

Traumatic Brain Injury in Idaho Needs and Resources Assessment

Final Report

by
Institute of Rural Health

Idaho State University

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Executive Summary

The purpose of this project is to develop, administer, and analyze a statewide needs assessment based on the Traumatic Brain Injury Reauthorization Act of 2014 and the Traumatic Brain Injury State Implementation Grant Program via the Administration for Community Living (ACL), Department of Health and Human Services. The overall purpose of the program is to increase access to rehabilitation and other services for individuals with traumatic brain injury (TBI). The goal of these Implementation Partnership Grants is to address barriers to needed services encountered by children, youth and adults with TBI. Results from this assessment will be used to develop an action plan for the state. The Institute of Rural Health at Idaho State University (ISU-IRH) in 2014 was the recipient of an implementation grant. One of the goals under this grant is to conduct a statewide assessment of needs and resources for persons with a TBI.

To gain a better understanding of an individual's needs, ISU created a needs assessment asking a variety of questions, that was then offered both via online, and in paper version. Gaining knowledge about the strengths and areas for improvement within each service area will allow the IRH to develop a well-suited program that is able to cater to a variety of individuals with a TBI. Furthermore, it will help the ISU-IRH understand which programs need more support, and which programs are already successful. Survey questions were intended to both elicit responses for data collection purposes, as well as educate survey respondents as to the availability, accessibility, of services.

This survey was designed and administered to address a number of issues: (1) estimate the current perception of, need for, and utilization of services for Idaho's traumatic brain injury population, (2) determine the current demand for different types and categories of service.

ISU administered the needs assessment survey and mailed 253 paper surveys based on request to several organizations that have their own mailing lists. Additionally, the survey was distributed via an online survey. Survey responses were received from each of the seven Public Health Districts, with a total of 175 respondents across Idaho. Seventy seven percent of the total responses came from the online version of the needs assessment, with the remaining 23% from the mailed in paper version, coming from TBI support groups, and from Boise Samaritan, a nonprofit serving adults receiving Medicaid waiver services in their own apartments.

Findings

The top three current needs most often identified by respondents were (1) social relationships and support (29.1%), (2) financial assistance (26.9%), and (3) TBI Ombudsman Services (26.5%). The data revealed 62.3% of respondents reported they are satisfied with their overall health care, while 37.7% reported not being satisfied. Regarding specific health care services and health care subsidies, only 16.4% report that they qualified for health insurance subsidies. However, 50.9% stated they were still able to afford the services they wanted, and 33.6% reported having outstanding medical bills. Given that 89.1% of persons responding are on Medicare or Medicaid, it is not surprising that such a small percentage qualify for subsidies.

However, it is noteworthy that 49.1% of individuals responded they are not able to afford the services they want and need.

In the area of employment, more than half (61.1%) of those experiencing a TBI reported they are not currently employed or volunteering, 52% of whom reported having a severe TBI. Individuals were not able to work due to an inability to perform a job, be hired, or lack of accommodations. Thirty-six percent of those seeking employment use Vocational Rehabilitation to access employment services, followed by 32% utilizing the Department of Labor as a resource.

Respondents were asked to include all sources of income for all persons in the household. Almost a third (28.3%) of respondents reported between \$10,000 to under 20,000 in total household income. Thirty percent of those aged 19 to 29 years old had less than \$10,000 in total household income. Overall, thirty-two percent reported more than \$50,000 year.

When we compared age and income, we found that the youngest and oldest have the highest incomes. Sixty three percent of Individuals 18 years of age and younger reported incomes over \$50,000. Fifty percent of individuals 70 and over reported incomes over \$40,000. Fifty percent to sixty-three percent of individuals between 19 and 59 reported incomes less than \$20,000. Comparing severity of TBI and income, we found that someone making less than \$20,000 a year in income, has an almost five times greater likelihood of having a severe TBI.

More than half of respondents (55.2%) stated their TBI occurred more than ten years ago. Medical costs were the highest for individuals who sustained a TBI as a result of a motor vehicle accident (38.8%). More than one-third of respondents reported more than one cause of TBI.

The survey identified problems with the communication of the utilization of services, as over half of respondents (52.6%) were not aware of services provided by the listed agencies and organizations. The needs assessment questions were also intended to address specific outcomes identified by ISU-IRH, as listed in the following table. The results are presented as a percentage of all respondents (N=175).

Table 1: Survey Outcomes

| Outcomes | Survey Results | Source |
|---|----------------|---------------------------------|
| Respondents who are aware of available agencies | 11% | Fig 19: Avg across all agencies |
| Respondents who access available services | 7% | Fig 20: Avg across all services |
| <u>Respondents who qualify for some aid:</u> | | |
| Percent of respondents with income less than \$20,000 | 41% | Figure 10 |
| Percent of respondents with income less than \$30,000 | 50% | Figure 10 |
| Percent of respondents covered by Medicare/Medicaid | 89% | Figure 23 |
| Percent of respondents age 65 and older | 11% | Figure 2 |
| Respondents who might use services in the future | 22% | Figure 20 |
| Respondents satisfied with their overall health care | 62% | Figure 21 |
| Respondents not-satisfied with health care: | | |
| Percent of respondents who need/want more health care or more health services | 54% | Table 10 |

Recommendations

The results of this needs assessment clearly identify the urgent need to plan for the provision of resources to meet the needs of persons with TBI in Idaho. Specific recommendations emerging from this needs assessment, including a review of previous and other state traumatic brain injury reports, are provided below.

1. **Provide information about employment services and supports for adults with a TBI.** More than half of individuals reported they are not currently employed or volunteering, with varied reasons for the unemployment. Reasons included the need to be retrained, needing help with job accommodations, needing assistance in finding and keeping a job, as well as a need for jobs that may be part-time with flexibility in terms of hours. A number of respondents did report they were in the process of seeking employment. If more respondents were aware of agencies like the Division of Vocational Rehabilitation, Department of Health and Welfare, and others who assist people in employment, household income would rise, and less reliance on government services could be a potential outcome. Even for individuals with the most severe TBI, aid in knowing where to go for employment assistance would be helpful.
2. **Increase awareness of the available agencies and organizations that work with persons with a TBI.** This might be through participation in more formal community events involving organizations, or simply being connected informally through social clubs and support groups. Connecting individuals with others in the community, and identifying similar types of naturally occurring opportunities for networking, peer support, and friendships, was a clear need identified from the data.
3. **Educate Idaho persons with a TBI, family members, and caregivers about prevention of TBI.** This will help to prevent more serious health and well-being difficulties, including the compounded or more severe consequences of having more than one TBI. Having access to health promotion programs and community education classes are two examples that are available to all persons, including persons with TBI.
4. **Continue to provide screening for traumatic brain injury.** The results reveal that over a quarter of respondents reported they had experienced more than one TBI, with over half of respondents reporting their TBI occurred over ten years ago. Often, individuals may not even be aware that their symptoms are the result of a previous brain injury. The literature supports the fact that many individuals with a TBI are living with a co-occurring disability in addition to their TBI. Clearly, individuals need timely access to screening and follow-up care. Additionally, persons with brain injuries may have complex health circumstances that are not always immediately recognized by health professionals.
5. **Providing low-cost services and information regarding other financial assistance options are important for persons with TBI.** Almost half (49%) of respondents reported a total household income of less than \$30,000 per year, and just over 40% reported an income less than \$20,000 per year. Just over 49% of respondents stated they are not able to afford the services they want/need. Slightly over 33% responded they have outstanding medical bills. Being aware of, and having access to, community health centers and health care clinics for assistance in paying medications, counseling, cognitive rehabilitation and other therapies could increase a person's overall quality of life.

6. **Care coordination and planning services are critical to help persons with TBI** maintain their independence and quality of life. The current systems of long-term care services and supports require substantial effort by both individuals and those assisting them. In many areas, these systems are not currently available or are inadequate. Further development of care coordination and planning services would greatly assist Idaho's population of persons with TBI who may require a broad range of long-term care options and services.
 - a. To help further the coordination of services and supports, Idaho would benefit from a TBI Trust Fund: At least twenty-four states have in place a traumatic brain injury trust fund. Unfortunately, Idaho has no state money specifically for TBI. A trust fund, which is a form of gap financing after all other insurance coverage has been exhausted, either private or publically funded, could help pay for service arrangement and care coordination (case management) for persons with a TBI in Idaho.
7. **Idaho State Universities, Institute of Rural Health should build and maintain an extensive registry** through social media (Twitter, Facebook, TBI website, etc.), to increase the response rate for future needs and resource assessment surveys, and to keep people apprised of research and policy changes both in Idaho and nationally.

The changes occurring in the structure of Idaho's population, and the perceptions reported in the needs assessment, predict a rapidly increasing need for expanded services. Changes in the organization, financing, and delivery of health services are currently beginning to take place in Idaho. For example, Idaho's Statewide Healthcare Innovation Plan (SHIP) is currently under implementation. This Centers for Medicare and Medicaid Services (CMS) grant funded project fosters health system changes to improve health care access, quality, and outcomes. This program is regionally based to accelerate the expansion of patient centered medical homes that improve care coordination and access to services through the use of community health workers, community health emergency medical services, and expanded telehealth services. The SHIP model will provide health care workforce and communications resources that can be aimed directly at the needs of Idaho's traumatic brain injury population in both rural and urban areas. All of these resources will be increasingly critical in meeting the growing demand for services by individuals with a TBI in Idaho.

Introduction

The Institute of Rural Health at Idaho State University (IRH-ISU) was awarded a competitive grant from the Health and Resources and Services Administration (HRSA), Maternal and Child Health Bureau in 2014. Included within the project work plan was the completion of a TBI needs and resource assessment for the state. Idaho's grant aims to increase access to rehabilitation and other services for individuals with traumatic brain injury (TBI). Given the increased focus on brain injury especially in the areas of sports-related concussions, returning veterans with TBI, and those impacted by domestic and other forms of violence, this report attempts to capture a snapshot of the current and future needs of Idahoans with a traumatic brain injury. This report reflects the most current information available, obtained from the 2017 needs and resources assessment.

Background

According to published 2010 reports from the Centers for Disease Control and Prevention (CDC), Traumatic brain injury—either alone or in combination with other injuries—accounted for about 2.5 million emergency department visits, hospitalizations, or deaths.¹ The total combined rates of TBI-related hospitalizations, emergency department visits and deaths was 823.7 per 100,000 in 2010.² In 2016, the United States Census Bureau estimated that 1,683,140 people lived in the state of Idaho.³ According to a report published by the Idaho Trauma Registry, 1,801 head injuries were reported in the state of Idaho during 2014.⁴ Of these reported injuries, 64% of all head injuries were among males. Of Idaho’s total population, 14.7% of the population is aged 65 and older. CDC reports determined that falls were the leading cause of TBI in the United States between 2006 and 2010. More than half (55%) of TBIs among children between the ages of 0 and 14 were caused by falls. Prevalence of fall-related TBI were even higher for the adults aged 65 and older population with fall-related TBI accounting for 81% of all TBIs in this age group.

The World Institute on Disability estimates that just over 2% of the population lives with a disability resulting from a TBI, which means that about 32,243 Idahoans are currently affected by a TBI.⁵ In 2012, Idaho’s trauma registry listed 1,558 brain injuries using the criteria of patients who were transferred from one hospital to another by ambulance, reported from 31 out of 38 acute care hospitals. Idaho ranks seventh in the entire nation for per capita hospitalization and disability rate due to TBIs. As a rural state, Idahoans are at higher risk for TBI compared to other populations; rural people are particularly vulnerable to chronic illnesses and diseases, and are at increased risk for injury-associated disability due to limited healthcare access and availability.⁶

Idaho is the 14th largest U.S. state but contains the 12th smallest population with an average population density of 15 people per square mile, five times less than the national average. Idaho’s population is concentrated in three geographical areas: northern Idaho, eastern Idaho, and south central Idaho. The vast majority of Idaho’s area, 88%, is captured in the Rural-Urban Commuting Area (RUCA) codes and meets the federal definition of rural (see Figure 1). Thirty-five of the 44 total counties have fewer than 25,000 people, and 92% of towns have populations less than 10,000. An Idaho State University Institute of Rural Health (ISU-IRH) geographic information systems study found more than 50% of non-metropolitan Idahoans live at least 66

¹ Centers for Disease Control and Prevention (CDC), National Center for Injury Prevention and Control: Traumatic Brain Injury & Concussion. https://www.cdc.gov/traumaticbraininjury/get_the_facts.html

² Centers for Disease Control and Prevention (CDC), National Center for Injury Prevention and Control: Traumatic Brain Injury & Concussion. <https://www.cdc.gov/traumaticbraininjury/data/rates.html>

³ United States Census Bureau, Census QuickFacts. <https://www.census.gov/quickfacts/table/PST045216/16,00>

⁴ Idaho Trauma Registry (2016). Trauma in Idaho-2014.

⁵ Thurman D.J., Alverson C., Dunn K.A., Guerro J., Sniezek J.E. (1999). Traumatic brain injury in the United States: a public health perspective. *Journal of Head Trauma Rehabilitation*, 14(6), 602-615.

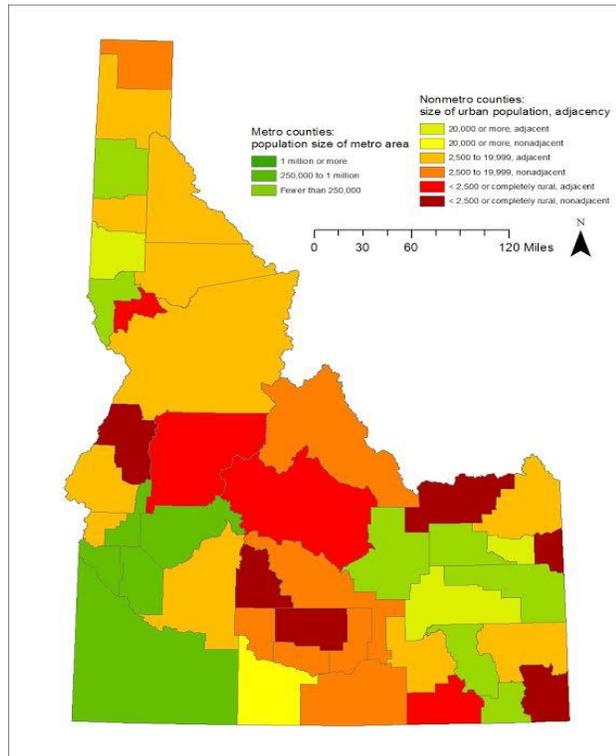
⁶ Beedasy, J. (2010). Rural designations and geographic access to tertiary healthcare in Idaho. *The Online Journal of Rural Research and Policy*, 5.2, 1-21.

miles (straight-line distance) from the nearest tertiary healthcare facility, while 25% live at least 95 miles away, and 10% live 106 miles away from these facilities.⁷ The actual distance people travel to access care is even higher, as roads are seldom straight lines and other factors such as slope, type of road, and weather conditions increase travel complexities.

Figure 1: Rural-Urban Commuting Area (RUCA) in Idaho 2013

Spaete, L. (2014). Boise State University.

Recent HRSA statistics indicate 91% of Idaho’s counties are designated as both Health Professional Shortage Areas and Mental Health Professional Shortage Areas. Even Ada County, the largest and most heavily populated county, is designated as having both Medically Underserved Areas (MUA) and Medically Underserved Populations (MUP).⁸ Rural Idahoans have higher rates of obesity, smoking, smokeless tobacco usage, and uninsured as compared to their urban counterparts; they also have higher death rates due to heart disease, cancer, cerebrovascular disease, liver disease, and accidents.⁵ In a rural state, formal supports are often extremely limited, and informal support networks become even more critical to both civilian and returning military personnel with a traumatic brain injury.



Idaho is a rural state. Rural Americans tend to have fewer medical resources and less access to physicians, and are at greater risk for chronic health problems. Thirty-five of Idaho’s 44 counties (80%) are designated as frontier or rural.⁶ The state office of Rural Health and Primary Care reported 97% of the state is designated as a Primary Care Health Professional Shortage Area (HPSA), with 100% of the state as a Mental Health HPSA. Seventy-one percent of the state is designated as a Medically Underserved Area or as having a Medically Underserved Population, including Ada County where the capital city is located.⁷ Generally speaking, TBI 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 TBIs for professionals to serve and, ultimately, a lack of appropriate services and supports. As an example, over half of Idaho’s hospitals qualify as federally designated Critical Access Hospitals,

⁷ Stamm, B.H. (Ed). (2003). Behavioral healthcare in rural and frontier areas: An interdisciplinary guide. Washington DC: American Psychological Association Press

⁸ Health Resources and Services Administration. (2014). Shortage Designation: Health Professional Shortage Areas & Medically Underserved Areas/Populations. <http://www.hrsa.gov/shortage/>.

as defined as hospitals with fewer than 25 beds. The only level II trauma center is in Boise, the state capital, which including the surrounding metropolitan area is home to about one-third of the state's population. This lack of access is compounded further based on the prevalence of both Hispanics (11.6% of the population)³ of whom about 50% lack medical insurance in Idaho⁹ and Native Americans whose population tends to have a higher incidence of TBI.

That Idahoans, due to their rural status, are at increased risk for TBI is no surprise. Coupled with the high rate of returning service personnel with TBI, and the high rate of military enlistment among Idaho residents, the current rate of individuals in Idaho touched by this disability is staggering. Unfortunately, relatively few resources are readily available at the community level, including those for returning service men and women, and fewer still are accessible by their family members. Anecdotal reports suggest that too often soldiers return home suffering the effects of TBI, effects that are, in many cases, not obvious except with continued contact. Often, consequences of TBI are compounded by depression, post-traumatic stress disorder, and substance abuse. Frequently, family members are “in the dark” with no information that might help them to understand the lasting effects of blast injuries on the personality or behavior of their soldier.

Children and youth—especially student athletes—in Idaho are also at risk for traumatic brain injuries. More than 60% of all teenage athletes will have experienced a concussion by the end of their high school sports experience. For young people aged 15-24, concussion is second only to motor vehicle crashes when it comes to traumatic brain injury.¹⁰ Lack of education about concussion and TBI among junior high and high school coaches is a barrier to adequate screening, diagnosis, and follow-up care for athletes who suffer a brain injury. Many Idahoans lack access to health insurance; 23 percent were uninsured in 2012.¹¹ For those without medical insurance or living in poverty, availability of needed screening, diagnostic, rehabilitation, and support services for TBI is greatly reduced. The uninsured are more likely to lack access to ongoing coordinated care within a medical home.

Report Purpose

This report seeks to increase access to rehabilitation and other services for individuals with traumatic brain injury (TBI). The goal of the Implementation Partnership Grants is to address barriers to needed services encountered by children, youth, and adults with TBI and use this assessment to facilitate the development or expansion of a comprehensive, multidisciplinary, and easily accessible system of care for individuals with TBI and their families.

⁹ Idaho Commission on Hispanic Affairs. (Feb 2013). Hispanic health. <http://icha.idaho.gov/docs/ID@G> – Hispanic Health (01 15 13).pdf

¹⁰ Institute of Medicine. (2013). Sports-related concussions in youth: Improving the science, changing the culture. <http://www.iom.edu/Reports/2013/Sports-Related-Concussions-in-Youth-Improving-the-Science-Changing-the-Culture.aspx>

¹¹ Institute of Medicine. (2013). Sports-related concussions in youth: Improving the science, changing the culture. <http://www.iom.edu/Reports/2013/Sports-Related-Concussions-in-Youth-Improving-the-Science-Changing-the-Culture.aspx>

In September 2012, Idaho State University was the recipient of a supplemental competitive award from the Health Resources and Services Administration, Maternal and Child Health Bureau to support an in-depth analysis of the longitudinal aspects of providing, receiving, and not having traumatic brain injury services and supports through a series of needs and resources assessments. Idaho's traumatic brain injury needs and resources have been evaluated periodically beginning in 2001, with subsequent assessments conducted in 2004, 2005, 2006, 2007, 2008, and 2011. The goal of these studies was to describe services and support needs, as well as service and support availability. A traumatic brain injury needs and resources manuscript summarizing this data has been submitted to the Brain Injury Journal and is currently under peer review.

Survey Methodology

A survey review of needs and resource assessments completed by other states was conducted to understand how to target the Idaho population. The Muskie School of Public Service conducted a Needs and Resource Assessment for the state of Maine during 2016.¹² Similar to rural Idahoans, those who live in rural areas of Maine face greater challenges to accessing many healthcare services. The 2014 North Carolina Traumatic Brain Injury Needs and Resources Assessment¹³ served as another great tool in targeting persons with a traumatic brain injury.

We also reviewed needs and resource assessments conducted by the IRH at ISU such as the *Needs Assessment of Older Adults in Idaho, 2016* which was completed by contract with the Idaho Commission on Aging.¹⁴ We collaborated with Grant Thornton, the collaborating and technical assistance entity who is contracted by the Administration on Community Living, to provide technical assistance to states. We also piloted the needs and resource assessment survey with the traumatic brain injury project team, Brain Injury Alliance of Idaho (BIA-ID) Board of Directors, and Idaho's TBI Ombudsman.

The needs assessment was developed to collect information regarding current service use, services respondents would like to receive more of, and whether or not the respondent is aware of programs and organizations that could help. The survey underwent many drafts during the creation process. Ultimately, a 27-question survey was decided upon (see Appendix B).

Survey Distribution

Without a database or registry of individuals in Idaho experiencing a TBI, getting the survey to the target audience was a challenge. The survey was created in both a printed form and an electronic (online) form to maximize the reach and response rate of the survey.

¹² Ciolfi, M., Griffin, E., Pratt, J., Richards, M., Gildard, S., Byrne, B. (2016). Living with a Brain Injury in Maine: Individual Experiences, Perceptions, and Needs. Muskie School of Public Service: Portland, Maine.

¹³ Bartel, S., Farmer, S., Griffin, R., Rickard, S., Ayers, C., Guerrier, T. (2015). 2014 North Carolina Brain Injury Needs and Resources Assessment. TBI Project STAR Carolina Rehabilitation: Charlotte, NC.

¹⁴ Kelchner, C., Spearman, R., & Piland, N. F. (2016). *Needs assessment of older adults in Idaho*. Institute of Rural Health, Idaho State University. Pocatello and Meridian, Idaho.

A press release was issued on February 6, 2017 through Idaho State University’s Marketing & Communications office, to raise awareness of the needs assessment and encourage those who received it to either complete the survey online or mail it back (Table 2).

Table 2: Distribution list for initial press release

| Media in Eastern Idaho and Treasure Valley, from ISU Marketing & Communications | | |
|---|---|---|
| Newspapers | TV News Stations | Radio |
| Sho-Ban News, Post-Register, Idaho Statesman, Idaho Press Tribune, Meridian Press, Valley Times, Idaho State Journal, Power County Press 4, Idaho Parents Unlimited Inc., MyMeridianPress | Blackfoot Morning News, Channel 8, Channel 12 TV, KTVB, KIVI, KBOI | Boise State Public Radio |
| Internet | | |
| E-newsletters for Idaho Parents Unlimited Inc. | Posted on AARP Idaho website | Facebook, Twitter |
| Aid-For-Friends site in Pocatello, ID | Posted to Idaho TBI VPC – www.idahotbi.org | |
| Paper Surveys | | |
| Distributed to attendees who screened likely during a TBI screening including 37 email addresses and 24 hard copies. | Disability Rights of Idaho the Protection and Advocacy System distributed 134 surveys | The Treasure Valley Support Group distributed at monthly meetings |
| ISU | | |
| Bengal Pharmacy, Counseling Clinic, Counseling & Testing Department, Bengal Health Clinic, Dental Hygiene Clinic, Psychology Clinic, Nursing Department, Physician Assistant Department, Speech-Language Pathology Clinic on the ISU-Pocatello Campus | | Speech-Language Pathology Clinic at ISU-Meridian |
| Other | | |
| Department of Health & Welfare in Pocatello, ID | Aid-For-Friends site in Pocatello, ID | Email lists deemed appropriate by above recipients |

Paper Survey

The paper surveys were mailed beginning February 6, 2017, with a requested return date of March 17, 2017, to allow time for mailing and data entry (Table 3).

Table 3: Survey Distribution - Paper

| Source of Distribution | Type of Distribution | Surveys Sent |
|---|------------------------------------|--------------|
| Disability Rights Idaho Inc. | Mailed – Paper | 134 |
| Good Samaritan Society Community Living Program | Coordinated by Director | 12 |
| 2 TBI Support Groups | Distributed at Meeting | 30 |
| Participants in Community Health Screenings screened likely for TBI | Mailed – Paper | 24 |
| Brain Injury Alliance of Idaho | Mailed - Paper | |
| Specialty Physician Practices | Flyer: Advertise /give to patients | 63 |
| ISU-Meridian Speech-Language Pathology | Made available to patients | |
| ISU-Pocatello Clinics | Flyer: Advertise /give to patients | |
| Department of Health & Welfare, Pocatello, ID | Flyer | |
| Aid-For-Friends, Pocatello, ID | Flyer | |

Online Survey

In addition to a paper copy, an online version of the survey was created using Qualtrics, a web based software program as an aid to research in a secure, password protected environment. The online version was intended to enable participation by those interested individuals who heard about the needs assessment but did not receive one in the mail, or those who simply prefer to use online surveys. The online survey contained the same questions used in the paper survey. The electronic survey was active February 6, 2017, and opened until March 31, 2017 (Table 4).

Table 4: Survey Distribution - Electronic

| Source of Distribution | Type of Distribution | Surveys Sent |
|---|---------------------------------|--------------|
| Disability Rights Idaho Inc. | Electronic Newsletter | unknown |
| Participants in Community Health Screenings who screened likely for TBI | Direct - Email | 37 |
| Idaho TBI VPC – Idahotbi.org | Online – Survey Link on Website | |
| ISU – Veterans Student Services | Electronic Newsletter | unknown |
| All Flyers Listed in Table 3 | Provided Link to online survey | 80 |

Response Rates

The online version of the needs assessment survey had the highest percentage of respondents at 77%. The least effective was the direct mailings at only 3% return (Table 5). This may be in part due to our lack of a database or registry of people in Idaho experiencing a TBI, which affects the overall numbers of direct mailing to our targeted audience. It may also be a reflection of the way society as a whole has moved to internet-based tools for managing many aspects of their lives. It is possible those who received a hard copy simply used the link given and went on-line to respond to the survey rather than mail the paper version in. Based upon the return rate, surveys handed out at group meetings or

in-home care facilities are an effective way to get participation in the survey. 86% of the surveys handed out during a group meeting or at a care facility were returned.

Table 5 : Proportion of respondents from each survey distribution category

| | Respondents | % of Total |
|---|--------------------|-------------------|
| All Sources | 175 | 100% |
| Paper – Mailed | 6 | 3% |
| Paper – Support Groups & Good Samaritan Society | 36 | 20% |
| Electronic | 133 | 77% |

Survey Results

Most survey results are presented as a percentage of respondents statewide. The initial demographic information is also presented broken down by Idaho Public Health Districts (Figure 2). Not all percentages will add up to 100%, as some questions allowed for multiple options.

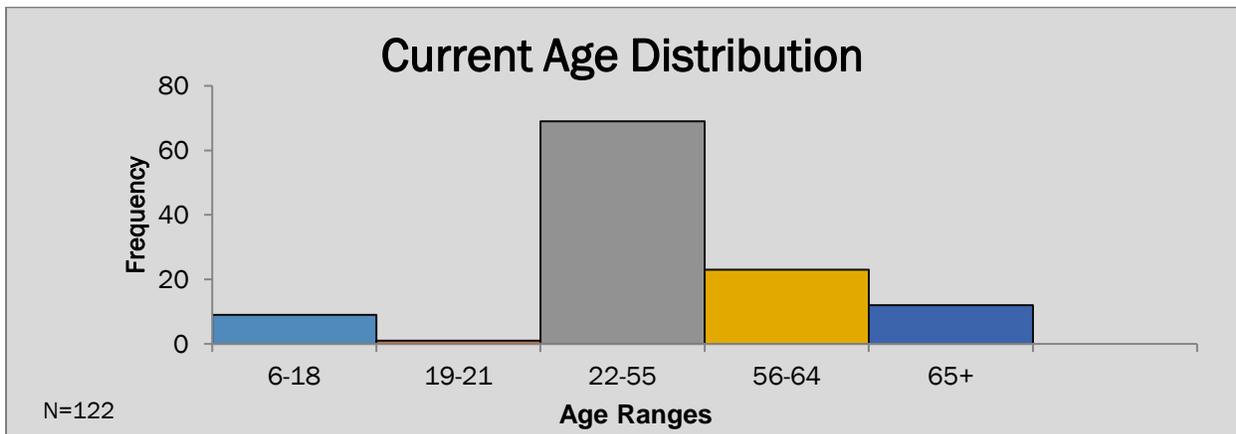
Demographics

The survey requested certain demographic information, in order to understand how best to serve the needs of the population of Idahoans living with or caring for an individual with a TBI. Respondents were asked, but not required, to answer questions about their current age, gender, veteran status, living arrangements, employment status, and household income.

Age

The current age of those taking the survey who experienced at least one TBI ranged from a minimum of 6 to maximum of 80 years. The greatest number of respondents 69% came from ages 34 to 52, with only 1 respondent in the 19 to 21 age range.

Figure 2: Age of Respondents



Gender and Veteran Status

Idaho is divided into seven health districts that operate independently as the primary outlet for public health services in the counties they serve (Figure 3). Individuals with a TBI responded to the survey from 100% of the Public Health Districts in Idaho. 60.5% of those responding were Male vs. 39.5% Female. Overall, 10.1% of those responding were veterans. The majority of respondents (49.6%) came from District 4, which includes Ada County, which is the county with the highest population in state.

Figure 3: Map of Idaho Public Health District

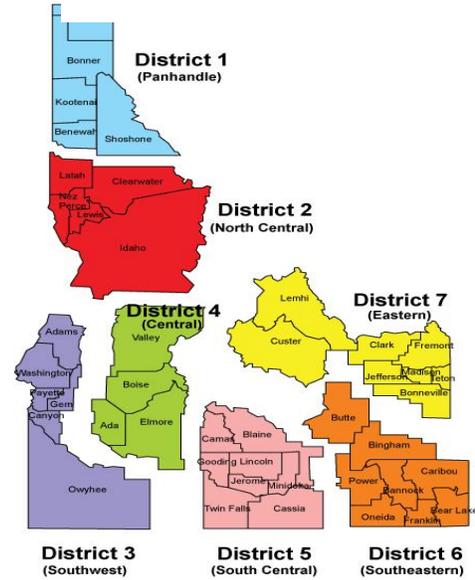


Table 6: Gender and Veteran Status of Respondents

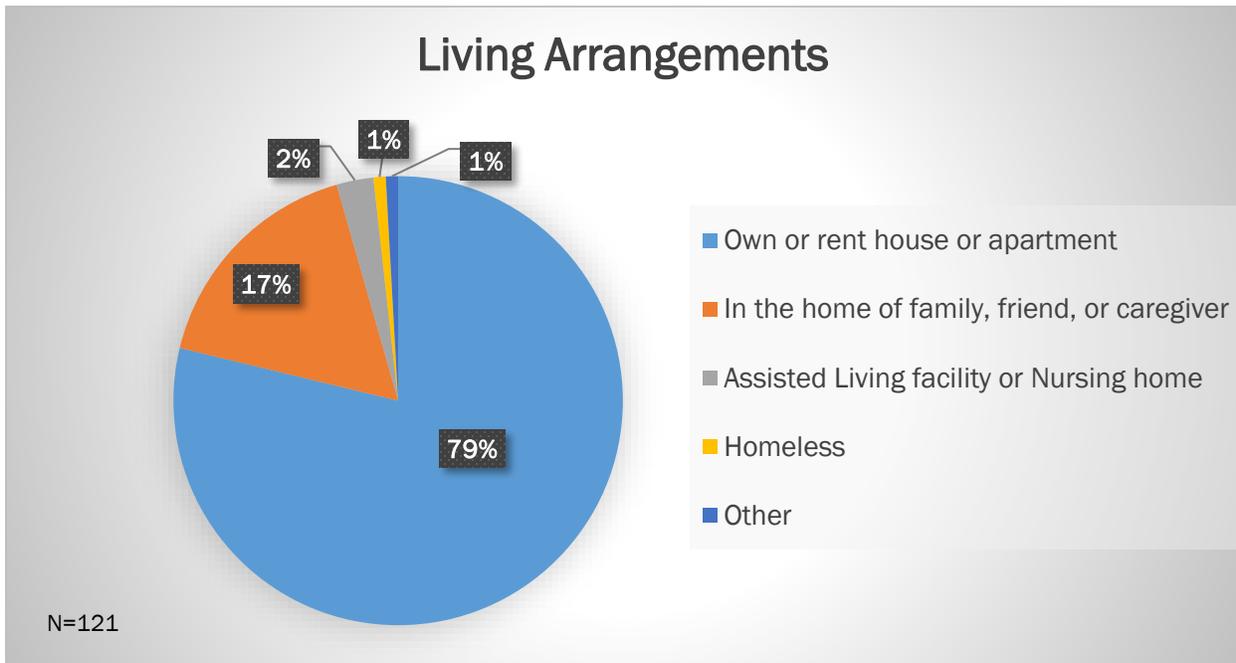
| Health District | Male | Female | Veteran |
|-----------------|--------------|--------------|--------------|
| District 1 | 0.8% | 0.8% | 0.8% |
| District 2 | 3.4% | 0.0% | 0.8% |
| District 3 | 3.4% | 3.4% | 1.7% |
| District 4 | 33.6% | 16.0% | 3.4% |
| District 5 | 4.2% | 4.2% | 0.8% |
| District 6 | 2.5% | 6.7% | 0.8% |
| District 7 | 12.6% | 8.4% | 1.7% |
| Total | 60.5% | 39.5% | 10.1% |

N=124

Living Arrangement

We asked individuals the type of residence they currently live in. A full 79% of survey respondents reported they owned or rented a house or an apartment, while 17% reported living in the home of family, friend, or caregiver. Only 1% of those responding reported being homeless.

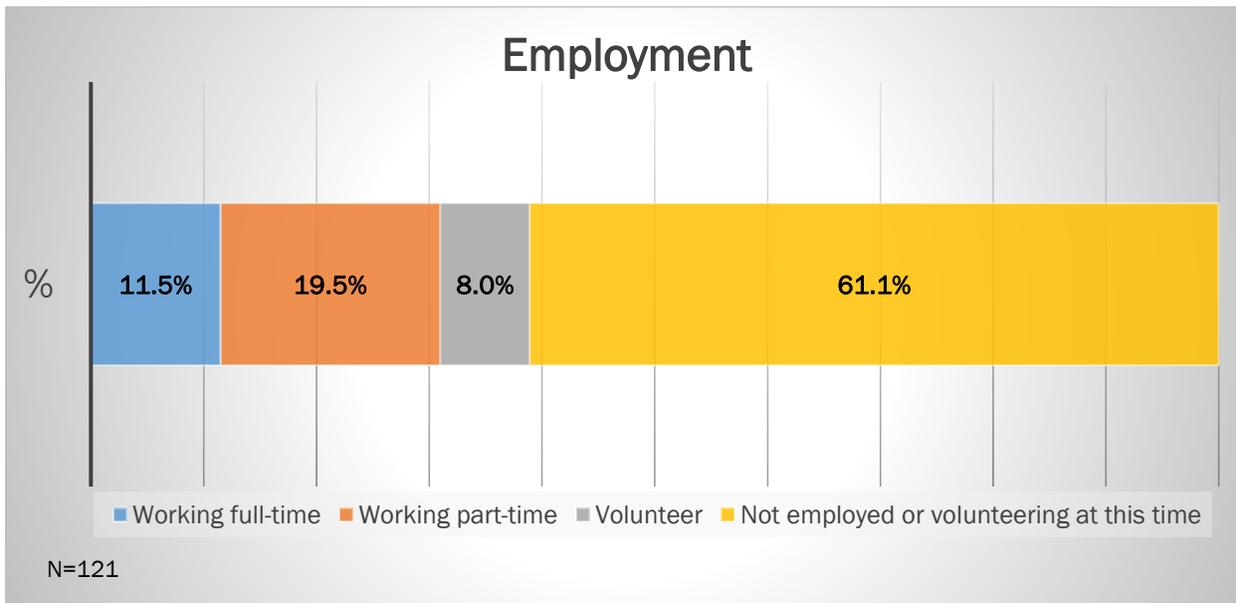
Figure 4: Living Arrangements of Respondents



Employment Status

More than half (61.1%) of those who have experienced a TBI reported they are not employed or volunteering. Only 11.5% reported they are working full-time, while 19.5% reported some part-time employment and another 8% reported they are volunteering.

Figure 5: Employment Status of Respondents

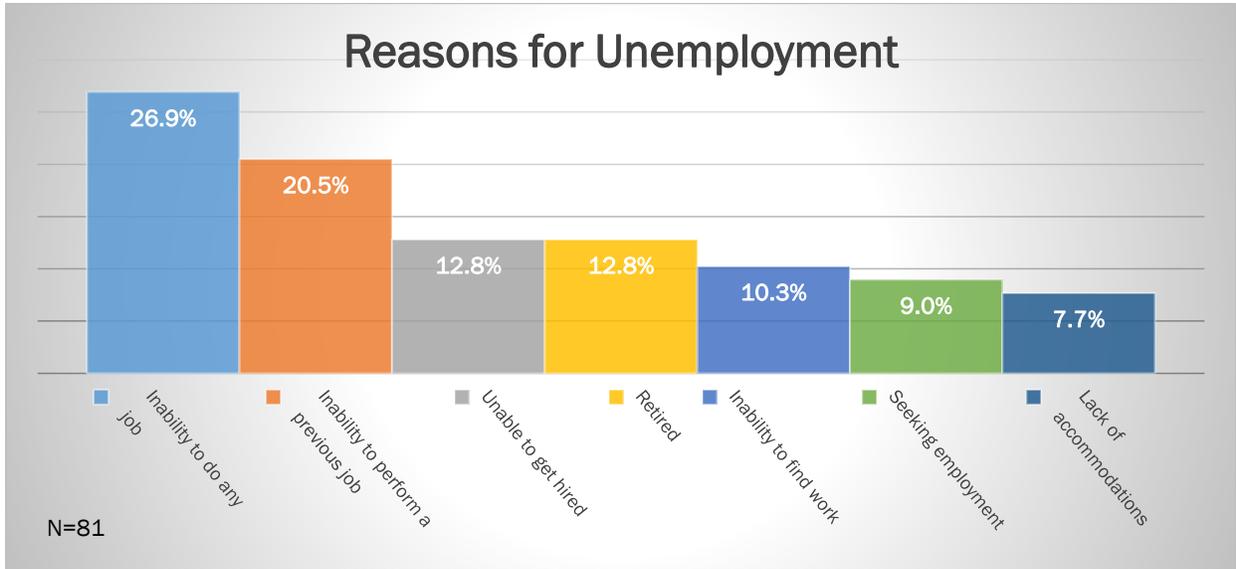


Unemployment

Reasons for Unemployment

When asked to list the reasons for unemployment, 47.4% cited an inability to do a job whether it was a previous job or any job. Only 9% responded they are seeking employment, and 10.3% reported an inability to find work, whereas 12.8% reported that they were unable to be hired. Multiple responses were allowed for this question.

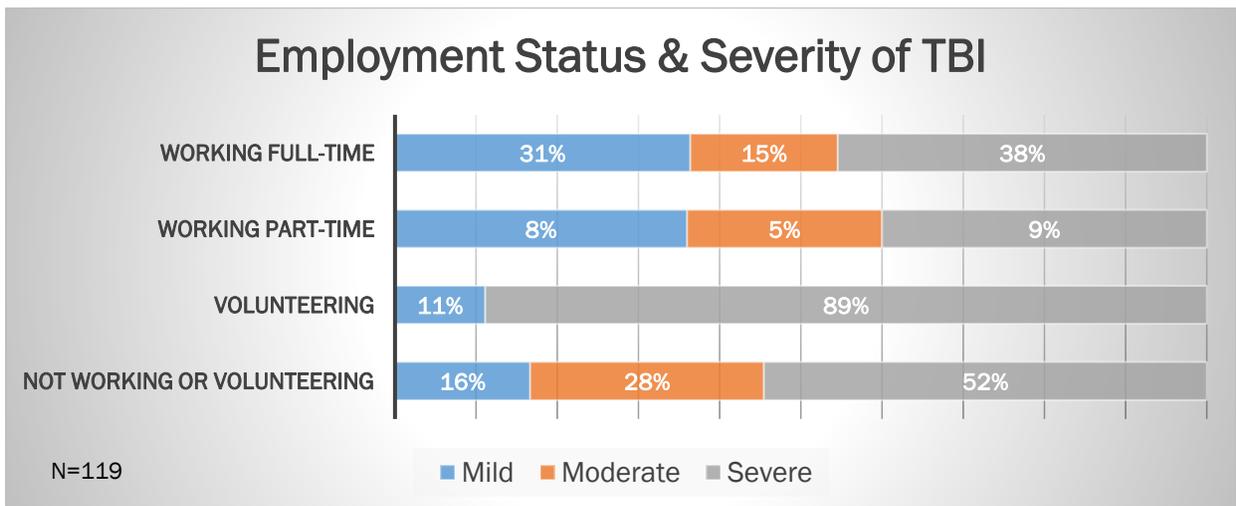
Figure 6: Reasons for Unemployment of Respondents



Employment Status and Severity of TBI

Fifty-two percent of those not currently employed or volunteering reported they experienced a severe TBI, whereas 38% of those working full-time reported they experienced a severe TBI.

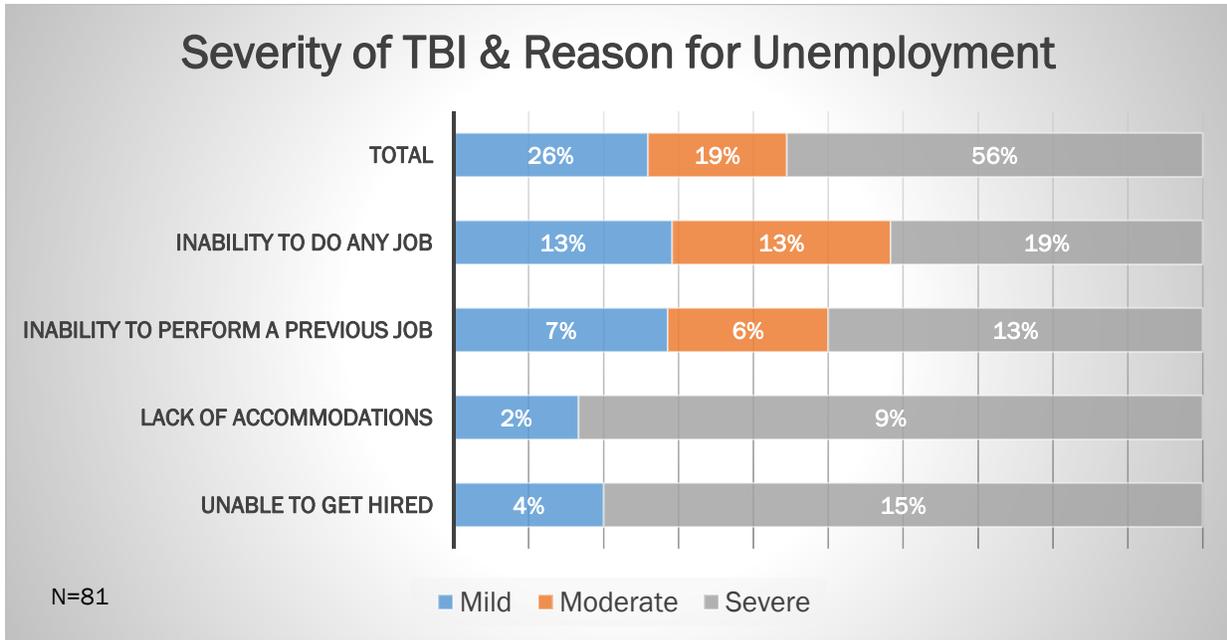
Figure 7: Comparison of severity of TBI experienced to employment status



Severity of TBI with Reason for Unemployment

Fifty-six percent of those experiencing a severe TBI and not working reported unemployment is due to an inability to perform a job, be hired, or lack of accommodations.

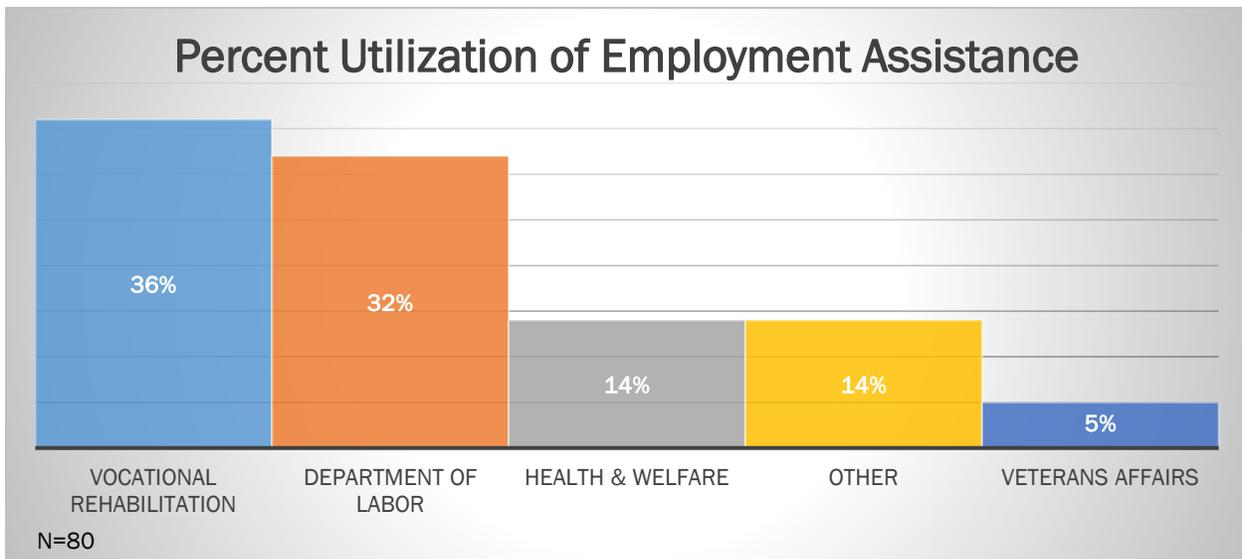
Figure 8: Comparison of the reason for being unemployed to the severity of the TBI



Accessing Employment Assistance

Those seeking help to find employment utilize Vocational Rehabilitation (36%) and Department of Labor (32%) the most. Department of Veterans Affairs (5%) was utilized least. Only 8.8% of respondents reported they were a veteran.

Figure 9: Employment assistance being utilized by respondents

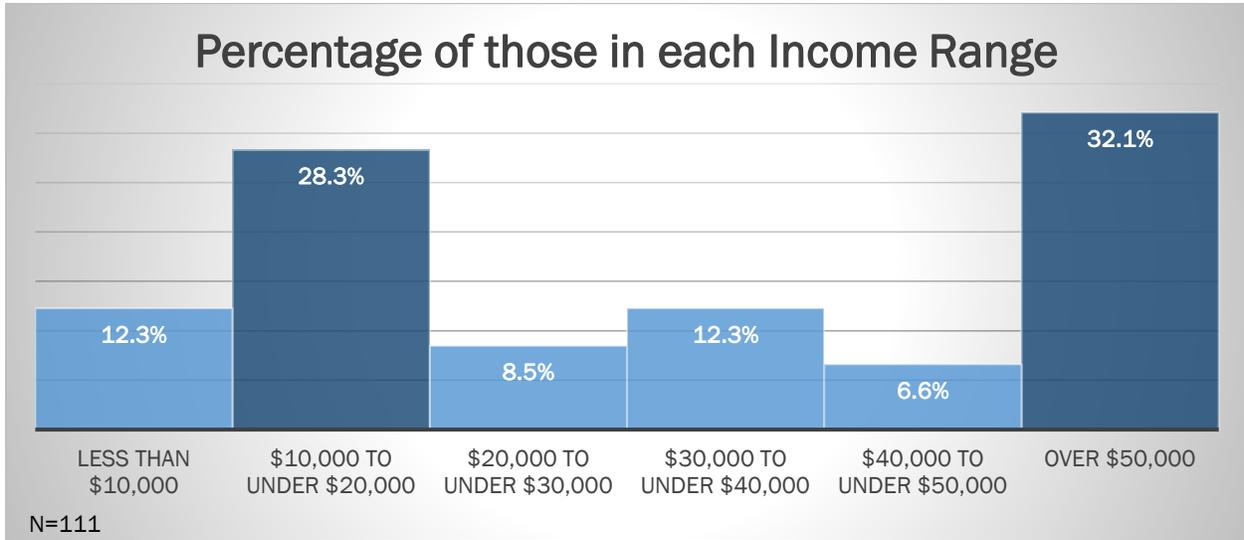


Income

Household Income

Respondents were asked to include all sources of income for all persons in the household including jobs, Social Security, retirement income, and public assistance. A little more than one third (32.1%) of the respondents reported income over \$50,000, while close to another third (28.3%) fell into the \$10,000 to under \$20,000 range.

Figure 10: Income range of respondents



Severity of TBI and Income

We also looked at the severity of the TBI and whether the individuals had income above \$20,000 (roughly the poverty line for a family of three). The table below shows there is an almost 5 times greater chance for someone experiencing a severe TBI to make below \$20,000.

Table 7: Comparison of severity of TBI to income range

| | < \$20,000 | | | \$20,000 & Over | | | | Total | Total |
|-----------------|--------------------|----------------------------|-------|----------------------------|----------------------------|----------------------------|---------------|-------|-------|
| | Less than \$10,000 | \$10,000 to under \$20,000 | Total | \$20,000 to under \$30,000 | \$30,000 to under \$40,000 | \$40,000 to under \$50,000 | Over \$50,000 | | |
| Mild | 2 | 5 | 7 | 2 | 3 | 4 | 10 | 19 | 26 |
| Moderate | 1 | 3 | 4 | 3 | 5 | 3 | 12 | 23 | 27 |
| Severe | 10 | 22 | 32 | 6 | 5 | 3 | 11 | 25 | 57 |
| Total | 13 | 30 | 43 | 11 | 13 | 10 | 33 | 67 | 110 |

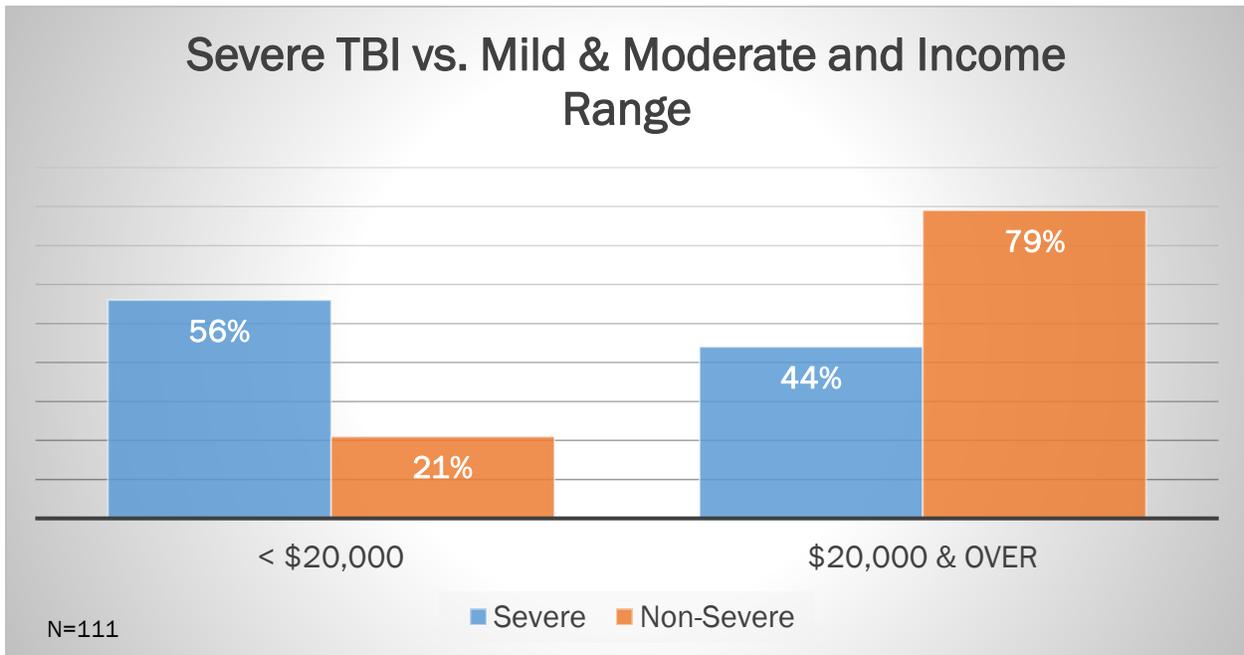
N=111

Odds of severe making < \$20,000 = $(32/57)/(25/57) = 1.27$.

Odds of not-severe making < \$20,000 = $(11/53)/(42/53) = 0.27$.

Comparing two: Severe to not-severe making < \$20,000 = $1.27/0.27 = 4.7$

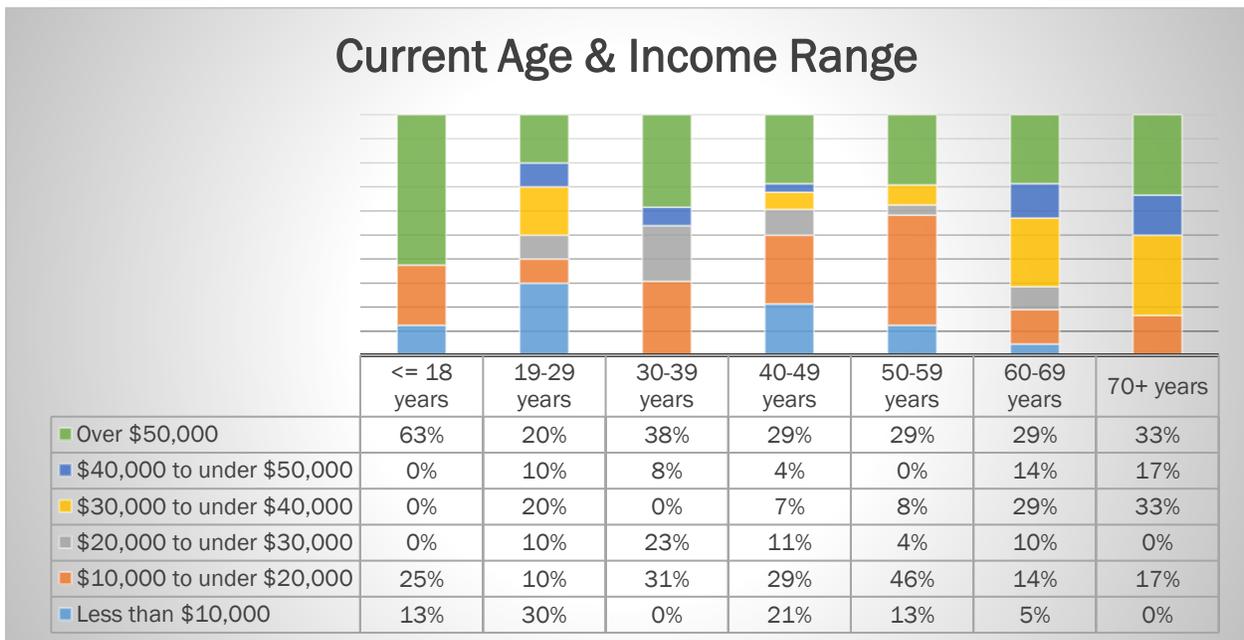
Figure 11: Comparison of severe TBI to mild/moderate and income range



Age and Household Income

When we look at the current age and the income range, the data shows that the youngest and oldest age groups have higher incomes, with 63% of those 18 and younger reporting an income over \$50,000 and of the 70 and over age group, 50% report an income of over \$40,000. Fifty to sixty three percent of those aged 19 to 59 report an income of less than \$20,000.

Figure 12: Comparison of current age to income range



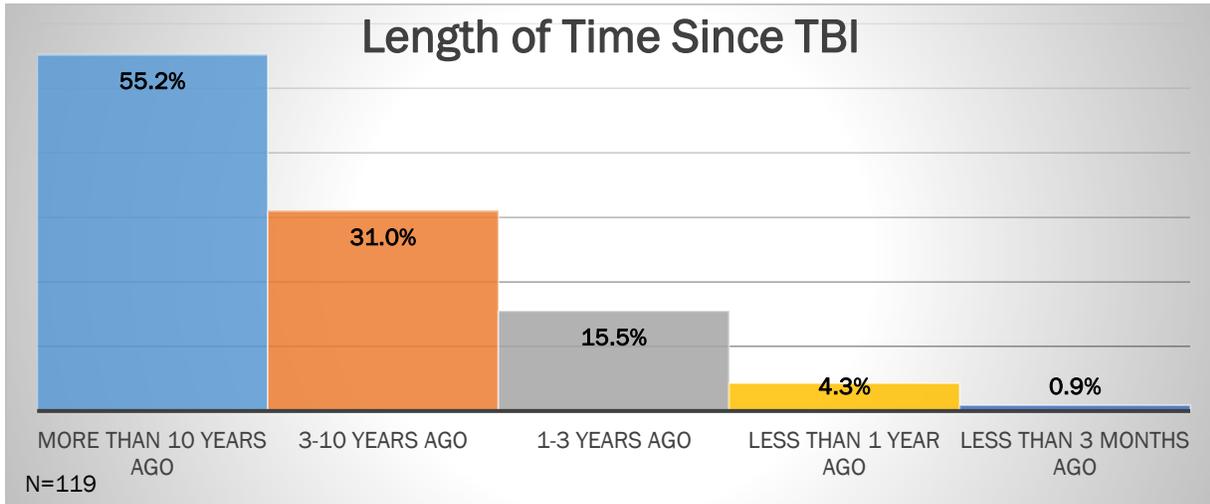
N=111

TBI Experience

Length of Time since TBI

More than half (55.2%) of respondents reported experiencing a traumatic brain injury more than ten years ago, followed by 31% reporting their last TBI was between 3-10 years ago.

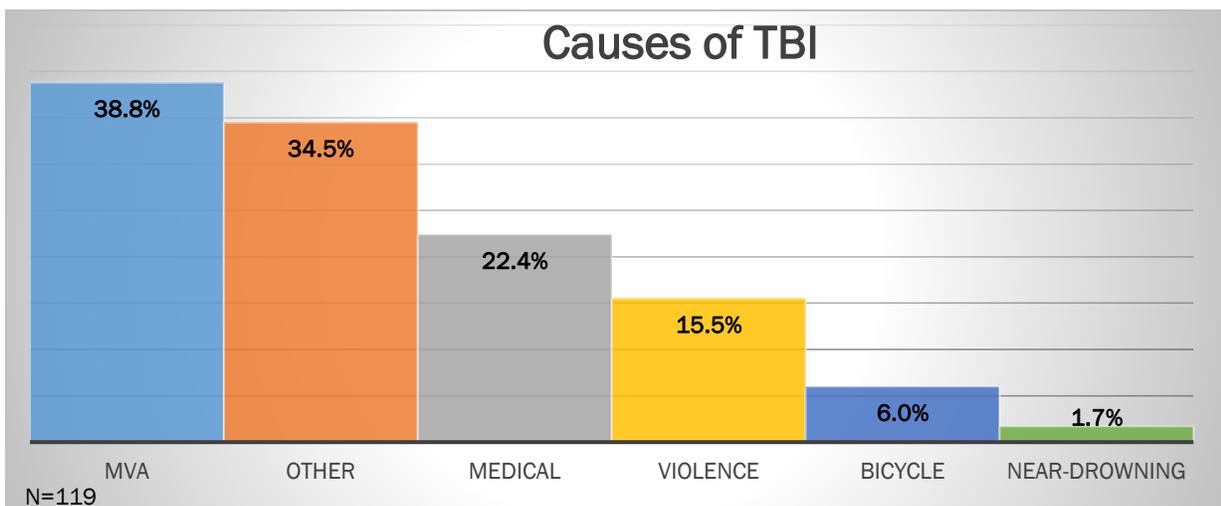
Figure 13: Length of time since TBI occurred



Cause of TBI

Respondents could select more than one cause if they suffered more than one TBI, and 26% of the respondents indicated they had suffered more than one TBI. Motor vehicle accidents (MVA) accounted for the highest incidence of TBI at 34.8%. Nationally, falls are the number one cause of TBI. The “Other” category listed below which includes falls and sports injuries was the second highest reported cause of TBI at 34.5%. A person’s medical condition, which includes stroke, brain tumor, infection, or epilepsy, was the third highest reported incidence of TBI.

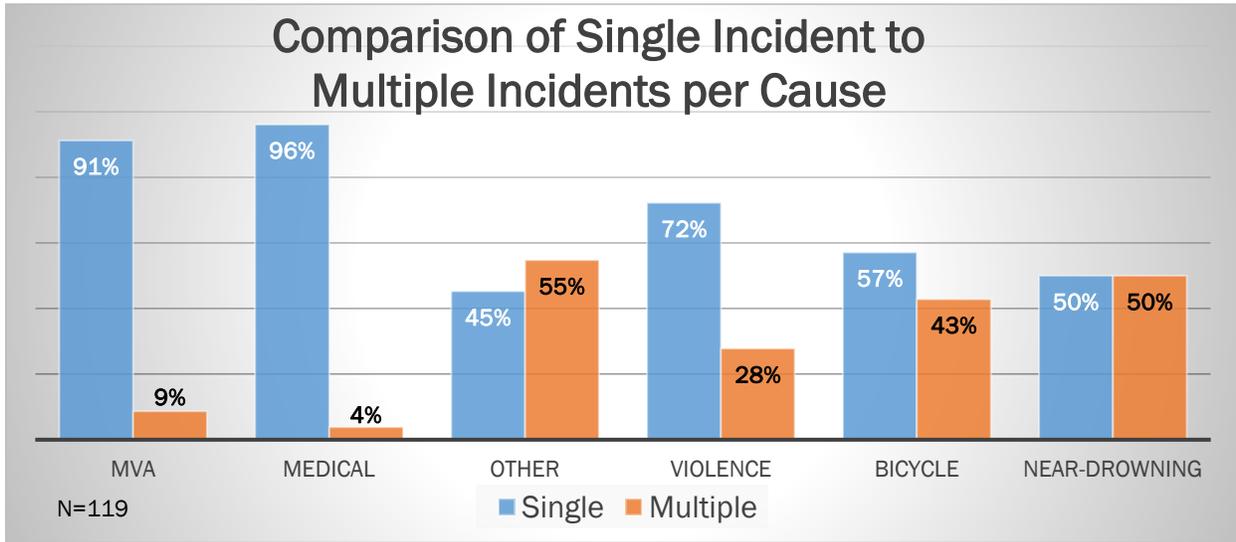
Figure 14: Causes of TBI in respondents



Single Cause vs. Multiple Causes

The chart below compares the percentage of respondents experiencing only one TBI to those having multiple incidents. For example, 45% of those reporting their cause was other (fall or sports injury) only had one incidence of a TBI, while the remaining 55% reported they experienced repeated causes of TBI.

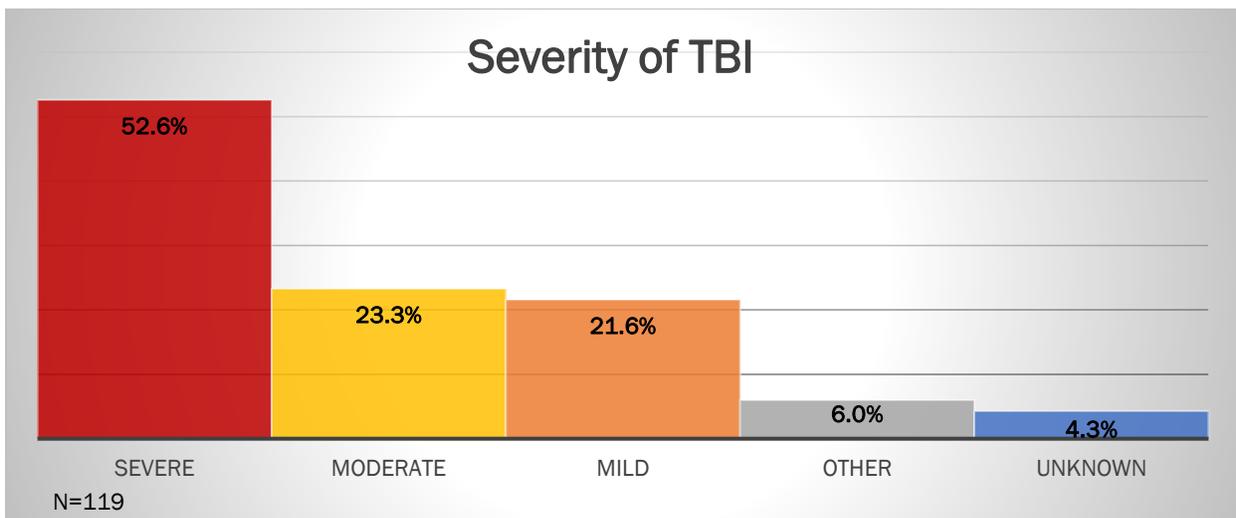
Figure 15: Comparison of single to multiple incidents per cause in respondents



Severity of TBI

Over half of respondents (52.6%) reported they had a severe TBI which was defined as a loss of consciousness for greater than 24 hours, followed by moderate (23.3%), which is a loss of consciousness of between 30 minutes and 24 hours, followed by mild (21.6%) defined as no loss of consciousness or loss of consciousness for less than 30 minutes.

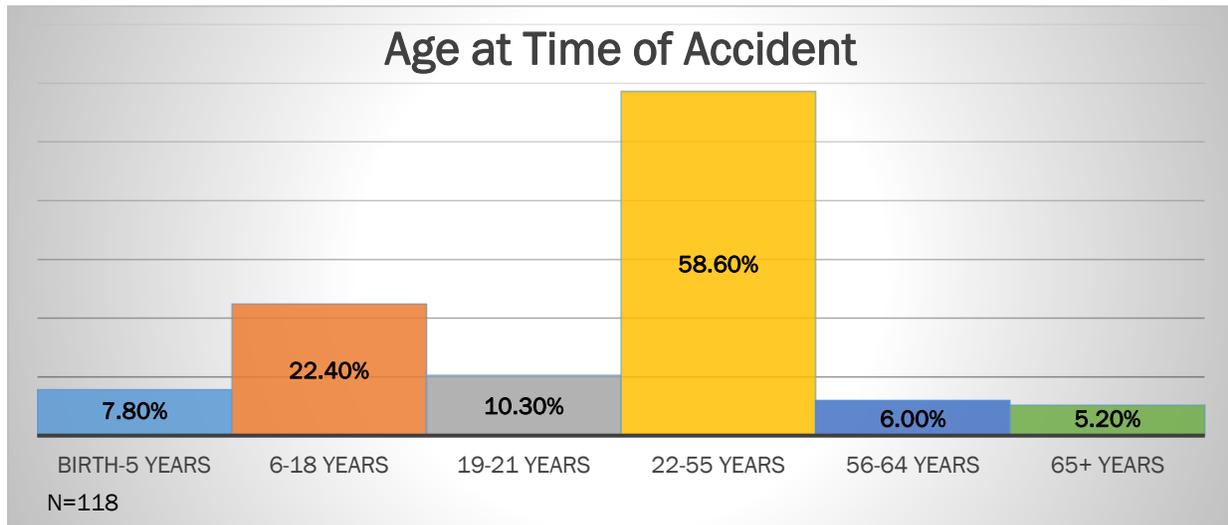
Figure 16: Severity of TBI



Age at Time of Cause

The majority of respondents (58.6%) were between 22 and 55 years of age at the time of their TBI, followed by 22.4% of respondents between 6 and 18 years. Only 5.2% of respondents, were sixty-five years and older when they experienced their TBI.

Figure 17: Age - Time of accident



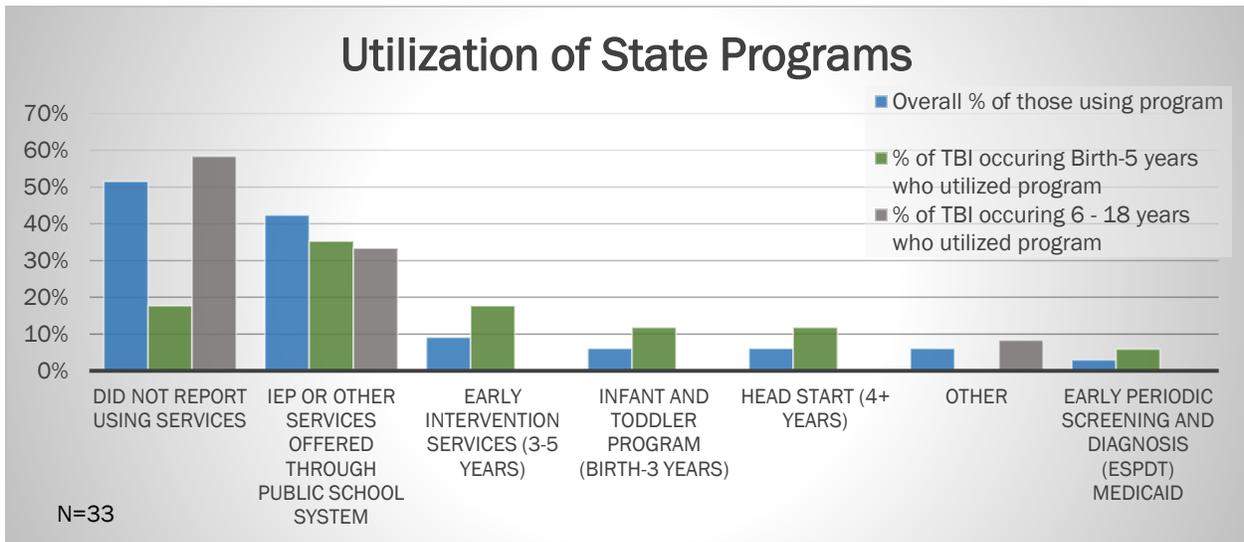
State Programs/Agencies and Support Services

The state of Idaho has a number of programs or agencies which provide services to people with a TBI. Some programs, such as IEP or public school services, early intervention, infant and toddler programs, Head Start, early periodic screening and diagnosis (EPSDT), are specifically for youth under the age of 21. Others such as the Area Agencies on Aging, Centers for Independent Living, and Vocational Rehabilitation focus primarily on adults. Other organizations address the needs of people of all ages, such as Disability Rights of Idaho, the Brain Injury Alliance of Idaho (BIA-ID), Idaho Parents Unlimited, and the Idaho TBI Ombudsman. Most of these programs address all types of disability and are not specifically for those with a TBI. Programs such as Idaho Center on Sports Concussion, BIA-ID, and the Idaho TBI Ombudsman, are critical in providing support and guidance for the unique issues of those with a TBI. Being an advocate for oneself and navigating through the array of other agencies/programs can be challenging.

State Programs for Youth (under the age of 18)

Four of the five programs listed capture pre-school age children and as such, if the TBI occurred after school age, these programs would not be applicable. The data supports this as we see 58% of those whose TBI occurred between 6-18 years of age, did not utilize any state program, and 33% only utilized services through the public school system. The remaining 8% who selected “other” commented that their TBI occurred close enough to 18 that they graduated from school before they were able to utilize a state program at the secondary education level. However, they did indicate they utilized IEP and 504 Plans.

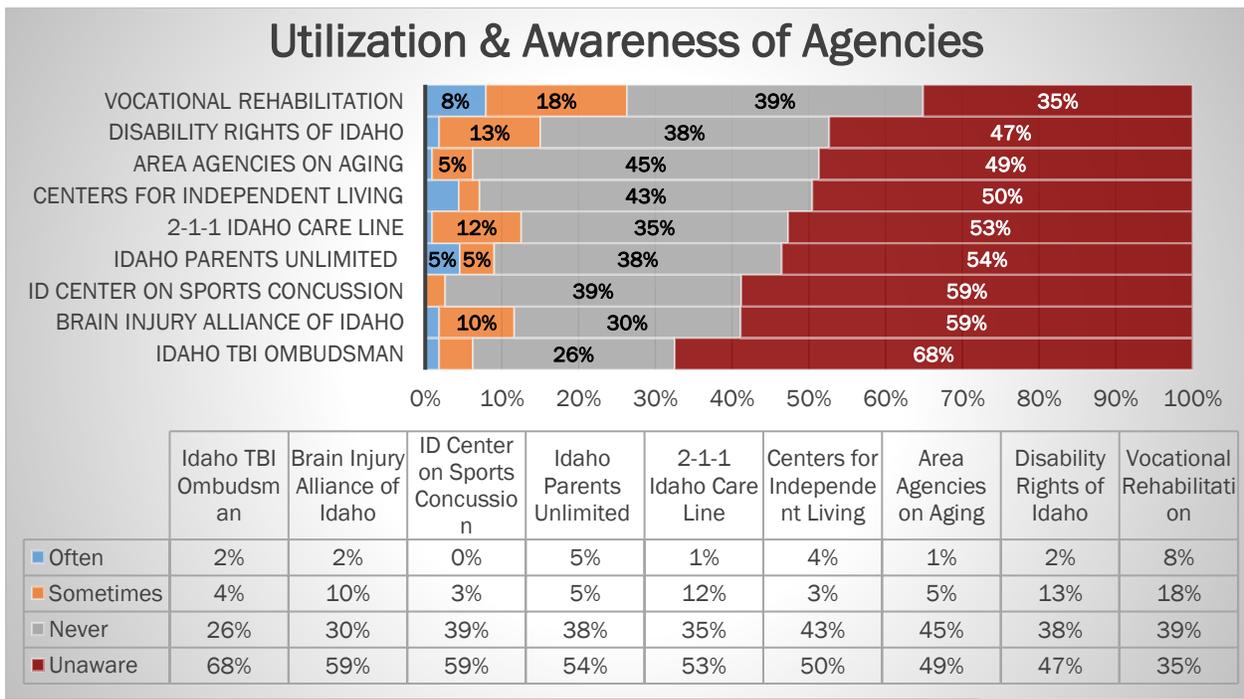
Figure 18: Utilization of state programs by respondents



Utilization/Awareness of Agencies

Respondents were asked if they were aware of the following agencies, and if so, how often they utilized the services provided by that agency. The data shows an underutilization of agencies with a low of 3% utilization for Idaho Center on Sports Concussion to a high of 26% utilization for Vocational Rehabilitation. The data suggests a significant problem with awareness, with 35% of respondents reporting that they are unaware of Vocational Rehabilitation services and all other agencies showing a lack of awareness greater than 47%.

Figure 19: Utilization and awareness of agencies by respondents

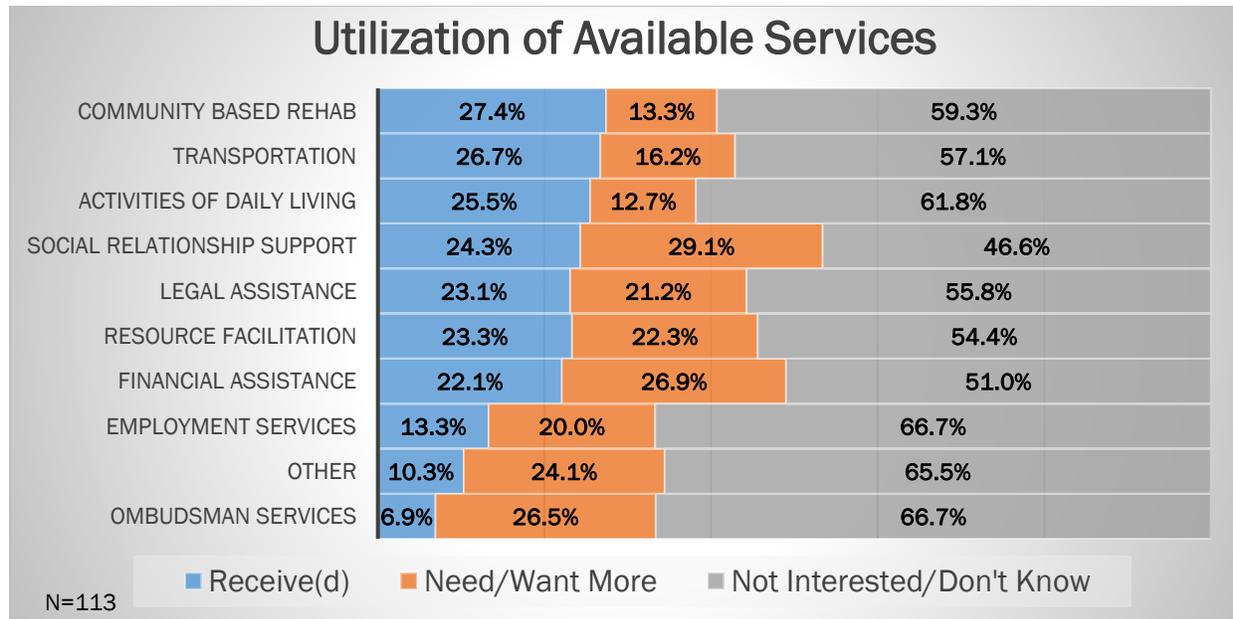


N=114

Utilization of Available Services

Respondents report receiving Community Based Rehabilitation Services (CBRS) most often, with 27.4%. The highest reported need/want is that of Social/Interpersonal Relationship Support, at 29.1%. When “receive” and “want/need” a service is combined, Social/Interpersonal Relationship Support prevails with 53.4% who want, need, or receive those services, followed by Financial Assistance (49%), Resource Facilitation (45.6%), Legal Assistance (44.3%), and Transportation (42.9%) rounding out the top five services. Ombudsman services have the highest gap between receiving services (6.9%) and needing/wanting services (26.5%).

Figure 20: Utilization of available services by respondents



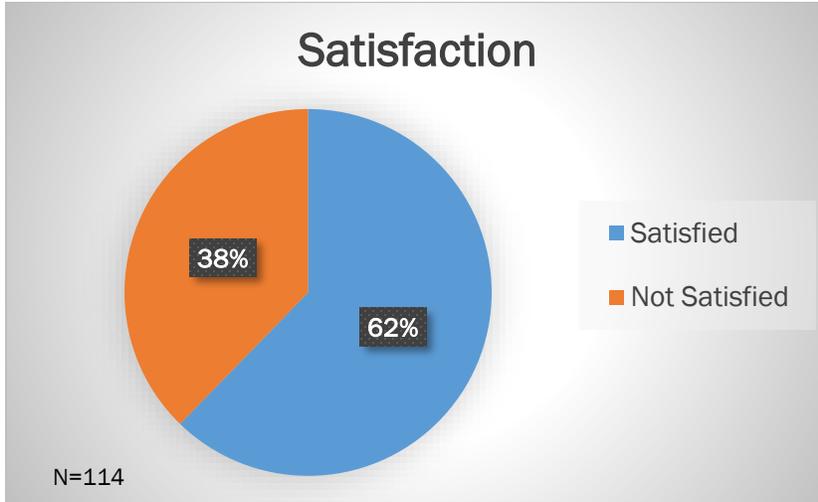
Health Care

In this section, information was gathered regarding the respondent’s satisfaction and interaction with the health care system. Respondents were asked about what services they used and which ones they wanted/needed more than they were currently receiving. This information was then cross-tabulated against the respondent’s type of health insurance and their overall satisfaction with their health care (Figure 24). The respondents were also asked about the types of transportation they used and how long it took in one direction to get to their primary care provider. The data shows an above average satisfaction with health care, but suggests there may be an issue with availability of specialty services in more rural areas. If we look at the counties by population, those respondents in counties with a population greater than 40,000 are 1.7 times more likely to be satisfied with their overall health care than those living in counties with a population less than 40,000. Similarly, respondents from the larger counties are 1.8 times more likely to receive or to have received health services from a specialty provider or a mental health provider (Table 8).

Satisfaction with Overall Health Care

Sixty-two and three tenths (62.3 %) of respondents reported they are satisfied with their overall health care, while 37.7% reported not being satisfied.

Figure 21: Satisfaction with overall health care across all respondents



Health Care Services Received/Needed

Across all respondents, 72.4% are receiving the services they need or want from primary care providers. However, when we look at the specialty services like specialty care providers and mental health the utilization drops below 50%.

Figure 22: Utilization of health care services across all respondents

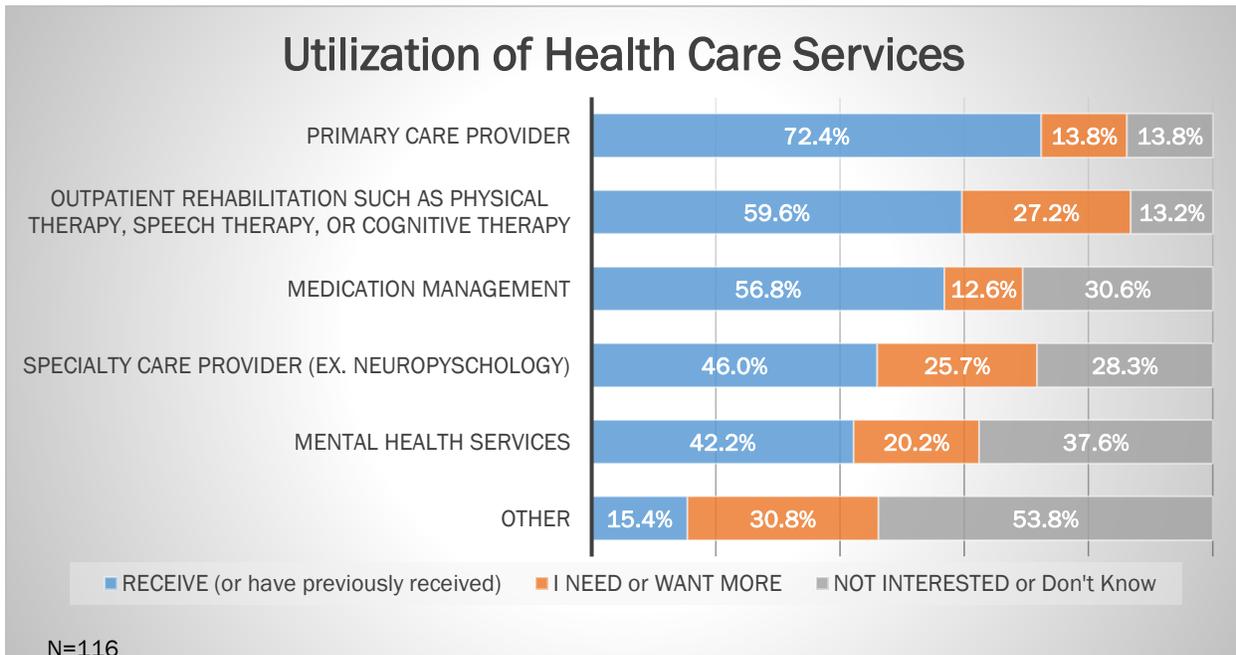


Table 8: Comparison of large counties to small counties and health care satisfaction

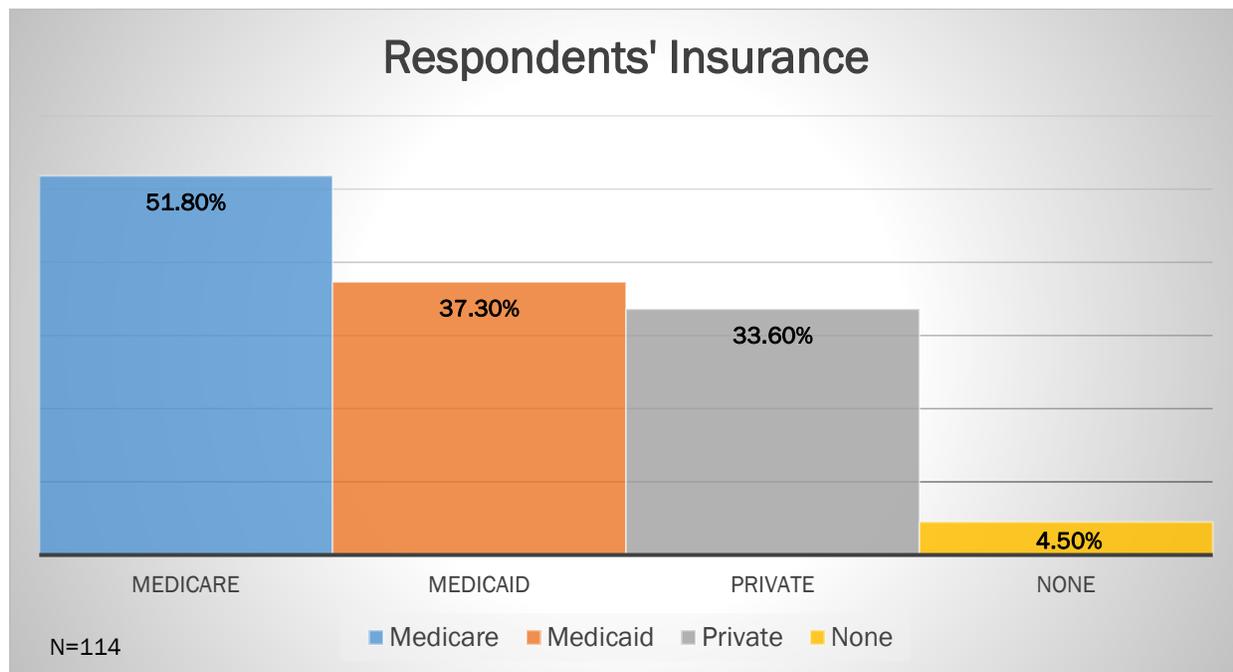
| | Satisfied | Not Satisfied | Odds of Respondent being Satisfied | Receive(d) Specialty Services | Did Not Receive Specialty Services | Odds of Respondent receiving Specialty Services |
|---------------------------------|-----------|---------------|------------------------------------|-------------------------------|------------------------------------|---|
| Counties population > 40,000 | 65% | 35% | 1.9 | 46% | 54% | 0.9 |
| Counties population < 40,000 | 52% | 48% | 1.1 | 34% | 66% | 0.5 |
| Comparing the Two: Large/ Small | | | 1.7 | | | 1.8 |

N=113

Health Insurance Used

Only 4.5% of those responding to this question do not have any type of health insurance. Respondents may have more than one type of insurance. Some form of government provided health insurance covers the majority of respondents: Medicare at 51.8% and Medicaid at 37.3%.

Figure 23: Respondents' health insurance utilization



Impact on Satisfaction: Health Insurance and Access to Health Care

Analysis of respondents’ satisfaction with their overall health care, the type of insurance they have, and whether or not they are receiving the specific services. The data in this table and the figure following indicate a correlation between satisfaction and access to the health care services needed or wanted.

Figure 24: Comparison of type of health insurance and satisfaction with overall health care

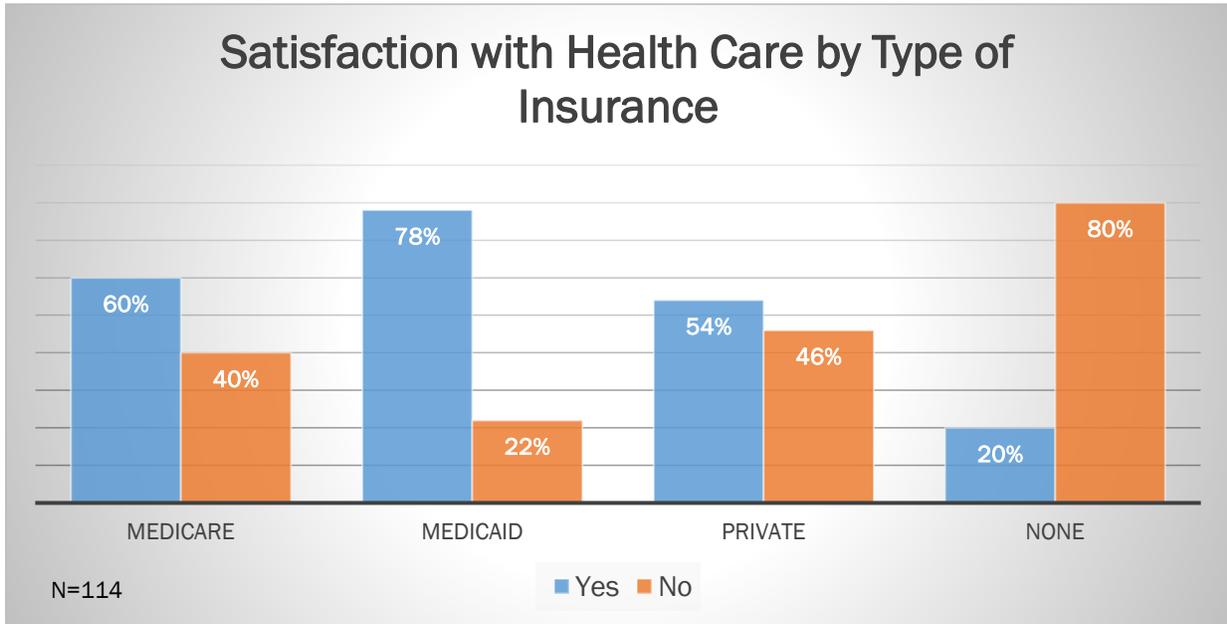


Table 9: Services and health insurance used by those satisfied with their overall health care

| Respondents who are Satisfied | | Current health insurance | | | |
|-------------------------------|------------------|--------------------------|----------|---------|------|
| | | Medicare | Medicaid | Private | None |
| Primary Care | Receive(d) | 38% | 39% | 22% | 1% |
| | I Need/Want More | 40% | 20% | 40% | 0% |
| | Not Interested | 55% | 27% | 18% | 0% |
| Medication Management | Receive(d) | 39% | 44% | 16% | 2% |
| | I Need/Want More | 67% | 33% | 0% | 0% |
| | Not Interested | 38% | 21% | 42% | 0% |
| Mental Health Services | Receive(d) | 38% | 44% | 18% | 0% |
| | I Need/Want More | 33% | 33% | 33% | 0% |
| | Not Interested | 45% | 24% | 31% | 0% |
| Outpatient Rehabilitation | Receive(d) | 39% | 38% | 22% | 2% |
| | I Need/Want More | 42% | 42% | 17% | 0% |
| | Not Interested | 40% | 20% | 40% | 0% |
| Specialty Care Provider | Receive(d) | 38% | 38% | 23% | 0% |
| | I Need/Want More | 36% | 36% | 27% | 0% |
| | Not Interested | 48% | 29% | 24% | 0% |
| Other | Receive(d) | 33% | 33% | 33% | 0% |
| | I Need/Want More | 0% | 0% | 0% | 0% |
| | Not Interested | 50% | 10% | 40% | 0% |

N=114

Table 10: Services and health insurance used by those not satisfied with overall health care

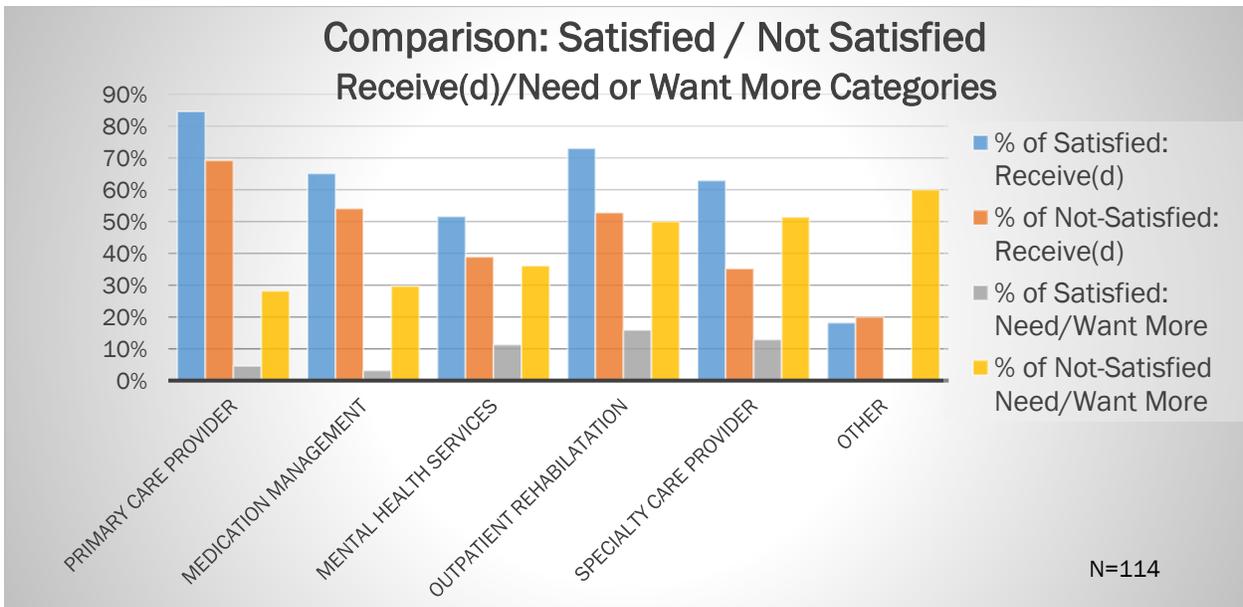
| Respondents who are NOT Satisfied | | Current health insurance | | | |
|-----------------------------------|------------------|--------------------------|----------|---------|------|
| | | Medicare | Medicaid | Private | None |
| Primary Care | Receive(d) | 40% | 26% | 34% | 0% |
| | I Need/Want More | 47% | 12% | 29% | 12% |
| | Not Interested | 60% | 0% | 20% | 20% |
| Medication Management | Receive(d) | 41% | 22% | 33% | 4% |
| | I Need/Want More | 40% | 13% | 40% | 7% |
| | Not Interested | 42% | 17% | 25% | 17% |
| Mental Health Services | Receive(d) | 39% | 22% | 39% | 0% |
| | I Need/Want More | 50% | 6% | 38% | 6% |
| | Not Interested | 39% | 22% | 28% | 11% |
| Outpatient Rehabilitation | Receive(d) | 40% | 24% | 32% | 4% |
| | I Need/Want More | 44% | 15% | 33% | 7% |
| | Not Interested | 50% | 17% | 17% | 17% |
| Specialty Care Provider | Receive(d) | 50% | 19% | 31% | 0% |
| | I Need/Want More | 44% | 15% | 33% | 7% |
| | Not Interested | 40% | 27% | 27% | 7% |
| Other | Receive(d) | 33% | 0% | 67% | 0% |
| | I Need/Want More | 33% | 11% | 33% | 22% |
| | Not Interested | 67% | 0% | 33% | 0% |

N=114

Health Care Services Received/Needed or Want More

If we look at the services, being received by those satisfied compared to those not satisfied, we see that the satisfied group receives more of the services. The data shows an even bigger gap between these two groups in the need/want more services category. In summary, those who receive the services they need or want, are more likely to be satisfied with their overall health care.

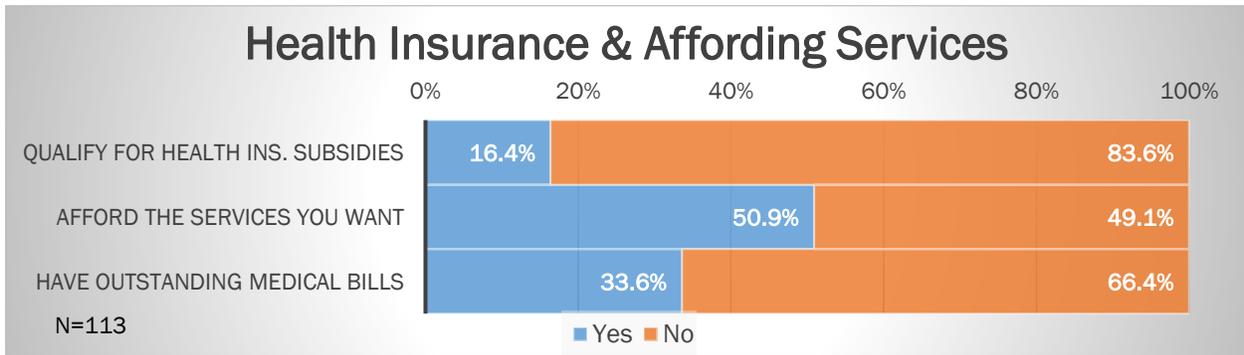
Figure 25: Comparison of satisfied to not satisfied in both categories



Health Insurance Subsidies

When asked if they qualified for health insurance subsidies, only 16.4% responded “yes.” However, 50.9% still stated they were able to afford the services they wanted and only 33.6% responded they have outstanding medical bills. With 89.1% of the respondents on Medicare or Medicaid, it is not surprising such a small percentage report qualifying for subsidies. Still it is notable 49.1% respond they are not able to afford the services they want/need.

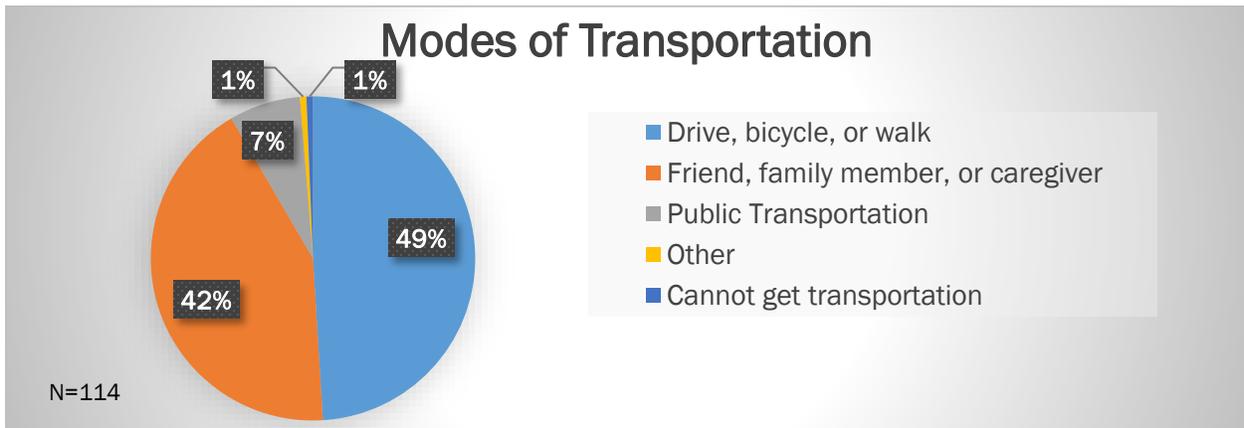
Figure 26: Health insurance and affording services



Types of Transportation Used

Respondents were asked to select each of the different types of transportation they used. With N=114 answering this question, only 1 respondent reported not being able to get transportation. Only 11 use public transportation, with the rest either driving themselves or relying on a friend, family member, or caregiver. The one respondent selecting “other” indicated they would like to use public transportation, but it is not available.

Figure 27: Modes of transportation



Travel Time to Primary Care Provider

Most respondents (95.6%) live less than 60 minutes from their primary care provider (PCP). Another 2.7% live 1 to 2 hours away, and the remaining 1.8% live over 3 hours away. Of those living within 60 minutes, 64% reported they are satisfied with their overall health care. When looking at those living more than 60 minutes away, 80% responded that they are not satisfied with their overall health care. However, due to the low percentage of those living more than 60

minutes from primary care who responded to the survey, there may not be as strong of a correlation between distance from care and satisfaction with the care as our data would indicate.

Figure 28: Comparison of distance from primary care and satisfaction with health care

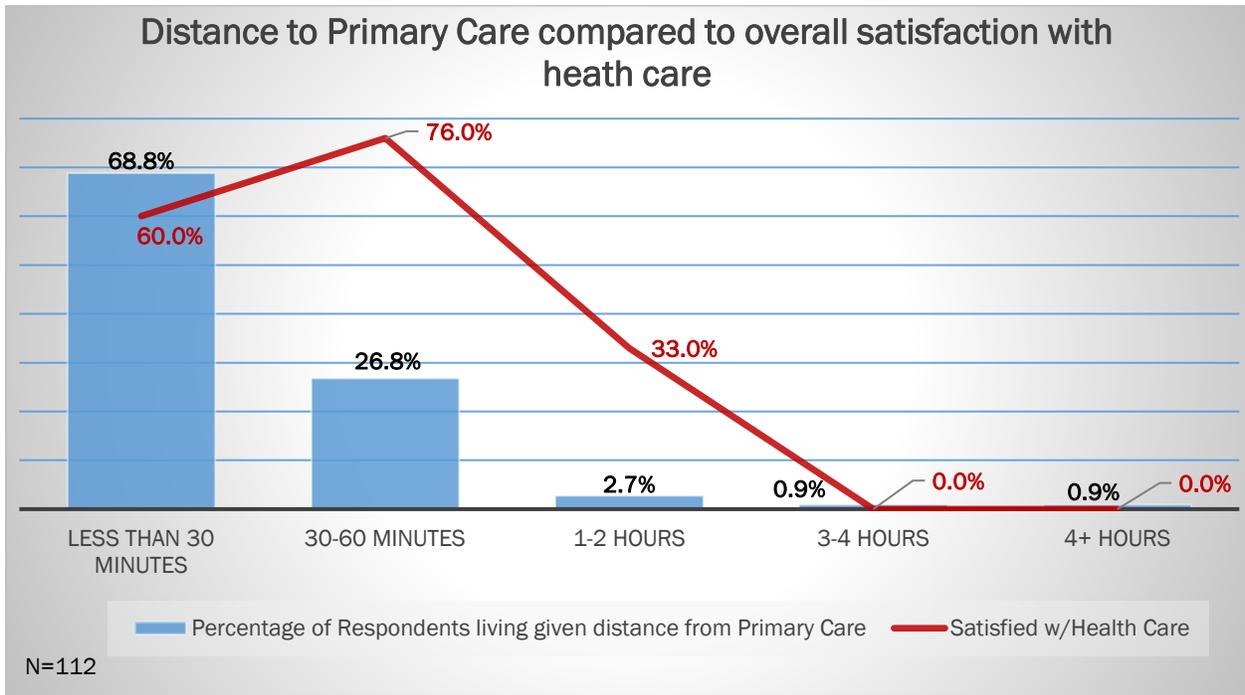


Table 11: Comparison of travel time to reach primary care provider with overall satisfaction with health care

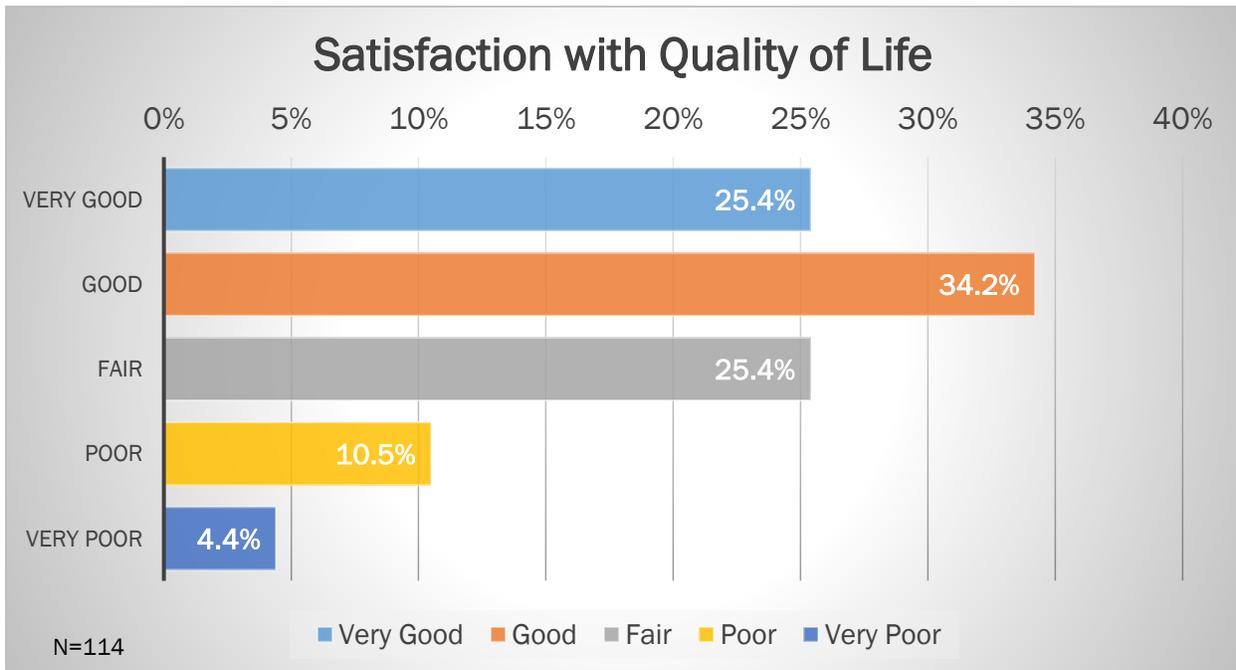
| | | Are you satisfied with your overall health care? | |
|--|----------------------|--|------|
| | | Yes | No |
| How long does it take you one way to reach your primary care provider? | Less than 30 minutes | 60% | 40% |
| | 30-60 minutes | 76% | 24% |
| | 1-2 hours | 33% | 67% |
| | 3-4 hours | 0% | 100% |
| | 4+ hours | 0% | 100% |

N=112

Quality of Life

Based on the responses, 59.6% of those who experienced a TBI rate their quality of life as good or very good. Another 25.4% rate their quality of life as fair. Only 14.9% believe their quality of life is poor or very poor.

Figure 29: Satisfaction with quality of life



Satisfaction with health care and quality of life

We analyzed the data to determine if there was a correlation between respondents’ overall satisfaction with their health care and their reported quality of life. As shown in Table 12, a higher percentage of respondents with a reported quality of life as “fair”, “poor”, and “very poor” answered “No” when asked if they were satisfied with their health care. In other words, 65% of those not satisfied with their health care believe their quality of life is fair or worse.

Table 12: Comparison of satisfaction with health care to quality of life rating

| | | Are you satisfied with your overall health care? | |
|--|-----------|--|-----|
| | | Yes | No |
| How would you rate your overall quality of life? | Very Good | 36% | 7% |
| | Good | 38% | 28% |
| | Fair | 19% | 37% |
| | Poor | 4% | 21% |
| | Very Poor | 3% | 7% |

N=114

We also analyzed the data to see if there was any correlation between the severity of the TBI and the reported quality of life. There does not appear to be a relationship between TBI severity and perceived quality of life. In fact, 68% of those who describe their TBI as “severe” report a “good” or “very good” quality of life. Only 13% with a severe TBI, compared to 15% overall, view their quality of life as “poor” or “very poor”.

Table 13: Comparison of severity of TBI to quality of life rating

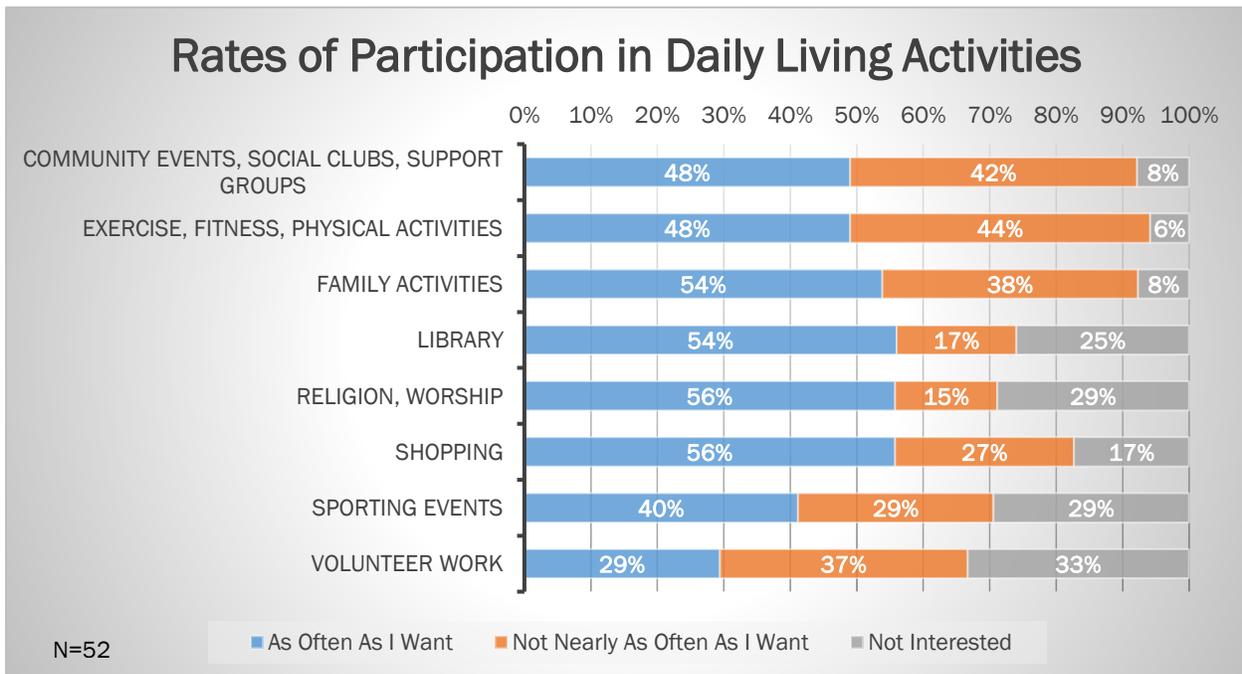
| | | How severe was your TBI? If you have had more than one TBI, select all that apply. | | | | |
|--|-----------|--|----------|--------|---------|-------|
| | | Mild | Moderate | Severe | Unknown | Other |
| How would you rate your overall quality of life? | Very Good | 17% | 11% | 28% | 40% | 43% |
| | Good | 33% | 33% | 40% | 0% | 29% |
| | Fair | 29% | 37% | 18% | 40% | 29% |
| | Poor | 13% | 15% | 10% | 20% | 0% |
| | Very Poor | 8% | 4% | 3% | 0% | 0% |

N=114

Participation in Daily Living

Across all categories, 31% of respondents report they participate in daily living activities “not nearly as often as I would like”. However, Figure 28 shows 60% of respondents perceive their quality of life as “good” or “very good,” and, on average across all categories, 48% of respondents report they participate “as often as I want.” There does not appear to be a direct correlation between respondents perception of their quality of life, and whether or not they are able to participate in the daily living activities as often as they want.

Figure 30: Rates of participation in daily living activities



Conclusion

The changes occurring in the structure of Idaho's population, and the perceptions reported in the needs assessment, predict a rapidly increasing need for expanded services. Changes in the organization, financing, and delivery of health services are currently beginning to take place in Idaho. For example, Idaho's Statewide Healthcare Innovation Plan (SHIP) is currently under implementation. This Centers for Medicare and Medicaid Services (CMS) grant funded project fosters health system changes to improve health care access, quality, and outcomes. This program is regionally based to accelerate the expansion of patient centered medical homes that improve care coordination and access to services through the use of community health workers, community health emergency medical services, and expanded telehealth services. The SHIP model will provide health care workforce and communications resources that can be aimed directly at the needs of Idaho's traumatic brain injury population in both rural and urban areas. All of these resources will be increasingly critical in meeting the growing demand for services by individuals with a TBI in Idaho.

Appendix A: Letter of Introduction to Survey

February 6, 2017

Dear Participant:

WE NEED YOUR HELP TO IDENTIFY AND IMPROVE SERVICES TO PEOPLE WITH A TRAUMATIC BRAIN INJURY AND THEIR FAMILY MEMBERS.

Traumatic brain injury, or TBI for short, is an injury to the brain that happened sometime after birth, when the head hits a stationary object, or is hit, penetrated, or violently shaken by some external force.

You may have assisted us in the past by completing a similar survey. If you did, we thank you, and want to assure you that because of your help, we have continued to move forward in identifying people with TBI in Idaho and to refer them to health care providers who can further help them access the care they need. We have been successful in the past in receiving funding from a federal agency to put into action a statewide plan to assist individuals with brain injury and their families. Now we need your help moving forward.

We are asking you to complete the enclosed anonymous questionnaire. This is our way of learning about how systems do, or do not, benefit people with TBI. This questionnaire is an important step in our work and your opinion matters. Please take a few minutes to tell us what you think people with TBI need, and how satisfied you are with the resources that you have found to be available.

We want to hear from you if you have a TBI or if you are filling out the questionnaire for someone with a TBI. You do not have to be receiving services to fill out a survey.

Please complete a separate questionnaire for each person in your family or close group who has a TBI or is helping someone with a TBI, and return them by Friday, March 17, 2017 to:

ISU-Institute of Rural Health
1311 E Central Drive
Meridian, ID 83642

Feel free to make extra copies. If you prefer, you can complete the questionnaire online. Just visit our website: <https://www.idahotbi.org> or directly access the survey at <https://goo.gl/D8B5Mk>. You can also scan the QR code at the bottom of this page. If you have questions, or need assistance in completing the survey, or need the survey in an alternative format (large print, audio tape, computer disc, etc), please call us directly: 208-373- 1769.

The information you provide will be kept private. Only group statistics are reported. We do not report data on individuals.



This project is supported in part by grant number 90TBSG007-01-00 from the U.S Administration for Community Living (ACL), Department of Health and Human Services (HHS), Washington, D.C. 20201. Grantees undertaking projects under government sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not, therefore, necessarily represent official Administration for Community Living policy.

Appendix B: Survey Instrument

Needs Assessment for Persons with a Traumatic Brain Injury (TBI) and Their Family/Friends/Caregiver

Please provide the following information. If you are not sure about a question answer the best you can. Please note that all questions refer to the person with the TBI unless the question specifically tells you differently. In most cases, you will be asked to place a check or X in a box. Sometimes you will be asked to write your answer down. If you need assistance, we will provide, free of charge, someone to help you fill out the form; please call 1-208-373-1769.

1. Have you been diagnosed with a Traumatic Brain Injury (TBI)? Select one.

- Yes
- No

2. What is your gender? Select one.

- Male
- Female

3. What is your current age? _____

4. Are you a veteran? Select one.

- Yes
- No

5. Which county do you live in? Please select from the list.

- | | | |
|----------------------------------|----------------------------------|----------------------------------|
| <input type="radio"/> Ada | <input type="radio"/> Caribou | <input type="radio"/> Latah |
| <input type="radio"/> Adams | <input type="radio"/> Cassia | <input type="radio"/> Lemhi |
| <input type="radio"/> Bannock | <input type="radio"/> Clark | <input type="radio"/> Valley |
| <input type="radio"/> Bear Lake | <input type="radio"/> Clearwater | <input type="radio"/> Lewis |
| <input type="radio"/> Benewah | <input type="radio"/> Custer | <input type="radio"/> Lincoln |
| <input type="radio"/> Bingham | <input type="radio"/> Elmore | <input type="radio"/> Madison |
| <input type="radio"/> Blaine | <input type="radio"/> Twin Falls | <input type="radio"/> Minidoka |
| <input type="radio"/> Boise | <input type="radio"/> Franklin | <input type="radio"/> Nez Perce |
| <input type="radio"/> Bonner | <input type="radio"/> Fremont | <input type="radio"/> Oneida |
| <input type="radio"/> Bonneville | <input type="radio"/> Gem | <input type="radio"/> Owyhee |
| <input type="radio"/> Teton | <input type="radio"/> Gooding | <input type="radio"/> Payette |
| <input type="radio"/> Boundary | <input type="radio"/> Idaho | <input type="radio"/> Power |
| <input type="radio"/> Butte | <input type="radio"/> Jefferson | <input type="radio"/> Shoshone |
| <input type="radio"/> Camas | <input type="radio"/> Jerome | <input type="radio"/> Washington |
| <input type="radio"/> Canyon | <input type="radio"/> Kootenai | |

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6. Where do you live? Select one.

- Own or rent house or apartment
- In the home of family, friend, or caregiver
- Assisted Living facility or Nursing home
- Homeless
- Other _____

7. What is your employment status? Select one.

- Working full-time
- Working part-time
- Volunteer
- Not employed or volunteering at this time

Go to question 10, if employed.

8. If unemployed which of the following reasons do you believe contribute to your unemployment? Select all that apply.

- Inability to do any job
- Lack of accommodations
- Unable to get hired
- Inability to find work
- Seeking employment
- Inability to perform a previous job
- Retired
- Not applicable

9. Where do you access employment assistance? Select all that apply.

- Health & Welfare
- Department of Labor
- Vocational Rehabilitation
- Veterans Affairs
- Not Applicable
- Other _____

10. What is the total combined income per year for all persons in your household? This includes all sources such as jobs, Social Security, retirement income, and public assistance. Select one.

- Less than \$10,000
- \$10,000 to under \$20,000
- \$20,000 to under \$30,000
- \$30,000 to under \$40,000
- \$40,000 to under \$50,000
- Over \$50,000

11. How long ago did your TBI occur? If you have had more than one TBI, select all that apply.

- Less than 3 months ago
- Less than 1 year ago
- 1-3 years ago
- 3-10 years ago
- More than 10 years ago

12. How did your TBI happen? If you have had more than one TBI, select all that apply.

- Motorized vehicle accident (car, truck, motorcycle, ATV, etc.)
- Bicycle accident
- Other accident (for example, fall, sports injury)
- Violence (for example, fighting, assault, gunshot, explosion, combat, or suicide attempt)
- Near-drowning
- Medical condition (for example, stroke, brain tumor, infection, epilepsy)
- Other (please describe)

13. How severe was your TBI? If you have had more than one TBI, select all that apply.

- Mild (No loss of consciousness or loss of consciousness for < 30 minutes)
- Moderate (Loss of consciousness for 30 minutes to 24 hours)
- Severe (Loss of consciousness for > 24 hours)
- Unknown
- Other

14. How old were you at the time of the accident? If you have had more than one TBI, select all that apply.

- Birth-5 years
- 6-18 years
- 19-21 years
- 22-55 years
- 56-64 years
- 65+ years

Go to question 16, if you were over 18.

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15. If you were under the age of 18 at the time of your TBI, did you use any of the following state programs as a result of your TBI? Select all that apply.

- Infant and Toddler program (Birth-3 years)
- Early Intervention Services (3-5 years)
- Head Start (4+ years)
- Early Periodic Screening and Diagnosis (ESPDT) Medicaid
- IEP or other services offered through public school system
- Other _____
- None of the above

16. Are you aware of the following agencies? If so, please indicate how often you access each agency for services and supports.

| | Often | Sometimes | Never | Unaware |
|---|-----------------------|-----------------------|-----------------------|-----------------------|
| 2-1-1 Idaho Care Line | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Area Agencies on Aging | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Brain Injury Alliance of Idaho (BIA-ID) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Centers for Independent Living | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Disability Rights of Idaho | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Idaho Center on Sports Concussion | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Idaho Parents Unlimited (IPUL) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Idaho Traumatic Brain Injury Ombudsman (information & referral) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Vocational Rehabilitation | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

17. Which of the following services have you received or do you need? Select all that apply.

| | RECEIVE (or have previously received) assistance with: | I NEED or WANT MORE assistance with: | NOT INTERESTED or Don't Know |
|--|--|--------------------------------------|------------------------------|
| Community based rehab services (CBRS) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Activities of daily living (ADLS) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Employment services | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Financial assistance | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Legal assistance | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Ombudsman services (Information & Referrals) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Resource facilitation (case management) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Social/interpersonal relationship support | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Transportation | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Other (specify below) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

18. Are you satisfied with your overall health care? Select one.

- Yes
- No

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19. Which of the following health care services have you received or do you need? Select all that apply.

| | RECEIVE (or have previously received) | I NEED or WANT MORE | NOT INTERESTED or Don't Know |
|--|--|------------------------------|---------------------------------|
| Primary care provider | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Medication management | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Mental health services | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Outpatient rehabilitation such as physical therapy, speech therapy, or cognitive therapy | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Specialty care provider (ex. neuropsychology) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Other | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

20. What health insurance do you currently use? Select all that apply.

- Medicare (for those over age 65 or disabled)
- Medicaid (for those with low income)
- Private health insurance
- None
- I don't know

21. Do you qualify for health insurance subsidies? Select one.

- Yes
- No
- I don't know

22. Are you able to afford the health services you need or want? Select one.

- Yes
- No

23. Do you have outstanding medical bills or difficulty paying for prescriptions? Select one.

- Yes
- No

24. Which modes of transportation do you use? Select all that apply.

- Drive, bicycle, or walk
- Friend, family member, or caregiver
- Public transportation
- Cannot get transportation
- Other _____

25. How long does it take you one way to reach your primary care provider? Select one.

- Less than 30 minutes
- 30-60 minutes
- 1-2 hours
- 3-4 hours
- 4+ hours

26. How would you rate your overall quality of life? Select one.

- Very Good
- Good
- Fair
- Poor
- Very Poor

27. How often do you go to or participate in the following? Select one response in each row.

| | As often as I want | Not nearly as often as I want | Not interested |
|--|-----------------------|-------------------------------|-----------------------|
| Community events, social clubs, support groups | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Exercise, fitness, physical activities | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Family activities | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Library | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Religion, worship | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Shopping | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Sporting events | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Volunteer work | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

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Appendix C: ISU Press Release Announcing Survey

Idaho State UNIVERSITY

Released by Idaho State University, Office of Marketing and Communications
Contact: Russell Spearman, Institute of Rural Health, (208) 373-1769

Feb. 7, 2017

Idaho State University seeks feedback to improve Traumatic Brain Injury services in Idaho.

Want to help chart the future of Traumatic Brain Injury services in Idaho? What services and supports do you need? Are they available in your community? These are a few of the questions a statewide assessment to improve Idaho's Traumatic Brain Injury services will attempt to answer.

Thanks to a federal grant from the Administration for Community Living, Idaho State University's Institute of Rural Health is developing a four-year statewide plan to assess Traumatic Brain Injury or TBI needs in Idaho, according to Russell Spearman, the ISU researcher in charge of the grant.

Spearman and his project team are encouraging Idahoans who live with a brain injury or provide care to someone who does to complete an assessment at www.idahotbi.org or goo.gl/D8B5Mk. Based on the responses, Spearman, community advocates and brain injury stakeholders—including disability rights and parental groups—will develop strategies to help fund brain injury services in Idaho communities.

“In essence, the responses will help us prioritize where the greatest needs in Idaho are and turn those needs into an action plan for the state,” said Spearman, noting that an estimated 35,000 Idahoans are living with a severe brain injury. A severe injury is one that can affect various levels of cognitive function.

Survey responses are anonymous, and the deadline to return them is March 17. Results will be posted on the Idaho TBI website at www.idahotbi.org in the coming months.

For more information, contact Spearman at the ISU-Meridian Health Science Center, 208-373-1769 or spearuss@isu.edu.

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Appendix D: Flyer Advertising Survey



Access the survey at
idahotbi.org or
goo.gl/D8B5Mk



*The Institute of Rural
Health needs your help!*

- *If you have had a traumatic brain injury*
- *If you are a family member of someone who has had a TBI*
- *If you are, or have been, a caregiver of someone with a TBI*

Help us chart the future for traumatic brain injuries in Idaho!

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