Update for the Iowa Advisory Council on Brain Injuries

November 1, 2013

July – September of 2013 saw a great deal of change at the Brain Injury Alliance of Iowa (BIA-IA). As you may recall as a result of advocacy and education the Iowa legislature provided a modest increase to Iowa’s Brain Injury Services Program at the Iowa Department of Public Health (IDPH). Some of these funds were allocated to increasing the capacity of the programs and services at BIA-IA. In addition BIA-Iowa is a contractor with IDPH for a number of goals associated with Iowa's Federal TBI grant. We have added staff and are adding capacity in our programs and services. This report is intended to communicate specific areas of effectiveness, efficiency and access. We continue to work to prove and improve the value of these programs and services.

Neuro-Resource Facilitation

Summary: The core of the BIA-IA programs is Neuro-Resource Facilitation (NRF). We have had some experienced staff depart for other opportunities in the past months yet we have had the good fortune to recruit excellent replacements and additions for these key roles. BIA-IA also made a strategic decision to place two new Neuro-Resource Facilitators (NRFs) outside of the Des Moines Metro area. We now have 4 NRFs in Urbandale, and one each in Iowa City and Waterloo. We have partnered with the County Social Services Region (CSS), a 21 county Mental Health and Disability Services Delivery Region in NE Iowa, for the NRF located there (June Klein). This partnership provides in-kind support for office, communications and equipment in that location. The NRF program continues to manage more than 25,000 calls and contacts annually. In response to a growing recognition of the complexity of serving Iowans with brain injury our Neuro-Resource Facilitators are becoming subspecialists in certain high-need areas (such as Employment, Pediatrics, and Mental Health), and are receiving additional education and training for these specialties.

1. Effectiveness: BIA-IA is in the process of working with an outside consultant (Dr. Alison Lynch) as part of our ongoing effort to increase our ability to improve and prove the value of our services and supports. To date we rely heavily upon the Service Obstacle Scale (SOS) (Kreutzer, 2000) to determine if NRF is succeeding in increasing our clients perceived satisfaction with services. Data from the SOS continues to indicate that NRF is succeeding in its goal and efforts to better connect Iowans with brain injury and their families to services and supports. For a number of months we experimented with a version of the Mayo-Portland Adaptability Measure, however this was discontinued, as NRF is designed to, nor able to, impact the key areas in this
2. **Efficiency:** 100% of new NRF calls and contacts are responded to within 24 business hours. Referrals come primarily from our Iowa Brain Injury Resource Network, Professionals, Community Providers, Hospitals/Rehab Facility, friends and the BIA-Iowa website. More than 95% of NRF clients receive a follow-up call at 3 and 6 months. Our “lost to follow-up” are due to clients who have moved, changed contact information, fail to respond or have voluntarily discontinued services.

At the end of September there were more than 2,100 active cases in the BIA-IA NRF system. With a modest increase in NRF staff we have been able to modestly reduce our caseloads, however Iowa is still at the high end of the national average for NRF with over 400 clients per staff. National caseloads for NRF range from 30 to 400 per NRF. Iowa continues to exceed most states’ ratios. As noted above NRF are now in place in two additional locations in Iowa with an eye to better learning and navigating services and supports in specific areas of the state.

3. **Access:** The geographical spread of NRF clients shows statewide utilization with highest use from the more populated regions of the state. In addition we regularly receive inquiries from across the nation from individuals with family members or clients / patients who reside in Iowa. When non-Iowans call for Neuro-Resource Facilitation support, they are provided basic guidance and brain injury information; then linked with supports in their own state, the United States Brain Injury Alliance or with the Brain Injury Association of America.

**Brain Injury Support Network (BISN Peer – Peer Mentoring)**

Summary: BIA-IA maintains staff assigned to the program in line with the demand of training and matching of mentors. Informational emails are distributed via e-newsletter (BrainStorming and Neuro Nuggets) as well mailings to those on BIA-IA mailing lists throughout the year. The program continues to have a positive, if modest, response and impact. During this quarter, there was 1 match made, 1 mentor has been screened and 2 partners have been screened. There have been 46 people trained since the inception of BISN.

1. **Effectiveness:** Evaluations YTD show 96% overall positive feedback and are used to adjust the program on an ongoing basis (3, 6 and 12 months). Since the inception of the feedback form for BISN, 28 responses have been received.

2. **Efficiency:** All inquiries receive a response within 72 hours. The amount of interest has remained high this quarter, with 61 inquires for BISN. Individuals who are not eligible or interested in BISN will often use NRF to meet their needs and many find support groups (where available) of help. The program for this quarter had 6 active matches with 4 of these (67%).
being mentor survivors and the other two family members, caregivers or friends.

3. **Access**: The geographical spread of mentors and mentees shows statewide utilization. Webinars training have occurred for mentors when requested. The Alliance Ambassador, along with other sources, such as website and monthly Brain Storming e-newsletter and monthly e-Neuro-Nuggets newsletter, also markets this program and create referral and intake accessibility.

**Training, Education and Consultations**

Summary: The Brain Injury Alliance of Iowa has increased its onsite trainings throughout the state, and continues to deliver webinars statewide. In September we co-sponsored a NE Iowa Regional Training which was well attended.

1. **Effectiveness**: Participant evaluations are consistently positive with measures in the 80% - 100% range (with most negative comments regarding the temperature of the meeting rooms, attire of Tom Brown, or quality of the food). BIA-Iowa staff continues to use evidence and research based information along with best practice guidelines to inform the technical aspects of our trainings.

2. **Efficiency**: The number of trainings this quarter of this fiscal year is 4; 2 Iowa Brain Injury Resource Network sites, and 2 out of network sites. Locations included Waterloo, Marshalltown and Ankeny. The total number of people trained was 247. This number represents professionals, survivors, family members and other community partners trained. One case consultation was provided this quarter.

3. **Access**: The geographic distribution of trainings of this specific year has been both in response to requests.

**Tote Bags**

Summary: The Brain Injury Resource Network Tote Bag was updated in 2012. Recently, due to a loss of permission to reproduce three key tote resources BIA-IA has been evaluating other equivalent material for dissemination. BIA-IA continues to provide access to the previous materials for those who are able to access the Internet and continue to provide alternative forms of brain injury education while this search is being done. Tote distribution is consistent and includes all IBIRN sites, including Level 1 and 2 trauma centers.

1. **Effectiveness**: Tote bag evaluation data continues to indicate a positive response. 75% of people **strongly agreed** that the tote bag contained information that was useful and beneficial to their understanding of brain injury. 58% of people **strongly agreed** that the tote bag contained information that helped them access services and supports. The items
ranked with highest necessity were the two books geared towards families. A majority of respondents indicate that they would “have liked the option of contacting another family who has experienced brain injury”. This is an ongoing challenge for BIA-IA and is being addressed, in part by the BISN program, as well as the Ambassador program that was established January 2013. Specific tote bag contents are preferred over others and this feedback has been refined and used in the tote bag update. IBIRN sites have also been provided the opportunity to view the Tote Bag webinar and provide feedback.

2. **Efficiency**: Totes are currently distributed to all 153 IBIRN locations, disseminated at conferences and events, and provided for all NRF clients. The Virtual Tote Bag is also available on the BIA IA’s website. Tote bags are shipped throughout the state as well as to others in bordering states. The average cost per tote is $16.00.

3. **Access**: The number of totes distributed during this quarter was 237. This is on target with our annual goal of more than 1,000 totes. IBIRN sites are at 153 this quarter, which is an increase of 3 since last quarter.