

# MINUTES Friday, January 24, 2014 1:00 p.m.

Members Present:

Jeffrey Barth, Ph.D. Lisa Bradford John Butrick Susan Elmore John Heath Deborah Johnson

Anne McDonnell Cynthia Millican

Amy Marschean

Cynthia O'Donoghue, Ph.D. (Vice-Chair)

Jodi Power, RN, JD (Secretary)

Barbara Seymour Camilla Schwoebel

Brian Shenal, Ph.D. (Chair)

Michelle Witt

Members Absent:

Charlotte Arbogast Heather Funkhouser Board

Gavl Brunk

Melissa Fox, DPT
Aaron Goldmann
Jocelyn Johnson
Katherine Lawson
Paul Sharpe, R.N.

Mark Salisbury (Immediate Past-Chair)

Julie Triplett

Others in Attendance:

Patricia Goodall

Kristie Chamberlain (Staff)

Mary-Margaret Cash Laurie Silva

Karen Brown

University of Virginia School of Medicine Salem Veterans Administration Medical Center Survivor, Member of Denbigh House Clubhouse

Department of Behavioral Health & Developmental Svcs

Family Ombudsman, DARS Federal TBI Grant

Department of Education

Senior Policy Analyst, DARS Alzheimer's Disease &

Related Disorders Commission Brain Injury Association of Virginia

Family Member

James Madison University

Department of health Professions / Board of Nursing

Department of Medical Assistance Services

Virginia Wounded Warrior Program

Salem Veterans Administration Medical Center Virginia Alliance of Brain Injury Service Providers

Dementia Services Coordinator, DARS
Department of Health / Injury Prevention
Valley Associates for Independent Living
University of Virginia Health System

Survivor, Richmond Survivor, Ashburn

Virginia Board for People with Disabilities

Department of Health / Statewide Trauma Registry

Family Member

Virginia Office for Protection and Advocacy

Department for Aging and Rehabilitative Services
Department for Aging and Rehabilitative Services
Department for Aging and Rehabilitative Services

NeuroRestorative Clinical Evaluator

Brain Injury Services, Inc.

**OPENING PROTOCOL**: Brian Shenal, Ph.D., Chair

Brian Shenal, Chair, called the quarterly meeting of the Virginia Brain Injury Council to order at 1:05 p.m. The meeting was held in Conference Room 101-103-105 at the Virginia Department for Aging and Rehabilitative Services, 8004 Franklin Farms Drive, Henrico, Virginia 23229. The Chair welcomed Amy Marschean (staff member for the Alzheimer's Disease and Related Disorders Commission, a Council of the DARS Division of Aging) as a new advisory member. Dr. Shenal asked members and guests to introduce themselves.

# Recognition of Service

Dr. Shenal recognized At-Large (voting) members Melissa Fox and Cynthia Millican for their service on the Virginia Brain Injury Council since 2011. Both were presented certificates thanking them for their three years of service on the Council. Melissa Fox was not present at the meeting; therefore DARS staff will mail the certificate to her.

### Approval of January 24, 2014 Meeting Agenda

The agenda was approved after Patti Goodall requested that "Remarks from the DARS Commissioner" be struck from the agenda, since Commissioner Rothrock was not able to be present at the meeting.

# Approval of October 25, 2013 Meeting Minutes

The October 25, 2013 meeting minutes were approved with no changes.

### Public Comment Period

A public comment period was offered and there was no public comment offered.

# **NEW BUSINESS:**

# <u>Virginia Alliance of Brain Injury Service Providers / Brain Injury Association of Virginia: Legislative Agenda Update</u>

Michelle Witt, Chair of the Virginia Alliance of Brain Injury Service Providers (VABISP), and Anne McDonnell, Executive Director of the Brain Injury Association of Virginia (BIAV), provided an update of the budget bill amendment request for this year's General Assembly totaling \$4,530,000 (\$2,480,000 for direct services to hire 28 staff to meet the needs of the wait list and \$2,050,000 for contract allocation increases). This \$4.5 million request, which was patroned by Delegate Cox and Senator Marsh, is to provide programs/services and address gaps in services for the unserved and underserved brain injury population in Virginia, as well as provide "infrastructure support" for existing program operations. It was also pointed out that for the period 2009-2014, there was a zero net increase in funding for brain injury services, yet a 14% increase in the number of individuals served. The average cost is \$1,020 to serve each person with a brain injury.

Anne McDonnell summarized talking points that BIAV developed for speaking with legislators, noting that Brain Injury Awareness Day at the General Assembly will be Thursday February 6, 2014. She added that a sample letter for contacting legislators is available on BIAV's website if individuals are not able to attend Awareness Day to meet legislators directly. She encouraged everyone to contact their legislators before "crossover" on February 13<sup>th</sup>. She summarized other noteworthy legislative initiatives with implications for the Council, including a study by the Joint Legislative and Audit Review Committee (JLARC) which was introduced by Senator Frank Ruff to follow up on progress made toward access to brain injury services in Virginia (following up on a 2007 JLARC study). Anne stated that the JLARC study would likely not be approved, but that it may go to the Virginia Joint Commission on Health Care (JCHC). She also mentioned a budget amendment put forward by BIAV that would provide funding to hire a full-time brain injury coordinator at the Virginia Department of Behavioral Health and Developmental Services (DBHDS). Finally, Anne mentioned that several brain injury professionals had been appointed to subcommittees of the governor's Mental Health Task Force.

### Appointment of Committees

Dr. Shenal provided a history and description of each of the standing committees of the Virginia Brain Injury Council. He reminded Council members that they are expected to serve on at least one committee during their time on Council. Dr. Shenal requested volunteers on the following committees

• *Bylaws Committee* – As Secretary of the Council, Jodi Power serves as Chair of the Council's Bylaws Committee. Susan Elmore and Dr. Jeffrey Barth agreed to serve on the Bylaws Committee. It was

- noted by DARS staff that only one telephone conference call is expected following individual review, as major work was done regarding the bylaws last year.
- Priorities Committee Michelle Witt agreed to serve as Chair of the Priorities Committee, and Anne McDonnell, Camilla Schwoebel, Barbara Seymour, and John Heath volunteered to serve on the committee.
- Funds Dissemination Committee This ad hoc committee was formed in response to new funding allocated by the General Assembly for SFY '15. DARS is required to "consider the recommendations of the Virginia Brain Injury Council when disseminating new funding for brain injury services." There is a short turn-around once the General Assembly session ends in March. The following members agreed to serve on the Committee: Mark Salisbury, Brian Shenal, Lisa Bradford, Cynthia Millican and Susan Elmore. In absentia, Mark Salisbury was nominated to serve as Chair of this Committee given his interest and service on past Committees and experience as Immediate Past Chair of the VBIC.

### Educational Meeting in April

Dr. Shenal initiated discussion about topics of interest for the Council's annual educational meeting typically held each April. Suggested topics included:

- legal issues affecting individuals with brain injury;
- educational issues related to students with brain injured (suggestion to have someone from the Disability Law Center as a resource to address this topic, but also to cover the continuum of issues in elementary and secondary schools, as well as community colleges and the workplace);
- aging and dementia among individuals with TBI;
- cognitive therapy (what it is; how it benefits individuals with brain injury; how to access and pay for it); and
- an update on the Mental Health Task Force whose report is due in October 2014. It was noted that Chuck Walsh, former VBIC member and current executive director of a Community Services Board (CSB) is a member, could facilitate this discussion at council's invitation. It was suggested that this report could be scheduled later in July versus April.

Dr. Shenal and DARS staff indicated the Council was not limited to receiving education on topics of interest only at the annual April meeting, given the level of interest on multiple topics.

Anne McDonnell moved that the Virginia Brain Injury Council receive information concerning legal and educational issues for brain injured clients at its April 2014 meeting designated for education, and then receive an update on the Mental Health Task Force workgroups at its July 2014 meeting when more work has been accomplished. The motion was seconded by John Heath and passed unanimously.

### Federal TBI Grant Update

Patti Goodall from the Department for Aging and Rehabilitative Services (DARS) provided a brief update, reminding members of the one-page written update provided in advance of and at this meeting. She noted the following:

- Year 5 of the current federal grant ends March 31, 2014. The last deliverable is an outreach letter to Community Services Board (CSB) executive directors, to be sent by DARS Commissioner as well as DBHDS and DVS commissioners; logistics for the outreach mailing will be handled by BIA). A copy of the final, signed letter will be made available to Council members upon request.
- 2014-2018 Health Resources and Services Administration (HRSA) Request For Proposals (RFP) for Federal TBI Grant The RFP for the new federal grant cycle was released and applications are due on March 7, 2014. It is for a four-year grant including \$250,000 in federal funding with a required \$125,000 state match (Virginia must provide). The grant must address four identified systems-change priorities described in the guidance documents: 1) information and referral; 2) professional training; 3) screening; and 4) resource facilitation. A meeting is scheduled for Wednesday, January 29, 2014 to

discuss ideas for Virginia's grant application. Council members and representatives of the state-funded Brain Injury Services Programs are invited to participate. A Commonwealth Neurotrauma Initiative (CNI) Trust Fund grant project will provide state cash match for the first year of the federal grant. The CNI project will provide a comprehensive update of the Council's 2010 Neurobehavioral Services "white paper." It was noted that VBIC serves as the advisory group for Virginia's federal grant, and members were encouraged to submit ideas and/or attend the January 29<sup>th</sup> planning meeting.

• Statewide Needs & Resources Assessment: The Department for Aging and Rehabilitative Services (DARS) contracted with Virginia Commonwealth University's Survey, Evaluation and Research Lab (SERL) to conduct a statewide *Brain Injury Needs & Resources Assessment* that included focus groups, written surveys, and telephone interviews. The purpose of the assessment was to identify current gaps and barriers in services for caregivers and individuals with acquired brain injury. Prior to the 2013 SERL needs assessment, Virginia's last assessment was conducted in 2000. The survey closed on October 4, 2013 and data were obtained and analyzed from the 213 survivors, 182 caregivers, and 60 providers. The results have been compiled into a 260 page report, which will be finalized and posted on the DARS and BIAV websites.

Jennifer Reid and Dr. Mary Moore presented a brief summary for Council members. Noteworthy data highlighted from the 2013 Brain Injury Needs & Resources Assessment included:

- o It was difficult to obtain responses from southern and southwestern parts of Virginia, to have the survey results representative of those areas of Virginia
- o Survivors have a mean age of 47 years; 87% were Caucasian; and gender was essentially equal
- While 65% of survivors were employed full-time before their brain injury, only 21% are employed full-time now;
- o Caregivers were 82% female, mostly over the age of 50; 51% were parents and 24% were spouses of the survivor
- Vast majority of respondents report a severe TBI (versus mild or moderate), with cognitive disability (94%) and behavioral or emotional problems (74%) being most commonly reported.
- o 61% Caregivers and 53% survivors report not receiving information/advice after their TBI
- o Caregivers need more help and Personal Assistant Services are needed for ADLs
- o Half of responders worry about future living arrangements
- Cognitive therapy is the greatest unmet need, reported by both survivors and caregivers; other unmet needs for survivors include individual counseling and alternative to medical services (acupuncture, massage, etc)
- o Greatest gap in services is for behavioral therapy (52%) and then for supported living environments (group living, residential rehab and ALF) and life skills training
- o Mild TBI survivors report needing more services that moderate/severe
- o Responses to open-ended questions have not been qualitatively analyzed (60 pages).

Council members were cautioned that, though the results of the survey are interesting and reflect important information, they should not draw or present "hard and fast" conclusions or assumptions about the results as there are limitations, such as the fact that this is not a truly representative sample but a report on "self-selected" respondents. It was noted that this data will be used as reference when writing the proposal for Virginia's federal Traumatic Brain Injury "systems change" grant, due in early March.

### **UNFINISHED BUSINESS:**

### Nominations and Elections Committee

Dr. Cynthia O'Donoghue, Chair of the Nominations and Elections Committee, presented the slate to fill three at-large VBIC member positions. These include two positions for professional members and one member in the survivor/family-member/caregiver category. The slate was presented:

- For the two available positions for *Individuals who are licensed, registered or certified healthcare professionals*, the Committee presented Dr. Kimberly Hemphill, PhD, RN as first choice for both positions, and presented Kimberly Welch, LPTA as second choice for the first open position and Mark Bender, PhD, as second choice for the second open position.
- For the one available position for *Survivor*, *family member*, *caregiver or representative of a person with a brain injury*, the Committee presented Brian Pearce, a survivor (and veteran) as its first choice, and Linda Wyatt, family member/caregiver as second choice for this position.

Anne McDonnell moved that the Virginia Brain Injury Council accept the Nominations and Elections committee slate as presented by the Committee. The motion was seconded by Cynthia Millican and passed unanimously.

It was noted by DARS staff that Lorraine Enright had submitted an electronic vote in advance and that the slate would be forwarded to Commissioner Rothrock for his consideration and decision about appointments.

Dr. Shenal thanked the Nominations and Elections Committee for their work. These members included: Cynthia Millican, Lorraine Enright, Lisa Bradford, Heather Board, and Mark Salisbury, in addition to the Chair Dr. O'Donoghue.

# <u>Update on Neurobehavioral Focus Groups</u>:

The Neurobehavioral Focus groups were a federal TBI Grant activity. DARS and the Brain Injury Association of Virginia (BIAV) worked with an outside consultant to convene three neurobehavioral focus groups in August and September of 2013; twenty-four stakeholders from various settings and disciplines participated in the groups. The key themes that emerged were funding for care, funding for advocacy, qualitative and quantitative data collection, and the need for a dedicated neurobehavioral coalition.

During November and December, previously invited focus group participants who were unable to attend were invited to complete an eight question survey. Thirteen additional stakeholders submitted surveys; their responses validated the findings of the focus groups, specifically, the lack of appropriate BI specific resources, lack of funding for programs, and lack of BI residential programs and services. Once the report is complete, it will be posted on the DARS and BIAV websites.

# CLOSING PROTOCOL: - Dr. Brian Shenal, Chair

Dr. Shenal noted that future quarterly meetings of the Council in 2014 are scheduled for April 25<sup>th</sup> and July 18<sup>th</sup> to be held at the Department for Aging and Rehabilitative Services in Henrico, and October 24<sup>th</sup> which will be held at Woodrow Wilson Rehabilitation Center in Fishersville.

The meeting was adjourned at 3:05 p.m.

# Department for Aging and Rehabilitative Services (DARS)

# Federal Traumatic Brain Injury Grant: Quarterly Report

Virginia Brain Injury Council (VBIC) - Friday, January 24, 2014

**Statewide Needs & Resources Assessment**: The Department for Aging and Rehabilitative Services (DARS) contracted with Virginia Commonwealth University's Survey, Evaluation and Research Lab (SERL) to conduct a statewide *Brain Injury Needs & Resources Assessment* that included focus groups, written surveys, and telephone interviews. The purpose of the assessment was to identify current gaps and barriers in services for caregivers and individuals with TBI and other brain injuries. An initial statewide assessment was completed in 2000. Current status:

### **Completed**

• Six focus groups were held; transcription, summaries, data analysis for all focus groups completed.

Survivor Responses		213
Caregiver Responses		182
Service Provider Responses		60

SERL is presenting during the 1/24/14 Council meeting. Additionally, a copy of the survey report is available upon request.

# Health Resources & Services Administration (HRSA) Request for Proposals:

The "request for proposals" for Virginia's Federal TBI Grant has been released from the Health Resources & Services Administration (HRSA).

**Due date:** March 7, 2014 (start date of June 1, 2014).

**Funding level:** \$350,000 in federal funds

\$125,000 required state match

After conducting a review of all previous Statewide TBI Needs and Resources Assessments, the HRSA TBI Program determined that four common barriers to accessing care continued to emerge across States and Territories. These include:

- (1) a lack of information of services and supports with little or no assistance in accessing them (information and referral services);
- (2) a shortage of health professionals who may encounter individuals with TBI but lack relevant training to identify or treat the resulting symptoms, including physicians, nurses, school staff, coaches, athletic trainers, social workers, psychologists, child care providers, domestic violence/ homeless/ emergency shelter staff, law enforcement, and assisted living facility personnel (**professional training**);
- (3) the absence of a TBI diagnosis, or the assignment of an incorrect diagnosis (screening); and
- (4) critical TBI services are spread across numerous agencies resulting in services being difficult for families to identify and navigate (**resource facilitation**).

To increase access to these services, **responsive applications must outline a plan to provide** *information and referral services, professional training, screening for TBI*, and *resource facilitation*.

*E* See the back for an update of Brain Injury Association of Virginia's grant activities (BIAV is the primary subcontractor on DARS' federal TBI Grant).

### **BIAV Update Year 5, Quarter 3**

# Targeted Group #2: Persons with Low Socioeconomic Resources

### Systems Change

- Educator's Guide revision completed and BIAV worked with Virginia Department of Education (VDOE)
  to disseminate digital and hard copies to school nurses. VDOE forwarded to their parent ombudsman
  for distribution to the parent resource centers; Digital copy put on VDOE website
- BIAV posted revised edition of BIAV publication 'Brain Injury in the Schools: A Guide for Educators' on website on 10/31/13 and during month of Nov. number of documents downloaded from site tripled including over 300 downloads of various sections of Educator's Guide; main targets for outreach include school nurses and local response teams

### Data Collection

Received 423 contacts to Information & Referral program (381 survivors/family; 42 professionals);
 barriers indicative of low socioeconomic status were reported 20 times; 18 people reported being a member of a minority population

#### Education

- 2,803 Virginia Statewide Trauma Registry (VSTR) Outreach letters sent to 2,096 people retroactively (those reported to VSTR in 2012) and 707 people reported to VSTR this quarter; 233 responses received (9%). Wait list of 59 people carried over from previous quarter; 221 received assistance this quarter, and wait list was reduced to 12. 221 outreach letters were returned for invalid addresses this quarter
- 2013 DARS and BIAV Caregiver Forum held in November- 58 people attended free of charge (43 were caregivers/respite recipients); additional 2 mileage stipends and 2 hotel scholarships awarded to caregivers
- Planning BIAV's annual conference on 3/15/14 in Richmond, VA; Registration now open!

### Outreach

Researching and selecting materials to provide to 40 Community Service Boards (CSBs) across the state
to guide CSB personnel in directing treatment to persons with brain injury and working with
Department for Aging and Rehabilitative Services (DARS) on cover letter

### **Targeted Area: Infrastructure Expansion**

### Data Collection/Analysis

VCU/SERL Brain Injury Needs and Resource Assessment survey complete; waiting for final results

#### Education

- BIAV staff attended NASHIA conference in MI in October
- Website: Total visits 14,189; Unique visits 12,676; Page Views 21,004; Docs Downloaded 2,601; 48 individuals requested info.
- Newsletter: 942; E-Newsletter: 464; Facebook: Educational posts: 13; 1,081 fans

### Outreach

- BIAV regularly leads a class at the Polytrauma Unit at the McGuire VA: 'Introduction for Families to Civilian Resources and Self Advocacy' - 5 family members attended on 10/18/13
- BIAV led Virginia Wounded Warrior Program (VWWP) training for 15 VWWP staff, presentation titled "Brain Injury: Hard Work, Heartache, and Humor" on 11/18/13