REHABILITATION RESEARCH AND TRAINING CENTER ON COMMUNITY INTEGRATION OF PERSONS WITH TRAUMATIC BRAIN INJURY

FINAL EDITION

We have spent the last 5 years increasing our knowledge of how TBI affects individuals, their family, friends and the community around them. The following information attempts to relay what we have learned during this time. We wish to thank all the individuals with TBI, their family members and friends, the clinicians and researchers as well as the community members who gave their support to this grant. In our final newsletter, we will review some of the findings of our research and training projects. The highlights of each project will be found here. However, all findings and more discussion of these results will be found at our web site: http://www.tbicommunity.org

We are happy to announce that the National Institute on Disability and Rehabilitation Research has funded us for another 5 years as a Rehabilitation Research and Training Center on Developing Strategies to Foster Community Integration and Participation for Individuals With TBI. Please continue to visit our website, which will be continuously updated with new information and products.

Research Highlights

Increasing Social Networking Opportunities following TBI

- Implementation of a social peer mentoring program designed to reduce social isolation following TBI is extremely difficult. However, mentors and mentees who completed the program report high levels of mentor and mentee satisfaction regarding their participation in the program.
- Difficulties encountered when implementing the study indicated that there are obstacles to providing peer mentoring in an expansive geographical area such as Houston. Obstacles included limited public transportation options, reliance on family members for mentees' participation, idiosyncratic preferences of mentors/mentees when being matched, extent of cognitive impairment in the mentees, and substantial geographical distances limiting feasibility of matches.
- ♦ Ideas for refinement and enhancement of future peer mentoring programs for persons with TBI include increased emphasis on personal characteristics of participants, greater integration of family members into the mentoring program, and greater attention to potential geographical constraints.
- ♦ A manual to assist others in setting up a social peer mentor program can be found at:

"Making Connections After Brain Injury: A Guide for Social Peer Mentors" http://www.tbicommunity.org/resources/publications/peer_mentor_manual.pdf

Ethnic Diversity in Acceptance of Disability, Community Integration Needs, Barriers and Supports

- ♦ Established construct validity of the Acceptance of Disability Scale-TBI version for persons with TBI from diverse racial/ethnic backgrounds
- Regardless of race/ethnicity, persons with lower education and lower annual household income (less than \$20,000) had lower acceptance of disability.
- Even after controlling for age, education, injury severity, and income, race/ethnicity was associated with overall community integration, independence in the home, and productivity, with minorities having less integration in all areas.
- A Regardless of race/ethnicity, lower income was associated with lower social integration and with lower subjective satisfaction with community integration.
- ♦ There were racial/ethnic differences in perceived importance of community integration activities, with Blacks and Hispanics placing greater emphasis than Whites on non-work activities, including parenting, housekeeping, cooking, and exercise.

Research Highlights continued

Family Members as Rehabilitation Paraprofessionals: Use of Distance Learning as a Training Tool for Family Members in Rural Areas

- Using web-based videoconferencing to train caregivers in rural areas to help persons with TBI is feasible and results in high levels of satisfaction for caregivers regarding new knowledge gained and confidence in helping their family members compensate for problems in their daily lives.
- ♦ Logistical issues, such as the time and cost involved in arranging for videoconferencing for caregivers, indicated that alternative ways of providing training should be explored, such as online workshops, educational DVDs, and Webinars

Effectiveness of a Brief Educational Intervention for Reducing Substance Abuse after TBI

- There was a significant binge history by treatment interaction for expectancy that alcohol use could result in cognitive and physical impairment. Persons who had binged in the month prior to injury were less likely to report that cognitive and physical problems could result from alcohol use. This suggests that persons who were binge drinkers prior to injury may be less likely to benefit from a brief intervention.
- ♦ The attribution of alcohol to cause of injury was positively associated with readiness to change alcohol use. This is consistent with prior research indicating that catastrophic injury may result in a "teachable moment," when persons with injury may be more open to interventions that target increasing readiness to change.

Exploring Intimacy following TBI

- ♦ The meaning of intimacy to participants was all-encompassing, including physical, spiritual, emotional, and intellectual aspects. Intimacy is perceived as related to a sexual relationship, but not synonymous with it.
- ♦ Factors affecting relationship strength after injury included: social support, strength of family bonds; good communication (especially regarding the injury); shared spirituality and religion; a common sense of humor; acceptance of life changes; the partner's understanding of disability; past experience with hardship and losses; quality of pre-injury relationship; and the extent to which the partners value and appreciate each other and the relationship.
- Factors contributing to conflict and threat in relationships after injury included: low self-confidence/feelings of self-worth in the person with injury; feelings of decreased masculinity or femininity in the person with injury; uncertainty about partner's feelings/love; sexual difficulties; role changes and conflict; lack of family support; lack of understanding about cognitive and emotional changes; role strain; and poor communication.
- Over half of the relationships terminated from baseline to 6-month follow-up. Deterioration was related to: instability of pre-injury relationship; difficulty coping with cognitive and emotional changes in the person with injury; financial stress; difficulty coping with role changes; decreased intimacy; and poor communication.

Understanding Factors that Contribute to Decreased Social Integration for Persons with TBI

- ♦ Validation of the LaTrobe Communication Questionnaire for persons with TBI
- After controlling for age, education, and performance on executive functioning measures, it was found that social communication performance contributes significantly to occupational outcomes and to social integration.

Training Highlights

National Information Educational Resources, Dissemination and Technical Assistance Center for the Community Integration of Individuals with TBI

- ⇒ Developed a website for English speakers and Spanish speakers (www.tbicommunity.org).
- ⇒ Provided technical assistance to 350 persons with TBI, their caregivers, and health professionals
- ⇒ Disseminated 10 newsletters targeted toward consumers and highlighting different RRTC projects. All are available in Spanish as well as English.

Increasing Community Awareness of TBI and Reducing Attitudinal Barriers

Online training videos can be found at:

"Increasing Community Awareness of TBI and Reducing Attitudinal Barriers: A Video Series" http://www.tbicommunity.org/training/publications/

T2/index.html

Social Action Networking in Persons with TBI

- ⇒ Participation in the Social Action Networking groups resulted in improvements in perceived choice and control regarding community living and participation, improved participation in a range of community activities, improved integration and sense of membership within communities of choice, and improved social supports and networking.
- ⇒ A manual to allow replication of the Social Action Networking Group for persons with TBI is available by contacting Dr. Joy Hammel at hammel@uic.edu

Center for Creative Expression for Persons with TBI

Successfully implemented a partnership with a local arts organization to offer 25 art classes to persons with TBI

Training of Healthcare Professionals in the Community Integration Needs of Persons with TBI

A training manual for Clinical Social Workers to facilitate serving persons with TBI can be found at:

"Systematic Approach to Social Work Practice:
Working With Clients With Traumatic Brain Injury."

http://www.tbicommunity.org/research/publications/
SW_Manual2009.pdf

A training manual for Clinical Psychologists to facilitate serving persons with TBI can be found at:

"Guidebook for Psychologists Working With Clients With TBI"

http://www.tbicommunity.org/research/publications/ Psych TBI Manual FINAL129.pdf

A series of 4 podcast modules to train primary care physicians to facilitate serving persons with TBI can be found at:

"Assisting Patients With Traumatic Brain Injury: A Brief Guide for Primary Care Physicians"

http://www.tbicommunity.org/resources/podcasts/index.htm

Training Highlights continued

Understanding Training Needs for Traumatic Brain Injury Among State Vocational Counselors

An online educational course to train state vocational counselors in the needs of persons with TBI and how to better serve them can be found at:

"TBI for VR Counselors" - and online manual and self-study course

http://www.tbicommunity.org/research/publications/ VR Manual/index.html

State-of-the-Science Conference on Community Integration for Persons with TBI

- ⇒ Held a State of the Science Conference April 12-13, 2007.
- ⇒ Recommendations for future research on community integration, based on lectures and roundtable discussions held during the conference, can be found at:

http://www.tbicommunity.org/training/T7/synopsis.html

How to use our web site:

- 1. Go to http://www.tbicommunity.org
- 2. Look at guide on left side of page in green box
- 3. Decide what you would like to view
- 4. Click on the item you chose.

http://www.tbicommunity.org

Check out our Publications

Struchen, M.A., and Clark, A.N. (2007) Systematic Approach to Social Work Practice: Working with Clients with Traumatic Brain Injury (PDF file)

Sander, A.M. (2007) Picking Up the Pieces after TBI: A Guide for Family Members (PDF file)

Margaret A. Struchen, Ph.D., DeLisa West, Ph.D., et al. (2006)
Making Connections after Brain Injury: A Guide for Social Peer Mentors (PDF file)

Margaret A. Struchen, Tresa M. Roebuck, Monique R. Pappadis, & Jason E. Ferguson (2008) I Have a What? A Guide for Coping with Mild TBI (PDF file)

Margaret A. Struchen, Monique R. Pappadis, Tresa M. Roebuck, & Jason E. Ferguson (2008) I Have a What? A Guide for Coping with Moderate-to-Severe TBI (PDF file)

"Is This Normal? Expectations after Traumatic Brain Injury and Helpful Tips."

Download a PDF version of the booklet.

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