

## PRACTICE BRIEF

# Acquired Brain Injury Club at a Community College: Opportunities for Support, Involvement, and Leadership

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### Abstract

*College students with acquired brain injuries face unique challenges. The likelihood of individuals with acquired brain injury experiencing isolation, lack of social support, and diminished self-esteem, along with cognitive impairments, is well documented in the literature. This article presents an overview of a community college's club for students with acquired brain injuries that attempts to address these concerns.*

Inpatient and outpatient rehabilitation of individuals with acquired brain injury has continued to improve over the last 20 years (Olver, Ponsford & Curran, 1996). However, research indicates that the psychosocial and cognitive impairments persist several years beyond initial rehabilitative efforts (Finsest, Dynes, & Berstad, 1995). Olver et al. state that while significant functional gains can be seen in the first five years of recovery, over half of those in their study reported they were socially isolated since their accident. Teasell and McRae (2000) found in their study of social factors following stroke in younger (under 50) individuals that along with return-to-work issues, relationships were also affected. Ellis-Hill and Horn (2000) found that participants in their study on identity and self-concept following stroke reported “a negative sense of self, reduced social activity, and psychological morbidity despite inpatient and outpatient rehabilitation.” In the area of minor brain injury, Kay (1993) refers to the “shaken sense of self...especially in the absence of external validation and in the presence of normal appearance” with a “loss of self-esteem, isolation and alienation as a result” (p.75). These impairments in the area of psychosocial functioning significantly impact the ability of individuals with acquired brain injury to resume and engage social roles, and result in significant social handicap (Wood, 2001).

In an effort to address the social aspects of disability along with the medical, The World Health Organization (WHO) has recently expanded the International Classification of Functioning and Health (ICF), thus

putting “health and disability into a new light” (World Health Organization, 2008). Its categories for measuring disability now include the categories of “activities and participation” that address community, social, and civic life. Addressing these areas for individuals with acquired brain injury remains a challenge. Community-based case management models and day treatment programs can approach this need (McMillan & Oddy, 2001), but funding limitations and access to such programs remain problematic. In her discussion of loneliness and isolation following brain injury, Rowlands (2000) offers a “Circle of Support” model where a network of friends consisting of “workers or volunteers” is built around an individual who may have lost friends and support as a result of disability, such as brain injury (p. 159). One of the limitations of establishment of this kind of network, according to Rowlands, is the “lack of reciprocity,” though there is potential for members to become “helpers” in the group. Neath and Schriener (1998) address the areas of participation and civic involvement for individuals with disabilities through the concept of empowerment. They advocate for an extension beyond the medical model of rehabilitation, toward a focus on facilitating empowerment that is more in keeping with the spirit of the disability rights movement where “individuals come together as equals...relationships are characterized by respect for and valuing of other group members...[with] an important social force that aids in the development of personal power for individuals” (Neath & Schriener, 1998, p. 219).

## **Problem**

Adults with acquired brain injuries turn to colleges and universities in search of education for new careers, to complete degrees previously started, and/or pursue opportunities to further improve cognitive and/or physical skills impaired due to their brain injuries. Higher education can prove particularly daunting for this population given the nature of their disabilities, which often include impairments in attention, memory, and executive functioning. Along with these impairments, psychosocial issues can interfere with academic success. The significance of this cannot be underestimated as Morton and Wehman (1995) remarked, "The rejection experienced through loss of social support [following brain injury] contributes to feelings of low self-esteem and depression..." (p.82). Tinto (1999) describes the importance of college students, especially first year students, receiving "academic, social and personal support" to facilitate college persistence (p. 5). Accommodations and support services through disability resources departments can do much to provide academic support to college students with acquired brain injury. Less defined are methods for providing social support and connecting these students to the larger student collegiate experience described by Tinto.

## **Student and Location Information**

Santa Rosa Junior College in Santa Rosa, California, enrolls over 36,000 students each semester, and approximately 200 students have verified acquired brain injuries. The Acquired Brain Injury Students (ABIS) Club was initially formed by students in 1999, becoming one of approximately 40 student-organized college clubs. Club membership ranges between 15 and 25 students each semester. Club members generally reflect a wide range of diagnoses, with stroke, traumatic brain injury, post-concussion syndrome, and brain tumor being the most common. Ages of the club members range from 18 to over 60, with most students in their thirties and forties. Educational goals range from personal interest to career development or university transfer.

## **Strategy**

The ABIS Club was established by a group of students completing a "Coping Strategies for Students with Acquired Brain Injuries" class. A group of three students from the class recognized the value of the support that had been fostered over the course of the

semester, and sought to establish an avenue where they could provide each other and other college students with ongoing opportunities for connection beyond the classroom setting. The students chose to utilize the structure of a student club in which they could establish regular meetings, participate in collegewide activities as a recognized club, and increase awareness in the college community of issues related to brain injury. This plan became the club's stated mission to "provide support, opportunities for socialization and education."

Since a faculty advisor is required for the activation of all SRJC clubs, the founding club officers invited the Disability Resources Department instructor who had taught their Coping Strategies Class to act as their faculty advisor. The advisor meets weekly with the club president to provide instruction in the process for agenda development and techniques for facilitating group discussion. In addition, the faculty advisor reinforces the implementation of cognitive strategies related to the particular challenges expressed by the president, and offers a framework for the student's problem solving and decision making related to club activities. Over the course of the year that a student serves as president, cues provided by the faculty advisor during these meetings are faded, and the student typically requires only minimal, if any, assistance in agenda development and strategy implementation to complete presidential duties by the end of the year. In addition to meeting with the club president individually, the faculty advisor attends weekly officer and general meetings that are run by the club president. The advisor's role in officer meetings is one of support to the students, providing occasional input for cognitive strategy implementation, or making inquiries that promote reflection in the decision-making process. Participation by the faculty advisor in club general meetings is usually limited to clarification of collegewide procedures and guidelines. Although the faculty advisor's involvement in club general meeting discussions is quite limited, the advisor's attendance at these meetings generates issues for discussion at the individual meetings with the club president. For example, how to deal with students interrupting, or how to reach out to new students in the club.

While the faculty advisor plays a role in fostering the leadership skills of club officers, the foundation of the club lies in the strong support experienced by members. The club president facilitates the weekly club general meetings. At the beginning of initial meetings each semester, the president reviews meeting guidelines, such as turn-taking rules, and an agreement is made to preserve confidentially due to the sometimes-sensitive nature of topics discussed. A positive tone is

set in the group when each member is asked to share one good thing that happened to them during the past week. Responses range from “I got my drivers license back” and “I got an ‘A’ on my physics test” to “I’m here.” The majority of the time is spent on the meeting’s topic selected by the officers. Meeting topics range from the mundane to the profound, such as “What strategies do you use to help you be organized?”, “How do you cope with fear?”, and “How are you moving forward in your life?”

Beyond the support provided by the club, members have the opportunity to hold office through annual elections. Participation in club leadership requires the implementation of a wide spectrum of cognitive skills in dynamic settings. It is precisely these demands that provide officers with occasions to apply strategies in novel and meaningful ways. While the faculty advisor serves as a resource to club members and officers, the club’s direction and success is determined by its officers and members. Opportunities for feedback on performance are inherent in the process. For example, if students have not effectively planned events, their errors eventually become apparent to them in very concrete ways. Club members play an important role in providing feedback to their officers on the success or perceived lack of success in planning or following through on a club activity. Students remind each other that feedback should be given in a way that reflects their motto, “Be excellent to each other.” The extent to which officers are successful in implementing strategies depends on the degree of their impairment and the goals the officers have chosen to pursue. While the success of carrying out a large event brings confidence and abundant opportunities for learning, some of the most meaningful learning stems directly from attempts that did not reach students’ initial expectations.

The uniqueness of this club model is inherent in the dynamic milieu the junior college environment offers. There are varied opportunities for socialization, development of leadership skills, and promotion of brain injury awareness for the college and community at large. Individuals in this student-driven club participate in various college activities, including “Day Under the Oaks,” Santa Rosa Junior College’s community open house, the Inter-club Council’s softball tournament, and the ABIS club-sponsored annual Brain Injury Awareness Day. This is consistent with the club’s mission to support and promote opportunities for socialization, and education, and resonates with the idea of empowering individuals with disabilities put forth by Neath and Schriener (1998).

## Observed Outcomes

The success of the ABIS Club can be measured by its longevity, its acknowledgement by the college community, data supporting its role in student persistence, and testimonies by the students themselves. The club is currently in its tenth year since its establishment. The club’s level of participation in club-sponsored activities and collegewide events has resulted in its being voted “Best Campus Club” on three occasions, and “Best Campus Involvement” twice by the college’s Inter-Club Council. Several ABIS officers have moved on to participate in student government. Regarding student persistence data, a correlation between participation in the ABIS Club and increased persistence is compelling. The total number of students enrolled at SRJC in fall 2005 who persisted to spring 2006 was 66% (Santa Rosa Junior College, 2007), whereas of those SRJC students who participated in the ABIS Club during the fall 2005 semester, 82% persisted to spring 2006 (Santa Rosa Junior College, 2005).

ABIS officers attest to the value this experience offers, including instilling a sense of confidence while reality-basing their perceptions of their abilities. Some have reported a direct link between their time spent as ABIS officers and their success in their vocational pursuits. As one student stated, “Being treasurer in the ABIS gave me a chance to try out my cognitive skills in a challenging but safe environment—it gave me the confidence to go back into the work world... I am now a successful realtor, and I owe part of my success to my participation in the ABIS Club” (P. Kelly, personal communication, October 11, 2005).

## Implications

Organizing a club like the ABIS in colleges and universities can provide an avenue for students with acquired brain injuries to receive support, participate in the higher education environment, and realize their capacity for self-determination. In a higher education arena, these individuals can easily become lost in a setting that varies in the degree of structure and the support it offers. A club model can be applied to colleges and universities to create supportive “laboratories” where students with acquired brain injuries can establish ongoing relationships, apply cognitive strategies, and develop leadership skills. Through their active involvement, opportunities are created that engage the students in the college milieu, which fosters academic persistence (Tinto, 1999). Faculty and staff can also benefit from developing a better understand-

ing of the unique challenges of students with acquired brain injuries, their capacity for success, and the special circumstances that continue to draw them to higher education. Ultimately, participation by these students in higher education enhances the diversity of college learning communities, and adds to the richness of experience that colleges and universities offer.

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## About the Author

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