

**State-of-the-Science Conference 2007****Community Integration of Persons with Traumatic Brain Injury**

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A State-of-the-Science conference sponsored by our Rehabilitation Research and Training Center on Community Integration of Persons with Traumatic Brain Injury and its sponsoring agency the National Institute for Disability and Rehabilitation Research (NIDRR) was held April 12-13, 2007 at the Ritz-Carlton-Pentagon City Hotel in Arlington, VA.

*“I’m doing more research in the area of minority issues”.*

The purposes of the conference were to provide the sponsoring agency, NIDRR, with an overview of the field and to help provide direction for future research priorities. Topics for the conference were selected to include those that persons with TBI believe are important, but that have not been studied much by researchers. The topics included: employment, education, transportation, cultural issues, parenting, friendships, intimacy, recreation, meaning in life, spirituality, and social advocacy. Many of these areas have been well-studied by researchers working in areas other than TBI, such as spinal cord injury and psychiatric illness. In order to benefit from their knowledge, we invited experts from these other areas to pair up with experts in the area of TBI. For each topic, each expert gave a 15-minute presentation about what scientific knowledge is already known and what gaps in knowledge are needed to be filled.

**Specific recommendations for each of the eleven topic areas and each of the speaker presentations can be seen on our web at:**

<http://www.tbicommunity.org/training/T7/index.htm>

Following the expert presentations, there were small group discussions that included the speakers and the audience members attending the conference. The audience members included clinicians who treat persons with TBI, survivors of TBI, and their family members. The goals of the discussion groups were to

come up with ideas for future research and to propose ways that the research could be supported (for example, by partnerships between organizations and/or researchers). There was a lot of enthusiasm among the discussion groups. A few of the recommendations include future research on how changes after TBI affect parenting; development of successful transportation methods for rural and urban areas; special needs of persons from diverse ethnic/cultural backgrounds; implications for school systems, such as how many students have TBI and what is the best educational environment for them; and how employer attitudes affect the ability of persons with TBI to return to work.

These recommendations and the complete list now become a part of the possibilities for study by other researchers and for funding by sponsoring agencies. Specific recommendations for each of the eleven topic areas and each of the speaker presentations can be seen on our website at: <http://www.tbicommunity.org/training/T7/index.htm>

*“In my clinical work, I’m placing more importance on assessment of community ties, spirituality, relationships and meaning”.*

One month after the conference, we sent an evaluation to all the participants to learn the effect of the conference and how they were using the information they learned. More than half of the participants said that they have made changes in their clinical practice as a result of what they learned at the conference. Nearly 75% said that they will make changes to their future research plans as a result of the conference. Some specific actions that people had already taken as a result of the conference included “I’m doing more research in the area of minority issues”; “In my clinical work, I’m placing more importance on assessment of community ties, spirituality, relationships and meaning. Many said they had presented the results to their research teams. The conference has the potential to affect clinical practice and future research, as more people read about it on our web site.

***Be sure to check out the website under Training Project T7***

**[www.tbicommunity.org](http://www.tbicommunity.org)**

## **The Word from the Street:**

### **The State of the Science Conference**

*Jason Ferguson, TBI Survivor*

In April of this year we, the Brain Injury Research Center (BIRC), hosted the State of the Science Conference in Washington D.C.. I believe the conference was a big success. This year there were doctors and researchers invited to present on a wide array of disabilities. Our objective was to hear about some things that have or have not been working for other disabilities. We had many different speakers giving a different perspective of what tools or protocols may be helping for other disabilities.

This whole thing reminded me of who I am, how I got here, and just how far I have really come. It was really evident of just how little is known about brain injury and a reminder of how looks are not always as they seem. I had a chance to speak with another TBI survivor (a professional) while in D.C.. We shared some similar stories of how society does not see our disability and acts as if we do not really have one.

Later, a Major from the U.S. Marines stopped by to pick up some literature about TBI and our conference. He stated that he was working with the "Wounded Warrior" Project and was sorry he would not be able to attend the conference. The Wounded Warrior Project they have is for the injured service members coming back from Iraq or Afghanistan.

When I introduced myself to him and told him that I am a TBI survivor, he looked me over and looked at the backside of my head asking where my injury was and stating that I must be recovered 100%. I told him that happens a lot and that I, like other TBI survivors will be recovering for the rest of my life. It's not like breaking your arm where you get a cast and it heals up. It is a lifelong process.

I got to meet people from around the U.S. and also give out the booklet my wife and I wrote, "Is This Normal?". It was nice to get good feedback and tell the story of my recovery and what helped and did not help. Getting to be included in this was a big honor for me and I want to thank everyone involved in this for letting me be a part of it.

#### **Caught**

*By Jason Ferguson*

Caught within my own self,  
HELP! HELP! HELP!  
Caught within my own self,  
I try to yell, can't, can't scream for help,  
I can hear the outside world, and I understand,  
Quit speaking for me! I try to yell again but no words come out,  
What happened to me? Who are you?  
I would tell you who I am if I could.  
The man in the mirror, is that me?  
There is some resemblance I can see.  
Parts of me that worked before aren't working now,  
Numb, no feeling! Hey, wake up!  
The constant spinning is slowing;  
I think I am catching up.  
Almost, but not quite there,  
If I can just get off this treadmill, I could make up ground,  
I will make it to the light, but for now I will bask in the  
warmth,  
It is not so cold in here any more, for I am not alone.  
A sense of peace and calmness reassures me that I will be  
okay.  
Jesus can hear me, why can't you. Peace

#### **New World**

A new world has been entered that does not like to have  
set boundaries of any kind,  
This world is foreign to others, stuck in your own mind,  
Silent, unseen, so it does not exist to most,  
But it will take anyone; it does not discriminate, it is proud  
to boast.  
Vision becomes distorted or may turn black as night,  
It may be just a knot or sensitivity to light,  
Verbal motions but no sound to the others,  
But ever so right to our family, there are many new sisters  
and brothers,  
Every 21 seconds another joins in,  
Without the knowledge of the journey about to begin,  
It may be mild or it may be severe but it is all the same,  
It will not be leaving anytime soon and TBI is its name.

**By Jason Ferguson**