

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

UPDATE: Social Peer Mentoring Clinical Trial

Margaret A. Struchen, Ph.D.

After traumatic brain injury (TBI), one of the major problems that people often face is loneliness. Many people with moderate to severe TBI lose friendships they had prior to their injury. This means that people with TBI often have fewer people with whom they can talk or do social activities with. Often, the family becomes the main source for social activities. The RRTC on Community Integration of Persons with TBI has been interested in finding ways that might help people with TBI who are having problems with loneliness to make new friends and get involved in more social activities.

Researchers at the RRTC have been conducting a clinical trial to see if using social peer mentoring might help persons with TBI in developing social relationships. Social peer mentors are people with TBI who have had a good social outcome and are interested in helping others with brain injury improve their own social outcomes. The mentors are trained by the RRTC research team to help others with TBI improve their social outcomes by:

- ⇒ Increasing how often a person does social activities (including activities like going to dinner with friends, having people visit your home, talking on the telephone, or attending sports events, for example).
- ⇒ Increasing the number of people that a person can do these social activities with. has been used in some groups.

The study has been designed as a randomized clinical trial, which is one way of testing how well a given treatment or intervention works. For the social

peer-mentoring project, what this means is that a person who wants to have a social peer mentor has an equal chance of being assigned to have a mentor right away or is assigned to a wait list. Those assigned to the wait list will be able to have a mentor after a four-month waiting period. This study compares how people do during and after working with a social peer mentor as compared to those who haven't had the chance to work with a mentor yet. We will be comparing these two groups on several things, including:

- ⇒ The number of times that they've participated in social activities
- ⇒ The changes in numbers of people they interact with
- ⇒ Symptoms of depression
- ⇒ Feelings of loneliness
- ⇒ Satisfaction with life

The study is still ongoing, so we do not know whether or not the program has been successful. Although results are not known at this time, many of those who participated in the social peer mentoring reported they found the experience to be a good one. So far, 8 people with TBI have received and completed the social peer mentoring period. In addition, 4 others are currently working with a social peer mentor. In the "wait list" group, 12 people have completed all of the evaluations and three more are waiting to finish their evaluations. We will update you on the results of this study once it has been completed. Check out our website at www.tbicommunity.org to view the updated results.

Tips to Help Improve Social Outcomes after TBI

Margaret A. Struchen, Ph.D.

Friendships and other relationships (with family, co-workers, etc.) can be changed after TBI. Friendships are particularly vulnerable to change since, by definition, the bonds of friendship are voluntary. That is, there is no formal tie (like marriage license, kinship, or work structure) that keeps friends together. Friends stay together because they enjoy each other's company and like to spend time together. If one of the friends changes in how they behave or in their interests, which can happen after a TBI, it may affect the friendship.

Studies have shown that people with moderate to severe TBI often lose friendships and have problems with loneliness. However, there has not been a great deal of information to help people with injury or their family members to try to improve social outcomes for their loved one with TBI. As part of the social peer mentoring project of the RRTC, a manual was developed to help with training mentors to help their partners to make new friends and get involved in more social activities. This manual has a lot of practical suggestions that may be helpful for family members to use with their loved ones with TBI. The manual is called: "Making Connections After brain injury: A guide for social peer mentors." It is available for downloading at the Center's website at: www.tbicommunity.org.

Continued on next page ⇒

Tips to Help Improve Social Outcomes after TBI (continued from page 1)

Social Resources:

Here are some suggestions about how to help your family member with things to do:

Talk to your family member about his/her interests.

- ⇒ What kind of activities does he/she like to do?
- ⇒ What kinds of things have they been doing in the past few months?
- ⇒ Who do they do things with?

Help your family member find out what is available in the local community and assist them in developing a strategy for learning about future social activities.

- ⇒ Is there a local newspaper? Encourage your family member to look at the activities section of the paper (if this exists) to find out about upcoming events.
- ⇒ Does your family member have access to the Internet? And are they able to use the Internet effectively? Can this be taught?
- ⇒ Look through the phone book to get an idea of possible resources in the community (like restaurants, theaters, community centers, etc.). Assist your family member in creating a list of places of interest.
- ⇒ Contact local churches and community centers to find out about activities. Again, help your family member make a list of such centers and/or their regular activities.

Initiation:

You can work with your family member to help with initiation, planning, and remembering social activities. Remember to emphasize that organization skills used for social events and activities can be used for other life activities (like keeping medical appointments, etc.).

Develop Ideas for Social Events

- ⇒ Create a menu of activities that your family member can select based on their interests and availability of the activity.
- ⇒ Use local papers, Internet, or community sources to help identify possible events.
- ⇒ Help your family member organize this “menu” of activities in written form or in a computer file, so that they can easily access the information later.

Communication:

There are several aspects of communication that go into planning a social activity.

- ⇒ Your family member may need to have some assistance with setting up a phone list of people who might be available to engage in social activities with them.
- ⇒ Your family member might need to get organized to contact people for a particular activity and may need to develop a system to keep track of whom they have called and who has accepted the invitation.
- ⇒ Your peer family member might need some assistance with their communication skills on the phone. This could include making a short note of the important information to present to others to help with memory problems, or could include providing some feedback on their communication style.
- ⇒ In addition to contacting others to set up social plans, your family member will need to take responsibility for notifying family/friends who reside with them about their plans.

Time Management

- ⇒ Encourage your peer partner to create an accurate estimate of how long it takes them to get ready for the activity.
- ⇒ As part of planning, your peer partner should estimate the time that it will take to get to the event or activity, how long they plan to stay, and how long it will take to return home. If more than one destination is planned for an outing, transportation time and the time at each destination should be estimated.

Teach Planning Strategies

- ⇒ Use a structured worksheet to help your family member plan, organize, and remember social activities. Make copies of the worksheet for them to use for future events.
- ⇒ If your family member already has a system for organizing information (like a memory notebook, day planner, or calendar), try to help them integrate this worksheet with their existing system.
- ⇒ You can also encourage your family member to use the worksheet to plan other events in their day-to-day life activities as well.

These ideas are just a few that may help your loved one in developing a more satisfying social life. For more information or ideas, please access the manual on our website: www.tbicomunity.org. The manual is available under the “Resources and Publications” section of the website. If you do not have access to the internet and would be interested in receiving a copy of the manual, please contact us at (713) 630-0522.