



PEER MENTORING TBI CONSUMER REPORT #7

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Individuals with Traumatic Brain Injury, Department of Rehabilitation Medicine,
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What is Peer Mentoring?

The essence of peer mentoring is that individuals who are ‘veterans’ of an experience such as TBI help others ‘new’ to the experience to adjust. Peer mentoring programs have been developed for individuals coping with a variety of medical conditions and physical disabilities. An example is the Parent-to-Parent Program initiated by the Beach Center on Families and Disability at the University of Kansas to help parents of children who are newly diagnosed with developmental disabilities.

In 1998, the Research and Training Center (RTC) adapted the Parent-to-Parent model for use with individuals with TBI and their family members. We are currently evaluating this program, known as the TBI Mentoring Partnership Program. This issue of *TBI Consumer Report* describes how the program works and initial data on its impact. The *Report* also discusses how similar peer mentoring programs might be established in other areas of the country.

What is the TBI Mentoring Partnership Program (MPP)?

The TBI Mentoring Partnership Program was developed as a joint venture of the RTC and the Brain Injury Association of New York State (BIANYS). In the program, trained TBI ‘veterans’ are matched with peers across New York State seeking individualized support. The goals of partnerships are to provide emotional support, expand coping skills, improve knowledge about TBI (particularly resources) and teach advocacy skills.

In developing the program, BIANYS was responsible for the recruitment of individuals with TBI and family members as mentors (the ‘veterans’ of TBI) and as partners (those seeking mentoring). BIANYS also selected program coordinators to provide continuing technical assistance to mentors. The RTC was responsible for mentor training and for program evaluation.

All mentors attended a full-day training workshop focused on enhancing their communication, listening and advocacy skills, as well as increasing their knowledge of TBI and community resources. A smaller group of mentors - the Hospital Advocacy Team (HAT) - received additional training, to play an active role in recruitment of potential partners within hospital settings.

Who volunteered to become mentors?

The majority of individuals (70%) who volunteered as mentors are individuals with a TBI. Most (75%) have remained active as mentors, with many involved in four or more

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partnerships since initiation of the program. Mentors *with TBI* were as likely to be male as female; they were predominantly white (despite major efforts to recruit individuals from diversity backgrounds) and over the age of 30. *Family members* who volunteered as mentors were predominantly female, white and somewhat older.

Who participated as partners?

Recruitment of individuals in need of peer support was done through outreach to acute care hospitals and rehabilitation facilities by the HAT team members; through a BIANYS phone hotline; through meetings with independent living centers, rehabilitation hospitals and support groups; via presentations at local and state TBI conferences; and through a notice on the RTC's website. All persons seeking peer support completed an interview with program staff to determine their support needs and suitability for the program. The individual was then 'matched' with a specific mentor who had a common medical and/or personal background. Partners were predominantly female, white and between the ages of 31 and 45, with more individuals with TBI than family members seeking peer support.

What was the nature of the mentoring partnerships?

The duration of the partnership and its intensity was a decision made by the mentor and partner together. The majority of contacts were made via phone, with personal contact or e-mail also used. On average, partnerships lasted seven months and consisted of 13 contacts. Partnerships ended either because the partner's needs were satisfied or the partner elected to end the partnership. To date, more than 125 partnerships have been created, with approximately 50% completed.

What were the benefits of peer support for partners?

Partners reported many positive effects of program participation on their lives:

- More **knowledge about TBI**
- Better **ability to cope** with the consequences of TBI, including depression and sadness
- Improved **quality of life**

Partners also reported that program participation had *little if any impact* on:

- Social support from family, friends and community
- Coping with anger and anxiety

Family members, in general, were more conservative in their evaluation of the degree of the program's impact, tending to state that the program had "some" rather than a "major" impact across most areas explored in the study. Comments from partners can be found on the next page.

What were the benefits of peer support for mentors?

Mentors described benefits in six areas:



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- Increased **ability to cope**: better equipped to face challenges, to communicate effectively and to be advocates for themselves and others in the community
- Satisfaction in **helping others**
- **Shared experiences** with another person
- **Learning more** about TBI and community resources
- Increased **self-confidence** and acceptance of brain injury
- **Decreased isolation** and improved ability to get along with others

What have we learned?

The evaluation of the Mentoring Partnership Program is continuing, but initial results show that individuals with TBI and family members have been empowered in shaping their own program of mutual support. As *partners*, individuals formerly isolated after the onset of TBI have had the benefit of a connection with someone who has ‘been there’. As a direct result of the program, *mentors* have been empowered and now serve as resources to others in the community. This type of program is a ‘win-win’ situation for all involved.

Can the mentoring program be replicated in other communities?

Expansion of the mentoring program model to other communities is the logical next step. Using technical assistance from RTC staff, the Brain Injury Association of New Jersey has created a similar program (“TBI Family CARE”) as part of a project funded by the Health Resources and Services Administration. Preliminary findings from New Jersey suggest that the Family CARE mentors and partners are similar to those in the RTC program, and satisfaction with the program is positive for mentors and partners alike.

Starting a Peer Mentoring Program

Based on the RTC’s experiences with programs in New York and in New Jersey, we have found that several key elements are associated with initiation and maintenance of **quality programs**:

- An **organization** is needed to provide structure and support for program development and maintenance.
- **Financial resources** are needed to support one or more individuals to administer the program, as well as to cover expenses associated with mentoring (e.g., phone, travel).
- Mentors need systematic **training**, as well as continuously available technical support from program staff.
- Program staff needs to engage in systematic **quality assurance** - gaining feedback from both mentors and partners to insure that partnerships are addressing needs.
- Access to a large number of individuals with TBI and family members must be obtained, to insure **recruitment of qualified mentors**.
- A network of community services (e.g., rehabilitation units, support groups, acute care facilities) is helpful in providing access for **recruitment of individuals in need of peer support**.

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The RTC suggests that **agencies** and community service settings work with their **state brain injury association** in planning program development. In this process, consider drawing on the experience of the RTC (mary.hibbard@mssm.edu), which provides technical assistance for program development (including training), implementation and quality assurance. **Individuals** with TBI and family members who would like to see a mentoring program initiated locally, should contact their state brain injury association to encourage its involvement in working with others to get such a program started.

Comments from Partners

From partners with a TBI:

“I am more open to people about what happened to me.”

“My mentor stood by me through all the ups and downs and explained to me why I was going through that. She even heard me crying a lot.”

“The program helped me with communication and socialization. It helped me get out more and talk to other people. I have reincorporated myself into society more.”

“The mentoring program allowed me to speak my mind and be the way that I am.”

“The mentoring program made me see that there were people out there willing to help.”

From family members:

“With time and more knowledge, I learned to separate a little from my daughter and her problems and to understand that she also has a life. I can be there for my daughter, but that is not my only role.”

“The mentoring program gave me more of a feeling about how TBI can affect members of the family.”

“I knew that if my own personal support group failed, I would have somewhere else to go to pick me up and put me on my feet again.”

Comments from Mentors

“I am able to deal with my emotional problems better because I have learned that I am not the only one who is going through this problem.”

“I have enjoyed feeling as though I could be helpful to someone- that from my family’s misfortune, something good can be found.”

“The mentoring program is a precious link for most. Because we can’t remember yesterday and even sometimes what we had for breakfast, brain injured individuals benefit uniquely from having a mentor. It is often the mentor who instills hope, energy and joy by reminding us of all we have accomplished. The program has defined the meaning of sharing and concern.”



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“The opportunity to connect with someone else who has been through a similar trauma and who has experienced the same kind of family upheaval and who is trying to rebuild her own life serves to lessen the isolation that trauma can bring. My partner has enriched my life with her courage.”

“It has let me see how far I have come since the bad, confused beginning of this journey. It let me feel proud that I was accepted to be a mentor; it made me feel I must be okay if they think I can help others. It has given me the courage to try harder and to overcome some of my remaining problems. I wish I had a mentor when I was starting the journey of my recovery.”

For more information:

Hibbard, M.R., Cantor, J.B., Charatz, H.J., Rosenthal, R., Ashman, T.A., Gundersen, N., Ireland-Knight, L., Avner, J., & Gartner, J. (2002). Peer support in the community: Initial findings of a mentoring program for individuals with TBI and their families. *Journal of Head Trauma Rehabilitation*, 17, 112-131.

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