapist to get funding for wheelchairs and equipment through DHS Aids and Equipment Program (A&EP) and through a number of external sources.

Tom received an automated compensation payment of A$20,000 from the sporting league’s insurance, but recalled that the amount ‘got chewed up’ in the first month he was home. Tom noted that he did not have any opportunity to negotiate the payment. He recalled that he had decided not to take any further action against the sporting league, despite their ‘inadequate cover’ and instead had tried to remain focused on his physical rehabilitation. In hindsight, Tom now felt that he should have pursued further options for compensation. Tom qualified for the DSP after a year, and utilised the payments to pay for living and household expenses.

Tom completed his spinal rehabilitation after 10 months. In transitioning home, Tom’s previous apartment was not accessible, so Tom and his wife moved into his mother-in-law’s house (which was more accessible) while his apartment was sold. Six months later however, Tom and his wife separated. In addition to the emotional trauma of the separation, Tom was forced to return to his parent’s home and utilise both the Royal District Nursing Service (RDNS) and the Local Council workers for personal care until his attendant care program could be established. Tom was placed on a waiting list to receive a package of attendant care hours funded through a DHS program. After 2 years, Tom was allocated a package of 25 hours of attendant care per week for his personal care and community access. Tom recalled feeling that there had been a gap in the spinal rehabilitation education process in him not being informed about available attendant care that was available and with the presumption by spinal rehabilitation staff that his wife would always take on his full personal care role.

In remaining at his parents, extensive housing modifications were required to make the house accessible. Funding for the modifications was partly funded by Tom and his parents and partly through fundraising at a local sporting club. Tom received upgrades
for wheelchairs and other needed equipment from DHS, but the A&EP program did not provide enough funding for a ceiling hoist needed in his room to assist with transfers or for a hoist needed in his van. To obtain this equipment, Tom was forced to utilise further assistance from the local Lions and Rotary Clubs. In addition, Tom was required to source personal healthcare provisions through the federally funded Continence Aids Assistance Program (CAAS) program as he could not privately fund these. He noted however that there was often a shortfall in with funding parameters associated with this program and he often had to find income to privately purchase all of his required provisions.

In terms of employment, Tom described being unsure as to what employment roles he could have taken early on, and did not pursue any form of employment in the first few years following his SCI. Approximately 10 years ago however, Tom took on a voluntary role with an advocacy organization seeking to improve health conditions for people with SCI. Tom has remained in this role and is highly motivated in supporting and promoting the organization and recently took on the role of director of the organisation. Tom is also involved in committee work seeking to improve the rights of people with impairment in relation to their medical treatment, and in general community advocacy campaigns seeking to improve access to transport.

Twelve years after acquiring his SCI, Tom is still in the same home. He describes feeling secure there and feels that the place is well setup for his needs. He remains busy with his advocacy and committee roles, and has recently also taken on a public speaking role to improve education and awareness of impairment and SCI. Tom now utilises 36 hours a week of attendant care from a HomeFirst package and finds this level of hours adequate. If required, Tom’s parents also provide informal support. Tom noted that he still felt particularly unsatisfied with the parameters of the equipment and personal healthcare programs.
Emerson

Emerson is a 30 year old man who acquired a SCI as a result of a diving accident in Victoria approximately 10 years ago. Fault for the accident was not attributed to anyone or anything. Emerson acquired his SCI at a C5-C6 complete level, which categorises him as a mid level quadriplegic. This level of injury effects bodily motor function from the mid-chest level down and reduces most hand function. As such, Emerson needs assistance with most day-to-day living tasks including personal care, preparing food, home duties and transportation. As he chooses to use a motor wheelchair, once assisted into the chair, he is very independent and mobile.

When Emerson acquired his SCI, he had been studying full time at a regional University and was working part time for 5 hours a week. Emerson was living close to the University in a share house with some friends. He was financially independent, had his driver’s license and was enjoying the University experience. Emerson was dating but single when he acquired his SCI.

During his spinal rehabilitation, Emerson received an automated compensation payment from the University’s student insurance scheme of A$9,000. The amount was fully automated and he was not given any opportunity to negotiate the amount or make a claim for any further compensation. Emerson however stated that he was not interested in pursuing any further claims for compensation through the courts as this would be a ‘huge battle’, and did not feel he had the time or energy for this. Emerson utilised the automated compensation payment to purchase his first wheelchair, a gel cushion and a hoist, and then utilised the DHS Aids and Equipment Program (A&EP) for any further equipment required.

Emerson completed his spinal rehabilitation after 5 months. In transitioning home, Emerson moved back to his parents’ home for a few months, with his mother providing his personal care. Emerson’s parents privately funded access modifications to their home
that included a bathroom fit-out and a ramp for an entrance. After another 3 months, Emerson returned to University, living near campus in a rented flat. He recalled that the University had paid for the access modifications required in the flat. In the first few months back at the University, Emerson trained up a team of attendant carers with the assistance of his mother, and then lived independently with the assistance of carers. Emerson utilised 34 hours per week of attendant care for his personal care needs (the full allocation available through the HomeFirst package), and also utilised the Disability Liaison Unit at the University to obtain further support hours for assistance with University tasks (such as getting reference books, note-taking, photocopies).

After completing his University degree, Emerson moved into a new inner-suburban home. He did not clarify if his home was purchased or rented, however stated that he had used funding from the DHS home modification scheme to fund the required access modifications. This suggests that the home was purchased as DHS are usually reluctant to approve funding for modifications on a rental property. Emerson utilised the home-cleaning services available through the Local Council HACC program for a time, however soon felt that it was restrictive as he needed to remain at home while the cleaning was being completed. Emerson has since incorporated home-cleaning tasks into his general attendant care hours. He also noted that he used the A&EP for equipment and the federally funded CAAS program for his personal healthcare needs, but that because of the shortfall with funding within these programs, was often forced to use his own income to purchase required items.

Emerson is now employed and has worked full-time for a number of years. He continues to live independently in his inner-suburban home with the assistance of attendant carers. His home is well set-up for his needs and is convenient to shops and his work. Emerson continues to utilise 34 hours a week of attendant care from a HomeFirst package, and although this level of hours is mostly adequate, believes ‘a few extra hours’ would provide him with the full level of support he needs and extra flexibility with
social activities. Emerson still utilises his own income occasionally to privately purchase items when there is a shortfall in availability. If required, Emerson still utilises his parents to provide some informal support. Emerson did not ever pursue any further claims for compensation, noting that the TAC was not the ‘be all and end all’, and feels satisfied with his full-time employment.

David

David is a 48 year old male who acquired a SCI as a result of a boating accident in Victoria twenty years ago. Fault for the boating accident was not attributed to anyone however there was avenue for a public liability claim against the boat owner (who was his father). He acquired his SCI at a C6 complete level, which categorised him as a low level quadriplegic. This level of injury effects bodily motor function from the mid-chest level down and reduces some arm and hand function. He requires assistance with some day-to-day living tasks such as personal care, preparing food, home duties and transportation. David chooses to use a motorised wheelchair, and with this level of function, is very independent and mobile in this wheelchair.

When David acquired his SCI, he had been employed full time as an apprentice in the manufacturing and services industry and was studying at night school to advance his career prospects. He was still living at home with his parents, but was financially and socially independent and had his driver’s license. David was single and dating at the time.

During his spinal rehabilitation, David received no loss-of-earning payments or compensation and moved straight onto the DSP. With the support of an occupational therapist, he obtained a wheelchair and some base level equipment funded by the hospital. David recalled there had been some discussion about him moving into a nursing home after he had completed his spinal rehabilitation, but that he had been adamant that he would not consider this as an option. He recalled knowing that if you
didn’t have compensation at that time (in the early 1980s) that ‘you either survived on somebody else giving you a hand and you worked out some way or you ended up in a nursing home’ as community-based attendant care did not exist at that time.

David completed his spinal rehabilitation after 7 months and moved back into his parent’s home. His mother and father assisted him with his full personal care needs and with community access, and privately funded all of the access modifications to their home which included a bathroom fit-out and a front entrance ramp. All of the equipment he required, including his wheelchair, showerchair, gel cushion and hoist, were purchased through his allocations of A&EP funding. As soon as he could afford, he privately purchased a van and a lifting platform so that his father could drive him to and from work more easily.

As noted, there was an avenue for David to make a public liability claim for compensation against the owner of the boat, however as this was his father, this created considerable tension. His father did not have any boating insurance, and if David was to pursue any claim for compensation, it would have involved him personally suing his father for damages. As such, David decided not to pursue any claim for compensation. Approximately 2 or 3 years later however, David sought different legal advice about pursuing a different compensation claim not involving his father (possibly an authority in charge of the lake management). He was advised however (possibly incorrectly) that he could only expect to receive A$80,000 and that as he would then be classified as a private client (as TAC and VWA clients) he would then be obliged to pay the amount back to cover medical costs for his spinal rehabilitation (which virtually totalled this amount). As such, David did not pursue any further claim for compensation regarding the accident.

Soon after returning home, David resumed full-time employment in his previous place of employment in an administrative role. He recalled that an occupational therapist had
been particularly helpful in advocating for him, and in pushing the employers to create a position for him so he could resume employment.

For the first 3 years after having acquired his SCI, David's parents continued doing his full personal care, including pick-ups and drop-offs for work on most days. David was then involved in an advocacy campaign that sought to have in-home attendant care support introduced for people with impairment across the state in the mid 1980s. Following the success of this campaign and the establishment of the InHome Accommodation Support (IHAS) program (the precursor to the DHS HomeFirst program), David received 24 hours per week of in-home attendant care.

David has now been employed for approximately 20 years, working in various roles in the services and manufacturing area. He has not married and continues to live with his parents in their suburban home. He is fairly independent and generally manages with the support of attendant carers only, utilising his parents only occasionally to still provide some informal support. In regards to compensation, David viewed that a compensation payment may have at least provided him with funding to purchase his own house. Very recently David transitioned from the HomeFirst program to an Individualised Support Package.

**Colin**

Colin is a 57 year old man who acquired a SCI as a result of a diving accident in Victoria approximately 37 years ago. Fault for the diving accident was not attributed to anyone, however there was some query as to if signage should have been visible on the pier to advise of the dangers of diving off the pier into shallow water, and hence opportunity to make a claim for compensation through a public liability claim. Colin acquired his SCI at a C5 incomplete level, which categorised him as a low level quadriplegic (not including his incomplete function). This level of injury effects bodily motor function from the mid-chest level down and reduces most hand function. As such, Colin needs assistance with
most day-to-day living tasks including personal care, preparing food, home duties and transportation. He chooses to use a push wheelchair, and with this level of function requires assistance with a significant amount of his mobility.

When Colin acquired his SCI, was employed full time in the car manufacturing industry and was seeking a promotion to become a production manager. He was also studying part-time to be a quality controller. He was living at home with his parents and had a girlfriend at the time.

During his spinal rehabilitation, Colin worked with an occupational therapist in obtaining a push wheelchair and a few basic equipment items funded by the hospital. He chose not to pursue any claim for compensation even though there was opportunity for him to make a claim for compensation. He described a moral objection in making a claim for compensation due to the personal fault he felt associated with how his SCI had been acquired. Colin’s parents privately funded access modifications to their home including a bathroom fit-out, sitting room and an entrance ramp. Colin’s parents had to take out a second mortgage in order to fund the housing modifications that placed his father and his immediate family in considerable financial stress.

Colin completed his spinal rehabilitation after 10 months and moved back to his parents’ place. As there was no formal in-home attendant care services available at that time, his brothers and father assisted him with all of his personal care needs. Colin also initially sought to resume employment at his previous place of employment, however the employer did not believe there was anything he would be able to do there and did not offer him any employment position.

Colin then described that for the next 11 years he had not wanted to go out of the house except for the rare family function. He described himself as having been ‘homebound’, and he did not engage in any community activity and lost most of his social networks.
Colin’s brothers and father helped with Colin’s personal care for the first 17 years after Colin acquired his SCI. He recalled after 11 years he had received a power wheelchair and that this had made him much more mobile, and that he had then began re-engaging in some community activity. Colin described getting a power wheelchair as ‘how I got my freedom’. Following this Colin began visiting a nearby nursing home, took on some advocacy interests in regards to access to train stations and then enrolled in a course at a nearby University.

Colin completed his degree 6 years later. He described that by this time, his brothers and father had become weary of their personal care roles, with his brothers wishing to move on and get married and his father ageing. Colin recalled that at that time, he had resigned himself to the fact that he would most likely have to move into a nursing home to have his personal care needs met, and that it had only been by chance that he became aware of the availability of in-home attendant care through a social worker at the nursing home he visited. After discussions with DHS and the social workers, Colin was moved into a nursing home for 6 weeks for assessment of his personal care needs, and was then (pending funding) to re-transition home with the support of in-home attendant care.

Colin surprisingly enjoyed his time at the nursing home and quite liked the social aspect of the place. Due to a shortfall in funding, he remained in the nursing home for a total of 6 months, but while there, managed to train up a team of attendant carers so he could re-transition home. Colin returned home with an allocation of 21 hours of attendant care per week, funded through the DHS InHome Accommodation Support (IHAS) program, the precursor to the DHS HomeFirst program. He recalled the particular difference at the time in having females as formal attendant carers after having utilised his brothers and father for support for so many years. Colin also utilised the A&EP program to source equipment.
Colin did not gain employment after re-transitioning home however took on a peer-support/advocacy role at a local nursing home. He noted that re-transitioning home and having formal attendant care had given him more freedom and control over what he wanted to do in his life and had dramatically eased the pressure off his immediate family.

Colin now continues to live with his parents in their suburban home. For the last 15 years he has been utilising 24 hours per week of attendant care, funded through the DHS HomeFirst program, while still occasionally utilising his brothers to provide him with some informal support. He is now receiving the DSP as financial income and although not employed, is continuing with his voluntary peer-support/advocacy role at a local nursing home. Colin describes feeling happier and more independent these days and very supported by his immediate family and team of reliable attendant carers.

**Graham**

Graham is a 55 year old man who acquired his SCI as a result of a cyst on his spine approximately 5 years ago. Fault for the cyst and acquired injury from surgery related to removal of the cyst was not attributed to anyone or anything. Graham acquired an incomplete SCI at the T2 – T3 level, which categorises him as a high level paraplegic (not including incomplete motor function). Graham’s level of injury affects his bodily motor function partially from the lower-chest level down, and function in one arm and hand. He requires assistance with most day-to-day living tasks including personal care, preparing food, home duties and transportation. Graham chooses to use a push wheelchair and requires considerable assistance with his mobility.

When Graham acquired his SCI, he had been employed full time as a manager at an employment recruiting centre, and had an established career in the employment/job-
seeking area. Graham was living in a rented inner-suburban house, was financially secure and independent and was single at the time.

Graham did not complete any specific spinal rehabilitation. Initially he had some neurological deficit where he lost some bodily motor function, had numbness and was falling and losing his balance a lot, however no condition was ever diagnosed and Graham just managed these conditions. Five years later, Graham's bodily motor function became significantly worse, and following tests, a cyst was located on his spinal cord. Graham underwent surgery for the removal of a cyst that was affecting the function of his spinal cord. Following surgery, Graham attended a generalised rehabilitation unit and then transitioned home. His bodily motor function was permanently affected to the extent that he was unable to stand and weight-bare and required a wheelchair for mobility.

Graham initially thought he could manage independently in the home with the support of friends and by privately purchasing a number of support hours per week. He had returned to his area of employment in a differing role, but had difficulties managing the work hours and contributing to the employment role effectively while trying to manage his SCI. Graham noted this effected his overall employment position and that he had eventually ceased his employment role soon after. After a few months, Graham recalled that he was not managing his situation well at home and was having many falls and accidents. He also described at one point, spending 6 weeks in bed and developing a pressure sore on his shoulder as he had not managed his support well enough for there to be someone coming in to assist him. He recalled struggling with a less than accessible bathroom.

To manage this more effectively, Graham began privately funding some attendant care including support with personal care, cleaning, food preparation, washing, required paperwork and general daily living tasks. Graham noted the private support he was
funding was not consistent and varied between 0 to 8-10 hours per week depending on his needs and access to informal support.

After 2-3 years, the costs of privately funding his support from his own finances were becoming too much of a financial burden. Graham realised that his personal care needs were not being met, and that this was affecting his overall health and wellbeing. Not having been referred to any support service, Graham scouted around to find out about what services may be available. After having found a disability service program, he recalled having extreme difficulties in accessing the services available. Graham recalled at length the considerable battle he had had in trying to obtain an allocation of services and this had involved extensive correspondence, an extended waiting time and him ultimately contacting and utilising his Local Member of Parliament to campaign to the State Services Minister to gain an allocation of services.

Graham finally obtained 34 hours per week of attendant care through the DHS HomeFirst program, and a further 5 hours per week through a Linkages package. Graham then recalled particular difficulties in training up a team of attendant carers and in learning to direct the attendant carers. Graham also began to utilise the Local Council to access 2 hours of home-cleaning per week, but because of the poor quality of staff, had stopped utilising the service after a time. Graham made no reference as to how his personal healthcare provisions were funded or whether he utilised the federally funded CAAS program.

Graham did not have any opportunity to claim for compensation as there was no fault associated with how his SCI had been acquired. Graham was also reliant on the DSP for his income and continued living in rented accommodation. Graham noted that he believed that if he had been able to receive a compensation payment, that at least he may have been able to purchase an accessible home.
Graham is currently not employed. He is a committee member of a Local Council Disability Advisory Committee, and continues to live independently in his inner-suburban home with the support of attendant carers. He is currently seeking funding to complete needed home access modifications in the near future to be completed in-conjunction with the DHS home modifications scheme. Graham utilises 34 hours per week of attendant care through the DHS HomeFirst package, but does not to utilise Linkages hours consistently. He described being unhappy overall at some of the decisions he had made in relation to his support in the past such as trying to privately fund his support, and felt that if he had started with the DHS HomeFirst attendant care hours earlier, it would have made a big difference in terms of his capacity to work and his general social engagement.

Matthew

Matthew is a 59 year old man who acquired his SCI as a result of a trampolining accident in the state of South Australia 29 years ago. No fault was attributed to anyone in relation to the accident and no public liability claim was made despite there being some grounds. Matthew acquired his SCI at a C5 – C7 level which categorised him as a low level quadriplegic. As this level of injury effects bodily motor function from the mid-chest level down and reduces some hand function, Matthew needs assistance with most day-to-day living tasks including personal care, preparing food, home duties and transportation. Matthew chooses to use a motor wheelchair, and with this level of function is very independent and mobile.

When Matthew acquired his SCI, he was on a backpacking trip around Australia with some fellow students and his girlfriend. He had previously been studying full time at University and working part time, but had just dropped out of University. Matthew described himself at the time as being very independent and as being keen to see the sights and start exploring the world through travel.
During his spinal rehabilitation, Matthew transferred across from the spinal rehabilitation unit in South Australia to the Victorian spinal rehabilitation unit to be closer to his immediate family. Once in Victoria, he recalled there being considerable negotiations with the social workers and occupational therapists in obtaining funding for wheelchairs, equipment and ramps for housing. He recalled all of his original equipment had finally been funded by the hospital.

Matthew spent a total of 18 months in spinal rehabilitation, quite an extended period of time. In transitioning home, Matthew moved initially into a rented house that he shared with some friends and his girlfriend for the first 2 or 3 months. Refusing to then move into public housing, which he viewed at the time as 'living death', Matthew was fortunate instead to be able to move into a house his mother had purchased for him at considerable expense. Matthew and his mother self-funded the cost of the housing modifications, and Matthew lived with his girlfriend (and later wife) who provided all of his personal care.

As noted, no claim for compensation was made despite there being some opportunity to make a public liability claim. Matthew noted that they had sought legal advice around making a public liability claim, but had been advised against it as because of the level of personal negligence in how the accident had occurred.

During the next 6-7 years, Matthew completed a University degree and his girlfriend helped him with all of his personal care while she worked part time herself. Matthew noted that at that time, during the mid seventies, no formal services were available. He recalled being financially secure and of them both being generally happy with their living arrangements.

In 1985, around 8 years after acquiring his SCI, Matthew became involved in advocating for the establishment of in-home attendant care services. Following the success of this
campaign, Matthew received his first package of in-home attendant care of 26 hours per week funded through a DHS IHAS package. Although the receipt of formal attendant care hours were liberating for Matthew, his wife was less than happy about the transition and believed the uptake of attendant care changed the dynamic of their relationship. Soon after its introduction, Matthew and his wife separated and his allocation of attendant care was increased from 26 hours per week to 34 hours per week to assist him with his now increased need for support.

Following the completion of his University degree, Matthew gained full-time employment as an engineer. Through his employer, Matthew received an extra 10 hours of support assistance per week to complete work-based tasks. In terms of ongoing attendant care, Matthew noted difficulties in sourcing attendant carers because few people had been trained-up for the role. He recalled early-on that he had recruited friends to work as his attendant carers so that his personal care needs were met, and that he had a fairly high turnover of attendant carers because of these difficulties in finding attendant carers. He noted that overall he had a good work relationship (and post-work relationship) with most of the attendant carers.

Further, Matthew noted that he did have access to further hours of attendant care available through the HACC program, but that he had chosen not to use them because he didn’t like the type of people they were sending (as he described them) and because he viewed the coordination of the services as disorganised.

After a lengthy work career, Matthew recently resigned from his engineering position and has gone back to university to continue studying. He sold his original house and has moved into a new house in a regional setting, with the housing modifications funded partially through the DHS home modification program. Matthew is utilising his superannuation for income and the DSP. He is still on a full allocation of HomeFirst hours (i.e. 34 hours per week) but since ceasing employment, lost the 10 hours per week of
support provided by his employer and feels he is now struggling considerably with his decreased allocation of support. He continues to utilise the A&EP to replace and purchase his equipment, although on most occasions, has subsidises costs of the equipment from his own income because he choses to purchase items that are more expensive than those available through the parameters of the A&EP program. He describes being fairly satisfied with his current life situation and is still single and dating.

2.3 Summary Table of Participants

<table>
<thead>
<tr>
<th>Participant</th>
<th>Age</th>
<th>Year SCI was acquired</th>
<th>Summary Points</th>
<th>Compensation Status</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ben</td>
<td>45</td>
<td>1999</td>
<td>funded through VWA</td>
<td>automated compensation process</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>C6 Quadriplegic from car accident at place of employment</td>
<td>no opportunity to negotiate amount awarded</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>continues to receive fortnightly loss-of-earnings from VWA</td>
<td>awarded ~$A200K</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>married with children at time of SCI</td>
<td>awarded lump-sum payment after 8 months</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>established career at time of SCI</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>low mobility due to wheelchair choice</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>did not return to employment - works now in community roles</td>
<td></td>
</tr>
<tr>
<td>Stefan</td>
<td>59</td>
<td>1999</td>
<td>funded through VWA</td>
<td>automated compensation process</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>C5 Quadriplegic from car accident overseas</td>
<td>no opportunity to negotiate amount awarded</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>continues to receive reduced fortnightly loss-of-earnings through VWA</td>
<td>estimate he was awarded at least ~ $A300K</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>married with children at time of SCI</td>
<td>awarded lump-sum payment after ~1 year</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>did not return to employment - now studying at Uni</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>utilises high allocation of support</td>
<td></td>
</tr>
<tr>
<td>Participant</td>
<td>Age</td>
<td>Year SCI was acquired</td>
<td>Summary Points</td>
<td>Compensation Status</td>
</tr>
<tr>
<td>-------------</td>
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<td>-----------------------</td>
<td>----------------</td>
<td>---------------------</td>
</tr>
<tr>
<td>Jim</td>
<td>44</td>
<td>2004</td>
<td>funded through TAC T10 Paraplegic from car accident very independent with minimal use of support services high level career at time of SCI married with children at time of SCI received time-limited fortnightly loss-of-earnings from private income protection insurance policy employed part-time and voluntary work</td>
<td>common law claim for compensation personally involved in negotiations awarded lump-sum payment after ~3 years awarded ~$A900K</td>
</tr>
<tr>
<td>Lawrie</td>
<td>60</td>
<td>1983</td>
<td>funded through VWA T12 Paraplegic from mining accident in NSW received time-limited fortnightly loss-of-earnings from VWA very independent with minimal use of support services single at time of SCI, now married with children returned to employment establishing new career</td>
<td>common law claim for compensation personally involved in negotiations and court case awarded lump-sum payment after ~6 years estimate he was awarded ~$A500K</td>
</tr>
<tr>
<td>Annie</td>
<td>57</td>
<td>1985</td>
<td>funded through TAC only female participant C6 Quadriplegic from car accident utilises moderately high level of support services established career at time of SCI separated and with young child at time of SCI continues to receive fortnightly disability support pension now employed part-time, committee work and art</td>
<td>automated compensation process no opportunity to negotiate amount awarded awarded ~$A25K awarded lump-sum payment after ~1 year</td>
</tr>
<tr>
<td>Participant</td>
<td>Age</td>
<td>Year SCI was acquired</td>
<td>Summary Points</td>
<td>Compensation Status</td>
</tr>
<tr>
<td>-------------</td>
<td>-----</td>
<td>-----------------------</td>
<td>---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
<td>-------------------------------------------------------------------------------------</td>
</tr>
</tbody>
</table>
| Tom         | 43  | 1996                  | funded through DHS  
C6 Quadriplegic from sporting accident  
low mobility due to wheelchair choice  
established career at time of SCI  
married at time of SCI, now single  
continues to receive fortnightly disability support pension  
utilises low level of support services  
own employed part-time as director of organisation                                                                                          | automated compensation process  
no opportunity to negotiate amount awarded  
awarded ~$A20K  
awarded lump-sum payment after ~1 year                                                                                                           |
| Emerson     | 30  | 1998                  | funded through DHS  
C5 Quadriplegic from diving accident  
good mobility once in wheelchair  
studying at Uni at time of SCI  
single at time of SCI, now single  
utilises low level of support services  
own has established career working full time financially supporting himself                                                                 | automated compensation process  
no opportunity to negotiate amount awarded  
awarded ~$A9K  
awarded lump-sum after ~ 5 months                                                                                                               |
| David       | 48  | 1988                  | funded through DHS  
C6 Quadriplegic from boating accident  
good mobility once in wheelchair  
employed as apprentice tradesperson time of SCI  
single at time of SCI, now single, lives with parents who did all personal care early on  
initially received fortnightly disability support pension, now has established career working full time financially supporting himself | no opportunity to claim for compensation                                                                                                                                                                    |
<table>
<thead>
<tr>
<th>Participant</th>
<th>Age</th>
<th>Year SCI was acquired</th>
<th>Summary Points</th>
<th>Compensation Status</th>
</tr>
</thead>
<tbody>
<tr>
<td>Colin</td>
<td>57</td>
<td>1971</td>
<td>funded through DHS C5 Quadriplegic from diving accident established carer at time of SCI single at time of SCI, now single, lives with parents housebound 11 years with no formal support for first 17 years continues to receive fortnightly disability support pension busy with voluntary peer-support/advocacy role</td>
<td>choose not to make any claim for compensation</td>
</tr>
<tr>
<td>Graham</td>
<td>55</td>
<td>2003</td>
<td>funded through DHS T2 Paraplegic from medical condition established carer at time of SCI single at time of SCI, now single continues to receive fortnightly disability support pension privately purchased support initially, now utilises low level of support services</td>
<td>no opportunity to claim for compensation</td>
</tr>
<tr>
<td>Matthew</td>
<td>59</td>
<td>1979</td>
<td>funded through DHS C5 Quadriplegic from trampolining accident travelling/studying at Uni at time of SCI in relationship at time of SCI, now single established career after SCI now self-retired, receives fortnightly disability support pension and lives off superannuation utilises low level of support service</td>
<td>choose not to make any claim for compensation</td>
</tr>
</tbody>
</table>

*explanation of functional elements of SCI listed in table, such as C5 or T10, are detailed in Appendix A*
2.4 Summary

As the individual participant biographies demonstrate, each of the participants had their own distinct journey associated with acquiring their SCI and associated utilisation of support usage. The biographies demonstrate the complexities of the SCI life-course, and demonstrate the support, impact, parameters and limitations of the various support service programs on each participants lifestyle and life-course. The biographies also provide an effective overview of the variety of compensation pathways, and the diversity of experiences associated with the single aspect of compensation after acquiring a SCI.

The following chapters will now provide an in-depth document analysis and historical chronology of the establishment of the Victorian disability support service framework, which provided the backdrop to each of the participant biographies and their support service and compensation eligibility. International movements and discourses that influenced the establishment and ongoing development of the community-based Victorian disability support service framework will be examined and the significant influence of movements such as deinstitutionalisation, the social model and Human Rights. The Australian and Victorian disability policy landscapes, including compensation landscapes, will then be examined in depth to obtain understanding as to the evolution of the current complex, diverse and fragmented the Victorian disability support service framework.
Chapter 3: Theories of impairment and disability

3.1 Introduction

Social responses to people with impairment such as SCI within westernised societies have shifted dramatically since the beginning of the twentieth century. These changes have radically altered how impairment and ‘disability’ are now viewed by society in the twenty first century. In this chapter, I examine the key international approaches, discourses and social movements that have defined this radical shift in social responses to people with impairment that have significantly influenced the establishment and ongoing development of the community-based Victorian disability support service framework.

Beginning with the Medical Model, I examine social responses to impairment based on rehabilitation, exclusion, segregation and institutionalisation that dominated social responses to impairment during much of the twentieth century. I then examine the radical transition in social responses to people with impairment that began during the late 1960s based on discourses such as the Principles of Normalisation, Self Valorisation and the Independent Living Movement which introduced concepts of community-based living and social integration of people with impairments. These discourses were pivotal in initiating deinstitutionalisation and provided the bases for the establishment of community-based support service frameworks to support people with impairments to live inclusively within society.

Further, I examine the Disability Studies genre that includes the Social Model and Disability Rights movements that redefined social responses to people with impairment during this transition. In redefining barriers to social inclusion as based on social and physical barriers and articulating the rights and entitlements that people with
impairment were entitled to be socially inclusive, the genre was extremely effective in repositioning people with impairment from that of a minority collective away from the mainstream and towards a position of inclusion and social integration.

Lastly, I examine recent movements and discourses that have again impacted on social responses to impairment and ‘disability’ and the ongoing development of the community-based Victorian disability support service framework, such as critiques of the Social Model, the development of the business of disability and establishment of the ‘care industry’, Human Rights approaches and the emerging discourse of Capabilities Approaches.

3.2 The Medical Model

The Medical Model, as it is now known, was a model of support characterised by ongoing control and dominance of people with impairment by the medical profession. It was defined by its promotion of rehabilitation, segregation, exclusion and institutionalisation of individuals based solely on impairment and was the dominant social response to people with impairment during most of the twentieth century.

The origins of the Medical Model stem from the Social Darwinist, biomedical and eugenics movements that emerged during the nineteenth century. These movements were based on principles of competition, physical fitness, aesthetic and survival of the fittest, and at the time it was felt that adherence to these principles would advance the quality of society. Inequality was thus rationalised and viewed as contributing to social advancement, and people with any form of impairment were thus viewed as weak, unfit and a threat to society’s ability to advance (Burleigh 1997; Gallagher 2001; Barnes and Mercer 2003). Social responses to people with impairment were thus highly focused on medical based interventions, treatment or rehabilitation that sought to cure an individual of their impairment so they could obtain a socially acceptable level of physical fitness. Where this was not achievable, and the impairment could not be ‘corrected’ by medicine
or rehabilitation, individuals were socially excluded and/or physically separated from society by being placed within institutions in order to ensure the social good (Kevles 1995; Barnes and Mercer 2003).

In its worst and most extreme form, the medicalised control of people with impairment was practiced during Nazi Germany. Under the guise of social reform and social improvement, medical interventions were implemented that lead to the widespread sterilisation, experimentation and later genocide of people with impairment. These brutal medical interventions were directed by the state and were sanctioned by much of the medical profession during this time (Morris 1991; Kevles 1995; Burleigh 1997; Oliver and Barnes 1998; Gallagher 2001).

Following World War II, many of these brutal medical interventions were condemned, however the medical profession continued to control and dominant the lives of people with impairment. Large-scale institutions continued to operate, and the medical profession continued to promote the removal of people with impairment from society based on impairment (particularly children from parents), as the best course of action for them and society (Stone 1984; Oliver 1990; Barnes 1997; Gleeson 1999; Manning 2008). People with impairment able to avoid institutionalisation and remain in society were often stigmatised and discriminated against by general society, based on the notions that impairment was a form of reduction, deficit and disruption to the social system (Goffman 1963). Social structures to support any form of social inclusion were nonexistent, and these individuals were often subjected to ongoing treatment and medical control in seeking to cure, hide or minimalise their impairments (Albrecht 1992; Oliver and Barnes 1998; Thomas 2004).

The foundations of the Medical Model continued to be reinforced throughout the 1950s by social theorists such as Parsons who, in 1951, examined the social experience and consequences that flowed from illness and impairment as a disruption to the functioning
of the social system. Parsons claimed that certain prerequisites were necessary for the functioning of all modern social systems - in particular the maintenance of optimal levels of health for the majority of population. Any diagnosed medical condition, including impairment, was therefore undesirable and an interruption to the social system (Parsons 1951; Gabe et al. 2004). Parsons social theory however did identify the sharp power imbalance that existed between the medical profession and people with impairment, and the expectation that the medical profession would take-on responsibility and decision making for people with impairment in relation to expected treatment. This form of constructed dependence was categorised by Parsons as the ‘sick role’ whereby people with illness and impairment were relieved of social role expectations and assumed a form of social dependence based on treatment defined by the medical profession. Parson’s ‘sick role’ therefore reinforced the control and dominance of the medical profession over people with impairment, where responsibility and decision-making capacity in relation to treatment was removed and placed solely in the hands of the medical profession.

3.3 Normalisation and Social Role Valorisation (SRV)

In the late 1960s and 1970s, criticism of the overt medicalised treatment and deficit status of people with impairment within society began to emerge. These critiques were influenced by many larger social movements occurring during this period that were seeking to improve social equality, such as gender, racial and gay rights movements. Drawing on these movements, a Swedish social theorist by the name of Nirje established the Principles of Normalisation in 1969 that sought to work towards the improved social positioning and citizenship of people with impairment. The bases of the principles were the establishment of ‘normal’ life pathways and social roles for people with impairment and an emphasis that diversity of the human condition was something that should be celebrated not marginalised (Nirje 1969). As such, people with impairment were to be identified in equal standing with all other members of the community and be included in normal life activities such as economic and political processes (including paid
employment), social relationships (such as marriage and parenting), education and community roles and have access to public transport and the built environment. Nirje emphasised that access to stimulating and rich social environments through social integration would allow growth of personal identity and initiate the social re-positioning of people with impairment (Nirje 1969). Nirje’s Principles of Normalisation thus defined a set of standards and lifestyle programs that would facilitate opportunities for people with impairment in normal life activities within society.

Nirje later noted that the Principles of Normalisation did not, as the name suggests, seek to assume that all people with impairment should meet a standardised norm (Perrin and Nirje 1985). Many commentators had sought to criticise the Principles of Normalisation, claiming the principles forced people with impairment into prescribed and predetermined normal social roles, rather than allowing society to expand to include the diversity of people with impairment (Perrin and Nirje 1985). Nirje responded to these criticisms by highlighting that the principles promoted the creation of opportunities and support for people with impairment that would allow them to engage in a lifestyle similar to that of other members of society, but that included options for variation and choice within the boundaries of normal social rights and responsibilities (Perrin and Nirje 1985).

The Principles of Normalisation were highly successful at an international level. They strongly supported deinstitutionalisation and effectively anchored a grand theory on the social inclusion of people with impairment into emerging community-based disability support service policy and practice. The principles defined the various kinds of service structures would be required to enable people with impairment to uptake these social roles within society, and provided a comprehensive and accessible approach in how these support service structures should be managed. This included development in how health professionals managed disability support services in terms of staff attitudes and responsibilities, and mechanisms to include consumer involvement and representation in

During the mid 1980s, Wolfensberger, a German academic who had worked alongside of Nirje, claimed that the Principles of Normalisation, despite the theoretical model, did not make available an actual mechanism for social change. In seeking to advance the principles, he formulated the concept of Social Role Valorisation (SRV) (Wolfensberger 1980). SRV sought to physically place people with impairment into professional and valued social roles and real living situations so they could experience ‘normal’ attitudes, responses and behaviours. SRV also enforced standards of behaviour to which a person with impairment was required to conform so as to acquire new competencies, improve their skill base and more rapidly advance their social inclusion. These standards of behaviour included improving physical appearances by upgrading clothes and attire, assisting in the obtainment of meaningful employment and increasing the intensities of relationships and social networks of individuals (Wolfensberger 1980; Wolfensberger 1995). As the name suggests, SRV sought to valorise the role of people with impairment by seeking to obtain the highest social role that could be attainable for that person (Perrin and Nirje 1985; Wolfensberger 1995). Wolfensberger also conceptualised SRV as working towards raising awareness of negative attitudes by the mainstream towards people with impairment and as improving social attitudes to difference (Wolfensberger 1980; Perrin and Nirje 1985; Wolfensberger 1995).

As with the Principles of Normalisation, SRV was also heavily criticised. SRV was criticised for its premise of shaping and conforming people with impairment into predefined standards and for its authoritarian manner in prescribing behaviour (Perrin and Nirje 1985; Abberley 1987; Nirje 1994; Barnes et al. 1999). Critics noted that SRV sought to minimise difference rather than include difference, and that it only allowed people with impairment to pass in society by making them meet a specified ‘standard’ of what was viewed as ‘normal’ (Perrin and Nirje 1985; Abberley 1987; Barnes et al. 1999).
SRV was thus criticised for not providing scope for individual preferences and for not addressing the strong material and cultural forces that often emerged in maintaining a person with impairment in a valued social role. SRV instead presumed society was ‘homogenised and uniform’, and that a person with impairment would simply fit into a normally prescribed social roles such as a wife, husband, parent, 9-5pm employee, home-owner or person of middle class socio-economic status (Perrin and Nirje 1985; Abberley 1987; Barnes et al. 1999; Gleeson 1999). SRV was therefore criticised for locating so-called abnormality within the ‘disabled subject’ and for placing people with impairment within a society that failed to accept diversity (Abberley 1987; Barnes et al. 1999).

At an international level however, both the Principles of Normalisation and SRV were significant in shifting social responses to people with impairment and in increasing the awareness of the rights to social inclusion and equality of people with impairment. Although fundamentally based on negating and minimising difference in seeking inclusion into a normalised social roles, the two models initiated real change and improvement the quality of life of people with impairment worldwide, in denouncing institutionalisation, instigating the development of community-based disability support services and in promoting the social reintegration of people with impairments into mainstream society (Perrin and Nirje 1985; Wolfensberger 1995).

### 3.4 Disability Studies Genre

Perhaps the most dramatic shift in social responses to people with impairment during the twentieth century however occurred around the development of models now categorised under the banner of the Disability Studies genre. The conceptualisation of Disability Studies as an academic genre was developed in the United Kingdom in 1992 to encapsulate the number of discourses that identified the segregation and exclusion of people with impairment from mainstream society as a result of physical and socially constructed barriers. In contrast to the Medical Model and its ‘treatment and exclusion’
based response to impairment, the Disability Studies genre explored the segregated social spaces of people with impairment, identified barriers to social inclusiveness and examined the collective experience of people with impairment as a minority group (Davis 1997; Barnes et al. 1999; Thomas 1999; Barnes and Mercer 2003; Barnes 2008). Specifically, the genre focused on barriers that served to ‘dis-able’ a person from being fully functional and inclusive in society. The term ‘disability’ was thus redefined as the reduction in the function and capabilities of people with impairment due to existence of socially constructed physical and attitudinal barriers (Davis 1997; Shakespeare and Watson 1997; Barnes et al. 1999; Thomas 1999; Barnes and Mercer 2003; Thomas 2004; Barnes 2008).

Notably, the approaches within the Disability Studies genre identify strongly with a social oppression paradigm, where socially constructed physical and attitudinal barriers were viewed as a form of social oppression (Shakespeare and Watson 1997; Barnes and Mercer 2003; Thomas 2004; Thomas 2007; Barnes 2008). As opposed to the Medical Model, the reduction of function and/or capabilities of people with impairment were viewed as a direct result of the surrounding inaccessible and exclusionary landscapes of society, rather than within the individual pathology of the body (Shakespeare and Watson 1996).

The Disability Studies genre has also been highly influential over the last 30 years as a political lever in promoting the realignment of these exclusionary spatial arrangements for people with impairment in society (Shakespeare 2005; Thomas 2007; Barnes 2008). In seeking to improve the rights and status of people with impairment, the Disability Studies genre became a powerful tool in understanding the relationship between oppression and identity, and in examining socially constructed inequality of people with impairment (Vernon and Swain 2002). The genre’s theoretical positioning of people with impairment as a minority collective underpinned wide-scale political mobilisation for
people with impairment and initiated the construction of barrier free and socially inclusive environments (Thomas 2007).

The Disability Studies genre however has meet with less success in the academic arena. Its critics claim that its theoretical perspective is highly reductionist in positioning people with impairment as a minority collective against the able-bodied mainstream. Further, the genre has also been criticised for not including the extent of bodily dysfunction in relation to the socially constructed barriers it promotes, and for not adequately addressing the historiography of disability. I will now briefly explore a number of approaches within the Disability Studies genre, their critiques and their particular nuances in relation to social responses to impairment and ‘disability’ and development of related support services.

3.4.1 The Social Relational Theory

The earliest approach classified within the Disability Studies genre is Finkelstein and Hunt’s Social Relational Theory (Hunt 1966; Finkelstein 1993; Finkelstein 2001). Finkelstein and Hunt sought to apply the critiques of overt medicalisation of individuals to the specific arena of impairment. Developed in 1967 (at the peak of institutionalisation in most westernised countries), the Social Relational Theory identified the dominance of medical power and authority in seeking to achieve social control of people with impairment through control of the body (Hunt 1966; Finkelstein 1993; Oliver 1996; Shakespeare and Watson 1997; Barnes et al. 1999; Drake 1999; Finkelstein 2001; Barnes and Mercer 2003; Thomas 2004).

Influenced strongly by Freidson and his discourse on the power and dominance of the medical profession (Freidson 1970; Gabe et al 2004), Finkelstein and Hunt highlighted the extensive power and sharp interventions by the medical profession into the lives of people with impairment. This included the forced and systematic removal and social segregation of people with impairments into institutions based on impairment, and medicalised interventions focused on ‘cure’ of difference and impairment (Hunt 1966;
Finkelstein 1993; Oliver 1996; Shakespeare and Watson 1997; Barnes et al. 1999; Drake 1999; Finkelstein 2001; Barnes and Mercer 2003; Thomas 2004). Finkelstein noted that the interventions assumed a deviation from the social standards of normality by assuming that people with impairment were medically dysfunctional and required either treatment or social segregation (Hunt 1966; Finkelstein 1993; Finkelstein 2001).

Finkelstein and Hunt also identified a number of key areas of social exclusion of people with impairment including social discrimination, exclusion from the labour market, exclusion from education, enforced poverty and lack of opportunity to access public transport and infrastructure (Hunt 1966; Finkelstein 1993; Oliver 1996; Shakespeare and Watson 1997; Barnes et al. 1999; Drake 1999; Finkelstein 2001; Barnes and Mercer 2003; Thomas 2004). They conceptualised these exclusions as being a direct result of the materialist landscape of the industrial era (of which 1970 United Kingdom was a part) where the production of material wealth determined social value. As most people with impairment were deemed unable to produce material items in the same span of time as the average person, people with impairment were viewed with reduced value, and categorised as an idle, non-productive class. The resulting subordination and exclusion of people with impairment thus became the basis for Finkelstein and Hunt’s Social Relational Theory and its identification of the segregated social position of people with impairment underpinned by this medically interventionist and materialist social landscape.

3.4.2 Oliver’s Social Model

Oliver (1990) advanced the work of Finkelstein and Hunt’s Social Relational Theory in his seminal text ‘The Politics of Disablement’. As with Finkelstein and Hunt, Oliver viewed the segregated social position of people with impairment within this materialist landscape as a direct result of the spatial arrangements created by physical and attitudinal barriers within society. However Oliver took the Social Relational Theory further in claiming that ‘all’ barriers to social inclusion for people with impairment were socially produced, and not the result of any bodily impairment or individual dysfunction.
Oliver viewed these socially constructed barriers as ‘dis-abling’ people with impairment on a day-to-day basis (Oliver 1990; Oliver 1996; Davis 1997; Shakespeare and Watson 1997; Drake 1999; Gleeson 1999; Thomas 2002; Barnes and Mercer 2003; Thomas 2004).

Notably, Oliver’s Social Model utilised a socio-political framework that defined the social exclusion of people with impairment as an outcome of social and political interactions, and constructed the problem of segregation and exclusion not in relation to the individual person with impairment, but as related to the lack of appropriate support services, structural and material conditions provided by society (Oliver 1990; Oliver 1996; Barnes et al. 1999; Dewsbury et al. 2004). Oliver’s Social Model was modernist in its approach in positioning people with impairment within a dualist landscape, characterised by a binary, us-and-them type dichotomy of a minority collective against the mainstream (Gleeson 1999; Shakespeare and Watson 2001; Thomas 2002).

Oliver’s Social Model was also highly class focused and inherently politicised. Emerging in the United Kingdom during the 1960s and 1970s within a highly unionised Labor period, it emerged alongside of other social justice movements, such as those associated with race, gender and sexuality, that sought to challenge established social policies and ideologies in relation to control, rights and choice. Oliver utilised the Social Model to demonstrate the lack of control, rights and choice suffered by people with impairment specifically as a result of society’s disabling barriers. He highlighted that the social oppression and inequality experienced by people with impairments was legitimised by society, and that the removal of these barriers was equivalent to that of a class struggle, where second-class citizens struggled for emancipation, inclusion, rights and choice (Oliver 1990).

Oliver’s Social Model was highly successful in media and policy arenas where it promoted the readjustment of social spatial arrangements and removal of exclusionary barriers.
faced by people with impairment (Barnes et al. 1999; Barnes and Mercer 2003; Thomas 2007). The Social Model highlighted a need for significant social restructuring and adjustment in working towards the reintegration and improved status of people with impairments into society, including the reassessment of attitudes by the mainstream, establishment of support services to promote social inclusiveness and the adjustment of labour markets/economies to remove disabling physical and attitudinal barriers preventing employment. The Social Model promoted political autonomy, democratic participation and the political engagement of people with impairment in working towards their full inclusion in society (Oliver 1990; Oliver 1996; Thomas 2002; Thomas 2007). The Social Model was thus highly successful in levering for social change to remove ‘disabling’ socially constructed barriers for people with impairment and for shifting the raison d’être for exclusion away from an individual’s physical and mental impairments and onto society’s exclusionary barriers (Thomas 2004; Shakespeare 2006).

3.4.3 Femininism, Postmodernism & Poststructuralism influences

The Disability Studies genre has been strongly influenced by feminist, postmodernist and poststructuralist influences in recent years. Although these discourses have not been strongly utilised in this study, they should be noted in their efforts to reduce the ‘impaired – non-impaired’, modernist binaries of Social Relational Theory and the Social Model, and for bringing the personal experience of impairment into the Disability Studies genre.

The influence of feminism on the Disability Studies genre has been its examination of oppression, objectification and gender based discrimination in relation to impairment. The discourse has sought to examine the origins and social construction of these themes and examine their intersections within the Disability Studies genre.

Although feminist approaches supporting status and autonomy of mainstream women gained considerable ground during the 1970s, women with impairment were in general excluded from mainstream feminist discussions in early debates. This centred on the
stereotypical perception that women with impairment were vulnerable, dependent, childlike, helpless, victimised and reliant on others for support. Many feminists thus took on the mainstream views of stigma and discrimination related to impairment and excluded women with impairment from feminist discussion (Wendell 1997). Sheldon (1999) notes non-impaired mainstream feminists ‘severed women with impairment from their sisterhood’ in an effort to advance more powerful, competent and appealing female icons that were strong, autonomous women with equal status in society. Only later were women with impairment successful in utilising mainstream feminist discourses to improve their overall social status and hold their place in the feminist movement. Only by identifying with the wider, dominant feminist discourses, did women with impairment eventually bring issues of gender, identity and rights to bodily integrity into the genre of Disability Studies (Wendell 1997; Sheldon 1999).

Feminist discourses within the Disability Studies genre now focus largely on the oppressed social positioning of women with impairments in specific relation to birth control, reproductive freedom, access to women’s health services, constructions of the impaired body and gender based identity (Asch and Fine 1987; Morris 1991; French 1993; Wendell 1997; Fawcett 1998; Sheldon 1999; Thomas 1999). Feminist discourses have highlighted the ‘double oppression’ often experienced by women with impairment and the further marginalised position of women in society with impairment (Asch and Fine 1987; Sheldon 1999). In bringing the body into a genre previously dominated by materialist and social relational approaches, the intersection of feminist discourses into the Disability Studies genre has promoted agency, the right to equal social status, autonomy, and improved gender-specific support services for all women with impairment (Asch and Fine 1987; French 1993; Morris 1993; Wendell 1997; Fawcett 1998; Sheldon 1999; Thomas 1999).

Poststructuralist discourses have also influenced the Disability Studies genre by critiquing the modernist dichotomy of the genre. In rejecting the impaired-non-impaired
binary and oppression frameworks, poststructuralists have come to view ‘dis-ability’ as a complex dialectic of biological, psychological, cultural and socio-political factors. As such, poststructuralists seek to position impairment along a graded continuum, where the differing aspects and experiences of impairment are positioned along a continuum of the social landscape (Corker 1999; Shakespeare and Watson 2001; Thomas 2004). The intersection of poststructuralism on the genre has highlighted the diverse and differing degrees of impairment and varying restrictions of bodily function from impairment (Fawcett 1998). As noted by Shakespeare (2001), a poststructuralist approach to impairment inherently seeks to dismantle the social divisions based on impairment by viewing everyone in society as impaired to some extent, with all individuals positioned along an impairment continuum based on different degrees of biological, social and agency structures (Shakespeare and Watson 2001:19). Poststructuralists thus promote a ‘normalisation of impairment’ by claiming that impairment is ubiquitous, and that people with impairment should not be distinguished as separate from the mainstream (Zola 1989; Thomas 2004).

Postmodernists take the approach that each individual experience of impairment is unique and thus can not be bound by any socially constructed divisions. The postmodernist approach reduces each individual experience of impairment to a singular viewpoint, declaring each individual experience of impairment as unique. An individual’s experience of impairment is thus singular and relative, and defined fully by the context of surrounding events and situations. Any overall truth is thus viewed as unobtainable, with individuals only capable of understanding one individual reality based on their unique perception and knowledge. Reality and truth for postmodernists are thus viewed as pluralist, interlinked and interwoven, and as a continuous and simultaneous interplay of contradiction and reality (Fawcett 1998).

Thomas (2004) noted that the postmodernist influences on the Disability Studies genre in-effect established a meta-analysis of all individual experience, and that even if this
was achievable, would not then be practical or theoretical useful. Shakespeare (2001) also supports this claim, noting that the singularity of postmodernism gives no recognition to the multiplicities or shared common experiences of impairment within any social framework. Shakespeare has positioned himself as supporting a postmodernist dialogue, but as maintaining a pluralist approach that encompasses the shared common experiences of impairment.

As is evident, these major critiques of the Disability Studies genre have impacted on how impairment is defined and positioned within society and how society has responded to impairment. The intersection of feminist, poststructuralist and postmodernist approaches on the Disability Studies genre have significantly altered how both impairment and ‘disability’ are understood in society, and together have reduced constructions of the dualist binaries characteristic of the Disability Studies genre.

3.5 Medical Sociology and the Critique of the Social Model

The Social Model and Disability Studies genre, and the influences of feminist, poststructuralist and postmodernist theories on them, have however been heavily critiqued by medical sociologist since the early 1990s. Medical sociologists claim that the Social Model and Disability Studies genre have over-socialised the emphasis of physical and social barriers in re-defining ‘disability’, and claim that the model and genre fail to acknowledge the impact of bodily impairment on the experience of disability. Bury (1986, 2001) and Gabe (2004) view the barrier-to-inclusion definitions and oppression frameworks of the Social Model and Disability Studies genre as too far removed from the daily realities of functional limitations caused by impairment. They view these discourses as not taking into account the social limitations reduced functional capacity of the body produces as a part of the everyday realities of people with impairment (Bury 1986; Hughes and Paterson 1997; Bury 2001; Gabe et al. 2004; Thomas 2007). These medical sociologists have sought to highlight that the strict application of the Social Model and Disability Studies genre deny any causative impact and restrictions impaired bodily
function produces, and seek to highlight that chronic and degenerative medical conditions, such as arthritis and multiple sclerosis, are undeniably disabling (Bury 1986; Hughes and Paterson 1997; Shakespeare 1998b; Bury 2001; Shakespeare and Watson 2001; Gabe et al. 2004; Thomas 2007).

Bury also viewed the Social Model as Marxist, constructionist and fundamentally flawed in locating ‘disability’ purely within materialist and capitalist structures. He claimed that the Social Model mistakenly viewed ‘disability’ as a result of purely economic and structural processes, that negated both the medical, cultural and contextual arenas in which impairment occurred (Bury 1986; Thomas 2004).

Shakespeare (1996) supported this view highlighting that if ‘disability’ was defined only within an oppression and barriers framework as within Social Model and Disability Studies discourses, how did people who did not identify as being oppressed then label themselves? Shakespeare also queried the them-and-us binary of the Social Model and the endpoints of the socially constructed positioning of disability, claiming it positioned people with impairment as some ‘disembodied Cartesian subject’ on a grid (Shakespeare and Watson 1996). As with Bury, Shakespeare now views the Social Model as outdated in defining ‘disability’ as a class difference only associated with the onset of capitalism and materialism (Shakespeare and Watson 1996).

As a part of these critiques, Bury (1986) called for the body to be brought back into discussions. In particular, he felt that the interactionist and relativist term ‘impairment’ should be used rather than the term ‘disability’, as utilisation of this terminology gave weight to the impact of the experience of illness and restrictions of activity. Bury viewed utilisation of the terminology of impairment as being more inclusive of the body, and of more readily acknowledging that sickness, pain or restricted activity remained a reality for those who suffered them on a daily basis (Bury 1986). Davis (1997:141) clarified...
these polarisations of views in looking at how advocates were using the terms noting that:

*Disability activists came to define ‘impairment’ as the physical limitation of a particular illness or a chronic physical limitation, while defining ‘disability’ as the social and political conditions that placed barriers in the way of that ‘impairment’, thereby creating a disabling condition. Thus impairment might be anything from HIV to paraplegia, and the disability anything from targeted discrimination to the absence of curb cuts or ramps.*

Perhaps unsurprisingly, Social Model traditionalists sought to refute these medical-sociological findings. They claimed that utilising the terminology of impairment shifted the deficit back onto the body and away from social and physical barriers preventing social inclusion, and that supporting the more universalistic terminology of impairment would mean that the need for change in regards to existing physical barriers around poor access to the built environment, public transport and/or places of employment could easily be side-stepped and ignored (Thomas 2007; Barnes 2008). Further, they claimed that blurring the identification and social awareness of the physical and attitudinal barriers experienced by people with impairment into more universalistic discourses based on bodily impairment risked diminishing the political leverage gained by the Social Model and the continued reduction of social barriers the model was instigating (Thomas 2007; Barnes 2008).

Thomas (2004; 2007) has to some extent taken on a theoretical middle ground. She has aligned herself with the original supporters of the Social Relational Theory in acknowledging the spatial separation between people with impairment and mainstream society, based on existing social barriers that continue to exclude, disable and oppress people with impairment (Thomas 2004). However Thomas also supports Bury and his efforts to ‘bring-the-body-back-in’ to disability discourses by acknowledging that restrictions on bodily function from impairment do impact on individuals considerably in
many instances. Thomas however has stated that until all social and physical barriers are removed, that it is not possible for her to support Bury’s medical sociological approach in full. Instead she has called for the development of a ‘Sociology or Sociologies of Impairment’ which would explore the individual experiences of people with impairment as a collective, and not only acknowledge social oppression, exclusion and inequality frameworks but would more adequately include restrictions and limitation caused by reduced bodily function (Thomas 2004; Thomas 2007).

Shakespeare (2006) however has taken on a neutral epistemological approach in the debate. Influenced by poststructural approaches, he claims that a level of impairment restricts all individuals to some extent, and that impairment is a normal and natural part of social construction. He counters what he views as the ‘negative oppression binary’ of the Social Model (and its overly socio-political leanings), and instead supports a more universalistic and holistic view of impairment which works towards increased ‘social responsibility’ by all members of society. Shakespeare’s emphasis on social responsibility associated with impairment, and increased focus on the need for interdependence and support, is thus progressive (Shakespeare 2006; Shakespeare 2008).

Efforts to incorporate the body and functional limitations of the body into Social Model structures have produced new fields within sociological discourses and have shifted the debate on impairment to the realms of more universal and generic social justice discourses. Yet the theoretical divide remains, and the debate between terminology and discourses on ‘impairment’ as a universal condition, and ‘disability’ as socially constructed barriers, remains contentious and will no doubt continue to influence and impact future social responses to impairment.

3.6 The Human-Rights perspective

In contrast to social responses to impairment in the United Kingdom and other western countries influenced by the Medical Model and the Disability Studies genre from the
1960s, social responses to impairment within many other parts of the world, particularly in the United States, were instead strongly influenced by the emergence of rights, specifically Human Rights discourses, and the development of United Nations frameworks. The development of the Human Rights frameworks within the United Nations in particular influenced many governments at a nation-state level, influencing how governments chose to respond to impairment and how policy was implemented. Although many of the Human Rights instruments developed during this time were not binding, they were influential enough to initiate real change for people with impairment at domestic policy levels, and raise considerable awareness of the plight and difficult living conditions being endured by most people with impairment across the globe.

I will now briefly examine the development of rights and international Human Rights frameworks in relation to people with impairment and development of support services.

### 3.6.1 Defining Rights and Human Rights

A right is a statement of an action that is taken to protect and advance an individual or collective’s situation. This action is often the correctness of a judgement, the granting of an entitlement or a prescription for change in a standard of conduct. Rights assist in defining the parameters of acceptable behaviour and action within a social group. They serve as a set of standards or ground rules for more equitable and fairer behaviour and often involve the identification of unequal entitlement or poor treatment of a disadvantaged entity, group or individual (Jones 1994). Changes in behaviour based on an identified right often serve to uphold justice, freedom, ethical considerations and morality for the greater well being of all members of the group (Michailakis 1997; Ishay 2007).

Rights often challenge many established and previously embraced social views, and when enacted, serve to reform various social platforms associated with entitlement, possession, status, benefit or rectitude (Jones 1994; Freeman 2002; Donnelly 2005; Ishay 2007). Rights can be used to achieve a level of equity for an individual or
collective, or raise an expectation that an individual or collective will be treated in a certain manner in keeping with a specified standard (Jones 2004).

The historical discourse associated with rights is substantial. It draws on debates associated with religious and theological foundations, moral principles, social rules, ethical considerations and philosophy (Ishay 2007). By the sixteenth century, the concept of rights had developed into a philosophical discourse within western societies. Rights philosophers sought to construct what was categorised as ‘...a new secular language, affirming a common humanity that transcended sectarianism’ (Ishay 2007:xxiii). Early rights philosophers such as Grotius, Pufendorf, Descartes, de Vattel, Hobbes and Locke all sought to utilise a language of rights in debating areas of moral equality, social justice, social inclusion and equality of power (Ishay 2007). These philosophers examined how social parameters should be defined and what it should mean to be a part of civil society within the jurisdiction of prescribed governance, or as they termed, within the social contract (Freeman 2002; Donnelly 2005). Hobbes and Locke sought to debate what they defined as ‘the principles of rights’ and how rights within the context of the modern nation-state could be utilised in maintaining individual freedom and status (Freeman 2002; Donnelly 2005; Nussbaum 2006; Ishay 2007).

The operationalisation of rights thus promoted empowerment and respect to facilitate the betterment of life (Jones 1994; Donnelly 2005; Ishay 2007). Rights effectively tied together abstract values such as liberty, equality and security to social practice, and sought to realise those values through action and behaviour modification (Jones 1994, Freeman 2002; Donnelly 2005). To claim a right, it was necessary to determine firstly which right would be drawn upon and promoted, then establish the exact contents of any rights claim. Lastly, one was required to determine the justification of declaring the right in light of epistemological and moral justifications (Jones 1994; Drewett 1999; Donnelly 2005).
As such, claiming a right therefore required a possessor or a bearer. An individual or collective was required to claim ownership of a particular right, to posses a right, and then set about asserting their claim to this right. Once a right had been defined and claimed, it was then the role of the individual or collective to defend their capacity to maintain that right. To operate a right, it was necessary to maintain a landscape of mutual obligation and relationship between two parties and maintain the duty bearers decision in determining how one was to behave (Jones 1994; Donnelly 2005). In this sense, rights contrasted significantly with rules. Although a rule had the capacity to prescribe a standard of behaviour upon a collective, a rule did not require a possessor or bearer or any mutual obligation between any parties (Jones 1994; Donnelly 2005). A right could also be viewed as either subjective or objective in that both the result of a right could be the objective modification of a standard of behaviour imposed on a collective, or the subjective claiming of a benefit or entitlement by an individual in seeking to improve a situation. Rights were thus viewed as an active and strategic mechanism for individuals or collectives to realise a gain and achieve a desired outcome (Jones 1994).

Rights in the modern context are most frequently discussed in terms of Human Rights. During the twentieth century, rights in the context of Human Rights were utilised in two pivotal areas. Human Rights were firstly utilised to support the self-determination of many nation-states, particularly within Africa, the Americas and Asia in their claims for independence and political autonomy. Secondly, Human Rights were utilised as a fundamental discourse in supporting the development of the institution of the United Nations, whose role was to support marginalised and disadvantaged groups such as women, children and refugees through use of its legal framework of binding Human Rights based conventions.

Human Rights most generally operate within a legal framework of ‘legal reasoning’, whereby legal discourse seeks to find authoritative principles to underpin obligations and
agency to fulfil a Human Rights claim (Michailakis 1997). Once a claim to a Human Right is made, a set of legal arrangements and obligations are then assumed between the individual and/or collective, and a moral imperative (where an expected level of reciprocal benefit or behaviour is legally specified on moral grounds) is sought to strengthen or add to existing legal entitlements (Michailakis 1997). The basis of modern Human Rights is thus the philosophy of legal positivism. A Human Right must be legally enforceable and must be within the parameters of legal interpretation of the nation-state (Freeman 2002). As Human Rights are not based on any assessment associated with the moral value system of any universal religious or secular traditions, a claim for a Human Right must resonate around a particular legal principle and must be assessed on ethical and legal justifications of what is just and fair.

Mann et al (1999), in his summary on the principles of modern Human Rights, highlighted that the role of Human Rights was often to address the direct relationship between government and an individual. He noted that the promotion and protection of Human Rights was often not bounded by nation states, and applications and claims for Human Rights in many cases required an unsteady balance between a government and an individual or collective while pursuing a more universal claim (Mann et al. 1999). Mann viewed Human Rights as defining a set of international law standards that governments could uphold. He viewed the role of Human Rights as both independent from and interrelated to the function of governance, and as traversing a path of allegiances to both governmental authority and protection from governmental control. Human Rights thus served as a mechanism to support disadvantaged and marginalised human collectives within a nation-state to maintain their aspirations and hopes for an improved quality of life, and provided a means through which common and universal responsibility to protect disadvantaged and marginalised human collectives was established (Gruskin et al. 2005; Ishay 2007).
Of significance, recent discussion on Human Rights philosophy has debated the extent to which distinctions of culture, religion and opinion can intersect through modern Human Rights discourses. The interface of Human Rights with real-life cultural distinctions, religious diversity and political disparities all serve to place considerable strain on the legal structures of modern Human Rights (Ishay 2007). The intrinsic and autonomous rights of various cultural or religious groups, often viewed as fundamental to structure of those cultural groups, in many cases sit in sharp contrast to many basic and well-established Human Rights afforded by western societies based on individual freedom and equality. Where Human Rights are required to address an existing and defined custom or social rule of a particular group, there is often considerable debate and dialogue as to the extent the parameters of the Human Rights dialogue, and indeed the social contract, should flex or be redefined to be inclusive or exclusive of this particular practice while still retaining its moral foundations of universal justice and equality (Ishay 2007). The extent to which the Human Rights discourse can stretch and waver to incorporate these differing contingencies and transcend the array of ideological positions of the postmodern era is thus an area of ongoing debate for Human Rights philosophers.

3.6.2 Human Rights and the United Nations

Central to the operationalisation of Human Rights at an international level has been the establishment of the United Nations (UN) in 1945. Succeeding the previous League of Nations, the UN was developed in response to the extreme human suffering, atrocities and injustices that occurred during World War II (Jones 1994; Mann et al. 1999; Donnelly 2005; Ellis 2005; United Nations 2009a; United Nations 2009b). It was founded on principles of universal Human Rights, dignity, equality and justice for all human beings. It defines its role as ‘maintaining international peace and security, developing friendly relations among nations and promoting social progress, better living standards and human rights’ (United Nations 2009b:1).
Human Rights within the context of the UN operate within a legal framework of Conventions, Declarations and Standards. The principle and framing agreement of the UN is the Universal Declaration of Human Rights (UDHR), adopted on 10 December 1948 (Mann et al. 1999; United Nations et al. 2002; Manderson 2004; Donnelly 2005; Ellis 2005; Rioux 2008; United Nations 2009a). The UDHR, although symbolic, provides the UN with its pre-eminent statement and vision for ‘a common standard of achievement for all peoples and nations’ (Mann et al. 1999; Ishay 2007; United Nations 2009c:1). In 1966, the International Covenant on Civil and Political Rights (ICCPR) and International Covenant on Economic, Social and Cultural Rights (ICESCR) were formulated as additions to the UDHR. The ICCPR and ICESCR are legally binding and provide the UDHR with further clarity and weight. The ICCPR and ICESCR, together with the UDHR, form the International Bill of Human Rights (United Nations 2009c).

Since 1948, approximately two hundred Conventions, Declarations and Standards have been adopted worldwide (Mann et al. 1999; Freeman 2002; Donnelly 2005; Ellis 2005; United Nations 2009a). Within this structure, nation-states commit themselves to implementing Human Rights principles into their domestic legal systems and policy landscapes by becoming party to these international UN agreements (Freeman 2002). Conventions ratified by nation-states are binding, and being a signatory to a UN Convention ‘charges governments (and the populace represented by it) with the duty to honour the obligations and responsibilities explicated in the convention’ (Manderson 2004:33). In contrast, Declarations and Standards are not binding. They instead provide a guide to aspirational principles and protocols that a nation state may be expected to incorporate into domestic law, and it is through these mechanisms that the UN exerts most of its influence (Freeman 2002; Donnelly 2005).

**3.6.3 Declaration on the Rights of Disabled Persons (1975)**

During the early 1970s, the effectiveness of the International Bill of Human Rights to address the specific rights of people with impairment was questioned. These debates
were driven by the emergence of ‘disability’ movements, such as the Disability Rights movements in the United States, that were seeking to improve the standard of living for people with impairment. Discussion identified that the generalised and broad International Bill of Human Rights was struggling to reform and initiate action in relation to improvement of conditions for people with impairment who were generally marginalised within most nation-states globally. These viewpoints were supported by the implementation of the Convention of Elimination of Racial Discrimination (1966) and the Convention on the Elimination of Discrimination Against Women (1979) that had been implemented in addition to the International Bill of Rights to increase the leverage of rights-based need in these specific areas.

The UN Declaration of Rights of Disabled People in 1975 was one of the first documents to formally articulate the view that people with impairment had a right to a decent and inclusive standard of living (Lindsay 1996; Michailakis 1997; Cooper 2000a). The principles sought to ‘ensure that people with a disability were to be treated with dignity and respect, that people with a disability should be recognised as equal rights bearers and that people with a disability should be provided with the ability to participate fully in society’ (Basser and Jones 2002:254). The Declaration supported deinstitutionalisation of people with impairment, empowerment, improved civil liberties and development of socially inclusive living models for people with impairment (United Nations 1975; Michailakis 1997). In particular, the Declaration at an international level communicated a strong anti-discrimination message and articulated that no person with impairment should be ‘subjected to differential treatment’ or subjected to treatment of a discriminatory, abusive or degrading nature (Basser and Jones 2002:254).

The Declaration was also viewed as providing a lever to allow effective advocacy for people with impairment to claim various Human Rights through domestic law (Cooper 2000a; Basser and Jones 2002). Its introduction was viewed as acknowledging the rights of protection, privacy, confidentiality and dignity of people with impairment to receive
social support such as support services, and more broadly, as socially repositioning people with impairment as bearers of Human Rights on an international landscape (Basser and Jones 2002; Ellis 2005). The Declaration, although non-binding, provided a strong statement on general principles of decency and protection for people with impairment that were readily accessible by nation-states for transference into their domestic law, policy structures and education programs (Cooper 2000a; Basser and Jones 2002). The influence of the UN Declaration of Rights of Disabled People in 1975 was considerable, and at an international level, it provided a major step in working towards improving the Human Rights of people with impairment globally.


Following the implementation of the Declaration in 1975, the UN declared 1983 - 1992 Decade of the Disabled Persons. Administered at a governance level, the initiative sought to raise financial resources to improve education and employment opportunities for persons with disabilities and consequently increase social participation (United Nations 2003). Further, the Decade of Disabled Persons oversaw the implementation of the first UN Special Rapporteur assigned to study the connection between Human Rights violations and disability. A further initiative under the Decade of Disabled Persons was the establishment of the annual International Day of Disabled Persons to acknowledge the social place of people with impairment on 3 December each year.

By the early 1990s however, disability rights supporters were viewing the non-binding structure of the 1975 Declaration as ‘lacking enforceability and legislative weight’ (French 2008). The existing Declaration was viewed as lacking flexibility and comprehensiveness, and of failing to incorporate newly emerging ideas and contemporary models associated with impairment (French 2008).
In response, the United Nations developed the Standard Rules on the Equalisation of Opportunities for Persons with Disabilities in 1993. The non-binding Standard Rules provided a set of basic international legal standards of moral and political values that could effectively be utilised at a domestic level for programmes, laws and policies (United Nations 1993; Michailakis 1997). The Standard Rules attempted to influence policy structures that would maximise the opportunities for people with impairment to participate in society, and establish a balance between individual-centred and person-environment approaches (United Nations 1993; Michailakis 1997). As summarised by Cooper (2000c), the standard rules sought to:

- raise awareness in society about persons with disabilities, their Human Rights, their needs, their potential and their contribution
- ensure the provision of effective medical care to persons with disabilities
- ensure the provision of rehabilitation services to persons with disabilities in order for them to reach and sustain their optimum level of independence and functioning, and
- ensure the development and supply of support services, including assistive devices for persons with disabilities, to assist them to increase their level of independence in their daily living.

The Standard Rules of Equalisation of Opportunity thus sought to ensure that all persons with impairment could exercise equal Human Rights and that nation-states met their obligations (United Nations 1993; Michailakis 1997). They focused on the key areas of accessibility, education, employment, income maintenance and social security, family life, personal integrity, culture, recreation, sports and religion (Cooper 2000c).

At a policy level, the establishment of UN frameworks and specific Declarations and Standards in relation to impairment provided a solid platform for nation-states globally to begin to address issues of deinstitutionalisation and social inclusion for people with impairment. Although not creating rapid change and not binding in nature, the 1975
Declaration, Decade of Disabled Persons 1983-1992 and Standard Rules of Equalisation of Opportunity of Disabled Persons 1993, established significant policy frameworks that, at a government level, would begin to establish positive change in relation to social responses to impairment. Specifically, the Declarations and Standards influenced how government responded to impairment, how policy frameworks could be established or developed to support deinstitutionalisation of people with impairment and how reintegration into the social networks could occur.

3.6.5 Disability Rights

Within the United States, social responses to people with impairment were considerably influenced by Human Rights discourses. Unlike the United Kingdom, the concept of Human Rights emerged in a landscape where rights concepts were already embedded within the federal constitution and where, to a large extent, rights were ingrained within the psyche of the United States citizen (Albrecht 1992; Shakespeare 1993; Meekosha 2004). The utilisation of Human Rights in the United States reflected the differing platforms of protest and reform between the United Kingdom and United States. In the United States, Human Rights underpinned many of the changes in social responses associated with impairment. Further, Human Rights-based changes developed within a fierce free market economy where competitive-value systems dominated the social landscapes, and where strong emphases on self-help ideologies and market driven consumerism were the dominant mechanisms through which reform for people with impairment was required to navigate (Albrecht 1992; Shakespeare 1993; Meekosha 2004).

The emergence of the Disability Rights movement in the United States in the 1960s emerged amidst significant other Human Rights movements of the times, such as the rights to equal status of women and the elimination of racial discrimination. These social movements questioned many entrenched social prejudices that still existed at the time, and sought to promote equality and improve quality of life for these disadvantaged
groups by claiming associated Human Rights to equality and freedom from discrimination. Supported by these movements, the Disability Rights movement sought to promote the Human Rights of people with impairment to live socially inclusive lives and enjoy the equity and prosperity others enjoyed in society. Through social protest and campaigning, the movement promoted the advancement in social status of people with impairment by drawing on the principles of Human Rights such as equity, freedom, dignity and overall advancement of human life, and in seeking to halt impairment-based institutionalisation and social segregation (Mann et al. 1999; Fleischer and Zames 2001).

The Disability Rights movement in the United States was particularly successful in providing a strong identity for people with impairment. People with impairment were themselves able to advocate for improved conditions, and successfully utilised Human Rights debate to stimulate discussion on many misconceptions and negative attitudes directed towards people with impairment (Charlton 1994; Fleischer and Zames 2001).

3.6.6 Disabilism

One particular aspect of the Disability Rights movement was the development of Disability Rights terminology such as ‘disabilism’. Paralleling other social movements during the period, and their utilisation of terminology such as racism and sexism, the concept of ‘disabilism’ was developed during the mid 1960s to raise awareness of levels of social oppression and discrimination experienced by people with impairment. Disabilism was utilised in both social and judicial settings to raise awareness of discrimination and stigma experienced by people with impairment (Albrecht 1992).

The concept of disabilism preceded the development of formal legal mechanisms, such as the Americans with Disability Act (ADA) (1992) within the American judicial system. It created substantial precedent to improve the civil, moral and cultural rights of people with impairment, and generated effective change in community attitudes and values towards people with impairment within the American landscape. It helped establish a language with which people with impairment could challenge historically entrenched
prejudices, discrimination and forms of social oppression (including systemic discrimination) based on bodily impairment (Albrecht 1992; Cooper 2000a; Cooper 2000b; Johnstone 2001; Handley 2001; Basser and Jones 2002; Beecher 2005; Thomas 2007).

3.7 Independent Living Movement (ILM)

Building on these developments, the Independent Living Movement emerged in Berkeley, California, in the early 1970s. Its development centred on a group of students with impairments who had been living on campus at the University of California, Berkeley during completion of their degrees. The students were resisting the enforced relegation back to institutions once their degrees were complete, and following an extended campaign advocating for the Human Right to live within mainstream society, the group were successful in obtaining residential housing accommodation within the community. They then went on to establish one of the world’s first network of accessible, community-based residential housing accommodation for people with impairment (Barnes et al. 1999).

The Independent Living Movement was also successful in establishing one of the world’s first networks of community-based attendant care services for people with impairment (Albrecht 1992; Shapiro 1994; Thomas 2002). The model of community-based attendant care services challenged the established dominance of professional service providers who had previously only provided support to people with impairment within an institutional facility. The Independent Living Model established a network of community-based attendant carers that provided disability services within the home, and that allowed these students to live independently while remaining within the community. These students were encouraged to formulate their own service plans to work towards achieving their personal goals, and were encouraged to make use of natural and mainstream support networks to assist them with daily living tasks and recreation (Rioux and Bach 1994; Scotch 1994b; Dempsey and Nankervis 2005).
The Independent Living Movement was radical in its action for that time. As noted by one of its founders, Ed Roberts in 1977, the Independent Living Movement was ‘the civil rights movement for millions of Americans with disabilities’. It provided a wave of protest against segregation and discrimination, and affirmation of the right and ability of persons with disabilities to share fully in the responsibilities and the joys of society’ (Charlton 1994:1). Its participants, in seeking to improve their own social status, promoted the citizenship, responsibility and the Human Rights of people with impairment around the world to participate in mainstream living and social activities (Rioux and Bach 1994; Scotch 1994b; Dempsey and Nankervis 2005). The Independent Living Model was innovative in developing a model for the wide-scale implementation of community-based attendant care services, and in providing a clear and definitive alternative to the policy of impairment-based institutionalisation (Rioux and Bach 1994; Shapiro 1994; Scotch 1994b; Barnes et al. 1999; Dempsey and Nankervis 2005).

3.8 The Business of Service Delivery and the Support and Care Industry

Within most western countries, social responses to people with impairment became more commercially focused with the transition towards community-based attendant care services. Throughout the 1980s and 1990s, the first wave of private businesses opened, whose primary task was to provide community-based attendant care services to individuals. This also expanded to the establishment of private businesses such as occupational therapists, physiotherapists, podiatrists, community-nursing services, providers of mobility equipment and medical supply businesses, whose roles were to service the health care needs of people with impairment transitioning from institutions to community-based living (Ellis 2005; Spall et al. 2005).

The commercialisation of the community-based services arena became known as the ‘business of disability’ and ‘care industry’. It brought with it a new language based on ‘delivery of services’ and ‘client need’. ‘Service providers’ provided care within fixed
schedules and allocations of time, with ‘funding’ for ‘attendant care hours’ allocated on a weekly basis. Staff providing care within this landscape often lacked training, with occupational, health and safety guidelines virtually non-existent. Within the newly emerging landscape of community-based, commercialised care, individuals transitioning out of institutions into the community often struggled to have their support needs met by haphazard service provision and a community that had not yet adjusted to the needs of people with impairment. From the beginnings of deinstitutionalisation, the sector was already hampered by un-met need, under-funding and rationing of support services, with a significant burden of support transferring onto informal networks (Albrecht 1992; Ingstad and Reynolds-Whyte 1995; Ellis 2005; Spall et al. 2005).

A goods and services culture rapidly developed around attendant care agencies, with agencies establishing control over how allocations of support services were utilised and rostered based on competing need. In addition, attendant care agencies self-determined the extent of margin that could be made within allocations available. People with impairment often became positioned as commodities, consumers and clients, with allocation of restricted hours often defined by budgetary constraints of the service provider. Provision of support services often became characterised by complexity, inconsistency and variation in allocations of funding available as businesses within the care industry sought to achieve a comfortable balance between adequate provision of care for clients, while effectively managing their agencies as successful and profitable business ventures (Albrecht 1992; Scotch 1994b; Ingstad and Reynolds-Whyte 1995; Ellis 2005; Spall et al. 2005). In many cases, the move away from institutionalisation towards commercialised, community-based support services often brought along a differing set of issues and complexities to manage on a day-to-day basis while individuals attempted to make their way in a social landscape still highly fraught with social barriers. Community-based support services were often conceptualised during this period as ‘looking after’ those deemed dependent, and despite the hard-fought battle of deinstitutionalisation, individuals now living in the community struggled to gain rights
and obtain social inclusion within the early development stages of community-based living and establishment of the support service framework.

Standards for delivery of attendant care, seeking to improve the quality of care being provided within this commercialised support landscape, only filtered into the disability support services industry slowly. Although the implementation of standards went someway towards addressing variation in standards of support services being delivered in the home-setting, these standards were far from encompassing and often lacked monitoring and accountability. Further, increasing diversity in how businesses delivered disability support services meant maintaining standards was often difficult, and standards that were initially introduced failed to encapsulate the varying situations and breadth of events associated with provision of home-based support (Albrecht 1992; Ingstad and Reynolds-Whyte 1995). Key business criteria of efficiency, margin and costs were increasingly enmeshed with ensuring adequate provision of disability support services, meeting and adhering to disability support service standards and attempting to delivery disability support services in a supportive and friendly environment.


By the early 2000s, there was broad realisation by ‘disability’ advocacy groups globally, and the United Nations itself, that the existing Human Rights-based instruments of Declarations and Standards meant to promote and protect the Human Rights of people with impairment were not providing adequate protection for people with impairment in many localised settings (United Nations 2007a). It was viewed that a Convention was needed to bind governments to act on matters associated with the Human Rights of people with impairment, and ensure that people with impairment enjoyed a more equitable level of Human Rights, social inclusion and self-determination (United Nations 2007a).
Following extensive consultations with both people with impairment and non-government organisations representing people with impairment, the General Assembly of the United Nations formally adopted the Convention on the Rights of Persons with Disabilities (CRPD) on 16 December 2006 (United Nations 2007a). The CRPD was one of the fastest conventions to pass through United Nations, with a formal consultation period of just over 3 years. The 50 Article ‘thematic convention’ was progressive, and provided a tangible means of working towards improving the fundamental freedoms, rights and inherent dignity of the 650 million people worldwide living with impairments (United Nations 2007a; French 2008). It included mandates for reasonable adjustment of still existing physical barriers, articulation of measures aimed at achieving equality, influence on policy and program design, and increased consultative processes for legislative reform (French 2007; United Nations 2007a; Rioux 2008). It was also viewed as having the potential to deliver significant outcomes for people with impairment by focusing on areas of government and societal responsibility, rather than individual responsibility or pathology. Further, it also encapsulated many of the more recent Human Rights to emerge specific to people with impairment such as freedom of movement and mobility, accessibility and socially inclusive living (Rioux 2008). The Convention was also a hybrid Convention in that it incorporated both Civil and Political and Economic, Social and Cultural Rights (which many other UN Conventions had been unable to achieve), and was unique in promoting a principle of ‘substantial equality’ rather than ‘formal equality’ as a relevant standard to be met by the nation-states in addressing pre-existing disadvantage (French 2008). An Optional Protocol was also linked to the Convention that established an individual complaints process associated with Human Rights violations (French 2007; French 2008; Rioux 2008).

3.10 Capabilities Approaches

Social responses to impairment in recent years have also been influenced by a concept known as The Capabilities Approach, developed by economist Amartya Sen and philosopher Martha Nussbaum (Sen 1993). The concept is based on achievement of
social justice and human dignity through the advancement of individual capability. The approach utilises a comparative Quality of Life mechanism to explore, evaluate and assess the individual capacity of an individual and determine the fundamental human entitlements they require to uphold human dignity. In doing so, it utilises an idea of ‘threshold level’ capabilities to examine essential requirements to uphold quality of life, dignity and social inclusion (Nussbaum 2003b).

At one level, the Capabilities Approach requires an initial evaluation of an individual’s capabilities or ‘functionings’, defined as the basic capabilities and capacities demonstrated by an individual (Nussbaum 2003b:34). The evaluation of functionings is not based on utilities of real income, wealth, opulence, primary goods or resources, but more on an individual’s quality of life, their ability to flourish, their ability to achieve happiness, and the extent of felt freedom, fulfilment and empowerment by the individual. Evaluation of capacity is noted as creating a target, an upper goal and/or a conception of good created through the improvement of an individual’s capabilities (despite this evaluation having the potential to be influenced by ‘personal characteristics, social arrangements, ethical and political criteria’) (Nussbaum 2003b:33).

At an applied level, the approach strongly relies on the concept of social responsibility and interdependence of the group to ensure an individual can flourish to improve their capabilities (Nussbaum 2006; Shakespeare 2006). The concept of interdependence acts on the premise that of all members of a society will support each other, including people with impairment, in contributing to society and the social good. The personal capabilities of an individual within the social group are thus examined in seeking to improve overall levels of social justice through the improvement of the individual. The Capabilities Approach can thus be thought of as a tool for development, where an individual is supported in improving their own capacity and capabilities for both their own increased wellbeing and the reciprocal benefit of the group (Nussbaum 2006; Shakespeare 2006).
The Capabilities Approach is characterised by a distinct duality that emerges between improving an individual’s status, quality of life and well-being, and improving the overall levels of social justice and human dignity for the social good. As described by O’Neill (1995), constraints, such as human vulnerabilities and degrees of powerlessness can prevent an individual from fulfilling these capabilities and taking up opportunities. Thus, in achieving these goals, a process of eliminating vulnerabilities, in themselves highly variable and sensitive to context, is often required in order for an individual to flourish.

Nussbaum however highlighted that The Capabilities Approach is highly reliant on the distribution of resources (Nussbaum and Glover 1995). If an individual was deemed as needing resources to improve their capacity, according to Nussbaum, ‘it must be evaluated that the functions of human beings are most worth the care and attention of public planning’ (Nussbaum and Glover 1995:145). Nussbaum sought to utilise an objectivist approach of constructing a list that utilises ten mutually supportive capabilities as central requirements (requirements a nation-state may wish to endorse) for true human ‘functioning’ and dignity of the human being (See Appendix B) (Nussbaum and Glover 1995). She argued that an individual must first be able to meet the most important human functions and basic functional capabilities before they are able to improve and advance their level of functioning (Nussbaum and Glover 1995).

Nussbaum describes this list as abstract, open ended and subject to ongoing revision and interpretation. She describes drawing on Rawls’ concepts of social contract and conceptualisations of primary justice, and notes that the list is reliant on nation-state sovereignty and the consent and commitment of the social group of the people to whom the list is applied. It ‘provides individuals scope to move towards choice and activity, and provides individuals with scope to adjust to what they want to do and what they want to achieve’ (Nussbaum 2003b:73).
Despite its universalism, the list is criticised for not identifying many inequalities in the attainment of capabilities between gender and culture, and is viewed as requiring an independent theory of equality to supplement the list. Rawls described the Capabilities List as a 'partial moral conception', and highlighted that a commitment of social resources to citizens who are 'less capable' and 'less able' to contribute socially (however this was defined) may be needed. Rawls highlighted that for certain individuals, social reciprocity can be difficult to achieve, and hence it was important to ensure fairness of resources are demonstrated. Rawls acknowledged that justice based on equality and fairness alone may not always succeed, and that for this reason, concepts of cooperation, mutual advantage and reciprocity (with hopeful gain) such as within the Capabilities Approach, may need to be developed (Nussbaum 2006). Rawls also acknowledged that although the law of society can address claims for need and entitlement (and rights to these) the extent to which political justice is comprehensive and should be expected to cover everything is contentious.

To some extent, Nussbaum has critiqued Human Rights with her list in claiming the Capabilities Approach has increased choice for the individual. She views Human Rights as pushing an individual into functioning in a particular way considered valuable by others, and views Human Rights as too legally orientated and political by nature. She also questioned the extent to which Human Rights alone provided the scope to achieve well-being, and the extent to which support could be ensured under a Human Rights framework (Nussbaum 2003b). Nussbaum viewed the Capabilities Approach as providing more precision with it list, and as more effectively canvassing both Civil and Political and Social, Economic and Cultural rights (Nussbaum 2003b). As with the Principles of Normalisation and SRV, Nussbaum’s Capabilities Approach seeks to socially reposition people with impairment upwards to achieve improved social justice. However in furthering the Principles of Normalisation and SRV, it could be argued that the approach more effectively emphasises the increased role of support and social responsibility
required in achieving the upward social repositioning of people with impairment (Nussbaum 2003b; Nussbaum 2006).

3.11 Summary

As these discussions demonstrate, social responses to impairment and ‘disability’ have altered dramatically over the last century. An array of theoretical discourses, movements, legal frameworks and approaches over this time have sought to transform impairment and disability and re-evaluate how western culture understands and responds to impairment and disability. Policy responses to impairment that had been dominated by the Medical Model, and its previous forms of social control and exclusion, have made way for policy and legislative frameworks promoting increased social inclusion and status for people with impairment. Further, discourses such as Normalisation, SRV, the Social Model, the Disability Studies genre and Human Rights have dramatically influenced how support service structures in Victoria have developed in seeing to improve the social status of people with impairment.

In many ways the Medical Model and the Social Model have developed in relation to each other, and continue to create a significant disjuncture in how impairment and ‘disability’ are socially defined. Further, medical sociological critiques of the Disability Studies genre, which have brought the body back in to disability and impairment discourses, continue to emphasise the place of medicine and impacts of impairment on individual function, regardless of the reduction of many social and physical barriers. These contrasting perceptions and the differing ways in which impairment and ‘disability’ are viewed thus continue to divide the discipline and influence the way in which society responds to impairment and ‘disability’.

Social movements such as the Independent Living Movement, Disabilism and Disability Rights have also forged new ground in terms of social responses to people with impairment in working towards reducing stigmatisation, discrimination and the physical
exclusion of people with impairment. Within the United States, these movements forged the construction of community-based support service frameworks and provided the foundations for the current business orientated community-based model of support service delivery.

Further the development of the United Nations in the later half of the 20th century, and associated Human Rights frameworks, created significant social awareness of the plight of people with impairment at an international level. An array of disability specific Declarations, Standards and Conventions now support the International Bill of Rights in seeking to uphold the dignity, quality of life and freedom of people with impairment globally through engagement with individual nation-states. In contrast, recent discourses such as the Capabilities Approach, are seeking to again influence social responses to impairment utilising concepts of mutual-interdependence and social responsibility dialogues, rather than Human Rights frameworks.

The history of social responses to impairment and ‘disability’ and associated discourses, social movements and frameworks are thus crucial to the understanding of the experiences of people with impairment. These discourses are embedded within each individual’s narrative of impairment, and continue to influence and impact on the day-to-day experience and context of support service provision. In the next chapter I will focus specifically on Australian and Victorian social responses to impairment and disability. I will examine domestic policy responses that emerged in response to these key international discourses, and specifically examine the establishment and development of support service frameworks for people with impairment in Victoria, and more broadly Australia.
Chapter 4 : Establishment and Development of Victorian and Australia Disability Support Service Frameworks

4.1 Introduction

The establishment and development of community-based support service frameworks for people with impairment and ‘disability’ in Victoria and Australia have been strongly influenced by the many international movements and discourses discussed in Chapter 3.

In this chapter, I explore the formulation of domestic policy responses associated with people with impairment in Victoria, and more broadly in Australia, over the twentieth century, that have led to the development of the complex and fragmented support service frameworks that exists in Victoria today. I examine the influences and impacts of international discourses on the construction of domestic support service policy in Victoria from a historical, chronological viewpoint, and examine the evolution of the construction of the community-based disability support service framework, policy structures, legislation and disability service standards associated provision of disability support services in Victoria.

4.2 Australia: The Charity Model and Welfare State

4.2.1 1788-1901 – The Charity Model

Social responses to impairment and ‘disability’ in Australia from European settlement in 1788 until Federation in 1901 mirrored social responses to impairment in the United Kingdom at the time (Kennedy 1982; Cass et al. 1988; Lindsay 1996; Gleeson 1997; Gleeson 1998; Gleeson 1999; Cooper 1999). As Australia was increasingly colonised, large-scale asylums and institutions were built in major cities mirroring those already established in the United Kingdom. Social responses to people with impairment in Australia during this period were dominated by the Medical Model, with people with impairment generally excluded from society or, based on assessment by the medical profession, confined to asylums and institutions based solely on the existence of impairment.
As in the United Kingdom, the confinement of people with impairment within institutions in Australia during his period was viewed as a social good and in the best interests of the individual and their families. These views reflected the negative social attitudes and practises towards people with impairment that existed at the time within western cultures that viewed people with impairment as ‘less than human’ and as ‘external to mainstream society’ (Cass et al. 1988). Records from the Benevolent Society in New South Wales during the period show that people with impairment were often categorised as the ‘infirm’ and ‘the deserving poor’, and were viewed as objects for pity, protection and charity (Lindsay 1996). As Lindsay (1996:1) highlights:

> [U]ntil the end of the nineteenth century people with disabilities who were unable to work were accorded low priority for welfare support and relief by a society often struggling to cope with the needs of the able bodied. Public and professional attitudes to people with disabilities continued to be characterised by fear, paternalism and the need for segregation and the major policy response continued to be custodial institutionalisation

Conditions within these asylums and institutions however rapidly became poor and overcrowded for people with impairment (Kennedy 1982; Gleeson 1999; Gleeson 2001). The asylums and institutions were run on strictly medical lines under treatment and rehabilitation styles, and were often only staffed by a small team of nurses. Upon being institutionalised, the overall health of individuals most often rapidly deteriorated and individuals in many cases struggled to simply survive on a day-to-day basis (Kennedy 1982; Quibell 2004; Manning 2008).

Some people with impairment able to rely on informal care did avoid institutionalisation during this period. In these cases, individuals and their families were only able to obtain a minimal amount of support provided by philanthropic and church organisations, through what was known as the Charity Model (Kennedy 1982; Cass et al. 1988; Lindsay...
The Charity Model involved informal provisions, known as out-door and home-based relief, to be provided directly to the ‘poor and deserving’ in their homes. Organisations and societies received a minimal amount of resources from the State or affiliated church although these mostly were only able to provide little more than sustenance support for individuals in need (Kennedy 1982; Cass et al. 1988; Lindsay 1996; Gleeson 1999; Gleeson 2001). People with impairment (and their families) however were often highly stigmatised and discriminated against by society under this Charity Model, and were most commonly scorned upon and viewed as unable to contribute to society in any meaningful way.

4.2.2 1901-1986 - The Welfare State

With Federation and the establishment of Federal Government in Australia in 1901, policy responses to impairment and ‘disability’ were delegated to individual states. Section 51, subsection xxiii of the Australian Constitution listed the formal separation of powers between the Commonwealth and States. It defined a number of responsibilities that would be retained by the Commonwealth, and defined the residual powers for funding and provisions for health services, including management of formal institutions for people with impairment, to the States (Australian Government 1901; Lindsay 1996).

The period of Federation also oversaw the provision of the first formalised benefits to many Australians following the formalisation of the Constitution. In 1908 the Federal Government, following the lead of a number of the States, introduced the first national means-tested, non-contributory Invalid and Old Age Pension (Cass et al. 1988; Lindsay 1996; Australian Government 2002; Goggin and Newell 2005). The introduction of the Invalid and Old Age Pension established the basis of a benefits framework in which the Federal Government assumed responsibility for income support of people unable to provide for themselves, that included people with impairment that had been able to remain outside of institutions (Cass et al. 1988; Parmenter et al. 1994; Lindsay 1996; Australian Government 2002; Goggin and Newell 2005).
In social policy terms, Federation in 1901 also coincided with the beginnings of the Welfare State Model, a model whereby the State took on an increased level of responsibility over its population and sought to establish a welfare safety-net for the population through expansion of its entitlements and benefits programs. The assumption of the ‘classic’ Welfare State Model was generally characterised by full employment, industrialisation, progress and development. As people with impairment were often viewed as a tragedy, inefficient, unproductive and as unable to contribute anything of value to society during this period however, they often received little support from within this Welfare State Model (Parmenter et al. 1994).

However as prescribed by the Welfare State Model, the State took on responsibility for the treatment and rehabilitation of men having returned from war service with impairment following World War I. In 1917 the Repatriation Commission was established by the Federal Government to provide medically orientated rehabilitation and vocational training. In 1948, following World War II, the Repatriation Commission was further expanded into the new Commonwealth Rehabilitation Services (CRS) that provided rehabilitation, vocational training and employment programs for all ex-service people with physical or sensory impairments (Parmenter et al. 1994; Lindsay 1996; Australian Government 2002; Goggin and Newell 2005).

Where the harsh conditions of the institution could be avoided, support for people with impairment was most often provided informally by immediate family members. Mothers most often shouldered the burden of providing support to their children or loved ones, trying to keep them out of institutional facilities (Parmenter et al. 1994; Lindsay 1996; Australian Government 2002; Quibell 2004; Manning 2008). Employment options were virtually non-existent, and the few existing sheltered workshops that did exist paid minimal and token wages. Social responses to impairment and ‘disability’ during this period were characterised by the continuation of institutionalisation and a high reliance
on informal support for people with impairment seeking to remain outside of asylums and institutions.

### 4.3 New Directions

The institutionalisation of people with impairment remained the dominant and static policy response to impairment up until the late 1970s and early 1980s in Victoria and Australia. It was not until the emergence of key international theoretical discourses, such as The Principles of Normalisation, the Independent Living Model and Disability Rights movements that policy responses to impairment in Victoria and Australia began to shift. The influence of these discourses and movements lead to a growing awareness by policy makers in Victoria and Australia of the capacities of people with impairment to live independently within society and contribute to society as equals (Ashman 1989; Parmenter et al. 1994; Gleeson 1997; Bigby and Ozanne 2001; Bostock et al. 2004). In addition, the release of the United Nations Declaration on the Rights of Disabled Persons in 1975, as discussed in Chapter 3, was highly influential at an Australian domestic policy level in initiating policies for deinstitutionalisation.

The deinstitutionalisation of people with impairment in Victoria and Australia signalled a virtual paradigm shift in domestic policy and social responses to people with impairment. It signalled the beginnings of a new direction in how government responded to impairment, and created social awareness of the possibilities of people with impairment living inclusively within society. However the ideals of the deinstitutionalisation and the reality of wide-scale deinstitutionalisation of people with impairment were somewhat removed. It rapidly became evident that a significant expansion in numbers of residential accommodation options was needed, and that a support service framework would need to be developed in moving towards a model of community-based living for people with impairment. Further, a raft of legislative and policy reform would be required to support this transition, including the development of a community-based support service industry (Ashman 1989; Parmenter et al. 1994; Gleeson 1997; Bigby and
Ozanne 2001; Bostock et al. 2004; Quibell 2004). The following sections examine these key changes in relation to policy and social responses to impairment associated with deinstitutionalisation.

4.4 Royal Commission on Human Relationships (1977)

Initial attempts by the Federal Government to identify provisions that would be required for the wide-scale deinstitutionalisation of people with impairment were instigated within the Royal Commission on Human Relationships that began in 1974 (Australian Government 1977). The Federal Government’s Royal Commission was the first attempt by any government in Australia to actually establish exact figures on the numbers of people with impairment, either institutionalised or living within the community. It also sought to identify levels and quality of care being provided to people with impairment, and sought to gain an overall picture of the plight of people with impairment during the 1970s in Australia.

The final report of the Royal Commission was released in 1977. It identified many levels of disadvantage and social oppression experienced by people with impairment, both within and outside of institutional settings (Australian Government 1977). In particular, it identified disturbing and inadequate conditions in most state serviced institutional facilities, and the particularly detrimental personal costs to individuals confined to these institutions (Australian Government 1977).

In canvassing community attitudes to people with impairment, the Royal Commission noted widespread un-acceptance of ‘the disabled’ and ‘the handicapped’ within Australian society (Australian Government 1977). The Royal Commission identified widespread social hostilities and discrimination encountered by people with impairment remaining outside of institutional care, and identified low levels of home-help programs in existence. Difficulties were also identified within family units where ‘handicapped children’ remained in the home. This included where some parents had difficulties in
accepting their ‘handicapped child/ren’, and where the presence of a ‘handicapped child/ren’ in the home considerably increased levels of stress and strain within these family units (Australian Government 1977; Lindsay 1996).

Recommendations by the Royal Commission in relation to impairment included the formulation of a comprehensive list policies aimed at reducing social discrimination against people with impairment (such as public education programs and legislative reform), transition from a model of institutional care to a model of community-based care and development of a community-based disability support service framework (Australian Government 1977).


Calls for deinstitutionalisation of people with impairment in Australia gained momentum with the declaration by the United Nations of the International Year of the Disabled Person (IYDP) in 1981 (Ashman 1989; Lindsay 1996; Parmenter 1999; Australian Government 2002; United Nations 2008). Australia’s contribution to the year included a large media campaign (based on approaches of The Principles of Normalisation, the Independent Living Movement and Disability Rights) that sought to counter the negative stereotypes of people with impairment that prevailed through much of Australian society (Victorian Government 1982; Ashman 1989). The media campaign utilised positive and empowering images of people with impairment, and included images and film of people with impairment playing sport, engaging in social activities and as independent adults with decision-making power.

The IYPD campaign in Australia was extremely successful in raising awareness of the capabilities of people with impairment at a community level. It acted as a catalyst for deinstitutionalisation and social reintegration of people with impairment, and provided a strong platform for people with impairment in Australia to begin advocating for improved rights and conditions. The momentum from the IYPD enabled the development of a

### 4.6 The New Directions Report (1985)

By the mid 1980s however, the momentum for deinstitutionalisation of people with impairment gained from the IYPD had slowed. Development of community-based disability support services were viewed as at best ad hoc, and generally seemed to be based around particular advocacy groups or specific medical conditions. There appeared to be a lack of any systemic structure or framework, and availability from the few support services organisations in operation were characterised by unevenness of distribution and unmet need (Lindsay 1996). Further, inaccurate data about the needs of people with impairment and levels of support services actually required continued to impede the development of any coherent based policy response (Lindsay 1996).

The aspirations of the IYDP were also contrasted by a descriptive report released by the Victorian Government in 1982 that identified 25% of people with impairment living outside of institutions were living below the poverty line, and that many people with impairment were forced to rely on daily food handouts and pensions just to survive (Kennedy 1982; Victorian Government 1982). The report also identified that additional financial support was required by people with impairment on a day-to-day level if people with impairment were going to live independently and inclusively within community (Victorian Government 1982). The report also highlighted a need for increased government funding to establish stocks of adequate community-based residential accommodation (Victorian Government 1982).

In 1983, the Federal Government instituted a review of all community-based disability support services that had developed since 1970, based on the findings of the Victorian review. It acknowledged that financial entitlements, benefits and levels of funding to
assist the States in establishing community-based residential accommodation and
disability support services structures for people with impairment remained low (Cass et
al. 1988; Ashman 1989; Lindsay 1996; Parmenter 1999). The working title of the review
- the Handicapped Programs Review, was both unique and extensive. It contained 1700
submissions and took the unprecedented step of consulting with 5000 participants,
including people with impairments themselves, to gain insight and knowledge of the
lived experiences of impairment and community-based support services required
(Ashman 1989; Parmenter et al. 1994).

In 1985, the findings of the review were published in a report entitled 'New
Directions' (Australian Government 1985; Cass et al. 1988; Parmenter et al. 1994). The
report confirmed overwhelmingly that people with impairment sought to live inclusively
within society and be included in all decision-making processes (Cass et al. 1988). Many
of the findings confirmed the findings of the 1982 Victorian Government review at a
national level, noting that ‘...existing structure[s] of providing assistance to people with
disabilities were complex, and therefore not well understood, and in places, not well
coordinated’ (Cass et al. 1988:34). The New Directions report identified that people with
impairment, their families and carers were all ‘extremely critical of existing services
based on institutional living arrangements, sheltered workshops and activity therapy
centres’ and were critical of levels of authoritarianism and paternalism involved in the
provision of services (Lindsay 1996:1).

The New Directions report also reflected the ideological shift away from the tolerance of
impairment as a reason for institutionalisation, to awareness that deinstitutionalisation
and social inclusion of people with impairment was preferable for the overall wellbeing of
society. Further, the report identified a definitive shift in policy formulation - from policy
based on the dependency and the Welfare State Model to policy based on principles of
social equity and inclusion (Lindsay 1996).
In practical terms, the report identified the need for significant policy and legislative reform at both Federal and State levels. This included need for an expansion of in-home attendant care services, construction of community-based residential accommodation units and short-term respite care (as relief for primary carers), employment options and need for improved income benefits (Cass et al. 1988). The report also recommended that at a community level there was a need for establishment of an accessible transport systems, access to the built environment and establishment of impairment self-help, sport and leisure programs (Cass et al. 1988).

4.7 Disability Support Pension

In addition to policy and legislative reforms required to ensure deinstitutionalisation, it became evident that a review of income benefits and financial entitlement arrangements for people with impairment would be required to ensure re-integration of people with impairment, particularly as lack of financial stability had been identified as a long standing barriers to social inclusion (Lindsay 1996). In 1986, the Federal Government conducted the Social Security Review. It identified that there had been no changes in entitlement arrangements for people with impairment since the implementation of the Invalid Pension in 1908, excepting rate increases. It also identified that there had been gradual increase in dependency on the Invalid Pension since 1970, and that there appeared to be complexities with the non-comprehensive eligibility criteria in obtaining the Invalid Pension (Lindsay 1996). Following on from the review, a Disability Task Force was established based on the recommendations from the review, whose focus was to coordinate ‘a package of measures’ to ensure income support for people with impairment. It aimed to encourage and assist people with impairment to access to labour markets and to address identified disadvantages experienced by people with impairment in entering the labour market (Lindsay 1996).

In 1991, the Disability Reform Package implemented structural changes to income support payments for people with impairment nationally. The reforms saw the formal
implementation of the Disability Support Pension (DSP), with individuals previously on the invalid pension transferred onto the DSP. A focus on increased training for people with impairments was encouraged, in particular for individuals with less severe impairments, to encourage integration back into the workforce and subsequently into normal social roles. A disability panel was also established to assess rehabilitation and workplace integration, seeking to reduce lifetime dependency on the DSP. It acknowledged that the employment of many people with impairment would be an extensive and long-term process, but sought to work towards the goal of ‘quality employment, with permanent hours and opportunity for advancement’.

4.8 Development of the Home and Community Care (HACC) program (1985)

One of the first systemic structures developed to deliver community-based support services was the Home and Community Care (HACC) program in 1985. The aim of the HACC program was to provide ‘a comprehensive and integrated range of basic support services to enable older persons and people with impairment to continue to living independently in their own residential accommodation’ (Lindsay 1996:1; Duckett 2004). Services available through the HACC program included home help, community nursing, transport facilities, respite care and meals on wheels (Cass et al. 1988; Lindsay 1996; Duckett 2004).

Funding for the HACC program would be provided jointly between the Federal, State and Local Governments, with the Federal Government contributing approximately 50% of funding to the HACC program and the remainder of the funding being provided by a combination of funding from both the States and Local Governments. Clients would pay a fee for HACC services, aka a user pay system, and services would be administered at a local government level (Duckett 2004).

However numerous difficulties emerged with responsiveness and coordination of the HACC problem soon after it commenced. Although implementation of the HACC program
eased some of the high demands on many informal carers and provided a level of respite, high demands were placed on the HACC program from its instigation and the program struggled to meet demand (Lindsay 1996; Duckett 2004). Further, coordination problems, tensions with eligibility and problems with high expenses contributed to difficulties in running the HACC program (Duckett 2004). By 2004, figures showed that just over 50% of HACC program users utilised less than 10 hours per week (Duckett 2004).

Later, difficulties would emerge where the locally administered and user pay system of the HACC program intersected with newly established State Government support service programs, where it became necessary for individuals to access similar support services from multiple levels of government to meet need. An increased burden was placed on people with impairment in having to go through multiple assessment and eligibility processes in gaining to access each the various support service programs offered by each level of government (Australian Institute of Health and Welfare 2007).

4.9 The Disability Services Act (1986)

At a Federal and State level, the recommendations of the New Directions report culminated in significant change. In 1986, the Federal Disability Services Act was formulated, the first major piece of legislation that established the basis for a national community-based disability support service framework for people with impairment (Cass et al. 1988). The formulation of a national Disability Services Act signalled the biggest policy restructuring in Australia in relation to impairment since formulation of the Welfare State Model (Bigby and Fyffe 2006). The Disability Services Act, in formalising community-based disability support service needs, reduced the reliance of people with impairment on charity and informal care, and introduced a more positive shift towards consumer driven choice in relation to receipt and availability of support services (Parmenter et al. 1994; Lindsay 1996).
The principle objectives of Disability Services Act were to oversee the establishment of flexible, innovative and responsive support service programs for people with impairment. These programs would work towards increasing community inclusiveness by providing funding for accessible residential accommodation units, in-home community-based attendant care services and funding for equipment and support aid requirements (such as the Program of Aids for Disabled People (PADP) (Lindsay 1996). It was thus envisaged that the Disability Services Act would support increased participation and integration of people with impairment into society (Victorian Government 1986).

Despite the positive objectives of the Disability Services Act, many of the traditional support service providers opposed the implementation of the Act (Parmenter et al. 1994). These service providers feared losing control of the financial resources of the capital assets of institutional facilities, sheltered workshops and activity therapy centres as they were closed. They believed the new Act was biased in favouring the smaller community-based support service providers, which they viewed as ‘intrinsically insecure’. They viewed the Act as not providing administrative structure and were concerned with capacity of these organisations if there were insufficient resources to fund community-based support over a longer period of time. In response, the Federal government reinforced that the Act’s aims were to support the provision of quality community-based disability support services, regardless of the size of the organisation providing them or scale of the task overall (Lindsay 1996).

4.10 The Commonwealth State Territory Disability Agreement (CSTDA)

The establishment of the Federal Disability Services Act (1986) however did create significant problems in terms of the vertical funding arrangements between the Federal and State Governments in meeting the outcomes of the new legislation (Ohlin 1999). It became evident that further policy reforms would be required to clarify the parameters of funding between the Federal and State Governments to reduce overlap and
inefficiencies in funding between the two levels of Government (Parmenter et al. 1994; Yeatman 1996; Ohlin 1999; Parmenter 1999).

In 1991, the first Commonwealth State Disability Agreement (CSDA) was negotiated between the Federal and State Governments to define the responsibilities of funding (Ohlin 1999; Australian Government 2002). The five year CSDA agreement sought to enhance administrative efficiency and establish more streamlined funding pathways between the two levels of Government. The CSDA clarified that the Federal Government would be responsible for employment services and financial income benefits associated with ‘disability’, and that State Governments would be responsible (with partial funding from the Federal Government) for operationalisation of all residential accommodation and community-based support service delivery (Lindsay 1996; Ohlin 1999; Australian Government 2002; Australian Institute of Health and Welfare 2003).

However, the aims of the CSDA in providing clarity of responsibility of funding between the Federal and State Governments appeared to entrench much of the existing funding fragmentation. By compartmentalising various disability support service needs between differing levels of Government, the implementation of the CSDA created confusion and added another layer of complexity to the developing disability support services framework. People with impairment became forced to navigate between support services funded and provided at a Federal Government level (such as employment services and income benefits), support services funded and provided at a State Government level (such as residential accommodation, in-home community-based attendant care and provisions for equipment) and the HACC program administered at Local Government level. Notably, this devolution of responsibilities to individual State Governments of delivery of the majority of disability support services occurred at a time when other sectors, such as funding for Aged Care, were consolidating service provision within the national system to create uniformity and consistency (Australian Institute of Health and Welfare 2005b).
Further, predicted shortfalls in allocations of disability support services available for people with impairment outside of institutional care soon became evident. The principle source of support for many people with impairment became unpaid care provided informally by family members. During the mid 1980s, the Australian Institute of Health and Welfare (AIHW) estimated that up to 65% of people classified as impaired were utilising informal support or providing self-care. Only 26% of people classified as impaired were utilising a combination of both formal support services and informal care, and only 3% of people classified as impaired were utilising formal support services only (Australian Institute of Health and Welfare 2005b).

Outside of the CSDA funding arrangement, the State Governments were also responsible for the administration of a range of insurance and compensation schemes for people who acquired impairment through transport or work-place related accidents. These statutory schemes delivered support services for people with impairment outside of the CSDA agreement and operated independently of Federal legislation (Australian Institute of Health and Welfare 2005b). Individuals who received funding for disability support services through Veterans Affairs at a Federal level also remained outside of the parameters of CSDA funding arrangement. Further, individuals who obtained damages through the courts following a public liability claim funded their disability support services privately and were only eligible for CSDA funded support services based on assessment of capitol assets (Australian Institute of Health and Welfare 2005b).

In 1998 a further CSDA was renegotiated. Re-titled the Commonwealth State Territory Disability Agreement (CSTDA) to include Australia’s two Territory Governments, the CSTDA was a further attempt to resolve funding disparities between the Federal and State Governments amidst the complex, fragmented maze of disability support services that were emerging. Under the second CSTDA, people with impairment continued to face challenges with continued levels of institutionalisation, difficulties in sourcing and
accessing disability support service allocations, shortages in residential accommodation, inflexible program parameters and gaps in eligibility for disability support services (Australian Institute of Health and Welfare 2005b). Individuals described being forced to adapt their needs to fit into the plethora of program parameters, and struggled to navigate the complexities of the disability support service framework in meeting individual need (Australian Institute of Health and Welfare 2003). By 2003, it was estimated that the State, Territory and Federal Governments were responsible for more than 60 separate health and community support service programs related to impairment, both within and outside of CSDA (Australian Institute of Health and Welfare 2003).

By the 1990s, the principle objectives of deinstitutionalisation had only started to be met despite the establishment of a national Disability Services Act and 2 CSTDAs. The process of deinstitutionalisation in Australia could at best be described as gradual, and in Victoria, despite growth in the availability in levels of community-based residential accommodation, overcrowded and outdated institutional facilities continued to operate (Ashman 1989). At the beginning of the 1990s, approximately 2600 clients were still housed within 11 of the state’s main institutions, with a further 1200 people on supported residential housing accommodation waiting lists (with the situation mirrored in most other Australian states) (Ashman 1989; Manning 2008). Over two-thirds of formalised disability support services in Australia thus continued to be provided through institutionalised facilities. The achievement of deinstitutionalisation, although significant, was thus fraught with ongoing challenges particularly in relation to parameters of funding for community-based support services and availability of residential housing accommodation to support deinstitutionalisation.

4.11 Human Rights Equal Opportunity Commission (HREOC)

The gradual emergence of Human Rights on the social and political landscapes in Australia during the 1980s raised the issue that a more coordinated strategy in relation
to Human Rights across the board was needed in Australia. In response, the Federal Government established the Human Rights Equal Opportunity Commission (HREOC) in 1986. The statutory authority was established to oversee the development and operationalisation of Human Rights and anti-discrimination legislation and guidelines in Australia at a national level, with the further goal of promoting community understanding and awareness of emerging Human Rights and anti-discrimination structures and principles about to be introduced in Australia (Human Rights Commission 2009).

In seeking to achieve these goals, HREOC took on a multiplicity of roles that included development of Human Rights education programs to industry and community, provision of independent Human Rights interpretation and advice to the courts, parliaments and governments, resolution of complaints based on discrimination, independent contributions to public inquiries and research into the theory and operationalisation of Human Rights (Human Rights Commission 2009). In the absence of a Bill of Rights in Australia, HREOC played a crucial role in assisting the government and parliaments in Human Rights law interpretation, and in playing the role of amicus curiae ('friend of the court') where it was often given permission by the courts to intervene in a case and provide specialist advice on Human Rights and discrimination issues.

The HREOC complaint resolution process allowed individuals to lodge complaints of discrimination, which involved the complainant and respondent being given the opportunity to discuss an issue and reach an agreement. Conciliation was confidential, and where a complaint could not be successfully conciliated by HREOC, it was forwarded to the Federal Court of Australia or the Federal Magistrates Service for determination.

Since its inception, a significant number of disability cases have been brought before HREOC, including claims related to individual and systemic discrimination based on impairment and ‘disability’. In realising its goals of improving Human Rights for
Australian citizens, it has successfully reduced discrimination across many areas of society including in the disability area. More recently in 2008, HREOC was rebadged and now operates as the Australian Human Rights Commission (HRC) retaining its operational functions.

4.12 The Disability Discrimination Act (DDA) (Commonwealth) (1992)

Perhaps the most significant legislative social response to impairment and ‘disability’ in Australia has been the introduction of the (Commonwealth) Disability Discrimination Act (DDA) in 1992. With the support of authorities such as HREOC, the DDA was established as a legal mechanism whereby individuals who identified themselves with impairment could take legal action against a person or entity where it was felt discrimination, based on impairment, had been experienced (Cooper 2000a; Handley 2001; Basser and Jones 2002; Productivity Commission 2004; Beecher 2005). As with the American with Disabilities Act (ADA) 1990, the fundamental aims of the Australian DDA were to reduce and eliminate discrimination based on impairment, promote community recognition and acceptance of people with impairment, and create equality of opportunity for people with impairment before the law (Handley 2001; Basser and Jones 2002; Productivity Commission 2004; Beecher 2005). As Human Rights are not upheld formally within the constitution in Australia, legal mechanisms such as the DDA were utilised in seeking to embed Human Rights for people with impairment into domestic legislative structures (Cooper 2000a; Handley 2001; Basser and Jones 2002; Productivity Commission 2004).

The Australian DDA adopted a three dimensional approach in seeking to reduce discrimination and promote the Human Rights of people with impairment. Firstly, it assumed that the state would be proactive in guarding the interests of people with impairment. Secondly, it required the community to consider that issues of inequality associated with impairment would be within its powers to resolve, and thirdly, it anticipated that people with impairment would be empowered to act and make a claim against any form discrimination to uphold their Human Rights (Basser and Jones 2002;
As noted by Basser (2002:259), the distinctiveness of the Australian DDA was its commitment to social welfare, its Australian cultural expression of a ‘fair go’, its political ideology of individualism and its use of the law to facilitate social change. The DDA was and remains a unique and powerful mechanism in Australia in utilising a no-fault approach to identify and redress any occurrence of discrimination based on impairment at both systemic and individual levels (Basser and Jones 2002:261).

Crucially, the DDA sent a clear and direct message to the community that any form of discrimination based on impairment was not acceptable, and that there was now scope for any claim of discrimination to be run through the courts. The DDA also provided the means for a series of legally-binding disability ‘standards’ to be established to address disability-based discrimination at systemic levels. These standards canvassed a range of areas related to disability, such as employment, education, access to the built environment and public transport. The standards functioned in detailing particular standards of behaviour and performance required to be met at a systemic level in seeking to reduce discrimination for people with impairment (Human Rights Commission 2009). In partnership with industry, community and disability groups, HREOC oversaw the codification of many of the disability-standards with the DDA, such as the Access to Public Transport Standards (2002), Access to Education Standards (2005) and Access to Premises (Built Environment) Standards (2010).

As a legal mechanism, the DDA remains extremely effective in addressing disability-based discrimination complaints and in promoting concepts of social justice and Human Rights for people with impairment in Australia. The broad social mandate of the DDA continues to adhere to the principles of a commitment to social welfare, advancement of Human Rights and reduction of discrimination based on impairment (Cooper 2000a; Handley 2001; Basser and Jones 2002; Productivity Commission 2004).

4.13 The Commonwealth Disability Strategy
At an internal government level, the Federal Government established the Commonwealth Disability Strategy (CDS) in 1994 to assist all Federal Government agencies to meet their obligations under the DDA. The ten year CDS provided a framework, developed by the national Office of Disability, aimed to assess all mainstream programs in relation to disability discrimination. It aimed to identify and remove any discriminatory barriers associated with the utilisation of mainstream programs by people with impairment, and ensure opportunity for people with impairment to utilise mainstream programs were fair and equal (Australian Government 1994; Lindsay 1996). To ensure the needs and choices of people with impairment were taken into account, people with impairment were actively included on boards, advisory committees and reference groups of service and equipment programs (Australian Government 1994). The CDS thus sought to ensure equality of access to the social system for people with impairment and raise awareness of where reform was required across the services system to promote full inclusion of people with impairment (Australian Government 1994).

Although the objectives of the CDS were progressive at a bureaucratic level, and the CDS successful in utilising cross portfolio strategies to reduce discrimination related to utilisation of mainstream programs, the aims of the CDS were somewhat hampered in their implementation (Australian Government 2008). The CDS was criticised for providing delayed, fragmented and slow implementation of required reform of mainstream program processes. Although clearly identifying where policy changes and legislative reform were required in relation to discrimination, the CDS in many instances, failed to meet its broad objectives of wide-scale reform and reduction of discrimination in relation to provision of mainstream services in its first ten years (Lindsay 1996).

4.14 National Disability Advisory Council

In 1996, the National Disability Advisory Council was established to strengthen the links between Government and the disability community and to give stronger voice to the disability community. The aim of the council was to work with the Federal Minister for
Family and Community Services, Housing and Indigenous Affairs (FaCSHIA) and advise them on ways in which the lives of people with impairment could be improved. The council was made up of people with personal experience of impairment, people with experience as carers and support service providers.

The role of providing advice on key issues under consideration by Government has been challenging. The Council has been heavily involved in development of the new CSTDA agreements, providing Government with advice on welfare reform initiatives, consulting with State/Territory disability advisory bodies and national disability peak bodies to progress joint activities and promote the interests of people with disabilities, provide advice on establishing Disability Standards linked to the DDA and in working to ensure that the needs of people with disabilities of diverse cultural and linguistic backgrounds and those ageing with impairment are carefully considered in policy development and implementation (Australian Government 2010).

**4.15 2000 and Beyond**

Since 2000, a number of distinct trends have influenced social responses to impairment in Victoria and Australia, and the development of the support service frameworks. Generally disability related policy has been driven from a national level and has included the introduction of national Disability Standards inline with the DDA, increasing outsourcing and privatisation of service provision, improved data reporting and formulation of a national framework associated with support service delivery. Further, the recent formulation of the international UN CRPD and the first Human Rights and disability test cases to be run through Australian courts have successfully embedded Human Rights into the Australian legal frameworks. In this section, I explore these most recent social policy and legislative developments associated with provision of support services in Australia.

**4.15.1 The (Commonwealth) Disability Services Standards (2002)**
In seeking to improve quality and professionalisation of support service delivery across Australia, the first set of Federal Disability Service Standards were implemented in 2002. The Disability Service Standards sought to create a benchmark in safety and quality of delivery of community-based disability support services.

The Disability Service Standards identified the rights of a person with impairment to access a support service based on relative need (and available resources), having support services designed to meet individual needs and personal goals and ensuring people with impairment had opportunity to fully participate in decision-making activities related to their support service provision.

Further, the Disability Service Standards sought to ensure that all disability support services were delivered in a means that ensured the right to privacy, dignity and confidentiality, and that disability support services were sufficient and adequate to provide opportunities for individuals to develop skills and participate in valued community activities. Where these opportunities were not observable, an individual would have the right to raise a complaint, and have the complaint resolved without fear of retribution. Under the Disability Service Standards, service providers were also required to adopt quality management systems to optimise outcomes for service recipients, including recruitment of qualified staff, acting to prevent abuse and neglect and acting to uphold the legal and Human Rights of service recipients.

In 2007, these standards were reviewed and replaced with more advanced standards, the Disability Services Standards (FaCSHIA) (2007). These reviewed standards provided further clarification and detail in relation to the previous standards with specific reference to the Privacy Act and Employment Awards, expanded detail on management by service providers (such as employment conditions for staff recruitment, training and support) and a specific standard on the operationalisation of Human Rights.
4.15.2 Privatisation

Since 2000, privatisation in the provision of disability support services has rapidly expanded. As noted in chapter 3, the development of the ‘business of disability’ and privatisation of community-based disability support services produced significant change in the support service delivery landscape. During the late 1990s and 2000s, an increasing amount of government run community-based support services were outsourced and transferred into the private sector, with the view that the establishment of a Disability Services industry would improve efficiency and increase professionalisation of support service delivery. The Disability Support Standards were meant to oversee the administration and delivery of support services that had been outsourced to private industry to ensure that basic-standards and quality service delivery were provided.

Under a ‘Market Model’ approach, the delivery of community-based support services, in many cases, became driven by neo-liberal economic approaches designed to increase efficiency and create workplace flexibility. As in the United States, a goods and services culture rapidly emerged within Australia, with service providers seeking to operate and manage successful and profitable businesses in complex policy, legal and economic landscapes. Often the reality of this culture at a ground level was economic rationalisation that included increased levels of labour casualisation, cost cutting to increase profit margin, difficulties with recruitment and retainment of carers, and uptake of competitive free market strategies to obtain customers/clients and gain market share (King 2007). In some extreme cases this involved re-contracting out of services and stringent entrepreneurial management practices to sharpen costs. The Market Model approach thus saw the development of service provider franchises and rapid professionalisation and commercialisation of service provider businesses (King 2007).

The introduction of many Quality Assurance measures, in conjunction with the Disability Service Standards in theory meant service providers were increasingly responsible and
accountable to Government. However, ongoing managerial practises and continual efforts to secure funding were viewed as impacting on quality of disability support service delivery. Service providers in many cases were focused only on efficiency of management and demands on human resources at the expense of quality of service. The business of disability thus redefined the landscape and conditions in which support was provided within (King 2007). As Fine (2007) noted, the provision of disability services in Australia had ‘gone public’, with decreasing levels of support being provided through informal care, increasing demands for formal-paid disability support services emerging and private service provider corporations becoming increasingly more aggressive. By the mid 2000s in Australia, the provision of community-based services for people with impairment was supported by approximately $A7 billion per annum of Federal Government funding (Lindsay 1996; Disability Investment Group 2009).

4.15.3 The 3rd CSTDA

In 2002, a third CSTDA was negotiated between the Federal and State Governments. The main feature of this renegotiated agreement was the introduction of individual bilateral funding agreements between the Federal Government and each State and Territory Government. These bilateral funding agreements were designed to resolve ongoing funding overlaps, inefficiencies and disparities between the Federal and State Governments.

However, despite these renegotiations, tensions around parameters and amounts of funding provided by the Federal Government to the State and Territory Governments remained, with many State Governments struggling with shortfall and unmet need of services. In 2006-07, government expenditure on CSTDA services alone remained split, with the Federal Government contributing 26% of funding (excluding the Federal Governments $13 billion per annum in income and financial entitlements), while the State and Territory Governments remained responsible for the rest of the funding,
providing up to 74% of the funding for disability support services and residential accommodation (Australian Government 2008).

4.15.4 Australian Institute of Health and Welfare (AIHW) – data reporting

Funding shortfalls related to disability service delivery and residential housing accommodation at both Federal and State levels appeared to be further hampered by inaccuracies and unreliability of data on exact numbers of people with impairment. In response to this, the Federal Government commissioned the Australian Institute of Health and Welfare (AIHW) in the late 1990s to accumulate more accurate data of prevalence and trends of ‘disability’ and impairment in Australia.

In its biannual publication now entitled ‘Australia’s Health’, the AIHW outlines trends, prevalence, statistics and annual usage of disability services and residential accommodation by people with impairment in Australia. Much of the AIHW work is supported by statistical data obtained by the Australian Bureau of Statistics (ABS) since data collection on disability began in the 1981 census. In 1998 and 2003, the ABS released the Disability, Ageing and Carers, Australian: Summary of Findings Reports, which have provided a more accurate gauge of need and requirement associated with impairment since 2000 (Australian Bureau of Statistics 1998; Australian Bureau of Statistics 2004).

Further, availability of more accurate data sets by the AIHW in recent years in relation to provision of disability services and residential housing accommodation has documented high levels of informal support still being provided by family and friends outside of any CSTDA parameters (Australian Institute of Health and Welfare 2005a). In its 2008 report, the AIHW estimated that 1.1 million people with a severe or profound core limitation needed assistance with at least one of ten specific activities. Of these individuals, 77% had their needs fully met, 16% had their needs partly met and 7% felt their needs were not being met at all (Australian Institute of Health and Welfare
In recent years, ABS data reported by the AIHW has identified significant levels of informal support and unpaid care roles being provided by many immediate family members and carers across the community. Recent policy initiatives have sought to provide increased financial benefits for immediate family members and carers taking on these unacknowledged and unpaid care roles.

4.15.5 Operationalisation of Human Rights

The operationalisation of Human Rights and a culture of Human Rights has taken hold in Australia during the 2000s. Although case law within Australia associated with rights-based claims for improved support services is still an emerging area, significant decisions made in the United Kingdom based on European Union Human Rights Charter have started to influence the Australian services landscape (Ellis 2005). This has included decisions on Human Right associated with allocation of disability support services.

Skene (2008) views the extent to which Australian patients have ‘rights’ to medical and support services as contentious. Although viewing Human Rights to services in Australia as being met in terms of access to emergency services, Skene does not feel Human Rights to medical and support services are meet to as great an extent. Despite Australia implementing many international Human Rights-based instruments, such as the UDHR, CRPD and the DDA, and actively acknowledging statements within the UDHR associated with rights to an adequate standard of living that includes health and medical care, Skene claims that Human Rights to access support services in Australia at a domestic level are not fully met. Skene documents three reasons for this:

i. Rights-based international treaties, such as the UDHR, that promote adequate standards to health law, have no direct force in Australia unless they have been given effect in domestic law (citing Mabo v Qld no 2 1992). So although ongoing efforts have been taken to ensure general obligations of these instruments are placed into domestic
law and hence become operational, as the ratification of any treaty is not binding, they do not create any entirely new, legally enforceable Human Rights obligations.

ii. Australian courts are reluctant to review decisions requiring allocation of resources, despite claims of Human Rights to support services, preferring to leave such matters to the political judgement of politicians and parliament.

iii. Even if a Government decision is justifiable because it is a policy decision, for practical purposes, the judge can only remit a decision back to the decision-makers with a direction that a new decision be made with procedural fairness and clarify reasons for the decision. This accorded with a number of recent cases where patients or relatives have sought court orders requiring particular treatment be provided by Government, however the courts held that resource allocations were not judiciable.

Skene (2008) notes that more recently, courts in Australia have been prepared to examine decisions of health authorities on application, which has resulted in rulings that patients receive treatment (and could extend to disability services) - even though the courts do not strictly have jurisdiction in this area (Kennedy and Grubb 2000).

The ability of an individual to utilise rights-based instruments as a platform to claim for any improved provision of disability support services, through the layers of complexities of the organisational structures and privatised support providers, will however require testing. It is recognised that any Human Rights-based claim associated with provision of disability support services would also be affected by both the availability of resources in any jurisdiction and by interpretations of the claim by the judiciary (Skene 2008). However, where a duty of care or obligation of care can be proven to exist, it could be possible to 'enforce' by prosecution receipt of disability support services by the proprietor. For example, where the service provider is under obligation to another party (such as the state) to provide support, then the client has an enforceable right and is in a strong position to make a legal claim to obtain adequate support. Indeed, the duty of
care maybe extended to a third party where there is an expectation that the duty will be performed and support provided (Skene 2008).

The development of a Human Rights-based culture in association with the receipt of disability support services was described by Ellis (2004) as progressive change and fostering a Human Rights culture in social care. However, the extent to which provision of disability support services can be influenced by operationalisation of Human Rights through legal instruments, such as the CRPD and the domestic Human Rights instruments, remains uncertain.

4.15.6 National Disability Agreement (NDA) 2009

A new National Disability Agreement (NDA), effectively a fourth CSTDA, was renegotiated and implemented on 1 January 2009 (Australian Government 2010a; Australian Government 2010b). The re-branded CSTDA retained the joint, bilateral funding agreement of the previous CSTDA, but placed an increased emphasis on improving support for families and individuals providing informal care roles, and in establishing improved ‘supportive and sustainable living arrangements’ for people with impairment in the community (Australian Government 2010a; Australian Government 2010b). The new NDA was complemented by a significant increase in funding for residential accommodation and community-based disability support services provided by the Federal Government to the State, that provided an injection of funding to State-based funding of disability support services.

The NDA also aimed to reform disability support services by supporting individuals in informal care roles (Australian Government 2008). The Federal Government has also sought to implement a ‘single entry point platform’ for improved navigation of people entering the system that includes uniform assessment processes, a national quality assurance system and population bench-marking of disability support services (Australian Government 2010a; Australian Government 2010b).
In addition, the NDA aims to strengthen access and linkages to mainstream government services, strengthen social networks of people with impairment, improve provisions where there is still unmet need and demand for disability support services and ensure more consistent access to required aids and equipment (Australian Government 2010a; Australian Government 2010b). Further, recent funding additions have been provided through the NDA to reduce the number of young people with impairment still receiving care in nursing homes across Australia (Australian Government 2010a; Australian Government 2010b).


A major response to impairment in Australia has been its ratification of the United Nation’s Convention on Rights of Persons with Disability (CRPD) in 2007. The Australian Government joined over 80 other countries in being the first signatories to sign the CRPD on 30 March 2007, and formally ratified the Convention on the 18 July 2008 (French 2007; United Nations 2007).

Within Australia, the ratification of the CRPD placed emphasis on empowering people with impairment to play a greater role in decisions that affected them (United Nations 2007a). It provided ‘additional layers of protection’ through specific applications, embodied attitudinal change, and has sought to ensure all people with impairment are given the opportunity to reach their full potential (French 2007; United Nations 2007b).

As noted by French, Australia’s ratification of the thematic CRPD is binding, and Australia must now adhere to the spirit and principles of the CRPD in both good faith and through completion of UN monitoring and reporting requirements (Australian Government 2010d). Its ratification of the CRPD will thus require activation of domestic constitutional and consultative processes (French 2007). Although Australia has in place the DDA,
HREOC and a Disability Services Act, Australia currently does not have a Charter of Human Rights at a Federal level through which it can meet its Human Rights obligations (French 2007).

Australia is also a signatory of the CRPD’s Optional Protocol, the complaints and inquiry mechanism to the CRPD, which allows individuals to communicate with the treaty body about Human Right’s violations where domestic remedies have not be able to provide resolution (French 2008). Australia became a signatory to the Optional Protocol in September 2009.

4.17 National Disability Strategy (2011)

Following on from the NDA, the Australian Government recognised the need for ‘a new whole-of-government, whole-of-life approach to disability issues’ to manage the increasing demands of ‘disability’ at a national level. In 2011, a ten year National Disability Strategy was developed that aimed to oversee needed reform to mainstream disability support services, inclusive of reforms associated with the newly ratified CRPD (Australian Government 2010a).

The across government strategy, functioning within the structures of COAG (Council of Australian Governments) includes development in specific areas of need, such as providing additional community-based residential and respite accommodation, expanding early intervention programs, implementation of Universal Design concepts, development of an online disability portal, increased support of leadership of people with impairment, improving telecommunications and digital content for people with impairment, addressing barriers to workforce participation, improving assessment for Disability Support Pension (DSP), establishment of disability trusts and implementation of a national carer strategy to acknowledge and provide support for informal carers (Australian Government 2010c).
The implementation of the National Disability Strategy has also included establishment of a 28-member National People with Disabilities and Carer Council (NPWDACC) to provide expert advice to government. Recent work of the Council has included the publication of ‘Shut Out: The Experience of People with Disabilities and their Families in Australia’, a report presenting recent experiences of life with impairment and service usage in Australia. The report was launched in August 2009 (Australian Government 2010c). In addition, the Disability Investment Group published ‘The Way Forward: a new disability policy framework for Australia’, which has led to the establishment of an Inquiry into Long Term Care and Support currently being conducted by the Productivity Commission, a statutory authority to the Australian Government designed to review economic parameters of policy implementation. The Australian Government has asked the Productivity Commission to conduct an independent inquiry into the costs, benefits and feasibility of long-term care and support for people with impairment that may include implementation of a National Disability Insurance Scheme (Australian Government 2010c).

4.18 Summary

As is evident, responses to impairment in Victoria and Australia associated with support services for people with impairment have been gradual and diverse. Victoria, influenced by responses at a national level, has experienced radical transformation in shifting from a medicalised, charity and institutionalised response to impairment, towards construction of a community-based support services framework supported by a national Disability Services Act, the DDA, HREOC, the CRPD, Disability Service Standards and prescribed national-state funding agreements of CSTDAs and more recent NDA.

However the pathway to achieving deinstitutionalisation and the establishment of community-based disability support services for people with impairment has been long and challenging, and fraught with unmet need, service fragmentation and under-funding. The development of the business of disability has created unique issues in terms of
monitoring and evaluating quality of support services, with distribution of resources and support service allocation an ongoing and contentious issue. Social responses to impairment in Australia were dramatically impacted by the decision of Australian Governments to out-source provision of community-based disability support services to private industry in the mid 1980s. The privatisation of community-based disability support services, although monitored by newly established Disability Service Standards, has seen many social responses to impairment become economically motivated, and provision of community-based disability support services driven by a profit and margin mentality in seeking to rationalise resources for financial gain. The wide-scale privatisation of community-based disability support services, and its associated issues, have thus dramatically impacted on the way in which Australian society has in recent years, responded to impairment.

Lastly, social responses to people with impairment in Australia have been aided through improvement of monitoring and reporting mechanisms, and through obtainment of more advanced statistical and qualitative data. These improved means of obtaining information, and increased capacity to identify status, needs and conditions of people with impairment has dramatically impacted on how Victoria and Australia have responded to people with impairment and how individuals with impairment, such as those with SCI have received support. In the next chapter, the development of the disability support service framework in Victoria will be examined, including the parallel developments of DHS Disability Services Division, the TAC and VWA as parallel funders of disability support services in the state, and the development of the raft of varying guidelines and parameters associated with provision of support services that has evolved at a state level in creating the complex support landscape that exists today.
Chapter 5: Victoria’s Disability Service landscape

5.1 Introduction

Although the Australian Federal Government continues to hold responsibility for overall policy direction and partial funding responsibility related to support services, the operationalisation of disability support services for people with impairment in Victoria has, since 1901, been the responsibility of the State Government of Victoria.

As with Federal legislation related to responses to impairment, the principles and values driving policy and legislation associated with the operationalisation of formal disability support services at a State level have been strongly influenced by international discourses. While Charity and Welfare Models and policies of institutionalisation dominated the State’s policy landscape in the first half of the twentieth century, movements such as the Independent Living Movement and Principles of Normalisation also drove policy reform towards deinstitutionalisation and the establishment of community-based disability support services framework within the state. Human Rights declarations such as the United Nations Declarations of Rights of Disabled Persons and the Standard Rules on the Equalisation of Opportunities for People with Disabilities defined how community-based support services would be administered across the state and helped define the parameters of support service and service standard operationalisation (Bigby and Fyffe 2006).

However, as with many other Australian States and Territories, the development of the disability support service’s frameworks and provision of community-based disability support services in Victoria rapidly became siloed and fractured. The development of the Department of Human Services (DHS) – Disability Services Division in the mid 1980s, the primary government department that would oversee deinstitutionalisation and the development of community-based disability support services, meant that the DHS
suddenly found itself positioned alongside of the Transport Accident Commission (TAC) and the Victorian WorkCover Authority (VWA) as a major funder of community-based disability support services in the State. The near simultaneous establishment of these three funding bodies, each governed by individual legislation, differing guidelines and parameters, varying program structures, separate internal financial structures and differing jurisdictions thus created significant disparities in how the provision of community-based support services were allocated. The raft of varying guidelines and parameters meant individuals with similar levels of impairment and need, in particular individuals having acquired SCI, received vastly differing amounts of support service allocation based on how their impairment was acquired.

In this chapter, I will examine the development of each of these authorities within the State of Victoria, and will examine how the development of this complex disability support service framework has created a fractured and uneven landscape for provision of community-based disability support services.

5.2 The Department of Human Services (DHS)

Since the mid 1980s and implementation of deinstitutionalisation policies, the State Government of Victoria has administered community-based disability support services through the Department of Human Services (DHS) - Disability Services Division. The operationalisation of the Disability Services Division has been governed by three significant pieces of legislation in Victoria: the Intellectually Disabled Persons Act (1986), the Disabled Services Act (1991) and the reviewed Disability Services Act (2006). In addition, the Victorian Disability Plan 2000-2012 strongly influenced policy direction related to provision of support services. I will now briefly canvass the establishment of these Acts and the State Plan related to provision of DHS support services.

5.2.1 Intellectually Disabled Persons Act (1986) and the Disabled Services Act (1991)
The development of community-based disability support services framework for people with impairment in Victoria began at a formal level with implementation of the Intellectually Disabled Persons Act (1986) and the Disabled Services Act (1991). These two pieces of legislation reflected the goals and objectives of the Federal Disability Services Act (1986) in supporting a moratorium on institutionalisation and establishing community-based support services to support people with impairment to live inclusively within society.

Somewhat late chronologically, the principles of Intellectually Disabled Persons Act (1986) focused in particular on people with intellectual impairment who had been institutionalised across the state on a routine basis since the previous century (Victorian Government 1986). The Intellectually Disabled Persons Act (1986) outlined provisions for planning, development, management, delivery and administration of new community-based support services for these individuals that would include in-home attendant care services, residential accommodation units, day placement programs, respite, community access programs, education integration, aids and equipment and a variety of home-help services (Victorian Government 2002). The Act was highly prescriptive in detailing development, maintenance and evaluation of these new support services. It also provided guidelines to improve the standard of support being provided to people with impairment still within institutions (Victorian Government 1986).

The Act was also designed to inform people of their new rights and opportunities to aspire to ‘a quality of life equal to that of other citizens’ (Victorian Government 1986). The Act aimed to support the development of opportunities for inclusion and participation, and support individuals in advancing their full potential with dignity and choice. This would be achieved through development of individual care plans that would define individual goals (reviewed regularly against objectives of the Act), and include adherence to standards, staff training goals and education programs on disability awareness. The Act also included guidelines for administration of funding agreements.
with registered residential service providers, complaints procedures, privacy and security guidelines, guidelines on maintaining individual finances/trusts and guidelines on restraint, seclusion and aversion therapies.

In 1991, the Disability Services Act (1991) was implemented in addition to the Intellectually Disabled Persons Act (1986) to provide increased ‘facilitation and direction’ in implementing the framework for community-based disability support services (Victorian Government 1991). The state based Disability Services Act was orientated towards guidelines for service planning and provision. Although restating the aims of increased integration and opportunity to enable individuals to reach their maximum potential, the Disability Services Act was more specific in outlining the specific tasks service providers were required to undertake in achieving these objectives. These included documenting and facilitating positive outcomes met by individuals, seeking to achieve conditions normal to that of mainstream Australians, tailoring services to meet individual needs and goals, ensuring that no single provider should control the life course of an individual, that support services were accountable and age appropriate to individuals, that individuals had opportunity to plan and consult about services, that privacy and confidentiality were respected and that individuals had access to advocacy and complaint processes.

Both of the the Intellectually Disabled Persons Act (1986) and the Disabled Services Act (1991) had broad philosophical underpinnings, incorporating both Medical and Social Models into their guidelines. However, these underpinnings meant the provision of support was implemented while trying to meet multiple strategies and objectives. Deinstitutionalisation in some cases resulted in only institutional-style of support occurring in residential accommodation, sharp increases in levels of unmet need, high reliance on friends and family and poor social connectedness (Bigby and Fyffe 2006). Community-based disability support service provision, although client centred, often became associated with client and consumer allocation, market availability, service
response, service brokerage and case management. Although not leading to the complete closure of institutions across the State, the State Government and DHS were successful in at least reducing the number of individuals in institutional care in its first two decades from 4439 people in 1976 to 1126 in 1996 following implementation of the Acts (Bigby and Ozanne 2001).

5.2.2 The Victorian State Disability Plan 2002-2012

In 2002, Victoria implemented its Victorian State Disability Plan 2002-2012 (Victorian Government 2002). The State Plan sought to create a whole-of-government, whole-of-community response to impairment in strengthening provisions around community inclusion and participation of people with impairment in Victoria. The vision of the plan was that ‘...by 2012, Victoria will [would] be a stronger and more inclusive community - a place where diversity is embraced and celebrated, and where everyone has the same opportunities to participate in life of the community [with] the same responsibilities towards society as all other citizens of Victoria’ (Victorian Government 2002).

A significant part of the State Plan involved streamlining access to disability support services and increasing accountability of disability support service providers. This was to be achieved through improved systemic responses for individuals entering the disability support service framework, establishing program reviews to ensure disability support services were in fact contributing to social inclusion and lifestyle choice, and developing effective strategies to deal with an ever increasing demand for support services (Victorian Government 2002).

In aspiring to meet these goals, the State Government recognised it needed to reorientate disability support services towards a model of more personalised, individualised support packages to both acknowledge the way that many support providers were already providing innovative community-based support, and to facilitate more movement, flexibility and choice in how individuals utilised their support service allocations (Victorian Government 2002).
5.2.3 The New Disability Services Act (2006)

In 2006, as a part of the Victorian State Disability Plan 2002-2012, a major review of the Intellectually Disabled Persons Act (1986) and the Disabled Services Act (1991) was undertaken. The review identified that many parts of the 1986 and 2001 Acts had become redundant and that the multiple Acts and their differing parameters and styles were creating confusion and inconsistency. Further, the Acts came to be viewed as not fully articulating the Human Rights and protections for individuals that had developed in the proceeding decade and of not clearly defining the parameters of the term ‘disability’ (creating confusion around eligibility criteria). The Acts were also viewed as not adequately articulating the accountability of service providers, and it was recognised by DHS themselves that these legislative Acts ‘...no longer reflect[ed] the direction of support provision in Victoria’ (Victorian Government 2006).

The review culminated in the implementation of the Disability Services Act (Vic) (2006). The new Act sought to clarify many factors associated with the delivery of disability support services and significantly, introduced mandatory Disability Services Standards for service providers across the State (Victorian Government 2006). The features of the new Act also included the introduction of a number of ‘outcome standards’ based on broad thematic concepts (e.g. empowerment), a broadening of client grievance processes (which including the implementation of an ombudsman and a Disability Services Commissioner) and expanded roles for the State’s Senior Practitioner and Victorian Civil Administration Tribunal in relation to complaint resolution (Victorian Government 2006).

The review and implementation of the new Disability Services Act provided a modern overhaul of legislation and policy associated with Victoria’s disability support services sector, clarifying the roles and responsibilities of providers in delivering services. It served to formalise the Human Rights and status of people with impairment to receive
support services in a dignified and respectful manner, and provided specific, formal
grievance and conciliation processes to be followed when it was felt disability support
services were not meeting standards (including specific details as to support staff
boundaries, communication of information and administration of individualised plans)
(Victorian Government 2006).

5.2.4 DHS service programs

The provision of community-based disability support services provided through DHS
(until the recent implementation of individualised plans), has been provided through a
number of main disability service programs. The HomeFirst program funds up to 34
hours per week of in-home attendant care, with services administered by a service
provider who employ’s staff to provide the actual in-home service for individuals. DHS
also have an Aids and Equipment Program, Respite services and Futures for Young
Adults program.

In recent years, individualised program models that provide direct payments to clients to
enable them to individually purchase services inline with their personalised need, goals
and objectives have been developed by DHS. DHS administer funding packages, known
as Individualised Support Packages, under the banner of Support & Choice. A Support &
Choice package provides an allocation of funding directly to a client so that needed
disability support services are purchased directly by the client. The Direct Payment
Model is consistent with person-centred approaches being supported in both the
Victorian State Disability Plan and the Disability Services Act (2006), which encourage
choice, self-determination, control and more cost-effective use of funds (Lord and

5.3 Transport Accident Commission (TAC)

Compulsory motor vehicle insurance was first introduced in Victoria in 1939. Under the
Motor-Car (Third Party Insurance) Act (Vic) vehicle owners were required by law to
insure their motor vehicles were covered against liability if deaths or bodily injury were caused by the use of their motor vehicle. The bill was based on principle that compensation would be provided to every person injured as a result of negligent use of a vehicle, irrespective of who was driving (The Adelaide Advertiser 1939). Compensation for damages resulting from a motor vehicle accident would be provided through the insurance from premiums paid by vehicle owners. A person thus held the right to sue a negligent party through Common Law for damages, and it was the jurisdiction of the courts to hear and assess such cases (The Adelaide Advertiser 1939; Public Records Office 2009).

Until 1986, the Motor Accidents Board (MAB) and a number of independent insurers had provided transport insurance across the State under this legislation. These insurers however had struggled to effectively manage the State’s transport accident insurance and by the mid 1980s the scheme was virtually bankrupt. In its place, the Transport Accident Commission (TAC), a statutory authority of the Victorian State Government, was formed in 1986. The TAC was a comprehensive, no-fault scheme, established to fully cover costs of transport accident related injury. The objectives of the TAC are to provide effective rehabilitation of persons injured as a result of transport accidents in Victoria, to reduce the incidence of transport accidents, to provide suitable and just compensation in respect of persons injured (or who die) as a result of transport accidents and fund long-term support services required by individuals permanently incapacitated by a transport accident (Transport Accident Commission 2008). The TAC thus sits as a parallel funder to the DHS of support services required for people acquiring permanent impairment and disability.

In funding the cost of treatment for the recovery and rehabilitation of any injury sustained in a transport accident within Victoria, TAC fund provisions for ambulance, hospital, medical, pharmacy, dental and nursing expenses, rehabilitation services, travel costs, a visitation allowance for family, support with household tasks, childcare,
equipment or aids. The TAC also provides fortnightly loss-of-earning payments to cover income lost as a result of any transport accident. Opportunity to claim for compensation for pain-and-suffering as a result of the acquiring of a permanent impairment or disability is also available through TAC (Transport Accident Commission 2008).

In 2008, the TAC celebrated its twentieth year of operation in Victoria. During its operation, it has firmly established itself in Victoria as economically profitable and viable entity (Transport Accident Commission 2007). It is a world leader in motor accident education and accident prevention campaigns, most notably with its ‘shock tactic’ TV advertising campaigns in seeking to reduce road injury and trauma. It actively sponsors many entities in promoting road-safety, injury prevention and road toll reduction. Internationally, it is viewed as highly progressive in its use of marketing accident prevention strategies (Transport Accident Commission 2007).

Conversely, the TAC environment is viewed by some TAC clients as a litigious and tense environment. In receiving funding for disability support services through the TAC, clients are often required to appeal decisions, complete annual review processes, challenge service usage and justify expenses to maintain allocation of disability support services, similar to the rationing of DHS resources for support service allocation.

5.4 The Victorian WorkCover Authority (VWA)

Introduction of Workers’ Compensation schemes occurred on a state-by-state bases in Australia. Compensation for worker’s injured in a workplace accident was formally established in Victoria with the introduction of the Workmen’s Compensation Act 1914 (VIC). The Act sought to provide compensation to all workers sustaining injury ‘arising out of, or in the course of, their employment’ and compelled all employers to pay damages for injuries sustained to workers (Productivity Commission 2004). As with the various other worker compensation arrangements across Australia, this scheme was designed to provide ‘income replacement, medical cover and ancillary costs for workers.
and their dependents in the event of work-related injury or death’ (Purse 2005:11). By the 1970s, workers could claim unlimited compensation/damages through Common Law actions and had the ability to claim weekly ongoing loss-of-earnings payments (up to 100% of previous wages in some cases) (Purse 2005:14).

In 1985, claims for workplace injury were consolidated under the Victorian WorkCover Authority (VWA), a new statutory authority of the Victorian Government. Operating under the revised jurisdiction of the Accident Compensation Act (1985) and Occupational Health and Safety Act (1985), the establishment of the VWA was characterised by substantial reform including being underwritten by the State rather than private insurance schemes, implementation of vocational rehabilitation programs and workplace Occupational Health and Safety standards (Purse 1996; Productivity Commission 2004).

The Act required employers to obtain an insurance policy and pay a premium to the VWA. In the event of a work-place injury and/or acquirement of a permanent impairment or disability, the VWA would provide the cost of reasonable treatment for the recovery and rehabilitation. This included related provisions for ambulance, hospital, medical, pharmacy, therapy, ongoing in-home attendant care, dental and nursing expenses, rehabilitation services, travel costs, support with household tasks, childcare and equipment or aids. The VWA, as with TAC, thus sits as another parallel funder to the DHS of support services required for people acquiring permanent impairment and disability.

The VWA also provided ongoing, fortnightly payments for loss-of-earnings in cases of permanent impairment and disability. As with TAC, the VWA provide opportunity to claim for compensation for pain-and suffering, however unlike the TAC, claims for compensation in some cases are awarded through an automated process and internal assessment pathways within the VWA itself. Only limited opportunity exists for individuals acquiring a permanent impairment and disability from a workplace accident
to claim compensation for pain-and-suffering and loss-of-earnings through a Common Law claim run through the courts. Of note, compensation awarded through VWA's internal automated processes usually provide a quicker resolution to the compensation claim, however no opportunity is provided for the individual to contest their claim, present their version of events or challenge and negotiate compensation awarded.

5.5 Summary

While Victoria has sought to meet the challenges of providing community-based disability support services following deinstitutionalisation through development of a range of policies and legislative structures, as is evident, the disability support service framework in Victoria is now complex, multi-layered and siloed in its operationalisation. The development of three main funding providers related to the provision of disability services: the Department of Human Services – Disability Services Division (DHS), the Transport Accident Commission (TAC) and the Victorian WorkCover Authority (VWA), each governed by individual legislation, differing guidelines and parameters, varying program structures and jurisdictions has created significant disparity in the provision of community-based disability support services for people with impairment across the state. This complex policy landscape has evolved predominantly over the last 25 years and has produced dramatic and contrasting parameters in the provision of disability support services for individuals acquiring a permanent impairment and disability within the state.

In this next chapter, I will briefly examine existing compensation pathways for pain-and-suffering and loss-of-earning claims across the state for individuals having acquired a permanent impairment and disability such as SCI.
Chapter 6 : The Machinations of Compensation

6.1 Introduction

Following the acquirement of a permanent impairment or disability in Victoria, there is opportunity for individuals to obtain financial compensation for pain-and-suffering and loss-of-earnings. Claims for financial compensation often involve debate on levels of culpability, negligence and blameworthiness associated with how the impairment was acquired. Where a claim for financial compensation is successful, the amount of financial compensation awarded is generally determined by the level of fault or negligence that can be established related to how the impairment was acquired, the extent of pain-and-suffering and permanent incapacity, and the potential for loss-of-earnings over the lifetime of the individual.

The opportunity to claim financial compensation provides the individual with increased financial support over their lifetime, and enhanced opportunity to make lifestyle choices in relation to living with an impairment and disability. The obtainment of financial support in the form of compensation can thus dramatically impact on the wellbeing and quality-of-life of the individual with a serious impairment and disability such as SCI over their life-course.

In this chapter I explore firstly, the historical development of the concept of compensation, which includes the emergence of the concept of compensation, the establishment of the first formalised Compensation Insurance schemes in western societies and the development of modern day Common Law processes. Secondly, I explore the role of the Common Law of Tort as a specific aspect of Common Law in assessing the receipt of compensation in the State of Victoria. I explore the varying limitations and parameters of these processes within the Transport Accident Commission (TAC) and the Victorian WorkCover Authority (VWA) systems, and discuss the distinct
advantages and disadvantages of claims for compensation within the context of these Victorian legal statutes.

Lastly, I explore the two contrasting processes of assessment for compensation in Victoria following the acquirement of impairment that sit external to the courts and Common Law processes, for example the assessment of compensation through various internal schedules such as those prescribed by VWA.

6.2 Compensation as a concept

The concept of compensation is universal. It emerged within many social groups in order to prevent revenge and eye-for-an eye reactions following the occurrence of negligent or wrongful acts. Where a negligent or wrongful act was said to have occurred, an item was paid to the wronged party to make amends, redress and compensate that party for the wrongful act. This included where a defined and known standard had not been adhered to, where a level of responsibility had not been met or where an act of negligence by one party had caused loss to another (Robinson 2009). Once a breach of social duty had been identified and responsibility for the breach assigned, an item of compensation could be served to restore the injured party back to the position they were in prior to when the breach occurred (Rickett 2003; Drabsh 2005). Receipt of an item as compensation was thus viewed as a mechanism that served to limit personal vengeance, deter further injuries and repatriate the injured party following a wrong (Rickett 2003; Robinson 2009).

In 1841 Emerson, in ‘Compensation: An Essay’ highlighted that compensation was fundamentally associated with justice, retribution and natural life balance. He discussed the various representations of compensation and the potential of compensation to provide a level of justice or judgment invisible in nature. He highlighted particularly the polarity of compensation through the dual lenses of action-and-reaction and standards of good-and-ill (Emerson 1841). Emerson viewed compensation as a mechanism to regain
balance, re-level circumstances and as a form of evolution, lifting man above nature, and moving man away from the 'old law' and the entity of physical retribution. Receipt of compensation thus ceased the cycle of retribution through evil acts and instead enabled the use of law to achieve equal rightness and revise wrongs (Emerson 1841).

The development of the first formal injury related compensation schemes within westernised societies was during the late eighteenth century. Men who had been disabled in the American War of Independence began receiving financial compensation from the Government for their injuries. In Europe compensation, began being awarded in the medical arena where it could be proved by a patient that a doctor had been negligent in practice (i.e. medical Laws of Negligence) (Fox 1993). In Germany, during Bismarck's rule, compensation for medical negligence was expanded to work-place negligence by an employer and financial reimbursement began being awarded for injury resulting from generalised acts of negligence in the workplace. Statutory protection for workers in Germany was formally enacted in 1884 (Easton 2003). The receipt of financial compensation following a workplace injury also provided some of the first official connections between the medical profession and the state within western legal systems (Fox 1993).

Across Europe, the role of the courts in assessing the provision of compensation was extended as a result of these developments. The function of the courts came to include investigation into how and where the injury had occurred, the extent of negligence involved in how the injury was acquired, and making a finding and nominating a mechanism for redress (Rickett 2003). The burden of proof was thus placed strongly on the claimant to demonstrate where and in what way negligence had occurred (Rickett 2003). Where negligence was established, the courts then assessed contributory negligence by the claimant and then determined the extent of monetary reimbursement against legal standards of moral blameworthiness (Goudkamp 2004; Drabsh 2005).
A famous English legal case associated with the establishment of negligence and the concept of legal liability is that of Donoghue v Stevenson 1932 (A.C. 562). Donoghue v Stevenson established the legal concept of liability where a shop owner was found in breach of their social duty of care in serving a contaminated beverage. The prevailing understanding of the tort of negligence had been that the notions of moral blameworthiness furnish the philosophical foundation for liability. Donoghue v Stevenson established that blame on the part of the wrongdoer justifies allocating the cost of accidents on those that cause them, and supported the general public sentiment of an offender paying for a moral wrongdoing (Goudkamp 2004).

6.3 The Common Law of Tort

Law associated with the provision of compensation is now known as the Common Law of Tort, Tort law or Injury law. Tort law has developed primarily through the Common Law system, with the term ‘tort’ being the French word for ‘wrong’ or ‘injury’ (Cane and Trindade 1999). Tort Law is made up of a number of torts including trespass, defamation and negligence. It is used in assessing civil wrongs, such as some breaches of contract, protecting an individual’s physical and mental health and safety and in resolving differences between interests in land, goods or property. Most commonly however it is used in relation to personal injury (Cane 1999).

The use of Tort Law to assess personal injury draws on the principles of duty to one’s fellow subjects and breaches of this duty. As duty to one’s fellow subjects is imposed by law, and not between the parties themselves, each member of society in theory takes it upon themselves to act in a manner that ensures the safety of their fellow citizens. The role of Tort Law is thus to determine the extent of negligence where there is a breach of this social duty by one subject resulting in the injury of another (Cane 1999).

The use of Tort Law in assessing a breach of duty is directed by a number of key criteria. These include evaluating the nature and extent of a claimant’s loss, assessing assets in
determining appropriate amounts of restitution, assessing the forms of compensatory relief available, awarding monetary damages to provide remedy and establishing if there are any restrictions, parameters or legal technicalities associated with the scope of a remedy (Cane 1999; Luntz 2002; Rickett 2003). There are also requirements to determine the extent of compensation required to prevent the continuation of any breach of duty or injurious actions occurring again and in assessing if the breach was foreseeable (Cane 1999; Luntz 2002; Rickett 2003). Determining real life costs (i.e. personal loss) in relation to breaches of duty and negligence, evaluating conditions attached to negligence and assessing levels of equitable compensation are all part of the complex tasks for the courts in assessing damages. Of note, once damages have been assessed in association with a claim and compensation awarded, a claimant may not reapply for adjustments to the compensation amount awarded, even if the situation worsens at a later date (Luntz 2002).

A claim against a breach of duty is thus initiated by the injured party or their representative. Once court proceedings are commenced, agreement is first sought informally through legal negotiation outside of formalised court proceedings in an effort to determine the extent of negligence and potentially settle a claim (Cane 2003). If the claimant can successfully argue that a breach of duty has occurred and establish negligence during these legal negotiations, and both parties agree on an amount of compensatory monetary damages that should be awarded to the injured party, the claim is said to have been settled out of court. Upon payment of the compensation, the claim is then finalised and ended.

If a claim cannot be settled through legal negotiations however, the claim for compensation then proceeds to the courts. Following assessment by the courts of the negligence claim, a finding is then made by the courts in relation to the claim, and if successful, a claimant will receive compensation in relation to the extent of the injury and degree of negligence as prescribed by the courts. After the assessment of personal
injury and compensation is awarded, the claimant is then said to be in ‘restitutio in integrum’, or put back in the position they would have been in had the Tort not been committed (Cane and Trindade 1999). The state of restitutio in integrum differs depending on circumstances of the type of loss and how assessment of the loss is applied. Factors influencing assessment include the extent of the injury on future physical and/or cognitive function, the predicted potential financial earnings of the individual, the estimated future need and future tax and inflation implications. The awarding of compensation following an injury such as a SCI is thus viewed as remedy for a breach of duty and redress for the injury that occurred (Luntz 2002).

6.4 Tort Law in Australia

The utilisation of Tort Law in assessing breach of duty and negligence after injury provides a means of using established principles of protection and redress, pre-requisites for liability. It is a practical mechanism in responding to a compensatory claim allowing scope for the courts to mark their disapproval at negligent misconduct by defendants engaged in reprehensible behaviour (Mullany 2002a; Mullany 2002c). It allows negligent conduct to be tested in a legal setting and for the extent of individual responsibility associated with the cause of the injury to be emphasised and clearly assigned. Tort Law also allows for a decision to be appealed by both parties if the outcome is deemed not satisfactory (Mullany 2002b).

Assessment of negligence and breach of duty through Tort Law and utilisation of the courts aims to ensure that the basic principles of judgement and standards of Common Law are met. Mullany (2000a) notes that assessment of negligence through the judicial process allows for a judge to adjudicate a claim as per their prescribed role, and allows personalised assessment of individual circumstances in a judicial setting, surrounded by established principles and criteria of assessment (Mullany 2002a). The utilisation of Tort Law processes and schedules within the courts allows for a claim to be thoroughly explored and debated within the judicial setting and a considered evaluation made.
Further, the courts are generally viewed as a thorough setting in which to thoroughly assess medical injury. Within the court setting, medical professionals can be questioned and specialist in specific areas brought into the courts for further examination. Findings made by medical professionals out of the courts and within the setting of an insurance sector assessment panels are often viewed as less accountable, offering no scope for testing of findings, no options or rights to appeal the injury assessment, and in some cases, no scope to include assessments by treating doctors or specialists (Drabsh 2005; Chu 2007). Utilisation of the courts in assessing medical injury is viewed as reducing the likelihood of medical professionals acting in the interests of insurance companies. The courts are also viewed as a more personal way of evaluating a claim and as less harsh in that claimants are not exposed to the whims of insurance companies and are protected by the neutral, unbiased setting of the court to make their claim and its more advanced procedures of assessment and justice (Cane 2003).

Threat of a legal claim for breach of duty or negligence is also regarded as an effective form of behaviour modification and an advantage of Tort Law (Spigelman 2002). The threat of litigation has historically acted as an incentive for industry to maintain high levels of safety in the workplace. Fear of a legal action has also proven effective in encouraging individuals in general to behave in a safer manner, in deterring unsafe or dangerous practices and of encouraging individuals to be more accountable for their actions (Spigelman 2002; Mullany 2002a; Cane 2003; Drabsh 2005).

A range of views however exist on the extent to which the obtainment of compensation through Tort Law is an adequate and equitable mechanism in providing remedy and redress for injury in Australia. In recent times, assessment of compensation has moved to being assessed privately within the setting of the insurance sector. Proponents of Tort Law view as problematic the high number of inconsistencies that occur across the compensation landscape in both Victoria and Australia. Under current compensation
parameters, only half of the population who acquire a serious injury have the opportunity to claim for compensation through the courts (Luntz 1975; Atiyah 1997; Drabsh 2005). Further, the variety of compensation schemes across Victoria and Australia are viewed as providing random coverage, inadequate levels of compensation and inequitable outcomes for claimants (Palmer 2003; Drabsh 2005). Clayton (2003) describes these differentiations as chaotic, inconsistent, limited and an expensive mishmash of measures for dealing with personal injury. Atiyah (1997:144) claims that the receipt of compensation is a matter of chance and akin to a lottery:

[i]t is not too much to say that it is a lottery, a lottery by law. It is almost a matter of chance whether you can obtain damages for disabilities and injuries; it is almost a matter of chance who will pay for them; it is almost a matter of chance how much you will get.

Luntz (1975, 2002, 2003, 2008) re-asserts this view, and claims that the compensatory landscape across Australia has created ‘inexplicable and unjustified variations’ in terms of who has the opportunity to claim for compensation. He claims that the different number of schemes across Australia creates a distorted appearance of universal access to compensation, where in reality there are significant limitations on those who can actually make a claim for compensation. He highlights that opportunity to claim for compensation through Common Law is not available in South Australia or the Northern Territory, and that in Victoria, New South Wales and Western Australia opportunities to claim for compensation are restricted. Only in Queensland, the ACT and Tasmania does opportunity exist to claim for unrestricted compensation through Common Law (Hanks 2008). Mullany (2002a) goes as far to assert that statutory limitations on compensation awarded fundamentally shift the costs of personal injury from the insurer onto Australia’s social security system, leading to the need for increased taxation to fund income benefits and social expenses not covered by limited compensation parameters (Mullany 2002a; Chu 2007).
Further, where a claim is made, the impact of contributory negligence highly impacts on the amount of compensation that can actually be awarded. As Tort Law only compensates for injuries caused in a particular ways; i.e. it is a ‘cause-based’ system of compensation, it is often seen as discriminating between people with precisely the same needs. Spigelman (2002) reinforces this view, questioning why access to compensation should fundamentally be different depending on whether an injury occurred in a car, at the beach, at work or on the operating table.

Peter Hanks QC, in an extensive review on the Accident Compensation Act (2008), noted that a claim for compensation utilising Tort Law was naturally adversarial and that this focus has adverse effects on an individual’s capacity to return to work where claimants, needing to ensure they obtain the maximum amount of compensation, emphasise their personal injury and reduced capacity. Hanks identified that Tort Law processes were, in many instances, slow, expensive and inefficient, and noted that there were high transaction costs associated with obtaining compensation through the courts and Tort Law processes, particularly the administrative costs and costs associated with undertaking required medical assessments (which in some cases has been as high as 40% of the overall legal action). A 2004 survey of Common Law workers’ compensation claims in the State of New South Wales found that the average time for finalisation of a Common Law claim in 2000 was 4.7 years, down from a peak of 5.6 years in 1996 (Productivity Commission 2004). These timeframes were noted as being consistent with that of other jurisdictions where there was opportunity to claim for compensation.

Utilisation of Tort Law is also often viewed as not being a strong enough mechanism for injury prevention and behaviour modification (Palmer 2003; Drabsh 2005). Palmer (2003) asserts that the capping of compensatory claims has ‘blunted’ the effectiveness of legal action, dampening its ability to act as an impediment to injury prevention and deterring negligence (Palmer 2003). He noted that the occurrence of a negligent act in the current legal landscape more often resulted in an insurance premium increase,
penalties and potential criminal charges, rather than the wrongdoer being sued personally for damages (Ison 1994; Palmer 2003). In recent years, the extensive development of education programs and direct regulation in addressing negligence (such as harsher penalties, license suspension, fines and imprisonment) have been viewed as far more effective deterrents of negligent behaviour than the threat of being personally sued for negligence and damages. The utilisation of Tort Law in assessing negligence and awarding compensatory damages in Australia is thus surrounded by many issues of complexity and contention.

6.5 Compensation in Victoria

Individuals in Victoria that sustain a serious and catastrophic permanent impairment are only partially able to make a claim for compensation through Tort Law. Claims for compensation can be sourced through a number of compensatory schemes including:

- Transport Accident Commission (TAC)
- Victorian WorkCover Authority (VWA)
- Crimes Compensation-criminal injury
- Victorian Private insurance schemes e.g. volunteer bushfire fighters compensation scheme, specific sporting league insurance schemes, Bicycle Victoria
- General Public liability claims

Approximately half of the individuals that acquire any form of impairment in Victoria have eligibility to claim for compensation through legal action (Luntz 1975; Rickett 2003; Luntz 2003; Drabsh 2005; Walsh et al. 2005). Individuals who acquire a SCI specifically are directed down a range of pathways to claim for compensation, based on how they acquired their injury. If the SCI was a result of a transport accident or workplace injury, some opportunity to make a claim for compensation through Tort Law claim is available. Where the SCI is a result of fault or negligence on the part of another person and a level of fault can be proven, a claimant has grounds to make a claim for compensation. If the accident is not a transport or work related accident, and no fault in
association with how the SCI was acquired can be proven, then no opportunity to claim for compensation is available. As discussed by Hanks above, statutory limitations limit the amount of compensation that can be awarded through the TAC and VWA systems.

The AIHW (2006) has shown that on average 300-400 Australians per year acquire a permanent SCI. This adds to an estimated prevalent population of approximately 9000 people with SCI across Australia (2005 estimates) (Cripps 2006). Although extremely variable across the states, approximately half of this group had the ability to access some forms of compensation with 60% of people acquiring a SCI through a motor accident able to claim for compensation, 100% of people acquiring a SCI through a work related incident able to claim for compensation, 50% of people acquiring a SCI as a result of a medical incident able to claim for compensation, and the remaining 20% of people acquiring a SCI able to obtain compensation through general insurance schemes (Drabsh 2005; Walsh et al. 2005). This reflects statistics related to SCI in Victoria, where 60% of SCI are a result of transport accident, 13% work-place accidents and the remaining 27% a mix of SCI occurring as a result of diving accidents, falls or medical incidents.

### 6.5.1 Compensation and the Transport Accident Commission (TAC)

In 1971, the formation of the Road Accident Hospital Accounts Committee (RAHAC) saw the establishment of the first no-fault insurance system for Victorians injured in road accidents. Its role was to oversee the automatic payment of 70% of an injured person's hospital bills by the two insurers (State Insurance and the RACV) before compensation matters had been considered by the courts. As the payments were made regardless of fault, the payments effectively established a system for insured provision of care following a car accident regardless of who was at fault in an accident, in effect, a no-fault accident benefit scheme (Transport Accident Commission 2006). During the same period, a second committee was established to explore the extensive delays and high costs that were emerging with increasing numbers and complexities of litigation claims.
through the Common Law process. This committee drafted detailed provisions for a ‘no fault’ accident insurance scheme that would effectively transfer a bulk of compensation away from that of a legal, fault-based claim model, to a model of social liability where the payment of compensation was paid collectively by all motor vehicle owners (Public Records Office 2009).

In 1973, the Motor Accidents Act 1973 incorporated the RAHAC system and committee recommendations, and established the Motor Accident Board (MAB). The MAB commenced operations on 12 February 1974, enshrining the no-fault concept into law (Transport Accident Commission 2006; Public Records Office 2009). The MAB in Victoria was very progressive on an international level, and stood as the first no-fault accident insurance scheme to operate in Australia (Drabsh 2005). The MAB automatically paid any person’s injury related medical expenses, and from 1 September 1980, provided weekly benefit payments for life accidents where no Common Law entitlements were available (Drabsh 2005; Transport Accident Commission 2006).

After a review of the State’s motor vehicle insurance in 1986, the Transport Accident Act (Vic) established the Transport Accident Commission (TAC) to replace the MAB. In re-establishing the parameters and viability of the new motor vehicle insurance, the no-fault accident benefits model was retained, however access to a Tort Law action was restricted to more serious injuries where fault could be proven. The framework was somewhat unique in combining Tort Law principles and no-fault benefits. It successfully established a scheme where, regardless of fault, every person obtaining a transport injury in Victoria would be covered by insurance that would cover all medical costs, while still providing opportunity for a person to take on a Tort Law action were fault was evident (Luntz 2003; Drabsh 2005). To support itself, the TAC established a private insurance funding model whereby insurance premiums were paid to the scheme through the yearly renewal of vehicle registration when a person registered his or her motor vehicle in Victoria. Registration was compulsory, and the TAC insurance premium
payment was built into the vehicle registration cost (usually a third of the registration premium) (Transport Accident Commission 2006). The TAC as an insurer was also underwritten by the state.

The TAC scheme allowed people who can prove fault to pursue further compensation through a Common Law case where the injury was serious enough. Section 93 of the Transport Accident Act (Vic) (1986) allows a Common Law action to be undertaken where the degree of impairment has been determined by the TAC as over 30% of permanent physical and/or psychological conditions (Drabsh 2005; Transport Accident Commission 2008). Compensation is then awarded through two main categories: pain-and-suffering and loss-of-earnings, with statutory limitations placed on both categories limiting the amount of compensation able to be received in any one claim (Transport Accident Commission 2008).

Combined pain-and-suffering and loss-of-earnings compensation payments in 2009 were capped at A$1,419,240 with the majority of cases settled out of court (Slater and Gordon 2009). TAC loss-of-earning benefits (where a Common Law claim is not undertaken) are payable until the age of sixty-five if an individual is unable to return to work as a result of their injuries (Slater and Gordon 2009). Extended Common Law actions against the TAC and VWA have been known to affect return-to-work processes, and in some cases have created hostility and tension between parties in being the provider of services yet the opponent (defendant) in legal proceedings.

6.5.2 Compensation and the Victorian WorkCover Authority (VWA)

As noted above, in 1985, claims for workplace injury were consolidated under the Victorian WorkCover Authority (VWA). The VWA operated under the revised jurisdiction of the Accident Compensation Act (1985) and Occupational Health and Safety Act (1985) (Purse, 1996; Productivity Commission 2004).
Since 1985, the VWA has undergone tumultuous policy reform. From 1985 until 1997, a claim for compensation could be made following the acquirement of any work-related injury. This included injuries occurring on the way to or on the way home from any employment site. In 1997, the Victorian Government under the then premier Kennett, introduced radical workplace accident reform and halted opportunity to claim for compensation utilising Tort Law and the courts. In its place, it established an internal VWA assessment review process and introduced an automated compensation review system. Under the system, the VWA, conducting its own review processes, determined levels of los-of-earnings and awarded a determined level of compensation outside of the court setting (Productivity Commission 2004; Purse 2005). The VWA system awarded an automated payment usually in between 6-12 months following the acquirement of the injury, with the automated scheme providing no avenue for negotiation or appeal.

This system remained in place for nearly two years between 12 November 1997 and 19 October 1999 when following a change of state government in 1999, opportunity to claim through Common Law was restored under the newly elected Labor Government (VictorianWorkCover Authority 2008:12; Luntz 2003).

6.6 Summary

The universal concept of receipt of compensation as a legal remedy for redress of a wrongful or negligent act has developed into a complex and contentious area of law in relation to personal injury in Australia and Victoria. Assessment for receipt of financial monetary damages where negligence or a breach of duty has been proven to have occurred is now governed by a complex framework of limitations, parameters and guidelines reviewed both within the traditional judicial settings of the courts, and more frequently by internal insurance boards adhering to prescribed schedules and time frames. As discussed, each of the particular legal areas has advantages and disadvantages for an individual seeking to make a claim for compensation following the physical impact of having acquired a serious personal injury, if indeed there is scope to
claim for compensation. As shown, the success of a claim is governed by considerable legal guidelines and limitations based on how the injury was acquired, the extent to which negligence can be proven, the existing statutory limitations set down by the State and if a claim is prescribed as being assessed in an insurance-based or judicial setting. What is evident is the considerable impact the compensation process has on an individual and the extent to which a successful claim for compensation can have on the life-course of an individual following the acquirement of a permanent injury such as SCI.
Chapter 7 : Study Design

7.1 Introduction

In this chapter I discuss the study design. Firstly I discuss my utilisation of a relativist ontological approach and a constructivist epistemological approach in examining the concept of support for people with a permanent impairment of SCI in Victoria. I examine the role of each of these philosophies in informing the study methodology and in providing a solid theoretical platform for the generation of themes and theory based on participant experience. This includes the utilisation of a Constructivist Grounded Theory approach in data collection and analysis, and discussion of thematic coding and analysis protocols used within the study.

Secondly, I examine the processes undertaken to ensure methodological rigour and validity of the study. This includes discussion on data collection and management, ethics and analytic processes and also the utilisation of a number of instruments to ensure methodological rigour such as reflexivity, assessments of trustworthiness and the utilisation of a qualitative validity instrument - Lincoln and Guba’s Model of Rigour.

7.2 Study philosophies

7.2.1 Relativist ontology

In this study I utilised a relativist ontological approach as opposed to traditional realist and positivist ontological perspectives. The utilisation of a relativist ontological approach allowed me to examine how each participant perceived their known worlds and understood their personal experiences (Duncan et al. 2007). It allowed me to gain understanding of multiple realities and interpretations of each participant experience, and enabled the construction of local and specific mental constructions for each participant (Strauss 1990; Guba and Lincoln 1992). Understanding and knowledge was
then drawn from each participant’s individual experience and used to generate themes and knowledge.

Competing viewpoints of participants were viewed as true and valid and supported obtainment of knowledge and themes. Utilising a relativist approach, I placed emphasis on individual perspectives and upheld ‘no single truth’ (Annells 1996:387). Each participant’s perception of reality was viewed as being their own and no one single truth was viewed as being attainable. As discussed by Guba (1992), findings would become more sophisticated but would never become more true. Truth was viewed as being enacted and linked with time and place, such that any reality could only consist of local and specific realities constructed by each participant.

As the study’s relativist approach supported no single uni-dimensional external or objective truth, truth was drawn from individual participant experiences or actions (Patton 2002:128). Each participant’s viewpoint was viewed as their own unique, subjective reality, rather than any single discovered truth. This approach provided a more interpretative understanding of how each participant perceived their worldview as their particular unique reality (Patton 2002). The approach provided me with an effective exploration of how participants constructed their social realities, and gave value to these layered understandings and experiences (Denzin 2002). Experiences communicated by participants were thus presumed as real and believed (Charmaz 2000; Mills et al. 2006; Mills et al. 2007).

The use of a relativist ontological approach effectively allowed individual experiences to be understood as valid and reliable forms of knowledge. As Guba (1992) noted, the utilisation of a relativist ontological approach allowed for the varying degrees of subjectivity to be examined and ‘multiple socially constructed realities’ to be formulated from a plurality of viewpoints. It allowed knowledge to be constructed from contrasting social realities, and themes and theory generated from the diverse array of experiences
communicated (Guba 1992; Patton 2002). A relativist approach supported and maintained the integrity of each participant’s experiences as informed and credible (Guba 1992). Understanding and knowledge were then gained based on the obtainment of this data as valid and trustworthy (Duncan et al. 2007).

The approach also allowed knowledge and understanding gained from participant experience to be effectively situated and the social positioning of each participant experience to be defined (Duncan et al. 2007). As supported by Thomas (1999), a relativist approach acknowledges that all knowledge is situated and positioned as a part of the social product, and that all knowledge bears the marks of time, place and social positioning. It allowed effective exploration of how participants situated themselves within socio-political and cultural settings, and exploration of the extent to which participants within these known social places constructed their realities.

7.2.2 Constructivist epistemology
I utilised a constructivist epistemology to support my relativist ontology. In utilising a constructivist epistemology, I was able to explore the viewpoints of participants at an interactive level and participant experience from a less objective stance. Unlike many traditional studies that provided objective, positivist, and passive testing of function or social place, the utilisation of a constructivist epistemology allowed me to emphasise the inductive obtainment of knowledge and subjective understanding (Strauss 1987; Strauss and Corbin 1994; Charmaz 2000).

A constructivist epistemology thus allowed for knowledge to be generated through inductive and interactive processes and for understanding to be gained through the construction of individual experience and known social worlds communicated by participants during the interactive interview (Riouix and Bach 1994). The interactive process of the interview allowed for good communication and establishment of rapport with each participant, and supported interrelationships between me as the researcher,
and the participants (Clear 1999; Carter and Little 2007). Known social worlds were then expressed through personal narrative and communication of the individual life experience and story (Thomas 1999).

A constructivist approach acknowledged differentiation in what participants could know and perceive as real. Although participant realities were based on what they knew and understood, a constructivist approach allowed flexibility in what could be legitimated as knowledge by an individual (Charmaz 2000). It acknowledged that a level of ambiguity was required to be tolerated in constructing these individual realities and that the production of differing realities and degree to which any construction of experience could truly be investigated was fluid (Annells 1996).

The utilisation of a constructivist approach thus provided movement in the ways in which participant realities and understanding were understood in acknowledging dialectic viewpoints in how each reality was constructed (Doucet and Mauthner 2008). This approach thus allowed for the construction of multiple realities and for knowledge to be generated based on these varying individual constructions and divergent levels of experience. Each individual’s unique experiences could be then be identified and validated and seen with a degree of authenticity (Doucet and Mauthner 2008).

This approach effectively allowed for the voice of participants to be heard and given validity in a landscape where the voices of people with impairment are often buried and elided by the normal processes of human knowledge formation. The utilisation of this approach gave validity to the historical and socio-cultural dimensions of each participants construction of reality, and allowed for emphasis on individual interpretation of the known and understood realities of each participant based on their differing understandings, narratives and practices experienced through life (Schwandt 2000).

7.2.3 Grounded Theory Approach
Glaser and Strauss developed the traditional Grounded Theory approach in 1967. The theory challenged the then dominant logico-deductive means of generating theory through testing, and instead sought to generate theory through utilisation of inductive data collection and analysis processes (Glaser and Strauss 1967; Strauss and Corbin 1990; Glaser 1992; Charmaz 1994; Charmaz 2000; Charmaz 2006). Although Grounded Theory maintains a positivist, objectivist approach (i.e. assuming that an external world is out there waiting to be discovered and analysed), the approach differed in seeking to generate knowledge purely from data obtained from social and psychological processes and in not supporting the use of existing theory and knowledge in theory construction until analysis and interpretation phases of the research (Charmaz 2000; Patton 2002; Holloway and Todres 2003; Charmaz 2006). Glaser and Strauss (1967) claimed that knowledge generated purely from data collected would then be unbiased and would create a more true knowledge construction of the topic area.

Constructivist Grounded Theory approach emerged in the early 1990s as a critique to traditional Grounded Theory and its positivist generation of theory (Atkinson et al. 2003; Walker and Myrick 2006; Giske 2007). Developed most prominently by Charmaz (2000), Constructivist Grounded Theory also supported inductive, interactive and reciprocal approaches to data collection, but differed from traditional Grounded Theory approach in acknowledging existing conceptual frameworks and discipline-based knowledge in theory construction (Charmaz 2000).

For this study, I chose to draw on Charmaz’s Constructivist Grounded Theory approaches in utilising existing knowledge and known conceptual frameworks. A theoretical line in the sand was drawn between use of existing knowledge and known conceptual frameworks at the beginning of the data collection processes, so that knowledge generated by individual participant experiences could be formulated. Following constant comparison analysis techniques, substantive theory was then generated drawing on existing discipline-based philosophical and theoretical knowledge (Salick and Auerbach...
2006). Data collected from participants thus drove the direction of the study, allowing the generation of themes and later emergent theory based on comparison with existing knowledge.

Further, these grounded data collection and analysis techniques allowed for the increased ‘theoretical sensitivity’. Strauss (1990) describes the concept of theoretical sensitivity as an emphasis on experiences being seen and interpreted (observation and inter-actional skills) in trying to tap into assumptions, implicit meanings and tacit rules. Theoretical sensitivity was thus achieved by developing themes and patterns of the realities and expanding these into rich, tightly woven, explanatory theories. In building density of experience, combinations of various themes emerged allowing for development of theory.

The utilisation of a Constructionist Grounded Theory analysis approach thus effectively allowed me to explore the individually constructed realities of participants. It allowed for the generation of theory and knowledge based on data communicated through interactive interview processes, and generation of theories that were grounded, fit and aligned with data collected (Guba and Lincoln 1994; Charmaz 2006; Mills et al. 2006). I was able to enter the world of the participant and gain an interpretive portrayal of their realities, drawing on their implicit meanings, words and actions and allowing their realities to be discovered, tracked and categorised (Charmaz 2000:678). Use of Constructivist Grounded Theory thus provided a platform to place my interpretations, constructions of these realities, my biases and theoretical knowledge in constructing participant realities (Guba and Lincoln 1989). Reconstruction of participant experience and meaning was then directed by concepts and themes generated from the inductive and cyclic processes within the interview process (Mills et al. 2006a). The approach allowed for data to be obtained through interactive processes, while acknowledging researcher values and knowledge as an inevitable part of the study findings (Guba and Lincoln 1989; Dey 1999).
The utilisation of a Constructivist Grounded Theory approach also allowed theory to be generated through formal analytic procedures, such as thematic coding, constant comparison and theoretical sampling (Charmaz 2000; Walker and Myrick 2006). The approach provided systemic and flexible guidelines for the collection and analysis of data and a set of general principles and heuristic devices for analysis (Atkinson et al. 2003; Walker and Myrick 2006; Giske 2007).

7.2.4 Thematic Coding Processes

Thematic coding was achieved through utilisation of a three-stage analysis technique that included open, axial and selective coding. Data obtained from interviews was firstly transcribed and verified by participants, then openly coded and separated into relevant concepts and categories (Glaser and Strauss 1967; Strauss and Corbin 1990; Fielding and Lee 1998; Charmaz 2000; Silverman 2001). The technique allowed new data trends and patterns to be coded into emerging category and topic areas.

As each interview was completed and further data obtained, data was coded to pursue concepts and themes, so that the interview questioning could be refined. Where a particularly relevant theme or concept was identified, the direction of subsequent interviews sought to pursue these themes and/or concepts through increased weighting of questioning and discussion in these areas. Further, as interviews progressed, discussion time within the interview was weighted towards these newly emerging concepts and themes, further driving the analysis process (See Appendix G for modified versions of interview guides). Themes and concepts emerging in the data were thus pursued for clarification and verification through sampling strategies and through weighting of interview discussion.

Secondly, data was then analysed utilising axial coding technique. Interviews were deconstructed line-by-line and emergent categories and topics were then repeatedly
compared to other topics, categories and theoretical discourse, including related policy documents (Glaser and Strauss. 1967; Strauss and Corbin 1990; Fielding and Lee 1998; Charmaz 2000; Silverman 2001; Giske 2007). The constant comparison technique of axial coding allowed for exploration of relationships, dimension, conditions, actions and interactions within the data. Axial coding allowed for exploration of subjective interpretations and constructions based on individual experience including shared concerns and points of tension communicated by participants (Doucet and Mauthner 2008). Axial coding thus allowed for the construction of knowledge, meaning and understanding through comparisons of the layered interactions of participant experience (Creswell 1994).

Finally, selective coding was utilised to reconstruct the data. Overarching concepts and categories were developed and refined into the main study themes. Once these main themes were identified, these themes were utilised to generate substantive theory and knowledge (Strauss and Corbin 1990; Mills et al. 2006). As noted by Charmaz (2000), this technique allowed for themes to be generated and built into rich, tightly woven, explanatory theory that approximated the reality it represented. It allowed for the development of connectors between categories and their properties and for data to be effectively deconstructed and reconstructed.

These approaches allowed me as researcher to drive and direct the construction of knowledge based on communicated participant experience. The inductive and cyclic process of obtaining and analysing data allowed me to draw out particular aspects of participant experiences, and construct and generate knowledge from that data through interactive and comparative processes. The use of a three-stage thematic coding techniques allowed me to formulate realities, and allowed for effective analysis of perceived conditions, meanings actions and interrelationships to drive analyses and knowledge construction (Charmaz 2000; Grix 2004).

7.3 Methodological rigour
A number of strategies were utilised to ensure the study was methodologically rigourous and robust. These strategies aimed to assess validity, dependability and accuracy of data obtained in relation to the inductive style of the study (Angen 2000; Rolfe 2006; Denzin 2009).

The four criteria utilised to obtain methodological rigour were: reflexivity, methodological coherence, trustworthiness and Lincoln and Guba’s (1985) qualitative assessment tool.

### 7.3.1 Reflexivity

Reflexivity was used to ensure methodological rigour in the study. The utilisation of reflexivity ensured that all researcher bias that may have influenced data collection and analysis of the study was fully declared (Angen 2000).

My position as a researcher and a person with a SCI meant that there was a strong potential for bias. I was researching within my own medical-cultural group and receive funded services within Victoria funded by the TAC. I had also received compensation through legal action and Common Law process. In these respects, I see this position as an advantage in allowing me to gain in-depth understanding of the experience of service delivery, based on common and shared experience with participants. I view my personal experience, as a person with a SCI and as a person who is a recipient of disability services, as increasing insight and allowing in depth of experience. I felt my position allowed me to explore views and participant knowledge from a shared level, encouraging a more relaxed, open and forthcoming level of communication. I viewed my role as researcher with a SCI as reducing objectivity, increasing interview interaction and supporting the transfer of experience from a more integrated viewpoint (Rioux and Bach 1994; Schwandt 2000). I felt my shared experience of SCI assisted me to develop rapport with participants during interviews, and encouraged a more relaxed, open and forthcoming environment in which participants could communicate their experiences (Rioux and Bach 1994; Schwandt 2000).
My position as researcher was also influenced by my experience as someone who has received compensation themselves and who has gone through the legal processes required in obtaining compensation from TAC. My position as researcher was also influenced by a short time spent in committee roles advocating for rights and the improved status of people with impairment. From this position I was able to view policy structures that impacted people with impairment at a day-to-day level, and view areas of both positive change and no change occurring in the disability services sector. Again, I sought to remain flexible to emerging new themes, perceptions and concepts presented by participants communicating experiences of challenge and advocacy while utilising my own experience base in this particular area.

Although acknowledging my own knowledge and experiences, I sought to remain neutral in interpreting the data and flexible to emerging new themes, perceptions and concepts presented by participants. I felt my personal experience of the study area placed me at an advantage, reducing objectivity, providing shared insight into experiences and allowing the development of good rapport with participants.

7.3.2 Methodological coherence

I sought to strengthen the rigour and robustness of the study through clearly articulating research processes and method. All processes that shaped and directed the study during its development were documented, including sampling and data collection methods, methodological procedure for analysis techniques and categorisation of data analysis processes. Clear articulation of study methods strengthened validity and rigour of data, and articulation of the study processes ensured a close link was maintained between the research objectives and the study analysis processes (Morse et al. 2002; Rolfe 2006).

7.3.3 Trustworthiness
In ensuring methodological rigour, I utilised trustworthiness as a strategy to achieve validity, plausibility and accountability of data obtained in the study. During interviewing, questions were repeated in differing styles and forms in seeking to obtain consistency of answers provided. Although answers given by participants were presumed to be true and correct, answers provided by participants were checked against known parameters of policy frameworks to assess accuracy of comments. Knowledge of policy frameworks and program parameters provided was achieved through document analysis of disability policy frameworks and disability service programs in Australia and Victoria.

Secondly, trustworthiness involved participants validating their own interview transcripts once interviews had been transcribed as an extra verification process to ensure validity and accuracy of the data provided by participants. This strategy allowed participants to reflect on discussion from the interview and verify details and statements made by them, increasing the authenticity and truth of their communicated experience.

### 7.3.4 Lincoln and Guba’s Model of Rigour

Components of Lincoln and Guba’s 1985 Model of Rigour were also utilised to strengthen the study’s rigour and robustness. Although considerable debate exists as to the utilisation of assessment instruments in assessing qualitative research, such as claims of positivism in assessing data from an external position, components of Lincoln and Guba’s Model of Rigour were utilised to measure the overall soundness of the study design and to define theoretical parameters of the study (Anfara et al. 2002; Rolfe 2006).

The components of Lincoln and Guba’s Model of Rigour utilised were:

- **credibility** (internal validity of quantitative research)
- **transferability** (external validity of quantitative research)
- **dependability** (reliability of quantitative research)
- **confirmability** (objectivity of quantitative research) (Lincoln and Guba 2005; Rolfe 2006)
Credibility was achieved through triangulation. Triangulation involved obtainment of knowledge from multiple sources, including in-depth interviews, in-depth document analysis, knowledge of the sector from personal experience and knowledge of current advocacy issues (Anfara et al. 2002). To assess credibility, data obtained from participant interviews was cross-referenced with key policy documents and then against researcher knowledge. Triangulation processes thus underpinned interview interpretations and aided in identifying errors and variations with data obtained (Rice and Ezzy 1999).

Transferability was obtained through the use of purposive sampling of participants to target the widest contrast of participants in terms of services utilised across the three funding streams, differences in gender, geographic location, age and socio-economic status. Purposive sampling thus increased the accuracy and strength of the data in including the most diverse and widest range of participant experience possible and widest range of concepts and interpretations available.

Dependability was achieved through verification techniques. As noted, it was difficult to ensure all accounts of data obtained were credible, useful or legitimate. Data relating to an individual situation, phenomenon, activity, text or institution were no doubt influenced by the time and place in which these instances occurred and when participants underwent their particular experience (Grix 2004). Data may also have been influenced by participants’ own biases and past knowledge and participants may have been selective about the information they chose to disclose during interviews for any number of reasons, such as undermining of personal status, fear of repercussions from disclosure of true/real situation, moral or ethical standpoints, peer pressure, reasons of personal safety or wanting to maintain the status quo in relation to service provision (Grix 2004). Participants may also have had equally valid accounts of a similar event/s, phenomena, institutions or activities, but presented markedly different interpretations.
about the same event (Grix 2004). Dependability of data was thus ensured through acknowledging the individual differentiation in data presented and acknowledging individual biases and influences that may have affected accuracy or validity of participant accounts. Awareness and acknowledgement of these issues thus contributed to a measure of dependability and plausibility of data.

Confirmability was achieved through my role as a researcher and a person myself with SCI, which assisted me in assessing the validity, reliability and accuracy of much of the data obtained. My personal experience, knowledge of the research field and processes of triangulation assisted me to acknowledge and assess variation, and confirm interpretations and findings from the data.

7.4 Ethics Review Process

Ethics approval to complete the study was granted by the University of Melbourne’s School of Population Health Human Ethics Advisory Group (HEAG) and Health Sciences Human Ethics Sub-Committee (HESC) in August 2006. In addition, ethics approval to source participants onsite was granted by the Austin Health Research Ethics Unit Austin Health in September 2006.

As a part of these ethics processes, a Plain Language Statement and Consent Form (see Appendix C) was provided to each participant prior to undertaking interviews. These forms provided a summary of the study, the extent of involvement required by a participant if they agreed to participate in the study, an outline of any anticipated risks with involvement in the study (e.g. distress) and information on what would happen to any data they provided. At the beginning of each interview, each participant was briefed to ensure they fully understood their participation in the study and then asked to formally give consent to participation in the study by either signing a Consent Form or, if unable to sign (such as in the case of some quadriplegics), allowing their verbal agreement of a spoken version of the Consent Form to be recorded.
A particular issue of ethical consideration was retaining the emotional integrity of participants during interviews. As participants included in the study were required to have experienced a major medical trauma of a SCI and significant life adjustments in adapting to a SCI, a number of protocols were developed to reduce the potential of participant distress from participation in interviews. Firstly, a limitation was placed onto recruitment of participants in terms of the period of time since they had acquired their SCI. Individuals who had acquired their SCI in the last 5 years (later amended to 3 years) were excluded from recruitment due to sensitivity around discussion of how they acquired their SCI.

Secondly, it was recognised that participants may still have had difficulty in discussing the trauma of acquiring their SCI, frustrations with current living arrangements, relationship breakdowns, isolation, lack of ability to re-enter previous employment, financial difficulties, anger with level and quality of services or distress around health related issues. To manage any distress that may have emerged, a participant Distress Protocol was developed (see Appendix E). The basis of the Distress Protocol was intervention in the interview where there was observed distress such as mood swings, tearfulness, anger or yelling. If any of these indicators were observed, the Distress Protocol stated that the interview would be paused for a short period of time and/or ceased if required. The Distress Protocol however did not have to be enacted in the course of participant interviews.

A Participant Support Referral List (see Appendix F) was also provided to all participants at the completion of each interview. The Participant Support Referral List provided referral information to a number of resources such as SCI counsellors, SCI social workers, contacts to funding bodies, legal and advocacy support and medical resources. Participants were offered assistance in making contact with these support resources at the completion of each interview.
Also included in the ethics processes was declaration of the 2-3 research assistants that supported me during the data collection phase of the study due to my physical constraints. All research assistants signed a confidentiality form prior to commencing their research assistant roles (see Appendix D). Tasks required by research assistants included driving me to interviews, attending interviews to assist with setting up of audio recording devices, attending interviews to ensure my personal safety (where interviews were undertaken at the participants private homes) and assistance with administrative tasks.

Lastly, in relation to ethical protocol in conducting the study, every effort was made to ensure participant confidentiality and to protect the identity of study participants. Pseudonyms were used to de-identify participants and contacts referred to in interviews, and all personal information and references that could potentially identify a participant and/or contact were removed. Data transcripts were stored in a password-protected computer, and back-up copies of interview transcripts and participant data were stored in a locked cabinet according to University of Melbourne storage protocols. All data provided in the study sought to meet the guidelines of Section 95 of the Privacy Act produced by the National Health & Medical Research Council (NHMRC). At completion of study, all data will be stored according to University of Melbourne storage protocols for a minimum of five years from the date of the final publication from the study.

**7.5 Study Population and Sampling Strategy**

All individuals recruited for the study were individuals living in Victoria with a permanent impairment of SCI. Individuals with a permanent impairment of SCI were sampled because uniquely, this group utilised funded services from across all of the State’s three major funding providers - the TAC, VWA and DHS, unlike other medical conditions, such as Multiple Sclerosis or Motor Neurone Disease, where support services were funded solely by the DHS alone. By focusing on individuals with a SCI only, it was possible to
achieve an effective comparison of utilisation by participants of funded services from across the entire complex disability support service framework.

Individuals from all geographic areas in Victoria, i.e. metropolitan, regional and rural areas, were eligible for inclusion in the study, while two age limitations were put in place regarding recruitment. Firstly, only adults over the age of 18 years of age were included in the study. This was to ensure that individuals receiving youth and early intervention funded services were excluded from the study as these fall under a differing set of funding parameters, criteria and eligibility. Secondly, an upper age parameter of 55 years of age was put in place. This limitation sought to exclude people with impairments that received Federally funded Aged Care services and not State Government services. During the recruitment phase of the study however, the upper age parameter was increased from 55 to 64 years of age as fewer older persons with a SCI were found to be utilising federally funded Aged Care support. The age limitation of 64 years of age was utilised as 64 is the oldest age in which someone can be assessed to begin receiving state-based disability services.

Further, only individuals who were currently receiving funded services through TAC, VWA and DHS or who had received a compensatory payout or settlement through TAC or VWA were eligible for recruitment. Individuals whose funding for support services was provided by the Department for Veterans Affairs (DVA) or who received any federally funded Aged Care services were also not recruited for the study as funding for these services is provided at a Federal Government level. In addition, individuals who had acquired a SCI as a result of an event that produced a public liability action and had received a one-off lump-sum compensatory pay-out were not recruited as these individuals effectively purchase all of their support services privately. Further, people who fell within the study parameters above but were unable to comprehend study information because of limited English skills or cognitive capacity were not included in the study.
Two phases of sampling were utilised for recruitment: convenience sampling and theoretical sampling. In phase 1 of the recruitment phase, a convenience sampling strategy sought to recruit a diverse array of participants within the recruitment parameters. Recruitment strategies for convenience sampling were through print advertisement (see Appendix H) and later on-site recruitment, described in the following sections. Convenience sampling sought to target the widest contrast of participants in terms of ranges of services utilised, differences in gender, geographic location, age and socio-economic status. Convenience sampling sought to increase the accuracy and strength of data collated, encompassing the most diverse level and widest parameters of service utilisation across the funding streams.

Phase 2 of the recruitment phase utilised a theoretical sampling strategy where possible. Following the emergence of concepts and themes from initial interviews, participants were theoretically sampled in order to broaden the application of these theoretical insights and allow pursuit of concepts and themes that had emerged during preliminary analysis. Theoretical sampling allowed emerging concepts and themes to be pursued and refined, until these concepts and themes were repeated and saturation achieved. As these themes became sufficiently grounded, they were compared and contrasted against the existing literature to increase and improve conceptual validity of the themes (Creswell 1994). Theoretical sampling thus allowed knowledge to be generated based on the pursuit of emerging concepts and themes, while existing theories of knowledge were utilised to support study findings and theory generation.

Although considerable difficulty emerged in recruiting participants, these sampling strategies effectively provided a sample of participants that provided thick and rich descriptions of the experiences of receiving support services. They allowed communication of personal details that embodied the day-to-day realities of support
service utilisation, and provided a means of examining the impact of policy frameworks on these experiences.

7.6 Data collection methods

Two methods of data collection were utilised in the study – document analysis and in-depth, semi-structured interviews.

7.6.1 Document Analysis

The first form of data collection involved analysis of key international, national and state-based legislation, policy documents and reports related to provision of disability services. These documents were critically examined to map the structures and parameters of the current disability support services framework in Victoria, and to map the Victorian framework in contrast to other disability support services frameworks nationally and internationally. This included analysis of documentation to clarify the historical development of disability support services in Victoria, and documents related to international theories of ‘disability’ and impairment that have influenced and impacted on the development of the disability support service framework in Victoria. Analysis of these documents provided validation and supported triangulation for methodological rigour, overall trustworthiness and robustness in the study.

As discussed in preceding literature chapters, this included analysis of literature on international movements and models such as the Principles of Normalisation, the Independent Living Movement, Medical and Social Models, Social Role Valorisation, the Disability Studies genre, Human Rights frameworks and United Nations legal instruments such as United Nations of the Declaration on the Rights of Disabled Persons (1975) and Convention on Rights of Persons with Disability (2007) that have all influenced policy development in Victoria.

National documents analysed included the Disability Services Act (1986), Commonwealth State and Territory Disability Agreements (1994 -2011), Disability

7.6.2 In-Depth, Semi-Structured Interviews

The second form of data collection was 11 in-depth, semi-structured interviews of individuals with a permanent impairment of SCI. All of these individuals were currently living in Victoria and were receiving funded support services and/or had received a lump-sum compensation payment from TAC or VWA.

Recruitment of these individuals was predominantly through flyer advertisement at the central spinal outpatients department at Austin Hospital Heidelberg, and through print advertising in a number of local disability sector magazines and email lists (see Appendix H). Publications in which advertisements appeared were Inform (published by the Victorian paraplegic and quadriplegic association Paraquad) and in the Housing Resource and Support Services (HRSS) member newsletter. Emails advertising was placed on the electronic bulletin boards of the Victorian Disability Advocacy Network (VDAN) and University of Melbourne Postgraduate Association (UMPA). Further, participant recruitment for the study was also undertaken at the University of Melbourne Disability Liaison Unit (DLU) with flyers being placed in the information stand.

Following difficulties with recruitment, a formal amendment to the recruitment protocol was made, and individuals were also recruited in-person at the central spinal outpatients department. As researcher, I attended the central spinal outpatients in-person for two half days per week for 10 months. Recruitment involved being in the waiting room of the central spinal outpatients clinic, approaching out-patients attending the clinic and
providing a 30 second briefing of the study parameters. Clinic attendees were handed a recruitment flyer, which included contact details, and were prompted to contact me as researcher if they wished to participate in the study. On-site print advertisement for recruitment continued during this time.

Interviews were conducted face-to-face with each study participant and ranged in length from 50 minutes to nearly 2 hours. Interviews were conducted in private, however partners, family members, friends and/or attendant carers were given the opportunity to sit in on interviews if the participant wished, and this occurred on two occasions. Participants were also given the choice of where interviews took place and venues included a café, private homes, local libraries, public meeting rooms and University premises. A research assistant attended the beginning and end of each interviews to assist in setting up recording instruments. Where interviews were at the private homes of participants, the research assistant remained present at the house to increase personal security.

An interview guide of approximately 15 - 20 open-ended questions was utilised during interviews to ensure that all of the main topic areas were raised. Following introductions and general conversation to develop rapport, interview discussion moved through the four main topic areas: events associated with acquiring the SCI and spinal rehabilitation, disability service usage and experience, understanding and experience of compensation and understanding and knowledge of rights.

Probes and prompts were utilised during these topic discussions to further explore concepts and themes identified through initial analysis, however interviews in the main were flexible and participant-driven around topic areas. Where unexpected information arose during the interview, questions were reassessed and these topics were pursued.
Following the interview, field notes were written to capture the overall context, impressions, ideas and emotion from the interview. Field notes included personal perceptions and observations about the interview, observations on the space the interview was held in, how discussion had flowed, a physical description of the participant, any particular behavioural observations of the participant and a personal reflection of questioning style and interviewing technique.

As individual interviews were completed, data was transcribed and verified, and then a three-stage modified grounded theory analysis was undertaken. As concepts and themes emerged during analysis, the interview guide was modified to place emphasis on emerging concepts and themes in subsequent interviews.

The 11 interviews were successful in gaining in-depth and detailed understanding of individual perspectives of service utilisation and compensation pathways. The semi-structured form of the interviews enabled participants to drive the discussion topics and openly communicate their personal narratives and experiences. The privacy of the face-to-face interview also created a safe and secure space for communication of these experiences.

A hypothetical question was utilised with participants that were not in receipt of compensation. These participants were presented with a question on how they thought receipt of compensation may have changed or contributed to their lifestyle. The use of a hypothetical question explored perceptions of compensation and how compensation was perceived as contributing to lifestyle. Questioning on the non-receipt of compensation and perceptions of the capacity of compensation were viewed as a means of identifying perceived gaps in the disability service framework.

7.7 Data Management
Management of data involved a number of processes. All interviews were audio-recorded to assist with analysis processes. Following each interview, observational field notes were written. Audio-data collected from each interview was then transcribed into written format in a Microsoft Office word document to create a written transcript of each interview. The Dragon Voice Speech Recognition Program was utilised in completing transcription processes.

Once the transcription of each interview had been completed, a copy of the interview transcript was emailed back to the participant. To maintain privacy and security of personal or confidential information communicated, all interview transcripts were emailed or posted to an address specifically provided by the participant. The participant was instructed to read the transcript, and then verify either by reply email or phone-call that the interview transcript was an accurate representation of the interview discussion that had taken place.

Participants were provided with a copy of the written interview transcript foremost to ensure accuracy and authenticity. This verification process drew on Forbat’s (2005) discussion on ‘what it may mean for participants to see a transcribed version of their spoken interview’. It was hoped that by providing participants with a copy of the interview transcript, that this would provide a record of their participation and contribution to the study, giving something tangible back to participants for their time and effort in contributing to the study (Forbat and Henderson 2005). It was felt that receipt of the interview transcript would also allow participants to reflect on their interview discussions and provide a pathway for participants to clarify any discussion details of their experiences if required. Further, it was felt that this process would increase transparency of data obtained.

Of the 11 interviews completed, written or verbal verification of all transcripts was obtained. In terms of participant responses, only minor corrections or comments were
received from participants. Participants were free to do as they chose with the interview transcript. It is not known the extent to which any participant later discussed or displayed interview transcripts with colleagues, partners or friends. Once verification of the written transcript was received, interview transcripts were then transferred into NVivo 7 computer software to begin data analysis processes.

All participants involved in the study were provided with a summary report of the initial thesis findings. Again, this process sought to acknowledge the contribution of participants and provide them with tangible evidence that their contribution to the study was valued.

7.8 Summary

The methodological design of the study allowed in-depth exploration of the phenomena of the experience of support service provision and compensation in Victoria. The ontological and epistemological theoretical perspectives supported the study’s Constructionist Grounded Theory approach in terms of data collection and complex analysis processes.

The methodological techniques of reflexivity, trustworthiness, clarification of study design and utilisation of components of a qualitative assessment instrument all added to the rigour and robustness of the study. The study adhered to ethics processes and privacy protocols of participant confidentiality. Every effort was made to support participants involved in the study and to acknowledge their great contribution.
Chapter 8: Participant experience of receiving funded services

8.1 Introduction

Analysis of interview discussions saw the emergence of six broad themes: knowledge of disability services received, navigation of the disability services framework, perceived adequacy of disability services, administrative burden, work relationships and experience of compensation. In this chapter I explore participant experiences through the first four themes identified. Each of these areas was important in exploring the individual experience of utilising disability support services and in examining how participants interacted with the disability service framework to obtain and maintain service allocations. Although each participant’s experience of utilisation of disability support services was unique, these particular themes emerged as common themes for most participants. Of note, participant experience of receiving disability support services under newly introduced Individualised Support Packages (ISPs), such as the DHS Support & Choice program or ISPs run through TAC and VWA, could not be examined as only one participant acknowledged having transitioned very recently onto an ISP.

8.2 Knowledge of funded disability support services

Exploring participant knowledge of disability support service programs and the disability support services framework was important in assessing how participants obtained and maintained allocations of funded disability support services.

Knowledge was defined by the extent to which participants were able to name the program they received funded disability support services through, understand the parameters and limitations of the program they received disability support services through, and if they understood where funding for their disability support service program/s had originated from.
Participant knowledge of disability support services programs and the disability support services framework overall was diverse and often influenced by individual agency. Participants that had made an effort to navigate the complex disability support service framework, learn program parameters and availability of disability services, and test the limitations of disability support services appeared to be more knowledgeable about the pathways required in obtaining needed support. These participants described gaining knowledge of disability support services available from social networks, disability advocacy and support organisations, social workers, websites, direct discussion with attendant care agencies and from simply utilising the disability support service framework itself. Participants with a good level of knowledge drew on a number of these pathways in obtaining knowledge of disability support services.

In contrast, participants with minimal knowledge of disability support services (i.e. those participants who lacked knowledge of disability support service program names, parameters of funding available for disability support services or knowledge of who funded the disability support services they received) demonstrated little to no effort in seeking to learn about the disability support service parameters. These participants had simply maintained the allocation of disability support services they had first received when they had left spinal rehabilitation, and week after week, never queried their allocation of services, nor sought to change any aspect of their service allocation. These participants, such as Emerson and Colin, were unsure of the name of the program from which they received their attendant care through and understood only that they received an allocation of attendant care hours from an attendant care agency each week. These participants were not aware of the origins of funding of their disability support services and described only that their attendant care hours were provided through a government department. Both Emerson and Colin were unaware of an ability to vary their allocation of disability support services and were not aware that they had any opportunity to challenge or dispute their allocations.
In some respects, in-depth knowledge of disability support services may be less essential for these participants. Where allocation of disability support services were low and participants felt that their support needs were met, participants obviously felt no need to question their allocations of services and viewed their allocations as adequate and sufficient. However, in terms of modern life with impairment and changing life circumstances and support needs, the extent to which having limited knowledge of the disability service framework and parameters raised issues of capacity for future management of support needs, and the extent to which effective decisions on support needs could be made if circumstances changed.

Other participants such as Graham and Lawrie also described being less aware of availability of disability support service allocations available and instead described where they had privately purchased services to meet need or relied on informal support. Graham recalled that soon after his SCI, he had struggled with his personal care on his own, and not being aware of disability support services available, had utilised informal support and had privately purchased services to meet his support requirements. Lawrie had chosen not to engage with the disability support service framework because he had been unwilling to wait on waiting lists and was frustrated with delays. Instead he had privately purchased his services and equipment and felt more satisfied with the support he had received:

[I]n terms of entitlements that I receive, I think there a few times when I have been disparaged. In terms of funding for entitlements that are set out in the funding provisions, I think that is because I am not that familiar with [what] I am entitled to receive and what I am not entitled to receive, and I don’t have the social networks. And it is what I want to do, do I want to spend an hour or half an hour on the phone and wait an extra five weeks, or do I just pay for it now and I go and get it?
Knowledge of disability support service program parameters and the disability support service framework overall was also linked to the level of allocations of disability support services utilised. Participants with high levels of disability support service allocation (for example, greater than 25 hours of attendant care per week) appeared to have more knowledge of parameters of programs and of the disability support service framework. Participants such as Ben and Stefan had thorough knowledge of program names, parameters and limitations of programs and solid knowledge of pathways to obtain further support needs. These participants also demonstrated being able to initiate an action to obtain a variation with their disability support service allocations and challenge the levels of their existing allocations where they felt this was required. These participants appeared to be able to negotiate a higher allocation of services because of the fact that they were continually engaging and interacting with the disability support service framework and were confident in navigating the disability support service framework in order to have their needs met. As Matthew notes:

[I]t must be horrendous not to be able to argue for these things, I have to do it so often, and I do see people struggling along with a rusty old chair, and they’ve been knocked back. Even in the apartment where I live, in old chairs, and I’m like ‘do this, do that, ring this guy’. I am a bit privileged, I have knowledge of the system, I help them out.

A second group that did demonstrate extensive knowledge of service programs and the disability service support framework were participants with a shortfall in disability support service allocation. David and Tom for example described utilising resources external to the disability support service framework to meet their support needs such as Rotary Clubs, Lions Clubs, sponsorship from private industry, charities and philanthropic organisations where parameters to support service allocations were restricted. As Tom noted:

[T]here is still funding through A&EP for new stuff, this is a relatively new chair and I still have a relatively new commode, and they were funded
through A&EP, so they give you a certain amount; they fell under the criteria, so I got them alright; and a few things, I have had to either scout around to a few different funding bodies for things; and I’ve been lucky with them, like the hoist, the flying-fox... the hoist in my bedroom, the ceiling hoist, they [Rotary and the Lions Club] paid for that, and another mob paid for the hoist in my van

A further area of discussion focused on knowledge of disability support services and the disability support service framework associated with initial developments of community-based support in the 1980s. Knowledge and awareness of disability support services available during this period appeared particularly low, with most of the participants that had acquired their SCI post 20 years ago describing times when they had not been aware of the existence of the few disability support services that were then available.

Tom and Colin recalled that during the 1980s, they had not been aware that attendant care was available until many years after the establishment of community-based disability support services. In Colin’s case, there was a gap of 6 years before he learnt of the availability of in-home attendant care services, and in Tom’s case, 2 years. Both Colin and Tom recalled relying heavily on ongoing informal care provided by immediate family members during this time. Tom described that he felt the education processes at the spinal rehabilitation at the time were to blame for not providing him with enough detailed information on how and where he could obtain services and for wrongly assuming that his primary care would always be provided by his then wife.

Knowledge of the impact of compensation on funded disability support services was particularly sketchy at the disability support services and compensation interface. Where participants had had an opportunity to make a claim for compensation and/or pursue legal action, there was considerable confusion with participants as to the exact level of disability support services they were entitled to use and the impact any compensation payment would have on their access to services. Some participants appeared to view
their compensation payment as linked to their disability support services allocation and wrongly presumed that they would be required to utilise their compensation payment to privately purchase required disability support services.

Emerson was concerned that if he successfully pursued a compensation payment, that he might spend his compensation payment on something other than attendant care, believing his compensation payment would be funding his attendant care. He described not wanting to make a claim for compensation as he was under the impression that he would be excluded from access to funded disability support services once he received any compensation payment:

[I]f you get compo payments, that could stop, and with a compo payout or like with TAC though, you would get a payout, but that is all you get, and if you run out of that, you can’t go back on general government funding as far as I know; like if you spend money that is supposed to be on attendant care… I don’t know, it is a tough call, I’ve got no interest in pursuing that

Annie also assumed that any receipt of compensation would impact on her current allocation of disability support services. Lawrie described being uncertain as to whether he would be entitled to receive any funded disability support services when he was undertaking legal action to obtain his compensation payment, and recalled having settled his claim for compensation at a particular level in anticipation that he would be privately funding his disability support services on a long-term basis:

I was aware that if I had a successful outcome, well I believed, that if I had a successful outcome, I wouldn’t be entitled to any government benefits, that I wouldn’t have a right to any government support, so I had factored that into the amount… …so I thought I wasn’t entitled to any support, and I very much valued that highly, and that ability, as I saw that support as a safety net for me.
Participant knowledge of disability support service framework and disability support services available in relation to receipt of compensation were thus not comprehensive. Knowledge of the disability support service programs and the disability support service framework fluctuated from extensive knowledge (for participants with high support usage or shortfall in services) to minimal knowledge where allocations were regular and disability support service usage remained constant over many years. Gaps in knowledge of disability support service structures included lack of awareness of availability, particularly during the period of initial development of the disability support service framework in the mid 1980s, reduced knowledge of availability of disability support services in relation to receipt of compensation payments and decreased knowledge of names and parameters of disability support service programs being utilised.

8.3 Navigation of the support services framework

The ability of participants to navigate the disability support service framework was the second major theme that emerged during analysis. Navigation was defined as a participant’s ability to access required support services from within the disability support service framework through the array of differing limitations and parameters of programs provided through differing levels of government, i.e. how participants managed to ‘find their way’ in obtaining services.

The ability of participants to navigate the disability support service framework was varied. Participants funded by VWA and TAC tended to navigate their disability support service framework with ease, in a clear straightforward manner. This was most likely due to the fact that support services provided through VWA and TAC were funded from a single entry point and at one level of government (i.e. State Government). Participants funded through VWA and TAC also in general had widened parameters of funding available for support services and equipment, and as such did not need to source services from multiple areas of the disability support services framework or from areas
external to their disability service framework (i.e. through charities or informal support) to support their needs.

In contrast, participants funded through DHS demonstrated significant difficulty in navigating DHS support service programs and in accessing support services. These participants noted difficulty in finding the support service programs that would provide the services they required, and then difficulty with establishing eligibility and entry requirements to access these programs. These participants noted that the array of support service programs that needing to be accessed just to have their basic needs met, and the multiple entrance points to access support services, often created difficulty and confusion in obtaining support. Secondly, these participants described difficulty in maintaining adequate support service allocations due to the limitations and restricted parameters of most DHS programs. They described instances where they had been required to navigate two separate support service programs just to meet attendant care requirements, and that each program had been funded by a different level of government. Further, they described how each support service program had differing guidelines, staff, pay rates and administrative processes all administered through individual agencies. The experience of navigating multiple pathways in order to obtain and maintain support services was thus viewed as complex, stressful and tiresome. The process of having to learn and then navigate the parameters of each of these different support service programs was also viewed as an administrative burden. Participants funded through DHS however noted that they had no choice but to navigate their way through this complex support service framework in order to have their support requirements met.

Tom and Matthew for example utilised support service programs administered by Federal and Local Governments, such as CAAS and HACC services respectively, in addition to support service programs funding attendant care at a State Government level. In these instances, they had been required to navigate parameters of support service programs
vertically through multiple levels of government and horizontally across state funded programs. Where DHS support service programs had limitations placed on them, participants also described having to source support from sources external to the disability support service framework.

Tom for example described utilising a string of support service programs to meet his support needs that included:

- attendant care hours funded through the DHS HomeFirst program at a State Government level
- additional attendant care and home cleaning hours administered by the Home and Community Care (HACC) program at a Local Government level
- respite support services administered at Federal and State Government levels
- assistive equipment and personal healthcare provisions administered through the DHS Aids and Equipment Program (A&EP) at a State Government level
- provisions for personal healthcare purchased through the Continence Aids Assistance Schemes (CAAS) administered at a Federal Government level
- and income support administered by Centrelink at a Federal Government level

A further issue that emerged associated with navigating the disability support service frameworks was the delay in the realisation by some participants that there were difficulties in navigating the disability support service framework. These realisations seemed to occur when participants had left spinal rehabilitation with a particular allocation of services and equipment, and then realised a number of years later when equipment needed replacing or when allocations needed changing because of a change in life circumstances, that there were difficulties and limitations to sourcing further services and equipment. Participants described the realisation that additional allocations for disability support services and equipment were limited and that they were often required to negotiate a variety of support service programs just to obtain a variation in allocations. Hence realisation of difficulties in navigating the disability support service
framework were often delayed and emerged a number of years after participants had transitioned home from spinal rehabilitation.

Ease of navigation of the disability support service framework was thus evident for participants funded through VWA and TAC, and conversely, considerable difficult for participants funded by DHS.

8.4 Adequacy of funded disability support services

Adequacy of disability support services received was the third major theme that emerged during analysis. Adequacy was defined by the extent to which participants perceived that the support services met their day-to-day support requirements, and included the capacity of participants to obtain and maintain an allocation of support services to a perceived satisfactory level. Adequacy in this sense was subjective, based on the perception of what each participant viewed as a sufficient and ample amount of service allocation.

Perceived adequacy of support services received was often correlated with knowledge and navigation of the disability support services framework. Participants required knowledge of services available and an ability to navigate the disability support services framework in order to achieve an adequate allocation of support.

Approximately half of the participants felt that their support service allocation was adequate. These participants were satisfied with their allocation and felt reassured in knowing that their allocation of services met their base level personal care needs (regardless of employment status, life events or health situations). They described being grateful that they at least received some allocation of services.

Stefan regarded his allocation of support services as adequate. He viewed his allocation of services as essential to his survival and to his and his family’s wellbeing, and felt that
his allocation of support services provided him and his family with capacity to cope with the stresses that had developed since he had acquired his SCI. Jim also viewed his allocation of support services as adequate. He felt that his allocation of services allowed him to do ‘more meaningful things in life’ and improved his quality of life. Ben and Annie also viewed their allocations of support services as adequate and felt reassured in knowing that support would be available regardless of any future employment or health situations. Colin and Matthew described receiving their initial allocation of support services in the early 1980s as ‘extremely adequate’ and ‘liberating’. For Colin, the receipt of support services had taken the pressure off his immediate family of them having to provide his personal care support. He thus viewed his allocation of support as giving him some control of lifestyle. Matthew also viewed his allocation of support services as contributing to the restoration of his ‘social status’ and re-engagement with community:

[It] allowed me to go to conferences, and I could take personal carers with me to do all of these things that would have been impossible to do otherwise; it allowed me to do things in life I wouldn’t have been able to do; it gave my wife a break for a while, my wife was a bit jealous I think, also at a bit of a loss ‘what do I do now?’; it was good for me, I was more independent, could keep relationship and personal care separate, it was liberating for me

However for the other half of participants, allocations of support services overall were viewed as inadequate. These participants discussed having to manage shortfall of allocation on a week-by-week basis, such as not enough attendant care hours per week, and described instances where equipment allocations had not extended far enough to adequately meet their requirements. Emerson described his allocation of support services as inadequate because of limitations and restricted parameters of many of the support service programs. He was particularly vocal and stressed with the inadequacy of his overall service allocation of only 34 hours a week of attendant care. He described that as a medium level quadriplegic, he required assistance with most of his daily living, personal care and community access tasks, and that 34 hours of attendant care per
week was not a high enough allocation of hours for him to meet most of his personal care needs. He communicated that this was the maximum hourly allocation of attendant care available under the HomeFirst support service program, but that it struggled to meet his needs:

- I don’t get enough hours, I do all of the showering, toileting, dressing and stuff; I do get a couple of hours of community access and I use that to go shopping and stuff with carers, but otherwise I do stuff myself, so it is mainly personal stuff at home, if I need to do other things, I do them on my own; but sometimes I need an extra hour or two, so if I went from 34 hours a week to 37 hours a week, I would be laughing... you know

Emerson also noted that there were particular issues with adequacy of attendant care services available outside of standard times, i.e. from 7am>11pm. Emerson felt these time restrictions compromised his lifestyle, restricted his social movements and created a lifestyle that was scheduled and lived by the clock:

- Well I think the main problem is going out late at night and how you manage then; either my mates give me a hand with things or a carer comes over at 10 or something... well more like 8:30 or 9 or whatever it is

Further, Emerson chose not to utilise other disability support service programs to top-up his allocation as his previous efforts to source extra support through the Local Government HACC program had been so frustrating. He commented that he felt even further restricted with the additional scheduling of these services and as such did not feel it suited his lifestyle. He also resented having to personally subsidise allocations of support service usage, as required by HACC, and felt that the additional administrative work required in accessing these extra support services was tedious and not worth the effort for the amount of support he was obtaining.
Other participants described utilising a number of different pathways in seeking to counter inadequate service allocation. These included utilising services funded through the Local Government HACC programs, Lions or Rotary Clubs, Disability Liaison Units at Universities, work-assistance support hours from employers (internal to organisation), privately funding extra support hours and utilising informal support to obtain extra services and equipment. Tom noted that using such a matrix of different services and being resourceful was sometimes ‘the only way’ to get through. David utilised extensive amounts of services obtained from outside of the disability support service framework to meet his needs, which included sourcing allocations from philanthropic organisations and utilising informal support:

If you can get some of these organisations to support people with disabilities to access philanthropics, I know things like the Lions club; I like go to the public purse and if DHS doesn’t do it, I’m like ‘can we get it through a private organisation?’ I think that that resource use is under utilised, you know if some people turned around and said ‘we are going to try and utilise some of these organisations’… and it will be hard, filtering through the legitimate people that do have a need, from the people that are wanting [but] I think that that is another possibility to get resourcing for attendant care; I also think there should be a sense of community, for someone in my situation, so when my parents are away, I have good neighbours and I can call on them if I need help getting something pulled out of the oven for tea; you know, I don’t have to have a carer here; there are a couple of neighbours, they look after us and keep an eye out for us

Informal support was utilised considerably in countering inadequate allocations of disability support services. Informal support was defined as the receipt of support from an individual or group where no financial gain was made in providing the support, and where support was not provided through a registered service provider. Informal support included receiving funding from philanthropic organisations for equipment, private
fundraising efforts, parents, friends and/or partners providing personal care, neighbours assisting with private transport to drive someone to and from work each day or a neighbour assisting with meal preparations.

Informal support was most often utilised in conjunction with funded disability support services. Tom used a substantial amount of informal support due to limitations with his disability support service allocation. Tom utilised his funded allocation of support services in the mornings for his personal care, and then utilised informal support from his parents for the support he required in the afternoons and evenings. Tom’s parents were very committed to their son and had provided him with this level of informal support for nearly 20 years. Emerson described utilising informal support on a less regular basis and at fluctuating levels. This included his mother taking-on his full personal care load for a number of months until an attendant care team had been trained up, and his mother and father privately funding some housing modifications so that he had accessible accommodation for a time until he returned to University studies.

Matthew described having previously been very dependent on informal support due to shortfalls in disability support service allocation, but raised significant difficulties with utilising informal support on a long-term basis. Matthew felt that informal support, although provided in good will, had a shelf life and end time overall. He highlighted that motivations in providing informal support often waned, and where opportunities to work in paid employment positions for higher wages arose, people quickly moved away from providing informal support. Matthew viewed the utilisation of informal support as inefficient, and felt the irregular hours of informal support reduced the motivation of people in providing informal support:

*I’ve noticed that no matter how much they like me or no matter how much good will, it is difficult for an hour shift, it is difficult for someone to be motivated, it’s still just an hour. Like a friend I know works in a restaurant and she gets 6 hrs and all that. It is better to have longer shifts with the*
support of friends and girlfriends to help out in between [but] it’s still very inefficient.

Matthew was also conscious of being left without any support if the person he was relying on to provide informal support withdrew for any particular reason. Matthew described how he was forced to negotiate the arrangements of his informal support interactions and attempt to establish what the expectations of both sides of the interaction were and the motivations of people in providing informal support. He highlighted that often when the informal care relationship had broken-down, that the individual often fell back onto more formal structures of the disability support service framework and into critical support situations. Matthew aptly identified implications of loss or withdrawal of informal support where responsibility or obligation to continue with ongoing support had suddenly stopped. Matthew noted that most informal support was provided without training, and further, that partners, parents and friends received no income or superannuation for extended periods or were not covered by any form of WorkCover or insurance if an injury was obtained whilst providing support. Matthew thus described being more confident utilising funded disability support services where there were fixed structures of employment and payment, and where there were obligations by attendant carers to attend rostered shifts and attendant care agencies to fill shifts. Matthew felt that utilisation of funded support services, despite some inadequacies, at least provided greater levels of reassurance, responsibility and motivation for services to be provided.

Inadequate allocation of disability support services were also responsible for some participants perceiving themselves as a burden on immediate family members and friends where these family members and friends were providing informal support. These participants described what they viewed as a forced dependency in having to obtain informal support from immediate family members, particularly where partners, parents or friends were required to provide support for long hours over an extended period of
time. These participants described wanting to keep certain relationships separate from support tasks, such as personal care, rather than be forced to rely on partners, parents or friends for support, and were frustrated that an inadequate allocation of disability support services was the reason for this. As example, Jim described his situation of not wanting his teenage daughter to have to take-on a role as a support provider:

   I have tried very hard not to make my teenage daughter a carer, because I think she should be able to have her childhood. She was 11 when I was injured, and I'd like her to have her childhood and adolescence as unaffected by this and is possible. I mean, there is no way that she is not affected by it, but she doesn't have to be my carer.

In other situations, informal support roles appeared to be taken on willingly, despite adequacy or inadequacy with disability support service allocations. Individuals seeking to provide care to a partner or parents wanting to assist their son or daughter with personal care tasks described taking on these informal support roles out of a sense of duty and responsibility. They described providing this support as a natural part of wanting to help someone in need and as an expectation of their relationship role.

Perceived adequacy of disability support services however were strongly correlated with where participants received funding for services from, and thus directly linked with how participants acquired their SCI. Participants who acquired their SCI as a result of transport or workplace accidents (and hence were funded by TAC or VWA respectively) clearly had access to higher allocations of disability support services than those funded through DHS or other sources. The perceived adequacy with allocation by these participants funded through TAC and VWA was generally higher, and it was evident that these differing funding structures and allocation levels significantly impacted on participant’s perceived adequacy of support services.
Participants funded through TAC and VWA had opportunity to receive extensive allocations of disability support services, such as up to 24 hours a day - 7 days a week of attendant care in some instances, and high allocations of equipment, such as expensive wheelchairs, transfer hoists, housing access modifications and private transport access modifications. Stefan, funded by the VWA, received an electric wheelchair, a commode, a transfer hoist, utilisation of a physiotherapist, a psychologist, an occupational therapist, a podiatrist, a gardener, home-cleaning services, district nurse visits and 24/7 attendant care.

Ben and Jim, funded through VWA and TAC respectively, were also aware that their allocation of support services and equipment was more than adequate in comparison to what others received. Ben described feeling guilty about the high level of support service allocation he received in comparison to others and felt that he now had an obligation to contribute to advocacy within the disability sector to make up for this:

*It is mighty unfair, I feel really guilty about it sometimes, and I feel extremely guilty sometimes when I come to ____ [town name], and Ethel [attendant carer] and I are wheeling up the street, and I’m sitting there like Lord Muck; and I might go to a meeting sometimes and pop in and have some sandwiches for lunch somewhere, and I see some people much worse off than I am, sitting there by themselves, and I feel really guilty; I just don’t think that that’s fair ...what is fair and equitable? I don’t know... but these are people that need to be cared for, in terms of more than what they get; and I guess that’s why I do a lot of what I do, which is giving back and helping out, I do a lot of work to help people that can’t help themselves*

Similarly, Jim described his allocation of support services funded through TAC as being ‘on the better side of the funding road’. He was aware that being funded by TAC placed him in a better position to access disability support services than others, and knew that
his allocation of support services was better and more secure than others based solely on how he had acquired his SCI:

[T]here were inequities, but I am very much on the receiving end and better side of getting things. If you are going to have an accident like this, the road is the place to have it... I didn't have to worry about how I was going to pay for my wheelchair or what I had to apply for here and there and everywhere... but you know, for the people that fall through their own home wall or fall down the stairs, you know, they get absolutely nothing. They were applying for grants here, there and everywhere. One bloke had dived into his own pool and broken his neck, [and] you know the football club, the guy that I was in the room with, the football club were trying to raise money for him just to pay for a wheelchair.

Participants funded for equipment through TAC and VWA in general described their allocation of equipment as very adequate. They felt reassured knowing that a particular piece of equipment would be provided if within reason, and that equipment allocations were not restricted on a year-by-year basis or upper amount as they were through DHS funded equipment programs. Jim emphasised that receiving equipment through TAC was relatively easy and was not encumbered by any particular limitations or time restraints. As Jim recalled ‘basically they said ‘what do you want?’ and I tried out a dozen wheelchairs and different things, and they set me up with a chair and some bits and pieces that they thought I might need’. Participants funded through the TAC and VWA also described their allocation of personal healthcare supplies as ‘satisfactory’. They noted that all of their personal healthcare supplies, within reason, were fully funded and that there were no complexities or difficulties in obtaining allocation.

In contrast, participants receiving allocations for support services funded in the main through the DHS more commonly described being unsure and uncertain about their allocations and felt that they did not adequately meet need. These participants had high
levels of anxiety about where ongoing services would be sourced from, and expressed frustration at the limitations and restrictions placed on most of their service and equipment allocations. They described being aware that people with a SCI receiving funding through the TAC and VWA were receiving higher allocations of disability support services than themselves, and that these were more than adequate:

[I feel] a little bit p**d off, because you are not adequately funded. You guys [in reference to me as a TAC client], anything that you need, you guys, you can just put up your hand and say we need this bit of equipment. But I need assistance to get it, I have to fight to get it... so like a person has to pay for their stuff, because their needs outweigh the actual cost of the item. In terms of what is federally and state funded, [it] doesn’t cover that person, [but] someone under the other system is covered by that body because of a certain instance about their accident.

David, who received funding for services through DHS, was openly hostile and resentful with the inadequacy of support services he received and with the limitations placed on his allocation of disability services. He viewed the differences within the DHS disability service framework as creating significant division in the disability sector overall, and of generating a culture of resentment and greed. In particular, David viewed most TAC clients as trying to ‘rip off the system’. He vehemently denigrated them for over utilising the system and abusing a good thing while others struggled, and perceived the TAC as being an ‘open book’ by simply granting a client anything they required as soon as they put up their hands. Although acknowledging some of these views may have been based on stereotypes, he was adamant that TAC clients had things much easier, and were in a better position overall in not having to deal with inadequacy of support service allocation.

Participants who received allocations for equipment through DHS described having to frequently contribute to costs from their own wages or pension allocations to meet
shortfalls in purchasing new equipment, and described the Aids & Equipment Program (A&EP) program as very restrictive and inadequate in fully meeting their requirements. Tom voiced that he was very annoyed at having to use his money to subsidise the cost of equipment purchases that he could have been directing towards financially supporting himself or contributing to his superannuation. He noted that at times he had been required to source equipment from sources external to the disability support service framework when he had not had access to further allocations, but had further need. Matthew also viewed his equipment allocation as inadequate, and was frustrated by the restrictive parameters of the A&EP program and in having to actively argue to obtain equipment allocations. He described having to contribute large amounts of his own finances to subsidise his A&EP equipment allocation so he could purchase the more expensive pieces of equipment preferred:

[T]he government offered some support but not a lot, so often you had to accept something inferior from what you needed or you subsidised it yourself if you could come up with the money. Meanwhile A&EP did not increase and the chairs doubled in price, so people get progressively less and less... it is just luck depending on how you had your accident. Like I paid $10000, and that had to come out of my super, which I really need to support me later, but I wanted a luxury chair, that stands up so I can reach a cupboard, so that is not standard... they [DHS] contributed a fair bit, they contributed $8500, a good chair is over $17000 these days

DHS participants also viewed the continual waiting lists in obtaining equipment as inadequate. Lawrie noted that getting equipment through the A&EP equipment program often took considerable time and effort, and with assessments and negotiations, it was often a struggle and a fight just to obtain equipment. Lawrie noted that instead of trying to deal with these issues, he often utilised funds from his own wages to avoid having to spend a lot of my time on waiting lists and having to ‘wait and wait and wait and wait’ for equipment to arrive:
It is what I want to do, do I want to spend an hour or half an hour on the phone and wait an extra five weeks, or do I just pay for it now and I go and get it?... I gather with PAPD, I am entitled to something there, and I am hesitant... I am not looking forward to the negotiations about that, I don't want any arguments or abuse about what I am entitled to or not, you know arguments and all of that... they have funded a few cushions and that, although that was pretty drawn out too. Look, what makes a lot of this difficult, is that you have to make a time with the OT [occupational therapist] and they have to come and measure it, and you don't want to be missing out on work and all of that, and it has to be during the day, I am just saying, it makes it a bit tricky

Participants funded by DHS also found funding allocations for personal healthcare inadequate. They described having to obtain personal healthcare supplies through combinations of the State funded A&EP equipment program and the Federally funded CAAS program, and at times needing to subsidise costs from their own purse. They described the parameters of all of these programs as heavily restricted and that there were complexities and frustrations in having to utilise dual schemes to meet need. As Tom demonstrated:

That is money that if it hadn’t come out of my pocket, I could have put it towards something. I may have been able to afford to pay that $600 a year to pay for incontinence aids, but in saying that, I still think they should have been funded by government and not me... It is costing me money out of my pension which I can ill afford to give... those sort of issues affect my life. If I had to tell my friends that I had to pay to go to the toilet they’d go 'what? everyone else takes it for granted... but that is what happens.

Allocations for house and vehicle access modifications for participants funded by DHS were also viewed as inadequate. DHS participants received only minimal allocations for
required housing modifications (i.e. a one-off $4500 grant), and in most cases were forced to privately fund these home modification requirements. Participants also had no access to any vehicle modification schemes (however since 2008, a A$10000 private vehicle access modifications allocation been introduced by DHS as a part of the A&EP equipment program). Where allocations were inadequate or non-existent, participants were forced to source provisions from outside of the disability service framework, such as through the Rotary and Lions Clubs for example, or privately raise capital to fund house or vehicle access modifications. Matthew described challenges in funding access provisions for a new bathroom:

   at least a day a week keeping everything together; getting a bed fixed, a commode chair, modifications for apartment, my project at the moment, trying to modify the bathroom, they’ll give me $4000…it will cost $10000, now I’ve got to get the money first

Colin described his difficulties in funding housing access modifications and the extent his parents had gone too in seeking to obtain finance for required housing modifications. Colin recalled that at the time of his accident, no housing modification programs had been established and that his farther had been required to take on a considerable financial burden:

   well, dad applied for a loan and it was rejected, although it wasn’t rejected at first, how can I put it... he sort outside help from the local member of Parliament; and they couldn’t help, so they put the house on second mortgage and then he got a loan, and then he got the building done for me and we built the two units; that was heartbreaking that for the family... a second burden for dad, on dad

As is evident from these discussions, distinct variation in adequacy was evident between participants receiving service and equipment allocations, including house and vehicle access modifications. Participants funded through TAC and VWA characterised the receipt
of these allocations as generally adequate and easy to access. All allocations were
taken through one level of government and no participant funded through TAC or
VWA noted having to utilise private funding to meet shortfall or utilise sources external
to the service framework to meet need. Funding allocations for more expensive
equipment and housing modifications were fully covered by TAC and VWA.

In contrast, participants funded through DHS felt funding for disability service
allocations, equipment, personal healthcare services and house and vehicle access
modifications were generally inadequate. Shortfall in program parameters, meaning
additional allocation was unavailable, was common. In the case of allocations for
housing access modifications, shortfall was dramatic with only minimal allocations
available for all DHS funded participants. Participants also noted in particular that
waiting lists for allocations were a contributing factor in the complexity of receiving
funding for equipment and contributed to inadequacy with allocations of services.

Although availability of disability support services were heavily influenced by defined
policies and parameters of policy structures, and thus determined by how the SCI was
acquired, adequacy of support allocation was also highly subjective. Individual
perceptions of adequacy of support service allocation differed extensively between
participants. Felt adequacy of support service allocation was highly influenced by factors
including extent to which informal support was available to be utilised in conjunction
with formal disability services, the extent to which the participant was financially secure,
the level of individual agency and physical function of each participant, and the ease at
which services could be sourced from external to the disability support service
framework if required. All of these factors impacted on the subjective perception of
adequacy and the extent to which service and equipment allocations adequately met
support requirements. Issues of dependency, reciprocity, sustainability of support and
levels of agency were thus strong themes related to adequacy of services. The dynamics
of the support interaction, the allocation of support services available, flexibility and reliance on informal support all affected perceptions of adequacy of support services.

8.5 Administrative burden

The fourth major theme that emerged during analysis was that of administrative burden. Administrative burden was defined as significant effort, frequency and time required in obtaining and maintaining allocations of support services. Tasks required in obtaining and maintaining support services included phonecalls, emails, faxes and written correspondence to attendant care agencies or funders/insurers, rostering of attendant carers, forwarding of group timesheets on a weekly basis, interviewing and training of new attendant carers, and completion of required annual review processes for insurers/funders and attendant care agencies. Some participants also took on the additional role of recruiting attendant carers themselves, which included advertising and then interviewing potential attendant carers. Tasks also extended to meetings, phonecalls and emails with occupational therapists, physiotherapists and equipment manufacturers in maintaining upkeep of equipment. An administrative burden was defined as being evident where these tasks, in terms of time, effort and frequency appeared to be impacting on participant quality of lifestyle.

Participants not experiencing administrative burden described maintaining and obtaining their support service and equipment allocations as functioning very smoothly, with no particular concerns regarding rostering and invoicing of their service allocations and/or maintaining equipment. They stated that their need for correspondence with service providers was minimal, and that they were generally only contacted by the attendant care agency if there was some discrepancy with the phone login system or if a change in rostering was required. Both Tom and Emerson described their administrative burden as low, and that they did not have any difficulty in coordinating their support needs:

*We don't have timesheets, it is all done on the telephone. They have an automatic system, and when they [the attendant carers] come-in in the*
morning, they log onto a computer using a phone, and when they leave, they do the same.

For half of the participants however, completing administrative tasks to maintain the running of their support program and obtain and maintain support service and equipment allocation was burdensome. For these participants, completing administrative tasks required considerable effort, taking up to 1 day per week in one instance, and 3-4 hours each week in general for others. Participants such as for Ben, Stefan and David described having a high administrative loads which involved coordinating their support programs, filling out schedules and completing paperwork, making phone-calls to clarify attendant carer shifts, training of new attendant carers and organising and attending appointments to obtain and service equipment. This is despite the fact that attendant care agencies are paid to take on the role in coordinating services within the unit cost paid to attendant care agencies.

In particular, recruitment and training of attendant carers added to the administrative burden of participants. Although recruitment and training of attendant carers is officially a role of attendant care agencies, recruitment and training of attendant carers was often a shared task between the attendant care agencies and participants themselves. Participants described being involved in recruiting, interviewing and training of attendant carers which included placing advertisements in local papers, letter box flyer drops, sourcing attendant carers informally through acquaintances, word-of-mouth or self-advertising in their local area, and conducting their own interviews. These processes involved considerable time and effort and added significantly to the administrative burden of these participants.

David viewed his administrative burden as high because of difficulties in recruiting attendant carers online through online employment agencies. He viewed his administrative burden as having increased in recent years because of having taken on
this task. He also felt that the attendant carers being recruited recently were less skilled and qualified, which required increased time and effort in training:

Back then, Quality Support [the agency] would just say ‘what do you want?’, and I would say ‘I want someone in every morning and I want someone in every alternate evening to help me get into bed at night’. Quality Support would send you their details, you would interview them, they would arrange the starting date and the employment for them, and [then] start them off the next day. Then at home, you could run your own race, and you knew if everything was going ok, that was good, but that if you needed help you could ring them. You know trying to find people now, it is sooo haaard. You put an add out in the paper, you know in ‘Seek’, and you get 20 replies but they are people applying from Bendigo [distant regional town], it’s just ridiculous. I don't know if they are doing it just because they want to get applications in for Seek or stuff like that, but you’ve got to just sift through all these rubbish applications to get through to maybe 2 or 3, and when you get to 2 or 3, they are nowhere near the quality you used to be able to get.

High turnover of attendant carer numbers on any given support program also contributed to increased administrative burden. High levels of attendant carer numbers dramatically increased administrative burden, for both the participants and the attendant care agencies, in terms of extra time and effort required in advertising, interviewing, training and re-coordinating each new attendant carer.

Further, despite the implementation of automated log-in systems by attendant care agencies, intended to reduce the administrative burden associated with attendant carers administering timesheets, an increase in administrative burden was noted with the log-in system by some participants. This occurred particularly where there were inaccuracies in how attendant carer hours had been recorded by the log-in system and where participants had been required to clarify the records. Matthew described the process of
fixing these amendments as ‘ludicrous’ and that over the previous 3-4 months, it had taken him between 10-15 hrs per week to manually amend the times recorded. David was also particularly angered at having to notify the attendant care agency to amend the log-in system in advance if there was going to be a change to the roster. In addition to adding to the administrative load, he viewed this as demeaning for people with impairment:

Say I turn around and have a day off on Friday and I want to get up at 8 in the morning rather than 6 in the morning, why the hell do I have to let them know? Let them just login! but no, I have to send an email telling them about it saying ‘by the way, on this day I’m going to change this shift’, it is demeaning, it ‘totally’ goes against my principles of having a flexible, responsible system. There’s no flexibility... why, because I have a disability, why do I have to account for every hour of the day? So that part of it, it is completely wrong.

Completion of review processes by service providers were also viewed by participants as contributing to administrative burden. Reviews of allocation are required to be completed by any person in receipt of a disability service allocation, on either an annual or biannual basis, to ensure service requirements are appropriate, ‘reasonable’ (a term utilised most particularly by the insurers/funders) and meeting support requirements. Reviews most usually involve a participant meeting with an occupational therapist for 2 to 3 hours to discuss service and equipment allocations, equipment condition, levels of informal support being utilised and general lifestyle goals. A recommendation is then made by the occupational therapist to the funding body to increase, decrease or retain service and equipment allocation based on this review. Participants are entitled to appeal these recommendations, however any appeal was often viewed as further administrative burden, particularly when appeal proceedings extended for months.
Jim described a lengthy appeal of a review recommendation that his home-cleaning allocation be reduced by an hour. He noted being particularly frustrated that the appeal of the review recommendation had nearly taken until his next review to be resolved. Jim noted that his administrative burden had significantly increased during the period when he was appealing the review decision:

The house cleaning, they upped the house cleaning when my wife left, from 3 hours a week to 6 hours a week. But there are these ridiculous reviews that they try to do. Like last year, they tried to take 1 hour of house cleaning away from me, and you know, it is just such a ridiculous waste of time and resources for somebody like me, where they know that my condition is not going change, yet they still do a review. So we had a big fight over that last year, and then blow me down, they do the next review only 6 months after the other one had been completed and the last one was settled, you know, it was just so ridiculous... we argued over it for 3 months, it was just a total waste of time and resources... I had to fill out this big form, you know and then make myself available for an occupational therapist to come in and check it all out, and then after that, to have the argument.

Participants readily acknowledged that there was a need for insurers/funders to assess usage of disability service and equipment allocations, and understood insurers/funders had to be accountable for the funding that was provided, and understood that allocations for services and equipment could not be a ‘free-for-all’. Yet although participants acknowledged that funders/insurers had to be accountable to how their funding allocations were distributed, most participants described being nervous, anxious and cautious around their review processes. Reviews were described as ‘a constant inspection’ and an ‘intrusion’ on their lifestyle as they involved an examination of personal daily activities and lifestyle.

8.6 Summary
The four major themes of knowledge of disability support services, navigation of disability support service frameworks, adequacy of disability support service allocations and administrative burden were all significant in terms of impact on the experience of utilising disability support services. Knowledge of disability support services, eligibility of allocations and capacity to navigate the disability support services frameworks dramatically impacted on how formal disability support services were utilised and thus on quality of life and lifestyle choices of participants. As noted in discussion, many participants moved outside of the disability support service framework where needed services could not be obtained, relying on support and/or funding from family and friends, charities or in some cases, going without support and making-do. Many participants reliant on disability support services described inequity in disability support services available between themselves and others with SCI, shortfall in program parameters in seeking to obtain allocations and difficulties in having to navigate a variety of programs at multiple levels of government to obtain services. Further, once allocations of formal disability support services were obtained, at least half of the participants spoke of administrative burden in maintaining the running of services and equipment at considerable effort and cost to personal time. Again, the quality of life and experience of receiving disability support services were significantly affected by these factors.

In the next chapter, I will discuss another major theme identified from participant interviews, the impact of participant work-relations on the experience of receiving disability support services.
Chapter 9: Participant Work-relationships

9.1 Introduction

The theme of work-relationships emerged as significant theme in relation to the experience of receiving funded disability services. A work-relationship was defined as an employment-based interaction between either a paid staff member/attendant carer, a service provider or a funder of services/insurer related to the provision of disability services.

The ability of participants to establish and maintain work-relationships with paid staff, service providers and funders significantly impacted quality of life and lifestyle choices of participants. The standard of work-relationships was often influenced by the ability of participants to negotiate the work-relationship and by the extent of service allocations provided. Participant work-relationships also operated at various intensities, with work-relationships viewed as fluid and flexible (similar to that of a friendship), to more structured, professional and formal. Work-relationships were also characterised by continual, extended or repeated interactions on a day-to-day basis, to single, monthly or formal written correspondence with a distant coordinator.

In this chapter I examine participant work-relationships and the impact of these work-relationships on the experience of receiving funded disability services. I explore the theme of participant work-relationships using three categories - participant and attendant carer work-relationship, participant and service provider work-relationship and participant and funder/insurer work-relationships, and examine the characteristics of each of these work-relationship categories.
9.2 Participant and Attendant Carer Work-relationship

Work-relationships between participants and attendant carers occurred most often in the participants’ home, with the work role of the attendant carer being completion of tasks to support the daily living activities of participants. This included completion of personal care tasks such as assistance with showering, toileting, chair and bed transfers using hoists, dressing, meal preparation and household tasks. This also included assistance with community access and tasks, such as shopping and errands, visiting family and friends and/or attending social activities. The attendant carer’s role could also include non-active sleepovers where the attendant carers remained at the participant’s house overnight to provide security, medical or general attendant care support where required.

The ability of the participants and attendant carers to negotiate their work-interactions, and establish stable and balanced work-relationships was crucial to quality of life for participants. Negotiating a work-relationship often involved negotiating differences in workplace expectations, managing individual differences and mannerisms, negotiating any disputes or conflicts that emerged and providing scope for the participants to direct tasks as required. Negotiating work-relationships also extended to management and negotiation of boundaries between other family members in the home setting and management of boundaries in community settings.

Participants in general characterised a positive work-relationship as where the attendant carers were respectful, thorough and attentive with their work tasks. Consistency and reliability in attending shifts was viewed as an essential aspect of a positive work-relationship, and it was noted that it took time to establish a good work-relationship (at least a number of months in some cases). Participants also characterised a positive work-relationship as where trust with the attendant carer could be achieved, and where a balanced, non-overpowering work-relationship had been established.
Tom characterised a good attendant carer work-relationship with his ability to make friends with the attendant carer (which he described as happening 95% of the time). He felt that attendant carers needed to be able to get on well with all of the people in the household while in their work-role and also needed to be able to balance interactions with his friends in the social arena while in their work-role.

David viewed familiarity as crucial in developing a good work-relationship with an attendant carer, while Emerson described a good work-relationship as developing more readily if the attendant carer had a positive and enthusiastic work attitude, had a bit of ‘get-up-and-go’ in them and were enthusiastic and efficient in completing the required tasks.

Stefan supported many of these views. He also characterised a positive work-relationship as where a ‘reciprocal interaction’ with an attendant carer could be established, and held the view that if he treated an attendant carer right, they would treat him right in return. Colin agreed with this view, and described a positive work-relationship with an attendant carer as being based on mutual respect and longevity. He noted that many of the attendant carers, ‘my girls’ as he called them, had worked on his support program for between 5 and 14 years, and viewed the longevity of these work-relationships as based on the effort he had put into establishing a balanced work-relationship. Colin emphasised that the work-relationship with the attendant carers should not be based on ‘you do what I want you to’ type directives and power, but on mutual understanding of tasks based on good communication.

Ben described a positive attendant carer work-relationship as being based on loyalty, trust, mutual good treatment and respect. He also felt that a positive work-relationship was more able to develop where adequate allocations of attendant care hours were provided that allowed attendant carers to complete their required tasks without having
to continually rush. Graham agreed with this, and viewed a good attendant work-relationship as based on loyalty, reliability and maturity.

From a differing perspective, Annie described a positive attendant carer work-relationship as where things were more one-sided and where she was fully able to direct attendant carers. She described preferring to take on an intensive role of training the attendant carers herself, and viewed the work-relationship as more sound once she had trained an attendant carer to complete tasks in a manner she wished. Annie noted that she was genuinely concerned for the wellbeing of the attendant carers working on the program:

I guess also for me, I take a lot of care of the people who are around me, and I think that it is important that people feel satisfied in the work they do around me, and they need to feel comfortable around me. You know these people are in my life, and they need to feel comfortable in helping me do things that I would otherwise do on my own, and that is the job, to help me live my life. So I suppose that the people that have been able to do that have been the ones that have been successful

In contrast to these experiences, nearly all participants had experienced a poor attendant carer work-relationship on at least one occasion. Participants characterised a poor attendant carer work-relationship as where confidentiality or privacy guidelines had been breached, where tasks had not been completed to a satisfactory level, where attendant carers were continually late or where attendant carers were distracted or lazy while completing support tasks. Emerson noted that a poor attendant carer work-relationship often developed where it was obvious that an attendant carer was unhappy in their work-role:

They don’t understand things, so that is a problem, particularly if it is someone from an agency or somewhere, they are usually pretty good, but every now and again you get one, they are so useless. Sometimes they are a
bit blasé and are like ‘whatever’. Some of the attendant carers, not all but some, say they have to start cooking something, some of them are involved in it, and some people just want to stand there and talk to you, like they don’t tidy up and stuff ... so there are differences between the ones I like.

Many participants described complete breakdowns in the work-relationship with attendant carers, to the extent that participants had been required to remove the attendant carers from their support program. Participants described where they had received verbal abuse, been met with aggressive attitude, experienced theft and household damage, and where attendant carers had unfairly manipulated the rostering to benefit themselves. Participants also described a number of instances where attendant carers had breached their duty of care.

Annie recalled a number of breakdowns in the attendant carer work-relationship where there were different expectations or understandings of the work-role between her and the attendant carer. She described these experiences as ‘awful’ and noted that once a work-relationship had deteriorated to this point, it often became difficult to ‘find a common language’:

*The carer from hell? People who didn’t turn up on time. There was one lady that thought she could do two jobs at the same time with me and someone else, and she left me in bed one day because she had to be at the other job. Or they treat this place like a hospital and thye change the roster, and she was changing times on me and not discussing it and I didn't know. I've had attendant carers that have stolen money from me, including from my bank-accounts, one carer was bleeding money from my bank account... really horrible*

Graham described instances of damage to his house and property that had occurred as a result of the actions of attendant carers. He noted that these instances had caused him
considerable distress, and as a result of these instances, he had had ongoing difficulties in establishing solid work-relationships with new staff and in retaining confidence to direct tasks:

*I'm actually afraid to buy things, because I just can't cope with any more wrong things. There is so much money spent on things that are wrong. Or half of my time seems to be cleaning up after the carer because, you know, taking the washing machine hose out from the bath means we spend the rest of the day cleaning up the flooded carpet and trying to cope with the smell that comes from that*

From a different perspective, Stefan’s poor work-relationship with attendant carers appeared more internally driven. Stefan was highly dissatisfied with his current work-relationships, and described receiving funded disability services as ‘being forced to compromise on everything’. He appeared resentful that since his SCI, he now had to rely on attendant carers to support him with required tasks, and quite negatively described his attendant carers as ‘replaceable’ and ‘as just another pair of hands to do tasks’, and was highly denigrating of attendant carers that had worked on his program.

Lawrie described having a particularly difficult work-relationship with the attendant carers employed by local government. He viewed the support he received through these pathways as extremely disorganised (in terms of the rostering and coordinating of shifts), and characterised their recruitment and employment processes as ‘terribly worn-out’. Lawrie noted that many of the attendant carers overstepped privacy and confidentiality boundaries and he described the standard of work provided as poor:

*I'm just not up to dealing with the council, because the quality of the care is just so disappointing. I mean there is no use having somebody here to clean if they are going to make a bigger mess than what I would make by myself, like when you are watching someone clean and thinking ‘it was actually cleaner before you started’.*
Participants described using a number of strategies to respond to worsening attendant carer work-relationships. These included confronting attendant carers and openly discussing any concerns they had, clarifying all of the work tasks required to be completed by an attendant carer before they began on the support program and discussing issues with the attendant care agency. Colin, who viewed himself as diplomatic, non-judgemental and reasonable, noted that if an attendant carer could not conform to his way of doing things, that he would immediately address the issue with open discussion. He described getting a ‘vibe’ about the attendant carers and described that on the few occasions where the work-relationship with an attendant carer had deteriorated, he had asked the attendant care agency to remove the attendant carer from his support program. Stefan also utilised this strategy in attempting to manage his work-relationships with attendant carers:

My main thing with the carer is, I tell them, if they don’t like me doing anything, to talk about it, not keep it inside, because eventually if we don’t resolve conflict, then they can leave. There are plenty of jobs in Australia... we have to be able to work together. Thankfully it doesn’t happen too often. Sometimes communication with them fails, but most of the time you can talk to them, they know what kind of a person you are.

Graham described having to summon-up the strength to confront an attendant carer where the work-relationship was not developing well, and that confronting a carer over an issue was not something he was comfortable with. In contrast, the participants who had utilised attendant carers for an extended period of time appeared to have refined their abilities to manage the work-relationships and were more comfortable in negotiating and addressing issues where required to maintain the work-relationship.

An important element linked with the work-relationship between participant and attendant carer was the frequency of turnover of attendant carers working on a support
program. High turnover included where attendant carers worked for a very short period of time, say for 2 – 3 months, or where attendant care agencies covered a single shift with a new staff member.

Where the frequency of turnover of attendant carers on a support program was high, participants described the work-relationships as unstable. High frequency of turnover of attendant carers certainly destabilised many of participant’s support programs, forcing participants to receive support from many new or different people in any given week. Participants noted that high levels of attendant care turnover required increased time and effort in recruiting, interviewing and training of new attendant carers, led to high levels of administrative burden and generally disrupted the support program. Participants described high levels of attendant carer turnover as reducing the quality of the attendant care they received and of reducing the confidence they had with attendant carers. Participants described feeling disempowered by the frequency of the changes, and that high attendant carer turnover created uncertainty and increased anxiety in not knowing who would be providing basic personal care tasks in the subsequent days and weeks. High levels of attendant care turnover also meant gaps in the provision of support were more likely to occur while advertising, recruiting and training were being completed. Matthew described feeling like he was being psychologically damaged in having to continually negotiate levels of trust, reliance and personal boundaries with new attendant carers every few weeks. Participants attributed high levels of attendant carer turnover to the low wages paid to attendant carers, work conditions, the irregularity of hours and an inability of attendant carers to obtain regular or substantial shifts.

Emerson encountered many difficulties in seeking to reduce the frequency of attendant carer turnover. He believed that the situation had worsened over the last few years, with attendant care agencies having to ‘hunt around to find people to work’. He described having had quite a few attendant carers work on his program over the 6 or 7 years and described frequent changes of attendant carers ‘a hassle’:
Well they are not too bad at the moment, one went away for other work, and one went to Queensland on a holiday- that seems to be a problem in November and December, they go overseas and stuff... Like one guy went away to Singapore with his family and that, and he'll be back at Easter, another one went to do voluntary work in Cambodia, and he will be back in March or February, so you get a lot of that stuff as well.

Stefan viewed the high frequency of turnover of attendant carers as attributed to low rates of pay received by attendant carers, the style in which attendant care agencies rostered them onto shifts and in some instances, the poor manner in which attendant carers were treated. He believed that many long-term, career attendant carers had moved out of the industry recently for these reasons, and that this had led to a reduction in the number of career-attendant carers overall working in the sector. Stefan also felt that there was an observable trend of ‘casualisation’ of attendant carers working in the industry, such as students working as casual attendant carers over the summer holidays. He viewed these factors as reducing the quality of attendant carers available and viewed good carers as ‘few and far between’. Matthew also viewed the high frequency of attendant carer turnover as contributing to a decrease in attendant care standards and his ability to properly coordinate his support program. In particular, he attributed policy directives of various Local Governments as contributing to high frequency of attendant carer turnover:

*It is very piecemeal with different councils. It seems like depending on your local councils, there are all these different versions of things, and it affects success or not. Another council told me they were sending me a new carer every 2 weeks, so that I didn’t become attached to them, they thought that was a good policy. I was like, it was psychologically damaging having to train someone new every 2 weeks.*
Although viewing the frequency of turnover of attendant carers on his support program as only moderate (i.e. noting that attendant carers usually stayed 18 months to 2 years), David viewed factors such as the employment landscape and wage conditions as contributing to high attendant carer turnover in general. In his interview, David specifically identified 3 reasons why he felt an attendant carer would leave his support program:

1. they move and then have to travel too far
2. they leave the industry
3. they change employment - they turn around and say 'I’m starting a new job in a nursing home’ and instead of having 3 shifts in a day over 12 hours, they work somewhere else where they work a 6 hour shift in a block shift.

Surprisingly gender did not emerge as a major theme within the participant and attendant carer work-relationship. Although the gender dynamic within most of the work-relationships was a male participant and female attendant carer (reflecting the fact that males make up 80% of the population of people with SCI and that ~70% of people employed as attendant carers in Australia are female), participants did not describe gender as impacting substantially on their work-relationships. Managing work-relationships across this gender dynamic, i.e. males in receipt of support from female attendant carers appeared to be normalised by most participants. Negotiating this gender dynamics was in most instances, incorporated into the usual elements of managing the participant-attendant carer work-relationship, and in only a handful of instances, was there a dispute within the work-relationship based specifically on gender (such as one instance of a complaint by an attendant carer over a wall poster of a scantily clothed women displayed in his home/her workplace which ended up in the Victorian Equal Opportunity Commission (EOC)). In only a handful of instances did a differing pathway of resolution occur in addressing a breakdown in the attendant carer work-relationship based specifically on gender. More commonly, work-relationship
boundaries and balances were negotiated and managed without gender specific strategies.

9.3 Participants and service provider/attendant care agency work-relationships

Work-relationships between participants and service provider/attendant care agencies were defined as interactions required in organising disability services, most usually attendant care. These interactions included emails, faxes and phone calls to attendant care agencies to coordinate appointments, carer-rosters, timesheets or organise equipment repairs. Interactions also extended to actual meetings between participants and attendant care agencies on allocation usage, annual service reviews, completion of Occupational Health and Safety reviews or discussion on any particular issues or grievances. The interactions of this work-relationship were usually on a daily or weekly level.

Work-relationships between participants and attendant care agencies usually involved an interaction with a coordinator employed by the attendant care agency. The role of the coordinator usually involved recruitment of attendant carers, rostering and general support with the participant support programs. Attendant care agencies employed attendant carers to work on any given number of clients support programs. The work-relationship between participants and attendant care agencies thus revolved around recruitment, employment and rostering of attendant carers who would then work on a participants support program.

Work-relationships between participants and attendant care agencies were diverse. Participants that were satisfied with their work-relationship with the attendant care agencies described their support program as simply rolling along each week. They described being satisfied with the staff provided by the attendant care agency and with their allocation of disability services. Participants characterised a positive work-relationship with attendant care agencies where coordinators were confident with
program coordination processes and immediately followed-up on queries regarding rostering, recruitment or payroll. Participants also characterised a positive work-relationship as where coordinators maintained a good balance between interest but non-interference of participant lifestyles, where coordinators were easily accessible, where adequate levels of communication were maintained (however ‘adequate’ was perceived) and where attendant care agencies provided consistency with rostering of attendant carers. Satisfaction with the participant attendant care agency work-relationship was also linked with the extent to which participants chose to take on a role of coordinating their support program themselves, and in these instances, participants communicated being satisfied in remaining independent of the attendant care agency to the greatest possible extent.

David was satisfied with the work-relationship he had established with his attendant care agency. He was impressed when a coordinator at an attendant care agency had immediately returned a call about an emergency shift replacement, and that the coordination of the replacement shift had occurred promptly and swiftly. Graham was also satisfied with his work-relationship with his attendant care agency, describing an instance where a coordinator had been willing to fight for him to help increase his service allocation. Annie was happy with the work-relationship she had with her most recent attendant care agency and felt they had established a good balance in terms of levels of communication:

What I like about this agency is that the owner was previously a nurse in the spinal unit and they have found me very good staff and they don’t interfere. So they are present, and I have a very good working relationship with them, they don’t constantly ring up and ask and nose into things – ‘is this happening?’ or ‘is that happening?’ or ‘how are you going with this?’ and they don’t constantly look and come and see what I’m doing. So they basically leave me to get on with it and I find that works.
However, all participants noted that on at least one occasion, the work-relationship between themselves and the attendant care agency had become destabilised. Participants characterised negative work-relationships as developing where attendant care agencies were inefficient with coordinating rosters, where there were ongoing challenges with timesheet processes, where response times to queries was poor (including occasions where coordinators had not returned calls), where there were low levels of communication and where coordinators/attendant care agencies had not been able to recruit a sufficient numbers of staff for their support program (leading to gaps in service provision).

Where work-relationships had become strained, participants described being extremely angry, frustrated and confused with the mismanagement of their support programs, particularly if there had been numerous times when roster requests to the attendant care agency had not been meet or different rosters to those discussed had been generated.

Participants communicated responding to these strains in the work-relationships by complaining to the attendant care agency management, by challenging the coordinators in seeking to get them to improve their personal performance, by distancing themselves from the attendant care agency, by changing attendant care agencies, by reducing levels of communication and/or by taking on the coordinating roles themselves.

Jim described a particular occasion where he had been very disappointed with the work-relationship with his attendant care agency after a mix-up with a coordination process. After the incident, Jim described that he had felt that the coordinator was unaware of the importance and their level of responsibility in needing to coordinate a person’s roster:

_The people that are in these agencies don’t understand how much more important it is for someone with a spinal cord injury to have these services_
done. If they don’t get back to you and you miss out on your services, it is not like ‘oh I will do it myself then’ because you can’t, or not within a reasonable time frame.

Emerson described being unsatisfied with the work-relationship with his attendant care agency due to mix-ups with coordinating processes, such as between regular coordinators and after hours staff, and described instances where the attendant care agencies had forgotten to fill a shift:

When I have issue and I ring to try and get some help and nobody rings me back. When I finally get onto them and I say ‘you didn’t ring me back?’ they say ‘oh, I was busy’, and I just say ‘that is not good enough’; I just tell them straight that that annoys me, but they are notoriously bad with communication with carers and with clients.

Stefan and David viewed the work-relationship with attendant care agencies as strained because too much focus seemed to be placed on increasing income and profit margin, rather than servicing the requirements of them as clients or employees:

The agencies are just there to make money, and they will try and squeeze out as much money from you as they can. The care is so bad and they try to rip you off. A lot of carers tend to leave, and then when you ask for a new carer, they cannot provide them, because there are not that many carers around. Most of the agencies don’t have structure for the carers, and they have never met the carers but they manage them from somewhere... the people who open the care agencies need to be some people that understand...[and] set up certain systems to make sure that the care of the patient is met all of time, so I don't have to worry about ‘oh, who is coming tonight?’ or ‘have I got anybody?’. I rely a lot on myself to be nice to the carers, and not rely on the agencies because I ring-up, and they say ‘no, we can’t do that for
you’, and they send somebody in that doesn't even know your care... it makes me really concerned about everything.

Colin described his work relationship with his attendant care agency as good because they left him alone to run his support program. Ben also described having 'stepped back' from the attendant care agency work-relationship and that because of this things were now improving:

*I still don’t tell them [the agency] all the things I do, I don’t let them know anything that I do, I tell them as little as possible. I sort out all of my own hours, and I just fax through the timesheet to the care provider, they’re probably used to that I’m sure... I just tell them what I want, I deal with all of my own carers... so the office have got no idea what is happening at my place, until I send in at the end of the fortnight what everyone has worked; sometimes I ring them up, sometimes I do and sometimes I don’t, to tell them the hours they’ve been doing... unless there is a problem, otherwise I don’t have any contact them, and things just roll along.*

As noted, a strategy by participants in addressing dissatisfaction within the attendant care agency work-relationship was for participants to change attendant care agencies, or use a second attendant carer agency simultaneously to obtain services. It was not uncommon for participants to change attendant care agencies in response to difficulties that emerged despite significant effort required in making such a move (such as sourcing a new attendant care agency, learning new guidelines and administrative systems of the new attendant care agency, transferring existing staff over and training of new staff). Participants cited constant administrative problems, high administrative costs, low rates of pay of attendant carers and the inability of attendant care agencies to adequately provide attendant carers on a regular basis as the most common reasons for changing attendant care agencies (of note, the number of attendant care agencies able to be utilised at any one time is not regulated. Provided the individual is prepared to
take on any increase in administrative burden, individuals may use any number of attendant care agencies they choose). Where communication levels had deteriorated to a point that the work-relationship was no longer sustainable and the participants had lost confidence with their attendant care agency, participants viewed changing attendant care agencies as a useful strategy in seeking to improve support outcomes and improve support provision.

Annie, Emerson and Matthew noted having changed attendant care agencies 2 or 3 times over a 5 – 10 year period in seeking to improve their support outcomes. Stefan had utilised the highest level of attendant care agencies, having utilised 4 attendant care agencies over approximately 10 years (noting that he was still not satisfied with the support he was receiving from his current attendant care agency). David described utilising 2 different attendant care agencies simultaneously to increase the overall access to attendant carers and to improve the overall consistency with support received, despite the increased administrative burden this involved.

Annie recalled where an attendant care agency had refused to provide her with staff over a pay disagreement and she had been forced to change attendant care agencies:

> well, Quality Care [the attendant care agency] and I fell out, they dumped me basically... they said that they wouldn't employ people for me anymore, because they were so displeased with my approach about my attendant salaries which I thought needed to be dealt with in a more appropriate way... I found another agency and I have been with them ever since.

### 9.4 Participant and insurers/funder work-relationships

The work-relationship between participants and insurers/funders most often involved discussion and negotiation in regards to disability service and equipment allocation. In most cases, following reviews and assessment, the insurers/funders provided funding to
the attendant care agencies to provide disability services to participants or invoiced the insurer/funder on a monthly basis based on disability service usage.

The work-relationships between participants and insurers/funders were highly influenced by the funding origin of each participant, i.e. whether a participant was funded through DHS, TAC and VWA. This is due to the extreme differences between disability service and equipment allocation guidelines and limitations between each funder/insurer. Most evidently, parameters of funding allocated by DHS were significantly limited by regulations that restrict the availability of disability service and equipment allocation. In contrast, both TAC and VWA were governed by broader statutory regulation that provide more generous allocations for disability services and equipment, based on ‘reasonableness’. For participants funded through TAC and VWA, a coordinator is assigned to a participant and their key role is to approve increases or decreases in disability services or equipment allocations on an annual basis and/or provide clarification and supporting documentation associated with these allocations.

Participant work-relationships with insurers/funders in the main thus involved negotiation of disability service and equipment allocations. Negotiation usually involved communication through written correspondence of letters and emails, phonecalls and/or in rare instances meetings. Frequency of communication between participants and attendant carers varied. Some participants described having frequent and ongoing discussions and negotiations with coordinators regarding allocations and clarifications, while other participants had no contact with their insurers/funders at all or in some cases, no knowledge of who their actual funder/insurer was.

The small number of participants with no interaction (and thus no work-relationship) with their insurer/funder were funded by DHS. These two participants, Emerson and Colin, were unsure who was actually providing funding for their disability service and equipment allocations, and noted only that they knew a ‘government health department’
provided funding to their attendant care agency. Emerson and Colin both noted that as they viewed their disability service and equipment allocations as fixed, recurrent and mostly adequate, that they instead communicated with their attendant care agencies in relation use of the allocations. Other participants funded by DHS described being aware that DHS was funding their disability service and equipment allocation, but noted that they had no need to interact with DHS in relation to their disability service and equipment allocations and thus no work-relationship had been established.

Of the participants in discussion with their insurers/funder, i.e. most participants funded by TAC and VWA, a positive work-relationship was characterised by a good level of communication, adequate assistance with queries from the coordinator and receipt of ‘expected’ levels of disability service and equipment allocation. Participants viewed a positive work-relationship with funders/insurers as developing where they had confidence in a coordinator fulfilling their role, where the coordinator was professional, helpful and was cooperative in responding to claims and queries.

Annie noted that her coordinators at TAC had been professional and cooperative and that the minor hiccups that sometimes occurred in administration were usually resolved promptly. Ben also described having a good work-relationship with his insurer VWA, describing them as helpful and generous with their assistance, however noted that, as with his work-relationship with his attendant care agency, he felt he maintained a good work-relationship with his insurer/funder by keeping communications to a minimum.

Other participants described many breakdowns in their work-relationship with their funders/insurers. These breakdowns did not appear to be linked to any one specific insurer or funder. Participants defined these breakdowns in the work-relationships as occurring where they had lost confidence in the capacity of the insurers/funders to adequately provide allocation for their requirements, where there was dissatisfaction with the frequency of communication and responses to queries, and where insurer/
funders had not been clear about their decision-making processes. These participants described feeling that they lacked the confidence to clarify their needs and requirements, and that they often felt stressed, anxious, angry and/or frustrated following an interaction with their insurer/funder. In some cases, participants distanced themselves from the work-relationship, or in contrast, described being forced to challenge their insurer/funder (i.e. utilising raised voices or persistent contact) in seeking to secure allocations for a particular disability services.

Ben described having to take his insurer to the internal arbitration board to resolve a dispute over a claim, while Stefan recalled forwarding claims and queries further up the management line for resolution. Matthew described a heated interaction with his funder which had considerably strained their work-relationship:

> Well they often have what I consider bulls**t guidelines and regulations, like I needed assistance with a bed, and I knew there was $2000 available, and they are like ‘well it has to be a high low bed for the attendant carers and so forth’, so I said ‘fair enough’. Then they said ‘you can only have a single one’, and I said ‘no, I want a Queen size one, I’m in a relationship’, and they said ‘no, that’s against the rules’. So because I had worked for TechLab [a consultancy firm] I got a few people to ring and go ‘what the hell?’ It eventually went through committee channels, but I guess they pulled a few strings, they were worried about setting a precedent… but I came out with the extra $2000 in partial funding basically

Stefan also recounted significant amounts of frustration and distress in his work-relationship with his insurer VWA. Stefan viewed VWA as not meeting its overall objectives of returning a client’s lifestyle to the level it was before their accident and thought their objectives were unobtainable. Stefan felt as though he was being perceived as a liar by the insurer, and felt his claims were being turned down without good explanation. He described the manner of his coordinator as accusing, felt worn
down by the negotiation processes and felt that he did not have an option as to who the
people ‘in charge of him’ were. Stefan described having lost considerable agency and
confidence within the work-relationship as a result of these interactions, and felt
increasingly despondent, depressed and hopeless over time after communicating with
his insurer. The work-relationship appeared to be very power-orientated and one-sided,
with significant barriers emerging in Stefan’s means of communicating with his case-
managers. Stefan described the insurers response as continually deferring him sideways
and upwards (to the point of him having to contact the minister in seeking to have his
claim properly heard) and of having no opportunity to negotiate with the insurer.

Ben and Graham described specific frustrations in their work-relationships with their
insurer and funder respectively. Ben recalled that these disagreements had undermined
his confidence with the provision of disability services:

> we had lots of fights in different ways… like when we got home, it was
> suggested that we have a hoist to get in and out of the vehicle, so just a
> hoist that goes in the car. It took them a long time to get that, and we
> fought. We wanted that before Christmas, I came home 2 months before
> Christmas… so we fought and argued and tried to get it in before Christmas
> so we could get around, but it didn’t happen… [we] then worked out what our
> needs were once we got home so we didn’t have a car straight away and so
> we didn’t need a hoist straight away, but once we did, we wanted it, and it
> didn’t happen, so that was a big ***fight. Then there was continuing
> arguments about how much and what sort of level they were going to fund
> towards our house, our needs and towards taps and different bits and pieces
> and that so… nowadays we don’t really argue about things, everything just
> sort of happens and everything is running smoothly. Some of it depends on
> your case manager, some of them are absolute a****es, you end up
> screaming at them on the phone… but we have just been persistent, and kept
As such, participants that did communicate with their insurer/funder thus in general had a good-work relationship, feeling they had received adequate assistance with their queries and felt supported by coordinators in their negotiations. However a larger number of participants recalled at least one negative experience in their work-relationship with their insurer/funder that had produced frustration, lack of confidence or a significant breakdown in the work–relationship.

9.5 Summary

As is evident, participant work-relationships with attendant carers, service providers/attendant care agencies and insurer/funders significantly impacted on the day-to-day living situations of the participants. Where participants were able to develop good work-relationships with attendant carers, based on trust, respect and established understanding of work roles and boundaries, the experience of receiving funded disability services was supportive and beneficial in supporting quality of life and the social inclusion of participants. The establishment of a good work-relationship between participants and service providers/attendant carers strongly centred around responsiveness to queries, capacity to send trained-up attendant carers regularly and consistently, and a caring but not invasive manner of providing disability services. A good work-relationship with funders/insurers, where a work-relationship was formed, was where funders/insurers were viewed as transparent and reasonable with decision making related to service allocation and responsive to queries.

In contrast, poor work-relationships between participants and attendant carers developed where there was misunderstanding and different expectations of the work role, where there was disinterest by the attendant carer in the work-role and where the participant was experiencing instances of bullying, theft and abuse. Poor work-
relationships between participants and service providers developed where there were inconsistencies with rostering, high staff turnover, slow response to queries and difficulties with communication and admin systems. Poor work-relationships between participants and insurers/funders were characterised by slow responsiveness to queries, unreasonable decision processes, non-allocation of needed disability services and equipment and an intrusive manner by insurer/funders.

Clearly, the ability to establish and maintain good work-relationships impacted on participant quality of life. Work-relationships clearly ebbed and flowed in terms of intensity and duration, with participants utilising a variety of strategies to maintain and/or challenge the balance of the work-relationship where required. The experience of receiving disability services was clearly impacted by how these work-relationships were developed and maintained and how participants were able to negotiate these work-relationships.
Chapter 10: Participant experience of compensation

10.1 Introduction

[W]ell I think that overall in this country we are very fortunate; if you don't have a car accident and you are not insured, you still have some sort of... something, there is at least something there, it is not just nothing, whereas in many countries there is nothing, so nothing... there is basically death; so if we put ourselves into that comparison with countries that are less privileged; we are very privileged and we are very lucky, yet we don't compare; and I think that in any system where there are inequities, then one person will be looking at another, even within the disability area, and I look at people that are paraplegics and go 'wow, aren't they lucky' ...so there are always inequalities

- Annie

The experience of receiving funded disability services following the acquirement of a SCI was intrinsically linked with receipt or non-receipt of compensation. Receipt or non-receipt of compensation impacted dramatically on the overall experience of receiving disability services, how disability services and equipment were used, how supported participants felt across the lifecycle of their SCI and employment, accommodation and lifestyle choices.

Notably receipt of compensation awarded varied significantly. Variations in compensation awarded were based primarily on how participants acquired their SCI. If a participant acquired their SCI through a transport or workplace accident (i.e. falling within TAC and
VWA schemes) and in a manner in which a level of fault could be attributed, then opportunity to claim for compensation was available. If no fault could be attributed to how the SCI was acquired and no insurance scheme covered the participant, then access to compensation was not available.

In this chapter, I firstly identify participant pathways to receipt or non-receipt of compensation. I map the disparate array of compensation pathways and explore the associated policy structures and guidelines of each of these pathways. Secondly, I explore the prominent themes that emerged in relation to receipt compensation by participants including knowledge and understanding of compensation, degree of satisfaction with compensation awarded, dependency, awareness of others in relation to receipt of compensation and the role of compensation as redress for SCI. Lastly I explore the contrasting themes associated with non-receipt of compensation such as financial stress, dissatisfaction and ambivalence, and perceptions of compensation through use of a hypothetical exercise.

10.2 Compensation Pathways

The opportunity for participants to claim for compensation was disparate. Opportunity to claim for compensation was prescribed primarily by how a participant obtained their SCI and the extent to which fault could be attributed to another party. This determined the pathway a participant could pursue in seeking compensation and the extent and manner in which compensation could be awarded. The awarding of all forms of compensation however was heavily governed by state-based policy structures, legal process and limitations.

Five diverse compensation pathways were identified from discussion with participants in relation to the receipt or non-receipt of compensation. Four of these pathways were determined by how participants had acquired their SCI, while the fifth compensation
pathway was defined by participants not choosing to pursue any claim for compensation.

The five compensation pathways identified were:

- participants pursuing a Common Law claim and being awarded a single, lump-sum compensation payment
- participants being awarded a single, automated, lump-sum compensation payment and then receiving ongoing, fortnightly loss-of-earnings payments
- participants being awarded a single, automated lump-sum compensation payment only
- participants having no opportunity to make a claim for compensation in any form
- participants choosing not to make any claim for a compensation or enter the legal system in any way

Of the eleven participants included in this study, two participants, Lawrie and Jim pursued claims for compensation and were awarded compensation through Common Law processes. Two participants, Ben and Stefan, received automated, lump-sum compensation payments and then ongoing, fortnightly payments, while Tom, Annie and Emerson received single, automated lump-sum compensation payments only. Colin and David chose not to make any claim for compensation through Common Law or enter the legal system in any way, while the two remaining participants, Graham and Matthew had no opportunity to claim for compensation in any form.

Of the seven participants who did receive a compensation payment in some form, Stefan, Ben and Lawrie received compensation through the VWA (i.e. work accident related schemes), Jim and Annie received compensation from TAC/MAB (i.e. transport accident schemes) and Emerson and Tom received minor compensation payments from privately based-insurance schemes.

The characteristics of each of these compensation pathways will now be discussed.

**10.2.1 Receipt of compensatory payment through Common Law claim**
The first compensation pathway identified was the opportunity for participants to claim for compensation through pursuit of a Common Law claim. As evident in the above diagram, larger compensation payments were awarded to participants claiming compensation through Common Law processes under the VWA and TAC schemes as a result of a workplace and transport accidents. The awarding of these larger compensation payments included a single, lump-sum payment inclusive of pain-and-suffering and potential loss-of-earnings payments usually in the range of A$400 000 to A$1.2 million. Both Lawrie and Jim’s compensatory payments fell into this category.

Lawrie and Jim’s claims for compensation through Common Law were extended processes of 6 and 3 years respectively. Lawrie’s claim also involved court proceedings until a settlement was reached, while Jim’s claim was settled just before court proceedings were about to begin.

Both participants described being satisfied that they had an opportunity to challenge and negotiate their claim and that they had the opportunity to be personally involved in the negotiations and decision-making processes related to their claims. Lawrie and Jim described it as advantageous that they were given opportunity to voice their account of events, personally contribute to negotiations associated with the claim and decide for themselves (with legal advice) on when or if they wished to settle their claim. Opportunity for participant involvement and negotiation in relation to receipt of compensation was unique to this pathway.

Some disadvantages with the Common Law claims however were noted. Lawrie become quite agitated and angry during the interview when recollecting the experiences of his legal action. He described instances where he had had difficulties in understanding, coping and enduring the court proceedings, and had felt overwhelmed by the adversarial nature of the courts. He described the court proceedings as ‘dreadful’, ‘awful’ and ‘unpleasant’, and recalled that he had been highly anxious, stressed and out-of-his-depth
during much of the negotiations. He noted that on many occasions he had been emotionally hurt by the aggressive tactics used by the opposing legal team in trying to discredit him in relation to his previous employment position:

[I]t wasn't good, because you are dealing with people that make their living by fending off people who make actions like this; it was very unfamiliar and I didn't have the background that would prepare me for that or would allow me to do that sort of thing effectively, I had no understanding, it is very foreign to me, and as a miner and just as an individual, I don't think I had as broader a perspective as I needed; I don't believe I was naive in any way, but I didn't have... no one has that for-sight.

Jim also felt that his legal negotiations had been adversarial and stressful. He noted that his legal negotiations had started early while he was still in spinal rehabilitation and that they had continued over three years until his claim for compensation was settled. He recalled that the legal negotiations had required multiple medical assessments by the TAC and numerous meetings between his lawyers and TAC's lawyers. Jim noted that he had been extensively involved in the negotiating processes of his claim, had personally attended negotiation meetings and had debated with lawyers the complexities of his claim. He also recalled that he had felt okay about the prospect of going to court and that he was prepared to defend his claim in court if that was what was required. Jim described his experience of making a claim for compensation through the Common Law process overall as a form of a ‘legal dance’:

[J]ust the goings-on... backwards and forwards, the comings and goings, all of that sort of stuff... and with all of the solicitors, and then you have to go into what is nearly a bluff situation in getting all of the barristers, at about a $1000 a day or whatever it costs, and the barristers go in there and negotiate with each other and you are there too, I never actually spoke with the barrister, but I was there and he would come back and say 'they are offering us this much’ and I would say 'no, I am x, y, and z, and this is how it
is, and this is how I feel’ and he would go back to them again, you know all of that sort of negotiation thing.

Both Lawrie and Jim however agreed that the awarding of their single, lump-sum compensation payments, despite the stress and complexities of the claims, had increased their lifestyle freedom and flexibility. Both participants felt that they now had greater choice with lifestyle decisions and that the lump-sum compensation payment had allowed them to be independent from assessments and scrutiny in relation to their employment and income status. Lawrie described how he was grateful that he was now able to avoid waiting lists for procedures or in purchasing equipment because he could utilise the funds from his compensation payment to privately purchase extra disability services and/or equipment if required.

10.2.2 Receipt of single, automated compensation payment and then ongoing payments

The second compensation pathway identified was the awarding of single, automated lump-sum compensation payments and then receipt of ongoing, fortnightly payments to participants. Single, automated lump-sum payments were awarded as compensation for pain-and-suffering related to acquirement of the SCI and ongoing, fortnightly payments were awarded for loss-of-earnings. The ongoing payments were between 80% and 100% of the participant’s pre-injury wage. As with the first compensation pathway, this compensation pathway was determined by how a participant acquired a SCI. Ben and Stefan fell into this category.

The particular characteristics of this compensation pathway are thus the dual processes in the awarding of compensation (i.e. a lump-sum payment and ongoing payments) and the lack absence of any Common Law claims. In the case of Ben and Stefan, this variation in the awarding of compensation is specifically related to a policy decision made by the State Government to withdraw any access to Common Law claims related to work-place injury (i.e. through the VWA scheme) for a period of two years in the mid
1990s. During this period, individuals were only eligible to receive automated compensation payments that were determined solely by the insurer, and then ongoing, fortnightly loss-of-earning payments. As a result of this policy change, participants such as Lawrie remained able to claim for compensation through Common Law processes after acquiring his work-related SCI, whereas Stefan and Ben, although also acquiring their SCIs through work-related accidents, were only able to claim an automated lump-sum compensation payment and then receive ongoing, fortnightly payments.

Ben and Stefan had varied responses to being awarded this form of compensation. In some respects, they appreciated that their automated compensation payments were awarded with speed and efficiency. Both Ben and Stefan were awarded their lump-sum compensation payments within approximately a year of their injuries. They also noted that to some extent they felt reassured and financially secure in receiving their ongoing, loss-of-earning compensation payments each fortnight knowing that bills and financial commitments could continue to be made.

Ben recalled having had an extremely fast turn around time of between 10 and 12 months in relation to assessment and receipt of his automated compensation payment. Ben noted that no legal teams or court proceedings had been involved in the awarding of his compensation payment, but that they had just done everything themselves (referring to him and his wife dealing with the insurer). Ben recalled that the automated compensation payment had been ‘in our bank account before we got home’ from the spinal rehabilitation unit, and that once they had received their payment, the insurer’s attitude had been abrupt with a ‘that’s all there is to it, full stop, no questions asked’ type of attitude. Similarly Stefan described receiving his automated compensation payment ‘early on’ just after he had returned home from his spinal rehabilitation at the spinal unit, and that there had not been any negotiation or dispute in being awarded his automated compensation payment.
However a level of dissatisfaction with the compensation awarded was evident with Ben and Stefan. Both Ben and Stefan noted that they felt resentful that he had not been able to pursue a claim for compensation through Common Law processes. They felt they had not been given any opportunity to contribute or input their views or experiences in events around how the SCI had been acquired, and that they had had no opportunity to negotiate the amount of compensation to be awarded. They noted that the amount of compensation that was awarded had been determined totally in-house by their private insurers without any scrutiny or transparency.

Ben also described being frustrated with the low amount of compensation he had received compared to people he knew who had been awarded considerably larger, lump-sum compensation claims through Common Law processes. Further, both Ben and Stefan now felt locked into the fixed, ongoing payment schedule of their fortnightly loss-of-earnings payments, similar to a reliance on a pension. They noted that the generally fixed schedule of their ongoing, fortnightly loss-of-earnings payments were problematic because of increasingly rising living costs. They viewed their payments as not going as far as they used to and of not providing adequate income for them to meet their immediate family needs. Stefan and Ben also described feeling dependent, tied and ‘locked in’ with the VWA in relation to these ongoing compensation payments.

Notably neither Stefan nor Ben had returned to employment since receiving their automated compensation payment and beginning on their fortnightly, ongoing compensation payments. Instead of employment, Stefan and Ben had chosen to take up tertiary studies and community roles respectively. To some extent, this appeared to be the result of a level of dependency on the fixed, ongoing payments. Both Ben and Stefan appeared to be reluctant to return to full time employment for fear of having their ongoing, fortnightly compensatory payments reduced (as per VWA return-to-work policy guidelines) from wage amounts earned from any employment. They were particularly
concerned about losing their income source if they were then not be able to return onto ongoing payments if they became either unemployed or ill after resuming employment.

**10.2.3 Receipt of a single, automated compensation payment with no ongoing payments**

The third compensation pathway identified was the receipt of a single, automated lump-sum compensation payment only. In these instances, a compensation payment was made by a private insurer, such as a local sporting club and a university, where liability had been determined in relation to the injury. Annie, Emerson and Tom fell into this category.

These single compensation payments were characterised by being small in size in comparison with Common Law or other automated compensation amounts awarded by the statutory authorities, and ranged from A$9000 [Emerson], A$20,000 [Tom] to A$25,000 [Annie]. No avenues for negotiation related to the awarding of the compensation payment were available and no legal teams or solicitors were able to be involved in the compensation assessment processes. Further, no opportunity to obtain loss-of-earnings payments existed. Participants within this compensation pathway were thus reliant on the Disability Support Pension or were required to take up employment to meet income requirements.

Annie, Emerson and Tom all noted that their compensation payments only provided enough money to purchase some basic equipment and contribute to housing modifications. Tom, who felt he received only a minor compensation payment, noted that the payment did not cover more than his first month of living expenses once he returned home from rehabilitation, an asked rhetorically how the amount was supposed to provide support for him for the rest of his life. Tom described how he had briefly explored other options to claim for further compensation, but that during his rehabilitation, he had been more focused on his physical health, lifestyle transition and personal wellbeing, and at that time had felt ‘unprepared legally’ to make any further
claims. Tom noted that a number of years later, he had sought legal advice about pursuing a larger compensation claim so that he could source sufficient finances to live comfortably, but that his legal counsel had advised against this:

[Y]ou know, money will never buy you happiness, and millions of dollars to me wouldn’t change my life, but if I had enough money in the bank to buy something when I needed it, or to pay for certain services, like for someone to come in and mow the lawns, that sort of thing, or to pay for the shortfall with my incontinence aids, you know, that way you could then live comfortably without having to worry about it all of the time.

In contrast, Annie viewed her smaller compensation payment as ‘brilliant’. Annie described the automatic receipt of her compensation payment as very efficient and was glad she had not had to fight to receive her compensation payment, and described being satisfied with the amount of compensation she had received. Surprisingly she described being relieved that she did not have the responsibility of administering any large compensation payment and felt TAC were better positioned to take on the financial investment role in administering services.

10.2.4 No opportunity to claim for compensation

The fourth compensation pathway identified was where no opportunity to claim for compensation existed. For participants unable to establish any level of fault in how their injury had been acquired, no opportunity to claim for compensation through Common Law or a public liability claim was available. This non-compensation pathway included where SCI had been acquired as a result of a trampolining accident on private property and where a cyst on the spine had resulted in SCI. No legal claim could be made against any insurer/funder in relation to these SCIs, and fault could not be attributed against any person or entity.

Graham and Matthew fell into this category and received no compensation following their SCI, i.e. A$0. Because they had acquired their SCIs through a fall and a medical incident
respectively, no fault could be attributed to their SCIs and no opportunity to claim for compensation through either an insurance scheme or public liability was available. These participants were thus required to obtain full time employment to meet income requirements or rely on the Disability Support Pension (DSP) for income. Matthew cited that if he had had the opportunity to be able to make a claim for compensation he would most certainly have:

[W]ell with compensation, initially I thought compensation would have been fantastic if I had got it, and if I’d been anywhere except South Australia, I would have got something because I was in a commercial institution so there was a possibility, but this politician, _____ [name’s politician] bought out all of these special laws basically exempting business people from anything, they have all been rescinded now, but at that time and place, the lawyers were like ‘If it was Victoria, we could’ve got you a few million’, and I was like grr

The compensation framework thus specifically excluded two of the eleven study participants from accessing any form of compensation because of how their SCIs were acquired.

10.2.5 No claim for compensation made

The fifth and final compensation pathway identified was where participants themselves had chosen not to pursue any claim for compensation. Both David and Colin fell into this category. David and Colin described making the decisions not to claim for any compensation based on the events associated with how they had acquired their SCI.

Colin viewed the act of not pursuing any claim for compensation as him taking on a level of personal responsibility and accountability for his actions associated with how he had acquired his SCI. He communicated that he felt a level of blameworthiness in relation to the events surrounding how he had acquired his SCI because his actions had contributed to the occurrence of his injury. Despite being aware of their being an opportunity for
legal action, he felt he had no social right to make a claim for compensation and viewed his non-receipt of compensation as a balance for the events. Colin described feeling personal blame for the circumstances around how his SCI had occurred, similar to that of a drink driver that had caused injury to himself in a car accident, and felt that his actions had been ‘wrong’. Colin however did not view his receipt of disability services as a ‘drain on community resources’ but felt that taxpayers should not provide him with compensation when he had acted wrongly:

[I]t is like having a young teenager jump into a car, and smashes the car and kills somebody else with him; and if there was a passenger who survives, he would sue the driver... my reasons were that it was my fault; whether there was a sign or not is besides the point, if there had been 100 signs, I still might of perhaps avoided the signs, but why should taxpayers cop it for my mistake? I know you can argue the point on that... still... it is open for debate, but honestly, I contributed to my accident; if it was a car accident, then maybe I could understand that, because there would be another party, but I made the choice to jump, so why should I blame someone else for my mistake and then get the taxpayers to fund me? you know it would have been nice for my life if someone had come up and given me $1 million... it would have turned things upside-down... but can you see it is not fair ethically? and I know that others did it, but ethically, that is just me.

David chose not to make any claim for compensation or pursue any legal action after acquiring his SCI as his father would have been legally liable for his SCI. As his father had been the owner and driver of the ski boat at the time of the accident, David would have been required to sue his father to obtain compensation rather than a statutory authority. He noted that he did not wish to take up legal action against his father which would have made his father legally responsible for his SCI, and was not prepared to make a claim for compensation that would impact on an immediate family member. David recalled that, without any receipt of compensation, his post-rehabilitation options
had been limited, and that the only options he had at the time were to either utilise informal care provided by his parents or be placed into institutional care facility such as an aged care home.

Four of the participants, David, Colin, Graham and Matthew thus received no compensation following their SCI, i.e. A$0.

Further Emerson, who received had received only a minor compensation payment of A $9000 from a private insurance based scheme, described having ‘no interest’ in pursuing any larger claims for compensation. Despite scope to claim for compensation through Common Law processes, Emerson felt that pursuing a legal action would be a significant challenge, difficult and time-consuming, and that undertaking a claim for compensation through a public liability claim and going through the courts, would be a ‘huge battle’ that he was not motivated enough to take on. Instead, Emerson noted being satisfied with his employment and current lifestyle and of feeling ‘better off’ with security and satisfaction of being in full-time employment.

Thus it appeared evident that to some extent, personal moral judgement was a factor in deciding if a claim for compensation was made. Individual responsibility associated with how the SCI had been acquired did influence participant decisions to pursue or not pursue a claim for compensation. Moral blameworthiness and the extent of contributory fault did impact on decisions to claim for compensation, and the reduction or non-receipt of compensation based on personal blame and contributory fault seemed to be justified by the participants themselves.

Claims for compensation also appeared to be influenced by felt levels of financial security. The 2 participants choosing not make any claims for compensations both viewed their financial positions as adequate, and did not feel that there was any urgency to make any claim for compensation. In contrast, participants in financial strain following
the acquirement of their SCI viewed the opportunity to claim for compensation and loss-of-earnings payments as crucial as this would potentially become the only means of income they had.

In summary, it is clear that the regulatory framework associated with the receipt of compensation within the state produced significant variations in opportunity to claim access to compensation. The five compensation pathways identified clearly demonstrated significant differences in opportunity to claim for compensation based on how the SCI was acquired. For some participants, no avenue for compensation existed within the parameters of any of the legal or insurance-based structures. These participants fell through what would best be described as a regulatory and legal gap in the compensation framework based solely on the way in which their SCI was acquired. The compensation framework for these participants thus demonstrated significant inequity in opportunity to claim compensation and amounts of compensation awarded.

### 10.3 Participants in receipt of compensation

A number of themes emerged that were specific to participants that had received compensation. These included terminology and understanding of compensation, compensation as redress for SCI, perception of others that had received compensation, satisfaction with compensation received and dependency on compensation. In total, seven participants received some form of lump-sum compensatory payment. These themes will now be discussed.

#### 10.3.1 Terminology and understanding of compensation

Participants in receipt of compensation used a variety of terms to describe the compensation they had been awarded. This reflected the differences in the understanding of the role of compensation and differences in the types of compensation awarded (as identified by the differing compensation pathways). Most of the terminology utilised in describing compensation was strongly associated with the receipt of monetary benefits and included terms such as a ‘payment’, ‘settlement’, ‘lump-sum’, ‘the money’,
‘a package’, ‘funding’, ‘resources’, ‘compo’, ‘benefits’, ‘the payout’ and ‘damages’. The terminology utilised also demonstrated that participants associated receiving compensation with ‘being covered’, being provided for or being looked after. The terminology used also reflected the legalistic nature of compensation for some participants, with terminology such as ‘undertaking legal action’, having ‘to sue [an entity]’, ‘getting a million dollars’ and getting ‘financial services’ being utilised. In contrast, participants receiving compensation in the form of weekly or fortnightly payments described their compensation as ‘regular income’ and as receiving an ‘ongoing payment’. Certain terminology demonstrated that participants associated making a claim for compensation as a challenge, with terms such as undertaking, embarking and taking on a legal claim being used.

One participant, Lawrie, was adamant in using the term ‘settlement’ rather than ‘payout’ to describe the compensation payment he was awarded through his legal action. Lawrie appeared to have very negative associations with the term ‘payout’ and strongly indicated that the use of the word ‘settlement’ was preferred during the interview. Possibly this related to negative associations and stigma associated with these terms and the implication that a person receiving a payout or being on compo was not legitimately injured and was trying to rip-off the system. Lawrie also appeared to associate the term ‘settlement’ with not having been awarded a proper compensation payment and communicated that he felt he had not received his full entitlement of compensation because he had settled the claim and had not been awarded the claim. Tom utilised distinctive terminology to identify the compensation he was awarded, labelling it as ‘an insurance benefit’ rather than as compensation because of the modest size and felt inadequacy with the amount that had been awarded.

In terms of participant knowledge and understanding of compensation, all participants in general understood that compensation was awarded as a block of monetary funding received from a funder or insurer following the acquirement of a SCI. However
knowledge of the legal processes, structures and parameters associated with the receipt of compensation were only moderate and most participants were unfamiliar with the parameters of the legal compensation processes.

Lawrie and Jim had both been involved in extensive legal actions processes and noted that they had been intimidated by the legal processes. Lawrie described being unfamiliar with the legal parameters associated with the receipt of his compensation, and of learning a lot along the way. He noted that at the time he had not had an understanding of what his liability would be in terms of costs in making a compensation claim, and that he thought he would have to contribute costs for the legal action. He also equated his poor knowledge of the legal processes as leading to his poor outcome in terms of compensation awarded:

*I had worked for 7 or 8 years... and had saved up a little bit of money; if the court case went badly, I would have had to pay the court costs, and if that happened, I would be wiped out completely; so this is probably another example of not having a broad enough perspective; I think that the solicitors give their clients that warning, but they didn’t give me a warning and I had no understanding of how much of a chance that was...I was aware that if I had a successful outcome, well I believed that I wouldn't be entitled to any government benefits, that I wouldn’t have a right to any government support I thought... so I had factored that into the amount... I thought if I was successful, I wouldn’t have been entitled to any of this ongoing support... I saw that support as a safety net for me.*

Lawrie’s understanding of the role of compensation however was quite good. He contextualised compensation as a valued social entitlement and felt that it provided an important safety net for someone unable to work after having acquired an injury. He viewed society as having a duty to provide financial support in the form of compensation to an individual who had acquired an injury, and felt that the awarding of compensation
provided an effective mechanism to assist people with disabilities to maintain involvement in community.

In contrast, Jim had an extensive knowledge of the legal proceedings associated with his claim for compensation. He recalled being very comfortable and familiar with the legal negotiations and that he had been confident in telling his story without being too intimidated. Although viewing the legal arena as quite adversarial, he personally viewed his involvement in the legal process as softening the so-called divide between him as the client and legal teams. Jim thus described his involvement in the awarding of his compensation as positive.

Annie, Stefan and Ben had poor familiarity with overall compensation frameworks. As these participants were not actively involved in negotiations or court proceedings and were awarded their compensation automatically, the reduced exposure to legal processes and reduced involvement in the processes of claiming for compensation may have attributed to reduced understanding of compensation processes. Instead, these participants had considerable knowledge of parameters of ongoing loss-of-earnings compensatory payments.

Compensation was also strongly understood in terms of justice and fairness. Colin felt that his decision not to claim for compensation was just, based on his perception that there were particular levels of personal fault in relation to the acquirement of his SCI. Annie also understood the receipt of compensation as related to justice, and felt the level of compensation awarded should be based on how an individual acquired their SCI. As an example Annie understood why the awarding of compensation following a SCI should be equated with liability, and that drink drivers who seriously injure themselves or cause serious injury to others in transport accidents should be awarded reduced amounts of compensation. Similarly, David, Colin and Tom noted that the non-receipt of compensation where there was no fault for the SCI was unjust, communicating that they
understood why an individual would be disappointed or angry if they were not in receipt of any compensation or entitlements where they had no fault associated with the acquirement of their injury. Of note, these discussions brought up considerable emotion for some of the participants where decision making had obviously been a factor in events associated with acquiring the SCI. David and Tom expressed particular anger with the unfairness in the awarding of compensation, while Tom felt there were particular disparities in levels of compensation received across the board.

10.3.2 Compensation as redress for SCI

Compensation as redress for SCI emerged gradually as a theme throughout interview discussion, with participants in later interviews asked directly if they felt compensation provided redress for SCI. Overall, receipt of compensation was not viewed as providing redress for having acquired their SCI. Compensation was not viewed as redress for being able to walk again or viewed as a mechanism in regaining past status and lifestyle.

However despite these views, all participants in receipt of compensation communicated that they valued the compensation they had been awarded, and that it had been advantageous in providing funding to purchase preferred equipment, personal transport and accommodation. Compensation was certainly viewed as a financial buffer by participants and as resource through which required lifestyle changes and choices could be made.

Jim and Colin stated that receiving millions of dollars of compensation could not bring back their previous lives nor restore past status and lifestyle. They noted that they would readily give back their compensation amounts if they could walk again, with Colin noting that no amount of money could make his life easier or compensate for his accident. Jim valued the compensation he had been awarded but described the life he had had before his SCI as ‘priceless’. He also noted that his perspectives on compensation had changed and recalled that he had previously believed that
compensation would assist an individual to get their lives back to a level similar to that prior to their SCI, however did not view this as achievable now.

Similarly, Stefan felt that compensation had made things in his life better, but that compared to his old life, his life was now ‘nothing at all’, while Emerson felt that the awarding of large sums of that money just ruined people. David also equated walking with the be-all-and-end-all and was sceptical compensation provided any real redress following a SCI:

$I couldn’t care if I had 50 million dollars... if I could walk, you know as far as monetary concerns, it would certainly help, but I think anyone in our situation would happily say ‘I don’t want the compo’ if they could walk.$

These participants thus viewed compensation as providing resources to assist with the purchasing of additional disability services, equipment, personal transport and accommodation. Compensation was certainly viewed as providing a financial buffer and a financial security net and where compensation amounts were large, as creating lifestyle flexibility and choice. Compensation was also understood as providing remuneration of lost wage earning capacity of previous employment roles and as meeting insurers and employees obligations and responsibilities related to liability, however overall was not viewed as redress for the SCI itself having occurred.

**10.3.3 Participant viewpoints/perceptions of others**

Participants also described being aware of the amounts of compensation, or lack of compensation, received by other individuals that had acquired SCIs that they were friends with or had meet in spinal rehabilitation. Participants were readily able to compare their situation with that of other individuals and the comparison of disparate levels of compensation awarded produced significant amounts of emotion during interviews.
David described being angry and resentful that he had not been awarded a large compensation payment in comparison to many others. He expressed considerable anger at being forced to rely on the informal support of his parents or be placed in a nursing home because he had not received a significantly large compensation payment and at that time, no formal community-based disability services existed. He described being very resentful of others that who had been given more independence and lifestyle choices than he had after being awarded large compensation payments. Tom was also very aware of levels of inequity in terms of access to compensation for individuals that had acquired a SCI. He viewed the system as unbalanced and as creating and us-and-them type division between those that had been awarded large amounts of compensation and those that hadn’t.

Both Tom and Annie felt individuals that had not been awarded any compensation would lack needed resources and face significant financial hurdles in life. Annie felt that the act of having to continually source funding for extra disability services, equipment, personal transport or accommodation was ‘a life distraction’, and that individuals in these situations would have a much more difficult life-situation in comparison to hers. Jim was also empathetic towards individuals in this situation and was concerned with how these individuals managed in life:

\[T\]hat poor old lady who became a quadriplegic because she fell down her own stairs... I came across her just crying saying ‘I don't know what I am going to do?’ and did you know there aren’t many places to go away and cry there, and she was about 70, and gee, you know... they are trying to teach her to stand up and all of that sort of thing, and she was trying as much as she can, but she was just exhausted and in pain and all of that sort of thing... and I would go in there when I had some time, and all she had done was fall down 3 steps on the stairs at her home... the public liability of the home doesn't cover the owner, which I also think is another get-out clause for the insurance companies.
Lawrie perceived that it must be financially stressful for people without compensation reliant solely on DHS funded disability service and equipment programs. He noted having experienced delays in receiving equipment from DHS due to shortfall in funding with DHS services and equipment programs, and had only managed to obtain the equipment he required immediately by utilising funds from his compensation to privately purchase it. Lawrie was thus very empathetic towards this group of individuals and perceived that their lifestyles must be difficult and a struggle. Lawrie expressed a disapproval of receipt of excessive compensation payments awarded to individuals such as multi-million dollar public liability claims. He felt that the amounts of compensation awarded needed to be kept within reason (what was reasonable was not defined) and that an individual shouldn’t be awarded millions of dollars for something as simple as slipping on a path.

10.3.4 Degree of satisfaction
The most distinct theme emerging for participants that were awarded compensation was satisfaction with the compensation amount awarded. Participants that had been awarded considerably larger compensation payments were generally satisfied with the compensation they had been awarded and viewed their compensation as providing financial security, comfort and choice.

Ben and Annie were both awarded large compensation payments and were satisfied with the overall level of financial security and comfort the compensation provided. Both noted that compensation provided extra resources to fund extra disability services required and/or purchase a better standard of equipment if required. Annie was satisfied particularly with the fact that her compensatory payment had provided her with increased lifestyle choice, and had allowed her to return to the community setting and live independently (with her daughter), as opposed to having fewer options and potentially having been forced into an institutional or aged care setting. Annie would have had difficulties with her living arrangements if she had not received a lump-sum
compensatory payment, and the only way she had managed to purchase a house (with assistance from her father) and remain living independently in the community was because of the finances she had be awarded through her compensatory payment:

*I'm very fortunate in that I am not struggling for money [because of the receipt of compensation], I have been able to be reasonably financially independent, which has made a huge difference, huge, which you would know if you live in your own place; it’s being able to know that I can stay in my own house, and no-one can kick me out for financial reasons, and I don’t have to keep moving, I just think I am incredibly fortunate, it has been a great privilege.*

Ben was satisfied with his compensation payment as it allowed him to pay for housing modifications and purchase more fashionable house fittings, rather than the standard fittings budgeted for in the general government funded modification schemes. Ben was satisfied that he had greater flexibility and choice in decision making in relation to fittings, and that this provided an increased sense of security in knowing that he had choice to purchase the specific items he wanted. He emphasised that compensation had provided him with a means to live a comfortable and flexible lifestyle and that it provided him with financial security.

Lawrie was also satisfied with his receipt of compensation. He felt that things were easier as he was able to avoid the perceived stresses and instability associated with the general DHS disability services system. He had utilised his compensatory payment to privately fund disability services and purchase required extra equipment. He also viewed his receipt of a compensatory payment as a means of skipping the public system waiting lists for medical procedures in being able to privately fund any needed medical procedures. Lawrie placed high personal value on the support compensation had provided him with, viewing the increased financial security as a ‘safety net’. Both Jim
and Tom agreed with this, viewing compensation as a means to privately fund shortfall in disability services or personal healthcare needs where needed.

Stefan regarded his compensation as essential to his very survival. He was heavily reliant on his ongoing compensation payments, and viewed them as essential in providing his family with income support. He viewed his receipt of compensation as providing him with financial security, and in helping him retain his social status.

Participants described being dissatisfied with the compensation where inadequate levels of compensation had been awarded, where compensation for loss-of-earnings continued to be provided in a fixed, ongoing schedule, and where there was lack of opportunity to pursue legal action and make a more substantial claim for compensation. Emerson and Tom, who had received minor compensation amounts of A$9000 and A$20 000 respectively, were both dissatisfied with the levels of compensation they had been awarded, which they viewed were inadequate to meet their personal needs. Tom noted that his compensation payment had been spent on base equipment and set-up costs in his first year post-spinal rehabilitation, and that his compensation payment had not provided him with any substantial or long-term support or financial security. He viewed the compensation he had been awarded as an ‘insurance policy’ rather than compensation, and described it as covering ‘bugger-all’ and ‘an absolute joke’.

Lawrie was also dissatisfied with the amount of compensation he had been awarded. He believed that the amount of compensation he had been awarded had been reduced because he had demonstrated a capacity to work during the legal proceedings. He believed that this had influenced the assessments of the extent of his injury from the SCI, despite the overall more positive aspect of his capacity to return to work. Lawrie viewed the amount of compensation he had agreed to settle for with uncertainty and distrust, and believes now that he should have allowed the court proceedings to finish and allowed the courts to make a judgement on his claim.
Further, both Lawrie and Tom were dissatisfied with the pathways they had chosen to claim compensation, and consequently, the amounts of compensation they had been awarded. Both participants commented that with hindsight, they would have pursued a different legal pathway in claiming compensation, and would have sought to make a number of claims from a wider array of sources, and that they would have pursued their claims for compensation more aggressively.

Ben was dissatisfied with how assessment for his compensation claim had been made by the insurance assessment panel. He believed there was inconsistency in how his compensation claim (and all compensation claims) were being assessed, and described being frustrated with instances where people less seriously injured than him and still able to walk and/or resume work, were being awarded larger compensation payments by the insurance assessment panel. He described resenting the size of these payments, and of being frustrated with the inconsistency of assessments being made by the panels. Further, Ben was dissatisfied with the limitations on amounts of compensation that could be awarded by the insurance assessment panels. He viewed it as unfair that individuals covered by the VWA had been awarded more substantial compensation payments, and that they had been able to make a claim for compensation through Common Law processes rather than through an automated compensation payment determined by an insurance assessment panel. In this instance, Ben was referring specifically to the policy variation made by VWA which for nearly two years during November 1997 and October 1999 provided compensation assessment through insurance assessment panels only, and where eligibility to make a claim for compensation through the courts had been removed. Ben described his compensation process as an ‘automated-no-questions-asked’ type action, and described resenting his lack of opportunity to negotiate a more substantial claim through Common Law processes.

10.3.5 Dependency
A theme of dependency was identified for participants on fixed, ongoing, fortnightly loss-of-earning compensation payments. These participants demonstrated high levels of reliance on ongoing payments for income, with none of these participants having resumed any full-time or permanent employment in order to move off these payments. All of these participants were thus fully dependent on ongoing payments for income and there was a significant disincentive for them for to return to employment. This situation had occurred mainly out of fear and anxiety that if they resumed employment again, they would jeopardise the ongoing receipt of these payments and hence their secure financial position if they were unable to maintain employment for any reason. This situation thus created dependency on these ongoing payments, with participants reluctant to return to work and jeopardise this secure income. In place of employment, participants described having taken on community and voluntary roles or study so that their ongoing loss-of-earning payments would not be impacted.

Ben noted that the practice of the insurers of reducing ongoing compensatory payments when a client resumed employment, as per their policy schedules, created much of this dependency and anxiety in returning to work. He had not returned to work in fear of jeopardising his ongoing payment and was fearful that it would be difficult to get back onto the ongoing compensation payment system if he was unable to continue with his employment. He noted he was not prepared to risk or compromise his secure financial position and fixed income where employment may not be stable and his income may not be ensured.

In contrast to dependency on ongoing payments by these participants, both participants who had received compensation through a Common Law lump-sum payment had resumed employment reasonably quickly following the completion of their spinal rehabilitation. Without any dependency on ongoing payments, these participants were not deterred from resuming employment and instead demonstrated a good capacity and
willingness to resume employment and enjoy the increased lifestyle choice and flexibility
the increased income of employment provided.

10.4 Participants not in receipt of compensation

Four of the participants interviewed did not receive any compensation after having
acquired their SCI. This was either by choice in not wishing to claim for compensation or
because that there was no legal avenue to pursue a claim for compensation. As
expected, the experiences and perspectives of these participants in relation to
compensation varied considerably from participants in receipt of compensation. This
section will discuss the major themes of participants not in receipt of compensation, and
includes discussion on a hypothetical on how receipt of compensation may have
improved or altered their lifestyles.

10.4.1 Financial stress

All participants not in receipt of compensation described being in some form of financial
stress. These participants described being frustrated by this financial stress and
attributed it to the DHS disability service program parameters frequently not being able
to meet need. Shortages in allocations of disability services and equipment available
through DHS programs meant these participants were often forced to privately purchase
and/or personally subsidise additional disability services, equipment and personal
healthcare supplies to meet their requirements. In many cases, these purchases were
subsidised from their DSP, wages or personal savings leaving participants short of money
for general living expenses and in financial stress. Further, no access to loss-of-earning
payments or lump-sum compensation meant that these participants were often reliant
solely on either employment or the DSP for income.

Tom described being in financial stress and angry at having to continually subsidise
equipment and personal healthcare purchases from his DSP because allocations of
disability services did not meet need. He noted that he should have been using this
income to top up his is superannuation at this stage in his life to more adequately
support himself in later years, not spending his income on subsidising items he should have been entitled to in the first place. Tom believed that if he had received at least some form of compensation, that at least these shortfalls in equipment and personal healthcare provisions could have been funded privately from that payment.

Matthew also described being in financial stress, particularly since he had left full time employment and moved onto the DSP in the previous year. Matthew noted that when he had been employed full time, he had had the resources to subsidise equipment where required. Since moving onto the DSP however he viewed his financial situation as strained and was now struggling to keep up with his living expenses. As an example, he described where he had recently sought to purchase a wheelchair considerably more expensive than the DHS equipment allocation would allow. The chair was valued at A$17 000, however the equipment allocation through the DHS equipment program (A&EP) only allowed for a maximum allocation of A$7000 per electric wheelchair. Matthew had thus been forced to pay the difference in order to obtain a wheelchair that was most suitable for his needs.

Matthew was also critical of the fact that capping of wheelchair allocations did not exist for clients funded under TAC or VWA, and that TAC and VWA clients were not only more likely to be in receipt of a compensation payment and in a better financial position to subside any shortfall in equipment purchases, but that TAC in general would fully fund the purchase of the more expensive wheelchair if it was assessed as of reasonable need. Matthew thus viewed himself in greater financial stress than individuals funded by TAC or VWA on two levels in terms of not receiving any compensation and in having to personally subsidise extra disability services and or more expensive equipment required.

Further, these participants viewed themselves as in increased financial stress due to recent inflation and increased costs of living. They viewed their DSP as not increasing enough to cover the increase in living costs and that having to subsidise disability
service and equipment purchases only added to this financial stress. They felt allocations of disability services and equipment within DHS programs did not appear to be keeping up with inflation, and that allocations from these programs were progressively contributing less and less to their requirements meaning they needed to personally subsidise more and more to purchase certain items.

Financial stress was also prevalent where participants were required to privately fund the purchase of private accessible vehicles and/or complete accessible housing modifications. Participants noted that these two items were not been funded under any DHS program parameters (until 2008 when limited vehicle and housing modification schemes were introduced by DHS) and that they had been required to privately fund accessible vehicles and/or accessible housing modifications at great personal expense, contributing too their financial stress. Participants described how they had been forced to source funding for these items through varying means, such as fundraising through friends, approaching charity organizations (such as Rotary Club or Lions Club), obtaining sponsorships or having parents fund items.

10.4.2 Dissatisfaction and ambivalence

Participants that did not receive compensation spoke with either aggression or ambivalence at not having had any opportunity to receive compensation. Participants that had knowledge that other people with a SCI had received substantial compensation while they had no opportunity to claim for compensation frequently spoke with force and aggression about their dissatisfaction with this situation.

David felt that it was unfair that he had been unable to make a claim for compensation. He felt that individuals that had been awarded a substantial compensation payment were on an easier, first-class funding system, while he was forced to negotiate a restricted, second-class funding system. David described feeling alienated from people that had received compensation and chastised and ridiculed individuals he knew of who had received compensation because he perceived them all as living a lifestyle of luxury that
included pools, expensive houses, expensive cars and ‘compo’. David was thus acutely aware that this difference in lifestyle was based solely in relation to how individuals had acquired their SCI and if they had had the opportunity to obtain compensation.

Tom described his non-receipt of compensation as unjust. He was angered at the inequity across the entire compensation framework and was resentful that other individuals he knew had received compensation and had ample resources for disability services and equipment, while he struggled with the challenges of being fully reliant on the DHS system with no compensation. He despaired being unhappy with having to utilise his personal finances to meet shortfall and wished that he had extra resources from a compensation payment to make up these differences:

*I would have had extra funds to say ‘ok, I can afford that $600 shortfall every year’ because if I have got $100 000, I would be getting $10 000 a year in interest to cover it, but having never had that, I haven’t had that availability to cover those types of things*

Similarly, Matthew described not having compensation as a struggle. He spoke of having to continually fight the DHS system in seeking to gain adequate levels of disability services and equipment because he did not have any resources from compensation to privately purchase such items. He noted that he had had to educate himself about the service framework so that he was able to challenge the system required in order to survive, and he was often forced to negotiate the purchase of required disability services rather than simply receive them as required.

Yet in contrast, Colin, Graham and Emerson were ambivalent and philosophical about not having pursued compensation or not being eligible to pursue compensation. They expressed gratitude that they owned their own homes (if that was the case), were healthy, that they had enough friends, family and/or employment and were able to maintain a good lifestyle. These participants appeared more concerned with ensuring
their lifestyle was maintained to a good standard and seemed to meet similar challenges of allocation shortfall with more calmness, and appeared to prioritise achieving wellbeing, obtaining fulfilment from family and friends and gaining meaningful employment rather than dwelling on non-receipt of compensation.

Colin described the love and support of his family as being a more important than receipt of any compensation payment or financial gain. He viewed receipt of a compensation as of less an importance than a comfortable level of support provided by attendant carers, friends and family. He was described enjoying his current lifestyle and work/community roles and felt he was in a better situation than many other people he knew, such as people he knew that were required to live in a nearby aged care facility:

*Each to his own, that is how I see it. But I sort of think I am one of the lucky ones. I have a family that loves me, and I don't need money to be quite frank. I may need some to purchase a van to make it easier, because it is a bit of a hassle going to the train station and that, but besides that I don't need money to buy a house. I have a house here [with parents], and I am comfortable... Maybe I would have been miserable on my own? It may turn out not to be to your benefit; like I said, if I was to become compensated and moved out with my own house the swimming pool, my own van, and away from home, you know, maybe I wouldn't have liked it?*

Emerson took a very casual, c'est la vie attitude towards the low amount of compensation he was awarded. He viewed this as just a normal part of life’s inequalities and imbalances and utilised metaphors such as ‘that is just how the cards fell’ and ‘that is just how it is’. He viewed undertaking a major claim for compensation as too much of a challenge and described being very satisfied with having resumed employment and with the income he received from this (although still noted that compensation would have been ‘fantastic if he had got it’).
Matthew, despite describing considerable hardship in not having received compensation, was of the view that compensation only provided a short-term utility and immediate satisfaction, and was ineffective at creating life change. He was of the view that any compensation awarded for loss-of-earnings should in real terms take into account 30-40 years of anticipated earnings, and that present amounts of compensation awarded were unable to meet this need. He was thus somewhat sceptical as to the role of compensation in supporting income for the life-course post SCI:

[I]t depends how much it was. People think that a million dollars is a lot, but it’s not really, not when it has to last 40 years or so. Especially with house prices at the moment, it might make you happy for the moment... [so] whether a lot of money would have changed much, it is hard to say.

Graham equated receiving compensation with a level of stigma, similar to that of workers being out on compo. Although not having any opportunity to claim for compensation given the medical nature of his SCI, Graham was reluctant to pursue any claim for compensation as he viewed himself as not being ‘that sort of person’. He appeared to associate making a claim for compensation with a particular personality trait, and felt that only a certain type of person would claim for compensation. Graham appeared to link being awarded compensation with some sort of moral value and viewed himself as above the moral level of needing to make a claim for compensation.

10.4.3 Hypothetical exercise on compensation

All of the participants that did not receive compensation were asked a hypothetical question on how they perceived receipt of compensation may have altered their lifestyle or life-course. The question sought to explore perceptions and knowledge about compensation and gaps in the disability service framework. Participants were asked the question: Can you envisage how your life may have been different if you had received compensation after your SCI accident?
Responses to the hypothetical question were generally that receipt of compensation would have provided increased resources and reduced financial hardship. All of the participants perceived that receipt of compensation would have provided them with resources to complete accessible house modifications, purchase private accessible transport, purchase additional disability services if required and subsidise costs of equipment and healthcare items with greater ease. Participants also perceived that receipt of compensation would have provided them, and their families, with resources to improve the lifestyles and would have provided increased long-term financial security.

David hypothesised that the receipt of compensation would have allowed his parents to have regained their independence and life flexibility sooner, as he would have been able to set up his own place. He believed that the trajectory of his their lives would have been considerably different as they would not have been required to provide such an extensive level of informal support for so many years during the years immediately following his SCI. Both David and Tom hypothesised that the receipt of compensation would have provided them with more resources to replace equipment more frequently and promptly without the delays and waiting usually associated with the system. Tom noted that if he had received compensation he would not have been so significantly out-of-pocket over the 19 years in personally subsidising disability services and equipment. Similarly, Graham hypothesised that receipt of compensation would have provided him with resources to complete still required accessibility modifications at his residence, and would have provided resources to fund more flexible utilisation of disability services. He also felt that that these accessible housing modifications, once completed, would increase his level of mobility and independence, meaning he would be less dependent on attendant carers and hence reduce hours of support required. Matthew hypothesised that the receipt of compensation would have provided him with resources to resume travelling which his SCI had prevented him from doing.
From a different viewpoint, Tom hypothesised that if he had received a considerable amount of compensation, he may not have been as politically active in writing letters and in challenging the physical and attitudinal barriers he had come across since acquiring his SCI. He believed the receipt of compensation would have meant his needs were more adequately met, and that with that level of comfort, he probably would not have challenged things so frequently.

The utilisation of the hypothetical was thus successful in identifying perceived gaps and shortfall in the current disability service framework, and it was possible to gain insight as to where participants felt current resources were not meeting need and how the awarding of compensation may have altered a participants life-course. The utilisation of the hypothetical also allowed participants to envisage a lifestyle direction they may wish to move towards, or wished they had moved towards, if resources had been available. It also examined the role compensation may have had in supporting a participant to resume their previous life trajectory and social roles after having acquired a SCI. The hypothetical question was thus successful in identifying the extent to which this life rebalance was effected by the non-receipt of compensation.

### 10.5 Summary

As the above discussion demonstrates, participant experience associated with compensation was diverse and impacted strongly on how disability services and provision of equipment were utilised. The array of parameters associated with receipt or non-receipt of compensation, and the differing means in which compensation was awarded (where it was awarded), meant participants had many unique experiences associated with receipt of compensation, allocation of compensation or non-receipt of compensation.

As is evident from interview discussion, the compensation framework following the acquirement of a SCI in Victoria is complex, with the array of legal and policy structures
contributing to significant diversity of experience. The five compensation pathways identified through participant discussion supported this, and demonstrated that the awarding of compensation (in most cases) and the method in which compensation was awarded, was determined solely by how the SCI was acquired and which compensation pathway a participant was propelled down.

As demonstrated, participants responded to their particular situation in relation to compensation in different ways, with participants utilising many different strategies in seeking to improve and maintain their financial position and lifestyle. The most significant juncture related to compensation was certainly the receipt or non-receipt of compensation, with receipt or non-receipt of compensation impacting dramatically on the overall experience of receiving disability services and how supported participants felt across the lifecycle of their SCI. Receipt or non-receipt of compensation impacted significantly on how disability service and equipment allocations were utilised, if extra resources were available to personally subsidise extra disability services and/or equipment, long-term financial stability and employment. Further, receipt or non-receipt of compensation strongly influenced employment, transport, accommodation and lifestyle choices.

Participants also demonstrated diverse levels of satisfaction in relation to receipt or non-receipt of compensation, such as where participants with large compensation allocations were dissatisfied with compensation received and where participants receiving no compensation were ambivalent. In addition, although participants demonstrated only an average knowledge of compensation processes and parameters, participants were acutely aware of their compensation situation in relation to other individuals and showed particular empathy of others in more difficult financial situations than themselves.

Participants not in receipt of compensation all experienced financial stress, and described significant financial hardship and difficulties in having to subsidise extra disability
services and equipment out of their already reduced personal income. These participants thus had the shared experiences of struggling to have needs fully met, and awareness that other individuals received higher allocations of disability services, equipment and compensation than themselves.

Further, although participants did not view the receipt of compensation as redress for having obtained a SCI, the receipt of compensation was viewed as a financial buffer by participants and compensation received was valued. Receipt of compensation was utilised as income support, as a resource to assist with purchasing any shortfall in disability services, equipment, accessible housing modifications, vehicle assistance and general lifestyle choices. The receipt of any compensation provided a level of reassurance for participants, while the receipt of more minor compensatory payments did not appear to effectively provide participants with any form of long-term support or advantage.

Receipt of compensation thus played a significant role it returning a person back into their previous life role and providing more adequate levels of support for a person to move towards their desired career or life-course post SCI. However receipt of compensation was not viewed as essential where adequate levels of financial income and support services were available.
Chapter 11: Support for people with impairment

11.1 Introduction

In this chapter, I will discuss the construct of support based on participant experience of receipt of disability support services and compensation. I will discuss how provision of various forms of support, such as funded disability support services and compensation, have served to improve the quality of life, wellbeing and social inclusion of participants within society since deinstitutionalisation in the mid 1980s in Victoria. This includes discussion on how a construct of support, rather than care, serves to more effectively promote individual capacity and opportunity, and identification of various constructions of support such as formal and informal support, objective and subjective support and micro and macro support. I examine the construct of support through the lens of related international theoretical discourses and movements on disability and impairment, including Medical and Social models, the Principles of Normalisation and Social Role Valorisation, the ‘Business of Disability’, Human Rights and the Capabilities Approaches. The construct of support is thus examined within the parameters of disability and impairment.

Further, I examine the conceptualisation of a ‘platform of support’ for people with impairment based on the utilisation of various support structures. A platform of support would incorporate the array of support people with impairment utilise to enable them to live inclusively in the community, such as formal attendant care, financial, emotional and legal support, and support from accessible physical infrastructure. I examine how a platform of support would serve to effectively identify areas of risk, where support structures may be reduced, where essential or crucial support was required assessment of support structures would be required to maintain optimal social inclusion and wellbeing.

11.2 A construct of support
Support can be defined in an array of ways. Support can be defined as an act or entity that seeks to up-hold, promote, advance or maintain the social position, health, wellbeing or status of an individual. Support is understood as being required to ensure quality of life, choice and wellbeing, and is known to reduce the impacts of stressful events, bolster self-esteem and facilitate positive change (Thoits 1986; Horowitz 2006; Turin and Horowitz 2010). Support is also understood as a basic human need, whereby humans demonstrate need for each other and are required to interact with each other in order to survive (Thoits 1986; Horowitz 2006; Turin and Horowitz 2010). Support must occur within an interactive field of give and take, where there is an expectation of reciprocity and exchange of mutually rewarding activities (Thoits 1986; Langford et al. 1997). Support provided through an interactive network is viewed as providing helpfulness and protection, and is influenced by the extent, strength and depth of emotional ties, social embeddedness and connectedness (Langford et al. 1997).

Langford et al (1997) defines four specific attributes of support. The first - 'emotional support' is the most frequently identified support. Its attributes include caring, empathy, love, trust, affective assistance, liking, admiration, respect, communication of value, esteem, mutual obligation, subjective feelings of belonging, being accepted and being needed. The second attribute of support is 'instrumental support', a more tangible aspect of support that includes the performing of concrete tasks, such as provision of goods and services. The third attribute of support defined by Langford is 'informational support', defined as support provided from information to allow problem solving. The last attribute of support is, 'appraisal support', defined as support required for self evaluation, and obtained through communication of information and the affirming of expressions/acts. Further attributes of support include to sustain, maintain, provide foundation for, reinforce, encourage, champion, sponsor, assist, help and aid (Thoits 1986; Turin and Horowitz 2010).
Need for these specific forms of support are, in most cases, influenced by an individual’s living situation and behaviour. Individuals have demonstrated that they will move towards any of these various forms of support for differing reasons based on their perceived need, and that individuals will utilise various amounts of these support attributes to ensure wellbeing, social inclusion and survival.

In living with a SCI on a day-to-day basis, participants demonstrated a need to utilise a high level of instrumental support in completing their daily living activities. This included the performing of tangible tasks by attendant carers and disability service providers on a day-to-day basis such as personal care, community access, house cleaning, gardening and rostering, and coordinating of services by disability service providers. Participants in most cases also required a significant level of informational support to navigate the disability services and compensation framework to achieve adequate allocations. Informational support was achieved through a combination of sources including Occupational Therapists and related allied health services, relevant websites, advocacy organisations, disability service providers and lived experience. Where allocations of disability services and/or compensation did not meet need, participants sought information on resources from various sites often from outside of the disability service and compensation framework, in order to meet support shortfall.

Emotional support was provided almost entirely at an informal level (excepting the rare use of counsellors by participants) and at an individual level. Emotional support was provided through interactions with friends and family, but also included interactions with attendant carers, disability service providers and funders. The quality and satisfaction of emotional support was thus reliant on the participant’s support network and their ability to obtain and receive emotional support from friends, family and through work-relationships. Of note, at an individualised level, participants were often able to obtain emotional support from friends and family more readily where work-relationships in themselves were positive and based on mutual respect as these interactions worked to
place participants within socially inclusive and participatory settings where emotional support could be achieved.

Appraisal support, as with emotional support, was mostly obtained at an informal and individualised level were assessment, adequacy and confirmation of support were self-identified by each participant or by a participant's immediate social network. A minor exception to this would be assessment of disability service allocations conducted annually by insurers/funders to formally review and assess allocations of disability services utilised by individuals.

As opposed to a construct of care, with attributes of dependency, need, being 'cared-for' or looked after, and often characterised by unequal work-relationships based on power and dominance by the care giver within the interaction, a construct of support, as described by Langford, more readily allows for attributes of respect, mutual obligation, positive affirmation and value to be achieved within the support interaction. The utilisation of a construct of support in relation to provision of daily living activities thus more readily provides opportunity for an equal and mutually beneficial work-relationship interaction to occur. In removing attributes of care from the support interaction, such as being looked after and cared-for, a construct of support more readily creates a landscape in which an individual’s status is promoted and advanced within the work-relationship interaction facilitating improved quality of life, choice wellbeing and positive change.

All forms of support utilised by participants however required some form of social interaction or relationship with another person, entity or landscape and as such, these various forms of support interactions could also be characterised as both individualised and systemic. Support was individualised where a support interaction was between two individuals only, such as an attendant carer providing support to a participant in the home on a day-to-day basis, while support was systemic where a support interaction involved the interaction between say a participant and an entity or the landscape. For
example, this would include where participants had described utilising support from UN Conventions or Human Rights or a participant had obtained income support from TAC or VWA. A support interaction with a landscape included where a participant interacted with the landscape physically, such as physically moving through the built environment and/or utilising public transport networks.

A construct of support for participants was thus multi-factorial. Participants drew on various forms of support, from a variety of sources and at varying intensities to support their lifestyles. Participants with high levels of support often required a large network of support to maintain a basic standard of living. Participants who were less dependent, or had higher levels of physical function, did not require as many support structures, however still utilised multiple support structures.

Participants developed their own construction of what they viewed as required support and an adequate level of support needed for their own wellbeing. Participants made an evaluation of their own support needs and self-determined what levels of support would be utilised, with the exception of where parameters of disability service programs restricted allocation of support available. Although each participant formulated an individual construction of what they viewed as needed, opportunity to obtain support varied with differing life circumstances, dependency and availability of informal support, the ability to access various allocations of disability services within the disability service framework, and the extent of individual agency of each participant.

### 11.3 Formal Support

Obtaining formal support was certainly impacted by the range of differing parameters of allocation available for disability services and compensation, each with differing parameters and eligibility criteria. The utilisation of formal support was characterised by drawing on multiple support structures and mechanisms, often across differing levels of government and statutory authorities. Obtaining formal support was also impacted by
various factors such as motivation, previous positive or negative support experiences, varying dependency over time and individual financial circumstances. In addition, obtaining support was also impacted by an individual’s functional capacity and the level of physical assistance needed with daily living tasks, emotional needs, economic needs, accessibility of surrounding public transport and built environment and availability of support. As such, formal support was often utilised in varying levels of intensity and frequency.

Formal support included attendant care, maintenance support (such as gardening or house cleaning), community nursing and medical support from GPs. Participants were able to make a clear delineation between formal and informal support. Formal support was defined as support that was provided at a cost by a service provider, where one party was in a paid work role in providing support. As such, the provision of formal support involved negotiation, such as establishing boundaries in the work place, establishing funding and allocation arrangements with agencies and managing administration associated with support. It normally included the establishment of set routines and tasks in providing support on an ongoing basis.

Allocations of formal support were generally established while participants were in spinal rehabilitation and were strongly impacted by how an individual acquired their impairment. Allocations of formal support available were objectively determined by legislation, which defined the parameters of allocation available. After acquiring a SCI, participants in most cases were forced to increase their level of knowledge of the disability service framework rapidly in order to distinguish which formal support allocations they would be entitled to. This included determining eligibility of allocations, negotiation of allocation and guidelines and parameters of each program. Once obtained, formal support allocations were often recurrent on a week-by-week basis but subject to annual reviews. Utilisation of formal support was recognised by participants as requiring
annual reviews, ongoing rostering of staff, ongoing training of staff, emails, paperwork and involvement in completing care plans.

Utilisation of formal support was often characterised as being structured, controlled, provided at a set cost and provided at scheduled times. Tasks were required to be finished before x and y time. Formal support was thus a defined and controlled form of support.

Formal support was understood by participants as a means of maintaining social inclusion and valued social roles, such as parenting, employment, friendships and relationships. Participants understood that formal support provided by the community aimed to support them in completing required daily living activities and in maintaining social integration.

Participants did not link provision of formal support to government policy directives and obligations to met international conventions. There was no expectation that formal support was linked to any external frameworks, only that it was provided within the restraints of financial budgets and available government funding. Formal support was understood as being provided within a Human Rights framework in seeking to improve social inclusion for people with impairment, with the provision of formal support recognised as a means of meeting the social objectives of deinstitutionalisation.

Some participants identified feeling unsupported with the allocation of formal support available to them. This included where support had not been provided in a way that was anticipated, where allocation did not meet need, where support was unreliable or where there was unreliability in how support was provided. Participants were able to identify inequities with receipt of formal support provided, and recalled where considerable amounts of time and energy were required in challenging the need for improved and increased support at systemic and landscape levels.
11.4 Informal support

Informal support was viewed by most participants as more abstract and fluid. Participants understood informal support as support provided from friends and family in a voluntary and unpaid role. Informal support included attitudinal and emotional support received from friends and family. It also included provision of physical tasks, such as friends providing after hours personal care, parents taking on primary personal care roles, friends cooking meals, friends or family purchasing equipment, houses or paying for house modifications, or even just support from an employer on returning to work soon. Informal support was often used in conjunction with formal support.

Participants viewed informal support as requiring increased interaction and negotiation. This included negotiating what the support would entail, how much time the support would take and the frequency with which the support would be required. To a large degree, informal support involved reciprocal negotiation in determining the style and manner of the work-relationship. As friends or family often provided informal support in a voluntary capacity, intent and reasoning behind why the support would be provided was relevant. Utilisation of informal support usually had a significant impact on immediate family members who most often provided informal support. Reasons for individuals providing informal support extended to an individual wanting to provide a moral good in helping another community member, contributing to the ‘common good’, to maintain a relationship, as a parental obligation and as a means of extending social networks.

Informal support was characterised by the fact that most often it was provided at times suitable to the volunteer rather than the participant. Informal support was also characterised as being casual, intermittent, more localised, and less routine in nature. Noticeably, any informal support provided was unregulated and if there were any problems with the support being provided, participants had no avenue for complaint or tribunal except maybe the police if an incident was of a criminal matter. Further, informal
support was not governed by policy standards, and as such no adherence to attendant
care agency guidelines, oh&s parameters or WorkCover were available. Any conflict in
the work environment and within the work-relationship was not supported, and no third
party, such as a disability service provider, was able to act as a mediatory if any conflict
or difficulties emerged.

Choice to utilise informal support was influenced by many factors. Participants utilised
informal support primarily where allocations of formal support did not meet need. In
these cases, participants were forced to arrange informal support just to have daily
support requirements met where no formal support was available. Informal support was
required to compensate for shortages of disability service allocations, equipment,
compensation and physical barriers in the built environment. In meeting these shortfalls,
participants often drew on different forms of informal support to ensure their full support
requirements were met, such as friends, family, neighbours and charities.

On the positive side, participants also chose to utilise informal support for reasons such
as privacy, wishing to avoid waiting lists associated with formal support, increased
flexibility with times, lifestyle choice or where remoteness of accommodation made
utilisation of high levels of formal support difficult. Informal support was often utilised
intermittently during transitional times such as during physical moves, episodes of illness
or changes in relationship status. Informal care was characterised by reduced
administrative burden, as being less fixed and as involving different forms of
recruitment. For participants acquiring their SCI pre 1986, utilisation of informal support
became the only means in which institutionalisation could be avoided.

11.5 Financial support

Receipt of financial support was viewed as a form of support. Participants identified
receiving financial support from a range of sources including loss-of-earnings payments,
compensation payments, the DSP and government benefits such as maxi-taxi discount
cards, healthcare cards, mobility allowances and reduced tax requirements (i.e. when purchasing a new car).

Financial support was viewed as contributing to wellbeing and quality of life. Receipt of financial support was viewed as providing a level of financial security and a basis from which life decisions could begin being made following the SCI. It was viewed as a comfort, a buffer, as reducing stress, as vital incomes, and as a resource to allow participants to plan ahead for needed support items if not provided from within the disability services framework.

Participants described financial support received from the awarding of compensation as strongly advantageous. Support from compensation in particular provided resources to make lifestyle transitions following the acquirement of their SCI, such as purchasing an accessible home, completing accessible housing modifications or purchasing an accessible private vehicle, resources not available to any significant extent through the disability service framework. Financial support from compensation was viewed as providing a buffer from income lost from the occurrence of the SCI.

Where participants did not receive loss-of-earnings or compensation, financial support was often only available through employment or the DSP. Where participants were reliant on the DSP, they viewed themselves as financially unsupported and viewed income received from the DSP as only sufficient enough for survival. Although all forms of financial support were restricted by limitations and parameters defined by policy parameters, adequacy of financial support was highly objective and strongly influenced by the financial position participants were in prior to acquiring their SCI, whether they already owned a home and the capacity to return to employment.

11.6 Micro and Macro forms of Support
Support could be categorised as occurring at micro and macro levels. Micro levels of support were defined as smaller levels of support provided to participants regularly, or on a day-to-day basis, essential to survival and quality of lifestyle. Micro support included personal care provided by attendant carers, community access for shopping or banking, cleaning or gardening, purchasing small pieces of needed equipment, being helped with a meal, study support provided by a University Disability Liaison Unit (DLU) or a neighbour regularly driving a van to pick someone up from work. Micro support was particularly crucial for participants with more severe levels of impairment. Provision of micro forms of support impacted significantly on participant quality of life and lifestyle choice.

Micro support was highly reciprocal in nature and provided through a combination of formal and informal support. Participants relied extensively on their support network for most of the micro support they received, and the extent to which micro support needs were met highly influenced participants overall life experience of SCI.

Provision of micro support thus played an important role in increasing and maintaining the social inclusion of people with impairment. Further, micro support, in addition to helping with provision of daily support requirements, micro support promoted community responsibility and awareness of issues and needs by people with impairment in were interactions and work-relationships were established in provision of micro support.

Macro levels of support were defined as larger, more broader forms of support provided at a systemic level. Somewhat more abstract in form, macro support included support provided through legal instruments (such as the UN Convention on Rights of the Disabled), support provided through policy and legislation (such as Disability Discrimination Acts) and support obtained from accessible and barrier free built
environments. Macro support also included financial support such as loss-of-earning payments, compensation payments and support from the DSP.

Macro support in one sense was socially constructed. It was generally provided through formal government or legal structures at a top down level, and provided a basis to challenge and make a claim for improved conditions or the cessation of a discriminatory practice. Although forms of macro support were broader in their scale and occurring at a higher social level so to speak, they were specifically defined by parameters and guidelines and structured in their role. They thus acted at a broader level to meet community aspirations of support and objectives of social inclusion for people with impairment.

Participants engaged with macro support in various ways. This included where participants had utilised legal pathways to have inaccessible parts of the built environment modified, such as the car parks at Bunnings, and where participants had drawn on the DDA to draw awareness to poor community attitudes and Human Rights at various stages. Most certainly, macro support in the form of financial support provided at a systemic level provided crucial income for participants while rehabilitating and re-establishing social roles after acquiring their SCI. In some cases macro supports such as long term pensions provided a means of survival where employment prospects were low. Macro support was thus provided at a variety of systemic levels but was crucial in ensuring participants were financially and legally supported following the acquirement of their SCI, and that support against discriminatory practices and poor social attitudes were systemically addressed through legal means.

11.7 Objective and subjective support

Support could also be conceptualised as both subjective and objective. Support was subjective in that each participant conceptualised support requirements differently in relation to their unique set of life-circumstances. Participants themselves made choices
as to which forms of support they chose to source, based on need, and with the exception of restrictions with disability service program parameters and allocations, each decided how much support would be required for their individual circumstances. Adequacy and usage of support was thus subjective in terms of participants individually defining and assessing their own support needs.

Support was also objective. Availability of formal support was impacted by parameters of disability service programs within the service framework, and allocations available were often restricted and limited by disability service program parameters despite need. This was particularly noticeable for participants who received disability services funded through DHS. Support was objective in that allocations of formal support were determined by an external party from the top-down, such as a set allocation of support provided through an attendant care agency, and was provided through structured and controlled pathways. Availability of funding for support was often allocated by the funder (i.e. DHS, TAC or VWA), and was defined by the policy structures of each of these separate entities. This structure thus dramatically influenced a participant’s support allocation and level of choice and decision making in receiving support.

Of note, utilising macro support (such as between a participant, an entity, or the legal system, the bureaucracy or the built environment) often involved frustration for participants as it involved conflict in seeking to obtain an improved outcome. The utilisation of macro support thus ranged from continual and frequent interactions (as with the built environment, receiving income and society attitudes), to singular, more intense interactions (for example with a single legal claim associated with a discrimination incident).

11.8 Support Interactions

In exploring the construct of support, it was evident that all forms of support required an interaction. Receipt of support involved various levels of interaction, ranging from short-
term and intermittent support interactions to complex interactions sustained and frequent interactions.

Support interactions were significantly influenced by the standard of work-relationships developed and then maintained. Where the support interaction was positive, solid, loyal and dependable, participants described being supported by the work-relationship and that the work-relationship improved their quality of life and lifestyle choices.

Participants viewed poor interactions as creating unstable, untrustworthy and unreliable, support, and significant burden of their lives. Participants felt very unsupported when solid work-relationships could not be established, and in these situations viewed themselves as un-empowered and as having difficulties in having their basic and fundamental support needs.

All support interactions involved negotiating how support would be received. The ability to negotiate support was impacted by both individual agency (particularly around ability to obtain informal support), and the ability to access formal support structures. At a micro level, interactions were essential for survival and wellbeing. Participants were required to interact in various ways, such as undertaking recruitment, negotiating motivations in why support would be provided, managing differences in behaviour/work-styles/personalities, obtaining clarifications in how support would be provided and with training of attendant carers or friends and family to complete day-to-day tasks. Further, support interactions included negotiations with attendant care agencies and funders/insurers in negotiating allocations of formal support available.

Various characteristics were identified as aiding and strengthening the support interaction. A solid support interaction was viewed as requiring the establishment of trust, good levels of communication, clear identification of tasks required, establishment
of loyalty and reliability. Where these characteristics had been demonstrated, the support interaction was viewed favourably and positively.

The support interaction was also characterised as requiring the establishment of boundaries. In relation to formal support, participants described needing to establish boundaries with attendant carers, service providers and legal authorities. Participants described the establishment of boundaries as requiring various forms of communication such as formal written correspondence, phone-calls, emails, and formal meetings. Interactions involved establishing exactly what the support interaction would entail, establishing and defining formal parameters or restrictions and defining support structures. The support interaction thus varied with differing support roles and differing levels of responsibility.

Support interactions in the home setting on a day-to-day and face-to-face basis, whether formal or informal, were often complex. These support interactions specifically involved negotiating differing levels of personal boundaries, household boundaries and boundaries with other family members in the household. The support interaction in these instances often involved quite personal interactions such as with showering, toileting and dressing. Support interactions in the home often involved negotiating start times, rostering, managing difficulties with staff work standards or completing administrative tasks. Establishment of boundaries around these support interactions often varied with personal expectations and experience.

11.9 Legal support

Support received through legal structures was viewed as a form of macro support. Legal support was obtained through knowledge, adherence and utilisation of legal instruments, such as the DDA, the United Nations Convention on Rights of Persons with a Disability (CRPD) or Victorian's Charter of Human Rights and Responsibilities, in addition to
personal interactions with legal teams associated with individual compensation legal actions.

Support obtained through legal instruments was obtained at both an individual and policy level. At an individual level, participants obtained support from legal instruments where a direct claim for a status or entitlement was made. For example, one participant maintained it was his Human Right to be able to access a tram while utilising a wheelchair for mobility, while another participant utilised the DDA to claim he was being discriminated against where a major retailer had not provided adequate space for a person to be able to transfer from car to wheelchair in all of their disability car parks. Both participants utilised legal instruments to support their efforts to create improvement and change. Legal instruments such as Human Rights charters and DDA acts thus influenced how supported participants felt.

Participants also obtained support at a policy level. Formal legislation and policy guidelines often influenced how staff administered support. Participants were supported where staff where required to adhere to prescribed work-standards within national and international legal guidelines and policy frameworks. For example, the development of Disability Service Standards meant service providers were responsible for meeting these defined standards and fulfilling duties of care in providing formal support.

Legal support also provided information and guidance utilised to acquire or maintain various forms of support. Legal instruments were often to maintain adequate levels of support or gain a particular level of support. Legal support also defined how support services needed to be provided and the role of the state in providing disability services and compensation. Legal support included the monitoring of support administered in relation to Human Rights mechanisms and Disability Service standards and information as to what acceptable levels and expectations of support were.
In some instances however, participants felt unsupported by legal instruments and policy frameworks. Participants felt legal instruments did not do anything, and that they were not effective at creating change. Participants viewed some legal instruments as rhetoric and as lacking in strength, with some participants questioning if either the new Victorian Charter or the CRPD would improve their lifestyle significantly or create any improvement or change (for example obtaining accessible trams).

Also, differing legal instruments were perceived as providing differing levels of support. For example the newly implemented CRPD and the Victorian Charter were not yet viewed as strongly supportive legal instruments (with awareness of these instruments only moderate), yet most participants were familiar with and drew on support from the DDA. However, there was a considerable lack of knowledge of legal instruments in general by most participants. Participants did not use legal instruments to any substantial level to improve support..

11.10 Support and impairment and disability discourses

Viewed through the lenses of the Medical model, Principles of Normalisation, Social Role Valorisation, the Social Model, Disability Rights, medical sociological critiques and Capability Approaches, a construct of support for people with impairment both aligned itself with and junctured away from many of the theoretically positionings of the major disability and impairment discourses. Further, the concept of support in relation to commercial and legal frameworks was also questioned, as with how the ‘business of disability’ and Human Rights frameworks may have impacted on how support as understood and constructed by participants.

The construct of support will now be discussed through the lens of each of these major impairment and disability discourses to examine their individual influence and impact on the concept of support.
11.10.1 Support and the Medical Model

Support was not conceptualised by participants as being provided within the Medical Model except in instances where participants had acquired their SCI over 20-25 years ago. In general, participants did not conceptualise themselves as receiving support from within a medicalised framework based on oppressive, medicalised control and did not associate receipt of support with any form of control or power. Receipt of support at a day-to-day level was not viewed as being overt or controlled, and no experiences of forced institutionalisation or segregation were noted (with one exception of one participant forced to receive support in an aged care facility while awaiting provisions for attendant care for six months).

Medical support was described as attending a GP, having the RDNS attend the home on a regular basis for minor procedures, healthcare interactions such as seeing an Occupational Therapist and/or a Physiotherapist (whose roles were to visit the home to assess and/or recommend equipment, such as wheelchairs, shower chairs, vehicle modifications required for daily living activities), attending podiatrists, utilising psychologists or counsellors for emotional support and attendant carers visiting the home to provide personal support. All medical support was focused on maintaining health and wellbeing of participants to live inclusively in society, and all medical interactions were conducted within the community setting.

Although most medical support interactions were described as infrequent and unsustained, participants described a level of tediousness associated with medical appointments and a burden of having to attend medical appointments frequently. Many medical support interactions were described as tedious, time consuming and akin to an administrative burden. However medical support was not described as something overly time intensive, nor was it viewed as interventionist or overtly influential.
For participants that had acquired their SCI over 20-25 years ago, before the widespread transitions to community-based living and deinstitutionalisation had taken place, medical support was recalled as being received within a Medical Model and through a framework of oppression and control. These participants recalled that during this period, medical support had been provided within a framework of overt medical intervention, limited choice and lack of flexibility, and that they had been given little opportunity other than to rely on informal support networks or be placed within an institutionalised setting. For this group of participants, support in the form of medical support was associated with dependency, sick-role status, stigma and discrimination.

11.10.2 Support and the Principles of Normalisation and Social Role Valorisation

Support received by participants, whether medical, financial, legal or equipment based, was viewed in general as enabling participants to obtain and maintain ‘normal’ and valued social roles as prescribed within the Principles of Normalisation and Social Role Valorisation. Receipt of formal and informal support did provide opportunity for participants to obtain normal social roles and improve social status.

The maintenance of these normal and valued social roles was only able to be maintained through receipt of different pathways of support. There was certainly a reliance on formal community-based support structures in addition to informal social networks in maintaining these social roles. By utilising these various forms of support, participants described being able to obtain and maintain normalised social roles such as obtaining education, having relationships, parenting, being employed, committee roles, home ownership and employment. Participants did utilise support to advance their social networks and social status in line with Social Role Valorisation discourses. This included participants taking on full-time employment in high level roles, strengthening immediate friendships and relationships and moving towards more advanced political and community roles. Provision of support allowed participants to improve their quality-of-life by taking up these increasingly valued social roles, challenging many of the previously
prescribed, low status roles and low expectations experienced by people with impairment in the past.

Of note, participants that had acquired a SCI more recently (such as post 2000) described increased levels of support, and greater ease in being able to move into these valued social roles. In particular, Emerson as a younger man who had just acquired a SCI, had difficulty comprehending many of the barriers to social inclusion that long term SCI participants spoke of with familiarity. He had resumed university studies quite rapidly after acquiring his SCI and had then obtained full-time employment soon after completing his university studies. He described not understanding the difficulties and barriers other people with SCI spoke about in resuming work or living independently with attendant carer support. To some extent, Emerson could exemplify the success of theoretical discourses such as the Principles of Normalisation and Social Role Valorisation, in perceiving himself as socially integrated and living a socially inclusive lifestyle. Emerson described feeling well supported and living in the physical landscape in which he felt was barrier free, and where in his wheelchair, he was able to easily move around his local neighbourhood and generally access shops and buildings. Forms of support in recent years thus appeared to have succeeded in supporting participants to be socially inclusive, and achieve ‘normal’ and valued social roles.

11.10.3 Support through the reduction of barriers – Social Model

A more abstract form of support was associated with support received from a barrier free environment and the reduction of physical and attitudinal barriers, concepts that define the Social Model. Freedom of movement through the built environment and creation of societies where people with impairment were fully accepted and integrated (and where not discriminated against or excluded) where viewed as a form of support. This form of support was particularly successful for participants where it worked towards creating socially inclusive environments and reducing ‘disabling’ attitudinal and physical barriers.
Most participants described instances where they had faced many physical and attitudinal barriers, and had not been supported to live inclusively. These participants recalled the social disjunction and segregation associated with the lack of support at a physical and attitudinal level. They recalled difficulties in achieving support, and moved very easily into narratives identifying social barriers to inclusion. This included where participants had experienced, or continued to experience, shortfall or inadequacy of support received as a barrier. These participants identified gaps in formal support and social structures which included difficulties with physical access to infrastructure and public transport, inadequate allocations of disability services, experiences of discriminatory social attitudes, exclusion from labour markets, economic and political processes and access to the built environment.

Support achieved through the reduction of physical and attitudinal barriers was thus viewed as providing opportunity to obtain more valued social roles and overcome the barriers that led to the construction of these dualist, segregated spatial arenas. Support, in the form of increasingly barrier free landscapes, was effective in repositioning participants within the mainstream social landscape, and of reducing the reductionist constructions of people with impairment as a minority collective away from the mainstream as defined by the Social Model.

**11.10.4 Support and Disabilism**

The concept of Disabilism was not strongly viewed by participants as a component of support. Although participants described having experienced discrimination at an individual and systemic level, participants did not draw on the conceptualisation of Disabilism in association with how they were supported, and did not utilise Disabilism terminology as a means of improving or challenging levels of support or reducing discrimination.

Where participants experienced discrimination or challenges with individual or systemic support, participants more readily took on a Disability Rights approach in making a claim
to increase or improve support or act on discriminatory treatment. Participants were more familiar with utilising a Human Rights and Disability Rights discourses as a lever for changing support and discrimination rather than a Disabilist argument.

11.10.5 Support and bodily impairment – the Medical Sociological Critique

Support contextualised within a medical sociologist framework sought to highlight bodily impairment and the pathology of impairment in relation to provision of support. Participants viewed support as being essential to quality of life regardless of the extent of existing physical and social barriers in any community. Support was viewed as being required on a day-to-day basis to ensure survival and quality of life regardless of existing social and attitudinal barriers. Participant views thus supported the medical sociological critique of the Social Model and the need for disability services and support to survive regardless of reduction in physical and attitudinal barriers in society.

Although participants were not generally aware of this medical sociological construct in their discussions, participants agreed that they would need ongoing utilisation of support and that this would always be required regardless of the extent to which physical and attitudinal barriers still existed or were removed. Participants noted that they require support in many forms, particularly on a day-to-day level with physical tasks and daily living activities, to ensure quality-of-life.

Further, many participants did not identify themselves as living within an oppression paradigm, or as a minority collective facing physical and social barriers as per the social model. Participants viewed themselves as individuals with physical functional limitations in need of support, and viewed the community as having a responsibility to ensure that the support requirements related to their impairment were met. Participants had an expectation that support, even if restricted, would be provided by the State and that they were entitled to receive this support allocation from the State as any other individual in need in society received services.

11.10.6 The Business of Support
The concept of support for people with impairment has been dramatically influenced by the development of the ‘business of disability’ in the last 15-20 years. The business of disability has included the privatisation of formal support and the establishment of a large number of attendant care agencies, employed attendant carers, equipment providers and related medical and health service provider businesses in the provision of support.

Participants described a diverse array of experiences related to the commercialisation of receiving support on a day-to-day basis. At the positive end of the spectrum, these experiences ranged from interactions with businesses that were efficient, provided quality disability services and met disability service standards in the delivery of support at a day-to-day level. In contrast, other negative experiences with the commercialisation of support included participants being frustrated the bureaucratic systems and policies of many businesses that impacted on how they received support (such as hours and times being limited by agencies, oh&s details). This also included where businesses continually changed systems and protocols forcing participants to adapt to the businesses changes in practice. In particular, there was dissatisfaction with the high turnover of staff employed within businesses providing support which then impacted on the support of participants. This was usually a reflection of poor wages and heavy workloads experienced by attendant carers which meant there was little incentive for most attendant carers to stay in the field long-term. Although businesses themselves were often restricted in provision of disability services by the funding allocations they received, participants did describe ‘businesses of disability’ at their worst as being more focused on increasing their profit margin than on providing quality disability services and equipment provisions.

As such, participants described needing to find an effective balance in dealing with the commercialisation of disability service provision. Participants described utilising strategies such as searching around for more efficient and stable service provider
businesses to source support through that were able to demonstrate integrity and genuine interest in providing quality disability services. Other strategies including employing friends and family through a business entity to ensure the staff were of quality, or utilising informal support to avoid having to deal with commercial schedules and policy.

Participants also acknowledged that support received within the commercial structures involved administrative burden. Participants spoke of having to become their own business managers in terms of managing and directing the receipt of their support. Participants also acknowledged however that negotiating the ‘business of disability’ was required in utilising formal support, and that the quality and manner in which support was provided was highly contingent on the style and professionalism of the service provider business they were dealing with.

11.10.7 Human Rights

The discourse of Human Rights was strongly embedded within participant understanding of support. Participants viewed Human Rights as a means with which to obtain or maintain fair and equitable allocations of support. Human Rights were very much associated with obtaining equal entitlement of support and receiving ‘what the average person gets’. Participants used phrases such as having ‘the right to the same access that everyone else has’, having ‘the right to live a normal life’ and having the right to receive an allocation of support ‘within reason’.

Support contextualised within a Human Rights paradigm was also strongly associated with a legal duty-of-care. The Human Right to receive disability services in a respectful and correct manner was strong theme in participant narratives. Participants understood that utilising a platform of Human Rights helped ensure adequate support was obtained, and that support was provided in a manner which was respectable, reliable and that supported human dignity and quality of life.
Participants described conceptualising Human Rights as a component of support within three categories. Firstly, participants understood that it was their Human Right to receive particular aspects of support, such as funding for disability services, accessible housing modifications or equipment. Secondly, participants understood that they had the Human Right to have their status maintained, such as the Human Right to live independently in the community, to express their ethnicity and to express their sexuality or have children. Thirdly, participants understood that they had a Human Right to have an action prevented from occurring such as the Human Right for a person with impairment not to be discriminated against, treated unfairly or be placed unwillingly within an institution.

Participants certainly felt the Human Right to receive support was as a social right and community responsibility and equated this with social equality and justice. Receipt of adequate support was associated with social justice, while conversely, inadequate provision of support, such as shortfall in support allocation, was viewed as an injustice.

Participants viewed it as a Human Right that they would receive at least base level lifetime support, and that they had the Human Right to obtain support that would ensure they had a standard of living comparable to that of the mainstream. Human Rights were thus viewed as a means through which a level of support could be obtained that could bring an individual up to the mainstream. Of note, most participants highlighted that they only viewed it as a Human Right to obtain a level of support that would ensure their equal status in society, and did not view themselves as entitled to receive to support over or above what was normal or needed (however normal was defined).

Human Rights to support were also viewed by participants on a hierarchical level. Participants described conceptualising Human Rights to support on two levels. The first level of support was support required to ensure survival and a base standard of quality of life and human dignity. This level of support was viewed as undeniable for any individual and as a community responsibility. This level of support was viewed as a
fundamental Human Right by participants. The second level of support was where participants viewed themselves as entitled to what was reasonably possible where there was availability of resources. These included the Human Right to access the built environment and public transport, support to engage in community and recreation activities or support to help obtain employment. These forms of support were viewed as an advanced level of Human Rights where there was responsibility to provide them if there were resources. There was thus a clear distinction between what participants conceptualised as fundamental Human Rights to support needed for survival and wellbeing, and Human Rights to support of secondary importance that were associated with maintaining status and reducing social disadvantage.

Participants also associated the Human Right to support with choice. Participants felt upholding their Human Right to support provided them with opportunity to make their own choices in relation to support (within their objectively prescribed allocation of support). These choices included opportunities to enhance lifestyle, such as the choice of when to eat, the choice of what time to go to bed and choices associated with community, leisure and recreation activities. Participants viewed obtaining and maintaining their allocations of support as the means to gaining these choices, and Human Rights frameworks as the means of gaining this needed support.

All of the challenges made by participants in relation to support allocations utilised Human Rights discourses and on occasion Human Rights instruments. Participants utilised Human Rights discourses to promote and maintain social status, combat discrimination, enhance equity of support and increase inclusiveness. At a day-to-day level, participants were familiar with utilising Human Rights as leverage in seeking to improve conditions and entitlements, to further support allocations and to improve their personal situation in relation to society. Utilising Human Rights to challenge receipt of support was highly normalised by participants who readily identified with Human Rights
as a mechanism for change and as a means of ensuring government and community met their obligations in providing support.

However formal Human Rights challenges in relation to support, where participant’s contacted legal advocacy and statutory authorities to challenge a status quo were less frequent. Only a few participants discussed having formally made a Human Rights claims in seeking to improve support, whether on an individual or systemic level. These formal challenges included utilisation of Human Rights instruments in making a claim though, and included utilisation of statutory authorities, such as the Victorian Equal Opportunity Commission, to provide arbitration and solve claims.

Where support was not able to be achieved utilising Human Rights mechanisms, participants often moved outside of the formal disability service framework to obtain support. As discussed earlier, strategies for obtaining support outside of the disability service framework included sourcing funding for equipment from charity organisations, making do without, privately financing support needed (including funding equipment, house modifications and private vehicle) or increasing dependency on informal support.

Participants did however describe utilising Human Rights informally as a means to challenge support allocations, such as where participants approached the media to campaign for the Human Right to increased allocations of support, or where Human Rights claims were made to government through letters and emails in seeking to improve access to the built environment or public transport.

A small group of participants however viewed Human Rights as less significant, and did not view them as having an impact on support. In these instances, participants described Human Rights as something ‘others’ went on about, as rhetoric and as a concept that did not impact directly on their received allocation of support. This was usually associated with dissatisfaction of prescribed allocations of support, where
participants described their ‘Human Rights’ to support as not being adequately being met and where they were unable to change this situation to due policy parameters. In these instances, Human Rights were viewed as absent, abstract and as not related to daily living. These participants viewed Human Rights as not ‘practical’ or real enough in being able to create change at a day-to-day level, and that they did not have confidence in Human Rights mechanisms to effectively create change or improve things. Human Rights mechanisms for these participants were thus viewed as not impacting on felt levels of justice in relation to support allocations.

One participant had no interest in challenging or claiming a Human Right in relation to their support, despite receiving low levels of formal support and being in need. The participant appeared content to make do with the low amount of support they received, and preferred not to utilise Human Rights or any other basis to challenge their allocation of support. They viewed challenging their support allocation in general as an unpopular action that would not win them any friends. They viewed making a Human Rights claim for support as a ‘a high profile thing to be doing’, and did not wish to be viewed socially as being overtly negative in criticising the current structures associated with their support.

11.10.8 Support and Capabilities Approach

Nussbaum’s Capabilities Approach draws on concepts of positive advantage, social responsibility, reciprocal benefits and interdependencies. It explores fundamental human entitlements and human functioning to ensure human dignity is upheld. The approach seeks to achieve this by improving overall levels of social justice through advancement of individual capabilities. The capabilities of each individual are examined and explored in order for them to achieve their highest capabilities so that in turn they can contribute the maximum to the social good. In addition to advancing human dignity, the approach allows a threshold level of each capability to be measured, with moving this threshold becoming the social goal.
Notably, the Capabilities Approach places a reemphasis on support. In seeking to advance individual capabilities, it is recognised that a base level of support is required for all members of society in order to achieve basic human functioning and in turn, social inclusion, citizenship and advancement. The approach re-emphasises support as a social good and introduces the concept of mutual advantage associated with provision of support.

Although support was recognised by participants as being essential for survival at a base level, and as crucial to obtaining successful social roles and upward social re-positioning, these factors were not understood or conceptualised as the Capabilities Approach. Participants described gaining improved social status and taking on valued social roles, such as relationships, parenting, employment, home ownership, and described improved quality of life, happiness, freedom, fulfilment and empowerment, however these factors were not understood as having been achieved within a Capabilities Approach framework. Instead participants demonstrated that they understood advancements in lifestyle, social positioning and quality of life as having been achieved through utilisation of a Human Rights platform. Participants thus viewed support obtained through Human Rights frameworks as allowing them to be more socially inclusive and able to contribute to society than Capability Approach discourses.

The Capabilities Approach however was demonstrated, although not recognised by participants, in relation to receipt of informal support. The utilisation of mutual interdependence was evident in relation to support received at an informal level. Where support was negotiated at an informal level, mutual interdependence in taking on the support role was evident. In these instances, support was characterised by cooperation and responsibility, with taking on a support role viewed as a social good. Increased emphasis on the importance and value of individual social roles, and awareness of the mutual advantage of this by providing support, was however certainly evident.

**11.11 Platform of support**
In examining a concept of support for people with impairments, the ability of participants to engage in society utilising various forms and attributes of support could be conceptualised as a platform of support. The conceptualisation of a ‘platform of support’ effectively captures the multi-factorial attributes of support required in having acquired a SCI, and incorporates the various elements of support required by individuals at both individual and systemic levels to survive and advance in society following a SCI. Each individual’s platform of support would then be influenced by the intensity and range of these support elements.

An individual’s platform of support would be influenced by a range of factors, such as an individual’s functional capacity, individual agency, their perceived level of need, their ability to be re-employed or return to education, the availability of accessible accommodation and infrastructure, the extent of financial support able to be obtained (particularly from compensation), and the extent to which each participant could utilise informal support. Each support interaction and relationship would influence an individual’s support platform, and would influence the dynamic of each individual platform. The establishment and maintenance of an individual’s support platform would thus require knowledge of forms of support available, capacity to negotiate support and knowledge of the extent of administrative burden in maintaining support.

The aim of a platform of support would be to provide a base level of supports required to maintain relationships, interactions, services and equipment required to maintain the health and wellbeing of a person having acquired a SCI and encourage social advancement. A platform of support would thus identify the diverse levels of support required for survival, wellbeing, and social inclusiveness. A platform of support would aid in identifying where any particular support element was reduced or not available, and the extent to which an individual may be at risk of reduced social inclusion, wellbeing and quality of life because of a missing support element.
As the study findings have shown, a range of supports from a diverse array of areas is required to maintain and advance social inclusiveness and valued social roles of people acquiring a SCI. At an individual level, support is provided through provision of attendant care and informal support to assist with completing personal care and daily living tasks. At a systemic level, support included attitudinal support, financial support, legal support, policy support and/or support received from barrier free physical environments.

Tentatively, a platform for support may also serve to advance exploration of an individual’s capabilities, and advance social engagement as defined by Nussbaum’s capability approach. In seeking to further the uptake of valued social roles by people with impairment and explore individual capabilities, the utilisation of a platform of support for people with impairment could act as a basis from which standard support requirements are met so that greater capabilities can be explored to further improve an individual’s social status and levels of inclusion. A platform of support would serve to promote exploration of individual capabilities, increased social engagement, uptake of valued social roles enhanced identity and improved capacity to contribute to community. To this extent, a platform of support would work in with emerging conceptual frameworks of Nussbaum’s capabilities approach in seeking to advance individual capabilities in achieving desired life goals and improved lifestyle. Construction of a theoretical platform of support, incorporating differing elements, attributes and forms of supports, would advance choice of lifestyle, valued social roles, flexibility and capability of people with impairment.

11.12 Conclusion

The experiences of people with impairment in Victoria receiving formal support from within the service and compensation frameworks provided opportunity for people with impairment to engage with society and obtain increased levels of social inclusiveness.
The receipt of support in its various forms did serve to reposition the place of participants within society, increasing social inclusion, quality of life and wellbeing. Participants utilised the various support structures drew on varying forms of support in order to ensure survival, social inclusion and wellbeing.

Participants readily understood a construct of support and were able to identify and express where they were and were not supported, and were able to draw a metaphoric line in the sand between where they felt supported and not supported - based on their assessment of their individual experiences of receiving and utilising support mechanisms and knowledge of support received by others.

The receipt and utilisation of all forms of support required an interaction. The utilisation of formal services and receipt of support through compensation thus involved an array of interactions governed by varying guidelines, limitations, restrictions and parameters. The conceptualisation of support was thus highly unique to each participant. Certainly work-relationships influenced how support was provided, how participants felt about receiving and managing their support on a day-to-day level and expectations in receiving support. Allocation of support available through the service framework, based on how the SCI was acquired, strongly influenced how supported each participant felt, and despite significant levels of inequity in distribution and issues of dependency that emerged around ongoing payments, the receipt of compensation provided significant financial support and financial resources to increase flexibility and lifestyle choice associated with acquiring a SCI for those eligible to receive it.

The receipt and utilisation of a platform of support readily mapped these variations and created opportunity to monitor individual levels of support around these existing service and compensation frameworks. A platform of support thus provided the mechanism to better support individuals, improve navigation of these frameworks and work towards advancing the capabilities and social advancement of individuals with SCI. A support
platform allows you to ask– what levels and forms of support, in particular from services and compensation, are required by individuals with a SCI to maintain wellbeing, quality of life and wellbeing?

How support is conceptualised and the manner in which support has been provided by society have certainly altered since the mid 1980s. Certainly what was viewed as a reasonable provision of formal support allocation required by participants to be inclusive and socially engaged has shifted in recent years. Provision of formal support now seeks to advance the social positioning of people with impairment to one of inclusion and advancement, despite marked inequity within service and compensation frameworks. The conceptualisation of support is thus broad. Each allocation of support received, each degree of informal support available, availability of compensation and amounts of legal and financial support all served to create a unique experience of support.

When we ask what we mean by support, we are thus examining the extent to which each individual with a SCI is held-up and aided by state-funded service and compensation structures, informal support and the wider community itself in working to achieve our communities goals of social integration and the advancement in capabilities of all people with impairment.
Epilogue

As an epilogue to this research, awareness of the significant fragmentation and shortfall in resources related to receipt of disability services in Victoria and in Australia, as evident in a significant amount of the study’s data, has led to the instigation of reform in the disability services landscape in recent years. Reports such as the ‘Shut Out: the experience of people with a disability and their families in Australia’, produced by the National People with Disabilities and Carer Council as a part of the Federal Government’s National Disability Strategy Consultations gave voice to the experiences of Australians with disabilities and disability service utilisation. Consultations related to the report included 750 written submissions and 2500 attending the public forums in each capital state. The report identified a significantly large proportion of people felt disability services were actually a barrier to social inclusion and participation, rather than a facilitator, and that the disability service system was characterised as ‘broken and broke, chronically under-funded, under-resourced, crises driven and struggling against a vast tide of unmet need’ (National People with Disabilities and Carer Council 2009:6). The report was thus successful in highlighting funding shortfall and genuine hardship for many people in Australia with impairment and amongst its recommendations supported a nationalisation of the disability service framework. As per the National Disability Strategy, the Shut Out report recommended the creation of a national Office of Disability, the alignment of Australian disability policy with the CRPD and Human Rights frameworks, development of clear, national performance and outcome measures and increases in advocacy and ngo funding to improve evaluation and monitoring strategies (National People with Disabilities and Carer Council 2009:61).

As a result of the Shut Out report, the Federal Government announced two major responses. Firstly, the 2010 Federal budget included a substantial funding increase (A $5billion over 5 years) for disability services as a part of the revised National Disability
Agreement. This was aimed at immediately addressing shortfall in funding for disability services.

Secondly, the Federal Government commissioned the Productivity Commission, Australia’s chief independent research and advisory body on economic, social and environmental matters pertaining to the welfare of Australians, to complete a public inquiry on Disability Care and Support in Australia. Its brief was to examine the feasibility of a National Disability Long-term Care and Support Scheme and assess the cost-effectiveness and feasibility of such a scheme and if it would provide the best solutions to meet the long-term care and support of all Australians with a disability. The brief included examining alternative and better approaches to funding and delivery of disability services for Government, examining international models of funding support for people with disabilities, what safeguards and protections should be a part of the scheme, inclusion criteria, the feasibility of individualised disability funding approaches, interactions with health/aged care/informal care/income support and examining social insurance models of funding disability services (Productivity Commission 2011).

The Productivity Commission began the public inquiry in April 2010. In total, 1062 submissions were received by the Productivity Commission with the Productivity Commission conducting 23 public hearings. On 10 August 2011, the Productivity Commission released its report on Disability Care and Support in Australia. The main recommendations from the Productivity Commission public inquiry were that the Australian Government should oversee the establishment of a National Disability Insurance Scheme (NDIS) and National Injury Insurance Scheme (NIIS). These schemes would provide insurance cover for all Australians in the event of significant disability, and include funding for long-term, high quality care and support (but not income replacement) for the approximately 450000 Australians currently living with impairment in need of support. These schemes would also aim to:
• cost-effectively minimise the impacts of disability, maximise the social and economic participation of people with a disability, create community awareness of the issues that affect people with disabilities and facilitate community capacity building targeted at all Australians
• provide information and referral services, which should be targeted at people with, or affected by, a disability
• provide individually tailored, taxpayer-funded support, targeted at people with significant disabilities who are assessed as needing such support (Productivity Commission 2011: 63-90)

On 30 April 2012, the Federal Government announced it would move a year ahead of the Productivity Commission’s recommendations to implement an NDIS beginning in 2014, and invested an additional A$1 billion dollars over 4 years into the Federal disability services budget to support the implementation of the NDIS in 4 trial areas beginning 1 July 2013.
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Appendices

Appendix A

What is a Spinal Cord Injury (SCI)?

SCI is the result of some form of damage to the spinal cord. Depending on the severity of the injury to the spinal cord, an injury can cause loss of function to correlating areas of the neurological system and paralysis of function of the nerves, limbs and organs below the site of the injury. Trauma related SCIs can occur through car or bike accidents, falls, workplace accidents, diving, medical trauma (cyst, cancer on spinal column), shootings, being struck by an object/person or sport/recreation injuries.

Functional classifications of SCI: Quadriplegia and Paraplegia

Quadriplegia affects movement to varying degrees in the arms, shoulders, head and neck along with breathing, bladder and bowel function, sexual function and temperature regulation. There is usually full paralysis below the chest line (i.e. no leg function and inability to weight bare) and in the hands.

Complications can include skin integrity/pressure sores, muscle spasm, various levels of pain above the injury level, high risk of infections, reduced lung capacity, sexual dysfunction, and issues associated with permanent catheterisation and bowel care.

High level quadriplegic:
C1 - C3 possibly ventilator dependent, full body paralysis excepting head/shoulders
C3 – C4 reduced lung capacity, paralysis of body including trunk and lower arms, some upper arm function

Low level quadriplegic:
C5 – C7 paralysis of body including trunk. some hand function

Paraplegia affects movement to varying degrees in the lower abdominal region, legs, bladder and bowel. Complications include skin integrity, muscle spasm and various levels of chronic pain above the injury level but to a lesser degree, and to a lesser extent, sexual dysfunction, and bladder and bowel care complications.

High level paraplegic:
T1 – T10 paralysis of some of trunk and leg function, full arm and hand function

Low level paraplegic
T11 – L5/S paralysis of some leg function, full arm and hand function

A further specific classification refers to the specific level of injury to the spinal column, e.g. the fifth cervical vertebrae – C5, the fourth thoracic vertebrae – T4. Of most significance to SCI, is the occurrence of injury on the spinal column. The higher up the spinal column an injury occurs, the greater the level of injury sustained will be, and subsequently, the greater the need for assistance and provision of support services on a day-to-day level.

Other classifications of SCI include complete or incomplete injury. A complete injury to the spinal cord is defined by total paralysis below the level of injury. An incomplete injury means that only partial paralysis has occurred below the level of injury and partial sensation or functional capacity is retained.
Incidence of SCI in Australia and Victoria

Each year in Australia, about 300–400 new cases of SCI from traumatic and non-traumatic causes are added to an estimated prevalent SCI population of about 9,000 (Walsh et al. 2005; Cripps, 2006). Approximately 300 Spinal Cord Injuries (SCI’s) occur each year across Australia, with approximately 50-60 spinal cord injuries occurring within Victoria each year. Just over half of those sustaining a SCI will be injured to an extent where lifetime care will be required. (AIHW 2002, 2003, 2004; Walsh, et al, 2005).

AIHW data has shown that 61% of catastrophic injuries in Australia come under the motor vehicle scheme, 13% are part of workers’ compensation, 11% are due to medical negligence, and 15% fall under public liability (Dabrsch 2005).
Appendix B

Nussbaum’s Capabilities Approach list

- Life - Being able to live to the end of a human life of normal length
- Bodily health - Being able to have good health; to be adequately nourished; to have adequate shelter
- Bodily integrity - Being able to avoid unnecessary and non-beneficial pain, so far as possible, and to have pleasurable experiences
- Senses, imagination and thought - Being able to use the senses; being able to imagine, to think, and to reason—and to do these things in a way informed and cultivated by an adequate education, and including freedom of expression with respect to both political and artistic speech, and of freedom of religious exercise
- Emotions - Being able to have attachments to things and persons outside ourselves; to love those who love and care for us, to grieve at their absence; supporting forms of human association crucial for development
- Practical reason - Being able to form a conception of the good and to engage in critical reflection about the planning of one's own life; being able to seek employment and participate in political life
- Affiliation - Being able to live for and with others, to recognize and show concern for other human beings, to engage in various forms of social interaction, compassion, justice and friendship.
- Concern for other species - Being able to live with and have concern for animals, plants and the world of nature
- Play - Being able to laugh, to play, to enjoy recreational activities
- Control over one’s environment
- Political - Being able to live one’s own life and nobody else’s; having certain guarantees of non-interference in relation to identification of selfhood, including political allegiance, marriage, childbearing, sexual expression, speech, and employment;
Material - Being able to live one's own life in one's own surroundings and context, including freedom of association and integrity of personal property (Nussbaum and Glover 1995:83; Nussbaum 2003a; Nussbaum 2003b; Nussbaum 2006:78)
Appendix C

Participant Plain Language Statement (PLS) and Consent Form (CF)

THE UNIVERSITY OF MELBOURNE

SCHOOL OF POPULATION HEALTH

PROJECT TITLE: Rights, Compensation and Disability Service Delivery in Victoria

Plain Language Statement for Study Participants

What is a Plain Language Statement (PLS)?
The purpose of a Plain Language Statement (PLS) is to provide you with information about my study, so that you can make a decision about if you would like to participate in the study.

What is this study about?
The study is a PhD study that will explore the experiences of people that are recipients of funded disability support services in Victoria. The study will focus on recipients’ understandings of rights and the impact of compensation in relation to the receipt of these funded support services. The study will specifically target adults with a permanent impairment of spinal cord injury who utilize ongoing funded disability support services.

Tell me more about the researcher
My name is Raelene West. I am a PhD student at the School of Population Health at the University of Melbourne. This study is being conducted by the School of Population Health and is funded by a Department of Human Services Disability Scholarship. My Supervisors for the study are Dr Alison Brookes and Dr Kathleen Brasher. The study has been approved by the Human Research Ethics Committee of the University of Melbourne (no. 060541).

I also have a spinal cord injury myself. I have received a compensation settlement and receive ongoing funded disability support services through the Transport Accident Commission (TAC).

Who else is taking part in the study?
I hope that 20 - 30 people with permanent impairments of spinal cord injury will take part in the project. They will come from all over the State.

What would my involvement in the study be?
If you agree to take part in the study, I will set up a time to conduct a face-to-face interview with you at a place that you choose (including negotiated regional sites). First, I will check that you understand what the study is about and obtain your consent to take part. The interview will then take one to two hours, with rest breaks as required. During the interview, I will ask you questions about your ideas and experiences related to receiving support services, compensation and rights. So that I can accurately recall your
ideas, I hope that you will agree to allow the audio-recording of the interview, which I will later transcribe as a computer document. If you do not wish to have the interview audio-recorded, you can still participate in the study and I will take written notes during the interview. I will bring an assistant to the interview, and you are very welcome to do the same.

Some months after the interview, I will conduct a series of group discussions to check my findings and interpretations. At the end of the interview, I will ask you whether you would like to be part of one of the group discussions. If you agree and if required, group discussions will involve a small group of people, say 6 to 8, and will involve further discussion on the topic areas. Group discussions will take one to two hours again with a rest breaks as required. Group discussions will be held at either the University of Melbourne premises or at a central regional location to be decided. The group discussions will be audio-recorded so that I can accurately record your ideas and thoughts. Participants must consent to audio-recording to be included in the group discussions.

A transcript of the interview, and the group discussions if undertaken, will be sent to you to authenticate and verify the content of your contribution before inclusion in the study.

How will my privacy be protected?
Every effort will be made to assure your anonymity and protect your privacy associated with the study. A pseudonym will be used for you (or for anyone else mentioned) in the study report or any publication. Any references to personal information that might allow someone to guess your identity will be removed from the study report prior to any publication. All information you provide will be stored in a password protected computer. Only principal researchers and a small number of research assistants (2-3) will have access to this information. Back-up data will be stored as per University of Melbourne storage protocols.

On completion of the study, all data obtained from the study will be stored at the University of Melbourne for a minimum of five years from the date of the final thesis publication again in accordance with University of Melbourne storage protocols. After 5 years a decision will be made as to whether the data will be retained for use in future studies.

All information provided in the study is subject to Guidelines under Section 95 of the Privacy Act produced by the National Health & Medical Research Council (NHMRC). All information provided in the study however will be subject to legal transparency requirements and freedom of information legislation if required.

What will happen if I agree to take part?
I will contact you by phone or email a few days after you receive this Plain Language Statement (PLS) to discuss your involvement in the study. If suitable, a time and place for an interview will then be arranged.

Are there any risks to me?
Given the topic of the study, and that as a requirement of participation in the study you have undergone a major medical trauma and life readjustment as a result of a spinal cord injury, there is a risk participation in the study may cause you mild distress.

If you decide to take part in the study and any topic during the interview or group discussions causes you distress, I would encourage you not to continue. You can refuse to answer any question in the interview or stop the interview at any time. You may refuse to respond or participate in any particular topic of discussion during group discussions or take leave from the group discussions at any time. In the instance of any distress, discussion associated with the cause of the distress will be undertaken with the researcher. A support contact list containing relevant support referrals will also be
provided. You are be encouraged to make contact with the relevant support group if required. Assistance will be given in making contact with the relevant support groups if required. Support in most instances is no or low cost.

In addition, if any physical discomfort is experienced during participation in the interview, such as fatigue, difficulties with temperature regulation or medical complications, you are again encouraged to suspend the interview or take leave from the group discussions until the discomfort is attended to.

Also, it is necessary to highlight that participation or non participation in the study will not place at risk, effect or influence your current levels or access to funded disability support services in any way.

**What if I decide not to take part?**
Your participation in either an interview or a group discussion is entirely voluntary. You can decide not to take part in the study, or can withdraw from the study at any point. You may ask to have any data that remains unprocessed withdrawn from the study at any time.

Again, participation or non participation in the study will not place at risk, effect or influence your current levels or access to funded disability support services in any way.

**How do I find out more about the project?**
Approval for this study has been granted by the Human Research Ethics Committee (HREC) of the University of Melbourne. If you would like any further information about the study or have any concerns about this study, you can email me at r.west4@pgrad.unimelb.edu.au. You can also contact my Principal Supervisor Dr Alison Brookes at the School of Population Health on (ph) 03 8344 0826. In addition, you may also contact the Executive Officer of the Human Research Ethics Committee of the University of Melbourne on (ph) 03 8344 2073 or (fax) 9347 6739.

If you would like to participate in the study, please indicate that you have read and understood this information by signing the accompanying consent form.

Thank you in advance for your consideration of this study.

*HREC 060541 August 2006 Version 2*
Participant Consent Form

Name of participant:
Name of researcher: Raelene West

1. I consent to participate in the study named above, the particulars of which include participation in an interview. The details of my participation in the interview have been explained to me and a written copy of the information about these methods has been given to me to keep.

2. I understand the interview is a component of a study on the experience of receiving funded disability support services for adults with a permanent impairment of spinal cord injury in Victoria.

I am aware that the study is being conducted as a PhD study through the School of Population Health at the University of Melbourne. I understand that a funding grant has been obtained from the Department of Human Services to carry out this study.

4. I understand that approval for this study has been granted by the Human Research Ethics Committee (HREC) of the University of Melbourne and that concerns about this study should be directed to the Principal Supervisor of this study, Dr Alison Brookes at the School of Population Health on (ph) 03 8344 9350. I understand that I may also contact the Executive Officer of the Human Research Ethics Committee of the University of Melbourne on (ph) 03 8344 2073 or (fax) 9347 6739.

5. The researcher has declared to me her position as someone with a spinal cord injury themselves and who is a recipient of compensation and funded disability support services through the Transport Accident Commission (TAC).

6. I acknowledge that:
(a) the possible effects of participating in interviews such as distress and fatigue have been explained to me to my satisfaction;
(b) I have been informed that I am free to withdraw from the study at any time without explanation or prejudice and to withdraw any unprocessed data previously supplied;
(c) the project is for the purpose of research

I have been informed that the confidentiality of the information I provide will be safeguarded subject to any legal requirements.

I consent to interviews being audio-recorded (or if I choose not to have interviews audio-recorded, that written notes will be taken throughout the interview) I acknowledge that a copy of the transcript from the interview will be returned to me for verification before being included in the study. I understand all efforts will be made to ensure confidentiality, and that pseudonyms will be used to protect and limit my identification in
any publication. I understand that participation in the study will in no way place at risk, alter or effect my current level of, or access to current funded disability services.

Signature __________ Date _______
(Participant)

Name:
Phone:

This form will be retained by the researcher.

*(Quadriplegics unable to physically sign this consent form, may give verbal consent to participation in the study by audio recording their verbal consent once the consent form has been read out aloud by the researcher).

*HREC 060541 August 2006 Version 2
Appendix D

Research Assistant Confidentiality Form

THE UNIVERSITY OF MELBOURNE

SCHOOL OF POPULATION HEALTH

KEY CENTRE FOR WOMEN’S HEALTH IN SOCIETY

PROJECT TITLE: Rights, Compensation and Disability Service Delivery in Victoria

Confidentiality agreement for research assistants assisting with study

Name of research assistant: 
Name of researcher: Raelene West

1. I agree to maintain confidentiality while assisting in the above named project. I understand that information and data involved with the study are to remain private and that all details and information are subjects to protocols of confidentiality.

2. I understand that my role as a research assistant may entail transcription of sensitive information and that, except where subject to legal requirements, that confidentiality and privacy of this information will be maintained.

3. I understand that the PhD study is being conducted through the Key Centre for Women’s Health in Society, School of Population Health at the University of Melbourne. I understand that a funding grant has been obtained from the Department of Human Services to carry out this study.

4. I understand that approval for this study has been granted by the Human Research Ethics Committee (HREC) of the University of Melbourne and that concerns about this study should be directed to the Principal Supervisor of this study, Dr Shelley Mallett on (ph) 03 8344 4333. I understand that I may also contact the Executive Officer of the Human Research Ethics Committee of the University of Melbourne on (ph) 8344 2073 or (fax) 9347 6739.

Signature Date
(Research Assistant)
Name: Phone:

* HREC 060541 August 2006 Version 1
Appendix E

Distress Protocol guidelines

A Distress Protocol was designed to manage potential participant distress if it arises and will operate in the following manner:

During all interviews the researcher will observe for indicators of distress. These indicators may include mood swings, increased physical gestures, tearfulness, anger and/or raising of the voice. If distress by any participant is observed during the interview, the interview will be stopped for a short period of time, and the participant then prompted as to if they wished to continue with the interview. If further distress is observed once the interview is recommenced, the interview will be ceased and a list of contacts containing support group referrals will be given to the participant. It will be suggested that the participant contact these support groups to obtain support and advice. If required, assistance will be given to the participant to make contact with these support groups. This list, the Participant Support Referral List, will include the contacts of SCI counsellors; SCI social workers; funding body case managers/information contact; legal and advocacy support and medical support - Austin Hospital Spinal Clinic.

In the case where the Distress Protocol is invoked, follow-up contact will be made with the participant to allow debriefing and to provide further support if required. Follow-up contact will be made by phone, or if sought by the participant, a follow-up meeting. Follow-up contact will seek to determine if the participant made successful contact with the listed support groups from the Participant Support Referral List and if any successful outcomes were achieved as a result of this contact.

The researcher will also discuss the incident with supervisor to debrief.
Appendix F

Participant Support Referral List

SCI counsellors:
Bridget Bassilios
Justine Diggens
03 9415 1200
psychology@paraquad.asn.au

SCI social workers:
Beth Hogan and The Team
03 9415 1200
theteam@paraquad.asn.au

Contact Information of Funding Bodies:

TAC
Telephone:
1300 654 329
1800 332 556 (toll-free outside the Melbourne metropolitan area)
8:30am to 5:00pm, Monday to Friday
Email:
info@tac.vic.gov.au
Visit:
TAC Customer Service Centre
Level 7 222 Exhibition Street Melbourne
8:30am to 5:00pm, Monday to Friday
Write to:
TAC
GPO Box 2751
Melbourne VIC 3001

VWA
The WorkCover Advisory Service offers:
- detailed recorded information service 24 hours a day covering the most frequently
  asked questions in both Compensation and Occupational health and Safety including the
  option to speak to an advisor during business hours (8.30am to 5pm Monday to Friday).
- answers to general occupational health and safety enquiries explaining return to work
  and rehabilitation rights and obligations
- help to resolve worker and employer concerns that could not be resolved with the
  WorkCover agent
- order and enquires about all VWA and WorkSafe publications

Telephone:
(03) 9641 1444
1800 136 089 (Toll Free)
Email:
info@workcover.vic.gov.au
Write to:
WorkCover Advisory Service
GPO Box 4306
Melbourne VIC 3001

DHS
Telephone:
Disability information and support – Statewide 1800 783 783
Website: www.disability.vic.gov.au
Legal & Advocacy support:
Disability Discrimination Legal Centre
Ross House Association
2nd Floor; 247 Flinders Lane
Melbourne 3000, Vic
Ph: 03 9654 8644
Country Ph: 1300 882 872
Email: info@ddlsl.org.au
Web: www.communitylaw.org.au/ddls

Disability Resource Centre (Inc)
Representing People with a Disability since 1981
266 Johnston St, Abbotsford, Vic, 3067
Ph: 03 9417 3211
Abbotsford Office Hours: 11am-5pm, Mon., Tue., Thu., Fri. (closed Wednesday).
Email: drcinc@connexus.net.au
The DRC also has an advocate serving the South-East Metropolitan region:
DRC South East Metro Office,
Level 1, 229 Thomas St,
Dandenong VIC 3175
Ph: 8792 2218
Hours: 9:30am - 4:30pm, Mon., Tue., Wed.
*researcher a previous DRC committee member

Medical support - Austin Hospital Outpatients Spinal Clinic:
Austin Health
Austin Hospital Outpatients Spinal Clinic
145 Studley Road
Heidelberg Vic 3084 03 9496 5000
Appendix G

In depth Interview Guide Version 1
General greetings/ casual conversation/ thank you for participating
Set up equipment
Explanation of study/ interview as data collection process
Signing of consent form

1. As a participant in this study, you will have sustained a Spinal Cord Injury (SCI) and permanent physical impairment. Firstly could you tell me ’where your life was at’ before the spinal injury?

2. And then briefly, how did the SCI occur?
prompts:
-when
-where
-how
-why (?)

3. What happened then?
prompts:
-rehabilitation
-family support
-employment
-transitions

4. How did you feel about this process?
probe:
-why?
-what aspects?

5. Looking back now, is that what you would expect of a spinal rehabilitation process?
prompts:
-observable inequities
-adequate services
-role of govt in providing rehab
-entitlement to rehab process

6. How would you describe your current situation?
prompts:
-support
-employment
-lifestyle
-social activities
-living arrangements/accommodation
-mobility

7. What has changed the most?
prompts:
-how?
-why not?
-physical changes
-non-physical changes
-social changes
For TAC/VWA
8. You have told me that you receive funding under the [TAC/VWA], can you tell me about the compensatory process?
   probe:
   - process
   - court case / attendance in court
   - length
   - outcome

9. How did that process feel?
   probe:
   - satisfactory?
   - emotional response (anger, frustration, boredom, confusion, relief)

10. Do you think you received all that you were entitled to?
    prompt:
    - why/why not?

11. How do you think your life would be different if you didn’t had received any compensation?
    prompts:
    - social status
    - financial status
    - flexibility
    - security

12. How has that compensation been utilised at an everyday level?
    prompts:
    - investments
    - income
    - housing
    - holidays

For DHS
8. You have told me that you receive services from DHS. To clarify, that means that you did not receive compensation?
   - [should be no]

Why did you think that was?
prompts:
- DHS system
- system
- knowledge of compensation system

9. How do you feel about that?
   probe:
   - equity

10. How do you think your life would be different if you had received compensation?
    prompts:
    - financial
    - social
    - living arrangements
    - status

[ALL]
13. Turning now to funded services, what services did you use last week (Mon-Sun)
    prompts:
    - attendant care
    - home help-cleaning, gardening
14. What is involved on a weekly basis in making them all work?
probe:
-telephone calls
-emails
-admin
-legal
-liaise with agencies
-liaise with coordinators
-liaise with funding body

15. What percentage of your week is taken up with these services and then what percentage of the week was taken up in organising these services?

16. How did you feel about that?

17. Do you feel these services are adequate for you?
prompt: why/why not?

18. Do you feel that you receive all of the services that you are entitled to?
Yes/No
[Yes]
In what way?

[NO]
what do you think prevents you from receiving all of the services you are entitled to?
prompts:
-knowledge of services available
-attitude of provider
-attitude of individual in sourcing services
-system
-rights to services
-equity in entitlements
-funding parameters

19. Do you view any aspects of the service delivery as problematic?
prompts:
-hours
-funding arrangements
-times
-flexibility
-staff
-privacy
-inconsistencies
-gaps
-service agencies
-coordination

20. What would be your ideal situation in terms of service delivery?
21. What do you believe is the role of the state in providing disability service delivery?

22. Turning to rights, firstly can you explain to me your understanding of a right? Can you give me an example?
23. Do you feel your rights are met in terms of the funded services you receive?
   prompts:
   - equity
   - benefits
   - possession / ownership of a right

24. Is there any aspect of state service delivery where you feel your rights are not met?
   prompts:
   - hours
   - choice
   - flexibility
   - quality

25. Are there any additional comments you would like to add?

Conclusion
what have you learnt most?
what are you doing the best in relation to managing SCI?

PARTICIPANT REFERRAL LIST
Thank yous for sharing time, knowledge and personal experiences.

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In-depth Interview Guide Version 2
General greetings/ introduce assistant – check location, thank you for participating,
Physical area ok – temperature, fluids, toileting etc
Set up equipment (has agreed to be audio recorded)
Explanation of study/ interview as data collection process/ *Legal transparency – see PLS/ *questions from PLS
Signing of consent form

Quick Stat questions:
Age
Level of injury
Place of residence
Employment status
Relationship status
Funding

General Questions
Pre SCI life role – Acquirement of SCI
1. As a participant in this study, you will have sustained a Spinal Cord Injury (SCI)
   Firstly could you tell me ‘where your life was at’ before the spinal injury?

2. And then briefly, how did the SCI occur?
   prompts:
   -when
   -where
   -how
   -why (?)

3. What happened then?
   prompts:
   -rehabilitation
4. How did you feel about this process?
probe:
-why?
-what aspects?

5. Looking back now, is that what you would expect of a spinal rehabilitation process?
prompts:
-observable inequities
-you v others there?
-adequate services/ differences in services
-role of govt in providing rehab

**Transition Phases**
-employment
-housing
-attendant care
-equipment

**Current Situation**
6. How would you describe your current situation?
prompts:
-support
-employment
-lifestyle
-social activities
-living arrangements/accommodation
-mobility

7. What has changed the most?
prompts:
-how?
-why not?
-physical changes
-non-physical changes
-social changes

*time

**Compensation**
8. What do you understand as compensation?

For TAC/VWA/PUBLIC LIABILITY
9. You have told me that you receive funding under the [TAC/VWA], can you tell me about the compensatory process?
probe:
-process
-court case / attendance in court
-length
-outcome
10. How did that process feel?
probe:
-satisfactory?
-emotional response (anger, frustration, boredom, confusion, relief)

11. Do you think you received all that you were entitled to?
prompt:
-why/why not?
12. How do you think your life would be different if you hadn’t received any compensation?
   prompts:
   - social status
   - financial status
   - flexibility
   - security

13. How has that compensation been utilised at an everyday level?
   prompts:
   - investments
   - income
   - housing
   - holidays

For DHS
9. You have told me that you receive services from DHS. To clarify, that means that you did not receive compensation?  
   - [should be no]
   Why did you think that was?
   prompts:
   - DHS system
   - system
   - knowledge of compensation system

10. How do you feel about that?
    probe:
    - equity

11. Hypothetical - How do you think your life would be different if you had received compensation?
    prompts:
    - financial
    - social
    - living arrangements
    - status

**Service usage now**
14. Turning now to funded services, what services did you use last week (Mon-Sun)?
    prompts:
    - attendant care
    - home help-cleaning, gardening
    - community access programs
    - physios, osteopathy, chiropractors
    - medical
    - district nursing
    - specialists
    - employment programs
    - aids and equipment
    - HACC
    - respite

**Administration**
15. What is involved on a weekly basis in making them all work?
    probe:
    - telephone calls
    - emails
    - admin
    - legal
    - liaise with agencies
-liaise with coordinators
- liaise with funding body

15. What percentage of your week is taken up with organising your services?

16. How did you feel about that?

17. Turnover Of Staff?
18. Turnover Of Agencies?
19. Recruitment?

20. Do you feel these services are adequate for you?
   prompt:
   why/why not?

21. Do you feel that you receive all of the services that you are entitled to?
   Yes/No
   [Yes]
   In what way?
   [NO]
   what do you think prevents you from receiving all of the services you are entitled to?
   prompts:
   - knowledge of services available
   - attitude of provider
   - attitude of individual in sourcing services
   - system
   - rights to services
   - equity in entitlements
   - funding parameters

22. Do you view any aspects of the service delivery as problematic?
   prompts:
   - hours
   - funding arrangements
   - times
   - flexibility
   - staff
   - privacy
   - inconsistencies
   - gaps
   - service agencies
   - coordination

   What is good care?
   What is bad care?
   What are ads support services?
   What are disads of receiving support services?
   Are there any restrictions? What does it allow?

   Can you tell me about your review process? What happens there?

23. What would be your ideal situation in terms of service delivery?
What do you view as your future need for support services?

24. What do you believe is the role of the state in providing disability service delivery?

**Rights**
25. Turning to rights, firstly can you explain to me your understanding of a right? Can you give me an example? What words do you associate with rights?

26. Do you feel your rights are met in terms of the funded services you receive? prompts:
- equity
- benefits
- possession / ownership of a right

27. Is there any aspect of state service delivery where you feel your rights are not meet? prompts:
- hours
- choice
- flexibility
- quality

28. Are there any additional comments you would like to add?

**Conclusion**

what have you learnt most?
what are you doing the best in relation to managing SCI?

*transcript of interview to be provided for you to check

PROVIDE SUPPORT REFERRAL LIST
Thank yous for sharing time, knowledge and personal experiences.

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**In-depth Interview Guide Version 3**

General greetings/ introduce assistant – check location, thank you for participating,
Physical area ok – temperature, fluids, toileting etc
Set up equipment (has agreed to be audio recorded)
Explanation of study/ interview as data collection process/legal transparency – any questions from PLS?
Signing of consent form

**Quick Stat questions:**

Age
Level of injury
Place of residence
Employment status
Relationship status
Funding

**General Questions**

**Pre SCI life role – Acquirement of SCI**

1. As a participant in this study, you will have sustained a Spinal Cord Injury (SCI) firstly could you tell me ‘where your life was at’ before the spinal injury?

2. And then briefly, how did the SCI occur? prompts:
- when
- where
- how
- why (?)

3. What happened then?
prompts:
- rehabilitation
- family support

4. How did you feel about this process?
probe:
- why?
- what aspects?

5. Looking back now, is that what you would expect of a spinal rehabilitation process?
prompts:
- observable inequities
- you v others there?
- adequate services/differences in services?
- role of govt in providing rehab
- entitlement to rehab process

**Transition Phases:**
- employment
- housing
- attendant care
- equipment

**Current Situation**
6. How would you describe your current situation?
prompts:
- support
- employment
- lifestyle
- social activities
- living arrangements/accommodation
- mobility

**Service usage**
7. In terms of support services, what services did you use in the last week (Mon-Sun)?
prompts:
- attendant care
- home help-cleaning, gardening
- community access programs
- physios, osteopathy, chiropractors
- medical
- district nursing
- specialists
- employment programs
- aids and equipment
- HACC
- respite

**Administration**
8. What is involved on a weekly basis in organising the use of these support services?
(time/ percentage of your week?)
Probe:
- telephone calls
- emails
- admin
- legal
- liaise with agencies
- liaise with coordinators
- liaise with funding body
9. How did you feel about that?

**Adequacy/ Satisfaction**

10. Do you feel these support services are adequate for you?
    prompt:
    why/why not?

11. Do you feel that you receive all of the services that you are entitled to?
    Yes/No
    [Yes]
    In what way?

    [NO]
    what do you think prevents you from receiving all of the services you are entitled to?
    prompts:
    -knowledge of services available
    -attitude of provider
    -attitude of individual in sourcing services
    -system
    -rights to services
    -equity in entitlements
    -funding parameters

12. Do you view any aspects of the service delivery as problematic?
    prompts:
    -hours
    -funding arrangements
    -times
    -flexibility
    -staff
    -privacy
    -inconsistencies
    -gaps
    -service agencies
    -coordination

**Work Relationship with carers / agency / funders**

13. What is good care then?

14. What is bad care?

15. What are the advantages of utilising support services?

16. What are the disadvantages of utilising support services?

17. Are there any restrictions to utilising support services? What does it allow?

18. Can you tell me about your review process? What happens there?

19. In terms of staff, how would you rate frequency of staff turnover?

20. In terms of agencies, how would you describe your work-relationship with your agency?
    Prompt:
    -turnover of agencies?
    -recruitment process?

21. In terms of funders, how would you describe your work-relationship with them?
**Broad**

22. Hypothetical - What would be your ideal situation in terms of receipt of support services?

23. What do you believe is the role of the state in providing disability service delivery?  
Probe:  
- general concepts of need  
- entitlement  
- benefits

**COMPENSATION**

24. What do you understand as compensation? as a concept

Receipt of compensation (TAC/VWA/PUBLIC LIABILITY):

25. You have told me that you receive funding under the [TAC/VWA] and received a compensation payout, can you tell me about the compensatory process?  
probe:  
- process  
- court case / attendance in court  
- length  
- outcome

26. How did that process feel?  
probe:  
- satisfactory?  
- emotional response (anger, frustration, boredom, confusion, relief)

27. Do you think you received all that you were entitled to?  
Prompt:  
- why/why not?

28. How has that compensation been utilised at an everyday level?  
Prompts:  
- investments  
- income  
- housing  
- holidays  
- life goals

29. Did you feel compensation was an adequate means of redress for your injury?  

30. Hypothetical - How do you think your life would be different if you hadn’t received any compensation?  
Prompts:  
- social status  
- financial status  
- flexibility  
- security

31. How do you feel about other people with SCI that did not receive any compensation?  

*Non – receipt of compensation (DHS):*

25. You have told me that you receive services from DHS. To clarify, that means that you did not receive compensation?  
- [should be no]  

Why did you think that was?  
Prompts:  
- DHS system
26. How do you feel about that?
probe:
-equity

27. Hypothetical - How do you think your life would be different if you had received compensation?
prompts:
-financial
-social
-living arrangements
-status

**Rights**
32. Turning to rights, firstly, what words do you associate with rights?

33. Can you give me an example?

34. Can you explain to me your understanding of a right?

35. Is there an area you feel where others rights are not met? From tv or your own knowledge?

36. Is there an area you feel where your rights are not met?

37. Do you feel your rights are met in terms of the funded support services you receive?
prompts:
-equity
-benefits
-hours
-choice
-flexibility
-quality

38. What pathways do you know of to address if your rights are not met?

39. What is your knowledge of rights legal instruments? such as Charters or Conventions?
prompts:
-knowledge of specific instruments
-how they may work
-how they came about
-what they seek to achieve at a local level
-parameters

40. Additional comments you would like to add?

**Conclusion**
what have you learnt most since acquiring your SCI?
what are you doing the best in relation to managing SCI ?
*transcript of interview to be provided for you to check

THANK YOU FOR SHARING TIME, KNOWLEDGE AND PERSONAL EXPERIENCES.
Appendix H

Recruitment Flyer

**Do you have a Spinal Cord Injury and use disability support services such as attendant care?**

*Are you 21-64 years of age?*

*Are your rights to support services being met?*

Tell me more!

Very little is known about the experience of living with a Spinal Cord Injury (SCI) and receiving disability support services such as attendant care, home cleaning, home gardening, etc. How does access to these support services impact on the day-to-day experiences of living with a SCI? And further, what does having a right to receive these services actually mean for someone with a SCI?

A new study, conducted by University of Melbourne PhD student Raedene West, is seeking volunteers with Spinal Cord Injury (SCI) to conduct one-off interviews to discuss these experiences and understandings.

Your interview will:

- provide a voice to people with a SCI on the experience of living with a SCI on a day-to-day basis
- provide understanding of the impact of disability support services on individuals with a SCI
- assist with learning and understanding the concept of rights in relation to funded support services
- contribute to ongoing development of policy and practice of disability support services in Victoria

Who to Contact?

If you would like more information about the study OR would like to take part in the study and have your say, here is your chance.

Email Raedene on: raedene_west4@yahoo.com.au

I look forward to hearing from you.
Author/s: WEST, RAELENE

Title: What do we mean by support? The receipt of disability services and compensation for people with a Spinal Cord Injury (SCI) in Victoria

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