"YOU'RE PRETENDING, YOU DON'T NEED A WHEELCHAIR":
CHILDREN AND ADOLESCENTS WITH SPINAL CORD INJURY

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ABSTRACT

This thesis examines the requirements of children and adolescents with severe spinal cord injuries. The requirements are expressed by the parents of the children and by adolescents and are in contrast to official views of their "needs".

There is no literature on the needs of these children and adolescents. The thesis thus begins with a examination of the literature on the needs of people with disabilities and people with spinal cord injury. Proponents of the social model of disability, which is based on the experiences of people with disabilities, contend that the main requirements of people with disabilities is ending their social marginalisation, and it is hypothesised that the requirements of the children and adolescents will be related to ending social marginalisation.

Open-ended unstructured interviews with parents, parents and adolescents and adolescents alone (a total of 20 interviews) provided data for analysis. Analysis of the data shows that the requirements of the children and adolescents, like adults with spinal cord injuries, differ from those of people with disabilities in that there are important concerns in addition to marginalisation.
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PART ONE
1 INTRODUCTION

This thesis examines the requirements of children and adolescents (people under 20 years of age) resident in New South Wales (NSW) and who have sustained a severe spinal cord injury. This is a small group and little is information is available on their experiences or on the helpfulness of responses to their injury.

The spinal cord is a complex part of the nervous system in which brain cells connect to cells in the cord, which in turn connect to sensory receptors and to muscle fibres. The term "complete" injury refers to the fact there is loss of all movement and sensation below the level of injury; an "incomplete" injury means some of the nervous pathways are spared so that there may be some sensation or muscle movement below the site of injury (Dickson, Martens, Dever and Tonkin, 1993).

The causes of spinal cord injury are both traumatic and non-traumatic. Traumatic causes are related to local social factors. For example, a major cause of spinal cord injury in South Africa has been violence and repression which has operated in that country especially in the African community (Cock, 1989) and in the United States of America, gunshot wounds have overtaken motor vehicle accidents as a cause (Dreher, 1996; BackLetter, 1995). In Australia, 43 per cent of traumatically caused spinal cord injuries in people over 14 years of age in 1998/99 were transport related, 31 per cent were from falls (Australian Injury Prevention Bulletin, 2000). Data comparisons between Australia and European countries (Germany, Switzerland, Austria and the Rhone-Alps region of France) in 1987 indicated that Australia had approximately twice the percentage of spinal cord injuries caused by road traffic accidents than the European countries (Australian Injury Prevention Bulletin, 2000).
Data on non-traumatic causes of spinal cord injuries such as tumours indicate this may be as high as 23% of all injuries recorded in a year (Quadcare, 1991).

The number of children and adolescents who experience severe spinal cord injury each year in NSW is uncertain. Data on adult numbers are collected from Spinal Units in major teaching hospitals; children may be treated in these Units but are usually treated in paediatric hospitals who do not contribute to the spinal cord injuries statistics collection (Australian Injury Prevention Bulletin, 2000). Information from the Motor Accidents Authority indicates that 49 claims involving paraplegia or quadriplegia for people under 19 years have been coded by compulsory third party compensation (CTP) insurers in NSW between July 1989 and June 1999 (MAA, 1999). This number may be regarded as a conservative indicator of numbers of children and adolescents because it omits a) those who may have this injury but are ineligible to claim because, in the case of those driving they were unable to attribute negligence to another driver, (this applies to a very small proportion of the age range); b) those whose accident was not caused by a motor vehicle accident - for example, water sports, contact sports and falls; and c) those who cause of injury is non-traumatic. Data from admissions 1985-90 of those under 18 years to the spinal units of two of Sydney's hospitals, Royal North Shore Hospital and Prince Henry Hospital, indicate an average of 16 cases per year in this period (Walsh, 1993). However, this data also must be treated cautiously. It may have included non-New South Wales residents, such as injured people flown from Pacific countries. It is also unclear whether all admissions are permanent injuries; and the data include no numbers from other NSW hospitals such as Westmead or Prince of Wales.

The trend in numbers of people over 14 years with spinal cord injuries is stable - that is, the prevalence rate estimated at 14.5 per million of population is neither increasing nor decreasing (Australian Injury Prevention Bulletin, 2000). Whether this trend also applies to those under 14 is not known,
although statistics from claims to CTP insurers indicate a declining trend (MAA, 1999).

Spinal cord injury is not spread evenly across the population. The most “at risk” age is 15 to 24 years and there is a higher rate of spinal cord injuries for males than females (Australian Injury Prevention Bulletin, 2000).

**The Effect of Severe Spinal Cord Injury**

The effect of severe spinal cord injury is quadriplegia (also known as tetraplegia) or paraplegia. Quadriplegia results from injury in the neck of cervical area and results in paralysis or weakness in all four limbs; paraplegia results from a lower spinal cord injury and means paralysis or weakness of the legs only. In addition, there may be a loss of proprioception and touch, a tendency for skin to develop pressure areas where ulcers may form, interference with bladder and bowel control, spasticity and spasms in muscles, contracture of joints, blood pressure problems, loss of regulation of body temperature control and weakened chest muscles which may increase susceptibility to lung infections and require people with high level quadriplegia to use assistance with breathing (Dickson, Martens, Dever and Tonkin, 1993).

Children with spinal cord injuries experience similar effects to adults but x-ray evidence of the fracture or dislocation is frequently lacking due to the resiliency of young bones (Flett, 1992). As children continue to grow after their spinal cord injuries, they have a high incidence of scoliosis, a curvature of the spine, which frequently requires surgical treatment (Flett, 1992).

In addition to the spinal cord injury, when the injury is traumatically caused there are frequently other injuries which occur at the same time. Some of these injuries respond to treatment; others result in permanent disabilities such as acquired brain injury after, for example, motor vehicle accidents.
Other Consequences Of Spinal Cord Injuries

The literature is replete with references to consequences for adults and there is no information about children. However, adolescents gradually merge into adulthood so it is pertinent to examine common consequences for adults briefly.

Employment

The employment rate of people with spinal cord injury is low. ABS data indicate that 66 per cent of working age people with a profound or severe restriction (for example, self-care or mobility) are out of the workforce. Of those in the workforce with profound or severe restrictions, 32 per cent were employed; 68 per cent were unemployed (ABS, 2000).

Income

A survey in the United States of the population with spinal cord injuries which used a sample of 758 people from various locations suggests that those working had a 33% drop in earnings from what they would have expected to earn had they not been injured (Hemenway, 1994). In Australia, most people with spinal cord injuries are on low incomes derived either from the Disability Support Pension (DSP) or from settlement moneys derived from compensation claims.

Sexual functioning and marital status

Sexual functioning after spinal cord injuries tends to be a neglected area in rehabilitation. The extent to which a normal sex life is regained depends on such factors as the level of lesion and prognosis is generally better for women than men (Sishuba, 1992). However, women report that pregnancy is discouraged by doctors which many women successfully ignore (Shaul, Dowling and Laden, 1981; Perry-Sheridan and Seiden, 1995; Temby, 1996).
The marital status of people sustaining high level spinal cord injuries is generally single: 65 per cent (Freeth, 1993); for all people with spinal cord injuries this status is unknown. How spinal cord injuries affects this status is uncertain although anecdotal evidence suggests single women with spinal cord injuries are less likely to marry than single men with spinal cord injuries. The effect of spinal cord injuries on marriage breakdown, while changing the nature of the marriage, has not been significant (Richards, 1982; Oliver, Zarb, Silver, Moore and Salisbury, 1988; Freeth, 1993).

**Depression and suicide**

The onset of depression, non-compliance with treatment and various forms of self-destructive behaviour have been observed in some adults with spinal cord injuries. The suicide rate of people with spinal cord injury indicated by Judd and Brown (1992) is 6 per 342 persons which is higher than the general population of Australia (22/100,000 persons) and this is a measure of "overt and deliberate acts" and does not include "passive suicides" due to self-neglect, alcohol and drug abuse (Judd and Brown, 1992). In their study of 6 suicides, Judd and Brown found five of their patients had developed "moderately severe depression" and one had faced "legal and social problems" and believed his conduct would make him "unacceptable to his family and community"; moreover, all six believed they would not be able to adjust to life with severe spinal cord injuries.

**The Effect Of Severe Spinal Cord Injuries On The Public**

People with spinal cord injuries evoke a great deal of public feeling because of the nature of the injuries. The degree to which the feeling is sympathetic or viewed as "tragic" is related to circumstances of the injury, such as whether it was the person's "fault", the age of the person, their family responsibilities and their social status. Many assumptions are made about people with spinal cord injuries: for example, that they will not be able to work, play sport and have children. It is generally thought that they will not be visible members of the community. These assumptions are mistaken,
despite the fact they have been officially held - for example, spinal cord injury has been regarded as a "manifest" condition entitling an applicant to a pension without demonstrating incapacity to work (Cass, Gibson and Tito, 1988: 131).

Most people with spinal cord injuries who are politically active view themselves as members of a larger community, people with disabilities. Distinctions are also made between people with physical disabilities, people with sensory impairments and people with intellectual disabilities and people with spinal cord injuries are placed in the first group. The term “people” denotes all age groups but an examination of the literature for people with disabilities and people with spinal cord injury suggests that the term covers adults only, with rare acknowledgements of adolescents and children. This means comparatively little is known about children and adolescents with spinal cord injuries.

**The Focus Of This Study**

The focus of this study is to examine the needs of children and adolescents from the point of view of those experiencing spinal cord injuries. The children's views have been interpreted by parents and it is inevitable that some of the requirements of parents are also revealed in the study. However, the views of parents are not the main focus although their requirements and those of other family members are a worthy subject for examination.

Adolescents at the study's upper age range of 19 years are adults so that the study encompasses the views of young adults as well as children and adolescents.

The concept of "needs" has been used in the thesis in a particular way. Because official terminology uses "needs" in such terms as "needs based planning" and "needs-led services", the use of "needs" has been reserved for official and professional references. When referring to the views of people
with spinal cord injuries or people with disabilities or parents or adolescents about their needs, "requirements" or "concerns" have generally been used to distinguish their views from those from official sources.

Definitions

In this thesis, "impairment" refers to a defective mechanism of the body such as spinal cord injury. "Disability" refers to the social restrictions which people with impairments experience (Oliver, 1983: 24). These are the definitions which people with disabilities have chosen to use to describe their experiences and, as this thesis has used the views of people with disabilities, it is appropriate to follow their definitions. The aim of the political movement of people with disabilities is to make the category "people with disabilities" unnecessary so that it could be replaced with "people with impairments".

The International Classification of Impairments, Disabilities and Handicaps (ICDH) definition of disability sees disability as "any restriction or lack (resulting from an impairment) of ability to perform activity in the manner or within the range considered normal for a human being". This definition of "disability" contrasts with Oliver's definition of disability which emphasises social causes, rather than impairment, as responsible for the marginalised experiences of people with disabilities. However, Oliver's definition does not prevent the examination of the role of impairment, as discussed in Chapter 2.

The Organisation of the Thesis

Part A of this thesis contains Chapters 1-3. A literature review of the requirements of people with disabilities and people with spinal cord injury is presented in Chapter 2. The fact there is little known about children and adolescents is highlighted and thus their requirements are hypothesised to be similar to people with disabilities and adults with spinal cord injuries.

Chapter 3 contains an examination of the responses to adults, children and adolescents from the social welfare system and the insurance system.
These systems are assessed for their helpfulness to children and adolescents after examining their evaluations by people with disabilities, people with spinal cord injury or others made on their behalf.

In Part B, data from interviews with children's parents and adolescents are analysed which reveal their concerns. These have been broken into four areas:
1. Hospital and return to home (Chapter 4);
2. Living in the community (Chapter 5);
3. Education issues (Chapter 6);
4. Claiming compulsory third party insurance (Chapter 7).

In the Conclusion (Chapter 8), the findings from the interviews are tied back to the research questions and the implications of the findings are considered.

The Research Questions

Using interview data, this thesis has set out to elucidate the following questions:
1. What do parents of children with spinal cord injuries and adolescents with spinal cord injuries consider their requirements to be? What do they remember of their past requirements and how well were they met? What requirements do they foresee in the future?

2. How do the requirements of children and adolescents relate to those identified for people with spinal cord injury and people with disabilities in the literature review?

3. How helpful have the public welfare systems been in meeting the requirements of the children and adolescents?
4. What differences are emerging between those who received insurance settlements and those who are receiving social welfare benefits?

**Methodology**

**Sampling frame**

The research for my study uses a qualitative methodology. The research data is derived from 20 unstructured interviews: 5 adolescents, 11 parents speaking on behalf of their child and 4 joint parent and adolescent interviews. These interviews were conducted in 1994 but there have been few changes in public responses to spinal cord injuries in the past 6 years. Information on characteristics of the participants is contained in Appendix IV. As parents represented the experiences of children their views on the requirements of children could omit or distort important detail. However, parents' interpretation of children’s requirements appear "logical" in that their views and actions parents stemmed from their understanding of their situation (Phillips, 1973).

A potential limitation in the data collection also lies in the joint interviews of parents and adolescents. Each party may have been constrained by the presence of the other in raising particular requirements. However, the choice to participate together was made by the participants prior to the interview and there no signs of disagreement or inhibition in the interviews. The interviews were held 6 years ago (1994-5). I argue that the data from these interviews remains pertinent and that there has been little change in the world of disability since that time that would affect the interview data.

The names of potential interviewees were obtained from treating doctors who saw the children and adolescents regularly. A number of "patients" were "lost" from hospital records or had not maintained contact or were reluctant to participate in the research. Thus, the participants may have been biased in favour of those who were "compliant" with doctors and who wished to be perceived as "co-operative". Further, those who had "bad experiences" and
were angry would probably be less likely to participate so that the research may reflect the views of those who had relatively "good experiences".

**Data analysis**

The data from the unstructured interviews has been analysed thematically. Concepts were developed and all facets of these explored. The concepts were developed in the light of "meaning" for the participants and their view of their requirements. The guiding light through the abundance of data was the theory which originated from the literature review.

A restraint which occurred in some situations was that participants were uncertain of their requirements. It was relatively easy to feel critical of particular events but it was not clear what was required or if any "remedy" existed. Such an event is the grief related to the awareness of paralysis. Whether adolescents or parents or children wanted more than acknowledgement is unclear and is a topic requiring further research. Moreover, recalling past events also brings certain difficulties. People can say now, after years of reflection, what would have been helpful but, at the time that events were occurring, these were not their requirements.

The study has used the principles of "analytic induction" (Robinson, 1951) as a basis for "universal" statements about requirements. Due to the study numbers, statements are based on small numbers but are true for all relevant cases in the study. However, the statements are to be viewed as hypotheses for further research and refinement, which is an important element of qualitative methodology.

A more detailed account of the Methodology is in Appendix I.
2 LITERATURE REVIEW

There appear to be no studies on the needs of children or adolescents with severe spinal cord injury from their own perspectives. There is also a lack of available material on children and adolescents with physical disabilities from their own perspectives. This review therefore examines the literature on the requirements of all people with disabilities, which includes people with spinal cord injury and other impairments, as well as the more specific literature on the requirements of people with spinal cord injury. Both of these literature areas have used material which is based on the experiences of people with disabilities. In these reviews the word "people" seems to refer to adults as no studies refer to children or adolescents.

The literature review provides the basis for formulating key questions on the requirements of children and adolescents with spinal cord injuries.

Requirements Of People With Disabilities

Individuals have widely differing experiences of disability. They are active, negotiate responses to deal with their impairment to make their lives more satisfying and are not passive recipients expecting all of their requirements to be met (Bury, 1991). Nonetheless, they experience common problems which legitimate the transition from statements about individual requirements to the position for the community of people with disabilities. Moreover, within the community of people with disabilities, individuals have other common experiences related to gender, race, ethnicity and other characteristics.

The views of individuals on their personal requirements lack official status and are considered "wants" or "desires". This distinction stems from the ontological assumptions of liberal individualism that individual “wants” are
infinite and that individuals are seeking to maximize their pleasures (Macpherson, 1977: 29, 30). Hence, the state has sanctioned other depoliticised, technical interpretations which have received minimal challenge (Wilding, 1982). That these versions are not "value-free" and reflect vested interests has been little recognised (Scott, 1969; Smith, 1980). In addition, these versions have yielded comparatively few benefits for people with disabilities and little material for their empowerment (Zarb, 1992).

The Medical Model

The dominant interpretation of the requirements of people with disabilities in the 20th century has been the medical model which continues to exert a strong influence on official statements on the needs of people with disabilities. Prior to the medical model, interpretations stemmed from charitable and religious organisations who in pre-Federation Australia interpreted the requirements of people with disabilities as food, clothing, treatment for health problems and the work opportunities so individuals could fund their own "self help" (Rathbone, 1994; Olliff, 1992).

According to the medical model, the main requirement of people with disabilities is treatment to "cure" or "correct" their impairment; however, clinical medicine, is interested only while the impairment is amenable to treatment (Zola, 1981; Brisenden, 1986; Oliver, 1990). Further, if medicine cannot apply a "label" to the conditions of individuals and they are left without a diagnosis, they experience "social abandonment" because of the need for medical diagnosis for accessing many services (Wendell, 1996). Moreover, medical professionals, according to this model, are concerned solely with physical suffering and are not interested in the meaning of illness or trauma for their patients (Charmaz, 1983).

Contact with medical professionals is frequently experienced by people with disabilities as overbearing power, in which they feel their humanity is ignored and they are mere "diagnostic categories" (Brisenden, 1986; Oliver, 1990). Many feel they do not participate in "medical" decisions in a "meaningful
way” and that they are often not given opportunities to weigh up choices (Brisenden, 1986; Oliver, 1990). People's own experiential knowledge lacks importance in the medical world and their disability is regarded as "static" rather than "situational" (Oliver, 1990: 5). Moreover, medical treatment often has adverse effects on the quality of life. Technologies for severely disabled people, such as ventilators, impose heavy burdens on people with disabilities and their carers and technical services are acquired with great difficulty. The small numbers of people using technical equipment have highly varied, specialised requirements so that formation of a political constituency to lobby for change is difficult (DeJong and Lifchez, 1983; Zola, 1981).

The life-saving role medicine plays, particularly in trauma such as spinal cord injury, is acknowledged by people with disabilities who endorse the need to treat, cure or ameliorate the effects of impairment but are critical of medical involvement, after the acute stage, which determines facets of their lives (Oliver, 1990). The dominant social position which medical professionals have achieved under this model has awarded them the right to interpret the requirements of people with disabilities in such spheres as policy-making (Wilding, 1982: 64) and clinical certification is commonly a prerequisite for non-medical goods and services, such as housing and income support (Hahn, 1986: 130; Stone, 1984: 103).

This model stresses impairment as the cause of the social position of people with disabilities and imposes an assumption of "biological inferiority" which insults and disempowers people with disabilities (Hahn, 1986). As problems belong to "individuals", the medical model keeps disability issues depoliticised and, by focusing on individuals through service provision such as therapy, rehabilitation and education programs, the environment remains untouched and "fixed" (DeJong and Lifchez, 1983; Brisenden, 1986; Oliver, 1990; Davis, 1995; Hahn 1986). Concentration on impairment also fuels stories about those who have overcome disadvantages imposed by their impairment and who thus have determination or "grit" and this has led to the categorisation of people with disabilities as either "super-heroes" or "pathetic under-achievers" (Zola, 1988; Oliver, 1990).
Use of clinical medicine to interpret the requirements of people with disabilities stems from the belief that medicine could distinguish clinically whether "genuine" impairment existed and thus who could be excused from work and receive welfare (Stone, 1984). Apart from reliability problems with indicators of impairment, the link between impairment and ability to work cannot be established objectively and there is reliance on stereotypes (Stone, 1984; Webster, 1986; Rubinstein, 1982:302).

Medical interpretations of the requirements of people with disabilities usually vary markedly from the views of people with disabilities. However, the medical interpretation has carried the authority of the state while, in comparison, the views of people with disabilities have lacked status.

Increasingly, the gatekeeping role of medicine is supplemented by administrative screening of applicants which provides simple, direct, dichotomous categories such as age, residency status, income limits; these administrative categories allow claimants of social benefits to “self-filter” and, in large part, to assess themselves (Blaxter, 1976; Hirst, 1997). Administrative decision-making produces speed and consistency in decision-making as well as reductions in administration costs by allowing clerical decision-making, computerisation and fewer successful appeals (Volker, 1988: 48; Carney, 1994: 196). However, from the point of view of people with disabilities, categories often produce distorted views of their requirements, for example, when the need for aids and equipment no longer exists because the claimant receives income at a particular level.

The Social Model

The social model and its views on the requirements of people with disabilities is about 3 or 4 decades old. Although most people with disabilities remain hopeful of a cure for their impairment, the major requirement of people with disabilities is an end to their marginalisation from community life, their lack of "social participation" (Finkelstein and French, 1993; Barnes, 1991; French, 1993; Oliver, 1992; Oliver, 1990; Davis, 1995; Wendell, 1996). This view
originates from activists and academics, not from the majority of people with disabilities whose views are unknown and who are elderly and female (Williams, 1999; Priestley, 2000). Marginalisation is therefore to be regarded as a "working" hypothesis, and a question which this thesis seeks to examine in the specific instance of children and adolescents with spinal cord injuries.

The term "marginalisation" is used without precision. "Marginalisation" refers to the material aspects of living with an impairment (housing, employment, income earned, opportunities for education and training) and the non-participation of people with disabilities form a wide variety of human activities including culture, politics, discourses on people with impairments, cultural representations and organisation decision-making (Hevey, 1993; Wendell, 1996). Marginalisation also encompasses social attitudes to people with disabilities: the denial of their humanity and their citizenship, if this is based on "able-bodied workers all contributing" (Oliver, 1992; Wendell, 1996; Davis, 1995; Walmsley, 1991). Marginalisation further incorporates the self-imposed separation of people with disabilities from society which originates from their shame and embarrassment (Charmaz, 1983; Goffman, 1961; Woolley, 1993).

People with disabilities have experienced marginalisation as "oppression" (Susman, 1994; Abberley, 1987; Oliver, 1992; Barton, 1993). Oppression, defined as unjust and unnecessary restraint and overbearing power (Macquarie Dictionary, 1991) implies a unilateral flow of power from non-disabled society to people with disabilities who are unable to exert little power in return and a lack of alternatives. Moreover, many disabled people are not only oppressed by the operation of social barriers but also many, are "oppressed from within because we have internalised those same attitudes [of society] towards ourselves" (Woolley, 1993: 81). "Internal" oppression will be discussed further, below.

The cessation of marginalisation would mean inclusion and social participation and would require the dominance of new social norms which would value all human beings because of their humanness and their diversity
rather than qualities such as their productive capacity (Leipoldt, 1993; Fullagar and Hardaker, 1993; Bogdan and Taylor, 1989; Morris, 1992; Meekosha, 1990). Implementing this change in values could not originate from people with disabilities who are powerless in comparison with the state, capital and public opinion.

Ending marginalisation would mean the presence of people with disabilities in social institutions which affect their lives such as service-providing organisations, disability research and social movements such as the women's movement (Barton, 1993; Zarb, 1992; Meekosha, 1990; Morris, 1992). The abilities of people would be viewed as a continuum in which all abilities have a part (Davis, 1995). However, proponents of inclusion do not state how society would manage abilities which are injurious to self or others. Ending marginalisation would also involve major changes in the current market-dominant value system and changes in social expenditures as money was directed to remove barriers. Resources, Leipoldt (1993) argues, would be shifted from the current welfare model of meeting specified needs to the development of human beings. However, the way in which choices, priorities, decision-making, the numerical preponderance of some diagnostic groups and other issues would be managed is not discussed. Further, it is also clear that countries such as Australia are attempting to bring about change, such as ending discrimination, without major upheavals in resource distribution by placing the onus for change on individuals rather than social organisation.

Explanation of why marginalisation has occurred have usually involved capitalism and its labour requirements. The Marxist "reserve army" concept, sees people with disabilities as flexible labour commodity, manipulated by capital, available for labour shortages and providing a category to where surplus labour can be shunted (Stone, 1984; Hahn, 1987).

While ending marginalisation based on disability would lead to social participation for people with disabilities, those who are marginalised for such
reasons as race, different sexuality, Aboriginality, may remain “oppressed” because of other characteristics (Stuart, 1993; Mokak, 1997).

The social model of disability proposes that marginalisation is produced by cumulative "social barriers" or "social arrangements" which prevent the participation of people with disabilities in the community. Participation is more than visible presence but must involve people with disabilities in decision-making to the same extent as other citizens (Drake, 1992). The meaning of "social arrangements" or "social barriers" is open. These terms are used to refer to capitalism, dominant value systems, attitudes or operational methods in organisations. Moreover, social barriers operate in many forms which overlap and reinforce each other.

Social barriers

As ending marginalisation is the main requirement of people with disabilities, the nature of social barriers must be understood. Social barriers shield "mainstream" society in a number of ways and their function is maintaining control over public expenditure made on behalf of people with disabilities, such as social welfare expenditure.

People with disabilities and low incomes have interpreted their lack of legal rights to welfare such as goods and services as a major barrier to their social participation. Rights to entitlements are attractive to people with disabilities because it is believed the rights would reduce the numerous humiliating assessing and rationing mechanisms conducted by professionals (Zola, 1982; Barnes, 1992; Barton, 1993). The likelihood of obtaining such legal rights are low, however, because of the perceived expenditure burden for the state, the fact no other social group has their "wants" met and administration of the scheme would be extremely complex (Handley, 2000; Rioux, 1994; Titmuss, 1971).

Social expenditure is also protected by the ideologically constructed attitude of service providers who regard people with disabilities as people to be
"taken care of", "in need of help", "dependent" and "to be looked after" which is a significant hindrance to their social participation (Zola, 1988; Hillyer, 1993; Oliver, 1993; French, 1996; Finkelstein, 1993). The attitude of service providers is operationalised by not listening to the ideas of people with disabilities, not believing in their capabilities and potential, not consulting them but defining their goals, clinging to stereotypes and offering few choices regarding service provision (Safilious-Rothschild, 1976; Zola, 1982; Hillyer, 1993; Oliver, 1993; Morrison and Finkelstein, 1993; Ireland, 1993). Moreover, until recently, the views of people with disabilities have been represented by peak service providers who have interpreted the requirements of people with disabilities as more services rather than social policies based on moral values such as equality (Leipoldt, 1993: 15; Bickenback, 1994: 121). Organisations of "consumers" such as the Physical Disability Council of New South Wales (PDCN) have now developed to represent views directly to government.

"Controlling" care has been rather interpreted by people with disabilities as an abrogation of basic human rights (Brisenden, 1986; Leipoldt, 1990; Morris, 1993). Personal assistance is usually delivered in a "custodial" manner where people with disabilities are denied input into decisions such as time to go to bed, time to rise and mealtimes. Consultations with people with disabilities are dispensed with because consultations are too "time-consuming", or because professionals have left few choices for people with disabilities to make, or because trade union awards have dictated requirements for staff working with people with disabilities (Morgan, 1991; Oliver, 1993). In addition, government-sponsored agencies have interpreted the meaning of "efficient" services as 'task oriented" with no time allowed for staff to listen to the views of those they are serving (Leipoldt, 1990).

People with disabilities seek a choice in personal assistance arrangements. "Enabling" care for some would mean buying their own personal assistance, expressing their priorities and escaping from perpetual "gratitude" and the risk of abuse which flourishes in powerlessness (Morris, 1992). Others, in
limited experiments with personal assistance arrangements, have found administering their services too burdensome (Clark, 1985: 198).

Institutionalisation in nursing homes or other institutions also constitutes major barriers for the social participation of people with disabilities. Society has benefited from institutions because economies of scale and the lack of expectations of community participation from residents has meant comparatively inexpensive care. Currently, little supported accommodation in the community is available for many people with disabilities such as those leaving hospitals without family support (Sach & Associates, 1991). Moreover, people with disabilities view institutions as places to "dump the socially dead" - those without medical cures (Finkelstein, 1993); institutionalisation also means that the community loses knowledge of disability (Zola, 1988).

People with disabilities also argue that they lack support for their roles as parents, employees and other social roles. This places extra responsibilities on families rather than the state or employers who might be expected to take some responsibility. When women with disabilities are unable to provide care, frequently there is family disruption; with no support for women to manage their families, some husbands have to relinquish their paid work to care for their families and their wives with consequent decreased family incomes (Temby, 1996). Clearly, the state has tried to prevent this problem from arising by discouraging women with disabilities from marriage and having children (Temby, 1996; Shaul, Dowling and Laden, 1981) and married women who become disabled have found professionals encouraged their husbands to end the marriage (Morris, 1989).

Institutional discrimination functions to ensure opportunities in education, employment, housing, medical treatment and so on are given to those who are perceived likely to use their opportunities in the most socially productive way. Discriminatory actions of individuals and organisations are also seen as hampering the participation of people with disabilities in social life. However, the behaviour of individuals is merely reflective of institutional
discrimination or unequal treatment which is socially accepted practice, supported by ideologies and stems from our materialist production arrangements (Barnes, 1991; Barnes, 1992; Oliver and Barnes, 1993; Rioux, 1994; Gleeson, 1995). Underpinning this system is public welfare which provides sustenance for those "rejected" from social participation. Discrimination is based on observing "difference" and, with justification from medicine and science, assuming that individuals cannot exploit their opportunities so that systematic exclusion of people with disabilities from opportunities in education, employment and so on, occurs (Rioux, 1994; Hahn, 1986). This focus on inabilities has been viewed by people with disabilities as a denial of the right to be treated as fully competent (Oliver and Barnes, 1993; Barton, 1993).

Other barriers operate to discourage people with disabilities from making demands on the rest of society. The nineteenth century categorising of bodies as "normal" and "abnormal" established people with disabilities as a separate category from the rest of the population, despite their strong desire to be regarded as "normal" with "different" appearance and bodily function and the categorising effect remains today (Davis, 1995). The "average worker" concept also separated people with disabilities and moral evaluations developed. The current "idealization" of the normal body which generates profits and strengthens the contrast between the bodies of people with disabilities and "normal" bodies adds a further obstacle to social participation for people with disabilities (Wendell, 1996). In addition, the normal body internalises various controls which are linked with social acceptability and self-respect. Thus, people with disabilities who are unable to "measure up" feel shame and self-hatred. The rest of society regards people with disabilities as "devalued people because of their devalued bodies" and these bodies are shunned (Wendell, 1996: 89). Moreover when people with disabilities flout the expected rules of interaction when in contact with "normals", people with disabilities are aware of the negative evaluations and the embarrassment of "normals" and they frequently attempt to avoid contact, or when in contact, adopt strategies to lessen the shame they feel (Hilbourne, 1973; Davis, 1963).
Stigma associated with impairment also constitutes a barrier which has kept people with disabilities hidden but has weakened in recent years for some who have learnt to disconnect shame from impairment and to attack the social perception of people with disabilities through political activism. The stigma of disability was recognised as an imposed identity which can be replaced with a "positive" one (Anspach, 1979; Susman, 1994). The question of whether all people with disabilities can create new self-concepts and influence their social image or whether such transformations are restricted to young, urban, educated disabled people receiving group support remains unanswered.

Negative stereotyping by the media and in cultural portrayals (Susman, 1994), both areas in which people with disabilities are absent and thus without influence, also adversely affects the capacity of people with disabilities to present their views and make demands on society. Knowing that impairment is a metaphor for such negative personal qualities as cruelty, bitterness and deviant behaviour within the general community deters people with disabilities from interacting with non-disabled people. Further, the existence of the general social "compulsion" that all should work, means those not working are morally suspect status in the eyes of the community and inhibits people with disabilities (Abberley, 1987: 16). Beliefs about women with disabilities, "double stereotyping", which assume they are dependent, incapable of sexuality, motherhood and employment have rendered this group invisible (Meekosha, 1990). The de-eroticised representation of people with disabilities is also disturbing and inaccurate in its linking of sex with youth and physical attractiveness (Zola, 1982; Davis, 1995) but this belief has justified particular institutional arrangements.

A further source of negative self-perceptions that make people with disabilities retreat rather than actively engage with the world is their self-evaluations of their industry and their work capacity. Charmaz (1983) examined statements of chronically ill people and found that they measured themselves against typical social values of hard work, independence and individual responsibility, and found themselves wanting, a discovery which
led to loss of self-esteem and perceptions of themselves as "burdens". It is suspected people with disabilities engage in a similar process. The images used by charities that reinforce dependency contribute to the view of people with disabilities have of themselves as "pitiable" (Oliver; 1993). Lack of ability to reciprocate for personal assistance causes the notion of "burden" although "reciprocity" should be viewed as a return made to the community rather than particular individuals (Hillyer, 1993). Further, the dismissal by professionals of the views of people with disabilities and their self-knowledge reinforces these negative views.

Public skepticism that an impairment exists, especially if there is no empirical evidence is a further barrier faced by people with disabilities which operates to limit claims on society's surplus (Stone, 1984). Such disbelief has contributed to negative feelings of those impaired, for example sufferers of "Repetitive Strain Injury", and produced a restricted life, social isolation, family strain and financial crises, and lack of sense of purpose (Charmaz, 1983; Ewan, Lowy and Reid, 1991; Temby, 1996). Skepticism also discourages false claimants and encourages people, as much as possible, to "normalise" their injury or impairment and not claim on society's surplus (Stone, 1984; Abberley, 1987).

Making claimants of disability status who have experienced trauma or sudden disease onset construct a new self-identity, with lower social status also discourages false claimants (Albrecht, 1976; Murphy, 1987). The reconstruction occurs through social interactions with others (family, friends, medical staff, co-workers and other people with disabilities) and the reconstruction occurs in the context of social values and normative structures which makes individuals susceptible to negative evaluations (Albrecht, 1976). High status sporting "heroes" and "film stars" lose their status and fade into the world of disability.
The relationship between impairment and marginalisation

Crow (1996) supports the social model of disability and that the main requirement of people with disabilities, social participation, originates from the operation of social barriers. She argues that impairment of individuals or "internal", "in our bodies" experiences, for example, pain, lack of energy, depression, chronic illness, also contribute to lack of social participation, and impairment conditions will remain when social barriers are conquered. Thus, the full experience of people must be examined to understand their requirements (Crow, 1996). Impairment, she contends, has subjective meaning which means individuals will interpret it differently. However, this does not mean that the interpretations of people with disabilities should be rejected and replaced with other interpretations as occurs under the "medical model" (French, 1993; Crow, 1996; Temby, 1996).

Crow appears to be saying that there are two causes of marginalisation: social arrangements and impairment. However, the existence of "impairment conditions" may actually be due to social barriers. For example, the existence of pain, depression and so on may be related to the failure of people with disabilities to have their concerns prioritised on research and technology agendas, their lack of representation on relevant committees and their low status. Irrespective of whether impairment is subsumed under social barriers or remains a separate cause, ending marginalisation remains the dominant requirement. Moreover, the rejection of impairment and the body as precipitators of marginalisation and the concentration on social factors in the current model of social disability, concedes the body to medicine, "rather than remaining open for sociological discussion" (Williams, 1999: 803). Thus, a question in this thesis will be the extent to which both social barriers and impairment are sources of the requirements of children and adolescents with spinal cord injuries.
Summary

The social model of disability is a theory, a hypothesis, which must be viewed as in its infancy with further research needed to check its application for various groups within "people with disabilities", leading to refinement or, if needed, abandonment of the theory if data do not support its tenets.

This thesis is concerned with the views of children (as represented by their parents) and adolescents on their requirements and shares with the social model the value of the interpretations by people with disabilities. However, at an official level the "medical model" and administrative data generally inform the state and society about the requirements of people with disabilities.

According to proponents of the "social model", the main requirement of people with disabilities is an end to their social marginalisation from such valued community activities as education, employment, politics, cultural and media activities and recreation. The model attributes the lack of participation by people with disabilities to social barriers which protect mainstream society from the possible demands of people with disabilities; from the point of view of people with disabilities, the barriers infringe their human rights. In addition to social barriers, Crow (1996) has argued that impairment also contributes to the lack of participation of people with disabilities, although this does not mean a reversion to the "medical model" as the views of people with disabilities are the best indicators of their requirements.

Needs Of People With Spinal Cord Injuries

The literature on people with spinal cord injury is limited by the high proportion of it which derives from survey data. Most of this data was obtained by interviews in which the meanings of questions and answers could have been clarified with participants. Of more concern, are the topics on which questions are based and whether there has been an omission of an area of importance and the effect of the research process on the participants
(Zarb, 1992). Two sources are autobiographical (Hitchcock, 1998; Murphy, 1987), and another, a UK project based on survey data from 205 women with spinal cord injuries was developed by a "16 strong Editorial Group" of the women (Morris, 1989).

The examination of the requirements of people with spinal cord injury shows that they are related to the "stage" in their "career" from able status to disabled status (Davis, 1963). Moreover, Davis highlights the fact that research interviewees redefine, re-evaluate and reconstruct past events in order that they are compatible with the present and in this way ensure the past and current form a seamless whole (Davis, 1963) so that requirements presented at the time of the interview may have been recognised later than the actual time when the events occurred.

It is argued that, like people with disabilities, ending marginalisation is a major requirement of people with spinal cord injury. However, this is not the main requirement of people with spinal cord injury at the onset of injury. Marginalisation becomes a concern at a later stage and it co-exists with other substantial requirements.

The first concern of people who have sustained spinal cord injuries is that they receive the best possible medical treatment. In Queensland, the medical treatment of respondents was considered to be "good" in the acute stages but later after leaving hospital, respondents felt isolated and in need of periodic visits from the spinal injury unit (Richards, 1982). Except for a quarrel between ambulance and rescue helicopter personnel, Hitchcock (1998) remembered his initial acute care treatment in New South Wales as "the calmness of the experienced medical team". This contrasted with the views of people in the UK study of Oliver, Zarb, Silver, Moore and Salisbury (1988) where many interviewees claimed that aspects of their medical treatment such as delay in transfer to a spinal unit had resulted in later complications.
While in the hospital, adults are aware of the problems their injury and consequent hospitalisation brings for their families who are torn between attending to the hospitalised person and other family members, and register guilt (Morris, 1989; Hitchcock, 1998). Adults who saw close relatives "upset" by their injury "worked" at cheering them up (Hitchcock, 1998). They also saw the hospital accept the work of their relatives (feeding, helping at wash time, giving drinks and medication) without acknowledgement and the hospital asserting its authority and ordering the helpers to conform to visiting hours despite the patient's need for their presence (Hitchcock, 1998).

Lack of attention to the emotional impact of severe spinal cord injury on the injured person and their family was a serious concern. Attention to the emotional impact was sought urgently by patients and their families but medical and hospital staff are remembered as paying little or inappropriate attention. For some, the bluntness of their diagnosis was hurtful although others appreciated this method (Oliver, et al, 1988). In Morris' survey of 205 women with spinal cord injury in England, a common cause of distress was the poor communication of consultants, doctors and nurses who did not inform the women they were permanently paralysed or told them very late (Morris, 1989: 280). The shock of one day being a mobile non-disabled person, and the next, a paralysed person with spinal cord injury was not acknowledged by professionals and no opportunity was offered to discuss the change (Oliver et al 1988, Morris, 1989). Some patients found that they were assumed to pass through "stages of grief"; others were instructed to "accept life as 'quad' and to get on with it" (Oliver et al, 1988; Freeth, 1993; Hitchcock, 1998).

People with spinal cord injuries also wanted the emotional distress of their families acknowledged. In hospital, the respondents in Richard's survey felt there was too much focus on them, the patients, and their tasks, which meant there was scant support for families and partners who were given little opportunity to discuss how they felt about the injury and its consequences (Richards, 1982). Similarly, some UK patients felt that hospitals concentrated on practical matters and ignored the psychological needs of
patients; no comments were made to the families of patients (Oliver, et al 1982). This lack of understanding is supported by Hitchcock's experience with a social worker who was surprised that his family was so "upset" by his diagnosis (Hitchcock, 1998).

The rehabilitation phase of their treatment was interpreted by many patients as rigid, carried out with little consultation and focused on practical rather than psychological needs (Richards, 1982; Oliver et al, 1988; Morris, 1989; Freeth, 1993; Hitchcock, 1998). Hitchcock recalled being "simply wheeled in … exercised and wheeled out. Nothing is asked of me or about me." (Hitchcock, 1998: 128). UK women, it was assumed, were returning to passive lives and thus were not offered training for active social participation (Morris, 1989). Interviewees in Morris' and Freeth's studies contended that rehabilitation was "male" oriented because it emphasised sport, competition and physical activity and alienated those interested in other forms of activity (Morris, 1989; Freeth, 1993). Quadriplegic patients who usually require greater assistance than paraplegic patients believed they were offered less training because professionals preferred working with patients who were more rewarding (Richards, 1982; Freeth, 1993; McSweeney, Forchheimer and Tate, 1996). Patients living outside the metropolitan areas perceived rehabilitation, when it was available, as lacking "expertise" and "focused on the elderly" (Freeth, 1993: 50).

Informing patients of the effect of their injury on their sexual functioning has continued to be regarded by patients as badly managed by professionals (Richards, 1982; Morris, 1989; Oliver et al, 1988; Freeth, 1993). Moreover, female interviewees in Freeth’s study commented that the information was "male focused" and women's sexuality was considered only in terms of reproduction (Freeth, 1993, 51).

Leaving hospital requires people with spinal cord injuries to adjust to their physical living environment and to obtain services to support or assist them. "Patients" require not only accommodation but modification of the entry to such rooms as the bathroom and bedroom. Most single people wanted to
return to living in the community in "supported" accommodation but frequently found their only choices were to return to living with their parents or to go into a nursing home (Richards, 1982; Oliver et al, 1988; Morris, 1989; Freeth, 1993). "Modified" public housing in New South Wales was available but individuals had to make their own support arrangements; in private rental properties, most landlords did not permit "modifications" so the question of who should meet these costs was avoided.

Returning to the family home to be "cared" for by parents was a difficult decision. Families had often been given no opportunity to express their thoughts on care arrangements during hospitalisation (Richards, 1982). People lost their "pre-injury status" in society, re-learnt the family lifestyle and "reverted to childhood" as the actions of parents were interpreted as "over-protective" (Cleveland, 1980; Oliver et al, 1988; Morris, 1989). These feelings were further complicated when parents gave up work to "care" and parents were affected by ageing (Oliver et al, 1988; Morris, 1989; Freeth, 1993). However, a number of people in Freeth's study stated they were currently satisfied living with their parents; the minority who expressed dissatisfaction felt unable to move because they would be unlikely to obtain sufficient personal assistance from elsewhere (Freeth, 1993: 34).

People with spinal cord injuries who had partners and children were usually keen to leave impersonal hospitals and return home. However, a number of new issues had to be continually re-negotiated in the family e.g. roles relating to income sources and sources of personal assistance. Spinal cord injuries did not appear to precipitate marriage breakdown with the rate being similar to that for non-disabled marriages (Richards, 1982; Oliver et al, 1988). Nonetheless, many men felt "emasculated" by their lack of sexual functioning and their change of status within the family from "head of the household" with "control over the family" (Murphy, 1989; Hitchcock, 1998). Women with spinal cord injuries stated that they lost their sexual interest when first disabled but this gradually returned as they felt more positive about themselves. Where women had been expected to care for their male partners prior to injury, after injury these relationships often broke down
because the male partners could not accept the reversed role of caring for women (Morris, 1989).

The source of most personal assistance is the "informal sector" and both men and women stated their dislike of dependence on family members for personal assistance and sought alternate sources of these tasks that would remove the "burden of care" from their parents or partners (Morris, 1989; Murphy, 1987; Hitchcock, 1998). The basis for this dislike is the lack of opportunities to reciprocate to the carers and this relationship "erodes the very compact upon which association between adults is premised" (Murphy, 1987: 195). Further, the dependent person is racked with guilt but also worried that their source of assistance may become ill or depart from them (Morris, 1989); other disabled people are embarrassed at the pay their carers who resigned from their work receive from the state (Freeth, 1993). Although a "formal care" system of personal assistance often supplements informal care, formal care usually restricts people with spinal cord injuries. Freeth (1993) has observed that formal care may be categorised as: 1) operating under a medical model, and 2) operating under the independent living model (Freeth, 1993: 20). Under the latter model, people with spinal cord injuries usually select, employ and train their personal assistants who are instructed to take an "enabling" role. The former group of services take a "custodial" attitude to people with spinal cord injuries who have very few rights with regard to the offered service (Freeth, 1993; Morris, 1989).

Dependence on others can be reduced through removal of obstacles, (for example, shifting residence to a one level house) and acquiring such aids as self-propelled bathchairs. Independence can be regained to such an extent that women who could afford aids resumed their role as primary household carers; those unable to reduce their dependency registered feelings of loss of dignity and privacy, ugliness, anger and frustration (Morris, 1989). Interviewees stated narrow eligibility criteria operated for welfare which prevented many people from receiving expensive equipment and aids free. Moreover, for those ineligible or unable to obtain funding for aids and equipment through insurance settlements, buying and maintaining of these
items was often unaffordable (Richards, 1982; Oliver et al; 1988; Freeth, 1993). Further, people with spinal cord injury were not always consulted about their requirements which resulted in the offer of unsuitable aids (Hitchcock, 1998; Oliver et al; 1988;). In addition, some women found they had to become resigned to the non-existence of certain aids (Morris, 1989) which exemplifies the powerlessness of this group to have their requirements recognised on research and technology agendas.

Studies support the argument that most people with spinal cord injuries are strongly motivated to work (Athanasou and Murphy, 1993; Hitchcock, 1998; Freeth, 1993: 53; Crisp, 1990). However, a number of barriers such as lack of transport to take the worker to and from their employment and having suitable aids and equipment, made this impossible for many (Richards, 1982; Oliver et al; 1988; Murphy, 1995). Thus, the question of what leisure activities people engaged in makes little sense to people who feel they are constantly at leisure (Kleiber, Brock, Lee, Dattilo and Caldwell, 1995). Of those employed, some worked as "slave labour" in workshops for people with disabilities. Students found their return to their education institutions was not welcome because of the expensive modifications that would have to be installed (Oliver et al, 1988). Moreover, the operation of Social Security in many countries, including Australia, deters people from employment because they lose a number of supplementary benefits and additional income above disability pensions attracts a high marginal tax rate. Where people did return to work, they tended to work harder than before their accident to prove their ability to themselves and to others (Murphy, 1987; Hitchcock, 1998).

Lack of work participation has meant many people with spinal cord injuries have low incomes. Some receive pensions from the state although the income testing of family incomes excludes some people with spinal cord injuries from this claim and further reinforces their dependency; (Richards, 1982; Oliver, et al, 1988; Morris, 1989). People with spinal cord injuries who claimed compensation from insurance companies for their accident discovered the claim process was a time-consuming, legalistic process which yielded large amounts of money to be "managed" and often caused
difficulties in family relationships (Oliver et al, 1988; Freeth, 1993). Moreover, for those who received compensation, erosion of the capital base was a common experience for people with high level quadriplegia especially those who were ventilator-dependent and this erosion meant claimants eventually turned to state pensions (Freeth, 1993). The additional costs caused by their impairment combined with low incomes meant many people with spinal cord injuries experienced hardship (Richards, 1982; Oliver et al, 1988; Morris, 1989; Freeth, 1993).

The impairment of spinal cord injury means "a narrow margin of health" which requires constant monitoring (Freeth, 1993). It was the common experience of participants in studies that there is little knowledge of the repercussions of spinal cord injuries outside the expertise of spinal units in major teaching hospitals. This has meant that people with spinal cord injuries are returned to spinal units when any complications occur which is "disruptive" and often means they pick up hospital infections (Richards, 1982; Oliver et al, 1988; Morris, 1989; Freeth, 1993). Moreover, some people expressed concern over their reliance on drugs and their side effects, especially when these caused depression and confusion (Oliver et al, 1988; Hitchcock, 1998).

**Social contacts**

Over time, people with spinal cord injuries usually found their pre-injury friendships gradually faded away. The literature review shows that people have different attitudes to this loss. Some feel that, although they want to mix with "normal" people, they would "burden" them; in addition, visiting friends accompanied by carers was difficult (Oliver et al, 1988). Murphy observed about himself and others, that people with spinal cord injuries withdraw, and allow contacts with former friends to decline, and that their new "friends" tend to be of a lower social strata (Murphy, 1987: 124). The views of women who participated in Morris' study was that women with spinal cord injuries are "oppressed" by their isolation from each other rather than their isolation from non-disabled people (Morris, 1989).
Mental issues

The mental state of a person with spinal cord injuries, their sense of self, their subjective life, is assaulted and dominated by spinal cord injuries (Murphy, 1987; Hitchcock, 1998; Yoshida, 1993). The mental domination follows recognised themes. Whether this domination wanes over time and is always negative is contestable.

The negative mental themes which people with spinal cord injury have are already mentioned. First is the change of status from "able" to "disabled"; second, disability dominates all other attributes such as age, ethnicity, academic and social attributes are overlooked and deference due to position in family, community or work is no longer paid (Murphy, 1987). In addition, many people with spinal cord injury are weighed down by the stigma. The registration of stigma is linked to the dominant cultural values of youth, physical beauty, activity, virility which people with spinal cord injury are unable to match and which can cause self-hatred.

Another dominant mental theme relates to the signs that people with spinal cord injury are not welcome in the community as evidenced by transport and building arrangements. Thus, many people with spinal cord injury are angry, not only about this social rejection, but also in relation to their deal by fate ("Why me?") (Murphy, 1987). "Culpability" for causing their spinal cord injuries and the ensuing arrangements also worries people with spinal cord injury (Hitchcock, 1998). The uncertainty of all the minutiae of daily living of life and the need to plan aspects including one's bodily functions to prevent humiliation and degradation also occupies thoughts of people with spinal cord injury who are continually appraising their encounters and their next manoeuvres.

Murphy (1987) argues that the dominant mental state for people with spinal cord injury is negative and they have a strong urge to withdraw from the world which is a rational response to their social experiences. (Murphy became quadriplegic in later life and carried out research on people with
disabilities). In fact, Murphy notes most people with spinal cord injury resist the temptation but Murphy describes the study of people with paralysis as individuals against society which values freedom, movement, physical strength and beauty.

Other researchers argue that the mental state of people with spinal cord injury is not wholly negative. In Richards study (1982) a few respondents felt life was not worth living, and people with quadriplegia were more anxious about their future than those with paraplegia. Oliver et al (1988) argued that expressions of dissatisfaction and negative feelings decrease with increased length of time since injury and that social and material factors are implicated in a person's sense of satisfaction. In Freeth's study (1993), 21% of people considered their quality life was poor with half expressing regret they had been "saved".

A positive mind set is possible after spinal cord injuries when people have received tertiary education (Boswell, Dawson and Heininger, 1998). In this study, 10 out of the 12 study participants had tertiary qualifications and 8 out of the 12 were "gainfully" employed. Participants stated they had adopted a positive attitude to disability admitting that it could be viewed as a "burden or a gift", they had changed their "priorities" and developed their cognitive abilities and had become less interested in monetary status. In Richards study a number people described themselves as contented but they had no tertiary education (Richards, 1982) while Murphy (1987) who was extremely depressed was a university professor. The meaning of spinal cord injuries for individuals is likely to depend on a number of factors and tertiary education may be one but the picture is likely to more complex and highly variable depending on meanings derived from current interactions.

Based on her study of 35 people with paraplegia, the mind set of people with spinal cord injury fluctuates, Yoshida (1993) argues. She examined the forms of "identity reconstruction" which study participants used and found individuals moved in a "pendulum" motion between 5 different forms of self: 1) their former self, 2) a super-normal identity in which a person engages
unaided in demanding activities; 3) the disability identity as total self; 4) a negative state in which the person feels anger about their fate and has high expectations of assistance; and 5) the middle self which involves concern for others. The cause of these movements in self-conception could not be causally linked because it depended on how individuals interpreted particular experiences.

While further work is needed to understand the interpretations and self-conceptions of people with spinal cord injury, there is general agreement that a state of acceptance of spinal cord injuries is never reached and that people with spinal cord injury are continually negotiating their adjustment with the rest of the world (Richards, 1982; Oliver et al, 1988; Freeth, 1993; Murphy, 1987; Hammell, 1992; Hitchcock, 1998).

**Summary**

The literature shows that the first requirement of people with spinal cord injury was attention to their injury and quality treatment. People with spinal cord injury were aware of family tensions created by their hospitalisation; they also had to "survive" in authoritarian hospitals. No acknowledgement was made of the emotional impact of spinal cord injuries and information on sexual functioning was considered inadequate.

After their return to the community, participation in social life pre-occupied people with spinal cord injury. A number of barriers affected their return, such as lack of accommodation options for community living, the barriers of physical inaccessibility, the loss of friends, enforced family dependency and a world in which income earning is difficult and often financially unrewarding.

A number of other requirements besides social participation also manifested themselves. People with spinal cord injury longed for independence from drugs and their side effects and frequent episodes of re-hospitalisation. They also wanted freedom from the mental domination of spinal cord injuries which presented as questions about their unlucky fate, the need to re-work
continually "acceptance" of their injury, the need to plan ahead and difficulties in maintaining a positive mindset.

Crow (1996) has argued some of the impediments to social participation may stem from their impairment as well as social barriers. A number of the conditions inherent in spinal cord injuries such as the lack of acknowledgement of the psychological impact of the injury, the side effects of drugs and the "narrow margin of health" (Freeth, 1993) affect social participation, although there is a need for further detailed examination of the origin of these issues.

**Conclusion**

This thesis seeks to throw light on the requirements of children and adolescents with severe spinal cord injuries. In the absence of literature on their requirements, literature on the requirements of people with disabilities and people with spinal cord injury has been reviewed. The review of both groups supports the ending of social marginalisation as a central requirement although the literature also indicates a number of other important requirements held by people with spinal cord injuries in addition to ending marginalisation.

As this study is based on the views of adolescents and parents of children with spinal cord injuries, it may be assumed that its findings will be similar to the studies examined above which were also based on the views of those who directly experienced impairment.

However, the requirements of children and adolescents with spinal cord injuries may be quite unlike adults or other adolescents and children with disabilities for a number of reasons. For example, many children and adolescents with spinal cord injuries may not remember the dramatic change from non-disability to disability and may be spared the emotional shock involved. Also, children and adolescents are located within the protective realm of families who are likely to advocate strongly for them. Because of the
younger age of onset, it also seems possible to adapt education and training to ensure that future quality employment is more probable.

To develop a more definite picture of the situation, it was thus necessary to undertake research to examine the requirements of the adolescents and children and the origins of these requirements. The results of this research are discussed in Part II, Chapters 4 - 7.
3 THE SOCIAL RESPONSES TO DISABILITY

In the previous chapter the concerns of both people with disabilities and people with spinal cord injury were examined because they foreshadowed issues for children and adolescents.

In this chapter, the social environment in New South Wales for people, including children and adolescents, with spinal cord injuries is examined: social welfare, settlements paid by insurance companies and other measures. The social welfare system in this chapter is defined as income support, services, aids and equipment. The principal form of insurance on which people with spinal cord injuries draw is Compulsory Third Party (CTP) from motor vehicle accidents, although workers' compensation, a similarly operated insurance, is also drawn by adults injured at work. In addition legislation to remove discrimination and to ensure positive outcomes from services for people with disabilities is also examined.

The aim of this chapter is to address the question of how well the above measures assist people with disabilities, including adolescents and children with spinal cord injuries. The examination considers how the welfare state addresses marginalisation and the removal of social barriers, the treatment of impairment, the interpretations made by others of the requirements of people with disabilities, the adequacy of benefits provided and the effects of eligibility criteria. Repeated themes in this examination are:

- The requirements of people with disabilities are framed in particular ways as "needs" and may bear little resemblance to what people with disabilities are seeking;
- Welfare provision reflects the practices and ideologies of "managerialism" which include "targeting", "rationing", "externalising" costs to other non-state agencies or sectors, such as the family, and increasing
responsibility for individuals to meet their own requirements and regulate their own behaviours (Purdy and Banks, 1999: 3-6);

- Services and support are based around the characteristics of individuals rather than removal of social barriers and preventing marginalisation;

**The social welfare system**

The existence of the welfare state, a twentieth century phenomena, has been accompanied by ideologies such as *the state takes ‘care’ of the ‘disabled’*, which has been accepted by the non-disabled population. The extent of this "care" usually shocks new recipients of “disability” welfare who come to perceive welfare as mean, miserable form-filling and only for the destitute (Taylor-Gooby and Dale, 1981).

The welfare state, it can be argued, was never intended to address such requirements as ending the marginalisation of people with disabilities. The welfare state represents a continued development of a compromise position, an attempt to placate the feuding sides of capital and labour in the late nineteenth century (Roe, 1976; Rowbothan, 1994; Donzelot, 1991). Given its origins, the welfare state could not attack the causes of marginalisation which are social arrangements in capitalist society. Rather, the welfare state operates within existing capitalist relations and attempts to ameliorate capitalism’s negative effects and compliments, rather than changes, economic and social policy (Oakley, 1994).

The operation of the welfare state has ignored claims of “need” from people with disabilities and applied an eligibility criteria to individuals which benefits only a proportion of claimants. All societies use criteria to decide who is excused from work and eligible for social benefits (Stone, 1984). Decisions on inability to work and treatment of disability from particular causes (war, deliberate and accidental injury from others, self-injury and congenital injuries) are ultimately political decisions which define moral and immoral behavior through the recognition and dismissal of claims (Blaxter, 1976).
Exclusion from welfare leaves many people with disabilities dependent on the "informal sector": family and friends.

**Income support**

- Pensions for adults

A primary requirement for people with disabilities is income derived from employment. When impenetrable social barriers prevent employment, people with disabilities have turned to the state which began the provision of the Invalid Pension, now the Disability Support Pension, in 1910, initially, only for those "who lacked family support" (Commonwealth Parliamentary Debates, 2/6/08: 1678, quoted in Kewley, 1980: 17).

Although Australia's pension is lauded because it is not dependent on previous earned income, the amount paid has been minimal - a replacement of private with state "charity" (Dixon & Hyde, 2000; Castles, 1985: 16). The adequacy of the invalid pension has been raised at various inquiries: the 1977 Australian Government Commission of Inquiry into Poverty, the 1985 Handicapped Persons Review (HPR) and at the Social Security Review where the lack of supplementary payments recognising the extra costs associated with disability was noted, a serious concern for people with spinal cord injury (Cass, et al 1988:61; Australian Quadriplegic Association, 1999).

The minimal nature of the payment has been further compounded by the operation of income and assets tests. These impact harshly on many married women with disabilities, those drawing some income from workers' compensation or damages or other sources. The effect is not only to ensure pension recipients are "trapped" in their poverty but they are also discouraged from a gradual return to work (Meekosha, 1990: 39; Bedwell, 1986: 40).

Eligibility for the Disability Support Pension is restricted by age, 16 to 64 years, the point of eligibility for age pension. Recently, the payment amount for those under 21 years living at home was reduced which has effectively
reinforced dependence at a time when young people are seeking independence.

The use of the Disability Support Pension category to absorb unemployment has complicated public support for people such as people with spinal cord injury. The number of invalid pension recipients has grown steadily since 1969 as a percentage of working age population and analyses of claimants' characteristics reveal a concentration of older male pensioners (Sullivan, 2000; Cass, Gibson and Tito, 1988). The cause of these increased numbers has been attributed to structural labour market changes and the shedding of older male workers, many of whom had injuries and disabilities and lacked qualifications to gain alternate employment. This finding supports Stone's thesis (1984) that "disability" is a category which the state uses to "store" excess labour. The fact that there are large numbers in the "disability" category currently is likely to mean that the state, as the funder of pensions, will be reluctant to increase pension adequacy or reduce the severity of income tests.

- Income support for parents of children with disabilities
The state has framed the needs of parents as a monetary payment which will encourage them to maintain the child in the family rather than turn to institutionalisation (Australia, Senate, 1974). In 1974, the Handicapped Child's Allowance (HCA) was initiated for children under 16 years of age. The payment attracted criticism in both the Handicapped Persons' Review (1985, 54-56) and the Social Security Review (Cass, Gibson and Tito, 1988: 66-68) for its stigmatising qualities, its inadequacy and its administrative complexity. In 1987, the non-means tested, one level Child Disability Allowance (CDA) replaced HCA. The eligibility criteria of CDA resulted in an uneven regional spread and an increase in medical conditions for which CDA was claimed (Thomson, 1993: 3, 4) and it was replaced with the Carer Allowance and Health Care Card, or Health Care Card only. Eligibility for the Carer Allowance is based on children's functional ability for their age which has reduced the numbers of children with medical conditions such as diabetes and asthma claiming benefits (Stratton and Delaney, 2000).
Services

Some of the services commonly used are examined below. Many of the services are funded by governments but provided by the non-government sector which has meant cheaper costs for government.

- Employment assistance
  The state has developed a number of employment programs for people with disabilities but these programs usually work on individual characteristics rather tackle the social barriers preventing employment. Further, programs are "targeted" to benefit only those defined as "needy" and a large proportion of potential claimants, estimated at 60 per cent, obtain no employment services (Baume and Kay, 1995). Unlike income support, disabled people are not "entitled" to participation in an employment program. Participation is "serendipitous" and "dependent on the presence of a powerful advocate". This situation arises because employment programs are "budget-capped" and "with no growth mechanism related to need" preventing many people with disabilities from participating in programs (Baume and Kay, 1995: 1-7). Moreover, sifting through the proliferation of programs at Commonwealth and State levels is confusing and time-consuming (Baume and Kay, 1995: 7).

The state also provides incentives to encourage employers to provide employment opportunities for people with disabilities. Incentives take the form of "wages subsidies" to employ suitable employees and financial assistance for workplace modification or the purchase of special or modified equipment (Dept of FaCS, 1999: 147). While these programs make the employment of people with disabilities more attractive, this approach ignores the perceptions of employers and their employment decisions about people with disabilities as employees (Disabilities & Learning Unit, Dept of Education and Training, 1998).

Formidable barriers encountered by people with disabilities participating in employment remain unaddressed, such as lack of information on state financial incentives to fund the transition from pension to employment
(Newey, 1987). Moreover, the cost and unreliability of transport has also been a major disincentive and many people with disabilities have identified "a lack of flexible options" such as part-time work, either as a "trial" or permanently, as barriers, and lack of support for "job finding", for training and "on the job" (HPR, 1985; Newey, 1987; Ronalds, 1991; DHS & H, 1994). In addition, work often incurred extra costs such as wear and tear on orthopaedic devices (Ronalds, 1991; HPR, 1985). Many workers with disabilities experience discrimination by employers and co-workers and many disabled workers felt they had to "prove themselves" and work without the informal help workers usually give each other (Ronalds, 1991: 9, 16).

Participation in employment also affects eligibility for other benefits, such as Continence Aids Assistance Scheme (CAAS) and Mobility Allowance. Only the continence needs of those who are employed, participating in job training or looking for work and have permanent disability-caused continence and are aged between 16 and 65 years are acknowledged by CAAS, a Commonwealth Scheme, started in 1992, to reduce the cost of disability for those working (Eayrs, 1994). The cost of CAAS is minimised by excluding those unable to participate in work (paid or voluntary) who are the largest proportion of people with disabilities and people with disabilities in nursing home residents, already losing a high proportion of their DSP in accommodation charges (Kidd, 1994: 4). The Mobility Allowance, similarly, does not recognise the needs of people with disabilities outside of the labourforce or unable to participate in training or voluntary work.

**Provision of aids and equipment**

The Program of Aids and Appliance for Disabled People (PADP) is a joint Commonwealth-State program, administered by the NSW Dept of Health, which also frames need to exclude certain groups and minimise its expenditure. PADP aims to reduce dependency at home and at work and has excluded compensation claimants and nursing home patients (Kidd, 1994: 4). New South Wales administration exercised through hospital boards, has produced wide disparities in consumer charges and income
testing and claimants have been discouraged through such methods as lack of advertising of PADP, substitution of prescribed aids and appliances with cheaper but less effective devices (Brice, 1994; Law, 1995: 33; Disability Council of NSW, 1987: 38).

- **Transport**
  A dominant issue for people with disabilities affecting social participation remains the inaccessibility of public transport. Work on removing the access barriers on public transport under the Commonwealth Disability Discrimination Act (DDA) indicates that it will be up to 30 years before all public transport will be accessible (Corcoran, 2001). The Taxi Transport Subsidy Scheme (TTSS) which allows people with disabilities a 50% discount in taxi fares remains too expensive for many people with disabilities and those using the Scheme in rural areas find they easily exceed the distance limits of the Scheme (Gambetta, 1996: 26).

- **Supported accommodation**
  Accommodation and accompanying support has been limited in New South Wales where government has acknowledged this need for people with psychiatric and intellectual disabilities, only. Before 1981, need was recognised as institutional care and after the Richmond Report in 1982-83, "deinstitutionalisation" and community care satisfied this need (Hardwick, James and Brown, 1987: 28). Implementing this report was estimated to save the NSW government, "at least 10 to 15 per cent [of operating costs]" (Richmond, 1983: 18, 44. Many people with disabilities living at home with their parents and many leaving hospital after injury have sought supported community housing but there has been little available for these people, a fact that has been masked by "deinstitutionalisation" (Sach and Associates, 1991: 8). Remaining in hospital or nursing homes is forced upon some people with spinal cord injury, for example those who are ventilator dependent, because community accommodation and support for using medical technology is unavailable. Under the Commonwealth-State Disability Agreement, the NSW Government has acknowledged some people
with disabilities including people with spinal cord injury and limited supported accommodation has been provided for individuals in crisis when funding has been available.

- **Health**
  Once out of hospital, people with disabilities are likely to be excluded from the "user pays" health system because of their low incomes. They must find general practitioners willing to "bulk-bill" or attend an outpatient clinic at a public hospital. Other health services such as dentistry, counselling and therapies (physiotherapy, occupational and speech) which are not covered by Medicare, must be sought from hospitals and community health centres. These services, frequently assessment only, vary between areas and, if available, involve long waiting periods (New South Wales Health Department, 1994). Access to reduced price drugs through the Pharmaceutical Benefits Scheme (PBS) Safety Net depends not on the requirements of consumers but on the cost of drugs to the state, the medical profession's opinion on a drug's efficacy and price arrangements with pharmaceutical companies (Kemp, 1996: 83, 84).

- **Education**
  A major concern of parents and adolescents is the education available to students with disabilities. The government school system provides a dual pathway for students with disabilities: integration into the "normal" classroom or attendance at a special school or a support unit to receive special education. Various arrangements exist in the non-government sector. These services are discussed in detail in Chapter 6.

**Assistance available from settlements paid by insurance companies**

People involved in accidents at work or motor vehicle accidents may receive "welfare" via payments from insurance companies. While this examination concentrates on the NSW Compulsory Third Party (CTP) insurance scheme for motor vehicle accidents, workers' compensation insurance claimants are
likely to have similar experiences. Insurance makes no attempt to address the marginalised status of people with disabilities and removal of social barriers. The result of a successful claim is to shift the responsibility for managing disability to the individual and to close the case; unsuccessful claimants must turn to the social welfare system.

The "needs" of only a proportion of those injured in motor vehicle accidents are recognised through Compulsory Third Party (CTP) insurance. The NSW scheme, initially established to meet the interests of the state, the insurance industry and the legal profession, has applied a narrow recognition of "need" based on a particular interpretation of "cause" and a value judgment that those who caused an accident should not benefit from insurance. This interpretation, which incidentally depicts social welfare benefits as punitive and the last resort, is based on a social construction of motor vehicle accidents in which driver negligence, is defined as the main cause of accidents and the "bad behaviour" of one person causes undesirable consequences for others (Douglas, 1970: 29; Johnson and Covello, 1987). The "constructed" nature of "driver negligence" can be seen when common experience suggests that a number of factors precipitate accidents, for example - road design, vehicle design, weather conditions and "the high use of road transport to produce an atomised, flexible workforce requiring minimal employer organisation" (Roberts and Coglan, 1994: 752). Immoral behavior and the perceptions of public risk justify state management and control of accident consequences for "public good" (Nelkin, 1985).

In New South Wales, the inability to show fault in another restricts the potentially large numbers of road accident claims and prevents a significant proportion of injured people from claiming any compensation despite their serious injuries (New South Wales Law Commission, 1984: 6). The proportion of road accident victims recovering compensation is unknown in New South Wales but the National Committee of Inquiry into Compensation and Rehabilitation in Australia, the "Woodhouse" Inquiry, cited NRMA estimates of only 60 per cent of accident victims having potential tort cases; of those, some would fail for various technical reasons (National Committee
of Inquiry, 1974: 51). The New South Wales construction of injury as caused by negligent drivers contrasts with “no fault” constructions in other states where injury is a risk associated with roads and all injured person are potential claimants.

It is a regular practice of insurance to exclude many social groups either initially as premium payers or later as claimants. A common device is to scapegoat particular groups as the “cause” of their fate. Young males are depicted in motor vehicle accidents as “great risk takers” and this justifies their higher premiums and other financial penalties; children are seen as “careless pedestrians” which legitimates education programs and then the assumption that they are responsible for their fate (Roberts and Coglan, 1994). In the US, private insurance calls for excluding certain individuals or reducing the benefits of those deemed not to take ideologically defined "personal responsibility" such as “smokers” who “are causing all to pay increased premiums” (Crawford, 1977: 663). These groups then become subjected to moral and psychological condemnation (for example, smokers are "unable to control their addiction") and to social controls which also encourage divisiveness and tension among groups (Minkler, 1983: 166).

Ordinary people, including people with disabilities, are powerless against insurance companies. There are no clear statements of what policy-holders have received in exchange for their insurance premiums. Insurance companies argue premium payers have no “rights” with regard to insurance as private institutions cannot guarantee rights - this is the role of the state; ideologies, such as individuals are responsible for their state of health, “justify a retreat from the language of rights and policies of entitlements” (Crawford, 1974: 668).

Many "successful" CTP settlements provide insufficient moneys for long-term care for those with severe injuries. Some of the insufficiency is due to "victims contributory negligence" in which those who are believed to have contributed to the “cause” of their accident have reduced compensation amounts on which to manage, an advantage to insurance companies. The
current proportions for contributory negligence are not known but damages were reduced for twenty-three per cent of all Australian cases with total damages reduced by an average of 40 per cent in a 1974 survey (National Committee of Inquiry, 1974: 50-52).

In other cases, the reason for insufficient settlement amounts are more complex. Often, the amount provided is insufficient when claimants have waited many years. Before compensation is received many respondents have exhausted their savings, amassed debts and are drawing on state benefits and families for financial support (New South Wales Law Reform Commission, 1984,a). A further cause of inadequacy is court predicted "future accident-related expenses and losses". An examination of these estimates showed in 16 out of 17 cases that the courts' predictions were substantially wrong (Law Reform Commission, 1984,b: 3). Surveys in 1984 for the New South Wales Law Reform Commission showed the deficiencies in lump sum payments: half of the surveyed respondents were "financially vulnerable", living on Social Security or extremely small amounts, highly dissatisfied, due to the erosion of their awards and their limited employment opportunities (quoted in NSW Law Reform Commission, 1984,b: 2).

Examination of the workers' compensation scheme suggests insurance schemes are deliberately premised on shifting the costs of long-term claimants on to the public social welfare system (Bohle, James and Quinlan, 1991: 250). Insurance companies, it is argued, take legal action, usually successfully, to terminate weekly payments to workers' compensation recipients, particularly if medical evidence is "ambiguous", such as soft tissue injury. It is likely similar activities occur in CTP, where payments are paid in a similar manner such as payments from the "Transcover" period of CTP insurance in NSW and inter-state payments. The shift to public welfare from insurance means a drop in income and services, particularly noticeable where payments have been earnings-related, and the effect of claiming welfare is experienced as humiliating, stigmatising and controlling (Arup, 1993: 270). While the stigma of welfare is not present in people with disabilities supported on CTP settlements, the shift to public welfare means a
loss of a "symbolic status", which is replaced with "failure to be competitive" in the labor market (Arup, 1993: 271).

**Recent reforms**

The Handicapped Persons' Review (HPR), began in 1983 and culminated in a report with recommendations, *New Directions*. A major aim of the HPR was to review the programs of Commonwealth-funded special services for people with disabilities and formulate recommendations in line with aspirations of people with disabilities. An important feature of the HPR was the strong input from people with disabilities. The analysis of their views showed the complexity of their requirements. A dominant concern was that the service system produced few "positive consumer outcomes" and resources were diverted to organisational activities. Further, it was noted that the institutional, rather than community, origin of many services isolated people with disabilities, that insufficient state resources were allocated to meet needs and that people with disabilities lacked service choices (Handicapped Programs Review, 1985).

Following the HPR, both Commonwealth and State governments enacted Disability Services Acts and Disability Services Standards. These pieces of legislation establish contractual relations between the funder (government) and provider of services. However, service organisations which have not shared the values in the legislation have found it relatively easy to evade or delay meeting legislative requirements (Leipoldt, 1993: 15). In other cases, the substitution of organisational goals with consumer-centred goals has merely been a change in rhetoric (Kendrick, 1992). Governments, due to decreased public service spending, have not monitored the performance of community organisations closely (Department of Health Services and Housing, 1994: 35) and the Commonwealth government has extended the time for meeting standards indefinitely with sheltered workshops and therapy centres reluctant to cease operations (Baume and Kay, 1995: 18).
The legislation is also places heavy responsibility on individuals with disabilities. Consultations with disabled people about their requirements for their "individual service plans" assume shared language and meaning between "clients" and professionals in plans and contracts, and ignores the different discourses used by each group and the power of professionals to impose their meaning (Rodger, 1991; Rojek and Collins, 1988). Moreover, many service plans are based on encouraging individuals to express their "needs" without consideration of the feasibility of meeting the "needs", hence creating disillusionment and disappointment (Mitchell and Graham, 1994). In other cases, the implementation of service plans is strongly resisted by parents and staff, concerned at loss of control and power (Mitchell and Graham, 1994). Generally, people with physical disabilities have resisted "individual service plans" believing these are an unsuitable model for them; such action may mean they disqualify themselves from services.

A further recommendation from New Directions is the increased participation of people with disabilities in the management of services. Overseas experience indicates organisations can avoid the participation by people with disabilities in management by using various devices such as heavy emphasis on written English, questioning "representation" and the continued regard of lack of participation by people with disabilities as "natural" (Drake, 1996; Drake, 1992; Bewley and Glendinning, 1994).

The Disability Discrimination Act (DDA) aims to end discrimination on the grounds of disability by imposing an obligation not to discriminate, and gives a corresponding right to complain if the rights of disabled people are not equal to the rights of other citizens. The DDA covers both direct and indirect discrimination in most aspects of community living such as employment, access to buildings, public transport and education (Halliday, 2000; Ronalds, 1991; Newey, 1987). When a complaint is made, the Human Rights and Equal Opportunity Commission (HREOC) investigates and, if appropriate, conciliates. If the matter is not resolved it may be referred to the Federal Court for a binding decision. The Act allows persons or organisations which
can demonstrate they would experience "unjustifiable hardship" to be excused from the obligations imposed by the Act.

In addition to the two mechanisms above, Disability Standards may be made under the DDA for certain areas such as education or transport and these provide some certainty, some clarity of expectations around rights and expectations (Halliday, 2000; Innes, 2000). The development of Standards which has involved people with disabilities, industry and government is a lengthy process - for example, Transport Standards have taken 6 years - but the process has been educative for all participants (Corcoran, 2001; Innes, 2000). Moreover, the development of Standards is a better process than defining expectations on a case-by-case basis.

Reduced public spending, a feature of managerialism, has impacted on HREOC staff who have commented publicly on the lack of resources they have in comparison with the tasks to be performed. This problem subjects HREOC to criticisms about delays in handling complaints and may affect the prospects of awarding appropriate remedies (Innes, 2000; 2000; Jackson, McAfee and Cockram, 1999:7). The privatised nature of conciliated complaints has also attracted criticism because it shuts off from public view existing injustices and inequality; the educative role of HREOC’s work is lost and people with disabilities are robbed of development of collective understanding of their issues but it is also accepted that many individuals would not pursue their complaint if it were a public matter (Innes, 2000; Thornton, 1990).

On the other hand, there are problems with pursuing complaints to the public arena, the Federal Court. Although the complaints process was designed for low income people to use, most complainants feel disadvantaged without legal representation. This is costly and little Legal Aid money is available for this use and the question of whether complainants will have to pay all court costs will have an inhibiting effect (Banks and Kayess, 1999: 27; Morley, 1999:5). A further issue about individuals pursuing complaints relates to an individual problem receiving an individual response. There may be
widespread benefit from a public inquiry on an issue with a procedure which allows a number of interested parties to comment and lifts responsibility from individual complainants. Some "individual complaints", however, have had far reaching ramifications, for example, *Scott v Telstra* which impacted on policy and the contents of the *Telecommunications Act* 1997 (Goggin and Newell, 2001: 92).

The influence of a neo-liberal value of individual responsibility can be seen in the mechanisms to activate disability discrimination complaints. It is unlikely that the social arrangements which produce marginalisation will be dented by cases brought by individuals. In addition, legal approaches place the responsibility to challenge behaviours on people with disabilities, many of whom are struggling to survive lack of time, energy and resources and are reluctant to take on a DDA or similar case (Azzopardi, 1994: 5; Newell, 1995). Moreover, people with disabilities are critical of the use of legislation to correct their marginalisation; the legislation, they claim, came from "above": bureaucrats meeting with peak bodies who represent service-providers, while people with disabilities remained voiceless (Leipoldt, 1993: 23; Newell, 1995: 63). Although the legislation has brought some improvements for some people with disabilities, many others feel their goal of an inclusive society, welcoming all human beings, cannot be promoted through legislation and administrative reforms; change in social values cannot be legislated into existence (Leipoldt, 1993; Newell, 1995; Bogdan and Taylor, 1989). As people with disabilities cannot wield power and enforce rights, change can only occur if social values develop which affirm their inclusion.

Further, the exemptions from DDA may increase marginalisation of some people with disabilities. For example, the exemption from the DDA of charities, increasingly important service deliverers, interacts with their exemption from the Federal Sex Discrimination Act, allowing charities to discriminate on a gender basis, a concern for women with disabilities (Cooper, 1993). Immigration policy is also exempted to prevent entry to the country of people who may make later claims on disability funds (Hastings,
In addition, the implementation of provisions required by legislation such as "access" provisions, leaves untouched who will bear the ultimate costs. In organisations such as universities, negotiations may involve a number of parties and people with disabilities, if unsupported, may be disadvantaged in the final decisions (O'Connor and Watson, 1995: 46, 47).

Summary

This chapter has examined the helpfulness of the forms of public assistance for people with disabilities including children and adolescents; the likelihood that children and adolescents with spinal cord injuries will fare differently is slight.

The assistance provided is "partial" in that the benefit is usually insufficient and that it usually benefits only a proportion of people with disabilities. This assistance is provided in a climate which values reduced public sector spending, individual responsibility, targeted assistance to those who must be helped and which acknowledges no power differential between different social groups such as people with disabilities and service providers. Moreover, little effort is directed at removing barriers which prevent social participation because the state has realised that it is easier and more economic to provide minimal payments and assistance to those who meet tight eligibility criteria and are members of targeted groups.

Ideological constructions such as "living in the community" have disguised the inadequate service provision underpinning such initiatives which are turned into desirable social goals.

Insurance companies also limit who they assist and the amount they provide by using various technical distinctions. When the claims of individuals are successful, the management of money becomes their responsibility. Further, the amount received is likely to be inadequate for the expenses of individuals over an extended period and eventually they become claimants on the social welfare system.
The mean nature of public assistance indicates that the state has counted on families to plug gaps and this forces many people with disabilities into dependent family relationships. Most people value families for an affective relationship and dependency frequently destroys this relationship (Dean and Taylor-Gooby, 1992).

The helpfulness of the legislative measures (the Commonwealth Disability Services Act 1986, the NSW Disability Services Act, 1993 and the Commonwealth Disability Discrimination Act 1992) is also limited. Marginalisation stems from social arrangements and challenges by individuals with disabilities of the actions of organisations or individuals is unlikely to produce the change in social values needed for inclusion of people with disabilities in society. Moreover, the personal inclination and capacity of individuals with disabilities to challenge professionals and large organisations has not been recognised. The success of these pieces of legislation is also limited by the lack of public expenditure to implement their aims.

Whether these public forms of assistance benefit children and adolescents with spinal cord injuries will be examined in the following chapters (4 - 7) in Part B.
PART TWO
4 FROM HOSPITAL TO HOME

In this chapter, data from interviews with parents and adolescents on their early experiences is examined and discussed in light of the literature review. Interview participants varied in the length of time since onset of spinal cord injuries: the average time was 5 years. (Further details: Appendix IV, Table 5). I contend that the requirements of children, parents and adolescents stem from the wholly medical interpretation of their requirements at this early stage and the disregard of other aspects of their injury.

Background

Life with spinal cord injury is a modern phenomenon. Men with spinal cord injury in World War I almost always died within a year of injury of complications such as urinary tract infection. In World War II, the prognosis was only slightly better. In 1944, Guttman, one of the "pioneers" in spinal treatment established a specialist spinal unit at Stoke Mandeville, England. Treatment following the principles established there has dramatically improved life expectancy of people with spinal cord injury to 85-95% of the general population (Australian Health Ministers' Advisory Council Superspeciality Services Subcommittee, 1990: 1-7).

After the incident which precipitated their spinal cord injury, children and adolescents usually were in intensive care wards in major hospitals, and when stabilised, transferred to wards with specialist treatment of spinal cord injuries. This acute care is provided through Australia's Medicare program which provides free universal treatment to residents and reinforces the notion that the state will provide crisis care but the family will be the main provider of everyday care. Adolescents then usually went to rehabilitation. Until recently, no children's rehabilitation has been available.
Periods in hospital varied. Hospitalisation for adults with complete quadriplegia at Royal North Shore Hospital, in 1982, required 24 weeks for 50% of patients (Dowda, 1982: 161), but times have gradually been reduced since then, driven by a push to reduce costs. One adolescent spent four weeks in hospital followed by three months in rehabilitation; this was considered a short period. One child spent four months in hospital, not an unusual time span.

**The acute period in hospital**

An important requirement for adolescents recovering from their acute treatment was understanding their treatment and the rationale behind decisions. One puzzling aspect for adolescents was the determinants of their length of stay in hospital which they described as "raced", "too short" and "tense". Indicators for their length of stay, assumed to be physical progress, were not obvious to the adolescents and, for them, physical progress lacked meaning. One adolescent, praised by hospital staff for how quickly he was up and out of hospital, gave a different interpretation: "I was rushed ... and three months after my accident I'm home wondering what on earth I'm going to do with my life".

Under the influence of the "medical model", medical professionals have felt no necessity to explain their actions and often questions from patients have not been welcome. It may be argued that hospitals must function bureaucratically as hierarchical, goal driven "total institutions" (Goffman, 1961) and medical treatment must be dominated by medical profession and its discourses. But this does not deny the negative effect it has on patients and families.

While many individuals in the medical profession have relaxed, there are now pressures for cost containment in the health system. "Control of hospital based spending" has meant application of economic principles to influence public hospital service delivery (De Abreu Lourenco, Foulds,
Smoker and Hall, 1999). Increased "efficiency" is emphasised which means hospitals aim for a greater "throughput" which may be achieved by a number of means including transferring costs of convalescence to the family "sector" (Clarke, 1999: 58).

Managing family life when one member is hospitalised so family members other than the person with spinal cord injuries also have their requirements met is an issue which affected the families of children and adolescents as well as adults (Hitchcock, 1998; Morris, 1989). Although parents appreciated the acute care for their child, they wanted their multiple demands acknowledged, and if possible, concessions granted, a requirement also sought by adults with spinal cord injuries (Hitchcock, 1998). Hence parents viewed their child's length of stay in hospital as "too long". The stays caused particular problems for non-metropolitan families who believed they should be with the injured child/adolescent. City accommodation had to be found; competing interests of other children had to reconciled, and parents had to organise for continuing workforce participation while meeting these requirements. In a number of cases, parents or other family members were also hospitalised from the same accident as the child's. Hospitalisation often occurred away from the support of other family members and friends from whom there were lengthy separations. Family misunderstandings developed such as between spouses, separated to resolve family responsibilities in different locations. However, economic efficiency, the small number of cases and the distribution of specialist knowledge and equipment dictates the centralised location of hospitals which leaves a myriad of difficulties for both metropolitan and non-metropolitan families and exacerbates financial problems for those on low incomes (Blackburn, 1999).

When the accident occurred interstate, treatment and rehabilitation occurred interstate but later, on returning home, the family had to orient to local services. This had meant, for some children, up to four different hospitals, some of which attempted to change children's routines with detrimental effects.
Unlike children, hospitalised adolescents and adults are usually aware of the difficulties of the situation and register guilt (Morris, 1989; Hitchcock, 1998). In addition, they may "work" by cheering others up, such as depressed relatives (Hitchcock, 1998).

While their child was receiving treatment in hospital, parents found their authority over their child was challenged. Parents generally believed they had power to make decisions about their children and were uncomfortable with ceding authority to medical professionals. The hospital experience was perceived as "not normal" in that "the child lived with hundreds of people" and was not "under parental control". When the rationale for particular treatment modes was well explained to parents, the power over parents was not felt; however, when disagreements occurred parents were overpowered:

"We were always confronted by a team of 3 to 4 doctors and several nurses ... we weren't able to make any impression on this strong team". (Parent of A)

The literature on adults with spinal cord injuries indicates no clashes of authority over adult patients as occurred with children. However, hospitals asserted their authority over the families of adult patients when needed - for example, informing the spouse and children of a man that they had to conform to visiting hours despite his strong desire for their presence and the assistance they provided (Hitchcock, 1998).

During hospitalisation, parents managed the demands of two systems: those of the family and those from the hospital. Parents mentioned other children being in "critical years at school" and also needing parental support at the same time as the injured child or adolescent. Like family members of adults with spinal cord injuries, parents also "worked" and the work similarly had to be performed on the hospital's terms (Hitchcock, 1998; Strauss et al: 1984). One form of work was psychological support of the patient, a tacit acknowledgment that the hospital's work was about the "physical". The task of bringing the child to an understanding that he/she would not walk again fell to parents which was emotionally draining.
Another form of hospital work was practical services which parents expected to be valued. Hierarchical hospital work arranged medical professionals at the apex and unpaid parent labour at the base but parents' lack of understanding of hierarchical, hospital organisation caused them to be perplexed by many aspects such as nurses' lack of co-operative working arrangements with them. Most parent work was personal procedures such as catheterising, rationalised as "useful knowledge for later". Staff's ideological commitment to mothers as carers caused them to challenge fathers acting in this role. The fathers in these roles were not comfortable especially when criticisms of their role were apparent; it is unclear why the critics offered no alternative arrangements to remedy these situations.

Parents and adolescents required smooth organisation within hospitals which did not make them feel unwanted or "embarrassed" but the many hospital specialties, each with their own "conflicting frames of reference", were rich sources of disputes when decision-making by one affected the vested interests of the other (Taylor, 1970: 26). Parents sensed friction between hospital teams when hospital staff discussed whether the child should be in the spinal unit with adults or a children's ward, or when they argued about whether the child should be at therapy or hospital school.

Responses to the emotional impact

Clearly, adolescents, parents and children wanted the emotional impact of spinal cord injuries acknowledged and forms of assistance offered to them, a requirement which was strongly felt by adults with spinal cord injuries (Richards, 1982; Oliver et al, 1988; Morris, 1989; Freeth, 1993; Hitchcock, 1998). On reflection, both adolescents and parents believed they should have received "counselling" which should have comprised "preparation" and "examples" plus practical information. Adolescents mentioned their continuing feelings of shock, depression, grief, anger and frustration. All adolescents except one who believed concentrating on the present and the immediate future prevented "flashbacks", reasoned that their negative feelings could have been lessened by "preparation" for their first public
appearance in their wheelchairs, for attending school and for the sight of
home, modified with ramps. One adolescent stated that no one could
explain why he felt tired and depressed but he reasoned that, as the effects
had been observed in others, he could have been warned.

Parents also said they would have valued preparation for the range of
emotional feelings they had felt - "anger, frustration, ... coming to terms with
a family member in a wheelchair". Preparation could have included
reinforcement for handling professionals: "You don't have to take 'no' for an
answer".

Both adolescents and parents believed forewarning and preparation should
have been carried out by social workers (who instead "asked a lot of silly
questions" and "worried more about taxi forms"), counsellors and
psychologists and "counsellors in wheelchairs, early in hospital or into
rehabilitation units".

The second part of emotional assistance should have been "example".
When adolescents later came across other "successful" people in
wheelchairs, they had felt encouraged and learned practical information.
Therefore, they argued that meeting these people earlier would have helped
them to feel fewer negative emotions. Parents thought other parents ("Only
people who've been through it can understand") and "counsellors in
wheelchairs" and "peer support models sent into the wards by community
disability organisations to show there's life after injury" would have been
helpful. However, one parent who had been forewarned of some difficulties
such as "the likelihood of marriage breakdown" said that parents were in
such a state of shock in the first year that "you can't take anything in".

Without the ideals of "preparation" and "example", parents and adolescents
talked about their continuing handling of emotional aspects in individualised
terms ("We're on our own") and the requirement of personal strength ("I can
cope, I've learned to cope - I've had to"). Adolescents stated they had been
offered no assistance which they interpreted as counselling. The picture was
less clear for parents: some stated no offers were made and that "everything was concentrated on the physical side". Others reported rejecting "feelings-based social work " ("How did you feel when you saw your daughter couldn't pick up a pencil?"). Another parent stated that she had been asked how she was "coping" but later, wondered if this was an enquiry as to whether she wanted counselling, which a few years later she believed would have benefited her.

Why acknowledgement of the emotional impact of spinal cord injury does not occur seems linked to the medical interpretation of spinal cord injury. Critics of the medical interpretation of suffering see emphasis on physical distress, with the broader meaning of the injury to the patient ignored or minimised (Charmaz, 1983). It seems likely that this emphasis has now been replicated in economic definitions of medical work which must now perform measurable, physical "curing" work in line with indicators such as "case-mix", rather than "caring" work, which incorporates inquiry into emotional reactions and which lacks formal recognition and institutional support (Small, 1996); further, if this work is also "externalised" to the family sector it represents a savings on hospital expenditure.

The form of recognition of the emotional impact of spinal cord injury is important and requires further research. It may be that adolescents, children and parents would have found simple acknowledgement of the impact of the injury, rather than "the stiff upper lip" which occurs in many hospitals, sufficient (Morris, 1989). The helpfulness of formal counselling is questionable if it reinforces an individualistic perspective (Oliver 1987; Oliver, 1983): in most counselling perspectives, the "problem" lies in the individual or the family or parents of the individual who are maladjusting to the social world, rather than the social world's structure and design which is left unquestioned, and thus legitimated (Oliver, 1983: 15; Oliver, 1987: 115). A further "danger" for people with spinal cord injury is the expectation by some professionals that they must make a psychological adjustment which requires passing through "adjustment stages" despite that the lack of
evidence that this model reflects the experiences of people (Trieschmann, 1980: 47; Oliver, 1983: 15-22).

Rehabilitation.

Adolescents, like adults with spinal cord injuries, were critical of their rehabilitation (Richards, 1982; Oliver et al, 1988; Morris, 1989; Freeth, 1993; Hitchcock, 1998). The definition of rehabilitation was medical, allowing non-medical areas such as emotional concerns, information and connection with community services, practical issues on using wheelchairs to be overlooked. Adolescents noted that this was an arena in which counselling might have occurred; instead, adolescents reported rehabilitation was "boring" and "lonely", although some learning did occur. They had expected connections with other organisations such as the Commonwealth Rehabilitation Service (CRS) might have occurred rather than some time after they arrived home. When connections with the Program of Appliances for Disabled People (PADP) for obtaining equipment such as wheelchairs were not made during this period, adolescents later experienced delays and inconvenience. Moreover, adolescents were generally viewed as lacking expertise and the insistence of rehabilitation professionals on knowing the "right" kind of wheelchair and dismissing their opinions meant some adolescents were later using unsuitable chairs at home.

The lack of children's rehabilitation facilities generally meant children either had unsuitable rehabilitation or none. Some children, "rehabbed" outside of Sydney, reported placements with severely handicapped children with cerebral palsy and spina bifida or "rehabbed" with amputees or with elderly stroke victims whose requirements dictated the programme. In the Sydney area, children had to wait until old enough, usually adolescence, to obtain rehabilitation, in some cases returning years after their accident. Some adolescents have returned to rehabilitation on a regular basis.

The experience of adolescents is supported by the literature on adults (children in this study had not received any rehabilitation after their initial
hospital stay). Both groups saw the treatment as lacking direction, with no discernible pattern to the treatment, little consultation and opportunities to connect with other services were not made. In addition, the treatment was perceived as inappropriate when other patients such as the elderly were also participating and people with quadriplegia believed they received less attention than people with paraplegia. Moreover, the treatment was criticised by adolescents for its sporting emphasis and “male” orientation and, where it was available, was considered to be inferior outside of the metropolitan area.

Better integration between hospital services, rehabilitation services and community services and the development of children’s rehabilitation services, have been acknowledged as lacking in NSW. The provision of quality rehabilitation, however, is impeded by a number of organisational factors such the lack of integration between acute care and rehabilitation services and general economic pressures on the health, system, such as casemix formulae, for the management and funding of acute care (NSW Rehabilitation Working Group, 1995).

The purpose of the spinal cord injury

Individuals attempt to re-establish order in their lives after an illness or "biographical disruption" by establishing purposive causes for why the event occurred (Williams, 1984:179). Making sense of the event was resolved by one parent who subsumed the puzzle in a theodicy of God's purpose (Voysey, 1975: 165):

"I still truly believe He's done it for a reason - F is something important; she's got a purpose. People have to believe there's a reason why. That's kept me sane." (Parent of F).

Viewing spinal cord injury as a "compensation" occurred in the immediate consequences of the accident by parents who had feared death or brain injury and were grateful these had not occurred; one parent stated how he found it helpful to remind himself continually of what he had, "instead of what
was lost”, a view which is reinforced by voluntary agencies and magazines (Voysey, 1975: 185).

Other parents retained their views of the meaninglessness of the event, a random act of unfairness and cruelty. Where parents believed disability was a punishment for sins, they were indignant that they did not deserve the responsibility of a child with disability and it should have happened to others: “[those] who deserve it and drink beer all the time and bash up their wives” (Parent of K). When a similar accident produced different outcomes - quadriplegia in one case but not the other - these events were also hard to reconcile. One adolescent mentioned how a nearby resident had “a similar accident to mine and he's up and walking with a caliper on his leg” (Statement of O).

Summary

The requirements expressed by parents and adolescents refer to the beginning “career” of children and adolescents with spinal cord injuries. These requirements are their reflections now on what they think they required or what should have happened.

The Australian public welfare system in the form of universal acute medical care meant that all children and adolescents were entitled to treatment. Nonetheless, the operation of the hospital and its medical personnel were the main source of requirements at this stage. While there were no complaints about the quality of the acute care, the importance for parents and adolescents of understanding the rationale for particular treatments or the length of stay was not recognised by medical professionals. Where practicable, adolescents and parents stated they wanted to participate in decision-making.

Parents found the authoritarian nature of the hospital difficult and wanted a more co-operative “working together” relationship with hospital in which the efforts of both parties were acknowledged, difficulties were negotiated and
hospitals checked with the opinions of parents regarding treatment of children.

Adolescents required rehabilitation in which they understood and participated in the development of goals and during which opportunities were taken to connect with community organisations. Children also required quality rehabilitation which was tailored to their particular needs.

The focus of the hospital treatment on the physical impairment meant that a requirement of great importance to parents, children and adolescents was not acknowledged: the emotional impact of the injury.

Why their child was singled out for spinal cord injuries and significance of this had been questioned by some parents. Most did not mention seeking an answer on this issue but that they considered the random act which led to spinal cord injuries was unjust and unfair.
5    LIVING IN THE COMMUNITY

Introduction

The purpose of this chapter is to examine the dominant concerns of parents, their child and adolescents returning home after hospitalisation and, for some, after rehabilitation. For many adults where they would live and with whom were major issues to be negotiated (Richards, 1982; Oliver et al, 1988; Morris, 1989; Freeth, 1993). However, for the children and adolescents in this study, return to the family home was automatic.

Analysis of the requirements of children, adolescents and parents showed they are in a state of constant change and are affected by a myriad of factors such as the development of knowledge of parents and adolescents, the discovery of services and the rejection of others, the developmental needs of children and adolescents, changes within families and in some cases the availability of settlement money. The evidence in this chapter indicates that the requirements of parents, children and adolescents are associated with medicalised management of an injured person. This requirement weakens and the dominant requirements are related to the resumption of age-appropriate activities which are impeded by a number of barriers.

Returning to the community

The main requirement for parents and adolescents which arises in returning to the community is for a smooth transition which is supported by the preparation of the hospital with local medical treatment available and information and referral to local community services. The narrow medical definition of spinal cord injury as physical suffering treated in hospital by the medical profession means living in the community is given no serious examination. Hospitals prepare discharge plans but there is no monitoring
that services identified in the plans are received by discharged patients; moreover, patients are leaving hospitals in highly dependent states because of hospital policies to reduce length of stays (Reedy and Bragg, 2000).

The early experience of parents and adolescents at this time was dominated by a sense of uncertainty and abandonment which stemmed from their poor preparation for community living by hospitals and from the lack of continuing sources of information after leaving the hospital. The hospital experience emphasises professional expertise and the amateurism of parents thus the overwhelming requirements for parents caring for children and adolescents after hospital discharge were assurances that they were managing children and adolescents correctly and sources of supplementary information and support. Feelings of poor preparation and having to learn by "trial and error" similarly plagued adults after hospitalisation (Freeth, 1993; Oliver, 1988).

Except in one case where the strength to return back to work after the accident was attributed to God, parents and adolescents viewed their transition as self-resourced: "I had to figure it all out myself. That's been the big shock of it all." (Statement of E) The remarks of parents and adolescents are strewn with references to "the fight" and "we have to battle alone". "They" in these cases are authority figures with professional or administrative power such as doctors, lawyers, social workers, insurance companies, the Public Trustee and nursing agencies.

Most of the community services on which families drew required prior knowledge of their existence or referral, usually on medical grounds. Parents, then, relied on professionals such as social workers to inform them of these services. But most hospital professionals were concerned with hospital services and did not look beyond to community organisations. Parents discovered such services as Home Care months after discharge. Two parents made no comment along these lines because the hospital social worker continued involvement in their affairs.
Initially, parents were uncomfortable contacting disability organisations because they represented a reality which parents had not accepted. Also, the organisations were viewed as stigmatising and families managed their sense of "normal" by distancing themselves (Gray, 1993: 105). A disability organisation providing direct services to "children with mental deficiencies", cerebral palsy or spina bifida, was perceived by parents and adolescents, to carry greatest stigma.

Adolescents, unless they were "thinking politically" or about future work and accommodation prospects, viewed disability organisations as "adult oriented" or "more interested in commoner disabilities". A number of parents and adolescents maintained contact with one organisation because it was a source of disability products while contact with others faded.

Adolescents and parents expected community services to provide services in accord with doctor's statements or the promises of the organisation. However, adolescents and parents judged them as indifferent to the requirements to people with disabilities because they were unreliable and were unresponsive to requests to meet requirements. One family who found their three prescribed hydrotherapy sessions at a country hospital averaged one per week, resolved "to get a heated swimming pool after settlement". Prior to settlement, compensable claimants were charged "exorbitant" amounts for community services; the rationale for higher prices was the potential family income rather than actual income at the time. Non-metropolitan children and adolescents found many services were unavailable. Moreover, the medical certification for accessing almost all community service and "disabled parking" was a further inconvenient procedure parents and adolescents.

Parents and adolescents, surprised at first to discover community professionals such as general practitioners knew little about potential complications from spinal cord injury, educated these professionals. Women with spinal cord injuries in the UK also noted this situation in their communities (Morris, 1989: 56). Gradually, parents and adolescents
became very knowledgeable about community services. Where equipment was available, it was invariably adult-centred and required adaptations; similarly, knowledge on children with spinal cord injuries was inferred from adult sources.

Parents and adolescents expected their experiential knowledge to be respected and appreciated the professionals who did not maintain “expert” and “amateur” distinctions. In conflict with the norm of deferential treatment of professionals, parents and adolescents often challenged professional opinions, because they believed, over time, that they had accumulated a “true knowledge” of the situation which professionals lacked. Parents challenged decisions on suitable drugs for children, hospital management, suitability of orthotic devices, whether a monetary grant from the Public Trustee was essential and so on. In contrast, professionals and administrators drew on more abstract, specialised knowledge based on typical behaviour and were motivated by efficiency, costs and “good practice”.

Parents and adolescents roamed the range of information, considering orthodox medicine and alternatives. Mentions of “cures” on television shows and in newspapers gave parents further research work. Obtaining this information resulted in rejecting some treatments such as anti-depressant drugs with the addictive qualities and experimenting with acupuncture and massage techniques, as well as “keeping up” with the latest advances in medical research publicised in the popular media. New equipment for exercising meant “soul searching” for parents especially when it involved “battling” to obtain the trust funds to take a child overseas to visit specialists. The experience of parents supports the literature on the difficulties of adults evaluating and making decisions regarding new discoveries or techniques (Hitchcock, 1998).

In only two cases, parents made no mention of either their increasing knowledge and challenging professional knowledge or turning to alternatives. In one case, the child's care had been taken over by a "home ventilation
which undoubtedly prevented the development of confident parental knowledge. In the second case, a single parent from a non-English speaking background with one other child, was very dependent on a social worker's services and had no critical comments.

Parents also engaged in "doctor shopping" to supplement their information and assure themselves that all possible actions had been taken (Darling, 1988). Many parents visited a number of "spinal experts" unless their treating doctor informed them he was "professionally offended" that they were checking his information, although parents were motivated by different reasons:

"One doctor will tell you something you don't know ... like how she should be sitting ... probably we had been told but it didn't make enough of an impact" (Parent of F).

Parents observing professionals attending courses on matters such as compensation claims, criticised that this information could be passed directly to them rather than mediated through others, such as social workers. Parents were also keen to learn from one another and some expressed a desire for parent support groups. Adults with spinal cord injuries showed no interest in mixing with others at this stage although women in hospital found their best sources of information were each other (Morris, 1989). Adolescents also expressed no interest in support groups, one person stating "Personally, I don't want to see people the way I am", possibly because, in seeing others, they would be confronted with a mirrored appearance of disability and how they must appear to others (Strauss, 1959).

Parents and adolescents' requirement for information and community services changed continually. Parents concerned about their child moving into adolescence searched for information and service guides and wondered if there is any community agency to advise on adolescence with spinal cord injury. In the end, service and information gaps either remained unfilled or became another task which the family acquired.
Home exercise programs

Participating in age-related activities by children and adolescents was hampered by home exercise programs which parents felt were not "normal" because they competed with homework and "general play as a kid - other kids are outside playing and these kids are inside exercising". In addition, parents wanted to be liberated from the responsibility for their adolescent or child’s home exercise programs, or if, the program was to be maintained then parents wanted arrangements that were more sympathetic to the needs of the family (Foy, 1997; Rees and Emerson, 1984; Steinberg, 1981). Adherence to programs also requires a clear understanding of the benefits for children and adolescents of programs and the progress they were making.

Most children and adolescents with spinal cord injuries, either on leaving hospital or at a later stage, were prescribed home programs to be followed. These programs, to parents and adolescents, meant time-consuming, often costly, work schedules such as regular swimming (hydrotherapy), standing- or walking-frame "work", electric muscle stimulation programs, "keeping weight down", "drinking lots of water", "learning the keyboard to help hands", "stretching tendons" and physiotherapy sessions.

The programs usually involved extra costs which particularly impacted on non-compensable adolescents. One adolescent stated how he had used a standing frame in rehabilitation but, now at home, could not afford to buy one and lacked space for its storage. Another mother expressed surprise that "some people pay out $2,800 for an RGO [reciprocal gait orthosis]". Both one-off costs and on-going costs such as maintaining a heated swimming pools were incurred. Where there had been a settlement, some families also employed "a carer" to take their child to a session such as hydrotherapy if parents were unavailable.

Another concern was the time programs consumed. Parents' time was saved when children and adolescents participated in programs during school
hours; one special school student received all his therapy at school and another student at a mainstream primary school went into his standing frame at school. Two adolescents had their physiotherapy sessions at home. Three children were taken to sessions by carers; sometimes, younger children attended the hospital sessions with their siblings because the mother had no carer for them. The time spent was variable but one pre-school child was standing in a pelvic support brace two hours per day for six days per week plus carrying out other exercises.

The travelling to participate in programs sometimes exceeded parents' capacities. One parent knew physiotherapy would decrease his child's spasms but his car was unreliable for the necessary trips. Declining these services left parents feeling uncomfortable.

Professionals expected parents to manage programs and while children and adolescents co-operated to some degree, some programs met resistance: children objected to drinking large quantities of fluids, "keeping ... weight down", and swimming led to urinary tract infection (UTI) and tiredness, and was thus avoided by two adolescents.

If participation is hard work and benefits are dubious, then why are the programs followed? When parents had seen professionals work hard they felt they had to make a similar effort: "Dr X really cares about the patients". Parents felt they were judged by their co-operation and adherence to programs; instinctively, they knew "impression management" was an important protective strategy to minimise negative judgments and interference in family life (Voysey, 1975: 158). There is a further question which is related to why some discourses dominate over others: how is it the medical risks of children and adolescents are emphasised when there are many other risks such as future education, employment and mental health which are not addressed?

Liberation from medical regimes is not an issue for adults with spinal cord injuries. Perhaps more medical regimes were expected of children and
adolescents, or adults had accepted their regimes as part of life or regimes were not imposed on adults.

**Re-hospitalisation**

Like the rest of the community, children and adolescents with spinal cord injuries want robust good health and no episodes of hospitalisation which interfere with their engagement in age-related activities such as schooling or study. However, as with adults with spinal cord injuries, many children and adolescents had “a narrow margin of health” (Freeth, 1993). The frequent re-hospitalisation of people with spinal cord injury is generally viewed as integral to the impairment. However, the re-hospitalisation rate might be reduced with different organisation of medical services, such as training of local doctors or teams from spinal units visiting people living in the community (Richards, 1982).

Re-hospitalisation was usually due to one of the complications of spinal cord injury such as chest problems or scoliosis operations and, sometimes, had been planned in advance or a suddenly sparked crisis. It was often in a different hospital with different doctors from the initial acute treatment and planned short stays sometimes were drawn out as complications developed.

Return visits to hospital - re-hospitalisation - meant interruptions in "normal life", a return to high stress and disruption to family and personal routines. Personal care routines, usually considered “sacred”, were not always respected, particularly if the hospital was different from the initial acute care hospital and this meant parents, children and adolescents were left with restoration work after a hospital visit.

Re-hospitalisation also meant parents had to be vigilant and prepared to challenge and educate hospital staff on facets of care for children and adolescents with spinal cord injuries such as the suitability of different drugs. During hospital stays, parents were surprised that unrelated complications could arise such as urinary tract infection and three parents commented on
pressure sores developing because staff were unfamiliar with the nursing needs of spinal cord injuries.

Distance from the hospital was not a criterion for priority admission to hospital and country families were astounded by the lack of special consideration for cost and time they had expended, when re-hospitalisation was postponed for a few more days.

**Normal Family Life**

Parents had a goal to return as fast as possible to their version of "*normal family life*." This is an ideological construct which reinforces the ideal that the family should be the source of all support and assistance to its members by stigmatising the use of community resources. Parents expanded the meaning of "*normal*" to include keeping receipts and noting all expenditure on a particular child. However, "*normal*" did not include personal assistance coming into the home if it was believed family privacy was threatened; if assistance was used and families could manage, it was not used at weekends. Events such as re-hospitalisation continually threatened the stable picture that families had crafted of "*normal*" life.

Parents stated family life was "*normal*" when their work had resumed; (being in paid work in contrast to a pension was a necessary ingredient of "*normal*" life); routines for incorporating the extra disability-related tasks had been established; the child had been observed to have typical emotions and behaviours of children of the same age; for one parent, it was having her child mix in the ordinary world "*rather than the confined world of wheelchairs*" and having quadriplegia shrink from its dominance of their lives.

If too many facets of life differed from the family ideal then a parent described himself as "*hankering for a normal life*" and "*flitting between a normal world and a disabled world*". For this parent, "*normal family life*" was about two parents, at least one of those in workforce, the family not requiring outside services to manage itself and having healthy active children. Thus, a
family was distant from its ideal where the parent was unable to work, the
two parents had "split up", the parent felt burdened with family caring tasks
but believed no carers should come into the house to "reinforce disability".

The concept of "normal family life" family is important to parents. It is not
mentioned by adolescents and the appearance of "normal family life" is not a
requirement of adults with spinal cord injury. However, the inability of men to
follow the "normal" family role as "head of the family" and women to act as
the main carers of their children concerned both men and women in families
who observed that social barriers such inaccessible schools, lack of
assistance to maintain family roles and the attitudes of professionals
increased their difficulties (Murphy, 1987; Hitchcock, 1998; Morris, 1989).

The requirement of “normal family life” means parents manage disability and
entails the absence of intervention from professionals and disability
organisations (Voysey, 1972). This is a risk for parents because they are
excluding themselves from the "gatekeepers" of services which may benefit
them. In addition, professionals and disability organisations are sources of
information, for example, on latest research developments. Moreover,
parents of children with disabilities other than spinal cord injuries are critical
of disability services for their failure to support the family and their
concentration on the child and disability (Llewellyn, Dunn, Fante, Turnbull
and Grace, 1996; Foy, 1997; Rees and Emerson, 1984; Steinberg, 1981)
and this criticism seems at odds with the requirement for “normal family life”.
The explanation may lie in the form of support, who initiates the support and
who controls other elements such as how and when support is available.

Interactions

After hospitalisation, children and adolescents looked forward to returning to
participation in their communities. Behaviour by non-disabled people which
shows they regard disability as a stigma creates a barrier which leads to the
social withdrawal of people with disabilities (Murphy, 1987). In most formal
aspects of life this behaviour is discrimination under the DDA. Adolescents
losing friends, children experiencing teasing at school, parents not receiving invitations and the public reacting to adolescents in wheelchairs are evidence at an informal level of a negative reaction to disability. Stigma has been linked with failure to conform to "normal" social expectations of perfect bodies, employment in the workforce, independence and taking charge of personal affairs (Hahn 1987; Charmaz, 1983; Davis, 1995). Stigma is further reinforced by social arrangements such as provision of insufficient personal assistance hours, lack of independence-facilitating equipment and the inaccessibility of public buildings and transport.

The impairment, spinal cord injury, also contributes to the stigmatisation of people with spinal cord injury. The impairment may cause unusual bodily activities such as spasms which draw public attention. When the impairment prevents certain activities such as self-feeding, this also attracts a negative reaction and it is more persuasive to associate the cause of stigma in these instances with judgments about "normal" and "devalued bodies" (Wendell, 1996: 89).

Adolescents wanted the retention of their pre-accident friendships and the ebb and flow of friendships they had previously known. However, friendships established prior to accidents were observed to fade shortly after returning home from hospital and the experience of adolescents with their friends parallels the experiences of adults who experienced friendship losses (Morris, 1989; Murphy, 1987; Richards). One year after injury, a high school student stated his home, earlier "swamped with friends", was rarely visited. Although this adolescent had confirmed with others that this was a common pattern, he said it made him feel he was a "hassle" and a "burden" and he wondered why he had not been forewarned of this possibility. One parent thought his daughter may have alienated her peers at school by acting "too independently" and this explained her lack of friends.

Although primary school children were described by their parents as having many friends, both boys and girls endured teasing at some stage at school despite their hopes that they would be seen as "just ordinary". In one case,
parents described behaviour of taunting six to eight year olds and in another, the mother had noted how her six year son hid "everything to do with his disability"; another child was accused by peers of "pretending to need a chair" and another of "being lazy". An upper primary student was teased for "wearing a pad" which his mother said "hurt him deeply".

At adolescence, friendships between the disabled student and the non-disabled student were revealed as weak. At school, many students lacked an aide or had one only part-time so that they to rely on "friends" to help, even in one case, carrying a student where there were stairs and this enforced helpfulness obscured the fact that other students were not always mixing with the disabled student from choice. Thus, friendship loss was more apparent away from the structured contact of school when students with disabilities were not invited to parties or on boat cruises.

Rate of friendship loss was influenced by accident circumstances, one adolescent argued. As the school football hero, he described himself as:

"remaining a celebrity some time after the accident although the younger ones [students] who hadn't known me before the accident were hesitant but when they saw the others talking to me they all came around " (Statement of M).

Adolescents attributed the dwindling in friendships to themselves. They had chosen their friends unwisely or behaved too independently or perceived themselves to be a burden to friends, an explanation which excludes the attitudes and actions of the able-bodied students. One reason for the friendship losses may be the priority differences in life tasks (Richards, 1982; Morris, 1989); the two groups may be so different it is difficult to find common areas for conversation or the able-bodied "friends" may have wanted to distance themselves from the stigma of disability. It is also possible that, like Murphy (1989), that the adolescents contributed to dwindling friendships because they ceased to initiate social contact as they registered feelings of lowered self-worth.
Parents also experienced loss of friendships and fewer social invitations due to the "courtesy stigma" of a disabled child (Goffman, 1963: 31). Parents interpreted their loss of friends as "access problems" at the houses of their friends, an explanation which does not fully explain why the friends could not meet in an accessible place or in the home of the child with disabilities.

In public places, the experience of adolescents resembles that of adults where members of the public showed that they thought people in wheelchairs were deviant, not normal (Richards, 1982; Murphy, 1987; Morris, 1989). Adolescents and parents recounted how people stared, made inappropriate remarks to their children usually about the possible causes, were tongue-tied, looked at the child/adolescent as if they had a disease and were unable to speak and think. On first meeting a person, adolescents stated that people stared at the chair and not at them and, according to one young male, girls in particular, then "fled". The only effect of this public behaviour which adolescents specifically mentioned was that they avoided swimming in public.

**Personal assistance**

People with disabilities require personal assistance so they can fulfil age-related roles. The effects of spinal cord injury on adolescents and children means they may require assistance in such personal tasks as toileting, showering/bathing, dressing, eating, ventilating and setting up work/activities. The amount of personal assistance an individual requires depends on a number of factors including an individual's access to technology, the extent of home modifications, the level of cord damage and age of the adolescent/child.

Most publicly funded personal assistance is provided by Home Care Service of New South Wales. Personal assistance is also supplied by private agencies, staff employed by families and by family members. Over time, many children and adolescents had experienced personal care from different sources, as their circumstances changed. Except for two interviewees with
paraplegia, who mentioned no aspects, personal assistance was an important issue.

**Personal assistance from Home Care**

Home Care was used by adolescents who were not compensable. Home Care, a welfare-based statutory service, assessed "customers" giving "priority to the most needy and most disadvantaged people". Adolescents found they had few rights and that they had to accept workers and, in other ways, "fit the service". Young women commented that the service was not "client oriented" and not reliable or punctual; young men commented positively about Home Care, raising the possibility of differences in attitude and treatment by gender of "customer".

In publicly funded personal assistance, insufficient funds to meet the demand for services translates into frequent "customer" assessment, rationing of services and meeting only the most essential of customer needs. Staff turnover means "customers" must train new people about their requirements and when jobs take longer then their designated times, staff run late and are perceived as "unreliable".

Attitude was most important for both male and female adolescents receiving personal assistance who wanted "a happy outlook". One adolescent explained what she was seeking:

"Somebody ... who doesn't treat you mechanically, ... interested in you, friendly, who doesn't make you feel uncomfortable" (Statement of N).

Criticism was also made about lack of knowledge of the effects of spinal cord injury and how to carry out personal assistance tasks. Moreover, one adolescent felt angry that the service addressed questions about the quality of the service to parents, rather than to her.
Personal assistance from other sources

Settlements from compensation cases provided funding for employing assistance, although in two cases parents carried out all the assistance. This situation occurred when parents were the paid carers or parents were unable to recruit staff.

In some cases, personal assistance staff were from an agency or the staff were employed directly by parents. Direct employment, used by one parent, meant 3 to 4 hours work per week on administrative tasks but a considerable saving on the cost of care which was deducted from the settlement.

Employment of staff, either from an agency or direct employment of staff, relieved parents of physical effort. But with both methods, parents had to assume varying degrees of responsibility. Direct employment with its lower costs but greater "paperwork" gave parents more knowledge and control over the quality of work offered by care staff which parents did not have with agency staff; in fact, agencies were also a source of problems when their administrative arrangements failed and staff became disgruntled. With both forms, parents had to train staff for the child's particular requirements and also explain aspects of the household and its equipment.

The responsibility of parents also included ensuring no service gaps emerged such as when the paid carer attended school which had aides and each had relied on the other to carry out vital services like "suctioning out"; parents resolved such difficulties by training both parties.

Children and adolescents with spinal cord injury with high level injuries and who are ventilator dependent require high levels of care. Having 24 hour agency care and technical attention can distance the family from understanding the care needs of the child:

"We have about 9 permanent nurses. There's 4 who have looked after H since the accident … We have a team meeting every 3 months at the school with the social worker, the occupational therapist, and
with physiotherapy if there any chest problems, and the home ventilation doctor and nurse”. (Mother of H).

This amount of assistance was funded from an insurance settlement but there would clearly be difficulty in meeting these requirements when a person is not eligible for a settlement.

Some parents observed that it took some time for the agency to recruit "suitable staff", a gap which parents filled. Problems arose also when agency carers changed because children became attached to carers and felt "sad" when their carers moved on. This problem which parents faced periodically involved further "work", explaining to children and training new staff.

**Personal assistance (unpaid) from parents**

Parents waiting for settlement usually carried out the child’s personal assistance. This arrangement was usually considered by parents to be "transitional". However, the length of time parents waited, especially under the old CTP scheme, made the arrangement seem permanent. Because of the financial strain in this period, both parents were likely to be working and this created tension, as one parent expressed it, "a hell of a strain looking after the family, looking after R. and going to work" (Parent of R).

**Relationship between personal assistance and home modifications**

Home modifications such as ramps, widened doorways and benchtops cleared underneath and lowered to wheelchair height increase independence and reduce the personal assistance needed by people with spinal cord injury. Publicly-funded home modifications are carried out by non-government organisations after an assessment by an occupational therapist of the "client's" requirements and often require contribution from the recipient. The cost of modifications is usually allowed for in settlements of CTP claimants. However, some children and adolescents with spinal cord injuries were
unable to obtain modifications because of their housing type. Modifications were not possible in units where Body Corporates disapproved of changes and in private rental housing. One young person claimed he would not need the services of Home Care if he could obtain modifications, - "But this is a rented house and we can't get access under the house to do modifications to the bathroom and toilet" (Statement of E). A 12 year old with a settlement also claimed he could be "independent" if the body corporate allowed their modifications.

Lack of physical accessibility into and inside public buildings has received attention under the DDA. Although not yet tested in law, the prevention of modification of private premises such as private rental accommodation or units in residential blocks is also a barrier which prevents people with disabilities from equitable access to facilities and increases their personal assistance requirements and may be seen as a form of discrimination.

Two families (one settled and the other waiting settlement) housed by the Department of Housing found their accommodation modified for adults rather than children with disabilities.

**Participation in Recreation**

Both adolescents and parents of children recognised participation in recreational activities as an important element in everyday life and it contrasted with the discipline of attending school. However, for adults with spinal cord injuries particularly those not employed, participating in recreation is not a pressing requirement (Kleiber, Brock, Lee, Dattilo and Caldwell, 1995), a situation which differs from that of children and adolescents. The lack of participation by people with disabilities in recreational activities typifies their marginalised status. The stronger participation of children and adolescents in recreation may be due to the expectations of parents and their advocacy and facilitation role.
Participation in recreational activities, a source of pride for parents, meant positive experiences for children and adolescents. Recreation brought a sense of achievement and uplifted their spirits ("I didn't feel tired when I was playing sport"). Adolescents praised its therapeutic benefits and parents described it as "releasing the tension".

Recreation, defined as non-school or non-work activity, helped families and adolescents to feel "normal". Recreation was frequently a specifically organised event, often requiring transporting to a site usually in Sydney. Some activities required special equipment, some offered fun, competition and potential travel, mixing with similar others; in contrast, one adolescent stated his "fun" was playing computer games by himself. For some, swimming became a form of recreation as well as therapy.

What recreation adolescents and children participated in was partly a result of trial and error. One adolescent noted sports created skin problems for her and swimming and scuba diving were suitable whereas others believed swimming caused adverse health problems.

Participation also depended on awareness of activities. A pre-school child's parents were unaware of suitable sport for him nearby. Participation also depended on knowing what activities were available for a particular level of lesion; one adolescent believed there was no suitable recreational activity in which he could participate.

Distance from the venue where the activities were held affected participation. This was a problem if the child or adolescent lived in a country town distant from any activities. Non-compensable adolescents and children with settlements pending were the most affected by distance. "Settled" cases often had transport for driving the child and a carer who could take the child to activities if the family were unavailable.

Participation in some forms of recreation was limited by physical access barriers and this curtailed the activities of adolescents:
"Currently, my greatest concern is my social life - what you do on Friday and Saturday nights - because the really interesting nightclubs and restaurants tend to be either downstairs or upstairs or the toilets are inaccessible … only the RSL clubs are accessible". (Comment of B)

Earlier, it was also noted that the social life of adolescents was also affected by the extent to which they are accepted by their peers or left out of social activities.

Transport Options

Children and adolescents anticipated participating in a range of activities including recreation, visiting friends and attending therapy sessions (Travel to school is discussed in the next chapter). Participation outside the home necessitates transport which, ideally, has to be adapted to meet particular needs to minimise injury and lifting and other work for carers.

Finding affordable wheelchair accessible transport is an issue and generally, children and adolescents used a mixture of private and public transport in the form of taxis, although other forms of accessible public transport is slowly becoming available. Private transport included the family car which was not modified in any way usually or a car bought from settlement money specifically for the transport of the child or adolescent.

The developmental task of becoming independent from parents is threatened by disability (Morris, 1989), as typified by transport arrangements. Adolescents who were ineligible for CTP settlement relied on parents and friends for transport except for one person who was employed and owned a car. Adolescents commented negatively on the costs, unreliability and advance planning associated with taxis and the inaccessibility of cheaper public transport. Freedoms already won from parents were endangered: one young man feared losing the ability to "go out whenever I like"; other adolescents had not yet tasted "freedom". Adolescents irritated by the threatened loss of independence expressed a strong desire to own and drive
their own car and planned to tap money held in trust where this was available. Earning money through employment was not raised by any adolescents.

Transport was not an issue for children or adolescents with settled cases unless the settlement was small or the parent was expecting tax relief available for working people with disabilities but not students.:

“If my daughter was working, her new car would be sales tax exempt, but because she’s a student, it’s not exempt. The argument is students get public transport subsidies … but in our case, in the country, there’s no public transport.” (Parent of P).

As public transport in the form of taxis and/or the family car were generally used while waiting for settlement, the reliability of the family car and the absence of hoists for lifting heavy children and adolescents became issues the longer families waited.

**A fair and helpful welfare system**

Parents and adolescents who were non-compensable commented on the “unfairness” of the system of welfare benefits and services which had the greatest impact on non-compensable children but also affected those waiting for settlements and some who had settled with less generous settlements. This sense of “unfairness” was generated where “welfare” was available but children, parents and adolescents were excluded from it: examples were PADP, CAAS, Pharmaceutical Benefits Scheme and rebates on income tax.

“We buy aids like catheters from [disability organisation]. You’ve got Buckly’s of getting them from PADP and she’s got to be over 16 to apply for Continence Aids Assistance Scheme ... Until she’s 16 we have to pay for everything! It all adds up but on your tax you’ve got to have spent over $5,000 to make a claim [on tax returns]. We get close but not over it. With pharmaceuticals, they gave us the Health Care Card so we can get cheaper drugs but one of the drugs she
uses a lot is not listed on the PBS schedule." (Parent of P who is non-compensable).

The number of welfare "benefits" and agencies was regarded by parents and adolescents as “mind boggling”. Parents derided the amount paid by Centrelink for Child Disability Allowance, now Carer's Allowance, given the costs associated with their child/adolescent's disability, an experience vindicated by parents of children with other disabilities (Mathews, Graham and Doyle, 1988; Rees and Emerson, 1984).

A further element of unfairness relates to the differences in compensation status between people with spinal cord injuries which was raised by two non-compensable adolescents who felt disadvantaged. One set of disadvantages related to the expenses which families had to meet and the lack of assistance, particularly for those under 16 years, as discussed above. The second set of disadvantages related to the fostering of passive dependency and the discouraging of social participation by the welfare system. This message was implicit in the operation of welfare. An example is PADP which required numbers of time-consuming steps for small numbers of goods and disallowed bulk orders and was premised on applicants or their carers not participating in work or education but available to spend a day obtaining supplies. The dependency of welfare contrasted with the autonomy and independence which compensation claimants were able to exercise, although both had similar levels of impairment.

Summary

Three main requirements were observed in the period after hospitalisation: support in management of the "injured" person, resumption of social participation and equity in the support available to the children and adolescents.

The management of the injured child or adolescent was hindered by the poor quality of linkages between hospital and community support services and the
lack of confidence and experience of parents which contrasted with “expert” hospital services.

Avoiding marginalisation from society was a key requirement of adolescents and parents organising the lives of children. A number of inhibiting barriers were identified. The negative reaction of “friends” to their impairment and self evaluations of themselves as “burdens” created barriers for children and adolescents which interfered with social interactions. The limited amount of available public personal assistance and its administration meant this service did not facilitate social participation, particularly for young women. Medical definitions of spinal cord injuries and the structure of non-hospital medical services impacted on how children and adolescents used their time and the frequency of their re-hospitalisation. Lack of access to public transport has been recognised as a “discrimination” issue and is receiving attention through the processes of the DDA; the right to modify certain housing types is yet to be recognised as a “discrimination” issue.

Generally, the requirements of children and adolescents support the requirements identified in the literature by both people with disabilities and people with spinal cord injury although specific components such as “recreation” and “normal family life” are not requirements by adults and people with disabilities.

In this chapter, differences between compensable and non-compensable children and adolescents are emerging which is recognised by those who are non-compensable as “unfair”. Compensable children and adolescents can afford private services and facilities instead of waiting and using the public systems. Many are able to build their own customised accessible accommodation or at least generously modify the family home. Compensable children and adults also make private travel arrangements and at this stage act independently and autonomously in contrast to those dependent on social welfare.
Access to education is highly prized by most individuals in the community including people with disabilities. Lack of participation in valued educational opportunities is an indicator of marginalisation and, without education and training, individuals are likely to be excluded from employment, another aspect of marginalisation, and thus forced to lead a life of poverty and dependency on the state and family.

Education trains individuals for labour market participation by imparting marketable skills and promoting acceptance of authority and rules. Education allows the allocation of people to positions on a basis of "manifest ability". It also contributes to inter-generational commitment and transmission of culture; without education, people are usually stigmatized (Waters and Crook, 1993: 301-316). Education has been valued for its promotion of individual aptitudes and abilities development even though the belief that education would end wealth and power disparities has now been discredited (Giddens, 1989: 423).

The educational status of the adolescents and children

The requirement of people with disabilities for social participation including engaging in education opportunities was highlighted in the literature examining their concerns. Ideally, education would value and recognise their different experiences and this recognition would necessitate improving access for a wide variety of human abilities (Wendell, 1996). In addition, high level education is observed to be one of the factors associated with employment of adults with spinal cord injuries although there are numerous problems to be overcome including the attitudes of employers (Crisp, 1990).
This chapter focuses on the requirements of children and adolescents in relation to education and the barriers that were encountered in the education system (primary, secondary and tertiary and government and non-government sectors). The evidence indicates the education system does not treat students with disabilities as potential participants in the workforce but contributes to their construction as passive marginalised people.

Of the twenty children and young people in the study, three were no longer involved in education - two were employed (one full time and the other part time) while one was not in the labourforce. At the time of interviews, one child had attained pre-school level, 10 primary school level, 6 secondary level and 3 tertiary education. Both the government and non-government education sector were represented. In the comments on their educational experiences, students at higher levels such as tertiary, ranged back over their earlier years; those with fewer years of disability talked more of their current situation and what lay ahead.

**The response of the education system to students with disabilities**

Both the Commonwealth and State governments provide funding to meet the needs of students with disabilities in both public and private schools. Some students are educated in separate “special” schools, Schools for Specific Purposes (SSPs) but in recent years it has been the policy of both government tiers to "integrate" students with disabilities into "mainstream" or "regular" schools wherever practicable (McRae, 1996).

**Government Schools**

The Special Education Policy of the New South Wales Department of School Education aims at "equality of educational opportunities" between students which can be achieved in an "active partnership with parents and the community" (NSW Department of School Education, undated).
Special Education moneys are obtained from both the State and Commonwealth governments and these moneys are then devolved to schools and the regional level of the education system. In addition, schools may be raise funds or receive contributions in kind, for example, through the efforts of Parents and Citizens' Associations and service clubs.

The decision to enrol or continue enrolment of a student with disabilities is made at the school level:

"Principals in collaboration with School Councils where appropriate, will ... provide a supportive school environment for students with disabilities by ... obtaining and using available resources and support services." (NSW Department of School Education, undated, 10).

The principal with Special Education personnel, if determined, may tap Regional funds. Money for "minor works" may be available but money for major works may be delayed until the particular expenditure is "prioritised". Professional assessments conducted on students enrolling or returning to a previous enrolment indicate their requirements such as need for ramps or lifts and assistance from an aide. If these needs cannot be met, then the implication is that the student must travel to another school, possibly a special school. Ultimately, the decision that a student cannot be accommodated is a matter of funding priorities.

Where parents are allowed to enrol or continue enrolment at their "regular" mainstream school, the quality of "integration" has disturbed parents and students (McRae, 1996; Epstein-Frisch, 2000). The principal of the school may believe the school and the student will "manage" with no additional resources e.g. the teacher can give a student who is unable to access a classroom, some extra time in the subject at another time. Parents and students realise, over time, that "equality of educational opportunity" is not occurring; but parents lack alternatives: to remove the child would mean loss of the student's peer group and beginning more negotiations with education authorities. Schools Policy indicates assessments and placements are reviewed and that appeal to the Director-General of School Education is
available, an option of which parents seemed unaware and no independent appeals process has been developed (Epstein-Frisch, 2000).

Implementation of the official “integrated” students policy has been hindered by funding programs (Working Party on a Plan for Special Education in NSW, 1982; McRae, 1996). McRae (1996) argues that funding for “integrated” students, including teachers' aides, therapy and transport, is located within budgets for special schools and that when students are integrated into their local school there is comparatively little funding available to meet their needs because this funding is based on a different arrangement. Thus, schools with students in “integrated” settings draw on “capped” funding for which submissions must be lodged every 6 months. In addition, the number of students enrolled in special schools has been dropping in the past decade and the number of "integrated" students has been increasing which aggravates the funding problem.

The State also receives supplementary funding for Special Education under the Commonwealth National Equity Program for Schools (NEPS) administered by the Department of Employment, Education and Training (DEET). The amount received is related to enrolment numbers and is considered to make only a meagre contribution to the costs of education for students with disabilities. A priority use of the funding is promotion of students' integration which historically has included salaries of "support personnel", "purchase of educational equipment and materials" and "minor building and equipment projects". (DEET, 1993 NEPS Guidelines, 62). Schools access this funding by application through the State Department of School Education.

**Non-government Schools (also known as independent schools)**

Every school in this system is autonomous resulting in each school deciding whether it will have a policy on students with disabilities, although some schools work together on particular issues, some are parent controlled and others are community controlled. The Independent sector has a higher
enrolment of students with disability than state schools because it includes schools operated by disability organisations (Conversation with Consultant for Independent Schools Association, 1995).

Non-government schools may be members of the Independent Schools Association which offers Special Education consultancy and other related services to member schools; the onus is on schools to invite consultants in. The consultants in New South Wales have special education qualifications and are “firmly committed to parent involvement”.

Independent schools have seen their relationships with parents as contractual in contrast to a relationship which is based on a right to education. In the case of independent schools, parents are considered to have chosen the school and schools state what they offer and parents accept or reject this offer. This view has recently been questioned when parents of a student successfully challenged the discrimination of a non-government school which refused her enrolment (*Hills Grammar School v. Human Rights and Equal Opportunity Commission* (2000)).

Independent schools obtain Commonwealth and State money to promote integration which may be spent on aides or equipment. Parents or teachers are not necessarily involved in the application for this money which is allocated to the school for "education services", rather than to benefit a particular student (Conversation with Consultant for Independent Schools Association, 1995).

Funding is also available from the Commonwealth for capital projects but the maximum amount for any project is quite small and very inadequate for the demands of the sector (Conversation with Consultant for Independent Schools Association, 1995). In addition, for schools to be eligible for funding they must own their premises or have long leases on them which disadvantages some community schools. There is frequently a delay of 12 months or so before a school knows whether it will receive funding in which time the contribution of the school and its financial status are considered. A
contribution is also received from the State government for Special Education.

There is wide variety in the services independent schools offer; for example, some schools have counsellors. Other schools use generic or community services as much as possible, such as community health services for catheterisation. Parents, usually mothers, are also used to supplement service gaps such as personal care needs.

**Tertiary institutions**

There is no additional funding to meet the extra requirements of students with disabilities in this education sector in Australia. This is out of step with practice in other countries such as New Zealand, UK, Canada and Sweden where additional funding may take the form of grants to institutions and/or grants to individuals (Devlin, 2000). However, the number of students with disabilities in the tertiary sector is growing and this is increasing financial pressures in the administration of higher education centres such as universities and diminishing their ability to provide students with the quality of assistance they seek.

**Transport for students with disabilities**

Transport, often referred to as "the Education Dept taxis", may transport eligible students to school. This service is State funded and is available for government and non-government school students, and is administered by regional offices of the Department of School Education. Parents have to prove that they cannot take the student to school to be eligible for this service.

Students undertaking tertiary level education may be eligible for a Mobility Allowance from Centrelink or they may use taxi vouchers which discount their fares by 50%. If public transport (buses or trains) cannot be used and
students have to use taxis, then even with the assistance provided, many students will have with large amounts to pay.

**Students' experiences**

All parents who had children at school and all adolescents in the education system expressed strong views on the importance of education. Parents and adolescents were concerned that the impairment would create disadvantage; it was therefore crucial that all obstacles relating to obtaining an education were removed. The belief of parents and adolescents was that there should be equal access to the education offered at the educational facility, including all relevant rooms and facilities such as classrooms, libraries, computer rooms, laboratories, home economics rooms; this meant, in secondary and tertiary education, unrestricted subject choices. Usually, equal access also involved installation of ramps or stair-climbing devices, or lifts and student aides, equipment and furniture e.g. benchtops that were compatible with wheelchairs, toilets which were wheelchair accessible, aides available to help with aspects of schooling such as "getting out" books, turning pages, writing if needed, aides to help with personal tasks such as eating and toileting. Equal access to education could mean a student with disabilities employed different instructional techniques to acquire their information, for example, "Distance Education", but the student is offered the same quality of learning opportunities that is offered to others.

Parents who linked learning and future employment also strove to see their child had maximum participation in school activities. Participation with other students in all activities such as sports carnivals was important to parents. Inclusion of students with disabilities meant they formed opinions, discussed issues with other students and could respond to others as a "participant"; knowledge flowing from participation was of a higher order than second-hand information which made the student with disabilities a passive by-stander.

Being part of school activities was also important for "normal" interaction with peers; it helped develop similar interests, and "difference" could melt away;
this was "good" and "normal" and an aim of parents and adolescents. "Normal" also meant, for many parents, attendance at the local community school which was important for the student and often for the family. Thus, many parents chose a local "normal" school at which to enrol their child; students already at school usually wanted to maintain their school after their accidents.

Parents assumed they had the right to choose their child's school and some registered shock and anger when this belief was challenged by school authorities. Parents wanted their child "integrated" into the local school where they expected their child to be included in all activities. Except where parents had re-located the family home, attending special schools removed students from their local area and involved them in long taxi trips, which parents considered inappropriate for very young children. Parents argued that "special school" reinforced the message that the child was negatively viewed as "not normal" and the professed school policy of accepting of student diversity and including students in school activities did not apply to their child. Consequently, many parents opposed sending their child to Special School.

"The Education Department wanted A. sent to a special school which is a long way from here. It's 40 minutes each way. It took 6-7 months of fighting to get another school assessed. The first school ... the principal said she wasn't prepared to take the responsibility of having A in her school." (Parent of A)

The outcome of a child assessment often exaggerated the medical risks students faced and parents found it difficult to refute professional opinions recommending a "special" school. The emphasis in assessments is on the "disability" of students rather than their educational requirements or their positive abilities (Epstein-Frisch, 2000). Professional language and concepts used excludes non-experts from both a clear understanding and a role in the decision-making process and therefore is an exercise of power (Fulcher, 1989). The parent-education system relationship is further compounded by a lack of transparency in decision-making. This was seen in parents not
understanding or agreeing with the evidence which informed decisions about whether the student should enrol at a "special" or local neighbourhood school. Many parents opposed the assessment fiercely and enlisted their own professionals to battle with them, such as the hospital doctor and social worker.

The "best atmosphere" for the child was of paramount importance and parents conceded on their local school only after trial, such as when the local school had 50 children in the class and "the teacher couldn't cope"; the local Catholic school in this case offered "a more accepting, quieter environment." (Parent of C).

Already enrolled students returning to school after their accident faced similar challenges. Parents were informed by the principal that "they couldn't handle [the student] because most of the classes would be upstairs and they'd have to modify the whole school. And they don't have an aide" (Parent of H). One set of parents noted the teachers' apprehension about their daughter returning to her school; they won the school over by one of the parents attending school for a few months with their daughter everyday and acting as her aide and demonstrating the everyday manageability of her disability.

All of the primary students with paraplegia, except one, had access to an aide at school. Not to have an aide meant the student drew on other, less secure arrangements (such as the community nurse) or parental work (mother visiting school several times per day) or acts of personal charity ("the Assistant in the school office helps A into the `stair climber' - she altered her work days so she can help on A's library days" [Parent of A]). One parent felt the aide service was always in a state of "threat" because the school kept giving the message they wanted to cut back aide services; in fact, the school's caution was probably related to their need to submit for integration funding every 6 months (McRae, 1996). Where aides, in addition to assisting with school work, were able to exercise children in their standing frames parents were relieved - "It's one less thing I have to do" (parent of K).
Because parents were speaking on behalf of children, the children's views on exercising at school is not known but children may have found exercising further stigmatised them.

All of the primary students with quadriplegia had their own insurance funded "nurse" or "carer", regardless of type of school and whether attending an ordinary primary or special school. The only comment made in relation to "nurses" attending school was that parents had to ensure no "gaps" in vital medical services between school aides and nurses tasks occurred.

Two secondary students had graduated to "independence" at school; both stated how they kept away from the "special" facilities which were obviously stigmatising. No secondary student had a "carer" at school although two students required help. Not to have the help of an aide meant incomplete education in comparison with peers: for example, one student stated that her "chair was not hooked up to the stair climber ... and quite a few classes held upstairs are missed" (N and parent). It also meant the District Nurse or a student's mother coming into school for personal assistance. Part-time aides spread over too many students ("due to budgetary restraints") forced students into relying on the "kindness" of fellow students and teachers "to get books out and pick up anything she drops" (Parent of P).

When students received no tuition or very little in some subjects held in specialized facilities such as computer rooms, schools devised various ways to reduce these problems, such as making an individual student or teacher responsible.

"One of W's friends is s'pose to let W know what happens in the 'maths group' but her friend's quite whimsical about it - it's not her responsibility; it's the teacher's" (Parent of W).

Another student who lacked access to science lessons said the science teacher “because of his conscience” tutored her in a free period. The school suggested a correspondence art course for P after two years of her art
lesson at one level in the school and the remainder of the class at another, with the teacher running between the two.

Missed subjects meant disabled students were disadvantaged in comparison with their class-mates, a situation which angered parents and students. Both parents and students came to realise their powerlessness to move education authorities to improve learning conditions. Two secondary private school students noted that their schools received funding to improve their access but had not used it: "they haven't even started work on the lift which was promised for my access and that they've received money for" (Adolescent N). Frequently students and parents were locked into gratitude for particular teachers' actions while at the same time registering frustration with their schools. Three private school students stated they could not complain because, as one student stated, "the school's done a lot for me" but, in fact, individual teachers and students had helped rather than the school system. One student observed the school installed ramps after he had an accident at school but, usually, the school bureaucracy remained unyielding. Most parents saw "putting pressure on the school" as their only weapon; one set of parents mentioned the Federal Disability Discrimination Act but was concerned the child would suffer a "backlash" because the family would have to lodge the complaint, although the private nature of the conciliation process protected the parties from publicity (Innes, 2000).

The responsibility for funding modifications in schools was unclear to parents who had CTP claims pending: are modifications funded by education authorities or are the modification costs covered by the settlement? Mystification of funding responsibility is obviously in the interests of both the insurance companies and the education authorities; both CTP insurance and education authorities (including private schools) are publicly funded and public accountability and clarity are owed to the public, especially to people with disabilities. From the parents' point of view, the provision of access facilities by insurance companies created problems because parents thought it diminished their child's settlement:
"We wanted a ramp put into the school to give our daughter, G, access at school. .... I was told to keep quiet because if we ended up paying for it the money would have come out of G's claim, her settlement." (Mother of G)

In some cases parents did mention the access facilities as a deduction from the expected settlement:

"The school has ramps and special toilets which were made and put in place at the request of the insurance company. I think the cost of these is to be deducted from my son's money that he will get from the insurance company". (Father of B)

The remarks of another set of parents suggest that, in their case at least, the costs of school modifications would be allowed for in the settlement:

"The school will need two lifts. Initially, we allowed for the lifts in our requirements for her future." (Parents of W)

When an insurance company has agreed to fund school modifications, its first concern is minimising its cost:

"The insurance company tried to push us to go to a particular high school with ramps in it but they're very long and steep .... the QC said we've just heard that they [the insurance company's lawyers] are saying there's a high school in your city that she's going to have to go to X school, the one with the unsuitable ramps." (Parents of W)

Most parents did not understand their case to this extent and were unaware of the bases of insurance company calculations. Parents were pitting their wits against insurance companies' legal and technical knowledge; denting this specialised knowledge required time, appropriate educational background, alertness, being taken seriously by the lawyers for the child or adolescent and a number of other personal factors that made the chances of succeeding most unlikely.

A practical consequence of parents' apprehension on provision of access facilities was that they anticipated and thus avoided difficult situations with education authorities. One parent received an invitation to send his upper primary son to a class for academically advanced students. The parent believed the class would be held in an inaccessible environment and therefore declined the invitation having already encountered problems
negotiating future high school access. In this student's case, three schools would have required "access" provisions: whether this was an insurance or education expenditure was what parents wished to know.

A further issue is the helpfulness of school modifications and whether they contribute to educational equality and dignity of students. Stair-climbing devices were criticised by parents and students because they were awkward, heavy and needed "competent operators", and where aides and school staff were inadequately trained, they were unable to operate them. Students therefore continued to miss lessons or, in one case, the teacher carried the student up and down the stairs: "not good for the teacher and not good for [the student]." In this instance, parents could have suggested an alternative - more dignified, more flexible, and cheaper - but they were not consulted; the assumption that educational authorities have superior knowledge of these matters is ideologically based and related to maintaining control over resources.

School attendance usually involved extra work for parents. As previously mentioned, this often took the form of battling education authorities for resources; parents also had to work on professionals attitudes: "The Education Department's Integration Officer was very negative about his prospects" (A's parents). When a parent managed to keep a child in a "normal" school, parents often paid a high price: "Her mother went to school 3 times a day to catheterise her" (C's parent). Obviously, this mother's life, including her employment opportunities, was determined by this requirement.

Parents donated time to school to allay both their child and teachers' fears. If parents wanted their child to go on school excursions, then parents often had to be prepared to take the child; beforehand, the venue had to be checked for accessibility: "As a parent, you've got to do a lot of chasing up and researching ..." (W's parent). At least one year ahead of moving from primary to secondary and secondary to tertiary levels, aspects of the next institution had to be checked such as accessibility; in addition, well-
researched, assertive parents had to be available for meetings with professionals.

The education system kept tight control over information so budgets were not exceeded, which is understandable in the light of the budgetary problems associated with for "integration" funding (McRae, 1996). Parents learnt of student aids that could be made available, late in the day and accidentally.

"[T]hings like desks at various heights and computers. It would not hurt if this information was published so parents could go along and say, 'We can get this' and 'Why don't we get that?'" (Parent of P)

Generally, parents were unaware that the education system placed a higher priority on balanced budgets than on educating students.

Transport to school

This was generally not a problem for children and young people who had received a settlement or for whom liability had been admitted:

"The carer takes my son to school in my son's own car, paid for by the insurance company" (Parent of B).

The Education Department taxi was "a relief" for other families but knowledge of its existence and any rights in relation to the service was an accidental affair. One family had struggled for six months after hospital discharge before discovering the existence of the service. Children and young people were usually eligible for the service, except in one case where the parents were informed of a bureaucratic decision but not about any appeal rights -

"The taxis are not air-conditioned and he can't regulate his body temperature, and it's too much of a responsibility for them." (Parent of A).

Anticipation of tertiary education

Parents and older students were enthusiastic for tertiary education to follow secondary education. However, disability liaison officers argue there is a lack of funding in universities to facilitate access by students with disabilities,
and thus there is a tension between the encouragement of more students and managing their support services with shrinking budgets (Devlin, 2000). Consequently, difficulties such as lack of information are incomprehensible to parents and adolescents unaware of this background:

"What's available, what faculty, what courses? The University Admissions book ... could show two things - one, what's available ... and two, what's not available and pressure groups can take this up and put pressure on facilities to upgrade." (Parent of P).

Transport posed another problem. Two likely students anticipated travel costs even with taxi vouchers covering 50% of costs as "prohibitive" because of the distance from home to university and they were unaware of the Mobility Allowance or considered themselves ineligible for it.

**The experience of tertiary education**

Lack of access to buildings and thus curtailment of subject choices had already affected two young people already attending university. The injustice of present public transport arrangements, as anticipated by others, was keenly felt:

"The university I attend is a 40 minute drive for me. I pay the costs of transport out of my settlement. [Accessible] Public transport would reduce my transport costs to Uni very much." (Comments of S)

Attributing all people with disabilities with the same educational requirements insulted one student who went to CRS asking for a desk-top publishing course but was placed with "some intellectually disabled people ... on a very basic secretarial course held at a TAFE". A better course was found at another TAFE:

"This course was really helpful; things were accessible; the teachers were good; the building had lifts so getting in and out was no problem." (Comments of D)
Summary

A central requirement of children and adolescents is to receive the best possible education so that they are equipped to participate in various ways, including employment, in society.

The barriers for students at government schools stem from the arrangement of the education system which uses professional and administrative authority to steer parents towards the special education system rather than their local school. The education system is motivated by administrative convenience in that special education has funding to meet requirements such as classroom aides and the schools have accessible buildings and toilets. The fact that students would not have suitable educational experiences was not a consideration because students labelled "disabled" were not viewed by education professionals as serious participants in society.

Students "integrated" into their local "regular" government school also encountered barriers to equal educational opportunity. Equality of educational opportunity with other students is affected by the paucity of "integration" funds from the State government and the meagre Commonwealth funding. The lack of dignified, independent forms of assistance meant students often had to rely on others (peers, teachers, office assistants) which created indebtedness and stigma. Students who had insurance settlements were less affected by school arrangements if they had a "carer" who could attend school to assist them.

A major barrier for students in non-government schools is that the schools are unregulated regarding their treatment of students with disabilities. Lax accountability to government for funds provided for "education services" for students with disabilities allows schools to spend the funding in their own time on projects of dubious benefit to students with disabilities. Funding from the Commonwealth government to both government and non-government schools was described as insufficient for meeting the requirements of students with disabilities. The assumption by the Commonwealth
Government that students with disabilities will lead passive, dependent lives has also meant little funding in the tertiary sector for support services for students with disabilities.

Lack of information is a further barrier which helps to curb the expectations of parents and students. Parents are unaware of their rights regarding "regular" and "special" schools, what criteria is used in decision-making and their appeal rights. Information on the existence of the Education Department aids and equipment is not disseminated presumably because school staff would have the irksome task of making refusals. In non-government schools, parents and students are unaware of whether the school has a disability policy and thus what they can expect. In the tertiary sector, universities with "accessible" facilities are already attracting more students with disabilities than less accessible universities causing the former increasing financial strain (Devlin, 2000). A further area where parents lack clear information is the negotiation between insurance companies and schools regarding payments for school modifications and how this is treated in the calculation of settlement moneys. There is no clear explanation about what is occurring in these instances but undoubtedly the process is considered by lawyers to be simpler if parents are excluded from it.

Transport constitutes a further hurdle, particularly for students on public welfare or with small settlements. Accessible public transport would contribute to the solution of this problem; where taxis are used the subsidy (50% of the cost) is regarded as insufficient for long distances. Intending higher education students were unclear of their eligibility for Mobility Allowance or were unaware of the Allowance. Students with settlements may have their own car or may be able to afford taxi fares.
7 THE EXPERIENCE OF PRIVATE INSURANCE

Introduction

The literature on both people with disabilities and people with spinal cord injuries indicates that ending social marginalisation is a key requirement. Many people with spinal cord injury also mentioned the distress they registered in mounting their compensation claim and the continuing anxiety they felt managing their settlement money. Having an easier claim process is not a requirement stemming from social marginalisation; rather, it is a difficulty which arises from a "means", a "solution", provided to a select group of individuals to manage their disability.

The money which is derived from a CTP claim is usually the “final” amount which claimants receive in respect of their accident and a deed of release is signed. The amount received is expected to cover all hospital and medical expenses to date as well as future related expenses, "economic loss" for past and future earnings and "non-economic loss" (a "capped" amount) for pain, suffering loss of amenities, disfigurement and loss of expectation of life (MAA, 1992). Usually, the payment is a "lump sum". However, there is currently interest in substituting lump sums with "structured settlements" which pay part of the award and the remainder is received over the claimant's life because "lump sums … have a habit of running out, forcing catastrophically injured people .. to seek income support form the Australian Government" (MAA, 1999: 11).

The data in this study indicates that CTP claimants are advantaged by receipt of settlements which allows the acquisition of houses, cars, and services. In this section, the nature of the "advantage" of insurance claimants is examined more closely. It is argued that the "advantage" is a
material one only, it comes at a high price and, over the long term, the "advantage" is likely to evaporate. Moreover, settlement money can only be exchanged for particular goods and services and it cannot address the social barriers which maintain marginalisation. The goods and services which settlement money buys are only able to address certain requirements, for example, therapy needs, but the money cannot buy an end to discrimination or stigma. At a social level, however, insurance claims, like social welfare, allow the status quo (discrimination, unemployment, poverty) to continue and do not threaten existing social arrangements.

The NSW Government established the first CTP insurance scheme in 1942. It was designed to provide funds for meeting medical costs, damages claims, waged-related payments for injured workers and to regulate "sharp practices" in the insurance industry (New South Wales Parliamentary Debates, 1942: 3,805-3,905). The original parties designing insurance schemes in NSW (the legal profession, insurance companies, trade unions and government) included no representation from injured claimants and the compromises which resulted from the hammered out agreements of the parties disadvantaged injured claimants. Over the years, this scheme became increasingly unwieldy: all insurers except the Government insurer eventually left the scheme, delays of 10 years or more were common before claims were resolved and funds were depleted. In 1981, the New South Wales Law Reform Commission investigated the scheme and confirmed the injustices suffered by injured claimants. The Government abolished the scheme and replaced it in mid-1987 with "Transcover", an administrative scheme operated without legal input which paid immediate regular payments instead of lump sums several years later. This scheme stimulated vigorous campaigns from the legal profession for the installation of a new scheme requiring legal input which was installed in 1989. This third scheme was recently overhauled (1999) to improve waiting times for payments and admissions of liability by insurers and to allow alternative dispute resolution services to circumvent prolonged litigation (Motor Accidents Authority, 2000).
Fourteen of the twenty young people and children in this study were eligible to claim compulsory third party insurance (one person made a public liability claim) and the 3 CTP schemes in NSW are represented in the data below.

Claiming compensation from insurance companies

An important characteristic of the claim process is the power differential between the participants: individual claimants are relatively powerless in comparison with the other participants, insurance company officials, and the medical professionals they engage and legal professionals. Almost all claimants described the process negatively; one parent from a non-English speaking background was not so much negative as perplexed. Three described it as "a battle"; others mentioned frustration, anxiety, uncertainty, "going crazy" and an "emotionally traumatizing" process. These comments were made about the pre-settlement stage as well as the actual settlement decision-making.

"We had 4 days allocated and in that time we met 6 times to consider offers and counter-offers. It was extremely stressful and a 24 hours a day commitment. W was a witness for 40 minutes and we [the parents] each had 3-4 hrs..." (Parents of W)

The key aspects of parents' experiences are illustrated below.

Waiting time between accident and settlement

The average length of time families had been waiting for settlement, at the time of interviews, was 4 years (Range: 1 - 7 years). The delay made parents feel impotent, anxious, guilty and pained; the only stance most could take was "trust" and "just hope" and "wait". Reasons for the delay in settlement depended on the source of information (insurance officials blamed lawyers, lawyers blamed insurance officials) and the operating insurance scheme. Under the "old" CTP insurance system (1942 to mid-1987), it took 3 to 4 years to have a matter listed for hearing and then another 4 or 7 or 10 years for the hearing. Reasons mentioned in Parliament were "insufficient
judges” and “the nature of the adversary system” and “the nature of common law actions”. From the injured person's perspective, there were two disturbing aspects: one, that no rehabilitation usually occurred in this interval because the effects of injury had to be maximised to ensure the largest possible damages assessment; and two, the "prohibitive" costs of administering claims for this time affected net settlement amounts (New South Wales Parliamentary Debates, 1987: 12,227-12,229). Fears have been expressed that the current scheme is also developing a "tail" of moderate to severe injury claims and the measures introduced in 1999 aim to improve this situation. Lawyers claim actions by insurance companies cause many delays by making multiple requests for particulars to solicitors just before the expiry of the period for commencing proceedings in court and by keeping "liability" an issue; insurers are able to ignore their duty to resolve claims quickly when the legislation lacks an effective means of enforcement (Morrison, 1993: 3-11). Moreover, insurance companies and solicitors appeared to have a vested interest in claimants' delays. Usually aware of claimants' financial difficulties, they offered loans to parents in this study, some of which were taken up. Parents who declined the offers commented on the very high interest rates on these loans.

**Depleted finances between accident and settlement of CTP claim**

During this waiting period, family incomes frequently became depleted for two reasons. Firstly, parents labour force participation was likely to have diminished or even halted. At first, this was due to one parent or perhaps both being injured in the accident as well as their son or daughter.

"In my case we lost a salary - I couldn't go back to work so we were suddenly short four hundred dollars a week. People don't like to admit that, after it's happened, financial problems are starting to build up and that you're starting to get a bit short ... You've still got to pay your rent or your mortgage ... we were in hospital for four months." (Parent of F)
Later, when injured parents had recovered, one parent often had to spend extended time caring for the injured child (siblings are also often injured) and is thus unable to work. This effect was most profound in the study's two one-parent families. One father spoke of the financial strain of caring for his nine year old paraplegic daughter and her injured brother, the mother having died in the accident. In this period, the father's own business fell away until he was on the verge of bankruptcy.

Secondly, family expenses typically increased due to the effects of the child's disability. Children now required incontinence aids, expensive drugs not on the Pharmaceutical Benefits Scheme list, extra clothes, extra bed linen, extra heating and cooling, mobility aids such as wheelchairs and walking-frames. For non-metropolitan families there were increased travel and accommodation costs associated with city medical and legal appointments.

The depleted family financial situation meant that some women were both working as well as caring in order that sufficient income came into the household. Settlement was eagerly anticipated because many believed it meant reduced work and fewer financial tensions.

Two interviewees made little reference to financial stress: one, where the settlement had not been received, the father did not mention financial stress, possibly because it was culturally inappropriate to mention it or because the insurance company did seem to provide many services e.g. a nurse, a car and so on. In the other case, the reason the parent made no mention this period was probably that it was ten years since the accident and presumably other issues now dominated his thinking.

**Behaviour of insurance companies**

Insurance companies used a number of strategies to avoid making payments to parents in this period. Parents' interpretation of these events varied. Some reacted aggressively; others thought that they had to accept their fate. Insurance company attitudes surprised parents; ideological constructions of
caring insurance companies evaporated when confronted with claims and parents gradually learned they had to "battle" insurance companies. Parents were generally aware that once insurance companies admitted liability, they should begin paying for some expenses, yet, in practice, many parents found this difficult to achieve. Generally, the onus was on parents to "discover ways" to mitigate their costs.

"The insurance bought his wheelchair but that was after months and months of ringing up and just pushing and pushing. Eventually, I just ordered it and billed them." (Parent of T)

Insurance companies used medical determinations to restrict payments before settlement. Medical definitions of disability established "objectively" the requirements for the condition, justifying the insurance companies imposing their views on necessary requirements:

“They [the insurance company] covered all the medical side of things quickly and liability was decided quickly. But the problem was with non-medical things. We were told, 'Oh, that will help the family. That doesn't help just W'. Everything kept getting knocked back.” (Parent of W)

Some insurance company employees obstructed requests and argued about the necessity of various items.

"The emotional trauma we had to go through to justify getting a wheelchair when you've got this seven old who'll never walk again - I found extremely rude!" (Parent of R)

Many families were harassed by insurance companies: nine occupational therapists were sent to one home to assess modification needs; many families made multiple trips to numerous insurance medical specialists. Parents gradually realised that insurance companies were not motivated by their claimants' disability which became apparent in court when parents discovered that they knew more than the insurance company's "consultants", about life with paraplegia or quadriplegia:
"She cannot afford to get rundown and tired; she cannot afford not to do her swimming .... that's a practical outcome of her situation... The insurance company had no idea of any of this ... their understanding was very low... They questioned us very thoroughly where we got our knowledge from". (Parents of W)

If the liability for the injury was contested by the insurance company, then the insurance company did not meet any pre-settlement costs until liability was determined. Three families experienced this problem. In K's case (see Table in Appendix 5), a single parent family with three children including K, the extra costs have been borne by the family and this will continue until the Court hearing, 9.5 years after accident. The parent was uncertain why his case was taking so long except that there were two other parties and both denied any liability. In another case of denied liability, the accident was "inter-state" and there were complications relating to the owner of one of the vehicles concerned.

The experience of claiming compensation from insurance companies has been described as "deliberate, structured status degradation" designed into the compensation process to reduce liability claims (Watson, 1985: 90). For those with spinal cord injuries and their families, this process is in addition to the emotional shock of the injury. Status degradation results at a number of points in the process such as when claimants have to negotiate with experienced professionals and when claimants have to prove their injury is "genuine" and "manage their impressions" (Watson, 1985: 83 -89). Many claimants are confused by the changed role of some of the medical profession whose therapeutic doctor-patient role is transformed from treatment to judgment when employed by insurance companies (Lloyd and Stagoll, 1979). In contrast, recipients of social welfare such as income support claimants usually find the decision-making quick, especially for conditions such as spinal cord injuries.
Parents' main contact with the process was through their solicitors. Explanations for lengthy delays were thus less likely to blame the legal system. One family had a solicitor look into the reason for the delay and was told it was the insurance company causing the problem. The longest delay was experienced by a family whose case was under the "old system":

"Our case has been 7 1/2 years and nothing has happened.... - they [the solicitors] don't expect to get a listing in the court for another two years and that means we have to wait until then to go and get a listing... So it could be any time after that, which is 9 years after the accident. It could be up to 12 years before it's in court." (Parent of K)

Two families who requested their solicitors to "expedite" their cases on the grounds of financial hardship found this request unhelpful. It took two years for one of these cases to come to court and, in the other, a parent stated it added to their financial burdens.

"When the hearing date was announced we went into the city ... my husband took the day off work. Despite the request for an expedited hearing, the case was "re-scheduled" and all the costs incurred for the day - the QC, witnesses and so on - all had to be paid for. In addition, we lost a day's pay. The solicitor took out a loan for us to cover these costs." (Parent of A)

Concern over the appropriate time to settle claims

The individuality of claimants' problems rather than their commonality is stressed in professional services: lawyers, tend to view each claimant's problem as unique and requiring a tailor-made solution. Clients are then socialised in their interactions to see their problems as "unique", the "isolated victim and author", which is due to "individual fault" and susceptible to "individual, professional solution" (Ewald, 1991: 203). Thus, when parents had to make important decisions in areas where, in contrast to professionals,
they lacked knowledge, understanding and experience, they worried about their choices, and felt alone.

When to settle was such a dilemma: should the claim be settled as soon as possible so the family can use the money for the child's benefit? If this is done, the family take a gamble that sufficient money for future requirements has been included in the settlement calculation. (The existence of choice of settlement now or later is not a choice for the family of K whose case may take up to 12 years to come to court).

One parent expressed her concerns:

"There's a dilemma whether we settle now and that money gets locked away in the Public Trust and she gets charged management fees and tax, or we settle later. She can't really touch the money until she's 18... The longer you wait the more they're inventing - we don't know whether to wait." (Parent of G)

Other parents acknowledged that there could be benefits in delaying settlement but they could not afford to wait, especially if business or farming crises were occurring simultaneously: "... we were finding things were starting to get pretty tight on the land and we needed the money" (Parent of P). However, parents continued to worry after settlement about their haste to settle, especially when medical problems, such as scoliosis, occurred after settlement and they believed this had not been factored into calculations. Where parents and young people had settled and new needs or medical techniques came to light, they had experienced difficulty extracting further money from administrative based insurance schemes such as Transcover and interstate schemes and from trust funds:

"At high school I have to have my own computer. So, the occupational therapist's asking for a lap-top. But in the deeds [of settlement] it only says that I can have a computer i.e. one. The insurance is saying 'No'". (Statement of V)
Deductions from settlement money

Generally, parents perceived the purpose of the settlement as capital for future income generation. They were thus very wary of eroding the capital base, both before and after settlement. Before settlement, many service providers charged extra for compensation cases and few parents understood that payments would be deducted from settlements. One parent noted,

"The insurance company paid an agency to employ a carer for us - at $25/hr - double the rate a carer's paid. We thought that this cost was on the insurance company... we didn't realise that all the money the insurance company has spent already comes out of the settlement that you get ... They're not the only ones who do it: occupational therapists, pools at hospitals - all at much higher rates! But this all comes out of the settlement." (Parent of W)

Once parents understood costs were deducted from settlements, another dilemma arose: consideration by parents of their own expenditures and claims.

"Every catheter we use, every diaper we use, every kilometre we travel - it comes off her settlement. You're in two minds whether to write the costs down... That's money she could use elsewhere." (Parent of G)

Similarly, drawing on the money after settlement, although a parental right, was stigmatising and structured to discourage parents:

"Over a period of time things like extra hot water would add up. But they're the things you find are difficult to claim - the money might be there to claim but I find it very hard to go in and say [to the trust manager] I want an extra $100 because we've used extra." (Parent of V)
The basis of the settlement

The rationale for the settlement amount and its components remained a mystery to many parents e.g.

"I don't know if [the extra costs of clothes, bed linen, hot water and laundering] gets taken into consideration in the settlement. I really couldn't fathom how they worked a lot of the costs out." (Parent of V)

The orientation of professional services encourages client inaction, "faith" and "dependency" on professionals as well as "ceding control of a problem" (Scheff, 1968). Parents who admitted they did not comprehend the legal implications of their case had little choice but to "put their trust in their solicitor and insurance companies" to arrive at an appropriate settlement. Resignation seemed the only option, especially for parents from non-English speaking backgrounds:

"I think it's a good insurance company. .. I have no experience in these matters ... I just wait for my solicitor." (Parent of B)

These attitudes forced upon parents not only prevents their viewing matters critically but it also inhibits claimants' skill formation and reinforces messages of dependency which claimants are likely to be receiving from others.

Parents' interpreted their lack of understanding of settlements in two ways. One, related it to the shock they had experienced - "... in those initial phases because you're in a state of shock ... you can't take it [information] in." (Parent of K)

The second interpretation was parents lacked information at the appropriate time and in an appropriate format –

"The solicitors weren't very good at relating and the aim seems to be to keep it a big mystery; we were battling the whole time to keep up with the demands of what the solicitors were asking. We didn't have a full understanding of why they were asking us to do things. You'd
cope a lot better if you understood what you were going through and why." (Parent of W)

Information about benefits from the public welfare system are generally available and advocacy services exist to assist claimants. However, the insurance claims process has taken no cognizance of claimants' inadequate information (Encel and Johnson 1978). Lack of knowledge of choices, negative attitudes from insurance companies, lawyers who were "too slow", "ineffectual" and "disloyal", unfamiliarity with court procedures and, later, with investing money causes problems for claimants. In addition, formal safeguards against abuse of the claims process are "of limited value when claimants do not understand the working of the system and are wholly or partly ignorant of their rights or of available remedies" (Encel and Johnson, 1978: 87,88).

Generally, claimants were excluded from understanding and participating in damages quantification. Lack of information meant parents interpreted various factors relating to the settlement amount quite differently. For example, one family's daughter whose intelligence was assessed interpreted her good score as an indication they would get more in the settlement:

"The brainier you are the more you get." (Parent of F)

Another family arrived at an opposite meaning:

"W's intelligence was tested by both sides and they say she's in the top 5% but in the court settlement you get less because that means you're likely to go on to tertiary education and to work." (Parent of W).

The publicity about some "excessive" damages awards has made most claimants isolated and reticent to discuss their settlement amounts. In addition, some judges and politicians have criticised lump sums as "windfall[s] for relatives", believing claimants will die prematurely (Papadopoulos, 1995, 2). Others have acknowledged the serendipitous nature with one judge remarking in a child's case, that making an award was "… simply entering into an area of speculation, … judicial guesswork. This is
a task that no man or woman on this planet could wisely discharge.” (Papadopoulos, 1995, 3).

Parents and adolescents viewed their settlement amounts, its adequacy and its management as "private" matters. Only one person referred to her settlement amount, from several years ago, which was now yielding very small amounts:

"No one can live off their investments at the moment. If you had other medical needs to meet, you'd be under big pressures. You realise that if you start taking from your capital you'll be in big trouble one day." (Statement of Y)

Summary

Although a high proportion of children and adolescents in this study were claiming CTP insurance, only a small proportion of people with disabilities claim compensation. This percentage is higher for people with spinal cord injury.

Claiming compensation is not related to the key requirement of people with disabilities which is ending their marginalisation. If marginalisation ended and people with disabilities were included in society then there would be no need to "battle" for money to provide for people with disabilities. Literature on the requirements of people with spinal cord injury supports the recognition of claiming insurance and, later, managing the settlement moneys as processes with which people experienced difficulties.

The experience of claiming lasted a number of years for the families in this study and had several negative aspects which largely stem from non-professionals, such as parents, dealing with professional insurance, medical and legal personnel whose agendas are not related to the child with disabilities. Parents concerned about the injured child were surprised to discover that insurance companies were motivated by other considerations. The incomprehensibility of the claiming process created frustration.
Moreover, the claims process prevented the resumption of "normal family life" which is an important goal of parents. Parents felt alone in their "battle" believing the events about their claim were unique.

Longer term, management of the settlement money and decisions which have to be made around expense claims on the settlement are also issues which disturb parents and adolescents.
PART THREE
This thesis has addressed a number of research questions in an area where there has been little research. Most disability research based on the views of the interpretations of professionals; however, this research has built on the views of those who have either experienced spinal cord or cared for a child with spinal cord injury.

The research data shows that the requirements of the children and adolescents in this study relate to their "stage" in their disability "career". After diagnosis, the immediate requirements are for quality medical treatment. This is followed by requirements which originate from the institutional hospital organisation. New sets of requirements develop on returning to the community. As children and young people move into age-related activities further concerns emerge related to education, career, recreation and socialising with peers. Co-existing with these patterns are individual differences such as living in a non-metropolitan area or a one parent family which may complicate requirements.

Parents and adolescents in this study were critical of many aspects of their requirements such as the lack of recognition and inadequate responses to their requirements. Much of this criticism centres around how professionals interacted with parents and adolescents and the failure of professionals to include them in decision-making. For example, adolescents were not consulted regarding goals and programs for rehabilitation. Parents and adolescents were also critical of unacknowledged aspects of their injury such as the emotional impact. However, these criticisms are made with current knowledge years after events and it is unclear whether parents and adolescents would have had these requirements when the events were actually unfolding.
Parents and adolescents were also concerned about the immediate future and meeting the requirements they foresaw. They required information, guidance and advocacy in such complex areas as making friends, forming relationships and negotiating education requirements with education authorities.

Like other people with disabilities, the data shows that parents and adolescents were critical of the prolonged medicalised interpretation of their requirements and that they seek to have other aspects recognised, although the importance of medical treatment initially and on other occasions is accepted.

The social model of disability has been used to explain the requirements of people with disabilities. The main requirement of people with disabilities, according to this model, is an end to marginalisation from valued social activities. When this proposition is tested against the data for children and adolescents with spinal cord injuries, it can be seen that this requirement occurs for this group at a particular stage in their “career”, when children and adolescents attempt to resume their previous places in the community. At this point, they realise the extent to which society marginalises them in such arenas as education, transport, the ability to spontaneously join in social and recreational activities with friends.

The social model further asserts that marginalisation stems from social barriers. Crow (1996) has argued that impairment also contributes to marginalisation. The forms of marginalisation identified in this study appeared to be closely linked with such social barriers as insufficient funding for personal assistance services, a lack of community medical services for people with spinal cord injuries, a lack of information services and cumbersome administrative arrangements within education systems. However, children in this study had experiences such as frequent re-hospitalisation which over time contributed to their marginalisation but whose origins may be attributed to social barriers or may be viewed as impairment related. Thus, this study cannot be conclusive about the contribution of
impairment or social barriers to some forms of marginalisation without further research into the factors producing these requirements.

Importantly, the data reveals that children and adolescents and parents have a number of other requirements besides ending marginalisation. Some of the other non-marginalisation requirements such as quality acute medical treatment are time limited and others such as forming friendships and relationships remain for much longer periods of time. Some of these non-marginalised requirements are addressed by the welfare system and others are not acknowledged.

The "social model" of disability has been widely acclaimed because it has shifted the focus on disability from the individual to the social sphere and its contribution to the marginalisation of people with disabilities.

There is a danger, however, if we slavishly adhere to the social model to inform us on the requirements of groups such as children and adolescents with spinal cord injuries. This danger is that the requirements which do not neatly fit the social model will be overlooked, as has occurred with the medical model, and people with disabilities will continue with unacknowledged concerns because their requirements do not fit a particular construction of disability.

The argument that the requirements of children and adolescents are likely to be more substantial than just ending social marginalisation is supported by the more general literature on the requirements of people with spinal cord injury. The literature on people with spinal cord injury indicates that medical issues and interaction with medical professionals were their first concern. Some of the serious omissions in the requirements of people with spinal cord injury (such as lack of complete information on sexual functioning, lack of meaningful rehabilitation, lack of acknowledgement of the emotional impact of the injury) are attributed to the dominance of medical definitions of their injury while the origins of other requirements such as ending the mental
dominance of spinal cord injury and, in some cases, managing compensation claims, are more complex.

There are some important differences in requirements between adults with spinal cord injuries and younger people. One difference is that the children and adolescents in this study were readily accepted back into the family home and did not need to seek accommodation and support. Return to a family environment is not always an option for adults. Adults were also less concerned about educational issues. However, the literature on adults indicates that the mental life of individuals may be dominated by the various aspects of living with spinal cord injury; this did not appear to be the case for children and adolescents although further research is needed to confirm this.

The public welfare systems (social welfare and insurance settlements) meet only a proportion of the requirements of the children and adolescents. The social welfare system offers assistance in areas such as acute medical treatment which is universally available, purchase of pharmaceutical products, continence aids, supply of products such as wheelchairs and taxi subsidies and other transport subsidies. As noted earlier, except for acute medical treatment, eligibility is tightly drawn so that only those in dire need are eligible for assistance. Consequently, many families are unable to benefit and thus draw on their own resources for the extra disability related expenses. In contrast, children and adolescents with insurance settlements are provided with funding to expend on these items and thus need not draw on family resources.

Many of the other requirements of children and adolescents are not items which can easily be purchased with insurance moneys or supplied by social welfare. Some requirements stem from the unilateral power relationships between professionals and adolescents and parents, as exemplified by a lack of consultation, explanation and respect for experiential knowledge. Other requirements arise from the isolation experienced when children and adolescents are discharged from hospital, the complexity of claiming compensation and the lack of current and on-going information on living with
spinal cord injuries. A further set of requirements revolve around personal relationships such as teasing at primary school, loss of friends by adolescents, fear of dependency on parents and other requirements are psychological, such as feelings of grief and depression.

Children and adolescents who receive insurance moneys can afford to satisfy some of their requirements (services, aids and equipment) which confers extra advantages on this group. Examples are nursing care from qualified staff rather than personal assistance from less qualified workers, innovative muscle stimulation programs, equipment for recreational and rehabilitation activities and extensive home modifications. However, many of the expenditures made by parents and adolescents may be seen as privatised welfare or replacements of the welfare which would be provided to those drawing on social welfare. In this study, when hydrotherapy and physiotherapy were unavailable or unreliable in supply, parents used insurance money to build heated pools and buy physiotherapy privately; similarly, students took their own "carers" to act as aids at school, provided their own transport to school and had lifts or "stair climbers" installed; equipment such as wheelchairs were also bought and the inaccessibility of public transport was avoided by owning private, accessible transport.

These forms of privatised welfare may confer advantages on this group in the early years which may assist this group of children and adolescents gain skills for independence and employment. Whether this is so, how long the advantage lasts and other aspects of the "advantage" requires further research. However, it should be acknowledged that the welfare systems are perceived as inequitable by those who have the same injury but only draw on social welfare. This point is all the more serious when it is realised that the source of funding for both of these welfare systems (CTP insurance and social welfare) is public funding.

The requirements of children and adolescents with spinal cord injuries and the social responses to their requirements reflect the prevailing social attitude towards disability. This attitude is revealed as one which ignores
certain requirements, recognises other requirements with piecemeal responses which convey variable benefit and allows inequities in recognition of requirements between social welfare recipients and those who have insurance settlements. In summary, our social values do not dictate the full inclusion of people with disabilities in society; full inclusion would necessitate new social arrangements underpinned by a set of values which acknowledged people with disabilities as equal members of society.

The contribution of this thesis

This thesis has contributed to the development of the social model of disability by illustrating the complexity of the requirements for a specific group, children and adolescents with spinal cord injuries some of which are additional to "marginalisation" and complicated in their origins. The model would benefit from other groups also comparing their requirements against the model in order that the theory may be further refined.

The thesis has also illuminated elements of the insurance system and contrasted this with the social welfare system. A comparison of the outcomes for people with disabilities of these two systems appears to be an under-researched area which would benefit from further examination to clarify the extent of inequities between the systems.

The thesis also recognises non-material requirements of parents, children and adolescents such as depression following spinal cord injury. Further research is needed to establish whether these requirements are products of the current value system or whether they are tied to the nature of the impairment. Certainly, this recognition challenges the common perception that welfare systems can meet all requirements of groups such as the children and adolescents in this study.
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APPENDIX I

METHODOLOGY

This thesis started with the broad question of what are the requirements of children (as represented by their parents) and adolescents with severe spinal cord injuries and how do these requirements arise.

The first step was a literature review from which the theory underlying the thesis was derived. Although there is no literature on the needs of this particular group from their perspectives, the literature on the needs of people with disabilities from their perspective offers an explanation for their requirements and their origins. The literature on the needs of people with spinal cord injury, assumed to be adults, indicated a possible pattern for requirements of children and adolescents.

Obtaining the research data

Children and young people who were injured before 18 years of age were targeted to provide data for this study. These children and young people had been patients at Sydney hospitals and applications were made to ethics committees of these hospitals for approval to carry out the study. It was realised that many of the children would not be interested or sufficiently knowledgeable to participate in the research so that their views were conveyed by their parents. Thus, to some extent, the study may have under-represented children's requirements if parents were unaware of children's views. There is also the possibility that parents and children's requirements do not coincide and the likelihood that parents views will dominate as they are presenting the information.

Following the approvals of ethics committee for the research, letters were sent to parents and young people inviting their participation in the project and providing information sheets and consent forms. In the meantime, I spoke to service providers, such as doctors, orthotists, social workers, occupational
therapists and “special” educators. The purpose was to increase my understanding of how children and adolescents with spinal cord injuries are treated. This knowledge helped me formulate sensible questions in the “native language” (Bernard, 1994:141). I also read hospital records of potential interviewees, initially to check addresses and phone numbers. However, this was invaluable for giving treatment history but it also sensitised me, for example, when family members had died in road accidents.

**Sampling Frame**

As indicated in Chapter 1, there are no complete statistics on the number of children in New South Wales who incur complete spinal cord injury each year but it is likely that at least 49 children and adolescents incurred this injury between July 1989 and June 1999 (MAA, 1999).

At Royal North Shore Hospital (RNSH) doctors working on the Spinal Unit produced a list of children and adolescents with whom they had intermittent contact through re-admissions and other contacts. This list contained 26 names. From this, a further 10 names were cancelled because a full or partial recovery was made or the file with contact details was unavailable. Of the 16 left on the doctors’ list a further 6 did not participate in the project.

At both the Children’s Hospital and Westmead Hospital (these hospitals have since merged), doctors produced lists of children and adolescents with whom they had contact. This method had the benefit of quickness because files did not have to be checked for addresses and also the doctors knew whether the child or adolescent had sustained permanent spinal cord injury. On the other hand, this recruiting method biased the sample in favour of those who remained in contact with their respective hospital.

The table below indicates the number of participants in the study and the source of their names and contact details.
Table 1: Interviewees from Royal North Shore, Children’s and Westmead Hospitals

<table>
<thead>
<tr>
<th>Hospital</th>
<th>RNSH</th>
<th>Children's</th>
<th>Westmead</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of names on doctors' lists</td>
<td>26</td>
<td>15</td>
<td>2</td>
</tr>
<tr>
<td>Names cancelled due to:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- full / partial recovery</td>
<td>7</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>- files unavailable</td>
<td>3</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Potential interviewees:</td>
<td>16</td>
<td>15</td>
<td>2</td>
</tr>
<tr>
<td>- declined to participate</td>
<td>2</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td>- unable to be contacted</td>
<td>2</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td>Actual participants</td>
<td>10</td>
<td>9</td>
<td>1</td>
</tr>
</tbody>
</table>

Representativeness

Because the information on the “paediatric” population who sustained severe spinal cord injury is incomplete and its population characteristics are unknown, it is difficult to be certain of the representativeness of the sample. However, there is variety in the major characteristics in the participants such as gender, age, non-English speaking background, metropolitan and non-metropolitan addresses, compensatable status, medical diagnosis and causes of spinal injury. Further details are found in Appendix II. An important omission is the lack of representation from Aboriginal and Torres Strait Island people – Two people were listed for contact but one declined participation and no contact was established with the other.

Interviews

Two pilot interviews were conducted: one with parents and one with an adolescent. In both of these interviews, participants ranged over a wide
number of issues. It was thus invaluable to record the interviews and play them back, listening to comments made and their tone.

Generally, interviews were carried out in people’s homes. In some cases, non-metropolitan families were interviewed when they visited Sydney; thus some interviews were in a private room at a hospital or a motel room. In one case, a telephone interview was conducted. Permission to record interviews was sought (and given) in every case although sometimes interviewees wanted to be critical of a particular professional by name and asked that the tape-recorder be turned off.

Most parents spoke at great length on the subject; some were emotionally moved as they recounted events. As a researcher, I felt I had to work hardest at establishing “rapport” with adolescent males. This could be because an older generation female was perceived to have no understanding of their situation. The requirement for "drawing out" some participants reinforced the necessity of having good knowledge before the interviews of both spinal cord injury and personal histories (Zuckerman, 1972). Follow-up letters thanking participants for the interview were sent out at completion of interviews.

Analysis of data

The interviews were initially unstructured interviews - that is, no schedule of questions was used. Participants were reminded that the subject was their needs and concerns. After the first few interviews, some rough "hypotheses" began to develop, such as, "Waiting for settlement of an outstanding CTP claim caused financial hardship". Thus, if participants did not mention this aspect, I raised it for comment.

Four themes were discerned in the resulting data: (1) "hospital and when we first came home"; (2) everyday life; (3) about school experiences, and (4) about claiming compensation. Within these themes, sub-themes or concepts were recognised. For example, within "everyday life", recreation, transport
and personal assistance were "concepts". These concepts were defined and then the qualities or properties of the concept elaborated so that the concept was "rich" (Glaser and Strauss, 1967; Blumer, 1956). An example is "transport" which had the following qualities: public/private; own/family; choice/no choice; CTP claim settled/not settled and so on. The qualities were then exposed to other concepts and properties such as - "quadriplegia/paraplegia", "compensatable/non-compensatable", "settled/not settled", "metropolitan resident/non-metropolitan resident" and so on. In this comparative process, relationships become obvious and hypotheses could be formed. Where exceptional cases did not fit the hypothesis, analytic induction techniques were employed, modifying the original concept definition or hypothesis until the statement was true for all cases (Robinson, 1951).

It is critical in qualitative research to confront analysis - "Data do not speak for themselves" (Lofland, 1971). Analysis at this point requires the researcher to state the "meaning" or "significance" of the participants' everyday experiences. For example, the "meaning" of insurance companies not paying for some "necessity" was increased financial strain for the family. Quotations from participants illustrate this analysis (Lofland, 1971; Bernard, 1994: 363). The "meanings" could be further abstracted and clumped together so that a higher level abstract term was generated. Some examples were "degradation" and "non-participation"; the higher level abstract terms often related to concepts in the literature review. The requirements of children and adolescents were compared to the requirements of "people", those with disabilities and those with spinal cord injuries, and the origins of requirements were also compared.

**The personal and public connection**

A strength of this research has been the connection made between individuals' statements on their requirements and societal structures. Mills' urged the connecting of "the personal troubles of milieu" with "the public issues of social structure" (Mills, 1959: 3-11) so that an understanding of the
origin of "felt needs" could be developed. The frustrations of research participants with insurance companies, education authorities and so on are typical of the personal milieu: "Men often feel ... trapped ...[that] they cannot overcome their troubles... Their visions and their powers are limited to the close-up scenes of job, family ..." (Mills, 1959: 3). Frequently, individuals view themselves as the cause of their problems - ("I should have chosen a different solicitor") or subject to chance ("My bad luck to have such friends") (Mills, 1959: 5; Borsay, 1986: 180). With this view of cause, "the statement and resolution" of any problem is within the grasp of any individual - "open to his willful understanding ... within the scope of the immediate milieu" (Mills, 1959: 6). Thus, not only is the individual the "original cause" of the problem but s/he is also the cause of the problem remaining. It is not surprising a further characteristic is personal troubles are viewed as "private matters" and values cherished by the individuals are threatened (Mills, 1959: 6). "Privacy" also prevents people in similar positions talking and comparing experiences. Hence, the similarities in individuals' experiences remains unrecognised; it is this similarity that provides grounds for investigating the "public issue" element of matters raised.

Understanding "personal troubles" requires pursuing an investigation at a social and historical level. An example is pursuing development of compulsory third party insurance, "risk", insurance and compensation mechanism. "The history that now affects every man is world history" (Mills, 1959: 4) and this can be seen in "managerialist" ideology and declining labour market opportunities which affect, inter alia, students' quality of school education. Revealing the private troubles/public issue nexus has a practical advantage in that enlightened actors may feel stimulated to take action (Fay, 1975: 104). It has also been argued that the consequences of sociological enquiry may be a "contribution to political freedom by weakening myths, refuting distortions and from preventing imbalanced views of social reality from dominating collective consciousness" (Bulmer, 1982: 46); this obviously depends on the use to which the information is placed.
Emancipatory research

A weakness in this study's methodology, from the point of view of people with disabilities, is that the research is not based on the "emancipatory research" model. The model was devised by a group of disabled people in the UK, critical of government-sponsored research on people with disabilities such as an 1989 survey which portrayed disability as "individualised" rather than "social", concentrated on functional limitations and viewed people with disabilities as "passive" and "isolated" (Abberley, 1992). Acknowledging that neither researchers nor the researched have much control over research production, the proponents of "emancipatory research" believe these constraints should be challenged. Disabled people should control research, deciding what will be done and how, with the researcher accountable to them. Non-disabled researchers should be part of the people with disabilities network, if they are not to be suspected of "exploitation" (Zarb, 1992). Research should be relevant to the lives of people with disabilities and confront social oppression and power; it should be based on "reciprocity" between researchers and the researched, and have potential to empower people with disabilities (Oliver, 1992: 111); it should spotlight oppression and "create space for absent subjects [people with disabilities]" in the "world view" (Morris, 1992); and it should systematically demystify structures and processes (Barnes, 1992). The outcome of "the usual research" made little contribution to the lives of people with disabilities other than to alienate them (Oliver, 1992) and it has wasted public funds which could have been prevented by consulting people with disabilities (Zarb, 1992).

While this research has not been a study directed by adolescents and children with spinal cord injuries or parents to achieve their specific aims, it has used the definitions of disability and impairment from the disability movement and the research has viewed people as active beings and examined the social component of their experiences. The study has also sought to demystify the structures and processes behind origins of
requirements identified by the participants in this study and reveal oppressive practices.
APPENDIX II

Sampling Frame

Table 1: Indication of number of potential children and adolescents with spinal cord injuries for study

<table>
<thead>
<tr>
<th>Accident Year</th>
<th>Unknown</th>
<th>Under 16</th>
<th>16</th>
<th>17</th>
<th>18</th>
<th>19+</th>
<th>ALL AGES</th>
</tr>
</thead>
<tbody>
<tr>
<td>1989/90</td>
<td>3</td>
<td>7</td>
<td>0</td>
<td>2</td>
<td>3</td>
<td>35</td>
<td>50</td>
</tr>
<tr>
<td>1990/91</td>
<td>2</td>
<td>4</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>26</td>
<td>35</td>
</tr>
<tr>
<td>1991/92</td>
<td>1</td>
<td>4</td>
<td>0</td>
<td>3</td>
<td>0</td>
<td>15</td>
<td>23</td>
</tr>
<tr>
<td>1992/93</td>
<td>0</td>
<td>2</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>27</td>
<td>29</td>
</tr>
<tr>
<td>1993/94</td>
<td>1</td>
<td>3</td>
<td>1</td>
<td>0</td>
<td>1</td>
<td>18</td>
<td>24</td>
</tr>
<tr>
<td>1994/95</td>
<td>0</td>
<td>3</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>20</td>
<td>24</td>
</tr>
<tr>
<td>1995/96</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>2</td>
<td>1</td>
<td>18</td>
<td>21</td>
</tr>
<tr>
<td>1996/97</td>
<td>0</td>
<td>2</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>8</td>
<td>11</td>
</tr>
<tr>
<td>1997/98</td>
<td>0</td>
<td>3</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>14</td>
<td>18</td>
</tr>
<tr>
<td>1998/99</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>3</td>
<td>5</td>
</tr>
<tr>
<td>ALL</td>
<td>7</td>
<td>29</td>
<td>4</td>
<td>10</td>
<td>6</td>
<td>184</td>
<td>240</td>
</tr>
</tbody>
</table>

Source: NSW Motor Accidents Authority Claims Register, data as at June 1999.
Table 2: Numbers of potential and actual participants for the Study from hospital lists of patients

<table>
<thead>
<tr>
<th>Hospital</th>
<th>Number identified</th>
<th>Number participating</th>
</tr>
</thead>
<tbody>
<tr>
<td>Royal North Shore Hospital</td>
<td>16</td>
<td>10</td>
</tr>
<tr>
<td>Children’s Hospital</td>
<td>16</td>
<td>9</td>
</tr>
<tr>
<td>Westmead Hospital</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Total number of potential participants</td>
<td>34</td>
<td></td>
</tr>
<tr>
<td>Total number who participated</td>
<td>20</td>
<td></td>
</tr>
</tbody>
</table>
INFORMATION ON INTERVIEWS

<table>
<thead>
<tr>
<th>NUMBER OF INTERVIEWS</th>
<th>20</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Young people interviewed alone:</strong></td>
<td>5</td>
</tr>
<tr>
<td>Male</td>
<td>3</td>
</tr>
<tr>
<td>Female</td>
<td>2</td>
</tr>
<tr>
<td><strong>Parents interviewed apart from child/adolescent</strong></td>
<td>11</td>
</tr>
<tr>
<td>Mothers</td>
<td>5</td>
</tr>
<tr>
<td>Fathers</td>
<td>4</td>
</tr>
<tr>
<td>Both parents</td>
<td>2</td>
</tr>
<tr>
<td><strong>Parents and child/adolescent both contributed to interview:</strong></td>
<td>4</td>
</tr>
<tr>
<td>With mothers only</td>
<td>3</td>
</tr>
<tr>
<td>With father only</td>
<td>-</td>
</tr>
<tr>
<td>With both parents</td>
<td>1</td>
</tr>
</tbody>
</table>
APPENDIX IV

CHARACTERISTICS OF CHILDREN & ADOLESCENTS IN STUDY

Table 1: Children & Adolescents in Study by gender

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Females</td>
<td>12</td>
</tr>
<tr>
<td>Males</td>
<td>8</td>
</tr>
<tr>
<td>Total</td>
<td>20</td>
</tr>
</tbody>
</table>

Table 2: Children & Adolescents in Study by Non-English speaking background

<table>
<thead>
<tr>
<th>Non-English speaking background</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>6</td>
</tr>
<tr>
<td>English-speaking background</td>
<td>14</td>
</tr>
<tr>
<td>Total</td>
<td>20</td>
</tr>
</tbody>
</table>

Table 3: Children & Adolescents in Study by Home Location

<table>
<thead>
<tr>
<th>Home Location</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Sydney Metropolitan address</td>
<td>12</td>
</tr>
<tr>
<td>Non-metropolitan address</td>
<td>8</td>
</tr>
<tr>
<td>Total</td>
<td>20</td>
</tr>
</tbody>
</table>
Table 4: Children & Adolescents in Study by Age

<table>
<thead>
<tr>
<th>Ages of children &amp; adolescents</th>
<th>Years</th>
</tr>
</thead>
<tbody>
<tr>
<td>Under 5</td>
<td>2</td>
</tr>
<tr>
<td>6 - 12</td>
<td>8</td>
</tr>
<tr>
<td>13 – 18</td>
<td>7</td>
</tr>
<tr>
<td>Over 18</td>
<td>3</td>
</tr>
<tr>
<td>Total</td>
<td>20</td>
</tr>
</tbody>
</table>

Table 5: Children & Adolescents in Study by Years since onset

<table>
<thead>
<tr>
<th>Number of years</th>
<th>Children &amp; Adolescents</th>
</tr>
</thead>
<tbody>
<tr>
<td>2 years and under</td>
<td>4</td>
</tr>
<tr>
<td>3 – 5 years</td>
<td>7</td>
</tr>
<tr>
<td>6 – 10 years</td>
<td>9</td>
</tr>
<tr>
<td>Total number of participants</td>
<td>20</td>
</tr>
</tbody>
</table>
Table 6: Children & Adolescents in Study by Medical Diagnosis

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>Number of Children &amp; Adolescents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Paraplegia</td>
<td>7</td>
</tr>
<tr>
<td>Quadriplegia</td>
<td>13</td>
</tr>
<tr>
<td>Total</td>
<td>20</td>
</tr>
</tbody>
</table>
Table 7: Children & Adolescents in Study by Cause of Spinal Cord Injury

<table>
<thead>
<tr>
<th>Cause</th>
<th>Number of Children &amp; Adolescents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Motor vehicle accidents</td>
<td>15</td>
</tr>
<tr>
<td>Sport</td>
<td>3</td>
</tr>
<tr>
<td>Other</td>
<td>2</td>
</tr>
</tbody>
</table>

Table 8: Children & Adolescents in Study by Compensable Status

<table>
<thead>
<tr>
<th>Compensable status</th>
<th>15</th>
</tr>
</thead>
<tbody>
<tr>
<td>Non compensable status</td>
<td>5</td>
</tr>
<tr>
<td>Total</td>
<td>20</td>
</tr>
</tbody>
</table>
Table 9: Children & Adolescents in Study by Settled Compensation Claim

<table>
<thead>
<tr>
<th>Status</th>
<th>Numbers</th>
</tr>
</thead>
<tbody>
<tr>
<td>CTP claim settled</td>
<td>8</td>
</tr>
<tr>
<td>Not settled</td>
<td>7</td>
</tr>
<tr>
<td>Not eligible for CTP insurance compensation</td>
<td>5</td>
</tr>
<tr>
<td>Total</td>
<td>20</td>
</tr>
</tbody>
</table>
Table 10: Children & Adolescents in Study by CTP Scheme

<table>
<thead>
<tr>
<th>CTP Scheme</th>
<th>Numbers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Current insurance scheme</td>
<td>7</td>
</tr>
<tr>
<td>Transcover, transferred to current scheme</td>
<td>2</td>
</tr>
<tr>
<td>“Old” scheme</td>
<td>4</td>
</tr>
<tr>
<td>Interstate</td>
<td>1</td>
</tr>
<tr>
<td>Not eligible for CTP insurance compensation</td>
<td>5</td>
</tr>
<tr>
<td>Total</td>
<td>20</td>
</tr>
</tbody>
</table>

Table 11: Children & Adolescents by highest level of education attained at time of interview

<table>
<thead>
<tr>
<th>Educational level</th>
<th>Numbers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pre-school</td>
<td>1</td>
</tr>
<tr>
<td>Primary school</td>
<td>10</td>
</tr>
<tr>
<td>Secondary school</td>
<td>6</td>
</tr>
<tr>
<td>Tertiary</td>
<td>3</td>
</tr>
<tr>
<td>Total</td>
<td>20</td>
</tr>
</tbody>
</table>
Table 12: Children & Adolescents by Labourforce Status

<table>
<thead>
<tr>
<th>Status</th>
<th>Numbers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not in the labourforce:</td>
<td>18</td>
</tr>
<tr>
<td>Student</td>
<td>17</td>
</tr>
<tr>
<td>Other</td>
<td>1</td>
</tr>
<tr>
<td>Employed:</td>
<td>2</td>
</tr>
<tr>
<td>Full time</td>
<td>1</td>
</tr>
<tr>
<td>Part time</td>
<td>1</td>
</tr>
<tr>
<td>Total</td>
<td>20</td>
</tr>
</tbody>
</table>
APPENDIX V

COPIES OF LETTERS OF APPROVAL FROM THE ETHICS COMMITTEE -

- Royal North Shore Hospital
- The Children's Hospital
- Western Sydney Area Health Service, Westmead Hospital.
Ms Marilyn Leeds
33 Wunyas Street
MARRICKVILLE NSW 2204

Dear Ms Leeds,

Re: Protocol No. 9303-50(M) - T Taylor, M Leeds, S Rutkowski, A Davis

Investigation of social needs of children with severe spinal cord injury.

Thank you for providing a revised Consent Form for your protocol on the above study. (Please note that the statement in Item 6, Consent Form, Appendix C - "My involvement in this project may be terminated if any of the following circumstances develop." should be deleted).

The Medical Research Ethics Committee (MREC) considered your application at its meeting on 21 April, 1993 and approved a pilot study of 20 subjects. Following this, could you please provide a report to the MREC on the progress of the study and inform the Committee of the final questionnaire/interview format. If any problems are encountered or the questions to be asked have to be changed in any way, these can be considered for further approval.

In order to comply with the Guidelines for Good Clinical Research Practice (GCRP) in Australia, and in line with RNSH MREC policy, may I remind you that it is the Chief Investigator’s responsibility to ensure that:

i) A report is provided to the MREC at the completion of the pilot study.

ii) The MREC is notified as soon as possible of any changes to the protocol. All changes must be approved by the MREC before continuation of the research project. This includes notifying the MREC of any changes to the staff involved with the protocol.

Yours sincerely,

GILLIAN M SHENFIELD
Chairman
Medical Research Ethics Committee
The Children’s Hospital

RESEARCH OFFICE
2nd Floor, Hospital Education Centre
Ext: 6336, 6122

JFK:bl

18 May 1993

Ms M J Leeds
33 Wernys St
MARRICKVILLE NSW

Dear Ms Leeds,

At its meeting on 14 May 1993 the Ethics Committee approved your project entitled “Investigation of social needs of children with severe spinal cord injury”. It has been given the number 93013 and this should be mentioned in any future correspondence.

Ethics approval is subject to a number of conditions. The conditions specific to your project and the general conditions which apply to all research carried out under the auspices of the Children’s Hospital are attached.

Good luck with your project. Do not hesitate to contact the Research Office if you need any assistance with it.

Yours faithfully,

J F Knight
Coordinator of Clinical and Laboratory Research

The Royal Alexandra Hospital for Children established 1880
30 August 1993

Ms M Leeds
33 Wemyss Street
Marrickville
NSW 2204

Dear Ms Leeds

re: Research Proposal: 'Investigation of social needs of young people and children with Severe Spinal Cord Injury'

Your research proposal was considered at the meeting of the Western Sydney Area Health Service Human Research Ethics Committee held on Tuesday 24th August 1993 and was approved.

In relation to the Consent Forms particular to the research at Westmead Hospital, the Committee wished some minor corrections. Page 12, point number 3, to remove ambiguity, we suggest ‘The results obtained from the study may benefit the medical management of...’ Page 14, in the first paragraph, the correct title of this Committee is the Human Research Ethics Committee.

The Committee also wished assurance regarding the eventual safe disposal of tape recordings to protect the confidentiality of participants in this study.

The NH&MRC Statement on Human Experimentation ‘Supplementary Note 1’ states that institutional Ethics Committees (IEC) must provide surveillance of research projects until completion of the project.

In accordance with these guidelines, approval for your protocol is given on the understanding that you will provide the Committee with a progress report of not more than one page in length on your research, by no later than July 1993.

Approval has been given for one year, and renewal is contingent upon the provision of a progress report.

Please note that this approval relates to the ethical content of the trial and individual arrangements should be negotiated with the Heads of Diagnostic and Service Departments in those situations where the use of their resources is involved.
In future correspondence, please quote your approval number: HREC/93/9/4.11.
The Committee wishes you well with your project.

Yours sincerely

[Signature]

Dr Howard Smith
Secretary
Western Sydney Area Health Service
Human Research Ethics Committee
Ends
FORM LETTER SENT TO PARENTS AND REPLY FORM

ML:Img

18 May 1993

Name/add ~

Dear Mr/Mrs/child~

Re: Research project on social needs of children / adolescents with severe spinal cord injury

I am writing to interest you in participating in a project with which Dr S. Rutkowski and I are associated. The project will be carried out by a postgraduate student of the university of Sydney (Ms Marilyn Leeds) and has been approved by the Ethics Committee of this hospital. The research project aims to document what parents, young people and children with spinal cord injuries consider are the most important needs for children with disabilities in the period after hospitalisation after their injury. Some children will be old enough to have definite opinions in addition to their parents - these would also be most welcome. The information that is received from parents, young people and children will be collected into a report but will not in any identify those who gave information. The intention of the report is to use the information to plan better services. If you have any suggestions for dealing with the needs you identify these too will be carefully noted.

Participation in this project will involve you and /or your child talking to Ms Leeds for approximately one hour. This conversation will be tape-recorded. The information disclosed in the interview would not be stored with your name and address. Thus, it would be anonymous information. Any
information disclosed to Ms Leeds, the researcher, would be strictly confidential. After the writing of the report the interview tapes would be erased. If possible, the interviews for this project will be held in May, June and July. If you have an appointment at the hospital in this period then it would be desirable to have the interview before or after the appointment. If you do not have an appointment but are willing to participate, please let me know and we can consider an alternate arrangement.

Could you please give an indication of your interest in this project by completing the attached form and returning it in the supplied envelope. Thank you for your co-operation in this matter. If you decide not to participate please feel assured that this will not in any way affect your medical care.

Yours sincerely

Thomas K F Taylor
Professor of Orthopaedic & Traumatic Surgery
RESEARCH PROJECT

Social Needs of Children / Adolescents with Severe Spinal Cord Injuries

Please return this form in the envelope supplied to:

Department of Social Work & Social Policy
R C Mills Building - A26
The University of Sydney
SYDNEY NSW 2006.

Patient's name:………………………………………………………………………

Parent's name………………………………………………………………………

Address:………………………………………………………………………………

Suburb:..................................................State:...........Postcode........

Telephone:...............................................Contact:................................

Please tick for your reply:

I am willing to participate in the project as described above.............

I would like further information

I would not like to participate

Please return in the supplied envelope.

Thank you.
INFORMATION SHEET FOR PARENTS AND PATIENTS

Research Project: *Investigation of social needs of adolescents and children with spinal cord injury*

The services, equipment and aids which are offered to children and young people who have sustained spinal cord injury are based on the community's beliefs of what is needed by patients and their parents. Apart from medical services, patients draw on various community systems such as Third Party Insurance, legal systems, the Department of Housing for modifications, suppliers of equipment and aids and so on. Thus, it is appropriate to check from time to time what patients and carers' say their needs are. In this way, the services provided and how they are provided may take patient and carers' views into account.

The researchers for this project would like to hear the concerns or needs of parents, young people and children and what you think could be helpful, based on your experiences. The information would be collected by tape-recording your views, then putting them with the views of others to produce a fuller picture of needs and concerns. This could be used as evidence to support claims for new services or to argue for different ways of running services. The information collected would not identify any patient in any way and any information given to the researcher would be treated with strict confidentiality. Interview tapes will be wiped when the research is completed.

Interview time will not exceed one hour. If a patient or carer wishes to end the interview before this point, he/she is entitled to do so.

*Thank you for your time.*
ROYAL NORTH SHORE HOSPITAL CONSENT FORM TO PARTICIPATE IN A RESEARCH PROJECT

(For parents who may be joined by their children if parents and children both wish to participate)

I, --------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------
Of --------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------
-----------------------------------------------------------------------------------------------------------------------------------------Postcode -----

have been invited to participate in a research project entitled - Investigation of social needs of young people and children with severe spinal cord injury.

In relation to this project I have been informed of the following points:
1. Approval has been given by the Medical Research Ethics Committee of the Royal North Shore Hospital.

2. The aim of the project is to discover the needs of young people and children with spinal cord injury. In the case of young children this will be obtained primarily from parents although if younger children would like to express views and parents are agreeable the children may be interviewed with parents. No children will interviewed without parents present.

3. The results obtained from the study may or may not be of direct benefit to the patient's medical management.

4. The procedure will involve a tape-recorded interview of one (1) hour's duration.
5. There are unlikely to any adverse effects or risks related to this project.

6. My involvement in this project may be terminated if any of the following circumstances develop:

7. Should I or my child develop a problem which I suspect might have resulted from my involvement in this project, I am aware that I may contact Dr S. Rutkowski on 9438 7111.

8. I can refuse to take part in this project or withdraw from it any time. I am aware that opting out of the project at any stage will not affect my child's medical care.

9. Participation in this project will not result in any extra cost to me.

10. The results of the interview or information regarding my child's medical history will not be published so as to reveal our identities.

After considering all these points, I accept the invitation to participate in this project.

I also state that I/we have not participated in any other project in the past 3 months.

If I/we have, the details are as follows ---------------------------------------------

---------------------------------------------------------------------------------

SIGNATURE & DATE:-----------------------------------------------------------------

(of parent)
WITNESS

(Please print name)

SIGNATURE & DATE

(Witness)
APPENDIX IX

ROYAL NORTH SHORE HOSPITAL CONSENT FORM TO PARTICIPATE IN A RESEARCH PROJECT

(For young people [14 years & over]) who may be joined by their parents if both parties wish to participate)

I, -------------------------------------------------------------------------------------------------------------------------------------
(name of young person)

and -------------------------------------------------------------------------------------------------------------------------------------
(Names of parents if also participating)

Of Address-------------------------------------------------------------------------------------------------------------------------------------

-------------------------------------------------------------------------------------------------------------------------------------Postcode ----

have been invited to participate in a research project entitled - Investigation of social needs of young people and children with severe spinal cord injury.

In relation to this project I have been informed of the following points:
1. Approval has been given by the Medical Research Ethics Committee of the Royal North Shore Hospital.

2. The aim of the project is to discover the needs of young people and children with spinal cord injury. In the case of young people, they may choose to be interviewed by themselves or with parents.

3. The results obtained from the study may or may not be of direct benefit to the medical management of me/my relative.

4. The procedure will involve a tape-recorded interview of one (1) hour's duration.
5. There are unlikely to any adverse effects or risks related to this project.

6. My /our involvement in this project may be terminated if any of the following circumstances develop:

7. Should I/we develop a problem which might have resulted from involvement in this project, I/we am /are aware that contact may be made with Dr S. Rutkowski on 9438 7111.

8. I and my parents can refuse to take part in this project or withdraw from it any time. I am aware that opting out any stage will not affect my medical care.

9. My involvement in this project will not result in any hospital charges other than those related to normal treatment.

10. The results of the interview or information regarding my medical history will not be published so as to reveal our identities.

After considering all these points, I/we accept the invitation to participate in this project.

I/we also state that I/we have not participated in any other research project in the past 3 months.

If I have, the details are as follows-----------------------------------------------

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SIGNATURE---------------------------------------------------------------
(of young person)

SIGNATURE(S):-------------------------------------------------------------(of parent/s if participating)

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WITNESSS------------------------------------------------------------------------------------

(Please print name)

SIGNATURE----------------------------------------------------------------------------------

(Witness)

DATE---------------------------------------------------------------------------------------