

Idaho State  
UNIVERSITY  
Institute of Rural Health

Pocatello and Meridian, Idaho

# Traumatic Brain Injury in Idaho:

A Longitudinal Analysis of Needs and  
Resource Assessment Data (2001-2011)



Primary Investigator:  
Russell C. **Spearman**, M.Ed.

Project collaborators:  
B. Hudnall **Stamm** Ph.D.  
Rick **Tivis**, M.A.

Technical writing:  
Debra L. **Aubrey**, Ph.D.  
Cyndy **Kelchner**, Ph.D.

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*Address all correspondence to:*

Mr. Russell C. Spearman, Senior Research Associate, Idaho State University, Institute of Rural Health, ISU-Meridian Health Science Center, 1311 E. Central Drive, Meridian ID 83642. E-mail: [spearuss@isu.edu](mailto:spearuss@isu.edu); Phone: (208) 373-1773; Fax: (208) 373-1777.

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## INTRODUCTION

In July 1996, Congress enacted Public Law 104-166 “to provide for the conduct of expanded studies and the establishment of innovative programs with respect to traumatic brain injury”. Under this law, the Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB) is charged with implementing a State Grants Program to improve access to health and other services for individuals with traumatic brain injury (TBI) and their families. The Federal TBI Program was reauthorized with enactment of the Traumatic Brain Injury Act of 2008 (P.L. 110-206). Through this program, states and territories are eligible to receive funding to improve the state’s ability to make systems changes that will sustain the TBI service delivery infrastructure.

Idaho State University, the state’s lead agency for TBI, has been competitively awarded a HRSA Planning Grant (2000-2003), an Implementation Grant (2003-2006), two Implementation Partnership Grants (2006-2009 and 2009-2014), and is in the first months of a third Implementation Partnership Grant (2014-2018). As part of the HRSA/MCHB Federal Program, all states that received competitive funding were required to complete a needs and resource assessment at least every five years. In an attempt to measure change across time, Idaho has chosen to complete a needs and resource assessment at least every other year, on average. Corrigan’s comparative analysis of needs and resource assessments from eleven states identified accessibility, availability, appropriateness, and acceptability as the domains that challenge effective services for individuals with TBI.<sup>1</sup> In performing this repeated assessment of Idahoans’ TBI needs and resources, the results of that comparative analysis<sup>1</sup> were incorporated in the development of appropriate measurement tools and strategies for residents of this rural state.

An accurate understanding of the needs and resources associated with TBI has become increasingly more important. Recent estimates from the Centers for Disease Control and Prevention (CDC) indicate that 1.7 million non-military personnel living in the United States sustain a traumatic brain injury (TBI) each year.<sup>2</sup> Ranging from mild to severe, these injuries are often the result of motor vehicle accidents, falls (particularly among the elderly), and assaults. In 2009, TBIs resulted in more than 52,000 deaths, 2.4 million emergency room visits, 300,000 hospitalizations, and approximately 125,000 persons living with a disability in the U.S.<sup>3</sup>

The prevalence of TBI in Idaho is extrapolated from CDC national estimates since Idaho does not have a system for identifying individuals with TBI. According to CDC published reports, traumatic brain injuries occur at a rate of 132 to 367 injuries per 100,000 population, with the best estimate placed at 200 injuries per 100,000 people. This translates in Idaho to approximately 3,224 TBI injuries per year.<sup>4</sup> The World Institute on Disability estimates that just over 2% of the population lives with a disability resulting from a traumatic brain injury, which means that approximately 32,243 Idahoans are currently affected by a TBI. Moreover, the Brain Injury Association of America (BIAA) estimates that 14% of civilians with a TBI will have a re-injury.<sup>5</sup>

In addition to the importance of TBI issues due to prevalence, there are critical economic issues as well. The estimated cost to society for medical care and lost wages associated with TBI is \$76.3 billion annually.<sup>5</sup> According to the Congressional Budget Office, the average cost for each service member treated for TBI at the VA was \$11,700 for the first year of treatment. For PTSD, the average cost for first year treatment was \$8,300 and the combination of TBI/PTSD was

\$13,800 for first year treatment.<sup>6</sup> Since Idaho is among those states with the highest rates of military service per capita at 6% to 8.9%,<sup>7</sup> these veteran issues are particularly relevant.

Other financial considerations are important in relation to TBI consequences. According to the 2004 National Organization on Disability/Harris Survey of Americans with Disabilities, the number of individuals living in poverty with annual household incomes below \$15,000 and who are disabled is three times the number of those without disabilities and living in poverty (26% vs. 9%).<sup>8</sup> Compounded with this fact are the income statistics for Idaho residents. Idaho's per capita income remained 49th among the states, at \$33,749 in 2012 compared to \$42,693 nationally.<sup>9</sup>

Throughout TBI needs and resource literature, there is a lack of a variable setting, scientifically validated assessment instrument. This has resulted in limitations in existing TBI needs and resource assessment studies. Additionally, summarizing and comparing data across TBI needs and resource assessment studies across states is difficult due to differences in the various questionnaires used by each state.<sup>1</sup> Given the limitations in existing studies, we wondered how a comprehensive assessment of needs and resources among individuals with a TBI living in a rural state might change over time, given that TBI has received an increased level of attention in recent years.

In September 2012, Idaho State University was the recipient of a supplemental competitive award from HRSA/MCH to support an in-depth analysis of the longitudinal aspects of providing, receiving, and not having TBI services and supports through a series of needs and resource assessments to answer these questions. As in other rural states, TBIs are a significant health concern in Idaho. Treatment is complicated in rural states by difficult geography, minimal or inadequate infrastructure, and isolation. In addition, low population density translates to fewer people with TBI for professionals to serve and, ultimately, a lack of appropriate supports and services.

This report is a cumulative analysis of a series of seven years of Idaho's statewide traumatic brain injury needs and resource (N&R) assessments. The first N&R was conducted in 2001, with subsequent assessments conducted in 2004, 2005, 2006, 2007, 2008, and 2011. The goal of this study was to describe service and support needs as well as service and support availability. Three research questions were posed:

1. Do the reported needs and resources change across time?
2. Do the reported services and supports change across time?
3. What is the quality of match between the reported needs and resources and the available services and support?

The research questions in this study were addressed through analyses of the consistent data obtained from seven TBI Needs and Resources Assessment reports in Idaho over the ten years between 2001 and 2011.

## **METHODOLOGY**

A TBI Needs and Resource (N&R) Assessment was conducted in 2001, 2004, 2005, 2006, 2007, 2008, and 2011 with the purpose of analyzing need and changes in need over time. Each year, a

questionnaire was mailed to individuals with an incidence of brain injury in their families and a separate questionnaire was mailed to service provision agencies. The service provision agencies were instructed to complete and return the measure only if they served people with TBIs. The exception was 2011 when only one questionnaire was administered, the one for individuals with TBI and their families, and it was only offered online.

## **Materials**

A review of the relevant literature revealed there is a dearth of psychometrically reliable and valid measures of TBI systems with which we could track availability and acceptability of services and supports. Consequently, two assessment instruments were developed for use in the Idaho N&R assessments. These instruments were modifications of a 1998 HRSA/MCHB needs and resources assessment instrument that concentrated primarily on state agencies and private providers. The tools developed included one for individuals personally affected by a TBI and one for private providers of services and state agency personnel. Both assessments were continually evaluated and refined over time. The overall Cronbach's alpha subscale reliabilities range between 0.63 and 0.94 with the highest reliability associated with items about the access to, need for, and acceptability of services ( $\alpha=0.94$ ). The subscale relating to changes to health, work, family, and social status as a result of the TBI had an  $\alpha=0.84$ . The subscale related to stigma and discrimination both from the community and providers was the lowest alpha  $\alpha=0.63$  which, given the few items on the scale, is in the acceptable range.

The original provider/agency version used in Idaho's 2001 N&R assessment contained 15 items about a respondent's organization including accreditation, proportion of individuals served with TBIs, size and location, and TBI-specific programs and services. The original individual/family member version used in Idaho's 2001 N&R assessment contained 34 items. The questionnaire was designed to be completed by individuals who had sustained a TBI (regarding their own TBI experiences) or by a family member (on behalf of the person who had sustained a TBI). Questionnaire items included basic demographic information, cause of the TBI, services and evaluations received, facilities utilized, work history, income and sources of income, living arrangements, transportation provisions, possible legal trouble, perceived life changes, and pre/post injury life quality. Respondents were reminded that questions (unless otherwise noted) referred to the injured individuals.

## **Design and Procedure**

Repeated measurement with self-report questionnaires was completed using convenience sampling (individuals and agencies contacted through known TBI organizations and associations). For the survey targeting individuals with TBI, the assessment of needs was measured across several domains such as housing, transportation, and personal care. Response options included "Don't need help", "Need help", and "Have help". Select items pertaining to caregivers' experiences were also included. Data from individuals with a TBI and their family members were reported in aggregate. The provider version of the needs and resources assessment was made available to healthcare providers and agencies within Idaho through the U.S. mail, e-mail, or online via the Idaho State University Institute of Rural Health (ISU-IRH) website.

Mailing lists were obtained from a variety of sources including the Brain Injury Alliance of Idaho (BIA-ID), Disability Rights Idaho (Idaho's protection and advocacy organization), Idaho

Division of Medicaid, Idaho Trauma Registry, emergency medical services, and the Idaho State Division of Vocational Rehabilitation. In addition, area hospitals, agencies identified as potentially providing TBI services, rehabilitation facilities, and insurance providers were given copies of the assessment tool and asked to distribute them to individuals known to provide care to people with a TBI.

The individual and family member version of the needs and resources assessment was provided using the same mechanisms as described above. To protect patient confidentiality, organizations with access to a TBI mailing list such as hospitals, TBI agencies, rehabilitation facilities, and insurance providers all received copies of the instrument and were asked to distribute them to individuals affected by a TBI (i.e., individuals with a TBI and/or their family members). Because mailing lists were compiled from a variety of sources, it is likely that the names and addresses of some people were on multiple lists causing those individuals to receive more than one copy of the mailed assessment tool and potentially reducing our calculable return rate.

To preserve anonymity, agreement and recognition of informed consent was provided by the completion of the needs and resources assessment instrument, rather than returning signed participation agreements. Individuals choosing not to participate were instructed not to complete and return the measure. Paper surveys (years 2001 through 2008) were mailed to both individual and provider groups.

One of the most difficult aspects of determining if any TBI grant has an impact on its state is assessing change across time. We chose to repeat our needs and resources assessment to see if there was (a) an increase in available services and (b) an improvement in acceptability and need for those services. Needs and resources assessments were completed in 2001, 2003 (as part of a larger disability study that is not included here), 2004, 2005, 2007, 2008, and 2011.

Accommodation for difficulty in completing the forms was made through the availability of BIA-ID members to assist people in filling out the forms. While the BIA-ID participated in the study, they were a neutral third party available to participants through their toll-free phone number. In addition to reminder cards, volunteers from the BIA-ID and TBI advisory council members made phone calls to potential participants to encourage them to participate and to offer assistance in completing the forms if needed.

## Participants

Over 1,000 individual and family questionnaires and over 550 agencies and provider questionnaires were completed during the seven survey years. Return rates and other sampling characteristics are noted in the following table.

**Table 1. Sampling Characteristics**

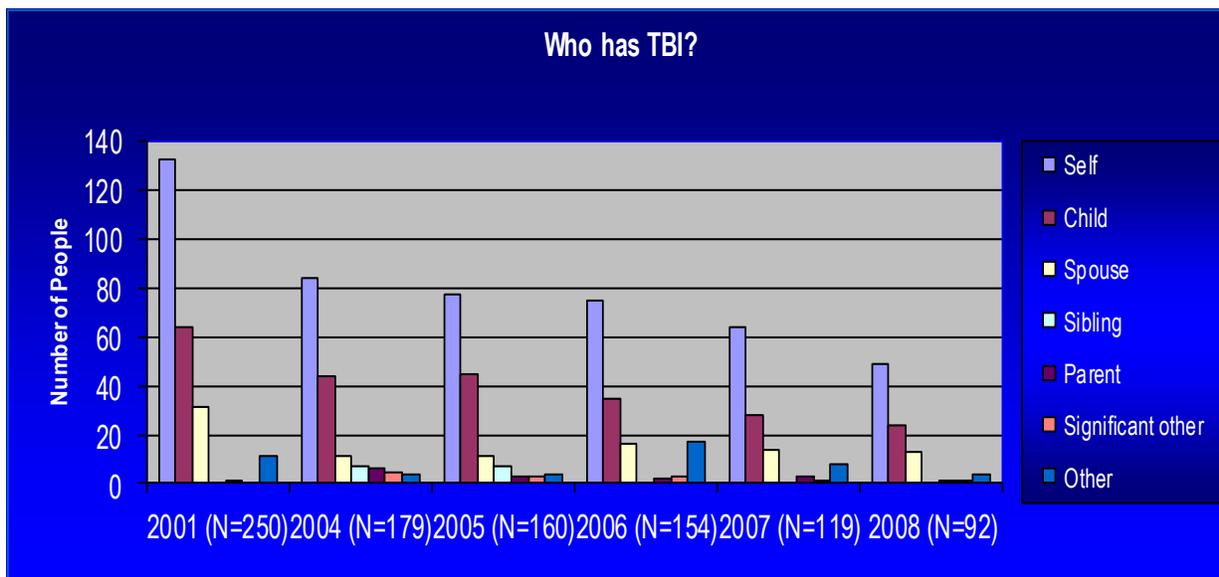
<b>Sampling Characteristics</b>	<b>2001</b>	<b>2004</b>	<b>2005</b>	<b>2006</b>	<b>2007</b>	<b>2008</b>	<b>2011</b>
Idaho Counties Represented (%)	80	59	70	64	52	43	79
Individuals/family with TBI (N)	250	179	160	152	127	137	76
Individual Return Rate (%)	33.3	37.1	36.6	23.9	17.8	21.7	N/A
Providers (N)	194	163	106	48	35	30	N/A
Provider Return Rate (%)	19.4	7.8	17.1	17.1	13.3	9.7	N/A

Information about respondents to the surveys (individuals with TBI or family members) is presented in Figure 1 below. Discrepancies between the total N for each year and the results noted in this figure represent item response differences or omissions.

### Demographic Information of Individuals with TBI

As noted earlier, at times a family member completed the individual surveys for the person with TBI in the household. The relationship of respondents to the target individual is noted in Figure 1. The majority of respondents self-identified as a person with a traumatic brain injury, followed by parents of children with a TBI.

**Figure 1. Relationship of Respondents to the Identified Individual with a TBI**



The demographics for individual participants with TBI are reported in Table 2.

**Table 2. Participant Characteristics for Individuals with TBI**

Participant demographics	2001	2004	2005	2006	2007	2008	2011
Total number of respondents	250	179	160	152	127	137	105
Age (mean) of respondents	37.4	39.0	41.0	41.1	41.3	35.7	n/a
M/F-individual respondents (%)	63/37	42/58	48/48	49/51	48/52	44/36	43/57
M/F-family member respondents (%)	75/25	70/30	62/29	59/41	66/34	9/33	n/a
<b>Education completed (% of respondents per year)</b>							
Elementary school	8	3	6	5	9	8	<5
Middle school	11	11	9	13	11	6	-
High school	18	29	30	33	34	28	30
Technical or trade	-	32	34	37	39	31	7
College	28	17	17	0	22	16	61
Other	14	7	4	13	7	6	-

## *Income and Employment Statistics*

Participant responses across five study years indicate that 71% of the respondents (n=695) have an annual household income of less than \$25,000 as shown in Figure 2. Furthermore, 39% reported their annual income to be less than \$10,000, indicating that they likely struggle with daily concerns regarding food, housing, and other basic needs.

**Figure 2. Total Household Income**

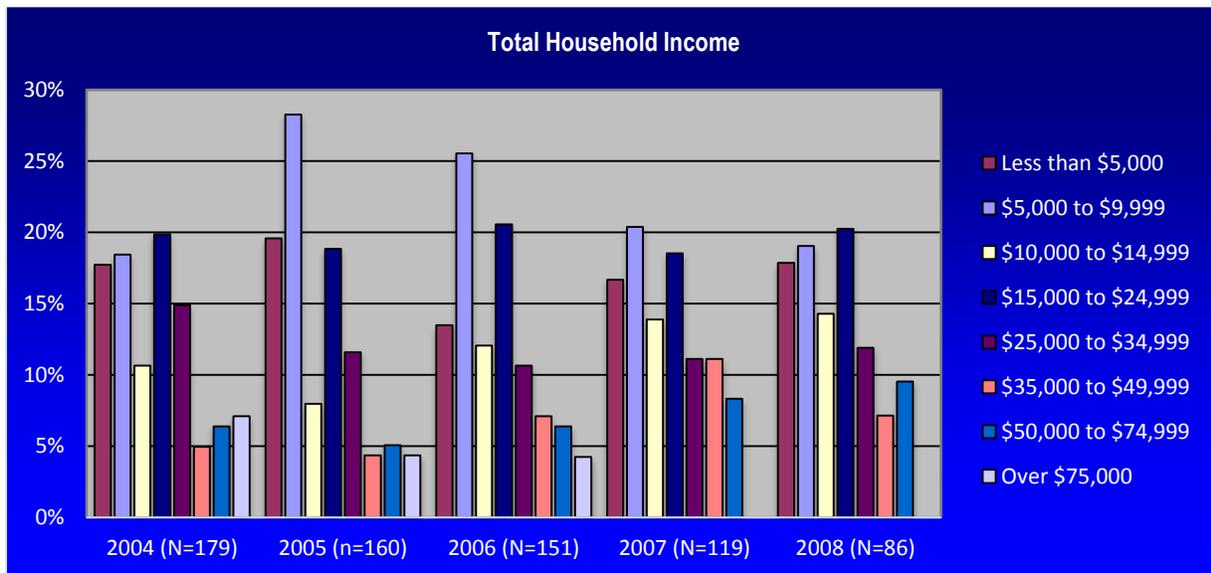
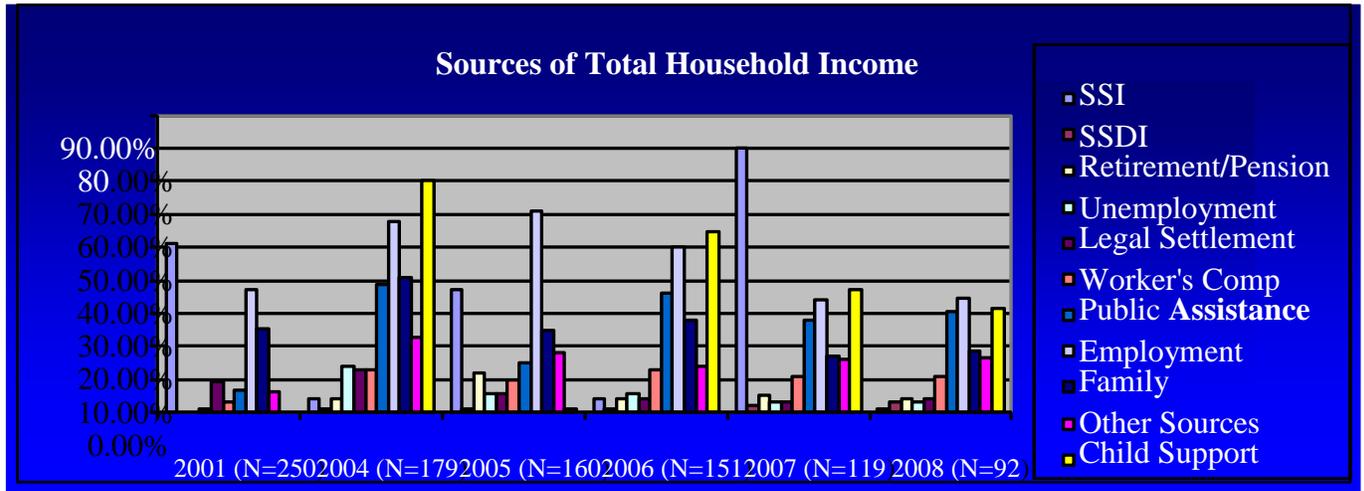


Figure 3 below reflects the average percentage of respondents who identified a source of income as contributing to their total household income. Thirty percent (30%) of respondents indicated that supplemental security income (SSI) made up any part of their total household income, 5.8% reported retirement/pension income, and 26% reported public assistance as making up a part of their total income. Employment earnings were reported as contributing to income sources by 46% of respondents and child support by 39%. Support from family remained relatively consistent across the six years of data, contributing to household income for about 30% of respondents.

**Figure 3. Sources of Total Household Income**

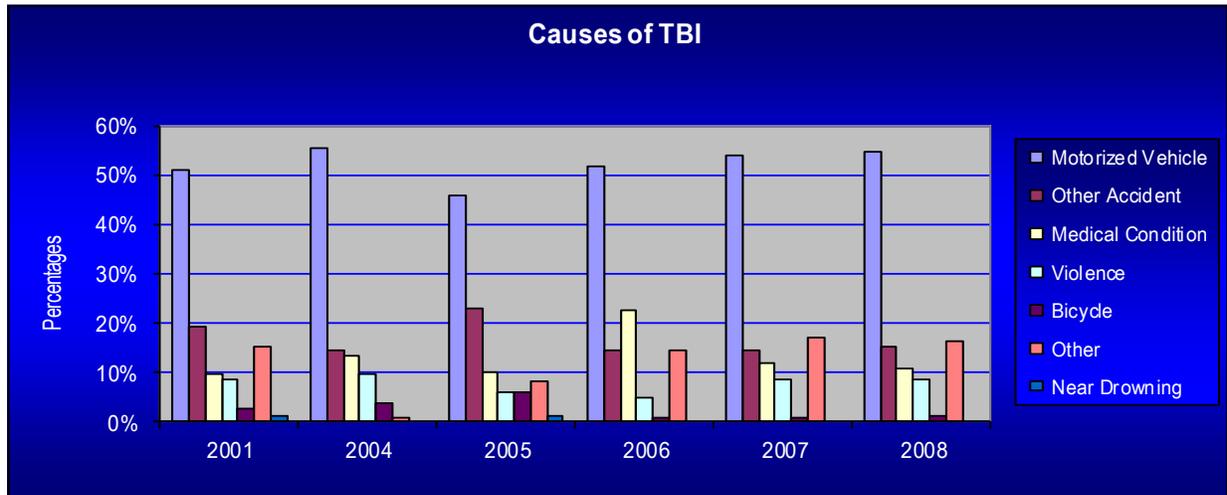


About seven out of eight (88%) employment-age individuals in this sample indicated that they had worked for wages prior to their TBI. Individuals choosing not to work (e.g., in school or retirees) were first eliminated from the analysis, thus reflecting a relatively high unemployment rate (12%) among rural individuals who later become survivors of a TBI. By comparison, recent data from Idaho Commerce and Labor indicate that the state average unemployment rate is currently 4.9%, slightly less than the national average of 6.3%.<sup>10</sup>

***Traumatic Brain Injury Statistics***

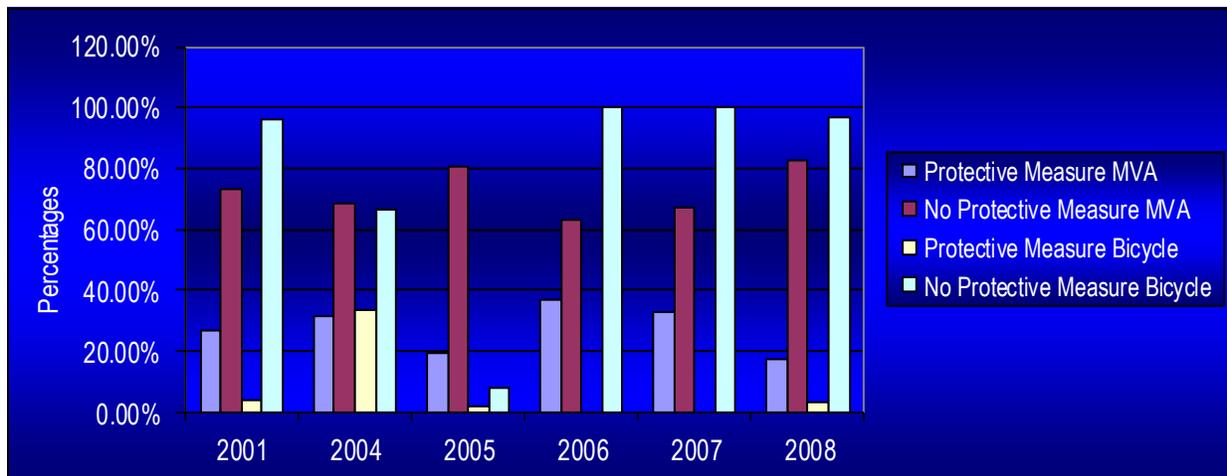
Regarding TBI causes, the data suggest that over 50% of Idaho respondents acquired their brain injury via a motor vehicle accident. This figure differs from recent CDC estimates indicating that motor vehicle accidents cause only 20% of brain injuries nationwide.<sup>3</sup> While CDC data suggest that the current findings may differ from their estimates, other national sources including the American Academy of Neurology<sup>11</sup> and the National Institute of Neurological Disorders and Stroke<sup>12</sup> support these findings.

**Figure 4. Reported Cause of Traumatic Brain Injury for Respondents**



Concerning whether or not the individual took protective measures related to motor vehicle use and bike riding, Figure 5 shows that a large proportion of TBI incidents involved individuals who were not using seatbelts or protective headgear. This finding supports the need for continued public awareness campaigns around the importance of seatbelts, helmets, and other types of protective gear.

**Figure 5. Use of Protective Measures at Time of Injury for Individuals with TBI**



**Analysis Methods**

Data from all surveys were analyzed using SAS routines for descriptive statistics. Analysis of variance (ANOVA) and Chi Square tests were conducted using SAS version 8.2. Professional posters, presentations, and journal articles have been developed resulting from the data as a way of providing ongoing information to inform decision makers and stakeholders about the needs of individuals with TBI and their families.

## RESULTS FROM NEEDS AND RESOURCE ASSESSMENTS

Results are presented below for individual surveys and for service provider surveys across all available years. In compliance with the reporting policies of the Idaho State University Institute of Rural Health (ISU-IRH) and the ISU Human Subjects Committee, data cells containing observations of fewer than five respondents are reported as <5 to avoid potential breaches in confidentiality.

### Survey Results for Individuals with TBI or Family Members

Questions were asked across multiple domains of need such as housing, transportation, and healthcare, and the results are presented in the various figures and tables below.

Note that the last two years of the needs assessment, 2008 and 2011, were designed as a guide to direct the future work of the Institute of Rural Health TBI team. Because of the change in purpose, the 2008 and 2011 surveys do not match completely the data in the previous years. The same need domains were included in the 2008 survey, but only the first six of the fourteen total need domains presented here were included in the 2011 survey.

More significantly, the response choices were changed. Four responses were available in the 2008 and 2011 surveys instead of the three responses available in earlier surveys, as shown in the table below. While this change adds to the detail of these later surveys, it limits the appropriateness of including all survey years in the graphical analyses. Therefore, information from the 2008 and 2011 surveys will not be included in the graphs but will be reported in a separate table and discussed in the interpretation of the graphical analyses.

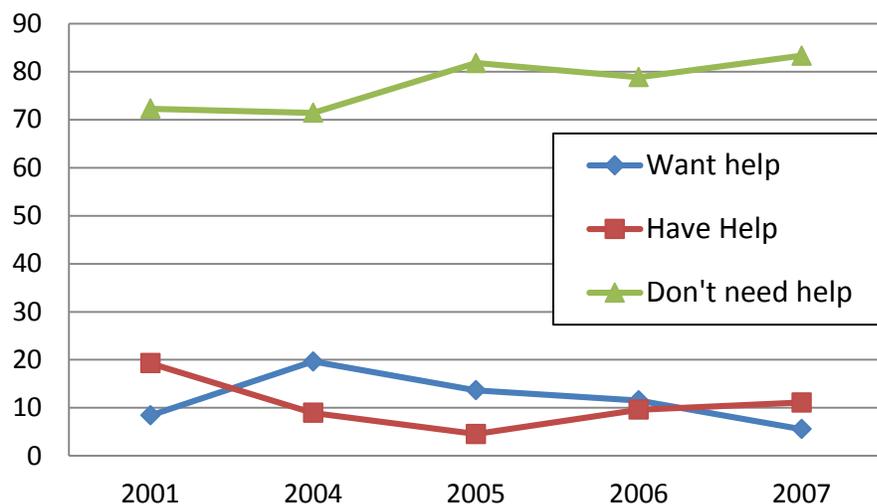
**Table 3. Response Options for Individual Surveys**

<b>2001-2007 survey responses</b>	<b>2008, 2011 survey responses</b>
Don't need help	Don't know how to get help
Need help	Need help
Have help	Receive help
	Want more help

## Housing Assistance

An average of 77.5% of those responding to the question on housing assistance from 2001-2007 reported that they did not need help with housing, leaving 22.5% who either have help (10.7%) or need help (11.8%).

**Figure 6. Housing Assistance, Percent of Responses**



As anticipated, the changes in these variables over the years are inversely related such that for a year when the percentage of those “wanting help” goes up, the percentage of those that “Don’t need help” goes down. From 2004 to 2007, we see a downward trend in those who need help and an upward trend for those who have help. This trend is reversed in 2008 (see Table 4) when the percentage of those having assistance falls below the percentage needing assistance. There are significant gains made again in 2011, with an 18% increase in housing needs being met.

**Table 4. Housing Assistance, Percent of Responses**

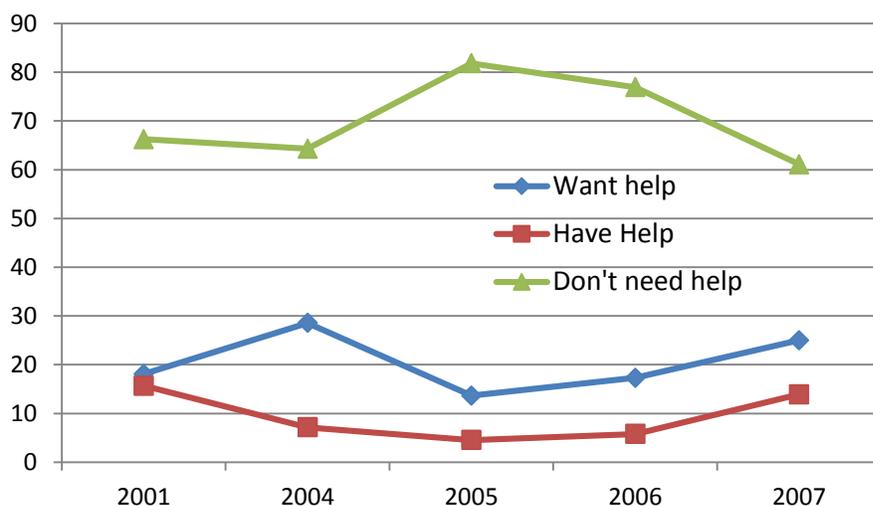
Response	2008	2011
Don't know how to get help	6.6	9.4
Need help	7.3	14.1
Receive help	10.9	10.9
Want more help	8.0	-

In 2008, the percentage of those not needing housing assistance dropped to 46.7%, while those with help remained at 10.9%. That leaves 13.9% in 2008 that either “need help” or “need help and don’t know where to find help” for housing assistance and 8% who are receiving some help but would like more. This is a total of 21.9% of respondents reporting some level of additional housing assistance needed; however, it is important to note that the 2008 survey was the only year when a response was available regarding additional need for individuals already receiving services. In 2011, the percentage of those not needing housing assistance was 64.1%, while those with help remained at 10.9%. That leaves 23% in 2011 that either “need help” or “need help and

don't know where to find help" for housing assistance (see table below). This is an increase from the 12% average from 2001-2007.

### ***Employment Assistance***

**Figure 7. Employment Assistance, Percent of Responses**



An average of 70.1% reported not needing employment assistance across survey years. This average represents a great deal of variability, however, ranging from a high of 81.8% in 2005 to a low of 61.1% in 2007 reporting they “don’t need help.” In the 2008 survey, 41.6% report that they don’t need help and 22.6% report that they need or don’t know how to get help. Having help was reported by 7.3% of respondents. In the 2011 survey, 50.0% reported that they “don’t need help” and 34.9% reported that they “need” or “don’t know how to get” help. Having help was reported by 12.1% of respondents (see table below).

**Table 5. Employment Assistance, Percent of Responses**

<b>Response</b>	<b>2008</b>	<b>2011</b>
Don't know how to get help	8.0	12.1
Need help	14.6	22.7
Receive help	7.3	12.1
Want more help	5.1	1.5

Additional questions regarding the reasons for unemployment in the 2001-2008 surveys indicated that an average of 25.6% reported post-TBI unemployment due to “inability to do any job.” An average of 6.8% report barriers in the workplace that are described as “lack of accommodation.” An additional average of 15% reported being “unable to get hired” despite efforts to do so.

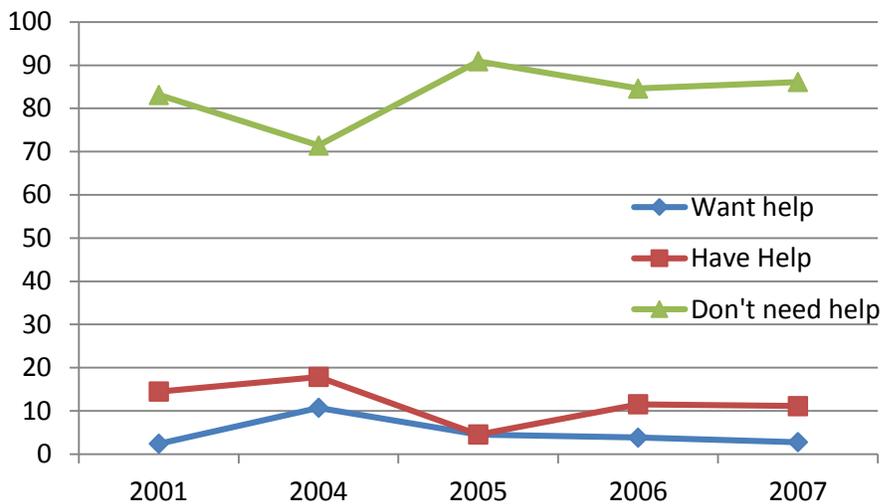
**Table 6. Reasons for Post-TBI Unemployment (%) among Individuals 18 and Older**

	2001	2004	2005	2006	2007	2008
Total percentage unemployed	55	46	41	43	59	46
“Inability to do any job”	26	24	22	30	30	22
“Lack of accommodation”	14	5	6	4	10	7
“Unable to get hired”	15	17	13	9	19	17

**Personal Care Assistance**

The need for personal care assistance has averaged 83.2% across the years with the majority of respondents reporting that they “don’t need help.” Only an average of 11.9% reported needing assistance. In 2008, 49.6% reported not needing help with personal care. Those in need of help, either reporting a need or not knowing how to get help, remained consistent with previous years at 9.7%, with 24.8% receiving adequate help. The 2011 data reveal that, again, about 9% are in need of personal care assistance while 13.4% report an adequate level of care.

**Figure 8. Personal Care Assistance, Percent of Responses**



**Table 7. Personal Care Assistance, Percent of Responses**

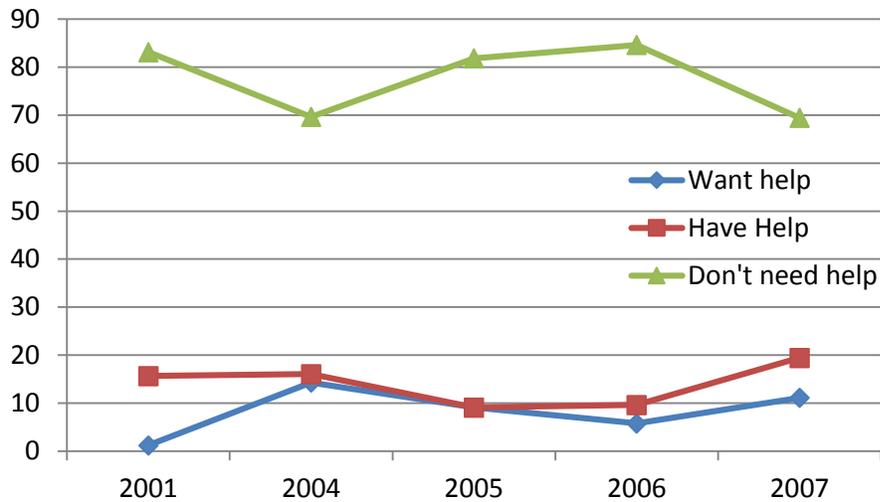
Response	2008	2011
Don't know how to get help	3.5	3.0
Need help	6.2	6.0
Receive help	24.8	13.4
Want more help	2.7	4.5

**Assistance with Household Chores**

The need for assistance with household chores was at its highest in 2007, with 30% wanting or having help. There was an increase in those reporting unmet need, with growth from 2006 to 2007 (from 6% to 11%). This pattern of an upturn has continued for those needing assistance,

climbing to 14.1% in 2008 and 20% in 2011, while those receiving chore assistance dropped from 23.0% in 2008 to 11% in 2011.

**Figure 9. Assistance with Chores, Percent of Responses**



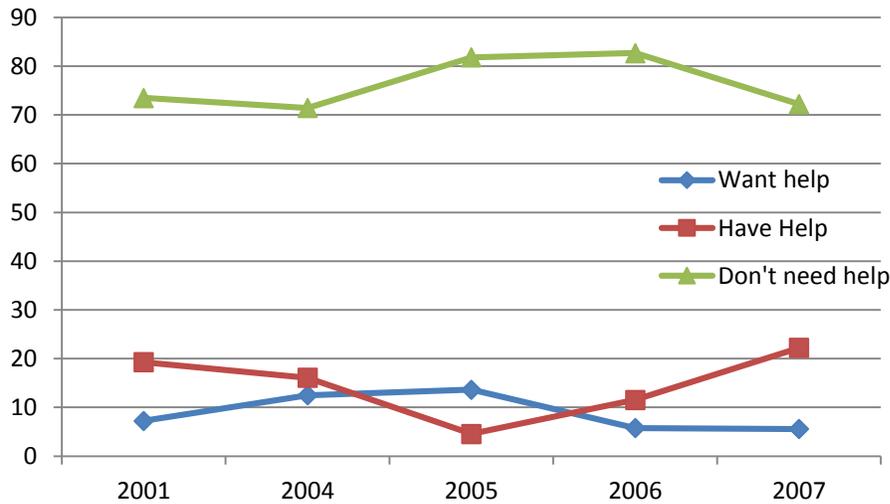
**Table 8. Chore Assistance, Percent of Responses**

Response	2008	2011
Don't know how to get help	5.3	4.6
Need help	14.1	20.0
Receive help	23.0	10.7
Want more help	10.6	9.2

***Assistance with Transportation***

Those reporting needs for transportation assistance have averaged about 25% (reporting either need or receipt of assistance) with the percentage of individuals receiving help exceeding the percent of need in all years but 2005 and 2011. In 2008, the needing help group remained at about 13% and those receiving transportation assistance increased to 20.9%. In 2011, the percentages are about equal with 14% both needing and receiving transportation assistance. There is additional unmet need noted in the 2008 and 2011 data in the 8.7% and 3% of respondents who report they are receiving assistance but would benefit from more supports.

**Figure 10. Assistance with Transportation, Percent of Responses**

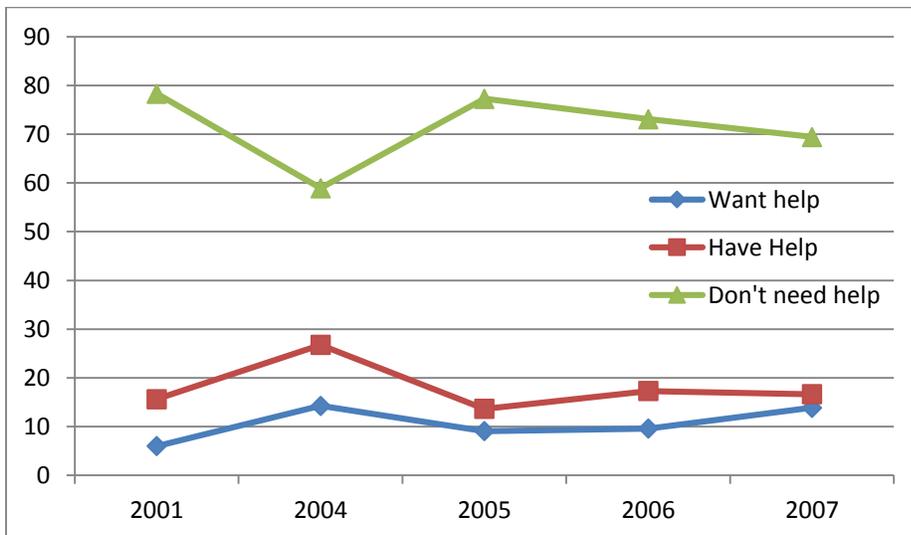


**Table 9. Transportation Assistance, Percent of Responses**

Response	2008	2011
Don't know how to get help	2.6	4.6
Need help	11.3	9.1
Receive help	20.9	13.6
Want more help	8.7	3.0

**Money Management**

**Figure 11. Money Management, Percent of Responses**



Across the years an average of 30% reported a need for money management assistance (“want” and “have” combined). Except for a slight spike in 2004, this has remained fairly constant with

2/3 of those in need receiving assistance. In 2008, slightly more individuals reported receiving help (23.7%) than those needing help (21.1%). For 2011, the level of need (25.3%) exceeded the percentage receiving assistance (20%).

**Table 10. Money Management, Percent of Responses**

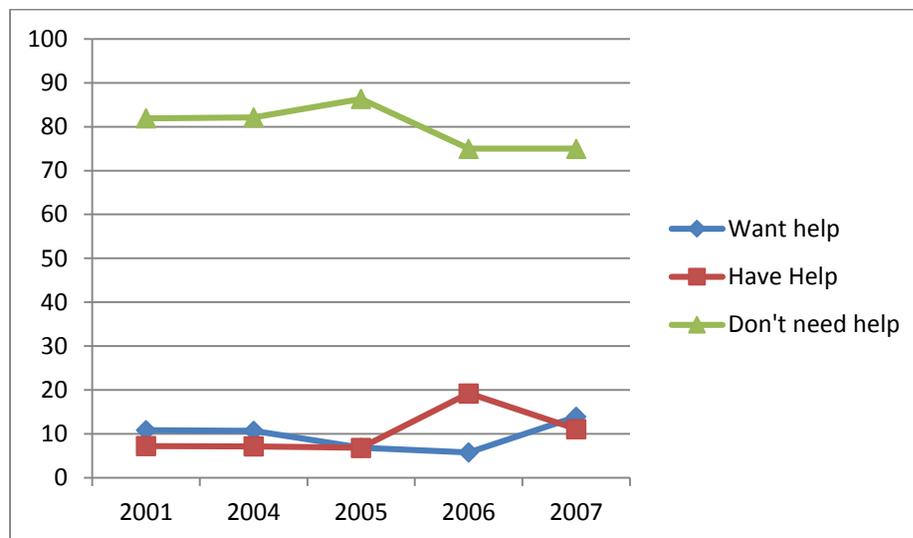
Response	2008	2011
Don't know how to get help	7.9	4.48
Need help	13.2	20.90
Receive help	23.7	19.40
Want more help	6.1	<5

***Assistance with Speech Therapy***

For the remaining domains presented below, there was no assessment of need in the 2011 data as mentioned earlier. From this point, only the 2001-2007 data will be presented and 2008 data will be discussed as appropriate.

The need for speech therapy remains fairly steady, reported at about 20% across the years (“want help” and “have help” combined) with about half of those receiving assistance. This remains consistent in 2008 with 12% of respondents reporting an unmet need and 80% reporting that they “don’t need help.”

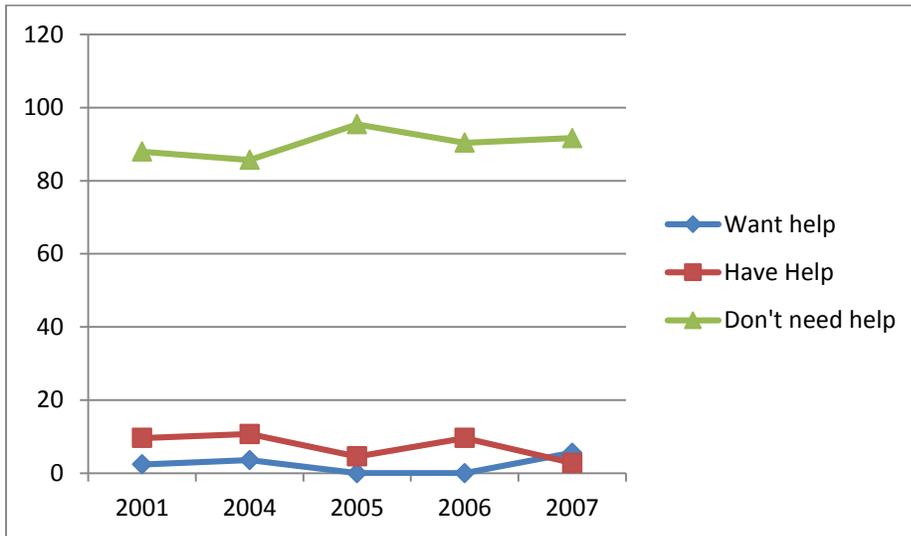
**Figure 12. Assistance with Speech Therapy, Percent of Responses**



### *Nursing Assistance*

The reported need for nursing assistance is low at less than 10% of respondents. In 2008, it remained low with less than 5% reporting needs and 80% reporting they don't need help.

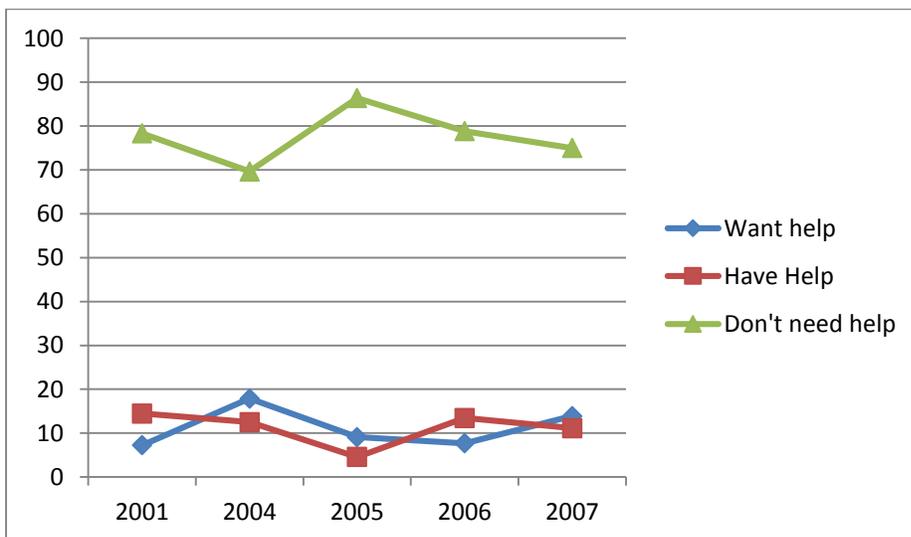
**Figure 13. Nursing Assistance, Percent of Responses**



### *Recreational Services*

Recreational assistance also remains fairly constant at about 22% needing assistance (“want” and “need” help combined) with approximately half the individuals with need receiving recreational assistance. The 2008 data showed little change with 7% reporting a need and 14% receiving assistance.

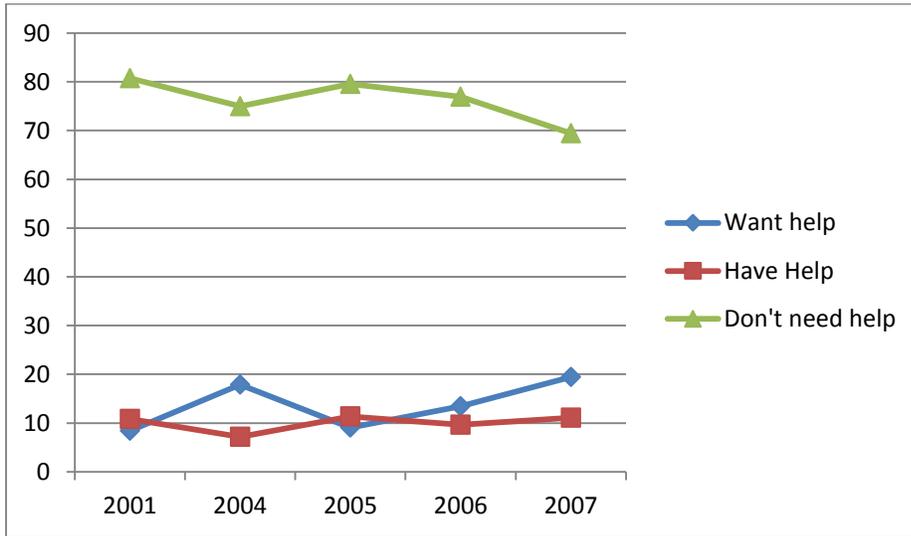
**Figure 14. Recreational Services, Percent of Responses**



### *Community Skill Assistance*

There has been a variable rate in the percentage reporting needing assistance with community skills (9%-20%), while the percentage of those receiving assistance has remained constant at around 10%.

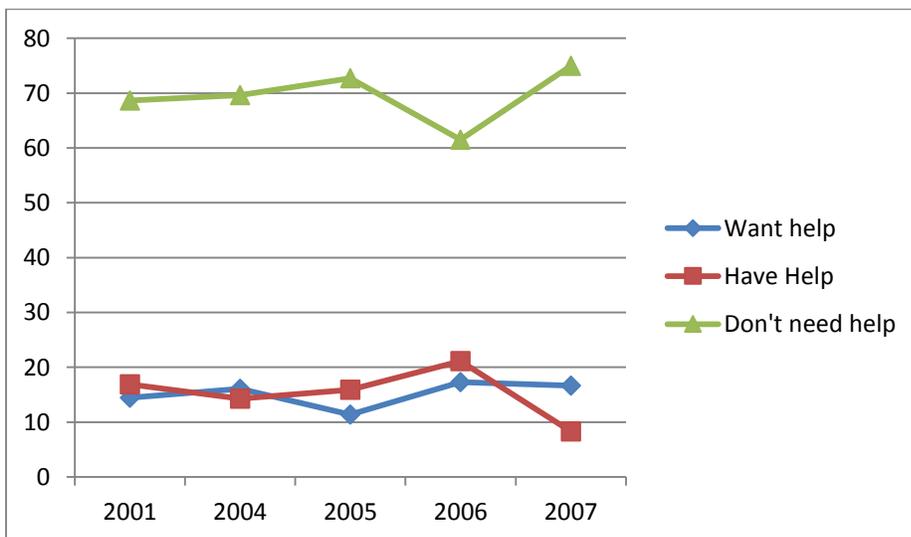
**Figure 15. Community Skill Assistance, Percent of Responses**



### *Physical and Occupational Therapy Assistance*

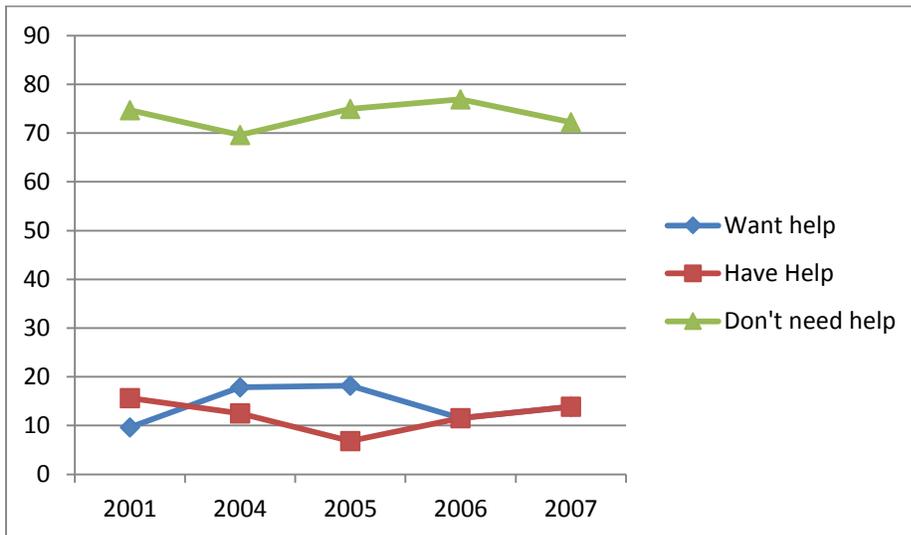
Physical therapy needs are reported as ranging between 30% and 38% (“want” and “have” help combined) with anywhere from 9% to 21% actually receiving the services needed. There was little change in the 2008 survey results with 18% reporting a need and 17% receiving assistance.

**Figure 16. Physical Therapy Assistance, Percent of Responses**



The percentage of respondents receiving occupational therapy has remained fairly constant, averaging about 12%, with those receiving assistance perfectly paralleling those in additional wants in 2006 and 2007. In 2008 the need increased to 22% while the percentage reporting having assistance remained at 16%. The percent reporting no need dropped to 47%.

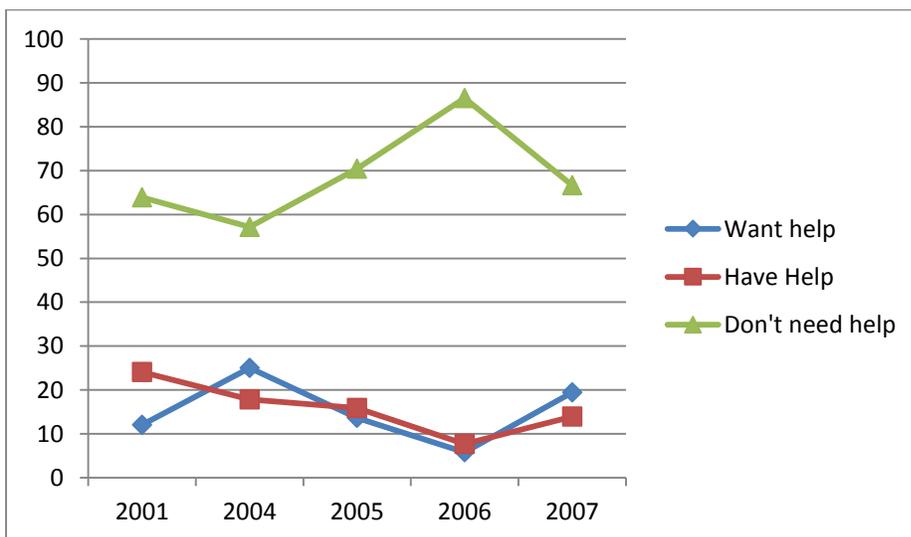
**Figure 17. Occupational Therapy Assistance, Percent of Responses**



***Mental Health Counseling Assistance***

Mental health counseling assistance has a more variable pattern, with need for a given year as high as 43% (in 2004) and as low as 13% (in 2006). After 2001, the percent “wanting help” has fairly consistently paralleled the percent of those “having help”. In 2008, there was an increase but it was within the variation seen in the past with 22% reporting a need and 23% receiving assistance.

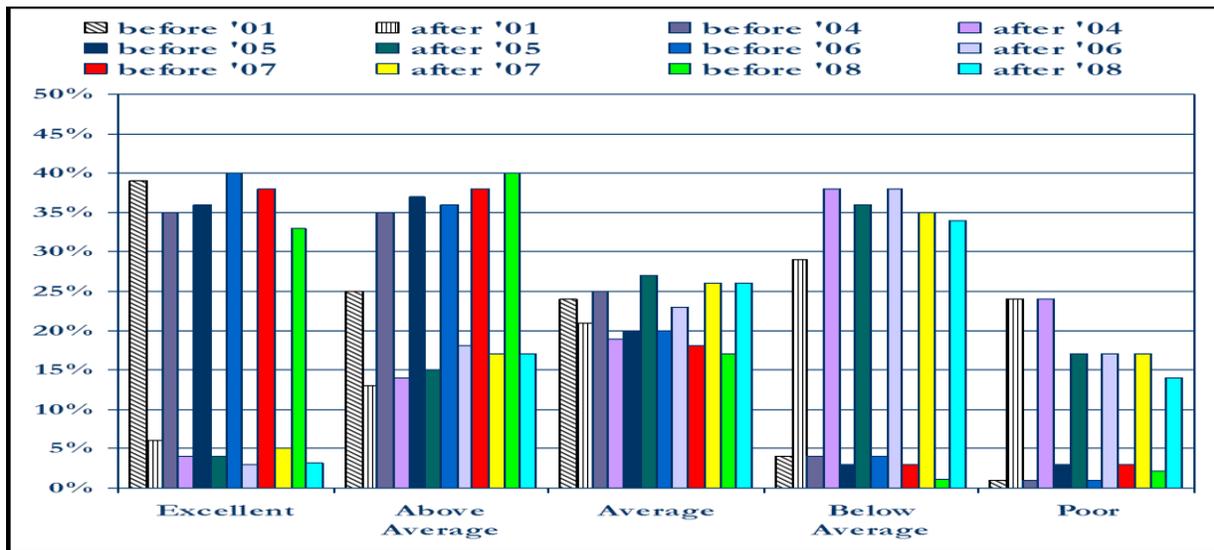
**Figure 18. Mental Health Counseling Assistance, Percent of Responses**



## Quality of Life

**Post-TBI Decreases in Quality of Life.** Repeated measures ANOVA revealed a main effect of life quality, perceived to be significantly higher before the TBI than afterward as shown in Figure 19 [F(1,793) =880.60, p<.0001]. This varied by assessment year, as reported life quality was lower in 2001 than in 2004-2007 [F(4, 793)=4.68, p< .001]. There were not significant differences in the pattern of change across the years 2001, 2004, 2005, 2007, and 2008 with quality of life being reported much higher prior to the TBI incident by most respondents. The difference across assessment years is comparable.

**Figure 19. Quality of Life Pre/Post TBI**



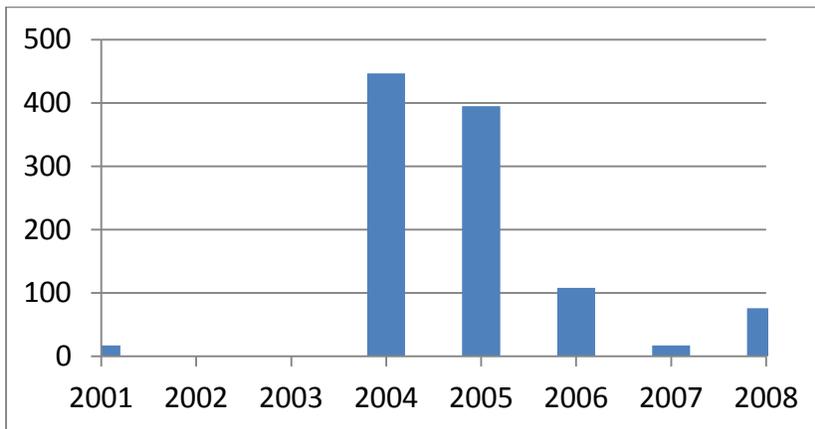
The data also revealed that females reported a significantly higher life quality than males, regardless of the year. However, the pre-TBI to post-TBI reduction in life quality did not differ between males and females. In other words, retrospective reporting of life quality prior to TBI was perceived among males with a brain injury to have been lower compared to the perceptions of their female counterparts.<sup>13</sup>

## Survey Results for Service Agencies

### Agencies Providing Services

The mean number of people served by agencies who reported working with brain injury has varied dramatically over the years. As shown in Figure 20, the average rose precipitously from 17 in 2001 to 447 in 2004, dropping slightly in 2005 to 395, with a significant drop in 2006 to 108, then 17 in 2007 and 76 in 2008.

**Figure 20. Average Number of People Served**



The table below compares the frequency of various services provided in specific service settings. The 2001 and 2007 provider surveys were used for comparison due to the similarity of the questions which made findings from these two surveys the most comparable. Unmarked items in Table 11 indicate that fewer than 3% of responding agencies regularly provided that service.

**Table 11. Services Reported as Available by Agency Respondents**

Service	Inpatient		Community Based		Day Treatment		Home Based		Skilled Nursing		Community Re-entry		Residential	
	2001	2007	2001	2007	2001	2007	2001	2007	2001	2007	2001	2007	2001	2007
Acute rehabilitation	X	X		X	X	X	X	X	X	X	X	X		
Advocacy training	X	X	X				X	X						
Assistive technology	X	X	X	X	X	X	X	X			X	X		
Case management	X	X	X	X	X	X	X	X	X	X	X	X		
Cognitive therapy	X	X	X		X	X								
Community referral	X	X	X	X	X	X	X	X	X	X	X	X	X	X
Dental care	X	X												
Driver education	X	X	X		X	X								
Education (special)	X	X	X											
Independent living skills	X	X	X		X	X	X	X						
Neuro-psychology	X	X	X		X	X								

Service	Inpatient		Community Based		Day Treatment		Home Based		Skilled Nursing		Community Re-entry		Residential	
	2001	2007	2001	2007	2001	2007	2001	2007	2001	2007	2001	2007	2001	2007
Nursing	X	X					X	X	X	X				
Occupational therapy	X	X	X	X	X	X	X	X	X	X	X	X		

***Methods for Accessing Services***

Beginning in 2003, a computerized decision support tool called the TBI Virtual Program Center (VPC) was created to join people with services and resources, via a HRSA/MCH funded Idaho TBI Implementation Grant. For more information about the TBI Virtual Program Center, visit the website at <http://www.idahotbi.org>. This one-stop shop continues to serve as a resource for individuals both in and outside the state. Over seventy hours of archived instruction exist via Idaho TBI virtual grand round series. A snapshot of the TBI-VPC homepage is provided on the following page.

Figure 21. TBI Virtual Program Center Homepage

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# Idaho Traumatic Brain Injury Virtual Program Center

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 DEVELOPMENT PROJECT  
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**INSTITUTE OF RURAL HEALTH**  
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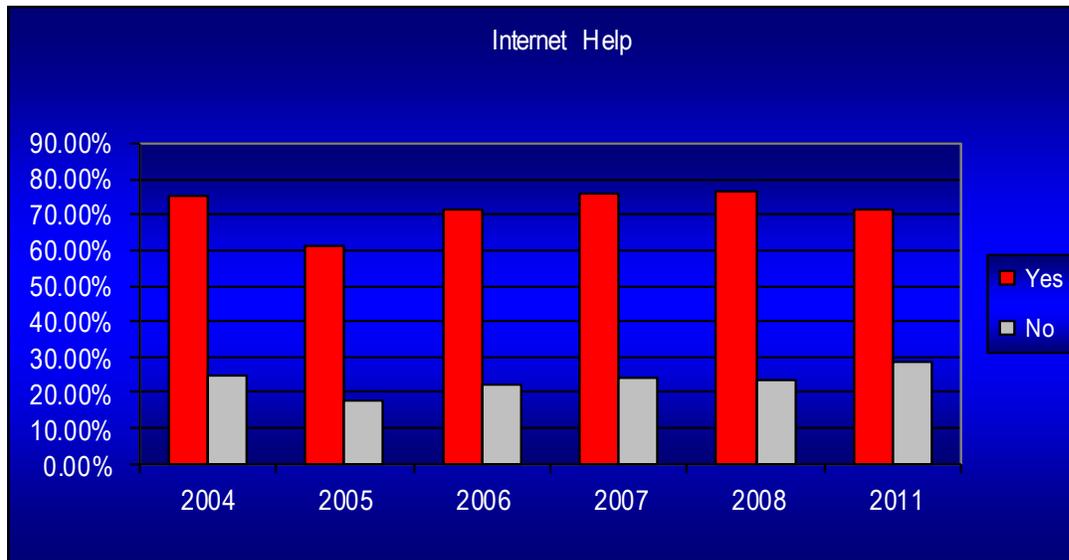
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Beginning in 2004 thru 2011, we asked respondents if they would use the internet to help find TBI services and supports information if the resource was available. Nearly 70% of respondents indicated they would use the internet to help them look for available services.

**Figure 22. Use Internet to Find TBI Services and Supports**



### ***Access to Psychiatric Services***

There are currently 108 licensed psychiatrists in Idaho, meaning there is one psychiatrist per 14,465 citizens in Idaho. Most of these providers are located in the major population areas of Idaho. Nearly two-thirds of Idaho’s counties (28 out of 44 counties) have no psychiatrists at all. Over 335,953 citizens (21.5% or 1 in 5 residents) live in counties where there is not a psychiatrist.<sup>14</sup>

In addition, it is not clear how many of those psychiatrists are practicing and to what extent. With over one quarter of those providers (26.9%) having had their license for over 20 years and quite a few over 30 years, this group likely includes some providers who have either retired or shifted to working fewer hours. This limits access to psychiatric services even further for Idaho residents.

The table below identifies how rates of service access to psychiatric care vary across different districts of the state of Idaho. The location of psychiatrists was determined by a list of providers from the Idaho Medical Licensing Board. As noted in the table, the district with the most population density (Central 4) in which Boise, the state capital, is located, has the greatest access to psychiatrists.<sup>15</sup>

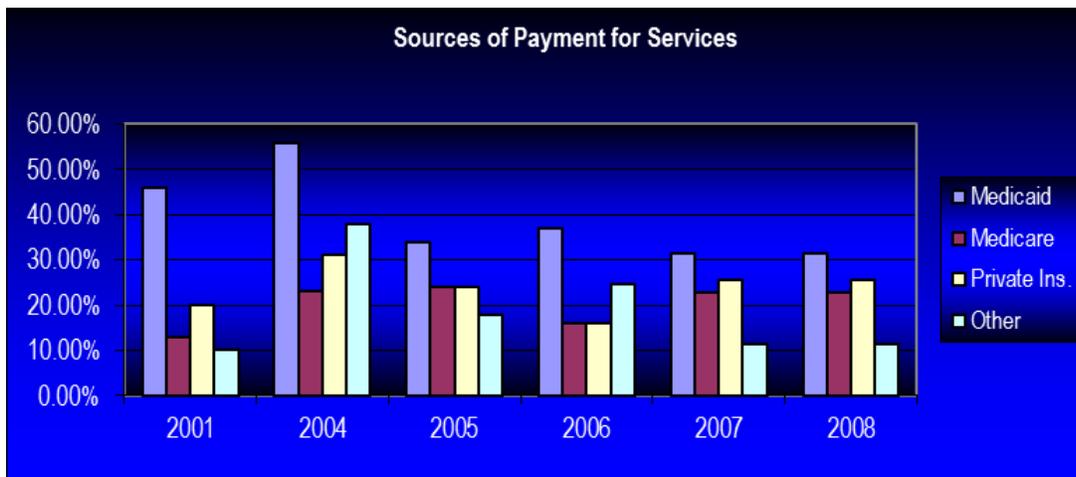
**Table 12. Distribution of Psychiatrists in Idaho, 2013**

Idaho health district	Population of district	Population with no psychiatrist in home county	% with no psychiatrist in home county	Number of psychiatrists in district	Number of psychiatrists per capita in district
Panhandle 1	212,393	20,257	9.5%	21	1/10,114
North Central 2	105,358	3,821	3.6%	6	1/17,556
Southwest 3	253,965	65,042	25.6%	2	1/126,983
Central 4	436,293	34,066	7.8%	52	1/8,390
South Central 5	185,790	87,184	46.9%	9	1/20,643
South Eastern 6	169,175	40,729	24.1%	9	1/18,797
Eastern 7	199,258	84,854	42.6%	9	1/22,140
<b>All Idaho</b>	<b>1,562,232</b>	<b>335,953</b>	<b>21.5%</b>	<b>108</b>	<b>1/14,465</b>

**Sources of Payment**

There are a number of possible sources of payment for the various services necessary for rehabilitation and independent living following a TBI incident. We asked providers to estimate what their percentage of payment was from the following sources, shown in Figure 23 below. Approximately 40% of payment came from Medicaid followed by about 18% from Medicare, 23% from private insurance, and 27% from “other” which included sources such as service fees and contractors, school state funding, and state tax dollars.

**Figure 23. Sources of Payment for Services**



### *Percent of Unmet Need*

The first avenue is to examine the degree to which needed service are available. This merely asks the question of whether or not needs identified are being met and/or are available for access in the community. The table below demonstrates service gaps or deficits identified by respondents.

**Table 13. Services Still Needed by Rural Respondents Affected by TBI (%)**

	2001	2004	2005	2006	2007	2008
Employment	19	29	14	17	25	7
Occupational Therapy	10	18	18	12	14	14
Transportation	7	13	14	6	6	3
Speech Therapy	11	11	7	6	14	9
Physical Therapy	15	16	12	17	17	15
Mental Health	12	25	14	6	19	15
Housing Assistance	8	20	14	12	17	6
Chore Assistance	1	14	9	6	11	9
Personal Care Assistance	2	11	5	4	3	2
Nursing Assistance	2	4	5	3	2	2
Recreational Assistance	7	18	9	8	13	11
Money Management	6	14	9	10	14	11
Community Skills	8	18	9	13	19	14

### *Satisfaction of Consumers with Existing Services*

The proportion of respondents who have received assistance and are satisfied with services related to community re-entry/life skills ranged from 74% to 88% in 2001, with the exception of employment services which was significantly lower. Only 55% were satisfied in 2001 with the available job-related services. Satisfaction appears to have remained relatively stable over time with 82% - 94% satisfied in 2007 for most services, and an increase to 66% satisfaction rating for employment services. This increase was not statistically significant [ $\chi^2(4)=4.65, p=0.11$ ].

**Table 14. Satisfaction with Idaho's Community Re-entry/Life Skills Services (%)**

	2001	2004	2005	2006	2007	2008
Chore Assistance	84	90	69	78	87	46
Personal Care Services	88	93	70	78	84	58
Money Management Assistance	80	88	71	79	94	52
Transportation Services	75	84	76	76	89	46
Community Skills Assistance	74	75	57	70	85	37
Housing Services	80	68	70	71	82	54
Employment Assistance	55	65	58	41	66	45
<b>Mean Service Satisfaction</b>	<b>76.6</b>	<b>80.4</b>	<b>67.3</b>	<b>70.4</b>	<b>83.9</b>	<b>48.3</b>

The proportion of respondents reporting satisfaction with medical/rehabilitation services in 2001 ranged from 67% - 78%. In 2007, satisfaction was 77% - 81%, a statistically significant overall increase [ $F(4, 524)=68.4, p<.0001$ ].

**Table 15. Satisfaction with Idaho’s Medical/Rehabilitation Services (%)**

	2001	2004	2005	2006	2007	2008
Physical Therapy	67	67	75	79	81	45
Occupational Therapy	69	73	57	64	77	43
Speech Therapy	78	82	76	75	81	40
Mental Health Counseling	70	83	69	80	80	46
<b>Mean Service Satisfaction</b>	<b>71.0</b>	<b>76.3</b>	<b>69.3</b>	<b>74.5</b>	<b>79.8</b>	<b>44.0</b>

Respondents reported the lowest level of satisfaction with both types of services in 2008 and the highest level of satisfaction in 2007.

## DISCUSSION AND CONCLUSIONS

This study represents a longitudinal analysis of traumatic brain injury needs and resource assessment data over a period of ten years and seven survey efforts. While there are certain to be differences within any state as to proximity, availability, and distribution of resources, it is believed the current analytical approach provides a better way to generalize the information from Idaho to other states. For the current study, three research questions were posed in an effort to better understand (1) if the reported needs change across time, (2) whether or not the services and supports change across time, and (3) the quality of the match between reported needs and available support.

### Question 1: Do the reported needs and resources change across time?

Although income data were reported as part of the demographic characteristics of the respondents, it is important to note that there is a clear deficit of financial resources reported by individuals with TBI. The data indicate that the majority of Idaho residents with a TBI live at or below poverty level. This finding was evident in all years of the surveys, changing very little over time. This means that individuals with TBI are likely to struggle with daily financial burdens regarding attaining food, housing, and other basic needs. Financial resources are reported to be limited and stably so for the majority of individuals with TBI. This is likely due in part to the interesting finding from this study that rates of unemployment prior to the TBI injury are 9% higher than the general population. It may be that the data reflect a higher proportion of younger risk-taking males working for subsistence, not wages, in small family businesses (e.g. farms or commerce). It is widely agreed upon that young, risk-taking males are over-represented in the brain injury population. Regardless of the cause of the pre-injury unemployment, post-injury unemployment rates among individuals having a TBI jumped substantially from 12% pre-injury to 63% post-injury. This severely impacts financial resources.

Housing services is the one domain in which a report of “no need” for services implies some sort of property or housing resource. Respondents reported the lowest levels of this resource in 2001 and 2011 surveys. The peak in housing resources appear to have been in 2007 with rapid decline in the last two surveys. Not surprisingly, the need for assistance (23%) peaked in the 2011 survey

when resources were reported at an all-time low. Consequently, the need for services has changed significantly over time for housing needs and resources.

The level of need, as defined by the percentage of individuals both receiving and wanting services, varied significantly across service domains. As seen graphically in the results section, the level of need in five domains was particularly high: Mental Health Counseling, Physical Therapy, Occupational Therapy, Employment, and Money Management Services. The average need exceeded 25% of respondents across survey years reporting either wanting or needing services in these domains.

The question of stability of need is interesting, however, since some of the areas of highest average need also had the greatest range of variability across years. For example, there was a 19% difference in the high and low years reported for needs in Money Management and Employment. The range was even larger for the Mental Health Counseling need, with a 29% difference between the reported peak and low need years. This extreme variability suggests significant change over time for these three categories of support. In contrast, the domains of Occupational Therapy, Community Skills, and Nursing Assistance had the most stable needs across time, with a range less than 10% wide. However, stability of need across time does not correspond to the level of need. This is illustrated by the fact that Nursing needs are relatively low and stable while Occupational Therapy needs are high and stable across time.

There are some notable trends to the changes in service and support needs across time. As with employment status, there is an upward trend in those reporting a need of assistance with chores starting in 2005. The good news is that the percentage reporting they have help has taken a sharp upturn (from 9% to 19%).

In summary, the answer to whether needs and resources change over time is that it depends on what you are asking about. A few needs are stable across time, but as with stable financial resources, stability does not mean the resources are high or strong; they can be consistently poor. This would imply ongoing need even if the need is stable.

## **Question 2: Do the reported services and supports change across time?**

There are several possible aspects relevant to reporting changes in services and supports: (1) the frequency of services being provided and (2) changes in sources of support for services. Service frequency changes are evident in several domains surveyed, where the data repeatedly indicated a decrease in received services from 2001 to 2005 and then a resurgence of services to the original levels by 2008. This pattern was evident in the following domains: Housing, Employment, Personal Care Services, Assistance with Chores, Transportation, Recreation, and Occupational Therapy. This is also represented in the width of the range of reported percentages of received services. For example, the most dramatic variance in received services was seen in Mental Health Counseling with a high of 24% and low of 8%, making the width of the range or the breadth of service change 16% across the years. On the opposite end of the spectrum for change are community skill supports, which remained within a range only 4% wide over time.

The data in Table 11 also indicate that there is very little change in the services provided in most settings. The most diverse number of services available are in the inpatient setting. The community was the only setting in which there was a significant change in available services.

This reduction in community services noted in 2007 is somewhat discouraging, given that community-based services are critical to independence for many individuals.

Finally, changes in financial supports for services reported by providers are potentially important due to the chronic nature of TBI support needs. While insurance and Medicare supports remained relatively stable, Medicaid and “other” sources of support have seen a 25% drop over the course of the years. This has significant implications in the climate of implementation of the Affordable Care Act. It is unclear whether such efforts will have an impact on either the availability of services or the financial support available, but it is an important domain to examine as these changes are implemented.

The bottom line in terms of service changes is that both the availability of services and financial sources of support have changed significantly over time. At times, as in the parabolic nature of Housing and Employment services, there has been a significant recovery in services. It is unclear what is driving these changes at this point, and it may be difficult to predict this given the variable sources of financial support and the variability seen across settings of service.

### **Question 3: What is the quality of the match between needs and resources and the available services and support?**

Consumer satisfaction is perhaps the best indicator of the quality of the match between needs and services/supports. Survey results showed satisfaction to be relatively stable and high for those respondents who have received assistance. (The one exception to this is repeatedly poor satisfaction ratings by the 2008 cohort. It is unclear why this cohort has such negative response patterns, but it may be due to a bias associated with the lower return rate on this survey. Consequently, we are inclined to believe that these numbers are less representative of the general population than other cohort responses due to the outlier characteristics noted in the scores.) It does seem paradoxical that, despite limitations in service availability, satisfaction-with-services ratings are relatively high. However, it is important to note that service satisfaction was measured by consumer survey, while service availability was assessed via providers. It is perhaps hopeful to note that when consumers actually have access to services, providers are doing an excellent job of providing those services in a satisfactory manner.

Another indicator of the quality of match between needs and supports is the degree to which the available services meet existing needs. In examining Figures 6 through 18, it is interesting to note how often the reported need intersected the percentage of individuals reporting receiving services over time and reversed whether those “receiving” help or “wanting” it were highest. For example, Employment Assistance (Figure 7) is the only category of supports in which the reported percent of individuals “wanting” services consistently exceeded the percentage “receiving” them. It should be remembered, however, that any reported desire for services suggests an unmet need or a degree of poor match to services. This is the case whether a high number of other people are already receiving the services or not.

Consequently, the data indicate that the answer to this third question is that the degree of match between need and services/support as measured by consumer satisfaction is relative strong. However, the degree of match is more problematic when examined from the perspective of the number of individuals reporting an unmet desire for services. In other words, quality of services is good if you can get the service, but access may be a significant problem.

## **Implications**

It is very important to note that many of the findings reported in the comparative analysis by Corrigan (2001) were replicated by the findings of this project. Accessibility barriers regarding information access were evident in the 2008 data reporting a relatively high number of individuals who wanted help but did not know where to find it. Similarly, availability barriers were associated with rural living, transportation problems, high behavioral health concerns, affordable housing limits, and reductions in Medicaid support. The additional data regarding the dearth of psychiatrists and the reduction of community-based services create further indications of availability barriers. Appropriateness issues were clearly evident in the employment supports that were reported to be inadequate. In short, the replication of several of the Corrigan findings suggests that the findings of this project are very applicable to both rural and national samples.

Unemployment rates are stable but relatively high; respondents reported 40%-50% unemployment rates across the decade. Stated reasons for not working suggest that anti-stigma campaigns, workplace accommodation, and other employment-related advocacy programs may be especially beneficial. Unfortunately, this study assessed only post-TBI income and was thus not able to make pre-and post-TBI comparisons. However, these data clearly confirm that, at least in a rural state, many people who have experienced a TBI live in very low income and/or impoverished circumstances. This may be impacted by more targeted employment supports. Community-based services are particularly important to focus on given that so many of these services are reported to have declined over time.

## ***Role of Telehealth***

Telehealth/telemedicine is a highly viable solution to the lack of access to services and supports for rural areas. As both tool and discipline, it continues to gain attention among academics and service providers. Telemedicine is viewed as a cost-effective alternative to the more traditional face-to-face way of providing medical care. As such, states have the option/flexibility to determine whether (or not) to cover telemedicine; what types of telemedicine to cover; where in the state it can be covered; how it is provided/covered; what types of telemedicine practitioners and providers may be covered/reimbursed, as long as such practitioners/providers are recognized and qualified according to Medicaid statute/regulation; and how much to reimburse for telemedicine services, as long as such payments do not exceed Federal Upper Limits.

The range of technology-augmented services and supports is very broad and may include consumer/provider visits with one person local and the other at a distance, telehealth-augmented home health, and accessing information on the internet. Telehealth and telemedicine do not, at this point, solve service access problems for all people in all places. However, increased affordability of computer systems coupled with continued technological advances support increased growth in this area. Anecdotal information from recent queries of consumers with a TBI suggests that a large proportion of individuals would be willing to use technology to assist them in finding and accessing TBI-related services and resources if made available.

A telehealth pilot was conducted in Orofino, Idaho, a rural community which had a substantial lack of access to psychiatry services. Clearwater Valley Hospital and clinics collaborated with Saint Alphonsus Regional Medical Center to deliver adult and pediatric psychiatry specialty services using telehealth. Access to care for this high risk population clearly improved indicators

of overall health and reduced cost of care. Enrolled patients decreased their utilization rates for Emergency Department care from an average of 5.4 to 1.8 visits per patient per year. All cause hospitalization rates declined from 0.48 to 0.24 admissions per patient per year. Primary care clinic visits also decreased from 0.48 to 0.15 visits per patient per month.

In addition to creating greater access to behavioral health and substance use disorder treatment services, another benefit from a telehealth model would be an increase in support for communities recruiting primary care physicians. According to research conducted in Idaho, lack of support for caring for patients with mental illness is a major barrier for potential primary care physician candidates choosing to locate in a rural/underserved area.<sup>16</sup>

### **Limitations**

The data reported was a convenience sample although every attempt was made to solicit responses from individuals with TBI and from those who provide services to individuals with TBI. Persons with mild TBIs are commonly overlooked, don't prompt the seeking of services, and often remain undiagnosed by the medical community. Therefore, this group is likely to have been under-represented, may or may not have been treated for their injury, and are even less likely to seek post injury support through associations or services.<sup>17</sup>

The change in purpose and methodology of the 2008 and 2011 surveys limits the time comparability of the longitudinal data for these last two surveys. Finally, the survey was collected anonymously so individual change could not be accounted for in the analyses. It is important to acknowledge that there are certain risks to data interpretation associated with asking people to retrospectively report life quality following any life-changing event (e.g. TBI). While there is undoubtedly an inflation effect when looking backwards to a "better time" before the injury, the drop from pre-event quality of life to current quality of life was relatively large (1.51 for males and 1.42 for females on a 5-point scale) and warrants further investigation.

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