**WV TBI/SCI Fund Board Meeting**

**WVU Extension Office, Charleston, WV**

**September 14, 2016 10 AM**

Appointed members in attendance: Ginger Dearth, John Yauch (by phone), Jodi Calissie (by phone), Joseph McCagg, Jennifer Rhule, Brad Anderson, Dr. Lawrence Dolecki (by phone)

Agency representatives in attendance: Tiffany D Redman, Sherry Rockwell (by phone), Carla Cleek

Associates in attendance: Teresa McCourt, Cassandra Toliver (by phone), Jennifer Logan, Angela Morales, Terry Cunningham, Bonnie Hicks

* **Call to Order** – Chair Dearth called the September meeting of the TBI/SCI Fund Board meeting to order at 10 AM with welcome and introductions by all in attendance, both in person and by phone.
* **Approval of the minutes** is delayed until the meeting packet can be sent via email to those in attendance by phone.
* **WV Legislature PERD** - Chair Dearth opened the discussion about the WV Legislature Performance Evaluation and Research Division letter and report by explaining the process of the legislative review and the actions that will take place next.

The Legislative Review is conducted, the agencies involved are permitted written responses that will be submitted with the report to the legislature. When the Joint Committee Reports are officially presented during the legislative session, the agencies effected will have 5 minutes to address the legislature in regard to the report. That 5-minute opportunity was originally scheduled for a time during the September 18-20 session, but has been postponed until the December 4 – 6 session.

Electronic copies of the meeting packet were received by those on teleconference and Chair Dearth gave everyone several minutes to review the information: Letter from John Sylvia, August 29, 2016 report, recommendations.

* Chair Dearth opened the floor for a **question and answer** period.

Have we experienced this situation from the legislature in the past?

* Not in recent memory

Who will advocate for the TBI survivors if the TBI/SCI Fund Board takes away the voice?

* This is the main concern expressed by Chair Dearth in her response to the review. Oversight and services provided are necessary. A reorganization of the current board would be an opportunity to improve the board rather than elimination of the board altogether.
* The board discussed the advocacy for survivors and the “grassroots” efforts of education across the state.

Will we lose the FFY program?

* No funds will be removed from the TBI/FFY program
* Cassandra Toliver reviewed with the board the legislative process that DHHR and specifically the Funds for You program went through over the past several months.

Is the TBI Waiver program going through an audit?

* Each bureau was audited as to their portion/role in regard to the WV Traumatic Brain Injury program.

What will happen when Chair Dearth goes before the legislature?

* Chair Dearth may be questioned about her role, but program questions will go to the appropriate bureau or agency that can answer them.
* Cassandra Toliver stated that at her level, they cannot go before the legislature unless requested and then the Commissioner will go on behalf of the BHHF.

Chair Dearth requested the DHHR response to the legislative review.

* Cassandra Toliver stated she will relay the request to the deputy commissioner for the needs of the TBI/SCI Fund Board.
* **Spinal Cord Injury**

The board discussed the connection of TBI and SCI.

* Dr. Lawrence Dolecki stated that the Spinal Cord Injury component became tied to the Traumatic Brain Injury component years ago when the Veteran’s Administration and the Director of Rehabilitation Services met and the thinking at the time was the TBI and SCI are dual disabilities for many residents of WV. The TBI program was strong in the state and SCI was added to it with the thought that TBI could enhance the awareness of and bring more education to the SCI issues in the state.

Penny Burnside faithfully tracked the SCI information over the years, but that process eventually fell off in implementation.

The true emphasis has always been on the TBI community.

* Sherry Rockwell, who holds the position formerly held by Penny Burnside, stated the information is in the statewide registry and can be tracked. The information is available although not currently being tracked and reported.
* Cassandra Toliver asked what other states may be doing with SCI information in regard to tracking. Is it in the public health registry? Is it collected in other states and recorded with the TBI information?

* **Services for TBI survivors**

The board discussed the limited opportunities for rehabilitation and recovery in the state of West Virginia, the advocacy required to change that lack of service and the other (border) states that offer those opportunities.

* Joseph McCagg addressed the board regarding the prevalence of TBI survivors leaving West Virginia for services in Kentucky, Virginia and other states. Also, the lack of community based services, support mechanisms and facilities for moderate to severe needs.
* Brad Anderson concurred with the information from Joseph McCagg and stated people who are in the midst of the TBI process are overwhelmed and left feeling there is nothing for them. The short answer to what services for moderate to severe needs are available is that there are none.

Where do people get information in the state of West Virginia when they have a TBI? How are people referred to the TBI program?

* Terry Cunningham related the process of the TBI Registry to the TBI/SCI Fund Board – the hospitals of WV are to report any head injury to the WVU TBI Services program (24 hour stay at the hospital criteria), who then forwards information. This is WV State Code and in that code, it is noted that the CED maintains a central registry of persons with head injury. TBI services provides a survey and initial information letter to the survivor by mail. The only information received on the survivor is: name, address, age, reporting hospital. The form needs to be updated to include the phone number so more direct contact can be made.
* Teresa McCourt stated CED is capturing unmet needs and reporting those numbers to DHHR on a monthly basis. The data on what is needed in WV exists.

The board discussed what was in the initial mailing, its effectiveness and the need to update that process for more effective outreach.

The board discussed the former BIAA group that operated in West Virginia and how it worked with the needs of TBI survivors, the current B.I.G group in West Virginia and what survivor-based supports can be utilized by TBI survivors, caregivers, healthcare workers and family members.

* **TBI Waiver**

West Virginia TBI Waiver program provides home and community services to residents with TBI. They are provided in concert with support and assistance of family, friends and healthcare workers.

* Teresa McCourt noted there is no “umbrella” organization in West Virginia for the TBI community and no “tie-in” group other than the TBI/SCI Fund Board. All the agencies represented seem to work independently of one another rather than cohesively and there is no group focus. That leads to spinning wheels in each agency and no one moves forward.

How does the Quality Improvement Council for the TBI Waiver program differ from the responsibility of the TBI/SCI Fund Board responsibility? Is Waiver capturing unmet needs?

* Jennifer Logan, Waiver representative, stated the Waiver Quality Improvement Council assesses the needs of the TBI Waiver program ONLY as opposed to the services of all TBI services, which is the TBI/SCI Fund Board area. The Waiver is currently working under managed enrollment and referrals are down. The APS/now Kepro – yes, are capturing unmet needs. The Waiver Quality Improvement Council – no, they are not.
* Brad Anderson stated the Quality Improvement Council recommends and amends the TBI Waiver process.
* **Board participation**

Chair Dearth stated the services that are lacking for TBI survivors, how to work with SCI information and what to do about people leaving the state for better services are issues that need to be brought to the forefront, to the board, so that they can be addressed. These issues cannot be addressed when the board participation is lacking.

The membership of the board does not provide the updates and reports necessary.

There is a lack of participation that then leads to the board not fulfilling their role for the legislature.

The board discussed the various agency roles and what reports should be included in board meetings.

* Tiffany Redmon, WV Department of Education and the Arts, attending for Cabinet Secretary Kay Goodwin – reinforced the point that attendance is a statutory requirement of members for this board. Article 10-K lists the people who are mandated to attend and those that are appointed by the Governor. Those requirements need to be reiterated to the membership and brought to the attention of those agencies that have not been in attendance.
* Jennifer Rhule stated the board member reappointment process needs to be taken care of ASAP to bring the board to full strength and effectiveness

**\*\*Motion:**

For the November meeting – each agency should be prepared with a 5-minute report on the TBI related issues within their agency, how they are being addressed, what needs to be addressed and how the board can provide oversight or support.

* + - Motion by Jennifer Rhule
    - Seconded by Brad Anderson
    - All in favor – no dissention

**\*\*Motion:**

The minutes for the May 18, 2016 WV TBI/SCI Fund Board meeting are submitted, reviewed and approved with the change in spelling to Jodi Calissie’s name.

* + - Motion by Brad Anderson
    - Seconded by Larry Dolecki
    - All in favor – no dissention
* **WVUCED Updates**:

**TBI Federal Grant** – Presented by Terry Cunningham

The TBI Federal Grant report will cover 6/1/2015 – 5/31/2016 and what was accomplished in that fiscal year.

* Developed new trainings in substance abuse, children, family, boomer consumers
* Maintained registry and increased reporting hospital compliance
* Conducted 4 rural town halls for resource/outreach
* Assistance in establishing the Huntington Support Group and facilitating meetings
* 16 HELPS programs, 35 TBI 101, 6 TBI & Substance Abuse, 5 TBI 201 multi-day conferences
* Attended WV State Fair and conducted screenings, distributed helmets, promoted helmet awareness and safety
* Graduate Assistant is in place and focused on sports concussion issues
* Attendance at state festivals, health fairs, advocacy days, university and college presentations
* New neuropsychological testing contracts were established
* Attendance at the OT Conference and NASW Conference
* 25,000 copies of materials and information distributed throughout the state of WV
* 55 partner agencies within the state received TBI trainings

The board asked for more information on the Federal trainings that took place.

* Terry Cunningham explained who received the trainings, what compensatory strategies will be provided, what videos are available on the website.
* Brad Anderson requested the TBI presenters attend a B.I.G meeting and provide a compensatory strategies training event.

**TBI Registry** – Presented by Angela Morales

* + Several hundred registry surveys and letters were sent out over the past few months
  + The current mailing is not effective, but it is planned to improve it, changing contact information, etc…

**TBI State Program** – Presented by Angela Morales

* + Established more contacts and opportunities for neuropsychological evaluations
  + Identified and developed the Graduate Student project: developing a communication strategy for all sports in all areas (schools, community, etc…); develop curriculum to train after concussions; return to learn programs

**FFY Program** – Presented by Angela Morales

* Please see the report in the packet for the 2015-16 fiscal year numbers. Those were not complete during the May 2016 meeting.
* There was no meeting in July 2016, August 2016 had 4 applicants and those numbers are not complete at this time so have not been finalized.

**Support Group Event**

Teresa McCourt stated that CED/TBI will provide more support groups for the community and to bring those to fruition, a proposal for a statewide Support Group Conference has been submitted. That conference is planned to build, educate and provide information on how to sustain support groups across the state. The two tracts in the conference will be 1. Facilitators/advocates and 2. Survivors. The conference funding will include: conference space, support group professional speakers, attendance assistance, meals, etc…This is proposed for the spring 2017 timeframe.

**Legislative Breakfast**

* Brad Anderson expressed his concern that there was no Legislative Breakfast event during the legislative session in February/March 2016. The need to put advocates, survivors, healthcare and caregivers in front of the legislators to promote the awareness and the need for services.

The board discussed alternative venues to pursue legislators and garner support for TBI related issues.

* Teresa McCourt explained that due to the delicate nature of the budget in the state of WV, CED must be prudent with their resources. The event is important, but needs to have broader focus from the survivors, support groups, community, etc…rather than being a CED-led event.
* **TBI Waiver Updates**

**Waiver Report** – Presented by Jennifer Logan

* Please see the Implementation Report through July 2016 in the packet
* 300 applications submitted
* 1 applicant in Managed Enrollment (currently up to 4 as of September)
* 63 active participants as of July 2016
* Please note the applications received in 2016 (chart on page 1)
* Several important changes in the last year including, what goes out in the information packets, who can sign for services and most importantly the age 3 rather than 22 to participate.
* **Summation**

**Where do we go from here?**

Chair Dearth reviewed several items that will be addressed:

1. Agency reports will be expected at the next board meeting. A message to the board members reminding them of this expectation will go out with the board meeting reminder and minutes.
2. Establish the priorities of the board
3. Funds for You reports will show a breakdown of the categories – how the money is being used/dispersed
4. Legislative event – ideas on reaching out for support – who are the legislators we have sent things to in the past? Who is on the legislative review committee? Get that information to the board by the next meeting
5. Update the TBI/SCI Fund Board list on the WVU TBI Services website

* Joseph McCagg addressed the board about making the WV TBI Waiver and TBI services a priority item to address. He stated the Legislative Review is correct in that there are great thoughts and advocates in the room for the TBI/SCI Fund Board, but nothing comes to fruition from it.

There needs to be a checks and balance system with the board.

There are people in WV who are not being served and are leaving the state for place like Kentucky, where there are more and better services.

The legislature has to invest in the end result or we are spinning our wheels on the board trying to get services for the residents of the state.

Mr. McCagg went on to state that he advocates for an update to the waiver and to the state services and will go to the legislature to report his thoughts and opinions on how to keep people in the state of WV and what services are required to do so.

* **Adjournment**

Having no further business the board adjourned at 11:58 AM

* + - * Motion by Tiffany Redmon
      * Second by Joseph McCagg
      * All in favor – no dissention

Respectfully submitted,

Bonnie Hicks

WVU TBI Program Assistant