

**Traumatic Brain Injury in Iowa:  
Iowa Brain Injury Resource Network Outcome Evaluation  
2007-2009**

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## Table of Contents

LIST OF TABLES.....	2
LIST OF FIGURES.....	2
EXECUTIVE SUMMARY .....	3
INTRODUCTION.....	5
METHODS.....	6
RESULTS.....	9
Demographics.....	9
Type of Services Received after Traumatic Brain Injury .....	10
SOS Screening.....	10
Health and Social Outcomes.....	11
DISCUSSION.....	13
Evaluation .....	13
Limitations.....	14
Conclusion and Recommendations .....	14
REFERENCES.....	16
APPENDICES .....	17

### LIST OF TABLES

Table 1: Demographic Characteristics comparing IBIRN clients and STR patients.....	9
Table 2: Number and percent of TBI Survivors and Types of Services Received .....	10
Table 3: Health and Social Outcomes comparing IBIRN and STR patients .....	12

### LIST OF FIGURES

Figure 1: SOS Services Scales comparing IBIRN clients and STR patients .....	11
Figure 2: Work Status Before and After Injury comparing IBIRN clients and STR patients .....	13

## **EXECUTIVE SUMMARY**

### Purpose of the Report

Traumatic brain injury (TBI) is the most debilitating outcome of injury and is a major public health problem in Iowa. Individuals who have sustained TBIs must have access to trauma care, specialized rehabilitation, long-term disease management and individualized services in order to live healthy and satisfying lives. The Iowa Brain Injury Resource Network (IBIRN), which is one among many services offered by Brain Injury Association of Iowa (BIAIA), is defined as an “information and support system created to begin meeting the needs of Iowa families experiencing brain injury and the providers that assist them.”<sup>1</sup> This evaluation study set out to determine the impact of IBIRN on the lives of Iowans living with a brain injury and their families via a four-part survey.

### Methods

A retrospective cohort study design was implemented using a self-reported questionnaire to compare survivors of TBI identified from the IBIRN client list and those identified from the State Trauma Registry (STR). The analysis was limited to describing the differences between the IBIRN clients and the STR group. Statistical testing were implemented using Chi-square and Mantel Haenszel tests for categorical variables and student t-test for continuous variables. A p. value of 0.10 was considered significant.

### Results Highlights

Compared to STR group, IBIRN clients were more likely to receive services available to TBI survivors. They were 14 times more likely to have used the BIAIA helpline (59% vs. 5%), five times more likely to receive services through the “Brain Injury Waiver” (31% vs. 10%), and three times more likely to attend support groups for people living with brain injury and their families (33% vs. 10%). Moreover, IBIRN clients were 10 times more likely to apply for social security disability insurance (74% vs. 10%) and five times more likely to receive services using other Medicaid waivers (26% vs. 5%).

Overall 37% of the survey respondents were offered a tote bag. IBIRN clients were more likely than the STR group to have received the tote bag (42% vs. 25%). Among IBIRN clients who accepted the tote bag, 89% found it useful compared to 40% from STR. This finding is significant as IBIRN clients were five times more likely to report the tote bag as useful.

The outreach letters that IDPH sent every quarter did not have their desired effect. Only 26% of IBIRN clients and 15% of STR group reported receiving the letters.

IBIRN clients were more likely to report obstacles to receiving services compared to STR group. They were more likely to report dissatisfaction in the amount of professional help and services being provided (43% vs. 15%); more likely to report fewer resources for TBI related problems (74% vs. 25%) and having little confidence on the quality of care provided (38% vs. 15%).

IBIRN clients were more likely to report negative health and social outcomes. They were less likely to rate their “health during the last four weeks” as good or very good (62% vs. 85%) and more likely to report anger and frustration within the last four weeks (57% vs. 35%). However, there were no differences between the two groups in the proportion of individuals who reported wanting to hurt themselves, feeling sad or depressed, having social and emotional support, being satisfied with life and seeing great health improvement.

With regard to community reintegration as estimated by work status, IBIRN clients presented a higher proportion of unemployed (40% vs. 10%) and a higher increase in the proportion of retirees compared to the STR group. Before the occurrence of TBI, there were no retirees in the IBIRN group compared to 20% in the STR group. After the injury, 29% of the IBIRN group retired compared to 30%.

#### Conclusion and recommendations

This evaluation finds that IBIRN has a positive impact in the lives of its clients. IBIRN clients seem to be more responsive and knowledgeable about services offered to TBI survivors. However, this does not translate into better perception of access to care and better health and social outcomes. IBIRN clients reported more obstacles in the SOS scale and more issues related to physical and emotional health. The main explanation of these findings may be the severity of the TBI.

Designing better screening tool to identify TBI clients is recommended to the BIAIA. As for IDPH, trauma coordinators should collect better information on TBI patient by verifying addresses and telephone numbers.

**Traumatic Brain Injury in Iowa:  
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**INTRODUCTION**

Termed the “silent epidemic,” traumatic brain injury (TBI) is the most debilitating outcome of injury, and is characterized by the irreversibility of its damages, long-term effects on quality of life and healthcare costs. The latest data available from the CDC estimate that nationally, 52,000 people die each year from TBI<sup>2</sup>.

In Iowa, TBI is a major public health problem. The numbers and rates of hospitalizations and emergency department (ED) visits due to TBIs are steadily increasing. From 2006 to 2008, there were on average 545 injury deaths per year. Among the injured Iowans, TBI constituted nearly 30 percent (545) of all injury deaths, ten percent (1,591) of people hospitalized and seven percent (17,696) of ED visitors.<sup>3</sup> The state of Iowa has been supporting secondary prevention services to TBI survivors for several years. An Iowa organization that has made a significant effort in assisting TBI survivors is the Brain Injury Association of Iowa (BIAIA). The BIAIA administers the IBIRN program in cooperation with the Iowa Department of Public Health (IDPH) through HRSA TBI Implementation grant funding and state appropriations.

The IBIRN is defined as an “information and support system created to begin meeting the needs of Iowa families experiencing brain injury and the providers that assist them”<sup>1</sup>. The IBIRN system is the product of eleven years of state appropriation and Health Resources and Services Administration (HRSA) for traumatic brain injury. The network distributes *1200 totes* every year. The IBIRN employs an information dissemination system that has increased access to comprehensive services for TBI individuals and their families. In addition, IBIRN facilitates the creation of local support groups, which informally meet on a monthly basis. According to the BIAIA, there are 11 communities in Iowa that have at least one support group. In addition, as a part of IBIRN, BIAIA manages a peer-to-peer mentoring program called the Brain Injury Support Network (BISN). This program, originally created by families and providers, offers support and guidance to survivors with the help of trained volunteers. Moreover, under a mandated contract with the IDPH since 2006, the BIAIA offers neuro-resource facilitation (NRF). The goal of NRF is to help survivors of brain injury and their families to better cope with the effects of

brain injury, lead a more productive life and reintegrate into the community. NRF places emphasis on information dissemination, linkage to appropriate services and training of service providers. Federal HRSA funds are used to increase capacity and build program sustainability. One of the primary resources distributed by NRF is the IBIRN tote bag or virtual tote bag. Both the tote bag and the virtual tote bag contain information about brain injury and resources for individuals and families experiencing brain injury. There are two versions of each tote bag: adult and pediatric.

In 2004, the IDPH through the direction of the Bureau of Disability and Violence Prevention surveyed the IBIRN clients. The results showed some important results as evidenced by France, Jill, et al.<sup>4</sup> In the earlier study, questionnaires were mailed out to TBI clients who received an IBIRN tote bag. The main findings in this study were that individuals who received the “tote bag” were significantly more likely to feel that they had received social and emotional support. Unfortunately, the study had a low response rate (10%). In addition, the study had several fundamental design flaws such as non-randomization, selection bias and lack of definition of a clear outcome, which limited the value of the evaluation.

As a follow-up to the 2004 study, this retrospective cohort study was aimed to determine the impact of IBIRN on the lives of Iowans living with a brain injury and their families. It was assumed that IBIRN activities would improve the lives of the clients by increasing their level of awareness on brain injury issues, facilitating their reintegration into communities and stimulating better health related outcomes.

The follow-up study utilized a self-administered outcome evaluation questionnaire that assessed the emotional, social and financial status of participants that sustained the TBI. Moreover, the evaluation questionnaire aimed to assess the IBIRN as a whole: whether its broad objectives were met and impact of their outreach activities. We hypothesize that TBI individual’s receiving the IBIRN services will have greater psychological and social functioning and more productive lives as demonstrated by work and remunerated activities. Moreover, communities with the IBIRN services will have a better handle of brain injury related problems characterized by increased service provider awareness, a greater reach to brain injured and a greater number of brain injured receiving services from the waiver program.

## **METHODS**

### **Study design**

A retrospective cohort study design was used to assess the differences in outcomes between TBI survivors who were using the IBIRN services and those who were not.

### **Participants**

The 2010 study population was generated from people who survived a TBI from 2007-2009. There were two groups in the survey population. The first group was identified through the IBIRN

database and consisted of individuals who had received services from the IBIRN. The second group consisted of patients in the TBI registry, who did not receive IBIRN services.

## **Procedures**

### Staff & the Questionnaire

All staff members were trained adequately to understand the study process and identify threats to validity during the study. The IBIRN evaluation questionnaire (appendix A.1) was created by combining the 2004 TBI survey form and the SF 36 survey developed by the Performance Outcomes Measures Project of the Office of Management Budget (White House) and implementing variations pertinent to assessing the IBIRN. The “5 B’s” principles, identified by Scott Smith in his “The Five B’s for reducing measurement error in survey research”, were implemented during the creation of the questionnaire. Survey questions were well thought out, unbiased, exact, specific and considerate (not too intrusive). The survey was developed using a “funneling procedure.” General questions were asked at the beginning of the questionnaire, followed by specific questions and ending with more general *demographic* questions.

The study population addresses were checked for validity using ARC-GIS geo-mapping software and the United States Postal Office online address verification database. A first letter of contact with a self-returned envelope was sent to eligible study participants. Upon receiving the signed consent forms, the participants were sent a questionnaire packet containing a self-returned envelope. No incentive was given in this study. The evaluation questionnaire was accessible through the mailed paper format and an online format ([http://www.idph.state.ia.us/surveys/brain\\_injury/](http://www.idph.state.ia.us/surveys/brain_injury/)).

### Quality checks during the data collection

Upon reception of the surveys, staff checked for non-responses and discrepancies in questionnaire responses. The questionnaires collected were checked structurally, meaning that all documents were present, appropriately labeled and in the proper sequence. In addition, the range of responses for each question was verified. Only adequate responses and codes within the valid range were accepted. Errors that may have arisen depended on the subject interpretation of the questions as well as and his willingness to respond. In addition, respondents may have made mistakes in answering questions because they did not understand them clearly or failed to follow instructions. Participation monitoring was an integral part of minimizing participant loss during the study. It was expected that enrolled participants in the study would complete the questionnaire. Participants who did not return their questionnaire or submitted an incomplete questionnaire were contacted via phone or follow-up letter if no phone number was available.

### Data management

The questionnaire data was entered into a relational database which, served as the main data depository. The data entry forms resembled the questionnaire forms. The database was set up to reject invalid entries. Data validity was checked weekly by analyzing a random subset of the data collected to identify mismatched information, errors and outliers. The data dictionary can be found in the appendix, A.2.

### Data analysis

Respondents were classified as either IBIRN clients or STR (from the TBI registry and not receiving IBIRN services). The data analysis included univariate analyses, which estimated the basic frequencies, percent distribution and odd-ratios comparing the two groups. Significance testing was done using Chi-square and Mantel Haenszel for categorical variables. Means were calculated for age and tested using the student t-test. A p. value of 0.10 was considered significant. The Statistical Analysis Software (SAS 9.1) from the Cary Institute was used for data management and analysis. This study was reviewed and authorized by the IDPH Institutional Review Board.



## RESULTS

### Demographics

There were 4,527 individuals with TBI eligible for participation in the study; 627 individuals were identified from the IBIRN database and 3,900 from the TBI registry database. Out of the 3,900 cases identified, 1,050 addresses were unmatched, which made it impossible to contact the individuals for participation in the study. The unmatched cases consisted of 118 out of 627 (19%) IBIRN clients and 932 out of 3,900 (24%) TBI registry cases (STR group). Survivors with unmatched addresses were excluded from the study population. The final study population included 598 IBIRN clients and a simple random sample of 550 TBI survivors who had received a registry letter, but who had never sought out IBIRN services. Contact letters were sent to 1,140 people, which resulted in 133 (11.6%) people who agreed to participate by returning the signed consent form. Ten individuals from the IBIRN list called to report that they had not experienced a TBI and eight reported they sustained a TBI earlier than the study period. Among the 133 who agreed to participate, only 62 (46%) returned the survey, which corresponded to an overall response rate of five percent. Due to the low sample size, this evaluation does not have a scientific research value, but can still help provide insight to the value of IBIRN services.

The total sample size was 62 with 42 (66%) from the IBIRN and 20 (34%) from the STR group. Table 1 provides a demographic description of the study participants. Because of the low sample size, the reported magnitude of association was considered statistically significant when the statistical testing provided a p. value of 0.10 or less. There were no significant differences in the demographic make-up of the two groups. The average age was 52 years (SD=11.8). There was a greater proportion of females using IBIRN services than males; however due to the low sample size, the difference was not statistically significant at  $\alpha=0.10$ . A higher percentage of people filled out the questionnaire for the person with TBI in the IBIRN group (21% vs. 5%).

**Table 1: Demographic Characteristics comparing IBIRN clients and STR patients**

Demographics	IBIRN N= 42	STR N=20	p. value
Age (SD)	51.9 (11.8)	52.2 (15.5)	0.92
Female (%)	23 (54.8)	7 (35.0)	0.14
Person filling questionnaire NOT person with TBI	9 (21.4)	1 (5.0)	0.08

### Type of Services Received after Traumatic Brain Injury

Overall, 37% of the respondents were offered a tote bag. IBIRN clients were more likely to have received the tote bag (42% vs. 25%). Everyone who was offered the tote bag accepted it. Among IBIRN clients who accepted the tote bag, 89% found it useful compared to 40% from STR (non-IBIRN clients). This finding is significant as IBIRN clients were five times more likely to report the tote bag as useful.

The IDPH quarterly outreach letters did not seem to have the desired effect. Although the STR patients were selected from the list of addressees, only 15% reported receiving the letters compared to 26% of the IBIRN clients.

In general, IBIRN clients were more likely to receive services available to survivors of TBI than the STR group. They were 14 times more likely to have used the BIAIA helpline (59% vs. 5%); five times more likely to receive services through the “Brain Injury Waiver” (31% vs. 10%); ten times more likely to apply for social security disability insurance (74% vs. 10%); five times more likely to receive services using other Medicaid waivers (26% vs. 5%); and three times more likely to attend support groups for people living with brain injury and their families (33% vs. 10%).

**Table 2: Number and percent of TBI Survivors and Types of Services Received**

Services	IBIRN N (%)	STR N (%)	OR	p. value
Tote Bag offered	18 (42.9)	5 (25.0)	1.8	0.17
Tote Bag accepted	18 (100.0)	5 (100.0)	1.7	0.14
Tote Bag helpful	16 (88.9)	2 (40.0)	5.4	0.02
Received IDPH Outreach Letters	11 (26.2)	3 (15.0)	1.6	0.32
BIAIA Helpline	25 (59.5)	1 (5.0)	13.7	<.0001
Brain Injury Waiver	13 (30.9)	1 (5.0)	5.5	0.02
SSDI	31 (73.8)	2 (10.0)	10.2	<.0001
Other Medicaid Waiver	11 (26.2)	1 (5.0)	4.6	0.05
Support Group	14 (33.3)	2 (10.0)	3.1	0.05

Notes: BIAIA= Brain Injury Association of Iowa; IDPH= Iowa Department of Public Health; SSDI= Social security Disability Insurance

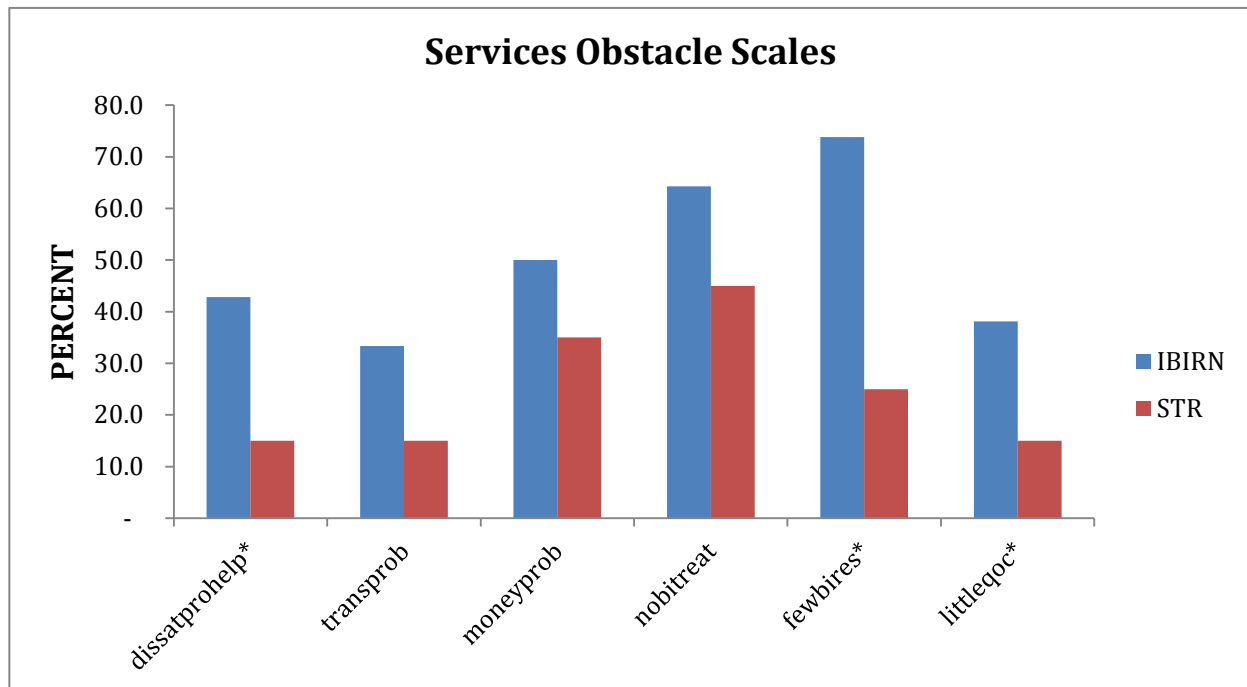
### SOS Screening

The Service Obstacles Scale (SOS) was developed by the Mayo Clinic to evaluate the perceptions of TBI clients and caregivers on the quality and accessibility of brain injury services in their communities. The six-item scale assessed obstacles to receiving brain injury services, knowledge of and availability of resources and satisfaction with the quality of care received. Items were rated on a five-point Likert scale ranging from Strongly Disagree through Strongly Agree, which was for the purpose of this report dichotomized into (YES- Strongly agree and agree; NO-Neutral, disagree and strongly disagree). The SOS

had three main components: (1) satisfaction with treatment resources; (2) finances as an obstacle to receiving services; and (3) transportation as an obstacle to receiving services.

Compared to STR patients, IBIRN clients were more likely to report obstacles to receiving services. They were more likely to report dissatisfaction with the amount of professional help and services being provided (43% vs. 15%); more likely to report few resources for TBI related problems (74% vs. 25%); and more likely to report having little confidence in the quality of care provided (38% vs. 15%). The differences among the other indicators on the scale were not significant.

**Figure 1: SOS Services Scales comparing IBIRN clients and STR patients**



Notes: dissatprohelp= “dissatisfied with amount of professional help”; transprob= “transportation is a major obstacle”; moneyprob= “lack of money to pay for medical, rehabilitation and injury related services is a major problem”; nobitreat= “I don’t know if there are good brain injury treatment resources in my community”; fewbires= “For brain injury related problems, there are few resources in my community”; littleqoc= “I have little confidence in the quality of care now being provided”;

### Health and Social Outcomes

Overall, IBIRN clients were more likely to report negative health and social outcomes. They were less likely to rate their “health during the last four weeks” as good or very good (62% vs. 85%). IBIRN clients were more likely to report anger and frustration within the last four weeks (57% vs. 35%) and to report cigarette use (40% vs. 15%). On a positive note, IBIRN clients were less likely to report alcohol use (29% vs. 65%). There were no differences in the proportion of clients who reported wanting to hurt

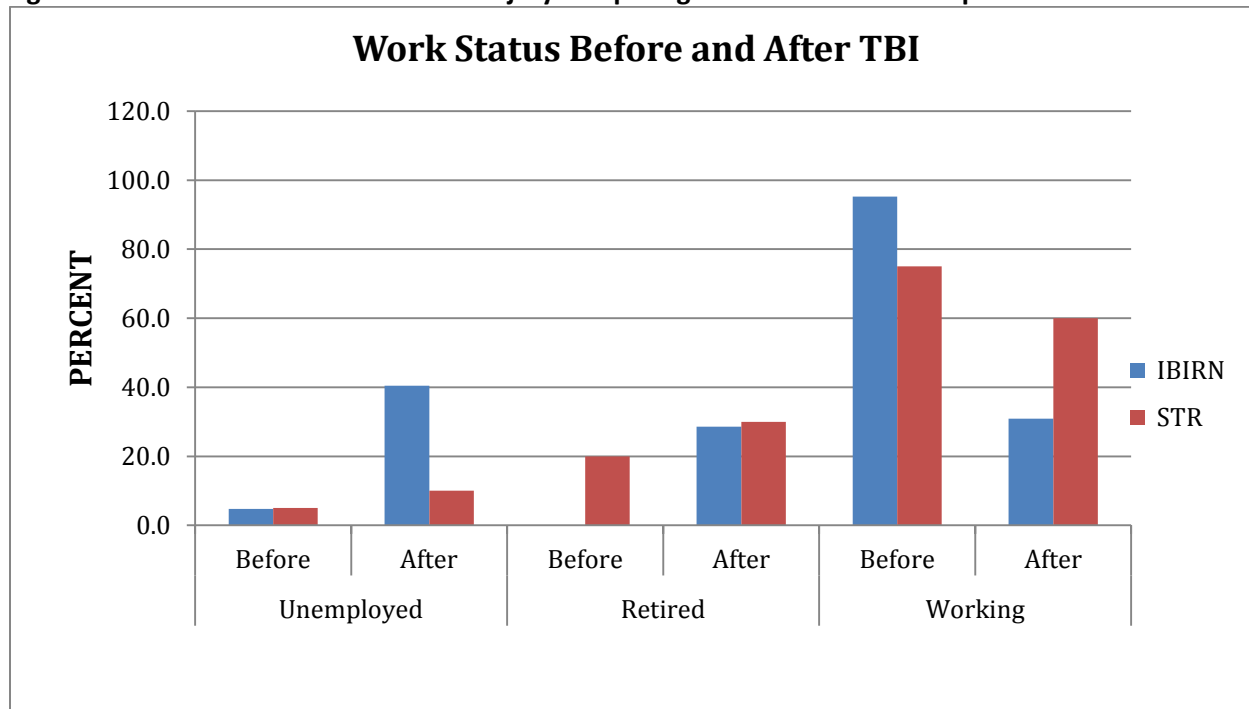
themselves, feeling sad or depressed, having social and emotional support, being satisfied with life and seeing great health improvement, (Table 3).

With regard to community reintegration as estimated by work status, IBIRN clients presented a higher proportion of unemployed (40% vs. 10%) and a higher increase in the proportion of retirement. Before the occurrence of the trauma, there were no retired respondents in the IBIRN group compared to 20% in the STR group. After injury, 29% of the IBIRN group retired compared 30% of the STR group (Figure 2). These results may be due to the fact that IBIRN clients who agreed to participate and responded to the questionnaire may have more severe TBI.

**Table 3: Health and Social Outcomes comparing IBIRN and STR patients**

<b>Outcomes</b>	<b>IBIRN</b>	<b>STR</b>	<b>OR</b>	<b>p. value</b>
Past Month Health Rating (Good to Very good)	26 (61.9)	17 ( 85.0)	0.3994	<b>0.06</b>
Past Month Wanted to Hurt Self (Some to All the Time)	3 (7.1)	1 (5.0)	1.3103	0.75
Past Month Sad or Depressed (Some to All the Time)	22 (52.4)	8 (40.0)	1.4063	0.36
Past Month Angry or Frustrated (Some to All the Time)	24 (57.1)	7 (35.0)	1.8571	<b>0.10</b>
Social and Emotional Support (Some to All the Time)	24 (57.1)	13 (65.0)	0.7969	0.55
Life Satisfaction (Satisfied to Very Satisfied)	17 (40.5)	12 (60.0)	0.5859	0.15
Health Improvement (Big to Great)	23 (54.8)	14 (70.0)	0.634	0.25
30 day Alcohol Use (Current user)	12 (28.6)	13 (65.0)	0.364	<b>0.01</b>
30 Cigarette Smoke (Current User )	17 (40.5)	3 (15.0)	2.698	<b>0.05</b>

**Figure 2: Work Status Before and After Injury comparing IBIRN clients and STR patients**



## DISCUSSION

### Evaluation

This study aimed to compare IBIRN clients who are currently receiving services that began within the last three years (2007-2009) and STR patients who were identified through the IDPH outreach letters. The rationale for not including information from the year 2010 was to allow individuals to have access to IBIRN services and also to have time for adjustment. Despite efforts to minimize the limitation of the previous survey, this study generated a very low response rate (5%).

The results of this survey are quite intriguing. As expected, IBIRN clients were more likely to have received services available to survivors of TBI. IBIRN clients were more likely to have received the tote bag, used the BIAIA helpline, accessed “Brain Injury Waiver” services, applied for social security disability insurance, and finally attended support groups. In addition, IBIRN clients had a higher proportion of people that responded to the survey on their behalf. However, assistance with survey response did not translate into better perception of access to care and better health and social outcomes. On the contrary, IBIRN clients reported more obstacles in the SOS scale and more issues related to physical and emotional health than the STR group.

The main explanation of these findings may be the differences in severity of the TBI among those who responded. IBIRN clients seemed to have more severe brain injuries, and consequently they

required more services and personal assistance, compared to STR patients. Unfortunately, access to the IBIRN clients' medical records was not possible so the study was not able to determine the severity of TBI related to diagnosis. Contrary to the STR database, the IBIRN database of clients does not include an assessment of injury severity.

This study had findings similar to the previous evaluation. IBIRN has a positive impact on the lives of clients. Compared to STR patients who did not use the IBIRN services, IBIRN clients seem to be more responsive to their own needs and are more aware of their rights, which in turn increase their expectations of services. However, caution is advised as these differences may be due to selection bias; particularly with the lower proportion of IBIRN clients reporting social and emotional support.

### **Limitations**

Although a systematic randomization method was used in the selection of the sample, the low sample size (selection bias) considerably limits the value and generalizability of these findings.

Among those who responded recall bias seems to be part of the problem. STR patients who were previously sent outreach letters, which were not returned, but did not contact IBIRN, were selected to represent the STR group. The fact they were more likely to report not receiving the outreach letters is intriguing. Either the letters were received and dismissed or forgotten.

### **Conclusion and Recommendations**

The IBIRN, through the BIAIA, provides essential services by educating, empowering and informing survivors of traumatic brain injury and their families about resources available to them. These services can lead to better social functioning and health outcomes. Therefore, it is important to evaluate as well the safety net of medical service connections and social support and other services provided by the BIAIA to individuals with TBI and their families.

The results of this evaluation suggest key steps that should be incorporated into the BIAIA and IDPH to facilitate the implementation of valid and significant future evaluations.

The overall response rate for the survey was very low, despite the combination of mail, online questionnaires, and follow-up phone calls. Future studies may consider mailing reminder postcards or the questionnaire a second time if the initial one was not returned to increase response rate. A necessary approach to increasing response rate is to improve the collection and tracking of individuals with TBI. The BIAIA needs to track the severity of TBI in clients served and record the source of the diagnosis and type of diagnosis concluded by clinicians. In addition, the BIAIA needs to identify callers who are simply seeking information on brain injury from callers who have sustained a TBI. Consequently, only TBI survivors who called would be added to the IBIRN list.

The IDPH needs to stress upon trauma coordinators the importance of collecting better information on TBI survivors. The STR needs to insist that trauma coordinators verify and update the addresses and include telephone numbers where the patients can be reached. To facilitate this process, the STR should acquire software that cleans addresses using the US Postal Services database or the Department of Transportation driver license database.

The low rate of outreach letter return indicates that a significant population of TBI survivors and families did not contact IBIRN or utilize its resources. As this population was more likely to report not receiving the outreach letters, a better design may attract people to open the outreach letter.

The majority of the funding for IBIRN goes towards program administration and supplies. Rather than depending on a limited impact survey, increasing IBIRN funding and allocation of money for a formal evaluation of each component of IBIRN would allow for the proper determination of the worth of IBIRN. The IBIRN should also implement a cost-effectiveness evaluation of its services to assess its objectives in relation to its cost. Moreover, a process evaluation of the program implementation would assist in establishing pertinent changes to improve outreach and impact of IBIRN. The conduction of such evaluations would require the involvement of a program evaluator to design and conduct a comprehensive evaluation of the IBIRN.

## REFERENCES

<sup>1</sup> Brain Injury Association of Iowa. "Support, Information and Education."

(<http://www.biausa.org/iowa/support.htm#network>, accessed Sept 2009).

<sup>2</sup> Centers for Disease Control and Prevention. "Injury Prevention & Control: Traumatic Brain Injury."

(<http://www.cdc.gov/traumaticbraininjury/statistics.html>, accessed Sept 2010).

<sup>3</sup> Diallo, Ousmane. "Traumatic Brain Injury in Iowa: An Analysis of Core Surveillance Data 2006-2008."

Iowa Department of Public Health, 2010.

<sup>4</sup> France, Jill, et al. "Iowa Brain Injury Resource Network (IBIRN) 2004 Survey." Iowa Department of Public

Health, 2004.



## APPENDICES

### A.1

#### Questionnaire

Thank you for taking the time to respond to our invitation. If at any time you feel uncomfortable working on this, you may quit answering the questionnaire. If you have started the questionnaire and decide to finish it at a later time, you will be able to return to it by using the personal access code that is provided below.

Personal Access Code Field:.....

If you choose to complete the questionnaire electronically online, the link is provided below.

[http://www.idph.state.ia.us/surveys/brain\\_injury/](http://www.idph.state.ia.us/surveys/brain_injury/)

This personal access code is a computer generated random number that is not linked to any of your personal information. If you lose your code please contact us and we can provide you a new one. Any information submitted with the previous code will be lost.

This questionnaire will allow the Iowa Department of Public Health, the Iowa Brain Injury Association (BIAI) and the Council on Brain Injury to evaluate the impact of the Iowa Brain Injury Resource Network, which is only one part of the BIAI's multiple services. The IBIRN facilitates the creation of local support groups that informally meet on a monthly basis. Originally created by families and providers, this program offers support and guidance to brain injury survivors with the help of trained volunteers and managers, as well as peer-to-peer mentoring called the Iowa Family Support Network. In addition under a mandated contract with IDPH since 2006, the BIAI offers neuro-resource facilitation (NRF), which helps clients and their families to better cope with brain injury, get back to leading a productive life and reintegrate into the community. The emphasis of the NRF is on information dissemination, providing linkage to appropriate services, training to increase capacity and guaranteeing program sustainability. The activities of the IBIRN are believed to improve the lives of Iowans with brain injuries by increasing awareness of the client and families alike on brain injury issues, facilitating the reintegration of communities and increasing service capacity.

There are four parts to this questionnaire.

- Section one asks general questions about your experience with the IBIRN.
- Section two asks questions related to your health and social functioning
- Section three asks about satisfaction with services and barriers to accessing needed services
- Section four asks basic demographic questions

This research was approved by the Internal Review Board of the Iowa Department of Public Health, which takes seriously the safeguard of confidential information.

Rest assured that all answers are confidential.

Thank you again for agreeing to participate in this important survey. We value your time and input.

Weblink: [http://www.idph.state.ia.us/surveys/brain\\_injury/](http://www.idph.state.ia.us/surveys/brain_injury/)

A.2

TBI Data Dictionary

Variable	Description	Code	Data Type	Results	Notes	Values
1. Prime_Per	Are you the Primary person who sustained the brain injury, a Family Member (Significant Other) to the person with the brain injury, or other?	1 = Primary 2 = Family Member/SO 9 = Other	Number			n = % = Missing =
2. Prime_Per_Other	Explanation of other person	Open Ended	Character			
3. Inj_Date	What is the date when the brain injury was sustained?	1 = Enter Date (MM/DD/YYYY)	Date			n = % = Missing =
4. Tote_Off	While the person with the brain injury was at the hospital or the rehabilitation center, was he/she offered the IBIRN packets called the "TOTE BAG" with information on brain injury and related services?	1 = Yes 2 = No 9 = Don't Know	Number			n = % = Missing =
5. Tote_Acc	If the TOTE BAG was offered to you, did you accept it?	1 = Yes 2 = No 9 = Don't Know	Number			n = % = Missing =
6. Tote_Help	Did you find the TOTE BAG helpful to you?	1 = Yes 2 = No 9 = Don't Know	Number			n = % = Missing =
7. Call_Help	Did you call the Brain Injury Association Family Help line?	1 = Yes 2 = No 9 = Don't have number	Number			n = % = Missing =

8. Fam_Cont	While the person with brain injury was in the hospital, was he/she offered a way to contact another family member through the Iowa Family Resource Network?	1 = Yes 2 = No 9 = Don't Know	Number			n = % = Missing =
9. Rec_Let	Six months after discharge from the hospital, has the person with brain injury received a referral letter from the Iowa Department of Public Health?	1 = Yes 2 = No 9 = Don't Know	Number			n = % = Missing =
10. Rec_Serv	Is the person with brain injury receiving services funded through Medicaid Home or Community Based Services – the “Brain Injury Waiver”?	1 = Yes 2 = No 9 = Don't Know	Number			n = % = Missing =
11. App_Insu	Has the person with the brain injury applied for Social Security Insurance as the result of the injury?	1 = Yes 2 = No 9 = Don't Know	Number			n = % = Missing =
12. Alt_Serv	Is the person with brain injury receiving need services funded through another Medicaid Waiver?	1 = Yes 2 = No 9 = Don't Know	Number			n = % = Missing =
13. Rat_Hlth	During these last four weeks, in general how would you rate your health?	1 = Excellent 2 = Very Good 3 = Good 4 = Fair 5 = Poor	Number			n = % = Missing =

14. Sad_7days	Thinking about mental health status during these last SEVEN DAYS, how many days of those days have you felt blue, sad or depressed? Enter the number	1-7	Number			n = % = Missing =
15. Sad_4wks	How much of the time during the past 4 weeks have you felt sad or depressed?	1 = All of the time 2 = Most of the time 3 = Some of the time 4 = A little of the time 9 = None of the time	Number			n = % = Missing =
16. Ang_7days	During the last SEVEN DAYS, how many days have you felt angry or frustrated? Enter the number	1-7	Number			n = % = Missing =
17. Ang_4wks	How much of the time during the past 4 weeks have you felt angry or frustrated?	1 = All of the time 2 = Most of the time 3 = Some of the time 4 = A little of the time 9 = None of the time	Number			n = % = Missing =
18. Hurt_7days	During the last SEVEN DAYS, have you felt like hurting yourself?	1 = Yes 2 = No 9 = Don't Know	Number			n = % = Missing =
19. Hurt_4wks	How much of the time during the past FOUR WEEKS have you felt like hurting yourself?	1 = All of the time 2 = Most of the time 3 = Some of the time 4 = A little of the time 9 = None of the time	Number			n = % = Missing =

20. Soc_Sup	How much of the time do you get social and emotional support?	1 = All of the time 2 = Most of the time 3 = Some of the time 4 = A little of the time 9 = None of the time	Number			n = % = Missing =
21. Life_Sat	How satisfied are you with your life?	1 = Very Satisfied 2 = Satisfied 3 = Neutral 4 = Dissatisfied 5 = Very Dissatisfied	Number			n = % = Missing =
22. Inj_Impv	Compared to the early times of your brain injury, how much improvement do you see?	1 = Great improvement 2 = Some improvement 3 = Little Improvement 4 = No improvement 9 = Decline	Number			n = % = Missing =
23. One_Alco	During the past 30 days, have you had at least one drink of any alcoholic beverage such as beer, wine, a malt beverage, or liquor?	1 = Yes 2 = No 9 = Don't Know	Number			n = % = Missing =
24. Alco_30	Considering all the types of alcoholic beverages, how many times during the past 30 days did you [5 for men, 4 for women] or more drinks on an occasion? Enter the number	1-30 0 = Never 9 = Don't Know	Number			n = % = Missing =
25. CigSmoke	Do you smoke cigarettes every day, some days, or	1 = Every day 2 = Some days	Number			n = % =

	not at all?	3 = Not at all 9 = Don't Know				Missing =
26. Dis_Serv	I am dissatisfied with the amount of professional help and services being provided.	1 = Strongly Disagree 2 = Disagree 3 = Neutral 4 = Agree 5 = Strongly Agree	Number			n = % = Missing =
27. Tran_Obst	Transportation is a major obstacle toward getting enough help.	1 = Strongly Disagree 2 = Disagree 3 = Neutral 4 = Agree 5 = Strongly Agree	Number			n = % = Missing =
28. Low_Mon	Lack of money to pay for medical, rehabilitation, and injury related services is a major problem.	1 = Strongly Disagree 2 = Disagree 3 = Neutral 4 = Agree 5 = Strongly Agree	Number			n = % = Missing =
29. Good_Reso	I don't know if there are good brain injury treatment resources in my community.	1 = Strongly Disagree 2 = Disagree 3 = Neutral 4 = Agree 5 = Strongly Agree	Number			n = % = Missing =
30. Few_Reso	For brain injury related problems, there are few resources in my community.	1 = Strongly Disagree 2 = Disagree 3 = Neutral 4 = Agree 5 = Strongly Agree	Number			n = % = Missing =
31. Conf_Care	I have little confidence in the quality of care now being provided.	1 = Strongly Disagree 2 = Disagree 3 = Neutral 4 = Agree 5 = Strongly Agree	Number			n = % = Missing =
32. Conc_Help	Please tell us about any other concerns that make	Open Ended	Character			n = % =

	it hard to receive the right kind of help.					Missing =
33. DOB	What is your date of birth?	1 = Enter Date (MM/DD/YYYY) 9 = Don't know	Date			n = % = Missing =
34. Gender	What is your gender?	1 = Male 2 = Female 9 = Other	Number			n = % = Missing =
35. Gen_Other	Explanation of other gender	Open Ended	Character			
36. Work_Bef	Were you working before the brain injury?	1 = Yes, Full Time 2 = Yes, Part Time 3 = No, Retired 4 = No, Unemployed	Number			n = % = Missing =
37. Work_Now	Are you working now?	1 = Yes, Full Time 2 = Yes, Part Time 3 = No, Retired 4 = No, Unemployed	Number			n = % = Missing =
38. Mon_Incom	What is your MONTHLY HOUSEHOLD INCOME, from all sources? Enter the amount	1 = Amount 9 = Don't Know	Character			n = % = Missing =

