EDUCATION AND EMPLOYMENT OUTCOMES IN PERSONS WITH PEDIATRIC-ONSET SPINAL CORD INJURY VS. ADULT-ONSET SPINAL CORD INJURY

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Employment is considered to be an important predictor of life satisfaction and success. Statistics on unemployment rates are of concern among our society, especially when the statistics involve individuals with disabilities. In an era where the American with Disabilities Act and Rehabilitation Act have pushed for the community and workforce to become more accessible, unemployment rates among individuals with disabilities still remain high. Spinal cord injury (SCI) is an interesting population in that individuals, who want to work, can work with the appropriate technology and accommodations. Yet, over half of the individuals with SCI who worked prior to their injury remain unemployed years later. Many of the past and current studies investigating employment recruit subjects who are at least 18 years of age, with some recruiting individuals who are 16 years of age. Children with disabilities have a plethora of resources and services offered to them within the school district. From Individualized Education Programs (IEP) to transition services, many individuals work with the child to help them become an active participant in society. This study looks specifically at SCI of pediatric-onset. Examining already existing data collected by the NSCID, we investigated: a) employment and education rates among individuals with pediatric-onset SCI (PO-SCI) compared with adult-onset SCI (AO-SCI); b) variables that may contribute to vocational outcomes among this population; and c) if acquiring an SCI at a young age is positively correlated with higher rates of employment and levels of education. Statistical results yielded no difference between PO-SCI and AO-SCI with respect to employment rates (working vs. not working). Differences were noted in level of education achieved between PO-SCI and AO-SCI, with individuals who had PO-SCI more likely

to pursue additional education and higher levels of education post-injury. Results do indicate that post-injury level of education does correlate with post-injury employment status; higher levels of education yielded higher employment levels at follow-up. Results from the study also indicate that individuals with spinal cord injury, regardless of age at injury, still remain unemployed years after their injury. Rehabilitation counselors can play a crucial role in helping individuals with SCI overcome employment barriers.

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SPECIFIC AIMS

The purpose of this study is to examine the pediatric spinal cord injury (SCI) population to evaluate post-secondary education and employment success and to assess variables that may be indicators of such success. A second goal of this study is to assess whether acquiring a spinal cord injury at a young age correlates with greater incidence of post-secondary education and employment. To date, much of the SCI employment research focuses on individuals 18 years of age and older. Little research has been conducted which looks at employment rates and educational achievement of individuals who acquire spinal cord injuries at a young age, more specifically below the age of 14 years. Special needs children and adolescents have a wide array of resources and services offered to them through school districts, including Individual Education Plans (IEP), assistive technology (AT), and therapeutic services. Exposure to these factors while simultaneously developing with a disability may contribute greatly to later independence and success in the community. Children with disabilities may also have a strong network of family, friends and peers contributing support while an individual is developing with a disability; this factor may also increase the likelihood that a person with a disability will pursue post-secondary education or employment. It is my hypothesis that individuals with spinal cord injury acquired at a young age will have a high incidence of employment or post-secondary education compared to individuals injured as adults. To examine this hypothesis, the following specific aims will be addressed:

1. Investigate the post-secondary education and employment rates of individuals with pediatric-onset spinal cord injury (PO-SCI) compared to individuals with adult-onset spinal cord injury (AO-SCI).
2. Assess variables that may contribute to post-secondary education and employment rates.
3. Determine if acquiring a spinal cord injury at a young age is positively correlated with obtaining post-secondary education and/or employment.

To accomplish these goals, we looked at existing data collected by the Model Spinal Cord Injury System and housed in the National Spinal Cord Injury Database (NSCID). This database contains relevant clinical information on traumatic spinal cord injury patients beginning in 1970's with data still being collected today. Variables assessed included model center location,

date of injury, age of injury and follow-up, etiology, gender, race, marital status (pre and post-injury), level of education (pre and post-injury), place of residence, primary occupation (work vs. not work), category of neurological impairment (paraplegic vs. tetraplegic), self-perceived health status, and follow-up year. In an effort to control the confounding factor of variability of services and resources available in a school setting and to allow for ample follow-up data, the time frame was limited to only include subjects injured between 1980 and 1990.

This study aimed to identify whether age at the time of injury is correlated with successful rates of employment or education. In an effort to address this question, PO-SCI subjects were matched to AO-SCI subjects and outcomes were compared between the two groups. This study investigated data collected on PO-SCI subjects who were injured between the ages 10 and 16 years and AO-SCI subjects between the ages of 18 and 26 years. To allow for at least a two-year time period in a school setting after the onset of the injury, we only looked at PO-SCI subjects up to 16 years of age. The two groups were matched on the following characteristics: model center location, gender, race (minority vs. Caucasian), etiology, level of neurological impairment (paraplegia vs. tetraplegia), insurance (private vs. public), and age at the time of follow-up.

BACKGROUND AND SIGNIFICANCE

The Model Spinal Cord Injury System was established in 1970 with the National Spinal Cord Injury Database (NSCID) being established in 1975 (Becker & DeLisa, 1999). The goal of the Model Systems was to establish a model of quality care for individuals with traumatic spinal cord injury (SCI) in the acute setting and to establish a continuum of care after these patients have been discharged. The database is now one of the largest of its kind, hosting information on over 19,000 traumatic SCI patients across the country, focusing primarily on "functional and vocational outcomes" (Becker & DeLisa, 1999). Since its implementation, the Model Systems database has been used to aid in developing and performing research, specifically in the clinical realm (Stover et al., 1999). Research has been conducted using the NSCID to assess pre-injury variables that influence an individual's likelihood to return to gainful employment or pursue additional education. Factors that have shown to correlate with educational and vocational outcomes include gender, pre-injury education and employment, race, and time since injury (Becker & DeLisa, 1999). However, much of the research today focusing on employment

concentrates on an SCI population of 18 years of age and older. There are few studies that include individuals who are 16 years of age and younger at the time of injury.

The presence of a disability of any kind in a child is a cause for concern. One must take into consideration the presence of resources and services offered through the community and school and aimed at the family and child with the disability (Patterson & Blum, 1996). In addition, one must take into account any assistive technology or other resources that will enable the child to become an independent member of society. Although the same factors may be considered in an adult with a disability, children are constantly developing both physically and intellectually. In a study by Patterson and Blum (1996), it was determined that approximately 30% of the youth population had a disability of some form. More recent literature has indicated that 20% of all SCI cases are children and young adults (DeVivo & Vogel, 2004). While this literature did not specify an age range for this statistic, a study by Garcia, Gaebler-Spira, Sisung, and Heinemann (2002) suggested the incidence of spinal cord injury among children below the age of 16 years of age to be less than 5%. Pediatric SCI encompasses a wide array of etiologies including vehicular accidents, violence, surgical complications, sport related injuries, and falls (Devivo & Vogel, 2004). As with adult onset SCI, the epidemiology and etiology of PO-SCI is dependent upon age, gender and race (DeVivo & Vogel, 2004).

Employment

While the lifespan of individuals with SCI is increasing, there is continued concern regarding functional outcomes, especially educational and vocational outcomes, following injury in this population. Most parents raise their children to become active participants in society. This includes gaining additional education and participating in gainful and competitive employment with other members of society. Parents of children with traumatic spinal cord injury fear that the disability may prevent the child from becoming an active member of society, and prevent the child from becoming independent and capable of holding a job (Anderson, Vogel, Betz, and Willis, 2004). Society believes in large part that employment is a predictor of success (Yasuda, Wehman, Targett, Cifu and West, 2002). Employment is equated with “greater life satisfaction, higher level of activities, and better overall health” (Krause, 2003). In examining differences among employment rates between individuals with and without disabilities, Trupin and Yellin

(1999) found that individuals who experienced functional limitations as a result of a disability were more likely to be employed part-time rather than full time and expressed little satisfaction and autonomy with their current positions. In addition, these individuals expressed little hope in obtaining a more desirable position (Trupin & Yellin, 1999).

There is a large variability in results of research studying post-injury employment rates of individuals with spinal cord injury. A study by Krause, Sternberg, Maides and Lottes (1998) investigated employment rates related to geographic region, gender and race. Results indicated that while 72% of individuals with SCI were employed pre-injury, only 14% returned to work post-injury (Krause, Sternberg, Maides, & Lottes, 1998). Results also showed that time since injury was correlated with employment. In other words, the longer the duration of the injury, the more likely an individual with SCI will be employed. A separate study by Krause, Kewman, DeVivo, Maynard, Coker, Roach, and Ducharme (1999) reported that of 58.6% of individuals reporting to have been employed pre-injury, only 22% were employed post-injury; the data for this study was obtained through the National Spinal Cord Injury Database (NSCID). Conroy and McKenna (1999) studied the impact of variables such as age at injury, duration and degree of injury, and pre-injury factors of employment and education to determine the effect on post-injury employment rates. Results obtained state that of 86% of individuals with SCI employed or in school pre-injury, 67% were working or in school post-injury and 44% were in gainful employment positions (Conroy & McKenna, 1999). Minority status and disability with regards to unemployment has also been the focus of numerous research studies. In a study by Meade, Lewis, Jackson, and Hess (2004), researchers investigated data collected through the NSCID. Results indicated that, in comparison with Caucasian Americans, (1) the rate of SCI in African Americans (and other minorities) is disproportionately high, and (2) the rate of unemployment among African Americans was higher (Meade, Lewis, Jackson & Hess, 2004). An article by Julie Smart (1997), also focusing on minority and disability, stated there is a strong correlation between disability and "age, education, income, race, living arrangements, and gender." Smart also emphasized that education is key in both "preventing" and "rehabilitating" an individual with a disability (Smart, 1997).

Studies have also been conducted to investigate the patients' perspective on vocational outcome. Schonherr, Groothoff, Mulder, Schoppen, and Eisma (2004) conducted a research study to discover the process an individual goes through when returning to work after experiencing a traumatic spinal cord injury (SCI), as well as looking at the relationship between early expectations of the patients about returning to work after their injury. Results found a positive relationship between expectations about returning to work and "successful work reintegration" (Schonherr, Groothoff, Mulder, Schoppen, & Eisma, 2004). Relationships were also found between participation in vocational programs (i.e. work placement, vocational counseling) and returning to gainful employment (Schonherr et al., 2004). As one can see, numerous research studies have been conducted that look at vocational outcomes of individuals with spinal cord injury, including research using the NSCID.

Regarding the topic of employment and individuals with spinal cord injury (SCI), much of the research today concentrates on the adult SCI population. In the Disability Statistics Report by Trupin and Yelin (1999), data was not obtained on any individual with a disability under the age of 18. The study by Krause et al. (1999) did not include any individuals who were in transition to a post-secondary educational program or equivalent. Another study by Krause et al. (1998), although it included individuals under the age of 18, did not provide any information regarding the ages or age range of those individuals or their age at injury. The study by Schonherr et al. (2004) also did not clarify the ages or age range of the individuals at the time of injury; the authors only stated that, to be eligible, participants must be between the ages of 18 and 60. Finally, the study by Meade et al. (2004) clearly stated that all individuals whose data was included in the study must be between the ages of 18 and 65 *at the time of injury*.

Education

There are few studies available that focus on post-injury education and spinal cord injury, more specifically PO-SCI. In a literature search conducted by the author using "spinal cord injury" and "education" as key words, few articles were found that discussed this subject matter in depth. In one study by Massagli, Dudgeon, and Wood (1996), 53 students with spinal cord injury completed a survey to examine differences in areas of school performance and post-secondary outcomes compared to non-disabled peers. The survey was completed by both

students with spinal cord injury and their teachers and included questions inquiring about level of injury, current GPA, services used, assistive technology used, and highest level of education completed by their parents. In addition, students were asked to compare themselves to their non-disabled peers on school performance (Massagli et al., 1996). The mean age of individuals participating in the study was 9.2 years and the mean duration of injury was 9.4 years. Massagli et al. found that students with spinal cord injury and their teachers rated themselves at or above those of their non-disabled peer students. In addition, compared to the 56% "college matriculation rate" of students with disabilities, 82% of students with spinal cord injury had gone to college and many (63%) were living independently. The study also showed that higher education rates were linked to greater employment rates, however, the number of participants was too small to determine if younger age at time of injury corresponded to greater employment rates. It should also be noted that the study by Massagli et al. found that only half of the participants in this study qualified for special education services…"the ticket to transition services."

A second study by Krause et al. (1998) investigated employment after spinal cord injury with some focus on education with respect to employment rates. This study found that the level of education corresponded to employment outcomes; individuals with less education were more likely to be unemployed than individuals with higher levels of education. The number of hours worked by an individual with spinal cord injury also increased with an increase in level of education.

Factors Influencing Level of Education and Rate of Employment

There is little known about the factors that determine education and employment outcomes of individuals who sustain a spinal cord injury (SCI) as a child, more specifically below the age of 16. There is conflicting information among research studies about what factors contribute to employment outcomes and adjustment among individuals who sustain SCIs as children. Anderson and Vogel (2000) conducted a research study to compare the differences in work experiences between adolescents with an SCI and without. They matched the two groups on age, administered the same questionnaire (via phone), and found that adolescents without disabilities had more paid work experience or work experience overall (volunteer, community, home chores)

than adolescents with an SCI. Anderson and Vogel also found that the longer the person had an SCI, the more likely they were to have a paid working experience. These findings correlate with a study conducted by Livneh and Martz (2003) to measure whether psychosocial adaptation is positively correlated with time since injury. In other words, if the amount of time since injury increases, does ones acceptance of the injury also increase? Time since injury has been a largely studied factor of determining acceptance of an individual's SCI, with a vast array of findings with mixed results (Livneh & Martz, 2003). In a recent study by Anderson, Krajci, and Vogel (2003), looking at community integration as a functional outcome of individuals who sustained an SCI as a child, age was not a determinant, nor was duration of injury. As one can see, there seems to be conflicting information among the research studies about the role that age and duration or time since injury play in determining functional outcomes such as employment and education.

There are limitations to doing comparisons among these research studies. As previously stated, much of the research today focusing on employment concentrates on a spinal cord injury population (SCI) starting at age 18 years of age and older. There are few studies that include individuals who are 16 years of age and younger. In the study conducted by Livneh and Martz (2003), the subjects ranged in age from 16 to 87 years, with a mean age of 50. One may not be able to generalize the results of this study to a younger SCI population. Other limitations include small sample size (Anderson & Vogel, 2000) and instrumentation, such as the questionnaire used in the study by Anderson, Krajci, and Vogel (2003) and the survey used in the study by Massagli et al (1996).

Services Available for Students with Disabilities

In 1975, Congress passed a law called the Individuals with Disabilities Education Act, or IDEA (Heward, 2000). IDEA became a "landmark piece of legislation" whose purpose was to ensure that all children with disabilities have the right to the same educational opportunities as children without disabilities (Heward, 2000). There were six main principles that make up IDEA. The first principle states that no child shall be denied public education based upon a disability. The second principle mandates that schools use a non-biased method of evaluation in determining if a student has a disability and in determining appropriate services for students with disabilities.

Principle 3 states that all students with disabilities must be provided with a free appropriate public education and an Individualized Education Plan (IEP) must be developed for a student with a disability. The fourth principle focuses on inclusion and the concept of a "least restrictive environment" (Heward, 2000). This principle states that all efforts should be made to ensure that students with disabilities are educated in classrooms with students without disabilities. Principle 5 states that schools must adopt safeguards to ensure the rights of students with disabilities are protected. Finally, the sixth principle focuses on education of students with disabilities being a collaborative effort between school personnel, students, and parents; all parties must be involved in determining what services are appropriate for the student with a disability (Heward, 2000). In addition to the principles listed above, IDEA also requires schools to provide additional services to students with disabilities, including counseling, therapy, transportation, and assistive technology (Heward, 2000).

The "centerpiece" of IDEA and special education is the Individualized Education Plan or IEP. Children in the school system have in place an IEP beginning as early as the age of 3 years. The IEP is a requirement by Individuals with Disabilities Education Act (IDEA) to implement a plan of action for every child with a disability in the school system (Heward, 2000). The IEP is a "joint effort" by the teachers, therapists, parents, and child (if at least 14 years of age) to account for educational goals and progress of a child with a disability, as well as a "measure of accountability for teachers and schools" (Heward, 2000). There are numerous components that make up the IEP. Included in the IEP must be a statement of present educational performance as well as annual goals and objectives for the student with a disability. Also included in the IEP are special education services and program modifications that are to be provided to the student to help achieve goals and objectives. Examples of such services and modifications include therapy, counseling, extended time during test taking, and assistive technology in the classroom. In addition, the IEP must provide an explanation if a student with a disability is not educated in a regular education classroom. Finally, the IEP must also address when services will begin, how often the IEP team will meet to discuss education goals of the child, and how parents and/or guardians of the child with a disability will be notified of progress or changes to the IEP (Heward, 2000). In addition to the above, beginning at the age of 14, the IEP addresses employment and/or post-secondary educational goals and community integration. By the age of

16, the IEP will define transition services that will aid in the community integration and transition goals identified (Heward, 2000). Transition, in this context, is the process by which an adolescent moves from "child-centered to adult-oriented systems" (White, 2002). To fulfill the transition process, many services and resources are provided to the child or adolescent that can enable them to become active and independent members of society. One of the most requested transition services requested by adolescents with disabilities is job training or guidance (White, 2002). Another resource offered to many children with disabilities in the school system is assistive technology. Part of the IEP process may include exposing the child to assistive technology (AT) that may enhance the opportunities of the child (Heward, 2000). Because the IEP team consists of teachers, therapists, parents, and the child, a whole team of individuals work together to decide what technology best suits the child and will foster independence. With children being exposed to AT earlier in life, they may be more in tune with the technology, and may be less apprehensive of using or trying new equipment later on in life.

The literature search presented has shown how important educational and employment outcomes are in a population such as spinal cord injury (SCI). By conducting this study, missing information regarding the level of education and rate of employment among pediatric-onset SCI compared to adult-onset SCI and what variables play a part in these rates will be clarified. It is also hoped to determine if, due to the vast amount of services and resources offered to children with disabilities, individuals who acquire an SCI at a young age are likely to be employed or pursue education than individuals who acquire SCI as an adult.

METHODOLOGY

A. Research Design - This study incorporated a descriptive, retrospective design to investigate: a) the educational and vocational outcomes among individuals with PO-SCI vs. AO-SCI; b) variables associated with educational and vocational outcome; and c) if acquiring an SCI as a child or adolescent is positively correlated with higher rates of post-secondary education and employment. To accomplish the above, data collected from the National Spinal Cord Injury Database was examined.

B. Participants – In the National Spinal Cord Injury Database (NSCID), all subjects have a spinal cord injury of traumatic etiology. Data was included on two sets of subjects enrolled in the database. Pediatric-onset spinal cord injury (PO-SCI) subjects injured between the ages of 10 and 16 constituted the first group of subjects. PO-SCI subjects were matched to a group of adult-onset spinal cord injury (AO-SCI) subjects injured between the ages of 18 and 26. Participants were matched on the following variables: model center location, age at time of follow-up, gender, race (Caucasian vs. Minority), etiology, level of neurological impairment, and insurance (private vs. public). All subjects have been entered into the NSCID between the years 1980 and 1990.

C. Protocol – In order to match on age at the time of follow-up, investigators compared variables from PO-SCI subjects' follow-up years 15 and 20 to AO-SCI subjects' follow-up year 10. While time since injury has been argued to be a factor that influences rate of employment (greater time since injury equals greater rate of employment), studies have shown that rate of employment levels off after a certain amount of time post-injury. In a study by Krause et al. (1998), there was little difference noted in rate of employment after 6 years post-injury. Therefore, difference in follow-up years should not present as a confounding variable. To assure that follow-up year is not a confounding factor, statistical analysis was also run between post-injury employment status and follow-up year (year 10 vs. year 15 vs. year 20). All subjects were entered into the NSCID between the years 1980 and 1990. This time frame was chosen for two reasons: (1) to allow ample time for follow-up data to be collected, and (2) Transition and vocational rehabilitation laws were not emphasized until the late 1970's and other laws on special education services (IDEA and emphasis on assistive technology) were not emphasized until the early 1990's. Variables compared between the two groups included the following: model center location (to account for geographic region), date of injury, age at injury, age at follow-up, pre-injury insurance (private vs. public), etiology, gender, race, marital status, change in marital status, pre and post-injury level of education, pre and post-injury primary occupation (work vs. not work), category of neurological impairment (paraplegia vs. tetraplegia), post-injury self-perceived health status, and follow-up year. For the purpose of this study, a subject was classified as

working if he/she was a student or was competitively employed. Table 1 depicts the variables assessed for the purpose of this study and the codes that were used.

Table 1: Variables Assessed on PO-SCI and AO-SCI

Variable	***How Variable was Defined***					
Race	Caucasian	Minority				
Etiology	Vehicular	Violence	Sports	Medical Trauma	Fall	Other
Pre Injury Insurance	Private	Public				
Neuro Impairment	Paraplegia (incomplete and complete)	Tetraplegia (incomplete and complete)				
Change in Marital Status	No change	Single	Married			
Occupation F/U	Working	Not Working				
Level of Education	Below High School	High School or GED	Higher Education			
Post-Injury Residence	Private	Other				
Self-perceived health status	Excellent	Good	Very Good	Good	Fair	Poor
Marital Status (Pre and Post Injury)	Single (includes single, widow, divorce)	Married (includes married, separated)				

D. Measurement and Instrumentation – No new instrumentation of data collection methods were introduced in this study. Individuals who consent to participate in the Spinal Cord Injury Model Systems program are interviewed one year post-injury and every five years thereafter for up to 25 years. The following information is collected on all individuals who are part of the Model Systems program:

a) Personal Data – This includes demographic and personal identifying information (e.g. date of birth, social security number, telephone number, etc.) and is collected at the time of entry into the Model Systems program.

b) Form I – Data is collected for the Form I at the time of entry into the Model Systems program, and documents all information related to the acute and post-acute stay. Information included in the Form I consists of injury related data, gender, race, employment status, marital status, insurance, treatment phase, level of impairment, medical services received in acute and post-acute settings, Functional Independence Measure (FIM) scores at the time of admission and discharge from rehabilitation, and hours of therapy. For the purpose of this study, we abstracted the following variables from Form I: date of injury, age at injury, patient ID, gender, race, marital status, level of education, place of residence, category of neurological impairment, primary occupation, and insurance.

c) Form II – Data is collected for the Form II at the 1, 5, 10, 15, 20, and 25 year anniversary of injury dates. Information included in the Form II consists of post-injury year, place of residence, marital status, employment status, employment title, additional hospital stays since discharge, medical complications, FIM scores, Satisfaction with Life Scale (SWLS), Craig Handicap Assessment and Reporting Technique (CHART), Craig Hospital Inventory of Environment Factors (CHIEF), questions related to the subject's health, drug, and alcohol use, pain level, and hours of therapy prescribed and completed (only collected at follow-up year 1). For the purpose of this study, we abstracted the following variables from Form II: post-injury year, marital status, change in marital status, level of education, primary occupation, category of neurological impairment, and self-perceived health status.

E. Statistical Analysis – Descriptive statistics were obtained on both pediatric-onset and adult-onset spinal cord injury using SPSS statistical software. Chi-square tests were computed on all matching variables to determine if kids and adult subjects were appropriately matched. The significance level was set a priori at $< .05$. As data were paired, McNemar statistical tests were used for univariate analysis. Data was stratified and chi-square tests were calculated on PO-SCI and AO-SCI respectively to determine what variables, if any, had a

significant effect on employment status and differences were then compared between the two samples.

RESULTS

Participants

141 matched pairs (282 total subjects) were pulled from existing data found on the NSCID. Due to missing post-injury employment and/or post-injury level of education information, 50 matched pairs (100 subjects) were eliminated leaving a total of 91 pairs (182 subjects). To determine if the subjects were appropriately matched, chi-square statistics were computed on all matched variables. P-values obtained were greater than .05 for all variables, indicating that subjects were matched appropriately.

Descriptive statistics were also obtained to determine if there was a normal distribution between PO-SCI and AO-SCI with respect to age at follow-up. The average age at the time of follow-up was 31.93 +/- 2.58, which was a normally distributed; therefore parametric statistics were used.

Due to multiple levels of categories for the variables of pre and post-injury education, multiple comparisons were done. P-values were calculated for each separate comparison to determine if a significant difference was noted between all categories.

Post-Injury Employment and Level of Education of PO-SCI vs. AO-SCI

Due to having matched pairs, McNemar statistics were used to determine if there was a difference in post-injury employment status between PO-SCI and AO-SCI.

Table 2: Work vs. Not Work vs. Student at Time of Follow-up

Variable	P-Value
Working vs. Not Working	.085
Student vs. Working	.000

Table 2 compares employment status at the time of follow-up between PO-SCI and AO-SCI. Results displayed in Table 2 indicate that there is a trend toward greater employment in PO-SCI. Although not statistically significant ($p > .05$), individuals with PO-SCI are more likely to be

working at the time of follow-up than those injured as adults, with 46 individuals with PO-SCI classified as employed vs. 38 individuals with AO-SCI. Conversely, those injured as adults are more likely to be students at the time of follow-up than PO-SCI, with 11 individuals with AO-SCI remaining in school at the time of follow-up compared to 4 individuals with PO-SCI.

Table 3: Differences between Pre and Post Injury Level of Education

Level of Education	Pre-Injury: PO-SCI		Pre-Injury: AO-SCI		Post-Injury: PO-SCI		Post-Injury: AO-SCI	
	%	N	%	n	%	N	%	N
8th Grade or Less	20*	18*	2	2	1	1		
9th – 11th Grade	80	73	14	13	6	5	8	7
High School/GED			74	67	44	40	56	51
Associates Degree			2	2	8	7	11	10
Bachelors Degree			6	5	25	23	19	17
Masters Degree			1	1	13	12	6	5
Doctorate			1	1	3	3	1	1

*Indicates Missing Data

Table 3 breaks down the levels of education to display the differences pre and post injury between PO-SCI and AO-SCI. The data indicates that individuals with PO-SCI are more likely to pursue additional education beyond a high school degree compared to individuals with AO-SCI. Post-injury, 49% of individuals with PO-SCI completed education beyond a high school degree while only 27% of individuals with AO-SCI pursued education beyond a high school degree. Differences can also be noted with respect to the percentage of individuals with PO-SCI who obtain bachelors (25%), masters (13%) or doctorate degrees (3%) post-injury vs. individuals with AO-SCI who obtain the same degrees (19%, 6%, and 1% respectively).

Variables Influencing Post-Injury Employment Status

Chi square statistics were calculated separately on both individuals with PO-SCI and individuals with AO-SCI; results were then compared between the two groups to determine: (a) what variables contributed to post-injury employment status; and (b) if results between the two groups were similar or different. Table 5 displays the results of the chi-square analysis.

Table 4: Variables Contributing to Post-Injury Employment Rates

Variables	PO-SCI		AO-SCI	
	Post-Injury Employment Status	P-Value	Post-Injury Employment Status	P-Value
Post-injury Marital Status	Approaching sig.	.082	Not sig.	.409
Post-injury Residence	Not sig.	.701	Not sig	.442
Post-Injury Health Status	Not sig.	.725	Not sig.	.849
Post-injury Education Level of Education	Sig	.000	Sig	.006

Results of the chi-square analysis indicate that post-injury level of education influences post-injury employment rates in both individuals with PO-SCI and AO-SCI. In both groups, if an individual achieved less than a high school degree, he/she was more likely to be *unemployed* at follow-up. On the other hand, if an individual achieved higher than a high school degree, he/she was more likely to be *employed* post-injury. In individuals with PO-SCI, there was a trend towards greater employment if an individual was married at the time of follow-up compared to individuals who were still single at the time of follow-up. In individuals with AO-SCI, there was no relationship between marital status and post-injury employment rates. Neither post-injury residence nor self-perceived health status influenced post-injury employment rates in individuals with PO-SCI or AO-SCI.

Finally, to determine if follow-up year was a confounding variable (greater time of injury equal greater rate of employment), chi-square statistics were calculated. A p-value of .875 indicates that there was no significant difference with respect to employment status between the follow-up years. Table 5 represents the percentage of individuals employed vs. not employed between the three follow-up years studied.

Table 5: Follow-up Year vs. Employment Status

	Employment Status			
	Work		Not Work	
	%	N	%	N
Follow-up Year				
10	46	49	54	42
15	57	33	43	25
20	49	17	52	16
P-Value = .875				

DISCUSSION

The proposed hypothesis suggested that due to increased resources, support, and programs offered in the educational setting, individuals with pediatric-onset spinal cord injury are more likely to be employed post injury than adult-onset spinal cord injury. The data presented in this study indicates that, while results were not statistically significant, there is a trend towards greater employment among individuals with PO-SCI. The results of this study do suggest that level of education does influence post-injury employment status; the higher the level of education, the more likely an individual is to be employed at follow-up. The data also suggests that individuals with PO-SCI are more likely to obtain higher degrees (bachelors, masters, or doctorate) than individuals with AO-SCI. While 36% of individuals with AO-SCI pursued higher degrees with respect to level of education post-injury, almost half (49%) of individuals with PO-SCI have higher degrees; this is a 13% difference. Post-injury, 94% of individuals with PO-SCI continued on in school, with 44% of individuals obtaining at least a high school diploma or GED and 49% obtaining a bachelors, masters, or doctorate degree. Adult-onset SCI had less of a change in education level with only 27% of adults pursuing additional education post-injury. While a trend of greater employment among individuals with PO-SCI was identified, there is still concern that the difference between the two groups was not more significant. Given that individuals with PO-SCI have higher degrees of education post-injury than individuals with AO-SCI, why is there not a greater difference in post-injury employment status between the two groups?

One reason why only a trend between the two groups was noticed was that the power of the study, due to the low sample size, was too low. Individuals enrolled in the Spinal Cord Injury Model Systems project are interviewed one year post-injury and every five years thereafter for up to 25 years. While there were a large number of participants in the database who were injured before the age of 16 years, due to attrition, the number of subjects with reliable follow-up data continued to decrease after each follow-up year (5, 10, 15, and 20). Missing information was also a limitation. While the original sample size was 282 subjects, 100 subjects (50 matched pairs), had to be eliminated from the sample size due to missing follow-up data with respect to rate of employment and/or level of education post-injury. Due to these two limitations, the sample size for this study was relatively small.

It is also concerning that while individuals with PO-SCI have high degrees of education post-injury, almost half of these individuals (45%) continue to remain unemployed years following their injury. One reason may be contributed to the school districts. The article by Massagli et al. (1996) stated that even though a large percentage of children with spinal cord injury were graduating from high school and going on to college (82%), only a small percentage of these students qualified for or were enrolled in special education services. To investigate this matter further, additional literature searches were conducted looking at transition services and students with various disabilities rather than targeting spinal cord injury only. What was found was rather alarming. Many of the journal articles on the delivery of special education services in the school district focused on developmental disabilities, learning disabilities or mental retardation. One article was found that discussed transition services (or the lack thereof) for students with physical disabilities. Mulkey & Brechin (1988) discuss in their article the disservice to individuals with physical disabilities, indicating there are less referrals and less delivery of rehabilitation and special education services to students with physical disabilities; the highest percentage of referrals for services are given to students diagnosed as “mentally retarded.” The article defines transition services as a “carefully planned process, which can be initiated either by school personnel of adult service providers, to establish and implement a plan for either employment or additional vocational training of a handicapped student…” (Mulkey & Brechin, 1988). The term “handicapped student” should incorporate both students with mental impairments as well as physical impairments according to P.L 99-506. Therefore, all students with disabilities are

eligible for special education services, however, those who get the most referrals are the students with some sort of cognitive impairment who require a modified educational program (Mulkey & Brechin, 1988). However, according to Mulkey & Brechin, the fault does not only lie in the school educators; students with physical disabilities are not requesting services. There is still the social stigma that special education services are only for those who have developmental of leaning disabilities, and, students with physical disabilities shy away from the programs because they do not want to be labeled by their non-disabled peers. By not receiving transition services or being educated on agencies and services available to them at the time of graduation, students with physical disabilities, although very capable of excelling in the academic setting, may experience difficulty later when trying to attain employment. Research also shows that students with spinal cord injury have far less paid word experience before they leave high school then their non-disabled peers (Anderson & Vogel, 2000). Again, transition services offer students the chance to become involved in their community through volunteer work, job shadowing, and/or paid work experience, which has been shown to correlate with positive employment outcomes in the future.

Problems may still be encountered by individuals with SCI with respect to community and/or transportation barriers, which ultimately affects employment status for all individuals with spinal cord injury regardless of age at time of injury. Individuals with spinal cord injury often comment on the barriers that prevent them from being more independent within the community. Examples of such barriers include transportation, climate, terrain, and building access. Wehman, Wilson, Targett, West, Bricout, and McKinley (1999) emphasize in their article on transportation barriers that "affordable, reliable transportation options are critical to successful community reintegration for individuals with spinal cord injuries (SCI)." While a person with spinal cord injury may have the necessary education or skills to attain a job, without dependable transportation, he or she may not be able to maintain that job. Wehman et al., examine the Americans with Disability Act (ADA), more specifically Title III of ADA, and note that the legislation only discusses accessibility; however, there needs to be additional emphasis on both "instruction and support" for the person with SCI in an effort to enhance mobility and community access. Wehman et al., go on to describe examples of such support, which include

personal support (e.g., family, friends, aides), ride sharing, targeted job placement, transportation co-ops, and influencing system change by becoming self-advocates.

CONCLUSION

In the recent years (1990's), transition has shifted away from the "disability-focused, deficit-driven" approach to more of a "service-delivery" program with an emphasis on education, training, and building upon one's existing abilities (Kohler & Field, 2003). Research studies investigating the outcomes of transition services have indicated a positive correlation between vocational education, work experiences (paid or volunteer), and support on both "school performance and post-school outcomes" (Kohler & Field, 2003). Research studies have also found that transition services, skill development, and work experience are positively correlated with post-school employment (Kohler & Field, 2003). The goal of transition services is to have an interdisciplinary team (teachers, therapist, and parents) work with the student with a disability to develop post-education goals and build on skills in an effort to achieve those goals. A second goal of transition services is community participation or socialization (Kohler & Field, 2003). However, to qualify for transition services, students must be enrolled in a special education program. Both educators and student [with disabilities] perceive special education services for individuals with mental impairments. This "shared misinformation among service providers and service consumers" causes the delivery of transition services to cease to exist for students with physical disabilities, including students with spinal cord injury (Mulkey & Brechin, 1988).

While the dates of injury for this study fell between 1980 and 1990, many of the transition laws were in full swing beginning in the 1990's, therefore, there should not be a reason why the pediatric-onset SCI population did not receive such services. It may be interesting to conduct a similar study in the future with dates of injury between 1990 and 2000 to investigate whether this population was taking advantage of transition services.

Implications for Rehabilitation Counselors

As a rehabilitation counselor, it is clear to see that there is still a misconception about disability. According to Mulkey & Brechin (1988), the role of the vocational rehabilitation counselor is critical in the delivery of rehabilitation services. As part of the interdisciplinary team, the

counselor should educate both the school staff as well as the students with disabilities on what constitutes a disability and how transition services significantly impact vocational outcomes. While there are various laws on disability, I still believe there needs to be more focus on what the laws mean and how they directly affect individuals with disabilities. It is unfortunate that services are not being utilized because (a) students with spinal cord injury are resistant to becoming labeled by peers, and (b) there is lack of knowledge on the part of educators about who is appropriate for services. Rehabilitation counselors should be involved in school districts to ensure students with physical disabilities are not excluded from the transition programs; it is imperative that *all* students with disabilities have referrals made to help them attain appropriate services and become involved with the necessary agencies upon graduation. While it may be that individuals with spinal cord injury simply do not want to work, it is hard to fathom that with 82% of students with SCI graduating from high school (Massagli et al., 1996) and 49% of students with SCI from this study graduating with a degree from college, these individuals are still unemployed because they have no desire to work.

It is also essential that rehabilitation counselors work with individuals throughout the community as well to help them become educated on disability. It is unfortunate that transportation still remains a barrier to independence as well as employment for individuals with spinal cord injury. Rehabilitation counselors should continue to advocate for additional transportation resources. The suggestions posed by Wheman et al. (1999) are good ones, however, ride-sharing, targeted job-placements, and transportation co-ops may still require the assistance of a knowledgeable professional to set these types of service up. Rehabilitation counselors have an advantage in that they work with individuals with various disabilities to assist them with finding employment. The counselor may be able to find a pool of individuals working in the same area and assist with setting up van-pools and co-ops. In 2004, the NSCID added various questions on assistive technology in their follow-up interview. One of the new variables inquires about who owns a modified vehicle (car or van). While there is not ample follow-up data yet on this variable, a study could be done in the future investigating and individual's employment status and whether an individual owns a modified vehicle. This study could benefit individuals with spinal cord injury in attempting to show that access to transportation does have an affect on employment status.

APPENDIX A

The National Spinal Cord Injury Database
Personal Data

To be submitted on all patients - Registry and Form I patients

NATIONAL SPINAL CORD INJURY STATISTICAL CENTER, BIRMINGHAM, AL

100. System ID .....__ __ 101. Patient Number .....__ __ __ __ __ __
102. Patient Name
__ __ __ __ __ __ __ __ __ __ __ __ __| __| __
First Initial Last

103. Social Security Number..... __ __ __-__ __-__ __ __ __
104. Date of Birth ..... __ __/__ __/__ __ __ __
105. Zip Code for Residence at Injury..... __ __ __ __ __/__ __ __ __
105_1. Zip Code for Residence at Year 01 Anniversary……... __ __ __ __ __/__ __ __ __
105_5. Zip Code for Residence at Year 05 Anniversary……... __ __ __ __ __/__ __ __ __
105_10. Zip Code for Residence at Year 10 Anniversary..... __ __ __ __ __/__ __ __ __
105_15. Zip Code for Residence at Year 15 Anniversary..... __ __ __ __ __/__ __ __ __
105_20. Zip Code for Residence at Year 20 Anniversary……..... __ __ __ __ __/__ __ __ __
105_25. Zip Code for Residence at Year 25 Anniversary..... __ __ __ __ __/__ __ __ __
105_30. Zip Code for Residence at Year 30 Anniversary……. __ __ __ __ __/__ __ __ __

APPENDIX B

The National Spinal Cord Injury Database Registry

NATIONAL SPINAL CORD INJURY STATISTICAL CENTER, BIRMINGHAM, AL

100. System ID .....__ __ 101. Patient Number ..... __ __ __ __ __ __
106. Date of Injury..... __ __/__ __/__ __ __ __
107. Date of First System Admission ..... __ __/__ __/__ __ __ __
109A. Number of Days from Injury to First System Admission ..... __ __ __ *computer-generated*
110. Date of Discharge from the Last System Inpatient Treatment Phase …. __ __/__ __/__ __ __ __
111. Age At Injury ..... __ __ __
112. Sex .....__
113. Racial or Ethnic Group ..... __
114. Hispanic Origin.....__
116. Traumatic Etiology ..... __ __
131D. Category of Neurologic Impairment at Discharge ..... __
132D. ASIA Impairment at Discharge..... __
136D. Level Preserved Neurologic Function at Discharge..... __ __ __L __ __ __R
138D. Utilization of Mechanical Ventilation at Discharge..... __
145. Date of Death ..... __ __/__ __/__ __ __ __

APPENDIX C

The National Spinal Cord Injury Database
Form I

Unless indicated, data are to be collected on all patients
100. System ID..... __ __ 101. Patient Number.....__ __ __ __ __ __

NATIONAL SPINAL CORD INJURY STATISTICAL CENTER, BIRMINGHAM, AL

106. Date of Injury ..... __ __/__ __/__ __ __ __
107. Date of First System Admission ..... __ __/__ __/__ __ __ __
108. Date of First System Inpatient Rehab Admission..... __ __/__ __/__ __ __ __
109. Number of Days from Injury to
A. First System Admission..... __ __ __ *computer-generated*
R. First System Inpatient Rehab Admission ..... __ __ __ *computer-generated*
110. Date of Discharge from the Last System Inpatient Treatment Phase __ __/__ __/__ __ __ __
111. Age At Injury..... __ __ __
112. Sex ..... __
113. Racial or Ethnic Group ..... __
114. Hispanic Origin ..... __
115. Is English The Patient's Primary Language? ..... __
116. Traumatic Etiology ..... __ __
117. Diagnostic Codes:
C. External Cause of Injury (Cause)..... __ __ __.__ __
L. External Cause of Injury (Location) ..... __ __ __.__ __
118. Diagnostic Codes: SCI Nature of Injury.....__ __ __.__ __ (1) __ __ __.__ __(2)
119. Work Relatedness ..... __
120. Place of Residence..... __ __ __ __
121. Marital Status at Injury ..... __
122. Level of Education..... __
123. Primary Occupational, Educational or Training Status ..... __
124. Job Census Code..... __ __
125. Are You A Veteran Of The U.S. Military Forces? ..... __
126. VA Healthcare System Services Used During System.....__| __| __| __| __|

During System
127. Sponsors of SCI Care and Services .....__ __| __ __| __ __| __ __| __ __|
128. Type of Reimbursement .....__| __| __| __| __|
129. Medical Case Manager ..... __

NEUROLOGIC EXAM
Admit to Discharge/End
Initial System Exam System Inpatient Rehab System Rehab*
(day1s only) (day1s only)
130. Date Neurologic Exam..... __ __/__ __/__ __ __ __ _ __/__ __/__ __ __ __
__ __/__ __/__ __ __ __

131. Category of Neurologic Impairment .....__..... __
132. ASIA Impairment Scale .....__..... __
133. ASIA Motor Index Score Left Right Left Right Left Right
C5 __ __ __ __ __ __
C6 __ __ __ __ __ __
C7 __ __ __ __ __ __
C8 __ __ __ __ __ __
T1 __ __ __ __ __ __
L2 __ __ __ __ __ __
L3 __ __ __ __ __ __
L4 __ __ __ __ __ __
L5 __ __ __ __ __ __
S1 __ __ __ __ __ __
Subtotal** __ __ __ __ __ __ __ __ __ __ __ __
Total** __ __ __ __ __ __ __ __ __
134. Sensory Level..... __ __ __L __ __ __R __ __ __L __ __ __R __ __ __L __ __ __R
135. Motor Level**..... __ __ __L __ __ __R __ __ __L __ __ __R __ __ __L __ __ __R
136. Level Preserved Neurologic Function..... __ __ __L __ __ __R __ __ __L __ __ __R
__ __ __L __ __ __R

Admit to Discharge/End
System Inpatient Rehab System Rehab*
137. Method of Bladder Management..... .....__ __
138. Utilization of Mechanical Ventilation…..... __..... __
**** Discharge from the last System inpatient phase or***
if there was no System inpatient phase then, this is the end of the last System outpatient rehab treatment phase.
** C***omputer-generated*

During Acute Medical Care During Inpatient Rehab
(day 1's only) (day 1's only)
139. Locations and Grades of Pressure Ulcers Left Center Right Left Center Right
Occiput __ __
Scapula __ __ __ __
Elbow __ __ __ __
Ribs __ __ __ __
Spinous Process __ __
Iliac Crest __ __ __ __
Sacral __ __
Ischium __ __ __ __
Trochanteric __ __ __ __
Genital __ __
Knee __ __ __ __
Malleolar __ __ __ __
Heel __ __ __ __
Foot __ __ __ __
Unclassified __ __ __ __ __ __
140. Number of Pressure Ulcers*(day 1's only)*.....__ __..... __ __

At Inpatient Rehab Admit

141. Grade of Worst Pressure Ulcer Present at Rehab Admit *(day 1's only)* ..... __

During Acute

COMPLICATIONS (*day1s only)* **Medical Care During Inpatient Rehab**

142A. Post-operative Wound Infection at the Site of the Spinal Surgery..... __ ..... __
142B. Number of Episodes of Pneumonia.....__ __..... __ __
142C. Pulmonary Embolism..... __ ..... __
142D. Thrombophlebitis, Deep Vein Thrombosis ..... __ ..... __

Operative Procedures (*day1s only)*

143A. Laminectomy ..... __ ..... __
143B. Spinal Decompression.....__| __| __|..... __| __| __|
143C. Spinal Fusion.....__| __| __|..... __| __| __|
143D. Internal Fixation of the Spine.....__| __| __|..... __| __| __|
143E. Surgical Repair of Failed Spinal Fusion.....__| __| __|..... __| __| __|
143F. Surgical Repair, Correction, or Removal of Internal Fixation Device ....__| __| __|..... __| __| __|
143G. Number of Operating Room Visits for Spine Surgeries.....__ __..... __ __
143H. Laparotomy ..... __ ..... __
143I. Traction ..... __ ..... __
143J. Halo Vest, Halo Brace or Other Orthosis for the Neck..... __ ..... __
143K. Closure of Decubitus Ulcer(s)..... __ ..... __

Inpatient Rehab

144. FIM **Admit Discharge**

Self Care A. Eating __ __
B. Grooming __ __
C. Bathing __ __
D. Dressing, Upper Body __ __
E. Dressing, Lower Body __ __
F. Toileting __ __
Sphincter Control G. Bladder Management __ __
H. Bowel Management __ __
Mobility Transfer I. Bed, Chair, Wheelchair __ __
J. Toilet __ __
K. Tub, Shower __ __
Locomotion L. Walk or Wheelchair __ __
LM. Mode of Locomotion __ __
M. Stairs __ __
T. Total Motor Score __ __* __ __*

* *computer-generated*

DEATH INFORMATION

145. Date of Death .....___ ___/___ ___/___ ___ ___ ___
146. Cause(s) of Death..... __ __ __.__ __ 1. _____ Primary Cause
__ __ __.__ __ 2. _____

__ __ __.__ __ 3. _____
__ __ __.__ __ 4. _____
__ __ __.__ __ 5. _____

147. Autopsy.....__

If the patient is alive at discharge (or at the end of the last outpatient rehab treatment phase) code all these variables "alive".
Update these variables if the patient dies during follow-up.

TREATMENT PHASES

Document the following treatment phases occurring from the time of injury to discharge from the System (or to the end of the last outpatient rehab treatment phase if the initial rehab was completed during an outpatient rehab phase):

1) Acute Hospitalization 5) Inpatient Subacute Rehab
2) Nursing Home Bed 6) Day Hospital Rehab Services
3) Inpatient Acute Rehab 7) Outpatient Rehab
4) Inpatient Subacute Medical Care 8) Home Rehab

Document each of these treatment phases separately, in sequence by date. At least 1 treatment phase must be documented.

If there is a delay in obtaining some information (e.g., hospitalization charges), submit this form when 80% or more of the information is available and code the missing items "unknown". Then, update the record when the missing data are available.

Treatment Phase # 1 2 3

148. Treatment Phase ..... __ .....__ .....__
149. System or Non-system..... __ .....__ .....__
150. Date of Admission (or Start of Phase) ..... __ __/__ __/__ __ __ __ ...__ __/__ __/__ __ __ __|.
__ __/__ __/__ __ __ __
151. Date of Discharge (or End of Phase) ..... __ __/__ __/__ __ __ __ ...__ __/__ __/__ __ __ __|.
__ __/__ __/__ __ __ __
152. Number of Short-term Discharge Days .....__ __ __.....__ __ __ .....__ __ __
153. Number of Days in Treatment Phase *(computer-generated)*__ __ __ __ ..... __ __ __ __ .....__ __ __ __
154. Charges *(System only)*....._ _ _ _ _ _ _ ..... _ _ _ _ _ _ _..... _ _ _ _ _ _ _
155. Charges Reliability Code *(System only)*..... __ .....__ .....__
156. Hours of Physical Therapy *(System only)* .....__ __ __.....__ __ __ .....__ __ __
157. Hours of Occupational Therapy *(System only)* .....__ __ __.....__ __ __ .....__ __ __
158. Hours of Recreational Therapy *(System only)*.....__ __ __.....__ __ __ .....__ __ __
159. Hours of Vocational Rehab *(System only)* .....__ __ __.....__ __ __ .....__ __ __
160. Hours of Psychological Counseling *(System only)* .....__ __ __.....__ __ __ .....__ __ __
161. Hours of Social Worker *(System only)*.....__ __ __.....__ __ __ .....__ __ __
162. Hours of Other Therapy *(System only)*.....__ __ __.....__ __ __ .....__ __ __

Treatment Phase # 4 5 6

148. Treatment Phase ..... __ .....__ .....__
149. System or Non-system..... __ .....__ .....__
150. Date of Admission (or Start of Phase) ..... __ __/__ __/__ __ __ __ ...__ __/__ __/__ __ __ __|.
__ __/__ __/__ __ __ __

151. Date of Discharge (or End of Phase) ..... __ __/__ __/__ __ __ __ ...__ __/__ __/__ __ __ __|.
__ __/__ __/__ __ __ __

152. Number of Short-term Discharge Days .....__ __ __.....__ __ __ .....__ __ __

153. Number of Days in Treatment Phase *(computer-generated)*__ __ __ __ ..... __ __ __ __ .....__ __ __ __

154. Charges *(System only)*.....__ __ __ __ __ __ __ ..... __ __ __ __ __ __ __..... __ __ __ __ __ __ __

155. Charges Reliability Code *(System only)*..... __ .....__ .....__

156. Hours of Physical Therapy *(System only)* .....__ __ __.....__ __ __ .....__ __ __

157. Hours of Occupational Therapy *(System only)* .....__ __ __.....__ __ __ .....__ __ __

158. Hours of Recreational Therapy *(System only)*.....__ __ __.....__ __ __ .....__ __ __

159. Hours of Vocational Rehab *(System only)* .....__ __ __.....__ __ __ .....__ __ __

160. Hours of Psychological Counseling *(System only)* .....__ __ __.....__ __ __ .....__ __ __

161. Hours of Social Worker *(System only)*.....__ __ __.....__ __ __ .....__ __ __

162. Hours of Other Therapy *(System only)*.....__ __ __.....__ __ __ .....__ __ __

Treatment Phase # 7 8 9

148. Treatment Phase ..... __ .....__ .....__

149. System or Non-system..... __ .....__ .....__

150. Date of Admission (or Start of Phase) ..... __ __/__ __/__ __ __ __ ...__ __/__ __/__ __ __ __|.
__ __/__ __/__ __ __ __

151. Date of Discharge (or End of Phase) ..... __ __/__ __/__ __ __ __ ...__ __/__ __/__ __ __ __|.
__ __/__ __/__ __ __ __

152. Number of Short-term Discharge Days .....__ __ __.....__ __ __ .....__ __ __

153. Number of Days in Treatment Phase *(computer-generated)*__ __ __ __ ..... __ __ __ __ .....__ __ __ __

154. Charges *(System only)*.....__ __ __ __ __ __ __ ..... __ __ __ __ __ __ __..... __ __ __ __ __ __ __

155. Charges Reliability Code *(System only)*..... __ .....__ .....__

156. Hours of Physical Therapy *(System only)* .....__ __ __.....__ __ __ .....__ __ __

157. Hours of Occupational Therapy *(System only)* .....__ __ __.....__ __ __ .....__ __ __

158. Hours of Recreational Therapy *(System only)*.....__ __ __.....__ __ __ .....__ __ __

159. Hours of Vocational Rehab *(System only)* .....__ __ __.....__ __ __ .....__ __ __

160. Hours of Psychological Counseling *(System only)* .....__ __ __.....__ __ __ .....__ __ __

161. Hours of Social Worker *(System only)*.....__ __ __.....__ __ __ .....__ __ __

162. Hours of Other Therapy *(System only)*.....__ __ __.....__ __ __ .....__ __ __

Treatment Phase # 10 11 12

148. Treatment Phase ..... __ .....__ .....__

149. System or Non-system..... __ .....__ .....__

150. Date of Admission (or Start of Phase) ..... __ __/__ __/__ __ __ __ ...__ __/__ __/__ __ __ __|.
__ __/__ __/__ __ __ __

151. Date of Discharge (or End of Phase) ..... __ __/__ __/__ __ __ __ ...__ __/__ __/__ __ __ __|.
__ __/__ __/__ __ __ __

152. Number of Short-term Discharge Days .....__ __ __.....__ __ __ .....__ __ __

153. Number of Days in Treatment Phase *(computer-generated)*__ __ __ __ ..... __ __ __ __ .....__ __ __ __

154. Charges *(System only)*.....__ __ __ __ __ __ __ ..... __ __ __ __ __ __ __..... __ __ __ __ __ __ __

155. Charges Reliability Code *(System only)*..... __ .....__ .....__

156. Hours of Physical Therapy *(System only)* .....__ __ __.....__ __ __ .....__ __ __

157. Hours of Occupational Therapy *(System only)* .....__ __ __.....__ __ __ .....__ __ __
158. Hours of Recreational Therapy *(System only)*.....__ __ __.....__ __ __ .....__ __ __
159. Hours of Vocational Rehab *(System only)* .....__ __ __.....__ __ __ .....__ __ __
160. Hours of Psychological Counseling *(System only)* .....__ __ __.....__ __ __ .....__ __ __
161. Hours of Social Worker *(System only)*.....__ __ __.....__ __ __ .....__ __ __
162. Hours of Other Therapy *(System only)*.....__ __ __.....__ __ __ .....__ __ __

163. Number of Days Hospitalized in the System's
A. Acute Care Unit.....__ __ __ __ (*computer-generated)*
R. Inpatient Rehab Unit.....__ __ __ __ (*computer-generated)*
164. Total System Hospitalization Charges *(day-1's only)*.....__ __ __ __ __ __ __ (*computer-generated)*
165. Total System Hospitalization Charges - Reliability Code*(day-1's only)* .....__ (*computer-generated)*

APPENDIX D

The National Spinal Cord Injury Database
Form II

Unless indicated, data are to be collected in post-injury years 1, 5, 10, 15, 20, 25, 30
100. System ID..... __ __ 101. Patient Number ..... __ __ __ __ __ __ 200. Post-injury Year .....__ __

NATIONAL SPINAL CORD INJURY STATISTICAL CENTER, BIRMINGHAM, AL

201. Category of Follow-up Care .....__
202. Reason for Lost.....__

STATUS ON THE ANNIVERSARY OF INJURY
203. Place of Residence.....__ __
204. Marital Status.....__
205. Level of Education.....__
206. Primary Occupational, Educational or Training Status .....__
207. Job Census Code.....__ __
208. Method of Bladder Management .....__ __

STATUS SINCE THE LAST FORM II *(If this is the year 1 Form II, this is "Status since Form I")*
209. Change in Marital Status Since Last Form II..... __
210. What VA healthcare system services have you used since the last Form II? ..... __| __| __| __| __|

STATUS DURING THE ANNUAL EXAM
! 211. Date of the Annual Exam .....__ __/__ __/__ __ __ __
! 212. Grade of Worst Pressure Ulcer Present at the Annual Exam.....__
! 213. Number of Pressure Ulcers Present at Annual Exam .....__ __
Note: The Neurologic Exam items on page 6 are required only during the year 01 (or year 02) annual exam.

STATUS DURING THE ANNIVERSARY YEAR
214. Sponsors of SCI Care and Services ..... __ __| __ __| __ __| __ __| __ __|
215. Type of Reimbursement *(deleted 7/2001)*
216. Medical Case Manager ..... ___
217. Rehospitalizations #1 #2 #3 #4 #5 #6 #7 8+
D. Number of Days..... __ __ __| __ __ __| __ __ __| __ __ __| __ __ __| __ __ __| __ __ __| __ __ __|
R. Reason..... __ __| __ __| __ __| __ __| __ __| __ __| __ __| __ __|
218. Number of Rehospitalization(s).....__ *(computer-generated)*
219. Number of Days Rehospitalized..... __ __ __ *(computer-generated)*
220. Number of Days in Nursing Home..... __ __ __

COMPLICATIONS DURING THE ANNIVERSARY YEAR
221A. Pulmonary Embolism .....__
221B. Thrombophlebitis, Deep Vein Thrombosis .....__
221C. Pneumonia.....__
221D. Presence of Calculus in the Kidney and/or Ureter.....__

OPERATIVE PROCEDURES DURING THE ANNIVERSARY YEAR

222A. Closure of Decubitus Ulcer(s) .....__
222B. Calculus Removal.....__
222C. Bladder Neck Resection .....__
222D. External Sphincterotomy or Other Sphincter Opening Procedures .....__

INTERVIEW ITEMS *Note: All Form II variables may be collected during the interview except those that are designated to be collected "During the Annual Exam".*

223. Date of the Interview.....__ __/__ __/__ __ __ __
224. How was the interview conducted? .....__
225. Self-perceived Health Status .....__
226. Compared to 1 year ago, how would you rate your health in general now? __
227. FIM Self Care A. Eating.....__
B. Grooming.....__
C. Bathing.....__
D. Dressing, Upper Body.....__
E. Dressing, Lower Body .....__
F. Toileting.....__
Sphincter Control G. Bladder Management .....__
H. Bowel Management .....__
Mobility Transfer I. Bed, Chair, Wheelchair.....__
J. Toilet.....__
K. Tub, Shower.....__
Locomotion L. Walk or Wheelchair .....__
LM. Mode of Locomotion .....__
M. Stairs .....__
T. Total Motor Score.....__ __ *(computer-generated)*
228_1. Satisfaction With Life Scale Question 1.....__
228_2. Satisfaction With Life Scale Question 2.....__
228_3. Satisfaction With Life Scale Question 3.....__
228_4. Satisfaction With Life Scale Question 4.....__
228_5. Satisfaction With Life Scale Question 5. .....__
228T. Satisfaction With Life Scale Total Score.....__ __ *(computer-generated)*

Collect the FIM on those whose current age is 6 years or older

Craig Handicap Assessment and Reporting Technique (CHART) - Short Form

229_1A. The CHART- Number of Hours of Paid Assistance/Day .....__ __
229_1B. The CHART - Number of Hours of Unpaid Assistance/Day.....__ __
229_2. The CHART- How much time is someone with you to assist you in your home .....__
229_3. The CHART- How much time is someone with you to assist you away from your home? .__
229_4. The CHART - Number of Hours Out of Bed/Day.....__ __
229_5. The CHART - Number of Days Out of the House/Week .....__
229_6. The CHART - Number of Nights Away from Home In the Past Year .....__
229_7. The CHART - Number of Hours/Week at Paid Job.....__ __
229_8. The CHART - Number of Hours/Week at School/Study.....__ __
229_9. The CHART - Number of Hours/Week at Homemaking.....__ __

229_10. The CHART - Number of Hours/Week at Home Maintenance.....__ __
229_11. The CHART - Number of Hours/Week at Recreation.....__ __
229_12- The CHART – How many people do you live with? .....__ __
229_13. The CHART – Is one of them your spouse or significant other? .....__
229_14. The CHART – Of the people you live with how many are relatives? .....__ __
229_15. The CHART - Number of Business/Organizational Contacts/Month.....__ __
229_16. The CHART - Number of Contacts/Month With Friends.....__
229_17. The CHART - How Many Strangers Have You Initiated a Conversation With/Month? .....__
229_18. The CHART - Combined Annual Family Income .....__
229_19. The CHART – Unreimbursed Medical Care Expenses .....__
229_20. The CHART - Physical Independence Total *(computer-generated)*.....__ __ __
229_21. The CHART- Cognitive IndependenceTotal *(computer-generated)* .....__ __ __
229_22. The CHART - Mobility Total *(computer-generated)* .....__ __ __
229_23. The CHART - Occupation Total *(computer-generated)*.....__ __ __
229_24. The CHART - Social Integration *(computer-generated*).....__ __ __
229_25. The CHART - Economic Self-sufficiency *(computer-generated)* .....__ __ __
229T. Total CHART Score *(computer-generated)*.....__ __ __

CHIEF-SF: Craig Hospital Inventoryof Environmental Factors
230_1. Problems with availability of transportation .....__
A. When this problem occurs, has it been a big problem or little problem? .....__
230_2. Problems with the natural environment make it difficult to do what you want or need to do?....__
A. When this problem occurs, has it been a big problem or little problem? .....__
230_3. Difficulties with other aspects of your surroundings make it difficult for you
to do what you want or need to do? .....__
A. When this problem occurs, has it been a big problem or little problem? .....__
230_4. Information you wanted or needed not been available in a format you can use or understand? .__
A. When this problem occurs, has it been a big problem or little problem? .....__
230_5. Availability of health care services and medical care been a problem for you? .....__
A. When this problem occurs, has it been a big problem or little problem? .....__
230_6. Need someone else's help in your home and could not get it easily? .....__
A. When this problem occurs, has it been a big problem or little problem? .....__
230_7. Need someone else's help at school or work and could not get it easily? .....__
A. When this problem occurs, has it been a big problem or little problem? .....__
230_8. Other people's attitudes toward you been a problem at home? .....__
A. When this problem occurs, has it been a big problem or little problem? .....__
230_9. Other people's attitudes toward you been a problem at school or work? .....__
A. When this problem occurs, has it been a big problem or little problem? .....__
230_10. Experience prejudice or discrimination? .....__
A. When this problem occurs, has it been a big problem or little problem? .....__
230_11. Policies and rules of businesses and organizations make problems for you? .....__
A. When this problem occurs, has it been a big problem or little problem? .....__
230_12. Government programs and policies make it difficult to do what you want or need to do? .....__
A. When this problem occurs, has it been a big problem or little problem? .....__
230_13. Policies Subscale *(computer-generated)*.....__.__ __
230_14. Physical/Structural Subscale *(computer-generated)* .....__.__ __
230_15. Work/School Subscale *(computer-generated)* .....__.__ __
230_16. Attitudes/Support Subscale *(computer-generated)* .....__.__ __
230_17. Services/Assistance Subscale *(computer-generated)*.....__.__ __

230T. CHIEF-SF Total *(computer-generated)*.....__.__ __

Patient Health Questionnaire (Brief Version)
231_1. Bothered by little interest or pleasure in doing things? .....__
231_2. Bothered by feeling down, depressed, or hopeless? .....__
231_3. Bothered by trouble falling or staying asleep, or sleeping too much? .....__
231_4. Bothered by feeling tired or having little energy? .....__
231_5. Bothered by poor appetite or overeating? .....__
231_6. Bothered by feeling bad about yourself – or that you are a failure or have let yourself or your family down? ...__
231_7. Bothered by trouble concentrating on things, such as reading the newspaper or watching television? .....__
231_8. Bothered by moving or speaking so slowly that other people could have noticed? Or the opposite – being so fidgety or restless that you have been moving around a lot more than usual?....__
231_9. Bothered by thoughts that you would be better off dead or of hurting yourself in some way?.....__
231_10. If you had any of the problems in questions1 through 9, how difficult have these problems made it for you to do your work, take care of things at home, or get along with other people? .....__
231M. Major Depressive Syndrome *(computer-generated)*.....__
231S. Severity of Depression Score *(computer-generated).* .....__ __

232. Drug Use ..... __| __| __| __| __| __|
233. Alcohol Use.....__
234. Alcohol Use: Number of Days Per Week..... __
235. Alcohol Use: Number of Drinks..... __ __
236. Alcohol Use: Frequency During the Past Month..... __ __
237_1. CAGE Question 1..... __
237_2. CAGE Question 2..... __
237_3. CAGE Question 3..... __
237_4. CAGE Question 4..... __
237T. CAGE Total Score *(computer-generated)*..... __
238. Pain: Severity of Pain ..... __ __
239. Pain: Interfering with work..... __

ALL THE VARIABLES ON THIS PAGE ARE TO BE COLLECTED ONLY AT YEAR 01 (OR YEAR 02 *)
240. From Injury to the First* Anniversary – Outpatient Physical and/or Occupational Therapy:
A. Prescribed ..... __
B. Hours Completed... __
C. Location..... __
241. From Injury to the First* Anniversary – Outpatient Psychological and/or Vocational Counseling:
A. Prescribed ..... __
B. Hours Completed... __
C. Location..... __
242. Utilization of Mechanical Ventilation at the First* Anniversary .....__
243. Post-operative Wound Infection at the Site of the Spinal Surgery Post-discharge to First* Anniversary...__

NEUROLOGIC EXAM [Data are required for year 01 (or year 02*); data for subsequent years are optional]
244. Category of Neurologic Impairment.....__
245. ASIA Impairment Scale.....__

246. ASIA Motor Index Score Left Right
C5.....__ __
C6.....__ __
C7.....__ __
C8.....__ __
T1.....__ __
L2.....__ __
L3.....__ __
L4.....__ __
L5.....__ __
S1.....__ __
Subtotal..... __ __ __ __ (*computer-generated)*
Total.....__ __ __ (*computer-generated)*
Left Right
247. Sensory Level .....__ __ __ __ __ __
248. Motor Level .....__ __ __ __ __ __ (*computer-generated)*
249. Level Preserved Neurologic Function ...__ __ __ __ __ __

ASSISTIVE TECHNOLOGY
250A. Walk for 150 feet in your home? ..... __
250B. Walk for one street block outside?..... __
250C. Walk up one flight of steps? ..... __
251. Mobility Aid(s) ..... __| __| __| __| __|
252. Wheelchair or Scooter Use..... __
253. Type of Wheelchair (or Scooter) Used Most Often __
254. Wheelchair (or Scooter) Used Most Often..... __ __ Manufacturer (V254A) __ __ __ Model (V254B)
255. Primary Funding Source for Wheelchair (or Scooter) Used Most Often ... __ __
256. Features on Wheelchair (or Scooter) Used Most Often ..... __| __| __| __| __| __|
257. Number of Repairs on Wheelchair (or Scooter) Used Most Often .....__ __
258. Consequences of Breakdown of Wheelchair (or Scooter) Used Most Often ... __| __| __| __|
259. Number of Additional Wheelchairs or Scooters:
A. Manual ..... __ __
B. Power ..... __ __
C. Power Assisted..... __ __
D. Other ..... __ __
E. Scooters.....__ __
260. Use a Computer?..... __
261. Type of Computer Access Device(s) .....
__ __| __ __| __ __| __ __| __ __| __ __| __ __| __ __| __ __| __ __|

262. Internet or Email Usage ..... __
263. Location of Internet /Email Use.....__| __| __|
264. Internet Categories:
A. Employment/vocation information ..... __
B. Disability/health information ..... __
C. Email.....__
D. Chat rooms .....__
E. Games .....__
F. Shopping .....__

G. Other .....__
265. Modified Vehicle?..... __
266. Driving a Modified Vehicle? ..... __
267. Cell Phone? ..... __

BIBLIOGRAPHY

Anderson, C.J., Krajci, K.A., Vogel, L.C. (2003). Community reintegration among adults with spinal cord injuries sustained as children or adolescents. *Developmental Medicine and Child Neurology, 45,* 129-134.

Anderson, C.J., Vogel, L.C. (2000). Work experiences in adolescents with spinal cord injuries. *Developmental Medicine and Child Neurology, 42,* 515-517.

Anderson, C.J., Vogel, L.C., Betz, R.R., Willis, K.M. (2004). Overview of adult outcomes in pediatric-onset spinal cord injuries: Implications for transition to adulthood. *The Journal of Spinal Cord Medicine, 27*(1) S98-S106.

Becker, B.E., DeLisa, J.A. (1999). Model spinal cord injury systems trends, and implications for the future. *Archives of Physical Medicine and Rehabilitation, 80,* 1514-1521.

Conroy, L., McKenna, K. (1999). Vocational outcome following spinal cord injury. *Spinal Cord, 37,* 624-633.

DeVivo, M.J., Vogel, L.C. (2004). Epidemiology of spinal cord injury in children and adolescents. *The Journal of Spinal Cord Medicine, 27*(1), S4-S10.

Garcia, R.A., Gaebler-Spira, D., Sisung, C., Heinemann, A.W. (2002). Functional improvement after pediatric spinal cord injury. *American Journal of Physical Medicine and Rehabilitation, 81*(6), 458-463.

Granger, C.V. (1998). The emerging science of functional assessment: Our tool for outcomes analysis. *Archives of Physical Medicine and Rehabilitation, 79,* 235-240.

Heward, W.L. (2000). *Exceptional children: An introduction to special education* (6th ed.). Upper Saddle River, New Jersey: Prentice-Hall, Inc.

Karamehmetoglu, S.S., Karacan, I., Elbasi, N., Demirel, G., Koyuncu, H., Dosoglu, M. (1997). The functional independence measure in spinal cord injured patients: Comparison of questioning with observational rating. *Spinal Cord, 35,* 22-25.

Kohler, P.D., Field, S. (2003). Transition-focused education: foundation for the future. *The Journal of Special Education, 33*(3), 174-183.

Krause, J.S. (2003). Years to employment after spinal cord injury. *Archives of Physical Medicine and Rehabilitation, 84*, 1282-1289.

Krause, J.S., Kewman, D., DeVivo, M.J., Maynard, F., Coker, J., Roach, M.J., Ducharme, S. (1999). Employment after spinal cord injury: An analysis of cases from the model spinal cord injury systems.

Krause, J.S., Sternberg, M., Maides, J., Lottes, S. (1998). Employment after spinal cord injury: Differences related to geographic region, gender and race. *Archives of Physical Medicine and Rehabilitation, 79*, 615-624.

Livneh, H., Martz, E. (2003). Psychosocial adaptation to spinal cord injury as a function of time since injury. *International Journal of Rehabilitation Research, 26*(3), 191-200.

Massagli, T.L., Dudgeon, B.J., Ross, B.W. (1996). Educational performance and vocational participation after spinal cord injury in childhood. *Archives of Physical Medicine and Rehabilitation, 77,* 995-999.

Meade, M.A., Lewis, A., Jackson, N., Hess, D.W. (2004). Race, employment, and spinal cord injury. *Archives of Physical Medicine and Rehabilitation, 85*, 1782-1792.

Mulkey, S.W., Brechin, C.C. (1988). Transition-to-work: The physical pursuit. *Journal of Rehabilitation, October/November/December,* 31-36.

Patterson, J., Blum, R.W. (1996). Risk and resilience among children and youth with disabilities. *Archives of Pediatric and Adolescent Medicine, 150*(7), 692-698.

Pavot, W., Diener, E. (1993). Review of the satisfaction with life scale. *Psychological Assessment, 5*(2), 164-172.

Schonherr, M.C., Groothoff, J.W., Mulder, G.A., Schoppen, T., Eisma, W.H. (2004). Vocational reintegration following spinal cord injury: expectations, participation and interventions. *Spinal Cord, 42*, 177-184.

Smart, J.F. (1997). The racial/ethnic demography of disability. *Journal of Rehabilitation, 64*, 9-16.

Stover, S.L., DeVivo, M.J., Go, B.K. (1999). History, implementation, and current status of the national spinal cord injury database. *Archives of Physical Medicine and Rehabilitation, 80*, 1365-1371.

Trupin, L., Yellin, E.H. (1999). The employment experience of persons with limitations in physical functioning: An analysis of the 1996 california work and health survey. *Disability Statistic Report, (12).* Washington DC: U.S. Department of Education, National Institute on Disability and Rehabilitation Research.

Walker, N., Mellick, D., Brooks, C.A., Whiteneck, G.G. (2003). Measuring participation across impairment groups using the craig handicap assessment reporting technique. *American Journal of Physical Medicine and Rehabilitation, 82*(12), 936-941.

Wehman, P., Wilson, K., Targett, P., West, M., Bricout, J., McKinley, W. (1999). Removing transportation barriers for persons with spinal cord injuries: An ongoing challenge to community reintegration. *Journal of Vocational Rehabilitation, 13*, 21-30.

White, P.H. (2002). Transition: A future promise for children and adolescents with special health care needs and disabilities. *Rheum Dis Clin N Am, 28*, 687-703.

Yasuda, S., Wehman, P., Targett, P., Cifu, D.X., West, M. (2002). Return to work after spinal cord injury: A review of recent research. *NeuroRehabilitation, 17*, 177-186.