



## **New Database Report HRSA grant January 15, 2013**

### **History of the Brain Injury Alliance of Iowa (formerly known as the Brain Injury Association of Iowa) and the Neuro-Resource Facilitation program.**

Starting in 1980, grown out of grassroots efforts, Iowa became the second chartered chapter of the National Head Injury Foundation. For the next decade, volunteers of the Iowa Head Injury Foundation (IHIF) responded to requests of information and resources from Iowans with brain injury and their families. Through the efforts of the IHIF, legislation passed to establish the Advisory Council on Brain Injuries (ACBI). In 1996, IHIF joined with the Brain Injury Association of America (BIAA) and became the Brain Injury Association of Iowa (BIAIA).

In the spring of 2005, members of the Advisory Council on Brain Injuries and the Brain Injury Association of Iowa (BIAIA), gathering informally, met to discuss how they had struggled and had little success in its fiscal efforts. Those who had been participating in the MH/MR/DD/BI Commission's (currently the MHDS Commission) system redesign process were discouraged that the commission's proposed plan did not include services for persons with brain injury until 2009. The only dedicated funding for brain injury was the Medicaid Home and Community Based Services (HCBS) Brain Injury Waiver, which had been in place for almost 10 years, only served a little more than 500 Iowans and also had a significant waiting list.

In 2006, Rep. Danny Carroll's meets with, and is inspired by members of ACBI, then works with IDPH to draft four components of a Brain Injury Services Program, including the Waiver-Eligible Component for those on the waiver waiting list, a Cost-Share Component for those who fell through the financial and functional eligibility cracks, the Neuro-Resource Facilitation Program (NRF) to assist families in navigating services and supports, and Brain Injury Training for providers. Governor Vilsack signs HF 2772 establishing a statewide Brain Injury Services Program with the Department of Public Health as the Lead State Agency.

BIAIA began with one NRF, which then grew quickly to two. Since 2008, BIAIA have had 4 full time NRF staff, growing caseloads from 50 per NRF to currently 400-600 per NRF. BIAIA has chosen to have all staff certified under the Academy of Certified Brain Injury Specialists, a national certification.

The main principle of Neuro-Resource Facilitation is to help people choose, get and keep needed services and supports. Neuro-Resource Facilitation works with people with brain injuries, families, professionals and other interested parties in the community. NRF is individualized and holistic; thereby keeping what the clients needs are as a priority. NRF not only works directly with individual clients,



but also assists with case consultations, trainings and other education. NRF has a follow up schedule to ensure that clients have advocates to turn to when in need.

### **Initial Database Efforts**

“The National Brain Injury Information Center (NBIIIC) was initially established to evaluate a toll-free 800 number in three pilot states: Minnesota, Michigan and Mississippi. The program provides information and resources to individuals with traumatic brain injury, family members, professionals, and the public. The program was initially funded through the Centers for Disease Control and Prevention. An individual calling the 800 number will link to his or her state affiliate information and resource department to access local services, resources, and information. The NBIIIC program will provide a standardized protocol for responding to calls, a customized packet of information on brain injury topics, consistent data element collection and resources to brain injury services to the caller’s local community.” (BIAA, 2006)

In 2007, the Brain Injury Association of Iowa began its Neuro-Resource Facilitation program and started collecting data on NRF callers. The NRF program was marketed with an 800 number that filtered through the Brain Injury Association of America, directly to the BIAIA. Those calling with an Iowa-specific prefix area code were routed to Iowa. If the person was not dialing from an Iowa-specific area code, they were routed to their state affiliate or to the Brain Injury Association of America. These calls were typically routed then to the BIAIA for further assistance. All Association members used the same 800 number throughout the country. NRF clients also accessed services via local phone, email, mail, Internet inquiry, walk-in or other measures.

At the inception of NRF in Iowa, data collected was inputted to a Microsoft Word document. BIAIA had worked with the BIAA in order to focus on what data to collect. Due to the type of document that the information was collected within, a concise reporting system was not implemented. This first data collection system was simply to gather all of the information for a client, and be able to have the NRF refer back to it with follow up calls. The ability to pull out trending data was not available with this system, nor was the ability to share data within the BIAIA staff. All data was collected and contained by that specific NRF.

In 2008, the Brain Injury Association of Iowa met again with Brain Injury Association of America (BIAA) staff to be trained in the National Brain Injury Information Center (NBIIIC) database. This database was an online database, which gathered information about Neuro-Resource Facilitation clients, such as: type of injury sustained, relation to person with injury and general demographics. Other information included a check box for types of resources given by NRF staff, a section for notes about contact and a place for indicating follow up needed.

A few of the limitations Iowa faced with NBIIIC included:

- NBIIIC collected age ranges, not specific ages. This was given in large chunk groups of year range (i.e. 40-65, 65+). This limited funding to certain clients, affected reports for trending data and were too large of chunks for ages to focus on specifics needs of specifics ages for lowans.
- The section that tagged that a follow up contact was needed could not be pulled out for a summary report for the NRF, as can be in the new database.
- Reports that could be pulled were not very robust, and the reports themselves would often experience glitches that would not give the best results (i.e. missing data).

While Iowa worked diligently with BIAA to continually improve NBIIIC- including assisting with updates/changes- the system did not have the capacity Iowa required as they moved forward in their maturation of NRF.

Iowa began to research other Resource Facilitation databases. Those evaluated by the Alliance were the database that the Brain Injury Association of Arizona, the Minnesota Brain Injury Alliance, and the Brain Injury Alliance of Connecticut. The Executive Director and Director of Programs and Services worked with each state to receive webinar trainings, cost analysis and pros and cons of each system. Weighing cost versus need, the BIAIA took all information to the BIAIA Board Executive Committee, which gave support to adapting the Minnesota Brain Injury Alliance database.

### **Minnesota Brain Injury Alliance Database Overview**

The Minnesota Brain Injury Alliance database was created to identify trends in service for brain injury, gaps in services and barriers to advancement for persons with brain injury. This information would assist in informing the creation or enhancing systems of care for persons with brain injury and support the individual to become a stronger self-advocate. The system was created internally, using an external computer programmer to create the online portion of the database and building the codes and reports.

In June 2012, BIAIA started working with the MN BIA to transfer client information in to the new database. Most of what was in the NBIIIC was able to transfer in to the appropriate sites. Other information that was did not have similar codes were dropped in to the general 'Notes' section of the new database, leaving the NRF to manually transfer the data. In July 2012, NRF staff began using the new database.

BIAIA has been assigned user names and passcodes, and have a unique section that other states are not able to access information from. The Associate Director



of Operations from the MN BIA has the access to Iowa's distinct section of the dedicated server.

This database is being used with other states, including Florida, Virginia, Montana and Colorado.

### **Capabilities**

As the NBIIC system was appropriate and useful at the initial stages of the NRF program, the Alliance began requiring a system that processed data in a more succinct manner. The NBIIC database captured demographic information, such as:

- Name
- Address
- Phone Number
- Email
- Race, Ethnicity and Language of Caller and Injured
- Age range of Caller and Injured

NBIIC also gathered data, such as Create Date and Company Name (the NRF or professional affiliation). NRF staff could filter out cases by: Company Name, First Name, Last Name, Create Date, Phone Number, Email or Address for querying.

This system captured whether or not the person calling and individual injured was a person with a brain injury, a family member, a veteran and/or a professional. These numbers could be reported on, but may misconstrue data, as the person could be a member of several groups, and would not be able to differentiate amongst those groupings.

Checkboxes were used to gather data that included contact method and source of the NBIIC 800 number (if this pertained), who referred them, the method of sending materials and if a tote was sent.

NBIIC had checkboxes to indicate what resources the NRF referred the caller to in the community. Some of these included: Support Groups, Peer Mentoring, books, artless, brochures, events, Vocational Rehabilitation, Protection and Advocacy, etc.

Additional resources that were available to document through the use of checkboxes were: Education, Employment, Legal, Financial, Acquired BI, Neuropsych, Behaviors, ABI, Caregiver, Mental Health, Pediatric, Violence, Relationship, Rehab, and Spirituality. Choices under each were very limited; and did not explain why the person was checking the checkboxes.

The Minnesota Database is able to capture most of the information above. The MN database utilizes more dropdown boxes that are customizable for state-

specific usage. This new database also captures information that a NRF performing an intake call would use, such as pre-injury status and affiliating two or more folders together to indicate relationships amongst NRF clients. There is also the ability to develop indicators of the client, thereby marking the client with what type of relationship they have with the Alliance. Some examples of indicators could be: Person with a Brain Injury, Family Member, Conference Speaker, Donor, Volunteer, etc.

Additional benefits of this system allows concise tracking of a person's age, as it asks for a birthdate, rather than an age group, such as the previous database. This then updates with the current date, and allows for reports to reflect exact ages for the person, such as current, when age injured and how long ago the injury had been.

During any contact in which the person reports a status change, an array of topics are asked, to cover what type of change has occurred and how best a NRF may work with that individual. Some of these include communication, employment, education, financial, self direction health and referrals (in which many of the referrals that NRF make are checked- such as waiver, social security, neuropsychology).

Along with the above, new sections also include: Barriers, Mailings, Salutation and Employer, Gifts, Membership and the Mayo Portland assessment. Barriers allows a NRF to choose from a listing of barriers that may be present at initial intake, and then what barriers may happen during subsequent follow up calls. The Mailings and Salutation and Employer allows for simple Mail Merges for mailings, as well as documenting where the person is employed (as well as spouse, if applicable). The Gifts section allows the BIAIA to document any donations, memorials, corporate sponsors, events dollars and gifts to the BIAIA. Membership allows BIAIA to track all membership dues, including corporate sponsors. The Mayo Portland assessment can be performed and inputted directly in to this database.

### **How new database is able to be customized and security of the system**

This new database can be customized directly by the BIAIA for their best use. BIAIA has the ability to change most codes, unless they are 'hard' codes, and make this database customizable for BIAIA's needs. If changes need to be made to hard codes, BIAIA must go through the MN BIA's computer programmer.

#### **Security/Backups**

The new database functions on a Remote Desktop Connection. The new database has built-in security, in which the user is assigned a specific user name and passcode. Only the state affiliate, and the MN BIA Associate Director of Operations will have access to these codes.

Backups: MN has 2 different backups on site, as well as one backup off site. The database is backed up daily.

## **Support**

With purchase of the MN BIA database, BIAIA receives numerous types of support. BIAIA staff have access to the Associate Director of Operations from MN BIA for any questions or concerns. Upon orientation to the system in June of 2012, the Association Director of Operations traveled to BIAIA and gave a one-day course on the system. 3 months in to the use of the new system, BIAIA was also able to send their Director of Programs and Services and Administrative Financial Manager to the MN BIA for additional training on higher functions of this system. The next phase of implementation of this system will be to create and implement the new changes by BIAIA and train on any existing tools that BIAIA has not begun to use.

## **Cost**

The cost incurred by the Brain Injury Alliance of Iowa includes the following: staff time, programmer time and actual cost of purchase. The Brain Injury Alliance of Iowa funded these services through the Health Resources and Services Administration (HRSA) grant. The total cost for from June 2012 until December 2012 has been \$10,435.33. The only additional costs forecasted are to change a few hard codes that the MN system had in place to capture Iowa data.

## **Status at present**

At present, BIAIA has been using most of the functions of this new database. Staff members are still in an orientation period, which has been finding out what works best for Iowans; then going forth and customizing the database as such. There are a few sections that are still being customized, and therefore will not have data yet.

## **Next steps**

This database will be a working database; meaning that it may change over the course of time with the needs of Iowans, as determined necessary by the BIAIA. More training will be received by BIAIA through MN BIA once staff is ready to start using the last few sections of the database. BIAIA staff members are currently meeting to determine what hard codes will need to be updated/changed, and dates to start changing those as well. BIAIA will work with the Department of Public Health in describing any changes to the database, as well as reports on statistics that this new database allows for, within reasonable timeframes for change.

## **Summary**

The Brain Injury Alliance of Iowa has adapted the Minnesota Brain Injury Alliance's database in July 2012, after utilizing the Brain Injury Association of



America's National Brain Injury Information Center since 2008. Both online databases contain basic demographics and utilize checkboxes for referral information that Neuro-Resource Facilitation has been utilizing for clients. Due to the constraints of NBIIC, the BIAIA has researched other databases, and selected the MN BIA database due to customizability, training and cost. Additionally, benefits of this database include the ability to store information about other functions of the BIAIA, such as gifts, membership and mailings. BIAIA has received several trainings on this database, and are currently looking to customize hard and soft codes to make the database work best for lowans.