



Increasing Community Awareness of Traumatic Brain Injury

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One of the problems in the recovery from traumatic brain injury (TBI) is the lack of understanding about TBI by the general public. Because a person often seems to be physically okay after the trauma, it is difficult for family, friends and neighbors to understand the other effects of TBI. This lack of understanding can cause problems that keep people with TBI from going out into the community. It often results in people with TBI feeling alone and not a part of a community. Some families or individuals understand TBI, but it is tiring to have to explain about it over and over. It is hard to explain to friends and relatives, but to have to repeat it every time your children make a new friend or every time your social group adds a new member, is very tiring.

Many people with TBI and their families want to give other family members, friends, neighbors, church and work friends something that tells them, "This is some of what has been happening with me, it will help you understand about TBI."

One of the projects of our RRTC is to find out from people with TBI and their families what would be the best way to help tell their community about TBI.

To help find the most important content and best format options, we had an online survey on our TBI Community website for people to complete. We got 83 surveys from people with TBI and 32 from parents of people with TBI.

Those with TBI said the top three things that **THEY** were most interested in learning more about were:

- ✓ **Marriage and relationship issues after TBI (61.4%)**
- ✓ **Making and keeping friends after TBI (60.2%)**
- ✓ **Changes in social skills after TBI (60.2%)**

The three things they think **OTHER PEOPLE** in their lives should know more about were:

- ✓ **Problems with mood after TBI (72.3%)**
- ✓ **Problems with thinking abilities after TBI (72.3)**
- ✓ **Changes in social skills after TBI (71.1%)**

When asked what things about TBI are the hardest to explain to others and that others have a problem understanding, three items rank at the top for those with TBI:

- ✓ **Problems with thinking abilities after TBI**

- ✓ **Changes in social skills after TBI**
- ✓ **Problems with mood after TBI**

These same three things were at the top of the parents' list too.

The parents of those with TBI said the top three things that **THEY** were most interested in learning more about were:

- ✓ **Problems with thinking abilities after TBI (71.9%)**
- ✓ **Changes in social skills after TBI (71.9%)**
- ✓ **Problems with mood after TBI (71.9%)**

The three things they think **OTHER PEOPLE** in their lives should know more about were:

- ✓ **Problems with thinking abilities after TBI (81.3%)**
- ✓ **Problems with mood after TBI (78.1%)**
- ✓ **Changes in social skills after TBI (75%)**

We not only wanted to know which topic areas were important, we also wanted to know how they would like the information presented. The two ways people liked the best were:



- DVD/videotape (67%)
- Written (booklets, pamphlets, etc.) (57.8%)

However, it is worth noting that those with TBI liked the DVD/videotapes more (67.3%) than the parents (59.4%) while the parents liked the Written (75%) over those with TBI (52.8%). This is probably not surprising since many younger people prefer videotape/DVD over written material for learning material.

The RRTC is now studying information we got from talking with people on the phone and in person in focus group sessions. These results will be put together with the online surveys and then educational materials will be developed. *The completed materials will be available through our Center's website at:*

www.tbicomunity.org

Please look for these materials to come.

The Word from the Street:

Common Questions I have heard

Jason Ferguson, TBI Survivor

Many recurring questions seem to come from the non-TBI sector whether I am speaking to medical students or junior high students.

- **How long did it take to recover?**
- **Are you 100% now?**
- **What was the hardest thing about recovery?**

I tell them that I will be recovering for the rest of my life. I will never be back to 100%. And I tell them that the hardest part of recovery was not re-learning how to walk, talk or swallow water. For me it was the emotional aspect of everything, losing my friends and family and becoming invisible. I could not understand what I did to make people not like me anymore. I think that has been the hardest part of recovery for me, rebuilding my social structure. Not only has it been the hardest part for me, but the best. I see the world in a different light now

and I try not to take things for granted anymore. One other statement I hear on a constant basis is, “I would have never known by looking at you”.



As we all know, looks are not always as they seem.

State-of-the-Science in Traumatic Brain Injury 2007 Conference: *Results Coming in Next Issue*

A State-of-the-Science conference sponsored by the Rehabilitation Research and Training Center (RRTC) on Community Integration of Persons with Traumatic Brain Injury will be held April 12-13, 2007 at the Ritz-Carlton-Pentagon City Hotel in Arlington, Virginia.

The purposes of the conference are to help provide the sponsoring agency, the National Institute on Disability and Rehabilitation Research (NIDRR) with an overview of the field and to help provide direction for future research priorities and research. In addition, there will be panel discussions regarding life areas related to the community integration of people with TBI. Some of the topics that will be addressed are those you said were of interest to you including: employment, education, transportation, cultural issues, parenting, friendships, intimacy, recreation, meaning in life and spirituality.

We will report some of the results of the conference here in our next issue of the newsletter and on our website at www.tbicommunity.org under Training, Project T-7.

