Returning to School After a Spinal Cord Injury: Perspectives From Four Adolescents

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Key Words: adolescence • environment

A phenomenological approach was used to explore the experience of returning to school following a spinal cord injury. Four adolescents who sustained spinal cord injuries and returned to premorbid school environments were interviewed concerning their perceptions, feelings, and experiences of returning to school. The responses were coded into six themes: people, role change, self-image, coping strategies, accessibility, and feelings. The themes were discussed as to their relevance on returning to school following a spinal cord injury. The research participants' suggestions on ways to ease the transition from the rehabilitation environment to the school environment and implications of the study are included.

The primary role of adolescence is that of student, and through this role, most of the major tasks of adolescence are addressed. Occupational therapy treatment, therefore, should be directed toward returning teenagers with spinal cord injuries to a competent student role. The issue of returning to a premorbid school environment as a person with a newly acquired disability, which includes the psychosocial and physical ramifications of spinal cord injury, poses worthy questions that have yet to be adequately explored in the health care literature. The purpose of this study was to describe the experiences, feelings, and perceptions of adolescents who have sustained spinal cord injuries and have returned to their preinjury school environments.

Many adolescents with spinal cord injury appear to meet the demands of the hospital environment and of their disabled peer group adequately. However, discharge from the hospital and reentry into preinjury school environments and peer groups challenge and threaten their perception of competency. Exploration of preinjury school environments from an adolescent's perspective begins to uncover the experience of what it is like to return to school and acknowledges the effect of environments on the adaptation to a traumatic injury, the well-being, and the perceived and actual competency of adolescents with spinal cord injury.

Literature Review

Literature on the medical management, rehabilitation, functional levels of independence, etiology, and psychosocial ramifications of a spinal cord injury is voluminous. Although a few articles have focused on spinal cord injury in pediatrics (Choi, Hoffman, Hendrick, Humphreys, & Keith, 1986; Cook, 1985; Gordon, 1987; Murphy, Ogden, & Bucholz, 1981; Smith, 1985; Sneed, Stover, & Fine, 1986), none have described the phenomenon of returning to premorbid school environments. Graham, Weingarden, and Murphy (1991) reported on the implications of the Education for All Handicapped Children Act of 1975 (Public Law 94–142) for students with spinal cord injury. The school life of 13 adolescents with spinal cord injury was described. The entire sample surveyed did not, however, return to preinjury classroom environments or peer groups. Additionally, the time period between the date of injury and the date of completing the survey was not controlled for. Perceptions of school life among adolescents with physical disabilities (i.e., long-term congenital disabilities) were investigated by Rich, Linor, and Shalev (1984). These adolescents, unlike their peers with spinal cord injuries, did not attend school as nondisabled persons or return to that same environment as persons with disabilities.

The literature contains conflicting perspectives on the psychosocial sequel to a spinal cord injury, the tasks of adolescence, and the effect of a traumatic injury during
Psychosocial Perspectives of Spinal Cord Injury

Despite the increasing amount of literature that challenges and refutes stage theories and reactive models of psychological adjustment following a spinal cord injury (Cook, 1976; DeJong, Branch, & Corcoran, 1984; Frank & Elliott, 1987; Freed, 1984; Haney & Rabin, 1984; Nelson, 1987; Richards, 1986; Trieschmann, 1988), emphasis continues to be placed on facilitation of the client's movement through a continuum of acceptance stages during the rehabilitation process. This requires a person with a spinal cord injury to experience depression, anger, and denial before he or she is considered by rehabilitation staff to have accepted the disability (Cook, 1985; Frank & Elliott, 1987; Richards, 1986). In some rehabilitation centers, the goal of facilitating acceptance of the spinal cord injury may take precedence over other functional goals that are meaningful to the patient. DeJong and colleagues (1984) have stated that the stage theory implies that problems associated with a disability are primarily individual rather than environmental in nature.

Historically, environmental factors influencing the well-being of a person with a spinal cord injury were neglected because of the short life expectancy and the reality of institutional living. With medical and technological advancement, however, a traumatic spinal cord injury is no longer a life-threatening event that guarantees death or institutionalization. As such, the gap between the medical community's ability to save lives and the medical and allied health communities' ability to provide services and opportunities for healthy and successful community reentry has widened. Equally inadequate are the attitudes and abilities of the nondisabled population at large (Haney & Rabin, 1984; Nelson 1987).

Haney and Rabin (1984) have identified negative societal attitudes as the core problem in resocializing persons with spinal cord injuries. In their study, attitudes of nondisabled college students toward patients with disabilities improved when these students participated in a resocialization effort for persons with spinal cord injuries. Results of the study suggest that participation of the community in the rehabilitation process may serve a dual role: to decrease the social stigmatization of persons with physical disabilities and to provide resocialization experiences for a person with a new disability.

Nelson (1987) has discussed the principles of normalization as the key to integrating persons with spinal cord injury into the community and offered a model for implementing social skills training into the rehabilitation process. Freed (1984) discussed quality of life at the 45th Annual Assembly of the American Academy of Physical Medicine and Rehabilitation and quoted a colleague as saying, "Now that we have added years to peoples' lives, it is also our responsibility to add life to their years" (p. 109).

The need for one to deal with an injury is not to be minimized. However, adapting to, rather than accepting, the injury is considered pivotal to the resuming of a self-satisfying life-style. Among some of the key ingredients that affect the adaptation to an injury such as spinal cord injury are the social, economic, cultural, religious, and geographic environments that influence persons' lives.

The ultimate goal of occupational therapy is to facilitate a person's sense of competence; therefore, environments and meaningful social activities are of primary importance. Belief in people as their own agent in the environment dominated occupational therapy's frame of reference through 1940 (Hopkins & Smith, 1983). Even with the effects of reductionism after World War II, when holistic, humanitarian orientations toward occupation were replaced by what was considered sophisticated, scientific thought, belief of people as actors in their environment was still found in the literature (Blacks, 1947; Pendergast, 1956; Smith 1958). Occupational therapists are concerned with a person's ability to achieve (Reilly 1969). They should emphasize the value of competency and a person's potential for competency in his or her skills, abilities, and interests and habits as well as in the value of play and work or occupational behavior (Reilly, 1969).

Roles of Adolescence

With the transition from childhood to adulthood come physical, emotional, and social changes that require adolescents to form self-concepts and establish identities. The importance of a peer group during this time is critical in that it provides a social arena where adolescents enact roles and experiment in those roles. From a social perspective, identity formation occurs in the process of enacting those roles in which adolescents experience successes or failures (Strax, 1988). An adolescent's physical image is his or her presentation of self to the world and is intimately linked to his or her self-concept. Adolescents are obsessively aware of society's ideal physical image and seek to conform to it (Rogers, 1984).

Erikson (1963) referred to adolescence as a period during which society must allow time for the adolescent to decide how he or she can make a contribution to society. A compulsive need to gain all possible experiences as well as feelings of control over the environment typifies this life stage. As a result of success during this period, the adolescent is left with a set of skills as well as confidence in his or her capacity for meaningful work.

Others have analyzed adolescence while looking at vocational role development (Basseches, 1986; Gould, 1972; Havighurst, 1972). Havighurst viewed vocational development and vocational maintenance from a biopsychosocial perspective. Thus, biological characteristics, so-
social expectations and demands, and an adolescent's sense of self all influence vocational development.

Crittenden (1990) also discussed adolescence as a period during which persons develop autonomy. She, however, defined autonomy as persons' capacities to take responsibility for their own behavior, to make decisions regarding their own lives, and to maintain supportive social relationships (p. 162).

Regardless of one's theoretical orientation, adolescence is a period between childhood and adulthood where one defines himself or herself within society. A traumatic injury resulting in paralysis is an unwelcomed situation that disrupts the transition into adulthood. The ensuing impact of the disability interferes with the opportunities during this life stage and the acquisition of lifelong skills.

The Impact of Disability During Adolescence

Hostler, Gessard, Hassler, and Linden (1989) identified the psychosocial outcomes of a physical disability during adolescence. Recurring themes included isolation, loneliness, fewer same- and opposite-sex friends, increased dependence on others, less assumption of responsibilities, and unrealistic future plans. Stewart and Roessler (1978) have analyzed paralysis in terms of age at onset. They spoke of adolescence as a time of uncertainty in which the integration of paralysis is difficult because of an incompletely formed personality. They maintained that paralysis causes adolescents to age prematurely. Roessler (1978) found that the population with spinal cord injuries is absorbed with bodily concerns. Adolescents with disabilities often reject themselves because they are unable to conform to society. Moreover, nondisabled adolescents often reject their peers with disabilities, resulting in the loss of a valuable tool for adolescents with spinal cord injuries, that is, the peer group (Smith, 1985; Strax, 1988).

The process of independence is abruptly reversed as a result of a spinal cord injury. The need for physical care, financial support, and assistance in mobility and self-care infantilizes adolescents. Cook (1976) identified a commonality of all persons with spinal cord injuries regardless of age or position on the dependence-independence continuum. This commonality, a state of physical and psychosocial dependency, is imposed on all who sustain spinal cord injuries. Consequently, at a time when the adolescent is pulling away from the family and seeking a social niche, a spinal cord injury regresses him or her to a stage of extreme dependency.

In addition to the social stigma and dependency issue, the potential for vocational opportunity and economic independence is poor. Rusch and Phelps (1987) found that of approximately 300,000 disabled youths who leave high school each year, the vast majority encountered severe underemployment. Thus, it becomes obvious that a physical disability such as a spinal cord injury interferes with the vocational, social, and emotional tasks of adolescence. Identities that are beginning to form become skewed, the search for independent autonomous functioning is replaced with excessive dependence, and the opportunity for acquisition of vocational skills and a meaningful vocation appears bleak.

Method

Sample

Purposive sampling (Williamson, Karp, & Dalphin, 1977) was employed to identify participants for this study. This method was selected because it enables the selection of subjects for their relevance to the issue being studied. Four adolescents volunteered to participate. Each participant met the following criteria:

1. Had sustained a spinal cord injury resulting in paraplegia or quadriplegia
2. Was between 15 and 18 years of age
3. Had sustained the injury for no more than 2 years
4. Had returned to preinjury school environments for at least 3 months of uninterrupted attendance
5. Had given written informed consent as well as the written informed consent of a legal guardian.

In determining selection criteria, the severity of the disability was not emphasized, thus quadriplegia and paraplegia were considered equally. The focus, instead, was on the subject's experience of returning to an environment in which he or she was once nondisabled but now is a person with a disability.

The 2-year time span was chosen after consideration of temporal commonalities of patients with spinal cord injury. These commonalities include a 4- to 6-month rehabilitation admission following the acute care hospitalization, the time spent after the rehabilitation stay at home and the receiving of homebound tutoring and instruction, summer vacation, and at least 3 months of school attendance without prolonged absences for medical or other complications. All participants returned to the same school environment in which they were enrolled prior to sustaining their spinal cord injury. Characteristics of the participants are outlined in Table 1.

Table 1

<table>
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<th>Subjects' Characteristics</th>
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<td><strong>Age</strong></td>
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Data Collection

Intensive interviews with the use of open-ended questions were used to elicit descriptive information on the experience of returning to premorbid school environments. Each interview occurred during a readmission to Shriners Hospital, Philadelphia Unit, for routine follow-up care. Each interview was initiated with a statement such as,

I'd like you to think about when you returned to school after being discharged from rehab. When you first went back, what was it like for you? What was the experience all about? Will you talk about what happened during the first time back to school?

Subsequent questions were then generated by the unique responses of the individual participants. Each interview, lasting from 90 to 120 min, was audiotaped and transcribed verbatim. Intonations in voices and nonverbal communication documented from observations during the interviews were included in the transcriptions.

Data Analysis

The content of the open-ended responses was analyzed, and the data were coded into descriptive themes. Fourteen general categories were generated from a rereading of the interviews. The categories were then examined and assigned specific themes. This process continued until the responses from each interview included reference to only one theme. No attempt was made to employ a quantitative statistical analysis because of the qualitative nature of this investigation.

Results

The responses were coded into six themes: people, role change, self-image, coping strategies, accessibility, and feelings. Figure 1 summarizes the specific contents of each theme.

People

During the interviews, each adolescent spoke of people. People included teachers, friends, peers, bus drivers, and others associated with school. This theme appeared to be the area to which the participants alluded most often and described in most detail.

The manner in which teachers treated the adolescent, how teachers reacted to him or her, and the perceived knowledge base that the teachers had regarding spinal cord injury recurred in all of the interviews. One adolescent explained,

One teacher made me feel really uncomfortable because he never used to make me do work, because he felt like a lot of times I was in pain and all, and he messed up my whole math career. I got to his class and he used to put me [Pause]... I didn't know anyone, and he used to set my desk right in the front. I couldn't even see the board, I was so close to it.

Another adolescent angrily talked about what teachers thought when she returned to school: "This teacher thought that because I had a car wreck I had a head injury and so she put me in a sixth grade reading level." This adolescent continued and, alluding to the teachers, pointed out, "They just need to get more knowledgeable."

Friends and peers were defined as two different types of persons by the participants. Generally, friends were friends and peers were other kids in the school. The reaction of peers was significant for all of the adolescents. Comments such as, "They all shied away," "They didn't know how to act," "They felt weird," and "Everyone always looked and stared at me," were related to the reaction of peers. One adolescent said, "This kid came up to me and said, 'God, I can't believe this happened to you, it's terrible, it could have happened to me.'"

Dialogue about friends dominated the interviews. Such comments as are shown below suggest the change in friendships that occurred following the spinal cord injury:

Before I got hurt, friends were people I hung with, smoked cigarettes with, and talked about boyfriends with. Now a friend is somebody with a whole lot of compassion.

My new friends—they're not scared; they're not scared of me being in a chair.

They're not nervous around me, but my old friends, they don't like to talk, they don't like to ask questions.

My new friends are a lot better than my old friends. My new friends are friends; my old friends are not friends.

One of the responses illustrates the pain involved in losing friends during adolescence:

Sometimes I wish I could have died with dignity and when I was to have my funeral I would have known that there would have been a
Role Change

Another theme identified from the interview responses was changes in premorbid roles. All of the adolescents described changes in their roles of student, friend, boyfriend or girlfriend, and person as well as changes in roles associated with extracurricular activities.

Limitations imposed by paralysis appear to be the predominant cause of role changes. The experience of no longer being able to be a member of the band, ski team, wrestling team, baseball team, and swim team were described. One adolescent described the change in her role as a member of the flag team as follows:

I used to like flags, that was my life, I loved it so much, and it was so hard to go back and see my friends still doing it. You need extracurricular activities in school, and I realized after that year [that] I lost my life and I'll never be able to go into anything.

Changes in the students' roles were described. These changes were not related to academics, but rather, to the type of student each was known for being. For example, one adolescent explained, “You can't go back to school after being the head troublemaker of the class as a little crippled girl.” Another adolescent said, “I would see people running down the halls and chasing each other. We weren't supposed to do that, but we did, and then I remembered [pause] that's what I used to do and then I would think, ‘Oh my God, I can't do that anymore.’”

Changes affecting the adolescents as people were also described. Comments such as, “I was happy, I was doing everything I was supposed to be doing, I was having fun,” and “I don't have all the opportunities I did,” and “I'm just not as free as I used to be, I can't go out when I want to and that sort of thing,” all represent a shift in personhood.

Self-Image

Self-image was another theme that surfaced during the interviews. Interestingly, each adolescent offered comments that reflected the existence of the wheelchair as a component of his or her self-image. For example, one of the adolescents was discussing herself in the school environment as “the girl in the wheelchair,” and another explained that he is “the kid who sits in the wheelchair.” One of the adolescents, while explaining that she was the only one in school in a wheelchair, said, “There was this thing, I kind of didn't like kids that were younger than me because I always felt like they didn't know that I used to walk, they all just think that I'm just some wheelchair person.” Another way the wheelchair influences one adolescent's self-image is portrayed in the following statement: “People look down at you, but they can't help to look down at you. You'll never be eye to eye with anyone else unless they stoop to your level.”

In addition to the wheelchair, an adolescent's self-image appears to be very much influenced by the loss of bowel and bladder function. “I'm ashamed I can't go to the bathroom like everyone else” and “I felt like everyone must know I wear a leg bag, I was so self-conscious” are two of many statements that emerged during the interviews that made reference to loss of bowel and bladder control. Without even alluding to how she thought of herself, one adolescent revealed her self-image in the statement, “When I see other people like me, I'm like, ‘Oh my God, Oh my God, I hate it.” A self-image shadowed by shame and embarrassment as a result of losing control of the bowel and bladder is typical for persons with spinal cord injuries (Cook, 1976; Stewart & Rossier, 1978).

Coping Strategies

Throughout each interview, I used probes to identify how the adolescents with spinal cord injuries handled the various situations they spoke about. Often, a simple statement, such as “How did you deal with that?” or “What did you do about it?” generated detailed explanations on the coping strategies that were used to meet or adapt to the demands of the school environment. All of the adolescents attempted to deal directly with situations. As one of them said, “Really, there is not one good thing about going to school, and there are a lot of tears, but you have to do it, just do it and look everybody in the eyes.”

Ignoring things, hiding from situations, dreaming, dealing directly with situations, and joking about things were identified as the predominant coping strategies used by the 4 subjects. All revealed that, upon returning to school, they frequently positioned themselves in the corners of classrooms, the lunchroom, and the library to hide so that they “did not stick out” from the rest of their peers.

Accessibility

Accessibility of the school environment was identified as inadequate by all 4 subjects. Initial return to school was confounded by small doorways, steps without ramps and elevators, and small bathrooms. “I didn't fit into the lunchroom, so I would eat in the library by myself,” “I need help getting lunch because as you go out to pay the cashier, the doorway is narrow, the turn is sharp, and I just can't make it,” and “When I returned to school I could not get around, up the stairs, in the bathrooms,” are statements that reveal inadequate preparation on the school's part to reintegrate the adolescent with spinal cord injury into the school environment. Additionally, one of the adolescents with quadriplegia described her
inaccessibility to the classroom as being the unavailability of a computer. She described the continued lack of access as follows: “They promised me they would get a computer. I really needed a computer. They needed to get me a computer—that was the only way I could be functional.”

**Feelings**

*Feelings* was a theme that was interwoven throughout all four interviews. The broad spectrum of feelings that were described indicate emotions associated with at least one of the themes depicted in Figure 1. Feelings that emerged were associated with loss of control and dignity, feelings of being an imposition and a disruption, and feelings of anger and fear and of being different. Table 2 contains statements that exemplify the emotions and feelings that emerged with returning to school.

Anger appeared to be associated with not being able to or not being allowed to perform simple activities or activities in which the subjects were capable of performing. For example, three of the subjects with quadriplegia reported that although they each had the capability of pushing their own wheelchairs, teachers, friends, and peers often assumed that they could not and therefore did it for them.

Feelings over loss of control and loss of dignity as well as general losses were common. Although each subject had feelings of individual losses, all alluded to the embarrassment, shamefulness, and disgrace associated with loss.

Feelings of being an imposition and of being different also surfaced with each of the respondents. Disrupting the normalcy of school life was a crime that the adolescent believed he or she committed.

Fear was another feeling that clouded each adoles-

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**Table 2**

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<th>Feeling</th>
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<td>Control</td>
<td>“I was the only one in a chair; I felt stranded but couldn’t do a lot about it. There is not much I can do.”</td>
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<tr>
<td>Imposition</td>
<td>“Well, it’s extra work for them; they have to get work sheets for you to take notes and stuff like that. They really didn’t like me in their class.”</td>
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<tr>
<td>Anger</td>
<td>“In every class, it started to get on my nerves, because I kept telling them everyday ‘No! You don’t have to slow down for me.’”</td>
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<tr>
<td>Loss of dignity</td>
<td>“It’s just that I feel like I’m being treated like I’m pitiful, like I’m helpless.”</td>
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<td>Disruption</td>
<td>“Like when my leg starts bouncing and hitting the desk, I’ve got to unlock my brakes, wheel out and, if my legs don’t stop I usually hit them. Then I have to stop taking notes and everybody is looking and everything.”</td>
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<tr>
<td>Loss</td>
<td>“I just feel like I’m never going to do anything with my life.”</td>
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<tr>
<td>Fear</td>
<td>“I felt like throwing up. I didn’t want to be late for class.”</td>
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**Discussion**

This study suggests that returning to preinjury school environments and peer groups may be difficult for adolescents with spinal cord injury. It also implies that both the adolescents with spinal cord injury and the environments to which they returned may be ill-prepared for school reentry.

Social interactions between adolescents with spinal cord injury and teachers, peers, and friends are often dictated by disabled adolescents’ self-images and levels of adaptiveness and by nondisabled persons’ preconceptions and level of comfort in interacting with disabled persons. Self-segregation of persons with newly acquired injuries has been said to be a result of uncertainty regarding socializing experiences (Haney & Rabin, 1984).

Stephens and Brown (1980) surveyed teachers of children in kindergarten through Grade 8 to determine their willingness to accept children with disabilities into their classroom. The results of their study suggested that teachers of Grades 7 and 8 were less accepting of the student with disabilities than were teachers of lower grades. Perhaps as subject matter becomes more important, teachers become less accepting of individual differences.

Reactions of others to a disability has been the focal point of research studies (Dunn, 1977; Rich et al., 1984) and publications (Goffman, 1963; Kashani, 1986). It has been noted that although society has considerable intellectual tolerance of disabilities, beneath the intellectualization, negative feelings exist (Kashani, 1986). In 1971, Richardson reported results of a study that investigated the social stigma of a disability. He reported that as the disability becomes more noticeable (e.g., necessitating the use of a wheelchair or prosthetic limb), the person with the disability becomes less liked.

Role changes, another theme that emerged from this study, is documented in the spinal cord injury literature. Nelson (1987) pointed out that once in the community setting, people with spinal cord injury are ill-equipped to deal with their problems associated with their roles in the family and society and that they are faced with being stereotyped. Richards (1986) stated, “Sudden onset of a disabling condition such as a SCI [spinal cord injury] necessitates a major shift in roles and activities” (p. 362). Nelson (1987) suggested that once one is physically stable, the predominant problems of a spinal cord injury are related to the disruption of and changes in life roles.
The 4 subjects alluded to their wheelchair and bowel and bladder management during dialogue on self-image. This theme is also documented in the spinal cord injury literature and is common among most persons with traumatic spinal cord injury regardless of age or living environment (Cook, 1976; Stewart & Rossier, 1978).

The problems of accessibility identified by the 4 subjects may not represent the typical problems faced by all students using wheelchairs. Only 1 subject attended an urban school; 2 attended schools located in rural areas, and 1 attended a private academy in an old building.

Conclusion

Although much dedication, effort, and money is spent on the rehabilitation of persons with spinal cord injury, many of these persons may experience difficulty in reentering premorbid environments, enacting meaningful roles, and assuming a self-satisfying life-style. The 4 adolescents interviewed revealed the existence of a major gap between the rehabilitation world and authentic environments. Clearly, each adolescent, although deemed by rehabilitation professionals to have acquired and mastered the skills for discharge and community reentry, experienced great hardship during school reentry. The adolescents’ responses also imply that the human and nonhuman support systems in the school environment may be inadequate for successful return to school.

At the end of the interviews, each of the adolescents was asked to convey a message to people in rehabilitation centers, people in the school environments, and newly injured people. The following responses were generated:

Number one, they should know that at times you are going to need help, but you don’t need to be pitied all the time, and number two, it’s not that big of a deal that you cannot walk and that your brain is not affected whatsoever and that you have to do different things, go to the bathroom differently and stuff like that. It’s just the way it is and you can’t, it’s nothing to ignore somebody about, and that teachers need to understand that we have a right to an education just like everyone else.

Well, just try to get a group of people that will help you when you need it, you know, try to have someone there so that you’re not left stranded. It didn’t quite work out like that for me.

First make sure who your real friends are, that would be what I would say, then to teachers, don’t be afraid of the person, don’t be nervous, because that will only make the person more nervous.

It sounds so simple, but just have a place for them in the class. It makes it easier to just have a place to go and sit like a normal person, and even aisles, where you can go up and bring your paper up to the desk. It sounds little, but it’s not, and to rehab people, take them out a lot, make sure they have nice clothes on and their hair looks good. They teach you everything you need to know about being independent, but they need to work on how to put it together when you go home.

Research Implications

This study touches on only a few of the issues that surface as one returns to school after a spinal cord injury. Investi-
References


