

Disability Studies Quarterly  
Spring 2001, Volume 21 No. 2  
[www.cds.hawaii.edu](http://www.cds.hawaii.edu)  
Copyright 2001

**Alcohol and Substance Use by Adolescents  
and Young Adults with Recent Spinal Cord  
and Traumatic Brain Injuries**

**Pamela Block, Ph.D.**

**Beth Bock, Ph.D.**

**Bruce Becker, M.D., M.P.H.**

**Brown University**

**Sarah Everhart, M.P.H.**

**Shake-A-Leg**

Abstract

Alcohol and substance use constitute a significant health risk for people with disabilities. Rates of alcohol and substance use are higher among individuals with disabilities, often play a contributing role in the onset of injury-related disability, and severely disrupt the effectiveness of post-injury rehabilitation. This ethnographic study of 24 youths participating in a 5-week residential rehabilitation program confirms a high prevalence of problematic use of alcohol and substances that create psychological and physiological barriers to rehabilitation. Family history and pre-injury alcohol and substance use were common among study participants; however, social needs appeared to significantly contribute to continued alcohol and substance use. This paper presents the results of this research employing individual case examples to explore these dimensions of alcohol and substance use among college-age youths with disabilities and discusses opportunities for alcohol and substance use intervention.

**Background**

The National Spinal Cord Injury Statistics Center (NSCISC, 1995) estimates that between 183,000 and 203,000 Americans are living with spinal cord injuries (SCI). Approximately 10,000 new cases are reported each year. Forkosch and colleagues (1996) estimate that 1.9 million Americans experience traumatic brain injury (TBI) each year.

Roughly half of these cases result in short-term disability and result in over 50,000 deaths each year. In the United States, over 5 million men, women and children are currently living with a permanent TBI-related disability (Guerrero et al., n.d.). TBI and SCI have important implications for US health care policy.

The direct medical costs for treatment of TBI and SCI have been estimated at more than \$4 billion annually. TBI and SCI have an especially devastating impact on work productivity. The majority of new cases of SCI and TBI are young people just beginning their productive work careers. The majority of individuals with SCI or TBI are typically Caucasian men injured in car crashes, diving accidents, or falls as adolescents or young adults (Heinemann, 1992). However, in recent years there has been an increase in firearm violence-related SCI and TBI, especially among urban minorities living in cities with high rates of gang violence (Groce, 1998).

The prevalence of problematic alcohol use among individuals with SCI or TBI is much higher than population norms. Up to 75% of people with SCI and 51% of people with TBI abuse alcohol (Bombardier, 1995; Heinemann et al., 1991; McKinley et al., 1999; Moore et al., 1994). These rates are as high or higher than among people with other disabilities. Alcohol is often an important factor in the onset of disability in as many as 50% of SCI cases and 66% of TBI cases (Bombardier et al., 1997; Corrigan, 1995; Dikmen et al., 1995). Studies have demonstrated that persons with disabling injuries of the brain or spinal cord often were intoxicated at the time of the trauma that created their disability, and, typically, have extensive prior histories of problematic drinking as well (Bombardier & Rimmele, 1998; Corrigan et al., 1995; Kreutzer et al., 1996). Moreover, drug use data also show that respondents with disabilities report higher rates of illicit drug use for nearly every drug category when compared with the general population (Moore & Li, 1998).

These individuals are at high risk for continued problematic alcohol and substance use after their injury. Numerous risk factors for problematic substance use including: economic and social isolation, low self-esteem, easy access to prescription medications, entitlement issues, decreased awareness of adverse consequences, impaired impulse control and reduced tolerance, are particularly relevant to individuals with disabilities. People with disabilities also face physical, psychological and vocational difficulties that include pain, sensory impairment, depression, and unemployment. For many, alcohol and substance use become methods of coping or self-medication.

Continued substance abuse can have devastating effects on individuals with disabilities. It can impede physical and cognitive recovery and may adversely influence the rehabilitation outcome thus reinforcing a vicious cycle of impaired recovery and continued alcohol abuse (Baguley et al., 1997; Bombardier & Thurber, 1998; Corrigan, 1995; Heinemann, 1991; Ronty et al., 1993). This is especially true if alcohol abuse was a contributing factor in the disabling traumatic injury (Ronty et al., 1993).

Unfortunately, alcohol and drug abuse prevention and treatment professionals often are not trained to meet the needs of persons with TBI or SCI. Likewise professionals who work with people with disabilities often do not know how to respond effectively to alcohol and drug abuse problems. Indeed, rehabilitation professionals may

inadvertently support addictive behaviors by recommending drinking alcohol (presumably at non-abusive levels) to increase relaxation, improve appetite, and enhance social interaction (Rohe and DePompolo, 1985). Alcohol and substance use have been cited as risk factors for suicide (Kewman & Tate, 1998). Kreutzer et al. (1990) found that repeated drinking and driving violations by persons with TBI lead to a higher incidence of manslaughter and suicide. Indeed, alcohol abuse has been reported as the seventh leading contributing cause of death among individuals with SCI (Smith, 1990).

Since this population is at high risk for continued substance abuse, the development of effective, innovative prevention and treatment interventions for persons with SCI and TBI has been strongly recommended (Gilson et al., 1996; Hubbard, 1996; Kewman & Tate, 1998; Moore & Li, 1994, 1998). Further research is needed to evaluate the relationship of changes in risk perception and other variables thought to mediate their drinking behaviors. Unfortunately, to date, research has rarely addressed alcohol and substance use reduction issues specific to young people with newly acquired disabilities. The stresses of healing from the physical and psychological traumas of their injuries and adjusting to life with a disability, combined with the desire to continue peer-interactions in contexts where youthful alcohol substance use is frequently high (i.e., on college campuses), put this group at substantial risk for problematic alcohol and substance use. Research has never explained the failure of conventional interventions and treatment for this population (Backer & Newman, 1994; Tyas & Rush, 1993). In order to explore factors supporting alcohol and substance use among adolescents and young adults with recent SCI and TBI, we conducted an ethnographic study of youth participating in a 5-week residential alternative therapy program for physical rehabilitation and recreation.

## **Study Methods**

This ethnographic study of alcohol and substance use and adaptation to disability was conducted at a non-traditional therapy program located in the northeastern United States. Program participants (n=24) were college age people with recent SCI, TBI, or related neuromuscular conditions. Participants received physical and occupational therapy, physical conditioning, and other non-traditional forms of body work, including massage therapy, reiki, and rolfing from certified professionals during the 5-week program. They participated in independent living seminars conducted by occupational therapists and specialists from the local independent living center. Group recreational activities such as hand-biking, water-skiing, kite flying, scuba diving, kayaking, and sailing were overseen by recreation therapists.

All program participants were required by program personnel to sign a written statement acknowledging that alcohol and substance use was prohibited on the campus where the program was housed. However, it should be noted that this is a program for physical rehabilitation and recreation, not alcohol and substance use treatment. None of the participants came to the program seeking treatment for problematic alcohol and substance use.

This study utilized qualitative methods of participant observation and semi-structured ethnographic interviews to collect information from program participants. Twelve program participants between the ages of 18-25 with traumatic spinal cord or

brain injuries were asked to discuss how they have adapted to their disability, their sources of social support, and their alcohol and substance abuse behaviors. All subjects interviewed were either current college students, about to enter college, were considering entering college, or (in one case) a recent college graduate. These semi-structured interviews were conducted by the first author, who is a Ph.D. in cultural anthropology. The reliability of interview data was supplemented and confirmed through participant observation and the collection of extensive field notes.

It was found that individuals interviewed did not exaggerate their alcohol and substance use behaviors, and if anything, under-reported their use sometimes denying having engaged in behavior that the first author witnessed personally. Capacity to give informed consent was required for participation in study interviews. Individuals who did not have SCI or TBI or who were not capable of giving informed consent were excluded from the study. This sample was representative of the general population of individuals with recent SCI and TBI and so was predominantly adolescent or young adult, Caucasian, and male.

It should be noted that this is an observational study of problematic alcohol and substance use. In findings consistent with the existing literature, the authors have found that excessive use of alcohol and substances interferes with participants stated goals for physical rehabilitation and independent living. However, at no time did the authors seek to assign moralistic responsibility or blame for any of the behaviors described and observed.

## **Data Analysis**

This interview data was organized thematically delineating reported family histories of drinking, pre-injury drinking behavior, alcohol use at the time of injury, social support for drinking, and consequences of alcohol and substance use. The response categories reported were derived through thematic analysis of interview data and review of topics frequently reported in the literature on substance use. The names of individuals interviewed have been changed to protect their privacy and to preserve confidentiality.

## **Results**

### **FAMILY HISTORY**

More than one third of the individuals interviewed related family histories of problematic alcohol and substance use. Lewis, a 20 year old man with SCI and TBI stated: "My mom divorced my father because he was an alcoholic, so I got to be kind of careful, cause it could run in the family, you know." George a 23 year old with SCI said the following:

Q: "Do people in your family drink?"

A: "Only on my dad's side, but I don't associate with them."

Q: "In general, how much would you say that they drank?"

A: "I don't know. Rumor has it that my dad quit drinking, but I don't know if I buy it. He was a heavy lush so I don't know."

- George

Approximately one third of the individuals interviewed recounted instances of moderate to heavy drinking in their immediate families and described alcohol use as a regular part of family social interaction.

#### PRE-INJURY ALCOHOL AND SUBSTANCE USE

More than half of the individuals interviewed related pre-injury drinking and substance use behaviors that ranged from problematic to harmful and hazardous.

"I've done almost every drug. Crystal, I've done it. I've never shot up, but I've done coke; I've done 'shrooms; I've done Special K; I've done ecstasy; I've done liquid acid, real acid, all kinds. I've tried all kinds of pills, just partying, you know growing up as a kid."

- Bill, a 23 year old with SCI

"I went through a time before my accident when I drank everyday. At least 8 beers a day, 8 to 12 to 15."

Q: "Have doctors or other professionals discussed your drinking habits with you?"

A: "Yeah, judges have...The courts, they ordered me to get a CADAC evaluation...It's a certified alcohol and drug awareness counselor to determine if you have a problem or some shit".

Q: "When did that happen or how did that happen?"

A: "Because I got a DWI, and then I had like a string of three times when I got picked up as a minor with possession. Because I would always think that I was slick and throw my beer aside, but then I would try to play the cool guy routine, and I'd always tuck a beer in the inside pocket of my jacket for the end of the night, when everyone else was out (of beer [sic]) so I could be like "Ha Ha!"and then, I'd always forget about that one that I had tucked in my pocket. So I'd be like, 'yeah, you can search me,' and there would always be that fucking one in my pocket."

- George

#### ALCOHOL USE AT THE TIME OF INJURY

Alcohol was a factor in many of the injuries, something mentioned, but not emphasized, by several the individuals interviewed. Several reported that the alcohol use of others was a factor in their injury (e.g., they were passengers in a car driven by someone who was intoxicated). In two cases, individuals reported that their own alcohol use was a factor in disability onset.

Q: "How did you acquire your disability?"

A: "I fell and broke my neck, fell on my back and broke my neck."

Q: "Was your injury alcohol related in any way?"

A: "Probably yeah. I had been drinking a little bit and probably would have been able to pull off the maneuver if had I not been. So yeah a little bit."

Q: "Was it a diving accident?"

A: "No. I was in a parking lot, and I was trying to get out of the parking lot and kind of shimmy on over to the ramp, and I was just ducking underneath some rope and gonna pull myself across and my hands slipped as I was pulling myself across, and my hands slipped, and I fell down this chute onto my back."

- Jim, a 25 year old with SCI

Q: "Was the accident alcohol related?"

A: "Yes, it was."

Q: "Do you mind telling me about it?"

A: "No, that's fine. It was my birthday party and so I took 21 shots of vodka in a row. Twenty for my twentieth and one to grow on and so I was basically walking around in an alcohol comatose (sic). It was pretty weird. They said that I just got way back in the yard and ran towards the swimming pool and jumped in the air, and I didn't come back up. And luckily one of my friends saw me do it and went over there and dove in and pulled me out. And I was dead, and they brought me back, and then I died again, and they brought me back again."

- Bob, a 20 year old with SCI

These two individuals were unique in explicitly articulating the connection between their alcohol use and their disability. Other individuals interviewed did not recognize this link, preferring to see their injury as "an accident" and "nobody's fault."

## SOCIAL SUPPORT AND PEER PRESSURE FOR DRINKING

The youth with recent SCI and TBI that we observed worked strenuously to heal their bodies typically spending 2-5 hours per day doing rehabilitation and body work. Simultaneously, they also struggled to re-establish old social networks and create new ones. In some cases friends had abandoned them, but even with strong social support from old friends participants with recent SCI and TBI felt distanced from their peers. Rehabilitation goals and social goals often came into conflict if alcohol and substance use figured substantially in the individual's life. Excessive alcohol and substance use were observed to undermine rehabilitation goals in ways that were both subtle and direct. During the final four weeks of the summer program, three individuals missed at least one appointment per week for rehabilitation or body work because they were too "hung over" to get out of bed.

Alcohol and other substances were often used to bridge social barriers. Individuals choosing to abstain perceived this choice as another factor distancing themselves from their friends. Steve, a 21 year old with SCI and TBI, felt socially isolated from his peers and struggled to find ways to increase their acceptance of him. He admitted that he had considered drinking as one avenue to feel closer to the people with whom he would like to be friends.

"Well, a few times I drink a few beers, socially but I try not to. But I get easily provoked because I'm like the way I am now in a wheelchair, and that's kind of difficult for me to fit in so I try to fit in doing all this stuff like drinking, and it kind of makes me feel like I'm cool with the kids, my friends. But really, it's not."

- Steve

Paul, an 18 year old with SCI felt secure in his peer relationships, but still felt the pressure to drink, not wanting to emphasize the differences between himself and his friends.

A: "Yeah, I mean, because there would be some days [before the injury] where I was, like, bored and a lot of friends would be, like, 'Let's go, you know, my dad's got a six pack or something. Wanna go to my house?' And that's kind of changed.... I just don't like the feeling I get after, the way it hurts my stomach, and I can't hold any amount down, so I just don't really pay attention to it anymore, but I know that, sometimes I'd feel like I'd like to, but because it seems like a lot of people - there are so many people who drink, everyone it seems like. I just try not to get caught in those situations as much as possible because one, I'm disabled and I already feel like more distant even though, even if I have close friends, I feel more distant from them than I did before. And so, not having a beer or doing something they wanted me to do would make me feel more away from the group."

- Paul

Other participants received social support for their drinking behaviors because they continued to maintain social relationships that they had had prior to their disabilities with individuals whose use of alcohol and substances was and continues to be problematic.

Q: "Do your friends drink?"

A: "Yeah."

Q: "How much?"

A: "I don't know. Two of my friends are real lushes, they drink quite a bit; actually three of my friends, four, yeah they're all lushes I guess. I don't know how much they drink, they drink a lot."

- George

Another challenge of post-injury social relationships is that friends must assume some care-taking responsibility for the individuals with disabilities. This creates complications for young people with SCI and TBI who wish to socialize. One young woman, Ann, went drinking after being discharged from the rehabilitation unit shortly after her injury. She did not realize that her tolerance of alcohol would be decreased and "passed out" after two drinks. Her friends had no idea how her wheelchair functioned, and she was in no condition to tell them, leading to great difficulties for everyone involved. Most of the individuals interviewed expressed fears of such situations.

Q: "How much do you drink when you are with friends?"

A: "I guess three or four drinks; I don't know."

Q: "Has this changed since your disability?"

A: "I think maybe yeah, 'cause it used to be that it didn't really matter where you ended up at the end of the night, so you have to be a little bit more careful now 'cause you have to keep track of 'Okay, who's taking me home' and make sure you stay with them. So, yeah, you can't wander off."

- Jim

Q: "How often would you say you drink with friends?"

A: "Now? After the surgery or before? After the surgery, not that much."

Q: "So that's changed since your disability?"

A: "Yes. Because, I mean, if I go out drinking with, if I go out with my friends to a party they'll probably be drinking too except for the designated driver, and I don't want some dumb-ass folding up my chair, my chair's a piece of crap as it is. And especially lugging me around - they'll dump me on my melon!"

- Lewis

## CONSEQUENCES OF ALCOHOL USE

All individuals interviewed were asked to relate their perceptions of the consequences of alcohol and substance use. Participants varied in their knowledge of the consequences of alcohol and substance use for people with SCI and TBI. Most appeared fairly well informed on this topic through discussions with professionals and their own research, though some minimized or discounted the health risks. They also discussed health and logistical issues that they considered significant to their personal situation and medical condition. Neither abstract knowledge nor personal experience of harmful consequences typically led to a modification of drinking or substance use behaviors.

Q: "Do you feel informed about the possible consequences of drinking related to your disability?"

A: "Do I know what it'll do to me? Yeah."



Q: "Like what?"

A: "Like alcohol? It's just bad for me. Number one it's a depressant, you know, and who wants to be depressed? I know that alcohol is bad for me, everybody knows that, but whatever, fuck it! I'm not gonna stop drinking, cause it's not me. I like to drink, you know?"

- Bill

Q: "Do you feel informed about the possible consequences of drinking related to your disability?"

A: "Yes."

Q: "What?"

A: "I don't have to worry about falling over. It makes me shake if I drink too much, in the morning. It messes up my whole wiring. It's not good for my liver. It's not good because it dries me out, my bladder. It encourages bladder infections. I've had other bad effects, but not usually pee."

- George

Q: "What are the consequences related to your disability?"

A: "Well my disability is balance associated so like, when you're drunk, it would be like ten times worse cause your balance would be way off. And I haven't been really drunk after my surgery, but New Year's Eve we had a little party, and since I've been on these new meds, and they said that it would make me kind of drowsy, that's, like, the only thing really that the consequences would be."

- Lewis

Q: "Do you feel informed about possible consequences of drinking related to your disability?"

A: "Yeah, I think so, as much as they know. I don't think they know a whole lot, the professionals. They don't say a whole lot. They say it's bad but they don't really say why, when compared to ...a person without disabilities. I guess when you're pushing yourself around it's harder to push around when you're really drunk so you might need to have more help there. Ran into that problem the other night."

Q: "Really when was that?"

A: "I'm talking about a few nights ago."

- Jim

Interviews and observation confirmed that many of the individuals used alcohol and substances regularly. Several participants were observed to mix alcohol with prescription medication including narcotics. Many also used marijuana regularly.

Participants reported changes in their drinking and substance use behaviors post injury. Some reported that they needed to switch from beer to hard liquor because of stomach problems. They also reported difficulties with bladder control. Other participants reported switching from alcohol to other substances due to stomach and bladder problems. Individuals who were underage reported that access to alcohol was easier after their injury and that they were seldom asked for identification.

Q: "Do you currently drink beer or alcohol?"

A: "Yes."

Q: "How much?"

A: "Now, it's about once a week. Maybe twice at the most. Sometimes my friends will come over, and we'll drink, and I'll have like three or two or one. But mostly just once a week."

Q: "And how much would you drink during that once a week?"

A: "I would usually drink a few, quite a few."

Q: "So, like putting a number on it?"

A: "I don't know. I don't drink as much beer as I used to. I've gotten into the hard stuff, you know. I can't burp right so I just drink the hard stuff. Oh, I don't know. Anywhere from a pint to a fifth."

- George

Q: "Is it easy for you to get beer or alcohol?"

A: "Yes."

Q: "How do you get it?"

A: "I just ask for it. I know I'm not of age but most people don't think about it actually, when you're in a wheelchair."

- Bob

Q: "Do you currently drink beer or alcohol?"

A: "Do I currently? Yeah. Not as much, not yet. Not as much because I'm on medication still. Like I talked to the doctors before I had my first drink just to find out what would happen, and they said that with the medication it might make me tired cause when I looked it up on the Internet, it told me not to mix it with alcohol. So I was like, I don't want to take this medicine if I can't drink."

- Lewis

"Well, as you know I am a frequent pot smoker, and I still am, and it takes a total ease out of me with like the rods in my back, and it's the only thing that loosens it 'cause I don't take pain medications at all."

- Bill

Few individuals openly discussed using marijuana or other substances in conjunction with or instead of alcohol. However, many of study participants were observed engaging in marijuana use on a daily basis, even those who denied use when interviewed. Participants who were willing to discuss the subject claimed to use marijuana to reduce pain or spasticity or to increase appetite. One individual with SCI stated that his doctor implicitly supported his use of marijuana for these reasons. What study participants considered to be a "medicinal" dose was quite subjective. One staff member with SCI scoffed at the cavalier way in which the term "medicinal" was used to describe use levels far above what she considered to be "medicinal." No one discussed the mixture of narcotics with alcohol and marijuana use, but this practice was observed in several of the individuals that we interviewed.

## **Discussion**

The results of this qualitative ethnographic study reflect the results of earlier quantitative research concerning the prevalence and severity of alcohol and substance use by individuals with SCI and TBI. Alcohol, substance use, and poly-substance use were common among study participants as were a family history of problematic alcohol use and pre-injury alcohol and substance use. Indeed, prior research has demonstrated that alcohol and substance use are often contributing factors in the onset of disability (e.g., Bombardier et al., 1997; Corrigan, 1995; Dikmen et al., 1995).

The increased risks from alcohol and substance use for individuals with disabilities (Baguley et al., 1997; Bombardier & Thurber, 1998; Corrigan, 1995) were also highlighted in the current study. Even though participants reported that their alcohol use was similar or lower than pre-injury levels, the physiological differences caused by the traumatic injuries resulted in lower tolerance and higher risk for complications. Several participants also reported changes in type of alcohol consumed (i.e., hard liquor instead of beer) and increased marijuana use to compensate for these physiological changes.

Alcohol and substance use were observed to undermine study participants' rehabilitation efforts resulting in missed therapy appointments which may complicate or delay anticipated therapeutic gains. Despite this, the presence of a disability sometimes provided a rationale for using substances or intensifying substance use. In some cases individuals had intentionally switched to stronger forms of alcohol (e.g., from beer to spirits) or drug use in order to avoid the negative physical consequences associated with excessive fluid consumption (e.g., bladder control difficulties). In other cases participants mentioned the "medicinal value" of certain substances such as marijuana as it related to their physical condition.

Among our interviewees the current social environment also seemed strongly influential in sustaining continued alcohol and substance use. Alcohol and substances were utilized to strengthen social networks that had been disrupted by the onset of disability or to establish new social connections. Alcohol and substance use play a large role in the lives of many college-aged individuals without disabilities, but, as we have shown above, youth with disabilities feel especially pressured to drink and use drugs in order to be accepted by their peers. Yet alcohol and substance use can be devastating to health and rehabilitation goals. Interventions empowering young people with disabilities to make healthy choices are clearly warranted.

The onset of a disability results in individuals entering a "liminal" state (Turner, 1974), a transitional domain that has few or none of the attributes of their past or future state or identity. According to anthropologist Victor Turner (1974) a person entering this state "becomes ambiguous, neither here nor there, betwixt and between all points of classification," (p. 232). Adolescence is a classic example of a liminal state as adolescents are no longer children, but have not yet been accepted as adults by society. In the United States, adolescence is traditionally a time of experimentation and rebellion against parental and social authority. Alcohol and/or substance use is often a part of this process. Other liminal states include transformations of social status through life-course events such as marriage, divorce, or widowhood.

The period following the onset of TBI and SCI is different from states such as adolescence. We are not equating the two nor are we implying that people with disabilities are like adolescents. However, we suggest that people with recently acquired SCI and TBI enter a liminal period as the transition from "abled" to "disabled" is a transformation in identity that requires months or years. The injury, its resultant disability, and social perceptions of both result in the forcible exclusion of individuals from their former identity as an "able-bodied" person; nevertheless, they do not immediately assume their new identities as people with disabilities. Personal relationships from before the injury may end or may be transformed and new social relationships are often initiated. The experience of injury and disability has no inherent pre-determined value, but rather is interpreted subjectively by each individual. Some see these changes as primarily destructive while others recognize positive experiences, lessons and relationships that develop as a result of the transformation.

When disability is acquired during adolescence, liminality is experienced on two levels: as adolescents, people are facing all the usual significant life choices of youth; additionally they are adjusting to the physical and emotional aspects of their disability. They are struggling to maintain a balance between achieving and maintaining physical health, which now requires a degree of dependence, and their need to establish independence from the social structures of childhood. They are also trying to redefine, reaffirm, or re-establish social relationships with their peers. When alcohol and substance use are factored into this equation, the two goals can come into conflict.

While this liminal state is an especially vulnerable period where young people with disabilities may engage in problematic use of alcohol and substances, it may also be considered a "teachable moment" wherein individuals are more open to making lasting behavioral changes (Wagner & Ash, 1998). If individuals acquire the tools and support

systems to navigate their new social identities successfully, they will be less likely to turn to maladaptive behaviors such as the problematic use of alcohol and substances.

## **Conclusions and Future Directions**

This study points to the need for interventions designed especially for young people with SCI and TBI who are struggling with establishing a new identity as well as social and health issues. The transformative period immediately following the acquisition of a disability may provide an opportune moment for alcohol and substance use intervention. This may be especially true for adolescents who are undergoing identity changes associated with the onset of disability and confronting the developmental transition from childhood to adulthood. Thus, programs developed for delivery in secondary and post-secondary educational settings may be well suited to meet the needs of this population. Research is needed which specifically addresses the impact of alcohol and substance use on secondary and post-secondary educational goals and objectives among disabled individuals.

Interventions are needed that employ strategies to empower these individuals helping them to improve their physical health and social fulfillment. Such interventions should assist the individual to establish a balance between health and social needs; a balance that is easily sabotaged by the problematic use of alcohol and substances. Interventions modifying alcohol and substance use would be beneficial, especially if provided in a context that increases independence, healthy life choices, and social supports that are not inescapably linked to alcohol and substance use.

Interventions will need to balance knowledge of the negative consequences of alcohol and substance use with skill building strategies. Knowledge alone does not appear to be a deterrent for continued substance use since many of our study participants were well informed on this topic. Neither general knowledge nor personal experience of the harmful consequences appeared to lead to reduction in drinking or substance use behaviors. Skill building must include the teaching of social skills including refusal skills for alcohol and substances which also teach skills for maintaining old friendships and acquiring new ones not linked to substance use.

This study also revealed how frustratingly difficult yet essential it is for rehabilitation programs to directly address the issue of alcohol and substance use. The program studied had a policy that all participants were required to sign acknowledging that alcohol and substance use was prohibited on the college campus where the program was housed. Activities were planned with the goal of reducing opportunities for participants to use alcohol and substances while away from the campus. Yet the policy was ignored and attempts to reduce opportunities for alcohol and substance use were ineffective. Additionally, there was an alarming interaction between the alcohol and substance use problems of staff and participants. Certain staff members, whose own use of alcohol and substances was clearly problematic, were observed to enable and even reinforce the problematic behavior of program participants. In response to both these difficulties and our research findings the program administration has implemented a zero-tolerance policy mandating abstinence for the duration of the program as a prerequisite for both staff and participants.

On the policy level, additional qualitative research might also be used to explore the significance of alcohol and substance use in the social lives of adults with SCI and TBI and in the social, cultural, and political structure of the disability-rights community. Disability-rights leaders are the mentors and role models for young people with disabilities. Personal care attendants and therapists are hired to maintain or improve the well-being of the people they support. If mentors, role models, and staff are themselves engaging in problematic use of alcohol and substances, it will be difficult to change the behavior of young people that look to them for guidance. The notion of independent living is commonly perceived to include the right to engage in the full range of social behaviors including alcohol and substance use. Discussions of modifying such behaviors are sometimes viewed as contrary to independent living philosophies that emphasize the right to individual choice. We must address the alcohol and substance use that are clearly a part of the lives of young people with disabilities while recognizing that promoting health is one of the most important responsibilities of the independent living movement.

### References

- Backer, T., Newman, S. (1994). Organizational Linkage and Information Dissemination: Strategies to Integrate the Substance Abuse and Disabilities Field. *Rehabilitation and Counseling Bulletin* 38(2), 93-107.
- Baguley, I. J., Felmingham, K. L., Lahz, S., Gordon, E., Lazzaro, Il, Schotte, D. E. (1997). Alcohol abuse and traumatic brain injury: Effect on event-related potentials. *Archives of Physical Medicine and Rehabilitation*, 78, 1248-1253.
- Bombardier, C. (1995). Alcohol use and traumatic brain injury. *WJM*, 162(2), 150-151.
- Bombardier, C.H., Rimmele, C.T. (1998). Alcohol use and readiness to change after spinal cord injury. *Archives of Physical Medicine and Rehabilitation*, 79, 1110-1115.
- Bombardier, C. H., Thurber, C. A. (1998). Blood alcohol level and early cognitive status after traumatic brain injury. *Brain Injury*, 12(9), 725-734.
- Corrigan, J.D. (1995). Substance abuse as a mediating factor in outcome from traumatic brain injury. *Archives of Physical and Medical Rehabilitation*, 76(4), 302-9.
- Corrigan, J.D., Lamb-Hart, G.L., Rust, E. (1995). A programme of intervention for substance abuse following traumatic brain injury. *Brain Injury*, 9(3), 221-36.
- Forkosch, J.A., Kaye, H.S., Laplante, M.P. (March 1996). The Incidence of Traumatic Brain Injury in the United States. Abstract 14, Disability Statistics Center.
- Gilson, S., Chilcoat, H., Stapelton, J. (1996). Illicit Drug Use by Persons with Disabilities: Insights from the National Household Survey on Drug Abuse. *American Journal of Public Health*, 86(11), 1613-15.

Groce, N. (1998). Firearm violence, disability rights, and rehabilitation. *Journal of Disability Policy Studies*, 9(2), 93-110.

Guerrero, J.L., Leadbetter, S., Thurman, D.J., Whiteneck, G., Sniezek, J.E. (n.d.). A method for estimating the prevalence of disability from traumatic brain injury. (Submitted for publication, 1999).

Heinemann, A.W. (1991). Coping strategies and drinking expectancies during spinal cord injury rehabilitation. *Journal of the American Paraplegia Society*, 14(2), 63-64.

Heinemann, A. W. (1992). *Substance Abuse & Physical Disability*. New York: Haworth Press.

Heinemann, A.W., Doll, M.D., Armstrong, K.J., Schnoll, S., Yarkony, G.M. (1991). Substance use and receipt of treatment by persons with long-term spinal cord injuries. *Archives of Physical Medicine and Rehabilitation*, 72, 482-487.

Hubbard, J.R., Everett, A.S., Khan, M.A. (1996). Alcohol and drug abuse in patients with physical disabilities. *American Journal of Drug and Alcohol Abuse*, 22(2), 215-231.

Kewman, D.G., Tate, D.G. (1998). Suicide in SCI: A psychological autopsy. *Rehabilitation Psychology*, 43(2), 143-151.

Kreutzer, J.S., Doberty, K.R., Harris, J.A., Zasler, N.D. (1990). Alcohol use among persons with traumatic brain injury. *Journal of Head Trauma Rehabilitation*, 5(3), 9-20.

Kreutzer, J.S., Witol, A.D., Marwitz, J.H. (1996). Alcohol and drug use among young persons with traumatic brain injury. *Journal of Learning Disabilities*, 29(6), 643-651.

McKinley, W.O., Kolalowsky, S.A., Kreutzer, J.S. (1999). Substance abuse, violence, and outcome after traumatic spinal cord injury. *American Journal of Physical Medicine and Rehabilitation*, 78, 306-312.

Moore, D., Li, L. (1994). Alcohol Use and Drinking-Related Consequences among Consumers of Disability Services. *Rehabilitation Counseling Bulletin*, 38(2), 124-133.

Moore, D., Li, L. (1998). Prevalence and risk factors of illicit drug use by people with disabilities. *American Journal Addictions*, 7(2), 93-102.

National Spinal Cord Injury Statistics Center (1995). *Spinal Cord Injury: Clinical Outcomes from the Model Systems*. Gaithersburg, MD: Aspen Publishers.

Rohe, D. E., DePompolo, R. W. (1985). Substance abuse policies in rehabilitation medicine departments. *Archives of Physical Medicine & Rehabilitation*, 66, 701-703.

Ronty, H., Ahonen, A., Tolonen, U., Heikkila, J., Niemela, O. (1993). Cerebral trauma and alcohol abuse. *European Journal Clinical Investments*, 23(3), 182-187.

Smith, J. (1990). Substance abuse: The spiral of denial. In S.N. Maddox (Ed). *Spinal Network*, 238-240. Washington D.C.: Library of Congress.

Tate, D.G. (1993). Alcohol use among spinal cord-injured patients. *American Journal of Physical and Medical Rehabilitation*, 72(4), 192-195.

Tate, D.G. (1994). The use of the CAGE questionnaire to assess alcohol abuse among spinal cord injury persons. *Journal of Rehabilitation*, 31-35.

Turner, V. (1974). *Dramas, Fields, and Metaphors: Symbolic Action in Human Society*. Ithaca, New York: Cornell University Press.

Tyas, S., Rush, B. (1993). The treatment of disabled persons with alcohol and drug problems: Results of a survey of addiction services. *Journal of Studies on Alcohol*, 54(3), 275-282.

Wagner, P.S., Ash, K.L. (1998). Creating the teachable moment. *Journal of Nursing Education*, 37(6), 278-280.

## Appendix

### Interview Questions

#### DEMOGRAPHICS

Age?

Country or countries of ethnic origin?

What is your racial/ethnic background?

Do you receive public assistance?

How many years of school have you completed?

What is your marital or domestic partnership status?

#### ADAPTATION TO DISABILITY

How old were you when you acquired your disability?

How did you acquire your disability?

How has your life changed since you acquired your disability?

How have you adapted to your disability?

How would you rate your level of independence?

How have friends helped you?



How have family helped you?

How have professionals helped you?

What structural or psychological barriers exist with family?

What structural or psychological barriers exist with friends?

What structural or psychological barriers exist with professionals?

Are you active in advocating for yourself to get the technology and services you need?

Do others advocate for you?

If so, who are they?

Have you experienced prejudice related to your disability?

Have you experienced discrimination related to your disability?

#### WORK AND RECREATION

Are you dating?

Are you satisfied with your sexual life?

Do you have a job?

If so what is your job?

If not, what do you do during the day?

What do you do for fun during the day?

What do you do for fun during the evenings?

What do you do for fun during the weekends?

#### DRINKING BEHAVIORS

Did you drink beer or alcohol prior to your disability?

How much?

Do you currently drink beer or alcohol?

How much?

Is it easy for you to get beer or alcohol?

How do you get it?

Where do you usually drink?

Has this changed since your disability?

With whom do you usually drink?

Has this changed since your disability?

Do people in your family drink?

How much?

Do your friends drink?

How much?

How much do you drink when you are with your family?

Has this changed since your disability?

How much do you drink when you are with friends?

Has this changed since your disability?

How much do you drink when you are with your partner?

Has this changed since your disability?

Would you say that drinking is an important part of your life and your significant relationships?

Has this changed since your disability?

Have you ever sought treatment for a drinking problem?

Have doctors or other professionals discussed your drinking habits with you?

Do you feel informed about possible consequences of drinking related to your disability?

#### Acknowledgements

The authors wish to thank John de Miranda, James Rimmer, Christopher Keys, Dennis Moore, Kristy Hart, and the faculty and postdoctoral fellows at the Brown University Center for Alcohol and Addiction Studies for their valuable suggestions and assistance with this article. We wish to thank Molly Hostetler for her assistance in data collection and transcription.

Pamela Block, Ph.D. is an adjunct assistant professor of cultural anthropology and sociology at the University of Rhode Island and a fellow at the Brown University Center for Alcohol and Addiction Studies. Her research interests include empowerment and multiple marginalization including intersections of gender, race, ethnicity, poverty, and disability. Currently she studies social relationships, adaptation to disability, and alcohol and substance use by people with recent traumatic brain and spinal cord injuries.

Beth Bock, Ph.D. is an Assistant Professor in the Department of Psychiatry and Human Behavior at Brown University Medical School. Her research areas include behavioral and preventive medicine with special focus on mediators of health behavior change and substance use.

Bruce Becker, M.D., M.P.H., is an Associate Professor in Community Health at Brown University Medical School. He is also an Attending physician in the Department of Emergency Medicine at Rhode Island Hospital. Dr. Becker maintains an active research program examining health behavior change and substance use among emergency medical patients.

Sarah Everhart, M.P.H. is the Program Director for Shake-A-Leg, a non-profit organization that provides second-stage traditional and complementary therapeutic and recreational opportunities for children, adolescents and adults who experience neurological disabilities. She is also an adjunct faculty member at the Community College of Rhode Island's Physical Therapy Assistant Program and has a spinal cord injury. While in graduate school she completed an internship at the National Council on Disability. She directed the program featured in this article from 1996-2000.

[< Back to the Table of Contents >](#)