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PROJECT TITLE: Meeting the long-term needs of adults with acquired brain injury through community-based clubhouse programming

PROJECT DESCRIPTION

This project involves a reciprocal relationship between students and faculty of the College of Health and Human Services (CHHS) and The Krempels Brain Injury Foundation (TKBIF) in Portsmouth, NH. TKBIF is a non-profit organization that operates SteppingStones, a community-based post-rehabilitation program for adults with acquired brain injury. This project involves many facets that address each element of the UNH academic plan. First, students have an opportunity to intern at SteppingStones, where they discover how a person’s life can be drastically altered by brain injury. They gain valuable knowledge from the members of the program while they apply their skills learned in the classroom helping members meet the long-term challenges of brain injury.

TKBIF operates SteppingStones on a limited budget. The UNH student and faculty support provides the program with resources that totaled over 7500 in-kind volunteer hours in 2006. Students interact closely with members of the program and accompany them on Functional Skill Outings into the greater Portsmouth area. In turn, members frequently provide guest lectures in CHHS classes. The support and encouragement that this relationship provides has resulted in a tremendous sense of community.

Students are often engaged in research with faculty at SteppingStones, which transforms the program into a living laboratory. Students investigate the long-term needs of survivors of brain injury, they seek to determine issues that impact community integration and quality of life, and they learn how community-based programming can help to address these issues. The feedback that is received from students and members about their experiences has allowed TKBIF and the CHHS to develop an increasingly effective relationship.

BACKGROUND INFORMATION/STATEMENT OF THE ISSUES/PROBLEM

For many of the nearly nine million Americans living with the long-term impact of acquired brain injury (ABI) from trauma or stroke, lack of substantial medical coverage has left them adrift in their communities without the resources or support to address their needs (Hare, Rogers, Lester, McManus, & Mant, 2006; McCarthy, Dikmen, Langlois, Selassie, Gu, & Horner, 2006). Survivors of ABI have reported numerous and diverse needs within the first year of their injury. Despite active involvement in rehabilitation, these needs tend to persist following the first year of recovery (Corrigan, Whiteneck, & Mellick, 2004).
Some communities have attempted to address these needs by providing access to community-based “clubhouse” programs. The aim of such programs is to provide “members” with support, socialization, and opportunities to develop skills to successfully integrate them into the fabric of their community and society. The ability of clubhouse models to meet the persistent needs of survivors of ABI has been documented (Jacobs, 1997, 1996; Malec, 2001; Powell, Heslin, & Greenwood, 2002). However, few facilities offer successful programming addressing long-term needs of ABI survivors and their families, and little is known about the successful qualities of facilities that attempt to provide an expanded continuum of care (Cicerone, Mott, Azulay, & Friel, 2004). The purpose of the present investigation is to report on the effectiveness of one such community-based clubhouse as perceived by members, family members and caregivers of survivors, and student interns, who participate in this program.

PROJECT DETAILS

Goals and Objectives: The purpose of this investigation is to determine the effectiveness of SteppingStones, a post-rehabilitation, clubhouse model approach to long-term support for survivors of ABI. Program participants (members, caregivers, and interns) will be asked to determine how effectively SteppingStones meets the needs of members. These needs have been identified in the literature, and feedback from practicing clinicians working with survivors of ABI was attained to validate the necessity of addressing such needs in a community-based approach. The project also seeks to determine how much participation in the program impacts the quality of life for the members. Finally, student involvement provides a driving force for the programs sustainability. The impact of the program on the academic and professional development of the students will also be determined.

Target Population/Audience: The project will be addressing the SteppingStones community. It is hoped that by disseminating the findings in peer-reviewed journals and national conference presentations that the broader brain injury community can be reached.

Methods: Quantitative and qualitative methodologies will be used to determine the effectiveness of the SteppingStones program to meet the needs of its members and provide students with an effective learning environment. Surveys and focus groups will be used to gain qualitative data. In addition, standardized measures of cognitive function, community integration, and quality of life will be administered to members.

Evidence of External Collaboration and Partnership: The relationship between UNH CHHS and TKBIF begun in 2000. At that time, one faculty member and five students from the Department of Occupational Therapy provided support to six members of SteppingStones. This semester five faculty and 40+ students from four CHHS departments provided resources to a membership of approximately 160 individuals. In addition, TKBIF Board of Directors has approved this research project.
**Expected Impact:** This project will help to reinforce the reciprocal relationship between the TKBIF and the CHHS. The findings should determine strengths and weaknesses of the program and allow us to better meet the needs of all participants.

**Scholarly Connection:** My involvement with TKBIF and SteppingStones has allowed me to fully integrate my pedagogical, research, and outreach initiatives. The relationship between CHHS and TKBIF has afforded me the opportunity to invite SteppingStones members into my classes to speak with students. This activity has been found to be therapeutic for members and thoroughly educational for the students. The research projects help to provide further interaction between students and members; and students further their knowledge about long-term issues impacting brain injury recovery.

**EVALUATION PLAN**

One element of success for this project will be whether or not TKBIF can use the findings to improve the needs of members. Follow up investigations can help determine if members feel their needs are being met. The results of the current study will be disseminated to TKBIF Board of Directors, the members of SteppingStones, and family and caregivers.

In addition, results will be submitted to peer-reviewed journals of brain injury, rehabilitation, and allied health. Findings will also be presented at regional and national conferences.

Finally, the findings from the evaluation of students can be used to develop multidisciplinary courses that focus on brain injury and community service with survivors of brain injury. Presentation of findings in pedagogical and allied health program development will be pursued.

It is hoped that SteppingStones can serve as a model for other communities seeking to provide support and resources to survivors of brain injury. These findings can be shared with these communities to encourage provision of this need.