Chapter, Support group and Online
Needs Assessment – 2013/2014

Background: From October, 2013 – February of 2014 the Brain Injury Alliance of Iowa conducted a statewide needs assessment with its membership, Chapters, Support Groups (Mason City, Tri-State/Dubuque, Quad Cities, Central/Des Moines, East Central/Cedar Rapids/Iowa City, Lakes/Spirit Lake, Northeast/Waterloo) IBIRN sites (145) BISN peer support members, corporate members, past attendees of conferences, webinars and workshops, and many others stakeholders via secondary contacts from collaborators such as IDPH and others.

Copies of the web based survey and the Chapter/Support group questionnaires may be found in Appendix A. While there were minor variations in questions there was substantial alignment in both efforts.

We received 80 responses to a Web based survey. With the exception of the Southwest portion of the state these online responses were from across the state. See Charts 1 and 2 below:

Chart 1 – Distribution of Zip codes from Web-based Respondents
Respondents to both the Online and Support Group based survey process were asked to identify themselves as primarily one of five groups. The web based survey gathered a distinct majority of family / member and caregivers followed by indirect / administrative providers, and then individuals with brain injury. See Chart 3.

**Chart 3 – Online Response Breakdown**

Please help us know more about who you are (you may fit into more than one spot):
In the Support Group / Focus group more than 70 individuals allowed BIA-IA staff to administer the needs assessment questionnaire in a group setting. Staff recorded the range of responses from attendees encouraging as much interaction and discussion as possible. As might be expected, there were a preponderance of individuals with brain injury followed by family members / caregivers and then providers. See Chart 4.

**Chart 4: Support Group Respondent Percentages**

When added to the online responses this input significantly increased the response rate from individuals with lived experience of brain injury from 26% to 36% as seen in Chart 5.

**Chart 5 – Combined Online and Support Group Response Breakdown**
Below are the results from a qualitative analysis of the needs assessment responses. This analysis combined the responses from the online and the support group data. Response items, areas and themes were first identified. Items, areas and themes were combined in cases where they aligned under a more major heading (i.e., memory issues and balance issues as top concerns after leaving the hospital were grouped into a category labeled “Sequela”).

The overall impressions from this 2013-2014 survey is that the same challenges and concerns that have faced Iowans with brain injury and their families still present significant obstacles to them. That said there are a number of novel themes compared to prior years. These include increasing comments on the need for family support and education for individuals with moderate to more severe brain injury to better help them understand and navigate the systems of care. Another emerging theme is significantly increased range of comments on the need for health and disability provider education, ability and skill in responding to, and caring for, Iowans with brain injury. include a continued lack of access to post acute services and funding for them. There is recognition that there has been incremental increase in outreach by BIA-IA, however there is a simultaneous recognition that changes to the MH/DS system as well as the waiting list for the BI waiver present new and additional obstacles to access.

The percentages portrayed in graphs are calculated based on the totals for the most frequent content areas. For example if the top three areas of comment garnered 100 comments combined and the top area garnered 44 comments it would show as 44%. There were substantively more comments as would be expected in open ended questions. However in this on is able to discern both which comments rose to the top and the relative weight of each of those comments compared to each other.
1. What have been your best and worst experience post-brain injury?

**Best:** (94% online response rate)

1. Recovering from BI, new skills, regaining independence.
2. BIAIA and BIAIA support groups
3. Service provider, therapy providers

(* - Although one might suspect that the support groups would have the most comments on BIAIA and BIAIA support groups this was not the case with 61% of these comments coming from the online survey)
Worst: (94% online response rate)

1. Lack of community based post acute services
2. Sequela of brain injury – primarily memory issues; balance, and depression)
3. Loss – of jobs; family and friends, driving
4. Lack of awareness of brain injury among providers, family and friends.

2. Describe your three top concerns regarding brain injury in Iowa. (93% online response rate)

In general there was marked agreement between the responses online and the support groups. This question is an exception. While the support group array of responses and themes was more varied than the online responses, there was still a dominant concern about Sequela.

Online Themes:
1. Access to community based post acute services (rural obstacle, housing, transportation, family supports)
2. Limits to accessing the BI waiver (extreme waiting list, level of care determination, caps, funding)
Support Group Themes:
1. Sequela (memory, relationships, anger, mobility)
2. Personal finances (decreased income, increased expenses, decreased savings, impoverishment)
3. Employment (finding, getting and keeping a job)

3. Are you currently in your preferred living setting? If not, can you tell us why? (60% online response rate)

6% of respondents total indicated that no, they were not satisfied with current living situation with home maintenance challenges, financial capacity, and waiver waiting list among concerns
4. What is your experience with services for persons with brain injury? (80% online response rate)

1. Lack of access to community based post acute services, therapies and psychiatric services.
2. Iowa Medicaid and Iowa Medicaid Enterprises extremely hard to navigate.

![Bar Chart: Lack of access to community based post acute services, therapies and psychiatric services. Iowa Medicaid and Iowa Medicaid Enterprises extremely hard to navigate. Mixed experience with quality of acute and post acute care.]

5. What is your experience with community based services for persons with brain injury? (78% response rate)

1. Rural Inaccessibility
2. Decreased funding via regionalization
3. Direct care staff un-trained or unskilled

![Bar Chart: Rural Inaccessibility. Decreased funding via regionalization. Direct care staff un-trained or unskilled.]

5. Imagine that a person you know has just sustained a brain injury: What advice would you give them about the changes they might be facing? (76% response rate)

1. Have patience and persistence
2. Connect with the Brain Injury Alliance of Iowa
3. Stay hopeful

6. **What type of community supports are you utilizing?** (70% online response rate)

1. Family, friends and church
2. Service Providers, Case Managers
3. Brain Injury Alliance of Iowa

7. **If funding were not an issue, what type of supports would you like to have?** (74% online response rate)

This question elicited perhaps the most varied array of responses including a wide range of community based and in-home services and supports. However these four areas rose to the top of the set.

1. In-Home services and supports
2. Ongoing Therapies
3. Employment Support
4. Transportation
8. Do you feel that your healthcare needs have been addressed? i.e. therapies, employment, financial health? (76% response rate)

1. No - Need post acute community services, Employment, Therapies (PT, ST, OT), BI Waiver, Staff training
2. Yes – Basic health needs being met

9. Other comments
   1. These comments were widely variable. The single most dominant theme was the need for more “family education and support”.