Charting a Parallel Course:

Meeting the Community Service Needs of Persons with Spinal Injuries

by

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Dedication

For all the persons with spinal injuries who travelled this journey with me.

And for Steve, Amanda, Christopher and Elizabeth who kept the way clear.
Acknowledgments

This journey could never have been completed without the constant support, encouragement and input of my wonderful friend and mentor Dr Pat Bazeley.

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Statement of Authentication

The work presented in this thesis is, to the best of my knowledge and belief, original except as acknowledged in the text. I hereby declare that I have not submitted this material, either in whole or in part, for a degree at this or any other institution.
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Abstract

This study, the first comprehensive investigation of persons with spinal injuries in New South Wales, aimed to explore and develop a fresh understanding of the community service needs of persons with spinal injuries, so that their needs may be properly addressed. Different concepts of need were explored—normative, felt, expressed, prescriptive, comparative, and intrinsic need, and need as a means to an end.

Exploring different concepts of need required multiple methodologies including a review of government policies and legislation, statistical and segmentation analyses of demographic, injury related and service usage data obtained from a census-type survey, and conceptual and grounded theory analysis of interviews with persons with spinal injuries and their carers.

Normative need is interpreted by government and service providers in terms of functional impairment and economic disadvantage. For persons with spinal injuries, such measures did not in any way reflect their individual needs. Neither were services for persons with spinal injuries provided to individuals according to the criteria of their felt or expressed need for services, their perceptions of the intrinsic importance of services, nor on the basis of redressing comparative inequities in service distribution.

Persons with spinal injuries' need for community services could only be understood on the basis of the contribution services made to the realisation of their plans of life, that is, to be ordinary. Ordinariness has little to do with level of impairment, or other objectifiable characteristics. Ordinariness is about interdependence, relationships, participation and not being special or different.

In order to parallel plans of ordinariness, services need to be offered in partnership with, or under the control of the person with spinal injuries, foster an essential relationship between the provider and the person with spinal injuries, and not inappropriately assesses and judge the life plans of persons with spinal injuries based upon providers' perceptions of difference.
Introduction

This study explores the many concepts of need in order to develop a fresh understanding of the community service needs of persons with spinal injuries in New South Wales.¹

The genesis of this study lay in the decision by the NSW Department of Health to close Lidcombe Hospital in Sydney’s inner south west. ‘Ward 43’, within Lidcombe Hospital, was the only public hospital based long stay unit specifically for persons with spinal injury in New South Wales. The sixteen residents of this unit, some of whom had lived there for many years, were all persons with a high level of dependency.

In keeping with the philosophy of deinstitutionalisation, the option of community placement for the residents following closure was explored. A hasty study of the residents’ needs was conducted by the Nursing Unit Manager and this author, which clearly indicated that the residents had a level of need for services which could not be supported in the community.

As a result of this data, and other political forces, the residents were subsequently relocated to Lottie Stewart Hospital at Dundas in the inner north-west of Sydney.

That brief study of a small, highly dependent spinal injured population highlighted two issues:

- the high level of need for services by some persons with spinal injuries,
- the inability of the community to meet these needs.

That study did raise a number of quandaries. There were approximately 300 to 400 adults who incurred a new spinal cord injury admitted to specialist acute spinal injury hospital units in Australia every year during the mid to late 1980’s (Walsh, 1992), with nearly half of all new spinal cord injuries occurring in New South Wales (O’Connor & Cripps, 1996). Most of these persons returned to the community post injury (personal communication from Dr Sue Rutkowski, Director Moorong Spinal Injury Rehabilitation Centre, Royal Ryde Rehabilitation Hospital). Amongst the 150 or so persons per year in New South Wales there must have been persons with spinal injuries as severe as those of the residents of ‘Ward 43’, but who returned to

¹ In this study the terms ‘persons with spinal injuries’ and ‘persons with disabilities’ will be used in preference to terms such as spinal injured people or disabled people. Although the chosen terms may at times seem grammatically cumbersome, their use is a recognition of the importance of defining people in terms of their individual personhood, rather than their disabilities or impairments.
the community. Such reasoning thus begged these larger questions as the focus for this study:

- What was the level of functioning and lifestyle of the spinal injured population living in the New South Wales community?
- What was the level of need for community services of persons with varying levels of spinal injury across all areas of New South Wales?
- How well was the New South Wales community meeting these needs?

In this context, 'community services' includes personal care, domestic, paramedical, respite and transport services utilised or needed by persons with spinal injuries in the community once they completed the acute and post-acute rehabilitative stages of treatment for their spinal injury. Community service needs, by definition, do not include the need for physical well-being, sexual, socio-economic or psychological well-being, except in-so-much as such well-being may be enhanced by meeting the need for community services.

**Current ideology**

Awareness of the needs of persons with disabilities, and the need for changes to policies of segregation and institutionalisation was heightened during the International Year of Disabled Persons in 1981. 'At the heart of these changes is a profound belief that by enabling people with disabilities to participate fully in society, benefits accrue not only to the individual and his or her family, but also to employers, the economy and society as a whole.' (Commonwealth Department of Health, Housing and Community Services, Comcare, & Australian Council of Trade Unions, 1992 p.26).

The current ideology of community participation, rather than segregation, is based on beliefs of human dignity, social integration, value, equality and the human rights of persons with disabilities (Kendrick, 1992), most eloquently stated by the then Minister of Health, Housing and Community Services, Mr Brian Howe:

> Our vision of a fair society is one where all Australians can share equitably in the distribution of resources, especially employment opportunities; where all Australians have equal civil, legal and industrial rights; where there is fair and equal access to essential services such as housing, health and education; and where all have the opportunity to participate in community life and decisions which affect the community. (Commonwealth Department of Health, Housing and Community Services et al., 1992 p.13)

This ideology was legislatively mandated in the principles of the Disability Services Act 1986:
• every person with a disability has the same rights as other members of society to realise his or her individual capacity for physical, social, emotional and intellectual development;

• people with disabilities have the same rights as other members of society to services which will support their attaining an acceptable quality of life;

• programs and services should promote participation of people with disabilities in the life of the local community through maximum physical and social integration; and

• programs and services should provide opportunities for people with disabilities to reach goals and enjoy life-styles which are valued by the community at large and are appropriate to their age.

(Commonwealth Department of Health, Housing and Community Services et al., 1992 pp.15-16)

Thus, the current practice is for persons with disabilities to live in the community, rather than in institutions, as was the case in the past. Persons with spinal injuries have demonstrated that, given appropriate support services, they can live comparatively independently in the community (Frieden & Cole, 1985). To facilitate this, the Australian Federal Government introduced the Home and Community Care Program (HACC) in 1985 to oversee and fund the provision of community services for people with disabilities living in the community.

In response to the first triennial review in 1988, Commonwealth and State HACC Ministers agreed to the HACC (Home and Community Care) Statement of Rights and Responsibilities in 1990. This statement, enunciating the rights of persons with disabilities with regard to community services, was prepared in response to the recognition that 'HACC consumers rely significantly on the services provided by HACC to maintain their ability to live in the community. The nature of this relationship imposes obligations on providers and requires that services are responsive to the changing needs of each individual'. Included were the consumers' rights to respect for their individual human worth, dignity and privacy, and the right to be assessed for access to services without discrimination. Providers have the responsibility to, inter alia,

• enhance and respect the independence and dignity of the consumer,

• ensure that the consumer's access to a service is decided only on the basis of need and the capacity of the service to meet that need, and

• be responsive to the diverse social, cultural and physical experiences and needs of the consumer (Home and Community Care, 1990).
The provision of community services

Over the last two decades, but particularly since the International Year of
Disabled Persons, many reviews of the services provided for persons with
disabilities in Australia have been conducted by government agencies,
service providers, academics and others (see Table 1) to determine the extent
of realisation of these reformed visions and fulfilment of the responsibilities
of service providers. These reviews chronicle a long history of a conspicuous
lack of resources and ineffective support services for disabled persons.

In 1981, the Victorian Council of Social Service listed the characteristics of
effective community services for disabled people as choice, flexibility,
dignity, personal development, integration, control, objectives,
accountability, need, and accessibility (Victorian Council of Social Service,
1981 p.56). The large number of systematic reviews, however, consistently
report the same findings—lack of coordination and fragmentation of
community services, inequitable distribution of community services,
inflexibility of community services and the failure of community services to
adequately respond to the needs of persons with disabilities.

In addition, meeting the needs of disabled persons has been seen by some to
be the secondary purpose of community services. It has been suggested that
the focus of community services has been to perfect administration, a focus
which may be detrimental to the aim of meeting the needs of disabled
persons (Baume & Kay, 1995 p.28; Rose cited in Lindsay, 1996 p.27). As
Higgins stated:

If one is permitted to use so crude a guide to government
priorities as government spending, one is led inexorably to the
conclusion that the aim is to administer the needy rather than

Indeed, Yeatman's review found that whilst the broad aims of the
Commonwealth/State Disability Agreement were:
• to establish an initial framework for the rationalisation of the
  administration of disability services...; and
• to develop... integrated services to ensure that people with disabilities
  have access to appropriate services which meet their individual needs.
activity to date has been almost entirely focussed on establishing the
framework (Yeatman, 1996 p.xii).
Table 1. Selected findings of Australian community services reviews (particularly those affecting persons with physical disabilities)

<table>
<thead>
<tr>
<th>Year</th>
<th>Author Paper</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>1975</td>
<td>Commission of Inquiry into Poverty: A model for welfare service planning and delivery.</td>
<td>Evidence of service gaps, inadequate services and facilities, inefficient use of resources.</td>
</tr>
<tr>
<td>1986</td>
<td>Department of Community Services: The Home and Community Care Program Commonwealth priorities for service development.</td>
<td>Need to improve access and equity, ensure services are responsive to individual needs, ensure a coherent and integrated program.</td>
</tr>
<tr>
<td>1987</td>
<td>Western Sydney’s Regional Information and Research Services: Home and Community Care in Western Sydney. Issues and Options.</td>
<td>Complexity of the system, insufficient and confusing information, inflexibility to meet individual needs (only serving 2% of potential clients), lack of complaints-appeals mechanism.</td>
</tr>
<tr>
<td>1988</td>
<td>Home and Community Care Review Working Group: First triennial review of the Home and Community Care Program.</td>
<td>Need to show improved access to and utilisation of services. Evidence of inappropriate services and client confusion.</td>
</tr>
<tr>
<td>1990</td>
<td>Disability Council of NSW: Disability services. A focus on outcomes.</td>
<td>Need for structural reform, more effective use of resources, ensure services respond to the needs and wishes of people with disabilities.</td>
</tr>
</tbody>
</table>
Table 1. continued

<table>
<thead>
<tr>
<th>Year</th>
<th>Author: Paper</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>1995</td>
<td>Department of Human Services and Health: The efficiency and effectiveness review of the Home and Community Care Program.</td>
<td>Need for improved assessment, targeting of services and planning measures. Failure to meet demand.</td>
</tr>
<tr>
<td>1995</td>
<td>Baume and Kay: Working solution. Report of the strategic review of the Commonwealth Disability Services Program.</td>
<td>Evidence of vast gap between service provision and need for services (only 40% of need was met). Need to focus on individual needs, clarify eligibility criteria.</td>
</tr>
<tr>
<td>1995</td>
<td>Council of Australian Governments Meeting 11th April, 1995. Communique.</td>
<td>Policy not focussed on meeting people’s needs, lack of information and access to alternate services, poorly integrated services, lack of continuity of care.</td>
</tr>
<tr>
<td>1996</td>
<td>Madden et al: The demand for disability support services in Australia.</td>
<td>Evidence of considerable unmet need (particularly for those with physical disabilities), interstate inequities, lack of information.</td>
</tr>
<tr>
<td>1996</td>
<td>Yeatman: Getting Real. The final report of the review of the Commonwealth/State Disability Agreement.</td>
<td>Lack of coordination and flexibility, large levels of unmet need, lack of accountability and nationally consistent objectives</td>
</tr>
</tbody>
</table>
The continued reporting of similar findings over many years must prompt one to ask whether the provision of coordinated, flexible community services which meet the individual needs of persons with disabilities is simply an ideal, a rhetoric which is impossible to realise. As stated by Kendrick:

It is almost a given that advocates, agencies and governments will not possess sufficient wisdom to implement their rhetoric with universal good judgment. Rather we must accept as fully as we can bear that these agencies will always be prone to dysfunctionality, failure, poor judgement, misplaced priorities, questionable motives and all the other litany of human imperfections and limitations that are not transcended by the presence of otherwise positive ideology... While this does not excuse their failings it suggests that simply advocating positive ideas is far different from living them in an exemplary manner. (Kendrick, 1992 p.12).

Whilst certainly not excusing providers, Kendrick has identified the limitations of such introspective analysis on the part of the reviewers, which has clearly failed to greatly improve outcomes for persons with disabilities. 'Although there has been growth in services, it appears that there is still a significant unmet demand for services... Consequently, there is a perception of diminution of direct services and real difficulties for people...in accessing direct services.' (Stern, 1993 p.15).

The ability of community service providers to meet their responsibilities to consumers, improve levels of met need, and improve outcomes for persons with disabilities, however, is not a task easily objectified due to debate around the issues of:

- Whose definition or value judgement is to be used to determine what are 'needs'?
- How should 'need' be assessed?
- How should 'need' be translated into practice to determine levels of service, types of service and address the issue of conflicting service priorities? (Bowling, 1992; Fine & Graham, 1991)

Defining 'need'

Most people would have a tacit, common understanding of the concept of 'need'. Need can be expressed in such terms as want, desire, or necessity (Endacott, 1997) The use of the term in the context of the provision of community services, however, is not so clear. There is a considerable lack of consensus about the meanings of the terms 'need' and 'unmet need' which is further complicated by their value laden nature (Baume & Kay, 1994) and a number of dualities inherent in the concept.
Need has been defined as both an evaluative notion, dependent on societal norms (Endacott, 1997), and a universal notion where needs are common to all mankind (Doyal & Gough, 1991; Maslow, 1970). Need can refer both to an undesirable situation and to the help which is required to alleviate it (Thayer, 1973). Need can be both intrinsic, where the means of achieving the outcome and outcome to be achieved through meeting need are the same, and the means to an end, where meeting need is necessary for the achievement of some other desired outcome (Miller, 1976).

**Evaluative and universal need**

Endacott (1997 p.474) considered need as an 'evaluative notion (or value judgement)', that is, 'someone has to define them as needs'. According to this understanding of the concept, need has a social parameter, 'defined according to standards of communal life'. It is relative in that 'meaning will vary between people and societies' (Billings & Cowley, 1995 p.722), depending on the attitudes, beliefs and knowledge of those expressing, and those identifying the need (Thomas, 1997). Needs, understood in this way, are not common to all people and are always contextual.

In contrast to this evaluative model, Maslow (1970) proposed that human needs were universal and could be ordered into a hierarchy in which satisfaction of basic physiological and safety needs is required before higher needs such as love, self-esteem and self-actualisation can be expressed. More recently, Doyal and Gough, (1991) have similarly argued that all humans have common basic needs, in this case, survival (physical health) and autonomy.

**An undesirable situation and the help required to alleviate it (social need)**

Endacott (1997 p.474) identified a number of attributes of the concept of need 'an undesirable state of affairs; a necessity; its presence confers responsibility to make good the deficit'. Thayer (1973) termed the undesirable situation as diagnostic need, and the help which is required to alleviate it, prescriptive need.

There is an inherent assumption in this understanding of need that an individual or group will fall short of a desirable standard which is laid down by an expert (Bradshaw, 1972), or determined according to societal norms (Miller, 1976), and that this situation needs to be rectified. Need thought about this way, is concerned with the determination of *who* is 'needy', and *what* is 'needed', and is focussed on how much is provided and how much is used by different social groups. The emphasis is on the equitable distribution of socially desirable commodities (Baker & Rawson, 1989; Centre for Health Economics Research and Evaluation (CHERE), 1995;
Commonwealth Department of Health, Housing and Community Services, 1993).

'Who is needy' is determined at the 'macro' level, based on the broader normative or comparative needs of a group or a community. 'What is needed' is determined at the 'micro' level, based on the particular felt or expressed needs of the individual (Routley, 1987b). The four aspects of social need, as termed by Bradshaw (1972), are:

- Normative need—what the expert professional perceives to be needed;
- Comparative need—deduced by an outside observer in circumstances where individuals not in receipt of a particular commodity have similar characteristics to others who do receive it;
- Felt need—perceived by the individual; and
- Expressed need—felt need turned into action in the form of a request for a commodity.

Intrinsic need and the means to an end

Intrinsic need is the term used by Miller (1976) to explain the situation where a needed commodity is both a means and an end, that is, having some desired thing is an intrinsic part of being some desired thing. The desired commodity is something valued by society, the lack of which is considered harmful. For example, to have love one needs to be loved, and further, one will suffer if one is not loved because love is a valued commodity in our society.

Such is the logic on which Maslow based his theory of motivation, where one engages in self-actualisation in order to become self-actualised (Maslow, 1970). Similarly, the concept of normalisation, or social role valorisation, is premised on the belief that the way for disadvantaged people to become socially valued is for them to have socially valued roles (Wolfensberger, 1983), that is, 'The use of culturally valued means in order to enable people to live culturally valued lives.' (Wolfensberger & Thomas, 1983 p.23).

Intrinsic need can be stated as:

\[ \text{A needs } X, \text{ equated to } A \text{ will suffer harm if he lacks } X \text{ (Miller, 1976).} \]

The concept of intrinsic need is thus somewhat circular, or even tautological, but is best understood when contrasted with the concept of need as a means to an end, stated as:

\[ \text{A needs } X \text{ in order to do } Y \text{ (Miller, 1976).} \]

Based on the concept of need as a means to an end, 'Need can then be defined as those things which are necessary for the formulation and
execution of plans and purposes which are self-determined.' (Stainton, 1994 p.115).

Doyal and Gough (1991), like Maslow, argue that needs are universal. Meeting the universal needs for survival and autonomy is considered by Doyal and Gough to be a precondition for all human endeavour, a means by which the individual can fulfil their potential for private and public success. Societal recognition of human endeavour places obligations on society to meet needs—"if [society] endorses some end, then [society] must also endorse the necessary means to that end (Gewirth, 1982 cited in Doyal & Gough, 1991 p.94).

Which definition for the spinal injured population of NSW?

Clearly, there are multiple understandings of the concept of need. No one definition could be said to be 'better' or 'worse' as each understanding has a different focus. The concept of universal needs was developed in the context of a non-disabled population. Would such a concept be useful in the case of a population with long-term or permanent disabilities? Can the community service needs of the spinal injured population be 'defined according to standards of communal life' (Billings & Cowley, 1995 p.722)? Would it be more useful to determine who is 'needy' or what is 'needed', or the outcomes to be achieved by meeting need? The question is:

Which understanding of need best describes the community service needs of the spinal injured population of NSW?

This study aimed to answer this question by systematically considering the usefulness of the many understandings of need.

Assessing and prioritising need

The process of determining the level and types of community services to be provided to meet the needs of persons with disabilities has altered considerably over the past twenty five years with a move away from institutionally based services to community services provided in response to the identified needs of persons with disabilities. This philosophy, currently embraced by Australian governments, represents a shift of government funding focus from services to consumers, with funding levels linked to consumer outcomes (outcome-based funding), and a shift from service-based to needs-based provision of care (needs-based planning) (Endacott, 1997; Lindsay, 1996).

In the past, services frustrated by inadequate resources have been forced to match needs to available resources (Bryan, 1990). They have not known the extent to which needs were being met, what sorts of services were needed, in
what combination, nor how many services, at what level, were necessary to meet needs (Fine & Graham, 1991).

More recently, the philosophy of needs-based planning and outcome-based funding has been legislatively enshrined in the New South Wales Disability Services Act, 1993, where the terms and conditions under which service providers are granted financial assistance may include the outcomes to be achieved by persons in the target group as a result of the provision of services, and the setting of performance indicators to be used in measuring these outcomes.

Although no single, commonly used definition of needs-based planning and outcome-based funding was found in the literature, a definition synthesised from the literature is that needs-based planning is:

Thorough planning to determine the provision and extent of services based upon an assessment of demonstrated needs which must be addressed in order to achieve a desired outcome (Billings & Cowley, 1995; Bolton et al., 1988).

Outcome-based funding in the context of needs-based planning is defined as:

funding tied to the ability to demonstrate a change in the level of unmet need in a target group (Baume & Kay, 1994).

The purpose of needs-based planning is to allocate 'resources in a way that best meets the need for those resources' (Staden, 1987 p.1).

The political risk and paradox of needs-based planning is that whilst the purpose of needs-based planning is to improve the match between needs and services, the identification of the shortfall between needs and services in the climate of restricted resources may be a meaningless exercise (Billings & Cowley, 1995). Needs-based planning and outcome-based funding has been hampered by the large gap between supply and demand, the dearth of information on levels of met and unmet needs in the community (Baume & Kay, 1994; Cornwell, 1992), and the reality that prioritising areas with the greatest need means that other areas receive fewer resources (Shepherd, 1992).

Genuinely needs-led assessment may be difficult to achieve as there can be 'no 'neutral' assessment—assessment must always be done with an eye to the resources available to fill an identified need' (Billings & Cowley, 1995; Home and Community Care Review Working Group, 1988 p.28; Wilson, 1993). Variations in supply influence demand, with increased levels of provision often leading to increased, rather than decreased, demand (Buchan, 1990). The complex nature of community service provision leads to the tendency for allocative decisions to be made procedurally or incrementally, rather than by rational allocation according to the greatest needs (Cornwell, 1992; Nosek & Howland, 1993).
Nonetheless, the Home and Community Care program, which, together with disability specific services funded under the Commonwealth/State Disability Agreement, is the major funder of community services in New South Wales, is premised on the ability of local areas to identify gaps in service provision, decide how to fill the gaps and determine priorities for new or expanded services (Chapman, 1988). The failure to facilitate this process through the assessment of the needs of smaller, less well identified groups will only exacerbate the incremental allocation of community service provision to well established populations, easily identified by social indicators, census and population based epidemiological data.

The process of needs-based planning is premised on the ability for rational decisions to be made about priorities for service based on clear, objective indicators of need for services (Bolton et al., 1988). Thus, it would be reasonable to expect that central to the processes of needs-based planning and outcome-based funding would be the comprehensive assessment of individual needs, and the assessment of individual abilities and potential, goals and achievements (Adamson & Tipper, 1992; Glendinning, 1991).

Proper needs and outcome assessment, done in such a way, would consume considerable time and resources, particularly if the population of interest is not easily identifiable, contactable, or visible in terms of readily available data gleaned from census or other large, central population studies. Hence, there is a considerable lack of detailed local studies of community service needs which would be useful for informing the future development of community support services (Fine, 1992). 'Creating measures of need and resources for some groups about whom little data exists...seems to take a lot of effort to find out what people familiar with the field already know—rarely are the needs of these groups being adequately met anywhere' (Staden, 1987 p.10). Under such circumstances, the identification of needs serves only to focus on issues of supply, rather than outcomes, in an environment where needs, once identified, are unlikely to be met.

There was clear evidence of such a focus on issues of supply in the small number of studies assessing the needs of persons with disabilities in the years 1990 to 1997. Most assessments of need appeared to have adopted an

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1 The Home and Community Care program (HACC) is a joint Federal and State funded program through which 'financial assistance is provided for services which support people living at home who are at risk of inappropriate institutionalisation' (Home and Community Care, 1989 p.1). HACC provides funding to approved organisations which provide approved services. HACC itself is not a direct service provider, however, in its role as both the approver and funder of organisations, HACC exerts considerable influence over the types of services which are offered to clients.

2 The studies were of the needs met by participation in support groups for carers of persons with head injuries (Acom, 1993), the need for driver education for people with disabilities in Newcastle, UK (Barnes & Hoyle, 1995), the need for housing and transport in Houston, USA (Gilderbloom & Rosenthal, 1990), the identification of needy persons in southern USA (based on census data) (Holzer et al., 1996), and the support needed by young adults with disabilities in east London (Doyle et al., 1994), persons with postpolio syndrome in Maine, USA (Foster et al., 1993), persons receiving ventilatory support at home in Alabama (Thomas
intrinsic notion of need, although none stated this explicitly, where the goal
was the identification of needed services and the means of provision of these
services. The outcomes to be achieved through the meeting of services needs
were sometimes assumed, but rarely tested.

The determination of appropriate consumer outcomes, and the needs to be
addressed to achieve outcomes can only be achieved if assessments of need
are 'genuinely needs-led rather than resource-led' (Morris, 1994 p.40). The
spirit of the Disability Services Act 1986, and the HACC Statement of Rights
and Responsibilities 1990, would suggest that such assessment should be
paramount. Yet, the most recent major needs assessment study in Australia
designed to direct policy, The Demand for Disability Support Services in
Australia (Madden et al., 1995), was concerned with equitable resource
allocation between regions, not what was needed to meet individual need or
goals. In this study census type data was used to estimate the unmet need
for services based on a normative view of the needs of persons with
disabilities.

Needs and outcomes

It is the intrinsic notion of need, rather than consideration of individual's life
goals, which has been the major focus of needs assessment in New South
Wales. The outcome of interest has been the extent to which individuals' rights to services, rather than their goals, are met by the equitable
distribution of services. This is highlighted by the nature of findings
contained in community service reviews (see Table 1 previous) where the
focus has been on;

- the normative identification of 'needy' persons who are under-served by
  community services, and
-remedying the situation through the geographically equitable provision
  of normatively defined community services,

so that all persons can be shown to have equal opportunity to satisfy their
right to access services.

Whilst it is certainly necessary to maintain a 'right to services' stance in order
to support the claims of persons with spinal injuries who seek services,
Moody comments that 'for long-term care... the language of rights [is]
dangerously simplistic' (Moody, 1992 p.4). When adopting this 'right to
services' basis for resource allocation, the focus is on equitable input and
distribution of services rather than the outcomes to be achieved. The gains or
outcomes to be achieved by individuals 'are weighted equally no matter the
level of need of the recipient.' (Mooney, 1995 p.334).

et al., 1992), persons with disabilities in the highlands of New Guinea (van Amstel et al.,
1993) and the severely disabled in Somerset, UK (Williams & Bowie, 1993).

This study was a support study for the Review of the Commonwealth/State Disability
The Disability Services Act 1986, highlighted the desirable outcomes to be realised by means of the right to services, that is, an acceptable quality of life, community participation and opportunities to reach goals and enjoy a valued lifestyle. These ends, however, have been lost by framing service standards in terms of rights, such as privacy, informed choice and quality services, rather than in terms of outcomes for the persons with disabilities (Commonwealth Department of Health, Housing and Community Services, no date; Commonwealth Department of Health, Housing and Community Services et al., 1992).

Indeed, if the right to services can be framed in terms of quality, which is not a constant, and can be over-ridden by calculations of priorities, 'then in what sense are they rights at all?' (Plant, 1988 p.65). Rights 'are not granted more or less: they are and must be granted without qualification' (March, 1994 online). The community service needs of the spinal injured population may indeed be better understood in terms of a services' contribution to achieving a desired outcome, rather than rights to services, or the provision of services in, and of themselves. Miller suggests that 'to decide what a person's needs are, we must first identify his plan of life, then establish what activities are essential to that plan, and finally investigate the conditions which enable those activities to be carried out' (Miller, 1976 p.134).

It is this author's contention that the many reviews of disability policy and provision have failed to consider, or indeed challenge the appropriateness of the current ideology of provision of community services to the life plans, or desired outcomes, of persons with spinal injuries. There has been no consideration of the desired outcomes of the provision of services for the lives of persons with disabilities. For example, two of the major foci of the reviews have been on the desired outcome of the provision of flexible services and coordinated services (see Table 1 previously), without there being any due consideration of what outcomes for the individual are to be achieved by the delivery of coordinated flexible services.

The reviews of disability policy have highlighted community service policy makers' and providers' failure to consider, or correctly identify the needs and desired outcomes of disabled persons, despite the large amount of community input which has been a feature of most reviews conducted since 1983. It is little wonder then, that the reviews have failed to have any significant impact on improving the provision of community services to contribute to the desired life outcomes for disabled people, particularly as perceived by disabled persons themselves.

This work intends to be a critique of the extent to which policy makers believe that 'the assertion of equal rights will generate their theorised Utopia.' (Stern, 1993), rather than a definitive critique of the disability policy ideologies from a philosophical point of view. Like Stern, this author is primarily concerned with 'practical outcomes for individuals with [a] ... disability and the resources available to facilitate their lives'. As Stern states,
'Should there be proper examination to ascertain what is really needed?'
(Stern, 1993 p.15)
Introduction

This study explores the many concepts of need in order to develop a fresh understanding of the community service needs of persons with spinal injuries in New South Wales.¹

The genesis of this study lay in the decision by the NSW Department of Health to close Lidcombe Hospital in Sydney’s inner south west. ‘Ward 43’, within Lidcombe Hospital, was the only public hospital based long stay unit specifically for persons with spinal injury in New South Wales. The sixteen residents of this unit, some of whom had lived there for many years, were all persons with a high level of dependency.

In keeping with the philosophy of deinstitutionalisation, the option of community placement for the residents following closure was explored. A hasty study of the residents’ needs was conducted by the Nursing Unit Manager and this author, which clearly indicated that the residents had a level of need for services which could not be supported in the community. As a result of this data, and other political forces, the residents were subsequently relocated to Lottie Stewart Hospital at Dundas in the inner north-west of Sydney.

That brief study of a small, highly dependent spinal injured population highlighted two issues:
• the high level of need for services by some persons with spinal injuries,
• the inability of the community to meet these needs.

That study did raise a number of quandaries. There were approximately 300 to 400 adults who incurred a new spinal cord injury admitted to specialist acute spinal injury hospital units in Australia every year during the mid to late 1980’s (Walsh, 1992), with nearly half of all new spinal cord injuries occurring in New South Wales (O’Connor & Cripps, 1996). Most of these persons returned to the community post injury (personal communication from Dr Sue Rutkowski, Director Moorong Spinal Injury Rehabilitation Centre, Royal Ryde Rehabilitation Hospital). Amongst the 150 or so persons per year in New South Wales there must have been persons with spinal injuries as severe as those of the residents of ‘Ward 43’, but who returned to

¹In this study the terms ‘persons with spinal injuries’ and ‘persons with disabilities’ will be used in preference to terms such as spinal injured people or disabled people. Although the chosen terms may at times seem grammatically cumbersome, their use is a recognition of the importance of defining people in terms of their individual personhood, rather than their disabilities or impairments.
the community. Such reasoning thus begged these larger questions as the focus for this study:

- What was the level of functioning and lifestyle of the spinal injured population living in the New South Wales community?
- What was the level of need for community services of persons with varying levels of spinal injury across all areas of New South Wales?
- How well was the New South Wales community meeting these needs?

In this context, 'community services' includes personal care, domestic, paramedical, respite and transport services utilised or needed by persons with spinal injuries in the community once they completed the acute and post-acute rehabilitative stages of treatment for their spinal injury. Community service needs, by definition, do not include the need for physical well-being, sexual, socio-economic or psychological well-being, except in-so-much as such well-being may be enhanced by meeting the need for community services.

Current ideology

Awareness of the needs of persons with disabilities, and the need for changes to policies of segregation and institutionalisation was heightened during the International Year of Disabled Persons in 1981. 'At the heart of these changes is a profound belief that by enabling people with disabilities to participate fully in society, benefits accrue not only to the individual and his or her family, but also to employers, the economy and society as a whole.' (Commonwealth Department of Health, Housing and Community Services, Comcare, & Australian Council of Trade Unions, 1992 p.26).

The current ideology of community participation, rather than segregation, is based on beliefs of human dignity, social integration, value, equality and the human rights of persons with disabilities (Kendrick, 1992), most eloquently stated by the then Minister of Health, Housing and Community Services, Mr Brian Howe:

Our vision of a fair society is one where all Australians can share equitably in the distribution of resources, especially employment opportunities; where all Australians have equal civil, legal and industrial rights; where there is fair and equal access to essential services such as housing, health and education; and where all have the opportunity to participate in community life and decisions which affect the community. (Commonwealth Department of Health, Housing and Community Services et al., 1992 p.13)

This ideology was legislatively mandated in the principles of the Disability Services Act 1986:
• every person with a disability has the same rights as other members of society to realise his or her individual capacity for physical, social, emotional and intellectual development;

• people with disabilities have the same rights as other members of society to services which will support their attaining an acceptable quality of life;

• programs and services should promote participation of people with disabilities in the life of the local community through maximum physical and social integration; and

• programs and services should provide opportunities for people with disabilities to reach goals and enjoy life-styles which are valued by the community at large and are appropriate to their age.

(Commonwealth Department of Health, Housing and Community Services et al., 1992 pp.15-16)

Thus, the current practice is for persons with disabilities to live in the community, rather than in institutions, as was the case in the past. Persons with spinal injuries have demonstrated that, given appropriate support services, they can live comparatively independently in the community (Frieden & Cole, 1985). To facilitate this, the Australian Federal Government introduced the Home and Community Care Program (HACC) in 1985 to oversee and fund the provision of community services for people with disabilities living in the community.

In response to the first triennial review in 1988, Commonwealth and State HACC Ministers agreed to the HACC (Home and Community Care) Statement of Rights and Responsibilities in 1990. This statement, enunciating the rights of persons with disabilities with regard to community services, was prepared in response to the recognition that 'HACC consumers rely significantly on the services provided by HACC to maintain their ability to live in the community. The nature of this relationship imposes obligations on providers and requires that services are responsive to the changing needs of each individual'. Included were the consumers' rights to respect for their individual human worth, dignity and privacy, and the right to be assessed for access to services without discrimination. Providers have the responsibility to, inter alia,

• enhance and respect the independence and dignity of the consumer,

• ensure that the consumer's access to a service is decided only on the basis of need and the capacity of the service to meet that need, and

• be responsive to the diverse social, cultural and physical experiences and needs of the consumer (Home and Community Care, 1990).
The provision of community services

Over the last two decades, but particularly since the International Year of Disabled Persons, many reviews of the services provided for persons with disabilities in Australia have been conducted by government agencies, service providers, academics and others (see Table 1) to determine the extent of realisation of these reformed visions and fulfilment of the responsibilities of service providers. These reviews chronicle a long history of a conspicuous lack of resources and ineffective support services for disabled persons.

In 1981, the Victorian Council of Social Service listed the characteristics of effective community services for disabled people as choice, flexibility, dignity, personal development, integration, control, objectives, accountability, need, and accessibility (Victorian Council of Social Service, 1981 p.56). The large number of systematic reviews, however, consistently report the same findings—lack of coordination and fragmentation of community services, inequitable distribution of community services, inflexibility of community services and the failure of community services to adequately respond to the needs of persons with disabilities.

In addition, meeting the needs of disabled persons has been seen by some to be the secondary purpose of community services. It has been suggested that the focus of community services has been to perfect administration, a focus which may be detrimental to the aim of meeting the needs of disabled persons (Baume & Kay, 1995 p.28; Rose cited in Lindsay, 1996 p.27). As Higgins stated:

If one is permitted to use so crude a guide to government priorities as government spending, one is led inexorably to the conclusion that the aim is to administer the needy rather than improve their circumstances (1982 p.219).

Indeed, Yeatman’s review found that whilst the broad aims of the Commonwealth/State Disability Agreement were:

- to establish an initial framework for the rationalisation of the administration of disability services...; and
- to develop... integrated services to ensure that people with disabilities have access to appropriate services which meet their individual needs.

activity to date has been almost entirely focussed on establishing the framework (Yeatman, 1996 p.xii).
Table 1. Selected findings of Australian community services reviews (particularly those affecting persons with physical disabilities)

<table>
<thead>
<tr>
<th>Year</th>
<th>Author/Paper</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>1975</td>
<td>Commission of Inquiry into Poverty: A model for welfare service planning and delivery.</td>
<td>Evidence of service gaps, inadequate services and facilities, inefficient use of resources.</td>
</tr>
<tr>
<td>1986</td>
<td>Department of Community Services: The Home and Community Care Program Commonwealth priorities for service development.</td>
<td>Need to improve access and equity, ensure services are responsive to individual needs, ensure a coherent and integrated program.</td>
</tr>
<tr>
<td>1987</td>
<td>Western Sydney's Regional Information and Research Services: Home and Community Care in Western Sydney. Issues and Options.</td>
<td>Complexity of the system, insufficient and confusing information, inflexibility to meet individual needs (only serving 2% of potential clients), lack of complaints-appeals mechanism.</td>
</tr>
<tr>
<td>1988</td>
<td>Home and Community Care Review Working Group: First triennial review of the Home and Community Care Program.</td>
<td>Need to show improved access to and utilisation of services. Evidence of inappropriate services and client confusion.</td>
</tr>
<tr>
<td>1990</td>
<td>Disability Council of NSW: Disability services. A focus on outcomes.</td>
<td>Need for structural reform, more effective use of resources, ensure services respond to the needs and wishes of people with disabilities.</td>
</tr>
<tr>
<td>Year</td>
<td>Author: Paper</td>
<td>Findings</td>
</tr>
<tr>
<td>------</td>
<td>-----------------------------------------------------------------------------</td>
<td>------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>1995</td>
<td>Department of Human Services and Health: The efficiency and effectiveness review of the Home and Community Care Program.</td>
<td>Need for improved assessment, targeting of services and planning measures. Failure to meet demand.</td>
</tr>
<tr>
<td>1995</td>
<td>Baume and Kay: Working solution. Report of the strategic review of the Commonwealth Disability Services Program.</td>
<td>Evidence of vast gap between service provision and need for services (only 40% of need was met). Need to focus on individual needs, clarify eligibility criteria.</td>
</tr>
<tr>
<td>1995</td>
<td>Council of Australian Governments Meeting 11th April, 1995. Communique.</td>
<td>Policy not focussed on meeting people’s needs, lack of information and access to alternate services, poorly integrated services, lack of continuity of care.</td>
</tr>
<tr>
<td>1996</td>
<td>Madden et al: The demand for disability support services in Australia.</td>
<td>Evidence of considerable unmet need (particularly for those with physical disabilities), interstate inequities, lack of information.</td>
</tr>
<tr>
<td>1996</td>
<td>Yeatman: Getting Real. The final report of the review of the Commonwealth/State Disability Agreement.</td>
<td>Lack of coordination and flexibility, large levels of unmet need, lack of accountability and nationally consistent objectives.</td>
</tr>
</tbody>
</table>
The continued reporting of similar findings over many years must prompt one to ask whether the provision of coordinated, flexible community services which meet the individual needs of persons with disabilities is simply an ideal, a rhetoric which is impossible to realise. As stated by Kendrick:

"It is almost a given that advocates, agencies and governments will not possess sufficient wisdom to implement their rhetoric with universal good judgment. Rather we must accept as fully as we can bear that these agencies will always be prone to dysfunctionality, failure, poor judgement, misplaced priorities, questionable motives and all the other litany of human imperfections and limitations that are not transcended by the presence of otherwise positive ideology... While this does not excuse their failings it suggests that simply advocating positive ideas is far different from living them in an exemplary manner." (Kendrick, 1992 p.12).

Whilst certainly not excusing providers, Kendrick has identified the limitations of such introspective analysis on the part of the reviewers, which has clearly failed to greatly improve outcomes for persons with disabilities. 'Although there has been growth in services, it appears that there is still a significant unmet demand for services... Consequently, there is a perception of diminution of direct services and real difficulties for people... in accessing direct services.' (Stern, 1993 p.15).

The ability of community service providers to meet their responsibilities to consumers, improve levels of met need, and improve outcomes for persons with disabilities, however, is not a task easily objectified due to debate around the issues of:

- Whose definition or value judgement is to be used to determine what are 'needs'?
- How should 'need' be assessed?
- How should 'need' be translated into practice to determine levels of service, types of service and address the issue of conflicting service priorities? (Bowling, 1992; Fine & Graham, 1991)

**Defining 'need'**

Most people would have a tacit, common understanding of the concept of 'need'. Need can be expressed in such terms as want, desire, or necessity (Endacott, 1997). The use of the term in the context of the provision of community services, however, is not so clear. There is a considerable lack of consensus about the meanings of the terms 'need' and 'unmet need' which is further complicated by their value laden nature (Baume & Kay, 1994) and a number of dualities inherent in the concept.
Need has been defined as both an evaluative notion, dependent on societal norms (Endacott, 1997), and a universal notion where needs are common to all mankind (Doyal & Gough, 1991; Maslow, 1970). Need can refer both to an undesirable situation and to the help which is required to alleviate it (Thayer, 1973). Need can be both intrinsic, where the means of achieving the outcome and outcome to be achieved through meeting need are the same, and the means to an end, where meeting need is necessary for the achievement of some other desired outcome (Miller, 1976).

**Evaluative and universal need**

Endacott (1997 p.474) considered need as an 'evaluative notion (or value judgement)', that is, 'someone has to define them as needs'. According to this understanding of the concept, need has a social parameter, 'defined according to standards of communal life'. It is relative in that 'meaning will vary between people and societies' (Billings & Cowley, 1995 p.722), depending on the attitudes, beliefs and knowledge of those expressing, and those identifying the need (Thomas, 1997). Needs, understood in this way, are not common to all people and are always contextual.

In contrast to this evaluative model, Maslow (1970) proposed that human needs were universal and could be ordered into a hierarchy in which satisfaction of basic physiological and safety needs is required before higher needs such as love, self-esteem and self-actualisation can be expressed. More recently, Doyal and Gough, (1991) have similarly argued that all humans have common basic needs, in this case, survival (physical health) and autonomy.

**An undesirable situation and the help required to alleviate it (social need)**

Endacott (1997 p.474) identified a number of attributes of the concept of need 'an undesirable state of affairs; a necessity; its presence confers responsibility to make good the deficit'. Thayer (1973) termed the undesirable situation as diagnostic need, and the help which is required to alleviate it, prescriptive need.

There is an inherent assumption in this understanding of need that an individual or group will fall short of a desirable standard which is laid down by an expert (Bradshaw, 1972), or determined according to societal norms (Miller, 1976), and that this situation needs to be rectified. Need thought about this way, is concerned with the determination of who is 'needy', and what is 'needed', and is focussed on how much is provided and how much is used by different social groups. The emphasis is on the equitable distribution of socially desirable commodities (Baker & Rawson, 1989; Centre for Health Economics Research and Evaluation (CHERE), 1995;
Commonwealth Department of Health, Housing and Community Services, 1993).

'Who is needy' is determined at the 'macro' level, based on the broader normative or comparative needs of a group or a community. 'What is needed' is determined at the 'micro' level, based on the particular felt or expressed needs of the individual (Routley, 1987b). The four aspects of social need, as termed by Bradshaw (1972), are:

- Normative need—what the expert professional perceives to be needed;
- Comparative need—deduced by an outside observer in circumstances where individuals not in receipt of a particular commodity have similar characteristics to others who do receive it;
- Felt need—perceived by the individual; and
- Expressed need—felt need turned into action in the form of a request for a commodity.

Intrinsic need and the means to an end

Intrinsic need is the term used by Miller (1976) to explain the situation where a needed commodity is both a means and an end, that is, having some desired thing is an intrinsic part of being some desired thing. The desired commodity is something valued by society, the lack of which is considered harmful. For example, to have love one needs to be loved, and further, one will suffer if one is not loved because love is a valued commodity in our society.

Such is the logic on which Maslow based his theory of motivation, where one engages in self-actualisation in order to become self-actualised (Maslow, 1970). Similarly, the concept of normalisation, or social role valorisation, is premised on the belief that the way for disadvantaged people to become socially valued is for them to have socially valued roles (Wolfensberger, 1983), that is, 'The use of culturally valued means in order to enable people to live culturally valued lives.' (Wolfensberger & Thomas, 1983 p.23).

Intrinsic need can be stated as:

\[
\text{A needs } X, \text{ equated to } A \text{ will suffer harm if he lacks } X \text{ (Miller, 1976).}
\]

The concept of intrinsic need is thus somewhat circular, or even tautological, but is best understood when contrasted with the concept of need as a means to an end, stated as:

\[
\text{A needs } X \text{ in order to do } Y \text{ (Miller, 1976).}
\]

Based on the concept of need as a means to an end, 'Need can then be defined as those things which are necessary for the formulation and
execution of plans and purposes which are self-determined.' (Stainton, 1994 p.115).

Doyal and Gough (1991), like Maslow, argue that needs are universal. Meeting the universal needs for survival and autonomy is considered by Doyal and Gough to be a precondition for all human endeavour, a means by which the individual can fulfil their potential for private and public success. Societal recognition of human endeavour places obligations on society to meet needs—'if [society] endorses some end, then [society] must also endorse the necessary means to that end (Gewirth, 1982 cited in Doyal & Gough, 1991 p.94).

Which definition for the spinal injured population of NSW?

Clearly, there are multiple understandings of the concept of need. No one definition could be said to be 'better' or 'worse' as each understanding has a different focus. The concept of universal needs was developed in the context of a non-disabled population. Would such a concept be useful in the case of a population with long-term or permanent disabilities? Can the community service needs of the spinal injured population be 'defined according to standards of communal life' (Billings & Cowley, 1995 p.722)? Would it be more useful to determine who is 'needy' or what is 'needed', or the outcomes to be achieved by meeting need? The question is:

Which understanding of need best describes the community service needs of the spinal injured population of NSW?

This study aimed to answer this question by systematically considering the usefulness of the many understandings of need.

Assessing and prioritising need

The process of determining the level and types of community services to be provided to meet the needs of persons with disabilities has altered considerably over the past twenty five years with a move away from institutionally based services to community services provided in response to the identified needs of persons with disabilities. This philosophy, currently embraced by Australian governments, represents a shift of government funding focus from services to consumers, with funding levels linked to consumer outcomes (outcome-based funding), and a shift from service-based to needs-based provision of care (needs-based planning) (Endacott, 1997; Lindsay, 1996).

In the past, services frustrated by inadequate resources have been forced to match needs to available resources (Bryan, 1990). They have not known the extent to which needs were being met, what sorts of services were needed, in
what combination, nor how many services, at what level, were necessary to meet needs (Fine & Graham, 1991).

More recently, the philosophy of needs-based planning and outcome-based funding has been legislatively enshrined in the New South Wales Disability Services Act, 1993, where the terms and conditions under which service providers are granted financial assistance may include the outcomes to be achieved by persons in the target group as a result of the provision of services, and the setting of performance indicators to be used in measuring these outcomes.

Although no single, commonly used definition of needs-based planning and outcome-based funding was found in the literature, a definition synthesised from the literature is that needs-based planning is:

Thorough planning to determine the provision and extent of services based upon an assessment of demonstrated needs which must be addressed in order to achieve a desired outcome (Billings & Cowley, 1995; Bolton et al., 1988).

Outcome-based funding in the context of needs-based planning is defined as:

funding tied to the ability to demonstrate a change in the level of unmet need in a target group (Baume & Kay, 1994).

The purpose of needs-based planning is to allocate 'resources in a way that best meets the need for those resources' (Staden, 1987 p.1).

The political risk and paradox of needs-based planning is that whilst the purpose of needs-based planning is to improve the match between needs and services, the identification of the shortfall between needs and services in the climate of restricted resources may be a meaningless exercise (Billings & Cowley, 1995). Needs-based planning and outcome-based funding has been hampered by the large gap between supply and demand, the dearth of information on levels of met and unmet needs in the community (Baume & Kay, 1994; Cornwell, 1992), and the reality that prioritising areas with the greatest need means that other areas receive fewer resources (Shepherd, 1992).

Genuinely needs-led assessment may be difficult to achieve as there can be 'no 'neutral' assessment—assessment must always be done with an eye to the resources available to fill an identified need' (Billings & Cowley, 1995; Home and Community Care Review Working Group, 1988 p.28; Wilson, 1993). Variations in supply influence demand, with increased levels of provision often leading to increased, rather than decreased, demand (Buchan, 1990). The complex nature of community service provision leads to the tendency for allocative decisions to be made procedurally or incrementally, rather than by rational allocation according to the greatest needs (Cornwell, 1992; Nosek & Howland, 1993).
Nonetheless, the Home and Community Care program, which, together with disability specific services funded under the Commonwealth/State Disability Agreement, is the major funder of community services in New South Wales, is premised on the ability of local areas to identify gaps in service provision, decide how to fill the gaps and determine priorities for new or expanded services (Chapman, 1988). The failure to facilitate this process through the assessment of the needs of smaller, less well identified groups will only exacerbate the incremental allocation of community service provision to well established populations, easily identified by social indicators, census and population based epidemiological data.

The process of needs-based planning is premised on the ability for rational decisions to be made about priorities for service based on clear, objective indicators of need for services (Bolton et al., 1988). Thus, it would be reasonable to expect that central to the processes of needs-based planning and outcome-based funding would be the comprehensive assessment of individual needs, and the assessment of individual abilities and potential, goals and achievements (Adamson & Tipper, 1992; Glendinning, 1991).

Proper needs and outcome assessment, done in such a way, would consume considerable time and resources, particularly if the population of interest is not easily identifiable, contactable, or visible in terms of readily available data gleaned from census or other large, central population studies. Hence, there is a considerable lack of detailed local studies of community service needs which would be useful for informing the future development of community support services (Fine, 1992). 'Creating measures of need and resources for some groups about whom little data exists...seems to take a lot of effort to find out what people familiar with the field already know—rarely are the needs of these groups being adequately met anywhere' (Staden, 1987 p.10). Under such circumstances, the identification of needs serves only to focus on issues of supply, rather than outcomes, in an environment where needs, once identified, are unlikely to be met.

There was clear evidence of such a focus on issues of supply in the small number of studies assessing the needs of persons with disabilities in the years 1990 to 1997. Most assessments of need appeared to have adopted an

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1 The Home and Community Care program (HACC) is a joint Federal and State funded program through which 'financial assistance is provided for services which support people living at home who are at risk of inappropriate institutionalisation' (Home and Community Care, 1989 p.1). HACC provides funding to approved organisations which provide approved services. HACC itself is not a direct service provider, however, in its role as both the approver and funder of organisations, HACC exerts considerable influence over the types of services which are offered to clients.

2 The studies were of the needs met by participation in support groups for carers of persons with head injuries (Acorn, 1993), the need for driver education for people with disabilities in Newcastle, UK (Barnes & Hoyle, 1995), the need for housing and transport in Houston, USA (Gilderbloom & Rosenthal, 1990), the identification of needy persons in southern USA (based on census data) (Holzer et al., 1996), and the support needed by young adults with disabilities in east London (Doyle et al., 1994), persons with postpolio syndrome in Maine, USA (Foster et al., 1993), persons receiving ventilatory support at home in Alabama (Thomas
intrinsic notion of need, although none stated this explicitly, where the goal was the identification of needed services and the means of provision of these services. The outcomes to be achieved through the meeting of services needs were sometimes assumed, but rarely tested.

The determination of appropriate consumer outcomes, and the needs to be addressed to achieve outcomes can only be achieved if assessments of need are 'genuinely needs-led rather than resource-led' (Morris, 1994 p.40). The spirit of the Disability Services Act 1986, and the HACC Statement of Rights and Responsibilities 1990, would suggest that such assessment should be paramount. Yet, the most recent major needs assessment study in Australia designed to direct policy, The Demand for Disability Support Services in Australia (Madden et al., 1995), was concerned with equitable resource allocation between regions, not what was needed to meet individual need or goals. In this study census type data was used to estimate the unmet need for services based on a normative view of the needs of persons with disabilities.

Needs and outcomes

It is the intrinsic notion of need, rather than consideration of individual's life goals, which has been the major focus of needs assessment in New South Wales. The outcome of interest has been the extent to which individuals' rights to services, rather than their goals, are met by the equitable distribution of services. This is highlighted by the nature of findings contained in community service reviews (see Table 1 previous) where the focus has been on;

- the normative identification of 'needy' persons who are under-served by community services, and
- remedying the situation through the geographically equitable provision of normatively defined community services,

so that all persons can be shown to have equal opportunity to satisfy their right to access services.

Whilst it is certainly necessary to maintain a 'right to services' stance in order to support the claims of persons with spinal injuries who seek services, Moody comments that 'for long-term care... the language of rights [is] dangerously simplistic' (Moody, 1992 p.4). When adopting this 'right to services' basis for resource allocation, the focus is on equitable input and distribution of services rather than the outcomes to be achieved. The gains or outcomes to be achieved by individuals 'are weighted equally no matter the level of need of the recipient.' (Mooney, 1995 p.334).

et al., 1992), persons with disabilities in the highlands of New Guinea (van Amstel et al., 1993) and the severely disabled in Somerset, UK (Williams & Bowie, 1993).

4 This study was a support study for the Review of the Commonwealth/State Disability Agreement (Yeatman, 1996).
The Disability Services Act 1986, highlighted the desirable outcomes to be realised by means of the right to services, that is, an acceptable quality of life, community participation and opportunities to reach goals and enjoy a valued lifestyle. These ends, however, have been lost by framing service standards in terms of rights, such as privacy, informed choice and quality services, rather than in terms of outcomes for the persons with disabilities (Commonwealth Department of Health, Housing and Community Services, no date; Commonwealth Department of Health, Housing and Community Services et al., 1992).

Indeed, if the right to services can be framed in terms of quality, which is not a constant, and can be over-ridden by calculations of priorities, 'then in what sense are they rights at all?' (Plant, 1988 p.65). Rights 'are not granted more or less: they are and must be granted without qualification' (March, 1994 online). The community service needs of the spinal injured population may indeed be better understood in terms of a services' contribution to achieving a desired outcome, rather than rights to services, or the provision of services in, and of themselves. Miller suggests that 'to decide what a person's needs are, we must first identify his plan of life, then establish what activities are essential to that plan, and finally investigate the conditions which enable those activities to be carried out' (Miller, 1976 p.134).

It is this author's contention that the many reviews of disability policy and provision have failed to consider, or indeed challenge the appropriateness of the current ideology of provision of community services to the life plans, or desired outcomes, of persons with spinal injuries. There has been no consideration of the desired outcomes of the provision of services for the lives of persons with disabilities. For example, two of the major foci of the reviews have been on the desired outcome of the provision of flexible services and coordinated services (see Table 1 previously), without there being any due consideration of what outcomes for the individual are to be achieved by the delivery of coordinated flexible services.

The reviews of disability policy have highlighted community service policy makers' and providers' failure to consider, or correctly identify the needs and desired outcomes of disabled persons, despite the large amount of community input which has been a feature of most reviews conducted since 1983. It is little wonder then, that the reviews have failed to have any significant impact on improving the provision of community services to contribute to the desired life outcomes for disabled people, particularly as perceived by disabled persons themselves.

This work intends to be a critique of the extent to which policy makers believe that 'the assertion of equal rights will generate their theorised Utopia.' (Stern, 1993), rather than a definitive critique of the disability policy ideologies from a philosophical point of view. Like Stern, this author is primarily concerned with 'practical outcomes for individuals with [a] ... disability and the resources available to facilitate their lives'. As Stern states,
'Should there be proper examination to ascertain what is really needed?'
(Stern, 1993 p.15)
This Study

In addressing the broader issues raised by the incident in 'Ward 43', within the context of the repeated failure of reviews and changes to disability service policy to achieve an improvement in the provision of services to persons with disabilities more broadly, this study aimed to provide a 'proper examination to ascertain what is really needed' (Stern, 1993 p.15).

A conceptual journey

The importance of the provision of community services in the lives of persons with spinal injuries has been well noted. Nosek and Howland (1993 p.789) have noted that 'The success of persons with severe physical disabilities in living independently in the community, engaging in self-directed productive activities and staying healthy depends, in part, on getting and maintaining adequate personal assistance with such tasks.' Other commentators (Anderle, 1995; Buchanan & Nawoczenski, 1987; Sipski, Hendler, & DeLisa, 1991; Wilson & Thompson, 1983) have compiled lists of the types of assistance needed by persons with spinal injuries, including such things as family support, personal assistance services, functional and emotional support and health services. On what basis, however, should decisions about the types of services needed by or provided to any individual with a spinal injury be made?

In the search for a definitive answer to this question, this study did not presume a particular definition of need. It was not known, at the outset of this study, which definition or understanding of need would be the most useful in ascertaining what community services were really needed for persons with spinal injuries. Rather, this study explored increasingly complex understandings of the concept of 'community service needs' in order to determine which understanding of need would be most useful in describing the community service needs of the spinal injured population of NSW and understanding ways to meet those needs.

This exploration of the community services needs of persons with spinal injuries in NSW first travelled through the familiar territory of a normative understanding of need. Whilst the normative needs of persons with spinal injuries in NSW have never been specifically explored, it is well documented that persons with disabilities, as a group, are amongst the most
disadvantaged in every society, including Australia.\(^1\) This disadvantage is based upon normative notions of unassailable rights developed in the context of persons without long-term disabilities. One could question, however, the extent to which such needs are common to all populations or individuals. Other commentators argue that population based normative understandings of need may lead to stereotyping, rather than recognition of individual need (Billings & Cowley, 1995; Routley, 1987a), and are not appropriate for understanding the needs of groups about whom population data is not regularly collected (Routley, 1987b; Staden, 1987). Thus, this journey of exploration could not be completed by focussing solely on the relative disadvantage of persons with spinal injuries as a group compared with the rest of society.

Expressed and felt need, measured by levels of service usage, have been the main focus of most need studies conducted in the past. Should 'need' thus be limited to the expressed and felt needs of individuals? Doyal and Gough (1991) would argue that any needs expressed by the individual, rather than determined by societal obligation, are subjective and relative, and thus not universally valid. Nevertheless, would the concepts of expressed and felt need be more useful in determining what persons with spinal injuries 'really needed' (Stern, 1993 p.15)?

Determination of the services needs of persons with spinal injuries must be based on not only felt and expressed needs, but also the comparative need of differing members of the population group. Comparative need, however, is rarely studied.\(^2\) This study therefore explored the usefulness of intrinsic understandings of the need for community services including expressed, felt, prescriptive and comparative need, where the goal is determining service priorities to meet service needs equitably.

Intrinsic understandings of the need for community services are focussed on the provision of adequate and equitably distributed community services to achieve the outcome of adequate and equitable services. The Disability Services Act, however, clearly articulates that there are individual goals to be achieved through the provision of services (beyond simply the receipt or equitable distribution of the service). Could the need for community services thus be thought of in terms of contributing to the desired life plans and goals of persons with spinal injuries? The answer to such a question would be found by developing an outcome-based statement such as:

A person needs a community service in order to achieve some defined outcome (other than the procurement of the service, equitably or otherwise).

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\(^1\) The disadvantage of persons with disabilities is well documented by Government (Australian Bureau of Statistics, 1993; Australian Institute of Health and Welfare, 1995; Henderson, 1975) and other commentators (Oliver, 1996).

\(^2\) Of the 97 need assessment abstracts reviewed for the period 1990-1997, only seven included some comparison, predominately comparing the needs of persons receiving different types of treatment, or care in differing settings.
The language of 'rights' then tells us that if the outcome is defined or endorsed by society (such as being enshrined in legislation, that is, the Disability Services Act), then society has an obligation to provide the needed service.

Few studies, however, appear to outline the specific outcomes to be achieved through the meeting of need. Rather, studies express assumptions that the provision of community services was required to achieve outcomes such as independence, although they do not appear to test these assumptions.

This study explored new territory by making no assumptions about the desired outcomes to be achieved by individuals, nor the role of community services in realising them. Using an interpretive paradigm, the final stage of the journey focussed on the individual meaning of services in the lives of persons with spinal injuries. Rather than assuming a traditional positivist paradigm with a focus on value free knowledge and causal explanations (Ward & Flynn, 1994), this reflexive study was able to finally ascertain what persons with spinal injuries 'really needed' (Stern, 1993 p.15).

A methodological journey

This comprehensive study of the community service needs of persons with spinal injuries is presented in five stages, each of which used a different method to explore a different understanding of the concept of need.

Stage One—Social indicators of need (normative need)

The normative identification of the 'needy' was the first approach taken. It was based on a survey of persons with spinal injuries in New South Wales. Epidemiological studies identifying persons with needs was the most common method for determining the need for community resources in the early 1990's, based upon lives lost, life years lost, or loss of social functioning (Billings & Cowley, 1995). These factors were augmented by the use of social indicators such as age and ethnicity, primarily based on census data. Social indicators such as income, education and employment are seen by Doyal and Gough (1991) as suitable measures of basic need satisfaction.

This study therefore began by conducting a census type survey of persons with spinal injuries living in the NSW community, in order to determine the normative needs of this population.

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3 Only one of the 97 need assessment abstracts reviewed for the period 1990-1997 specifically outlined the individual outcomes achieved through the provision of services, in this case, support groups for carers of persons with head injuries (Acom, 1993). A further two studies were premised on the assumption that provision of community services increased independence (Barnes & Hoyle, 1995; Williams & Bowie, 1993).
Identification of the sample

In late 1994 and early 1995, a cross-sectional study was conducted which included all persons injured and resident in New South Wales who were admitted to either Royal North Shore or Prince Henry Hospitals (the only two referral hospitals for persons with spinal injury in New South Wales) in the period 1st January 1977 to 31st December 1992, inclusive, with a diagnosis of spinal injury. For the purposes of this study, spinal injury was not considered to be synonymous with spinal cord injury, but was more broadly defined. A person was deemed to have experienced a traumatic spinal injury if they suffered a traumatic injury to any structure in the spine (spinal cord, bone, nerves, discs, ligaments, or musculature) sufficiently severe to warrant admission to a specialist acute spinal injuries hospital unit, regardless of whether there was resultant permanent neurological impairment or not. Spinal injury therefore included the subset of persons with spinal cord injury, as well as those with trauma to other spinal structures.

The sample database was collated directly from the ward admission books of the two hospitals. At Royal North Shore Hospital, computerised medical records were examined to extract the most recent address on file. Computerised medical records for Prince Henry Hospital were not made available to the researcher.

Persons not resident in New South Wales at the time of admission or discharge and persons known to be deceased were excluded, as were those with spinal impairment from other causes, such as spina bifida, carcinoma or multiple sclerosis. The sample was thus limited to only those persons whose spinal injury was the result of trauma incurred as an adult,

\[4\] in an effort to make the sample as homogeneous in their need for community services as possible.

\[5\] A total cohort of 2432 adults was identified from the admission records of Royal North Shore Hospital and Prince Henry Hospital spinal injury units for the 16 year period. Name, most recently recorded address and year of injury were the only data consistently available from both hospitals. Current addresses were able to be confirmed for 932 of the 2432 persons identified (38.32%).

\[6\] Responses were gained from 706 persons with spinal injuries (75.8%). This represented a response from 29.0 percent of the estimated spinal population of New South Wales who were admitted during the appropriate years, and were presumed to be still alive. Hence, this study of

\[4\] The usual minimum age for admission to Royal North Shore or Prince Henry Hospital is 15, however, female patients are sometimes admitted at an earlier age, depending on their level of development.

\[5\] By limiting the population to those who had incurred adult trauma, persons in receipt of different types of community services such as palliative care or services for children were excluded.

\[6\] Current addresses of all potential respondents were confirmed using the Australian telephone directory on CD-ROM.
the spinal injured population in the community was the largest and most representative ever undertaken in New South Wales.

For the purpose of analysis New South Wales was divided into the areas and regions determined by the New South Wales Department of Health. Those who responded to the survey were representative of the total cohort insofar as respondents were equivalent to the total cohort of 2432 in their geographic distribution across New South Wales (p=0.998) and in year of injury (p=1).

Upon analysis, 63 respondents were found to be non members of the cohort, either being less than 15 years old at the time of injury (n=34), less than two years post injury (n=5), or more than 19 years post injury (n=46) (respondents could be in more than one category). These people were excluded from some analyses where their inclusion would skew results, for example, when considering differences in cause of injury according to age at time of injury, but were included in analyses where their inclusion contributed to the richness of the data, for example, where the inclusion of persons with a greater time post injury contributed to a greater understanding of the changes in use of services over a long period of time. When analysis includes only the cohort, this will be identified as 'adult cohort' (n=637), otherwise, the results include data from all 706 cases.

Data collection

The 932 persons with spinal injuries whose addresses were confirmed were mailed a questionnaire package which consisted of a letter of invitation to participate signed by the director of the spinal unit to which they had been admitted (either Royal North Shore or Prince Henry hospital as appropriate), an instruction sheet, a questionnaire for their completion and a questionnaire to be forwarded to their carer for completion by the carer (see Appendix A for copies of letters and questionnaires). Reply paid envelopes were supplied for the return of the questionnaires. Those who did not respond were sent a reminder letter, or telephoned if they had not responded after being re-sent the original package and the reminder letter.

The questionnaire for persons with spinal injuries and their carers consisted of closed response questions which gained detailed information (from both persons with spinal injuries and their carers) regarding a large range of issues:

- biographical information
- geographic location
- education
- accommodation
- language and literacy
- employment
- income
- membership of support organisations;
and for those with spinal injuries only:
- cause of injury
- vertebral level of injury
- functional ability post injury.

Data analysis

The questionnaire included both continuous and categorical variables. The primary analytical techniques employed were descriptive analysis (means, frequencies (distribution)), cross tabulations and chi-square calculations of categorical (nominal and ordinal) variables, and t-tests and one-way analyses of variance of continuous variables.

For the purpose of this stage of the study is was necessary to be able to identify particular groups, or segments of the population which had stronger indicators of normative need, relative to other groups in the population. To achieve this, segmentation modelling (SPSS CHAID) was used to build models identifying those segments of the population with a greater likelihood of being employed, one of the two indicators upon which normative need is assessed.

Segmentation analysis was used rather than other model building techniques, because it is particularly useful when the majority of variables to be used in the model are categorical variables, containing either nominal or ordinal data. Segmentation analysis does not require the creation of dummy variables (such as is the case with regression).

CHAID divides a population into two or more distinct groups based on categories of the "best" predictor of a dependent variable. It then splits each of these groups into smaller subgroups based on other predictor variables. This splitting process continues until no more statistically significant predictors can be found....The segments that CHAID derives are mutually exclusive and exhaustive. That is, segments do not overlap, and each population unit (case) is contained in exactly one segment. In addition, since segments are defined by combinations of predictor variables, you can easily classify each case into its appropriate segment simply by knowing the categories of these predictors. (Magidson, 1993 p.3).

When reading the models, the absence of a variable from the model does not necessarily mean that such a variable is unimportant, but rather, that its influence is so closely associated with the impact of another variable that it is not needed to explain differences in outcomes.

In creating the segments CHAID may merge segments of the population whose values, relative to the dependent variable, are not significantly different at a predetermined level ($p \leq 0.05$). In the case of ordinal data,
categories may only be merged if they are adjacent to each other. The categories of nominal data are free to be combined in any way.

At each stage of the analysis, CHAID splits the population based on the relationship between the dependent and the predictor variable which has the lowest probability value, based on the likelihood-ratio (LR) chi-squared statistic. The probability value is adjusted using the Bonferroni adjustment to account for the simultaneous inference associated with the merging of categories to maintain maximum significance.

The probability value (p value) used in CHAID is the probability that the observed relationship between the predictor and the dependent variable would occur if the predictor and the dependent variable were statistically independent. (Magidson, 1993 p.127).

This analytical technique permits the identification of characteristics of segments of the population who have greater or lower relative odds of the event of interest occurring.

Stage Two—Service usage indicators of need (expressed and felt need)

Having explored the normatively defined 'neediness' of the spinal injured population of NSW, the next task was to determine what community services they needed. The need for community services has previously been assessed mainly by using service utilisation data and waiting lists as indicators of expressed need (Thomas, 1997).

Service use and waiting lists, whilst accurate indicators of expressed need, are poor indicators of felt need, being heavily influenced by the provision and accessibility of services (Thomas, 1997). In the landmark British 'Black Report' (Townsend & Davidson, 1982) the recommendation was made that planning be based on the demand created by unmet need, or total felt need, rather than the pressure on existing services demonstrated by waiting lists.

This current study, therefore, did not ask service providers to indicate the extent of any waiting lists for services. Rather, participants were asked about the services they used, as an indicator of expressed need, and also if there were any services they would like to use but could not, as a measure of unmet felt need. In addition, segments of the population who were more likely to be using services or wanting services were identified.
Data collection

The survey used in this study, as described above in Stage One, asked questions regarding:
- use and provision of non professional (informal) assistance,
- use of professional assistance including personal care, domestic, paramedical, transport and respite services, and
- problems obtaining professional assistance including personal care, domestic, paramedical, transport and respite services.

Data analysis

As in Stage One, the primary analytical techniques employed to determine the numbers and characteristics of persons with spinal injuries who needed and wanted services were descriptive analysis (means, frequencies (distribution)), cross tabulations and chi-square calculations of categorical (nominal and ordinal) variables, and t-tests and one-way analyses of variance of continuous variables.

Once again, segmentation analysis was used to identify those segments of the study population who were more likely to be using community services, or more likely to have problems obtaining community services.

Stage Three—Prioritising need (prescriptive and comparative need)

Stage Three of this study aimed to determine community service provision priorities based on what the spinal injured population of NSW felt they needed, the extent to which that need was met, and what was needed to correct the mismatch (prescriptive need), as well as the types of persons most in need by virtue of being less likely to have their service needs met (comparative need).

Data collection

Stage Three of the study made use of all the epidemiological, social indicator data gained from the survey conducted in Stages One. The service use and obtainment problem data from Stage Two were also used.

Data analysis

Prescriptive need was measured based on levels of felt and expressed need gleaned from the survey data. These data were used to compute the increase
in community service provision which would be required to make good the deficit between the amount of community services persons with spinal injuries felt they needed, and the current levels of service provision. The level of problems obtaining services, felt need and prescriptive need were then ranked in order to determine service priorities.

To explore comparative need the survey data were again analysed using cross tabulations and chi-square calculations of categorical (nominal and ordinal) variables and segmentation analysis (SPSS CHAID). Segmentation analysis was used to identify subgroups of the population who were more or less likely to have their community service needs met.

Segmentation analysis was particularly useful in undertaking this task as this technique facilitated the creation of models which predicted a categorical (either nominal or ordinal) outcome where there were more than two categories, in this case, the comparative odds of having your need for services fully met, partly met, or not met at all.

Stage Four—Personal perceptions of need (intrinsic need)

The fourth stage in this study was to determine service priorities based upon persons with spinal injuries' personal perceptions of need.

To address the need for needs assessment of poorly identified groups, a number of health researchers in the United Kingdom have advocated the use of multiple methodologies including the use of scales to determine the importance of needs, as well as in-depth interviews (Endacott, 1997).

Another method, used by Health Visitors in the United Kingdom, is community profiling. Community profiles bridge the gap between the 'macro' assessment—profiling of those likely to have needs through epidemiological and demographic profiles, and indicating their service priorities, and 'micro' assessment—identification of individual needs through consultation. Community profiling combines qualitative and quantitative methods to give a rounded picture of a population's needs, an indication for provision, and to present results 'highlighting miss-matches [sic] between need and...care delivery' (Billings & Cowley, 1995 p.723).

Data collection

All persons who were currently using services were asked to indicate their level of satisfaction with the service on a scale, as part of completing the quantitative survey described previously. In addition, use was made of additional comments made by survey respondents who were prompted to

7 Other modelling techniques such as logistic regression, only allow the creation of a model to predict the presence or absence of a dichotomous variable.
write comments in response to the question 'Do you have any general comments you would like to make about extended care service provision, access and use?'

Over one third of persons with spinal injuries who responded to the survey included written comments in their response to the questionnaire (n=250, 35.4%).

Unstructured interviews were held with a sub-sample of the spinal injured population who had participated in the survey (n=40). In contrast to those who provided written comments on the survey, the interview participants were informed that the purpose of the study was to investigate the broader issue of life in the community with a spinal injury, rather than the need for community services specifically.

In order to determine personal perceptions of need it was essential to collect data in which the participants were able to tell their own story, and highlight the needs which were important to them. 'There is little doubt that the aim of learning about personal perceptions of need can only be achieved by using qualitative approaches' (Thomas, 1997).

Each interview participant was asked the same question at the start of the interview:

_I want you to tell me the story of living with a spinal injury. So to get you started, “I came home from hospital and...”_

By allowing the participants to tell their story in a narrative form, the content of the interview, the issues covered and the amount of coverage given to particular topics during the interview was fully controlled by the participant.

Data analysis

The written comments from the survey were entered, along with the numeric data, onto a database (dBase IV). Numeric data (satisfaction scales) were exported into SPSS (SPSS for Windows, version 7.5.1.0 SPSS Inc.) for analysis to identify population trends and levels of satisfaction of groups with particular characteristics.

All the written survey comments were exported from dBase as a single text document. Each interview was transcribed from the audiotape recording, or from notes taken during the interview for those interviews which were not tape recorded, and then saved as individual text documents.

The text in each document was then divided into text units with each line of text (approximately 68 typed characters) forming one text unit. The text documents (one per interview, plus a single file containing all comments) were then imported into QSR NUDIST (Version 4; Richards, L. & Richards, T. Qualitative Solutions and Research Pty Ltd) to facilitate the
analysis. QSR NUD.IST allows the researcher to attach multiple codes to each text unit. The relationships between codes may be quite unstructured, or codes can be grouped into an hierarchical structure to reflect conceptual groups. Coding facilitates the retrieval of text in response to specific search criteria, the use of which allows the researcher to ask questions of the data. For example, when do two or more concepts occur in the same unit of text, and when do they not, or does one concept always occur following another?

In Stage Four of this study, the attaching and grouping of codes facilitated an analysis of personal perceptions of need which included both the numerical tabulation of the codes indicative of the content of the comments and interviews, and the essence of the content through the retrieval of the actual text of interest.

Stage Five—Outcome based indicators of need (conceptualising need as the means to an end)

The final stage in this study was to develop a model for addressing the community service needs of persons with spinal injuries based upon the life outcomes they wish to achieve.

When considered in terms of outcomes, 'Need can be defined as those things which are necessary for the formulation and execution of plans and purposes which are self-determined' (Stainton, 1994 p.115). Miller suggests that 'to decide what a person's needs are, we must first identify his plan of life, then establish what activities are essential to that plan, and finally investigate the conditions which enable those activities to be carried out' (Miller, 1976 p.134).

In this study this equated to identifying persons with spinal injuries' plans of life, establishing the role of services in that plan, and investigating the conditions under which people can get services.

Data collection

The collated written comments and unstructured interviews gathered in Stage Four of this study were further analysed to ascertain the role and function of community services in the plans of life of persons with spinal injuries.

Data analysis

The data were analysed using the grounded theory method of analysis.\textsuperscript{8} Grounded theory method is particularly useful where there is little research

\textsuperscript{8} This method was pioneered by Barney Glaser and Anselm Strauss in a study exploring patients' perceptions of dying. In response to requests to elucidate the method used in that study, they published 'The Discovery of Grounded Theory' in 1967 (Glaser & Strauss, 1967).
in the subject area, and where existing understandings of a concept fail to be useful in resolving persistent problems (Chenitz & Swanson, 1986). Such is the case here. Although there are legislated outcomes of community services for individuals, these outcomes are primarily philosophical, based on human rights. The reality, or appropriateness of these outcomes for persons with spinal injuries has not been questioned. Further, the many reviews of community services indicate that meeting the needs of persons with disabilities is a persistent problem which has not yet been solved.

Grounded theory method was particularly influenced by the Chicago School of Sociology, and especially symbolic interactionism. Symbolic interactionism focuses on interaction rather than on personality or social structure. It also focuses on definition rather than response, the present rather than the past (Charon, 1995 p.33). Grounded theory thus concentrates on an analysis of social interactions to generate a theory from the data, to explain current social processes. 'Generating a theory from data means that most hypotheses and concepts not only come from the data, but are systematically worked out in relation to the data during the course of the research' (Glaser & Strauss, 1967 p.5).

The grounded theory method is particularly suited to this study in that it is focused on persons with spinal injuries' constructions of interactions occurring in the process of obtaining and using community services to achieve their desired outcomes, rather than on outcomes or processes dictated by a priori social structures or theories. The purpose of Stage Five of this study was to describe persons with spinal injuries' desired outcomes and to understand the means, or processes, by which persons with spinal injuries use (or don't use) community services to achieve them. The grounded theory method is particularly useful in developing an understanding of the conditions and consequences, or outcomes, of processes and interactions.

In order to explore processes, the grounded theory method has two major strategies— theoretical sampling and the constant comparative method of analysis. Theoretical sampling is an ongoing process of data collection that is determined by the emerging theory and therefore cannot be predetermined... it is a critical element in the concurrent triad associated with grounded theory: joint collection, coding and analysis (Becker, 1993 p.256). Constant comparative analysis is the process of coding data to develop concepts which are then refined by reviewing and comparing other data. On the basis of these comparisons concepts may be confirmed, discarded, refined or elaborated, and their relationships to one another are explored.

Ultimately the concepts are integrated into a coherent theory which includes an awareness of the context and the conditions under which the

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9 Strauss obtained both his M.A. and Ph.D in sociology from the University of Chicago in the 1940's.
'constructions' are made, and considers the consequences of the 'interactions'. Such theory should both 'fit' and 'work'.

By "fit" we mean that the categories must be readily (not forcibly) applicable to and indicated by the data under study; by "work" we mean that they must be meaningfully relevant to and able to explain the behavior under study. (Glaser & Strauss, 1967 p.3)

Summary

Unlike many that have come before, this study focussed on both the normative and, particularly, the individual needs of a group of physically disabled persons, those with spinal injuries, and their access to appropriate services.

The study is presented in five stages. Each stage dealt with increasingly complex and unexplored understandings and measurements of the concept of 'need' in order to determine which understanding would be most useful in describing the community service needs of the spinal injured population of NSW and for ascertaining ways needs may be met.

Specifically, the study asked:
1. Can normative definitions of need, based upon functional impairment and social indicators adequately identify the community service needs of persons with spinal injuries?
2. Would the concepts of expressed and felt need be more useful in determining what persons with spinal injuries needed?
3. Are there types of services which should receive priority due to their being relatively under-resourced (prescriptive need), or are there groups of persons whose needs should receive priority due to their being relatively disadvantaged (comparative need)?
4. Would knowing persons with spinal injuries' perceived need for and satisfaction with services facilitate an understanding of individuals' needs?
5. Could the need for community services be more usefully thought of in terms of services' contribution to the desired plans of life and goals of persons with spinal injuries?

A new perspective on the measurement and conceptualisation of community service need was obtained by adopting these multiple foci in the one study for the first time, and by conducting a systematic examination of the relative merits and applicability of different theories of need to the community service needs and the lives of persons with spinal injuries.

In summary then, the intention of this study was to derive an understanding of the community service needs and concerns of persons with spinal injuries in New South Wales, and provide a fresh perspective on the ways that
services should be delivered in order to meet these needs. Ultimately, it is hoped that the findings of this study, when brought to the attention of policy makers and practitioners, will influence their policy and practices to the benefit of the lives of persons with spinal injuries and others with long term physical disabilities.
The Spinal Injured Population of New South Wales

Before attempting to develop any understanding of the community service needs of persons with spinal injuries in New South Wales it was mandatory that the characteristics of the population be known. The traumatically spinal injured population of New South Wales, however, has not previously been comprehensively described.

There has been little widely reported research into the incidence of spinal cord injury, or spinal injury more broadly, in New South Wales. In 1986 John Walsh instigated a national system of registration of cases spinal cord injury in Australia which operated until 1991 (herein after called the Walsh register). The primary goal was to produce life expectancy and readmission data for the purpose of actuarial assessments. A national register was re-instigated in mid 1995 to once again produce good actuarial information. In the current study information on persons injured over a wider range of years than that included in the register is provided.

Few studies have considered the incidence and cause of spinal injuries, regardless of the presence or absence of neurological deficits. A large population study by Hu (1996) found that of the 944 persons admitted to Manitoba hospitals with spinal fractures from any cause (primarily falls in older women and motor vehicle accidents in younger males) over a three year period, only 122 had neurological deficits, with 77 percent of persons with cervical injuries, 84 percent of thoracic injuries, and 93 percent of lumbar injuries being neurologically intact. Nevertheless, the majority of studies of persons with spinal injuries have focussed on those with permanent neurological deficits, that is, spinal cord injuries. Thus, the long term outcomes of persons whose neurological deficits were not permanent, did no result in significantly impaired mobility, or who incurred orthopaedic spinal trauma with no neurological deficits have not been much investigated. Failure to do so may have resulted in serious understating of the impact of spinal injuries on the costs and provision of services in the community.

This cross-sectional demographic study allowed the development of a comprehensive understanding of who persons with spinal injuries are, and the nature of the injuries they sustained.
The injuries

Gender

The majority of persons with spinal injuries who responded to this survey were male (n=535, 76.5 percent), as was to be expected based on previous overseas studies and the Walsh register.¹

Age at time of injury

The most common age at time of injury of the adult cohort was 19 years, but ages ranged from 15 to 89 years. Just over half (51.3%) of the adult cohort respondents were aged under 30 years at the time of injury, primarily due to the concentration of high risk activities in younger age groups (motor bike riding, contact sports, water sports). Almost ten percent (9.7%) of the adult cohort were aged 60 or over at the time of injury (Figure 1). This skew towards younger persons was consistent with the literature;² however, this study identified a larger proportion of older persons having spinal injuries than had been indicated in overseas studies. The age at time of injury (adult cohort) had increased significantly over the time period involved in this study (1977 to 1992). In the period 1977 to 1980, the average age at time of injury was 29.1 years. This had increased to 34.1 years by 1984-86 and 37.9 years by 1990-92 (F ratio 5.72 df=4,630 p<.001).³

Women in the adult cohort were significantly older than men at the time of injury (men mean age 33.1 years, women 37.9 years; t=2.76 p=.006).⁴

¹ The vast majority of those who incur spinal cord injury are male (ranged from 75% to 82% of those who are spinal cord injured) (New Data on Spinal Cord Injury, 1994; DeVivo, Richards, Stover, & Go, 1991; Kelly, 1991). Walsh found 72% were male in 1991 (O'Connor & Cripps, 1996)
² A review of evidence from overseas indicated that the incidence of spinal cord injury was greatest amongst the young, primarily those aged between 16 and 30 years (DeVivo, Kartus, Rutt, Stover, & Fine, 1990; DeVivo et al., 1991; Karamehmetoglu et al., 1995; Kelly, 1991; Lasfargues, 1993; Price et al., 1994; Thurman et al., 1994).
³ Some overseas studies have also reported an increasing number of spinal cord injuries occurring in persons over 60 years of age in more recent times (New Data on Spinal Cord Injury, 1994; DeVivo et al., 1990; Subbarao, 1991).
⁴ Spivak et al have also reported an increased percentage of women incurring spinal cord injuries at an older age (Spivak et al., 1994).
Cause of injury

The major cause of spinal injury in the total sample was motor car accidents (n=244, 35.2%). These, together with motor cycle accidents accounted for 44.6 percent of all spinal injuries. Other causes, in decreasing order of frequency, included falls and other trauma (n=178, 25.7%), sporting accidents (n=137, 19.8%, including primarily water sport n=76), and industrial and agricultural accidents (n=69, 10.0%). These results were within the ranges described in the literature.5

Figure 1. Age at time of injury (adult cohort)

Cause of injury varied significantly with age6 (Table 2) and gender (Table 3). Whilst the percentage of injuries due to motor car accidents remained fairly constant across all age groups, motor cycle and sporting accidents occurred primarily to younger males. Older people were more likely to have had an industrial or agricultural accident (males), or a fall or other trauma (females). Women were most likely to have incurred their injury as the result of a

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5 The major cause of spinal cord injuries in most countries was motor vehicle trauma, ranging from 45 to 69 percent of all spinal cord injuries. Falls were the next most common cause, ranging from 20 to 22 percent of all SCIs. Sporting accidents, primarily diving, were the cause of between 13 and 21 percent of spinal cord injuries in the United States of America (New Data on Spinal Cord Injury, 1994; DeVivo et al., 1991; Ditunno & Forman, 1994).

6 In the United States, cause of injury was found to vary significantly with age, with younger persons incurring their injury as the result of motor vehicle accidents, and older persons as the result of falls (Trends in Traumatic Spinal Cord Injury - New York, 1982-1988., 1991; Acton et al., 1993; DeVivo et al., 1990; Kelly, 1991).
motor car accident or due to a fall or other trauma, whilst men's injuries were due to a wider range of causes.

### Table 2. Cause of injury by age at time of injury (adult cohort)*

<table>
<thead>
<tr>
<th>Cause</th>
<th>Less than 30</th>
<th></th>
<th>30-59</th>
<th></th>
<th>60 or older</th>
<th></th>
<th>Total</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%#</td>
<td>n</td>
<td>%#</td>
<td>n</td>
<td>%#</td>
<td>n</td>
<td>%#</td>
</tr>
<tr>
<td>Motor car</td>
<td>119</td>
<td>36.5</td>
<td>86</td>
<td>34.8</td>
<td>20</td>
<td>34.5</td>
<td>225</td>
<td>35.7</td>
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<tr>
<td>Motor cycle</td>
<td>54</td>
<td>16.6</td>
<td>9</td>
<td>3.6</td>
<td>0</td>
<td>0</td>
<td>63</td>
<td>10.0</td>
</tr>
<tr>
<td>Water sport</td>
<td>41</td>
<td>12.6</td>
<td>24</td>
<td>9.7</td>
<td>4</td>
<td>6.9</td>
<td>69</td>
<td>10.9</td>
</tr>
<tr>
<td>Other sport</td>
<td>44</td>
<td>13.5</td>
<td>12</td>
<td>4.9</td>
<td>1</td>
<td>1.7</td>
<td>57</td>
<td>9.0</td>
</tr>
<tr>
<td>Industrial/agricultural</td>
<td>9</td>
<td>2.8</td>
<td>50</td>
<td>20.2</td>
<td>7</td>
<td>12.1</td>
<td>66</td>
<td>10.5</td>
</tr>
<tr>
<td>Falls and other trauma</td>
<td>59</td>
<td>18.1</td>
<td>66</td>
<td>26.7</td>
<td>26</td>
<td>44.8</td>
<td>151</td>
<td>23.9</td>
</tr>
</tbody>
</table>

*χ²=104.64 df=10 p<.001
# column percent

### Table 3. Cause of injury by gender (total sample)*

<table>
<thead>
<tr>
<th>Cause</th>
<th>Males</th>
<th></th>
<th>%#</th>
<th>Females</th>
<th></th>
<th>%#</th>
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<tr>
<td></td>
<td>n</td>
<td>%#</td>
<td>n</td>
<td>%#</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Motor car</td>
<td>161</td>
<td>30.3</td>
<td>83</td>
<td>51.2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Motor cycle</td>
<td>61</td>
<td>11.5</td>
<td>4</td>
<td>2.5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Water sport</td>
<td>70</td>
<td>13.2</td>
<td>6</td>
<td>3.7</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other sport</td>
<td>56</td>
<td>10.5</td>
<td>5</td>
<td>3.1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Industrial/agricultural</td>
<td>66</td>
<td>12.4</td>
<td>3</td>
<td>1.9</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Falls and other trauma</td>
<td>117</td>
<td>22.0</td>
<td>61</td>
<td>37.7</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*χ²=69.94 df=5 p<.001
# column percent

### Vertebral level of injury

The majority of injuries were cervical (n=329, 57.9%), with a cluster around C4 to C6 (n=225, 39.6%). There was another cluster in the thoracic spine at T12 (n=51, 9.0%). The pattern of increased cervical injuries in the elderly and those with sporting injuries described in the literature was apparent in this sample population where vertebral level of injury varied significantly depending on the age at time of injury (Table 4) and cause of injury (Table 5).

7 Overseas studies reported that injuries to the cervical spine were most common, occurring in approximately half of all cases, with injury mainly at the level of the fourth to sixth
Table 4. Vertebral level of injury by age at time of injury (adult cohort)*

<table>
<thead>
<tr>
<th>Level</th>
<th>Less than 30</th>
<th>30-59</th>
<th>60 or older</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%#</td>
<td>n</td>
<td>%#</td>
</tr>
<tr>
<td>C1-C4</td>
<td>120</td>
<td>36.7</td>
<td>96</td>
<td>38.9</td>
</tr>
<tr>
<td>C5-C7</td>
<td>99</td>
<td>30.3</td>
<td>58</td>
<td>23.5</td>
</tr>
<tr>
<td>T1-T4</td>
<td>20</td>
<td>6.1</td>
<td>16</td>
<td>6.5</td>
</tr>
<tr>
<td>T5-L2</td>
<td>80</td>
<td>24.5</td>
<td>70</td>
<td>28.3</td>
</tr>
<tr>
<td>L3 or lower</td>
<td>8</td>
<td>2.4</td>
<td>7</td>
<td>2.8</td>
</tr>
</tbody>
</table>

* $\chi^2=36.53$ df=8 p<.001
# column percent

Table 5. Vertebral level of injury by cause of injury (total sample)*

<table>
<thead>
<tr>
<th>Level</th>
<th>Motor car</th>
<th>Motor cycle</th>
<th>Water sport</th>
<th>Other sport</th>
<th>Industrial/agricultural</th>
<th>Fall/other trauma</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%#</td>
<td>n</td>
<td>%#</td>
<td>n</td>
<td>%#</td>
</tr>
<tr>
<td>C1-C4</td>
<td>100</td>
<td>41.3</td>
<td>18</td>
<td>27.7</td>
<td>32</td>
<td>42.1</td>
</tr>
<tr>
<td>C5-C7</td>
<td>67</td>
<td>27.7</td>
<td>10</td>
<td>15.4</td>
<td>39</td>
<td>51.3</td>
</tr>
<tr>
<td>T1-T4</td>
<td>20</td>
<td>8.3</td>
<td>11</td>
<td>16.9</td>
<td>2</td>
<td>2.6</td>
</tr>
<tr>
<td>T5-L2</td>
<td>49</td>
<td>20.2</td>
<td>26</td>
<td>40.0</td>
<td>3</td>
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<td>L3 or lower</td>
<td>6</td>
<td>2.5</td>
<td>0</td>
<td>0.0</td>
<td>0</td>
<td>0.0</td>
</tr>
</tbody>
</table>

* $\chi^2=114.98$ df=20 p<.001
# column percent

A disproportionately high number of cervical injuries occurred in those aged 60 or older, beyond that which could be attributed to cause, that is, whilst falls (the cause of 44.8% of injury in persons aged 60 or more) resulted in injury to the C1-C4 vertebra in 43.8 percent of all persons having falls, 75.0 percent of persons aged 60 or greater sustained C1-C4 injuries. This may have been due to osteoporosis in older persons, particularly women, however, accurate clinical explanation of this phenomena was beyond the remit of this study.

The data and the many studies cited above give a clear picture of the incidence and cause of spinal cord injuries, but this focus on the 'input' of cervical vertebra. Thoracic level spinal injuries occurred in 28 to 35 percent of cases, mostly at the level of the twelfth vertebra (DeVivo et al., 1991; Karamehmetoglu et al., 1995; Silberstein & Rabinovich, 1995). Persons with sporting injuries were more likely to have cervical level injuries and resultant quadriplegia (Kelly, 1991; Noguchi, 1994; Silver & Stewart, 1994; Spivak et al., 1994).
spinal cord injuries and actuarial assessment has meant that little was known about the lives of spinal cord injured persons once they returned to the community.

Persons with spinal injuries in the community

Crisp (1990) reviewed two small studies of persons with spinal cord injuries in the community in Australia which were reported in the early 1980's. Both studies focused on the vocational rehabilitation outcomes of persons with significant disabilities. These found that employment was related to a higher level of education, and unemployment resulted from lack of available transport and equipment, poor health and geographic isolation. One larger study of a sample the spinal cord injured population of New South Wales was conducted by the Paraplegic and Quadriplegic Association of NSW (ParaQuad) (ParaQuad, 1985). Whilst this study provided descriptive data of the spinal cord injured population, generally consistent with overseas findings, few correlations between life circumstances and level and type of injury were presented, and persons with traumatic spinal injury were not considered independently of persons with spinal cord injuries from other causes. Furthermore, persons with lower level injuries and particularly those who did not belong to the ParaQuad organisation were ignored.

Thus, there is little comprehensive information about the lives of the spinal injured population of New South Wales. Such information, which goes beyond actuarial assessment concerned with life expectancy and morbidity, is vital if adequate and appropriate community services are to be provided.

Geographic location and prevalence

Due to the representativeness of the sample (in terms of geographic distribution), the projected total spinal injured population of each area or region was able to be calculated as the number of respondents to the survey divided by the overall response rate (Table 6). Projected figures based on response rate were used rather than the figures in the original database collated from hospital records due to a non-significant, but none the less, over representation of persons in the Eastern Sydney area whose most recent address was recorded in hospital records as Ashton House or Kimberley Lodge, two hostels for person with spinal injuries located in Eastern Sydney and used as temporary residences for persons coming to Sydney for medical
Table 6. Prevalence of persons with spinal injury currently residing in New South Wales (in decreasing order of prevalence)

<table>
<thead>
<tr>
<th>AREA</th>
<th>Survey n</th>
<th>Projected spinal injured* n</th>
<th>Total adult population n</th>
<th>Projected prevalence per 100000 n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Central West Region</td>
<td>34</td>
<td>118</td>
<td>132122</td>
<td>89.31</td>
</tr>
<tr>
<td>Eastern Sydney Area</td>
<td>62</td>
<td>215</td>
<td>300779</td>
<td>71.48</td>
</tr>
<tr>
<td>Illawarra Region</td>
<td>52</td>
<td>181</td>
<td>259740</td>
<td>69.68</td>
</tr>
<tr>
<td>Central Sydney Area</td>
<td>44</td>
<td>153</td>
<td>238563</td>
<td>64.13</td>
</tr>
<tr>
<td>New England Region</td>
<td>29</td>
<td>101</td>
<td>167015</td>
<td>60.47</td>
</tr>
<tr>
<td>South Western Sydney Area</td>
<td>79</td>
<td>274</td>
<td>459806</td>
<td>59.59</td>
</tr>
<tr>
<td>Wentworth Area</td>
<td>32</td>
<td>111</td>
<td>196737</td>
<td>56.42</td>
</tr>
<tr>
<td>Northern Sydney Area</td>
<td>91</td>
<td>316</td>
<td>565536</td>
<td>55.87</td>
</tr>
<tr>
<td>Western Sydney Area</td>
<td>67</td>
<td>233</td>
<td>447382</td>
<td>52.08</td>
</tr>
<tr>
<td>Orana/Far West Region</td>
<td>16</td>
<td>55</td>
<td>106908</td>
<td>51.44</td>
</tr>
<tr>
<td>South Sydney Area</td>
<td>52</td>
<td>181</td>
<td>406690</td>
<td>44.50</td>
</tr>
<tr>
<td>South Eastern Region</td>
<td>31</td>
<td>108</td>
<td>243632</td>
<td>44.32</td>
</tr>
<tr>
<td>Central Coast Region</td>
<td>22</td>
<td>76</td>
<td>177112</td>
<td>42.91</td>
</tr>
<tr>
<td>South Western Region</td>
<td>22</td>
<td>76</td>
<td>187901</td>
<td>40.44</td>
</tr>
<tr>
<td>Hunter Region</td>
<td>41</td>
<td>142</td>
<td>398551</td>
<td>35.62</td>
</tr>
<tr>
<td>North Coast Region</td>
<td>25</td>
<td>87</td>
<td>291339</td>
<td>29.86</td>
</tr>
<tr>
<td><strong>Total#</strong></td>
<td>706</td>
<td>2432</td>
<td>4549813</td>
<td>53.45</td>
</tr>
</tbody>
</table>

* calculated as sample n/.29
# includes five respondents for whom region could not be identified
treatment. There was no response to the questionnaire from persons with these addresses (n=12). Hence, the projected figures gave a better estimation of the number of persons permanently residing in each area on a long term basis.

The State-wide prevalence of persons with spinal injuries, based on the total spinal injured population, was 53.5 per 100 000 adults (age 15 or older), a result very close to the rate of 55 per 100 000 predicted by Walsh in 1987 (Blumer & Quine, 1995).

The majority of persons with spinal injuries lived in the Greater Sydney Area (survey n=427, 60.7%), as do the general population (57.5%). The largest number of persons with spinal injuries currently resided in the Northern Sydney Area (sample n=91, projected total population n=316, prevalence per 100 000=55.87), however, the highest prevalence of persons with spinal injuries per 100 000 adults currently resided in the Central West Region, centred approximately 200km west of Sydney (sample n=34, projected total population n=118, prevalence per 100 000=86.31), followed by the Eastern Sydney Area (sample n=62, projected total population n=215, prevalence per 100 000=71.48).

There has been a perception amongst those involved with persons with spinal injuries that it is necessary for people with spinal injuries to move to the eastern or northern suburbs of Sydney to gain services. There would appear to be some evidence of a concentration of persons with spinal injuries around the two acute spinal injury hospital units sited in Eastern and Northern Sydney, however the absence of area specific incidence data made it difficult to judge the magnitude of any post injury migration.

**Length of time post injury**

The average length of time post injury of the adult cohort was 9.3 years. The most common current age of the adult cohort was 32 years, however, nearly one fifth of the population (n=115, 19.1%) were aged 60 years or older, with the oldest respondent currently aged 91 years (Figure 2).

**Language and literacy**

The majority of the respondents used English at home (91.5%) and considered themselves to speak and read English well (95.4%). This did not reflect a lack of response from persons who could not read the questionnaire as all non-respondents to the mailed questionnaire were telephoned, nor were persons who could be presumed to be of non-English speaking background, as determined by name analysis, more likely to be amongst those whose current address was untraceable. Rather, the result does suggest that the prevalence of spinal injury may be lower amongst the non-
English speaking community, however, the lack of ethno-specific Australian incidence data makes it difficult to confirm this proposition.

Figure 2. Current age (adult cohort)

Membership of support groups and other organisations

The majority (n=458, 65.1%) of the spinal injured population belonged to a support group (Paraquad or Australian Quadriplegic Association (AQA)) or other type of organisation including sporting groups, historical societies and service clubs amongst others. Over fifty percent of respondents belonged to more than one club or organisation. Paraquad was the organisation with the highest membership amongst this population group (n=364), followed by membership of other types of organisations (n=226). Men were more likely to belong to a club or organisation than women (men 69.7% belonged, women 51.8% belonged $\chi^2=17.78$ df=1 p<.001). Membership of support groups was significantly inversely related to functional ability with greater membership being held by those who were more limited in their functional abilities (Figure 3; $\chi^2=391.92$ df=10 p<.001).

Education

A large percentage (43.1%) of persons with spinal injuries in the community had had some form of tertiary education (technical and further education n=79, trade n=114 or college/university n=109). Only five percent of respondents had not continued on to high school. Men were significantly more likely to have trade qualifications whilst female respondents were significantly more likely to have completed college or university degrees ($\chi^2=19.44$ df=5 p=.002).
Based on this sample, the spinal injured population of New South Wales reported high levels of education, consistent with that reported in the overseas literature. The spinal injured population were more educated than the general population, with 15.8 percent of persons with spinal injuries having college or university qualifications, compared with only 9.2 percent of the general population. Whilst 68.1 percent of the general population had no post school training, only 56.6 percent of the spinal injured population had none (based on Australian Bureau of Statistics Census Data 1992).

Accommodation

The majority of the surveyed population lived in private residences (n=635, 91.2%). Forty two respondents lived in public housing (6.0%). There were very few respondents from hostels, nursing or group homes (n=19, 2.7%). This may be a true picture of this population or may represent the difficulties involved in accessing people who resided in community group or nursing homes, however, the finding was consistent with the literature.

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*The majority of spinal cord injured persons in the community, reported in overseas studies, had at least a high school education - many successfully furthering their education post spinal cord injury (Berkowitz et al., 1992; Castle, 1994; DeVivo et al., 1991; Krause, 1992; Paralyzed Veterans of America, 1994; Pilsecker, 1990).

*The majority of spinal cord injured persons (around 95%) in overseas studies lived in a private residence in the community. Fewer than five percent were discharged to a nursing home post rehabilitation (Berkowitz et al., 1992; Castle, 1994; DeVivo et al., 1991; Krause, 1992; Paralyzed Veterans of America, 1994; Pilsecker, 1990).
Overview of the characteristics of the spinal injured population of New South Wales

The respondents to the survey were highly representative of the total cohort of the spinal injured population of NSW, when compared in relation to the year their injury occurred and their geographic location. The overall prevalence rate based on the total population was very close to that predicted by Walsh in 1987. In addition, their cause of injury, gender, vertebral level of injury and prevalence were within the ranges described in the literature. The number of persons incurring a spinal injury when aged over sixty years, however, was somewhat higher than has been described elsewhere. The pattern of increased cervical injuries in the elderly and those with sporting injuries was also apparent in this population. Therefore, it could be said that the population in this study represents a reasonably accurate cross-section of persons who had incurred a spinal injury.

The spinal injured population of NSW reported high levels of education, consistent with that reported in the overseas literature. The spinal injured population were more highly educated that the general population. Almost all respondents reported being proficient in English and used English in their homes. This did not reflect a lack of response from persons who could not read the questionnaire as all non-respondents to the mailed questionnaire were telephoned.

There would appear to be some evidence of a concentration of persons with spinal injuries around the two spinal injury hospital units sited in Eastern and Northern Sydney, however, the lack of area specific incidence rates makes it difficult to judge the magnitude of any migration. It is clear, however, that persons with significant disability are over-represented in the more remote areas of the state, and are not necessarily relocating to Sydney post injury. The majority of those survey reported living in private accommodation. This may be a true picture of this population or may represent the difficulties involved in accessing people residing in hostels or nursing homes, or a sampling bias towards over-representation of persons whose address has remained unchanged over a long period of time. Persons with a more itinerant lifestyle or who had changed their address since their most recent admission to the hospital spinal units could not be sampled. Nevertheless, the accommodation pattern of the sample in this study was consistent with the literature.

Having determined the characteristics of the spinal injured population of New South Wales, it is now possible to endeavour to explore and understand their community service needs.
Stage One

Using Social Indicators of Normative Need to Identify the Community Service Needs of Persons with Spinal Injuries

Identifying persons in need of services by the use of population based social indicators has been the primary method for determining the allocation funds for the provision of government funded community services in Australia. Funding to provide services to meet need has been based primarily on the number of persons living in an area in receipt of Government pensions or benefits due to being, or caring for, someone who is aged or has a disability (Routley, 1987a). 'The use of this macro approach is said to enable more complete and precise answers to socially relevant questions and to make policy decisions more explicit and informed' (Routley, 1987b p.3).

The demand for services and hence the amount of funding needed to supply services for persons with spinal injuries is totally based on the data which is available from Australian Bureau of Statistics census studies (Yeatman, 1996). On the basis of such estimates of need, government funding under the auspices of the Home and Community Care (HACC) program¹ is directed towards assisting 'persons living in the community who, in the absence of basic maintenance and support services provided or to be provided within the scope of the programs, are at risk of premature or inappropriate long term residential care, including:

1. frail or at risk aged persons, being elderly persons with moderate or severe disabilities;
2. younger disabled persons, being persons with moderate or severe disabilities.' (Home and Community Care, 1989 p.3)

The original definition of the target group, as young disabled and aged people, has been more specifically defined, as those who are functionally

¹ Home and Community Care (HACC) in New South Wales provides funding for accommodation support ('in-home' support, Attendant Care, hostel, institution and group home accommodation support), community support (occupational therapy, physiotherapy, speech therapy, counselling), community access (independent living training, social and community support, community access), and respite (own home, centre-based).
disabled, that is, persons who need support or assistance in order to perform daily living tasks. (Home and Community Care, 1989 p.5).

Thus, the concept of the normative determination of need as applied in the provision of Government funded community services is based on two criteria—source of income, and level of impairment. Persons who derive their income from a government pension or benefit, and who have moderate or severe impairments are considered in need of community services (Figure 4). On the other hand, persons employed and getting wages, or who have less severe impairments would be considered to not be in need of community services (Figure 5).

Figure 4. Concept of normative need for those who need services

![Diagram of need for services]

Figure 5. Concept of normative need for those who do not need services

![Diagram of need for services]

It is difficult, however, to use official government information to comprehensively assess the allocation of resources for the provision of community services to specific population groups because disability data does not identify the specific cause or nature of disability, with spinal injuries being grouped under the 'other musculoskeletal disorders' category.
Therefore, the level of need in the spinal injured population of New South Wales cannot be estimated through the use of such categorisations or data.

Little is known about the functional abilities of the spinal injured population of New South Wales, their level and type of employment and source of income. Such social indicator data was collected in conducting the demographic study of the spinal injured population, and is essential to the development of an understanding of their needs.

Functional ability

Functional impairment for persons with permanent spinal injuries in this study was classified in the same manner as used in the Paralysis Society of America/Disability Income Systems Inc. (PSA-DIS) survey utilised by Berkowitz et al. (1992) in their large study of spinal cord injury in the United States. As in the PSA-DIS survey, the functional level of respondents was self-reported. No clinical examination of participants was undertaken.

The PSA-DIS defined four categories of spinal cord injury:

- **Complete quadriplegia**—cervical lesions with no sensation or muscle usage below the point of injury.
- **Incomplete quadriplegia**—cervical lesions with at least some sensation or muscle usage below the point of injury.
- **Complete paraplegia**—thoracic, lumbar, or sacral lesions with no sensation or muscle usage below the point of injury.
- **Incomplete paraplegia**—thoracic, lumbar, or sacral lesions with at least some sensation or muscle usage below the point of injury. (Berkowitz et al., 1992 p.57)

A further two categories were included in this study to allow response from persons without permanent neurological deficits:

- **Some movement or sensory problems**—any movement or sensory impairment not classified above, including pain, and limited mobility associated with orthopaedic, rather than neurological problems.
- **No movement or sensory problems**—persons with no permanent movement or sensory impairment resulting from their spinal injury.

There was a range of disability in the sample population, from persons with complete quadriplegia to persons with no physical (movement or sensory) problems. Level of function was inversely related to vertebral level of injury (injury to high level vertebra resulted in more limited level of function, \( r = .423 \ p < .001 \)) for persons with injuries below C4 (see Figure 6 for an indication of the impairments which would result from a complete lesion at

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1 The Australian Bureau of Statistics conducts a census of persons with Disability, Ageing and their carers every five years, last undertaken in 1993, and due again this year (1998).
Figure 6. Region of the body and functions which would be impaired as the result of a complete lesion at each vertebral level
each vertebral level).³ Over two thirds (67.8%) of persons who sustained an injury to vertebra C5-C7 had complete or incomplete quadriplegia. Three quarters (75.0%) of T1-T4 injuries and 77.8 percent of T5-L2 injuries resulted in complete or incomplete paraplegia. Two thirds (66.7%) of injuries below L2 resulted in some or no problems. Injuries to vertebra C1-C4 resulted in a wide range of functional abilities not consistent with the high level of the vertebra involved (28.7% complete or incomplete quadriplegia, 18.8% complete or incomplete paraplegia, and 52.5% some or no problems). Those with bony damage only at this level often reported recovery with little or no residual functional deficits, for example, a male respondent who sustained an injury to C2 in a fall at age at 18 stated:

'I know I have been very, very lucky to have recovered to a normal condition'.

Similarly, another young male with an injury to C3 due to a motor car accident reported:

'I was one of the lucky few who walked out with only a half loss of neck movement from the fusion'.

Level of function varied significantly by cause of injury (Table 7). Quadriplegia was significantly more likely to be the result of sporting injury and paraplegia resulted from motor cycle, industrial and agricultural trauma. Motor car accidents resulted in a wide range of functional abilities.

Table 7. Functional level by cause of injury (total sample)*

<table>
<thead>
<tr>
<th>Functional level</th>
<th>Motor car</th>
<th>Motor cycle</th>
<th>Water sport</th>
<th>Other sport</th>
<th>Industry/agriculture</th>
<th>Falls/other trauma</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%#</td>
<td>n</td>
<td>%#</td>
<td>n</td>
<td>%#</td>
</tr>
<tr>
<td>Complete quadriplegia</td>
<td>27</td>
<td>11.4</td>
<td>7</td>
<td>10.8</td>
<td>14</td>
<td>18.4</td>
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<tr>
<td>Incomplete quadriplegia</td>
<td>38</td>
<td>16.1</td>
<td>7</td>
<td>10.8</td>
<td>26</td>
<td>34.2</td>
</tr>
<tr>
<td>Complete paraplegia</td>
<td>39</td>
<td>16.5</td>
<td>24</td>
<td>36.9</td>
<td>3</td>
<td>3.9</td>
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<tr>
<td>Incomplete paraplegia</td>
<td>30</td>
<td>12.7</td>
<td>16</td>
<td>24.6</td>
<td>3</td>
<td>3.9</td>
</tr>
<tr>
<td>Some problems</td>
<td>72</td>
<td>30.5</td>
<td>6</td>
<td>9.2</td>
<td>14</td>
<td>18.4</td>
</tr>
<tr>
<td>No problems</td>
<td>30</td>
<td>12.7</td>
<td>5</td>
<td>7.7</td>
<td>16</td>
<td>21.1</td>
</tr>
</tbody>
</table>

* χ²=126.11 df=25 p=.001
# column percent

³The range of functional abilities associated with high level lesions is not surprising since complete lesions at C1 or C2 are always fatal, as are most complete lesions at C3 – although the advent of improved artificial respiration techniques means that people can now survive with a complete lesion at C3.
The level of function also varied by age at time of injury (Table 8). A disproportionately small number of persons aged 60 or older had quadriplegia or paraplegia. Indeed, no person aged 60 or older reported having complete quadriplegia, and only 14.3 percent reported incomplete quadriplegia. Yet falls and other trauma, and motor car accidents (the cause of injury in 44.8% and 34.5% of persons aged over 60 respectively) resulted for this group in complete quadriplegia in 5.6 percent of falls, and 11.4 percent of car accidents, and incomplete quadriplegia in 19.2 percent of falls and 16.1 percent of car accidents. Hence, older persons represented a greater proportion of persons with less limited functional abilities than the cause and vertebral level of their injury would indicate.

Table 8. Functional level by age at time of injury (adult cohort)*

<table>
<thead>
<tr>
<th>Functional level</th>
<th>Less than 30</th>
<th></th>
<th>30-59</th>
<th></th>
<th>60 or older</th>
<th></th>
<th>Total</th>
<th></th>
</tr>
</thead>
<tbody>
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<td></td>
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<td>%#</td>
<td>n</td>
<td>%#</td>
<td>n</td>
<td>%#</td>
<td>n</td>
<td>%#</td>
</tr>
<tr>
<td>Complete quadriplegia</td>
<td>42</td>
<td>13.2</td>
<td>21</td>
<td>8.5</td>
<td>0</td>
<td>0</td>
<td>63</td>
<td>10.1</td>
</tr>
<tr>
<td>Incomplete quadriplegia</td>
<td>58</td>
<td>19.1</td>
<td>46</td>
<td>18.5</td>
<td>8</td>
<td>14.3</td>
<td>116</td>
<td>18.5</td>
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<tr>
<td>Complete paraplegia</td>
<td>58</td>
<td>18.2</td>
<td>48</td>
<td>19.4</td>
<td>5</td>
<td>8.9</td>
<td>111</td>
<td>17.8</td>
</tr>
<tr>
<td>Incomplete paraplegia</td>
<td>49</td>
<td>15.4</td>
<td>42</td>
<td>16.9</td>
<td>9</td>
<td>16.1</td>
<td>100</td>
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<tr>
<td>Some problems</td>
<td>53</td>
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<td>64</td>
<td>25.8</td>
<td>26</td>
<td>46.4</td>
<td>143</td>
<td>23.0</td>
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<tr>
<td>No problems</td>
<td>56</td>
<td>17.6</td>
<td>27</td>
<td>10.9</td>
<td>8</td>
<td>14.3</td>
<td>91</td>
<td>14.6</td>
</tr>
</tbody>
</table>

* \( \chi^2 = 37.09 \) df = 10 \( p < .001 \)

# column percent

The sample population, overall, reported being somewhat less disabled than has been documented elsewhere in the literature, yet this population reported much higher levels of cervical and thoracic injuries than was reported in the population study of spinal injury by Hu et al (1996). Three reasons for this discrepancy could be hypothesised.

Firstly, this sample included only people who were at least two years post injury at the time of the survey. The literature cited generally evaluated functional level during the acute or immediate post acute period. The discrepancy may, then, have been the result of some functional recovery, or adaptation by the person with spinal injuries, which occurred over a longer period of time.

Secondly, vertebral level of injury, and cause of injury were not particularly accurate indicators of ultimate functional ability in this study, particularly for those aged 60 or over, undoubtedly due to the inclusion of persons with

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4 One third to half of those with spinal injuries were reported to have resultant quadriplegia (tetraplegia) (Karamelometoglu et al., 1995; Kelly, 1991; Subbarao, 1991).
spinal injury which did not result in neurological deficit. Such persons were necessarily less disabled.

Finally, the higher prevalence of quadriplegia in persons aged over 60 cited in the literature was not apparent in this population.\(^5\)

There has been a general impression amongst the spinal injured community of New South Wales that due to the extreme remoteness of parts of New South Wales and the difficulties gaining services in remote areas, persons with significant disability would need to move to the Greater Sydney Area post injury. It was found, however, those living in major coastal centres and in the country were more likely to have more limited functional abilities than those living in the Greater Sydney Area \((\chi^2=15.89 \text{ df}=5 \ p=.007)\), even though the cause of spinal injury was not significantly different across all areas of New South Wales. A possible explanation of this may be that accidents with the same cause may be more injurious in particular areas of the State, for example, motor car accidents in country areas may have involved higher speed and therefore have been more serious, however, information such as speed of impact or other in-depth details about the respondents' accidents was not sought in this study. Nevertheless, the important fact that these results highlighted was that there were large numbers of seriously disabled persons living in country areas, and hence, the adequacy of the distribution of services across all areas of New South Wales was an issue of paramount importance.

**Employment**

Persons with spinal injuries were asked to state their present employment category. In addition to vocational categories, respondents could state that they were engaged in home duties, retired, or not working. Those who responded that they were engaged in home duties or retired were considered to be not in the labour force. No attempt was made to determine the percentage of those not working who were actively looking for work, however, for the purpose of this study these persons will be termed 'unemployed'.

Of the total sample spinal injured population, 599 respondents were of working age (male 15-65, female 15-60 years old). One hundred and four of these respondents were not in the labour force, stating that they were either retired \((n=48)\), engaged full time in the home \((n=44)\) or studying \((n=12)\). Hence, 495 respondents had the potential to be employed. Fifty eight percent of these respondents were employed \((n=288)\).

\(^5\) Persons over the age of 65 were more likely to have cervical level injuries and resultant quadriplegia (Kelly, 1991; Noguchi, 1994; Silver & Stewart, 1994; Spivak et al., 1994). In addition, younger persons were found to make better functional recovery post injury and hence had better post-acute functional ability (Kelly, 1991; Penrod et al., 1990).
The adult spinal injured of New South Wales had a much lower overall employment rate and much higher 'unemployment' rate than the general adult population of New South Wales. Whilst the difference in the 'unemployment' rate must be viewed with some caution due to the differences in classification of labour status between the Australian Bureau of Statistics (ABS) and this study (ABS requires that people be actively seeking work to be classified as unemployed, whereas this study did not), the percentages of employed persons for both population groups were directly comparable (Table 9).

Table 9. Labour force status (%) of the spinal injured and general populations by gender

<table>
<thead>
<tr>
<th>Labour force status</th>
<th>Spinal injured</th>
<th>General population</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Male</td>
<td>Female</td>
</tr>
<tr>
<td>employed</td>
<td>45.8</td>
<td>30.5</td>
</tr>
<tr>
<td>not in labour force</td>
<td>19.4</td>
<td>40.9</td>
</tr>
<tr>
<td>unemployed</td>
<td>34.8</td>
<td>28.7</td>
</tr>
</tbody>
</table>

The spinal injured population who were employed (males n=242, females n=49) were more likely to be in professional or managerial occupations than the general population, and less likely to be employed as skilled or unskilled labour (Table 10). Such a result would be expected due to the mobility impairments imposed by spinal injuries.

Table 10. Employment type for employed persons with spinal injuries compared with the general population by gender

<table>
<thead>
<tr>
<th>Employment type</th>
<th>Spinal injured</th>
<th>General population</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Male</td>
<td>Female</td>
</tr>
<tr>
<td>unskilled labour</td>
<td>19.0</td>
<td>10.2</td>
</tr>
<tr>
<td>skilled labour</td>
<td>16.1</td>
<td>6.1</td>
</tr>
<tr>
<td>clerical/sales</td>
<td>25.2</td>
<td>46.9</td>
</tr>
<tr>
<td>professional/managerial</td>
<td>39.7</td>
<td>36.7</td>
</tr>
</tbody>
</table>

The most significant overall indicator of employment for persons with spinal injuries was functional level (Figure 7), and whilst the overall employment rate was influenced by the inclusion in this study of persons without neurological deficits, the level of employment for those with quadriplegia and paraplegia compared more than favourably with the figures cited overseas.\(^6\)

\(^6\) Reported levels of employment for persons with paraplegia or quadriplegia in overseas studies ranged from 13 to 48 percent. A higher level of post injury employment was significantly related to higher level functional ability, and those who gained employment
Figure 7. Level of employment by level of function (for those working or potentially in the workforce)

\[ \chi^2 = 68.23 \text{ df} = 5 \ p < .001 \]

Other significant indicators of employment were level of education (Figure 8), use of community services and having everyday help (Figure 9). \(^7\)

Figure 8. Level of employment by level of education (for those working or potentially in the workforce)

\[ \chi^2 = 29.74 \text{ df} = 5 \ p < .001 \]

Post injury were most likely to have been white-collar workers pre-injury, or to have moved into administrative, clerical or financial work positions (Berkowitz et al., 1992; Castle, 1994; DeVivo et al., 1991; Krause, 1992; Paralyzed Veterans of America, 1994; Pilsecker, 1990).

\(^7\) Everyday help was primarily provided by family and friends.
Figure 9. Level of employment by use of community services* and use of everyday help*

\[
\begin{array}{cccc}
\text{uses professional services} & \text{does not use professional services} & \text{has everyday help} & \text{does not have everyday help} \\
\text{% employed} & & & \\
0 & 10 & 20 & 30 \\
40 & 50 & 60 & 70 \\
80 & 90 & & \\
\end{array}
\]

* \(\chi^2=13.50\; df=1\; p<.001\)

# \(\chi^2=55.19\; df=1\; p<.001\)

Segmentation modelling (SPSS CHAID) was used to build a model of workforce participation for those persons potentially in the workforce. Variables considered as potentially impacting upon workforce participation by persons with spinal injuries were the above mentioned significant variables—level of function, level of education, use of community services, and use of everyday help. In addition, gender, vertebral level of injury, current age, length of time post injury, geographic location and problems accessing services were considered as potentially influencing employment levels.

Gender was an indicator of whether a person was potentially in the workforce or not (women 40.9% not in labour force, men 19.4% not in labour force, \(\chi^2=31.15\; df=2\; p<.001\)). Men and women who were in the labour market were equally likely to be employed (men 57.9% employed, women 61.3% employed, \(\chi^2=.31\; df=1\; p=.577\)). Similarly, age was an indicator of potential participation in the labour market but did not significantly affect the employment rate of those in the workforce (employed mean age 36.8 years, unemployed mean age 37.7 years; \(t=.83\; p=.405\); not in labour force mean age 55.7 years; \(F=87.92\; df=2,696\; p<.001\)), however, older persons with spinal injuries did not participate in the workforce at the same rate as the general population (Table 11). Unlike earlier Australian studies, unemployment was not related to geographic location in this study.\(^8\)

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\(^8\) See Crisp (1990) for a review of twelve studies of factors associated with vocational outcomes for persons with spinal cord injuries.
Table 11. Rate of employment (%) of spinal injured and general NSW population by age and gender

<table>
<thead>
<tr>
<th>Age group</th>
<th>Spinal injured</th>
<th>General population</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>male</td>
<td>female</td>
</tr>
<tr>
<td>less than 20</td>
<td>30.0</td>
<td>12.5</td>
</tr>
<tr>
<td>20-24</td>
<td>54.1</td>
<td>54.5</td>
</tr>
<tr>
<td>25-34</td>
<td>59.4</td>
<td>54.3</td>
</tr>
<tr>
<td>35-44</td>
<td>49.3</td>
<td>30.8</td>
</tr>
<tr>
<td>45-54</td>
<td>57.3</td>
<td>34.8</td>
</tr>
<tr>
<td>55-64</td>
<td>21.7</td>
<td>5.3</td>
</tr>
<tr>
<td>65 or older</td>
<td>7.8</td>
<td>nil</td>
</tr>
</tbody>
</table>

As expected, the most significant indicator of employment was level of function (a summary of the relative odds of workforce participation for each population segment in comparison with the total study population average is shown in Table 12; for full results of each stage of the analysis see Appendix B). For those persons with complete/incomplete quadriplegia or complete/incomplete paraplegia level of education was the next most significant indicator with those with higher levels of education significantly more likely to be employed than those with lower levels of education.

For persons with some movement or sensory problems the use of everyday help was the most significant indicator of employment status—those who had everyday help were significantly less likely to be employed than those who did not. For those who did not have everyday help, vertebral level of injury was the most significant indicator of employment with those who sustained injuries to their thoracic or lumbar spine significantly more likely to be employed than those who sustained injury to their cervical spine. Persons with no movement or sensory problems were more likely to be employed if they had been injured more than eight years ago.

Overall, those most likely to be employed were persons with no movement or sensory problems who sustained their injury more than eight years ago, or those with some movement or sensory problems due to injury to their thoracic or lumbar spine and who did not need everyday help (100% employed). Those least likely to be employed were persons with complete/incomplete quadriplegia or complete/incomplete paraplegia who had a lower level of education (36.1% employed).
Table 12. Indicators of workforce participation for those working or potentially in the workforce

<table>
<thead>
<tr>
<th>Segment*</th>
<th>n</th>
<th>% employed</th>
<th>relative odds of employment</th>
</tr>
</thead>
<tbody>
<tr>
<td>function 5, no everyday help, thoracic or lumbar vertebral injury</td>
<td>21</td>
<td>100.0</td>
<td>1.7:1</td>
</tr>
<tr>
<td>function 6, injured 8+ years ago</td>
<td>40</td>
<td>100.0</td>
<td>1.7:1</td>
</tr>
<tr>
<td>function 6, injured &lt;8 years ago</td>
<td>26</td>
<td>80.8</td>
<td>1.4:1</td>
</tr>
<tr>
<td>function 5, no everyday help, cervical vertebral injury</td>
<td>53</td>
<td>79.3</td>
<td>1.4:1</td>
</tr>
<tr>
<td>function 1-4, vocational or tertiary education</td>
<td>153</td>
<td>58.8</td>
<td>1.0:1</td>
</tr>
<tr>
<td>function 5, has everyday help</td>
<td>25</td>
<td>48.0</td>
<td>0.8:1</td>
</tr>
<tr>
<td>function 1-4, school only education</td>
<td>180</td>
<td>36.1</td>
<td>0.6:1</td>
</tr>
<tr>
<td><strong>Total population #</strong></td>
<td>498</td>
<td>58.4</td>
<td>1:1</td>
</tr>
</tbody>
</table>

*function 1 Complete quadriplegia  
function 2 Incomplete quadriplegia  
function 3 Complete paraplegia  
function 4 Incomplete paraplegia  
function 5 Some movement or sensory problems  
function 6 No movement or sensory problems  

# includes two persons who were working past retirement age

In summary then, the level of employment of the sample population was somewhat higher than that reported in the literature for persons with spinal cord injuries. Although the overall figure was influenced by the inclusion of persons without neurological deficits, the level of employment for those with quadriplegia and paraplegia in New South Wales compared more than favourably with the figures cited overseas.

The spinal injured population of NSW reported high levels of education and a pattern of employment in white-collar jobs, consistent with that reported in the overseas literature. In the other studies cited having higher education had been equated with the ability of persons with more limited functional abilities to move into professional/managerial positions, however, this fails to explain the high level of education, and higher status occupations of persons with minimal or no physical impairments in this study.

Unfortunately, this study did not assess occupation and level of education prior to injury, to allow comparison with current occupation and education. Such data would allow the researcher to ascertain whether those persons incurring spinal injuries in NSW included an over-representation of persons with higher education and/or professional/managerial occupations, or

---

(Berkowitz et al., 1992; Clayton & Chubon, 1994; Krause, 1992; Van der Kolk & Van der Kolk, 1990)
whether all persons who have sustained spinal injuries feel compelled to undertake higher education and more sedentary jobs, regardless of the level of their physical limitations.

Income

Over forty percent of respondents (n=288, 42.2%) derived income from a wage or salary. One third of respondents received a government social security pension or benefit as their sole source of income (n=233). Six respondents received some ongoing compensation payments, and a further 75 gained income from lump sum compensation payments which were subsequently invested. For 54 of these respondents this was their sole source of income. The remainder of those not working (n=172, 26.1%) gained income from investments including superannuation. One hundred and three respondents (14.7%) received income from more than one source, most commonly from private investments in addition to a wage or government pension.

As would be expected from the labour force data presented above, source of income was significantly related to the level of functioning of persons with spinal injuries, with those of lesser ability more likely to be in receipt of a government pension (46.1% of persons with quadriplegia receive a pension, compared with 19.1% of those with no movement or sensory problems), and those with greater ability more likely to be in receipt of a wage or salary (quadriplegia 27.5%, no movement or sensory problems 71.9% receive wage income; \( \chi^2 = 64.11 \text{ df}=5 \ p<.001 \)).

The spinal injured population were less likely than the general population to be receiving a wage or salary, more likely to be receiving a government pension or benefit, and nearly three times as likely to be supported by investments and other income than the general population (Table 13), a finding consistent with the large numbers of persons with spinal injuries on low incomes reported in other studies.\(^10\) The higher proportion of persons receiving government pensions/benefits was particularly marked for men with spinal injury.

Australia has a comprehensive social security system through which persons who are not in employment, whether due to retirement or disability, are entitled to receive income support from the Federal Government, subject to assets and means testing. In light of this it was interesting to have found such a large number of persons whose primary income was from private

\(^{10}\) The number of persons with quadriplegia or paraplegia reported as in receipt of pensions in previous Australian studies ranged from 45.5% (Paraquad, 1985) to 54.5% (Freeth, 1993), with up to 76.6% reported in receipt of pensions in one overseas studies (Dew et al., 1983). Other overseas studies have commented more generally on the lower economic status of spinal cord injured persons (Berkowitz et al., 1992; Clayton & Chubon, 1994; Oliver et al., 1988; Pilsecker, 1990).
investments. Persons with spinal injuries were, however, also more likely to rely on government pensions than the overall NSW population.

Table 13. Source of income (%): spinal injured and general NSW population by gender

<table>
<thead>
<tr>
<th>Income</th>
<th>Spinal injured</th>
<th>General population</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Male</td>
<td>Female</td>
</tr>
<tr>
<td>wages/salary</td>
<td>38.0</td>
<td>33.0</td>
</tr>
<tr>
<td>government pension/benefit</td>
<td>36.6</td>
<td>33.5</td>
</tr>
<tr>
<td>investment/other income</td>
<td>25.4</td>
<td>33.5</td>
</tr>
</tbody>
</table>

**Understanding normative need**

When considered in terms of the social indicators of employment and income (although, interestingly, not education), there can be no doubt from this study, as in many before, that the spinal injured population of New South Wales are 'needy', and that many would be considered to have moderate and severe disabilities and need support or assistance in order to perform daily living tasks.

Normative understandings of need, as expressed through the allocation of funding and service priority target groups, would appear to be premised on an assumption that level of functional impairment and source of income (or by proxy, employment status) are related. Persons with moderate or severe impairments do not work and thus are in need of services, or even conversely, are in need of services and thus don’t work. Persons with less severe impairments, however, are expected to be working and not be in need of services.

This study, however, makes it clear that a person with spinal injury’s likelihood of working (and thus source of income) is related to factors other than functional ability alone. Even when considering solely functional ability, persons with complete lesions, which would have resulted in greater functional impairment, were more likely to be employed than those with incomplete lesions. Other factors such as the number of years post injury, level of education and the receipt of everyday help also significantly impacted on the likelihood of employment. In particular, persons with some motor or sensory impairment were less likely to work than even some subgroups of those with quadriplegia or paraplegia. It would thus be difficult to determine who is 'needy' amongst the spinal injured population of NSW on the basis of source of income or level of functional impairment.
Further, even being able to identify the spinal injured population as 'needy', according to population norms of employment and income does little to assist in the process of determining what it is that persons with spinal injuries actually need in terms of care and services in the community. The use of social indicators merely show populations that may be at risk. It does not attempt to aggregate specific individuals needs (Routley, 1987a p.17).

This is cogently demonstrated when you encounter Rob and Jenny, two very different people with spinal injuries living in New South Wales.

Rob's story

Rob lives in a small country town, not far from a major regional centre. Although the urban sprawl is heading towards them, the people of the town maintain the country atmosphere. As Rob says, "Newcomers come here and they reckon they've got to be here 15 years before we even recognise them." As a teenager Rob left this country town to find work as a tradesman. At the age of twenty he crashed his motorbike. Rob has complete paraplegia. After his injury, Rob returned to the town of his birth. Now, at the age of 37, some 17 years later, he told the story of his current life.

We come back here, because all me mates are back here, and we come back here and that's it since. I just do whatever everyone does, I'm just one of the boys... Now I shoot, I go away shooting, I travel shooting pigs and that sort of stuff, I don't want a boring settled down life like most people. That's what a lot of the guys saying, shaking their heads and saying "Can't live like you do", so...

I'm too young to be working (laughing) too many other things to do, enjoy me life, because it did cut into me hunting and me going away, so now it's sit back and relax...Beautiful...There's a reason for everything I guess. There's a reason for everything. Karma, I believe in Karma, what goes around comes around...

[You must have been destined for a party life]

Yeah, I used to party hard before but now it's party harder, no sleeping.

Rob lives with his mother, but he manages all his own care. Rob uses no services, Rob wants no services. It would be hard to classify Rob as 'needy'. Certainly, Rob would never think of himself in such terms. Normative, social indicator based definitions of need, in a society which views people with impairments as necessarily dependent and subordinate (Kestenbaum, 1996; Morris, 1994), would, however, classify him as 'needy'—he does not work, is reliant on the government for income, has a moderate disability, and
his next of kin is his 71 year old mother. Indeed, based upon social indicators, funding would be provided for the provision of services for Rob, even though he does not want them.

The situation for Jenny, however, is very different.

Jenny’s story

Jenny lives in a large country town, the centre of a prosperous agricultural region. Here in this town Jenny grew up, raised her family and was looking forward to spending the best years of her life, free from worry, with her husband Steve. At the age of 47 Jenny was driving her car home from work when she crashed. Jenny damaged her twelfth thoracic vertebra. Jenny was told she would never walk again.

That is very true. They did tell me that. Doctor told me that, that what I got back in the first two years would probably be all I'd get back. I don't know that I quite agree with that because I did a lot more than that, but I think a lot of it is up to yourself and how hard you’re prepared to work at it and I mean, Steve took me to physio. twice a day for weeks.

Now, some six years and much hard work later, Jenny can walk, but still has some problems with urinary continence. During her interview she told the story of her recent attempts to find some help for Steve.

I'd like to see, yes, I feel Social Security are very hard, very, very hard. They really put us through the third degree, they really did. They sent out a social worker and honestly, she might as well have been a detective, you know. And there was no, as far as Social Security or from what I can see about it, as far as they’re concerned, there is no incentive to get up and get going because then they don't want to pay Steve a carer's pension. You know, they sort of, if you say you’re able to do this, that or something else, they say, well, you don’t need this, this, this. But what about the nights when we have accidents and we have to get up and change beds, those sort of things. And then you think, well, didn’t they Steve? They really did put us through a pretty traumatic time. See, there's nobody really there to bat for you. There's no-one to say, hey, listen, this is where these people are at. You know, it looks good on the outside. Yeah, I do the washing, he pegs it out, he brings it in. I do the ironing. I don't vacuum, I don’t make beds. Who does all that? Alright, I come to work, but all those things I don't do and they think because you go to work, yeah, you're capable of doing all those things. Well, you’re not capable of doing all those things. Do you see what I mean?

---

Yeatman (1996) highlights the additional pressure on the community service system created by the large numbers of ageing parents over 65 years old currently caring for children with disabilities.
Jenny and Steve certainly feel that their life is made more difficult by not being able to get help. When the allocation of services is based upon normative need defined according to source of income and level of impairment Jenny is certainly correct when she says that she is being judged as not needing help. Yet the weariness in her voice clearly tells of the distress such judgements are causing her.

A different concept of need

Rob's and Jenny's stories illustrate that provision of services on the basis of normative need would result services being allocated for persons who may not require them, and the failure to allocate services and resources for other who may well be in need of them. For some people the concept of normative need, as illustrated at the beginning of this stage, does not accurately indicate their individual need for services. Government cannot and 'should not say to the community 'We know what you need' or 'You do not need what you think you need'.’ (Stern, 1994).

Rather than allocating resources on the basis of the normative need of a total population, it may be better to base decisions about what community services are needed on the actual expressed and felt needs of the individual persons with spinal injuries.
Stage Two

Using Service Usage Indicators of Expressed and Felt Need to Determine the Community Service Needs of Persons with Spinal Injuries

A population based normative understanding of need has been shown in Stage One to be of limited value in determining appropriate allocation of services at an individual level, and certainly does not assist in determining the types of services needed. Understanding the expressed and felt needs of persons with spinal injuries themselves may be more useful. Felt needs are needs perceived by the individual, and expressed need is felt need turned into action in the form of a request for a community service.

The notions of expressed and felt need are based upon the premise that 'need' can be determined by ascertaining from individuals those services which they use or have requested to use, and services they feel they need (Figures 10 and 11).

In the past, service utilisation data and waiting lists have been used to indicate expressed need. Such measures do not reflect felt need, however, as they are dependent on a person's ability to locate and access the appropriate service provider and waiting list. Further, expressed need in the form of waiting lists may also be affected by persons remaining on waiting lists for one type of service, whilst in receipt of another similar service (Staden, 1987). When planning resource allocation for the provision of community services, the use of services and felt need for services may be more useful indicators than expressed need.
Figure 10. Concept of expressed and felt need for those with need

Figure 11. Concept of expressed and felt for those with no need

Little is known about the use of, and felt need for non-professional\(^1\) and professional\(^2\) assistance and services by persons with spinal injuries. This has been an area of research generally ignored in Australia as well as overseas.

\(^{1}\) Also called 'informal' care or assistance, meaning assistance provided by persons for which no wages, or other direct financial remuneration, is received by the provider of the care or assistance.

\(^{2}\) Also called 'formal' care or assistance for which the provider receives wages or financial remuneration.
The Walsh Register (1988) estimated the amount of assistance and services needed (in monetary terms) based on the experience of ‘experts’ (that is, normatively determined), but only one small Australian study, conducted by Freeth (1993), included a review of services actually used by persons with spinal injuries. Freeth’s study included only 53 persons with high level quadriplegia, at the vertebral level of C4/5 or higher. The only other Australian study which noted service usage by persons with paraplegia, quadriplegia or other mobility impairment was a membership survey conducted by ParaQuad in 1984. The ParaQuad study population, however, included people with paraplegia or quadriplegia from non-traumatic causes such as cancer, multiple sclerosis, head injuries and congenital causes, and thus cannot be directly related to the population in this current study.

This study explored persons with traumatic spinal injuries’ use of and felt need for community services, including everyday assistance with personal care and domestic tasks, rehabilitative, transport and respite services. This included both non-professional and professional assistance, government funded and private services used or needed by persons with trauma induced spinal injuries of all levels of impairment. This was done by conducting an informal assistance, service usage and service needs survey in conjunction with the demographic survey presented earlier.

Everyday assistance for persons with spinal injuries

Level of everyday assistance for persons with spinal injuries

Three hundred and fifty six (356, 50.6%) persons with spinal injuries received primary everyday care from another person. A further 62 persons with spinal injuries stated that they were primarily self caring, but received some secondary assistance from one or more other persons. Hence, 418 (59.4%) persons with spinal injuries identified themselves as having the assistance of one or more persons with some aspect of their everyday living, either personal care activities (such as bathing, dressing, or feeding—sometimes referred to as activities of daily living, or ADLs) or household tasks (such as cleaning, or shopping—sometimes referred to as instrumental activities of daily living, or IADLs).\(^3\) Overall, 285 (40.4%) persons with spinal injuries required no assistance at all in their everyday living, a figure somewhat lower than has been reported elsewhere.\(^4\) The lower rates in the current

\(^3\) In this study, participants were not asked to detail the particular ADLs or IADLs with which they required assistance.

\(^4\) The Paraquad survey of members reported that 58% did not require any everyday assistance, whilst Berkowitz (1992) reported that two thirds of persons with quadriplegia or paraplegia required no assistance with ADLs. Berkowitz did not, however, investigate the number of persons needing assistance with IADLs.
study were undoubtedly related to the inclusion of persons with minimal or no impairment.

The number of persons in receipt of some everyday assistance varied significantly according to functional ability (Figure 12. \( \chi^2=205.77 \) df=5 \( p<0.001 \)), ranging from almost 100 percent of persons with complete quadriplegia receiving assistance everyday, down to 14.0 percent of persons with no movement or sensory problems. In addition, the number of people providing everyday assistance was significantly correlated to the functional level of the person with spinal injuries, that is, the more disabled the respondent, the greater the number of people who assisted them with their everyday living \( (r=.522 \ p<.001) \). These findings were consistent with those reported previously.

Persons living in regional centres or the country were more likely to receive some everyday help than persons living in the greater Sydney area (66.4% and 55.0% received everyday help respectively; \( \chi^2=9.05 \) df=1 \( p=.003 \)), as would be expected, since those living in the country were significantly more disabled. Persons with spinal injuries who were in paid employment (and hence those whose income was derived from wages) were significantly less likely to be in receipt of everyday help than those who were retired or were unemployed (and hence derived their income from a pension or other source) (employed 41.7% received everyday help, unemployed or retired 72.8% received everyday help; \( \chi^2=69.13 \) df=1 \( p<.001 \)).

Figure 12. Receipt of some everyday assistance by functional ability

The receipt of some form of everyday assistance increased significantly with increasing age of the person with spinal injuries \(^5\) until reaching a plateau at the 40-49 age group (Figure 13. \( \chi^2=29.81 \) df=6 \( p<.001 \)). This was true for

\(^5\) Gerhart at al (1993) and Nosek et al (1993) have both reported an increase in the need for assistance with age and severity of disability.
persons of each level of functional ability, but particularly marked for persons with paraplegia (complete or incomplete), or some or no motor or sensory problems, regardless of the length of time post injury. Hence, the need for everyday assistance at age forty five could be considered a reasonable estimation of the level of need for everyday assistance for the remainder of persons with spinal injuries' life (average 69% of all persons with spinal injuries aged 40 or over need everyday assistance).

Figure 13. Receipt of some everyday assistance by current age of persons with spinal injuries (adult cohort)

Segmentation analysis (SPSS CHAID) was used to identify those in the survey population who were most likely to receive everyday help. The significant variables of level of function and current age were included in the analysis. Other variables considered to potentially influence receipt of everyday help for some segments of the population were gender, age at time of injury, number of years post injury, vertebral level of injury, employment status, primary source of income, level of education, geographic area of residence, and whether the person with spinal injuries used or had problems obtaining professional paramedical, transport or respite (non-care) services.

Level of function was the most significant indicator of the receipt of everyday help, as would be expected (a summary of the relative odds of receiving everyday assistance for each population segment in comparison with the total study population average is shown in Table 14; for full results of each stage of analysis see Appendix C). Age, whether at the time of injury or currently was also a significant indicator, such that those who were older were more likely to receive everyday help than those who were younger. For older persons with incomplete quadriplegia or complete paraplegia, source of income, which could be viewed as a pseudonym for employment, was important with there being a significant relationship between not working and the use of everyday help, whilst for younger persons, the use of professional non-care services was related to the use of everyday help. Conversely, for those persons with some movement or sensory problems the
use of everyday help was related to problems obtaining professional non-care services.

In summary then, the need for everyday assistance, whether that be with personal care or household tasks, did not have a direct linear relationship with level of function. The use of, or need to use other non-care services and age were also important indicators. Importantly, the age at which persons with spinal injuries were more likely to need assistance, around 50 years old, was much lower than that at which one would ordinarily expect persons to become more dependent on others for personal care and household tasks. Thus, as with employment, level of function and source of income could not be said to be adequate indicators of the need for assistance, normatively determined.

Table 14. Indicators of the receipt of everyday help

<table>
<thead>
<tr>
<th>Segment*</th>
<th>n</th>
<th>% receiving everyday help</th>
<th>relative odds of receiving everyday help</th>
</tr>
</thead>
<tbody>
<tr>
<td>function 1</td>
<td>74</td>
<td>97.3</td>
<td>1.6:1</td>
</tr>
<tr>
<td>function 2-3, aged 30+ at time of injury, pension or other income</td>
<td>84</td>
<td>96.4</td>
<td>1.6:1</td>
</tr>
<tr>
<td>function 2-3, aged &lt;30 at time of injury, uses professional non-care services</td>
<td>63</td>
<td>84.1</td>
<td>1.4:1</td>
</tr>
<tr>
<td>function 2-3, aged 30+ at time of injury, wages income</td>
<td>29</td>
<td>79.3</td>
<td>1.3:1</td>
</tr>
<tr>
<td>function 4, current age 50+</td>
<td>38</td>
<td>76.3</td>
<td>1.3:1</td>
</tr>
<tr>
<td>function 5, problem obtaining professional non-care services</td>
<td>36</td>
<td>75.0</td>
<td>1.3:1</td>
</tr>
<tr>
<td>function 2-3, aged &lt;30 at time of injury, doesn’t use professional non-care services</td>
<td>77</td>
<td>62.3</td>
<td>1.1:1</td>
</tr>
<tr>
<td>function 5, no problem obtaining professional non-care services, current age 50+</td>
<td>60</td>
<td>50.0</td>
<td>0.8:1</td>
</tr>
<tr>
<td>function 4, current age &lt;50</td>
<td>70</td>
<td>47.1</td>
<td>0.8:1</td>
</tr>
<tr>
<td>function 6, aged 40+ at time of injury</td>
<td>28</td>
<td>35.7</td>
<td>0.6:1</td>
</tr>
<tr>
<td>function 5, no problem obtaining professional non-care services, current age &lt;50</td>
<td>80</td>
<td>12.5</td>
<td>0.2:1</td>
</tr>
<tr>
<td>function 6, aged &lt;40 years at injury</td>
<td>65</td>
<td>4.6</td>
<td>0.1:1</td>
</tr>
<tr>
<td>Total population*</td>
<td>706</td>
<td>59.4</td>
<td>1:1</td>
</tr>
</tbody>
</table>

* function 1: complete quadriplegia
  function 2: incomplete quadriplegia
  function 3: complete paraplegia
  function 4: incomplete paraplegia
  function 5: some movement or sensory problems
  function 6: no movement or sensory problems

# includes five cases with incomplete datasets
Providers of everyday assistance

Assistance was primarily provided by the spouse or partner, for those who needed it (n=94, Figure 14). Spouse/partners also provided some everyday assistance in conjunction with another main carer (or the person with spinal injuries themselves) for a further 5.8 percent of injured persons. Parents were also significant providers of primary and secondary assistance, providing help to 17.5 percent of persons with spinal injuries overall (n=123). Many other commentators have reported a reliance on family members for the provision of care to persons with spinal injuries (and disabilities more broadly).\textsuperscript{6}

Whilst the bulk of everyday assistance was provided by immediate family members, other relatives and friends were important helpers, providing some primary or secondary everyday assistance to 19.0 percent of injured persons (n=133), a level somewhat lower than previously reported.\textsuperscript{7}

Figure 14. Primary providers of everyday assistance to persons with spinal injuries

\begin{itemize}
\item do not require everyday assistance
\item spouse/partner
\item parent
\item other relative/friend
\item paid carer/nurse
\end{itemize}

\textsuperscript{6} Morris (1994) and Donohoe et al (Donohoe et al., 1996) comment generally on the reliance of persons with disabilities on informal care. The Australian Bureau of Statistics (ABS) (1995) reported that, of persons reporting a handicap and receiving assistance, 91.9% received assistance from a family member.

\textsuperscript{7} The Paraquad member survey reported that 28% of those with everyday assistance received assistance from paid carers. Both the Paraquad member survey and the ABS (1995) reported that 18% received assistance from persons other than immediate family. The difference in findings is probably due to the disparity between samples in this and the other two studies, which were not specifically about persons with spinal injuries.
Non-professional care providers

Three hundred and thirty three (333) responses to the carer’s survey were received, a response from 79.7 percent of the primary or secondary carers identified by a person with spinal injuries. Spouse/partners were significantly over represented amongst the primary carer respondents representing 57.8% of the respondents, but only 51.1% of primary carers overall. Other relatives, friends and nurses were significantly under-represented in the responses by primary carers (Table 15). Hence, the results were more likely to represent the views of primary spouse/partner carers—the concerns of other carer groups may not be adequately expressed by the findings. Primary carer response rate was not related to the functional level, age, age at time of injury, gender, ethnicity or educational level of the person with spinal injuries.

Table 15. Primary carers relationship to the persons with spinal injuries by whether responded or not*

<table>
<thead>
<tr>
<th>Relationship to spinal injured person</th>
<th>Respondents</th>
<th>Non respondents</th>
<th>Overall</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%#</td>
<td>n</td>
</tr>
<tr>
<td>parent</td>
<td>52</td>
<td>21.9</td>
<td>29</td>
</tr>
<tr>
<td>spouse/partner</td>
<td>137</td>
<td>57.8</td>
<td>45</td>
</tr>
<tr>
<td>other relative</td>
<td>12.</td>
<td>5.1</td>
<td>15</td>
</tr>
<tr>
<td>friend</td>
<td>1</td>
<td>.4</td>
<td>6</td>
</tr>
<tr>
<td>nurse</td>
<td>6</td>
<td>2.5</td>
<td>11</td>
</tr>
<tr>
<td>paid carer</td>
<td>29</td>
<td>12.2</td>
<td>13</td>
</tr>
</tbody>
</table>

* $\chi^2=28.53$ df=5 $p<.001$
# column percent

Thirty one (31) responses to the carer’s survey were made by professional carers—eight nurses, 22 paid carers and one person caring for a person with spinal injuries in a nursing home. Fifteen respondents did not indicate their relationship to the person with spinal injuries. Hence, 287 responses to the carer survey were known to be from non-professional carers.

Ninety percent of non-professional carers lived with the person with spinal injuries (n=258). Twenty nine non-professional carers did not live with the persons with spinal injuries, 15 of whom were parents, 5 were other relatives, 5 were friends and 4 were spouse/partners not cohabiting but still providing daily care (one was caring for a spouse/partner residing in a nursing home). Fifty eight non-professional carer responses were received from persons who identified themselves as carers, but the corresponding person with spinal injuries stated that they did not have any everyday help. Forty percent of these non-professional carers were parents of persons with spinal injuries.
aged less than 40. In over half of these cases (n=33, 56.9%), the person with spinal injuries stated that they had only some or no functional problems. It is reasonable to hypothesise that these persons with spinal injuries and their carers felt some financial or emotional caring relationship, whilst not providing personal care recognised by the person with spinal injuries as necessary for their everyday living. Twelve of these carers did not live with the person with spinal injuries.

The majority of non-professional primary or secondary carers of the spinal injured in New South Wales were women (n=234, 81.5%) caring for their male spouse/partner (n=134), son (n=58) or daughter (n=15). Male non-professional carers were predominantly caring for their female spinal injured spouse/partner (n=35) or their son (n=6), daughter (n=4), or a friend (n=4). Parents caring for a son or daughter with a spinal injury were significantly more likely to be female, that is, the person with spinal injuries' mother (n=75, 88.2% of parent carers) rather than their father. Non-professional carers who were friends were more likely to be male (n=4 of the 6 friend carers)—a group significantly under-represented in this sample.

Use of professional care services

Forty seven percent of the 418 respondents needing everyday assistance received some professional care on an everyday basis from a nurse or paid carer (n=197). For 130 respondents this professional care was received in addition to care given by family or friends. Thus, 67 respondents (9.5% of all respondents, 16.0% of those receiving everyday assistance) were completely reliant on professional care services for their everyday care. A further 42 respondents used professional care services on a regular, but less than daily basis, thus giving a total of 239 persons who used professional care services on a regular basis (34.0% of all persons with spinal injury).9

The services used on an everyday or regular basis included the Home Care Service of NSW,10 herein after called Home Care, (domestic: n=128, 18.2% of total population, and personal care: n=114, 16.2%), private home nursing (n=33, 4.7%),11 and Attendant Care (n=43, 6.1%).1213 The percentage of

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8 The Australian Bureau of Statistics (ABS) (1995) reported a similar finding with only 8.1% of persons reporting a handicap and receiving assistance being totally reliant on professional care services.

9 Another 74 persons used professional care services on an occasional, or irregular basis. Such use was not deemed to be everyday care in this study.

10 The Home Care Service of NSW is an organisation funded under auspices of the Home and Community Care (HACC) program to provide personal and domestic care to persons living in the community.

11 Private home nursing includes primarily personal care services provided by non-government nursing agencies.

12 Attendant Care is a scheme funded under the auspices of the HACC program. Users of this scheme are provided with funding, usually through a broker, with which to employ an attendant. The person with spinal injuries and the Attendant Care worker have a direct employer-employee relationship.
persons in receipt of Home Care and Attendant Care in this study were generally consistent with Freeth's (1993) study, when controlled for level of function, however, this study reported much lower use of private professional care services.\textsuperscript{13}

The regular use of one or more professional care or domestic (everyday care) services was significantly related to the functional ability of the person with spinal injuries, with 93.2 percent of those with complete quadriplegia using services whilst no respondent with no movement or sensory problems used such services ($\chi^2=243.56 \ df=5 \ p<.001$). The use of everyday care services was significantly related to the current age of the person with spinal injuries, with those using services being, on average, four years older than those who did not (use professional services: average age 45.4 years, don't use professional services: average age 41.9 years; $t=2.67 \ p=.008$). In addition, those who were between 11 and 13 years post injury were significantly more likely to use everyday care services (43.4\% use professional care services) than those who had been injured for either a shorter, or a longer period of time ($\chi^2=11.96 \ df=4 \ p=.018$).

A segmentation model of the use of one or more everyday care services on a daily or regular basis was developed. Variables considered for inclusion in the model included level of function, vertebral level of injury, gender, age at time of injury, number of years since injury, current age, employment status, primary source of income, level of education and geographic area of residence.

Level of functional ability was the found to be the most significant indicator (a summary of the relative odds of using professional care services for each population segment in comparison with the total study population average is shown in Table 16; for full results of each stage of analysis see Appendix D).

For some segments of the spinal injured population, primary source of income had a significant impact with those in receipt of a government pension or income from other sources such as private investments, superannuation or compensation more likely to use everyday care services than those receiving a wage or salary. Persons with incomplete paraplegia living in a major regional centre or in the country were more likely to use everyday care services than those living in the greater Sydney area. Overall, those persons with complete quadriplegia were most likely to use everyday care services whilst those with no movement or sensory problems were least

\textsuperscript{13} Numbers add to more than the total of 197 as most individuals were in receipt of more than one service each day, primarily domestic Home Care service in addition to a personal care service.

\textsuperscript{14} Freeth reported that 48.6\% of males with quadriplegia received Home Care, 18.0\% Attendant Care, and 24.5\% received private services, however, Freeth does not make it clear whether these private services were specifically nursing services, or included other types of services.
likely to use them. Unlike Freeth's study (1993), receipt of everyday care services was not related to gender.\footnote{Freeth reported that 83.3\% of women with quadriplegia were in receipt of Attendant Care, and 66.6\% had Home Care, compared with 18.0\% and 48.6\% respectively for men. His sample, however, included only 10 women, 6 of whom had non-traumatic spinal injuries.}

Table 16. Indicators of the use of one or more everyday care services on a daily or regular basis

<table>
<thead>
<tr>
<th>Segment</th>
<th>n</th>
<th>% using one or more everyday care services</th>
<th>relative odds of using everyday care services</th>
</tr>
</thead>
<tbody>
<tr>
<td>function 1</td>
<td>74</td>
<td>93.2</td>
<td>2.7:1</td>
</tr>
<tr>
<td>function 2, pension or other income</td>
<td>93</td>
<td>67.7</td>
<td>2.0:1</td>
</tr>
<tr>
<td>function 2, wages income</td>
<td>33</td>
<td>42.4</td>
<td>1.3:1</td>
</tr>
<tr>
<td>function 4, lives in regional centre or country area</td>
<td>43</td>
<td>37.5</td>
<td>1.1:1</td>
</tr>
<tr>
<td>function 3</td>
<td>127</td>
<td>37.0</td>
<td>1.1:1</td>
</tr>
<tr>
<td>function 5, pension or other income</td>
<td>80</td>
<td>23.7</td>
<td>0.7:1</td>
</tr>
<tr>
<td>function 4, lives in inner or outer Sydney</td>
<td>60</td>
<td>13.3</td>
<td>0.4:1</td>
</tr>
<tr>
<td>function 5, wages income</td>
<td>98</td>
<td>2.0</td>
<td>0.1:1</td>
</tr>
<tr>
<td>function 6</td>
<td>93</td>
<td>0.0</td>
<td>0.0:1</td>
</tr>
</tbody>
</table>

Total population # 706 34.0 1:1

* function 1 Complete quadriplegia
* function 2 Incomplete quadriplegia
* function 3 Complete paraplegia
* function 4 Incomplete paraplegia
* function 5 Some movement or sensory problems
* function 6 No movement or sensory problems

# includes five cases with incomplete data

In summary, there would appear to be some indication that the use of, or more accurately, the allocation of predominantly government funded everyday care services was targeted to those persons with spinal injuries who were more 'needy', normatively defined. This contrasts with the need for everyday care, primarily informal, which was based upon age, and whether the person with spinal injuries used or had problems obtaining professional non-care services.

Use of community services by persons with spinal injuries for other than everyday care

Overall 37.8 percent (n=267) of all persons with spinal injury used one or more community service regularly or occasionally for other than everyday care. Of those who used one or more community services for other than
everyday care, 39.7 percent (n=106) used government services exclusively, 27.7 percent (n=74) used private services exclusively and 32.6 percent (n=87) used a combination of government and private services.

Government and private transport assistance (n=39 and n=42 respectively) were used regularly.\textsuperscript{16} Physiotherapy, both government and privately funded, were the services most used on an occasional basis (n=64 and n=75 respectively) (for full results for each type of service see Table 22 on page 129).\textsuperscript{17} Eight persons identified the use of other services including osteopathy (n=3), chiropractor (n=2), hydrotherapy, masseur, and naturopathy. In total, the service types most used, either regularly or occasionally, were paramedical services—physiotherapy (22.1% of the total study population), occupational therapy (7.8%) and counselling (5.3%), and transport services (20.3%) (Figure 15). Respite services were used by only 7.2 percent of persons with spinal injuries.\textsuperscript{18} The percentage of persons using paramedical services (24.8%) was somewhat lower than reported in overseas studies, but higher than reported in Australian studies,\textsuperscript{19} whilst the percentage using transport services was lower than previously reported.\textsuperscript{5}

\textsuperscript{16} Government transport assistance includes community transport services provided by both HACC funded transport services and transport services provided by local government. Private transport assistance is primarily the use of a government subsidised voucher taxi scheme.
\textsuperscript{17} Government funded physiotherapy is available through both the NSW Department of Health and may be based in both hospitals and community health services. Some government funded physiotherapy is also provided through HACC funded schemes. Private physiotherapy refers to the use of private practitioners in the community. Occupational therapy and counselling are similarly available from both government funded sources and private practitioners.
\textsuperscript{18} Respite services included—person minding, primarily HACC funded schemes providing respite in the person's own home; day care, HACC, community health and local government centres providing respite and activities on a day only basis; and respite care, overnight or longer term care provided usually provided in a privately run (but often government subsidised) facility or nursing home. Meals on Wheels, usually funded by local government or HACC, is included under respite services as this service provides 'respite' from the preparation of daily meals.
\textsuperscript{19} Other studies have reported considerably higher use of services; Pilsecker (1990) reported that about half of spinal cord injured persons were using community resources (not including care services) in the first 6 months post injury, whilst Berkowitz et al (1992) reported that at a median of 11 years post injury 34% of persons with paraplegia or quadriplegia were using physiotherapy, 15.2% occupational therapy, and 20.5% social work/psychologist services. Australian studies, however, have reported much lower levels of usage; the Paraquad member survey found only 6% of persons with quadriplegia or paraplegia used physiotherapy services, and a study of serious compensable injuries (not all spinal injuries) found that about 20% of persons were in receipt of a paramedical service at a mean of 12 years post injury (Neave & Howell, 1992).
\textsuperscript{20} Freeth (1993) reported that 60% of persons with quadriplegia used the disabled cab service on a regular basis, whilst the survey of Paraquad members (Paraquad, 1985) reported that 28.2% had used cab services at least once, although the number using the service on an ongoing basis was not reported. Neither of these Australian studies reported the use of community transport services. No other reporting of the rate of use of transport services was discovered, despite there being extensive commentaries on the importance of transport services for persons with spinal injuries (Boldy, 1990; Kestenbaum, 1996; see for example Oliver et al., 1988).
Figure 15. Most commonly used (either regularly or occasionally) non everyday care service types by number of users

Use of one or more community non everyday care services overall (either regularly or occasionally) and the use of specific types of services (paramedical, transport and respite) were significantly related to level of functioning of the person with spinal injuries. Persons with quadriplegia made use of all three types of services, whilst those with paraplegia mainly used paramedical and transport services. Persons with some or no movement or sensory problems primarily used paramedical services (Table 17).

Table 17. Use of one or more community non everyday care or domestic services and specific service types by function

<table>
<thead>
<tr>
<th>Level of function</th>
<th>Use of community non everyday care or domestic service (%)*</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Overall#</td>
</tr>
<tr>
<td>complete quadriplegia</td>
<td>58.1</td>
</tr>
<tr>
<td>incomplete quadriplegia</td>
<td>59.5</td>
</tr>
<tr>
<td>complete paraplegia</td>
<td>30.7</td>
</tr>
<tr>
<td>incomplete paraplegia</td>
<td>40.7</td>
</tr>
<tr>
<td>some problems</td>
<td>33.1</td>
</tr>
<tr>
<td>no problems</td>
<td>9.7</td>
</tr>
<tr>
<td>total population</td>
<td>37.8</td>
</tr>
</tbody>
</table>

* overall figure was not calculated from individual service type figure as any one individual could use more than one service type

# $\chi^2=73.74$ df=5 p<.001

^ $\chi^2=35.20$ df=5 p<.001

† $\chi^2=88.76$ df=5 p<.001

‡ $\chi^2=56.00$ df=5 p<.001
The only other variable which was significantly related to the use of one or more community services for other than everyday care was the use of everyday help, regardless of whether provided by non-professional or professional carers (has everyday help 49.2% use community non personal care services, no everyday help, 21.4% use community non personal care services; $\chi^2 = 55.53$ df=1 $p<.001$). Thus, the use of services for other than everyday care was significantly related to the need for everyday care. Unlike everyday assistance, the use of community services for other than everyday care was not related to the age of the respondent.

Segmentation modelling (SPSS CHAID) was used to build a model of use of community services for other than everyday care or domestic assistance. Variables considered as potentially impacting upon whether a persons with spinal injuries used community services were functional level, use of everyday help, work status, and primary source of income. Other possible variables considered were current age (although not significant overall, this may have been significant for certain segments of the population), age at time of injury, number of years post injury, vertebral level of injury, gender, geographic area of residence, and level of education.

As would be expected, level of functioning was the most significant indicator of the use of one or more community services for other than everyday care or domestic assistance (a summary of the population segments whose use of community non-care services (either personal care or domestic assistance), overall and specific service types, was above the total study population average is shown in Table 18; for full results of each stage of analysis see Appendix E).

Persons with quadriplegia were more likely to use non-care services if they had been injured less than eleven years ago. Male respondents with paraplegia or some movement or sensory problems who received everyday help and were not in the labour force were more likely to use non-care services than women with paraplegia or some movement or sensory problems who had everyday help or men with paraplegia or some movement or sensory problems with everyday help who were in the labour force (54.6%, 53.1% and 30.8% users respectively). Persons with paraplegia or some movement or sensory problems who did not receive everyday help were lower than average users of non-care services overall, however, those with cervical injuries who lived in outer Sydney did not use any non-care services at all compared with 22.2 percent of those living in inner Sydney, a major regional centre or the country.

The persons most likely to use paramedical services were those with quadriplegia who were injured less than 11 years ago and who were employed, or conversely, not in the labour force (60.7% use paramedical services), whilst no persons with no movement or sensory problems who were not in the labour force or unemployed used paramedical services. Those respondents with incomplete paraplegia or some movement or
sensory problems who sustained injuries to their thoracic, lumbar or sacral spine were more likely to use paramedical services than those who sustained cervical injuries, quadriplegia sustained more than eleven years ago or complete paraplegia (40.0%, 21.3%, 18.9% and 14.7% respectively).

Table 18. Indicators of the use of community services for other than everyday personal care or domestic assistance

<table>
<thead>
<tr>
<th>Service</th>
<th>type of persons with greater* level of use of community services for other than everyday care or domestic assistance</th>
</tr>
</thead>
<tbody>
<tr>
<td>overall</td>
<td>persons with complete/incomplete quadriplegia injured &lt;11 years ago (70.7%); persons with complete/incomplete paraplegia or some movement or sensory problems who have everyday help, are male and not in the labour force (54.6%); persons with complete/incomplete paraplegia or some movement or sensory problems who have everyday help and are female (53.1%); persons with complete/incomplete quadriplegia who were injured 11+ years ago (47.5%)</td>
</tr>
<tr>
<td>(37.8% used services)</td>
<td></td>
</tr>
<tr>
<td>paramedical services</td>
<td>persons with complete/incomplete quadriplegia who were injured &lt;11 years ago and who are employed or not in the labour force (60.7%); persons with incomplete paraplegia or some movement or sensory problems who sustained injury to their thoracic, lumbar or sacral spine (40.0%); persons with incomplete paraplegia or some movement or sensory problems who injured their cervical spine and have some post school education (36.0%); persons with complete/incomplete quadriplegia who were injured &lt;11 years ago and who are unemployed (27.7%)</td>
</tr>
<tr>
<td>(24.8% used services)</td>
<td></td>
</tr>
<tr>
<td>transport services</td>
<td>persons with complete/incomplete quadriplegia who were injured &lt;5 years ago (64.0%); persons with complete/incomplete paraplegia who were injured &lt;5 years ago (43.8%); persons with complete/incomplete quadriplegia who were injured 5-13 years ago (41.9%); persons with complete/incomplete quadriplegia who were injured 14+ years ago (20.5%)</td>
</tr>
<tr>
<td>(20.3% used services)</td>
<td></td>
</tr>
<tr>
<td>respite services</td>
<td>persons with complete/incomplete quadriplegia (17.6%); persons with complete/incomplete paraplegia or some movement or sensory problems who have everyday help and are not in the labour force or are unemployed (7.7%)</td>
</tr>
<tr>
<td>(7.2% used services)</td>
<td></td>
</tr>
</tbody>
</table>

* above the mean for the total study population

Persons with lower levels of functional ability who incurred their injury more recently were more likely to use community transport services than those injured a longer time ago, or who have a better level of function. Community respite services were only used by persons with quadriplegia (17.7%), or those with paraplegia or some movement or sensory problems who had everyday help and did not work (7.7%).
In summary, for persons with significant functional impairments, use of services was higher amongst persons more recently injured, although in the case of paramedical services, 'recently' included persons injured up to a decade ago. This may be an indicator that persons with significant impairment require a longer rehabilitative period, particularly to support those who return to employment. Paramedical services were particularly used by persons with incomplete paraplegia, or some movement or sensory problems. This was not surprising, as incomplete lesions such as these were often associated with significant pain levels. Interestingly, however, such persons, particularly if they had some independent mobility, would be unlikely to be considered to have a severe impairment and would probably not be considered to be 'needy', normatively defined. As expected, however, respite services were targeted towards persons with more significant impairment who did not work, that is, those who were 'needy'.

Use of government funded or private community services

Overall 51.4 percent (n=362) of all persons with spinal injury used one or more community services, that is, professional care, paramedical, transport or respite services, regularly or occasionally. These 362 persons accounted for 433 occasional service contacts and 375 regular service contacts, a total of 808 service contacts or, on average, contact with 2.2 services per service user. Of those who used one or more community services, 49.9 percent used government funded services exclusively, 13.2 percent used private services exclusively and 37.0 percent used a combination of government funded and private services.

The most significant indicator of the use of either government funded or private services was the level of function of persons with spinal injuries, as was to be expected (a summary of the population segments whose use of government funded and private services was above the total study population average is shown in Table 19; for full results of each stage of analysis see Appendix F). The receipt of everyday help, however, regardless of whether professional or non-professional,21 was related to the use of government funded services, whilst primary source of income was predictive of the use of private services.

Receipt of government funded services was totally related to functional ability and need for everyday help, with the exception that persons with complete/incomplete paraplegia who had everyday help and were female were more likely to use government services than men with the same characteristics. Thus it would indeed appear that the provision of government funded services, overall, was targeted to those persons who would be considered to be 'needy', that is those with more significant impairment and higher levels of dependency, who were most likely not

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21 For most this help is non-professional.
employed. It should be noted however, that the government funded services used primarily consisted of the provision of personal care, domestic assistance and respite services, together with some transport assistance, but very few paramedical services.

<table>
<thead>
<tr>
<th>Service</th>
<th>type of persons with greater level of use of services</th>
</tr>
</thead>
<tbody>
<tr>
<td>government funded services (45.60% use)</td>
<td>persons with complete quadriplegia (91.89%); persons with incomplete quadriplegia who have everyday help (76.42%); persons with complete/incomplete paraplegia who have everyday help and are female (75.68%); persons with some movement or sensory problems who have everyday help (52.54%); persons with complete/incomplete paraplegia who have everyday help and are male (47.73%)</td>
</tr>
<tr>
<td>private services (26.85% use)</td>
<td>persons with complete/incomplete quadriplegia whose primary income is from wages, private investments, superannuation, compensation or other income (56.60%); persons with complete/incomplete paraplegia or some movement or sensory problems whose primary income is from a government pension and who were aged 40-49 at the time of injury (40.00%); persons with complete/incomplete quadriplegia whose primary income is from a government pension (29.79%); persons with complete/incomplete paraplegia or some movement or sensory problems whose primary income is from wages, private investments, superannuation, compensation or other income (28.40%)</td>
</tr>
</tbody>
</table>

* above the mean for the total study population

The use of private services, primarily paramedical services, was related to income source as well as level of function, but not in a consistent way. Persons with quadriplegia were more likely to use private services if their income was derived from wages, investments or compensation, however, persons with paraplegia were more likely to use private services if they were middle aged and received a government pension.

Problems obtaining community services

Overall, 208 persons with spinal injuries (29.5%) stated that they had one or more problems obtaining one or more needed services. Obtaining

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22 The receipt of everyday care was shown in stage one to be a strong indicator of non-participation in the workforce.

23 The 1993 ABS Survey of Disability, Ageing and Carers (1993b) reported a slightly higher, though not dissimilar figure of 36% of persons having an unmet need for assistance. This figure, however, reflected the level of unmet need amongst the Home and Community Care (HACC) target group which is primarily defined as persons at risk of institutionalisation.
government funded services was a somewhat greater problem than obtaining private services overall (problem obtaining government services n=176, 25.0%; problem obtaining private services n=155, 22.0%). Of those who reported problems obtaining community services 24.5 percent (n=50) had problems obtaining government services exclusively, 14.2 percent (n=29) had problems obtaining private services exclusively and 61.3 percent (n=125) were experiencing problems obtaining both government and private services.

Cost was the most serious root of problems obtaining services overall, causing problems for 65.4 percent (n=136) of those experiencing problems. Availability of services was also a serious problem (n=114, 54.8%). Transport difficulties were not cited as a major cause of problems by the respondents (only 21 respondents indicated they had problems obtaining services due to transport difficulties). Generally speaking, cost was the major barrier to obtaining both government and private services, however, unavailability was a more serious barrier to obtaining government, rather than private services (Table 20). The number of persons citing costs as a barrier to obtaining Government services was surprising given that Government services had, at the time of the study, a stated policy that HACC services will not be denied to persons on the basis of inability to pay (Home and Community Care, 1989). 22 This policy has, however, been recently challenged by a Government move towards a 'user pays' policy for Home and Community Care services (Horin, 1997).

Table 20. Cause of problem obtaining government funded and private services*

<table>
<thead>
<tr>
<th>Problem</th>
<th>Government funded services</th>
<th>Private services</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%#</td>
</tr>
<tr>
<td>Availability</td>
<td>108</td>
<td>70.6</td>
</tr>
<tr>
<td>Cost</td>
<td>115</td>
<td>75.2</td>
</tr>
<tr>
<td>Transport</td>
<td>18</td>
<td>11.8</td>
</tr>
</tbody>
</table>

* For only those persons who had a problem of some kind with the particular type of service—government funded services total n=176, private services total n=155
# Adds to more than 100 because respondents could have more than one type of problem obtaining more than one type of service

22 Indeed the Australian Bureau of Statistics (1993a), when conducting the 1993 Disability, Ageing and Carers survey did not even include the option of cost as a response in the list of possible barriers to the use of services. Cost as a barrier to gaining services has only been previously cited with reference to the disabled cab service (Freeth, 1993) or the purchase costs of private transport (Paraquad, 1985).
Obtaining physiotherapy services, both government funded and private, was a problem for the greatest number of respondents, followed by Home Care domestic services, and government and private transport assistance. The ten services with which the greatest number of respondents experienced problems appear in Figure 16.

Overall, problems obtaining services were not significantly different for persons of all ages, gender, English language proficiency, level of education and employment status, nor for all causes of injury and ages at time of injury. However, persons who were less than 4 years post injury had a significantly greater problem obtaining services than those who had a longer post injury time ($\chi^2=12.55$ df=4 $p=.014$; Figure 17). As would be expected, having a problem obtaining one or more services was significantly related to functional ability, a reflection of the level of need for services ($\chi^2=49.71$ df=5 $p<.001$; Figure 18).

Figure 16. Ten services with which the greatest number of persons experienced obtainment problems by type of problem*

* Respondents may have more than one type of problem with obtaining more than one service

79
Figure 17. Problems obtaining one or more services by number of years post injury (adult cohort)

Figure 18. Problems obtaining one or more services by functional ability

Obtainment problems overall, problems due to cost, problems with different service types (personal care, paramedical, transport and respite) and problems with government and private services were not significantly different across New South Wales, however, availability of services was a somewhat more significant problem in country areas (22.8% had problems with availability) than in major regional centres (17.4%), inner Sydney (13.3%) or outer Sydney (13.5%), particularly in the North Coast and South West Regions (32.0% and 27.3% respectively) ($\chi^2=7.94$ df=3 p=.047 in area type groupings).\(^{25}\)

\(^{25}\) The relative disadvantage of persons living in rural and remote areas in Australia, in terms of obtaining community services of all types, is well documented by Government and others in most of the reports cited earlier in Table 1.
Segmentation analysis (SPSS CHAID) was used to identify those segments of the population who were more likely to experience problems obtaining services they desired. Variables which were considered as potentially affecting obtaining services for segments of the survey population were gender, function, vertebral level of injury, current age, age at time of injury, number of years post injury, work status and geographic area of residence. A summary of the persons experiencing greater problems obtaining services than the total study population average appears in Table 21. For full results of each stage of analysis see Appendix G.

The most important characteristic identifying persons with problems obtaining needed services was the receipt of everyday help. Other important characteristics were the age, education, income of the person with spinal injuries and the number of years since they incurred their injury.

Understanding expressed and felt need

It would certainly appear that community services do have a role in many lives of persons with spinal injuries based on the large numbers who have a realised expressed need for services, that is, those who have obtained services. Indeed, over half of all persons with spinal injuries were currently using at least one community service. Nevertheless, nearly one third of persons with spinal injuries had a felt need for services which they were unable to express due primarily to the cost and lack of availability of services.

Community services were not being provided to persons with spinal injuries on the basis of felt need, for if this were so, the level of expressed need would be equivalent to the level of felt need, that is, no-one would be unable to obtain the services they felt they needed. The Disability Services Act clearly states that ‘people with disabilities have the same rights as other members of society to services which will support their attaining an acceptable quality of life’ (Commonwealth Department of Health, Housing and Community Services et al., 1992 p.15), yet there are particular groups of persons with spinal injuries who were unable to obtain needed services.

Persons who were able to obtain professional care services, which were primarily government funded Home Care services (Table 22), were those who would be considered ‘needy’ on the basis of functional and employment definitions of normative need. Yet those whose rights to services were unfulfilled, being unable to obtain the desired professional care services, included persons with complete quadriplegia and those who could be considered to be somewhat dependent, as recipients of everyday help. Such persons would also be considered ‘needy’ based upon the normatively

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36 This everyday help was most likely to be non-professional assistance from family or friends (see Figure 14. previously).
defined criteria used to describe the target group for Home and Community Care (HACC) services.²⁷

Table 21. Problems obtaining particular types of services

<table>
<thead>
<tr>
<th>Service</th>
<th>type of persons with greater * problems obtaining services</th>
</tr>
</thead>
<tbody>
<tr>
<td>overall</td>
<td>persons who had everyday help and were injured &lt;5 years ago (59.4%); persons who had everyday help, were injured 5+ years ago and had post school education (46.8%); persons who had everyday help, were injured 5+ years ago and had school only education (31.5%)</td>
</tr>
<tr>
<td>government services</td>
<td>persons who had everyday help and were injured &lt;5 years ago (56.3%); persons who had everyday help and were injured 5+ years ago (31.8%)</td>
</tr>
<tr>
<td>private services</td>
<td>persons who had everyday help with tertiary education (50.0%); persons who had everyday help with school only or vocational education and currently aged less than 60 (31.8%)</td>
</tr>
<tr>
<td>care</td>
<td>persons who had everyday help with complete quadriplegia and had wages or other income (51.1%); persons who had everyday help with complete quadriplegia and had pension income (25.7%); persons who had everyday help with incomplete quadriplegia, paraplegia, some or no movement or sensory problems (21.8%)</td>
</tr>
<tr>
<td>paramedical services</td>
<td>persons who had everyday help who were aged less than 20 at time of injury (43.2%); persons with no everyday help who had thoracic, lumbar or sacral injury and were currently aged less than 30 (35.5%); persons who had everyday help who were aged 20-69 at time of injury with post school education (34.7%)</td>
</tr>
<tr>
<td>transport services</td>
<td>persons who had everyday help with post school education (24.4%)</td>
</tr>
<tr>
<td>respite and other services</td>
<td>persons who had everyday help (14.1%)</td>
</tr>
</tbody>
</table>

* above the mean for the total study population

²⁷ The target group for HACC services is legislatively defined in the Home and Community Care Act 1985 as 'persons living in the community who in the absence of basic maintenance and support services provided or to be provided within the scope of the program, are at risk of premature or inappropriate long term residential care, including ... younger disabled persons, being persons with moderate or severe disabilities.' (Home and Community Care Act 1985, Part 11, 6(a) and 6(a)(ii) cited in Home and Community Care, 1989 p.3). Further, persons deemed to have a moderate to severe disability 'will have been assessed as having a functional disability which makes it difficult for them to perform the tasks of daily living, such as dressing, preparing meals, house cleaning, home maintenance or using public transport, without personal assistance or supervision.' (Home and Community Care, 1989 p.4)
The users of paramedical services, primarily both government funded and private physiotherapy (Table 22), were persons who have lesions which are associated with greater levels of pain, together with those injured more recently and those with a greater capacity to pay for services. Persons with quadriplegia who were injured less than eleven years ago were also likely to be using paramedical services. Persons who could not obtain these services were also persons with lesions causing pain and younger persons, who, based on the data presented in Stage One, were also more likely to be those who are working, and thus able to pay for services. Certainly physiotherapy was the most difficult service to obtain, and being able to pay for it did not necessarily mean you could obtain it.

Transport services were used by those with recent injuries. This could be due to there being a longer period of rehabilitation or adjustment needed for persons with significant spinal injuries to be able to manipulate the controls in a car. Alternatively, the costs of purchasing a private vehicle may be prohibitive in the short-term, particularly for those pursuing compensation, a process which takes, on average, about five years. Problems in obtaining transport services, however, were not related to the number of years since the respondent sustained their spinal injury. Rather, they were related to having everyday help, which could be considered an indicator of dependency, and to having a higher level of education. Interpreting this result is problematic. A higher level of education, for persons with more significant impairments, was an indicator of being more likely to be employed, however, persons with everyday help were, overall, less likely to be employed. Thus, the group of persons with spinal injuries who had problems obtaining transport services may well be those with more significant impairments who were endeavouring to enter the workforce, or otherwise increase their level of participation in their community.

Respite services overall, were the only services for which the number of persons who could not obtain the service consistently outnumbered the number of persons who were currently using the service (Table 22). The small number of persons using respite services were those who would clearly satisfy HACC’s normative definition of being ‘needy’. In contrast, persons who could not obtain these services were only defined in terms of dependency, as indicated by having everyday help.

Indeed, having everyday help was the most consistent indicator of problems obtaining services of every type. As an indicator, receiving everyday help provides some challenges to the HACC definition of being ‘needy’. Having everyday help was a product of not only functional ability or impairment, but also the respondent’s age at the time of injury, current age, source of income, and even their felt need for community non-care services. Thus, persons with spinal injuries who need assistance to perform the tasks of daily living, such as dressing, preparing meals, house cleaning, home

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28 See footnote number 27 previously.
maintenance or using public transport, without personal assistance or supervision' were not necessarily those who would be 'deemed to have a moderate to severe disability' (Home and Community Care, 1989 p.4). This was particularly the case for persons with some movement or sensory problems, who, if they could not obtain community non-care services, were more likely to receive everyday help than some persons with quadriplegia or paraplegia.

Table 22. Summary of expressed need for services (current users) and problems of obtaining services

<table>
<thead>
<tr>
<th>Service</th>
<th>Uses service</th>
<th>Problem obtaining service</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%</td>
</tr>
<tr>
<td>Overall*</td>
<td>362</td>
<td>51.4</td>
</tr>
<tr>
<td>government funded services</td>
<td>321</td>
<td>45.6</td>
</tr>
<tr>
<td>private services</td>
<td>189</td>
<td>26.9</td>
</tr>
<tr>
<td>Care services*</td>
<td>240</td>
<td>34.0</td>
</tr>
<tr>
<td>Home Care (domestic)</td>
<td>128</td>
<td>18.2</td>
</tr>
<tr>
<td>Home Care (personal care)</td>
<td>114</td>
<td>16.2</td>
</tr>
<tr>
<td>home nursing (private)</td>
<td>33</td>
<td>4.7</td>
</tr>
<tr>
<td>Attendant Care</td>
<td>43</td>
<td>6.1</td>
</tr>
<tr>
<td>Paramedical services*</td>
<td>175</td>
<td>24.8</td>
</tr>
<tr>
<td>physiotherapy (private)</td>
<td>102</td>
<td>14.5</td>
</tr>
<tr>
<td>physiotherapy (government)</td>
<td>76</td>
<td>10.8</td>
</tr>
<tr>
<td>occupational therapy (private)</td>
<td>16</td>
<td>2.3</td>
</tr>
<tr>
<td>Occupational therapy (government)</td>
<td>43</td>
<td>6.1</td>
</tr>
<tr>
<td>counselling (private)</td>
<td>22</td>
<td>3.1</td>
</tr>
<tr>
<td>counselling (government)</td>
<td>25</td>
<td>3.6</td>
</tr>
<tr>
<td>Transport services*</td>
<td>143</td>
<td>20.3</td>
</tr>
<tr>
<td>transport assistance (private)</td>
<td>73</td>
<td>10.4</td>
</tr>
<tr>
<td>transport assistance (government)</td>
<td>98</td>
<td>13.9</td>
</tr>
<tr>
<td>Respite and other services*</td>
<td>51</td>
<td>7.2</td>
</tr>
<tr>
<td>meals on wheels</td>
<td>7</td>
<td>1.0</td>
</tr>
<tr>
<td>person minding</td>
<td>9</td>
<td>1.3</td>
</tr>
<tr>
<td>day care</td>
<td>11</td>
<td>1.6</td>
</tr>
<tr>
<td>respite care</td>
<td>32</td>
<td>4.5</td>
</tr>
</tbody>
</table>

* Overall figures for service type were not calculated from the figures for individual services because any one individual could have used and/or had problems accessing any number of services.
The complexity of the indicator 'having everyday help' means that it is not always particularly clear whether those who could express their felt need, and those who could not are two distinct groups. Many indicators of the expressed need for services and unmet felt need are similar, when mediated by the indicator 'having everyday help'. It is clear, however, that a proportion of those with higher than average felt or expressed need would be persons who are not included in the HACC target group for government funded services. Further, these persons with less significant impairments have not been included in previous studies.

The true extent of the need for community services has thus been understated and underfunded. HACC recurrent funding is largely based upon normative indicators of need—non-employment and severity of impairment. Expressed need (in terms of users) for services in this study (particularly the use of professional care and paramedical services) was also mainly defined in terms of characteristics such as functional ability and source of income or employment. Thus there is some evidence of the targeting of resources to those who could be considered more 'needy'. Unmet felt need, however, was primarily defined in terms of the need for everyday assistance, or what would elsewhere be termed as level of dependency.

Any increased recognition of the felt need for services, rather than normatively defined need, would have some massive implications in terms of resources. Persons with spinal injury who are unlikely to be included in normatively derived funding formulae include those persons with incomplete paraplegia in areas other than Sydney who have a higher than average use of professional care services, persons with incomplete paraplegia and some movement or sensory problems who have a higher than average use of paramedical and transport services, and persons who stated they had everyday assistance with unmet felt needs for all types of services.

That nearly one third of persons with spinal injuries are unable to obtain desired services certainly focuses attention on issues of supply, as suggested by Staden (1987). But is it just an issue of supply generally, or one of appropriate, or conversely, inappropriate targeting of services on the basis of normative definitions of need?

Two examples of the inappropriate reliance of service providers on normative definitions of need, rather than felt need, are clearly illustrated by Rob and Jenny's stories of their experiences of having or not having services.

**Rob's story**

Rob, you will recall, has complete paraplegia, lives on his disability support pension, and has some help from his mother in his everyday life.
Normatively defined, Rob is 'needy'. But Rob neither uses, nor wants community services.

I've never had a skin complaint, pressure, ever, and the only thing I have had is burns. I'm pretty good at that because I'm like welding and that, the last burn I had was one here and one here and another one down here, and the Doc came up to see me and said the district nurse will come in. They came in and dressed it and after a while they said I could do it myself. I could have done it all along but the Area Health Service wouldn't give me the material to do it. You know the plastic, like a skin, it covers what size you want and you tear it off, and you stick it there and leave it, or if it drops off you replace it. She said "Oh no, we can't give you that," and I said "It'd be saving the government a lot of money instead of sending a nurse out to see me they could be seeing someone else. I can do the damn thing." "No, no, we can't give you that." Wankers!

Rob did not express, or even feel the need for a service. Rob was angry that this service was, in his opinion, inappropriately thrust upon him.

Jenny, however, has a clear felt need for services. A need she feels will never be met.

Jenny's story

If Steve wants a night off, he's got a friend who often goes to Sydney and likes someone to drive for company, there's no-one to help me in the mornings. You know. If there was someone you can ring up and say, "Could you please come and put my shoes and stockings on?" I can have a shower. I can get myself dressed, you know. I can even get myself a bit of breakfast, I wouldn't starve. It wouldn't be anything very wonderful, but I wouldn't starve. But if there was just somebody there that you could ring and say, "Look, Steve's going to be away." I can manage for one or two nights, but you know, is there someone that you could ring to sort of say, "Can you come and give us just a half, you know, even ten minutes for me in the mornings?" You know. Just sort of help in this situation.

You know what I mean?

Jenny, who has some movement problems and is employed, would not be classified as 'needy' on the basis of normative definitions. Yet, unlike Rob, Jenny has a felt need for services, a need that she quite correctly predicts is unlikely to be met. The odds of Jenny being able to obtain the professional care service she needs are one in 600. Like Rob, however, Jenny was angry that services were not being appropriately provided.
A different concept of need

When one contrasts Rob and Jenny's stories it would seem that those who provide services are prioritising on the basis of a normative notion of need in preference to recognising an individual's felt need for services. Jenny can not obtain the services for which she has a felt need because she does not fit normative criteria. Rob is forced to have services for which he has no felt need because he fits normative criteria. It would seem nonsensical to provide services to persons who do not want them whilst not providing services to those who clearly feel they need them, particularly when many indicators of the expressed need for services and unmet felt need are similar.

It would thus be difficult to confidently state that those who are getting services are more entitled to them than those who do not. For example, is it equitable for persons with incomplete paraplegia who live in a regional centre or country area to have a higher than average use of professional care services whilst over half of those persons who have everyday help and quadriplegia and who work, are unable to obtain the professional care services they feel they need?

In addition, correcting the deficit in supply may not necessarily be achieved by simply directing more resources into supplying more of the same types of services to the same type of persons with spinal injuries who are already using the service. Consideration of normative, expressed and felt need do not make it apparent whether those who cannot obtain services are similar to or different from those who use services. A more explicit indication of the characteristics of those whose felt needs were able to be expressed through the use of services, and those with unmet felt needs, is required.
Stage Three

Using Prescriptive and Comparative Need to Prioritise the Community Service Needs of Persons with Spinal Injuries

Understanding expressed and felt need has been shown, in Stage Two, to be helpful in identifying the types of persons who use services and their level of service usage. The levels of expressed and felt need highlight the fact that felt needs were not being met by the current level of service provision. Some argument may be mounted that everybody who feels they need a service should not necessarily be entitled to receive it, and services should be targeted to those most needy, normatively defined. Nevertheless, there was evidence that some persons whose felt need was unmet had characteristics which would entitle to them to services according to the normative criteria set by the Home and Community Care Act.

The lack of services for persons with physical disabilities is an undesirable situation, or what Thayer calls 'diagnostic need', which has been well documented by government and other organisations in the community services reviews conducted over the past twenty years. This focus upon issues of supply certainly prompts an exploration of what is needed to fix the 'problem'. Indeed, Anna Yeatman, in her review of the Commonwealth/State Disability Agreement (CSDA), recommended that 'As a matter of urgency, work be undertaken to more accurately identify the costs of meeting the unmet [normative] need for [CSDA] disability services' (Yeatman, 1996 Recommendation 31, p.xx).

Thayer (1973) uses the term 'prescriptive need' to refer to the help which is required to rectify an undesirable situation, in this case, the level of unmet felt need for differing types of community services. The reality, however, is that resources are finite, and prioritising areas with the greatest unmet need means that other areas receive fewer resources (Shepherd, 1992). Rather than prioritising on the basis of unmet expressed or felt need, it may be more useful to base any shift in service or resource priorities on addressing any inequities in the current distribution.
To make an equitable distribution of resources on the basis of normative need without considering the inequalities in the level of expressed and felt need which should be addressed, could lead to the inappropriate distribution of resources and failure to reduce inequalities (Townsend & Davidson, 1982). Even the Home and Community Care (HACC) guidelines recognise that the establishment of appropriate services in an area does not ensure that persons within the target population will have access to those services...Service providers should therefore ensure that services are provided in such a way as to encourage their use by all members of the client group on an equitable basis. (Home and Community Care, 1989 pp.8-9).

The concept of equity has two aspects—horizontal and vertical equity.

Horizontal equity is the equal treatment of equals... individuals who are the same in relevant aspects are treated the same...vertical equity is the unequal treatment of unequals; so that those who differ in the relevant characteristics get different shares (Centre for Health Economics Research and Evaluation (CHERE), 1995 p.2).

The HACC guidelines for the provision of services appear to incorporate elements of both horizontal and vertical equity. Services are to ensure horizontal equity in that persons within the target group, who would have an assumed homogeneity in their level of normative need (the only relevant aspect based on HACC criteria), should not encounter geographic, cultural, physical access, sexual, religious, or financial barriers to service.

Where service demand exceeds supply, however, the target group is no longer considered homogenous, and principles of vertical equity are applied. Service providers are to give priority to those most crucially at risk of institutionalisation, provide the minimal level of support needed to prevent institutionalisation, ensure continuity of services for existing clients, and sustain services by charging users on the basis of their ability to pay (Home and Community Care, 1989 p.9).

In order to determine the equitable distribution of services, it would be necessary to elicit the basis of any discrimination between those whose needs are met and those whose are not (Figure 19). That is, ascertaining whether there are certain types of persons with spinal injury with a higher comparative need for services, where comparative need is that 'deduced by an outside observer in circumstances where individuals not in receipt of a particular [service] have similar characteristics to others who do receive it' (Bradshaw, 1972 p.641).
This study determined the prioritisation of services and clients based upon the prescriptive need for services, and the comparative need of groups of persons with spinal injuries.

Prescriptive need

It was clear from the service use and obtainment problem data presented in the previous stage, that the community care and support needs of many persons with spinal injuries were unable to be sustained by the current level of community service provision, evidenced by the number experiencing problems obtaining services, and despite the apparent large numbers currently receiving services.

Overall, 398 respondents (56.5%) felt they had a need for at least one community service (irrespective of whether that need was met or not), and, of these, 210 respondents (29.4% of all respondents) were experiencing problems obtaining needed services.

Prioritisation may best be facilitated by analysis based on the amount of resources (in this study measured in terms of numbers of persons served, rather than economic resources) required to alleviate the problem of obtaining services. Prescriptive need in this study was measured as the number of those who could not obtain the level of service needed as a percentage of the total number of those who would be currently using the service if there were no problems obtaining it, that is, all persons having a felt need for the service, calculated using the following equation:

\[
\text{prescriptive need} = \frac{\text{number of persons with obtainment problems}}{\text{total number of persons with felt need}} \times 100
\]

\(^1\) Total felt need includes both persons who are currently using the services, together with those who would use the service if they could obtain it.
The resultant figure is the percentage increase in service provision required above and beyond current levels, to meet all felt need.

The overall level of prescriptive need was 52.7 percent. This indicated that services were failing to meet the needs of just over half of the persons with a felt need of the services.

The current level of prescriptive need for services in this population varied considerably (Table 23). Only 27.4 percent of persons needing Home Care personal care services had their felt need for service unmet. This is an indicator that the service was by and large meeting demand. At the other end of the scale, 86.1 percent of persons needing person minding had a prescriptive need for this service. Generally, the level of prescriptive need was high for services which give respite, such as person minding and day care. There was also a high level of prescriptive need for rehabilitative services, physiotherapy and occupational therapy. The level of prescriptive need was higher for private services than government funded services (59.2% and 49.3% respectively).

It would appear that the level of prescriptive need is highest for those services with relatively small numbers of persons with a felt need for the service. Those services with highest felt need, for example Home Care services, are relatively better at fulfilling the demands upon them. Nevertheless, whilst the overall level of prescriptive need for Home Care services is relatively low when compared with other service types, in absolute terms there are a large number of persons with problems obtaining Home Care services (n=108).

It may be useful then to determine a ranking which reflects both the absolute felt need for services, and problems obtaining services, as well as relative prescriptive need. In keeping with the philosophy that needs assessments are best achieved by keeping data manipulation to a minimum (Staden, 1987), each service was ranked according to the three measures of felt need, obtainment problems and prescriptive need, with the rankings on each measure then averaged. Services were then ordered according to the average ranking (Table 24).

---

2 In contrast, the Home Care Service of New South Wales reported that their service capacity would have to more than double if all need in their potential client group (which includes both younger people with a disability and the aged) were to be met (Home Care Service of New South Wales, 1995). Need in the Home Care study was normatively based on data from the 1993 Australian Bureau of Statistics Survey of Disability, Ageing and Carers.
Table 23. Unmet need for community services by persons with spinal injuries

<table>
<thead>
<tr>
<th>Service</th>
<th>obtainment problem*</th>
<th>felt need†</th>
<th>prescriptive need†</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%</td>
<td>n</td>
</tr>
<tr>
<td>Care services</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Home Care (domestic)</td>
<td>71</td>
<td>10.1</td>
<td>176</td>
</tr>
<tr>
<td>Home Care (personal care)</td>
<td>37</td>
<td>5.3</td>
<td>135</td>
</tr>
<tr>
<td>private home nursing</td>
<td>55</td>
<td>7.9</td>
<td>79</td>
</tr>
<tr>
<td>Attendant Care</td>
<td>46</td>
<td>6.5</td>
<td>79</td>
</tr>
<tr>
<td>Paramedical services</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>physiotherapy (private)</td>
<td>112</td>
<td>16.0</td>
<td>176</td>
</tr>
<tr>
<td>physiotherapy (government)</td>
<td>92</td>
<td>13.2</td>
<td>145</td>
</tr>
<tr>
<td>occupational therapy (private)</td>
<td>45</td>
<td>6.4</td>
<td>58</td>
</tr>
<tr>
<td>occupational therapy (government)</td>
<td>38</td>
<td>5.4</td>
<td>75</td>
</tr>
<tr>
<td>counselling (private)</td>
<td>33</td>
<td>4.7</td>
<td>45</td>
</tr>
<tr>
<td>counselling (government)</td>
<td>31</td>
<td>4.4</td>
<td>49</td>
</tr>
<tr>
<td>Transport services</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>transport assistance (private)</td>
<td>59</td>
<td>8.4</td>
<td>109</td>
</tr>
<tr>
<td>transport assistance (government)</td>
<td>58</td>
<td>8.2</td>
<td>129</td>
</tr>
<tr>
<td>Respite services</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>meals on wheels</td>
<td>25</td>
<td>3.6</td>
<td>30</td>
</tr>
<tr>
<td>person minding</td>
<td>31</td>
<td>4.4</td>
<td>36</td>
</tr>
<tr>
<td>day care</td>
<td>24</td>
<td>3.4</td>
<td>32</td>
</tr>
<tr>
<td>respite care</td>
<td>34</td>
<td>4.9</td>
<td>61</td>
</tr>
<tr>
<td>Overall</td>
<td>210</td>
<td>29.4</td>
<td>398</td>
</tr>
</tbody>
</table>

* number and percentage of total sample population who reported having a problem obtaining the desired service
# number and percentage of total sample population who had a felt need for the service, that is, persons currently using the service plus those who reported having a problem obtaining the desired service
† prescriptive need, that is, the percentage increase in service provision required above and beyond current levels, to meet all felt need
Table 24. Rank ordered list of need for prioritising extra resources for community services arranged in order of average ranking (where higher ranking indicates services which should receive priority due to being more poorly resourced relative to felt need)

<table>
<thead>
<tr>
<th>Average rank</th>
<th>Service</th>
<th>Obtainment problem</th>
<th>Felt need</th>
<th>Prescriptive need</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>physiotherapy (private)</td>
<td>1</td>
<td>1</td>
<td>7</td>
</tr>
<tr>
<td>2</td>
<td>physiotherapy (government)</td>
<td>2</td>
<td>3</td>
<td>8</td>
</tr>
<tr>
<td>3</td>
<td>private home nursing</td>
<td>6</td>
<td>7</td>
<td>6</td>
</tr>
<tr>
<td>4</td>
<td>Home Care (domestic)</td>
<td>3</td>
<td>2</td>
<td>15</td>
</tr>
<tr>
<td>5</td>
<td>transport assistance (private)</td>
<td>4</td>
<td>6</td>
<td>12</td>
</tr>
<tr>
<td>5</td>
<td>occupational therapy (private)</td>
<td>8</td>
<td>11</td>
<td>3</td>
</tr>
<tr>
<td>7</td>
<td>Attendant Care</td>
<td>7</td>
<td>7</td>
<td>10</td>
</tr>
<tr>
<td>7</td>
<td>transport assistance (government)</td>
<td>5</td>
<td>5</td>
<td>14</td>
</tr>
<tr>
<td>9</td>
<td>person minding</td>
<td>13</td>
<td>14</td>
<td>1</td>
</tr>
<tr>
<td>10</td>
<td>counselling (private)</td>
<td>12</td>
<td>13</td>
<td>5</td>
</tr>
<tr>
<td>10</td>
<td>Home Care (personal)</td>
<td>10</td>
<td>4</td>
<td>16</td>
</tr>
<tr>
<td>12</td>
<td>occupational therapy (government)</td>
<td>9</td>
<td>9</td>
<td>13</td>
</tr>
<tr>
<td>13</td>
<td>respite care</td>
<td>11</td>
<td>10</td>
<td>11</td>
</tr>
<tr>
<td>14</td>
<td>meals on wheels</td>
<td>15</td>
<td>16</td>
<td>2</td>
</tr>
<tr>
<td>15</td>
<td>counselling (government)</td>
<td>13</td>
<td>12</td>
<td>9</td>
</tr>
<tr>
<td>16</td>
<td>day care</td>
<td>16</td>
<td>15</td>
<td>4</td>
</tr>
</tbody>
</table>

The rankings indicate that addressing the restriction of resources for services with high absolute felt need and obtainment problems, together with a moderate level of prescriptive need would take priority over addressing the resource deficits of services with high prescriptive need, but low absolute felt need. This analysis would suggest that resource priorities should be directed to rectifying the deficits in the provision of physiotherapy services, at the expense of respite and counselling services.

A number of difficulties would, however, preclude making resource allocation decisions completely based on such analyses. Firstly, the spinal injured population of NSW is not at all homogenous. Such heterogeneity should prompt decision makers to question whether resources should be increased to address the prescriptive needs of all types of persons for all types of services, or should some services for some groups be prioritised due to their being comparatively disadvantaged. In other words, did obtainment problems arise through the inadequate supply of services generally, or
through judicial targeting of services to those most in need (normatively defined)?

To identify the bases of individuals' obtainment problems, felt need and prescriptive need, respondents to the survey were classified into one of four categories according to their use of and desire to obtain services, in the following manner (Table 25).

<table>
<thead>
<tr>
<th></th>
<th>Problem obtaining service</th>
</tr>
</thead>
<tbody>
<tr>
<td>Uses</td>
<td>yes</td>
</tr>
<tr>
<td>service</td>
<td>need partly met</td>
</tr>
<tr>
<td></td>
<td>need fully met</td>
</tr>
<tr>
<td>no</td>
<td>need not met</td>
</tr>
<tr>
<td></td>
<td>no felt need</td>
</tr>
</tbody>
</table>

Four categories into which a person's need for services could be placed were derived:

- There were persons whose need for services was fully met. These persons were satisfied with both the level of service and the type of service they received, that is, they had an expressed need for the service and no problems obtaining the service, and hence no prescriptive need.
- There were persons whose needs were partly met, in that they received some services but they were insufficient to fully meet their needs, or the services were inappropriate or of poor quality, that is, they had an expressed need for the service and problems obtaining the service, and hence some prescriptive need.
- There were persons whose need for services was not met in any way, that is, they had felt need and problems obtaining the service, and hence the level of their prescriptive need was equivalent to their felt need.
- There were persons who had no need for services, that is, they had no felt need, and therefore no problems obtaining the service or a prescriptive need.

Prescriptive need thus consisted of two types of problems—the need for an increase in allocation or improvement in the quality of resources available to persons already receiving some services, and the need for the allocation of resources to persons currently not receiving any services.

Overall, 398 respondents (56.5%) had a felt need for one or more community services, including 188 respondents (26.6%) who had their felt needs fully met for all services. Persons with prescriptive need consisted of 176 respondents (24.6%) who had their felt needs partly met, and 34 respondents (4.8%) who had all their felt service needs completely unmet. Three hundred and eight (308) respondents (43.6%) had no felt need, and hence no prescriptive need, for any community services of any kind.
Care services

Nearly two thirds of survey respondents with a felt need specifically for Home Care services (either personal care or domestic) had that need fully met. Persons with problems obtaining Home Care services (either personal care or domestic) were likely to be both users and non users of the service, that is, the prescriptive need for Home Care services was due to both partly met and completely unmet felt need (Table 26).

Felt need for other care services was relatively low, but the level of prescriptive need was comparatively high. Persons with a prescriptive need for private home nursing and Attendant Care services were most likely to not be current users of those services, that is, their felt need for these services was not met at all (Table 26).

Table 26. Felt and prescriptive need for care services

<table>
<thead>
<tr>
<th>Felt need for care services</th>
<th>Home Care</th>
<th>Private home nursing</th>
<th>Attendant Care</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%</td>
<td>n</td>
</tr>
<tr>
<td>Current user</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Need fully met</td>
<td>157</td>
<td>22.2</td>
<td>24</td>
</tr>
<tr>
<td>Need partly met*</td>
<td>41</td>
<td>5.8</td>
<td>9</td>
</tr>
<tr>
<td>Not current user</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Need not met*</td>
<td>46</td>
<td>6.6</td>
<td>46</td>
</tr>
<tr>
<td>No felt need for services</td>
<td>462</td>
<td>65.4</td>
<td>620</td>
</tr>
</tbody>
</table>

* Indicates prescriptive need

Paramedical services

Persons with a prescriptive need for physiotherapy and counselling services were both users and non users of these services, therefore their prescriptive need arose due to both problems obtaining services and the level of services provided. In contrast, persons with a prescriptive need for occupational therapy (OT) were mostly persons with a felt need who could not obtain any service at all (Table 27).

Respondents who reported having problems obtaining one type of paramedical service often also had problems obtaining another type of paramedical service. This is particularly true for persons trying to obtain OT and counselling. Seventy percent of those with problems obtaining counselling also have problems obtaining OT, and ninety-two percent of those with problems obtaining counselling have problems obtaining

---

3 157 of the 244 persons with felt need.
physiotherapy. Similarly, those with problems obtaining OT also had problems obtaining physiotherapy and counselling (84.6% and 50.0% respectively). Conversely, those who were experiencing problems obtaining physiotherapy did not experience problems obtaining counselling and OT (33.8% and 26.2% respectively). Thus, persons with a prescriptive need for physiotherapy, experienced that need alone, whereas those with a prescriptive need for OT and counselling had a prescriptive need for all three types of paramedical services.

Table 27. Felt and prescriptive need for paramedical services

<table>
<thead>
<tr>
<th>Felt need for paramedical services</th>
<th>Physiotherapy</th>
<th>Occupational therapy</th>
<th>Counselling</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%</td>
<td>n</td>
</tr>
<tr>
<td>Current user</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Need fully met</td>
<td>95</td>
<td>13.5</td>
<td>44</td>
</tr>
<tr>
<td>Need partly met*</td>
<td>61</td>
<td>8.6</td>
<td>11</td>
</tr>
<tr>
<td>Not current user</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Need not met*</td>
<td>69</td>
<td>9.8</td>
<td>41</td>
</tr>
<tr>
<td>No felt need for services</td>
<td>481</td>
<td>68.1</td>
<td>603</td>
</tr>
</tbody>
</table>

* Indicates prescriptive need

Transport and respite services

Persons with a prescriptive need for transport services were primarily current users of the service, thus prescriptive need arose out of problems with the level of service, rather than the absence of services. In contrast, persons with a prescriptive need for respite services were non users of respite services who were unable to obtain any services at all (Table 28).

Table 28. Felt and prescriptive need for transport and respite services

<table>
<thead>
<tr>
<th>Felt need for transport and respite services</th>
<th>Transport</th>
<th>Respite</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%</td>
</tr>
<tr>
<td>Current user</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Need fully met</td>
<td>95</td>
<td>13.5</td>
</tr>
<tr>
<td>Need partly met*</td>
<td>48</td>
<td>6.8</td>
</tr>
<tr>
<td>Not current user</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Need not met*</td>
<td>30</td>
<td>4.2</td>
</tr>
<tr>
<td>No felt need for services</td>
<td>533</td>
<td>75.5</td>
</tr>
</tbody>
</table>

* Indicates prescriptive need
Overview

Prescriptive need for Home Care, physiotherapy and transport services was due to the dual problems of the need for an increase in allocation or improvement in the quality of resources available to persons already receiving some services, and the need for the allocation of resources to persons currently not receiving any services. Interestingly, services with the dual problem were services ranked highly in terms of the overall priority for the allocation of extra resources (see Table 24, previously). For other service types, prescriptive need mainly consisted of failure to allocate any resources for this population at all.

For those services ranked somewhat further down in priority, such as counselling and respite services, the problem was the failure to allocate any resources at all to those with prescriptive need. It could be possible to surmise that in a climate of limited resources, those services in greatest demand are endeavouring to spread their resources, albeit somewhat thinly, across a large population, whilst those in lesser demand are targeting their resources to fully meeting the demands of a smaller group (that is, an individual got all or nothing). Is this evidence that services and resources are in fact being allocated to those most needy? To answer this question it was necessary to determine the comparative need of different groups of persons with spinal injuries.

Comparative need of differing persons with spinal injuries

Comparative need is defined as need deduced by an outside observer in circumstances where individuals not in receipt of a particular service have similar characteristics to others who do receive it (Bradshaw, 1972). In order determine the comparative need of different persons with spinal injuries it was necessary to compare the various characteristics of the spinal injured population, and their felt and prescriptive need for services, to determine more precisely, the characteristics of those who get services and those who want services they cannot obtain.

The characteristics which were considered as being possibly related to the comparative need for services were those which had been significantly related to the use of services and/or problems obtaining services highlighted in Stage Two. Thus the characteristics considered were demographic characteristics—gender, age, education, income, employment and area of residence; injury characteristics—level of function, age at the time of injury and year of injury; and whether the persons with spinal injuries received everyday assistance.
Demographic indicators of comparative need

Gender

Men and women were similar in their felt need for services (55.2% and 60.1% respectively) and in the likelihood that their needs were fully met (26.7% and 27.0% respectively). The prescriptive need for specific types of service was not significantly different for men or women. Gender, therefore, did not predict either met or unmet need.

Age

The felt need for services generally was relatively constant across all age groups. Those respondents who were younger (currently aged less than 20 years old) were, however, slightly more likely to have their needs unmet (5.6%, compared with 4.8% overall), whilst older respondents (age 70 or older) were slightly more likely to have their needs fully met (34.9% compared with 26.8% overall). Neither of these groups were, however, significantly different from other respondents in their levels of felt or prescriptive need for services generally, nor for specific types of services.

Education

Level of education was not significantly related to the felt need for services, nor the likelihood that service needs would be met.

Employment

Labour force status was significantly related to the felt need for services generally ($\chi^2=15.01$ df=2 p=.001; Table 29), however, labour force status was not related to the likelihood that that need would be met.

<table>
<thead>
<tr>
<th>Labour force status</th>
<th>Felt need in the population group</th>
<th>Need fully met</th>
<th>Need partly met</th>
<th>Need not met</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n*</td>
<td>%#</td>
<td>%†</td>
<td>%†</td>
</tr>
<tr>
<td>Employed</td>
<td>144</td>
<td>48.0</td>
<td>45.1</td>
<td>43.8</td>
</tr>
<tr>
<td>Not in labour force</td>
<td>103</td>
<td>60.2</td>
<td>47.6</td>
<td>45.6</td>
</tr>
<tr>
<td>Not working</td>
<td>149</td>
<td>63.9</td>
<td>49.7</td>
<td>43.0</td>
</tr>
</tbody>
</table>

* Number of people with felt need
# Number of people with felt need as a percentage of total population in that subgroup
† Percentage of those with felt need whose need was fully, partly or not met (row percent)
In contrast, labour force status was significantly related to the prescriptive need, rather than felt need, for physiotherapy services (regardless of whether government or private). Although the felt need for physiotherapy was reasonably constant across the three labour force status groups, persons who were employed or not in the labour force (retired or home duties) were significantly more likely to have their need for physiotherapy fully met, when compared with those who were not working ($\chi^2=9.57$, df=4 p=.048; Table 30).

Labour force status was not significantly related to the level of felt or prescriptive need for any other services.

Table 30. Need for physiotherapy by labour force status

<table>
<thead>
<tr>
<th>Labour force status</th>
<th>Felt need in the population group</th>
<th>Need fully met</th>
<th>Need partly met</th>
<th>Need not met</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n*</td>
<td>%#</td>
<td>%†</td>
<td>%†</td>
</tr>
<tr>
<td>employed</td>
<td>101</td>
<td>33.7</td>
<td>47.5</td>
<td>24.8</td>
</tr>
<tr>
<td>not in labour force</td>
<td>57</td>
<td>33.3</td>
<td>47.4</td>
<td>31.6</td>
</tr>
<tr>
<td>not working</td>
<td>67</td>
<td>28.8</td>
<td>29.9</td>
<td>26.9</td>
</tr>
</tbody>
</table>

* Number of people with felt need
# Number of people with felt need as a percentage of total population in that subgroup
† Percentage of those with felt need whose need was fully, partly or not met (row percent)

Income

Felt need for services generally was related to the source of income of the respondents, with wage or salary earners significantly less likely to have a felt need for services ($\chi^2=19.75$ df=2 p<.001; Table 31), as would be expected based on employment status. This relationship could not be attributed to any specific type of service. No group, however, were more or less likely to have their service need met or unmet. In addition, the prescriptive need for individual services was not significantly related to the person with spinal injury’s primary source of income.

Table 31. Need for community services by source of income

<table>
<thead>
<tr>
<th>Source of income</th>
<th>Felt need in the population group</th>
<th>Need fully met</th>
<th>Need partly met</th>
<th>Need not met</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n*</td>
<td>%#</td>
<td>%†</td>
<td>%†</td>
</tr>
<tr>
<td>Wages/salary</td>
<td>136</td>
<td>47.4</td>
<td>44.1</td>
<td>44.9</td>
</tr>
<tr>
<td>Pension</td>
<td>166</td>
<td>65.4</td>
<td>48.8</td>
<td>42.8</td>
</tr>
<tr>
<td>Other income</td>
<td>88</td>
<td>62.4</td>
<td>51.1</td>
<td>45.5</td>
</tr>
</tbody>
</table>

* Number of people with felt need
# Number of people with felt need as a percentage of total population in that subgroup
† Percentage of those with felt need whose need was fully, partly or not met (row percent)
Area of residence

Overall, the felt need for services overall was similar in all areas of New South Wales, however, persons living in major regional centres and country areas were more likely to have their need for government funded paramedical services met, either fully or partly, than those living in the Greater Sydney region, and outer Sydney in particular ($\chi^2=18.57$ df=6 p=.005; Table 32).

<table>
<thead>
<tr>
<th>Area of residence</th>
<th>Felt need in the population group</th>
<th>Need fully met</th>
<th>Need partly met</th>
<th>Need not met</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n*</td>
<td>%#</td>
<td>%†</td>
<td>%†</td>
</tr>
<tr>
<td>inner Sydney</td>
<td>73</td>
<td>23.1</td>
<td>43.8</td>
<td>11.0</td>
</tr>
<tr>
<td>outer Sydney</td>
<td>25</td>
<td>22.5</td>
<td>28.0</td>
<td>20.0</td>
</tr>
<tr>
<td>major regional centres</td>
<td>28</td>
<td>24.4</td>
<td>34.3</td>
<td>42.9</td>
</tr>
<tr>
<td>country areas</td>
<td>44</td>
<td>27.2</td>
<td>43.2</td>
<td>29.5</td>
</tr>
</tbody>
</table>

* Number of people with felt need
# Number of people with felt need as a percentage of total population in that subgroup
† Percentage of those with felt need whose need was fully, partly or not met (row percent)

Persons living in major regional centres were also significantly more likely to have their need for occupational therapy (either government or private) fully or partly met than those living in the Greater Sydney region, and particularly those living in country areas ($\chi^2=13.47$ df=6 p=.036; Table 33).

<table>
<thead>
<tr>
<th>Area of residence</th>
<th>Felt need in the population group</th>
<th>Need fully met</th>
<th>Need partly met</th>
<th>Need not met</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n*</td>
<td>%#</td>
<td>%†</td>
<td>%†</td>
</tr>
<tr>
<td>inner Sydney</td>
<td>44</td>
<td>13.9</td>
<td>47.7</td>
<td>4.5</td>
</tr>
<tr>
<td>outer Sydney</td>
<td>12</td>
<td>10.8</td>
<td>50.0</td>
<td>8.3</td>
</tr>
<tr>
<td>major regional centres</td>
<td>20</td>
<td>17.4</td>
<td>60.0</td>
<td>25.0</td>
</tr>
<tr>
<td>country areas</td>
<td>20</td>
<td>12.3</td>
<td>25.0</td>
<td>15.0</td>
</tr>
</tbody>
</table>

* Number of people with felt need
# Number of people with felt need as a percentage of total population in that group
† Percentage of those with felt need whose need was fully, partly or not met (row percent)
Overview

In summary, level of felt need was reasonably constant for all demographic groups, with the exception that persons working, and who thus had an income from wages or a salary, were less likely to have a felt need for services generally.

The percentage of persons with a prescriptive need varied for just three particular groups in need of particular services. Those with a higher comparative need, that is, those less likely to have their community services needs met were:

- unemployed persons (potentially in the labour force) in need of physiotherapy services;
- persons living in outer Sydney in need of government paramedical services; and
- persons living in country areas in need of occupational therapy.

Injury related indicators of comparative need

Functional ability

The need for community services was significantly related to the functional abilities of the person with spinal injuries. Those with quadriplegia were much more likely to have a felt need for community services than those with some or no movement or sensory problems ($\chi^2=155.25$ df=5 p<.001; Table 34). Level of function did not, however, greatly distinguish those whose needs were fully met, from those with partly met need, and those with unmet needs, with the exception of those persons with no sensory or movement problems ($\chi^2=23.58$ df=10 p=.009; Table 34). Differences in the latter were primarily attributable to those with no problems having their needs either fully met, or not met at all. When persons with no movement or sensory problems were excluded from the analysis, it was clear that persons with some movement or sensory problems were just as likely to have their service needs met as those with quadriplegia or paraplegia ($\chi^2=8.99$ df=8 p=.343).

In the case of Home Care personal care services, no persons with quadriplegia or paraplegia were more likely than others to have their need for services met, either fully or partly, or not met at all, despite persons with complete quadriplegia having a clearly higher level of felt need. Not surprisingly, persons with less significant functional impairments were both less likely to need services, and less likely to receive them (Table 35).
Table 34. Need for community services by level of function

<table>
<thead>
<tr>
<th>Level of function</th>
<th>Felt need in the population group</th>
<th>Need fully met</th>
<th>Need partly met</th>
<th>Need not met</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n* % #</td>
<td>% †</td>
<td>% †</td>
<td>% †</td>
</tr>
<tr>
<td>complete quadriplegia</td>
<td>72 97.3</td>
<td>45.8</td>
<td>51.4</td>
<td>2.8</td>
</tr>
<tr>
<td>incomplete quadriplegia</td>
<td>99 78.6</td>
<td>50.5</td>
<td>44.4</td>
<td>5.1</td>
</tr>
<tr>
<td>complete paraplegia</td>
<td>78 61.4</td>
<td>47.4</td>
<td>39.7</td>
<td>12.8</td>
</tr>
<tr>
<td>incomplete paraplegia</td>
<td>61 56.5</td>
<td>49.2</td>
<td>41.0</td>
<td>9.8</td>
</tr>
<tr>
<td>some problems</td>
<td>63 40.1</td>
<td>42.9</td>
<td>50.8</td>
<td>6.3</td>
</tr>
<tr>
<td>no problems</td>
<td>15 16.1</td>
<td>53.3</td>
<td>13.3</td>
<td>33.3</td>
</tr>
</tbody>
</table>

* Number of people with felt need
# Number of people with felt need as a percentage of total population in that subgroup
† Percentage of those with felt need whose need was fully, partly or not met (row percent)

Table 35. Need for Home Care personal care services by level of function

<table>
<thead>
<tr>
<th>Level of function</th>
<th>Felt need in the population group</th>
<th>Need fully met</th>
<th>Need partly met</th>
<th>Need not met</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n* % #</td>
<td>% †</td>
<td>% †</td>
<td>% †</td>
</tr>
<tr>
<td>complete quadriplegia</td>
<td>40 63.5</td>
<td>75.0</td>
<td>7.5</td>
<td>17.5</td>
</tr>
<tr>
<td>incomplete quadriplegia</td>
<td>48 41.4</td>
<td>79.2</td>
<td>12.5</td>
<td>8.3</td>
</tr>
<tr>
<td>complete paraplegia</td>
<td>23 20.7</td>
<td>82.6</td>
<td>13.0</td>
<td>4.3</td>
</tr>
<tr>
<td>incomplete paraplegia</td>
<td>13 13.0</td>
<td>53.8</td>
<td>23.1</td>
<td>23.1</td>
</tr>
<tr>
<td>some problems</td>
<td>8 5.6</td>
<td>37.5</td>
<td>0.0</td>
<td>62.5</td>
</tr>
</tbody>
</table>

* Number of people with felt need
# Number of people with felt need as a percentage of total population in that subgroup
† Percentage of those with felt need whose need was fully, partly or not met (row percent)

Similarly, persons of differing functional abilities needing for physiotherapy (either government or private) were no more, nor less, likely to have their needs met or unmet. Persons with complete quadriplegia had the highest level of felt need but were no more likely to have their needs met. Indeed, persons with incomplete lesions were more likely to have their needs met than persons with the equivalent complete lesion (either quadriplegia or paraplegia: $\chi^2=4.48 \ df=1 \ p=.034$; Table 36). Further, persons with some movement or sensory problems had a level of felt need which was similar to persons with quadriplegia or paraplegia, but were rather more likely to have that need either fully or at least partly met.
Table 36. Need for physiotherapy by level of function

<table>
<thead>
<tr>
<th>Level of function</th>
<th>Felt need in the population group</th>
<th>Need fully met</th>
<th>Need partly met</th>
<th>Need not met</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n*</td>
<td>%#</td>
<td>%‡</td>
<td>%‡</td>
</tr>
<tr>
<td>complete quadriplegia</td>
<td>36</td>
<td>57.1</td>
<td>27.8</td>
<td>33.3</td>
</tr>
<tr>
<td>incomplete quadriplegia</td>
<td>51</td>
<td>44.0</td>
<td>41.2</td>
<td>33.3</td>
</tr>
<tr>
<td>complete paraplegia</td>
<td>34</td>
<td>30.6</td>
<td>29.4</td>
<td>20.6</td>
</tr>
<tr>
<td>incomplete paraplegia</td>
<td>41</td>
<td>41.0</td>
<td>48.8</td>
<td>19.5</td>
</tr>
<tr>
<td>some problems</td>
<td>48</td>
<td>33.6</td>
<td>54.2</td>
<td>33.3</td>
</tr>
<tr>
<td>no problems</td>
<td>12</td>
<td>13.2</td>
<td>58.3</td>
<td>8.4</td>
</tr>
</tbody>
</table>

* Number of people with felt need
# Number of people with felt need as a percentage of total population in that subgroup
‡ Percentage of those with felt need whose need was fully, partly or not met (row percent)

Age at time of injury

The person with spinal injuries age at the time of injury and the cause of their injury were not significantly related to the need for community services, or the likelihood that needs were met.

Year of injury

The need for services was quite constant regardless of year of injury ($\chi^2=4.81$ df=4 p=.307), however, respondents were significantly more likely to have their needs only partly met if they were injured after 1989 ($\chi^2=19.96$ df=8 p=.010; Table 37).

This was particularly the case for persons with quadriplegia or paraplegia who were in need of private paramedical services, who had a high level of felt need which was very unlikely to be met (Table 38).

Overview

In summary, levels of felt and prescriptive need differed according to the person with spinal injuries' level of functional impairment and year of injury, but not in relation to age at the time of injury. Thus, persons who have been demonstrated to have a higher comparative need for community services were:

- those with significant, or conversely minimal levels of functional impairment who had a felt need for Home Care personal care services;
- those with significant and complete-for-level functional impairment in need of physiotherapy services;
• those with significant functional impairment in need of private paramedical services, particularly if they had incurred their spinal injury after 1989; and
• those who were injured after 1989 who had a felt need for services of any type.

Table 37. Need for community services by year of injury

<table>
<thead>
<tr>
<th>Year of injury</th>
<th>Felt need in the population group</th>
<th>Need fully met</th>
<th>Need partly met</th>
<th>Need not met</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n* %#</td>
<td>%†</td>
<td>%†</td>
<td>%†</td>
</tr>
<tr>
<td>1977-1980</td>
<td>73 48.7</td>
<td>46.6</td>
<td>46.6</td>
<td>6.8</td>
</tr>
<tr>
<td>1981-1983</td>
<td>70 61.9</td>
<td>48.6</td>
<td>42.9</td>
<td>8.6</td>
</tr>
<tr>
<td>1984-1986</td>
<td>71 54.6</td>
<td>54.9</td>
<td>38.0</td>
<td>7.0</td>
</tr>
<tr>
<td>1987-1989</td>
<td>83 56.1</td>
<td>59.0</td>
<td>31.3</td>
<td>9.6</td>
</tr>
<tr>
<td>1990-1992</td>
<td>65 56.5</td>
<td>26.2</td>
<td>64.6</td>
<td>9.2</td>
</tr>
</tbody>
</table>

* Number of people with felt need
# Number of people with felt need as a percentage of total population in that subgroup
† Percentage of those with felt need whose need was fully, partly or not met (row percent)

Table 38. Need for private paramedical services by level of function and year of injury

<table>
<thead>
<tr>
<th>Level of function and year of injury*</th>
<th>Felt need in the population group</th>
<th>Need fully met</th>
<th>Need partly met</th>
<th>Need not met</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n* %†</td>
<td>%‡</td>
<td>%‡</td>
<td>%‡</td>
</tr>
<tr>
<td>Quadriplegia/paraplegia:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>injured before 1984</td>
<td>57 30.8</td>
<td>26.3</td>
<td>17.5</td>
<td>56.1</td>
</tr>
<tr>
<td>injured 1984-1986</td>
<td>30 36.6</td>
<td>33.3</td>
<td>36.7</td>
<td>30.0</td>
</tr>
<tr>
<td>injured 1987-1989</td>
<td>23 29.1</td>
<td>52.2</td>
<td>8.7</td>
<td>39.1</td>
</tr>
<tr>
<td>injured 1990-1992</td>
<td>28 52.8</td>
<td>17.9</td>
<td>14.3</td>
<td>67.9</td>
</tr>
<tr>
<td>Some or no functional problems</td>
<td>48 20.5</td>
<td>52.1</td>
<td>25.0</td>
<td>22.9</td>
</tr>
</tbody>
</table>

* fully, partly or unmet felt need by level of function, for the total population, χ²=11.69 df=2 p=.014
fully, partly or unmet felt need by year of injury, for persons with quadriplegia or paraplegia only, χ²=16.67 df=6 p=.011
# Number of people with felt need
† Number of people with felt need as a percentage of total population in that subgroup
‡ Percentage of those with felt need whose need was fully, partly or not met (row percent)
Care related indicators of comparative need

Persons who needed assistance with their everyday living were more than twice as likely to need community services as those with no everyday assistance ($\chi^2=143.19$ df=1 $p<.001$; Table 39). Despite having a lower level of felt need, those with no everyday assistance were more likely to have their needs fully met, whilst those who received everyday help (primarily informal assistance from family or friends) were significantly more likely to have their needs partly, rather than fully met ($\chi^2=10.18$ df=2 $p=.006$; Table 39).

Table 39. Need for community services by receipt of everyday assistance

<table>
<thead>
<tr>
<th>Everyday assistance</th>
<th>Felt need in the population group</th>
<th>Need fully met</th>
<th>Need partly met</th>
<th>Need not met</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n*</td>
<td>%#</td>
<td>%†</td>
<td>%†</td>
</tr>
<tr>
<td>has everyday assistance</td>
<td>313</td>
<td>74.7</td>
<td>45.4</td>
<td>47.6</td>
</tr>
<tr>
<td>no everyday assistance</td>
<td>83</td>
<td>29.1</td>
<td>55.4</td>
<td>30.1</td>
</tr>
</tbody>
</table>

* Number of people with felt need  
# Number of people with felt need as a percentage of total population in that subgroup  
† Percentage of those with felt need whose need was fully, partly or not met (row percent)

Thus, persons who were in receipt of everyday assistance had a higher comparative need for community services, in that their needs were partly, rather than fully met, as well as a higher felt need.

Multiple indicators of comparative need

Segmentation analysis (SPSS CHAID) was used to consider the possibility that characteristics of persons with spinal injuries, whilst not useful in isolation, may in combination identify those groups of individuals more likely to have met or unmet needs. The only characteristic which contributed to predicting fully met, partly met and unmet need was the year the person with spinal injuries incurred their injury (see Tables 37. and 38. previously). No other demographic, injury or care related characteristic contributed to understanding met or unmet need.

Those injured in the period 1990 to 1992 were significantly more likely to have their needs partly, rather than fully met, regardless of the specific type of service, or the persons with spinal injuries’ demographic characteristics, functional ability, or need for everyday assistance, and despite the reasonably constant level of felt need overall. Hence, there is some real
evidence that despite increases in service provision,\(^4\) services are not keeping pace with increased demand.\(^5\)

**Understanding prescriptive and comparative need**

Based on a ranking system that 'averages' problems obtaining services, and felt and prescriptive need, the services which should receive greater priority in order to meet the needs of persons with spinal injuries were physiotherapy, private home nursing and domestic Home Care services (see Table 24 previously). The rankings certainly suggest that paramedical, care and transport services (Table 40) are the service priorities for persons with spinal injuries that should be addressed at the expense of respite type services.

If, however, priorities were determined based on the ability of the service to demonstrate a significant percentage change in the level of unmet need (that is, reduced prescriptive need, based on the definition of outcome-based funding used by Baume & Kay, 1994), then it could be argued that resources should go to those services where a small amount of increased funding would have a dramatic effect on the level of unmet need, that is, those services with high prescriptive need, but small absolute felt need—respite type services.

The Australian Government's current philosophy for determining community service resource allocation priorities is based upon needs-based planning which is outcome-based. Services should be allocated to meet need, and funding is based upon the ability of the service to meet the needs of its target group. Clearly, however, services for persons with spinal injuries fall well short of meeting the needs of the population, even if the spinal injured population is restricted to those normatively defined as 'needy'.

How, then, can needs-based planning and outcome-based funding be interpreted for persons with spinal injuries, in order to determine service priorities and improve levels of met need? Certainly, the large gap between supply and demand for most services for persons with spinal injuries would make decisions about service priorities difficult when faced with the enormous increase in resources which would be necessary to eliminate unmet need. Further, the allocation of resources on the basis of normative

---

\(^4\) Notice in particular the halcyon days following the introduction of the Home and Community Care Act in 1985 (see Table 37). The Australian Institute of Health and Welfare (1995) reported that government expenditure on welfare services grew 7.1% (adjusted for inflation) over the five years to 1992-93.

\(^5\) Yeatman's review of the Commonwealth/State Disability Agreement (1996) reported that the expenditure growth of 20.5%, or $201 million, over the term of the Agreement (1991-1997), has not been adequate to meet demand.
need, which has been shown in this study to be an inadequate indicator, exacerbates these difficulties, particularly in the absence of any previous research identifying the service needs of the spinal injured population.

The process of needs-based planning is premised on the ability to make rational priority decisions based upon clear, objective indicators of need for services (Bolton et al., 1988), and requires that the needs of the population be known. Prioritising on the basis of prescriptive need is premised upon all felt need being equivalent for each services, and for each individual. Indeed, in Australia, 'resource-allocation formulae have been concerned with equal access for equal need [and] gains are weighted equally no matter the level of need of the recipient' (Mooney, 1995 p.334).

This study has identified the felt needs of persons with spinal injuries and, by calculating prescriptive need, developed a clear and objective indicator of the need for services with which to compare the need for different types of services. The stark differences between the ranking of felt and prescriptive need (Table 24 previously) of many services suggests that, for persons with spinal injuries, 'equal access for equal need' is not being achieved by thinly spreading the limited resources across the large number of people with felt need. Such spreading would result in all services being equally inadequate in their ability to meet need, in which case, felt need and prescriptive need would be more similar in their rankings, or, ideally, the level of prescriptive need would be constant for all services.

In times of limited resources, however, the Home and Community Care guidelines (1989 p.9) state that rather than providing a level of service to all within the target group, services should be targeted to persons with the most crucial need. Considerations of vertical equity, particularly as expressed in the priorities of HACC, would suggest that when resources are restricted, they should be concentrated in meeting the needs of those with higher levels of normatively defined need, that is, those with more severe disabilities, those who do not work, or perhaps even those with a higher level of felt need. There was, however, little evidence in this study of any such targeting of services.

Overall, only employment status, and thus source of income, were useful in identifying persons with a higher felt need for community services generally. No demographic characteristics were useful in identifying persons with a higher comparative need. The level of function of the person with spinal injuries was useful in distinguishing those who needed services, as opposed to those who did not, but did not clearly distinguish those who met and unmet need generally. The only exception was the somewhat limited capacity of level of function to determine comparative need for

---

4 Resources would need to be spread thinly since it is unlikely that funding for services would be able to be supplied at a level where all persons felt need for services is fully met.

5 Vertical equity is applied at times of limited resources so that those who differ in the relevant characteristics get different shares.
physiotherapy and private paramedical services. Conversely, whilst the need for services was constant regardless of the year of injury (and therefore the number of years post injury), those injured more recently were less likely to have their needs fully met.

Only the receipt of everyday assistance was useful in distinguishing both those who needed services, and those whose needs were likely to be met. This characteristic produced the somewhat anomalous result where those without everyday assistance were less likely to need community services, but also more likely to have any felt need fully met. This may be evidence, however, of a lower level of service provision to persons who were also receiving care from family or friends, and a concentration of services in those few persons with a felt need for community services who had no other means of assistance.  

Thus, with only a few exceptions, the ability of community service provision to meet the felt needs of the spinal injured population of NSW was not targeted on the basis of any normatively defined indicator of being 'needy', such as the demographic characteristics or functional abilities of the person with spinal injuries. Indeed, based on such characteristics it is impossible to distinguish those whose needs were fully met from those with partly met needs and needs which were completely unmet, or even from those who had no felt need for services at all.  

The only discriminating basis for the provision of services to meet the felt needs of the spinal injured population are characteristics which could be considered 'external' to the person with spinal injuries—the presence of a carer (everyday assistance) and the year in which they were injured.

Having everyday assistance determined both the need for community service and the likelihood that the need would be met. The year of injury determined the likelihood that an individual's service need would be fully met, rather than whether the individual needed services or not. Thus, there was little evidence of services being targeted to particular 'needy' groups, except perhaps for those without an informal carer. There was evidence, however, that those injured more recently are comparatively disadvantaged. It was the inability of services to meet new needs, not the level of need of the person with spinal injuries, and the presence or absence of carers, which were implicated as the only basis for determining comparative need in the spinal injured population.

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* A similar finding was reported by Mawby, Clark, Kalucy, Hobbin, and Andrews' (1996) study of the elderly. Formal service usage was associated with the absence of informal carers and living alone.

* The only exception were the higher level of felt need of persons with more limited functional ability, and persons who were not employed.
<table>
<thead>
<tr>
<th>Service type</th>
<th>Priority ranking</th>
<th>Higher comparative need</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall</td>
<td></td>
<td>All who were injured after 1989, all who have everyday help</td>
</tr>
<tr>
<td><strong>Professional care</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Home Care (domestic)</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>Home Care (personal care)</td>
<td>10</td>
<td>Significant or minimal functional impairment</td>
</tr>
<tr>
<td>home nursing (private)</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Attendant Care</td>
<td>7</td>
<td></td>
</tr>
<tr>
<td><strong>Paramedical</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>physiotherapy (private)</td>
<td>1</td>
<td>Unemployed, significant or complete-for-level functional impairment, significant functional impairment incurred after 1989</td>
</tr>
<tr>
<td>physiotherapy (government)</td>
<td>2</td>
<td>Unemployed, living in outer Sydney, significant or complete-for-level functional impairment</td>
</tr>
<tr>
<td>occupational therapy (private)</td>
<td>5</td>
<td>Living in country areas, significant functional impairment incurred after 1989</td>
</tr>
<tr>
<td>occupational therapy (government)</td>
<td>12</td>
<td>Living in outer Sydney, living in country areas</td>
</tr>
<tr>
<td>counselling (private)</td>
<td>10</td>
<td>Significant functional impairment incurred after 1989</td>
</tr>
<tr>
<td>counselling (government)</td>
<td>15</td>
<td>Living in outer Sydney</td>
</tr>
<tr>
<td><strong>Transport</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>transport assistance (private)</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>transport assistance (government)</td>
<td>7</td>
<td></td>
</tr>
<tr>
<td><strong>Respite and other</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>meals on wheels</td>
<td>14</td>
<td></td>
</tr>
<tr>
<td>person minding</td>
<td>9</td>
<td></td>
</tr>
<tr>
<td>day care</td>
<td>16</td>
<td></td>
</tr>
<tr>
<td>respite care</td>
<td>13</td>
<td></td>
</tr>
</tbody>
</table>

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Comparative need is only indicated where it was possible to identify a population group with higher comparative need for the service. Where no group is indicated, there is no characteristic by which any group of persons with spinal injuries could be identified as significantly disadvantaged compared with the overall spinal injured population.
This lack of determinants of comparative need may be evidence of a horizontally equitable distribution of services to all persons with spinal injuries on the basis of felt need—except where such distribution was geographically restricted such as the lack of government paramedical services in outer Sydney, and the lack of occupational therapy in country areas. There is little evidence, however, of the application of the principles of vertical equity. The reduction in the percentage of those with fully or partly met need in the period 1990 to 1992, however, did not result from the concentration of services for any particular group, but rather, from an across the board decrease in the level of met need.

In the case of physiotherapy, which was the service most difficult to obtain and most restricted in resources relative to the felt need of the population, services were more likely to be offered to groups of persons with spinal injuries who had a lower level of felt need and greater functional ability. Physiotherapy services were restricted for those persons with greater normative need, that is, those who were not working, and those with more severe disabilities. Thus, there was evidence of the concentration of services in a defined population group based on level of impairment—the targeting of physiotherapy services, albeit contrary to HACC priorities.

The analysis of prescriptive and comparative need has shown that there is little of evidence of the application of the principles of horizontal or vertical equity in the current provision of services for persons with spinal injuries. There are services which are markedly more, and conversely, less able to meet the felt need for their services. There is thus little evidence of any spread of resources to ensure that the broad range of services which may be required by persons with spinal injuries are equitably resourced relative to felt need. There is also little evidence, from the analysis of comparative need, of the targeting of services to meet the needs of those persons who would be most crucially at risk of institutionalisation, with the exception of some targeting of services to persons who do not have everyday assistance, even though they also have a lower level of felt need.

In addition, there is no evidence of consistent targeting on the basis of functional ability, demographic or geographic risk factors, or even felt need. Rather, the analysis of comparative need makes it quite clear that when two persons with similar characteristics have a similar felt need for a service, one is just as likely to have their need only partly met, whilst the other's need is fully met. The lack of consistent targeting is illustrated by the stories of Norm and Dave, and their need for Home Care services.

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11 Horizontal equity is where individuals who are the same in relevant aspects, in this case having a spinal injury and a felt need for services, are treated the same.
The stories of Norm and Dave

Norm was 58 years old when he was injured on his country farm five years ago. He sold his farm and moved into town where he now lives with his wife Mary. Norm and Mary own their home and live on a government pension, supplemented by investments from the sale of the farm. Norm has complete quadriplegia. Norm’s greatest support is his wife about whom he says "I have been fortunate. Mary is the main person and she’s wonderful. I’m the lucky one."

Dave was 52 when he was injured in an accident in his country factory thirteen years ago. He sold his factory and moved into town where he now lives with his wife Julie. Dave and Julie own their home and live on a government pension, supplemented by investments from the sale of the factory. Dave has complete quadriplegia. Dave’s greatest support is his wife about whom he says 'Julie has managed to do virtually all my gearing and needs.'

Beyond the year in which they sustained their injury, there is very little difference between these two men. They have essentially the same felt needs, and the same level of informal care. Indeed, the only distinguishing difference between Norm and Dave is that Norm was injured more recently. On the basis of the comparative need analysis, Norm might be expected to have his needs comparatively less well met than Dave. Their stories of their encounters with a service provider, however, tell a very different story.

Norm and Mary spoke about the service they receive from Home Care:

There are two Home Care, two really good workers. One comes everyday for about a half and hour. The other girl comes three days a week, two hours on Monday, Wednesday and Friday...They help to do my personal care. Really, they will do any mortal thing.

In contrast Dave and Julie were embroiled in a bitter battle with Home Care. They were fighting to retain the three hours of Home Care per week they receive which allows Julie to go to town to do the weekly groceries.12 They were struggling to understand why the Home Care service was conducting a very invasive means test and trying to stop providing services or instigate fees they could not afford.

Julie was upset about needing to fight, because, as Dave said, "I’m a letter writer but Julie’s not, not a stirrer, you know a stirrer letter writer." Julie explained her uncharacteristic behaviour saying:

12 This three hours of care is the only professional care or assistance that Dave and Julie receive. This involves a carer staying with Dave and providing supervision only—no personal or domestic care is included.
The point is we want to [live] with dignity and we want to be allowed to [live] with dignity.

Dave added;

If you are a C3 or C4 quad or something then you should be, you and your carer should be entitled to a certain level regardless of whether you’re supposed to have too much to eat or not enough, or whatever. Because otherwise all it does, you’re just going to grind the family down until the thing falls to bits and then one way or another the State will have to pick up the mess…That’s why I was so furious at Home Care for this pushing Julie to the point where she was breaking.

Despite being injured and using Home Care services for a longer period of time, Dave’s access to the service Julie and he need is precarious. Norm and Mary, however, have experienced few problems obtaining the Home Care service they need.

The concepts of normative, expressed, felt or prescriptive need are not helpful in explaining the level of comfort and, conversely, distress experienced by Norm and Dave. Home Care personal care was only ranked tenth in the list of service priorities, and was sixteenth in the ranking of prescriptive need, yet the presence or absence of this service was having a profound effect on the lives of Norm and Dave. Further, the concept of comparative need is certainly not helpful in explaining the different prioritising of these very similar men’s needs for the same service.

The limitation of prioritising on the basis of an analysis of prescriptive and comparative need is further illustrated by Jenny’s story. Based on comparative need, and the principles of equity which would dictate a consistency of prescriptive need, Jenny should have a reasonably equivalent chance as either Norm or Dave of having her felt need for professional care services either fully or at least partly met. Yet Jenny feels that it would be impossible for her to get the professional care service she needs.

Jenny’s story

I’d like to see just a little bit of help. Not twenty four hours a day, seven days a week, but Home Care’s hours are so up the creek, you know, there’s no way I could get anyone from Home Care to come and help me.

On the basis of the concepts of normative or expressed need it is indeed impossible for Jenny to ‘qualify’ for services, but an analysis of comparative need suggests that rather than failing to fit normative criteria of being ‘needy’, Jenny’s 'problem' may be that she was injured in 1991.
This same problem might also account for Jenny's difficulties in obtaining physiotherapy services. Even though Jenny is included in a subgroup of the population who were more likely to have their need for physiotherapy met in some way, those with less significant impairments who are working, Jenny clearly feels geographically isolated from services.

So, yes, there has to be somewhere, I'm not saying it has to be in [my town], I'm not saying. Probably Canberra or Orange or a central point where they can have a specialist unit in physiotherapy where they can put people.

No understanding of need which has been so far explored, however, enable an understanding of Rob's feelings about community services.

Rob's story

Rob, who would be normatively defined as needy, should have a felt and expressed need for services. Rob was injured in 1977, and thus should have any felt need for community services comparatively well met. Yet, Rob does not want any services for himself, nor for any other person in a wheelchair, who he feels should be made to be 'tougher', rather than being mollycoddled by having services:

I think a lot of people in chairs should be getting out and doing stuff instead of sitting around vege'ing. I've met some incredible people like just from going away shooting, and the place I go away shooting to is just two and half hours from here and his son is in a wheelchair.

A different concept of need

This study, thus far, has focussed upon the attempt to find some clear, objective criteria upon which to base an understanding of persons with spinal injuries' met and unmet need for community services. The concepts of normative, felt, expressed, prescriptive and comparative need have not been helpful in determining which service types are receiving priority, nor, with any great precision, to determine if there are any groups of persons with spinal injuries who are, or should be, receiving priority.

There is some evidence of a reliance by service providers on normative definitions to identify those who are 'needy', and some evidence that persons injured more recently are comparatively disadvantaged and have a higher prescriptive need. Neither of these, however, explain the incongruence between population based determinants of prescriptive service priorities and the equitable distribution of services, and individuals' experiences of the

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13 Vege'ing is an Australian colloquial term derived from the word vegetating meaning 'to be inactive'.
need for services. These issues are highlighted by the stories of Norm, Dave, Rob and Jenny.

When you consider the stories of Norm, Dave, Jenny and Rob, the lack of consistency between normative, expressed, felt, prescriptive, and comparative need highlights that prioritisation on the basis of any one, and indeed a combination of understandings of need, is problematic. For example, prescriptive need assumes that Jenny’s and Dave’s felt need for Home Care are equivalent, and further, that Jenny’s felt need for Home Care would be equivalent to her felt need for physiotherapy. Yet, Jenny herself would prioritise her need for Home Care above her need for physiotherapy. On the basis of normative definitions of need, however, one would have to prioritise fulfilling Dave’s need for Home Care ahead of any needs Jenny may express.

None of these conceptions of need clearly account for the difference in the way Norm and Dave are treated by the same service (albeit in different country locations), nor do they give a clear explanation of why Rob has services forced upon him, yet does not want them, whilst Jenny cannot get some desperately needed help. The stories of Norm and Dave, in particular, illustrate that whilst it could be argued that the principles of horizontal equity are operative at a population level, in that all groups of persons with spinal injuries are equally unlikely to have their service needs met, there may be little perception of this horizontal equity at an individual level.

The findings of this study suggest that the significant levels of unmet need, the lack of identifiable service priorities or target groups and the lack of horizontal or vertical equity in service provision has most likely resulted from the past failure to correctly identify either the ‘needy’, or what is ‘needed’. The reliance on a normative definition of need as the measure upon which resources are allocated, based upon level of impairment and socioeconomic disadvantage, neglects the most critical indicator of unmet service need in the spinal injured population of NSW—having everyday assistance. By limiting any assessment of felt or expressed need to just those persons normatively defined as ‘needy’, the community service needs of many persons with spinal injuries have not been accurately assessed or accounted for when allocating resources. Such limitation may have ensured that the ‘problem’ of unmet need has remained hidden and misunderstood. Needs-based planning processes and outcome-based funding, which focus upon achieving a reduction in levels of unmet need within a normatively defined target population, therefore, cannot address the problem of unmet need in the spinal injured population of New South Wales.

The stories of Norm, Dave, Rob and Jenny suggest that in order to understand and address the community service needs of persons with spinal injuries, one cannot rely simply upon population-based understandings of need. It is also necessary to consider the community service needs of persons with spinal injuries as they perceive and experience them. A fresh
understanding of community service needs may be gained by bridging this gap between the population based understandings of need and individuals' experiences of need.
Stage Four

Personal Perceptions of the Community Service Needs of Persons with Spinal Injuries

To address the assessment of the needs of poorly identified groups and bridge the gap between macro, or population based understandings of need, and micro assessment of individuals’ felt needs, a number of health researchers in the United Kingdom have advocated the use of multiple methodologies combining qualitative and quantitative methods. Suggested methods include the use of scales to determine the importance of needs, in-depth interviews (Endacott, 1997), and the identification of individual needs through consultation. Consultations, Endacott suggests, will give a rounded picture of a population’s needs for care, an indication for provision, and present results ‘highlighting mis-matches between need and…care delivery’ (Billings & Cowley, 1995 p.723).

An understanding of individuals' perceived need for services has been developed in this current study, based upon scales measuring satisfaction with services, written comments about community services, and the use of an unstructured qualitative approach. The latter approach allowed an understanding of what was needed as determined through the perceptions of persons with spinal injuries, rather than through any predetermined opinions which may have been held by the researcher. Thus, issues for consideration and individuals' perceptions of need, emerged from the community service concerns of persons with spinal injuries as expressed through both written comments and interviews.

Participants

The descriptive study of the spinal injured population of New South Wales indicated that the population is not at all homogenous. The ability to classify people according to given sets of characteristics was needed to facilitate an analysis of perceptions of need of persons with differing characteristics. To gain a sample for further qualitative interviews consisting of participants of
all ages, gender, level of functioning, living in both city, regional and country areas and both users and non-users of community services, invitations to participate in this stage of the study were sent to all survey respondents in three country areas (due to the small numbers in some country areas), and a sample of survey respondents from all three major regional centres and three areas in Sydney. A total of 225 invitations were sent (see Appendix H for copy of the invitation to participate).

Fifty-two persons with spinal injuries volunteered to be interviewed in response to that invitation. A suitable interview time could not be arranged for six volunteers, one was ill at the scheduled interview time, and a further five could not be contacted. Thus, interviews were conducted with 40 participants (see Appendix I for demographic information about the interviewees). Just three of those who were interviewed had also included written comments in their questionnaire response.

The persons who made survey comments were similar to the total spinal injured population in this study with the exception that they were more likely to not be in the labour force, were injured somewhat more recently and were much more likely to be persons who received everyday help. Persons who were interviewed were not so comparable with the total study population in that no interviews were conducted with anyone currently aged less than 20, or with anyone who had no movement or sensory problems. Those who were interviewed had a somewhat lower level of education than the total sample, and were more likely to not be in the labour force. Further, persons who were injured between six and 13 years ago, and those living in the Greater Sydney area (due to the sample design), were under-represented amongst interviewees, whilst persons with complete paraplegia and those who received everyday help were over-represented.

Thus, the interview group could be considered to be somewhat more impaired and dependent on everyday help than the total population. Importantly the interviewees and persons who wrote comments, however, were reasonably comparable to the total study population in terms of representing persons whose needs for community services were fully met, partly met, or unmet, as well as those who had no need for community services.

Process

Satisfaction scales were completed by persons currently using services in the process of undertaking the large quantitative study. Survey participants who provided comments wrote them in response to the specific question:

_Do you have any general comments you would like to make about extended care service provision, access and use?_
The interview participants were contacted by telephone and a time for
interview was organised. Most participants were interviewed in their own
home, however, two participants chose to be interviewed at work, and a
further two chose to be interviewed over a meal in a restaurant. Each
interview lasted between one and three hours. Most interviews were
recorded on audiotape, with the exception of the two interviews at
restaurants, and two others where the participants were uncomfortable with
the presence of the tape recorder.

The interviews were unstructured, commencing with a simple statement;

    I want you to tell me the story of living with a spinal injury. So to
get you started, "I came home from hospital and..."

and then covering issues of importance to the participant, as directed by the
participant.1 Hence each interview did not necessarily cover issues around
the need for or use of the community services of interest in this study
(professional care, paramedical, transport and respite services) unless this
issue was of concern to the participant, and raised by them.

Analysis

Satisfaction scales were analysed using SPSS to provide frequencies of
responses for the population as a whole, and cross-tabulation to identify the
levels of satisfaction for particular groups within the population.2

The documents generated by the written comments and unstructured
interviews were coded with 'base data' identifying the demographic, injury
and service usage characteristics of the participants (here meaning both the
interviewees and those who wrote comments). The text was then scrutinised
and coded for content. Initially much use was made of in vivo coding
(Strauss, 1987), that is, where the code was directly based on the actual
words used by the participants, and the coding system was quite
unstructured. After attaching coding to the text of a number of documents,
the codes became more abstracted and were grouped according to whether
they belonged in the following emergent categories:

- **Context**, that is, the topic of the interview or comment, for example, the
  particular community service being discussed, or other topics such as
  employment and housing;

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1 The author of this study has had first-hand experience of the needs of persons with spinal
injuries from both her work as a nurse, and more recently, the experience of her husband
sustaining a low level (L4-5) spinal injury as the result of a motor vehicle accident. The use
of an unstructured approach, with few predetermined questions minimised the impact of
her experiences on this current study.

2 Although satisfaction was measured on a three point scale ranging from completely
dissatisfied, though satisfied with some aspects to satisfied with all aspects, the resulting
data was highly skewed towards the latter two responses. Satisfaction was therefore treated
categorically for the purposes of analysis.
• *Service issues*, that is, issues arising from community service provision including availability, cost, the quality of services (which was primarily related to issues of reliability and flexibility), and the timing of service provision; and

• *Response*, that is, the person with spinal injuries' personal response to or feelings about the context and the issues including 'strong negative' feelings such as anger, 'negative' feelings like worry, 'passive' responses such as resignation or doing one's duty, 'positive' feelings such as satisfaction, and 'strong positive' feelings such as being very happy, or marvelling.

Multiple coding of text allowed for an examination of the relationship between concepts, while 'base data' coding allowed for an examination of difference across groups.

It quickly became apparent from the contexts within which participants spoke and wrote, that community service provision generally, and some service types in particular were a major concern for persons with spinal injuries. Different service issues, however, were of greater importance in some contexts, and less so in others. It also became apparent that not all service types evoked equivalent levels of concern or response. Thus there were services which could considered to be more, and conversely, less salient in the lives of persons with spinal injuries in terms of context, issues and response.

**Salient needs**

Just over half of the 250 persons who wrote comments on the survey commented on an issue of community services provision (n=131), as did thirty six (36) of the forty persons interviewed, a total of one hundred and sixty six (166) participants. Professional care services, particularly the Home Care Service of NSW, was the service type spoken of or written about by the most participants. Those writing comments on the survey did not write much, in comparison, about paramedical or transport services. These services were, however, areas of significant concern for interview participants. Respite care was not spoken or written about by many participants, either in comments or interviews (Table 41).

Participants who spoke or wrote about community services were primarily concerned about issues of the availability of services (36 interviewees and 69 persons who wrote comments). Other issues included service quality, including reliability and flexibility, (18 participants), the cost of services (38 participants) and the timing of service intervention (8 participants).
Table 41. Services spoken or written about by participants

<table>
<thead>
<tr>
<th>Service type</th>
<th>Participants who spoke/wrote about service</th>
<th></th>
<th></th>
<th></th>
<th>Total</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Survey comments</td>
<td>Interviews</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>n</td>
<td>%</td>
<td>n</td>
<td>%</td>
<td>n</td>
<td>%</td>
</tr>
<tr>
<td>Professional care</td>
<td>73</td>
<td>55.7</td>
<td>27</td>
<td>75.0</td>
<td>100</td>
<td>60.2</td>
</tr>
<tr>
<td>Paramedical</td>
<td>25</td>
<td>19.1</td>
<td>21</td>
<td>58.3</td>
<td>46</td>
<td>27.7</td>
</tr>
<tr>
<td>Transport</td>
<td>22</td>
<td>16.7</td>
<td>19</td>
<td>52.8</td>
<td>41</td>
<td>25.0</td>
</tr>
<tr>
<td>Respite</td>
<td>15</td>
<td>11.5</td>
<td>6</td>
<td>16.7</td>
<td>21</td>
<td>12.8</td>
</tr>
</tbody>
</table>

Availability and cost were issues associated with all types of service provision (Table 42).

In contrast, the quality, reliability and flexibility of services was a concern related to professional care services (n=12), and transport services (n=7) only, while the timing of service interventions was mostly raised as an issue in relation to the provision of services spoken about in general terms (n=6), and specifically paramedical services (n=3), and, on one occasion only, personal care. For example:

*There are too many changes in Home Care staff. Sometimes bowel routines are not professionally carried out, leaving my bed wet.*  
(issue of quality)

*I find the Home Care Service to be unreliable, for example, they’ll not turn up. Not receiving phone calls as to why.*  
(issue of reliability)

*Home Care’s flexibility is good and the out of hours relief is a good backup.*  
(issue of flexibility)

*Only disabled people know the feeling of being stranded and forgotten about by cabbies and made to feel like they are a nuisance.*  
(issue of quality and reliability)

*The support [counselling] comes too late, after you’ve got to the point of despair.*  
(issue of timing)

*I had Home Care [domestic services] for a year. That was good, til I was able to look after myself... The service was there when I wanted it.*  
(issue of timing)
<table>
<thead>
<tr>
<th>Service type</th>
<th>Availability Comments</th>
<th>Cost Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Professional Care</td>
<td>I am not allowed Home Care as my son lives at home.</td>
<td>Live-in Home Help is too costly and I can't afford it on a pension. Home Care payments have increased grossly in the last month.</td>
</tr>
<tr>
<td>(commented on by a total of 100 participants)</td>
<td>I am only granted the barest minimum of services available to clients under the Home Care scheme. Provide more care systems like Attendant Care. I get more or less continual aid from district nursing for pressure sores. The service could not be better. At the moment I am satisfied with the amount of care available to me.</td>
<td>I would love to have peace of mind if I can have more help with Home Care without feeling afraid that they want to take the service if I don't pay more. I did have Home Care but it was stopped because I receive a War Widows Pension. I was told that I could afford to pay for someone myself.</td>
</tr>
<tr>
<td>Paramedical</td>
<td>There are not enough accessible hydrotherapy pools.</td>
<td>I have to pay for my own physio since I am always in pain. I have had to have six [physio] sessions privately at cost of $26 a service which I really can't afford.</td>
</tr>
<tr>
<td>(commented on by a total of 46 participants)</td>
<td>Physiotherapy not available to so many with my type of injury.</td>
<td></td>
</tr>
<tr>
<td>Transport</td>
<td>We have no public transport.</td>
<td>The taxi subsidy should be increased, it is far too costly to travel, especially if you are on a pension and it would only cost a dollar to travel if buses were accessible.</td>
</tr>
<tr>
<td>(commented on by a total of 41 participants)</td>
<td>There is an unavailability of disabled cabs especially at night.</td>
<td></td>
</tr>
<tr>
<td>Respite</td>
<td>I would like to be able to get more Hostel Respite without booking 12 months ahead.</td>
<td>My wife is unable to have a break as no suitable carers are available at 5am at a reasonable cost.</td>
</tr>
<tr>
<td>(commented on by a total of 21 participants)</td>
<td>There is not enough respite care.</td>
<td></td>
</tr>
</tbody>
</table>
People wrote or spoke in both positive and negative terms about the services. Very few comments were made about services in a passive way. The issues associated with the provision of professional care services in particular evoked very strong responses, both positive and negative, for example:

*Home Care has put people in their graves, threatened them with the removal of services.*

*No I’m not bloody happy, I’m ticked off, I’m annoyed, I’m peeved.*

*I get Home Care and they’ve been marvellous.*

*We couldn’t possibly survive without them [Home Care workers].*

whilst participants were more likely to express a range of less intense responses to issues of paramedical, transport and respite care provision (Figure 20).

Figure 20. Strength of responses to service types

![Graph showing the strength of responses to service types](image)

Clearly then, the most salient need, as perceived by the spinal injured population who participated in this study, both in terms of the amount and depth of their concern, was the need for greater availability of professional care services (and The Home Care Service of NSW in particular). Importantly, as in the analysis of comparative need, this concern was similarly expressed by all persons regardless of their demographic, injury and service usage characteristics.

What also became apparent during the process of determining salient community service needs, was that the same service provision issue could
evoke both positive and negative responses. For example, the availability of a service may be perceived positively, whilst the quality of the service was perceived negatively by the one individual. Services could, at one and the same time, be perceived as both beneficial and detrimental, making it difficult to prioritise services on the basis of salience. It may be more useful to give priority to those services which were considered by persons with spinal injury to have the most benefit, or conversely, to be the least detrimental.

Beneficial and detrimental services

Many participants of all ages, level of functioning and age living in all areas of New South Wales (n=69), were receiving services that they felt were clearly beneficial:

They [Home Care] help to do my personal care. Really they'd do any mortal thing.

I was very happy with the physio. at the centre. I couldn't fault her in any shape or form.

This is reflected more generally in the levels of satisfaction with services expressed by respondents to the survey.

Overall, the majority of survey respondents who used community services expressed complete satisfaction with their contacts with service providers — 58.8 percent of users, and a further 34.0 percent of users were satisfied with some aspects of their contact with services. The small number of respondents who used person minding were the most satisfied (83.3% completely satisfied).

Only 7.1 percent of service users were completely dissatisfied with all the services they used. There were particular situations (n=38), however, where services were considered to be clearly detrimental to the recipient of the service, both physically and emotionally:

The attitude of some of my Home Care carers are inappropriate and they are not qualified as health care workers. I have wound up upside down and hurt because of this and Home Care central don't want to listen. I am powerless in many aspects and choices.

I do find that physiotherapists that are sent to country hospitals have very little or no idea of spinal injuries and I found that the biggest hurdle. And their attitude to spinal... you know, even my daughter said to her father, surely mum doesn't have to put up with that.

The highest level of dissatisfaction expressed by survey respondents was by the small number of meals on wheels users (18.2% dissatisfied completely), and respondents who had used government funded counselling services and
transport assistance (11.9% completely dissatisfied each), a result in keeping with previous reports. Persons in this study who used Home Care services were less satisfied with that service than was previously reported in an evaluation study conducted on behalf of the Home Care organisation.

Service users with complete or incomplete quadriplegia or complete paraplegia were more dissatisfied with services than those of greater functional ability (9.8%, 8.3% and 9.2% completely dissatisfied with all the services used compared with mean 3.9% respectively). Those whose income was derived from government pension/benefit, or from compensation payments were more dissatisfied than those whose income was derived from wages/salary, or superannuation/investments (9.2%, 7.6%, 6.1% and 3.7% respectively).

Deciding priorities on the basis of services being beneficial or detrimental was complicated by individual participants who could speak negatively about one aspect of service provision, whilst praising another aspect, for example:

_I was rather annoyed that the service [Home Care domestic] was recently cut from twice a week to once a week, but the quality of the service is good._

_We requested to have Home Care on Sunday instead of Saturday so that my husband can come to church with us...Near impossible so what do we do, as we are at the mercy of Home Care. Apart from this Home Care is an excellent service._

Even more complicating were situations where despite incurring detrimental consequences from having a service, participants still considered that having more of the service would be beneficial.

_Untrained staff are sent to do these duties mostly and I find myself constantly subject to recurring UTIs [urinary tract infections]. Another upsetting feature of this service is the fact that I am only granted the barest minimum of services available._

The only service which was always spoken about as being beneficial, and never detrimental, was the Attendant Care Scheme (11 participants spoke/wrote about Attendant Care, all positively). Similarly, survey respondents who used Attendant Care services were very satisfied (78.4% of users of Attendant Care were completely satisfied, 18.9% were satisfied with

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3 Both Freeth and the Paraquad member survey (Freeth, 1993; Paraquad, 1985) reported high levels of dissatisfaction with transport and counselling services.

4 The level of satisfaction with respite care was comparable between Home Care's Customer Satisfaction Survey (Frank Small & Associates, 1996), and this current study. The Home Care survey, however, reported considerably higher levels of satisfaction with other services (75% of persons receiving housekeeping services, and 84% of those receiving personal care were very satisfied in Home Care's report). Interestingly, both studies were conducted at approximately the same time in 1995.
some aspect of the service, and only one survey respondent was completely dissatisfied—a 30 year old man with quadriplegia who used many services, and was not completely satisfied with any of them). Generally, those who were using this service considered themselves 'lucky' and 'fortunate', whilst those who could not obtain this service clearly desired it:

*Attendant Care should be available to EVERYONE.*

High levels of satisfaction with Attendant Care have been a consistent finding in previous studies.\(^5\)

### Understanding personal perceptions of need

Persons with spinal injuries' personal perceptions of community services needs were based around two concepts—saliency, and whether the service is beneficial or detrimental. If priorities were to be based on salience, resources should be allocated to ensure increased availability of care services, and Home Care services in particular. It was found that if priorities were to be given to services consistently considered by persons with spinal injuries to be beneficial, priority would be given to the provision of Attendant Care.

Persons who considered services to be important, those who considered them beneficial, those who considered them detrimental and even those who were not clear about whether the service they received was beneficial or detrimental were represented by participants of both genders, various ages and level of functioning from all areas of New South Wales. Thus, there were no distinct groups of persons with spinal injuries for whom services were more or less salient. Nor were there any distinct groups who could be said to be gaining particular benefit, or suffering particular detriment from having services overall, or certain types of services.

Classifying services as beneficial or detrimental could not be achieved simply in terms of persons' positive or negative response to services as some persons seemed to endure considerable detrimental consequences in having services. Additionally, the issues of salient needs and beneficial and harmful services was further complicated by the situations where services which were perceived as salient were completely dispensed with in an effort to deal with the negative consequences of having services. There seemed to be no clear point at which the detrimental aspects of a service would outweigh its benefit.

There were, however, identifiable characteristics of service provision which were clearly considered by all to be beneficial if present, and also detrimental if absent. Services of all types, but particularly care services, which were

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\(^5\) Both previous New South Wales studies (Freeth, 1993; Paraquad, 1985) reported a high degree of satisfaction with Attendant Care services, as have other overseas studies such as those by Oliver (1988) and Morris (1994)
readily available when they were wanted were beneficial. Persons with spinal injuries expected services to be provided without incurring any financial penalty or hardship. Beneficial services needed to be high quality, flexible and reliable.

Thus whilst there were no characteristics by which persons with spinal injuries could be categorised as gaining greater benefit from having services, there were certainly characteristics of services which were considered to be beneficial (or conversely detrimental if considered on the basis of negative responses).

The most important issue for persons with spinal injuries was to have community services which were readily available, for cheap services which were reliable, flexible, high quality and timely, and, indeed, the characteristics of good services were availability, minimum cost, reliability, flexibility, quality and timeliness. That is, flexible, reliable, cheap, timely, high quality services were good, and good services were flexible, reliable, cheap, timely and high quality.

Such circular argument is the result of intrinsic understandings of need (Figure 21). It is this tautological result which has been reported in the many service reviews conducted by government and other agencies over the past two decades, based on the premise that persons with spinal injuries need community services, and persons with spinal injuries will suffer harm if they lack community services.

Such an intrinsic understanding of need is useful in determining service aims, service standards, and consumer rights such as those in place in the Home and Community Care National Guidelines (Home and Community Care, 1989) and the HACC Statement of Rights and Responsibilities (Home and Community Care, 1990), which amongst others include:

- to provide a greater range of services and more flexible service provision to ensure that services respond to the needs of users;
- the consumers’ right to be assessed for access to services without discrimination;
- the consumers’ right to be informed about available services;
- the consumers’ right to choose from available alternatives; and
- to be responsive to the diverse social, cultural and physical experiences and needs of consumers.

Such intrinsic understandings are also helpful in prompting service providers to recognise that where a person with a disability has a need for services, the lack of such services would be harmful. Thus, Home and Community Care recognise, in their statement of responsibilities, that ‘HACC consumers rely significantly on the services provided by HACC to maintain their ability to live in the community. The nature of this relationship imposes obligations on providers and requires that services are responsive to the changing needs of each individual’ (Home and Community Care, 1990 unnumbered).
The development of rights statements and the recognition of the obligations of service providers which result from intrinsic understandings of need are necessary to ensure that persons with disabilities can obtain 'good' services in an environment characterised by restricted resources.

One can envisage a possible world without material scarcity, and in such a world securing the rights to welfare goods would be costless.... in a community of saints, as in a world without material scarcity, rights would be irrelevant. What would be the point of insisting upon rights in such a world? Thus, rights have a place in a world where there is scarcity both of motivation and resources (Plant, 1988 pp.64-65)

But, in such a world, rights, obligations and service standards statements drawn from intrinsic understandings of need do not provide a mechanism for understanding or addressing the prioritisation of community service provision for, or by, persons with spinal injuries.

The stories of Norm and Dave, and Rob and Jenny illustrate the failure of rights rhetoric to address the community service needs of persons with spinal injuries.
The stories of Norm and Dave

You will recall that Norm and Dave are both older persons living with their wives in country New South Wales, both of whom have complete quadriplegia as the result of an injury incurred less than a decade ago.

When Norm and Mary were asked why they felt the community services they received were so good, Norm replied:

Its a two way thing — you have to respect them [the Home Care workers]
Mary added:
Yes, you can't treat them like the housemaid. There's two sides to it.
Norm continued, saying:
They are more like daughters. We couldn't possibly survive without them.

Norm and Mary had experienced no problems obtaining the good service they needed. For them, services were essential to their survival.

In contrast, Dave and Julie were experiencing considerable difficulty in obtaining the services they needed. Nevertheless, the presence of services served some important function in their lives, such that any future life plans were contingent upon them. As Dave said:

The difficulty that I can see coming is that [the children are] both going to want to settle up there [in Brisbane]. The difficulty I can see, there is no Home Care equivalent in Queensland so even if we wanted to move, closer to the kids that is, that it's simply not going to be possible unless there's some. I mean Julie is going to need help...and it's just not going to be possible although Queensland [in terms of climate] is vastly definitely better than here.

When Dave and Julie talk about the future it is clear that services are allowing them to achieve something in their lives, that the lack of them in Queensland would be harmful—a problem significant enough for them to forego the chance to be near family and live in a more suitable climate, and despite the fact that getting needed services is currently highly problematic and stressful for them.

For Norm and Dave, community services are performing some essential function in their lives, irrespective of the ease of obtaining them. Norm has 'good' services (in terms of quality, accessibility, and minimal cost), and Dave's experience was with 'bad' services (not available, poor quality and

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* Dave, like many persons with high level quadriplegia (in his case, damage at the level of C3), has problems maintaining his body temperature.
causing financial distress), yet Norm and Dave shared the perception that the presence of services (good or bad) was an essential prerequisite for living.

One is thus left asking, "On what basis did Norm get services and Dave not, when their normative need, felt need, expressed need, and perception of the salience of services is the same?" Certainly on the bases of such understandings of need, Dave could claim to have as legitimate a right to services as Norm. No understanding of need developed thus far can answer this question nor suggest a solution for this dilemma.

The stories of Rob and Jenny

Similarly, no understanding of rights and intrinsic needs, addresses the equally perplexing, but somewhat different dilemma posed in the stories of Rob and Jenny.

Rob would be considered to be 'needy' according to normative understandings of the concept. Yet Rob made it quite clear that not only was he not needy, but other people in wheelchairs should not be considered needy. Recall Rob's attitude:

I think a lot of people in chairs should be getting out and doing stuff instead of sitting around vegging.

Jenny and her husband Steve are trying to do just that, but their inability to obtain the services needed to facilitate their lives prevent Jenny and Steve from 'doing stuff':

If Steve wants a night off, he's got a friend who often goes to Sydney and likes someone to drive for company, there's no-one to help me in the mornings.

Rob and Jenny have very different personal perceptions of the need for community services. Like Norm and Dave, Jenny considers the lack of community services to be causing harm, particularly harm to her husband's attempts to be involved in his community. Rob, on the other hand, would support a greater emphasis on self reliance, rather than services.

As with Norm and Dave, understanding Rob and Jenny's personal perceptions of need brings us no closer to being able to understand the prioritisation of community services needs of persons with spinal injuries. No understanding of needs or intrinsic rights explains the denial of Rob's right to refuse services, especially as most community services, including those funded under the Home and Community Care Program, highlight services' responsibility 'to enhance and respect the independence and dignity of the consumer' and 'to respect a consumer's refusal of a service' (Home and Community Care, 1990 unnumbered).
Similarly, no understanding of rights or intrinsic needs explains the denial of Jenny’s right to services which would allow her husband and herself to participate in desired activities, particularly in an environment legislatively dominated by the Disability Services Act 1986. This Act clearly states that ‘programs and services should provide opportunities for people with disabilities to reach goals and enjoy life-styles which are valued by the community at large and are appropriate to their age’ (Commonwealth Department of Health, Housing and Community Services, Comcare, & Australian Council of Trade Unions, 1992 p.16).

Thus, according to the Disability Services Act 1986, Jenny has the right to services, in that the lack of services is impacting severely on her and her husband’s ability to participate in the community in an appropriate way. By normative definitions of need, however, Jenny’s right to services (under the Act) would not receive priority. But if the expression and satisfaction of intrinsic needs and the right to services can be over-ridden by calculations of priorities, ‘then in what sense are they rights at all?’ (Plant, 1988 p.65). Rights ‘are not granted more or less: they are and must be granted without qualification’ (March, 1994 online).

A different concept of need

The findings thus far clearly illustrate that ‘the ethics of rights is unsatisfactory in a situation where competing rights give no clear answer about which rights should have priority’ (Moody, 1992 p.180). It was clear that the prioritisation of need, and the identification of those persons upon whom the lack of community services most impacts, were tasks which were difficult to achieve with any degree of certainty. Despite extensive quantitative and qualitative analysis, no identifying characteristics of persons whose needs were likely to be met or unmet were found.

There were some indications from the comparative need analysis that what influenced met and unmet need was the ability of services to meet need, rather than the level of need of the person with spinal injuries or the availability of other (predominantly formal) care. Further, there was also some evidence that whilst having services was an important issue for persons with spinal injuries, such services could be both beneficial and harmful. The stories of Norm and Dave, and Rob and Jenny illustrate, however, that it has not been possible to clearly answer the question:

On what basis are decisions made for one person to receive priority over the other?

Thus, in a policy context which states that ‘all persons with disabilities have the same rights as other members of society to services which will support their attaining an acceptable quality of life’ (Commonwealth Department of Health, Housing and Community Services et al., 1992 p.15), and an era of
needs based planning, what are the 'real' determinants of met and unmet need for community services for persons with spinal injuries in New South Wales?

The problem with answering this question based upon intrinsic understandings of need arises from not knowing against what criteria to measure salience, benefit and harm in order to decide who should or should not have services. Intrinsic understandings are based on the notions that you need services because you have the right to be serviced, and that not having services is harmful. Against what standards, however, should the benefit or harm suggested by intrinsic understandings of need be measured?

Certainly it would be difficult to equate the salience of a having a service *per se* with the benefit gained by having a service, particularly where the salient service is not always beneficial, or indeed to equate one person's perception of salience with another's. Mooney (1997 p.7) suggests that the process of prioritising resources 'would be straightforward if all benefits could be measured in the same units.' It may therefore be more pertinent to ask:

Are there some criteria upon which to base an assessment the salience of services, and the benefit or harm of having or not having services?

Addressing the prioritisation of community services for persons with spinal injuries may be facilitated if it were possible to identify some universal criterion or criteria that persons with spinal injuries want to satisfy by having services, and what it is that services are currently achieving, rather than simply whether people get good services or not. The answers to these questions may indeed hold the key to addressing the community service needs of persons with spinal injuries in New South Wales.
Stage Five

Conceptualising Need as The Means to an End to Understand the Met and Unmet Community Service Needs of Persons with Spinal Injuries

When considered in terms of outcomes, '[n]eed can be defined as those things which are necessary for the formulation and execution of plans and purposes which are self-determined' (Figure 22) (Stainton, 1994 p.115). Miller suggests that 'to decide what a person's needs are, we must first identify his plan of life, then establish what activities are essential to that plan, and finally investigate the conditions which enable those activities to be carried out' (Miller, 1976 p.134).

It is important to note that Miller suggests identifying a plan of life, rather than a plan for life. Identifying plans for life would suggest that to determine need, one should identify a set of activities to be undertaken to reach goals to which one may aspire—a kind of roadmap to be followed to reach some destination. Plans for life are life dreams—'wish' lists for the future, for example, what a child plans to be when they grow up. To identify a plan of life, however, involves determining persons' ways of being in, and interacting with the world. Plans of life are emergent—changing as they deal with the situations they encounter and are thus focussed on the present rather than the past or the future (Charon, 1995 p.33-34).

Conceptualising community service needs as the means to an end involves:

- identifying the desired end—persons with spinal injuries plans of life, or way of being in the world, derived from the meanings of the objects that comprise their world;¹

¹ In the terms of symbolic interactionism, objects can be physical entities, or attitudes, beliefs and relationships which exist on the basis of the meanings individuals or groups attach to them (Charon, 1995).

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• identifying the role of services in persons with spinal injuries plans of life—the processes by which persons with spinal injuries and service providers act towards each other and interpret each others actions; and
• identifying the conditions under which persons with spinal injuries use or do not use services—understanding the process by which persons with spinal injuries and service providers note, interpret, and assess the situations confronting them based upon the common and pre-established meanings of what is expected in the actions of persons with spinal injuries and service providers (Blumer, 1969).

Figure 22. The concept of need as the means to an end

Process

It has been demonstrated throughout this study that conventional and traditional ways of determining need have failed to adequately address the community service needs of persons with spinal injuries. To address these needs requires a new way of understanding need which is based upon understanding the central concerns of persons with spinal injuries, and how they perceive their ways of being in the world. One must 'see their objects as they see them' and 'get inside their worlds of meanings'.

[To] identify the objects of central concern one must have a body of relevant observations. These necessary observations are rarely those that are yielded by standard research procedure such as questionnaires, polls, scales, use of survey research items, or the setting of predesignated variables. Instead, they are in the form of descriptive accounts from the actors [participants] of how they see the objects, how they have acted towards the objects...and how they refer to the objects in
their conversations with members of their own group (Blumer, 1969 pp.49-52). 

The grounded theory method, which was derived from the sociological philosophy of symbolic interactionism, facilitates the development of new ways of thinking about processes in the social world (Strauss, 1987), and is thus most appropriate for deriving a new understanding of the needs of persons with spinal injuries. The method is both inductive and deductive—endeavouring to discover what is going on, rather than testing an a priori theory or hypothesis (even though there was a conceptual framework and a distinct set of questions to answer). Deriving a new understanding requires that there be few, or preferably no, preconceptions inherently built into the analysis of the data.

This analysis began with the assumption that conceptualising need as the means to an end would provide a basis for addressing the community service needs of persons with spinal injuries. Further, it was assumed that such conceptions were to be found in the interactions between persons with spinal injuries and service providers. Beyond this conceptual framework, however, few preconceptions were made. The plans of life of persons with spinal injuries were not presupposed, nor were the roles of services in such plans, nor the conditions under which persons realised these plans. Certainly, the consequences of the interaction between persons with spinal injuries and community services were not presupposed. Moreover, whilst it was clear from the analysis in Stage Four that services have a significant role in the lives of persons with spinal injuries there was no prior assumption as to how they related or contributed to plans of life beyond the commencing knowledge that services could be both beneficial and harmful.

Grounded theory analysis is described as having two elements:

- theoretical sampling, that is, subjects for the study are not pre-determined, but rather are chosen as the study is proceeding, on the basis of emergent theory; and
- constant comparative analysis in which the researcher actively looks for both proving and disproving evidence in the data by drawing comparisons from both within and between cases (Strauss & Corbin, 1990).

Theoretical sampling is a challenge for any study such as this since it involves returning to the field to explore new cases which would assist in expanding or refining the emerging theory (Glaser & Strauss, 1967). In the present study, the geographic expanse of the 'field', the limited time frame,

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2 As this study proceeded it became increasingly important that the participants saw the author as a member of their own group. Whilst the author endeavoured to minimise the impact of her experiences on the study it was necessary, in many interviews, for her to reveal some of her professional and personal experiences of spinal injury to gain acceptance as a member of the participant's peer group.

3 The 'field' for this study consisted of the whole of the Australian State of New South Wales, and the Australian Capital Territory, an area of over 800 000 square kilometres.
and the need to organise interviews well in advance dictated that the sample be predetermined. Nevertheless, the data collected were so rich, and the participants so varied in their characteristics, that it was possible to sample within the original study, finding and analysing cases with particular characteristics to test the emerging theory.

For example, initial analysis of the first two interviews suggested that sustaining a spinal injury at a later stage in life, after establishing a family, home and lifestyle, made it easier to locate and utilise community services. To test whether stage of life had an important relationship with the ease of obtaining community services, interviews with two persons injured when young were analysed to determine the importance of stage of life for them. This analysis revealed that all four of these persons with spinal injuries felt that the stage at which they incurred their spinal injury was the best stage in life for such an injury to occur. Stage of life, per se was thus concluded to be unrelated to ease of obtaining services. Further analysis of the text about stage of life was then conducted to determine what were the common elements of the ‘best stage in life’ at which to incur a spinal injury for these four people. One common element of these four persons’ lives at the time of injury was the constancy of their family and community support. The remaining interviews were thus browsed to identify persons who did not have family and community support at the time of their injury, to test the hypothesis that family and community support were necessary to facilitate obtaining needed services.

Analysis was thus conducted using constant comparative method—coding data to develop concepts which were then refined by reviewing and comparing other data. Ultimately the concepts are integrated into a coherent theory which both ‘fits’ and ‘works’.

Coding data

In the process of undertaking the analysis of intrinsic need conducted in Stage Four all of the interviews and written comments collected were coded to identify text where participants were speaking or writing about community services.\(^4\) This included:

- text where persons with spinal injuries were speaking or writing about services they currently use;
- text about services used in the past;
- text about services they would like to use now or may need in the future;

\(^4\) To facilitate this coding, all textual data resulting from the transcribed interviews and written comments made by participants in the study was imported into a project set up using QSR NUD*IIST software (version 4). Using this software allows the researcher to attached multiple codes to lines of text which can then be easily retrieved for further analysis.
• text about services used by other persons with disabilities, and
• text about community services which was generated by family or friends who were present during the interview or who wrote comments on the survey

Other text from the interviews and comments, for example, text about issues such as health problems, employment and housing, was not included in the analysis in this Stage unless the issue arose in the context of community services. Thus, text where a participant spoke about employment in terms of relating some incident or event which had occurred in the workplace was not included in the analysis. If, however, the participants spoke about being unable to maintain employment because of the lack of transport services, or were relating a conversation they had had with a social worker about employment prospects, the text was included in the analysis. The text chosen for analysis was thus limited to that which had direct relevance to the identification and conceptualisation of issues associated with the provision of community services.

The grounded theory analysis was conducted by retrieving the relevant text and 'coding on' to derive new codes and concepts. 'Coding on' is a phrase coined by Lyn Richards to describe the process of taking data coded as being relevant to a particular issue or context (in this study, community services) and developing new codes to tap further detail, leading to new analyses. As supported by the NUD*IST software, this involves using the facility of computer access, creating new categories and rethinking, combining or dimensionalising the original categories. Returning to the original context is always available, but moving 'on' to new categories is sought.

Central concerns of persons with spinal injuries

Initially, all the text which was identified as being about community services (36 interviews plus written comments from 131 persons with spinal injuries and 73 of their carers—4760 lines of text) was coded in vivo, that is, codes with names based on the actual words used by the participants were attached to the text (Strauss, 1987).

When grouped together according to their conceptual similarities, this coding revealed that for most persons with spinal injuries who were interviewed in this study, the common language and discourse of community services was not a discourse of rights to services. The categories created were dependency, independency, interdependency and control in one's life, expectations and definitions of a normal life, adjustment to

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5 This included persons with other types of physical, mental or sensory disability as well as other persons with spinal injuries.
changed lives, relationships with others, and disability stereotypes (Table 43). 6

Only two interviewees, Stuart and Dave, spoke about the right to services. In both cases, the language of rights occurred in the context of suggesting ways of improving the availability and equitable distribution of services.

Assumptions about rights did strongly pervade the written comments of those who responded to the survey questionnaire. Almost all written comments about community services included a list of services to which the respondent felt they were entitled. These listings were occasionally accompanied by an explanation of the reason for their need, but more often they were of the form 'Access to all services without means test' or 'more Home Care', 'more hours', 'more counselling' and so on. Such data, however, offered no insight into the person's understanding of their situation and whether they saw the provision of these services as a right. From survey research it was not possible to explore the ways in which persons with spinal injuries see and interact with the objects in their world.

I would argue that the reliance of policy makers on such survey data has been a major factor contributing to the failure of service reviews to impact significantly upon the addressing of need in the community. Hence, the data available from written comments to the survey was included only where the respondent recorded very detailed comments, or ones which allowed the researcher to 'get inside their worlds of meanings' (Blumer, 1969 p.51) (34 persons with spinal injuries and 11 carers).

The eight concerns of persons with spinal injuries and their carers were not mutually exclusive. Indeed they were highly related. In eleven of the sixteen documents which contained text coded at the category 'mythical other', the relevant text was also coded at 'dependency', and text coded at 'having to adjust' was also coded at 'dependency' in eight of the sixteen relevant documents, and 'changed life' in fourteen documents. Text coded at 'life change' or 'taking control' was also conceptualised as being about 'dependency' (in the sense of autonomous independence) and 'having to adjust' to a new understanding of a 'normal life'.

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6 The dominant discourses of persons with spinal injury, were, for the most part, not associated with any particular socio-biological factors. The exceptions to this will be highlighted where appropriate.
<table>
<thead>
<tr>
<th>Conceptual code</th>
<th>Definition</th>
<th>In vivo code</th>
</tr>
</thead>
<tbody>
<tr>
<td>dependency (63)</td>
<td>issues of being independent (53), interdependent (7) or dependent (14)</td>
<td>'have to rely on them'</td>
</tr>
<tr>
<td></td>
<td></td>
<td>'feel like this terrible burden'</td>
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<tr>
<td></td>
<td></td>
<td>'not relying on others'</td>
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<tr>
<td></td>
<td></td>
<td>'it's a two way thing'</td>
</tr>
<tr>
<td>normal life (16)</td>
<td>being or feeling 'normal'</td>
<td>'this is normal'</td>
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<tr>
<td></td>
<td></td>
<td>'like everyone else'</td>
</tr>
<tr>
<td></td>
<td></td>
<td>'level with everyone else'</td>
</tr>
<tr>
<td>essential relationships (21)</td>
<td>the importance and nature of relationships with family, friends and service providers</td>
<td>'family are essential'</td>
</tr>
<tr>
<td></td>
<td></td>
<td>'too much for family'</td>
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<tr>
<td></td>
<td></td>
<td>'she was the key to my survival'</td>
</tr>
<tr>
<td>changed life (28)</td>
<td>altered life and expectations of life</td>
<td>'changed life'</td>
</tr>
<tr>
<td></td>
<td></td>
<td>'cutting ties'</td>
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<td></td>
<td></td>
<td>'what life would have been'</td>
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<tr>
<td>lowered expectations (4)</td>
<td>having to accept a life that is less than expected (or normal)</td>
<td>'at least it's something'</td>
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<td></td>
<td></td>
<td>'better than nothing'</td>
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<tr>
<td></td>
<td></td>
<td>'one day at a time'</td>
</tr>
<tr>
<td>having to adjust (16)</td>
<td>getting on with life, not dwelling on disability</td>
<td>'have to cope with it'</td>
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<tr>
<td></td>
<td></td>
<td>'get on with it'</td>
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<tr>
<td></td>
<td></td>
<td>'no fall back position'</td>
</tr>
<tr>
<td>'the other' (16)</td>
<td>talking about some known or mythical stereotypical disabled person</td>
<td>'all you do is play basketball'</td>
</tr>
<tr>
<td></td>
<td></td>
<td>'sit on a system'</td>
</tr>
<tr>
<td></td>
<td></td>
<td>'blokes...get to be bludgers'</td>
</tr>
<tr>
<td>taking control (5)</td>
<td>exercising control over aspects of life</td>
<td>'I can manage'</td>
</tr>
<tr>
<td></td>
<td></td>
<td>'take some sort of control'</td>
</tr>
</tbody>
</table>
'Lower expectations' was primarily about the dependency of and need for adjustment by others, rather than themselves. Only one participant, Norm, had a lowered expectation of his own life which was not related to dependency, but was based upon a fear of what the future may hold:

You can't plan too far ahead.

Norm, at 66 years old, however, was the oldest participant with complete quadriplegia who was living in the community. His low expectations of the future could be due to the combination of spinal injury and advancing age, an area about which little is known.

Thus having to adjust, taking control and lower expectations (with exception of Norm's case) could be conceptualised in terms of the one or more concerns to which they were related. These three concerns were thus incorporated into five distinct, yet inter-related central concerns—dependency, the other, normal life, changed life and essential relationships.

Dependency

Dependency, as defined by both the participants in this study, and the common language use of the term, was the state of relying on something or someone else for aid or support (based on definition of 'dependency' in the The Macquarie Dictionary, 1981)

The concept of dependency in the context of services was identified in the text of interviews with about half of those who were the current users of services. But it occurred as frequently in interviews with non-users of services. The concept was, however, identified in the text of a relatively greater proportion of interviewees who had had a problem obtaining services. But in this context the participants, those with quadriplegia in particular, spoke of independence forced upon them due to the lack of services, rather than dependency. In this sense, independence meant no reliance on community services, rather than independence in activities of daily living.

Community services were spoken about by persons of all levels of functioning (except for persons with no movement or sensory problems who were not represented in the interview sample), but whilst dependency was a

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7 The only study participant with complete quadriplegia who was older than Norm, was an 83 year old man living in a nursing home, who responded to the survey, but did not participate in the interviews.

8 It is rare for an older person who sustains serious spinal injuries to survive both the initial injury and early rehabilitating stage. Despite improved treatment, rehabilitation, and drugs, the prognosis for older persons with complete quadriplegia who do survive the acute period remains poor (DeVivo et al., 1992).

9 Of the twenty one interviewees who had no problems obtaining services, only ten spoke of dependency, compared with nine of the twelve who had had problems obtaining services.
concept identified in the interviews of all persons with quadriplegia (n=9), and most of those with incomplete paraplegia and some movement or sensory problems (n=8 of 11 participants), only four of the fifteen persons with complete paraplegia spoke about dependency. A combination of factors may account for this.

Firstly, the data indicated that persons with incomplete paraplegia or some movement or sensory problems had more problems with debilitating pain and spasms than those with complete paraplegia. Persons with complete paraplegia were also more likely to work than persons with either quadriplegia or incomplete paraplegia. Further, whilst dependency was an issue for persons with quadriplegia (as enforced independence due to lack of services), persons with complete paraplegia were relatively less likely to use or need professional services.  

It is clear, then, that the concept of dependency is complex—having differing meanings for differing persons in differing contexts. In order to clarify these meanings, the relationships between dependency and the concepts of 'the other', essential relationships, normal life, and changed life, were explored. This analysis yielded three distinct dimensions of dependency—dependence, independence and interdependence. The relationship of these to other concepts is illustrated in Figure 23.

Independence

Independence, that is, not relying on others for aid or support, was by far the concept most spoken or written about (see Table 43). For most participants (n=42, primarily persons who wrote comments), however, independence was a mere statement of fact indicating that they could attend to all their activities of daily living without assistance, and thus revealed little in terms of meaning. Twenty participants spoke of independence in terms of having to live, provide care, and undertake the rehabilitation and adjustments required by their impairments 'on their own'. Being 'on their own' did not equate with being alone, as this term also included the participants' families.

This statement of independence was moderated by the complaint that this independence was forced upon them by a lack of services (particularly for those from country areas and those with quadriplegia). Whilst this achievement of independence was viewed by fourteen participants as a major achievement of adjusting to a changed life in the face of adversity, their triumph was tempered by a sense of exhaustion from being forced to rely on their own resources.

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10 Persons with complete paraplegia were second only to persons with no movement or sensory problems in terms of being the group least likely to be using services (see Table 17 on page 109) and had a lower rate of need for professional services than persons with quadriplegia or incomplete paraplegia (see Table 34 on page 154).
Independence was related to normality by only two participants with quadriplegia who spoke about the normal life and independence which had resulted from their participation in the attendant care scheme. For another seven participants of varying age, gender and functional ability, independence was related to the ability to establish and maintain essential relationships (including relationships with service providers). This connection with essential relationships, rather than with normality was somewhat surprising in a service provision climate so steeped in the rhetoric of an independent normality. It is an indication of the inappropriateness of this rhetoric in the context of the provision of community services for persons with spinal injuries, an issue which will be discussed later in this chapter.
Interdependence

The concept of interdependence, when identified in the context of community services, was always defined by participants in terms of essential, reciprocal relationships between the person with spinal injuries, and their family, friends and service providers. Interdependency in this sense means mutually relying on each other for aid and support (The Macquarie Dictionary, 1981).

Interdependence was conceptualised as normal life by only two participants. As with the concept of independence, interpersonal relationships in the context of community services were not considered by most to be part of normal life.²²

Dependence

Dependence was most commonly described (by twelve of the nineteen participants who spoke or wrote about dependence) as a way of being which participants attributed to others, both known and mythical, rather than to themselves. Those other dependent people were 'poor people' and 'bludgers', who 'sit on the system' and get trapped there.

These stereotypes of dependency pervaded the lives of persons with spinal injuries. For nine participants, these negative stereotypes had damaged essential relationships with family, friends and service providers (through service providers having unfair expectations of family as carers, or service administrators frequently changing the actual 'hands-on' provider on the premise of the need to avoid dependency). Further, these negative stereotypes had inhibited four of these persons' and three other persons' participation in normal life activities (through the rigidity and intrusiveness of service provision). Avoiding these dependent stereotypes was a strong motive for 'having to adjust' for eight participants at all levels of impairment. The damage to essential relationships, and the effort required to avoid dependency engendered persons with spinal injuries with feelings of powerlessness and lack of autonomy in the face of autocratic and inflexible community services which enforced dependency.

The four other central concerns of persons with spinal injuries—the mythical other, normal life, changed life and essential relationships were all inter-related, in addition to being related to the concept of dependency. The relationships between these four central concerns is illustrated in Figure 24.

²² Interdependence was, however, an important concept in other contexts such as sexual relationships, and family roles.
Although not as significant as dependency in terms of numbers of participants, the meaning of these concerns and the relationships between them contribute to understanding the wide variations in the community services discourses of persons with spinal injuries.

Figure 24. The relationships between the other central concerns of persons with spinal injuries

'Character'

The participants in this study identified three types of 'the other'. The first type were those persons with a disability who take advantage of or feel owed by 'the system'—about whom participants spoke with scorn. The second type of 'the other' was individuals, or groups of persons with disabilities who were perceived to be receiving preferential treatment, such as persons with blindness.\(^{12}\) The final types of 'the other' were what could be considered to be the antithesis of other stereotypes of persons with disabilities and particularly dependence. These included high profile sports-persons with disabilities and those portrayed in popular culture as succeeding 'against the odds' by achieving goals not considered possible for persons with disabilities.

\(^{12}\) Due to an historical anomaly related to the repatriation of men who suffered blindness as a result of chemical warfare in WWI, benefits for persons with blindness are not subject to passing the means and asset test applied to persons with other disabilities.
(such as winning gold medals, walking or flying an aeroplane). These 'other' did not represent normal life for most of the participants in this study.

In the context of dependency, as described previously, the first type of 'the other' was, as Greg explained:

*like people being on the dole for too long...they adjust their life to suit. They don't want any more. The fire goes out in the belly. True, I've seen a few of them like that.*

These 'others' become trapped in 'the system' which enforces dependency, damages essential relationships and hinders participation in normal life.

Twelve participants in this study spoke about the existence of 'the system'. 'The system' was used most commonly to refer to the social security system of income support, and also, by some, health and community care systems. 'The system' was something that one could use for a short time, but a trap to be avoided in the long term. Being trapped on 'the system' long-term was akin to giving up, as Andrew explained:

*If you’re prepared to sit on a system and just get the pension, you know, you might as well jump off the deep end.*

For participants with some movement or sensory problems, Evelyn, Brian, Jenny and Emily, avoiding 'the system' was a significant motivator of rehabilitative efforts to adjust to a changed life and avoid dependency, as Evelyn said:

*I wasn’t going to sit round and become a veg...[voice trailing off]. As I said, I was independent in myself and I always was and I don’t like people having to fuss over me.*

The main problem with 'the system' was that one had to fit within it completely, and once in 'the system', enforced dependency made it difficult to take steps to escape it. Brett, who felt he was trapped, summed up the frustration with the all or nothing nature of 'the system' that was felt by Dave, Jeff, Stuart, Jenny and himself:

*What it means is that my position, I have to access basically the full range of government services to get anywhere, hopefully get somewhere, probably not a progression but maintaining the status quo. If I take steps to supplement that, like I might take a casual part time [job], if I do anything to supplement what I’m doing as a step in a particular direction, I’ll be penalised for that if I’m honest about it. So really what it forces me to do is to say ok, I can’t jeopardise the...*
benefits I’m getting so I have to fit completely within the system, I don’t have the option of straddling it.

Thus, reliance on ‘the system’ represented an ‘other’ — a level of dependency and lack of effort or adjustment — which was something to be avoided if possible.

Having a functional impairment, or associating with ‘the other’ persons with a spinal injury was not sufficient to make you part of ‘the other’. James, for example, had spent a number of years travelling and playing exhibition wheelchair basketball games to raise money for ‘the handicapped and retarded kids’. James, however, did not view himself or his team-mates as ‘the handicapped’, because the handicapped:

were completely warped, and we were nearly normal, I’m not saying completely normal (laughing) but nearly normal.

James’ basketball activities were, for him, a ‘mob of fellows having a get together’— an activity designed to promote and maintain essential relationships, rather than being ‘the other’ who achieve extraordinary goals. Dave and Brett also spoke positively about contact they had had with other people in wheelchairs. This contact, for them, formed part of an essential relationship with an information network which they used to learn skills for living a changed life with their spinal injury, such as where to get or how to make equipment, rather than an identification with ‘the other’.

Only one participant, Jane, identified herself as one of ‘the other’ who is owed by ‘the system’. The consistently pessimistic tone of Jane’s interview contrasted starkly with the positive tone that characterised large portions of all the other interviews. Prior to her injury Jane was a Home Care worker who provided personal care for ‘the disabled’. Jane lamented that:

I used to spend my time looking after those poor people and now I am one of them.

It may be significant that Jane was the only participant in this study who was known to have had any substantial amount of engagement with persons with disabilities prior to sustaining their own spinal injury.14

Len Barton, in his paper ‘Disability, Difference and the Politics of Definition (1994), commented that:

How we relate to disabled people is influenced, for example, by our past experience of such encounters and the way in which we define ‘disability’.

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14 There were no other characteristics which uniquely differentiated Jane from the other participants in this study.
Paradoxically, although sixteen participants could identify 'the other', fourteen commented that there is no school for learning how to live with a disability and that the adjustment to a changed life has to be achieved alone. So how or why one becomes, or avoids becoming one of 'the other' is not entirely clear. This problem may be due to the fact that this study did not include any persons with a spinal injury who would be described by the participants as 'the other' (perhaps with the exception of James when he was younger, and Jane). This study, however, was not designed to be a study of high profile sports-people, as one could reasonably argue that talking to high profile sports-people, whether disabled or not, would fail to give an accurate picture of what life is like for the majority of persons living in the community. Further, somewhat surprisingly, this study did not include many persons whose main reason for participating was to make complaints, despite the recruitment of participants on a volunteer basis which may have resulted in a tendency to over-sample persons who wished to complain.

Nevertheless, it is sufficient for the purposes of this study to know that many participants identified stereotypes of disability and/or dependence—'the other'—who were either wheelchair-sports-people, 'whingers', 'dependent' or 'poor people'.

Normal life

Sixteen interviewees and eleven persons who wrote comments in this study highlighted the fact that they returned to a 'normal' life, with 'normal' activities, 'normal' work, and 'normal' family and friends post-injury (the actual term 'normal' was used by nineteen participants to describe aspects of their lives, at their own instigation). In the context of community services this normal life and normal activity, where the terms were defined, was framed in terms of establishing and maintaining essential relationships with family and friends. Normal life and activity for the participants of this study, was, however, more easily described in terms of what it was not, rather than what it was.

Normal life and activity was defined by ten participants of varying age and gender as not being 'the other'. Greg summed up Andrew, Alex, Jeff and Matthew's views of normal life and 'the other' in this description of a conversation he had had with a social worker:

I suppose it's probably not politically correct, I don't know, but I don't have anything to do with people in wheelchairs. I said "Listen," I said "I didn't have anything to do with them before I had my accident, why should I now go and do it now?" And then they said "Oh, but you want to go down to the Club, you go down there, they [the disabled] get together on such-and-such a day and they, you

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19 The term 'normal' was never used by the interviewer, except in seeking clarification of a participant's concept of 'normal'.
know, everyone plays snooker or, you know, wheelchair basketball.”
And I said “Look, I don’t like basketball, why the bloody hell would I want to go and play basketball now? I didn’t play it before.” That’s true. So I think that’s, they say oh, now I’m para that’s my, they’re my people now. You know? It’s like you turn Aborigine overnight.

According to their definition, 'the other' spent large amounts of time with other people who were 'the other' by taking part in sporting or other activities for the disabled, rather than participating in 'normal' activities. According to Jenny, Kimberley and also Matthew, 'the other' are people who have not adjusted, and avoid normal life because they 'have got a chip on their shoulder' or who are what Matthew describes as;

a bunch of cripples who do nothing but whinge and moan and groan.

The concept of normality was fully explained by the concepts of essential relationships, dependency and not being 'the other'. Interdependence was only related to normality in terms of essential relationships. Independence was related to normality by only a few participants in situations where the autonomy of persons with quadriplegia who used attendant care facilitated participation in normal life activities. For other participants, however, having a normal life required having to adjust to a changed life and maintaining a balance between dependency and independence.

Changed life

Having a changed life was about redefining normality and essential relationships, and having the motivation to get on with life and avoid dependence, unlike like 'the others' who do not adjust to the changes and become dependent and part of 'the system'.

For two participants their changed life provided opportunities for the development of essential relationships they may not have otherwise had. A changed life for seven participants, most of whom had quadriplegia, however, resulted in the alteration of relationships between persons with spinal injuries and their family and friends.

Three participants spoke about the demise of long-term marital relationships after having sustained a spinal injury (Jeff, Brett and Jim).16 Only Jim, however, attributed his marriage breakdown to the changed life which resulted from his spinal injury:

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16 The fact that only three of the forty participants in the study had divorced (or separated) in the years since incurring their injuries was somewhat surprising. Persons with spinal cord injuries have been reported as having a higher risk of divorce than the general population (Berkowitz et al., 1992). In a study of marriage in persons with spinal injuries, DeVivo et al (1995) found that there was little increase in the rate of divorce during the first year after injury, a relatively greater risk of divorce in the second and third years, and close to the expected general population rate of divorce during the fourth and fifth years.
My wife would go on about how, saying "You ruined my life". It was so hurtful.

Jim blamed the lack of assistance from community services when he first returned home post-injury for his wife's inability to cope with his disability.

Nerida, Ryan and Christine had 'lost friends because of how I am'. Their changed life resulting from their injury and subsequent disabilities was a challenge to the steadfastness and appropriateness of their relationships with family and friends, as Christine said:

I told them straight, I didn't want anybody to be weak or weeping over me or doing anything. I want strong people around me, that's what I need. And a lot of them couldn't handle it..

Whilst in hospital, Carl realised:

The football guys, I realised that they had to go. You know football, they were just getting, they'd be getting in serious relationships, they were engaged, they were getting married, they were now going to have children, and that is what life would have been pretty well hopefully for me. But I didn't see that happening and I couldn't see past the wheelchair at the time.

Carl, subsequently, did get married about three years after sustaining his spinal injury.\(^7\)

Having a changed life for four participants involved creating a new definition of normal life by 'changing priorities' and resigning themselves to a life that was reasonable, but clearly not the life they had planned. Norm described his life:

Well I'm happy. I don't know about really happy but you've got to make the best...You can't turn back the clock.

Overwhelmingly, however, the most striking feature of adjustment to a changed life was that it was an activity which was undertaken independently. Fourteen of the twenty one participants who spoke or wrote about a changed life spoke about having to make the adjustment on their own.

A changed life is the only concept which was isolated in the sense of the activity being something internal to the persons with spinal injuries, and not part of a relationship between persons with spinal injuries and others. In this sense it is an activity that Goffman (1959) would describe in dramaturgical terms as occurring behind the scenes. Whilst the motivation to engage in this activity may be social where motivated by alterations in essential

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\(^7\) Dickson et al (1995) in their longitudinal study of the psychological consequences of spinal cord injury (SCI) commented that 'Perhaps two years is the minimum time a person needs to achieve some stability in his/her life following SCI'.
relationships or the need to redefine life and avoid dependency, the activity was essentially individual—sometimes by choice, but more often due to a lack of assistance.

Essential relationships

The participants in this study spoke about the relationships which they considered to be essential in their lives. A normal life free of dependency or being 'the other' was related to the establishment and maintenance of essential relationships with friends, family and service providers.

Relationships with friends and family

Long-term relationships with friends and family who have adjusted to the person with spinal injury's impairment, with whom one attends normal social activities rather than activities of 'the other', created an environment in which impairment and disability were rendered invisible.

The essential relationship to be maintained or established with one's family was an intimate relationship which can include personal care, but any care relationship, in the sense of assistance with activities of daily living (care of bodily functions in particular), must not usurp the family relationship. Such usurping, most often the result of the lack of available and reliable community services, renders disability visible and replaces interdependence with dependence.

Relationships with service providers

The relationships between persons with spinal injuries and service providers could be family-like, or established as an employer/employee relationship. Neither of these relationships entailed dependence, only interdependence and independence in the sense of autonomy.

Family-like relationships based upon emotional interdependence were primarily (although not exclusively) established between persons with spinal injuries and government funded services, whilst employer/employee relationships were more often associated with the attendant care scheme. Either way, persons with spinal injuries considered having one or other of these types of relationship with service providers to be essential. The lack of a relationship was related to feelings of powerlessness and dependence and was defined as poor quality care.

The relationship formed needed to be one within the realm of experience of the person with spinal injuries. A number of persons using the attendant care scheme were pleased with the autonomy it provided, but were troubled
by the difficulty of establishing and maintaining employer/employee relationships, a role they had not previously experienced.

In addition to speaking or writing about relationships related to dimensions of dependency, 'the other', changed and normal life, participants commented with annoyance about the bureaucratic barriers to forming relationships with service providers.

Components of essential relationships

Four essential components of good relationships were identified based upon the relationships desired by persons with spinal injuries, whether with family or friends, or family-like or employer/employee relationships with service providers:

- relationships were reciprocal, that is, there was a commitment to an interdependence (emotional and/or financial) from which both parties would benefit;
- relationships were clearly defined within the realms of the experience of persons with spinal injuries;
- relationships were long-term, that is, there was continuity in the relationship; and
- relationships were stable, that is, they were reliable and predictable.

Relationships which were based upon emotional interdependence required the presence of all four components to establish and maintain the relationship. In relationships with service providers, this was only possible where the number of persons involved in the relationship was limited to a very small number.

Relationships which were conceptualised as being employer/employee, regardless of whether the person with the spinal injury was the actual employer in term of the source of the payment for services, did not always require that the relationship be long-term. In these relationships persons with spinal injuries would countenance a 'turn-over' of staff. Nevertheless, long-term relationships with a small number of loyal employees greatly improved productivity, that is, the quality of life of persons with spinal injuries.

Regardless of the nature of the relationship, the result of the presence of these essential components was that disability and impairment were rendered invisible, and persons with spinal injuries felt they had a normal life, unlike that of the dependent 'others'.

Overview of central concerns

The discourses of persons with spinal injuries which occurred in the context of community services can be understood in terms of five central concerns,
and the relationship between them—dependency, 'the other', normal life, changed life, and essential relationships. Within this discourse, these objects were all inter-related and drew their meanings from each other. The dyad between 'the other' and a normal life was, however, the most significant process through which the objects gained their meaning (Figure 25).

The task was then to derive an understanding of the community service needs of persons with spinal injuries, and the ends they wished to achieve through the use of services based upon their central concerns, and derived from the meanings of these objects which comprised their world.

Figure 25. Model of the relationships between the central concerns of persons with spinal injuries
Plans of life

Miller's (1976) conception of need suggested that the end, in understanding
need as a means to an end, would be a plan of life, that is, a desired way of
being in the world. What do the five central concerns and the relationships
between them tell us about persons with spinal injuries' way of being?

The five central concerns of persons with spinal injuries clearly show that for
them, being in the world is a social process. Only adjusting to a changed life
resulting from impairment could be conceptualised as an individual
process—and even that process was, for some, motivated by the social
concerns of establishing and maintaining essential relationships and
avoiding images of dependency and 'the other'.

The model of the relationships between the central concerns of persons with
spinal injuries clearly shows that this individual process of adjustment was
but only one small part of the whole process of living with a spinal injury.
This one small part, however, has spawned the individual models of
impairment and disability which site the 'problem of disability' within the
individual's adjustment to their impairment (Oliver, 1996). This has been to
the detriment of the consideration of the social processes involved in living
with a spinal injury, shown by this study to be much more dominant. For
persons with spinal injuries, having an impairment may be an individual
process, but their way of being is located in the social dyad of 'the other' and
'the normal'—and whilst persons with spinal injuries had considerable
difficulty in defining what they were, 'the normal', they could clearly
articulate what they were not, 'the other'.

Not being different

Not being 'the other' was about not being different, that is, not separate or
distinct or differing in character (based on the definition of different in The
Macquarie Dictionary, 1981). Not being different involved the participation
of persons with spinal injuries in activities for and relationships with 'the
normal', rather than activities specifically for 'the other', or relationships with
'the other'. Not being different was not being dependent on, or trapped by
'the system', or subjected to stereotypical images of heroes, victims or
bludgers. Not being different

involves challenging definitions which isolate and marginalise
and replacing them with those which engender solidarity and
dignity. (Barton, 1994 online)

Interestingly, persons with paraplegia or some movement or sensory
problems, rather than persons with quadriplegia, spoke about not being
different. Those with quadriplegia did not speak about not being 'the other'
(with the exception of Dave who spoke about the benefits of an information network with others with spinal injuries) and only spoke of 'the system' where they felt discriminated against by the inequitable distribution of services. This may not be surprising, for the essence of not being different for participants with paraplegia or some movement or sensory problems, was to rebel against persistent stereotypical images of persons with disabilities.

Such images, as portrayed in popular culture, are primarily stories of persons with paraplegia, rather than quadriplegia, who succeed against the odds by achieving goals not usually considered possible for persons with disabilities (such as winning gold medals, walking or flying an aeroplane), or conversely, dependent victims of tragedy in need of charity (for whom telethons and fund raisers are held), or 'bludgers' (Hevey, 1993).

The importance of this rebellion against cultural stereotypes is, as Tom Shakespeare notes (1993 p.253), about 'the victim' refusing that label and the subversion of stigma in a society where:

The 'body beautiful' [is] exhibited in male and female 'pin-ups' and... the 'difference' of impairment is used as a cultural symbol or metaphor for all things bad (Chadwick, 1994 on line) and in which the socially valued roles are to seek wealth, material prosperity, material goods, health and beauty of body, youth and newness, competence, independence and intelligence, productivity and achievement, adult individualism and unrestrained choice, and hedonistic, sensualistic pleasure (Wolfensberger, 1983).

Jenny Morris (1991), in a critique of the films 'Born on the Fourth of July' and 'My Left Foot', notes that the portrayal of a man in a wheelchair is used to symbolise dependency and vulnerability. Mike Oliver (1996 pp.98-100) in a somewhat humorous critique of the cultural significance and the symbolic meaning of walking in language and popular music, highlights the ways that such media perpetuate stereotypical views of persons with a mobility impairment.

Thus, for the participants of this study (excluding those with quadriplegia), not being different could be seen as a rejection of popular notions of persons with disabilities as being either lazy, dependent, or heroic individuals. Persons with spinal injuries, above all, wished to demonstrate that they were, as Lorraine said, 'like anyone else'. But what is it makes an individual like anyone else?

The lack of a relationship between 'the normal' and independence or interdependence is indicative of the confusion persons with spinal injuries of all functional levels, including quadriplegia, have in defining 'the normal'. This confusion is brought about by a cultural rhetoric which demands that to be normal one must be independent.

...everyone agrees that human beings in society are interdependent, and yet, in daily life people tend to think of
healthy adults as persons who can take care of themselves, who are literally 'independent'. But of course, the best that people can ever hope to do is make sure that others take care of them...everyone depends on other people and almost everyone is needed by some others. That is what conveys to people their significance for their fellow human beings and that is where they find the fulfilment of existence (de Swaan, 1990 p.3).

Hence, the participants in this study could not comfortably define themselves in terms of independence. Yet there was a fear of interdependence and reliance on others. The self, however, cannot exist except in relation to others (Mead, 1934). Thus, the concept of normality which defines a person against a standard rather than in relation to others, could not define the social processes of persons with spinal injuries' ways of being in the world.

Although 'normal' was a term used by many participants in defining themselves, their understanding of normality consisted of establishing and maintaining essential relationships in their redefined lives, which were not different. To understand the plans of life of persons with spinal injuries of all functional abilities, the concept of social normality is needed.

Ordinariness, rather than normality

Whilst normality is defined against a standard—ordinariness is socially defined. To be ordinary is to be such as is usually met with and belonging to the fully recognised group (based on the definitions of normality and ordinary in The Macquarie Dictionary, 1981). Hence, in the context of service provision, the desired end to be achieved in the plans of life of persons with spinal injuries is best conceptualised as ordinariness.

Ordinariness is not about individualism, but rather is about the interdependence engendered by long-term, stable relationships. Independence, in this context, is compatible with Heumann's definition which states that 'To us, independence does not mean doing things physically alone' (cited in Frieden & Cole, 1985 p.738). Ordinariness is about the individual and social processes of adjusting to and living with long-term impairment, which cannot be defined according to medical or bureaucratic standards.

Being ordinary as the planned end to be achieved by persons with disabilities has, however, been deemed to indicate failure (Krause, 1992), or dismissed as inappropriate in the face of a normalisation rhetoric which implies that persons with disabilities should be actively seeking social roles valued by society. Such roles include the seeking of wealth, health and beauty of body, youth and newness, and individualism and unrestrained choice (Wolfensberger, 1983). Indeed, unwillingness to take risks to achieve such
roles has been labelled as a barrier to the personal goal of independence for persons with spinal injuries (Frieden & Cole, 1985), and as calculated defensiveness [which] while useful, must be combined with a clear vision of what life could be like for people if it were more enriched. In the face of the unanswerable dangers of living we should emphasise the things that make life richer not just safer (Kendrick, 1992 p.11).

There is a sense in Frieden's and Kenrick's views, however, that persons with disabilities should seek a life which is riskier, and somehow richer, than is the common experience of ordinary people. Whilst Stern cautions that basic needs (such as food, housing, safety) must be met before life enrichment can occur (Stern, 1993), life enrichment for the participants in this study was rooted in the ordinariness of their lives which facilitated the formation of 'the web of human relationships' (Moody, 1992 p.181) rather than individuality, normality or difference.

Understanding plans of life

The persons with spinal injuries in this study simply wanted to be ordinary, and not different, normal or self actualised. Indeed, other research into the roles of persons with spinal injuries have noted that the life plans of persons with spinal injuries are the same as everyone else, and their family roles and responsibilities remain the same as everyone else (Boldy, 1990; Frieden & Cole, 1985; Killen, 1990).

The central concerns of persons with spinal injuries, and the ordinariness of their plans of life can be seen in the stories of Norm, Dave, Rob and Jenny.

The stories of Norm, Dave, Rob and Jenny

Norm, Dave, Rob and Jenny all spoke about the importance of the ordinariness of their lives.

Norm and Mary spoke of the continuity in their life gained by living in a small town where everybody knows them and is friendly, as well as having long-term relationships with their Home Care workers. When asked to explain why they felt the service they received from Home Care was so good, when for others it was so poor, Norm explained:

We've had the same girl ever since we've been here. She is more like one of the family.

Norm, however, felt the confusion associated with the recognition of such interdependence, and so he went on to say, after a moments hesitation:
Although I wonder if that's not good.

The most important issue for Dave was to maintain the ordinariness of his essential relationship with his wife Julie. Dave was very sensitive to any threats to that relationship so, when they were battling with Home Care to get services, he was understandably:

so furious at Home Care for this pushing Julie to the point where she was breaking.

Dave and his wife Julie also spoke about the unhappiness created by the bureaucratic barriers to forming an essential relationship with a service provider, as Julie complained:

They don't want you to bond with anyone...
Dave interjected:
They don't want to become, to bond with anybody and that is absolutely ridiculous. (Laughing)
Julie added:
Because we do, our nature is to bond.
Dave continued:
And certainly when with personal care things, or anything you know, you really do need to feel happy with the person you're working with.

Rob and Jenny also spoke of the importance of the ordinariness of the activities in their changed lives.

Rob described his life:

I just do whatever everyone does in [my town]. I'm just one of the boys.

whilst Jenny spoke of picking her life up where she left off at the time of her injury:

We had fairly good back-up support, didn't we, when we came home?
And I picked up where I left off. I went back to, I was President of the church ladies' group so I went back to that. I belong to CWA I went back to that. I have outside interests and I went back to those.

Whilst all spoke of the ordinariness and essential relationships in their changed lives, only Rob and Jenny, who you will recall had complete paraplegia and some movement or sensory problems respectively, spoke about not being different.
Rob did not want to use services because services would be more appropriately given to other people—people different from him who could not look after themselves. According to Rob, however, such people should stop 'sit[ting] around vege'ing'. Jenny put it in terms of their not thinking 'that this world owes them something'. Against this background, Jenny often highlighted her own efforts to be ordinary, and avoid becoming a part of 'the system', for example:

He [the doctor] said, "you really don't want a full pension, do you?" And I said, "Not as long as I can work, but I don't want to have to fight the system all the time, you know."

The stories of Norm, Dave, Rob and Jenny illustrate that when speaking in the context of community services, ordinariness was important for all types of persons with spinal injuries. The concept of not being different, however, was characterised by persons with paraplegia or some movement or sensory problems only. This may be due to persons with greater functional abilities feeling greater pressure to appear either 'normal' or, conversely, 'different' in order justify their use, non-use or need for services in a culture of cost restraints in community service provision and heightened anxiety about measuring and meeting peoples' needs and preventing people 'sorting the system'.

This issue of the need for ordinary people to justify and legitimate their claims for services will develop, throughout this study, to be of central importance in understanding and addressing the community service needs of persons with spinal injuries.

Having established ordinariness as the desired end persons with spinal injuries wish to achieve, the next task in developing an understanding of need as a means to an end is to establish the role of services in realising this plan of life of persons with spinal injuries.

The role of services in life plans

The role of the state is to protect, support and enhance the capacity of citizens to formulate and exercise plans and purposes which are self determined. (Stainton, 1994 p.109) [Government] should not say to the community 'We know what you need' or 'You do not need what you think you need.' (Stern, 1994 online)

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Australian's concern to eliminate social security fraud is of such importance that a major advertisement used by the incumbent Coalition government in the 1998 federal election highlighted the amount of money the government has saved the economy by a 'crackdown' on fraud.
It would be reasonable to expect, on the basis of this understanding of the State, that persons with spinal injuries' desire for ordinariness would be supported by the State through the provision of services which would enhance peoples' capacity to be persons such as are usually met with, and who belong to the fully recognised group. Further, services should support persons with spinal injuries' desire to not be different. There is much anecdotal evidence, however, that limited government resources are failing to meet even the most basic needs of persons with disabilities.

It can be said with confidence that there will never be enough funding to meet all the demands of people with disabilities. It behoves the community to ensure that people with disabilities...are adequately accommodated, can participate in recreational and/or spiritual activities and feel comfortable in the community. (Stern, 1994 online)

It is well accepted that the success of persons with severe physical disabilities in living independently in the community, engaging in self-directed productive activities and staying healthy depends, in part, on getting and maintaining adequate personal assistance with such tasks (Nosek & Howland, 1993 p.789) (see also Berkowitz et al., 1992; Gething, 1995; Nosek et al., 1993; Oliver et al., 1988).

It was clear from Stage Four of this study that services were an important part of peoples' lives, however, the evidence that persons with spinal injuries could perceive services as both beneficial and harmful suggests that services may not always contribute to their plans of life.

To examine the role of services in the plans of life of persons with spinal injuries, a matrix was constructed in which the central concerns of the participants were categorised according to their response to or feelings about the context or issues.\textsuperscript{19} Dependency evoked both positive and negative responses. The interdependency associated with having essential relationships with service providers evoked a positive response (n=6), although two of these participants expressed concern that such relationships could be viewed as being dependent. The enforced independence associated with having to adapt to a changed life 'on their own' aroused feelings of both considerable anger with the poor treatment or abandonment by service providers, but also a sense of pride in accomplishment. The dependency created by rigid modes of service provision was viewed negatively.

Four participants responded positively to their changed life—feeling that as a result of their spinal injury they could participate in normal life activities they could otherwise not have, such as being able to stay home with young children, or, in Rob's case, having a 'party life'. These positive feelings, however, were not associated with the provision of services. In the three

\textsuperscript{19} These were the 'response' codes developed in the process of conducting the analysis of perceptions of intrinsic need (Stage Four of this study).
cases where participants attributed changes in their lives to the provision of services, this change was considered deleterious to the participants' normal life.

The services can have a role in both supporting and hindering the realisation of plans of life. These roles are well illustrated in Jim's recollections of his encounters with service providers:

More information, not for me but for my wife, not, oh I hate the word counselling, but advice as to what to expect and how useless I would be. I think it would have been better if there had been more help in the house more quickly, because the children were only young, my daughter was only one, and my wife really couldn't cope. I had a friend who was an occupational therapist and she said that my wife wasn't coping, but my wife said, "I can manage, no, no help. I can manage". When the help did come it was too late really. And anyway we didn't know where to go for help.

Yes, my wife went very strange. She complained that all the visitors came to see me, never to see her. It would have been difficult. Eventually a lady came two hours every day but it took a while to get that. The first months were difficult. No-one seemed to understand. Nobody explained to me how I would be and I didn't know who should tell me and so the first three months set the tone for the next six years until she left. It's funny though, my wife and I are still friends, but she can't cope with seeing me face to face. She can talk to me for ages on the telephone, but not face to face. She only lives a minute or two down the road here.

[So how has life been since then]

Life's been pretty stable since then. More peaceful. I didn’t have to worry about what I say any more, but even so, I was terrified that my wife would leave. It was the most frightening thing. I wondered how could I possibly manage on my own. It was very scary.

[So how did you manage?]

I've surprised myself with a lot of things, like driving the car. I thought gosh I'm never going to be able to manage this, but it is amazing that you can. Amazing just how you just kind of cope. You just manage somehow.

[Has there been anybody who helped you?]

There's been one wonderful person. She was the first person from Home Care. She was a tower of strength. She came everyday. A tremendous friend. She helped me to understand that my wife had a problem. She stayed with me 2 or 3 days a week on and off for six months when my wife left. She even postponed her wedding to look after me. We are still good friends. She was the key to my survival.
This case provides some classic examples of the role of services in the lives of the participants. Firstly, there is clear evidence of the impact of the lack of services on the life of this family. The failure to provide timely intervention (counselling) exacerbated Jim’s feelings of being different—useless and helpless. This clearly contributed to Jim’s inability to maintain an ordinary, essential relationship with his wife in the period immediately following his return to his community. Significantly, the instigation of a long-term, stable relationship with a service provider (Home Care worker) led to Jim’s increased belief in his ability to participate in ordinary activities.

Contributing to life plans

There is evidence, in the case presented above, as well as from thirteen other participants, that services contributed to the life plans of the participant where they were delivered to a persons with spinal injuries within an essential relationship. Persons’ understanding of ‘good’ services, particularly in the case of personal care from the Home Care Service of NSW, was based in the reciprocity, familiarity, continuity and stability of the relationship between themselves and the service provider:

\[ I \text{ had a lady from Home Care. She has been like a mother to me.} \]
\[ (Gwenda) \]

For Charlie and Sharon, the most important aspect of their current personal care service was that, by using the Attendant Care scheme and being the employer, they could choose to hire suitable persons with whom they could establish a stable and continuous employer/employee relationship.

Services also contributed to the plans of life of nine participants where their presence facilitated the maintenance of stable, ordinary relationships with family and friends. For example, Christine’s personal care needs were attended to by Home Care workers. Christine was thus able to maintain an essential relationship with her brother and sister-in-law about whom she said ‘I don’t know what I’d do without them’. Christine’s brother attended to Christine’s daily physiotherapy needs, but this activity was rooted in ordinary long-term play between siblings, that is, it was defined within the realms of their ordinary experience. Christine’s sister-in-law jokingly described the daily physiotherapy sessions:

\[ Oh, \text{ he gets her out there and tortures her, in the torture chamber.} \]
\[ \text{And they argue non-stop, in a nice way. Get one another going.} \]

For twelve participants, services directly supported their desired plan of life of not being different and participating in ordinary life activities. For Cheryl, the availability of a disabled taxi was useful.

\[ We’ve even got a disabled taxi now which is good. [The taxi] enables you to get in and out if you don’t want to take the car and have a few \]
drinks with dinner or whatever, so I think that's really important that they're available.

For Nerida, the availability of a personal care service in the morning, together with a disabled taxi, facilitated her entry into the workforce, although unfortunately the unreliable nature of the taxi service was seriously jeopardising her continued participation.

There was, thus, evidence of services contributing to the achievement of life plans. In this study, as well as that of Oliver et al. (1988 p.129), services which were most likely to be perceived positively and which most contributed to maintaining the ordinariness of persons' lives were those which were delivered under the control of, or 'in partnership' with the person with spinal injuries. Indeed, although focussed on social relationships, a higher number of reciprocal relationships has been shown elsewhere to be related to better mobility, health, social integration, and economic self-sufficiency for persons with spinal injuries (Anson et al., 1993; Rintala et al., 1994).

There was, however, evidence that inconsistent or unreliable services, the withdrawal of services and a lack of services were jeopardising the life plans of persons with spinal injuries.

Jeopardising life plans

Some services were doing little to contribute to the realisation of the plans of life of persons with spinal injuries, indeed, they could be said, at times, to be running contrary to them—damaging essential relationships and stereotyping, rather than supporting the desire to be ordinary and not different.

There was evidence, from Jim, Dave and Carl, of Home Care management actively undermining stable, long-term relationships between persons with spinal injuries and individual service providers. Carl likened the management's behaviour to

*the nuns in the convent in the olden days. If two nuns became too friendly then they would split them up—it's not natural.*

Brendan, Andrew, Stuart, and Carl commented that changeable services and the lack of services had a deleterious effect on their essential relationships with their wives, who had to undertake the role of a carer, rather than a wife. Andrew commented:

*I think the worst thing about [service providers], [my wife] was a nurse and everyone expected her to be my nurse and you know, you've got to just, she's your wife, not your nurse.*
This resulted in not only a challenge to their relationships, but also heightened awareness of being different, as illustrated in Carl’s tale of a visit to a restaurant.

[Because of problems getting a taxi] one day [my wife] pushed me from where we lived all the way down to a Chinese restaurant near the bridge. She pushed me up and down, there were no lips on the gutters so she had to lower me down and take me across the road then tilt the chair back and get me up and it was a hot summer’s afternoon and the flies were out. She was hot and by the time we got down there her hands were all red and she was crying her eyes out and I was just so upset that she was crying, you know for her. Again you feel like this terrible burden, you see.

For Stuart, his brief contact with, and the subsequent withdrawal of rehabilitation services convinced him that he was different, and destined to remain one of ‘the other’.

The rehabilitation service was a hindrance to me because what the outcome of my I.Q. test was that I can’t study I’m so dumb... I was so brainwashed by their I.Q. test results that I can’t study because I’m dumb. So instead of helping me, they hindered me and they, the exercising after they followed it up for two sessions after I left hospital, at the end of it they didn’t follow it up or anything.

After ten years of ‘wasted opportunities’, Stuart challenged this belief, and is now studying at university and maintaining a credit average in a prestigious professional degree.

So whilst the literature suggests that having services is essential to the lives of persons with spinal injuries there is evidence in this study, as in others, that services are in many ways failing to meet the needs of persons with spinal injuries (Wilson, 1993).

Some commentators feel that this failure is the result of a mis-match in purposes between service providers and their clients. 'Clients seek services and benefits; ...bureaucrats seek control over the process of providing them' (Lipsky, 1980 p.60). 'Tensions also develop where generic legislation [such as the Disability Services Act 1986] is intended to meet the needs of people with disabilities, but what they receive in practice is inappropriate or inadequate to meet their needs' (Stern, 1994 online). As Kendrick points out,

All service systems are prone to inequity and meeting needs and priorities other than those of their formal clients... Further, meeting the needs of individuals may not be of paramount importance to agencies and thus one can routinely expect much that is irrelevant in the content of services. (Kendrick, 1992 p.15, emphasis in original ).

Nevertheless, a great deal could be achieved by changes in the attitudes and practices of community service providers (Oliver et al., 1988) so that services
are delivered in a manner which contributes to persons with spinal injuries' life plan of ordinariness—particularly not promoting difference, and maintaining essential relationships. It is paradoxical then that under the current policies of need-based assessment, rights and individual autonomy, the most humanising elements of life, essential relationships, can be the most neglected (Moody, 1992). For, as desired by the participants in this study; 'Care' must be reciprocal, and such a concept of 'reciprocity' must not imply that the giving and taking should be in equal measure, but rather according to diverse need across the entire population... For what we seek is the realm of the gift, a primary orientation to reciprocity rather than to the ruthless pursuit of self-interest. (Branson & Miller, 1992 pp.20,26)

The importance of the unanimity or mis-match of purposes between persons with spinal injuries and community services can be illustrated in a model demonstrating the way services can either contribute to, or jeopardise the plans of life of persons with spinal injuries' (Figure 26).

Figure 26. Model of plans of life and the role of services
Understanding the role of services

Services can either operate in partnership with persons with spinal injury and assist them to realise their plan of life, or they can operate contrary to them, forcing a change from a life of ordinariness to one of difference. In reality, however the situation is not quite so clearly polarised. Different aspects of service provision, even within one service to a single individual, can both support and jeopardise plans of life. The stories of Norm, Dave, Rob and Jenny provide some good examples of the role of services in plans of life.

The stories of Norm, Dave, Rob and Jenny

Norm was certainly the recipient of 'good' service from the personal care workers provided by the Home Care Service of NSW. As Norm stated:

They [Home Care workers] help to do my personal care. Really, they will do any mortal thing...It's a two way thing. You have to respect them.

The relationship between Norm and Mary and their 'girls' was essential to the ordinariness of all their lives. Mary spoke of the 'girls' presence on family occasions, and of the garden cuttings she had propagated for them.

Unfortunately, for Dave and Julie, their relationship with their Home Care worker, whom they described as 'like our best friend', was being soured by administrative haranguing over fees, and the threat of withdrawal of services. This behaviour was damaging not only the essential relationship with the worker, but also Dave's relationship with his wife, whose ability to stay calm in times of crisis had been an essential cornerstone of their long marriage. Julie described her current state of mind:

I guess what I'm saying is that I cope with Dave but I must be skating on the edge and it just takes something silly and the tears come. And this situation, we've had Home Care here now for 11 years, three hours a week and never asked, never been asked to pay, and we've had this three hours a week and we've never abused it. Anyway this last assessment we had this lady came and she was, I suppose, a bit officious. You know, she knows her job and she was doing it. We were asked questions that we weren't prepared for... I hadn't said a word but I really worried about it. Worried and worried and cried myself silly over it and I was, just felt angry and I couldn't work out why.

Jenny was also very angry about her treatment by a service provider. She spoke of the condescending and patronising attitudes of the physiotherapist who was teaching her to walk:
[Physiotherapists'] attitude to spinal - whether it's their attitude to spinal injuries or whether it's that they don't understand spinal injuries - it's probably a bit of both in the end. But I found that, you know, even my daughter said to her father, surely mum doesn't have to put up with that. You know, just that whole attitude.

Jenny reported that when she could not complete a therapy task, the therapist would sarcastically say, 'Well, you should be able to'. Jenny certainly felt like she was being stereotyped as a 'bludger'.

Rob was also the victim of stereotyping, as someone who is, or should be, dependent. Rob felt he was capable of attending to the care of a burn on his leg. The services refusal to provide Rob with the necessary materials meant that he had to remain at home, and not participate in some of the ordinary activities he had planned:

The nurse just came. [She would do the dressing] and they did come off, so I still had to get in touch with her. It did cut into me hunting and me going away.

Services have very different roles in the lives of Norm, Dave, Rob and Jenny. One is still left wondering, however, why Norm and Dave have such different experiences? Why was Jenny made to feel like 'a bludger'? Why were dependency and difference forced upon Rob? What is occurring at the nexus where persons with spinal injuries meet service providers which determines whether services will support or jeopardise plans of life? Under what conditions were persons with spinal injuries able to obtain the services which are essential for their plans of life to be carried out?

Identifying these conditions is the next task in developing an understanding of need as a means to an end.

Conditions for getting services

[A welfare society] can exist if the public, the politicians and the administration fully accept the legitimacy of the claims, take them seriously and give them a high degree of priority. Against this background operate various forces, latent and manifest, which constrain all those on whom the implementation of the claims depends to carry out their duties honestly, impartially, consistently and in accordance with the intentions of the legislation on which the service is based. (Marshall, 1981 p.89)

It was clear from the comparative need analysis conducted in stage three of this study, that any individual person's access to services does not seem to be
based on any objective criteria. So, what was selection based on? Under what conditions are persons with spinal injuries able to obtain services which support their plans of life? What were the 'latent and manifest' forces which determined these conditions?

Blumer (1969) contends that people note, interpret, and assess the situations confronting them based upon the common and pre-established meanings of what is expected in the actions. Determining the conditions for obtaining services thus involved searching the discourse of persons with spinal injuries for the underlying meanings and expectations of the actions of both persons with spinal injuries and service providers. This discourse was located in the dyad of ordinariness and difference. To examine this discourse, the text from the interviews and comments was coded for whether the actions of service providers, as interpreted through the actual or expected reactions of persons with spinal injuries, were supporting ordinariness or difference.

Within the dyad of ordinariness and difference, or in the language used by persons with spinal injuries—the 'normal' and the 'disabled', two common meanings of what was expected in the actions of persons with spinal injuries were identified from the stories of the participants—the ascendency of providers and meeting the expectations of providers.

Ascendancy

Ascendancy is a position of dominance or controlling influence. Whether persons with spinal injuries could obtain services to support their plans of life, or had services which jeopardised these plans, was based upon who had, and who desired the controlling influence in the relationship between the service provider and the person with spinal injuries.

For eighteen of the thirty eight participants who spoke in any way about the relationship between themselves and providers, the relationships were characterised by the control exerted by providers over their clients' lives, impacting on even the most basic of life plans:

Thinking back more about services, really, the carers dictate your lifestyle. Conformation to particular regimes is mandatory. There is no making lifestyle choices.
(Brett)

We requested to have Home Care on Sunday instead of Saturday so that my husband can come to church with us. But Home Care can't come at the appropriate time on Sunday. So for him to come with us I would have to get three people ready to go out by 9.30 am, near impossible so what do we do, as we are at the mercy of Home Care.
(written comment from wife of a man with complete quadriplegia)
Service providers, the Home Care service of NSW in particular, asserted their ascendency by being 'nosey', invading peoples' privacy and exacting retribution upon anyone who complained. Transport services, particularly taxi cabs, were rude and inconsiderate, and paramedical services asserted their ascendency by belittling the efforts of participants and limiting the supply of services. The actions of service recipients were expected to be totally acquiescent to the ascendency of the providers by being:

...very grateful and put up and shut up.
(written comment from man with complete quadriplegia)

A small number of persons with spinal injuries, however, refused to submit to the ascendency of the providers and dispensed with services altogether, albeit, at some cost to their essential intimate relationships:

They tried to help us with personal care provided, but it’s so much bureaucracy around the personal care scene that I said to myself, my wife can help out, so my wife is sort of the personal carer, more a personal carer in a lot of things. Because I have a way out of here rather than having the headache of the bureaucracy with the assistance, you know? We quarrel sometimes because she doesn’t want to do it, but she has to do it for me and if I can help it, I’ll do it myself, you know, just to avoid the quarrels in the house, you know.
(Stuart)

There were rare occasions where a person with spinal injury had the controlling influence in the relationship between themselves and the service provider. This was certainly the situation for the three participants who were:

...lucky enough to be a part of the Attendant Health Care Scheme, which gave us back the control over who we employ, for all my husband’s personal care needs.
(Charlie’s wife)

and also where there was a good personal relationship with services at the individual provider level:

We went to the taxi rank there, the driver didn’t refuse. But it’s insulting and very offensive, nothing you can put your finger on to actually complain about. But the drivers who know me are very good.
(Gail)

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26 Please note that this study is not intended to level undue criticism towards any individual or type of service provider. This author recognises the influence on service provision of things such as funding levels, workloads, policies and legislation which are beyond the control of individual service providers. Nevertheless, this study is concerned with the meanings persons with spinal injuries attributed to the actions of service providers.
Thus, these persons with spinal injuries had to either resign themselves to the ascendency of the service providers and the resultant feelings of difference and dependency, or pay the cost of damage to essential family relationships. In either of these situations, persons with spinal injuries could not be ordinary. Life plans could only be realised in the rare circumstances where the client was ascendant, or working in partnership with the provider.

Providers' expectations—finding the middle ground

Beyond having to submit to the ascendency of service providers to gain needed services, twenty participants commented that their access to needed services was regulated according to service providers' expectations of the spinal injured population.

Independence, dependence, and care and respite services

Persons who were having difficulty obtaining care and respite services were those who believed that the service providers considered them either too independent:

_We had Home Care but my wife keeps the house very clean and tidy and everything right as it should be. So Home Care said ‘your standards are much too high for us to offer a service.’ If we lived in squalor, then they would help you. We were very angry about that._

(Richard)

or, conversely, too dependent on the receipt of services, that is, when the service provider felt that there were family or friends who should be providing the care:

_Home Care’s attitude is that because I have kids, the kids should do the house work. Why should the children have to do things other kids don’t because I am disabled. I’m made to feel guilty about using Home Care because I have friends and family who are supportive._

(Lorraine)

There was further evidence for this in the comparative need analysis undertaken in Stage Three of this study, which showed that those without everyday assistance (primarily provided by family members) were less likely to need professional services, but also more likely to have any service need met. Such persons could be being judged worthy of receiving services as they did not have any other sources of care, and would be thus suitably dependent upon services. In contrast, those with everyday assistance only have their needs partly met, possibly revealing a judgement by service providers that family should provide the needed care, and not be dependent on services. In addition, the persons most likely to have their need for Home Care personal care services at least partly met were those with complete paraplegia (only 4.3% totally unmet need), a group who could be considered,
at least in functional terms, to be in the middle, neither too dependent, nor too independent. In contrast, despite having a high level of felt need, nearly one fifth of persons with complete quadriplegia had their need for Home Care personal care services completely unmet.

Thus, the evidence in this study suggested that providers of care and respite services expected persons with spinal injuries seeking services to conform to notions of independence, being neither too independent, nor too dependent. On the one hand service providers expected 'a reliance...built on the notion of disabled people being 'dependent people' (Morris, 1994 p.25), necessarily 'subordinate and subject to the control of others' (Kestenbaum, 1996 p.4), whilst at the same expecting that people would be independent. This independence sought by persons with spinal injuries in this study was, however, more compatible with Heumann's definition which states that 'To us, independence does not mean doing things physically alone' (cited in Frieden & Cole, 1985 p.738). In this study, as in the 1800's, the truly deserving could be 'instantly recognized...by their rarity, concealment, and reluctance to accept help' (Kennedy, 1982 p.65). The 'deserving' were those who had become briefly dependent on relief through no fault of their own, and who, with some assistance, could return to independence: these were thought to be the proper objects of public sympathy' (Conley, 1982 p.282).

Marshall (1981 p.90) suggests that the reason for the discretionary award of benefits, such as care services, is based on a notion of the 'deserving poor' and:

lies in the relation between rights and duties... The obligation of the community to relieve destitution must somehow be matched by a duty on the individual not to become destitute, if he can help it. That is why the emphasis in the early poor laws was on the punishment of idle vagabonds... As it became increasingly difficult to do...these things, an easy substitute was found in reliance on the deterrent character of relief to keep the undeserving away.

Cure and paramedical services

Paramedical service providers were perceived by persons with spinal injuries of greater functional abilities as having the expectation that persons with spinal injury would engage in curative behaviour by engaging their services and enthusiastically undertaking the therapy offered:

They [paramedical services] were very condescending, saying that I wouldn't do things for myself, using terms like 'the girl makes no effort'.

(Gwenda)

Conversely, some persons with spinal injuries, particularly those with poorer functional abilities, once judged to have achieved as much as service
providers deemed possible, were denied any further access to paramedical services:

Obviously, they must have put in their file, patient rehabilitated or patient continuing well, end of file. That's the end of it. It would have been of more help if they didn't come into the picture at all, actually. Instead of intervening and making things look rosy at the beginning and then cutting themselves off from me as soon as they have fulfilled bureaucratic laws or whatever, you know. Just mainly the problem is the services are not followed up.

(Stuart)

despite the need for ongoing maintenance of health:

I would like to be able to do more physio but feel the resources are already stretched for people with greater needs. I would also like to see more concentration on staying fit and healthy, maintenance rather than simply treating people when they are sick or deteriorating.

(written comment from man with complete paraplegia)

The comparative need analysis conducted in Stage Three of this study provides further evidence of the concentration of paramedical services, physiotherapy in particular, on persons with minimal functional impairment and those with incomplete lesions, rather than on persons with more significant, or complete impairment.

Persons with spinal injuries seeking paramedical services needed to be able to demonstrate that they were engaging in curative behaviour, or had a possibility of being cured. The main purpose of medicine is the provision of acute and restorative care’ (DeJong, 1983 p.16). This purpose has little in common with the persons with spinal injuries' plans to be ordinary, even with long-term impairment. For the disabled, a major problem occurs when rehabilitation goals are decided by staff members and presented to patients as if engraved on tablets of stone. Patients have not been allowed to participate in the goal setting but, should they refuse to participate in the program,' or, as was also the case in this study, when the practitioner could see no further rehabilitative goals, 'they are labelled as "unmotivated" [or "rehabilitated"] and summarily discharged' (Falconer, 1982 p.142).

Insensitive and condescending attitudes have been shown to be quite common amongst physiotherapists (Johnson, 1993).

Access to paramedical services is thus based in a 'medical model' of care and results in the situation that, when confronted with more clients than can be accommodated, as is certainly the case with the provision of paramedical services for persons with spinal injuries, service providers;

Often choose (or skim off the top) those who seem most likely to succeed in terms of bureaucratic success criteria. This will happen despite formal requirements to provide clients with equal chances for service, and even in the face of policies
designed to favour clients with relatively poor probabilities of success...[due to the] gratification that comes with helping people who are thought likely to respond to help. (Lipsky, 1980 pp.107, 111)

Segregation and transport services

The participants in this study, particularly those using wheelchairs, were prevented from using transport services available to the general population, due either to transport services being physically inaccessible, or to the attitudes of service providers, taxi cabs in particular, who would refuse to provide a service, even where the person with spinal injuries could independently transfer themselves into the taxi seat.

Persons with spinal injuries were expected to only use transport specially designated for them. The number of taxi cabs which have been converted to be able to take persons in wheelchairs is very limited, however, both in major urban areas, and particularly in country regions. Consequently, a converted taxi cab can be available only by booking at least a day in advance, seriously limiting any spontaneity in the lives of persons with spinal injuries.

In addition, persons with paraplegia, rather than quadriplegia, who were capable of transferring themselves into a taxi cab were embarrassed when forced to use specialised transport.

One of the things that I do not like happened, it happened in Brisbane the other day was, you know, if I order a cab I might say, you know, there’s a wheelchair, yeah, just to say you know, they might bring a station wagon or you know, and then they turn up in one of them bloody things with a big ramp and a truck and a ramp comes down, and I said I’m not getting in that, and the bloke says 'this or you don’t go' you know? You’re in the back of this big truck, you know, with a big hoist and all the rest of it. You’d rather be as unobtrusive as possible. That’s one of my pet hates, I don’t like going in them things, yeah. Just an ordinary cab will do.

(Greg)

The dual impact of the lack of specialised transport for persons with quadriplegia, and the enforced use of specialised transport for persons with paraplegia, contributed to both these groups of persons with spinal injuries’ feeling that they were different, rather than ordinary.

Access to transport is considered to be a crucial to the participation of persons with disabilities in the community (Boldy, 1990; Oliver et al., 1988). Although commentators consider transport problems to be primarily the result of lack of funding, 'Solutions to transportation...problems require a basic belief in the expanding potential contribution of disabled persons' (Dunham, 1982 p.104). Thus, whilst some would argue that the provision of
segregated services can enhance participation in the community by catering for different needs and abilities;

We need...to transform these segregative environments to serve the interests of those so-segregated. Segregation needs to be a process that increases rather than decreases access to resources. (Branson & Miller, 1992 p.27)

Overview

Regardless of the criteria upon which the offering of the service was based, that is, independence or dependence, cure or segregation, the realisation of the plans of life of persons with spinal injuries, insofar as they relied upon services to achieve those plans, was mediated by service providers who had expectations of persons with spinal injuries based upon predetermined stereotypes.

Understanding met and unmet need for community services

This is not to deny that there have been some benefits deriving from needs-based provision in that the majority of disabled people now have more access to relatively more services and, on the whole, are less likely to end up in a segregated institution of one kind or another. On the other hand the price for those services is usually acceptance of invasions of privacy by a veritable army of professionals and the acceptance of services that the state thinks you should have or is willing to pay for, rather than those you know you need. (Oliver, 1996 p.69 emphasis added)

The task which was set for this final fifth stage of the journey was to understand what persons with spinal injuries know they need, by identifying their 'plan of life, then establish what activities are essential to that plan, and finally investigate the conditions which enable those activities to be carried out' (Miller, 1976 p.134). In completing this task it has so far been determined that:

- Persons with spinal injuries' plans of life are to be ordinary, and not different;
- The activities of services, whilst crucial in the realisation of these plans, more often act in ways which are contrary to these plans, with the notable exception of where services were controlled by or 'in partnership' with persons with spinal injuries; and finally
- The conditions under which persons with spinal injuries were able to obtain services were those of acquiescence to the ascendancy of providers and their expectations of persons with spinal injuries.
So, in relation to community services, what are the needs of persons with spinal injuries? Through the eyes of the participants in this study, the needs of persons with spinal injuries are for:

- a non-judgemental basis for obtaining community services, which
- contribute to the ordinariness of the lives of persons with spinal injuries, by
- recognising the ascendancy of the service recipient or working in partnership, to
- support the spinal injured to live with long-term impairment, maintain interdependent, reciprocal, and essential relationships (both socially, and with service providers) and participate in the community.

The need for non-judgmental services in this context should not be equated with the imposition of 'a rigidity of approach in administration...[which is] even worse if that rigidity arises from an assumption of omniscience or as a substitute for thinking' (Dr. Don Grimes quoted in Stern, 1994 online), but rather the removal of prejudicial expectations of behaviour based on traditional paradigms of the deserving poor, the medical model and segregation (Stainton, 1994), because;

The truth is that almost any benefit or service that is really designed to satisfy a particular individual need must include an element of discretion. For the assessment of needs in an individual case, and of the measures that are best suited to meet it, involves an act of personal judgement...Discretion exercised in this way does not make a right inferior in quality to other rights. On the contrary, it is from some points of view superior, because the question asked in each case is not 'What do the regulations say must be done?' but 'What action is most likely to produce the desired result?'. (Miller, 1976 pp.87,88)

Thus, the needs of the spinal injured population may be best understood in terms of the impacts of the actions of services providers on the plans of life of persons with spinal injuries. Lipsky (1980) has noted that 'After sustained exposure to the welfare system... recipients have been found to see themselves as "undeserving" and "lucky to get anything at all". (p.66). In response, clients engage in strategies of passivity and acquiescence, and 'humbled acceptance of their own responsibility for the situation.' (p.59). For example, recall the wife of a man with complete quadriplegia who had wanted help on Sunday rather than Saturday so they could go to church:

...near impossible so what do we do, as we are at the mercy of Home Care.

Clearly this family has acquiesced to the ascendancy of the provider, resigned themselves to services which make them different and relinquished the realisation of their plan of life. Thus, whilst it is likely that organising services for this family could be problematic in an environment of 'inadequate resources in circumstances where the demand will always
increase to meet the supply of services', (Lipsky, 1980 p.81) Lipsky also notes that:

the individual level street-level bureaucrats often convey to clients that they should expect few services...Welfare clients are told by social workers that there is nothing that can be done to increase their benefits...The problems is that "nothing can be done" is only another way of saying that the bureaucracy or individual worker does not intend to change priorities. (p.63)

The focus on supply of services rather than their impact has resulted in another two alternative outcomes for persons with spinal injuries. 'We have traditionally funded the services, and it has been up the individual, their family and perhaps a social worker to access that service...This leaves the definition of need and how best to meet that need with the service provider.' If a person with spinal injuries does not fit the provider's definition, they are either 'shown the door', as in the case of this man with complete paraplegia:

> Obviously, they must have put in their file, patient rehabilitated or patient continuing well, end of file. That's the end of it. It would have been of more help if they didn't come into the picture at all, actually. Instead of intervening and making things look rosy at the beginning and then cutting themselves off from me.

(Stuart)

or choose to 'make do with...no service.' (Stainton, 1994 p.162), as illustrated by this man with complete quadriplegia:

> I just waited and waited and no nurse... and when this Sydney Home Nurse arrived with some feeble excuse, [my wife] let loose and said that was it, never again...So with that [my wife] said well, if that's the best you can do, don't bother. So [my wife] took over all those duties...There was just no letting up to a degree but we still both did very well.

(Carl)

The first of these two outcomes, as perceived by the person with a spinal injury, was the result of the man with spinal injuries being forced to acquiesce to the ascendancy of the providers judgement that he was not near enough to being cured to be worthy of services, having services refused and withdrawn with a resultant limitation to his realisation of his plan of life. In the second case, this man and his wife were able to assert their ascendancy, refused to abide by the judgement that they were not dependently grateful enough to be worthy of services, and refused to have the services which were being made available only upon adherence to the providers expectations of their behaviour. The resultant outcome was increased ordinariness in this couples’ life (although perhaps this may result in damage to their relationship in the long term). Both of these outcomes are the result of there being
few structural means for the person to influence the nature of
the services, except, as often was the case, to organize their own
alternatives. We can call this "structural paternalism" in that no
specific person is dictating what is in your best interest, rather
it is the structure which inherently makes this determination.
(Stainton, 1994 p.162).

None of the three alternative scenarios illustrated above could be said to
have resulted in the positive outcome of the participants' community service
needs being met, based on the definition of community services needs which
was grounded in the stories of the study participants. Only in circumstances
where persons with spinal injuries received non-judgemental community
services which contributed to the ordinariness of their lives by recognising
the ascendancy of the service recipient or working in partnership, could it be
said that the needs of the persons with spinal injuries were being met. For
example, Charlie's wife commented that they were:

...lucky enough to be a part of the Attendant Health Care Scheme,
which gave us back the control over who we employ.

and Jim who, after struggling to get some assistance, eventually enjoyed the
ordinariness of an essential relationship with a service provider:

...one wonderful person. She was the first person from Home Care.
She was a tower of strength. She came everyday. A tremendous
friend.

In both these cases the providers judged the person with spinal injuries as
worthy of services which were supplied as either client controlled, or in
partnership, and which contributed to the ordinariness of the lives of these
persons with spinal injuries. Unfortunately, this scenario was the least likely
to be reported by the participants in this study. There were ninety six
instances of interaction with services reported by the seventy persons with
spinal injuries who were included in this stage of the study.\(^3\) Only sixteen of
those interactions fitted the criteria of meeting the needs of persons with
spinal injuries as determined in this study.\(^2\)

The four possible outcomes of the community service needs of persons with
spinal injuries are illustrated in the model shown in Figure 27. The model
clearly illustrates the way that judgements of worthiness and the ascendancy
of service providers can have a profound effect on whether the community
service needs of persons with spinal injuries are likely to be met.

\(^3\) For the 11 cases where a carer wrote a comment in their survey reponse, the written
comments of the person for whom they cared were also included in the study. In these cases
both participants wrote about the same interactions. The carer comments have thus been
excluded from this final part of the analysis.

\(^2\) Other service provision may have also met the criteria, and not been included because of
the sparcity of detail in many of the written comments.
A judgement of worthiness, based upon service providers' expectations, occurs at the nexus where the person with spinal injuries meets the provider. If the person with spinal injuries meets expectations and is judged worthy of receiving services, the plan of ordinariness can be achieved in situations where the service recognises the ascendancy of, or works in partnership with the client. Alternatively, if judged worthy to receive services provided where the service provider enforces their ascendancy, the person with spinal injuries must become resigned to services which promote difference, rather than ordinariness.

If the person with spinal injuries does not meet service providers' expectations, the person with spinal injuries can either assert their ascendancy and refuse to use services, or alternatively, submit to the provider's ascendancy resulting in the withdrawal, or the refusal of services.

Yet, despite the fact that so few interactions with service providers met the criteria for meeting need, the level of participant satisfaction with services was very high and most interviews were characterised by the extremely positive tone of the persons with spinal injuries. Why was it that the participants were 'happy' to be someone who, by their own definition, acted in a manner contrary to their own self-determined plans? Should one
wonder to what extent the plan to be ordinary was the true plan of life of persons with spinal injuries?

The truth or otherwise of persons with spinal injuries' representation of themselves, from an interactionist perspective, can only be known from the actions, reactions and interactions of those involved and the meanings they attached to them (Blumer, 1969). It was these meanings and representations of persons with spinal injuries with which community service providers would interact, and these are thus the 'truth' for this study. The apparent willingness of persons with spinal injuries to follow a plan of life contrary to their own can be explained by the perspective that people can only be what others allow them to be.

Only in so far as he takes the attitudes of the organized social group to which he belongs towards the organized, co-operative social activity or set of such activities in which that group as such is engaged, does he develop a complete self or possess the sort of complete self he has developed...He becomes a self in so far as he can take the attitude of another and act toward himself as others act. (Mead, 1934 pp.155, 171)

This understanding of the construction of the self explains the complexities of the central dyad in the plans of life of persons with spinal injuries—ordinariness and difference. For persons with spinal injuries, taking the service providers' attitude of judging the worthiness of persons with disability (so as to stereotype persons as dependent, bludging, lazy or a 'super cripp') would necessarily involve acting contrary to their own plan of life of ordinariness. This may have especially been the case in this study. Being injured as adults, the participants in this study would have had a very clear sense of what 'the other' was—the role was within their realm of experience.

In addition, the participants in this study, particularly those with less significant impairment such as having some movement or sensory loss, or incomplete paraplegia, in particular, could have been taking on the role of 'the other' in order to present themselves as the type of person that service providers would favour—taking the role of 'the other' in order to legitimate their claim for services. For these people, the conflict between being ordinary, and being the different other was most pronounced.

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23 This study was not intended to be a study of the extent to which participants may or may not present themselves truthfully, although it was very important to the participants that they could identify the researcher as one of their group, that is, someone with close personal experience of spinal injury.

24 The fact that the quantitative data gained in this study recorded lower levels of satisfaction with services than those reported in Home Care's own study of their organisation, which was conducted at the same time, tends to suggest that the participants in this study were reasonably satisfied that the researcher was, to some extent, 'on their side'.

25 The gendered language used here, whilst no longer generally acceptable, was commonplace at the time Mead was writing. The term 'he' should be thus be taken to represent persons of both genders.
In understanding need as the means to an end, an end at which there is conflict between the ordinariness desired by persons with spinal injuries, and the difference often imposed by service providers, there is finally a conceptual framework of need within which the community service experiences of Norm, Dave, Rob and Jenny can be understood.

Norm, Dave, Rob, Jenny and their families are existent individuals. They are not composites of elements of a number of different individuals gathered together in order to construct four fictitious types of typical, or representative characterisations. Nevertheless, these four people, in their similarities and differences, have captured the essence of the compatibility and the conflict between the plans of life of persons with spinal injuries and the actions of service providers, and the struggle between ordinariness and difference.

The stories of Rob and Jenny

The ordinariness of Rob's life was one of its most enduring characteristics. Rob was so ordinary in his community that his mobility impairment was often completely invisible. Rob was vehemently opposed to being made to feel 'needy'. Rob had adopted the view that there exists 'the other' who are different from him—'people in chairs' who are 'sitting around vegetable'.

Consequently, when Rob came into contact with a service provider, his reaction was to reject their attempts to force normatively defined notions of dependency and difference upon him, and fiercely assert his ordinariness. Rob was eventually successful in disrupting the efforts of the service provider to make him different, and was ultimately supplied with the equipment he needed for self care.

When plotting Rob's interaction with service providers on the conceptual framework of need as the means to an end, it is possible to illustrate his continual assertion of ordinariness, through the rejection of services (Figure 28). Services had no place in Rob's life.

Jenny's efforts to maintain her ordinariness was a persistent theme. Jenny, with the help of her husband, was able to maintain her ordinariness, however, 'When an incident occurs [such as Jenny's husband going away with his friend], the reality sponsored by the performers is threatened...thus forcing upon the audience an image of the [person] behind the mask' (Goffman, 1959 p.212). Consequently, Jenny's conflict between ordinariness and difference only occurred in the context of 'incidents' involving her husband who was her fellow performer, and without whom Jenny could not maintain her ordinariness.

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26 Pseudonyms have been used throughout.
Jenny, however, was refused services, and hence, in a sense she had a most difficult dilemma—the dilemma of the nearly-walkers (Oliver, 1996). Jenny tried to avoid 'the system' and was highly critical of those 'others' dependent on 'the system' who were different to her. The refusal of services to help to maintain the ordinariness of her essential relationship with her husband and the ordinariness of her own life when her husband was absent, however, enforced the realisation of her own difference, as illustrated in the model of Jenny's interaction with services (Figure 29).

For persons with paraplegia or some movement or sensory problems, it was possible to realise their plan of life in the absence of services. Such persons could reject normative notions of community services need and expectations of dependence, illness and segregation, which did not support their plan of life, such as Rob did, by having no expressed or felt need for services.

Contrariwise, it was also possible for community service providers to reject the felt need for services to support ordinariness for persons with paraplegia or some movement or sensory problems. Service providers could do so on the basis of normative definitions of need and expectations of peoples' independence, curative and participatory behaviour, which removed from them the imperative to view the felt needs of persons with paraplegia or some problems as normatively justified. Such was the case for Jenny's needs.
For persons with quadriplegia such as Dave and Norm, however, physical impairment could impose limits to the extent to which they could reject services which did not support their life plans. These same impairments also imposed legislatively defined limits upon providers' ability to refuse services to persons who were normatively defined as 'needy' (particularly in the case of personal care services). These legislative and physical limits, however, did not necessarily result in persons with spinal injuries (in persons with quadriplegia) having services which would support their plans of life.

The stories of Dave and Norm

The most striking feature of Dave's and his wife Julie's life was their exhaustion from fighting to maintain an ordinary life in the face of services determined to highlight their difference. For many years they had had an ordinary life supported by an essential relationship with a service provider who was, as Julie described, 'like my best friend.' The presence of new service management and assessment had had the result that;

"The previous and expected interplay between the teams is suddenly forced aside [by the officious administrator] and a new drama forcibly takes its place." (Goffman, 1959 p.210)

By changing 'the audience', the service provider ensured that the 'danger of affective ties between performers and audience', which challenged providers expectations of both dependence and independence, was counteracted (Goffman, 1959 p.215). This rapid and unexpected change, for which they were not prepared, allowed others to see behind Dave's and Julie's masks, revealing facts about their lives which they had not wanted to be known, that
is, how different, rather than ordinary, life was when living as, or caring for, a person with high level quadriplegia.

Dave and Julie were fighting to regain the ordinariness of their lives, a role for which Julie was ill-prepared, because 'if one puts up his side of the case, asserts himself over against others and insists that they take a different attitude toward himself, then there is something important occurring that is not previously present in experience' (Mead, 1934 p.196).

Hence, although the couple were continuing to battle the service provider, there was a clear sense that this lack of experience would ultimately force them to become resigned to having services which were counter to their plan of life. As Dave said, 'So you have to accept it that in, you'd like to tell them what they can do with it,' to which Julie replied, 'It's not going to do any good.' This resignation to difference is apparent in the model of Dave's interaction with services (Figure 30), where the person with a spinal injury is forced into a path parallel to the role of services.

Figure 30. Dave's interaction with services

In contrast, Norm's and Mary's plan of ordinariness was supported by an essential relationship with a small group of service providers, which had not been challenged. The reciprocal, continuous, stable relationship between Norm, Mary and their 'girls' facilitated ordinariness as '...we may expect individuals to relax the strict maintenance of front when they are with those they have known for a long time, and to tighten their front when among persons who are new to them' (Goffman, 1959 p.222).

Norm and Mary were very aware of the importance of these essential relationships with a small group of service providers. The ordinariness of their lives was, to a great extent, based upon their continuation, as;

It will be apparent that an automatic way of ensuring that no member of the team or no member of the audience acts
improperly is to limit the size of both teams as much as possible...Other things being equal, the fewer the members, the less possibility of mistakes, "difficulties," and treacheries. (Goffman, 1959 pp.218-220)

By having a small team of committed workers with whom they had an essential, non-judgmental relationship, the role of the services acted in parallel with the wishes of Norm and Mary, to realise their plan of life (Figure 31).

Figure 31. Norm's interaction with services

A different concept of services

The model of need presented in this study gives a clear indication of the community service activities which produce positive outcomes for the plans of life of persons with spinal injuries, as well as those which are failing to meet their needs. It is clear that the issue of meeting need is not simply one of more resources or services. Positive outcomes were affected by more fundamental issues than these—issues of traditional paradigms and ideologies, problems of power and conflicting roles and plans, which limit the ability of many services to support any real and enduring change in attitudes to the needs of persons with spinal injuries.

The challenge for community service providers is to actively avoid the pitfalls of tradition and habit, and to commit to ensuring positive outcomes, as determined by persons with spinal injuries, are achieved.

So, we may now answer the fundamental question, as articulated by Stern (1994);
How can support be improved, for people with disabilities and their families?
Meeting Need

The level of unmet need for services highlighted in this study clearly indicated that not all those who needed services were able to obtain them. Indeed, there were very few persons with spinal injuries whose needs were fully met nor even any distinguishable subgroups whose needs were met. How can this be? Current methods of identifying and meeting the community service needs of persons with disabilities are legislatively premised upon concepts of 'fair and equal access to essential services' and the right of individuals to 'realise his or her individual capacity for physical, social, emotional and intellectual development' (Commonwealth Department of Health, Housing and Community Services, Comcare, & Australian Council of Trade Unions, 1992 p.13-16). Such rhetoric would suggest that everyone who has an identified need for services to realise their capacity for development should have such services provided. There is no sense in this 'rights' framework of the need to prioritise.

If all persons have the right to services, and services have an obligation to provide the means for persons with spinal injuries to realise their capacity for development, there must be some ambiguity about the concept of 'need' as articulated in policy and legislation and interpreted by service providers, and 'need' as understood and lived by persons with spinal injuries.

There are multiple understandings of the concept of need, and this study commenced by asking whether the community service needs of the spinal injured population could be 'defined according to standards of communal life' (Billings & Cowley, 1995 p.722)? Would it be more useful to determine who is 'needy' or what is 'needed', or the outcomes to be achieved by meeting need? The question was 'Which understanding of need best describes the community service needs of the spinal injured population of NSW?'

This study has clearly shown that persons with spinal injuries' need for community services may only be understood on the basis of the contribution services make to the realisation of the plans of life of persons with spinal injuries. Persons with spinal injuries want to be 'like everyone else'. They wanted to be ordinary, not made to be or feel different.

Ordinariness as a plan of life for persons with spinal injuries, however, is problematic for service providers who need to be able define the goals and roles of persons with spinal injuries in terms of an objective standard. Ordinariness has little to do with level of impairment, or other objectifiable characteristics. Services may be able to make judgements about people based on standards of normality—but they could not judge ordinariness because
each person’s ordinariness can only be assessed according to the social world in which the individual interacts.\(^1\)

Normative need, defining who is ’needy’ requires that there be a demonstrable difference between persons with spinal injuries and the general population. The spinal injured population of New South Wales could be clearly demonstrated to be ’needy’ defined by normal standards of employment and functional ability. Such information may be useful in determining overall funding required for service provision, however, these population based normative definitions of need did not give any indication about what services were needed, nor did they encompass persons with spinal injuries’ individual experiences of the need for services.

It may be more reasonable to determine what types of service are ’needed’ by which ’needy’ persons by studying the services that are currently used (expressed need), or desired by persons with spinal injuries (felt need). Such considerations of need are the basis for historically based funding, that is, the continued supply or expansion of those services which are currently being used for persons already using them—or for others who present similar characteristics.

Felt and expressed need in this study was thus determined by collating service utilisation and obtainment data and considering their relationship to epidemiological and social indicators. Community services were not being provided to persons with spinal injuries on the basis of felt need, however, for if this were so, the level of expressed need would be equivalent to the level of felt need, that is, no-one would be unable to obtain the services they felt they needed.

Providing or prioritising services on the basis of felt and expressed need is based upon the assumption that the services which were currently being used were those which persons with spinal injuries most needed, or wanted. This may indeed be the case for everyday care services, however, whilst Attendant Care, for example, did not rate very highly on the rank ordered list of prescriptive need priorities,\(^2\) this may be due to the limited availability of Attendant Care places such that persons with spinal injuries had to substitute this with Home Care. Contrariwise, it would not be appropriate to suggest that everyday care services be curtailed in order to address the high levels of prescriptive need for paramedical services, as one cannot be considered to be a substitute for the other.

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\(^1\) It may well be that persons who were defined as ’the other’ by the ’ordinary’ people in this study would also consider their lives to be ordinary according to the social world in which they interact.

\(^2\) Attendant Care was ranked seventh out of sixteen services.
There is also the inherent assumption in felt and expressed understandings of need that those who were currently using services were those most in need of them. This study clearly indicated that those persons with spinal injuries whose felt needs for services were met were, on objective criteria, generally no different to those whose felt needs were not met. Only half the people who needed services could obtain them, and it was not possible from an assessment of comparative need to decide whether any one group of persons was more needy or different than any other, except where persons with more significant impairments had a higher felt need for services. But even though such persons' felt need was different, their chance of having that need met was no different to most of the spinal injured population.

So how did service providers decide who needed what resources when the characteristics of those who had services were the same as those whose need for services was unmet? Indeed in the rare situations where those with met and unmet need were different, as in the need for paramedical services, services were directed towards those with the lowest felt need, rather than the highest.

It certainly was clear that the distribution of services amongst persons with spinal injuries was not based on any population based definition of need or difference, nor, for the most part, on any definition based upon the objective assessment of individual characteristics such as level of impairment, age or gender. In the face of persons with spinal injuries' desire for ordinariness, measures of need based upon the necessity to demonstrate difference can not explain, nor assist in addressing the community service needs of persons with spinal injuries.

Rather than deciding which services should go to whom on the basis of non-functional, so-called 'objective' assessments of normative, felt, expressed, prescriptive or comparative difference, it may be better to give priority to services that were perceived by persons with spinal injuries as being the most important, or achieving the greatest benefit. Services which were easily obtainable, flexible, reliable and cheap were seen by persons with spinal injuries as most beneficial. Could the answer be to direct funding towards improving the flexibility, availability, reliability and costs to consumers of community services? This has certainly been the response of service providers, as represented in the many reviews that have been undertaken. But if good services have these characteristics, and services with these characteristics are good, how should availability be determined? Can one trade flexibility for reliability, or costs for availability? When does the importance of having a service outweigh concerns about reliability? Mooney (1997 p.7) suggested that, the process of prioritising resources 'would be straightforward if all benefits could be measured in the same units.'

The prioritisation of community services for persons with spinal injuries may be better facilitated if it were possible to identify some universal criterion or criteria which persons with spinal injuries wanted to satisfy by having 'good'
services. The Disability Services Act (Commonwealth Department of Health, Housing and Community Services et al., 1992 p.16) tried to enunciate what 'good' services should achieve:

Programs and services should provide opportunities for people with disabilities to reach goals and enjoy life-styles which are valued by the community at large and are appropriate to their age.

But whilst the Act suggests some notions of 'ordinariness', at least in terms of valuing by the community and age appropriateness, funding of community services is based upon the normative identification of difference. In order to obtain these normatively funded services, service providers required persons with spinal injuries to conform to definite conceptions of the 'different' roles and life-styles persons with spinal injuries should have. In these 'different' roles persons with spinal injuries were expected to demonstrate their worthiness to have services by being neither too dependent nor independent, neither too near to cure nor incurable, and wishing neither segregation from, nor participation in, ordinary life activities.

It was quite clear in this study that despite the many reviews of community service provision and presence of legislation and policy which dictate that needs and goals should be defined by the person with a disability, service providers are continuing to base the provision of their services upon pre-determined stereotypes and models of expectations of persons with disabilities. This would tend to suggest that inappropriate attitudes towards persons with disabilities are still quite pervasive among service providers, particularly those services where the provider is accountable to a service agency, and not the person with a disability.

As a result, there was considerable evidence of a clash of purposes between persons with spinal injuries and service providers—the plans of life of persons with spinal injuries (ordinariness), and the intent of many services as perceived by those with spinal injuries (to highlight difference), often ran contrary to each other.

Supporting ordinariness

The only service which was found to be consistently supporting persons with spinal injuries to be ordinary was the service provided under the auspices of the Attendant Care Scheme, where the relationship between services and the user was one of employee/employer, thus facilitating the maintenance of essential relationships with other persons such as family and friends. There is evidence that levels of satisfaction with Home Care can be just as high where there is an essential relationship between the service and the client, particularly in the delivery of intimate personal care, allowing such care to become part of an ordinary life.
The efforts of some Home Care workers to establish essential relationships and support the ordinariness of their clients' lives, however, were sabotaged by an underlying philosophy based on models of charity and the deserving poor. When Home Care services were not delivered in a way that supported the desire to be ordinary, and in the face of no alternatives such as Attendant Care, persons with spinal injuries became resigned to being different.

Paramedical services could meet need when they were part of a timely intervention to cure some short-term conditions, but there was little evidence of paramedical services meeting service needs of persons with permanent impairments. To do so would require paramedical service providers to challenge the medical model of cure which underpins their professions. There was also little evidence of transport services meeting need. Persons with spinal injuries, particularly those who used wheelchairs, were segregated from ordinary public transport services. The only solution to this source of difference was to have one's own private means of transport.

Charting a parallel course

Community service needs of persons with spinal injuries were only met in the rare cases where the plans of life of persons with spinal injuries and the intent of services charted a parallel course. For this to occur, service providers needed to acknowledge that services are not a privilege to be conferred upon the only those who are 'just right' to make them normal. What is needed to rectify the levels of unmet need is true needs based planning as dictated by the goal of ordinariness, rather than normative based planning dominated by providers' definitions of difference.

Service providers must allow persons with spinal injuries to act in roles which are considered by them to be ordinary, such as being the employer, as with Attendant Care, or the partner, or the consumer. It may be the seeking of such familiar roles which contributed to the high prescriptive need for private services, physiotherapy in particular. Interactions with private services would be within the realms of persons with spinal injuries' experience as autonomous consumers, rather than government funded services with their expectations of dependency. Accountability of the service provider to the person with a disability is the ultimate difference between the Attendant Care scheme and the Home Care service, as well as the difference between government and privately funded paramedical, respite and transport services.

Nevertheless, if services are provided in parallel with the plans of life of persons with spinal injuries, it would not matter whether the service was provided by government funded agencies such as Home Care, or whether they were funded privately or through the use of brokers, such as is the case with the Attendant Care scheme. The way to improve the support for persons with spinal injuries and their families is not so much a wholesale
shift of resources from one service to another, but rather to address the inappropriateness of the way services interact with persons with spinal injuries.

Every time services are in contact with a person with spinal injuries they should consider whether their actions are in parallel with maintaining the ordinariness of the life of the person with spinal injuries. What would this mean for the provision of community services for Rob, Jenny, Norm and Dave?

Rob, Jenny, Norm and Dave

Services have no place in the lives of persons like Rob whose ordinariness was defined by their absence. Rather than trying to enforce dependency, service providers should give such persons the means to care for themselves.

Services in the lives of persons like Jenny must support the desire for ordinariness by being more flexible in their interpretation of need. Providers need to consider new ways of allowing persons with less significant impairments to obtain services which do not require that the person with spinal injuries submit permanently to a life of difference in order to justify their needs. Providers need to develop a mechanism which facilitates access to short term services that do not require the person with spinal injuries or their carer be in a state of extreme difference from which they may not recover, before they can have their service needs met.

The provision of long-term services for persons with significant impairments like Norm and Dave should be administered under the control of the person with spinal injuries through the increased provision of services such as the Attendant Care scheme. Alternatively, services should be delivered in a partnership with the person with spinal injuries that facilitates the development of essential relationships or other roles which are located within the ordinary experiences of the service recipient.

Services such as those provided to Norm, and needed by Rob, Jenny, and Dave, should be furnished to all persons with spinal injuries who need them. Until then, persons with spinal injuries and their families will continue to struggle to find service providers who are willing to travel along the parallel course and support them in their plan to be an ordinary member of Australian society.

Implications for the resourcing, provision and delivery of community services

Overall, this study has primarily dealt with three issues which have implications for the provision of community services for persons with spinal injuries in New South Wales—who needs services (the 'needy'), what
services they need (the 'needed'), and how these services should be provided to meet the individual needs of persons with spinal injuries.

The complexity of the new model of parallel courses developed to understand the community service needs of this group clearly indicates that, conceptually, the existing objective measures and models of need are too simplistic and cannot adequately determine, understand or address the community services needs of persons with spinal injuries. The new model of service delivery developed as a result of this study has some practical implications for determining resource levels, the 'mix' of services to be provided, and the manner of service delivery.

Determining resource levels

The first three stages of this study clearly illustrate that the current 'objective' methods of measuring need and allocating resources are neither accurate, nor appropriate determinants of the community service needs of persons with spinal injuries in NSW. In order to more accurately identify the level of need for services, resources allocation formulae, which are currently based primarily upon measures of impairment and economic disadvantage, would need to include the existing measures of:

- level of functional impairment, and
- source of income

as well taking consideration of indicators of:

- levels of education,
- the injury profile of the population, including the age at which the injury was incurred and the length of time post-injury, and, most importantly,
- the presence of everyday assistance (primarily informal carers),

where the presence of everyday assistance is an indicator of the need to allocate more resources, not fewer.

Data on levels of education should be readily available in regularly collated census data collected by the Australian Bureau of Statistics. Injury profile data for the spinal injured population of New South Wales, however, has not been readily available and has seriously hampered needs-based planning at the regional level. The re-instigation in 1995 of a national register of spinal injuries should rectify this problem for those injured more recently. The injury profile data for the existing spinal injured population, which was collated in this current study have been made available, in order to improve needs-based planning by community service planning authorities.

The collation of data on the presence of everyday assistance would, however, be somewhat more problematic, as reliance on indicators such as the receipt of the disability support pension, carer's pension and/or the domiciliary nursing care benefit would, based on the findings of this study, underestimate the number of persons receiving everyday assistance. The development of a measure of the receipt of everyday assistance is absolutely
essential if the resources required to provide the level of services needed by persons with spinal injuries are to be determined more accurately. In developing such a measure, consideration needs to be given to the level of functional impairment, age, and source of income of the person with spinal injuries, and the complex patterns of the relationship between the need for professional non-care services and the need for everyday help.

Determining the 'mix' of services

Determining the 'mix' of services to be provided to meet need is a considerably more challenging task than determining an overall level of resources. Decisions need to be made between the options of spreading resources thinly across all types of needed services, for all those who need services, or, conversely, targeting resources to those services most needed, or persons most 'needy'. Stage Three of this study clearly indicated that neither option was currently being consistently applied to the determination of the range and spread of services for persons with spinal injuries.

The findings of Stages Four and Five of this study suggest that the appropriate 'mix' of services can only be determined by each individuals' assessment of what they need. Options need to be developed which allow individuals to determine the most appropriate 'mix' of services to meet their needs. The findings of Stage Five of this study would suggest, however, that such options may be difficult to develop in the current service climate which is dominated by assessment and which is unlikely to relinquish control to the consumer. Nevertheless, one such scheme currently exists, the Attendant Care Scheme, which allows the consumer of the service to purchase an appropriate mix of personal and domestic assistance. Other schemes, such as managed care packages and coordinated care are being extensively trialed. The findings of this study would support the continuation and expansion of such schemes as the most appropriate way of determining and providing the services needed by persons with spinal injuries.

Further, whilst the provision of services for persons with spinal injuries is currently focussed upon the provision of personal and domestic care for those normatively defined as the long-term 'needy' (although even these services are currently suffering increasing restrictions), service provision should be extended to include increased access to:
- brief intervention personal care and domestic services,
- brief intervention paramedical services, and
- transport services (including greater assistance for persons wishing to purchase their own modified vehicle),
as the provision of such services would decrease long-term dependency.

---

3 These trials are primarily focused on the provision of services for the elderly, but should provide some useful insights into ways that services could be organised for younger persons with permanent disabilities.
Determining the mode of service delivery

Community services should be delivered in a mode which parallels the plans of life of persons with spinal injuries by allowing people to pursue and achieve ordinariness. As previously stated, the needs of persons with spinal injuries are for:

- a non-judgemental basis for obtaining community services, which
- contribute to the ordinariness of the lives of persons with spinal injuries, by
- recognising the ascendancy of the service recipient or working in partnership, to
- support the spinal injured to live with long-term impairment, maintain interdependent, reciprocal, and essential relationships (both socially, and with service providers) and participate in the community.

Meeting these needs, it has been stated, does not require a wholesale shift of resources from one service to another, nor, I believe, a large increase in total resources, but rather, some attitudinal and procedural changes within the current service system.

In practical terms, community service policies and procedures should be focussed upon:

- minimal, transparent, non-judgemental and non-invasive assessment,
- fostering client/provider partnerships and consumer empowerment,
- limiting staff turnover to allow consumers to receive a high quality service from a small, consistent group of professionals, and
- minimising enforced dependency, including
  ⇒ the provision of short-term and intermittent services
  ⇒ allowing, valuing and providing the means for self-care.

In order to meet need, the ultimate goal of community services policy and provision must be the promotion of ordinariness for persons with spinal injuries, rather than administrative efficiencies. Policy makers and service providers can achieve this by re-orienting services towards the ideals of the Disability Services Act, by providing 'opportunities for people with disabilities to reach goals and enjoy life-styles which are valued by the community at large' (Commonwealth Department of Health, Housing and Community Services et al., 1992 pp.15-16) guided by a new understanding of 'ordinariness' rather than 'normality. Only then will persons with spinal injuries be able to reach their goal of 'ordinariness'—to be, as Jim and Gwenda said 'like everyone else'.
Reference List


Chadwick, A. (1994). For disabled people the body is the principal site of oppression, both in form and what is done to it. *Australian Disability Review, 4*(4). online Health Rom.


Appendix A

Letters, Participant Information Sheets, and Questionnaires sent to persons with spinal injuries and their carers.
Appendix A

Letters from participating hospitals
Dear

The purpose of this letter is to seek your assistance in the commencement of a research project which may have significant implications for yourself and others.

The research team is interested in examining the availability of extended care facilities for spinal injured persons and/or their carers. A comprehensive review and examination of your knowledge and use of such services has not been conducted previously. The information which may be yielded from such a study would be important for future health service planning and delivery.

As a former patient of the unit, the research team would appreciate your participation in the survey. Your response (and that of your carer if relevant) to the enclosed questionnaire/s would indicate your consent to participate in the survey.

You (and your carer) may be assured that your confidentiality and anonymity relating to any personal information will be stringently protected and no individual will be identifiable in any published results.

We would deeply appreciate your involvement in this research project.

Yours sincerely

[Signature]

Dr. Sue Rutkowski
Director
Spinal Injury Unit
Royal North Shore Hospital
Dear

The purpose of this letter is to seek your assistance in a research project examining the availability of extended care facilities for spinal injured persons and/or their carers. A comprehensive review and examination of knowledge and use of such services by spinal cord injured people has not been conducted previously. The information yielded by such a study may be important for future health service planning and delivery.

As a former patient of the unit, the research team would appreciate your participation in the survey. Your response (and that of your carer if relevant) to the enclosed questionnaire/s would indicate your consent to participate in the survey.

You (and your carer) may be assured that your confidentiality and anonymity relating to any personal information will be stringently protected and no individual will be identifiable in any published results.

We would deeply appreciate your involvement in this research project.

Yours sincerely,

[Signature]

DR S ENGEL
Associate Director
Department of Rehabilitation Medicine
The Prince Henry/Prince of Wales Hospitals
Spinal Injury Unit, The Prince Henry Hospital

A FACILITY OF THE EASTERN SYDNEY AREA HEALTH SERVICE
Information sheet for participants
Information Sheet

In your package you will find two (2) booklets and two (2) reply paid envelopes. The white booklet is for you to complete and return.

Please give the yellow booklet, and one (1) of the reply paid envelopes to the person who assists you the most in your everyday living.

For more information, you may ring:-

Mrs. Lynn Kemp on (02) 828-5359

Thank you for taking the time to assist us.
Appendix A

Questionnaire for persons with spinal injuries
**Extended Care Resources/Facilities**

**Questionnaire**

**Respondent:**

*Spinal Injured Person.*

The person responding to this questionnaire should be the person who has experienced a spinal injury. If the spinal injured person is unable to complete the questionnaire by themselves because of physical disability, and is unable to locate a suitable person to complete the questionnaire on their behalf, they may contact the project investigators, who will assist them to complete the questionnaire.

When the questionnaire is completed, please place in the pre-paid envelope and return to the Investigators.

**Project Investigators:**

Mrs. Lynn Kemp

can be contacted on 828-5359 or 600-0555

**Thank you for participating in this project**
1. What is your age __________ (in years)?

2. How old were you when you received your spinal injury? __________ (in years).

3. What sex are you? (Please tick one).
   
   Male.........................................................[ ]

   Female...................................................[ ]

4. What is the highest educational qualification you have achieved? (Please tick one).

   Primary School...........................................[ ]

   Year 7 - 10.................................................[ ]

   Year 11 - 12 (HSC)........................................[ ]

   Trade Certificate.........................................[ ]

   TAFE Course................................................[ ]

   CAE/University Course..................................[ ]

5. Which language do you use primarily at home? (Please tick one).

   English.......................................................[ ]

   European or European based language................[ ]

   Asian language............................................[ ]

   Other (Please State)........................................[ ]
Extended Care
Resources/Facilities

Questionnaire

Respondent:

Spinal Injured Person.

The person responding to this questionnaire should be the person who has experienced a spinal injury. If the spinal injured person is unable to complete the questionnaire by themselves because of physical disability, and is unable to locate a suitable person to complete the questionnaire on their behalf, they may contact the project investigators, who will assist them to complete the questionnaire.

When the questionnaire is completed, please place in the pre-paid envelope and return to the investigators.

Project Investigators:

Mrs. Lynn Kemp
can be contacted on 828-5359 or 600-0555

Thank you for participating in this project
1. What is your age ________ (in years)?

2. How old were you when you received your spinal injury? ________ (in years).

3. What sex are you? (Please tick one).
   Male.................................................................[ ]
   Female.............................................................[ ]

4. What is the highest educational qualification you have achieved? (Please tick one).
   Primary School....................................................[ ]
   Year 7 - 10..........................................................[ ]
   Year 11 - 12 (HSC)...............................................[ ]
   Trade Certificate................................................[ ]
   TAFE Course.....................................................[ ]
   CAE/University Course.........................................[ ]

5. Which language do you use primarily at home? (Please tick one).
   English..............................................................[ ]
   European or European based language.........................[ ]
   Asian language..................................................[ ]
   Other (Please State)..............................................[ ]
6. How well do you speak English? (Please tick one).

   Speak and read English very well.........................................................[ ]
   Speak and read English a little............................................................[ ]
   Can speak, but not read, English..........................................................[ ]
   Cannot speak or read English...............................................................[ ]

7. What was the cause of your spinal injury? (Please tick one).

   Motor vehicle accident.................................................................[ ]
   Motor bike accident.................................................................[ ]
   Water sport accident.................................................................[ ]
   Industrial/Agricultural accident..................................................[ ]
   Sporting (other than watersports) accident........................................[ ]
   Other (Please specify)...........................................................................[ ]

8. What is the vertebra level of your spinal cord injury (if known), eg: C4, T7)

   ...................................................................................................................

9. How now would you best describe yourself? (Please tick one).

   Complete Quadriplegic.................................................................[ ]
   Incomplete Quadriplegic.................................................................[ ]
   Complete Paraplegic.................................................................[ ]
   Incomplete Paraplegic.................................................................[ ]
   Some movement or sensory problems...........................................[ ]
   No movement or sensory problems.................................................[ ]
10. What type of accommodation do you live in? (Please tick one).
   - Private Residence (House) [ ]
   - Private Residence (Flat/Villa) [ ]
   - Public Housing (House) [ ]
   - Public Housing (Flat/Villa) [ ]
   - Hostel (Private) [ ]
   - Hostel (Government) [ ]
   - Nursing Home (Private) [ ]
   - Nursing Home (Government) [ ]
   - Community Group Home [ ]
   - Other (please specify) [ ]

11. Who assists you the most in your every day living? (Please tick one response).
   - Require no assistance [ ]
   - Parent [ ]
   - Spouse/partner [ ]
   - Other relative [ ]
   - Friend [ ]
   - Nurse [ ]
   - Paid carer [ ]
   - Voluntary carer [ ]
   - Other (please specify) [ ]
12. Who else assists you in your everyday living?
(You may tick more than one response).

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<tr>
<th>Requirement</th>
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<tr>
<td>Require no assistance</td>
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<tr>
<td>Parent</td>
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<tr>
<td>Spouse/partner</td>
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<td>Other relative</td>
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<td>Friend</td>
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<td>Nurse</td>
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<td>Paid carer</td>
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<tr>
<td>Voluntary carer</td>
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<td>Other (please specify)</td>
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</table>

13. How would you describe your present employment category?
(Please tick one response).

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<thead>
<tr>
<th>Employment Category</th>
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<tbody>
<tr>
<td>Home duties</td>
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<tr>
<td>Retired</td>
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<tr>
<td>Managerial</td>
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<td>Professional</td>
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<td>Clerical</td>
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<td>Sales/Marketing</td>
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<td>Primary Industry</td>
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<td>Skilled labour</td>
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<tr>
<td>Unskilled labour</td>
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<tr>
<td>Not working</td>
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14. What are your sources of income? *(You may tick more than one response).*

- Wage or Salary.........................................................[
- Government Pension.............................................[
- Government Benefit..............................................[
- Compensation Payments........................................[
- Superannuation....................................................[
- Private Investments................................................[

15. Do you belong to any of the following organisations. *(You may tick more than one response).*

- Australian Quadriplegic Association (AQA)..............[
- Paraplegic and Quadriplegic Association (ParaQuad) .[

16. What other organisations or clubs do you belong to? *(Please list).*

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

217
17. Which of the following extended care services do you currently use, or plan to use? (You should respond by considering each service and may tick more than one response option for each service).

<table>
<thead>
<tr>
<th>Service</th>
<th>Never Used</th>
<th>Occasional Use</th>
<th>Regular Use</th>
<th>Plan to use in next 12 months</th>
<th>Plan to use in next 5 years</th>
<th>Not Needed</th>
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<tbody>
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<td>Home care (domestic)</td>
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<td>Meals on wheels</td>
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<td>Physiotherapy (Private)</td>
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<td>Home care (personal care)</td>
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18. What reasons prevent you from using the following extended care services? (You should respond by considering each service and may tick more than one response option for each service).

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<thead>
<tr>
<th>Service</th>
<th>Not Relevant</th>
<th>Not Available</th>
<th>No Transport</th>
<th>No Access</th>
<th>Cost</th>
<th>Other</th>
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19. What is your level of satisfaction with the extended care services you have used? (You should respond by considering each service and may tick only one response for each service).

<table>
<thead>
<tr>
<th>Service</th>
<th>Never Used</th>
<th>Satisfied all aspects</th>
<th>Satisfied with some aspects</th>
<th>Dissatisfied completely</th>
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</table>
20. Do you have any general comments you would like to make about extended care service provision, access and use?
Thank you for completing this questionnaire.

You should now return this in the pre-paid envelope, as soon as possible, to the investigators. Your assistance is most valued.
Questionnaire for carers of persons with spinal injuries
Extended Care
Resources/Facilities

Questionnaire

Respondent:

*Carer for Spinal Injured Person.*

This questionnaire is to be answered by the person who assist the spinal injured person the most in normal everyday living. This may be by providing physical, social or emotional support.

When the questionnaire is completed, please place in the pre-paid envelope and return to the Investigators.

**Project Investigators:**

Mrs. Lynn Kemp
can be contacted on 828-5359 or 600-0555

Thank you for your participation in this project
1. What is your age? _________ in years.

2. What sex are you? (Please tick one)
   Male.................................................................[  ]
   Female.............................................................[  ]

3. What is the highest educational qualification you have achieved? (Please tick one).
   Primary School......................................................[  ]
   Year 7 - 10..............................................................[  ]
   Year 11 - 12 (HSC)..................................................[  ]
   Trade Certificate...................................................[  ]
   TAFE Course..........................................................[  ]
   CAE/University Course............................................[  ]

4. Which language do you primarily use at home? (Please tick one).
   English.................................................................[  ]
   European or European based language........................[  ]
   Asian language.......................................................[  ]
   Other (Please State)................................................[  ]

5. How well do you speak or read English? (Please tick one).
   Speak and read English very well...............................[  ]
   Speak and read English a little..................................[  ]
   Can speak, but not read English..................................[  ]
   Cannot speak or read English....................................[  ]
Appendix A

6. Do you live with the Spinal Injured person? 
(Please tick one box).
Yes.........................................................................................[ ]
No.........................................................................................[ ]

7. How would you describe your present employment category? 
(Please tick one).
Full time carer for spinal injured person..................[ ]
Home duties.................................................................[ ]
Retired.................................................................[ ]
Managerial.................................................................[ ]
Professional.................................................................[ ]
Clerical.................................................................[ ]
Sales/Marketing.................................................................[ ]
Primary Industry.................................................................[ ]
Skilled labour.................................................................[ ]
Unskilled labour.................................................................[ ]
Not working.................................................................[ ]

8. What are your sources of income? (You may tick more than one).
Wage or salary.................................................................[ ]
Government pension.................................................................[ ]
Government benefit.................................................................[ ]
Compensation payments.................................................................[ ]
Superannuation.................................................................[ ]
Private investments.................................................................[ ]
9. How long have you been caring for the person with spinal injuries? (Please tick one).
   Less than 1 year.................................................................[ ]
   1 - 2 years........................................................................[ ]
   3 - 5 years........................................................................[ ]
   6 - 9 years..........................................................................[ ]
   10 or more years.................................................................[ ]

10. What is your relationship to the person with spinal injury? (Please tick one).
    Parent.................................................................................[ ]
    Spouse/partner.....................................................................[ ]
    Other relative.......................................................................[ ]
    Friend................................................................................[ ]
    Nurse................................................................................[ ]
    Paid carer...........................................................................[ ]
    Voluntary carer....................................................................[ ]
    Other (please specify)............................................................[ ]

11. Who else assists you in the care of the person with spinal injuries? (You may tick more than one response).
    No-one else........................................................................[ ]
    Other relatives.....................................................................[ ]
    Other friends.......................................................................[ ]
    Paid health professionals (Private)......................................[ ]
    Paid health professionals (Government).............................[ ]
    Local service clubs (eg. Lions/Rotary).................................[ ]
    Other (please specify)............................................................[ ]
12. Which of the following extended care services do you currently use, or plan to use, to supplement your care of the spinal injured person? (You should respond by considering each service and may tick **more than one response** option for each service).

<table>
<thead>
<tr>
<th>Service</th>
<th>Never Used</th>
<th>Occasional Use</th>
<th>Regular Use</th>
<th>Plan to use in next 12 months</th>
<th>Plan to use in next 5 years</th>
<th>Not Needed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Home care (domestic)</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Meals on wheels</td>
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<tr>
<td>Physiotherapy (Private)</td>
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<tr>
<td>Physiotherapy (G'ment)</td>
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<tr>
<td>Home nursing (Private)</td>
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<tr>
<td>Home care (personal care)</td>
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<tr>
<td>Occupational therapy (Private)</td>
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<tr>
<td>Occupational therapy (G'ment)</td>
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<tr>
<td>Counselling (Private)</td>
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<tr>
<td>Counselling (G'ment)</td>
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<tr>
<td>Speech therapy (Private)</td>
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<tr>
<td>Speech therapy (G'ment)</td>
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<tr>
<td>Attendant Care</td>
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<tr>
<td>Person minding</td>
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<tr>
<td>Day care</td>
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<tr>
<td>Transport assistance (Private)</td>
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<td>Transport assistance (G'ment)</td>
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<tr>
<td>Respite care</td>
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<tr>
<td>Other (Please Specify)</td>
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</tr>
</tbody>
</table>
13. What reasons prevent you from using the following extended care services? (You should respond by considering each service and may tick more than one response option for each service).

<table>
<thead>
<tr>
<th>Service</th>
<th>Not Relevant</th>
<th>Not Available</th>
<th>No Transport</th>
<th>No Access</th>
<th>Cost</th>
<th>Other</th>
</tr>
</thead>
<tbody>
<tr>
<td>Home care (domestic)</td>
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<tr>
<td>Meals on wheels</td>
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<td>Physiotherapy (Private)</td>
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<td>Home nursing (Private)</td>
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<tr>
<td>Home care (personal care)</td>
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<tr>
<td>Occupational therapy (Private)</td>
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<td>Occupational therapy (G'ment)</td>
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<td>Counselling (Private)</td>
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<td>Person minding</td>
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<td>Other (Please Specify)</td>
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</tbody>
</table>
14. What is your level of satisfaction with the extended care services you have used? (You should respond by considering each service and may tick only one response for each service).

<table>
<thead>
<tr>
<th>Service</th>
<th>Never Used</th>
<th>Satisfied all aspects</th>
<th>Satisfied with some aspects</th>
<th>Dissatisfied completely</th>
</tr>
</thead>
<tbody>
<tr>
<td>Home care (domestic)</td>
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<tr>
<td>Respite care</td>
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<tr>
<td>Other (Please Specify)</td>
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</tbody>
</table>
15. Do you belong to any of the following organisations? (You may tick more than one response).

Australian Quadriplegic Association (AQA)........................[   ]
Paraplegic and Quadriplegic Association (ParaQuad)........[   ]
Carers Association....................................................[   ]

16. Do you have any general comments to make, about extended care service provisions, access and use?

_________________________________________________________________
_________________________________________________________________
_________________________________________________________________
_________________________________________________________________
_________________________________________________________________
_________________________________________________________________
_________________________________________________________________
_________________________________________________________________
_________________________________________________________________
Thank you for completing this questionnaire.

You should now return this in the pre-paid envelope, as soon as possible, to the investigators. Your assistance is most valued.
Appendix B

Segmentation analysis (CHAID) indicating segments of the population who are in employment.

Table B-1. Employment by level of function (all respondents potentially in the workforce)

<table>
<thead>
<tr>
<th>Function</th>
<th>employed</th>
<th></th>
<th>not employed</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%1</td>
<td>n</td>
<td>%1</td>
</tr>
<tr>
<td>quadriplegia or paraplegia</td>
<td>155</td>
<td>46.55</td>
<td>178</td>
<td>53.45</td>
</tr>
<tr>
<td>some movement or sensory problems</td>
<td>75</td>
<td>75.76</td>
<td>24</td>
<td>24.24</td>
</tr>
<tr>
<td>no movement or sensory problems</td>
<td>61</td>
<td>92.42</td>
<td>5</td>
<td>7.58</td>
</tr>
</tbody>
</table>

1 row percent
LR chi-square=71.01 df=2 prob=1.3e-14 (adj.)

Table B-2. Employment by level of education (persons with quadriplegia or paraplegia and potentially in the workforce only)

<table>
<thead>
<tr>
<th>Level of education</th>
<th>employed</th>
<th></th>
<th>not employed</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%1</td>
<td>n</td>
<td>%1</td>
</tr>
<tr>
<td>school only</td>
<td>65</td>
<td>36.11</td>
<td>115</td>
<td>63.89</td>
</tr>
<tr>
<td>vocational or tertiary education</td>
<td>90</td>
<td>58.82</td>
<td>63</td>
<td>41.18</td>
</tr>
</tbody>
</table>

1 row percent
LR chi-square=17.27 df=1 prob=0.00023 (adj.)

Table B-3. Employment by need for everyday help (persons with some movement or sensory problems and potentially in the workforce only)

<table>
<thead>
<tr>
<th>Need for everyday help</th>
<th>employed</th>
<th></th>
<th>not employed</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%1</td>
<td>n</td>
<td>%1</td>
</tr>
<tr>
<td>needs everyday help</td>
<td>12</td>
<td>48.00</td>
<td>13</td>
<td>52.00</td>
</tr>
<tr>
<td>doesn’t need everyday help</td>
<td>63</td>
<td>85.14</td>
<td>11</td>
<td>14.86</td>
</tr>
</tbody>
</table>

1 row percent
LR chi-square=12.83 df=1 prob=0.0010 (adj.)
Table B-4. Employment by vertebral level of injury (persons with some movement or sensory problems who do not need everyday help and potentially in the workforce only)

<table>
<thead>
<tr>
<th>Vertebral level of injury</th>
<th>employed n</th>
<th>%(^1)</th>
<th>not employed n</th>
<th>%(^1)</th>
</tr>
</thead>
<tbody>
<tr>
<td>cervical</td>
<td>42</td>
<td>79.25</td>
<td>11</td>
<td>20.75</td>
</tr>
<tr>
<td>thoracic of lumbar</td>
<td>21</td>
<td>100.00</td>
<td>0</td>
<td>0.00</td>
</tr>
</tbody>
</table>

1 row percent
LR chi-square=8.08 df=1 prob=0.040 (adj.)

Table B-5. Employment by number of years post injury (persons with no movement or sensory problems and potentially in the workforce only)

<table>
<thead>
<tr>
<th>Number of years post injury</th>
<th>employed n</th>
<th>%(^1)</th>
<th>not employed n</th>
<th>%(^1)</th>
</tr>
</thead>
<tbody>
<tr>
<td>less than eight</td>
<td>21</td>
<td>80.77</td>
<td>5</td>
<td>19.23</td>
</tr>
<tr>
<td>eight or more</td>
<td>40</td>
<td>100.00</td>
<td>0</td>
<td>0.00</td>
</tr>
</tbody>
</table>

1 row percent
LR chi-square=9.96 df=1 prob=0.014 (adj.)


Appendix C

Segmentation analysis (CHAID) indicating segments of the population who have everyday help (predominantly informal care from family or friends).

Table C-1. Has everyday help by level of function (all respondents)

<table>
<thead>
<tr>
<th>Function</th>
<th>has everyday help</th>
<th>no everyday help</th>
</tr>
</thead>
<tbody>
<tr>
<td>complete quadriplegia</td>
<td>72</td>
<td>2</td>
</tr>
<tr>
<td>incomplete quadriplegia/complete</td>
<td>205</td>
<td>48</td>
</tr>
<tr>
<td>paraplegia</td>
<td></td>
<td></td>
</tr>
<tr>
<td>incomplete paraplegia</td>
<td>62</td>
<td>46</td>
</tr>
<tr>
<td>some movement or sensory problems</td>
<td>67</td>
<td>109</td>
</tr>
<tr>
<td>no movement or sensory problems</td>
<td>13</td>
<td>80</td>
</tr>
</tbody>
</table>

1 row percent
LR chi-square=229.62 df=4 prob=5.6e-47 (adj.)

Table C-2. Has everyday help by age at time of injury (respondents with incomplete quadriplegia or complete paraplegia only)

<table>
<thead>
<tr>
<th>Age at time of injury</th>
<th>has everyday help</th>
<th>no everyday help</th>
</tr>
</thead>
<tbody>
<tr>
<td>less than 30 years</td>
<td>101</td>
<td>39</td>
</tr>
<tr>
<td>30 or more years</td>
<td>104</td>
<td>9</td>
</tr>
</tbody>
</table>

1 row percent
LR chi-square=17.37 df=1 prob=0.00040 (adj.)

Table C-3. Has everyday help by use of professional non-care services (respondents with incomplete quadriplegia or complete paraplegia who were aged less than 30 years at time of injury only)

<table>
<thead>
<tr>
<th>Use of professional non-care services</th>
<th>has everyday help</th>
<th>no everyday help</th>
</tr>
</thead>
<tbody>
<tr>
<td>uses services</td>
<td>53</td>
<td>10</td>
</tr>
<tr>
<td>doesn't use services</td>
<td>48</td>
<td>29</td>
</tr>
</tbody>
</table>

1 row percent
LR chi-square=8.51 df=1 prob=0.0035 (adj.)

235
Table C-4. Has everyday help by primary source of income (respondents with incomplete quadriplegia or complete paraplegia who were aged 30 years or more at time of injury only)

<table>
<thead>
<tr>
<th>Primary source of income</th>
<th>has everyday help</th>
<th>no everyday help</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%1</td>
</tr>
<tr>
<td>wages</td>
<td>23</td>
<td>79.31</td>
</tr>
<tr>
<td>government pension, other income</td>
<td>81</td>
<td>96.43</td>
</tr>
</tbody>
</table>

1 row percent
LR chi-square=7.35  df=1  prob=0.0046 (adj.)

Table C-5. Has everyday help by current age (respondents with incomplete paraplegia only)

<table>
<thead>
<tr>
<th>Current age</th>
<th>has everyday help</th>
<th>no everyday help</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%1</td>
</tr>
<tr>
<td>less than 50 years</td>
<td>33</td>
<td>47.14</td>
</tr>
<tr>
<td>50 years or more</td>
<td>29</td>
<td>76.32</td>
</tr>
</tbody>
</table>

1 row percent
LR chi-square=8.93  df=1  prob=0.036 (adj.)

Table C-6. Has everyday help by problem accessing professional non-care services (respondents with some movement or sensory problems only)

<table>
<thead>
<tr>
<th>Problem accessing services</th>
<th>has everyday help</th>
<th>no everyday help</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%1</td>
</tr>
<tr>
<td>has problem</td>
<td>27</td>
<td>75.00</td>
</tr>
<tr>
<td>no problem</td>
<td>40</td>
<td>28.57</td>
</tr>
</tbody>
</table>

1 row percent
LR chi-square=25.86  df=1  prob=3.7e-7 (adj.)

Table C-7. Has everyday help by current age (respondents with some movement or sensory problems who have no problems accessing professional non-care services only)

<table>
<thead>
<tr>
<th>Current age</th>
<th>has everyday help</th>
<th>no everyday help</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%1</td>
</tr>
<tr>
<td>less than 50 years</td>
<td>10</td>
<td>12.50</td>
</tr>
<tr>
<td>50 or more years</td>
<td>30</td>
<td>50.00</td>
</tr>
</tbody>
</table>

1 row percent
LR chi-square=24.05  df=1  prob=1.2e-5 (adj.)

236
Table C-8. Has everyday help by age at time of injury (respondents with no movement or sensory problems only)

<table>
<thead>
<tr>
<th>Age at time of injury</th>
<th>has everyday help</th>
<th>no everyday help</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%1</td>
</tr>
<tr>
<td>less than 40 years</td>
<td>3</td>
<td>4.62</td>
</tr>
<tr>
<td>40 or more years</td>
<td>10</td>
<td>35.71</td>
</tr>
</tbody>
</table>

1 row percent
Lr chi-square=14.44  df=1  prob=0.0019 (adj.)
Appendix D

Segmentation analysis (CHAID) indicating population segments who use professional care or domestic (everyday care) services.

Table D-1. Uses one or more everyday care services by level of function (all respondents)

<table>
<thead>
<tr>
<th>Function</th>
<th>uses everyday care services</th>
<th>doesn't use everyday care services</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%1</td>
</tr>
<tr>
<td>complete quadriplegia</td>
<td>69</td>
<td>93.24</td>
</tr>
<tr>
<td>incomplete quadriplegia</td>
<td>77</td>
<td>61.11</td>
</tr>
<tr>
<td>complete paraplegia</td>
<td>47</td>
<td>37.01</td>
</tr>
<tr>
<td>incomplete paraplegia</td>
<td>26</td>
<td>24.07</td>
</tr>
<tr>
<td>some movement or sensory problem</td>
<td>21</td>
<td>11.80</td>
</tr>
<tr>
<td>no movement or sensory problems</td>
<td>0</td>
<td>0.00</td>
</tr>
</tbody>
</table>

1 row percent
LR chi-square=284.30  df=5  prob=2.6e-58 (adj.)

Table D-2. Uses one or more everyday care services by primary source of income (respondents with incomplete quadriplegia only)

<table>
<thead>
<tr>
<th>Primary source of income</th>
<th>uses everyday care services</th>
<th>doesn't use everyday care services</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%1</td>
</tr>
<tr>
<td>wages</td>
<td>14</td>
<td>42.42</td>
</tr>
<tr>
<td>government pension or other income</td>
<td>63</td>
<td>67.74</td>
</tr>
</tbody>
</table>

1 row percent
LR chi-square=6.45  df=1  prob=0.075 (adj.)

239
Table D-3. Uses one or more everyday care services by area of residence (respondents with incomplete paraplegia only)

<table>
<thead>
<tr>
<th>Area of residence</th>
<th>uses everyday care services</th>
<th>doesn't use everyday care services</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%1</td>
</tr>
<tr>
<td>inner or outer Sydney</td>
<td>8</td>
<td>13.33</td>
</tr>
<tr>
<td>regional centre or country</td>
<td>18</td>
<td>37.50</td>
</tr>
</tbody>
</table>

1 row percent
LR chi-square=8.59  df=1  prob=0.050 (adj.)

Table D-4. Uses one or more everyday care services by primary source of income (respondents with some movement or sensory problem only)

<table>
<thead>
<tr>
<th>Primary source of income</th>
<th>uses everyday care services</th>
<th>doesn't use everyday care services</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%1</td>
</tr>
<tr>
<td>wages</td>
<td>2</td>
<td>2.04</td>
</tr>
<tr>
<td>government pension or other income</td>
<td>19</td>
<td>23.75</td>
</tr>
</tbody>
</table>

1 row percent
LR chi-square=21.95  df=1  prob=2.0e-5 (adj.)
Appendix E

Segmentation analysis (CHAID) indicating population segments who use professional services for other than everyday personal care or domestic assistance.

Table E-1. Indicators of the use of one or more professional services for other than everyday care

<table>
<thead>
<tr>
<th>Segment</th>
<th>n</th>
<th>% using one or more professional non everyday care services</th>
<th>relative odds of using professional non everyday care services</th>
</tr>
</thead>
<tbody>
<tr>
<td>function 1-2, injured &lt;11 years ago</td>
<td>99</td>
<td>70.71</td>
<td>1.87:1</td>
</tr>
<tr>
<td>function 3-5, has everyday help, male, not in labour force</td>
<td>44</td>
<td>54.55</td>
<td>1.44:1</td>
</tr>
<tr>
<td>function 3-5, has everyday help, female</td>
<td>64</td>
<td>53.13</td>
<td>1.40:1</td>
</tr>
<tr>
<td>function 1-2, injured 11+ years ago</td>
<td>101</td>
<td>47.52</td>
<td>1.26:1</td>
</tr>
<tr>
<td>function 3-5, no everyday help, cervical injury, lives in inner Sydney, regional centre or country, employed</td>
<td>40</td>
<td>35.00</td>
<td>0.93:1</td>
</tr>
<tr>
<td>function 3-5, no everyday help, thoracic, lumbar or sacral injury</td>
<td>85</td>
<td>34.12</td>
<td>0.90:1</td>
</tr>
<tr>
<td>function 3-5, has everyday help, male, employed or unemployed</td>
<td>120</td>
<td>30.83</td>
<td>0.82:1</td>
</tr>
<tr>
<td>function 6</td>
<td>93</td>
<td>9.68</td>
<td>0.26:1</td>
</tr>
<tr>
<td>function 3-5, no everyday help, cervical injury, lives in inner Sydney, regional centre or country, retired or unemployed</td>
<td>32</td>
<td>6.25</td>
<td>0.17:1</td>
</tr>
<tr>
<td>function 3-5, no everyday help, cervical injury, lives in outer Sydney</td>
<td>28</td>
<td>0.00</td>
<td>0.00:1</td>
</tr>
<tr>
<td><strong>Total population</strong></td>
<td>706</td>
<td>37.82</td>
<td>1:1</td>
</tr>
</tbody>
</table>

1 function 1 Complete quadriplegia
function 2 Incomplete quadriplegia
function 3 Complete paraplegia
function 4 Incomplete paraplegia
function 5 Some movement or sensory problems
function 6 No movement or sensory problems
Table E-2. Uses one or more services for other than everyday care by level of function (all respondents)

<table>
<thead>
<tr>
<th>Function</th>
<th>uses non everyday care services</th>
<th>doesn't use non everyday care services</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%1</td>
</tr>
<tr>
<td>complete/incomplete quadriplegia</td>
<td>118</td>
<td>59.00</td>
</tr>
<tr>
<td>complete/incomplete paraplegia or some movement or sensory problems</td>
<td>140</td>
<td>33.90</td>
</tr>
<tr>
<td>no movement or sensory problems</td>
<td>9</td>
<td>9.68</td>
</tr>
</tbody>
</table>

1 row percent
LR chi-square=77.58  df=2  prob=5.0e-16 (adj.)

Table E-3. Uses one or more services for other than everyday care by number of years since injury (respondents with complete/incomplete quadriplegia only)

<table>
<thead>
<tr>
<th>Years since injury</th>
<th>uses non everyday care services</th>
<th>doesn't use non everyday care services</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%1</td>
</tr>
<tr>
<td>less than 11 years</td>
<td>70</td>
<td>70.71</td>
</tr>
<tr>
<td>11 or more years</td>
<td>48</td>
<td>47.52</td>
</tr>
</tbody>
</table>

1 row percent
LR chi-square=11.23  df=1  prob=0.0072 (adj.)

Table E-4. Uses one or more services for other than everyday care by need for everyday help (respondents with complete/incomplete paraplegia or some movement or sensory problem only)

<table>
<thead>
<tr>
<th>Need for everyday help</th>
<th>uses non everyday care services</th>
<th>doesn't use non everyday care services</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%1</td>
</tr>
<tr>
<td>needs everyday help</td>
<td>95</td>
<td>41.67</td>
</tr>
<tr>
<td>doesn't need everyday help</td>
<td>45</td>
<td>24.32</td>
</tr>
</tbody>
</table>

1 row percent
LR chi-square=13.95  df=1  prob=0.00056 (adj.)
Table E-5. Uses one or more services for other than everyday care by gender (respondents with complete/incomplete paraplegia or some movement or sensory problem who need everyday help only)

<table>
<thead>
<tr>
<th>Gender</th>
<th>uses non everyday care services</th>
<th>doesn't use non everyday care services</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%1</td>
</tr>
<tr>
<td>male</td>
<td>61</td>
<td>37.20</td>
</tr>
<tr>
<td>female</td>
<td>34</td>
<td>53.13</td>
</tr>
</tbody>
</table>

1 row percent
LR chi-square=4.76  df=1  prob=0.085 (adj.)

Table E-6. Uses one or more services for other than everyday care by employment status (respondents with complete/incomplete paraplegia or some movement or sensory problem who need everyday help and are male only)

<table>
<thead>
<tr>
<th>Employment status</th>
<th>uses non everyday care services</th>
<th>doesn't use non everyday care services</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%1</td>
</tr>
<tr>
<td>employed or unemployed</td>
<td>37</td>
<td>30.83</td>
</tr>
<tr>
<td>not in labor force</td>
<td>24</td>
<td>54.55</td>
</tr>
</tbody>
</table>

1 row percent
LR chi-square=7.58  df=1  prob=0.041 (adj.)

Table E-7. Uses one or more services for other than everyday care by vertebral level of injury (respondents with complete/incomplete paraplegia or some movement or sensory problem who don’t need everyday help only)

<table>
<thead>
<tr>
<th>Vertebral level of injury</th>
<th>uses non everyday care services</th>
<th>doesn't use non everyday care services</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%1</td>
</tr>
<tr>
<td>cervical</td>
<td>16</td>
<td>16.00</td>
</tr>
<tr>
<td>thoracic, lumbar or sacral</td>
<td>29</td>
<td>34.12</td>
</tr>
</tbody>
</table>

1 row percent
LR chi-square=8.23  df=1  prob=0.037 (adj.)
Table E-8. Uses one or more services for other than everyday care by area of residence (respondents with complete/incomplete paraplegia or some movement or sensory problem who don't need everyday help and incurred a cervical injury only)

<table>
<thead>
<tr>
<th>Area of residence</th>
<th>uses non everyday care services</th>
<th>doesn't use non everyday care services</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%(^1)</td>
</tr>
<tr>
<td>inner Sydney, regional centre or country</td>
<td>16</td>
<td>22.22</td>
</tr>
<tr>
<td>outer Sydney</td>
<td>0</td>
<td>0.00</td>
</tr>
</tbody>
</table>

\(^1\) row percent
LR chi-square=11.66 df=1 prob=0.0096 (adj.)

Table E-9. Uses one or more services for other than everyday care by employment status (respondents with complete/incomplete paraplegia who don't need everyday help with cervical injury living in inner Sydney, regional centre or country area only)

<table>
<thead>
<tr>
<th>Employment status</th>
<th>uses non everyday care services</th>
<th>doesn't use non everyday care services</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%(^1)</td>
</tr>
<tr>
<td>employed</td>
<td>14</td>
<td>35.00</td>
</tr>
<tr>
<td>not in labour force or unemployed</td>
<td>2</td>
<td>6.25</td>
</tr>
</tbody>
</table>

\(^1\) row percent
LR chi-square=9.52 df=1 prob=0.014 (adj.)
### Table E-10. Indicators of the use of one or more professional paramedical services

<table>
<thead>
<tr>
<th>Segment 1</th>
<th>n</th>
<th>% using one or more professional paramedical services</th>
<th>relative odds of using professional paramedical services</th>
</tr>
</thead>
<tbody>
<tr>
<td>function 1-2, injured &lt;11 years ago, employed or not in labour force</td>
<td>61</td>
<td>60.66</td>
<td>2.45:1</td>
</tr>
<tr>
<td>function 4-5, thoracic, lumbar or sacral injury</td>
<td>115</td>
<td>40.00</td>
<td>1.61:1</td>
</tr>
<tr>
<td>function 4-5, cervical injury, post school education</td>
<td>50</td>
<td>36.00</td>
<td>1.45:1</td>
</tr>
<tr>
<td>function 1-2, injured &lt;11 years ago, unemployed</td>
<td>65</td>
<td>27.69</td>
<td>1.12:1</td>
</tr>
<tr>
<td>function 1-2, injured 11+ years ago</td>
<td>74</td>
<td>18.92</td>
<td>0.76:1</td>
</tr>
<tr>
<td>function 3</td>
<td>127</td>
<td>14.69</td>
<td>0.60:1</td>
</tr>
<tr>
<td>function 4-5, cervical injury, school only education</td>
<td>100</td>
<td>14.00</td>
<td>0.56:1</td>
</tr>
<tr>
<td>function 6, employed</td>
<td>74</td>
<td>12.16</td>
<td>0.49:1</td>
</tr>
<tr>
<td>function 6, not in labour force or unemployed</td>
<td>40</td>
<td>0.00</td>
<td>0.00:1</td>
</tr>
<tr>
<td>Total population 2</td>
<td>706</td>
<td>24.79</td>
<td>1:1</td>
</tr>
</tbody>
</table>

1 function 1 Complete quadriplegia
function 2 Incomplete quadriplegia
function 3 Complete paraplegia
function 4 Incomplete paraplegia
function 5 Some movement or sensory problems
function 6 No movement or sensory problems

2 includes five cases with incomplete datasets

### Table E-11. Uses one or more paramedical services by level of function (all respondents)

<table>
<thead>
<tr>
<th>Function</th>
<th>uses paramedical services</th>
<th>doesn't use paramedical services</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%</td>
</tr>
<tr>
<td>complete/incomplete quadriplegia</td>
<td>69</td>
<td>34.50</td>
</tr>
<tr>
<td>complete paraplegia</td>
<td>19</td>
<td>14.96</td>
</tr>
<tr>
<td>incomplete paraplegia or some movement or sensory problems</td>
<td>78</td>
<td>29.43</td>
</tr>
<tr>
<td>no movement or sensory problems</td>
<td>9</td>
<td>7.89</td>
</tr>
</tbody>
</table>

1 row percent
LR chi-square=41.64 df=3 prob=2.4e-7 (adj.)
Appendix E

Table E-12. Uses one or more paramedical services by number of years since injury (respondents with complete/incomplete quadriplegia only)

<table>
<thead>
<tr>
<th>Number of years since injury</th>
<th>uses paramedical services</th>
<th>doesn't use paramedical services</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>% 1</td>
</tr>
<tr>
<td>less than 11 years</td>
<td>55</td>
<td>43.65</td>
</tr>
<tr>
<td>11 years or more</td>
<td>14</td>
<td>18.92</td>
</tr>
</tbody>
</table>

1 row percent
LR chi-square=13.30 df=1 prob=0.0024 (adj.)

Table E-13. Uses one or more paramedical services by employment status (respondents with complete/incomplete quadriplegia injured less than 11 years ago only)

<table>
<thead>
<tr>
<th>Employment status</th>
<th>uses paramedical services</th>
<th>doesn't use paramedical services</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>% 1</td>
</tr>
<tr>
<td>employed or not in labour force</td>
<td>37</td>
<td>60.66</td>
</tr>
<tr>
<td>unemployed</td>
<td>18</td>
<td>27.69</td>
</tr>
</tbody>
</table>

1 row percent
LR chi-square=14.16 df=1 prob=0.0012 (adj.)

Table E-14. Uses one or more paramedical services by vertebral level of injury (respondents with incomplete paraplegia or some movement or sensory problem only)

<table>
<thead>
<tr>
<th>Vertebral level of injury</th>
<th>uses paramedical services</th>
<th>doesn't use paramedical services</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>% 1</td>
</tr>
<tr>
<td>cervical</td>
<td>32</td>
<td>21.33</td>
</tr>
<tr>
<td>thoracic, lumbar or sacral</td>
<td>46</td>
<td>40.00</td>
</tr>
</tbody>
</table>

1 row percent
LR chi-square=10.88 df=1 prob=0.0087 (adj.)

Table E-15. Uses one or more paramedical services by level of education (respondents with incomplete paraplegia or some movement or sensory problem with cervical injury only)

<table>
<thead>
<tr>
<th>Level of education</th>
<th>uses paramedical services</th>
<th>doesn't use paramedical services</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>% 1</td>
</tr>
<tr>
<td>school only</td>
<td>14</td>
<td>14.00</td>
</tr>
<tr>
<td>post school education</td>
<td>18</td>
<td>36.00</td>
</tr>
</tbody>
</table>

1 row percent
LR chi-square=9.17 df=1 prob=0.017 (adj.)
Table E-16. Uses one or more paramedical services by employment status
(respondents with no movement or sensory problems only)

<table>
<thead>
<tr>
<th>Employment status</th>
<th>uses paramedical services</th>
<th>doesn't use paramedical services</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%¹</td>
</tr>
<tr>
<td>employed</td>
<td>9</td>
<td>12.16</td>
</tr>
<tr>
<td>not in labour force or unemployed</td>
<td>0</td>
<td>0.00</td>
</tr>
</tbody>
</table>

1 row percent
LR chi-square=8.19  df=1  prob=0.029 (adj.)

Table E-17. Indicators of the use of one or more professional transport services

<table>
<thead>
<tr>
<th>Segment¹</th>
<th>n</th>
<th>% using one or more professional transport services</th>
<th>relative odds of using professional transport services</th>
</tr>
</thead>
<tbody>
<tr>
<td>function 1-2, injured &lt;5 years ago,</td>
<td>25</td>
<td>64.00</td>
<td>3.16:1</td>
</tr>
<tr>
<td>function 3-4, injured &lt;5 years ago</td>
<td>32</td>
<td>43.75</td>
<td>2.16:1</td>
</tr>
<tr>
<td>function 1-2, injured 5-13 years ago</td>
<td>136</td>
<td>41.91</td>
<td>2.07:1</td>
</tr>
<tr>
<td>function 1-2, injured 14+ years ago</td>
<td>39</td>
<td>20.51</td>
<td>1.01:1</td>
</tr>
<tr>
<td>function 3-4, injured 5+ years ago</td>
<td>224</td>
<td>15.63</td>
<td>0.77:1</td>
</tr>
<tr>
<td>function 5</td>
<td>157</td>
<td>7.64</td>
<td>0.38:1</td>
</tr>
<tr>
<td>function 6</td>
<td>93</td>
<td>1.08</td>
<td>0.05:1</td>
</tr>
<tr>
<td>Total population²</td>
<td>706</td>
<td>20.25</td>
<td>1:1</td>
</tr>
</tbody>
</table>

1 function 1 Complete quadriplegia
function 2 Incomplete quadriplegia
function 3 Complete paraplegia
function 4 Incomplete paraplegia
function 5 Some movement or sensory problems
function 6 No movement or sensory problems
2 includes five cases with incomplete datasets

Table E-18. Uses one or more transport services by level of function (all respondents)

<table>
<thead>
<tr>
<th>Function</th>
<th>uses transport services</th>
<th>doesn't use transport services</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%¹</td>
</tr>
<tr>
<td>complete/incomplete quadriplegia</td>
<td>91</td>
<td>40.50</td>
</tr>
<tr>
<td>complete/incomplete paraplegia</td>
<td>49</td>
<td>90.14</td>
</tr>
<tr>
<td>some movement or sensory problems</td>
<td>12</td>
<td>7.64</td>
</tr>
<tr>
<td>no movement or sensory problems</td>
<td>1</td>
<td>1.08</td>
</tr>
</tbody>
</table>

1 row percent
LR chi-square=95.72  df=3  prob=6.5e-19 (adj.)
Appendix E

Table E-19. Uses one or more transport services by number of years since injury (respondents with complete/incomplete quadriplegia only)

<table>
<thead>
<tr>
<th>Number of years since injury</th>
<th>uses transport services</th>
<th>doesn't use transport services</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>% 1</td>
</tr>
<tr>
<td>less than 5 years</td>
<td>16</td>
<td>64.00</td>
</tr>
<tr>
<td>5 to 13 years</td>
<td>57</td>
<td>41.91</td>
</tr>
<tr>
<td>14 years or more</td>
<td>8</td>
<td>20.51</td>
</tr>
</tbody>
</table>

1 row percent
LR chi-square=12.78  df=2  prob=0.036 (adj.)

Table E-20. Uses one or more transport services by number of years since injury (respondents with complete/incomplete paraplegia only)

<table>
<thead>
<tr>
<th>Number of years since injury</th>
<th>uses transport services</th>
<th>doesn't use transport services</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>% 1</td>
</tr>
<tr>
<td>less than 5 years</td>
<td>14</td>
<td>43.75</td>
</tr>
<tr>
<td>5 years or more</td>
<td>35</td>
<td>15.63</td>
</tr>
</tbody>
</table>

1 row percent
LR chi-square=11.96  df=1  prob=0.0049 (adj.)

Table E-21. Indicators of the use of one or more professional respite services

<table>
<thead>
<tr>
<th>Segment 1</th>
<th>n</th>
<th>% using one or more professional respite services</th>
<th>relative odds of using professional respite services</th>
</tr>
</thead>
<tbody>
<tr>
<td>function 1-2</td>
<td>221</td>
<td>17.65</td>
<td>2.44:1</td>
</tr>
<tr>
<td>function 3-5, has everyday help, not in labour force or unemployed</td>
<td>155</td>
<td>7.74</td>
<td>1.07:1</td>
</tr>
<tr>
<td>function 3-5, has everyday help, employed</td>
<td>65</td>
<td>0.00</td>
<td>0.00:1</td>
</tr>
<tr>
<td>function 3-5, no everyday help</td>
<td>72</td>
<td>0.00</td>
<td>0.00:1</td>
</tr>
<tr>
<td>function 6</td>
<td>93</td>
<td>0.00</td>
<td>0.00:1</td>
</tr>
<tr>
<td>Total population 2</td>
<td>706</td>
<td>7.22</td>
<td>1:1</td>
</tr>
</tbody>
</table>

1 function 1 | Complete quadriplegia
function 2 | Incomplete quadriplegia
function 3 | Complete paraplegia
function 4 | Incomplete paraplegia
function 5 | Some movement or sensory problems
function 6 | No movement or sensory problems

2 includes five cases with incomplete datasets

248
Table E-22. Uses one or more respite services by level of function (all respondents)

<table>
<thead>
<tr>
<th>Function</th>
<th>uses respite services</th>
<th></th>
<th>doesn't use respite services</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%¹</td>
<td>n</td>
<td>%¹</td>
</tr>
<tr>
<td>complete/incomplete quadriplegia</td>
<td>39</td>
<td>17.65</td>
<td>182</td>
<td>82.35</td>
</tr>
<tr>
<td>complete/incomplete paraplegia or some movement or sensory problems</td>
<td>12</td>
<td>3.06</td>
<td>380</td>
<td>96.94</td>
</tr>
<tr>
<td>no movement or sensory problems</td>
<td>0</td>
<td>0.00</td>
<td>93</td>
<td>100.00</td>
</tr>
</tbody>
</table>

1 row percent
LR chi-square=52.99  df=2  prob=1.1e-10 (adj.)

Table E-23. Uses one or more respite services by receipt of everyday help (respondents with complete/incomplete paraplegia or some movement or sensory problem only)

<table>
<thead>
<tr>
<th>Receipt of everyday help</th>
<th>uses respite services</th>
<th></th>
<th>doesn't use respite services</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%¹</td>
<td>n</td>
<td>%¹</td>
</tr>
<tr>
<td>has everyday help</td>
<td>12</td>
<td>5.45</td>
<td>208</td>
<td>94.55</td>
</tr>
<tr>
<td>no everyday help</td>
<td>0</td>
<td>0.00</td>
<td>172</td>
<td>100.00</td>
</tr>
</tbody>
</table>

1 row percent
LR chi-square=14.16  df=1  prob=0.00050 (adj.)

Table E-24. Uses one or more respite services by employment status (respondents with complete/incomplete paraplegia or some movement or sensory problem who have everyday help only)

<table>
<thead>
<tr>
<th>Employment status</th>
<th>uses respite services</th>
<th></th>
<th>doesn't use respite services</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%¹</td>
<td>n</td>
<td>%¹</td>
</tr>
<tr>
<td>employed</td>
<td>0</td>
<td>0.00</td>
<td>65</td>
<td>100.00</td>
</tr>
<tr>
<td>not in labour force or unemployed</td>
<td>12</td>
<td>7.74</td>
<td>143</td>
<td>92.26</td>
</tr>
</tbody>
</table>

1 row percent
LR chi-square=8.69  df=1  prob=0.022 (adj.)
Segmentation analysis (CHAID) identifying segments of the population who use government funded and privately funded professional services.

Table F-1. Indicators of the use of one or more government funded professional services

<table>
<thead>
<tr>
<th>Segment</th>
<th>n</th>
<th>% using one or more government services</th>
<th>relative odds of using government services</th>
</tr>
</thead>
<tbody>
<tr>
<td>function 1</td>
<td>74</td>
<td>91.89</td>
<td>2.02:1</td>
</tr>
<tr>
<td>function 2, has everyday help</td>
<td>106</td>
<td>76.42</td>
<td>1.68:1</td>
</tr>
<tr>
<td>function 3-4, has everyday help, female</td>
<td>37</td>
<td>75.68</td>
<td>1.66:1</td>
</tr>
<tr>
<td>function 5, has everyday help</td>
<td>59</td>
<td>52.54</td>
<td>1.15:1</td>
</tr>
<tr>
<td>function 3-4, has everyday help, male</td>
<td>132</td>
<td>47.73</td>
<td>1.05:1</td>
</tr>
<tr>
<td>function 3-4, no everyday help</td>
<td>85</td>
<td>28.24</td>
<td>0.62:1</td>
</tr>
<tr>
<td>function 2, no everyday help</td>
<td>20</td>
<td>25.00</td>
<td>0.55:1</td>
</tr>
<tr>
<td>function 5, no everyday help</td>
<td>98</td>
<td>15.31</td>
<td>0.34:1</td>
</tr>
<tr>
<td>function 6</td>
<td>93</td>
<td>6.45</td>
<td>0.14:1</td>
</tr>
<tr>
<td><strong>Total population</strong></td>
<td>706</td>
<td><strong>45.60</strong></td>
<td><strong>1:1</strong></td>
</tr>
</tbody>
</table>

1 function 1 Complete quadriplegia
function 2 Incomplete quadriplegia
function 3 Complete paraplegia
function 4 Incomplete paraplegia
function 5 Some movement or sensory problems
function 6 No movement or sensory problems

2 includes five cases with incomplete datasets

251
Table F-2. Uses one or more government services by level of function (all respondents)

<table>
<thead>
<tr>
<th>Function</th>
<th>uses government services</th>
<th></th>
<th>doesn't use government services</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%¹</td>
<td>n</td>
<td>%¹</td>
</tr>
<tr>
<td>complete quadriplegia</td>
<td>68</td>
<td>91.89</td>
<td>6</td>
<td>8.11</td>
</tr>
<tr>
<td>incomplete quadriplegia</td>
<td>86</td>
<td>68.25</td>
<td>40</td>
<td>31.75</td>
</tr>
<tr>
<td>complete/incomplete paraplegia</td>
<td>115</td>
<td>45.28</td>
<td>139</td>
<td>54.72</td>
</tr>
<tr>
<td>some movement or sensory problem</td>
<td>46</td>
<td>29.30</td>
<td>111</td>
<td>70.70</td>
</tr>
<tr>
<td>no movement or sensory problems</td>
<td>6</td>
<td>6.45</td>
<td>87</td>
<td>93.55</td>
</tr>
</tbody>
</table>

1 row percent
LR chi-square=187.10 df=4 prob=7.8e-38 (adj.)

Table F-3. Uses one or more government services by need for everyday help (respondents with incomplete quadriplegia only)

<table>
<thead>
<tr>
<th>Need for everyday help</th>
<th>uses government services</th>
<th></th>
<th>doesn't use government services</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%¹</td>
<td>n</td>
<td>%¹</td>
</tr>
<tr>
<td>needs everyday help</td>
<td>81</td>
<td>76.42</td>
<td>25</td>
<td>23.58</td>
</tr>
<tr>
<td>doesn't need everyday help</td>
<td>5</td>
<td>25.00</td>
<td>15</td>
<td>75.00</td>
</tr>
</tbody>
</table>

1 row percent
LR chi-square=19.19 df=1 prob=3.6e-5 (adj.)

Table F-4. Uses one or more government services by need for everyday help (respondents with complete/incomplete paraplegia only)

<table>
<thead>
<tr>
<th>Need for everyday help</th>
<th>uses government services</th>
<th></th>
<th>doesn't use government services</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%¹</td>
<td>n</td>
<td>%¹</td>
</tr>
<tr>
<td>needs everyday help</td>
<td>91</td>
<td>53.85</td>
<td>78</td>
<td>46.15</td>
</tr>
<tr>
<td>doesn't need everyday help</td>
<td>24</td>
<td>28.24</td>
<td>61</td>
<td>71.76</td>
</tr>
</tbody>
</table>

1 row percent
LR chi-square=15.39 df=1 prob=0.00026 (adj.)

252
Table F-5. Uses one or more government services by gender (respondents with complete/incomplete paraplegia who need everyday help only)

<table>
<thead>
<tr>
<th>Gender</th>
<th>uses government services</th>
<th>doesn't use government services</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%¹</td>
</tr>
<tr>
<td>male</td>
<td>63</td>
<td>47.73</td>
</tr>
<tr>
<td>female</td>
<td>28</td>
<td>75.68</td>
</tr>
</tbody>
</table>

¹ row percent
LR chi-square=9.51 df=1 prob=0.0061 (adj.)

Table F-6. Uses one or more government services by need for everyday help (respondents with some movement or sensory problem only)

<table>
<thead>
<tr>
<th>Need for everyday help</th>
<th>uses government services</th>
<th>doesn't use government services</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%¹</td>
</tr>
<tr>
<td>needs everyday help</td>
<td>31</td>
<td>52.24</td>
</tr>
<tr>
<td>doesn't need everyday help</td>
<td>15</td>
<td>15.31</td>
</tr>
</tbody>
</table>

¹ row percent
LR chi-square=24.39 df=1 prob=2.4e-6 (adj.)
Table F-7. Indicators of the use of one or more private professional services

<table>
<thead>
<tr>
<th>Segment</th>
<th>n</th>
<th>% using one or more private services</th>
<th>relative odds of using private services</th>
</tr>
</thead>
<tbody>
<tr>
<td>function 1-2, wages or other income</td>
<td>106</td>
<td>56.60</td>
<td>2.11:1</td>
</tr>
<tr>
<td>function 3-5, pension income, aged 40-49 at time of injury</td>
<td>20</td>
<td>40.00</td>
<td>1.49:1</td>
</tr>
<tr>
<td>function 1-2, pension income</td>
<td>94</td>
<td>29.79</td>
<td>1.11:1</td>
</tr>
<tr>
<td>function 3-5, wages or other income</td>
<td>243</td>
<td>28.40</td>
<td>1.06:1</td>
</tr>
<tr>
<td>function 3-5, pension income, aged &lt;20 at time of injury</td>
<td>28</td>
<td>21.43</td>
<td>0.80:1</td>
</tr>
<tr>
<td>function 6, injured &lt;5 years ago</td>
<td>24</td>
<td>20.83</td>
<td>0.78:1</td>
</tr>
<tr>
<td>function 3-5, pension income, aged 50+ at time of injury</td>
<td>46</td>
<td>13.04</td>
<td>0.49:1</td>
</tr>
<tr>
<td>function 6, injured 8+ years ago</td>
<td>52</td>
<td>7.69</td>
<td>0.29:1</td>
</tr>
<tr>
<td>function 3-5, pension income, aged 20-39 at time of injury</td>
<td>55</td>
<td>5.45</td>
<td>0.20:1</td>
</tr>
<tr>
<td>function 6, injured 5-7 years ago</td>
<td>36</td>
<td>0.00</td>
<td>0.00:1</td>
</tr>
<tr>
<td><strong>Total population</strong></td>
<td>704</td>
<td><strong>26.85</strong></td>
<td><strong>1:1</strong></td>
</tr>
</tbody>
</table>

1 function 1: Complete quadriplegia  
function 2: Incomplete quadriplegia  
function 3: Complete paraplegia  
function 4: Incomplete paraplegia  
function 5: Some movement or sensory problems  
function 6: No movement or sensory problems

2 includes five cases with incomplete datasets

Table F-8. Uses one or more private services by level of function (all respondents)

<table>
<thead>
<tr>
<th>Function</th>
<th>uses private services</th>
<th>doesn't use private services</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%1</td>
</tr>
<tr>
<td>complete/incomplete quadriplegia</td>
<td>88</td>
<td>44.00</td>
</tr>
<tr>
<td>complete/incomplete paraplegia, some movement or sensory problem</td>
<td>92</td>
<td>23.47</td>
</tr>
<tr>
<td>no movement or sensory problems</td>
<td>9</td>
<td>8.04</td>
</tr>
</tbody>
</table>

1 row percent  
LR chi-square=54.87  df=2  prob=4.3e-11 (adj.)
Table F-9. Uses one or more private services by primary source of income (respondents with complete/incomplete quadriplegia only)

<table>
<thead>
<tr>
<th>Source of income</th>
<th>uses private services</th>
<th>doesn't use private services</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%1</td>
</tr>
<tr>
<td>wages or other income</td>
<td>60</td>
<td>56.60</td>
</tr>
<tr>
<td>government pension</td>
<td>28</td>
<td>29.79</td>
</tr>
</tbody>
</table>

1 row percent
LR chi-square=14.78 df=1 prob=0.00085 (adj.)

Table F-10. Uses one or more private services by primary source of income (respondents with complete/incomplete paraplegia or some movement or sensory problem only)

<table>
<thead>
<tr>
<th>Source of income</th>
<th>uses private services</th>
<th>doesn't use private services</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%1</td>
</tr>
<tr>
<td>wages or other income</td>
<td>69</td>
<td>28.40</td>
</tr>
<tr>
<td>government pension</td>
<td>23</td>
<td>15.44</td>
</tr>
</tbody>
</table>

1 row percent
LR chi-square=9.02 df=1 prob=0.019 (adj.)

Table F-11. Uses one or more private services by age at time of injury (respondents with complete/incomplete paraplegia or some movement or sensory problem with pension income only)

<table>
<thead>
<tr>
<th>Age at time of injury</th>
<th>uses private services</th>
<th>doesn't use private services</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%1</td>
</tr>
<tr>
<td>less than 20</td>
<td>6</td>
<td>21.43</td>
</tr>
<tr>
<td>20-39</td>
<td>3</td>
<td>5.45</td>
</tr>
<tr>
<td>40-49</td>
<td>8</td>
<td>40.00</td>
</tr>
<tr>
<td>50 or older</td>
<td>6</td>
<td>13.04</td>
</tr>
</tbody>
</table>

1 row percent
LR chi-square=13.27 df=3 prob=0.32 (adj.)

255
Appendix F

Table F-12. Uses one or more private services by number of years since injury (respondents with no movement or sensory problems only)

<table>
<thead>
<tr>
<th>Number of years since injury</th>
<th>uses private services</th>
<th>doesn't use private services</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%1</td>
</tr>
<tr>
<td>less than 5 years</td>
<td>5</td>
<td>20.83</td>
</tr>
<tr>
<td>5-7 years</td>
<td>0</td>
<td>0.00</td>
</tr>
<tr>
<td>8 or more years</td>
<td>4</td>
<td>7.69</td>
</tr>
</tbody>
</table>

1 row percent
LR chi-square=9.87 df=2 prob=0.15 (adj.)

256
Appendix G

Segmentation analysis (CHAID) identifying population segments who were experiencing problems obtaining services.

Table G-1. Indicators of problems obtaining one or more professional services

<table>
<thead>
<tr>
<th>Segment</th>
<th>n</th>
<th>% with obtainment problem</th>
<th>relative odds of obtainment problem</th>
</tr>
</thead>
<tbody>
<tr>
<td>has everyday help, injured &lt;5 years ago</td>
<td>64</td>
<td>59.38</td>
<td>2.01:1</td>
</tr>
<tr>
<td>has help, injured 5+ years ago, post school education</td>
<td>139</td>
<td>46.76</td>
<td>1.58:1</td>
</tr>
<tr>
<td>has help, injured 5+ years ago, school only education</td>
<td>216</td>
<td>31.48</td>
<td>1.07:1</td>
</tr>
<tr>
<td>no everyday help</td>
<td>285</td>
<td>12.98</td>
<td>0.44:1</td>
</tr>
<tr>
<td><strong>Total population</strong></td>
<td>706</td>
<td>29.55</td>
<td>1:1</td>
</tr>
</tbody>
</table>

2 includes five cases with incomplete datasets

Table G-2. Problem obtaining one or more professional services by receipt of everyday help (all respondents)

<table>
<thead>
<tr>
<th>Receipt of everyday help</th>
<th>problem obtaining professional services</th>
<th>no problem obtaining professional services</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%¹</td>
</tr>
<tr>
<td>has everyday help</td>
<td>171</td>
<td>40.81</td>
</tr>
<tr>
<td>no everyday help</td>
<td>37</td>
<td>12.98</td>
</tr>
</tbody>
</table>

¹ row percent
LR chi-square=67.93 df=1 prob=5.1e-16 (adj.)
### Table G-3. Problem obtaining one or more professional services by number of years since injury (respondents who have everyday help only)

<table>
<thead>
<tr>
<th>Number of years since injury</th>
<th>problem obtaining professional services</th>
<th>no problem obtaining professional services</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%</td>
</tr>
<tr>
<td>less than 5 years</td>
<td>38</td>
<td>59.38</td>
</tr>
<tr>
<td>5 years or more</td>
<td>133</td>
<td>37.46</td>
</tr>
</tbody>
</table>

1 row percent
LR chi-square=10.58 df=1 prob=0.010 (adj.)

### Table G-4. Problem obtaining one or more professional services by level of education (respondents who have everyday help and were injured 5 or more years ago only)

<table>
<thead>
<tr>
<th>Level of education</th>
<th>problem obtaining professional services</th>
<th>no problem obtaining professional services</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%</td>
</tr>
<tr>
<td>school only</td>
<td>68</td>
<td>31.48</td>
</tr>
<tr>
<td>vocational or tertiary</td>
<td>65</td>
<td>46.76</td>
</tr>
</tbody>
</table>

1 row percent
LR chi-square=8.38 df=1 prob=0.026 (adj.)

### Table G-5. Indicators of problems obtaining one or more government professional services

<table>
<thead>
<tr>
<th>Segment</th>
<th>n</th>
<th>% with obtainment problem</th>
<th>relative odds of obtainment problem</th>
</tr>
</thead>
<tbody>
<tr>
<td>has everyday help, injured ≤5 years ago</td>
<td>64</td>
<td>56.25</td>
<td>2.25:1</td>
</tr>
<tr>
<td>has everyday help, injured ≥5+ years ago</td>
<td>355</td>
<td>31.83</td>
<td>1.27:1</td>
</tr>
<tr>
<td>no everyday help, function 1-4</td>
<td>96</td>
<td>18.75</td>
<td>0.75:1</td>
</tr>
<tr>
<td>no everyday help, function 5-6, male</td>
<td>135</td>
<td>6.67</td>
<td>0.27:1</td>
</tr>
<tr>
<td>no everyday help, function 5-6, female</td>
<td>54</td>
<td>0.00</td>
<td>0.00:1</td>
</tr>
</tbody>
</table>

**Total population**

<table>
<thead>
<tr>
<th>n</th>
<th>%</th>
<th>relative odds of obtainment problem</th>
</tr>
</thead>
<tbody>
<tr>
<td>706</td>
<td>25.00</td>
<td>1:1</td>
</tr>
</tbody>
</table>

1 function 1 Complete quadriplegia 
function 2 Incomplete quadriplegia 
function 3 Complete paraplegia 
function 4 Incomplete paraplegia 
function 5 Some movement or sensory problems 
function 6 No movement or sensory problems 
2 includes five cases with incomplete datasets
Table G-6. Problem obtaining one or more government services by receipt of everyday help (all respondents)

<table>
<thead>
<tr>
<th>Receipt of everyday help</th>
<th>problem obtaining government services</th>
<th>no problem obtaining government services</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%&lt;sup&gt;1&lt;/sup&gt;</td>
</tr>
<tr>
<td>has everyday help</td>
<td>149</td>
<td>35.56</td>
</tr>
<tr>
<td>no everyday help</td>
<td>27</td>
<td>9.47</td>
</tr>
</tbody>
</table>

1 row percent
LR chi-square=67.74  df=1  prob=5.6e-16 (adj.)

Table G-7. Problem obtaining one or more government services by number of years since injury (respondents with everyday help only)

<table>
<thead>
<tr>
<th>Number of years since injury</th>
<th>problem obtaining government services</th>
<th>no problem obtaining government services</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%&lt;sup&gt;1&lt;/sup&gt;</td>
</tr>
<tr>
<td>less than 5 years</td>
<td>36</td>
<td>56.25</td>
</tr>
<tr>
<td>5 years or more</td>
<td>113</td>
<td>31.83</td>
</tr>
</tbody>
</table>

1 row percent
LR chi-square=13.52  df=1  prob=0.0021 (adj.)

Table G-8. Problem obtaining one or more government services by level of function help (respondents with no everyday help only)

<table>
<thead>
<tr>
<th>Level of function</th>
<th>problem obtaining government services</th>
<th>no problem obtaining government services</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%&lt;sup&gt;1&lt;/sup&gt;</td>
</tr>
<tr>
<td>quadriplegia or paraplegia</td>
<td>18</td>
<td>18.75</td>
</tr>
<tr>
<td>some or no movement or sensory problems</td>
<td>9</td>
<td>4.76</td>
</tr>
</tbody>
</table>

1 row percent
LR chi-square=13.60  df=1  prob=0.0025 (adj.)

Table G-9. Problem obtaining one or more government services by gender (respondents with no everyday help and some or no movement or sensory problems only)

<table>
<thead>
<tr>
<th>Gender</th>
<th>problem obtaining government services</th>
<th>no problem obtaining government services</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%&lt;sup&gt;1&lt;/sup&gt;</td>
</tr>
<tr>
<td>male</td>
<td>9</td>
<td>6.67</td>
</tr>
<tr>
<td>female</td>
<td>0</td>
<td>0.00</td>
</tr>
</tbody>
</table>

1 row percent
LR chi-square=6.23  df=1  prob=0.037 (adj.)
### Table G-10. Indicators of problems obtaining one or more private professional services

<table>
<thead>
<tr>
<th>Segment</th>
</tr>
</thead>
<tbody>
<tr>
<td>has everyday help, tertiary education</td>
</tr>
<tr>
<td>has everyday help, school only or vocational education, currently aged &lt;60</td>
</tr>
<tr>
<td>no everyday help, injured &lt;5 years ago</td>
</tr>
<tr>
<td>has everyday help, school only or vocational education, currently aged 60+</td>
</tr>
<tr>
<td>no everyday help, injured 5+ year ago</td>
</tr>
<tr>
<td>Total population</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>n</th>
<th>% with obtaining problem</th>
<th>relative odds of obtaining problem</th>
</tr>
</thead>
<tbody>
<tr>
<td>has everyday help, tertiary education</td>
<td>56</td>
<td>50.00</td>
<td>2.27:1</td>
</tr>
<tr>
<td>has everyday help, school only or vocational education, currently aged &lt;60</td>
<td>280</td>
<td>31.79</td>
<td>1.44:1</td>
</tr>
<tr>
<td>no everyday help, injured &lt;5 years ago</td>
<td>51</td>
<td>19.61</td>
<td>0.89:1</td>
</tr>
<tr>
<td>has everyday help, school only or vocational education, currently aged 60+</td>
<td>83</td>
<td>13.25</td>
<td>0.60:1</td>
</tr>
<tr>
<td>no everyday help, injured 5+ year ago</td>
<td>234</td>
<td>7.26</td>
<td>0.33:1</td>
</tr>
<tr>
<td>Total population</td>
<td>706</td>
<td>22.02</td>
<td>1:1</td>
</tr>
</tbody>
</table>

1 includes five cases with incomplete datasets

### Table G-11. Problem obtaining one or more private services by receipt of everyday help (all respondents)

<table>
<thead>
<tr>
<th>Receipt of everyday help</th>
</tr>
</thead>
<tbody>
<tr>
<td>problem obtaining private services</td>
</tr>
<tr>
<td>n</td>
</tr>
<tr>
<td>---</td>
</tr>
<tr>
<td>has everyday help</td>
</tr>
<tr>
<td>no everyday help</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>n</th>
<th>%</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>has everyday help</td>
<td>128</td>
<td>30.55</td>
<td>291</td>
<td>69.45</td>
</tr>
<tr>
<td>no everyday help</td>
<td>27</td>
<td>9.47</td>
<td>258</td>
<td>90.53</td>
</tr>
</tbody>
</table>

1 row percent
LR chi-square=47.83 df=1 prob=1.4e-11 (adj.)

### Table G-12. Problem obtaining one or more private services by level of education (respondents with everyday help only)

<table>
<thead>
<tr>
<th>Level of education</th>
</tr>
</thead>
<tbody>
<tr>
<td>problem obtaining private services</td>
</tr>
<tr>
<td>n</td>
</tr>
<tr>
<td>---</td>
</tr>
<tr>
<td>school or vocational education</td>
</tr>
<tr>
<td>tertiary education</td>
</tr>
</tbody>
</table>

1 row percent
LR chi-square=10.76 df=1 prob=0.0072 (adj.)
Table G-13. Problem obtaining one or more private services by current age (respondents with everyday help and school only or vocational education only)

<table>
<thead>
<tr>
<th>Current age</th>
<th>problem obtaining private services</th>
<th>no problem obtaining private services</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%</td>
</tr>
<tr>
<td>less than 60 years</td>
<td>89</td>
<td>31.79</td>
</tr>
<tr>
<td>60 or more years</td>
<td>11</td>
<td>13.25</td>
</tr>
</tbody>
</table>

1 row percent
LR chi-square=12.28 df=1 prob=0.0059 (adj.)

Table G-14. Problem obtaining one or more private services by number of years since injury (respondents with no everyday help only)

<table>
<thead>
<tr>
<th>Number of years since injury</th>
<th>problem obtaining private services</th>
<th>no problem obtaining private services</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%</td>
</tr>
<tr>
<td>less than 5 years</td>
<td>10</td>
<td>19.61</td>
</tr>
<tr>
<td>5 or more years</td>
<td>17</td>
<td>7.26</td>
</tr>
</tbody>
</table>

1 row percent
LR chi-square=6.25 df=1 prob=0.11 (adj.)

Table G-15. Indicators of problems obtaining professional personal care services

<table>
<thead>
<tr>
<th>Segment1</th>
<th>n</th>
<th>% with obtainment problem</th>
<th>relative odds of obtainment problem</th>
</tr>
</thead>
<tbody>
<tr>
<td>has everyday help, function 1, wages or other income</td>
<td>45</td>
<td>51.11</td>
<td>3.031</td>
</tr>
<tr>
<td>has everyday help, function 1, pension income</td>
<td>35</td>
<td>25.71</td>
<td>1.53:1</td>
</tr>
<tr>
<td>has everyday help, function 2-6</td>
<td>339</td>
<td>21.83</td>
<td>1.30:1</td>
</tr>
<tr>
<td>no everyday help, function 1-4</td>
<td>109</td>
<td>9.17</td>
<td>0.54:1</td>
</tr>
<tr>
<td>no everyday help, function 5-6</td>
<td>178</td>
<td>1.69</td>
<td>0.10:1</td>
</tr>
<tr>
<td>Total population</td>
<td>706</td>
<td>16.86</td>
<td>1:1</td>
</tr>
</tbody>
</table>

1 function 1 Complete quadriplegia
function 2 Incomplete quadriplegia
function 3 Complete paraplegia
function 4 Incomplete paraplegia
function 5 Some movement or sensory problems
function 6 No movement or sensory problems
**Appendix G**

### Table G-16. Problem obtaining personal care services by receipt of everyday help (all respondents)

<table>
<thead>
<tr>
<th>Receipt of everyday help</th>
<th>problem obtaining personal care services</th>
<th>no problem obtaining personal care services</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%&lt;sup&gt;1&lt;/sup&gt;</td>
</tr>
<tr>
<td>has everyday help</td>
<td>106</td>
<td>25.30</td>
</tr>
<tr>
<td>no everyday help</td>
<td>13</td>
<td>4.53</td>
</tr>
</tbody>
</table>

1 row percent  
LR chi-square=60.64 df=1 prob=2.1e-14 (adj.)

### Table G-17. Problem obtaining personal care services by level of function (respondents with everyday help only)

<table>
<thead>
<tr>
<th>Level of function</th>
<th>problem obtaining personal care services</th>
<th>no problem obtaining personal care services</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%&lt;sup&gt;1&lt;/sup&gt;</td>
</tr>
<tr>
<td>complete quadriplegia</td>
<td>32</td>
<td>40.00</td>
</tr>
<tr>
<td>incomplete quadriplegia, paraplegia, some or no movement or sensory problems</td>
<td>74</td>
<td>21.83</td>
</tr>
</tbody>
</table>

1 row percent  
LR chi-square=10.51 df=1 prob=0.013 (adj.)

### Table G-18. Problem obtaining personal care services by primary source of income (respondents with everyday help and complete quadriplegia only)

<table>
<thead>
<tr>
<th>Primary source of income</th>
<th>problem obtaining personal care services</th>
<th>no problem obtaining personal care services</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%&lt;sup&gt;1&lt;/sup&gt;</td>
</tr>
<tr>
<td>wages or other income</td>
<td>23</td>
<td>51.11</td>
</tr>
<tr>
<td>government pension</td>
<td>9</td>
<td>25.71</td>
</tr>
</tbody>
</table>

1 row percent  
LR chi-square=5.42 df=1 prob=0.13 (adj.)

### Table G-19. Problem obtaining personal care services by level of function (respondents with no everyday help only)

<table>
<thead>
<tr>
<th>Level of function</th>
<th>problem obtaining personal care services</th>
<th>no problem obtaining personal care services</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%&lt;sup&gt;1&lt;/sup&gt;</td>
</tr>
<tr>
<td>quadriplegia or paraplegia</td>
<td>10</td>
<td>9.17</td>
</tr>
<tr>
<td>some or no movement or sensory problems</td>
<td>3</td>
<td>1.69</td>
</tr>
</tbody>
</table>

1 row percent  
LR chi-square=8.58 df=1 prob=0.037 (adj.)

262
### Table G-20. Indicators of problems obtaining professional paramedical services

<table>
<thead>
<tr>
<th>Segment</th>
<th>n</th>
<th>% with obtainment problem</th>
<th>relative odds of obtainment problem</th>
</tr>
</thead>
<tbody>
<tr>
<td>has everyday help, aged &lt;20 years at time of injury</td>
<td>74</td>
<td>43.24</td>
<td>2.18:1</td>
</tr>
<tr>
<td>no everyday help, thoracic, lumbar or sacral injury, currently aged &lt;30 years</td>
<td>31</td>
<td>35.48</td>
<td>1.79:1</td>
</tr>
<tr>
<td>has everyday help, aged 20-69 years at time of injury with post school education</td>
<td>124</td>
<td>34.68</td>
<td>1.75:1</td>
</tr>
<tr>
<td>has everyday help, aged 20-69 years at time of injury with school only education</td>
<td>199</td>
<td>18.59</td>
<td>0.94:1</td>
</tr>
<tr>
<td>no everyday help, thoracic, lumbar or sacral injury, currently aged 30+ years</td>
<td>66</td>
<td>7.58</td>
<td>0.38:1</td>
</tr>
<tr>
<td>no everyday help, cervical injury</td>
<td>190</td>
<td>5.79</td>
<td>0.29:1</td>
</tr>
<tr>
<td>has everyday help, aged 70+ years at time of injury</td>
<td>22</td>
<td>4.55</td>
<td>0.23:1</td>
</tr>
</tbody>
</table>

**Total population**<sup>1</sup> 706 19.83 1:1
1 includes five cases with incomplete datasets

### Table G-21. Problem obtaining paramedical services by receipt of everyday help (all respondents)

<table>
<thead>
<tr>
<th>Receipt of everyday help</th>
<th>problem obtaining paramedical services</th>
<th>no problem obtaining paramedical services</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%&lt;sup&gt;1&lt;/sup&gt;</td>
</tr>
<tr>
<td>has everyday help</td>
<td>113</td>
<td>26.97</td>
</tr>
<tr>
<td>no everyday help</td>
<td>27</td>
<td>9.41</td>
</tr>
</tbody>
</table>

<sup>1</sup> row percent
LR chi-square=35.70  df=1  prob=6.9e-9 (adj.)

### Table G-22. Problem obtaining paramedical services by age at time of injury (respondents with everyday help only)

<table>
<thead>
<tr>
<th>Age at time of injury</th>
<th>problem obtaining paramedical services</th>
<th>no problem obtaining paramedical services</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%&lt;sup&gt;1&lt;/sup&gt;</td>
</tr>
<tr>
<td>less than 20 years</td>
<td>32</td>
<td>43.24</td>
</tr>
<tr>
<td>20–69 years</td>
<td>80</td>
<td>24.77</td>
</tr>
<tr>
<td>70 or more years</td>
<td>1</td>
<td>4.55</td>
</tr>
</tbody>
</table>

<sup>1</sup> row percent
LR chi-square=17.53  df=2  prob=0.0079 (adj.)
### Table G-23. Problem obtaining paramedical services by level of education
(respondents with everyday help aged 20–69 at time of injury only)

<table>
<thead>
<tr>
<th>Level of education</th>
<th>problem obtaining paramedical services</th>
<th>no problem obtaining paramedical services</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%&lt;sup&gt;1&lt;/sup&gt;</td>
</tr>
<tr>
<td>school only</td>
<td>37</td>
<td>18.59%</td>
</tr>
<tr>
<td>vocational and tertiary</td>
<td>43</td>
<td>34.68%</td>
</tr>
</tbody>
</table>

1 row percent
LR chi-square=10.40 df=1 prob=0.0088 (adj.)

### Table G-24. Problem obtaining paramedical services by vertebral level of injury (respondents with no everyday help only)

<table>
<thead>
<tr>
<th>Vertebral level of injury</th>
<th>problem obtaining paramedical services</th>
<th>no problem obtaining paramedical services</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%&lt;sup&gt;1&lt;/sup&gt;</td>
</tr>
<tr>
<td>cervical</td>
<td>11</td>
<td>5.79%</td>
</tr>
<tr>
<td>thoracic, lumbar or sacral</td>
<td>16</td>
<td>16.49%</td>
</tr>
</tbody>
</table>

1 row percent
LR chi-square=8.11 df=1 prob=0.039 (adj.)

### Table G-25. Problem obtaining paramedical services by current age (respondents with no everyday help and thoracic, lumbar or sacral injury only)

<table>
<thead>
<tr>
<th>Current age</th>
<th>problem obtaining paramedical services</th>
<th>no problem obtaining paramedical services</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%&lt;sup&gt;1&lt;/sup&gt;</td>
</tr>
<tr>
<td>less than 30 years</td>
<td>11</td>
<td>35.48%</td>
</tr>
<tr>
<td>30 or more years</td>
<td>5</td>
<td>7.58%</td>
</tr>
</tbody>
</table>

1 row percent
LR chi-square=11.13 df=1 prob=0.011 (adj.)

### Table G-26. Indicators of problems obtaining transport services

<table>
<thead>
<tr>
<th>Segment</th>
<th>n</th>
<th>% with obtainment problem</th>
<th>relative odds of obtainment problem</th>
</tr>
</thead>
<tbody>
<tr>
<td>has everyday help, post school education</td>
<td>164</td>
<td>24.39%</td>
<td>2.21:1</td>
</tr>
<tr>
<td>has everyday help, school only education</td>
<td>255</td>
<td>10.98%</td>
<td>0.99:1</td>
</tr>
<tr>
<td>no everyday help</td>
<td>287</td>
<td>3.48%</td>
<td>0.32:1</td>
</tr>
<tr>
<td>Total population&lt;sup&gt;1&lt;/sup&gt;</td>
<td>706</td>
<td>11.05%</td>
<td>1:1</td>
</tr>
</tbody>
</table>

1 includes five cases with incomplete datasets
Table G-27. Problem obtaining transport services by receipt of everyday help (all respondents)

<table>
<thead>
<tr>
<th>Receipt of everyday help</th>
<th>problem obtaining transport services</th>
<th>no problem obtaining transport services</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%</td>
</tr>
<tr>
<td>has everyday help</td>
<td>68</td>
<td>16.23</td>
</tr>
<tr>
<td>no everyday help</td>
<td>10</td>
<td>3.48</td>
</tr>
</tbody>
</table>

1 row percent
LR chi-square=32.30  df=1  prob=4.0e-8 (adj.)

Table G-28. Problem obtaining transport services by level of education (respondents with everyday help only)

<table>
<thead>
<tr>
<th>Level of education</th>
<th>problem obtaining transport services</th>
<th>no problem obtaining transport services</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%</td>
</tr>
<tr>
<td>school only</td>
<td>28</td>
<td>10.98</td>
</tr>
<tr>
<td>vocational or tertiary</td>
<td>40</td>
<td>24.39</td>
</tr>
</tbody>
</table>

1 row percent
LR chi-square=12.88  df=1  prob=0.0023 (adj.)

Table G-29. Indicators of problems obtaining respite services

<table>
<thead>
<tr>
<th>Segment</th>
<th>n</th>
<th>% with obtainment problem</th>
<th>relative odds of obtainment problem</th>
</tr>
</thead>
<tbody>
<tr>
<td>has everyday help</td>
<td>419</td>
<td>14.08</td>
<td>1.55:1</td>
</tr>
<tr>
<td>no everyday help</td>
<td>287</td>
<td>1.74</td>
<td>0.19:1</td>
</tr>
<tr>
<td><strong>Total population</strong> 1</td>
<td>706</td>
<td>9.07</td>
<td>1:1</td>
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</table>

1 includes five cases with incomplete datasets

Table G-30. Problem obtaining respite services by receipt of everyday help (all respondents)

<table>
<thead>
<tr>
<th>Receipt of everyday help</th>
<th>problem obtaining respite services</th>
<th>no problem obtaining respite services</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%</td>
</tr>
<tr>
<td>has everyday help</td>
<td>59</td>
<td>14.08</td>
</tr>
<tr>
<td>no everyday help</td>
<td>5</td>
<td>1.74</td>
</tr>
</tbody>
</table>

1 row percent
LR chi-square=38.30  df=1  prob=1.8e-9 (adj.)
Appendix H

Invitation to participate in an interview
They don’t understand someone with a spinal injury!

Everything’s OK, I’m really lucky!

Why can’t I get a job?

I get all the help I need!

Why aren’t there any services near here?

Why can’t I get help?

The services here are great!

Why aren’t the services better?

CONFIDENTIALITY

You will be sent a written copy of what you said in the interview for approval before any information from the interview is used. Personal information you give will be kept entirely confidential. Your name will not be used in any reports (unless you would like it to be) and no-one will be able to identify you.

YOUR VOICE HAS BEEN HEARD

The concerns raised in the earlier survey have already been passed on to service providers including the Motor Accidents Authority, professional organisations, physiotherapists, occupational therapists and so on. Similarly, the experiences and views you express in this survey will be conveyed to relevant organisations.

IT WILL MAKE A DIFFERENCE

Living with a Spinal Injury in New South Wales

Lynn Kemp
Research Office
University of Western Sydney Macarthur
THANK YOU FOR PARTICIPATING

Sometime during the last 18 months you responded to a survey about the needs of spinal injured persons and carers in the community. A number of issues were identified as of concern to large numbers of spinal injured persons and carers.

These issues included:
- lack of understanding of spinal injury in the community
- limited job opportunities
- difficulties in accessing services
- problems in qualifying for services
- limited availability of services, particularly physiotherapy
- poor quality services
- inequitable distribution of services across New South Wales
- problems with the legal and compensation system

HOW YOU CAN HELP

A greater understanding of how these issues do or do not affect your everyday life would be of great benefit when expressing your concerns to government and service providers.

To gain this understanding the researcher would like to visit you at home (or wherever you choose) to hear your own story and concerns. The interview would take about one hour.

Your story is important even if you are experiencing no problems. We need to know what works, as well as what doesn't.

If you would like to participate please complete the tear-off section of this pamphlet and return it in the reply paid envelope.
Appendix I

Table I-1. Demographic characteristics of interview participants

<table>
<thead>
<tr>
<th>Name</th>
<th>Location</th>
<th>Age</th>
<th>Level of function</th>
<th>Years post injury</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adrian</td>
<td>Regional centre</td>
<td>20's</td>
<td>Incomplete paraplegia</td>
<td>5 or less</td>
</tr>
<tr>
<td>Alan</td>
<td>Country</td>
<td>50's</td>
<td>Complete paraplegia</td>
<td>14 or more</td>
</tr>
<tr>
<td>Alex</td>
<td>Country</td>
<td>30's</td>
<td>Complete paraplegia</td>
<td>6-9</td>
</tr>
<tr>
<td>Andrew</td>
<td>Outer sydney</td>
<td>40's</td>
<td>Complete paraplegia</td>
<td>14 or more</td>
</tr>
<tr>
<td>Brendan</td>
<td>Regional centre</td>
<td>30's</td>
<td>Complete paraplegia</td>
<td>10-13</td>
</tr>
<tr>
<td>Brett</td>
<td>Inner sydney</td>
<td>40's</td>
<td>Complete paraplegia</td>
<td>6-9</td>
</tr>
<tr>
<td>Brian</td>
<td>Country</td>
<td>60's</td>
<td>Some movement or sensory problems</td>
<td>5 or less</td>
</tr>
<tr>
<td>Carl</td>
<td>Inner sydney</td>
<td>40's</td>
<td>Complete quadriplegia</td>
<td>14 or more</td>
</tr>
<tr>
<td>Charlie</td>
<td>Regional centre</td>
<td>30's</td>
<td>Complete quadriplegia</td>
<td>14 or more</td>
</tr>
<tr>
<td>Cheryl</td>
<td>Country</td>
<td>40's</td>
<td>Complete paraplegia</td>
<td>10-13</td>
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<td>Christine</td>
<td>Regional centre</td>
<td>50's</td>
<td>Complete quadriplegia</td>
<td>5 or less</td>
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<td>Dave</td>
<td>Country</td>
<td>50's</td>
<td>Complete quadriplegia</td>
<td>6-9</td>
</tr>
<tr>
<td>Emily</td>
<td>Country</td>
<td>70's</td>
<td>Incomplete paraplegia</td>
<td>5 or less</td>
</tr>
<tr>
<td>Eric</td>
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<td>Some movement or sensory problems</td>
<td>14 or more</td>
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<td>Evelyn</td>
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<td>Some movement or sensory problems</td>
<td>14 or more</td>
</tr>
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<td>Gail</td>
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<td>40's</td>
<td>Complete paraplegia</td>
<td>10-13</td>
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<td>George</td>
<td>Regional centre</td>
<td>60's</td>
<td>Complete paraplegia</td>
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<td>30's</td>
<td>Some movement or sensory problems</td>
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<td>Gwenda</td>
<td>Country</td>
<td>30's</td>
<td>Complete paraplegia</td>
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<td>James</td>
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<td>50's</td>
<td>Incomplete paraplegia</td>
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<td>Jane</td>
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<td>Incomplete paraplegia</td>
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<td>40's</td>
<td>Complete paraplegia</td>
<td>14 or more</td>
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<td>Kimberley</td>
<td>Inner sydney</td>
<td>20's</td>
<td>Incomplete paraplegia</td>
<td>5 or less</td>
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</table>
### Table I-1. continued

<table>
<thead>
<tr>
<th>Name</th>
<th>Location</th>
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<th>Level of function</th>
<th>Years post injury</th>
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<tr>
<td>Lars</td>
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<td>60’s</td>
<td>Incomplete paraplegia</td>
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<td>Lorraine</td>
<td>Country</td>
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<td>Incomplete quadriplegia</td>
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<td>Matthew</td>
<td>Country</td>
<td>30’s</td>
<td>Complete paraplegia</td>
<td>14 or more</td>
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<td>Regional centre</td>
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<td>Incomplete quadriplegia</td>
<td>14 or more</td>
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<tr>
<td>Norm</td>
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<td>5 or less</td>
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<td>6-9</td>
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<tr>
<td>Stuart</td>
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<td>Complete paraplegia</td>
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