A DESCRIPTIVE SURVEY OF PERSONS WITH SPINAL CORD INJURIES IN OREGON

By

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TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

CHAPTER I

> . . . I believe that the Optimal Spinal Cord Injury System engages in a series of activities which will teach the person with spinal injury to be able to compete as a first class citizen in an able body's world. (Trieschman, 1978)

"Spinal injury is one of the catastrophic crippling conditions of our society" (Young, 1969, p. 1). The effect of such an injury, producing permanent paralysis, can totally disrupt an individual's physical, emotional, social, vocational and economic status. Society has the potential to reduce these catastrophic consequences by establishing a systematized approach to care. We must orchestrate, consolidate and integrate our system of care in order to effect a means of increasing independence, dignity and self-respect in these individuals (Faye, 1977; Bachman, 1978).

Each year from 6,000 to 11,000 Americans suffer traumatic spinal cord injuries which result in varying degrees of permanent paralysis. The majority of these injuries occur in males between 15 and 30 years of age (Roessler & Bolton, 1978; Bachman, 1978). Until recently, the most common form of paralysis was paraplegia, but in 1978 Thomas noted a change in the ratio of paraplegics to quadriplegics. Whereas a decade ago, 65% were paraplegics and 35% quadriplegics, today 65% to 70% are quadriplegic and 30% to 35% paraplegic. Estimates of the total number of disabled persons in America due to spinal cord injury vary between 125,000 and 250,000 (Bachman, 1978).

In an address in May 1979 to the Oregon Trail Chapter of the National Spinal Cord Injury Foundation (NSCIF), Bruce Marquis, director of the national office, calculated between 1,200 and 2,000 persons with spinal cord injuries live in Oregon. If one accepts Bucy's (1975) estimate of 25 to 50 new spinal cord injuries per million population annually, then Oregon, with a population of nearly 2.5 million, may expect 64 to 124 new injuries per year.

In 1977, five Oregon congressmen requested a study of spinal cord injuries in the United States from the U.S. General Accounting Office (GAO). That national study concluded that motor vehicle accidents are the leading cause (56%) of spinal cord injuries. This seems congruent with a national finding by the Insurance Institute for Highway Safety (1976) which reported 5,300 persons suffered severed, crushed, or severely damaged spinal cords during that year. The GAO report listed falls as the second leading cause of spinal cord injuries (19%), followed by assaults (12%), sports (7%) and "all other" causes (6%).

The costs of a spinal cord injury are staggering. Dunn (1975) reported $2.4 billion annual costs for care of persons with spinal cord injuries in America. Nickel (1975) quotes a lifetime expenditure at $400,000 per individual, while Bachman, in 1978, projected an expenditure of $600,000 plus an additional Gross National Product loss of $1.2 million per case. Using Bachman's estimate of $40,000 for the first year medical and rehabilitation expenses for new injuries, it could be projected that Oregon's expenditures for new injuries is between $2.6 and $5 million each year.

The cost of spinal cord injury both in terms of human suffering and in terms of dollars and cents can no longer go unnoticed by society. Only maximum independence can reduce these costs. Systematized care and community acceptance on equal terms to able-bodied persons are key elements towards achieving this goal.

CONCEPTUAL FRAMEWORK

Rapid, scientific advances within the last 30 years have brought life-saving and life-prolonging techniques of miraculous benefit to individuals suffering from spinal cord injuries. However, society has been slow to recognize and implement a service delivery system which will enhance the ability of these individuals to live independent, productive lives. This lack has been unfortunate to the individual and a great expense to society. Within the last decade, however, spinal cord injury centers have evolved in many parts of our country. As a result, there has developed what is referred to as the "system" approach to the care of spinal cord injured persons, in contrast to the earlier "nonsystem" approach.

The Nonsystem Approach to Care

A nonsystem approach to care of spinal cord injured persons is haphazard, uncoordinated, fragmentated and/or duplicative, which in turn results in preventable medical and social complications.

Several critics have described a nonsystem as lacking scientific guidelines for the care of spinal cord injured persons, including emergency care, acute care and rehabilitation (Sussman, 1978; Bucy, 1975; Charles, Fine & Stover, 1978).

Young and Dexter (1977) differentiate a system from a nonsystem as follows:

> Each Regional Spinal Cord Injury System has its own definitions of "system" and "nonsystem" cases depending on the local situation and the program's concept of a system. Basically, a "system" patient is one who receives an ongoing continuity of care under the influence or control of the regional system beginning soon (hours or a few days) after injury and continuing until discharge to home. A "nonsystem" patient is one who is treated in a fragmented, uncoordinated fashion by one or more institutions for a prolonged period of time before admission to a sytem hospital. (p. 54)

At this time, Oregon's approach to care of spinal cord injuries may best be described as a nonsystem. There are still many victims taken to small hospitals without appropriate facilities or experienced personnel. Even where there are competent facilities and staff to provide acute care, many medical centers do not provide comprehensive rehabilitation and long-term independent living skills and too often a total dependence on repetitive hospitalizatios and welfare programs.

The System Approach to Care

The system approach is designed to manage spinal cord injury care through a comprehensive, multidisciplinary delivery system from the point of injury through long-term maintenance. Ideally, the system includes appropriation and/or coordination of funding for such services. The system approach has proved to be beneficial for recipients and cost effective for funding agencies (National Paraplegia Foundation, 1977).

A systematized, comprehensive, multidisciplinary approach to care of spinal cord injured persons has been described as "holistic" by Young (1977) and Bachman (1978), and as a "systems approach" by Roessler and Bolton (1978).

The Commissioner of Vocational Rehabilitation for the State of

Massachusetts, Elmer Bartel (1977), a quadriplegic, states that the prime goal of the system is a medically stable, well-rehabilitated individual who returns to the community as a contributing member of society. This goal can be accomplished only by understanding the needs of the spinal cord injured individual, and by examining the effectiveness of resources within the system. Bartel says it is necessary to identify effective resources for the total problems of the spinal cord injured person from point of injury through long-term maintenance. This, he indicates, requires a high level of interaction and communication between resource personnel so that there will be continuity of care and management of spinal cord injured persons.

Bartel susgests that in some areas of the country it is logical to have the spinal cord injured system operate from a single rehabilitation center, while in other regions it may be more effective to operate the system under the established regional medical/rehabilitation organizations, using various resources within the region.

Bartel's conceptual framework is similar to that conceptual framework underlying "Standards and Criteria of Care" established in 1976 by the New England Spinal Cord Injury Foundation Committee. This committee of eight physicians and three other specialists was created to ". . . provide information and guidelines to the professional community that will result in improved care of persons with a spinal cord injury through rehabilitation and reintegration in the community" (National Paraplegic Convention Journal, 1977, p. 58).

Criteria similar to those of the National Spinal Cord Injury Foundation Committee were established by the Rehabilitation Service

Administration (RSA) for a "Model Spinal Cord Injury Program." These criteria have had great impact on the establishment of systems of care because funding was available from the Department of Health, Education and Welfare (DHEW) for systems which emphasized continuity of care from point of injury through long-term community adjustment. The three major components in the criteria are acute care, rehabilitation services and long-term follow-up services. Acute care includes evacuation from site of injury, emergency treatment and early acute care (1 to 10 days post onset). Rehabilitation services encompass both physical restoration and vocational rehabilitation. The time considered appropriate for these services is between 10 and 120 days post onset. Long-term comprehensive follow-up includes a continuation of medical, social, psychological and vocational services coordinated through community programs (see Appendix A for DHEW essential components of spinal cord injury system).

REVIEW OF THE LITERATURE

The problems related to a spinal cord injury are broad in scope. This injury has physical, emotional, social, vocational and economical consequences for the individual, which in turn have an impact on the total society.

The literature review will first explore the consequences of a spinal cord injury for the individual, and will then focus on society's responses to these individuals' needs through the care delivery system, legislative action, task force groups and consumer groups.

Consequences to the Individual

Physical

A spinal cord injury is an impairment of the spinal cord imposed by trauma. The physical consequences may be temporary, but more often are permanent. The result depends on the extent and location of the injury, but usually paralysis ensues with a corresponding loss of sensation below the level of injury. Secondary complications are loss of voluntary bladder and bowel control, impairment of sexual function and impairment of vasomotor and regulatory functions. Other common secondary complications involve joint contractures, tendency for pressure sores, metabolic derangement and vulnerability to infection (National Paraplegic Foundation, 1978). (An outline of functional outcome appears in Appendix B.)

Emotional

The catastrophic consequences are not only physical, but have emotional impact as well. Researchers generally agree that pre-injury personality traits influence how an individual will respond to a spinal cord injury (Cook, cited in Roessler & Bolton, 1977). However, a spinal cord injury is stressful to any person's capacity to adjust. It requires considerable time and adequate coping skills to confront the loss of mobilization, bowel and bladder control, and alterations in sexual functioning. Hohman (1977) suggests that spinal cord injured persons experience grieving and frustration over loss of vocational goals and usual family roles, which lead to feelings of uselessness and loss of self-esteem. In addition there is the social stigma of ". . . being different in the public's eye" (p. 15).

Coping mechanisms in coming to terms with a spinal cord injury have been described by Milhouse (1979) and Weller and Miller (1977). All three authors agree that the stages of response are shock, denial, depression, anger and reconstruction. Milhouse adds that reconstruction is founded on hope. It is hope that makes life worth living. At this stage intermediate and realistic goals can be made. However, Milhouse does not believe that vocational goals can be made until an injured person had come to peace with himself, his home and his friends. This, he believes, may take as long as two years. Weller and Miller emphasize that these stages vary with individuals. Stages vary in length, appear in different order or are omitted by some individuals.

Social

The disability of a spinal cord injury may restrict one's mobility and self-care activities, but society determines whether or not that disability is a handicap (DeJong, 1977). Think of the restrictions posed by limited access to housing, transportation, recreation, education and employment. These limitations are barriers to activities of daily living and often prevent achievement of life's goals. The Urban Institute described a handicap as ". . . an event or environment condition which interacts with a disabled person, causing a barrier to a goal accomplishment that a nondisabled person may not face, and which would not impede the disabled person if the world could change" (pp. 21-24).

External conditions which result in loss of independence are very difficult for many spinal cord injured persons to accept. The injured person may find lack of understanding or even revulsion to his condition by the able-bodied person on whom he depends.

Vocational

Intensive physical and emotional restoration is usually necessary before vocational rehabilitation (VR) can be started; thus it makes timing for VR difficult, even under the best of circumstances. Those persons who succeed under VR programs require not only personal motivation, but innovative job descriptions developed by VR counselors with expertise in severely disabled persons.

Another factor facing the disabled person in the area of vocation is that employment barriers are also prevalent, even though they may be well trained for jobs. Felton & Litman (1965) found that both paraplegics and quadriplegics showed employment stability in a wide range of occupations. However, quadriplegics had the greates number of refusals in applying for jobs. The most frequent reasons given for refusals were insurance company regulations and lack of physical accessibility. These reasons are no longer acceptable under the Rehabilitation Act of 1973.

Economic

Economic concerns following a spinal cord injury are multifold. One factor is the high cost of treatment for the injury itself and another factor is the long-term disability problems which provide disincentives to resume a work role.

According to Webb, Benzins and Wingardner (1978) the direct treatment costs of 85 patients with spinal cord injuries in a variety of settings averaged $35,676 with a mean cost of $42,340 for quadriplegics and a mean of $32,619 for paraplegics. Depending upon the eligibility for insurance coverage at the time of a person's injury, costs of the injury are usually picked up by funding resources such as Workman's Compensation, Veterans Administration and/or health and accident insurance. However, perhaps because of the young age at which most injuries occur, many injured persons do not have adequate insurance programs and become dependent on public resources for payment of care. From Oregon statistics reported by the Rehabilitation Institute of Oregon, and by Adult and Family Services, it would appear that 7% to 12% of spinal cord injured persons rely on state and federal assistance programs which fall under the Social Security Act.

Programs which most affect spinal cord injured persons funded under the Social Security Act include: income maintenance (SSI & SSDI), medical benefits (Medicare and Medicaid), and social service programs (Title XX). (A more complete summary of these benefits under the Social Security Act may be found in Appendix C.) Persons receiving these benefits frequently find themselves "trapped" into economic dependency on state and federal programs because of the work disincentives built into this law. A return to work with an income beyond the limitation of $240 per month means not only a loss of income maintenance, but also a loss of medical benefits and in many instances, loss of necessary funds for personal care attendants under supportive service programs. The severely disabled person who may desire to work, but who continues to have high medical expenses cannot afford to work if his income is less than benefits received under the Social Security Act.

Society's Response to the Needs of Spinal Cord Injured Persons

During the last decade, tremendous strides have been made to meet the needs of the severely disabled through the health delivery system, legislative action, task force committees and consumer involvement.

The Health Delivery System

In general, the health system has been slow to develop a systematized, comprehensive approach to care for spinal cord injured persons. Comprehensive care, however, is not a new idea. Hohman (1977) demonstrates this when he quotes Socrates, ca. 400 B.C., as saying "as you ought not to attempt to cure eyes without a head, or head without a body, so you ought not to treat body without mind" (p. 15). However, even with this early insight, studies in the first half of this century show that research for the most part has been confined to physical restoration. As late as 1976, Braakman, a neurosurgeon, remarked on the small number of papers dealing with psychological and counseling facets of spinal cord injuries in contrast to the physical aspects ". . . in spite of the fact that suddenly becoming paraplegic or quadriplegic must have enormous consequences on the philosophy and view of life of the patient, his family, and, perhaps, those therapeutically involved" (p. 95). Sink (1977) says that this is because initial concern is physical restoration and services therefore are more "medical" in nature.

Acute Phase. The acute phase begins at onset of injury and includes emergency care and hospitalization which may be as long as

36 days (Miller & Weller, 1977). Although many authors agree with Webb et al. (1978), who concluded from their study that ". . . attitudes towards therapy and consequent lengths of stay . . . differ markedly among institutions" (p. 317). Sussman (1978) spoke to the lack of a system after he reviewed x-rays and records of spinal cord injured persons and found gross inconsistencies in treatment of these persons. He said that this was serious and unnecessary in the approach to delivery of care for these individuals.

Rehabilitation Phase. Following the acute phase, most patients are transferred to a rehabilitation center. Hohman (1977) states that most of these centers are boring and result in idleness. He suggests the need for the patient to be involved in the program planning. Patient involvement is also stressed by Dunn (1975), along with family involvement in order that a near normalization of lifestyle can be achieved.

Rehabilitation programs should include physical rehabilitation, occupational therapy, vocational and educational planning, and independent living skills. Also, in most instances, these individuals must learn new behaviors in social roles, sexuality, recreation and self-assertion. These skills and behaviors are vital to the self-image of the spinal cord injured person as he prepares to return to the community.

Long-term Follow-up Phase. Transition from institutionalization to the community can be difficult for a severely disabled person unless he is adequately prepared. To bridge this gap, some rehabilitation centers have established outreach programs which send follow-up consultants to the injured's own setting. More often, however, there are inadequate funding resources to support these expensive teams (National

Spinal Cord Injury Systems Conference Proceedings, 1978).

Persons who are without a family and who are injured to the extent of becoming totally dependent on another for activities of daily living, too frequently end up permanently institutionalized. One of the alternatives to institutionalization is the use of a personal care attendant. A personal care attendant is a person who is hired and supervised by a disabled person to assist in ordinary activities such as eating, bathing, grooming and dressing. DeJong (1977) says that having ". . . control over something as intimate as one's own personal care is perhaps the single most important step toward self-determination and independent living" (p. 90).

Whether the person who suffers a spinal cord injury lives at home or in an institution, the long-term physical problems connected with this disability can mean frequent rehospitalization from skin breakdowns, genitourinary problems and broken bones (Dunn, 1975).

Development of Spinal Cord Centers. Hoffstra (1975) and Morgan (1976) credit the Veterans Administration with playing the lead role in lengthening the life span of spinal cord injured persons during World War II. However, Bucy (1975) gives primary credit to Sir Ludwig Guttmen for his improvements of care through developing the first successful comprehensive system of care in England in the 1940s. In any case, the V.A. hospitals did take an early comprehensive approach to the care of the spinal cord injured resulting in 18 spinal cord centers throughout the country by 1976.

Private hospitals and rehabilitation centers were much slower in developing spinal cord centers. In 1970, the first Regional Spinal

Cord Injury Center at Good Samaritan in Phoenix, Arizona was recognized and funded by DHEW ". . . to demonstrate a systematized, holistic program for persons traumatized by spinal cord injury" (Young, 1977, p. 54).

Since that time, 10 Regional Spinal Cord Injury Centers have been approved in Alabama, California, Colorado, Illinois, Massachusetts, Minnesota, New York, Texas, Virginia and Washington (Lauri, 1978). Oregon falls within the "catchment" area of the Regional Center located in Seattle, Washington. The relationship of rehabilitation centers in Oregon to this Center has not been finally determined.

In 1975, a Data Research Center was established at the first Regional Spinal Cord Injury Center in Arizona to analyze information from all Regional Centers. A common data base was developed for the Center through the collaborative efforts of the American Spinal Cord Injury Association, the International Medical Society of Paraplegia, and the DHEW, Rehabilitation Services Administration. Variables were identified in the data base which exert strong influence on rehabilitation outcomes and cost effectiveness. Nonsystems also add information to the Data Research Center so that comparative studies may be conducted between system and nonsystem patients. At this time, comparative studies on costs show a difference from $5,618 to $8,317 between system and nonsystems due to decreased lengths of stay and other increased efficiencies in a Spinal Cord Center (National Paraplegia Foundation Journal, 1977).

In summary, one can say that the treatment of spinal cord injured persons has improved over the last 30 years, and even more dramatically within the last decade. The development of a Common Data Base directs research to specific factors that relate to cost effectiveness and rehabilitation outcomes. Hamilton (1974) stresses the importance of this kind of research when he states that "the outcome effectiveness and cost of systems of comprehensive care for spinal cord injuries are important to casualty insurers, federal and state governments, the staff delivering the services and the primary consumers, patients and families" (p. 574).

Legislation

Issues concerning the disabled are currently being addressed at both state and federal levels through proposed legislation to remove employment, transportation and architectural barriers which now limit the severely disabled person from becoming independent in the community.

In Congress, three bills proposing amendments to the Social Security Act are directed to achieve the purpose of removing "work disincentives": HB285, "The Pickle Bill"; Senator Dole's Bill, S591; and Senator Javits' Bill, S603 (National Spinal Cord Injury Foundation, 1979). As previously stated, the primary work disincentive is that in many cases a return to work with an earned income of more than $240 per month results in termination of SSI (Supplemental Security Income), SSDI (Social Security Disability Income), and medical benefits. Passage of one or more of these bills would greatly enhance the possibility of the severely disabled to become more independent of public resources. As an example, S591 would allow Medicaid benefits to be continued to certain handicapped persons who are able to work, but have high medical expenses which cannot be covered out of his income. This bill would also allow a working disabled person a right to disregard costs of attendant care and certain medical devices in the determination of "substantial gainful activity" regarding eligibility for SSI benefits.

The Rehabilitation Act of 1973 has been very assistive to the severely disabled in areas of employment, transportation and architectural barriers by mandating affirmative action programs for the employment of disabled persons within the federal government and by creating the Architectural and Transportation Compliance Board.

Legislation affecting rehabilitation services began with public laws in 1943, 1954 and 1965, which primarily focused on vocational rehabilitation for those persons for whom a vocational goal was feasible. It was not until 1973 that The Rehabilitation Act placed a much greater emphasis on rehabilitation services for the more severely handicapped (Sink, 1977). For instance, Section 304 of this Act authorizes grants for special projects and demonstrations for spinal cord injured persons; (i.e., Spinal Cord Injury Centers) and The Rehabilitation Act added impetus to the independent living movement when the 95th Congress passed legislation under this Act authorizing new funding for independent living benefits.

Task Force Committees

In anticipation of independent living programs in Oregon, Carl Haugerud, State Administrator of Vocational Rehabilitation Division, appointed a task force to study independent living rehabilitation (ILR) and to develop a service delivery model for severely handicapped individuals. Recommendation from this task force was that the ILR service delivery model focus on client responsibility for living goals, and that implementation of plans be consistent with maximum range of activities and minimum dependence on others. The report emphasizes the need for counselor expertise in physical medicine, architectural barriers, handicapped equipment and ILR community resources. In addition, the report also recommends use of client advocacy groups and peer counseling.

Concern for spinal cord injured persons was expressed six years ago in a Department of Human Resources (DHR) task force report on severely disabled persons. At that time, a representative from the Office of Comprehensive Health Planning (now the Health Planning Agency) stated that most of the current costs of spinal cord injury care resulted from preventable medical complications and preventable custodial care. He stressed that a better organized delivery system for spinal cord injury care which emphasized prevention could reduce total costs by an estimated 20% to 30% (Porter, 1973). Recommendations from this task force were "shelved."

However, in April 1979, DHR again organized a task force at the initiation of State Representative Vera Katz. This task force primarily addressed the issue of inaccessibility to rehabilitation services by publicly supported individuals with a spinal cord injury due to the lack of funding beyond the 21-day limitation of hospitalization expenditures through Medicaid. Recommendations from this task force resulted in a $200,000 appropriation to Adult and Family Services (Welfare) for funding rehabilitation services for the severely disabled (DHR Task Force Report, 1979).

Consumer Role

According to Savilios-Rothchild (1970), the consumer movement is a "social movement" which will attempt to impose an image of a disabled person on an equal basis with that of the able-bodied person. DeJong (1978) describes the consumer involvement towards independent living as more than a social movement. He describes it as a shift from a "rehabilitation paradigm" to an "independent living paradigm." He asserts that this shift is beginning to redirect the thinking of disability professionals and researchers alike. He concludes that the locus of the problem is not the individual but the rehabilitation process, the physical environment and the social control mechanisms at large. DeJong bases his statements on three major propositions regarding the movement's commitments toward independent living as follows:

> Consumer sovereignty--disabled persons (consumers), not professionals, are the best judges of their own interests; they should ultimately determine how services are organized in their behalf.
>
> Self-reliance--disabled persons must rely primarily on their own resources and ingenuity to acquire the rights and benefits to which they are entitled.
>
> Political and economic rights--disabled persons are entitled to freely pursue their interests in various political and economical arenas. (p. 34)

Consumer Groups in Oregon

The Oregon Chapter of the Paralyzed Veterans' Association, formed in 1974, was the first spinal cord injury consumer group in Oregon, although the National Association has been the forerunner of such groups since the 1940s. In 1976, a quadriplegic, Kevin Hanson, organized the Oregon Trail Chapter of the National Paraplegia Foundation (since renamed National Spinal Cord Injury Foundation). The focus of this foundation, composed of consumers and interested individuals, is care, cure and coping. Quadriplegics United Against Dependency, Inc. (QUAD, Inc.) was founded by Bud Meyers, a quadriplegic, in 1976. The focus of QUAD, Inc. is to create an independent living center which will offer a transitional rehabilitation program for quadriplegics so they can move from an institutional setting into the community at a maximal level of independence. Meyers has coordinated the funding resources and planning for this project, which is presently in the stage of construction.

These consumer groups spend much of their time responding to individual everyday needs of spinal cord injured individuals. However, these groups must also attend to the larger picture of 1) legislation regarding the severely disabled; 2) education of providers of care, consumers and the general public to the needs of this population; 3) fund raising and/or initiating allocation of funding for programs and research and 4) attempting to plan programs to fill service gaps in Oregon's nonsystem of care.

Summary

The catastrophic consequences of a spinal cord injury affect the physical, emotional, social, vocational and economic aspects of individuals suffering such an injury.

Over the last decade, there has been an increased effort by providers of services, consumer groups and legislators to change the care of spinal cord injured persons from a fragmented nonsystem approach to a system approach to care. The system approach is a systematized, comprehensive, multidisciplinary approach to care from the point of injury through rehabilitation programs and long-term follow-up.

In order to plan, fund and implement effective system programs which will maximize independent living of spinal cord injured persons, we must have more information regarding their current life situation, what services they have utilized since their injury, and what services they perceive as necessary for maximum independent living.

In cooperation with the Oregon Trail Chapter of the National Spinal Cord Injury Foundation (NSCIF) and the AFS of the Department of Human Resources, this investigator intends to focus on the needs of spinal cord injured persons who are dependent on public resources within AFS. This group has received attention by service providers, funding agencies and state legislators because of their multiple, high-cost needs during their acute and rehabilitation phases, as well as during long-term follow-up programs funded by AFS. It is assumed that these individuals may have less access to medical and rehabilitation services than others due to limited and/or no funding for necessary services to achieve a maximum level of independent living.

CHAPTER II

METHODS

Design and Procedure

This descriptive study of spinal cord injured persons served by Adult and Family Service (AFS) of Oregon is part of a broader survey of all spinal cord injured persons in Oregon, conducted by the Oregon Trail Chapter of the NSCIF. The purpose of this investigation was to collect descriptive data on demographic and injury related characteristics of spinal cord injured persons, their utilization of resources, and the services they perceive as necessary for maximum independence. It is expected that this information will be useful to those who develop state policy and programs for spinal cord injured persons. It may also be useful in shaping the design and focus of further research efforts by suggesting areas of injury which might otherwise be overlooked.

The questionnaire used in the collection of data for this study was developed by this investigator in cooperation with the Oregon Trail Chapter of the NSCIF. The instrument was pretested for clarity in a pilot study conducted by the NSCIF with members who have spinal cord injuries. The pretest data were gathered by self-administered questionnaires and by personal intereviews. The revised version of the instrument is presented in Appendix D.

AFS mailed questionnaires to all spinal cord injured clients living in private residences. Simultaneously, all Medicaid certified nursing homes were contacted within the state to locate clients requiring assistance in completing the questionnaire. Personal interviews to complete the questionnaire were considered necessary for several patients in view of their greater disability.

Data

Five categories of data were collected. Data collected from questions in Category I describe demographic and injury related characteristics. Data in Categories II and III focus on utilization of resources and attempt to identify the ways in which spinal cord injured persons are presently using the "nonsystem" in Oregon, from time of injury through rehabilitation services and long-term follow-up programs. Data collected in Category IV address factors related to financial status and to work disincentives and environmental barriers, preventing individuals from returning to work.

The items in Categories I through IV are similar to those identified by the National Spinal Cord Injury Research Center, Phoenix, Arizona, as important for use as a Common Data Base. Where statistics are available, comparisons will be made from this study to national statistics and to statistics available from the Northwest Regional Spinal Cord Injury Center (NWRSCIC) located in Seattle (Progress Report, 1977-1978).

Data collected for Category V identify unmet needs and services needed to achieve maximum independence from the perspective of the spinal cord injured person. Items used in this category were developed from questions submitted by a number of service providers and funding agencies in Oregon. No attempt was made to measure the quality of individual services which have been utilized by spinal cord injured persons. These questions can only be answered by special studies developed by those who have experience and interest in specific service areas.

The Sample

The design of the survey lends itself to comparing three major groups of spinal cord injured persons living in Oregon. Group I (AFS) includes those clients of AFSD who live in the community outside of an institutional setting. Group II are persons who are not clients of AFS (NonAFS), but like Group I, live in a noninstitutional setting. Both of these groups are considered "independent living." Group III includes clients of AFS who reside in nursing homes (NH). These groups were selected for comparison because the personal needs and funding resources of each group were sufficiently different to merit special study and comparison.

Group I--AFS. AFS mailed questionnaires to 112 clients with spinal cord injuries. Original mailings and one interview resulted in 68 replies and 16 questionnaires returned undeliverable; a 70.8% overall response rate. Six respondents were eliminated because their lesions were a result of disease rather than trauma, leaving a usable response rate of 68.9% in Group I.

Group II--NonAFS. A list of 659 individuals with spinal cord injuries who were not affiliated with AFS was compiled by the Oregon Trail Chapter of the NSCI. It included persons of this organization, members of other spinal cord injury organizations and persons treated at hospitals and rehabilitation centers. All 659 persons were mailed questionnaires by the Oregon chapter or by the cooperating organizations. Over a third (222) responded to the survey. However, questionnaires of 35 respondents were eliminated because of the disease etiology of their spinal cord lesions. This left a total of 187 usable questionnaires, for a 30% usable response in Group II.

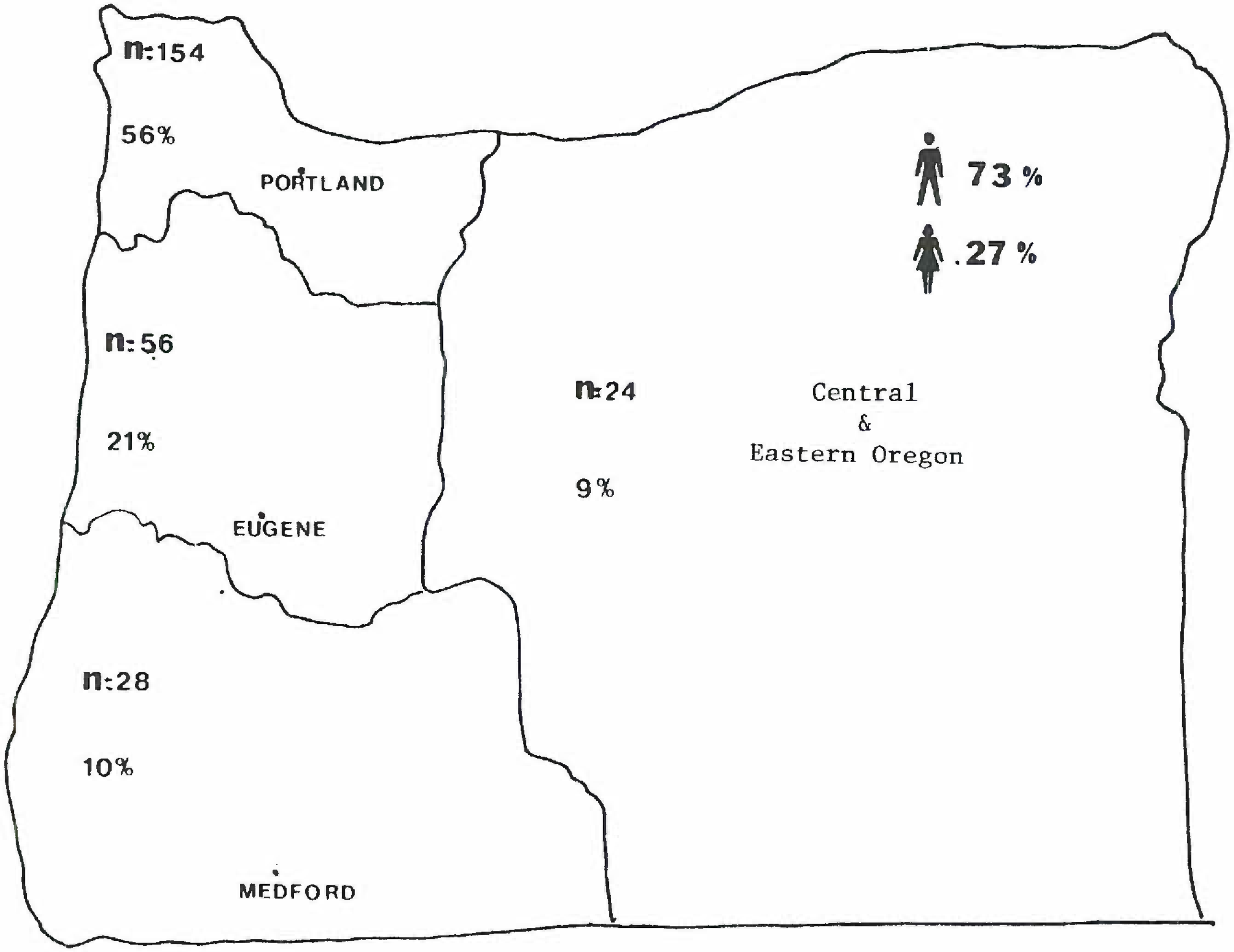
Group III--NH. Group III spinal cord injury persons are clients of AFS, as are those in Group I. However, Group III persons all reside in nursing homes. AFS funds 29 such persons, but of this number, two persons were eliminated because of their multiple and complex injuries, leaving a possible response of 27 persons. Response was elicited from all but one person for a 96.3% response. One half of these persons were personally interviewed. One-fourth returned their questionnaires by mail. Information regarding the remaining 24% of participants residing in nursing homes was retrieved from charts and interviews with nursing personnel. Six persons in the group have brain stem injuries. The rationale for including them is that their age at injury, cause of injury and acute care treatment can be compared to spinal cord injuries. Also, all six persons are quadriplegic. While brain stem injuries account for 23% of nursing home residents in Group I, they account for less than 2% in Group I, 0% in Group II, and 2.5% of the total sample groups combined.

Total Sample Groups. One can only estimate the proportion represented by the present sample. If we use Marquis's 1978 estimate of between 1,200 and 2,000 persons with spinal cord injuries imposed by external trauma living in Oregon, then the 275 respondents in the present study represent somewhere between 13.6% to 22.9% of the total population.

Figure 1 is a graphic illustration of the respondents in the combined sample groups, according to geographic location. As one can see, over half of the respondents live in the northwest corner of the state, primarily in the Portland metropolitan area. Another one-fourth

Figure 1

Distribution of Respondents by Number and Percent
Total Sample Groups



Unknown N=13: 4%

live in the central Willamette Valley. Ten percent of the respondents live in the southwestern portion of the state; and 9% live east of the Cascades. Clusters of spinal cord injury persons in this study live near rehabilitation facilities and organized follow-up programs located in Portland, Eugene, and Medford which would support personal observations that clients gather where services are available.

CHAPTER III

RESULTS AND DISCUSSION

The data are analyzed in five major categories: 1) Selected demographic and injury characteristics, 2) Supportive services following injury, 3) Personal support systems, 4) Factors related to financial status, and 5) Unmet needs and recommendations for improved delivery of services.

Category I:
Selected Demographic and Injury Characteristics

Demographic Characteristics

Sex. Over the last several years, national statistics have shown that the proportion of males to females among the injured is 4:1. In this survey, the proportion was 2.7:1 (see Table 1). The difference in the proportion of males to females might be accounted for by the differences in methods of gathering statistics. The national and NWRSCIC statistics are collected directly from hospital and rehabilitation center records, while identification of spinal cord injured persons in this survey was through multiple resources, including perhaps a higher proportion of AFS clients. More men than women are injured on the job or in the service, thereby entitling them to benefits not avilable women. Therefore, it is not surprising to find a higher proportion of women in the AFS sample groups (I and III) in comparison to the NonAFS sample group II. However, NonAFS, Group II, shows a male, female proportion of 3:1; not significantly different from groups I and III.

Table 1

Comparison of Selected Demographic Characteristics by Sample Group

Characteristic N = Possible Responses	Sample Group % or Median				
	I AFS (N=62)	II NONAFS (N=87)	III N.Homes (N-26)	Total (N=175)	Significance of Differences Chi-square
Sex	(61)[a]	(183)	(25)	(269)	
Male	68.9%	75.4%	64%	72.9%	n.s.
Female	31.1	24.6	36	27.1	
Race	(62)	(186)	(25)	(273)	
Non White	16.1	6.5	8	8.8	n.s.
Veteran	(58)	(180)	(19)	(258)	
Yes	3.5	28.9	10.5	22.5	18.2*
Current Age	(61)	(157)	(25)	(243)	
Median	27.1	32.5	30.6	29.7	7.37*
Age @ Injury	(61)	(155)	(25)	(268)	12.17*
Median	20.7	22.8	25.3	22.2	

*The significance of differences in frequencies was determined by Chi-square. Significant results ($p < .05$) are presented and marked by an asterisk. Nonsignificant results are labeled n.s..

[a] The number in parentheses represents the number of responses for each sample group.

Veteran Status. Table 1 also shows that nearly 30% of Group II persons are veterans, compared to 4% of the AFS clients in Group I. Only one-thrid of the responding veterans claim VA benefits, while the other two-thirds claim their main income from work and other resources. From this limited analysis, it would seem that higher VA monthly benefits and/or possible increased education and rehabilitation decreases the likelihood that veterans would also need state public assistance (AFS).

Race. All groups are predominantly white. The 16% of nonwhite in the AFS group in Table 1 represent only two blacks, six Indians and two clients of Hispanic origin.

Current Age. According to this survey, there are more Spinal Cord Injured Persons living in Oregon between the ages of 20 and 29 than any other ten-year bracket. Notice, however, in Table 1 that the median age for an AFS person in Group I is 5.4 years younger than the median age of the NonAFS person in Group II. This difference alone may account for many variations between the groups which are reported below.

Age at Injury. The median age over the total sample groups compares closely with the national and NWRSCIC statistics, with most injuries occurring in the early 20s. However, as may be seen from Table 1, there is a significant difference between groups. The median age at injury of Group I is two years younger than that of NonAFS or Group II. Conversely the Nursing Home Group is considerably older at injury than the other two groups. The younger age at injury in the AFS group may be explained by the lack of private funding resources for a Spinal Cord Injured Person at a lower age, i.e., fewer job related accidents, and less private health insurance coverage. The older age at injury for NH respondents combined with extensive injuries, a higher divorce rate, and lack of family support, require them to live in a nursing home setting.

Injury Characteristics

Cause. Motor vehicle accidents were the leading cause of spinal cord injuries (57%) in this survey. This is higher than the 48% reported by the PNWRSCIC (Table 2), although other literature would indicate this to be about a normal percentage. According to national statistics, most of these accidents occur close to home. While motorcycle accidents comprise only 8.8% of all spinal cord injuries, (see Figure 2). One in five nursing home respondents experienced this type of accident. This may be due to the high incidence of head and brain stem injuries from this type of accident resulting in institutionalization. After motor vehicle accidents, sports were the next most frequently reported cause of injuries in all groups, with twice as many sports related accidents in the AFS group as the other two groups (see Table 2). Out of 48 sport related accidents, 21 were a result of diving. All of these diving accidents resulted in quadriplegia. Only 21% of spinal cord injuries are associated with on-the-job accidents. Logging accidents account for 3.7% of all accidents in this study. This compares closely with the NWR logging accidents at 3%.

Category and Level of Injury. Injuries to the spine are commonly categorized into two major neurological levels: quadriplegia and paraplegia. Quadraplegia is an injury at the C or cervical level (neck). Paraplegia is an injury below this level; T, thorasic; L, lumbar; and S, sacral. Where the injury occurs on the spinal cord is the most important

Table 2

Percentage Distribution of Accident Responsible for Injury

Comparison of Oregon Sample Groups to Pacific Northwest Regional SCIC and National Samples

Accident	Sample Groups %				Significance of Differences Chi-square	PNWR (N=352)[a]	National (N=2800)[b]
	I AFS (N-61)	II NONAFS (N=186)	III N. Homes (N=25)	Total (N=272)			
Motor Vehicle	56%	54%	84%	57%	6.75*	48%	42%
Sports	33	15	4	18	14.08*	14	16
Falls	3	12	8	10	n.s.	18	17
Acts of Violence	7	5	4	6	n.s.	12	13
Other	2	15	0	6	n.s.	11	13

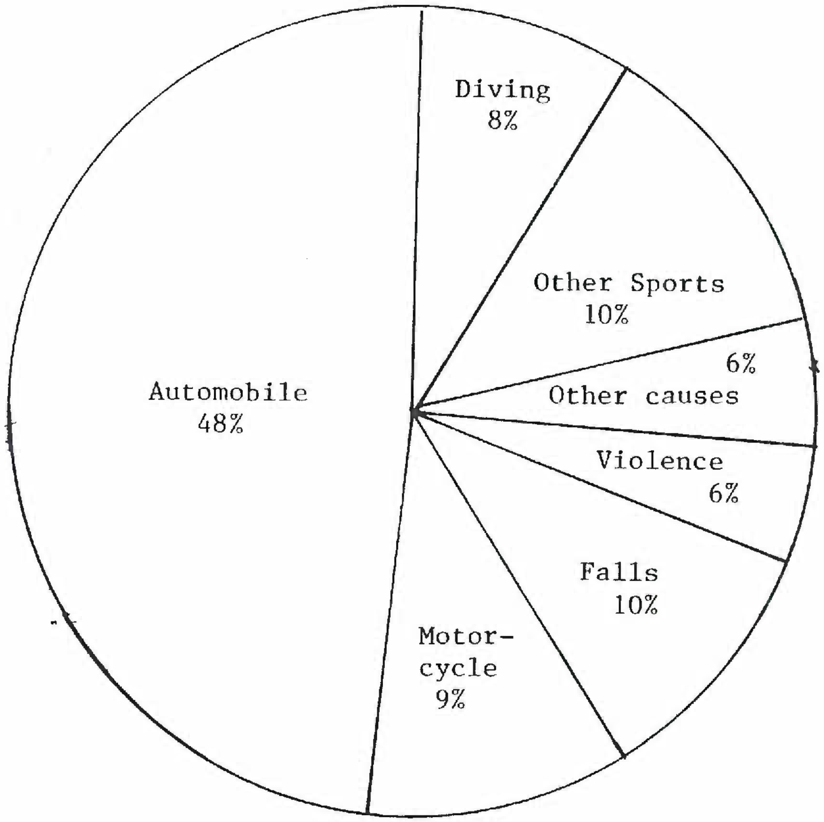
*The significance of differences in frequencies was determined by Chi-square. Significant results ($p < .05$) are marked by an asterisk.

[a] Statistics from Northwest Regional Spinal Cord Injury Center (NWRSCIC), Seattle, Washington, Progress Report (1977-1978).

[b] Estimated number: Percentages from NWRSCIC.

Figure 2

Accident Responsible for Injury in Total Sample Groups



Cause of Injury

predictor of potential independence. Although functional outcome varies from individual to individual, generally speaking, the higher the level of injury, the greater the extent of paralysis depending on completeness and permanence of the injury. Thus a person sustaining an injury at the cervical level has limited use of her/her arms and hands, requiring more assistance from another person. A person with a thoracic or lower level of injury, has normal use of upper limbs, and therefore can do most things independently. (Please see Appendix B for detailed description of functional outcome at specific levels.) The most frequent level of injury in this study was at the C5 to C7 level as shown in Table 3. This compares to NWRSCIC statistics which indicate the largest portion (36%) of spinal cord injuries occur at this level. Comparing differences between sample groups, it must be pointed out that 72% of all AFS clients (Groups I and III) are quadriplegic. This is significantly different from the 52% of persons in Group II. This is no doubt the reason for differences between sample groups in various types of services needed.

Discussion

To summarize Category I, this study points out that there are demographic differences between the spinal cord injured person who is currently in need of state assistance (AFS) and those persons who receive funding from other resources. The typical client is currently a 27-year-old white male, injured in a motor vehicle accident at the median age of 21. If this person sustained multiple injuries and/or brain stem damage, this person is now residing in a nursing home. If the AFS client was not injured in a motor vehicle accident, then the accident most likely

Table 3

Comparison of Level of Injuries by Sample Groups

	Sample Groups %				
Level of Injury	I AFS (N=53)	II NONAFS (N=157)	III N. Homes (N=22)	Total (N=232)	Significance of Difference Chi-square
Category Level					
Quadraplegic	71.7%	52.2%	68.2%	58.2%[a]	7.17*
Paraplegic	28.3	47.8	31.8	41.8	
Brain Stem					
Yes	1.9	0	27.3	3.0	59.8*
Vertebral Level					
C 1-4	30.2	13.4	9.1	16.8	9.05*
C 5-8	39.6	38.9	31.8	38.4	n.s.
T 1-6	13.2	18.5	13.6	16.8	n.s.
T 7-12	9.4	21.6	13.6	18.1	n.s.
L & S	5.7	7.6	4.6	6.9	n.s.

*The significance of differences in frequencies was determined by Chi square. Significant results ($p < .05$) are marked by an asterisk.

[a] This figure includes brain stem injuries.

occurred while participating in a sport and/or recreational activity such as diving. Whatever the cause, the consequences were catastrophic; 75% of the accidents resulted in quadriplegia, much higher than national figures which show this level of injury occurs about one-half of the time. All diving accidents in this survey resulted in quadriplegia. Persons injured from this accident comprise 13% of the AFS. Overall findings from this study were comparable to the NWRSCIC's study which shows that most lesions occur below the C-4 level. However, far more AFS clients sustained an injury or injuries above this level than would be expected. The anticipated functional outcome at this level of injury is considerably less than any lesion sustained below this level. Although it depends on the completeness of the injury, the individual with this degree of disability is completely dependent on another person for personal care and activities of daily living. One can conclude that an individual who sustains a high level of injury at a young age while participating in a non-job related activity may need financial assistance from AFS due to lack of other funding resources. This is understandable since the high cost care following such an injury is astronomical leaving many persons with no other recourse. The AFS client is comparatively still quite young, and in many instances is in the process of readjustment to this disability. Older clients seem to have greater disabilities and less supportive systems for maximum independent living.

Category II:

Supportive Services Following Injury

Initial Treatment

Evaluation. Most persons were evacuated from the point of injury by ambulance or rescue car. Only 10.1% were evacuated by private car, and 23% by helicopter or plane. In some cases, a combination of the above was used in transporting injured persons to treatment centers.

Acute Care. Nearly three-fourths of all persons were treated initially in a hospital of over 200 beds. All other persons were treated in hospitals with less than 200 beds. Only 3.8% respondents in this survey received their initial acute care treatment in a spinal cord injury center outside the State of Oregon. There was no significant difference between groups in length of stay during the acute care phase. Over 60% of all groups stayed in the acute care setting over six weeks, with many persons staying this long, remained over three months in a hospital setting. However, nursing home residents stayed less than six weeks, surprisingly less than the other two groups. One may account for this by assuming that their multiple injuries plus those having brain stem injuries were transferred to nursing homes because they were less likely candidates for rehabilitation; at least at that time.

Physical Rehabilitation. Of the 275 persons responding to this survey, 242 persons (88%) indicated that they received some physical rehabilitation. Eighty-one percent of these persons received rehabilitation services in a rehabilitation center or a spinal cord injury center. Contrary to what expectation before the survey, a higher percent of all

AFS clients received rehabilitation in a rehabilitation center than Group II persons funded by other resources. There was no significant differences between groups in length of stay during physical rehabilitation.

Length of Stay at Initial Treatment. Table 4 presents the median length of stay for each group during the acute care and rehabilitation treatment following injury. Note that Group I members with a higher level of injury than group II members, spent on the average only seven days more in an acute care setting. They also spent fourteen days less in a rehabilitation center. One could speculate that this is because of limitations of funding from Medicaid. The longer rehabilitation period for Group III may be attributed to the fact that 23% had experienced brain stem injury.

Funding. Figure 3 shows that state and federal funding accounted for 25.8% of the acute care funding in all groups, while insurance resources picked up the largest percent of payments (61.5%) and 13.9% came out of pocket, or other resources. Funding for rehabilitation is similar to acute care for persons on Federal or Workmens Compensation programs. However, private insurance paid for less rehabilitation necessitating increased reliance on state Medicaid and vocational rehabilitation funding.

Characteristics Related to Health and Necessary Utilization of Services and Providers

Health Problems. Table 5 summarizes health problems. Neurological impairment to the bladder as a result of an injury to the spinal cord results in chronic and/or serious problems to 60% of the respondents in this survey. Before antibiotics, urological problems resulted in a very

Table 4

Comparison of Sample Groups Median Length of Stay

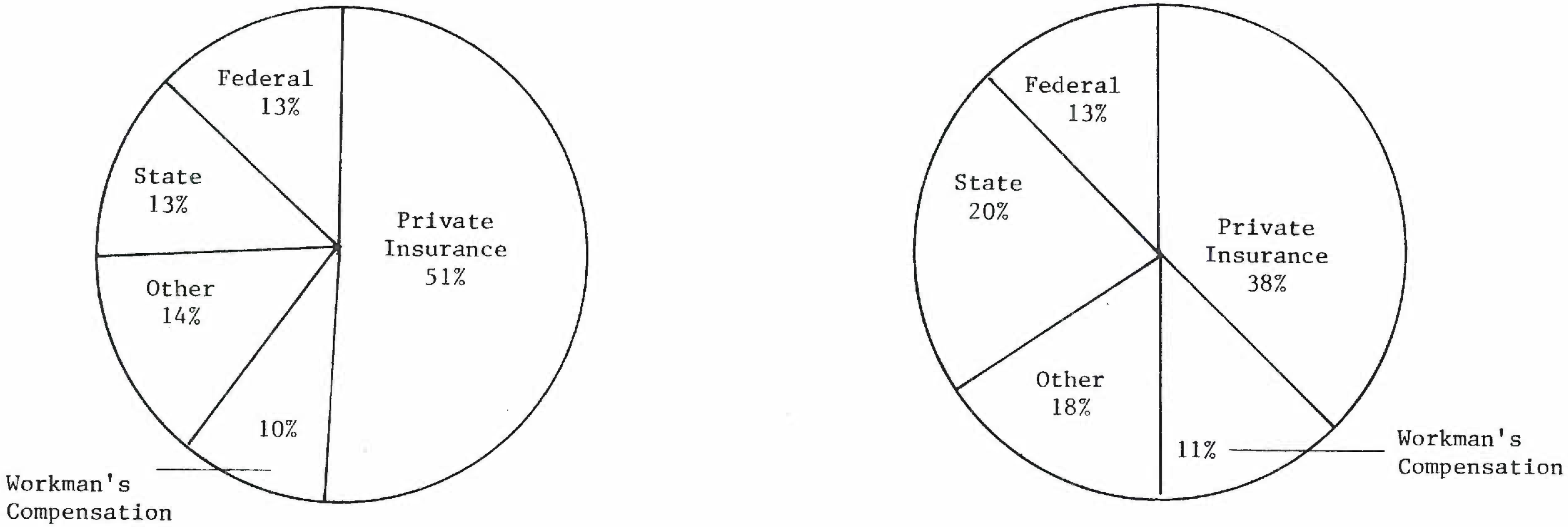
During Initial Treatment Following Injury

Sample Group	Average Stay Acute Care (Median Days)	Average Stay Rehabilitation (Median Days)	Total Average Stay Post Injury (Median Days)
Group I AFS (N=61)	64.4	84	148.4
Group II NONAFS (N=183)	57.4	98	155.4
Group III NH (N=18)	50.8	182	233.1
Total of Groups (N=262)	58.7	118.7	177.7

Figure 3

Distribution of Funding for Acute Care and Rehabilitation

<u>All Sample Groups</u>



Acute Care Funding

Rehabilitation Funding

Table 5

Comparison of Sample Groups in Characteristics Related to Health

Health Characteristic N = Possible Responses	Sample Groups % I AFS (N=62)	II NONAFS (N=187)	III N.Homes (N=187)	Total (N=275)	Significance of Difference Chi-square
Chronic/Serious Prob.	(55)[a]	(159)	(22)	(236)	
Bladder/kidney	70.9%	58.5%	45.5%	60.2%	n.s.
Pain	41.8	40.9	22.7	39.4	n.s.
Spasms	38.2	42.2	50.0	41.9	n.s.
Depression	38.2	25.2	36.4	29.2	n.s.
Temp. Regulation	29.0	20.1	9.1	21.2	n.s.
Pressure Sores	25.5	36.6	36.4	30.5	n.s.
Respiratory Problems	23.6*	6.9	18.2	11.9	11.85*
Bowel Problems	5.5	24.5*	22.7*	19.9	9.44*
Times Hospitalized Since Injury	(58)	(182)	(22)	(262)	19.07*
0	8.6	23.6*	4.6	18.7	
1-5X	50.0	53.3	40.1	51.5	
6-10X	20.7*	12.1	22.7	14.9	
11X & over	20.7*	11.0	31.8*	14.9	
Present State Health	(58)	(186)	(26)	(270)	n.s.
Good/Excellent	46.6	50	38.4	48.2	
Average	24.4	22	30.8	23	
Fair/poor	31	28	30.8	28.8	

*The significance of differences in frequencies was determined by Chi-square. Significant results ($p < .05$) are presented and marked by an asterisk. Non significant results are labled n.s..

[a] The number in parentheses represents the number of responses for each sample group.

high mortality rate for spinal cord injured persons. Obviously, the morbidity rate for this condition is still high. Only 20% of the respondents indicated they have "normal" bladder function. Over half are dependent on condom collection devices (25%), indwelling catheters (16%) and intermittent catheterization (15%). Another 18% have had surgical procedures for urinary diversions. Ninety-seven percent of those with serious or chronic urological problems have been hospitalized, sixty-five percent to undergo a surgical procedure for diagnostic or treatment purposes.

Spasms, pain, depression, and pressure sores are a serious or chronic problem for 30% to 40% of all respondents. Of those who have had pressure sores, 94% have been hospitalized and 82% of that number have required surgical intervention. Although respiratory problems account for only 12% of chronic or serious problems for all respondents, they are significantly more frequent problems for Group I members. One-fourth of this group indicated this as a chronic or serious problem, and 32% have been hospitalized, indicating perhaps that on occasions respiratory problems have been serious, but not chronic.

Frequency of Hospitalizations. As shown in Table 5 there is a significant difference in the number of times, persons within each group have been hospitalized since their initial treatment. Twenty-four percent of Group II have not been hospitalized at all since their injury, while only 10% of Groups I and III have been hospitalized this infrequently. One-half of total sample groups have been hospitalized from one to five times, but note that 21% of Group I, and 32% of Group III have been hospitalized over eleven times. Nine persons over 20 times! Reevaluation is not the reason for hospitalization in the nursing home group, since only two persons have been rehospitalized for this reason. Forty-three persons (23%) from Groups I and II have been hospitalized for reevaluation. As previously stated, urological problems, decubiti, and respiratory problems accounted for many hospitalization, however "other" problems required hospitalization for 65% of all persons. Thirty-nine percent out of 275 possible respondents to this survey have had either a laminectomy or a fusion, possibly during initial treatment. Over 40% of Group II have had one of these procedures, while fewer than 30% in Groups I and III have had back surgery. Another 41% have had other types of surgical procedures than those specifically listed in the questionnaire.

<u>Present State of Health</u>. Surprisingly, almost one-half of all respondents indicated that they were in good or excellent health, with 38% of the nursing home residents placing themselves in this category. Twenty-nine percent considered themselves in just fair or poor health, while 23% perceived themselves as in average health.

<u>Utilization or Service Providers</u>. A summary of how various service providers were utilized is found in Table 6. The table also indicates the percentage of spinal cord injured persons finding these providers helpful. The high utilization of urologist by 81% of the respondents corresponds with the high incidence of serious and/or chronic bladder problems. Since they are utilized so frequently, it is fortunate that they are also found helpful by almost all persons. Physical therapists, neurosurgeons and occupational therapists are slightly less utilized (60-80%) but found 80 to 90% of the time.

Overall, 40% of all groups have received services from vocational rehabilitation counselors, social service workers and orothopedic

Table 6

Comparison of Utilization of Service Providers And Evaluation of Helpfulness by Sample Groups

Provider Seen N = Responses	AFS (N=57)		NONAFS (N=181)		NH (N=19)		TOTAL (N=253)		Signif. Diff. Chi-sq.
	%seen	%helpful	%seen	%helpful	%seen	%helpful	%seen	%helpful	
Urologist	84.2%	95.8%	80.7%	91.8%	78.9%	100%	81%	93.2%	n.s.
Physical Therapist	75.4	93	85.6	92.9	78.9	86.7	80.2	92.1	n.s.
Neurosurgeon	64.9	70.3	73.9	78.9	42.1	87.5	70.4	87.5	n.s.
Occupational Therapist	61.4	91.4	65.7	81.3	47.4	100.0	64.4	81.6	n.s.
VR Counselor	54.4	87.1	37.6	69.1	31.6	100.0	41.5	76.2	5.80*
Social Service Worker	54.4	71.0	35.9	61.5	63.2	83.4	42.7	66.7	28.71*
Orthopodist	45.6	73.1	40.3	79.5	31.6	100.0	41.5	87.1	n.s.
Nurse	45.6	92.3	55.8	98.9	78.9	100.0	56.1	96.2	6.48*
Psychologist	42.1	58.3	18.2	51.5	31.6	83.3	24.9	57.1	13.9*
Psychiatrist	28.1	37.5	18.8	41.2	15.8	67.7	21.0	41.5	n.s.
Plastic Surg.	22.8	100.0	16.6	93.3	15.8	100.0	18.2	95.7	n.s.
Physiatrist	24.6	71.4	14.9	41.8	26.3	100.0	18.2	62.2	n.s.
Peer Counselor	12.3	100.0	8.8	62.5	8.8	67.7	10.3	73.1	n.s.

*Significance of differences in frequencies was determined by Chi-square. Significant results ($p < .05$) are marked by an asterisk.

surgeons. The social service worker is utilized by a higher percent of nursing home residents than of the independent living groups: 63% vs. 40%, and with a higher level of satisfaction than the other two groups.

Psychologists and psychiatrists only utilized by 25% of the sample groups, are not considered helpful to about half of the persons who have received their services. It would be interesting to know whether or not this low evaluation is because of the social stigma attached to using a counselor for psychological support, or whether this service was inappropriately timed for the stage of adjustment the spinal cord injured person must make in accepting the disability.

Only 50% of all persons in the study indicated they utilized the services of a nurse. This is interesting since 100% of all spinal cord injured persons have in reality used nursing services. Of those who indicated they used the service of a nurse, 97% found him/her helpful.

Physiatrists were also not perceived as being utilized frequently by the respondents (18%), in spite of the fact that most people received their rehabilitation in a rehabilitation center where this specialist practices. This, however, may be because respondents were not familiar with the term "physiatrist." Only 20% of the persons in all groups indicated they had been seen by plastic surgeons, but these physicians were found to be helpful almost 100% of the time. Peer counselors were not well utilized (10%), but were considered helpful by 75% of all groups.

Utilization of Services

Miscellaneous Services. Table 7 represents the percentage of persons

Table 7

Comparison of Services Received and Evaluation by Sample Group

Including Major Service Areas for Focus

Services Received N = Responses Good and Enough	AFS (N=58) %Received	AFS (N=58) %G&E[a]	NONAFS (N=160) %Received	NONAFS (N=160) %G&E	NH (N=18) %Received	NH (N=18) %G&E	TOTAL (N=236) %Received	TOTAL (N=236) %G&E	Signif. of Diff.[b] Chi-sq.
Physical Therapy	77.6%†	60%	85.6%†	58.4%	100%†	50%	84.7%†	58%	n.s.
Equipment	74.1 †	48.8	61.9 †	52.5	38.8†	4.3	63.3 †	51	7.67*
Vocational Rehabilitation	69.0 †	21.7	50.0 †	36.3	38.8†	28.6	53.3 †	36.2	7.91*
Occupational Therapy	60.3	51.4	61.3 †	44.9	44.4†	75.0	59.7 †	48.2	n.s.
Bowel/Bladder	50.0	65.5	62.5 †	52.0	38.8†	28.8	58.5 †	52.9	n.s.
Health Maintenance	46.6 †	33.3	61.3 †	52.5	31.8	4.3	56.4 †	48.1	n.s.
Personal Counsel	46.6	37.0	30.6	32.7	44.4†	25.0	35.6	33.3	n.s.
Housing Modification	41.1 †	25.0	26.9	23.3	16.7	33.3	29.7	24.3	n.s.
Physical Potential	39.7 †	21.7	42.5 †	29.4	44.4†	37.5	41.9 †	28.3	n.s.
Own Mobility	39.7	21.7	41.3	48.5	22.2	25.0	39.4	40.9	n.s.
Sex Counseling	39.7 †	21.7	38.8†	21.0	11.1	50.0	36.9 †	21.8	n.s.
Financial Counsel	24.1	7.1	20.0	12.5	22.2	50.0	21.2	14.0	n.s.
Family Counsel	22.4	30.8	26.3	19.0	22.2	25.0	25.0	22.0	n.s.

Table 7 (continued)

Services Received Good and Enough	%Received	%G&E	%Received	%G&E	%Received	%G&E	%Received	%G&E	Signif. of Diff. Chi-sq.
Attendent	19.0	27.3	8.8	28.6	22.2	0	12.3	24.1	n.s.
Recreation	19.0	27.3	28.8	30.4	16.7	66.7	25.4	31.7	n.s.
Peer Counseling	17.2	50.0	3.1	50.0	11.1	50.0	7.2	47.1	13.1*

*Significance of differences in frequencies was determined by Chi-square. Significant results ($p < .05$) are marked by an asterisk.

[a] Percent of those receiving services who thought they were good and enough.

[b] Significance of difference between groups was based on how often service was utilized.

†Represents what factors each sample group designated as a service to focus upon if time and money were available.

in each group who have received services that were listed on the questionnaire, and if so, were these services good and enough? There was a significant difference in services received between groups. Group I received more services in equipment, vocational rehabilitation, personal counseling, housing, attendant and peer counseling than the other two groups. Other services utilized by over 60% of the respondents were physical therapy, occupational therapy, and equipment, with approximately one-half of the recipients receiving benefit from these areas. The only exception to these services is equipment, where very few nursing home residents indicated that they have had enough. The question was asked, "Do you believe that if you had received different or additional or more coordinated care, you would now be able to lead a more independent, productive and healthier life?" At least 40% answered "absolutely" in all sample groups. In the AFS groups it was 55%. This corresponds with respondents' recommendations for improving services, where greater coordination of services was highly recommended.

Services for Focus. Sample groups varied in their answers to a question which asked them to list five services on which health care and social service providers should focus their time, energy and money. The exception to this variation was that 59% of all respondents agreed that physical therapy should be the most important service on which to focus. Services indicated as important by groups are in Table 7. Second to physical therapy, Group I felt a need to focus on vocational rehabilitation services (43%), although health maintenance was the second most important to combined groups (39%). Occupational therapy and bowel and bladder training were second in importance to Group II (42%), but not in the top five areas of importance in Group I. Personal counseling was a higher priority in the nursing home group (39%), while sexual counseling was more important in Groups I and II (30%). Services that would focus on understanding their own physical potential ranked very close to the top five services (31%). In summary, physical therapy, according to all respondents (69%), is the most important service which providers should stress. About half that many respondents thought other areas that needed to be focused upon were health maintenance, bowel and bladder training, occupational therapy and vocational rehabilitation, equipment, and services to understand your own physical potential. Interestingly, these correspond to the top seven services that respondents received most often. (Refer back to Table 7). In all cases, approximately half or less have found these services good and/or enough.

Vocational Rehabilitation Services. Table 8 shows that 82% of possible respondents from the AFS group have received services from the Vocational Rehabilitation Division (VRD), a much higher percent than the NonAFS and nursing home resident groups who indicated that 56% and 39% have utilized such services. The VR service most utilized by all three groups was education and training (56%). Equipment was the second most utilized (41%), primarily by the independent living groups. Counseling, physical and mental rehabilitation, and transportation were the other areas provided by vocational rehabilitation department to at least one-fourth of all groups combined. Employment services were received by only 5.9% of the AFS group and 18.3% by the NonAFS group. In all groups, 15% of the cases were closed with few or no services. The greater number of such closures occurred in the nursing home group.

Although three-fourths of the AFS group found VRD services to be "good," Table 8 shows that half of that number did not feel these services were well timed. In the other two groups, over half found VRD good, with 90% of satisfied persons thinking that they were well timed. Table 8 shows that 91% of all groups indicated that vocational rehabilitation should start after acute care, which of course is not surprising. Almost half of the NonAFS group indicated vocational rehabilitation should start during physical rehabilitation. Half of AFS group indicated that rehabilitation should start one year or more after physical rehabilitation, and another 14% did not know. This difference may be because of the higher level of injury in the AFS group requiring more time for physical and emotional readjustments as supported by Hohmann(1979). Thirty-six percent of the nursing home resident group does not know when vocational rehabilitation should be appropriate; perhaps because their own condition does not warrant vocational rehabilitation intervention.

Discussion

In contrast to what was earlier assumed, the AFS client had about the same access to treatment following injury as persons funded by other resources. This, however, is confusing with the limited statistics in this study. Respondents indicated that Medicaid paid for one-third of the AFS clients during their acute phase. However, 40% of these persons spent longer than three months in a hospital, much longer than the Medicaid 21 day limitation. Miraculously, 85% indicated they had received rehabilitation in a center; 45% was paid for by either Medicaid or Vocational Rehabilitation. More specific studies need to be made to draw

Table 8

Comparison of Sample Groups Receiving Vocational Rehabilitation

Services Evaluation of Services

Services Received N = Possible Respsonses	Sample Groups %				
	I AFS (N=62)	II NONAFS (N=187)	III N. Homes (N=26)	Total (N=275)	Significance of Difference Chi-square
Service	(51)[a]	(104)	(10)	(165)	15.09*
Education/Training	64.7%	51.9%	50%	55.8%	
Counseling	35.3	25	10	27.3	
Physical Rehab.	37.3	19.2	30	25.5	
Equipment	52.9	36.5	20	40.6	
Transportation	27.5	25	20	25.5	
Driver's Training	13.7	22.1	0	18.2	
Employment	5.9	18.3	20	14.6	
Post Employment	2.0	6.7	0	4.9	
Referred; Closed	9.8	17.3	30	15.3	
Service Evaluation	(45)	(99)	(9)	(153)	n.s.
Good	75.6	62.1	55.6	64.1	
Good, but not well timed[a]	50.0	22.0	20	31.6	
Best Time for VR	(57)	(162)	(14)	(233)	14.17*
During Acute Care	10.6	8.7	7.1	9.1	
During Physical Rehab	26.3	46.9	21.5	40.3	
At least 1 yr. After Rehab.	49.1	30.8	35.7	35.6	
Don't Know	14.0	13.6	35.7	15.0	

*The significance of differences in frequencies was determined by Chi-square. Significant results ($p < .05$) are presented and marked by an asterisk.

[a] The numbers in parentheses represent the number of responses for each sample group.

any meaningful conclusions.

Overall, utilization of other services by the AFS client is equal to or more than that of other spinal cord injured persons. This is especially true in areas of services provided by VRD; i.e., equipment, counseling, and education/training. However, the AFS client has had less drivers training and less employment services than NonAFS persons. Perhaps this is because of the higher incidence of quadriplegics. As an example, the AFS client with a C-1-4 level injury would not be able to drive and may have limited capacity for vocational rehabilitation. Also, with a 70% population of quadriplegics, it is certainly reasonable to accept that 50% of AFS clients would think that the best time for vocational rehabilitation would be at least one year following rehabilitation. Interestingly, 33% of the total sample agree and 15% don't know. Few nursing home clients have received any vocational rehabilitation services.

Another surprise in the study was that there was <u>not a significantly</u> higher incidence of chronic and/or severe health problems reported by the AFS client than NonAFS persons. (The exception to this was in a higher incidence of respiratory problems for AFS clients. One would expect this with a greater incidence of quadriplegic persons.) However, disputing these figures <u>is the significantly</u> higher incidence of hospitalizations for the AFS client. Forty-five percent of AFS clients have been in the hospital over six times since injury; with at least 19 persons (including nursing home residents) being hospitalized over 11 times. Only 8% of AFS clients have never been hospitalized, while 24% of NonAFS individuals have never been hospitalized since initial treatment. The difference between groups may be due to what are considered "chronic problems" and what are considered "serious" enough problems to require hospitalization. Also, this raises a question whether all hospitalizations were immanent, or were some the consequence of poor care due to lack of personal and community support systems. It also raises the question as to appropriateness. For example, it is not known whether the AFS client was admitted to the hospital with a problem that could have been managed at home had there been a stronger support system.

In summary, it would not appear that health problems and utilization of services vary that much between AFS clients and other spinal cord injured persons. However, certain indicators would lead one to question these findings. More evaluation and study needs to be done in this area.

Category III:

Personal Support Systems

Personal Support System

Marital Status. Significant group differences in marital status (Chi square = 48.7) can be seen in Table 9. The never married category accounts for 40% of respondents in the total sample, with the largest percentage of never married persons occurring in Group I (57.4%). This compares to national studies which report 53% of persons are single at injury. Married persons make up over one-third of all respondents. However, there is a great disparity among groups; 50% of Group II are married, in contrast to 7% and 15% in Group I and III, twice as great as in Group II. National figures quote 29% married after three years, thus Group II is higher than expected; Groups I and III are lower. There was more than twice the percent of persons divorced in Groups I and III as Group II. Group II compares to national figures, Group I

Table 9

Comparison of Personal Support Systems Following Injury Between Sample Groups

	Sample Groups %				
Characteristic N = Possible Responses	I AFS (N=62)	II NONAFS (N=187)	III N.Homes (N=26)	Total (N=275)	Significance of Difference Chi-square
Marital Status	(61)[a]	(184)	(26)	(271)	48.7*
Never Married	57.4%	34.2%	38.5%	39.9%	
Div./Sep.	31.1	15.8	42.3	21.8	
Married	6.6	49.4	15.3	36.5	
Widowed	4.9	0.6	3.9	1.8	
Supportive Persons Since Injury	(57)	(183)	(20)	(260)	52.64*
Family	80.7	72.1	75	74.2	
Friends	59.6	46.5	40	48.8	
Doctor	49.1	26.2	25	31.2	
SCI Persons	28.1	32.2	25	30.8	
Nurse	19.3	14.8	40	17.7	
SSW	19.3	7.1	10	10.0	
Partner	17.5	6.1	5	8.9	
Spouse	10.5	48.1	0	36.2	
Other	8.8	13.1	10	11.9	
No one	3.5	3.8	5	3.9	
Knew Life was Worth Living Following Injury	(56)	(176)	(15)	(247)	15.66*
Within 2 weeks	66.1	58	20.0	57.5	
Within 6 months	10.7	13	13.3	12.6	
1-3 years	7.1	13	26.7	12.6	
Longer 3 years	8.2	4	13.3	5.6	
Not decided	7.1	11.9	26.7	11.7	

*The significance of differences in frequencies was determined by Chi-square. Significant results ($p < .05$) are presented and marked by an asterisk.

[a] The number in parentheses represents the number of responses for each sample group.

and III almost double the rate. Over half of all divorced respondents say that the divorce was related to their injury with 73% occurring within two years following injury. One would expect a 1% widow rate, according to national figures. Groups I and III, AFS clients have 5% widow rate. Could this indicate spouses are killed at time of accident?

Supportive Persons. When asked "Who have been the three most helpful, supportive, informative persons since your injury?", all groups agreed family members were the most important. (See Table 9). None of the nursing home group indicated spouses were supportive. In contrast, 88 out of 91 married persons in the Groups I and II indicated the spouse as a supportive person. Friends were considered a source of support by over 40% of all groups as well as other spinal cord injured persons (30.8%). Physicians scored high among the AFS groups; with 49% finding doctors among the most supportive persons. Group I indicated social service workers (SSW) were significantly more supportive to them than the other two groups, perhaps reflecting less utilization by Group II and less satisfaction of SSW in Group 1. The nurse was more supportive to the nursing home group than the other groups.

Degree of Dispair. When asked "At what point after your injury did you decide that life was worth living?", almost 50% of all respondents knew within two weeks. However, 27% of the nursing home respondents are still undecided, and another 40% took longer than a year to make this decision. Milhouse (1979) asserts that reconstruction is founded on hope; it is hope that makes life worth living. More extensive injuries, lack of family support and loss of an independent living situation would add to the hopeless feeling of a nursing home resident.

Though there is a significant difference between groups in how respondents answered this question, approximately 70% of all respondents knew life was worth living within six months, 18% took longer than year, and 12% have yet to decide.

Living Arrangements

Living Situation. Eighty-seven percent of the 275 persons in this survey live in an independent living situation. Looking just at those who live outside an institution, Table 10 shows that almost 50% of the NonAFS group live with their spouse while another 23% live with their parents. In contrast, only 7% of AFS group live with their spouse, although approxiately the same percent of AFS persons live with their parents as that of NonAFS persons. More spinal cord injured persons in the AFS group live with a "partner." This may be due to funding restrictions in the Title XX law which states that spouses cannot be paid to be attendants. Partners may choose not to marry rather than lose this benefit. The question was asked, "There are certain laws that prevent a spouse from being paid as an attendent. How important an effect has this had on your marital status?" Sixty percent of the AFS group who answered the question responded that this law had an impact on their marital status. Only 32% of the NonAFS population who answered this question thought this law had affected it.

Caretaker Arrangements. The primary caretaker, "nonrelative," in Table 10 in most cases means care provided by an employed personal care attendant. AFS group members are noticeably higher in utilization of attendant services; 60% vs. 19% between independent living groups. This would be consistent with their low incidence of marriage and high level

Table 10

Comparison of Living Arrangements by Sample Groups

Arrangement N = Possible Responses	Sample Groups % I AFS (N=62)	II NONAFS (N=187)	III N. Homes (N=26)	Total (N=275)	Significance of Differences Chi-square
Living With	(61)[a]	(186)	NA[b]	(247)	63.16*
Non Relative	37.7%	9.1%		18.6%	
Parent	26.2	23.1		23.9	
Alone	16.4	15.1		15.4	
Partner	14.8	1.6		4.9	
Child	9.8	17.7		15.8	
Spouse	6.6	47.8		37.7	
Primary Caretaker	(57)	(141)	NA[c]	(198)	
Non Relative	59.7	18.5		30.3	
Family Member	33.3	33.3		33.3	
Spouse	7.0	48.2		36.4	
Amount Assist Needed/Day	(57)	(187)	(26)	(270)	49.12*
8 hrs or more	73.7	29.9	76.9	43.7	34.92*
Less than 8 hrs	15.8	36.9	23.1	31.3	
None	10.5	33.2	0.0	25.2	
Satisfaction with Arrangement	(58)	(143)	(21)	(222)	22.44*
Yes	62.1	71.3	42.9	66.2	
No	17.2	17.5	4.8	16.2	
Unsure	20.7	11.2	52.3	17.6	

*Significance of differences in frequencies was determined by Chi-square. Significant results ($p < .05$) are presented and marked by asterisk.

[a] The number in parentheses represents the number of responses for each sample group.

[b] All living in nursing homes.

[c] Caretaker assumed to be nursing home personnel

of injury which requires more assistance from another person. Of the AFS clients requiring the service of an attendant or housekeeper, three-fourths of them have attendants who live in. Less than one-half of the 19% needing attendant/housekeeping services in Group II, live in. In summary, there is a high proportion of spouses and family members who are primary caretakers in NonAFS homes (80%). Only 40% of the AFS group have spouses and family members for this purpose. Thus, more persons in the AFS group who have higher level of injuries rely on paid non-relatives than the NonAFS group. The most satisfied group with caregiver arrangements were the NonAFS, the least satisfied or unsure persons were persons residing in nursing homes.

Three-fourths of the AFS Group I clients indicated that they need eight hours or more care each day, while only one-third of the NonAFS group needed that much assistance (Table 10). Seventy-five percent of all spinal cord injured persons surveyed depend on wheel chairs for mobility. Half the AFS clients use electric wheel chairs, while only 16% of the NonAFS group do so. Observations in nursing homes support the statistics that even the most severely disabled person may be using a manually driven wheel chair, apparently relying on personnel for propelling the chair.

To summarize, there is a relationship between the level of injury, the amount of assistance needed, and live-in attendant care. Marital status also influences the need for a live-in attendant. AFS clients report the most severe injury, the most need for assistance, and the most need for live-in attendants. They also report fewer current marriages. Nine AFS persons indicated that they live with a partner who is also their paid attendant and that this relationship is related to the law that does not allow an attendant pay to a spouse. Two-thirds of all persons studied are satisfied with their personal care arrangement. Nursing home residents reported the least satisfaction.

Discussion

Family members of AFS clients have been very supportive since injury. In fact, one-third are dependent on family members for personal care services. However, only 8 out of 187 persons are currently married. Twenty-five persons were married either at the time of injury or following injury, but have since been divorced. Seventeen of these divorced persons suggested that it was related to their injury. This contrasts to the marital status of those who are not AFS clients; 50% of these persons are married and rely on their spouse for emotional support, personal care and as a potential source of income. On the other hand, the AFS client must rely on employed attendants or housekeepers, most of whom live in because the client needs more than eight hours a day of personal care. According to the respondents 1 out of 4 of these attendants are partners whom they chose not to marry because a spouse providing personal care services is not eligible for funding under Titles XIV and XX. It seems apparent that most AFS clients have not been able to sustain a marriage, or become married even if they so desired. Laws that inhibit marriage and should be adjusted to either pay wives for their personal care services and/or allow expenditures that would provide adequate respite time.

In addition to the high divorce rate, the high rate of widowhood in the AFS groups is startling. One would actually expect a lower percent in a younger population, especially in Group I. One must consider that at least in some cases, the spouse may have been killed at the time of injury. If so, then the loss of a spouse and having a spinal cord injury must be devastating. This individual would certainly need a strong family support system as well as personal counseling. Of course this is true for all spinal cord injured persons. However, according to the respondents in this survey, few persons have had adequate personal counseling, family counseling, sexual counseling or peer counseling. If they have had this service, it can be assumed that few of these services were provided in the community setting where the spinal cord injured person suddenly faces the reality of his/her disability. The Progress Report from NWRSCIC (1977-78) affirms that family support is a major factor determining rehabilitation outcome and thusly, great efforts must be made to assist the injured person and his family or spouse to successfully adjust to consequences of a spinal cord injury. It seems clear that more efforts should be made to help the AFS client to maintain his family unit and long-term adjustments in the community. Milhouse (1979) asserts that until socialization and integration of the injured person is made between his family, his friends and the community, it is unrealistic to think of vocational goals.

Category IV:

Factors Related to Financial Status

Main Source of Income

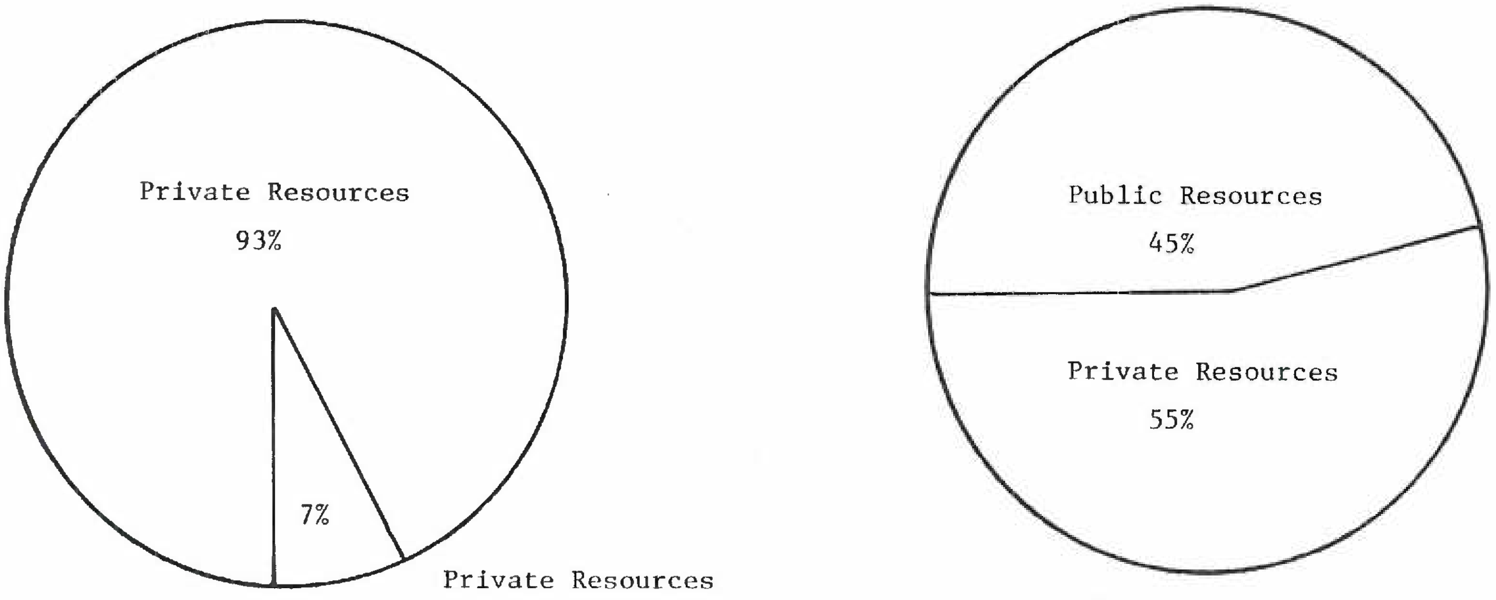
Figure 4 shows that 93% of the AFS population (Groups I and III) and 45% of the Group II population rely on public resources for their main source of income. Twenty-six percent of Group II report their own earnings as the major income resource. Family, friends and other means of resources make up the other 29% of private resources for this group. In summary, one can say that 51% of spinal cord injured persons in this survey rely on public resources for their main source of income. Whether this is representative of all spinal cord injured persons cannot be determined from this study.

Level of Income. Obviously there was a significant difference in income levels between Groups I and II (Table 11). Almost all AFS clients have a net monthly income of less than $600, while persons in Group II with other resources have a net monthly income of over $600 in 60% of the cases. When asked if their income met their needs, 83% of the AFS group responded negatively, while less than half of Group II responded in this manner.

Pre- and Post-Employment Status. Prior to injury employment rates between Groups I and II were similar (Figure 5), 46% versus 48% employment rates; slightly lower than National figures which show 58% working at the time of injury. Currently, only 7% of the AFS group are employed part-time and none are employed full-time. One-third of the Group II respondents are now either employed part- or full-time. Figure 5 also points up the fact that a significant percentage of

Figure 4

Comparison of Main Source of Incomes Between Sample Groups



Groups I & II

Group II

Table 11

Comparison of Independent Living Sample Groups Variables Related to Income

Variable N = Possible Responses	Sample Groups % I AFS (N=62)	II NONAFS (N=187)	Total (N=249)	Significance of Difference Chi-square
Main Source of Income	(59)[a]	(174)	(233)	
AFS	25.4%	0 %	6.4%	
SSDI	35.6	25.9	28.3	
SSI	32.2	4.6	11.6	
VA	0	6.9	5.2	
Family, Friends	5.1	18.4	15.0	
Workm. Comp.	0	8.0	6.0	
Own Earnings	0	25.9	19.3	
Other	1.7	10.3	8.2	
Level of Income	(59)	(164)	(223)	51.6*
Less than $600	91.5	38.4	52.4	
More than $600	8.5	61.6	47.6	
Income vs Need	(57)	(177)	(234)	17.2*
Adequate to Very Well	17.5	54.8	37.2	
Not Well to Poorly	82.5	45.2	62.8	
Standard of Living Now vs Preinjiry	(57)	(176)	(233)	22.2*
Same/Better	19.3	55.1	46.4	
Worse	80.7	49.9	53.6	

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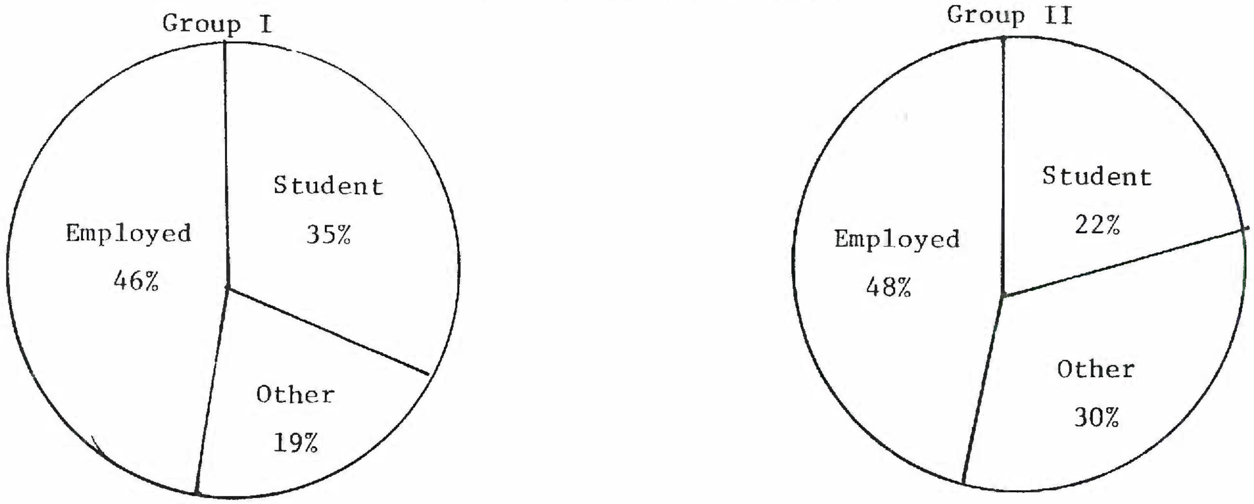
*The significance of differences in frequencies was determined by Chi-square. Significant results ($p < .05$) are presented and marked by an asterisk. Nonsignificant results are labled n.s.

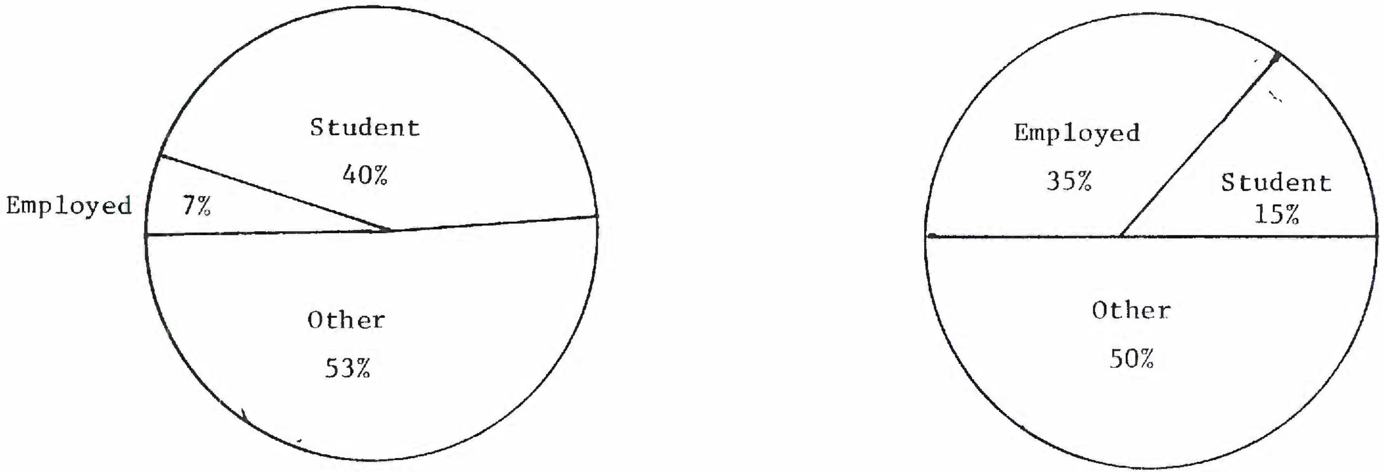
[a] The number in parentheses represents the number of responses for each sample group.

Figure 5

Employment Status Pre Injury



Employment Status Post Injury



respondents were students at the time of injury. This, no doubt, is related to their age at injury; i.e., the injury interrupting high school or college education. Combining both groups, 24% were students at the time of injury, the same as the national figures. There is a difference between the study groups in educational level as can be seen in Table 12. Nursing home respondents are the least educated, and Group II persons have attained the highest level of education; 18% achieving a bachelor or post-graduate degree (40% of those receiving this degree received it after their injury). Nearly half of AFS clients have had some college education. Fifty-five percent of this group have pursued educational programs after injury, and 40% are currently classified as students (see Figure 5).

Factors That Prevent Employment. Comparing just noninstitutionalized groups (I and II), 72% of the respondents are unemployed; another 7% work only part-time. These respondents were asked to indicate what factors prevented them from becoming employed, full-time, or in fact, employed at all. The factors on the questionnaire encompassed three general areas which would prevent employment: 1) personal needs, 2) job related factors, and 3) "work disincentives" in the law. Table 13 outlines these areas and demonstrates the significant differences between groups in all factors that keep respondents from becoming employed. 1) The greatest personal need indicated by both groups was the need for training/education/skills (36.5%) but far more need was expressed by Group I (54%). Transportation was a need almost equal in importance to the need for education for AFS clients (50%). Only 14% of Group II, however, indicated that transportation kept them from

Table 12

Comparison of Educational Level and Level Achieved Since Injury of Sample Groups

Education Level (N = Possible Respondents)	Sample Groups % I AFS (N=62)	II NONAFS (N-187)	III N. Home (N=20)	Total (N=275)	Significance of Difference Chi-square
Present Level Achieved	(58)[a]	(186)	(26)	(270)	5.507*
Less Than High School	19%	24.7%	50%	25.9%	
High School Grad.	24.1	22.1	19.2	22.2	
Some College	48.3	35.5	23.2	37.0	
Bachelors Degree	8.6	11.8	7.7	10.8	
Post Graduate	0	5.9	0	4.1	
Level Reached Since Injury?	(56)	(182)	(24)	(262)	10.21*
Yes	55.4	44	16.7	43.9	

*Significance of differences in frequencies was determined by Chi-square. Significant results ($p < .05$) are presented and marked by an asterisk. Nonsignificant results are labeled n.s.

[a] The numbers in parentheses represent the number of responses for each sample group.

Table 13

Comparison of Sample Groups I and II in Factors that Prevent Employment

Factors Preventing Employment N = Responses	Sample Groups % I AFS (N=54)	II NONAFS (N=149)	Total (N=203)	Significance of Difference Chi-square
Personal Needs				
Need Train/Skill	53.7%	30.2%	36.5%	9.45*
Transportation	50.0	15.4	24.6	25.51*
Need PT	31.5	10.1	13.3	13.69*
Reliable Attendant	29.6	8.7	14.3	n.s.
Job Factors				
Lack Flex. Hrs.	38.9	16.1	22.2	11.92*
Access to Jobs	37.0	20.1	24.6	6.1*
Society/Employer Attitude	25.9	6.0	11.3	15.6*
Low Disincentives				
Loss Med. Benf.	38.9	4.7	13.8	38.97*
Loss Disb. Pay	37.0	22.8	26.2	5.22*
Loss of Attend $	33.3	5.4	12.8	27.75*
Delay in Disb. Statis	25.9	12.9	16.3	5.05*

*The significance of differences in frequencies was determined by Chi-square. Significant results ($p < .05$) are presented and marked by an asterisk.

being employed. A need for physical therapy and reliable attendant care was also a greater need for the AFS Group (30%) than for Group II (9%) before employment could be considered. 2) In the area of job related factors, both groups agreed that there was a lack of adaptable/ accessible jobs for their degree of disability (25%); but more so in Group I (37%). Lack of jobs with flexible hours was also a concern to both groups (22%). Again, this was more true in Group I, with 39% perceiving this as a problem. Societal and employer attitudes toward the disabled is of concern to far more AFS clients in Group I than Group II (25% vs. 6%). 3) In the area of work disincentives in the law inhibiting employment, there is a significant difference between groups, especially in relation to loss of benefits for medical care and personal care attendants. There is less difference between groups in income maintenance benefits; i.e., loss of disability pay and delay in the resinstatement of disability status after one stops working. This most likely is because it affects both groups. Looking at the laws, one can accept why this might be true. Briefly, for AFS clients, a work disincentive is the termination of all benefits from SSDI/SSI (refer to Appendix C for a summary of benefits) if a severely disabled person returns to work and earns more than $240/month. This person is then considered "substantially and gainfully employed" (SGA) and is no longer disabled according to the definition of "disabled" under the Social Security Act. Lost benefits from becoming SGA include medical care (Medicare-Medicaid) and social benefits (i.e., attendant funding), as well as income maintenance. On the other hand, respondents in Group II, for the most part, are not totally dependent on SSDI.

Many, in fact, have disability benefits from the Veterans Administration and compensation from insurance companies, such as Workman's Compensation or private companies. For these respondents, a return to work does not necessarily mean a loss of medical or social benefits, but it will mean a loss of disability payments (which in some cases may be more than the income from employment). Also, if they do return to work, and for some reason they cannot continue to work, it takes considerable time to reestablish a disability status. Of course this is also true for AFS group.

In summary, we can say that only 21% of respondents in this survey are employed full-time. There are many reasons why unemployed AFS respondents do not seek employment. or at least full-time employment. Some of the reasons are because of personal needs for education and transportation. Other reasons are lack of jobs that are accessible and adaptable for their degree of disability. Jobs with flexible hours to accommodate personal care needs would also be desirable. A delay in disability status if one stops working is a concern to all respondents receiving income maintenance benefits. AFS clients are also concerned about medical benefits and loss of attendant funding if they should return to work. A focus on all of these factors would have an impact on employment for disabled persons according to the participants. In addition, one-third of the AFS group need physical therapy and/or a reliable attendant before they could become employed. Twenty-six percent of this group also indicated they believe that societal and employer attitudes toward the disabled are a factor which prevents their employment. Only 6% of the Non-AFS group indicated that this was a problem inhibiting their employment.

Discussion

The findings from this survey illustrate the point that the largest proportion of spinal cord injured persons are currently dependent on public funds for their main source of income. About 50% were employed before injury and about 30% are presently employed. Some of those who were employed at injury are now clients of AFS. There are many factors which keep the AFS client from returning to work. The major reason, according to the respondents, is that they need education and training. Forty percent of AFS clients in this survey are currently in educational programs, so that need is apparently being attended to, at least for some. Transportation, however, is almost an equal need, and adequate funding for special vehicles is a factor not yet resolved, and public transportation has yet to modify this need. Thirty-nine percent of AFS clients indicated that finding an accessible, adaptable job with flexible hours inhibited their return to employment. In many instances, this can be overcome with proper VR counseling and adequate preparation for jobs that accommodate the individual's disability. Loss of income maintenance, medical benefits, and attendant funding is a major work disincentive to over one-third of the AFS respondents. This is a more difficult problem to overcome. To alter this obtacle, it would take legislative action at the federal level. However, some states have chosen to fund medical and attendant benefits to allow a severely disabled person to return to work and become a productive member of society.

For the AFS client there seems to be many factors contributing to a continued unemployment status. Education and accessible, adaptable jobs can be overcome with time. However, adequate transportation and work disincentives in the law are more difficult obstacles. These factors require legislative intervention, both at state and federal levels.

Category V:
Needs and Recommendations from Perspective of Respondents

Needs. Participants in the study were asked to mark specific areas where they believe their present needs were not being met, and then to rank them in order of importance. Table 14 shows the percentages of unmet needs in each sample group and how each group ranked them in importance. As one can see there was a significant difference in the number of unmet needs in all areas except housing, supplies and health care. AFS Groups I and III, in most instances, have far more unmet needs than Group II; especially in the areas of finances, transportation and employment. Finances was ranked as a number one unmet need by all sample groups, and indicated as a need by over half of all respondents, and by 90% of Group I. Transportation is ranked number 2 overall, but a much higher need in Group I (66%). Groups varied the rank ordering of unmet needs in most other areas. Education/training ranked in the top five areas of importance by Groups I and II, eighth in Group I. Supplies ranked second in Group II, fourth in Group III and seventh in Group I. The need for rehabilitation, emotional support and attendant/housekeeper ranked higher in priority for the nursing home group than the other two groups.

Recommendations. Subjects were asked to indicate on a scale

Table 14

Percentage of Unmet Needs in Each Sample Group and Rank Order of Importance

	Sample Groups %								
Unmet Needs N = Responses	I AFS (N=57)		II NONAFS (N=132)		III N. Homes (N=20)		Total Groups (N-209)		Significance of Difference Chi-square
	%[a]	Rank[b]	%	Rank	%	Rank	%	Rank	
Finances	89.5	1	56.8	1	45)	1	57.2	1	19.10*
Transportation	66.7	2	37.1	4	50)		42.4	2	13.99*
Employment	59.6	4	31.1	5	40	5	35.2	5	13.59*
Housing	47.4	4	28.8	3	40	3	30.9	3	n.s.
Educ/Train.	45.6	3	25.8	8	35	2	28.4	6	7.24*
Rehabilitation	43.9	5	19.7)	9	45)	3	25.4	8	11.80*
Emotional Support	33.3	7	19.7)		35)		22	10	4.08*
Attendent/Hsk.	29.8	6	22.7	7	45)	4	23.7	7	57.03*
Supplies/Equip.	28.1)	7	35.6	2	25)		27.5	4	n.s.
Health Care	26.3)		21.2	6	30	6	20.8	9	n.s.

*The significance of differences in frequencies was determined by Chi-square. Significant results ($p < .05$) are presented and marked by an asterisk. Nonsignificant results are labled n.s.

[a] Represents percentage of persons in each sample group who have unmet need.

[b] Represents how each sample group ranked them in order of importance.

from 1 to 5, ways of improving the delivery of care and services to spinal cord injured persons, 1 indicating "not recommended at all" and 5 indicating "highly recommended." All areas were highly recommended by total sample answering this question (86%). Suggestions did not vary significantly between groups except for two recommendations (see Table 15 for median scores). First, better vocational and independent living rehabilitation was more highly recommended by Groups I and III than Group II. This most likely reflects a desire for increased independence in these two groups. Secondly, greater participation in planning and decision-making was more highly recommended by Group I than the other two groups. Perhaps their younger age and lack of power through funding makes them vulnerable to have decisions made by others.

Respondents concluded that better emergency care, better acute care and better physical rehabilitation were needed. However, the highest recommendation of all from total sample groups was to have greater coordination of all aspects of care (median = 4.69). A close second recommendation was that there be organized follow-up services in the community (median = 4.68). These recommendations support the basic premise of a system that offers a continuum of comprehensive services, not only in the institutional setting, but in the community as well. Better discharge planning, also recommended, would provide the link between the two settings. Greater use of spinal cord injured people in the actual delivery of care and services was the third highest recommendation by all groups; the highest recommendation by Group I (median 4.76). Apparently most respondents believe that a

Table 15

Comparison by Median Score of Sample Groups in Recommendations for Improved Services

Recommendations	Sample Groups Median Score I AFS (N=57) median	 II NONAFS (N=159) median	 III N. Homes (N=20) median	Total Groups (N=236) median	Significance of Difference Chi-square
Greater use of SCIP	4.76	4.43	4.25	4.59	n.s.
Better ILR & VR	4.74	4.26	4.00	4.59	10.06*
Better Emergency Care	4.72	4.52	4.25	4.54	n.s.
Greater Coordination of Services	4.68	4.63	4.69	4.69	n.s.
Better Followup Services	4.65	4.59	4.78	4.68	n.s.
Greater Particip. in planning and disc.	4.64	4.21	3.93	4.43	8.8*
Better Phys. Rehab.	4.59	4.21	4.72	4.37	n.s.
Better Acute Care	4.72	4.52	4.25	4.54	n.s.
Use of One Manager	4.56	3.93	4.68	4.16	n.s.
Better Disch. Planning	3.67	4.00	3.58	3.78	n.s.

*The significance of differences in frequencies was determined by Chi-square. Significant results ($p < .05$) are presented and marked by an asterisk. Nonsignificant results are labled n.s.

peer might better identify with their situation. "The use of one manager accountable through all aspects of care" was also highly recommended, especially by AFS clients who currently have "multiple managers" involved in their lives. This supports the concept utilized in other parts of the country, which is described by Bartel (1977) as follows:

> From the injured person's point of view, responsibility for movement through the spinal cord injury system rests with the injured person and the case manager. . . . This philosophy assigns absolute responsibility for the injured person's progress and status quo to one individual in one organization; there is no possibility of passing the buck. (pp. 51-52)

In summary, one can say that recommendations from the respondents for ways of improving the delivery of care and services exemplifies the need for an improved system of care in Oregon. Lack of such a system is costly in human suffering, in productivity and in dollars.

Discussion

The significance of differences between the AFS client and the NonAFS person is demonstrated in unmet needs. Obviously, one would expect the AFS client to have greater financial needs. Again, transportation is demonstrated as an unmet need and second in importance to finances for the AFS client. Education/training ranks as more important than employment. Housing and rehabilitation are also unmet needs, ranked in the top five as being the most important to the AFS client. It is also interesting to note what needs are being met. Attendant care, health care and equipment needs are being met according to 70 to 75% of AFS clients. The exception to this is that nine nursing home residents indicated attendant care to be an unmet need and ranked it as very important. This raises the question of whether or not these persons are institutionalized for lack of attendants. Observation during interviews would indicate that this is true for about 30% of the sample. This observation, however, could not be supported without further study.

A most poingnant finding of the study was the seemingly enthusiastic response to recommend ways to improve delivery of care and services to spinal cord injured persons. Only the item "better discharge planning" received a median score of under "4" for all AFS clients. Perhaps this is due to a greater utilization of a social service worker; or, perhaps to the involvement of a caseworker who may make the transition from institution to home or nursing home easier for the AFS client. Whatever the reason, better discharge planning must still be considered as an area needing improvement according to respondents. One might interpret from recommendations made by respondents that better emergency care, better acute care, and better physical rehabilitation are asking providers of these services to acquire more expertise in the initial treatment of a spinal cord injury. Greater coordination of services, better discharge planning, and better follow-up services in the community are recommendations asking for services to assist in making the transition from the institution to integration to the community more helpful. Greater use of spinal cord injured persons, greater participation in planning and decision-making, use of one manager, and better ILR and

VR ask for services that lead to maximum independent living.

In summary, one can say that all the recommendations made by respondents in this survey ask for a system which

> emerges in a series of activities which will teach the person with spinal injury to be able to compete as a first class citizen in an able body's world. (Treischman, 1978, p. 1978)

CHAPTER IV

SUMMARY, CONCLUSIONS AND RECOMMENDATIONS

Summary

Based on national figures, somewhere between 62 and 125 young Oregonians will sustain a spinal cord injury this year. According to findings in this survey, three-fourths of these injuries can be expected to be as a result of a motor vehicle accident, or a sports related activity, such as diving or skiing. Over one-half of these spinal lesions will occur at the cervical (neck) level, which will result in varying degrees of permanent paralysis in all four extremities. The cost of such an injury is profound in terms of human suffering by both the victim and their loved ones.

The purpose of this study was to focus on the spinal cord injury persons who are dependent on the state assistance programs (AFS) and to compare and contrast their life situation, utilization of resources, and needs to persons who have other financial resources. The rationale for this design lay in the assumption that the personal needs and funding resources were sufficiently different to merit special study and comparison. In this survey the findings over all respondents were not dramatically different from the findings of other studies across the country. In fact, the problems that confront spinal cord injury persons everywhere are tediously alike. However, by comparing groups, this study found significant differences between the AFS client and those persons who have other funding mechanisms. It is expected that by pointing out these differences, service providers and state funding agencies will be able to develop and assess programs and policy, based on more specific needs as perceived by the spinal cord injury persons themselves.

Conclusions

The consequences of a spinal cord injury are catastrophic to all persons sustaining such an injury, but even more so to very young persons who sustain a high level of injury without adequate insurance protection. These young persons frequently become dependent upon another person for personal care and activities of daily living for the rest of their lives. (Life expectancy is nearly "normal.") They also frequently become financially dependent upon state and/or family resources.

It would appear from this study that AFS clients receive as many or more rehabilitation services as an inpatient and as a VRD client. However, more specific studies would need to be conducted to establish if this is true or not. In any case, long-term follow-up programs have not been sufficient to overcome unmet needs in the areas of finances, transportation, employment, housing, education and physical rehabilitation by over 40% of AFS clients. Broken marriages as a result of injury, and persons living outside of legal marriages indicate a lack of response by community resources to facilitate normal social integration after disability. Continued dependence on parents for personal care for persons over 21 is also not indicative of normal lifestyle for either the parents or the disabled person. Other persons without family support or personal care attendants reside in nursing homes. Alternative living situations need to be explored and supported by the state if necessary.

One can also conclude from the study that prevention programs need to be expanded. The high incidence of motor vehicle accidents and sports related activities, especially diving, are areas on which to focus. Other states have significantly reduced their injuries through such programs. Other prevention programs need to be considered to prevent further complications from chronic health problems following an injury. This is particularly true for the AFS client who has required numerous hospitalizations since injury. Education programs for spinal cord injury persons themselves, their families, attendants and caseworkers need to be expanded to prevent any unnecessary institutionalization.

It can also be concluded that the nonsystem in Oregon is currently not meeting the needs of persons with spinal cord injuries. Mechanisms need to be found to identify qualified rehabilitation facilities whose standards comply with those established by national criteria. In addition, research programs must be developed to evaluate rehabilitation outcomes of these facilities.

Recommendations

Conclusions reached in this study are based on the perspective of the spinal cord injury persons responding to this survey. These respondents also made recommendations which contribute to worthwhile considerations for improving the situation for spinal cord injured persons in Oregon. Their suggestions are therefore incorporated where possible in the following summary of recommendations:

- Prevention Programs. Motor vehicle accidents and sports were the cause of 75% of all injuries in this survey. Preventive programs should be explored through the following areas.
    1. The Oregon Traffic Safety Commission.
    2. Pacific Northwest Regional Spinal Cord Center films on

safety in sports.
3. Workman's Compensation Safety Division.
4. Rehabilitation Institute of Oregon's public awareness programs.

- Standards and Criteria of Care. Standards and criteria are already established at the national level and can be implemented at the state level for evacuation procedures at the point of injury, through identification of adequate acute care centers and qualified rehabilitation programs within each community.

- Identification of Funding Mechanisms. According to this survey, the state pays for 10% to 20% of spinal cord injuries during the acute care phase and rehabilitation. Out of 275 persons, 32% are currently receiving benefits from AFS; another 41 (15%) were previous clients of AFS. Although this may be an overrepresentation of persons needing state assistance, it does point out that it is necessary to develop a system which will assess and identify needs and match them with appropriate funding resources, i.e., Titles XVII, XVIII and XX, as well as VR and ILR funds. This could be developed as a computerized program. With increased funding for independent living programs, it is conceivable that AFS clients might better be facilitated through becoming VRD clients with backup funds from Titles XVIII and XX. A similar concept is used in other states.

- Identification and Integration of Community Resources. The number one and two recommendations by respondents in this study were to coordinate services and develop organized follow-up programs in the community. Improved discharge planning and communication between institution and community resources are beginning to be developed by some service providers. Other recommendations from respondents need to be explored, such as, use of spinal cord injured persons for peer counseling, counseling in home modifications, and possible case management.

- Public Awareness Programs. Besides the prevention awareness programs, there are many people from various disciplines who would benefit from information regarding spinal cord injuries and resources, i.e., employers, insurance claimsmen, legislators, architects, caseworkers, etc. Compilation and distribution of information through multimedia resources is possible through cooperation of consumer organizations and rehabilitation centers.

- Development of Lobby Strategies at State and Federal Levels. Results from this study show that primary barriers to independence are in the laws which obstruct progress toward employment. Policy for personal care attendant and loss of medical benefits must be addressed. Lack of transportation and adequate housing are other social barriers. Programs to introduce legislative process and policy change to coalition and spinal cord injury groups would be useful to facilitate lobbying activity. Use of advocacy groups, such as Association of Rehabilitation Nurses, are another source of lobbying activity.

- Research Programs. Research programs need to be developed to (a) define the target population and provide baseline data to develop rehabilitation programs desinged to minimize health problems and maximize rehabilitation, and (b) to evaluate the effect and efficiency of programs to tie into the National Spinal Cord Injury Computer Program.

The purpose of this study was to provide some baseline data to persons interested in improving the quality of life for spinal cord injury persons. It was intended to cover a broad range of issues and suggest areas of inquiry for further research. Recommendations made from this study need further evaluation by a consortium of individuals who have categorical expertise in the areas outlined above. This consortium must include spinal cord injured persons . . .

> persons who are suffering from the problem and who will have their own perceptions about how such problems might be solved. . . . [They] should have an input into the decision-making process about new social programs; unless they do, it is unlikely that any social innovation discovered to be beneficial could actually be implemented. (Fairweather, Tornatsky, 1977, p. 1)

It is encouraging that providers of services, consumers and legislators are beginning to take steps to set goals for establishing a systemized approach to care for spinal cord injured persons in Oregon. This will require a commitment to the total problem, with a goal to return a medically stable, well-rehabilitated individual to the community as a contributing member of society. Accomplishment of this goal can be reached by comprehensive, short- and long-term planning with an integration of medical, social, vocational and financial rehabilitation. Obviously, planning for achievement of this broad ranged goal requires cooperation and responsibility, which must be shared across disciplines. But most importantly, it must also include spinal cord injured persons who are the most directly affected.

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APPENDIX A

Essential Components of a Spinal Cord Injury System

ESSENTIAL COMPONENTS OF A SPINAL CORD INJURY SYSTEM

Acute Care

A. Evacuation and transportation.

1. Personnel should be trained in proper handling and evacuation of spinal cord injuries and severely traumatized persons.

2. Evacuation personnel must be under medical supervision. Facilities for emergency and acute care that possess the necessary environment, equipped and staffed by specialists in all aspects of spinal injury care, for maximal stabilization and maintenance of vital bodily functions.

B. Emergency and early acute care (1-10 days post onset).

Rehabilitation Services

A. Physical restoration (10-120 days post onset).

1. A program of physical restoration and rehabilitation services that assures the opportunity for improving functional capacity and potential in all areas, including activities of daily living, bowel and bladder care, and training, fitting of rehabilitation equipment, vocational evaluation and early training services, psychological assessment, and support, family and social evaluation, etc. The availability of multispeciality and medical consultation must be assured, i.e., urology, plastic surgery, orthopaedics, etc.

2. Coordination of services, and appropriate program and advocacy administered and guided by a physician who has specialized training and experience in rehabilitating the spinal cord injured during the early phase of rehabilitation.

B. A vocational rehabilitation.

1. Coordination of services, and appropriate program and advocacy administered and guided by an allied rehabilitation professional as coordinator during the vocational and placement phases.

2. A vocational rehabilitation program through which effective coordination and communication assures maximal use of all necessary agencies, institutions, and private enterprises within the region to meet the individualized vocational or educational needs of spinal cord injured persons.

B. A vocational rehabilitation (continued).

3. Written cooperative agreements between all service components of the system should assure proper patient flow and momentum of rehabilitation. Such cooperative agreements should specifically describe referral procedures, cost reimbursements, scope of services to be provided, staff sharing programs and other information as might be necessary to constitute an adequate subcontractural arrangement for grants management purposes.

Long-term, Comprehensive Followup (includes medical, social, psychological and vocational).

A. Coordination of services.

A comprehensive, long-term followup program emphasizing community placement, health maintenance, and vocational and social adjustment, and assuring that each is evaluated and monitored regularly through direct contact by trained followup personnel. Such a followup system should provide an up-to-date registry including a dynamic, current status evaluation of all spinal cord injured persons discharged from the various subsystems.

B. Community services.

A program of community outreach and community education in connection with the problems of housing, transportation, recreation, employment and community activities.

For funding purposes, the DHEW also requires a regional system to include the following:

1. An adequate and substantial volume of patients to support such a demonstration project. For a 30-40 dedicated bed spinal cord injury service, a minimum of 70-100 new cases a year must be available, not including a census of 100-300 previously disabled persons. Prior rates of case identification, admissions, readmissions and discharges will be used to evaluate this requirement.

2. Opportunities and the environment for clinical research and evaluation of program effectiveness. This requires a sophisticated data collection, retrieval and analysis capability for each subsystem, and the total system collectively, cost effectiveness and systems analysis studies will evaluate the benefits of the various subsystems and the total system in light of regional variations and differences in project structure and design.

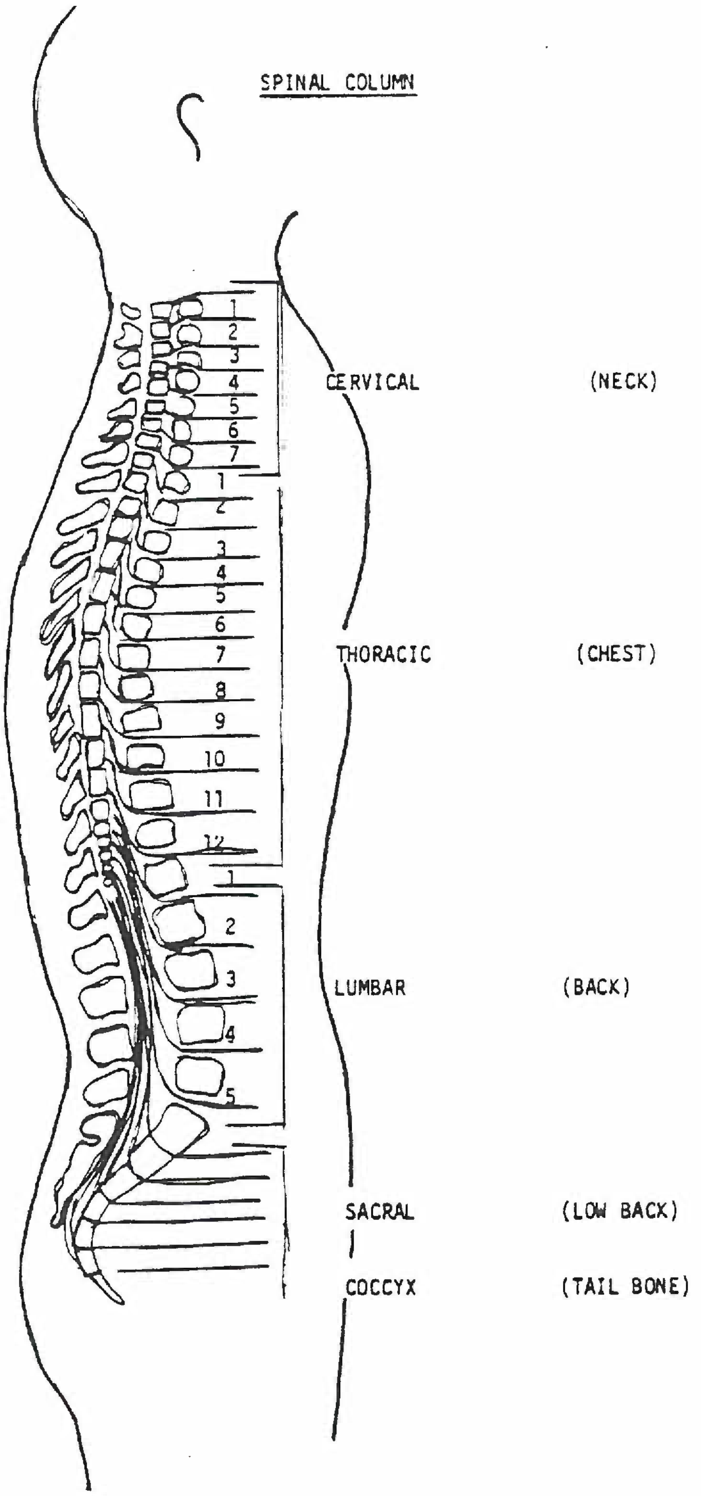
3. For the sharing of medical and allied rehabilitation staff by the acute medical care and rehabilitation staff by the acute medical care and rehabilitation services components, for rehabilitation plan development, treatment, research collaboration and training.

4. Training opportunities for specialists in the various disciplines involved in the rehabilitation of persons with spinal cord injuries.

5. Appropriate agency liaison, public and community education programs to decrease the incidence of traumatic spinal cord injury (prevention). (Federal Register, April 11, 1979, p. 15200.)

APPENDIX B

Functional Outcome



Drawing from CRAIG Discharge Manual

Activities	C1-3	C4	C5	C6	C7	T1	T6	T12	L4
Self Care:									
Eating	-	+/-	+	+	+	+	+	+	+
Dressing	-	-	-	-	+/-	+	+	+	+
Toileting	-	-	-	-	+/-	+	+	+	+
Skin Pressure Reliefs	-	-	-	+/-	+	+	+	+	+
Bed Independence:									
Rolling over & sitting up	-	-	+/-	+(Loops)	+	+	+	+	+
Moving about in bed; supine & sitting	-	-	-	+/-(Loops)	+	+	+	+	+
Transfers	-	-	-	+/-	+	+	+	+	+
Wheelchair Propulsion:									
Electric	+	+	+/-	+/-	+/-	-	-	-	-
Rim Projections	-	-	+/-	+	+	-	-	-	-
Standard	-	-	-	-	-	+	+	+	+
Driving	-	-	-	+/-	+	+	+	+	+
Job	-	-	-	+/-	+	+	+	+	+
Ambulation:									
Exercise (LLB)	-	-	-	+/-	+	+	+	+	+
Function	-	-	-	-	-	-	+/-	+(LLB)	+(SLB)
Public Transportation	-	-	-	-	-	-	-	+/-	+

LEVEL OF FUNCTION

C3	Diaphragm
C4	Neck Muscle Shoulder Abduction
C5	Elbow Flexion
C6	Shoulder Stabilization (fair) Radial Wrist Extensor
c7	Shoulder Stabilization (good) Finger Flexors & Extensors Elbow Extensors
T1	Hand Intrinsics Ulnar Wrist Extensor
T6	Upper Intercostal Upper Back
T12	Abdominals Thoracic Extensor
L4	Hip Flexors Knee Extensor
L5	Knee Flexors Dorsiflexors

FUNCTIONAL OUTCOME

C1-4	Totally Dependent
C5-6	Semi-Dependent
C7-11	W/C Independent
T12-L1	Independent Ambulation

Steven D. Feinberg, M.D.
Rehabilitation Institute of Oregon
April, 1976

FUNCTIONAL OUTCOME

C-1 to C-3 Quadriplegia

These patients have varying degrees of neck muscle control. The diaphragm is not functioning and artificial ventilation is needed. There is no upper extremity function. Patient is totally dependent and only limited self-care skills are possible using arm supports and/or externally powered hand splints. These activities require attendant supervision and set-up and therefore are indicated more to enhance the patient's self image and feeling of ability to do things rather than to show independence. One device which does allow a degree of independence is the breath "puff" control for call buttons, page turners, typewriters and overhead lighting. An occasional patient can use an electric wheelchair with a mouth wand or a chin cup.

C-4 Quadriplegia

These patients have neck and upper trapezius control, although they generally need assistance with intermittent artificial ventilation and usually need help with coughing since they have a poor cough mechanism. These patients can be taught glossopharyngeal breathing and can often benefit from a rocking bed. These patients are totally dependent but can do limited self-care activities using reacher-feeders and static hand splints or braces with ADL devices which are externally powered. The breath "puff" device is also useful to these patients. An electric wheelchair with mouth wand or chin cup is indicated.

C-5 Quadriplegia

These patients have full innervation of the trapezius, sternocleidomastoid and the upper cervical paraspinal musculature. This combined musculature enables the patient to stabilize and rotate his neck and to elevate the rotate externally the scapula. He also has rhomboids, deltoids and all the major muscles of the rotator cuff; although these are only partially innervated since they share their nerve supply with C-6. The patient, therefore, has partial shoulder motion. Elbow flexion is possible since the biceps and brachioradialus both remain partially innervated. In general, the shoulder function these people have lacks adequate stabilization. They have a low respiratory reserve. Some C-5 patients are able to do some upper extremity dressing and light hygiene along with self-feeding using externally powered hand splints or static splints with clip-on devices. The patient needs assistance in transferring from the bed and can turn himself in bed with the use of overhead arm slings. An electric wheelchair is indicated with a toggle switch as his endurance is low because of reduced respiratory reserves. The C-5 quadriplegic will need a full-time attendant and will not be able to earn a living using his hands. The exceptional patient may be able to operate a specially equipped telephone business, such as selling subscriptions.

C-6 Quadriplegia

A substantial functional increment is added with C-6 intact. The shoulder musculature is further innervated and the nerve supply to the elbow flexors is not complete. The extensor carpi radialus is evident at the wrist with wrist extension. The supinators are usually present to some extent as are the pronators. The patient still has a poor cough and needs continued pulmonary rehabilitation. The motivated C-6 patient can be independent in self-care using a wrist driven flexor hinge splint when prehension is required. He is able to transfer to and from the bed without assistance and can pull himself to a sitting position using a loop. He is able to roll over in bed and sit up using overhead loops. The patient can propel a wheelchair with wide spaced hand rims with spoke assists or knobs, but an electric wheelchair is often desirable for long distances. The C-6 level of quadriplegia shows the greatest variability between patients in terms of independence of self-care and mobility. The highly agressive and motivated C-6 quadriplegic can be extremely independent and even drive a car, but it is not unusual for a C-6 quadriplegic to need a full-time attendant.

C-7 Quadriplegia

The patient with sparing of the C-7 segment of the spinal cord has three important functional additions: 1) triceps, 2) common finger extensors, and 3) long finger flexors. The C-7 patient has adequate stabilization to show good shoulder function. He is able to flex his wrist with gravity and the shoulder and elbow are essentially normal. He has gross grasp hand function but often still benefits from a wrist-driven flexor hinge splint. He may still need some assistance with cough. He can be independent in transfers from the bed, car or toilet. He is able to propel a wheelchair, often without hand projections. He is able to maneuver his wheelchair in and out of his car and drive it. He can be independent in all self-care activities without hand splints and the exceptional C-7 patient can even catheterize himself with appropriate hand splints. He is able to do household activities from the wheelchair.

C-8 Quadriplegia

These patients have better finger flexor control and full innervation of the triceps. The upper extremity function is intact except for the hand intrinsics. They still have a low respiratory reserve and need assistance with cough. Their bed mobility is greatly increased and they are able to roll over and sit up. They can be independent in transfers. While they can grasp and release, they have little flexor strength or extensor dexterity. They can do wheelchair pushups and dress independently. These patients can live alone and are wheelchair independent.

T-1 Paraplegia

These patients have full innervation of the hand muscles and is the highest level of paraplegia. Many of them still need some assistance with cough. They are independent in transfers and wheelchair use. They are able to handle their own catheter care and therapeutic walking is possible with long-leg braces, a corset and underarm or forearm crutches.

T-1 to T-10 Paraplegia

These patients still have weak trunk stability with varying degrees of upper-back abdominal and intercostal innervation. They remain independent in self-care and wheelchair mobility and the exceptional patient can show partial functional walking with long-leg braces, a corset and forearm crutches. The metabolic cost is still very high for these patients and the majority of them prefer wheelchair ambulation.

T-11 to L-1 Paraplegia

These patients have full upper trunk stability with full abdominal and upper back control. They remain completely independent and while wheelchair may be used a substantial part of the time, walking with long-leg braces and forearm crutches can be functional.

L-2 to L-3 Paraplegia

These patients show pelvic stability with hip flexion and fair knee extension. They are functionally independent and where a wheelchair may be used, they are essentially functional with long-leg braces and forearm crutches for walking.

L-4 Paraplegia

These patients have, in addition to pelvic stability, good knee extension as well as his flexion. These patients can be functional with short-leg braces and forearm crutches but many of them continue to use a wheelchair during working hours.

L-5 to S-2 Paraplegia

These patients have additional strength and knee extension, hip flexion and dorsiflexion. These patients have varying degrees of muscle control with some of them having weakness of hip abductors and extensors. Knee flexors can be of varying strengths. Ankle support can be fair to poor. These patients often discard their wheelchair and use short-leg braces and forearm crutches or canes.

APPENDIX C

Summary of Social Security Benefits

SUMMARY OF SOCIAL SECURITY BENEFITS

Income Maintenance Programs

Title II Social Security Disability Insurance - SSDI

Eligibility: Disabled workers under 65 and their families.

Payment: Based on average earnings under Social Security over a period of years. Payments begin with the sixth month after determination of disability.

Return to Work: Full payments continue for nine month work trial. These months need not be consecutive.

Part-time Work: Full payments continue unless the work involves significant duties and is of substantial value or is in an amount greater than $295/month, SSDI will be discontinued.

Title XVI Supplemental Security Income - SSI

Eligibility: Disabled with little or no regular cash income Payments begin 6-12 months after eligibility determination.

SSI Self Support Plan: A plan designed to allow continued SSI payments while working and earning a full income. It is usually written by a rehabilitation professional itemizing the needs and uses of continued payments. The plan provides incentatives to disabled persons to return to employment and to contribute to his/her own financial support.

Medical Assistance Programs

Title XVIII Medicare

Eligibility: Primary assistance program to SSDI recipients who have been disabled and have received payments for two years or more.

Part A Hospital Benefits: $104 deductible. First 60 days in hospital and covers all services. 61st to 90th day all expenses except $25/day. Over 90 days, billed up to $52/day for 60 or more days.

Nursing Homes: 100 days/year. First 20 days all services - 21 to 100 days patient pays $13/day.

Title XVIII Medicare

Part B Medical Insurance: $60 deductible each year, then pays 80% of all "reasonable charges" of doctors services, out-patient hospital care, and out-patient physical and speech therapy.

Home Health Care: Plan A pays full cost up to 100 visits for up to 12 months after a hospital discharge. Plan B pays if patient is confined to home and the doctor determines that specialized care is indicated. All costs are paid after the first $60.

Personal Care Services: Under Part A and B.

Title XIX Medicaid

Eligibility: Financial need in combination with other factors. States must include: 1) all persons receiving cash benefits under Title IV-A (AFDC), and 2) either all persons receiving cash benefits under Title XVI (SSI) or those who meet more restrictive, Medicaid eligibility conditions.

Benefits Included in Oregon:
- In-patient hospital services - 21 day limit/year.
- Out-patient hospital services.
- Laboratory and x-ray services.
- Skilled nursing facility and home health services for those 21 and over.
- Physician's service.
- Skilled nursing facility.

Supportive Services

Title XX

Eligibility: Available to SSDI and SSI recipients.

Benefits: Include attendant (housekeeper) services, housing improvements and assistance, home delivered meals and other services which enable persons to remain in their own homes.

APPENDIX D

Questionnaire

QUESTIONNAIRE

GENERAL INFORMATION

Code

1 Source

2 1. Date of Birth ________

3/1-8 Category of Age

4 2. Sex: Male Female
(1) (2)

5 3. Veteran: Yes No
(1) (0)

6-10 4. Race of Ethnic Background. (Mark more than one if applicable.)
( ) Asian
( ) Black
( ) Hispanic (Spanish/Latin)
( ) Native American (Indian)
( ) White
( ) Other: ________

11 5. What State do you live in now? (Indicate County, if you live in Oregon)
(1) Oregon: County: ______
(2) Washington
(3) California
(4) Other: ____________

12-13 6. Date of Injury: ____________

14 7. In what State were you injured?
(1) Oregon
(2) Washington
(3) California
(4) Other: ____________

15-16 8. Level and completeness of your injury. (Write C-5, T-8, L-3, S-2, etc.)
Level Complete lesion?
Yes No
_____ (1) (0)

17 9. How would you describe your degree of functional return since your injury?
(1) None
(2) A little
(3) Moderate
(4) A lot
(5) Almost total

18 10. Cause of Injury: (Indicate specific Sport, Disease, Complication, Other)
(1) Motorcycle accident
(2) Motor vehicle accident
(3) Sport: ____________
(4) Fall
(5) Assault
(6) Disease: ____________
(7) Medical/surgical complication ____________
(8) Undetermined
(9) Other: ____________

Code

19 11. Your injury occurred in connection with
(1) Job
(2) Armed Services
(3) Recreation
(4) School
(5) Home
(6) Other: ____________

LIVING SITUATION AND FINANCES

20 12. What is your current marital status
(1) Married
(2) Widowed
(3) Divorced
(4) Separated
(5) Never married

21 13. If you were married at the time of your injury and then got divorced, how long after your injury did you get divorced?
(1) Within 1 year
(2) Within 2 years
(3) Within 3 years
(4) After 3 or more years

22 14. If you answered the above question, to what extent do you feel your divroce was related to your injury?
(1) Very related
(2) Somewhat related
(3) Not related
(4) Don't know

23 15. As you may know, there are certain laws that prevent a spouse from being paid as an attendant. How important an effect has this had on your marital status, whatever it is?
(1) Very important
(2) Somewhat important
(3) Not important
(4) Don't know

24 16. How many people are financially dependent on you?
(1) None, not myself
(2) One, myself only
(3) Two, myself and another
(4) Three or more

25 17. Where do you live now?
(1) Private residence
(2) Hospital or rehabilitation center
(3) Nursing home or the equivalent
(4) Short-term transitional housing
(5) Permanent independent group care
(6) Other: ____________

26 18. Would you live in an independent group living situation?
Yes No
(1) (0)

Code

27-33 19. Who do you live with now

		Yes	No
( )	Alone	(1)	(0)
( )	Spouse		
( )	Parent		
( )	Child		
( )	Partner		
( )	Non-relative		
( )	Other: ________________		

34 20. For the most part, what level of assistance do you need for the self-care activities of daily living? (Mark "Full assistance" if you have a live-in attendant or someone who performs the equivalent tasks, or if you live in a long-term care facility)

(1) Full assistance
(2) Much assistance (up to 8 hours per day)
(3) Moderate assistance (up to 3 hours per day)
(4) Minimum assistance (up to 1 hour per day)
(5) No assistance

35 21. Who primarily assists you in the self-care activities of daily living? (One answer)

(1) Spouse
(2) Family member(s)
(3) Partner
(4) Friend (other than partner
(5) Nurse
(6) Non-relative (other than partner or nurse)
(7) Other: ________________

36 22. If you have a paid attendant or housekeeper, does he/she live in?

Yes (1) No (0)

37 23. If you have any kind of paid attendant or housekeeper, how much is that person paid? (Indicate hourly, monthly, room and/or board, etc., whatever is appropriate)

____

38 24. What is the main funding source for your housekeeper/attendant?

(1) AFS (Medicaid)
(2) Medicare
(3) Private insurance
(4) Workman's Compensation
(5) Yourself, own resources
(6) Other: ________________

39 25. Do you find your present arrangement for assistance in the self-care activities of daily living satisfactory?

Yes (1) No (0) Unsure (2)

Code

40 26. What is the highest level of formal education you have attained?

(1) 8th grade or less
(2) Some high school
(3) High school graduate
(4) Some college
(5) Bachelors degree
(6) Advanced degree

41 27. Did you attain this education level since your injury?

Yes (1) No (0)

42 28. Have you completed any formal vocational training either before or after your injury? (Apprenticeship programs, trade schools, etc)

43

	Yes	No
Before your injury:	(1)	(0)
After your injury:	(1)	(0)

44 29. If you have had any formal education or vocational training since your injury, who paid for it?

(1) Private insurance
(2) Workman's compensation
(3) Veteran's or Service
(4) Vocational Rehab. Division
(5) Yourself, own resources
(6) Family or friends
(7) Other: ________________

45-51 30. What is your employment situation now, and what was it when you were injured? (Mark all applicable choic s)

	No (0)	Now (1)	When Inj. (2)	Both (3)
Regular paid job		( )	( )	
Sheltered workshop		( )	( )	
Self-employed		( )	( )	
Unpaid volunteer, homemaker, etc.		( )	( )	
Student		( )	( )	
Unemployed		( )	( )	
Other: ____________		( )	( )	

52-53 31. If you now have a paid job, is it full or part-time, and what are your average monthly earnings after taxes and deductions (take-home pay)?

	Full-time	Part-time
(1) Less than $200	( )	( )
(2) $200-399	( )	( )
(3) $400-599	( )	( )
(4) $600-799	( )	( )
(5) $800-999	( )	( )
(6) $1000 or more	( )	( )

54 32. What is your job title now, and what was it before you were injured?

(0) No (1) Yes

Now: ________________

Before: ________________

Code

55-70 33. If you do not now have a full-time paid job, which of the following factors are preventing you from being employed?

a( ) Loss/decrease in disability payments or status
b( ) Loss/decrease in medical benefits
c( ) Loss/decrease in attendant funding
d( ) Probable delay in the reinstatement of disability status if you had to stop working
e( ) Lack of transportation
f( ) Inadequate place to live
g( ) Lack of accessible/adaptable jobs
h( ) Lack of reliable attendant care
i( ) Lack of jobs with flexible hours
j( ) Societal and employer attitudes toward the disabled
k( ) Need equipment, devices
l( ) Need more physical therapy
m( ) Need more occupational therapy
n( ) Need training/skills/education
o( ) Need medical treatment
p( ) Other: ______________________

34. In your opinion, which <u>five</u> of the factors listed in the previous question would have the greatest impact on the employment situation of special cord injured people, if available time, energy, and money were focused on them. List them by letter.

_____ _____ _____ _____ _____

71-86 35. From which of the following sources do you receive <u>any</u> income or services?

a(1) Adult and Family Services
b(2) Vocational Rehab. Division
c(3) Social Security Disability (SSD)
d(4) Social Security Supplement (SSI)
e(5) Food Stamps
f(6) Private disability insurance
g(7) Workman's Compensation
h(8) Personal injury settlement
i(9) VA compensation
j(10) Support from family/friends
k(11) Own earnings
l(12) Savings and investments
m(13) Pension
n(14) Medicare
o(15) Medicaid
p(16) Unemployment benefits
q(17) Other: ______________________

87 36. Among the sources of income you marked in the previous question, which is your <u>main</u> source for meeting everyday living expenses? (One answer only; exclude health care and addendant/housekeeper funding sources; indicate by the appropriate letter.) (____)
1-17

Code

88 37. <u>Excluding</u> funds you may get specifically for paying an attendant/housekeeper, what would you estimate as your <u>total net monthly income</u> from all sources?

(1) Less than $200
(2) $200-399
(3) $400-599
(4) $600-799
(5) $800-999
(6) $1000 or more

89 38. Would you say that your total income covers your needs:

(1) Very well
(2) Adequately
(3) Not very well
(4) Very badly

90 39. How does your present economic standard of living compare with your pre-injury standard of living?

(1) Better than before
(2) About the same as before
(3) Not as good as before
(4) Much worse than before

PHYSICAL CONDITION

91 40. How would you rate your present state of health?

Exc.	Good	Average	Fair	Poor
(1)	(2)	(3)	(4)	(5)

92 41. What method do you <u>mostly</u> use for getting around? (One answer)

(1) Electric wheelchair
(2) Manual wheelchair
(3) Crutches
(4) Braces
(5) Confined to bed
(6) Other: ________________

93 42. What type of bowel program do you <u>mostly</u> use? (One answer)

(1) Cathartics
(2) Enemas
(3) Suppositories
(4) Digital stimulation
(5) "Normal"
(6) Other: ________________

94 43. What type of bladder care program do you <u>mostly</u> use? (One answer)

(1) Indwelling catheter
(2) Ileal loop
(3) Supra-pubic
(4) Condom collection
(5) Intermittant catheter
(6) Crede
(7) "Normal"
(8) Other: ________________

Code

95-96 44. Approximately how many times have you been hospitalizes since your initial acute care?
(1) 0 times
(2) 1-5 times
(3) 6-10 times
(4) 11-20 times
(5) Over 20 times

97-104 45. What were the reasons for your hospitalizations?
( ) Bladder/kidney
( ) Bowel
( ) Pressure sores
( ) Respiratory
( ) Other types of infection
( ) Emotional/psychiatric
( ) Reevaluation
( ) Other: ______________

105-110 46. What surgical procedures have you had since your injury?
( ) Fusion
( ) Laminectomy
( ) Plastic
( ) Bladder/kidney
( ) Bowel'
( ) Other: ______________

111-125 47. Mark any of the medical problems listed below which you feel have been serious and/or chronic:
( ) Bladder/kidney
( ) Bowel
( ) Pressure sores
( ) Respiratory ailments
( ) Contractures
( ) Spasticity
( ) Pain
( ) Obesity
( ) Low weight
( ) Fractures
( ) High or low blood pressure
( ) Temperature regulation
( ) Abuse or overuse of drugs
( ) Depression/emotional problems
( ) Other: ______________

126 48. On a scale of 0-10, circle the number that would best represent your present level of independence if "0" represented total dependence and "10" represented total independence:

total   total
1 2 3 4 5 6 7 8 9 10
dependence   independence

127 49. On the same scale, what do you think is the level of independence you could achieve given all the appropriate care and services?

total   total
1 2 3 4 5 6 7 8 9 10
dependence   independence

128 Difference Now and Potential
(1-10)

Code

129-138 50. Mark the areas where you feel your present needs are not being met, and then rank them by letter in their order of importance to you:
a(1) Housing
b(2) Employment
c(3) Education/Training
d(4) Transportation/Mobility
e(5) Health Care
f(6) Medical Supplies/Equipment
g(7) Attendant/Housekeeper
h(8) Emotional Support
i(9) Finances
j(10) Rehabilitation
k(11) Other: ______________

139 RANKING: (0-5) ______________

TYPES OF CARE YOU RECEIVED
(This is the next to the last section: hang in there!)

140 51. What types of emergency transport did you use to get to your initial acute care facility?
(1) Ambulance
(2) Rescue squad (Police/Fire)
(3) Helicopter
(4) Plane
(5) Private car
(6) Other: ______________

141 52. How much time elapsed between the onset of your injury and your arrival at an acute care facility (hospital)?
(1) Less than 3 hours
(2) 3-6 hours
(3) Between 6-12 hours
(4) More than 12 hours

142 53. From what kind of facility did you receive most of your acute care, and was it in Oregon? (One answer)
In Oregon? Yes (1) No (0)

143 Facility:
(1) Small hospital (under 100 beds)
(2) Medium hospital (100-200 beds)
(3) Large hospital (over 200 beds)
(4) Spinal Cord Injury Center
(5) Other: ______________

144 54. How long did you receive acute care in the above facility before beginning rehabilitation or being discharged?
(1) Not longer than 3 weeks
(2) Not longer than 6 weeks
(3) Not longer than 9 weeks
(4) Not longer than 12 weeks
(5) Not longer than 15 weeks
(6) 15 weeks or longer

Code

145 55. What was the primary funding source for your acute care? (One answer)
(1) Private insurance
(2) Workman's Compensation
(3) Veterans or Service
(4) Medicare
(5) Medicaid
(6) Out of your own pocket
(7) Other: ________________

56. In what kind of facility did you receive most of your rehabilitation, and was it in Oregon? (One answer)

		Yes	No
146	In Oregon?	(1)	(0)

147 Facility:
(1) Didn't really receive any
(2) Spinal Cord Injury Center
(3) Rehabilitation facility
(4) Same facility as acute care
(5) Different acute care facility
(6) Other: ________________

148 57. How long did you receive rehabilitation at the above facility?
(1) Not longer than 1 month
(2) Not longer than 2 months
(3) Not longer than 3 months
(4) Not longer than 4 months
(5) Not longer than 5 months
(6) Not longer than 6 months
(7) 6 months or longer

149 58. What was the primary funding source for your rehabilitation? (One answer)
(1) Private insurance
(2) Workman's Compensation
(3) Veterans or Service
(4) Medicare
(5) Medicaid
(6) Vocational Rehab. Div.
(7) Adult and Family Services
(8) Out of your own pocket
(9) Other: ________________

150 59. Who do you mostly see, and where do you generally go for your current health care needs? (Mark only one in each section)

Who do you see?
(1) Family doctor
(2) Physician specialist
(Type) ________________
(3) Chiropractor
(4) Naturopath
(5) Nurse
(6) Other: ________________

151 Where do you go?
(1) Rehabilitation facility
(2) Acute care facility
(3) Long-term care facility
(4) Office or clinic
(5) Spinal Cord Injury Center
(6) Other: ________________

Code

152 60. How frequently do you receive some sort of medical attention?
(1) Once a year or less
(2) 2-3 times a year
(3) 4-5 times a year
(4) More than 5 times a year

153 61. What is the primary funding source for your present follow-up health care? (One answer)
(1) Private insurance
(2) Workman's Compensation
(3) Veterans or Service
(4) Medicare
(5) Medicaid
(6) Vocational Rehab. Div.
(7) Adult and Family Services
(8) Out of your own pocket
(9) Other: ________________

EVALUATIONS AND RECOMMENDATIONS
(This is definitely the last section!)

154 62. In evaluating the level of coordination among all aspects of the care and services you have received, would you say that your total care has been:
(1) Very coordinated
(2) Somewhat coordinated
(3) Neither
(4) Somewhat uncoordinated
(5) Very uncoordinated

63. Looking back, who first told you about the nature and probable results of your injury, and what kind of a job did they do in telling you?

155 Who told you?	156 Good Job (1)	Marginal Job (2)	Bad Job (3)
(1) Was never really told	( )	( )	( )
(2) Family	( )	( )	( )
(3) Friend	( )	( )	( )
(4) Nurse	( )	( )	( )
(5) Doctor	( )	( )	( )
(6) Other: ________________	( )	( )	( )

157 64. At what point after your injury did you decide that life was worth living?
(1) Always knew it
(2) Haven't decided yet
(3) Within the first 2 weeks
(4) Within the first 6 months
(5) 1 year after injury
(6) 2 years after injury
(7) 3 years after injury
(8) Longer than 3 years

Code

158-170 65. Have you tried any of the following alternative or "nontraditional" treatments or therapies, and if so, did you find them helpful?

(1) Yes, tried	(2) Yes, helpful
( ) Chiropractor	( )
( ) Naturopath	( )
( ) Acupuncture	( )
( ) Biofeedback	( )
( ) DMSO	( )
( ) Hormones	( )
( ) Aloe vera	( )
( ) Marijuana	( )
( ) Special diet	( )
( ) Vitamins	( )
( ) Hypnosis/meditation	( )
( ) Special counseling	( )
( ) Other: ____________	( )

171-180 66. Besides yourself, who have been the 3 most helpful, supportive and informative people for you since your injury.

( ) Spouse
( ) Partner
( ) Family member(s)
( ) Other injured person(s)
( ) Social service professional(s)
(Type) ____________________
( ) Nurse(s)
( ) Doctor(s)
(Type)
( ) Friend(s)
( ) No one, really
( ) Other: ____________________

181-194 67. During your acute, rehabilitative and follow-up care phases, who did you see, and, in general, how helpful were they?

Who did you see?	No ans. (0)	Very (1)	Some what Helpful (2)	Not (3)
( ) Urologist		( )	( )	( )
( ) Neuro-surgeon		( )	( )	( )
( ) Orthopedist		( )	( )	( )
( ) Physiatrist		( )	( )	( )
( ) Plastic surg.		( )	( )	( )
( ) Phys.therapist		( )	( )	( )
( ) Occu.therapist		( )	( )	( )
( ) Nurse		( )	( )	( )
( ) Psychologist		( )	( )	( )
( ) Psychiatrist		( )	( )	( )
( ) Social worker		( )	( )	( )
( ) Peer counselor		( )	( )	( )
( ) Voc. counselor		( )	( )	( )
( ) Other: ________		( )	( )	( )

Code

185-212 68. Have you received the following services or information from health care or social service agencies, and if so, was it good and enough?

Yes, I received these services or information (1)	Yes, they were good and enough (2)
a( ) Phys.therapy	( )
b( ) Occu.therapy	( )
c( ) Bowel/bladder training	( )
d( ) Equipment and devices	( )
e( ) Sexual counseling	( )
f( ) Family counseling	( )
g( ) Personal counseling	( )
h( ) Financial counseling	( )
i( ) Peer counseling	( )
j( ) Vocational counseling	( )
k( ) Health maintenance	( )
l( ) Your physical potential	( )
m( ) Your own mobility	( )
n( ) Housing modification	( )
o( ) Dealing w/attendants	( )
p( ) Recreational opportunities	( )
q( ) Other: ______________	( )

69. Among all the services and information listed above, which, in your opinion, are the five most important ones on which health care and social service providers should focus their time, energy, and money? (List by letter)

(1)____ (2)____ (3)____ (4)____ (5)____

213-217 70. Check each of the following statements about transportation that is true for you:

( ) I own a motor vehicle
( ) I have a driver's license
( ) I could get a driver's license with appropriate training
( ) I think the Tri-Met "Lift" service is very inadequate
( ) I think the private "special transportation" services are very inadequate

218 71. If you have had (or are going to have) some sort of rehabilitation, how much would you say you participated in the planning of your own program?

(1) Full participation
(2) Moderate participation
(3) Minimal participation
(4) No participation

Code

219 72. Even if you didn't receive any, when did you think would have been the best time for your vocational rehabilitation planning to have started?
(1) During acute care
(2) During physical rehab.
(3) Within 1 year after physical rehab.
(4) 1-2 years after physical rehab.
(5) More than 2 years after physical rehab.
(6) Don't know

220 73. If you have ever been a client of Adult and Family Services in Oregon, how satisfied have you been with your experiences, and for what reasons?

Level of Satisfaction:
(1) Very satisfied
(2) Somewhat satisfied
(3) Neutral
(4) Somewhat dissatisfied
(5) Very dissatisfied

221-226 Reasons for your level of satisfaction:
( ) Caseworker
( ) Agency policies
( ) Services are irrelevant to the "real world"
( ) Ignorance about the needs of spinal cord injured people
( ) The time of services
( ) Other: ____________________

226-236 74. If you have ever been a client of the Vocational Rehabilitation Division of the Department of Human Resources, what types of services did you receive, and were they good services, well-timed?

Services received:
( ) Was referred but my case was closed prematurely, with few or no services
( ) Education/training
( ) Guidance and counseling
( ) Physical and mental rehab.
( ) Employment services
( ) Post-employment services
( ) Driver's training
( ) Transportation
( ) Equipment or devices
( ) Other: ____________________

237 Overall, the services were:
(1) Good and well-timed
(2) Good but not well-timed
(3) Well-timed but not good
(4) Not good and not well-timed

Code

238 75. All in all, do you believe that if you had received different or additiona or more coordinated care (in emergency, acute, rehabilitative or follow-up phases), you would not be able to lead a more independent, productive and healthier life?
(1) Absolutely
(2) Probably
(3) Not sure
(4) No

239-249 76. Below are listed some suggested ways of improving the delivery of care and services to spinal cord injured persons. From your point of view, how would you recommend each suggestion, using the following "1-5" scale, with "5" indicating your highest recommendation?

Not recommended at all 1 2 3 4 5 Highly recommended

Suggestions:	Recommendations: (Circle your choice)
- Greater coordination of all aspects of your care	1 2 3 4 5
- Better emergency care	1 2 3 4 5
- Better acute care	1 2 3 4 5
- Better physical rehab.	1 2 3 4 5
- Better vocational and independent living rehab.	1 2 3 4 5
- Better discharge planning	1 2 3 4 5
- Greater participation in the planning and decision-making processes of your own care	1 2 3 4 5
- Greater use of spinal cord injured people in the actual delivery of care and services	1 2 3 4 5
- One "manager", accountable to you, who will "see you through" all aspects of care delivery	1 2 3 4 5
- Organized follow-up care services in your own community	1 2 3 4 5
- Other: ____________________	1 2 3 4 5

Thank you very much for completing this questionnaire. Please feel free to use this space plus the next page to make any comments or explanations. We are looking forward to receiving your questionnaire in the mail.

APPENDIX E

Correspondence

OREGON TRAIL
NATIONAL SPINAL CORD INJURY FOUNDATION
(Formerly - National Paraplegia Foundation)
10126 N.E. Wasco Street
Portland, Oregon 97220
(503) 257-0706

February 19, 1979

Mrs. Barbara Giesy
4350 S.W. 86th Aveune
Portland, Oregon 97225

Dear Mrs. Giesy:

We are planning to conduct a survey of the spinal cord injured population in Oregon and will be hiring someone to work on this project in the very near future. We would welcome your assistance in this research because of the technical nature of the information we hope to acquire. Your background knowledge of spinal cord injuries will be a tremendous asset and we look foreward to working with you.

Yours very truly,

Frances O. Hansen

Frances O. Hansen, Executive Director
Oregon Trail Chapter

1859

VICTOR ATIYEH
GOVERNOR

Department of Human Resources
ADULT AND FAMILY SERVICES DIVISION
PUBLIC SERVICE BUILDING, SALEM, OREGON 97310

August 28, 1979

Frances Hanson, Executive Director
Oregon Trail Chapter
National Paraplegia Foundation
10126 N.E. Wasco
Portland, OR 97220

Dear Ms. Hanson:

This is an invitation for you to share with us the results of your current survey regarding quadraplegic population of Oregon. We are interested not only in the written report, but meeting with you and other members of your group to discuss the findings.

I am writing you as a member of a recently established Case Management Committee for Severely Disabled. Establishing this committee is the result of recommendations made to the recent Legislature by the Department of Human Resources. Additional funds of $200,000 were made available for physical rehabilitation services for spinal cord injured persons who are eligible for medical services through Adult and Family Services Division. Securing statewide information about this group of persons and their needs is also a charge to the committee. A report is to be made to the next Legislature. The information you are collecting will be valuable, as will be the linkage which the committee wishes to establish with organizations and individuals who are also concerned with these problems.

I am looking forward to hearing from you. My telephone number is 378-2263.

Sincerely,

Lucille Pugh, Executive Assistant
Health and Social Services Section

LSP:jl

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REHABILITATION
INSTITUTE OF
OREGON

2010 N.W. KEARNEY ST., PORTLAND, OREGON 97209
503/229-7151

May 1, 1980

Barbara Peterson Giesy
Thesis: "A Descriptive Survey of Spinal Cord Injured Persons in Oregon"

Dear Barbara:

I have reviewed your thesis "A Descriptive Survey of Spinal Cord Injured Persons in Oregon". I find it a very meaningful and valuable study on the problems confronting the spinal cord injured person in the State of Oregon. I am very pleased that the Rehabilitation Institute of Oregon has been allowed to assist you in preparing this data. I feel that the material that you have compiled in your thesis will help us to improve the quality of care that we provide to the spinal cord injury patient. I recognize how difficult and time consuming collecting this type of data has been; however, the impact on improving the quality of care and life for the spinal cord patient will be greatly improved by your work.

Congratulations on a job well performed.

Your friend,

[redacted]

J. H. Kennedy, M.D., Chief
Physical Medicine & Rehabilitation
Good Samaritan Hospital & Medical Center

JHK:jt

APPENDIX F

Letter and Consent Form

June 18, 1979

In partial fulfillment of requirements for a Master of Nursing degree from the University of Oregon Health Sciences Center School of Nursing, I am undertaking a survey of spinal cord injured persons served by the Adult and Family Services Division in Oregon. I am attempting to study what services spinal cord injured persons have utilized from acute care through long-term follow-up; what is the present life situation; and what services do spinal cord injured persons think are necessary to achieve maximum independent living.

This survey has been designed in cooperation with the National Spinal Cord Injured Foundation - Oregon Trail Chapter, The Adult and Family Services Division and interested rehabilitation specialists in order to plan improved services for spinal cord injured persons living in Oregon.

You are invited to participate. This will involve a personal interview to complete a questionnaire in your living situation (or otherwise arranged); it will take approximately 30 to 45 minutes of your time.

Any information that is obtained will be handled confidentially. Anonymity will be maintained on all documents which will be identified by code numbers.

If you choose to participate, please return your answer by mail in the enclosed addressed and stamped envelope. Upon receipt you will be called to arrange a convenient time for an interview.

Sincerely,

Barbara Giesy
4350 SW 86th
Portland, OR 97225

Consent Form for Human Research Project

Consent Form for Participation in Survey of Adult Spinal Cord Injured Persons

I, ____, herewith agree
First Name Middle Initial Last Name
to serve as a subject in a survey of Spinal Cord Injured Persons conducted by Barbara Giesy, R.N., B.S.N., under the Supervision of Linda Kaeser, M.S.W., University of Oregon Health Sciences Center, School of Nursing; and in cooperation with Oregon Trail Chapter of the National Spinal Cord Injury Foundation and the Adult and Family Services Division of Oregon.

The survey aims to collect information regarding what and how acute care and rehabilitation services are being used; what the life situation of spinal cord injured persons living in Oregon is at the present time; and to determine what services spinal cord injured persons think are necessary to achieve maximum independent living. The specific goal is to provide a data base for use as guidelines for professionals and consumers to improve the care of spinal cord injured persons in Oregon.

I understand my participation will involve a personal interview to answer a questionnaire and will take approximately 30 to 45 minutes of my time.

All information that I give will be handled confidentially. My anonymity will be maintained on all documents which will be identified by code numbers.

My participation does not involve any known risk. I may or may not receive any direct benefit from participation in this project, but understand my contribution will help expand the degree of knowledge in regard to treatment of persons with spinal cord injuries.

I understand that I am free to withdraw from participation in this investigation at any time.

Barbara Giesy has offered to answer any question I might have about this study.

It is not the policy of the Department of Health, Education and Welfare, or any other agency funding the research project in which you are participating, to compensate or provide medical treatment for human subjects in the event the research results in physical injury. The University of Oregon Health Sciences Center, as an agency of the State, is covered by the State Liability Fund. If you suffer any injury from the research project, compensation would be available to you only if you establish that the injury occurred through the fault of the Center, its officers or employees. If you have further questions, please call Dr. Michael Baird, M.D. at (503) 225-8014.

I have read the preceding explanation and agree to participate in study described.

Signature________________________________

Witness ________________________________

Date________________________________

APPENDIX G

Raw Data

DISTRIBUTION OF FREQUENCIES AND PERCENTAGES BY SAMPLE GROUP[a]

Category I

Selected Demographic and Injury Characteristics

Characteristic N=Total Possible Responses	Group I AFS (N=62)		Group II NonAFS (N=187)		Group III NH (N=26)		Total (N=275)	
Sex	(61)[b]		(183)		(25)		(269)	
Male	42	68.9%	138	75.4%	16	64%	196	72.9%
Female	19	31.1	45	24.6	9	36	73	27.1
Race	(62)		(186)		(25)		(273)	
Black	2	3.2	1	0.5	0	0	3	1.1
White	52	83.9	174	93.6	24	92	250	91.2
Other	8	12.9	11	9.9	2	8	21	7.7
Vet	(58)		(180)		(19)		(257)	
Yes	2	3.5	52	28.9	2	10.5	56	21.7
Current Age	(61)[a]		(157)		(25)		(243)	
Median	27.1		32.5		30.6		29.7	
Age at Injury	(61)[a]		(155)		(25)		(268)	
Median	20.7		22.8		25.3		22.2	
Cause	(61)		(186)		(25)		(272)	
Motorcycle	6	9.9	13	7	5	20	24	8.8
Motor Vehicle	28	45.9	87	46.8	16	64	131	48.2
Sports	20	32.8	27	14.5	1	4	48	17.6
Falls	2	3.3	22	11.8	2	8	26	9.6
Violent	4	6.5	10	5.4	1	4	15	5.5
Other	1	1.6	27	14.5	0	0	28	10.3
Injury Connection	(61)		(180)		(21)		(262)	
Job	6	9.8	47	26.1	2	9.5	55	21
(Logging)	1	16.7	9	19.2	0	0	10	18.2
Recreation	34	55.8	76	42.2	8	38.1	118	45
(Diving)	10	29.4	10	13.2	1	12.5	21	17.8
Other	21	34.4	57	31.7	11	52.4	89	34
Level of Injury	(53)		(157)		(22)		(232)	
Brain Stem	1	1.9	0	0	6	27.3	7	3
C 1-4	16	30.2	21	13.4	5	9.1	39	16.8
C 5-8	21	39.6	61	38.9	16	31.8	89	38.9
T 1-6	7	13.2	29	18.5	3	13.6	39	16.8
T 7-12	5	9.4	34	21.6	6	13.6	42	18.1
L&S	3	5.7	12	7.6	3	4.6	16	6.9
Categorical Level								
Quadriplegic	38	71.7	82	52.2	15	68.2	135	58.2
Paraplegic	15	28.3	75	47.8	7	31.8	97	41.8
Completeness	(61)		(157)		(22)		(240)	
Yes	16	26.2	58	36.9	2	9.1	76	31.7
No	29	47.5	80	51	12	54.5	121	50.4
Unknown	16	26.2	19	12.1	8	36.4	43	17.9
Functional Return	(61)		(186)		(23)		(272)	
None	14	23	56	30.1	5	20	75	27.6
A little	25	41	61	32.8	9	36	95	34.9
Moderate	15	24.5	38	20.5	6	24	59	21.7
A lot	6	9.8	17	9.1	5	20	28	10.3
Almost total	1	1.6	14	7.5	0	0	15	5.5

[a] Median score distribution where appropriate

[b] The number in parentheses represents the number of responses from each sample group

Category II

Supportive Services Following Injury

Characteristics N=Total Possible Responses	Group I AFS (N=62)		Group II NonAFS (N=187)		Group III NH (N=26)		Total (N=275	
Evacuation	(49)		(154)		(14)		(217)	
Ambulance and Rescue Car	45	91.8%	133	86.4%	12	85.7%	190	87.6%
Private Car	4	8.2	16	10.4	2	14.3	22	10.1
Helicopter--Plane	0	0	5	5	0	0	5	2.3
Acute Care	(58)		(185)		(20)		(263)	
Small Hospital	3	5.2	9	4.9	2	10	14	5.3
Medium Hospital	6	10.3	42	22.7	1	5	49	18.6
Large Hospital	47	81	128	69.2	15	75	190	72.2
SCIC	2	3.5	6	3.2	2	10	10	3.8
Time Acute	(61)		(183)		(18)		(262)	
6 wks. or less	17	27.9	70	38.3	8	44.4	95	36.3
6 to 12 wks.	21	34.4	49	26.8	4	22.2	74	28.2
3 mos. or longer	23	37.7	64	34.9	6	33.3	93	35.5
Acute Funding	(59)		(182)		(19)		(260)	
Private	28	47.5	101	55.5	5	26.3	134	51.5
Workmans Comp.	0		27	14.8	1	5.3	28	10.8
VA	1	1.7	17	9.3	1	5.3	19	7.3
Medicare	1	1.7	8	4.4	1	5.3	10	3.8
Medicaid	19	32.2	6	3.3	8	42	33	12.7
Pocket	1	1.7	12	6.6	1	5.3	14	5.4
Other	9	15.1	11	6.1	2	10.5	22	8.5
Rehabilitation	(60)		(181)		(21)		(262)	
Rehab. Center	49	81.7	116	64.1	11	52.4	176	67
SCIC	2	3.3	14	7.7	2	9.5	18	6.8
Other	7	11.7	38	21	3	14.3	48	18.3
None	2	3.3	13	7.2	5	23.8	20	7.6
Time Rehabilitation	(58)		(175)		(15)		(248)	
Up to 2 mos.	13	22.4	41	23.4	0	0	54	21.8
2 to 4 mos.	16	27.6	60	34.3	3	20	79	31.9
4 to 6 mos.	12	20.6	33	18.9	4	26.7	49	19.8
6 mos. or longer	17	28.3	41	22.7	8	53.3	66	26.6
Funding for Rehab.	(58)		(178)		(15)		(262)	
Private	18	30	75	42.1	2	13.3	95	37.8
Workmans Comp.	0	0	27	15.2	0	0	27	10.8
VA	2	3.3	21	11.8	1	6.7	24	9.2
Medicare	1	1.7	8	4.5	0	0	9	3.6
Medicaid	14	24.1	5	2.8	8	53.3	27	10.8
VR	12	20.7	10	5.7	2	13.3	24	9.6
Pocket	4	6.9	12	6.7	1	6.7	17	6.8
Other	7	12.1	20	11.2	1	6.7	28	11.5
Health Problems	(55)		(159)		(22)		(236)	
Bladder	39	70.9	93	58.5	10	45.5	142	60.2
Spasm	21	38.2	67	42.1	11	50	99	41.9
Pain	23	41.8	65	40.9	5	22.7	93	39.4
Emotional Depr.	21	38.2	40	25.2	8	36.4	69	29.2
Pressure Sores	14	25.5	58	36.5	8	36.4	72	30.5
Bowel	3	5.5	39	24.5	5	22.7	47	19.9
Temp. Reg.	16	29	32	20.1	2	9.1	50	21.2
Respiratory	13	23.6	11	6.9	4	18.2	28	13.1
Obesity	5	9.1	19	11.9	4	18.2	28	13.1
Low weight	5	9.1	18	11.3	5	22.7	28	13.1

Category II (continued)

Characteristics N=Total Possible Responses	Group I AFS (N=62)		Group II NonAFS (N=187)		Group III NH (N=26)		Total (N=275)	
Bladder Program	(55)		(181)		(22)		(258)	
Indwelling Catheter	11	20%	24	13.6%	6	27.3%	41	15.9%
Urinary Diversion	13	23.6	29	16	5	13.6	47	18.2
Condom Collection	10	18.2	50	27.6	4	18.2	64	24.8
Intermittent Cath.	11	20	27	14.9	0	0	38	14.7
Normal	7	12.7	37	20.4	7	31.8	51	19.8
Other	3	5.6	14	7.7	0	0	17	6.6
Reasons Hospitalized	(53)		(138)		(19)		(210)	
Bladder/Kidney	37	69.8	90	65.2	11	57.9	138	65.7
Pressure Sores	19	35.8	42	30.4	7	36.8	68	32.4
Reevaluation	13	24.5	30	21.7	2	10.5	45	21.4
Respiratory	17	32.1	13	9.4	4	21.1	34	16.2
Other infections	13	24.5	13	9.4	3	15.8	29	13.8
Other reasons	26	49.1	72	52.2	9	47.4	107	51
Surgical Procedures	(47)		(128)		(15)		(190)	
Bladder/Kidney	25	53.2	59	46.1	6	40	90	47.4
Plastic	18	38.3	35	27.3	3	20	56	29.5
Fusion	13	23.6	49	38.3	5	33.3	67	35.3
Laminectomy	5	9.1	32	25	2	13.3	39	20.5
Other	21	44.7	47	36.7	9	60	77	40.5
Present State of Health	(58)		(186)		(26)		(270)	
Good to Excellent	27	46.6	93	50	10	38.4	130	48.2
Average	13	24.4	41	22	8	30.8	62	23
Fair to Poor	18	31	52	28	8	30.8	78	28.8
Frequency of Medical Attention	(51)		(181)		(16)		(248)	
0-1 x per yr.	12	23.5	67	37	4	25	83	33.5
2-5 x per yr.	17	33.3	76	42	2	12.5	95	38.3
More than 5 x	22	43.2	38	21	10	62.5	70	28.2
Times Hospitalized Since Injury	(58)		(182)		(22)		(262)	
0	5	8.6	43	23.6	1	4.6	49	18.7
1-5 x	29	50	97	53.3	9	40.1	135	51.5
6-10 x	12	20.7	22	12.1	5	22.7	39	14.9
11-20 x & over	12	20.7	20	11	7	31.8	39	14.9
Provider	(57)		(181)		(19)		(253)	
Urologist	48	84.2	146	80.7	15	78.9	205	81
Not helpful	2	4.2	12	8.2	0	0	14	6.8
Physical Therapist	43	75.4	155	85.6	15	78.9	203	80.2
Not helpful	3	7	11	7.1	2	13.3	16	7.9
Neurosurgeon	37	64.9	133	73.9	8	42.1	178	70.4
Not helpful	11	29.7	28	21.1	1	12.5	40	22.5
Occupational Therapist	35	61.4	119	65.7	9	47.4	163	64.4
Not helpful	3	8.6	27	22.7	0	0	30	18.4
VR Counselor	31	54.4	68	37.6	6	31.6	105	41.5
Not helpful	4	12.9	21	30.9	0	0	28	23.8
SSW	31	54.4	65	35.9	12	63.2	108	42.7
Not helpful	9	29	25	38.5	2	16.6	36	33.3
Orthopod	26	45.6	73	40.3	6	31.6	105	41.5
Not helpful	7	26.9	15	20.5	0	0	24	22.9
Nurse	26	45.6	101	55.8	15	78.9	142	56.1
Not helpful	2	7.7	32	2	0	0	4	2.8
Psychologist	24	42.1	33	18.2	6	31.6	63	24.9
Not helpful	10	41.7	16	48.5	1	16.7	27	42.9
Psychiatrist	16	28.1	34	18.8	3	15.8	53	21
Not helpful	10	62.5	20	58.8	1	33.3	31	58.5
Plastic Surgeon	13	22.8	30	16.6	3	15.8	46	18.2
Not helpful	0	0	2	6.7	0	0	2	4.3
Physiatrist	14	24.6	27	14.9	5	26.3	46	18.2
Not helpful	4	28.6	13	48.2	0	0	17	37.8
Peer Counselor	7	12.3	16	8.8	3	8.8	26	10.3
Not helpful	0	0	6	37.5	1	33.3	7	26.9

Category II (continued)

Characteristics N=Total Possible Responses	Group I AFS (N=62)		Group II NonAFS (N=187)		Group III NH (N=26)		Total (N=275)	
Rehabilitation Participation	(53)		(155)		(15)		(223)	
Full	14	26.4%	48	31%	6	40%	68	30.4%
Moderate	20	37.7	31	20	2	13.3	53	23.8
Minimal	10	18.9	40	25.8	3	20	53	23.8
None	9	17	36	23.2	4	26.7	49	22
Coord. Services	(56)		(174)		(19)		(249)	
Absolutely	31	55.4	60	34.5	8	42.1	99	39.7
Probably	12	21.4	27	15.5	3	15.8	42	16.9
Not Sure	9	16.1	49	28.2	6	31.6	64	25.7
Not	4	7.1	38	21	2	10.5	44	17.7
Services	(58)		(160)		(18)		(236)	
Physical Therapy	45	77.6	137	85.6	18	100	200	84.7
Good/Enough	27	60	80	58.4	9	50	116	58
Equipment	43	74.1	99	61.9	7	38.8	149	63.3
Good/Enough	21	48.8	52	52.5	3	4.3	76	51
Vocational Rehab.	40	69	80	50	7	38.8	127	53.3
Good/Enough	15	21.7	29	36.3	2	28.6	46	36.2
Occ. Therapy	35	60.3	98	61.3	8	44.4	141	59.7
Good/Enough	18	51.4	44	44.9	6	75	68	48.2
Bowel/Bladder	29	50	100	62.5	7	38.8	138	58.5
Good/Enough	19	65.5	52	52	2	28.5	73	52.9
Health Maintenance	27	46.6	99	61.3	7	31.8	133	56.4
Good/Enough	9	33.3	52	52.5	3	4.3	64	48.1
Personal Counseling	27	46.6	49	30.6	8	44.4	84	35.6
Good/Enough	10	37	16	32.7	2	25	28	33.3
Housing Mod.	24	41.1	43	26.9	3	16.7	70	29.7
Good/Enough	6	25	10	23.3	1	33.3	17	24.3
Physical Potential	23	39.7	68	42.5	8	44.4	99	41.9
Good/Enough	5	21.7	20	29.4	3	37.5	28	28.3
Own Mobility	23	39.7	66	41.3	4	22.2	93	39.4
Good/Enough	5	21.7	32	48.5	1	25	38	40.9
Sex Counseling	23	39.7	62	38.8	2	11.1	87	36.9
Good/Enough	5	21.7	13	21	1	50	19	21.8
Financial Counseling	14	24.1	32	20	4	22.2	50	21.2
Good/Enough	1	7.1	4	12.5	2	50	7	14
Family Counseling	13	22.4	42	26.3	4	22.2	59	25
Good/Enough	4	30.8	8	19	1	25	13	22
Attendant	11	19	14	8.8	4	22.2	29	12.3
Good/Enough	3	27.3	4	28.6	0	0	7	24.1
Recreation	11	19	46	28.8	3	16.7	60	25.4
Good/Enough	3	27.3	14	30.4	2	66.7	19	31.7
Peer Counseling	10	17.2	5	3.1	2	11.1	17	7.2
Good/Enough	5	50	2	50	1	50	8	47.1
VRD Services	(51)		(104)		(10)		(165)	
Referred; closed	5	9.8	18	17.3	3	30	26	15.3
Education/Training	33	64.7	54	51.9	5	50	92	55.8
Counseling	18	35.3	26	25	1	10	45	27.3
Physical Rehab.	19	37.3	20	19.2	3	30	42	25.5
Employment	3	5.9	19	18.3	2	20	24	14.6
Post Employment	1	2	7	6.7	0	0	8	4.9
Drivers Training	7	13.7	23	22.1	0	0	30	18.2
Transportation	14	27.5	26	25	2	20	42	25.5
Equipment	27	52.9	38	36.5	2	20	67	40.6
Other	0	0	5	4.8	0	0	5	3
VRD Evaluation	(45)		(99)		(9)		(153)	
Good, Well timed	21	46.7	42	42.4	4	44.5	67	43.8
Good, Not timed	13	28.8	17	17.2	1	11.1	31	20.3
Well Timed, Not Good	3	6.7	7	7.1	8	17.8	11	7.2
Not Good, Not Timed	8	17.8	33	33.3	3	33.3	44	28.7

Category III

Personal Support Systems

Characteristics N=Total Possible Responses	Group I AFS (N=62)		Group II NonAFS (N=187)		Group III NH (N=26)		Total (N=275)	
Marital Status	(61)		(184)		(26)		(271)	
Never Married	35	57.4%	63	34.2%	10	38.5%	108	39.9%
Divorced, Separated	19	31.1	29	15.8	11	42.3	59	21.8
Widowed	3	4.9	1	0.6	1	3.9	5	1.8
Married	4	6.6	91	49.4	4	15.3	99	36.5
Divorce after Injury	(14)		(20)		(6)		(40)	
Within 1 year	7	50	8	40	2	33.3	17	42.5
Within 2 years	3	21.4	7	35	2	33.3	12	30
After 3 years	4	28.6	5	25	2	33.3	11	27.5
Relationship to Inj.	(17)		(22)		(8)		(47)	
Very	11	64.7	10	45.5	4	50	25	53.2
Somewhat	1	5.9	8	36.4	3	37.5	12	25.5
Not	4	23.5	1	4.5	1	12.5	6	12.8
Don't Know	1	5.9	3	13.6	1	12.5	4	8.5
Supportive Persons	(57)		(183)		(20)		(260)	
Family	46	80.7	132	72.1	15	75	193	74.2
Friend	34	59.6	85	46.5	8	40	127	48.8
Doctor	28	49.1	48	26.2	5	25	81	31.2
SCIP	16	28.1	59	32.2	5	25	80	30.8
Nurse	11	19.3	27	14.8	8	40	45	17.7
Social Serv. Wkr.	11	19.3	13	7.1	2	10	26	10
Partner	10	17.5	12	6.6	1	5	23	8.9
Spouse	6	10.5	88	48.1	0	0	94	36.2
No One	2	3.5	7	3.8	1	5	10	3.9
Other	5	8.8	24	13.1	2	10	31	11.9
Know Life Worth Living	(56)		(176)		(15)		(247)	
Within 2 weeks	37	66.1	102	58	3	20	142	57.5
Within 6 months	6	10.7	23	13	2	13.3	31	12.6
1-3 years	4	7.1	23	13	4	26.7	31	12.6
Longer than 3 yrs.	5	8.2	7	4	2	13.3	14	5.6
Not Decided	4	7.1	21	11.9	4	26.7	29	11.7
Place of Residence	(61)		(185)		(26)		(272)	
Private Residence	57	93.4	181	97.8	0	0	238	87.5
Nursing Home	0		3	1.6	26	100	29	10.7
Other	4	6.6	1	0.4	0	0	5	1.8
Living With	(61)		(186)		(26)		(273)	
NonRelative/ Other	23	37.7	17	9.1	26	100	66	24.2
Parent	16	26.2	43	23.1	0	0	59	21.6
Alone	10	16.4	28	15.1	0	0	38	13.9
Partner	9	14.8	3	1.6	0	0	12	4.4
Spouse	4	6.6	89	47.8	0	0	93	34.1
Child	6	9.8	33	17.7	0	0	39	14.3
Attendant/ Housekeeper	(47)		(39)		(0)		(86)	
Live-in	34	74.3	16	41			50	58
Not Live-in	13	27.7	23	59			46	42
Primary Caretaker	(57)		(141)		(0)		(198)	
Spouse	4	7	68	48.2			72	36.4
Family Member	19	33.3	47	33.3			66	33.3
NonRelative	34	59.7	26	18.5			60	30.3

Category III (continued)

Characteristics N=Total Possible Responses	Group I AFS (N=62)		Group II NonAFS (N=187)		Group III NH (N=26)		Total (N=275)	
Amount of Assistance	(57)		(187)		(26)		(270)	
8 hours or more	42	73.7%	56	29.9%	20	76.9%	118	43.7%
Less than 8 hours	9	15.8	69	36.9	6	23.1	84	31.1
None	6	10.5	62	33.2	0	0	68	25.2
Satisfied with Assistance	(58)		(143)		(21)		(222)	
Yes	36	62.1	102	71.3	9	42.9	147	66.2
No	10	17.2	25	17.5	1	4.8	36	16.2
Unsure	12	20.7	16	11.2	11	52.3	39	17.6
Mobility	(61)		(184)		(25)		(270)	
Electric Wheelchair	30	49.2	30	16.3	7	28	67	24.8
Manual Wheelchair	28	45.9	116	63	15	60	159	58.9
Bed	0	0	2	1.1	3	12	5	1.9
Other	3	4.9	36	19.6	0	0	39	14.4

Category IV

Factors Related to Financial and Employment Status

Main Source Income	(59)		(174)		(22)		(255)	
AFS	15	25.4	0		17	77.3	32	12.5
SSDI	21	35.6	45	25.9	3	13.6	69	27.1
SSI	19	32.2	8	4.6	2	9.1	29	11.4
VA	0	0	12	6.9	0	0	12	4.7
Family/Friends	3	5.1	32	18.4	0	0	35	13.7
Workmans Comp.	0	0	14	8	0	0	14	5.5
Own Earnings	0	0	45	25.9	0	0	45	17.6
Other	1	1.7	18	10.3	0	0	19	7.5
Net Income	(59)		(164)		(13)		(236)	
-$200	8	13.5	9	5.5	11	84.6	28	11.9
$200-400	27	45.8	26	15.8	2	15.4	55	23.3
$400-600	19	32.2	28	17.1	0	0	47	19.9
$600-1000	5	8.5	50	30.5	0	0	55	23.3
Over $1000	0	0	51	31.1	0	0	51	21.6
Income vs Needs	(57)		(177)		(19)		(253)	
Adequate to Very Well	10	17.5	77	54.8	7	36.8	94	37.2
Not Well-Poorly	47	82.5	80	45.2	12	63.2	139	54.9
Standard of Living Compared Pre-Inj.	(57)		(176)		(16)		(249)	
Same or Better	11	19.3	97	55.1	1	6.2	109	43.8
Not as Good/Worse	46	80.7	79	49.9	15	93.8	140	56.2
Employment Status	(57)		(183)		(17)		(257)	
Employed Now	4	7	65	35.5	1	5.9	71	27.6
Employed at Injury	26	45.6	87	47.5	7	41.2	120	46.7
Homemaker/ Volunteer Now	5	12.2	16	8.7	0	0	21	8.2
Homemaker/ Volunteer at Injury	7	12.3	7	3.8	2	11.7	16	6.2
Student Now	23	40.4	28	15.3	2	11.7	53	20.6
Student at Injury	20	35.1	40	21.9	1	5.9	61	23.7
Unemployed Now	35	61.4	72	39.3	16	94.1	120	46.7
Unemployed at Injury	9	15.8	16	8.7	0	0	25	9.7

Category IV (continued

Characteristics N=Total Possible Responses	Group I AFS (N=62)		Group II NonAFS (N=187)		Group III NH (N=26)		Total (N=275)	
Educational Level	(58)		(186)		(26)		(270)	
Less HSG	11	19%	46	24.7%	13	50%	70	25.9%
High School Grad.	14	24.1	41	22.1	5	19.2	60	22.2
Some College	28	48.3	66	35.5	6	23.2	100	37
Bachelors	5	8.6	22	11.8	2	7.7	29	10.8
Post Grad.	0	0	11	5.9	0	0	11	4.1
Education Since Injury	(56)		(182)		(24)		(262)	
Yes	31	55.4	80	44	4	16.7	115	43.9
Vocational Training Since Injury	(58)		(162)		(20)		(240)	
Yes	8	13.8	29	17.9	2	10	39	16.3
Funding Ed/VR	(25)		(66)		(4)		(95)	
VRD	21	84	38	57.6	2	50	61	64.2
Other	4	16	28	42.4	2	50	34	35.8
Employment Preventive Factors	(54)		(149)		(17)		(220)	
Need Training, Skills, Education	29	53.7	45	30.2	8	47.1	82	37.3
Transportation	27	50	23	15.4	6	35.3	56	25.5
Lack Flexible Hrs.	21	38.9	24	16.1	3	17.7	48	21.8
Loss Medical Benefits	21	38.9	7	4.7	2	11.8	30	13.6
Loss Disability Payments	20	37	34	22.8	1	5.9	55	25
Accessible/ Adaptable Jobs	20	37	30	20.1	6	35.3	56	25.5
Loss Attendant Dollars	18	33.3	8	5.4	2	11.8	28	12.7
Need Physical Therapy	17	31.5	15	10.1	3	17.7	35	15.9
Lack Reliable Attendant	16	29.6	13	8.7	4	23.5	33	15
Society Attitude	14	25.9	9	6	2	11.8	25	11.4
Delay Disability Status	14	25.9	19	12.9	3	17.7	36	16.4
Need Equipment	9	16.7	14	9.4	3	17.7	26	11.8
Need Occupational Therapy	9	16.7	12	8.1	3	17.7	24	10.9
Housing	6	11.1	6	4	2	11.8	14	6.4
Need Medical Treatment	5	9.3	5	3.4	10	58.8	20	9.1
Greatest Impact on Emp. for SCIP	(54)		(149)		(17)		(220)	
Transportation	39	72.2	82	55	6	35.3	127	57.7
Accessible/ Adaptable Jobs	30	55.6	98	65.8	7	41.2	135	61.4
Attendant Dollars	36	48.2	28	18.8	1	5.9	55	25
Loss Disability Status	24	48.2	62	41.6	0	0	86	39.1
Loss Medical Benefits	24	48.2	48	32.2	2	11.8	74	33.6
Training/Education	23	42.6	73	49	8	47.1	104	47.3
Disability Reinstatement	19	35.2	53	35.6	2	11.8	74	33.6
Flexible Hours	18	33.3	60	40.3	3	17.6	81	36.8
Attitudes	17	31.5	56	37.6	2	11.8	75	34.1
Need Phys.Therapy	8	14.8	16	10.7	2	11.8	26	11.8
Medical Treatment	4	7.4	13	8.7	10	58.1	27	12.3
Need Occupational Therapy	4	7.4	12	8.1	4	23.5	20	9.1

Category V

Needs and Recommendations

Characteristics N=Total Possible Responses	Group I AFS (N=62)		Group II NonAFS (N=187)		Group III NH (N=26)		Total (N=275)	
Needs	(57)		(132)		(20)		(209)	
Finances	51	89.5%	75	56.8%	9	45%	135	57.2%
Transportation	38	66.7	49	37.1	10	50	97	42.4
Employment	34	59.6	41	31.1	8	40	83	35.2
Housing	27	47.4	38	28.8	8	40	73	30.9
Education/Training	26	45.6	34	25.8	7	35	67	28.4
Rehabilitation	25	43.9	26	19.7	9	45	60	25.4
Emotional Support	19	33.3	26	19.7	7	35	52	22
Attendant/Housekeeper	17	29.8	30	22.7	9	45	56	23.7
Supplies/Equipment	16	28.1	47	35.6	5	25	65	27.5
Health Care	15	26.3	28	21.2	6	30	49	20.8
Recommendations	(N=57)[b]	Median Score	(N=159)	Median Score	(N=20)	Median Score	(N=236)	Median Score
Use of SCIP		4.76		4.43		4.25		4.59
Better ILR-VR		4.74		4.26		4.00		4.59
Better Emergency		4.72		4.52		4.25		4.45
Greater Coordination		4.68		4.63		4.69		4.65
Greater Followup		4.65		4.59		4.78		4.68
Greater Participation		4.64		4.21		3.93		4.43
Better Physical Rehabilitation		4.59		4.21		4.72		4.37
Better Acute Care		4.72		4.52		4.25		4.54
Use One Manager		4.56		3.93		4.68		4.16
Better Discharge		3.67		4.00		3.58		3.78

AN ABSTRACT OF THE CLINICAL INVESTIGATION OF

BARBARA PETERSON GIESY

FOR THE MASTERS OF NURSING

DATE OF RECEIVING THIS DEGREE:

TITLE: A DESCRIPTIVE SURVEY OF PERSONS WITH SPINAL CORD INJURIES IN OREGON

APPROVED: ____
Linda Kaeser, M.S.W., Clinical Investigation Advisor

Each year, based on national statistics, between 64 and 125 young Oregonians sustain a spinal cord injury which most often results in permanent paralysis below the level of injury. The cost of such an accident is profound in terms of human suffering and cost in dollars spent in reducing the catastrophic consequences of this injury. Prior to this study, there was very little information available about this population to adequately plan and implement programs and policy leading to maximum independent living.

The purpose of this investigation was to collect data on demographic and injury related characteristics of spinal cord injured persons, their utilization of resources, and what services they percieve as necessary for maximum independent living.

Two hundred seventy-five spinal cord injured persons participated in this study: 249 persons living in the community, of whom 62 were clients of Adult and Family Services (AFS), and 187 persons funded by other resources, and 26 nursing home residents, all clients of AFS.

An instrument prepared and tested by the Oregon Trail Chapter of the National Spinal Cord Injury Foundation provided five categories of data: 1) demographic and injury related characteristics, 2) supportive services following injury, 3) personal support systems, 4) factors related to financial status, and 5) unmet needs and recommendations. Participants responded by mail or by a personal interview.

The findings regarding 275 persons in this study were quite similar to findings regarding other spinal cord injured persons in other studies throughout the country. However, in comparing three groups of this study, the investigator found significant differences between individuals who were clients of AFS and those who were funded by other means. Chi-square analysis revealed major differences between groups in regard to cause, age, and level of injury; marital status and caretaker arrangements; employment status and factors preventing employment; and intensity of unmet needs.

From this investigation, it was concluded that very young persons who sustain a high level of injury to the spinal cord, and who are without adequate insurance protection, may become financially dependent on state resources, such as AFS. Lack of personal support systems, frequent institutionalization, and unmet needs for education, transportation, employment and rehabilitation distinguish the AFS clients from persons funded by other means.