Final Report From The 2000-2003 Traumatic Brain Injury State Planning Grant For The State Of Idaho

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IDAHO STATE UNIVERSITY

INSTITUTE OF RURAL HEALTH

IDAHO DEPARTMENT OF HEALTH & WELFARE

TBI
TRAUMATIC BRAIN INJURY
STATE GRANT PROGRAM

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Introduction to the TBI State Grant Program From The TBI Technical Assistance Program (www.tbitac.org)

What is the TBI State Grant Program?

The TBI State Grant Program is an initiative designed to improve access to health and other services for all individuals with brain injury and their families. The grant is administered by Health Resources and Services Administration's (HRSA) Maternal and Child Health Bureau (MCHB) within the U.S. Department of Health and Human Services.

The Program began with the TBI Act of 1996 (Public Law 104-166) which launched an effort to expand studies and establish innovative programs for TBI. It authorized HRSA to establish a grant program for States to help meet the needs of individuals with TBI and their families. It also delegated responsibilities in the areas of research, prevention, and surveillance to the National Institutes of Health and the Centers for Disease Control and Prevention, respectively. Title XIII of the Children's Health Act of 2000 renews and advances the authority of these government agencies to make life better after TBI.

What is the Goal?

The Program's primary goal is to ensure that the estimated 5.3 million individuals and their families who live with the effects of TBI in the United States have access to a comprehensive, coordinated system of care that is person-centered and attends to their changing needs from the moment of injury throughout the rest of their lives.

How is the Goal Achieved?

A comprehensive, coordinated system of care exists only by diligent work to:

- improve the delivery and the quality of services;
- establish favorable policy and legislation; and
- guarantee sustained financial support.

The federal TBI State Grant Program manages the national progress on these three fronts in partnership with organizations such as the Brain Injury Association of America and the National Association of State Head Injury Administrators, and through other federal programs, including the National Institute on Disability and Rehabilitation Research's TBI Model Systems. This enables the States to manage these three fronts on the State and local levels.

The TBI State Grant Program funds seed money to States to begin integration of services, establishment of policy, and procurement of financial support to bring about systems change. This change is achieved by expanding and improving State and local capacity to care for individuals with TBI and their families. States work to strengthen State infrastructure, improve community supports and services, develop and evaluate model approaches to the myriad challenges in integrating TBI services into the broader service delivery system, and generate support from local and private sources for sustaining their efforts after the grant's completion.

How is Success Measured?

Progress in achieving the goal of the Program is measured in a variety of ways, such as

...the number of States that have...

- a lead agency with autonomy in the State system;
- a TBI Advisory Council that is operationalized within the State system of agencies, boards, and councils;
- an assessment of the needs and resources;
- a State Action Plan that exists as a "living and breathing document;"
- a working knowledge of the State governmental structure;
- collaborative partnerships with other State agencies, disability groups, advocacy organizations, etc.;
- a coordinated system of care;
- data to support the integration of TBI supports and services into the broader service delivery system;
- multiple funding streams;
- mechanisms of evaluation; and
- policy and legislation in place to support the care of individuals with TBI.

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EXECUTIVE SUMMARY

PURPOSE

The purpose of this document is to report on the 2000-2003 traumatic brain injury state planning grant for the state of Idaho. The goals of the grant include the formation of an advisory council, the designation of a state agency, the identification of needs and resources for services and supports and the development of a plan that can be undertaken by state, private, and nonprofit organizations to begin integration of services, establishment of policy, and procurement of financial support to bring about systems change.

BACKGROUND

In the United States, about 1.9 million Americans experience a traumatic brain injury each year. Of these, about 50% experience short-term disabilities, while 90,000 people sustain debilitating loss of function. Approximately 52,000 Americans die because of their injuries. The annual cost of traumatic brain injury in the United States is an estimated $48.3 billion ($31.7 billion in hospitalization and $16.6 billion in fatal brain injuries). While there is no data on the number of Idahoans who have experienced TBI, extrapolating from the 1999 CDC estimates, about 25,880 Idahoans are living with TBI and 97 people died because of their injuries. Of those living with TBI, 146 have permanent disabilities. In addition, the 1999 IDHW Vital Statistics report indicates that 2580 children under the age of 18 experienced a motor vehicle accident—the highest reported cause of injury for this age group.

Idaho lacks comprehensive infrastructure to manage services and supports for persons with TBI. Boise has a Level II trauma center and there are Level I centers in the larger towns, but other Idahoans must travel out of Idaho for TBI-specific services and supports. Residents of northern Idaho, for example, travel to Spokane, Washington, while eastern Idaho residents go to Salt Lake City, Utah. Also, persons with TBI need ongoing rehabilitative, social, financial, psychological, vocational, and residential services and supports. While there are general health care services in each of the 44 counties, the most common service provided regarding TBI (other than emergency and acute care) is referral to subspecialties.

BACKGROUND OF THE PLANNING GRANT

The TBI State Grant Program is an initiative designed to improve access to health and other services for all individuals with brain injury and their families. The program is administered by Health Resources and Services Administration's (HRSA) Maternal and Child Health Bureau (MCHB) within the U.S. Department of Health and Human Services. As of fiscal year 2001, 22 states had received planning grants and 17 states had received implementation grants for this development. Idaho received a 2-year planning grant in fiscal year 2000 to design a plan to implement a comprehensive and coordinated community-based system of services and supports for Idahoans with TBI and their family members that addressed all age, racial, and ethnic groups, and all levels of acuity.

PLANNING GRANT GOALS

Four goals, summarized below, were addressed in order to plan a comprehensive, coordinated, community-based system of support for Idahoans with TBI.

- Goal 1: Establishment of a statewide TBI Advisory Council
- Goal 2: Designation of a Lead State Agency and staff position responsible for State TBI activities
- Goal 3: Completion of a statewide needs and resource assessment
- Goal 4: Completion of a final report and statewide action plan

RESULTS OF PLANNING GRANT

Goal 1: Establishment of a statewide TBI Advisory Council

In order to make sure all regions are represented effectively within the far reaches of Idaho's geography, three regional councils comprise the membership of the state council, rather than depend on a single statewide committee. The Idaho Advisory Councils were chartered by Karl Kurtz, the Director of IDHW. Project staff traveled to the regions in order to facilitate participation by people all over the state and avoid unnecessary travel by council members. An intra-agency working group coordinates efforts across IDHW. Members are connected to the project via telehealth technology and use in-person meetings, conference calls, and e-mail. The Council was informed of the activities of the Planning Grant, including the assessment, the design of the State Action plan, and the final report. A total of 35 people serve on the regional councils. Sixty-two percent are persons with a brain injury or a family member of a person with TBI; 32% are staff of key state agencies, including Idaho's MCHB. Sixteen percent are Hispanic or American Indian. All aspects of the service system are represented: injury prevention, the continuum of in-patient medical care, rehabilitation, community transition, vocational rehabilitation, and long term community re-integration. There is representation across areas such as severity of injury, rural vs. urban setting, SES, and age. Two representatives from each regional council and from the Intra-Agency working group form an Executive Committee to help achieve statewide representation, but this council was largely unused as a result of the administrative cumbersome of the design. A chartered Intra-Department Working Group—consisting of representatives from three Divisions within IDHW (Family and Community Services, Health, and Medicaid) was also chartered.

While some aspects of this design worked well, other aspects of it did not. In addition to the not uncommon issues around scheduling to accommodate multiple and waning of interest by some committee members across time, the IRH experienced administrative difficulties in coordinating the committees to make the best use of their collective voices. On the positive side, many committee members were very active via e-mail and other outside of meeting activities. For a variety of reasons, tied to time constraints and finances for both participants and the IRH, the Intra-Department Working group was largely unused.

Goal 2: Designation of a Lead State Agency and staff position responsible for State TBI activities The Idaho Department of Health and Welfare was designated as the lead agency with the Divisions of Family and Community Services (FACS) as the division housing the program activities.

Goal 3: Completion of a statewide needs and resources assessment The needs and resources assessment comprised the majority of the work completed under the planning grant. Data were collected and analyzed from over 1100 participants. Perhaps the most compelling result was the poverty faced by families with TBIs. Almost half (45.5%) of respondents reported total household income as less than $15,000 and 58% reported less than $25,000. The data collection instruments that asked for causes of TBI showed that motor vehicle accidents were the most common source of TBIs (48%), a finding consistent with the CDC national figures.

A Medicaid survey revealed that of 94 Medicaid eligible respondents with TBIs, 28 were in nursing homes and 25 additional people qualified for nursing home care. Thirty-seven lived in family homes. The most commonly used services were behavioral consultation, supervised care, transportation, and emergency response. The most commonly used daily services focused on activities of daily living (ADLs), including meal preparation and personal assistance, followed by OT/PT, and behavioral services and respite care.

The BIA-ID membership survey and call logs showed professionals and family members believed awareness/education, social support, and general resources were important. Family members considered healthcare and adaptive services important. Individuals with TBI and their families noted the need for vocational services and jobs, and support from family and friends. They found gaps in provider knowledge and recommended mentoring for injured and non-injured persons in school and employment settings. Professionals reported the need for support and respite care.

Focus group analysis indicated strengths in TBI Medicaid waiver and rehabilitation care, awareness and commitment of key leaders, access to telehealth, the presence of support groups, and parental involvement. Weaknesses included lack of general public awareness, overtaxed family support, and the fact that TBI is a “hidden disability”.

The mailed statewide needs and resources assessment noted that these issues could be grouped into major clusters. The first grouping contained information about who offered assistance following the TBI and included medical advice, social human services advice, and long-term validation of the TBI. Satisfaction with these services ranged from 78-89% except for employment which was at 54%. Another cluster identified was about services and supports and included community reentry/life skills and medical/rehabilitation services and supports. Satisfaction with these services ranged from 67-84%. Economic issues were identified with three key groupings including family socioeconomic issues, independent living, and ability to work. A fourth cluster included family life issues and included family function, caregiver issues and person with TBI issues. Satisfaction in the last two clusters varied dramatically as many of these were philosophical or values issues rather than services and supports, or reflected services and supports that were not available and thus no satisfaction score could be assigned.

RECOMMENDATIONS

The recommendations center around adequate services and supports that provide opportunities to participate in the workforce and in community life for people with a TBI and their families. There was clear evidence of the lack of a comprehensive system of services and supports but there was also evidence of mechanisms that were supportive of a comprehensive system, such as the presence of a Level II trauma center and the Medicaid TBI waiver. As with any system of care, there are profound financial challenges. These are made all the more difficult by the current economic situation of the nation and the increasing financial demands on states through the Medicaid system. The work also confirmed the value of a comprehensive, community-based system of services and supports. The data indicate that the best systems will emerge through collaboration of inter- and intra- state agency collaboration, coupled with collaboration with researchers and advocates, to help ensure the success of any system that is developed. The planning grant also recognizes the critical need to address services and supports not as a medical problem, but as an issue that affects all life areas across the life span. The method of development rests on improving access to services by improving access to information about available services and supports to avoid referrals creating situations where providers refer in good faith and consumers feel that they "get the run-around." Future programming should include (a) Strategic Alliances, (b) Anywhere-Anytime access to TBI information, (c) Ongoing assessment, and (d) Ongoing policy review and planning.

IDAHO TRAUMATIC BRAIN INJURY FACT SHEET

From The Final Report of the Traumatic Brain Injury
State Planning Grant for the State of Idaho
Full Report at http://www.isu.edu/irh/TBIPlanning.pdf

A traumatic brain injury (TBI) is an injury to the head arising from a blunt or penetrating trauma or from acceleration-deceleration forces resulting from an insult to the brain, not of degenerative or congenital nature caused by an external physical force that may produce a diminished state of consciousness.

General TBI Statistics

- ✓ An estimated 5.3 million Americans – greater than 2% of the U.S. population – currently live with disabilities resulting from brain injury.
- ✓ Every 21 seconds, one person in the U.S. sustains a brain injury.
- ✓ 1.5 million Americans experience a traumatic brain injury each year. The Centers for Disease Control and Prevention estimate that mild TBI accounts for 75% of at least 1.5 million new TBI's annually.
- ✓ It is estimated that one million people are treated for TBI and released from hospital emergency rooms every year.
- ✓ Each year, 80,000 Americans experience the onset of long-term disability following TBI.
- ✓ More than 50,000 people die as a result of traumatic brain injury.
- ✓ The risk of traumatic brain injury is highest among adolescents, young adults and those older than 75.
- ✓ After one brain injury, the risk for a second injury is three times greater; after the second injury, the risk for a third injury is eight times greater.
- ✓ Vehicle crashes are the leading cause of brain injury. Falls are the second leading cause, and the leading cause of brain injury in the elderly.

Costs of TBIs

- ✓ The cost of traumatic brain in the United States is estimated to be $48.3 billion annually. Hospitalization accounts for $31.7 billion, and fatal brain injuries cost the nation $16.6 billion each year.
- ✓ Respondents to the statewide mailed survey reported an average of 59 days in acute care (77%, mode 30 days), 94 days in rehabilitation (54% mode 60 days) following a TBI.
- ✓ Twenty-eight percent (28%) reported an average of 150-250 days stay in long-term care facilities.

Risk Factors

- ✓ Occurs regardless of age, gender, socio-economic status, or education. We are a society of people who are extremely mobile and active. As a result injuries occur and TBI has become a significant public health issue that must be addressed. The CDC proclaims TBI a significant national health concern.

State Prevalence/Trauma

- ✓ Exact figures are unknown because of a lack of systematic methods for tracking of TBIs and the difficulty in tracking mild or moderate TBIs. These usually are uncounted as people with these brain injuries may not be hospitalized overnight or have their TBIs diagnosed.
- ✓ The Centers For Disease Control and Prevention ranks Idaho “seventh in the nation” for per capita hospitalization and rate of disability due to traumatic brain injury.
- ✓ Centers For Disease Control published reports state 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 population. This would translate to approximately 2,600 Idahoans acquiring a TBI per year.
- ✓ In 1996, mortality data due to motor vehicle accidents was 1.4 times higher in Idaho than the U.S rate and a significantly higher accident death rate in rural areas compared to urban areas in Idaho. This places Idahoans at greater risk of sustaining a TBI.
- ✓ The Office of Highway Safety reports 276 deaths and 14,276 injuries from motor vehicle collisions in Idaho in 2000.
- ✓ The state-by-state trauma registry policy analysis reports 30 (59%) of the 50 states and the District of Colombia have a trauma registry. Of the 30 that have a registry, 26 have experienced positive consequences like improved safety, collaboration, quality improvement, patient flow, etc.
- ✓ In Idaho, over 18,500 people were treated and/or transported for trauma by ambulance personnel in 2000. Motor vehicle crashes were responsible for 45% of the trauma related events and falls were responsible for 30%.

Idaho’s Geography and Population

- ✓ Idaho’s 82,750 square miles contain geography, climate, and population challenges. Forty percent of the state’s residents live outside urban areas on 90% of the state’s land. Thirty-five of her 44 counties have populations less than 25,000 and 92% of towns have populations under 10,000. Idaho has 15.6 people per square mile compared with 79.6 people per square mile nationally.
- ✓ Idaho has 43 designated primary care shortage areas, covering 93% of the state’s counties, dental health profession shortage areas (HPSA’s) cover 73% and mental health profession shortage areas covering 80%.
- ✓ Over half the hospitals in the state (27 of 44) qualify as Critical Access Hospitals. On average the nearest Level II trauma care center, is 80 miles away. In 30 counties the drive averages 106 miles.

Idaho Education/Employment

- ✓ In 1999, the Idaho Department of Vital Statistics reported that 2,580 children under the age of 18 experienced a motor vehicle accident - the highest reported cause of injury for this age group - and the most frequent cause of TBI in Idahoans under age 18 years old.

- ✓ Idaho school districts served 158 children with TBI during the 2000-2001 academic year. Of these children, 11 were three to five years old and 147 were six to twenty-one years of age. Obviously children with TBI are not being identified for special education services and/or are misidentified.
- ✓ In federal fiscal year 2002, the Division of Vocational Rehabilitation served 331 people with TBI, assisting 48 into employment. Forty-one (41%) of respondents to the written survey stated they needed help with employment.
- ✓ The mean number of people in Idaho with a TBI served by any agency was five (5) making it difficult for any agencies or professionals to develop specific expertise around TBI.
- ✓ There are no Level III Trauma Centers (highest level of care) in Idaho.

Income

- ✓ Idaho has a high employment rate (16th nationally) yet has a low wage basis (42nd), with a per capita family income ($18,170) ranking 43rd nationally.
- ✓ Fifty percent (50%) of the respondents to the mailed state-wide survey reported total household incomes of less than $25,000.
- ✓ One third (33%) of the respondents to the mailed state-wide survey reported total household incomes of less than $7,500.
- ✓ The most common sources of income were social security/retirement and employment income.
- ✓ The least common sources of income were public assistance, workers compensation and unemployment payments.

Quality of Life

- ✓ Prior to the TBI, sixty-seven percent (67%) of respondents to the mailed statewide survey remembered their quality of life as above average or excellent.
- ✓ After the TBI, fifty-eight percent (58%) reported their quality of life to be below average or poor.

Individual Access to Services and Supports

- ✓ Between fifty percent (50%) and eighty percent (80%) of respondents to the mailed statewide survey reported that they did not need assistance with a variety of services and supports including housing, employment, personal care, chores, transportation, speech therapy, nursing, recreation, cognitive training, money management, communication skills training, occupational therapy, physical therapy and mental health care.
- ✓ Of the approximately twenty to forty percent (20-40%) who required assistance with services and supports, about as many needed assistance as were receiving assistance.
- ✓ Employment assistance (41%) and cognitive skills training (39%) were reported as the most needed service and support.
- ✓ Forty-four percent (44%) said they did not need mental health care, seventeen percent (17%) reported receiving cognitive skills training, and thirty-nine percent (39%) reported needing but not receiving cognitive skills training.

- ✓ Thirty-nine percent (39%) said they did not need mental health care, thirty percent (30%) reported receiving mental healthcare, and thirty-one percent (31%) reported needing but not receiving mental healthcare.
- ✓ Eighty-two percent (82%) reported not needing skilled nursing assistance and seventy percent (70%) reported not needing personal attendant care.
- ✓ Satisfaction with services ranged from 67-89% except for employment services, which were in the mid-fifty (50%) range.

Agency Reported Information

- ✓ Some type of TBI services is available in each of Idaho's 44 counties at one of 95 agencies who reported on the statewide mailed survey.
- ✓ Of the agency respondents to the statewide mailed survey, fifty-seven percent (57%) described themselves as public, fourteen percent (14%) classified themselves as private, and twenty-nine percent (29%) selected not-for-profit.
- ✓ The most common service available is "referral" with 89% of the 95 agencies reporting providing this service.
- ✓ Eighty-three to eighty-five percent (83-85%) of agencies provided social work, occupational therapy, physical therapy, and speech and language services.
- ✓ The least commonly provided services included telehealth (4%), oral health (18%), orthopedics (28%), and psychiatry (29%). Psychology services were provided by 48% of agencies.
- ✓ Outpatient and inpatient were the most common settings for all types of services with the provision of services in the home and community about half as common. Provision of services in skilled nursing and residential facilities were least common.
- ✓ Education, assistive technology, and family support were the most commonly reported services provided (n=17-24 agencies).
- ✓ Housing, substance abuse and employment services were the least commonly reported services provided by agencies (n=6-8 agencies).
- ✓ Of those employment services offered by agencies, the most commonly reported services offered (n=24-29 agencies) were prevocational counseling, assistive technology, career counseling, special skills training and coaching.
- ✓ Of those employment services offered by agencies the least commonly reported services offered (n=13-17 agencies) were work support, employment advocacy, and supported employment.

ACRONYMS USED IN THE REPORT

AACBIS	American Academy for the Certification of Brain Injury Specialists
BIA-ID	Brain Injury Association of Idaho
CDC	Centers for Disease Control and Prevention
CIC	Community Integration Committee
CID	Consortium for Idahoans with Disabilities
Co-Ad	Comprehensive Advocacy Inc.
DDC	Developmental Disabilities Council
DHW-DOH	Department of Health and Welfare-Division of Health
DOE	Department of Education
EMR	Electronic Medical Record
EMS	Emergency Medical Services
FACS	Idaho Division of Family and Community Services
HCBS	Home and Community Based Services
HPSAs	Health Professions Shortage Areas
HRSA	Health Resources Services Administration
IDC	Idaho Department of Corrections
IDHW	Idaho Department of Health and Welfare
HHS	Department of Health and Human Services
IHFA	Idaho Housing and Finance Association
IRH	Institute of Rural Health
ISU	Idaho State University
ITD	Idaho Transportation Department
MCHB	Maternal and Child Health Bureau
MVA	Motor Vehicle Accident
PADD	Protection and Advocacy of Persons with Developmental Disabilities
PAIR	Protection and Advocacy of Individual Rights
PHHS	Preventative Health and Health Services
SARMC	Saint Alphonsus Regional Medical Center
SES	Socio Economic Status
SIF	State Insurance Fund
SWOT	Strengths, Weaknesses, Opportunities, Threats
TBI	Traumatic Brain Injury
TBI-P&A	Traumatic Brain Injury-Protection and Advocacy System
VPC	Virtual Program Center(s)
VR	Vocational Rehabilitation

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BACKGROUND

In the United States, about 1.9 million Americans experience a traumatic brain injury each year. Of those, about 50% experience short-term disabilities while 90,000 people sustain debilitating loss of function. Approximately 52,000 Americans die because of their injuries. The annual cost of traumatic brain injury in the United States is an estimated $48.3 billion ($31.7 billion in hospitalization and$16.6 billion in fatal brain injuries).[1] While there is no data on the number of Idahoans who have experienced TBI, extrapolating from the 1999 CDC estimates, about 25,880 Idahoans are living with TBI and 97 people died because of their injuries. Of those living with TBI, 146 have permanent disabilities. In addition, the 1999 IDHW Vital Statistics report indicates that 2580 children under the age of 18 experienced a motor vehicle accident—the highest reported cause of TBI injury for this age group.

Idaho lacks comprehensive infrastructure to manage services and supports for persons with TBI. Boise has a level II trauma center and there are level I centers in the larger towns, but other Idahoans must travel out of Idaho for TBI-specific services and supports. Residents of northern Idaho, for example, travel to Spokane, Washington, while eastern Idaho residents go to Salt Lake City, Utah. Also, persons with TBI need ongoing rehabilitative, social, financial, psychological, vocational, and residential care. While there are general health care services in each of the 44 counties, the most common service provided regarding TBI (other than emergency and acute care) is referral to subspecialties.

The comments from people with TBI and their families voice many concerns about services in Idaho. Each has a story of personal struggle with TBI exacerbated by the struggle to identify and find services and healthcare professionals who have the knowledge and skills to care for the multiple needs of a person with a traumatic brain injury: “What services are available are at best piecemeal.” “Once my husband left the hospital, we were left on our own to find help.” “The local clinic just told me that my daughter had her bell rung.” “I’ve had to educate most of the health care providers and school counselors and teachers myself on how to work with someone with a traumatic

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[1] Lewin-ICF. The Cost of Disorders of the Brain, Washington, D.C. The National Foundation of the Brain, 1992.

brain injury." "I was told to stop working or divorce my husband in order for him to keep on Medicaid." "The insurance companies don't help much at all with long term rehab, we have to struggle to find a way to pay for the services we need." "I struggled for eight years thinking I was crazy until I was accurately diagnosed with a traumatic brain injury."

Idaho currently does not have a "system" of services and supports for individuals with TBI. The Level II trauma center in Boise, the Level I centers located in most of Idaho's larger towns, and the out-of-state trauma centers provide excellent medical care, but community services are scarce, especially in rural areas[2]. Progress also has been made in the development of a comprehensive, coordinated system of services and supports throughout Idaho to provide quality medical, rehabilitative, social, financial, psychological, vocational, and residential services to individuals with TBI and their families but problems abound, often because of lack of access to services and support or lack of information as to where to obtain or how to fund needed services and support. Exacerbating this situation is the fact that Idaho faces severe health professions shortages as well as the budgetary challenges faced by many states in the early 2000s.

Factors Influencing Availability of Services and Supports in Idaho

Idaho is characterized by a widely dispersed, at-risk population with varying access to services and support from professionals who have a diverse range of TBI expertise. The resources that do exist comprise a generic system for people with disabilities (see Figure 1), and have the potential of meeting the needs of persons with TBI and their family members. The dilemma is that *professionals and persons with a TBI and their family members alike may not be able to locate TBI-appropriate services and supports floating about in the generic system.*

Figure 1 Needs & Resource Data Sources

1. Brain Injury Association-Idaho
    a. 1998-2001 member survey, call logs (n=244)
2. Focus Groups
    a. 1998 St. Alphonsus Regional Medical Center (21 groups, n≅145)
    b. 1998 Comprehensive Advocacy Inc. (Co-Ad) (1 groups, n≅7)
    c. 2001 Focus groups w/advisory councils & ID Rural Health Association (4 groups, n ≅ 50)
3. Mailed surveys
    a. 1998 Idaho Medicaid survey (n=100)
    b. 2001 State TBI Planning grant consumers, family members (n=272)
    c. 2001 State TBI Planning grant agencies, providers (n=196)
    d. 2001 ID Legislators (n=105)
    e. 2001 UAP Family Support Survey (n=53)
4. Policy Analyses
    a. Duke Center for Health Policy, Law, & Management State Health Policy Web Portal
    b. State-by-state TBI policy protocols (Legislative, Exec. Order, Trust Funds)
    c. State-by-state trauma registry

Geography and Population

This dilemma is complicated by Idaho's geography, climate, and low population density. Idaho averages 15.6 people per square mile compared to a national population density of 79.6 people per square mile. Idaho has many rural areas and only one rapidly growing urban sector—Boise and surrounding areas—with 33% of the State's population. These issues affect

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[2] Facilities are ranked Levels I, II and III with III being the highest level. There are Level III Trauma centers in Salt Lake City and in Seattle.

consumers and professionals alike. Over half of the hospitals in the state (27 of 44) qualify as Critical Access Hospitals. On average, the nearest level II trauma care center is 80 miles away. In 30 counties, the drive averages 106 miles, and when mountainous topography and climate are considered, the lack of ready access to appropriate services and supports can be overwhelming. In addition to difficult geography, the low population density in Idaho translates to fewer people with TBIs for professionals to see. This is particularly true in the State's 17 frontier counties where the population density is less than 7 people per square mile.

Idaho's challenges are like most rural or frontier areas—workforce shortages, difficult geography and climate, inadequate infrastructure, and isolation. Idaho has 43 designated primary care shortage areas that cover 93% of the state's counties. Dental HPSAs cover 73% and mental health HPSAs cover 80%. According to the HRSA State Health Workforce Profiles, Idaho has fewer providers than the national average for most health professions. Many providers find themselves being "all things to all people" regardless of their training and background. These factors induce negative consequences like burnout, work-related secondary/vicarious trauma, high turnover, and increased medical error risk.

Racial / Ethnic Demographics

According to 2000 census data, whites comprise 91% of Idaho's population. Hispanics are the largest ethnic minority at 7.9% of the state's total population. Concentrations of people of Hispanic heritage live in southwest and south-central Idaho (15% of total population in these two regions). Table 1shows Idaho's demographic distributions.

Table 1 Idaho Race And Ethnicity Composition

African American	Native American	Asian/Pacific Islander	Other	Hispanic or Latino
0.4%	1.4%	0.9%	4.3%	7.9%

Traumatic Brain Injury in Idaho

Prevalence Estimates

The CDC ranks Idaho *seventh in the nation for* per capita hospitalization and rate of disability due to TBI. From 1999 CDC estimates, about 25,880 Idahoans live with TBI. The 1999 IDHW Vital Statistics reported that 2,580 children under the age of 18 experienced a motor vehicle accident—the highest reported cause of injury for this age group—and the most frequent cause of TBI in Idahoans under 18 years old. Idaho School districts served 158 children with TBI during 2000-2001 academic year.[3] In the federal fiscal year 2002, the Division of Vocational Rehabilitation served 331 people with TBI, assisting 48 into employment.

Because Idaho does not have a system for identifying individuals with TBI, the prevalence of TBI in Idaho is extrapolated from national estimates published by the Centers for Disease Control and Prevention (CDC). According to CDC published reports, traumatic brain injuries occur at a rate of 132 to 367 injuries per 100,000 population, with

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[3] Of these children, 11 were three to five years old and 147 were six to twenty-one years of age.

the best guess placed at 200 injuries per 100,000 people. This translates in Idaho to approximately 2,600 TBI injuries per year. CDC also estimates that just over 2% of the population lives with a disability resulting from a traumatic brain injury, which means that approximately 25,900 Idahoans currently are affected by TBI.

Mortality data from motor vehicle deaths is one indicator of risk for TBI. In 1996, the mortality due to motor vehicle accidents was 1.4 times higher than the U.S. rate. Idaho also has a significantly higher accident death rate in rural areas compared to urban areas. Since motor vehicle accidents are a significant cause of TBI, these data indicate a higher risk for TBI in Idahoans.

Preliminary work by Saint Alphonsus Regional Medical Center, with input from medical centers statewide, indicates that over 1,300 individuals have been identified with a TBI in the last two years.

The State, researchers, and advocacy groups alike are aware of the need to develop a system of services and supports to meet the full spectrum of services for all acuity levels, including prevention, initial acute treatment, community reintegration, and throughout life for both children and adults with TBIs. Since 1993, the state has taken numerous steps to develop these comprehensive services.

History of TBI Activities in Idaho

In 1993, the Division of Vocational Rehabilitation, State Independent Living Council, Council on Developmental Disabilities, and other key stakeholders from the brain injury community sought legislative action regarding head and spinal cord injury. This legislation proposed the creation of a program of services, supports and rehabilitation for persons who sustained a head or spinal cord injury and a central registry that would require providers to report incidence of injury to the Department of Health and Welfare. It also proposed the establishment of multi-disciplinary teams to assist persons with a brain injury (or their representatives) to design individual care plans and arrange for rehabilitation services. As proposed, funding would come from surcharges assessed on those found guilty of selected traffic violations that lead to accidents that cause head and spinal cord injury. While the legislation did not pass, the initiative laid the groundwork for future action and built a network of consumers and professionals to keep working on TBI services.

In 1996 the Governor’s Council on Developmental Disabilities in collaboration with Idaho’s University Affiliated Program (Center on Disabilities and Human Development) at the University of Idaho submitted an application for a planning grant to HRSA but it was not recommended for funding. Reviewers cited the absence of a separate advisory council, lack of MCHB involvement at the state level, and limited personnel commitment as reasons that “Idaho is not yet ready to get their plan off the ground.”

In 1997 individuals with TBI, their family members, and concerned professionals came together to form the Brain Injury Association of Idaho (BIA-ID), Idaho’s only statewide advocacy organization with the mission to advocate on behalf of and to assist persons with brain injury and their families. BIA-ID is governed by a board of directors and directed by its statewide members. BIA-ID members, consisting of consumers, family members and representative providers, began to educate the public about the need for more data on brain injury in the state. It encouraged the Council on Developmental Disabilities to provide infrastructure funding to begin to address TBI needs, and has identified individuals with TBI and family members to encourage attendance at planning meetings in order to provide guidance and input in the development of recommendations. BIA-ID provides information and resource services statewide.

In October 1998, the Department of Health and Welfare, Division of Medicaid, received approval for a 1915(c) Home and Community Based Services Waiver to serve one hundred adults with a traumatic brain injury who need nursing home level of care. The Division organized a team comprised of persons with brain injury, family members, private providers, representatives from disability advocacy organizations, and state agency personnel to develop the necessary infrastructure for implementation. This waiver has the ability to pay for supports by both the traditional fee-for-service method and by paying an individualized daily rate to a provider of services based on each individual's plan. This waiver created the first funding mechanism through Medicaid for community-based services for adults with a traumatic brain injury.

Prevention of TBI is the focus of the Department of Health and Welfare, Division of Health, Injury Prevention Program through Preventive Health and Health Services (PHHS) Block Grant funding. A small percentage of Injury Prevention Program funding is received from the Maternal and Child Health Bureau Block Grant. A large portion of PHHS funding is contracted to the seven local health districts to encourage increased use of motor vehicle occupant protection (seat belts and child car safety seats) and bicycle safety and helmet use. All health district programs foster injury prevention coalitions at local levels. These are composed of individuals working in health care, law enforcement, transportation, and private businesses. Additionally, the state-level program works closely with the Idaho Transportation Department to provide statewide prevention messages and activities.

Saint Alphonsus Regional Medical Center in Boise is a Level II trauma center. Level I centers are located in south-central, eastern, and northern Idaho. Residents in those areas frequently go to Level II centers in Salt Lake City, Utah, and Spokane, Washington, for medical care. Saint Alphonsus maintains a trauma registry for southern Idaho and is interested in expanding it into a full statewide registry. It is currently the best source of incidence data for individuals who use Idaho medical centers. Last year Idaho passed legislation to create a statewide trauma reporting system. Staff members from the Division of Health are researching alternatives for funding.

Advisory Council Development

Concurrent with these activities, the Idaho Council on Developmental Disabilities allocated resources in May 1999 to fund two requests for proposals. The first proposal involved developing a planning group of key stakeholders to work with the Idaho Department of Health and Welfare. The mission of that group was to guide the development of TBI services in Idaho and lay a foundation for a formal Advisory Council to that Department. The group would also assist in the development of a proposal for a TBI planning grant. Planning group meetings were then held in Boise, Idaho Falls (east), Coeur d'Alene and Spokane (north). Each group consisted of twelve stakeholders, with almost half being individuals with TBI or family members.

Existing Agencies and Infrastructure

The Idaho Department of Health and Welfare is a state agency responsible for over 30 health, welfare, and human services programs throughout Idaho. The Department's mission is to promote self-reliance and protect the health and safety of Idahoans. The Department Director is a member of the Governor's Cabinet.

Within the Department, the Division of Family and Community Services (FACS) has primary responsibility for child protection, adoptions and foster care, children and adult mental health, services to persons with developmental disabilities and traumatic brain injury, early intervention and screening for infants and toddlers, and substance abuse prevention and treatment. These programs are integrated to provide services for children and families that reflect the Department's family-centered philosophy. This philosophy affirms the belief that families are the best place for children to grow and develop, and services should focus on the entire family unit and build on family strengths while supporting and empowering families to be self-reliant.

The lead agency for TBI services and service coordination is the Idaho Department of Health and Welfare (IDHW). Director Karl Kurtz has designated the Division of Family and Community Services as the organizational home of TBI services with the responsibility to lead the planning, development, and coordination efforts. The Administrator of the Division, Ken Deibert, has oversight of this program. Operationally, the program will reside in the Bureau of Developmental Disabilities. The Developmental Disabilities Program currently provides habilitative and rehabilitative services to individuals with a TBI who sustained the injury prior to their 22nd birthday.

Other units within the Department of Health and Welfare have programs and activities targeting TBI prevention and treatment. The Division of Medicaid administers the TBI Home and Community Based Services (HCBS) waiver and continues to work on its successful implementation. The Division of Health, as the state Maternal and Child Health Bureau (MCHB), operates Idaho's injury prevention programs and has pledged its support and participation in ongoing coordination efforts. Ken Deibert monitors the contract between the IDHW and Idaho State University's Institute of Rural Health (IRH).

Values and Benchmarks for Systems Change

Difficult issues surrounding any plan for any state are determining benchmarks and forming value statements of multiple stakeholders. In Idaho, the Community Integration Committee (CIC), chartered in 2000, examined the cross-disabilities issues associated with community integration for people with mental illnesses and developmental, physical and age-related disabilities. The TBI community has representation on the CIC. The following statements were distilled by the IRH staff from the work of the CIC and formed the basis for a Systems Change grant, which was funded in fall 2001 by the U.S. Center for Medicare and Medicaid Services. Because of the close ties between the "Real Choices System Change" philosophy and the philosophy underlying, the TBI grant, these statements were integrated into the TBI planning activities forming a foundation to support community integration and reach across the disability community.

True Community Integration

True community integration includes all types of activities that support quality of life. These activities span housing, employment, access to services, social activities, etc. In a truly integrated community, disabilities are not stigmatized. Employers, landowners, transportation providers, community leaders, etc., engage consumers.

Community Alternatives

True community integration provides community alternatives, not just more institutions in communities. Comprehensive state-level plans for service delivery include crossover issues that can occur in disabilities, services, or communities. Alternatives exist across the lifespan and in culturally competent ways. Moreover, coordination supports stability. This calls for a plan of action, not just a response to each community crisis that arises. The system can respond to both a crisis and its long-term aftermath.

Information and Benchmarking

A third finding of the CIC Preliminary Recommendations involves information. An integrated system offers adequate information to make plans, establish needs, allocate resources, and determine costs. Consumers, family members and significant others are involved in the process and service providers of all types (healthcare, attendant care, etc.) can participate. There is access to health care organizations, employment options, housing options, transportation options, and the community at large.

Resource Development

The CIC Recommendations hope to spur community integration for persons with TBI. This means developing resources for consumer choice in housing, transportation, access to medications, access to appropriate providers and services, meaningful employment opportunities, and community participation. Under this plan, disabilities are not stigmatized. It requires employers, landlords, transportation providers, and community leaders to dialogue with consumers in understanding and meeting their needs.

The TBI State Planning Grant

Background of this Project[4]

According to the TBI Technical Assistance Center, the TBI State Grant Program is an initiative designed to improve access to health and other services for all individuals with brain injury and their families. The grant is administered by Health Resources and Services Administration's (HRSA) Maternal and Child Health Bureau (MCHB) within the U.S. Department of Health and Human Services.

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[4] This section is largely taken from the TBI Technical Assistance Center (http://www.tbitac.org). A larger portion of the website is reprinted at the beginning of this report.

The Program began with the TBI Act of 1996 (Public Law 104-166) which launched an effort to expand studies and establish innovative programs for TBI. It authorized HRSA to establish a grant program for states to help meet the needs of individuals with TBI and their families. It also delegated responsibilities in the areas of research, prevention, and surveillance to the National Institutes of Health and the Centers for Disease Control and Prevention, respectively. Title XIII of the Children's Health Act of 2000 renews and advances the authority of these government agencies to make life better after TBI.

The Program's primary goal is to ensure that the estimated 5.3 million individuals and their families who live with the effects of TBI in the United States have access to a comprehensive, coordinated system of care that is person-centered and attends to their changing needs from the moment of injury throughout the rest of their lives.

The TBI State Grant Program funds seed money to states to begin integration of services, establishment of policy, and procurement of financial support to bring about systems change. This change is achieved by expanding and improving state and local capacity to care for individuals with TBI and their families. States work to strengthen state infrastructure, improve community supports and services, develop and evaluate model approaches to the myriad challenges in integrating TBI services into the broader service delivery system, and generate support from local and private sources for sustaining their efforts after the grant's completion.

In the fall of 1999, the IDHW submitted a planning grant application to the TBI State Grant Program, proposing to gather information about Idaho’s TBI services and resources and identify gaps in service provision. Idaho received notice of its 2-year, $215,000 planning grant award in spring 2000. The primary goal was to develop plans for a comprehensive, coordinated, community-based system of services and supports for Idahoans with TBI and their family members that included all age, racial, and ethnic groups, and all levels of acuity.

Planning Grant Goals

Four core competencies, or goals, were identified by the TBI State Grant program for planning grants. The following are the goals addressed.

Goal 1. Establishment of a statewide TBI Advisory Council.

Goal 2. Designation of a Lead State Agency and staff position responsible for State TBI activities.

Goal 3. Completion of a statewide needs and resources assessment.

Goal 4. Completion of a final report and statewide action plan.

GOAL 1
ESTABLISHMENT OF A TBI ADVISORY COUNCIL

The TBI Advisory Council represents Idahoans with TBI. In order to ensure all of Idaho's diverse and distant regions were represented effectively, three regional councils comprise the membership of the state council, rather than depend on a single statewide committee. The Idaho advisory councils were chartered by Karl Kurtz, the Director of IDHW, to focus on the four core competencies in the Planning Grant. Project staff traveled to the regions in order to facilitate participation by people all over the state and avoid unnecessary travel by council members.

Two representatives from each council and from the Intra-agency working group formed an Executive Committee. The Committee intended to meet between the quarterly regional council meetings to take action on decisions needing approval. Unfortunately, given all of the activities of the individual groups, as well as the day-to-day work of the grant, the Executive Committee was largely unused. While there were cumbersome aspects of this organization, the method did have benefits. These benefits included improved representation of cultural, rural/urban, and disability diversity; increased participation by those not normally able to serve due to work, family, or caregiving constraints; reduced travel expenses, and reduced travel difficulty for those with disabilities.

A total of 35 people serve on the regional councils. Sixty-two percent are persons with a brain injury or a family member of a person with TBI; 32% are staff of key state agencies, including Idaho's MCHB. Others represent public and non-profit health-related organizations and disability groups. Sixteen percent are Hispanic or American Indian. All aspects of the service system are represented: injury prevention, the continuum of in-patient medical care, rehabilitation, community transition, vocational rehabilitation, and long term community re-integration. There is representation across areas such as severity of injury, rural vs. urban setting, SES, and age.

Members are connected to the project via telehealth technology and use in-person meetings, conference calls, and e-mail. The councils or, at times, their individual members, informed the project director of activities of the Planning Grant, including the assessment, the design of the state action plan, and the final report.

In addition to the advisory councils, an Intra-Department Working Group—consisting of representatives from three Divisions within IDHW (Family and Community Services, Health, and Medicaid)—was chartered. The intention was for this group to meet quarterly for the purpose of coordinating efforts across IDHW to review areas for internal service coordination, identify service needs, determine areas for improved collaboration, and explore coordination of resources. The Group participated in the assessment and action planning process in collaboration with the three regional advisory councils. A written collaboration agreement attempted to define what each party could contribute to the system, how information would be shared, and what set of actions should be included in the TBI action plan for the state. This group met about half as often as was planned, but much of the work of the group was shifted to the Community Integration Committee which was chartered at about the same time as the State's effort to work across disabilities, and across agencies to meet the goals of the federal New Freedom Initiative. The make up of the CIC includes consumers, advocates, and multiple agencies providing services and supports across all life areas.

GOAL 2
DESIGNATION OF A LEAD STATE AGENCY

IDHW was designated as the lead state agency with the Division of Family and Community Services as the office overseeing TBI grant efforts. IDHW maintains over 30 health, welfare, and human service programs. The agency includes Divisions of Family and Community Services (FACS), Medicaid, Health, Welfare, Management Services, Human Resources, and Information and Technology Services. FACS serves thousands of Idahoans and is the organizational home of TBI services. In August 2000 IDHW contracted the planning grant to the Institute of Rural Health at Idaho State University. The following points represent resources IDHW brings to bear on system change for children and adults with TBIs:

- The Department was the lead agency for the TBI Planning Grant and continues in this capacity under the implementation grant.

- IDHW-Division of Medicaid holds a 1915c Home and Community Based Waiver for persons with TBIs.

- The State supports the CIC to develop recommendations for Idaho related to Olmstead vs. L.C. and Community Integration.

- IDHW is the lead agency for Idaho's $1.1M Centers for Medicaid and Medicare Real Choices Systems Change Grant.

- The Division of Health operates the injury prevention program providing child safety seats and promotes their correct use with MCHB funds.

- The Department housed a legislatively mandated Trauma Care Advisory Committee, which supported passing legislation creating a statewide trauma reporting system.

- The Council on Developmental Disabilities (2000) and St. Alphonsus' Regional Medical Center sponsored 20 individuals statewide to take national training and examination to earn the brain injury specialist certification from the American Academy for the Certification of Brain Injury Specialist (AACBIS), a competency based affiliated program of the Brain Injury Association of America.

GOAL 3
COMPLETION OF A STATEWIDE NEEDS AND RESOURCES ASSESSMENT

The major effort of the planning grant was the completion of a thorough analysis of existing data, and the collection and analysis of new data regarding services and supports for people with TBIs and their families in Idaho. Data were compiled from twelve sources, representing over 1,100 participants, 80% of the state's counties, and from agencies providing services in 100% of counties. Figure 1 shows the data as organized by type of study. The narrative of the studies is organized chronologically and identified by their originating agency or organization, which may or may not reflect the funding source. This organizational schema follows the developmental course of the traumatic brain injury response efforts in the State of Idaho since 1998.

While each of the studies had its own goals, patterns emerge that support a systems change approach to TBI. Specifically, this refers to the necessity of including life area variables in any analysis or assessment of persons with TBI and family members and people who work in the TBI field.

In order to provide a framework from which to review all of the various studies, the schema of "life areas" was adopted. The categories used mirror those found in the federal New Freedom Initiative. A summary of these life areas is provided below.

- *Self Determination*—people having control, choice, and flexibility in the services and supports they receive.
- *Employment*—people getting and keeping employment consistent with their interests, abilities, and needs.
- *Housing*—adults choosing where and with whom they live and have services needed to support their choices.
- *Health*—people benefiting from the full range of needed health services.
- *Information/Education*—people accessing needed information and reaching their educational potential.
- *Community Support*—people being recognized and treated as valued and participating members of the community.

- *Transportation*—people having access to a range of opportunities in moving from one place to another over time.

Studies and Projects Initiated Prior to the Planning Grant (1998-2001)

Brain Injury Association of Idaho (BIA-ID)

Membership Survey Results

In spring 2000, BIA-ID conducted a survey of professionals/private providers or persons with a TBI and family members to ascertain the needs of people with brain injury (or TBI) and their families. There were 94 respondents to this survey. The key findings are listed below.

Of the 94 completed surveys, 56 (60%) respondents were women and 38 (40%) were men. The mean age at the time of injury was 28 years and modal age was 18 years, with age of onset of TBI ranging from 5 months to 60 years. Of the reported causes of TBI, 28 (61%) involved a motor vehicle, 7 (15%) were sports related, and less than 5 each came from violence; falls; workplace injuries; or unknown causes.

Table 2 shows the employment status of the respondents. Just over one-third of respondents (38%) were employed either full or part-time. 24% reported being unemployed but willing to work.

Table 2 Employment Status Of BIA-ID Respondents

Employment Status	Number and (Percent)
Unemployed, but desire to work	12 (24%)
Part-time employment	11 (22%)
Full-time	8 (16%)
Unknown Status	6 (12%)
Students	5 (10%)
Unemployed, Homemaker, Volunteer, Retired, Total Disability	Fewer than 5 for each category.

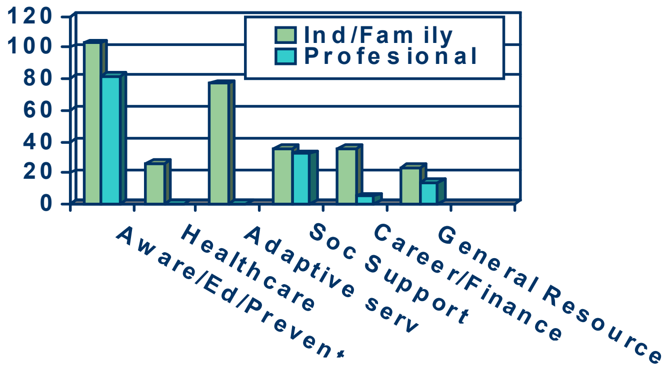
Respondents were also asked how important various life areas were to quality of life. Individuals, family members, and professionals strongly endorsed TBI awareness and education. Individuals with TBIs and family members considered adaptive services important but professionals did not (see Table 3 for frequencies and Figure 2 for a graphical representation).

Table 3 BIA-ID Survey and Necessities for Improving the Quality of Life, 2000

Necessity	Individual/Family Results (N=301) Number and (Percent)	Professional Results (N=133) Number and (Percent)
Awareness/Education/Prevention	103 (34%)	82 (62%)
Healthcare Services and Issues	26 (9%)	0 (0%)
Adaptive Life Services and Issues	77 (26%)	0 (0%)
Social/Support/Networking	36 (12%)	32 (24%)
Career and Financial Services Issues	36 (12%)	5 (4%)
General Resources and Services	23 (8%)	14 (11%)

Responses from Individuals with TBI and their Family Members Based on 301 responses from individuals with TBI and their family members, 103 (34.2%) of the respondents stressed Awareness/Education/Prevention as important, 26 (8.6%) of the respondents stressed Healthcare Services & Issues as important, 77 (25.6%) of the respondents stressed Adaptive Life Services & Issues as important, 36 (12%) of the respondents stressed Social/Support/Networking as important, 36 (12%) of the respondents stressed Career & Financial Services as important, and 23 (7.6%) of the respondents stressed General Resources & Services as important.

Figure 2 Importance of Life Area by Person



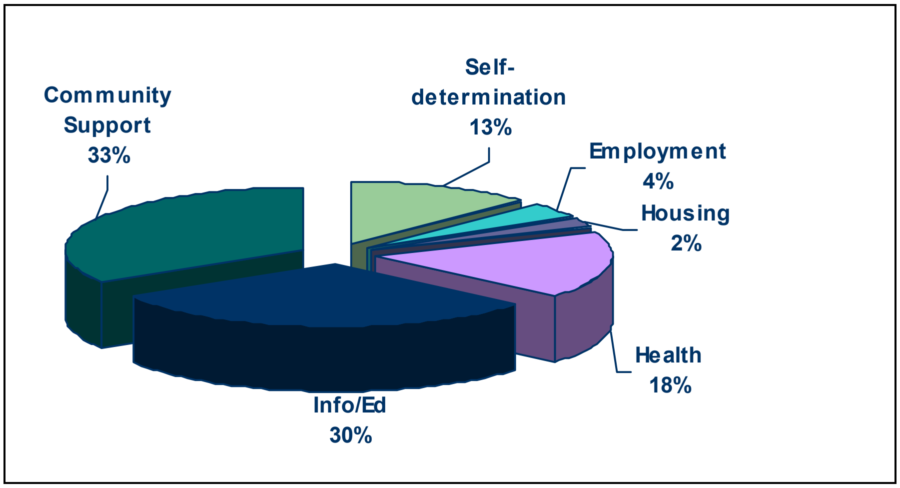
Responses from Professionals Working with Individuals with TBIs and their Family Members Based on 133 responses from members of the professional population, 82 (62%) of the respondents stressed Awareness/Education/Prevention as important, 0 (0%) of the respondents stressed Healthcare Services & Issues as important, 0 (0%) of the respondents stressed Adaptive Life Services & Issues as important, 32 (24%) of the respondents stressed Social/Support/Networking as important, 5 (4%) of the respondents stressed Career & Financial Services & Issues as important, and 14 (11%) of the respondents stressed General Resources & Services as important.

BIA-ID Information and Resource Tracking System 1998-2001

The Brain Injury Association of Idaho maintains a toll-free number to provide information and resources to callers. Call logs have been kept since 1998 and record basic information about type of caller and information sought. In this analysis, call log information was classified into one of six life areas, including self-determination, employment, homes and housing, health, education, and community support, using definitions as noted above. The 149 calls resulted in 228 life area categories. The most common information sought centered on the needs regarding community support (33%) and information/education (30%).

Figure 3 shows the frequencies of calls in each life area. The total number of calls exceeds the total number of callers because a single caller could have asked about multiple life areas.

Figure 3 BIA-ID Telephone Call Database Classified By Life Area



Saint Alphonsus Regional Medical Center & Idaho Council on Developmental Disabilities (2000)

The Idaho Council on Developmental Disabilities contracted with Saint Alphonsus Regional Medical Center to conduct a preliminary needs resource assessment study. The purpose of this study was two-fold. The first was to assess the availability and accessibility of resources for children and adults with brain injury (as well as services for their family members). The second was to identify gaps in acute and long-term resources that are necessary for persons with TBI to reintegrate with their community successfully. Based upon feedback from focus groups in the three regions of Idaho, surveys were constructed for three specific groups: individuals with TBI, their family members, and care providers. A total of 49 individuals with TBI and/or their family representative and 96 professionals who worked in the TBI field responded to the surveys. The top five responses from individuals with TBI and their family members point to the concern that was highlighted by the CIC and previous studies. That is, plans to meet needs associated with TBI should support a systems change approach, and specifically refers to the necessity of including life area variables, particularly those of employment and education/information, in any plan of action that responds to identified needs.

The focus group discussions were conducted in 2000. Two groups were targeted—individuals with a TBI and their family members (n=49) and professionals (n=96). Participants were asked (a) what resources are needed, (b) what are the resources available in Idaho, and (c) what actions are needed to fill service gaps, give access, and ensure availability?

The findings from the individual/family survey suggest that the issues of life area (e.g., job opportunities) and the stigma associated with TBI are concerns that warrant attention. The individuals and the families expressed need for vocational services and employment opportunities. Also, they identified the need for education/information for the medical community and the community-at-large regarding brain injury issues.

Figure 4 (below), which summarizes the results a part of this study, shows that professionals and individuals and families recognize the importance of life area variables with regard to access and awareness. Responses from individuals and family members as well as professionals focused on community integration. Specifically, the top five responses by people with TBI and their family members were: (1) specialized vocational services and jobs opportunities (2) TBI Education for p/w/TBI, family, professionals and the community (3) social skill training and social opportunities with non-injured individuals (4) an organized, coordinated system of services and (5) funding for specialized services: case management and counseling. The top five service needs by professionals were (1) support: respite/counseling for families, (2) funding for needed services as needs change long-term, (3) training programs for all levels of professionals, (4) return to work program/vocational rehab counselor who specializes in TBI, and (5) transportation.

Participants were also asked about current gaps and barriers. They were asked (a) what resources are needed, (b) what resources are available in Idaho, (c) what are the current gaps and barriers experienced and (d) what actions are needed *t*o fill these gaps. The top five barriers and gaps as identified by people with TBIs and their family members were (1) lack of support/confidence of the medical community, (2) lack of community awareness/acceptance/understanding of TBI, (3) lack of education and support for the family of people with TBIs, (4) lack of specialized services/non-developmental delay [this refers to service delivery by providers working in the developmental disability system], and (5) limitations/medical complications imposed by injury. Professionals identified the following: (1) hospital to home/lack of community based services for community reentry, (2) no long-term support, case management, tracking system, (3) lack of funding for services, shorter lengths of stay secondary to insurance policies/coverage for TBI specific services, (4) lack of personnel with solid TBI experience, and (5) system that does not encourage individuals to reach their full potential.

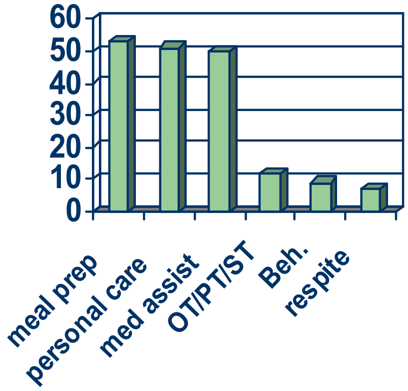
Figure 4 Summary of One Result From St. Alphonsus Focus Groups

Professionals	**Individuals and Families**
• *Needs*: support, respite care, family counseling	• *Needs*: social skills training and opportunities with non-injured individuals
• *Gaps:* lack of community-based services	• *Gaps:* lack of community awareness and acceptance of TBI
• *Solutions:* allow individuals with TBIs to access developmental disability services	• *Solutions:* increase access to services and supports for people with TBIs

Division of Medicaid (1998)

In May 1998, the Medicaid Division of the IDHW conducted a survey in an attempt to identify the number of persons with TBI who, at the time of the trauma, were 22 years old or older and who qualified for nursing facility care. The surveys were mailed in June to more than 250 Idahoans across the state. Two weeks later, the Division of Vocational Rehabilitation mailed 200 surveys. The response rate was 20.8% with returns of 94 unduplicated and completed surveys. Residence status varied from living in nursing homes (30%), living in the family home (39%), to "other arrangements" (13%). "Other" includes rehabilitation facility, assisted living, own apartment or home, or residential home. While 30% live in nursing homes, the respondents indicated that 27% met nursing home criteria, but lived elsewhere.

Figure 5 Medicaid Reimbursed Services Used Daily



When asked about services used on a regular basis, the most frequent response was behavior consultation/crisis management (34); followed by supervised care (30), transportation (27) and assistance responding to an emergency (26). The least frequent responses were chore services (6), followed by assistance with taking medications (10). Figure 5 shows the services used daily. Other regularly used services included behavioral consultation, supervised care, transportation, and responding to an emergency. The final report of the Division of Medicaid survey can be reviewed in the Appendix.

Idaho's Medicaid Home and Community Based Services (HCBS) Traumatic Brain Injury Waiver was approved in October 1998 to serve 100 individuals over a three-year period of time. The waiver was renewed in 2001 and serves approximately 30 individuals throughout the state. The Division of Medicaid and the Idaho Council on Developmental

Disabilities convened the traumatic brain injury waiver improvement workgroup in August 2001 to examine underutilization and recommend needed cost-effective solutions that could increase use. Many of these recommendations have been incorporated in the Real Choices Community Integration services subcommittee report. Idaho's TBI Medicaid HCBS Waiver was the first waiver in Idaho to pay an individualized composite rate based on each individual's plan.

Idaho Protection and Advocacy System Focus Group

A focus group was conducted on July 13, 1999, by Comprehensive Advocacy Inc. (Co-Ad), Idaho's Protection and Advocacy System for people with a traumatic brain injury (TBI-P&A). A follow-up reminder letter was also mailed. Some of the challenges reported by respondents in protecting their rights consisted of lack of supports and services, figuring out the system, and learning about resources. When asked what modifications/tools to the system would help meet needs, respondents reported they wanted someone to answer questions and to cut down on the waiting time for all services. The group felt that they often did not make the step toward achieving community participation because it was so difficult to access services necessary for recovery. They suggested providing a resource manual to help navigate systems post-injury. The following were suggested priorities recommended to Co-Ad by respondents.

- Provide self-advocacy information manuals specifically geared to accessing services and resources for individuals who are recovering from a brain injury. Protection and Advocacy of Individual Rights (PAIR)/Protection and Advocacy of Persons with Developmental Disabilities (PADD)
- Discuss barriers to publicly funded services that are needed by individuals with brain injuries but cannot be accessed due to restrictions based upon the date of onset of the injury. Protection and Advocacy of Individual Rights (PAIR)
- Increase access to the Medicaid waiver for individuals with TBIs by clarifying eligibility and service delivery issues. Propose revisions to the waiver to better meet the needs of individuals with brain injuries to be supported in community-based placements. Protection and Advocacy of Individual Rights (PAIR) Protection and Advocacy of Persons with Developmental Disabilities (PADD)
- Determine the number of individuals residing in nursing homes with TBIs who possibly could be served in community settings with proper supports. Propose possible remedies to assist these individuals with discharge from the nursing homes. Protection and Advocacy of Individual Rights (PAIR)/Protection and Advocacy of Persons with Developmental Disabilities (PADD)
- Advocate for increased state resources, such as a planning grant, a state registry, and funding dedicated to services for individuals with brain injuries. Protection and Advocacy of Individual Rights (PAIR)/Protection and Advocacy of Persons with Developmental Disabilities (PADD)

New Studies Completed Under the Planning Grant

TBI Regional Advisory Council

Strengths, Weaknesses, Opportunities, Threats (SWOT) Analysis

Analysis of the three TBI Regional Advisory Council's SWOT assessments, with added comments from the Idaho Rural Health Association, provides the first statewide needs survey. One of the first tasks of the regional advisory councils was discussing the strengths, weaknesses, opportunities for improvement, and threats to success in each of the three regions. The advisory councils focused on three areas: 1) increasing awareness and knowledge of TBI, 2) the continuity of services and supports available in the state, and 3) increasing funding to expand services. Although the issues discussed by each council were similar, the findings are presented separately in this section. The four groups (N = 50) identified the strengths, weaknesses, opportunities for improvement, and threats to success in each region of Idaho regarding TBI activities.

The section below reviews the strengths and weaknesses identified through a SWOT analysis, or Strengths, Weaknesses, Opportunities, and Challenges analysis with each of the three regional advisory councils. The figures are displayed with the regions in the columns with answers color-coded for similarities. Same colors across columns highlight similar answers while no color represents a regionally unique answer. Regions are designated as N for North, SW for southwest and E for eastern.

The common strengths (see Figure 6) include the need for change and the value of having committed stakeholders involved in the process for change. Agency providers, families, and consumers concur that opportunities for improvement involve the geography of the state. That is, the geography of Idaho makes it ideally situated for change. The frontier and rural locales have populations that are small enough to be able to change, and the residents understand the need for change. This yields fluidity in the system because people know each other. Additionally, Idaho is committed to consumer-driven services. Idaho charters and funds groups with substantial consumer input to address problems. Vertical integration, a penetrable infrastructure, and a commitment to include consumers in the process provide fertile ground for positive change.

The Regional Advisory Councils were optimistic about the TBI Medicaid waiver process and the presence of existing support groups, like BIA-ID. There seemed to be a general feeling among the advisory members that the time was right for action based on their perceived commitment to the process. All three Regional Advisory Councils valued the TBI planning grant as a way to consolidate actions.

Figure 6 Strengths Reported By The Idaho TBI Regional Advisory Councils

N Strengths	SW Strengths	E Strengths
Presence of voc rehab/TESH	Rehabilitation care available	Awareness and recognition of rehabilitation needs
Press works with agencies/organizations	Awareness of TBI	Increasing school awareness
Hospital telehealth network	More expertise	Internet, especially in rural areas
Desire to develop and sustain supports	Strong, consistent commitment to change	Idaho Assistive Technology
TBI support group in existence	Formal BIA of Idaho	BIS of Idaho, IF support groups
Kootenai Medical Center	Parent/family involvement	Idaho Parents Unlimited
Accessibility–success in centralized area	Access to trauma care	Acute care—hospitals, residency programs, speech programs
Independent living philosophy	People asking questions	Renew interest in TBI
Registry	Top physicians, medications, & rehab	Physicians outreach to rural areas
TBI waiver	Federal funding, planning grant, TBI waiver	

On the other hand, the stigma that is associated with TBI is a major weakness in the system. The geography of Idaho—while it provides an opportunity for change—also inhibits change because its rural nature adds to the difficulty of providing services and supports. The financial obstacles in the state's economy also threaten success. This, in turn, affects available resources.

Figure 7 Weaknesses Reported By The Idaho TBI Regional Advisory Councils

N Weaknesses	**SW Weaknesses**	**E Weaknesses**
Educating the public relating to TBI	Family Education	Public awareness, training, education
Lack of family support, caring for caregivers	Family members not included as partners	Lack of family support.
Transportation		Transportation
Funding issues, time limits	Expedited social security review/funding gap for outpatient rehabilitation	Lack of insurance companies, reimbursement rates
Accurate TBI diagnosis	Level of acuity	Life Flight
Lack of job development	Hidden disability	Hidden disability
Inappropriate/uneven distribution of service dollars and resources	Rural access	Lack of first aid refresher course for teachers
Transition difficulties	Transition difficulties	Lack of communication—need resource manual
Not tapping existing volunteer system	No guardian ad litum program	Difficulty with follow through with OT, schools
Transferring individual out of community	No lead agency of single point of contact	Lack of rehabilitation and day programs

Weaknesses were also consistent; each identified problems in patient and healthcare worker training. Generally, barriers included lack of a lead agency, absence of coordinated services and supports, and no resource manual. Specific weaknesses included lack of transportation, transitional services, and uneven or low reimbursement rates for rural areas. Difficulties also emerged concerning insurance coverage.

Opportunities identified included the chance for TBI to find a “home” in the health care system. Construction of strong community education and outreach programs was highlighted as a possible outcome of this process. Formation of the Advisory Councils themselves were seen as an opportunity due to the process of bringing together interested parties with varying areas of expertise and skill sets. Coordination of resources was highlighted as one of the most important opportunities.

Threats to the success of these efforts included professional and public apathy and the human desire to deny long-term disability. Inconsistent funding based on political change was seen as a threat by all three regional councils. Other threats included the lack of safety equipment used by schools and coaches to protect children, the long term need for services and funding for this condition, and the expectation that one service or program will work for all individuals.

Idaho Informatics TBI Review

The Duke Health Policy Cyber Exchange (http://hpolicy.duke.edu/cyberexchange) offers state health policy information, with links to agencies that work with rural health issues. Specifically, it is a state health policy web portal group. The Institute of Rural Health maintains Idaho's portal and includes a review of TBI-related information. Both sites offer information that concern state policies and traumatic brain injuries and serve as information bases for TBI.

During summer 2001 staff from IRH developed a compendium of all Idaho public and private healthcare links related to personal health in Idaho, including all key agencies, insurance companies, health professionals, universities, foundations, media outlets, and health data. The results are available through the Duke Health Policy Cyber Exchange. Each state used a standardized template provided by the Cyber Exchange. Many of the links on the standard state template could not be completed because the resources were not available in Idaho. This was true for both public and private resources.

Idaho Rural Health Association Focus Group

Staff from IRH facilitated a focus group involving ten individuals representing state agency personnel, private providers, persons with a TBI and family members during the Idaho Rural Health Association biennial meeting in Sun Valley on May 4-5, 2001. The staff presented an overview of the history of TBI activities in the state along with the preliminary results from the statewide needs/resource assessment. Participants critiqued the information through a question-and-answer presentation format based on their work experience. The strengths and weaknesses discussed were very similar to those identified by the Advisory councils. Much of the discussion focused on the distribution of services being weighted in favor of the large urban areas and against the rural areas.

Idaho State Legislature

In FY 2001 the Idaho legislature was surveyed in an attempt to determine their level of awareness and interest specific to TBI. The questions focused on knowledge of someone with a TBI or concussion; assistance in developing a system of support in Idaho; and could they be contacted for more information. Few legislators replied (n<10). Among those who did, there were legislators with TBIs, those with constituents who requested TBI support, and those who reported not being familiar with traumatic brain injury issues.

State-by-State Trauma Registry Analysis

The Idaho Trauma Care Advisory Committee was created within the IDHW in 2001 under Title 39, Chapter 83 of Idaho Code. One of the Committee's charges was to study issues associated with implementing an Idaho trauma registry. Trauma registries serve as a base for the gathering of TBI injury information.

At the direction of the committee, The IRH conducted a phone survey of 50 states and the District of Columbia to identify negative and positive results of implementing trauma registries. Most states experienced minimal negative consequences. The most positive consequences were quality improvement of TBI emergency care, implementation of prevention programs, improved survivor rates, and identification of high-risk locations where TBI events occurred. About half of the registries accepted data from locations other than hospitals, generally from Emergency Medical Services (EMS). Most registries were supported by grants or other sources of funding.

Data from 30 states with trauma registries and 14 states without trauma registries indicate that many states experienced negative consequences related to the registry (see Table 4 below). The majority of the negative experiences involved hardware or software problems, or funding difficulties. More importantly, however, most states reported positive consequences from the presence of a trauma registry.

Table 4 Negative Consequences Of Trauma Registries

Negative Consequence	First Consequence Mentioned	Second Consequence Mentioned	Total times mentioned
Software	7	2	9
Funding	5	2	7
Personnel	1	3	3
Politics	2	0	2
Other*	5	3	9
No problems	10	20	30

*1st Negative consequence other = 1 legal, 2 difficult for small/rural hospital, 1 did not have same definition of trauma, 1 difficulties collecting data

2nd Negative Consequence other = 1 territorial with data, 1 difficult for small/rural hospital, 1 lacked precise definitions throughout data

Positive issues include the ability to conduct quality improvement efforts (7 states), enhanced prevention activities (3 states), improved patient flow (2 states), the ability to save lives (2 states), the ability to share information with other agencies (2 states), improved research capabilities (2 states), and improved safety (2 states). Other positive comments listed by single states include the ability to license trauma centers, improved morbidity and mortality information, enhanced collaboration with hospitals, better safety laws, and improved planning and development for future trauma needs.

Table 5 Positive Consequences Of Trauma Registries

Positive Consequence	Number Reporting	Positive Consequence	Number Reporting
Quality Improvement	11	System analysis/evaluation	2
Prevention	4	Follow through	1
Improve safety	3	Planning and development	1
Collaboration /sharing information	3	Changed attitudes about registry	1
Saves lives	2	Better morbidity/mortality data	1
Research	2	Increased awareness of training needs	1
Locations clearer	2	Accurate data for public policy and protocols	1
Patient flow	2		

Funding for the registries came from multiple sources. State grants funded the largest number of opportunities, followed by funding from state legislatures, and state general funds. Other funding sources included hospitals, Emergency Medical Services, revenue generated through fines, and state budget authorities. The vast majority of respondents with trauma registries indicated that they would pursue the registry again if needed.

Idaho Statewide Needs and Resource Assessment

Person with a TBI or Family Member/Significant Other of Person with a TBI

Introduction

In late April 2001, the IRH mailed over 750 surveys to individuals with TBI or to their family members. Mailing lists were compiled from several sources, including BIA-ID, Idaho Medicaid Division, St. Alphonsus Regional Medical Center, Rehabilitation Unit, the Idaho Council on Developmental Disabilities, and the Division of Vocational Rehabilitation. These organizations contributed names and addresses for mailing lists. The compilation of the mailing lists meant that individuals could have been on more than one list, and therefore could have received more than one survey.

Hospitals, TBI agencies, rehabilitation facilities, and insurance providers received copies of the survey and were asked to distribute them to persons and families affected by TBI. Follow-up telephone calls were made to individuals in an attempt to maximize returns.

The individual/family surveys were also available through the internet and could either be downloaded, printed out and mailed in, or could be completed and submitted on-line. E-mails explaining the availability of the survey on the Internet were sent electronically to all agencies and providers where electronic addresses were available.

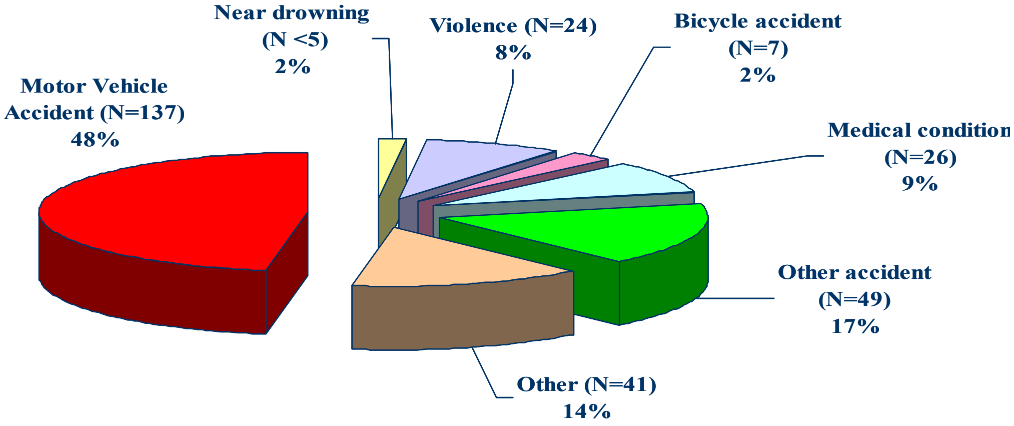
The survey was reviewed and approved by the Idaho State Human Subject's committee. All participants were given full informed consent making them aware of their rights and privileges as participants.

Results & Discussion

There were 272 (36.5%) surveys returned (see the Appendix); 146 by people with a TBI and 114 by family members of a person with a TBI. Sixty-six percent of the respondents were male; 35% were female. Twelve of the total number of surveys were returned late and not included in this analysis.

Like national results, TBI in Idaho primarily affects young adult males and those over age 65. Median age at first injury was 24. Responses were received from people in 35 of Idaho's 44 counties, representing 80% of the State's counties. On average, individuals and families had been living with TBI for 10 years, reflecting the long- term impact of TBI for all involved. Almost half (48%) of the injuries were motor vehicle related. Other accidents, such as sports related injuries, caused another 17% of injuries. This suggests that increased awareness of the importance of seatbelts and protective gear during recreational activities might reduce or prevent future TBIs.

Figure 8 Reported Cause Of First TBI

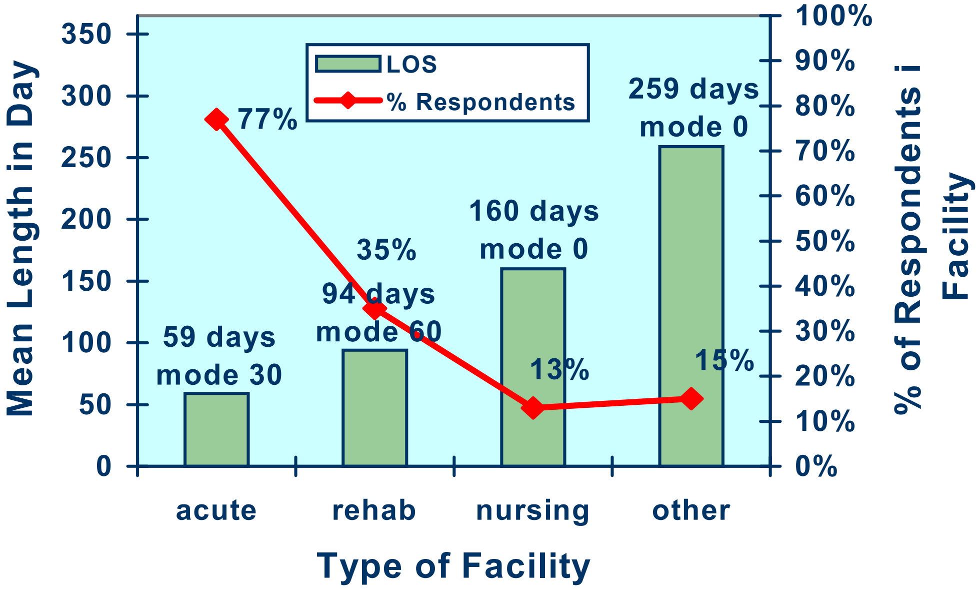


Total (n=288) exceeds participants (n=272) because some reported more than one cause

There were 288 individual causes of TBI listed for the 272 respondents. Twenty of the 25 persons who indicated a second TBI selected more than one cause (e.g. motor vehicle injury and a fall). Seven people who listed more than one TBI cause indicated more than two causes. It is unknown if these represent three separate events or a series of events (e.g. a medical condition caused by a motor vehicle accident resulting in a near drowning).

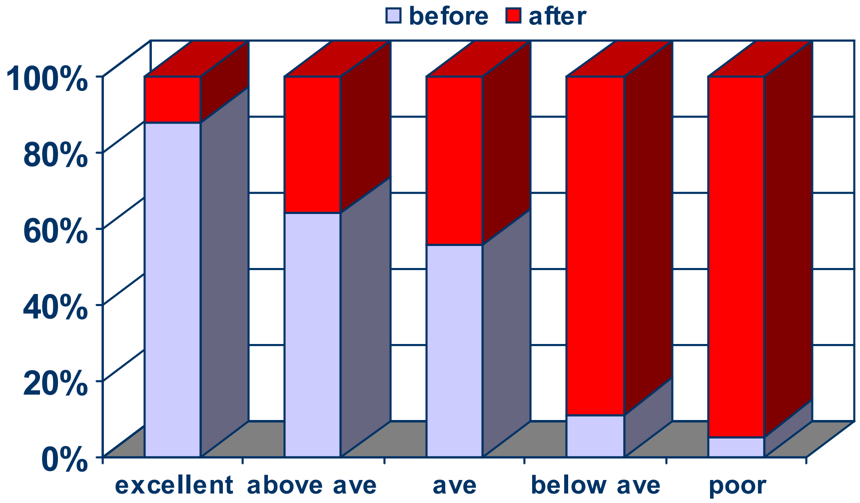
Two hundred thirty (230) people reported treatment in an acute care hospital with a median length of stay (LOS) of 30 days, ranging from 1 to 730 days. One hundred forty (140) respondents reported being treated in a rehabilitation facility. Median LOS in rehabilitation was 60 days, ranging from 1 to 720 days. 29 respondents received care in a nursing home with median LOS=100 days, ranging from 1 to 1,460 days (4 years).

Figure 9 Reported Time In Treatment Facilities



A key issue for persons with TBI is the impact it has on their life (see figure 10). Individuals rated their quality of life before and after the TBI. Generally, people perceived their before quality-of-life as much higher than after. The pattern of perceived before TBI quality-of-life shows a reversal with their perceived after TBI quality-of-life.

Figure 10 Person With TBI Quality-Of-Life Before and After Injury

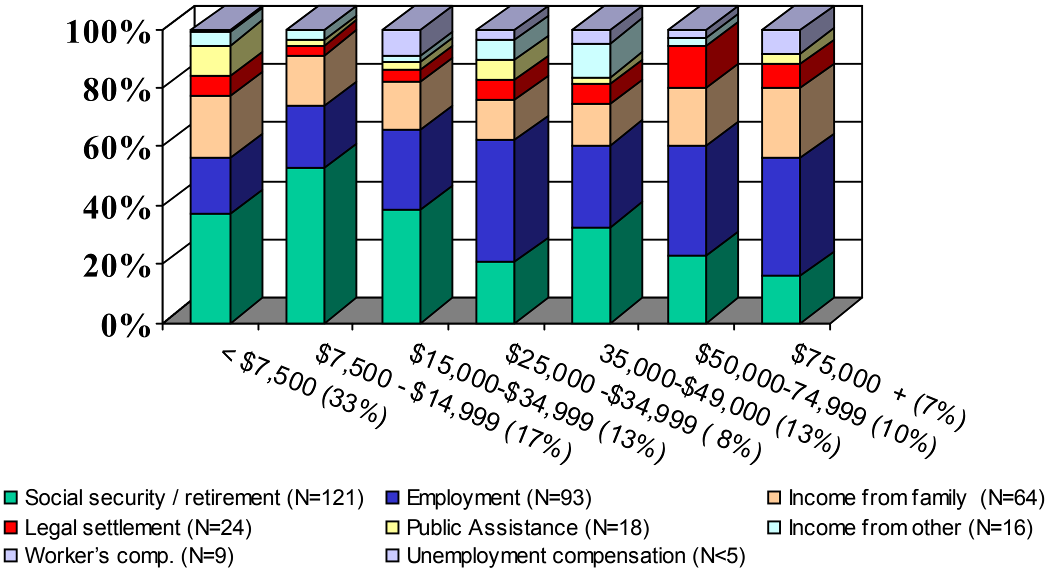


It is difficult to compare before-and-after TBI work histories because only 197 respondents answered the question about before-and after TBI work status. Most who answered, 195 (99%), worked for wages and 25 (about 13%) respondents of the 197 worked "off and on" before the TBI. One hundred eight (108) respondents answered the question about their current work status: 95 reported that they were working for wages. Thus, no clear comparison emerges for work histories before and after the TBI.

The survey asked respondents the reasons for unemployment. Of the 216 people who answered, the most commonly noted reason (n=65) for unemployment was "inability to do any job." The second most commonly noted reason offered was "lack of job accommodation for TBI." This suggests employment issues are important.

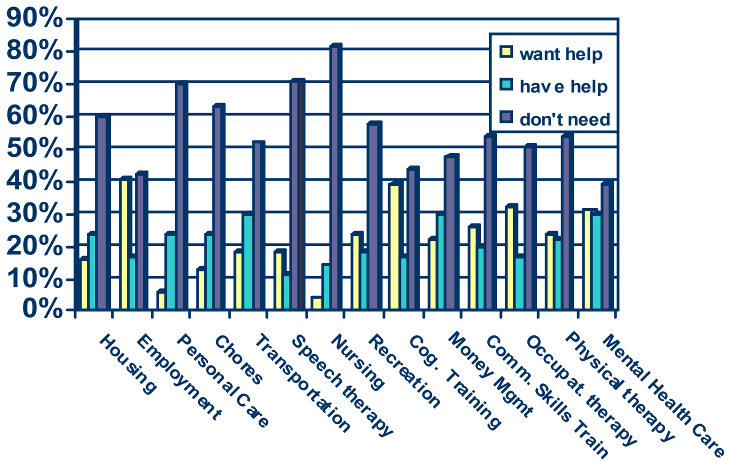
Socioeconomic status is negatively affected by the TBI. Reported income after TBI indicates that 33% of the respondents earn less than $7500 per year. Another 32% reported earnings between $7500 and $24,999. Seven percent of the respondents have incomes over $75,000. Figure 11 displays source of income and the relationship between income level and income source.

Figure 11 Sources Of Total Household Income



Specific needs were also examined. Thirty-two respondents (16%) indicated they need housing assistance but are not getting it. Twenty of the 32 (63%) stated they do not know how to get help with housing. Similar results were seen for employment, cognitive training, and occupational therapy, with 73 (41%), 73 (39%), and 57 (32%) of respondents, respectively, indicating they need assistance. 18% of respondents indicate a need for assistance with transportation and speech therapy. Personal care assistance, nursing assistance, and help with chores were not as significant—only 12 (6%), 8 (4%), and 24 (13%) respectively indicated a problem.

Figure 12 Reported Levels Of Services Needs



A separate section of the needs assessment asked caregivers to respond to what they perceive as their needs. 30% of caregivers indicated they needed respite care assistance, 28% indicated they need help with finances, and 22% indicated they need mental health counseling assistance. Fewer respondents reported need for assistance in other areas: money management (14%), chore assistance (14%), physical health care (12%), and transportation (11%).

Factor Analyses

Organizing the data is a difficult issue in understanding needs and resources. A review of the State TBI program needs and resources assessments, completed prior to the IRH assessment, pointed out the need to consolidate and summarize data in a meaningful way so that comparisons could be made across states.[5] The IRH, based on theory, hypothesized four models for grouping data: (a) Treatment Model—who offered assistance in relation to the event, (b) Services Model—the usefulness of and satisfaction with services, (c) SocioEconomic Model—economic issues, and (d) Life Status Model—life status changes as a result of the TBI. Using the Factor Analysis routine of SPSS v10, variables theoretically associated with the constructs were entered as a group and the factor analysis was completed using extraction with varimax rotation. Factors were retained based on theory, screen plots, and factor loadings. The factors were labeled based on the factor loadings, first by the research team, and then refined in discussions with the three regional advisory councils.

Treatment Model (Who Offered Help) Three factors emerged (see Figure 13). The first factor was identified as *Medical Advice*, with significant contributions from the factor loadings associated with the variables of hospital staff, specialists, emergency department staff, no one, and primary care provider. The second factor, *Social/Human Service Advice*, reflected contributions from variables of social work, hospital staff, no one, self-help, and vocational rehabilitation counselors. The third factor was composed primarily of variance from the variables of mental health and attorneys. While the relationship between these two sets of professions was not immediately obvious, all three Advisory Councils noted that they played pivotal roles in the *Long-Term Validation* of the TBI and were involved in validating and obtaining disability or other payments. The satisfaction with the services associated with the *Help* model ranged from 76% to 89% with the exception of employment, which posted a 54% satisfaction rating.

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[5] Corrigan, J.D. Ph.D.(2001) Conducting Statewide Needs Assessments for Persons with Traumatic Brain Injury, Journal of Head Trauma Rehabilitation 16(1): 1-19.

[5] Factor Analysis is useful for consolidating many variables into fewer theoretical structures

Figure 13 Factor Loadings For *Treatment*

Treatment: Who Offered Help?	Social/ Human Service Advice	Medical Advice	Long-term/ Validation
social worker	0.795	0.189	0.105
self-help/support groups	0.472	0.226	0.126
VR counselor	0.328	0.083	0.111
no one	-0.235	-0.595	-0.023
specialist	0.198	0.527	0.186
hospital staff	0.435	0.512	0.072
primary care provider	0.116	0.376	0.036
emergency room staff	-0.090	0.328	0.262
attorney	0.116	-0.015	0.672
mental health counselor	0.091	0.149	0.514
spiritual leader/minister	0.196	0.176	0.057
other	-0.178	0.033	-0.093
friend/family	0.259	0.152	0.293

Services Model (Services Used or Needed) Two factors were sustainable (see Figure 14). The first factor, *Community Re-entry/Life Skills*, included variables of personal care; assistance with chores, cognitive training, money management, community skills, nursing, housing, and employment. The other factor, *Medical/Rehabilitation Therapy,* included services such as occupational therapy, physical therapy, speech therapy; nursing, mental health counseling, and other assistance. The satisfaction with the services associated with the *Services* model ranged from 67% to 84%.

Figure 14 Factor Loadings For *Services Model*

Satisfied with:	Community Re-entry/ Life Skills	Medical/ Rehab Therapies	Percent Satisfied With Service
chore assistance	0.79	0.36	83%
personal care services	0.87	0.25	89%
money management assistance	0.69	0.40	80%
transportation services	0.77	0.28	76%
community skills assistance	0.61	0.50	80%
nursing assistance	0.52	0.61	84%
physical therapy assistance	0.34	0.71	81%
housing services	0.61	0.29	80%
employment assistance	0.46	0.27	54%
occupational therapy assistance	0.20	0.91	74%
cognitive training assistance	0.41	0.68	67%
speech therapy	0.37	0.69	79%
mental health counseling assistance	0.32	0.49	70%
other assistance	0.24	0.45	70%
quality of life before TBI	0.10	0.06	73%
quality of life now with TBI	0.01	0.08	44%

SocioEconomic Model (Community Integration Model) This grouping of variables also produced three factors. The first, *Family Socioeconomic Status*, related to SES issues that were changed or noted as a result of the TBI. It included variables of living in house/apartment, travel method; changed family/marriage, employment, living situation, medical health, psychological health, social status, and income from social security/retirement. The second factor related to issues of *Independent Living* and included living in house/apt, travel in own car, household income, income from employment, lack of income from social security/retirement, individual quality of life before and after injury. The final factor related to *Ability to Work* and included work potential, through job assessment, vocational testing, job training, and other work potential evaluation.

Figure 15 Factor Loadings For *SocioEconomic Model*

Socio Economic Model	Family SES	Independent Living	Ability/ Access to Work
No work potential evaluation	0.047	0.064	-0.996
Evaluation thru job placement	0.090	-0.058	0.260
Evaluation thru vocational testing	0.189	-0.062	0.526
Evaluation thru job training	0.076	-0.096	0.296
Other work potential evaluation	0.122	0.027	0.275
Person w/ TBI currently live in house/apt	0.267	0.396	-0.038
Travel by public transportation	0.253	-0.202	0.226
Travel w/friends or family	0.300	-0.480	0.099
Legal trouble since injury?	0.285	0.024	-0.056
TBI changed marriage/family?	0.474	0.014	0.110
TBI changed employment?	0.720	-0.011	0.047
TBI changed living situation?	0.689	-0.197	0.058
TBI changed medical health?	0.598	-0.010	0.010
TBI changed psychological health?	0.566	0.020	-0.036
TBI changed social status?	0.730	-0.078	0.009
Income from Social Security, retirement	0.555	-0.232	0.094
Individual QOL before TBI	0.374	0.272	-0.097
Travel w/other	0.117	-0.299	0.022
Travel w/own car	-0.024	0.998	-0.052
Individual QOL after TBI	-0.176	0.295	-0.059
Total household income last year	-0.079	0.298	-0.108
Income from employment	-0.199	0.309	0.010

Life status changes (As A Result of the TBI). This grouping also produced three factors. The first factor was *Family Function/Status*. This group included changed marriage/family, employment, living situation, psychological health, medical health, social status. The second factor related to *Caregiver Issues* including family quality of life before, quality of life after, and bothered by traumatic memories. The final factor related *Person With TBI Issues* and included variables of household income last year, individual quality of life before, and individual quality of life after.

Figure 16 Factor Loadings For *Life Status Changes*

How TBI Changed Life	Family function/ Status	Caregiver Issues	Person with TBI issues
Changed marriage/family?	0.475	-0.023	0.025
Changed employment?	0.704	-0.017	-0.001
Changed living situation?	0.689	0.090	-0.199
Changed medical health?	0.637	0.054	-0.069
Changed psychological health?	0.607	0.054	0.091
Changed social status?	0.694	0.004	-0.099
Household income last year	-0.091	0.166	0.396
Individual QOL before	0.369	0.193	0.520
Individual QOL after	-0.196	-0.049	0.934
Family QOL before	0.068	0.983	0.057
Family QOL after	-0.060	0.884	0.151
Family bothered by trauma	0.117	0.783	0.015
Individual bothered by trauma	0.303	0.044	0.178

Agency/Provider Study for Persons with TBI Needs Assessment

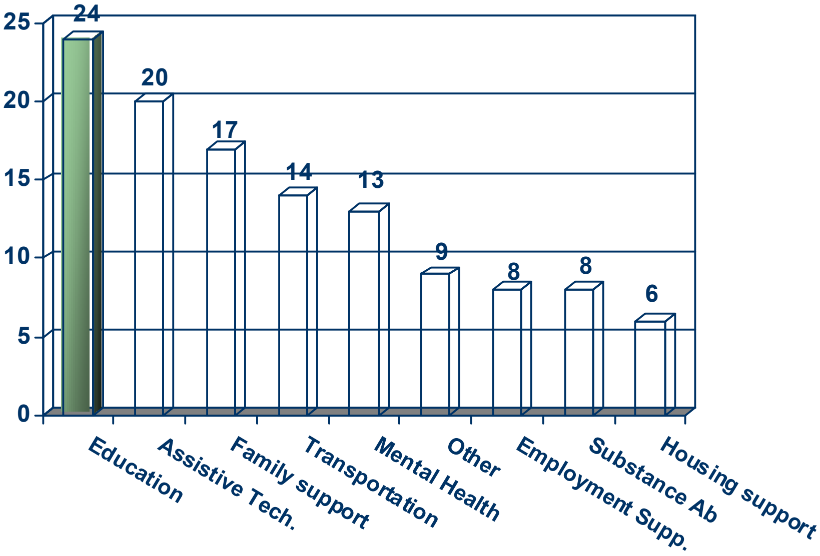
Introduction

In May 2001 IRH distributed over 1,000 surveys to health care providers and agencies that work with people with TBI. Mailing lists were obtained from several sources, including the BIA-ID, EMS in Idaho, and cases from the Division of Vocational Rehabilitation. Hospitals, TBI agencies, rehabilitation facilities, and insurance providers were given copies of the survey and asked to distribute them to providers of care for persons affected by TBI. Follow-up surveys were mailed to non-responding acute care facilities to increase the returns of provider surveys. Provider surveys were available through the internet to be downloaded and mailed in or could be completed and submitted on-line. Agencies and providers with electronic addresses were e-mailed about the availability of the survey on the Internet.

Results and Discussion

One hundred ninety-six (196) surveys were completed (20% return rate). The findings indicate that agencies are located in or provide TBI services to all 44 Idaho counties. On average, agency providers respond to five people with a TBI. Acute and emergency medical care comprises the most common type of care. This finding is consistent with the fact that TBI most likely results from an accident that requires emergency, acute care. Figure 17 displays the broad categories of services offered in Idaho.

Figure 17 Categories of TBI Services Offered In Idaho



Agency/Provider Information: 104 surveys (57%) were completed by agencies that described themselves as public, 25 agencies (14%) classified themselves as private, and 53 (29%) selected not-for-profit. When asked if their agency provided services for individuals or families with TBI, 95 (53%) indicated yes and 85 (47%) indicated no.

Agencies frequently served only a few individuals. Table 6 shows responses when provider/agency survey respondents were asked how many individuals they served in specific categories. A few organizations indicated they serve 100-200 individuals simultaneously, but the median number of individuals served was 5 per organization. This makes it difficult for most agencies to offer specialized care or services.

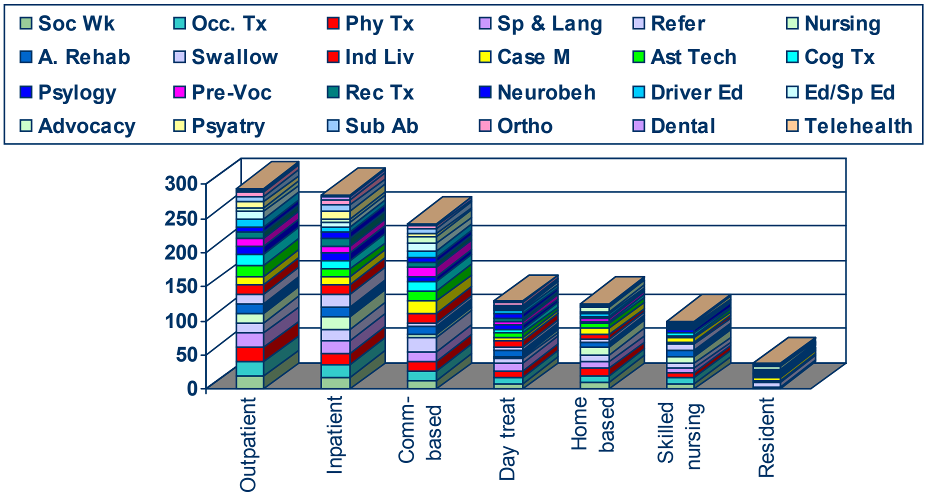
Table 6 Descriptions Of Individuals Served With TBI, Provider/Agency Needs Assessment

Characteristic	Median number served	Range served
Males	<5	0 – 356
Females	<5	0 – 180
Age Group		
Children	<5	0 – 158
Senior citizens	<5	0 – 37
White	<5	0 – 218
Hispanic	<5	0 – 62
African American	0	0 – 8
Asian	0	0 – <5
Native American	<5	0 – 5

Overview of Services

It is difficult to form an overall picture of services when so many are offered in so many settings. The two graphics below help clarify this situation. Figure 18 depicts the services arranged by setting, while Figure 19 displays the different services available in Idaho.

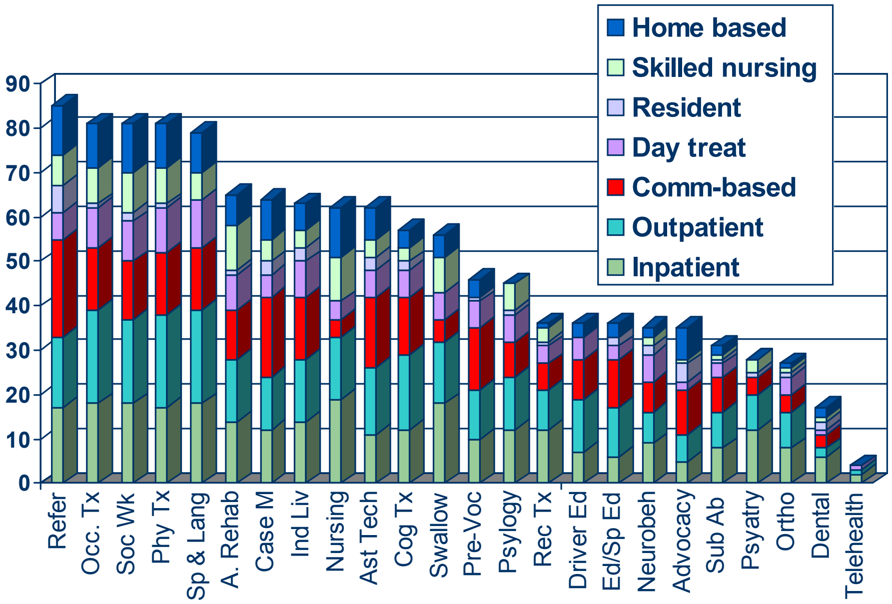
Figure18 Services Available Categorized By Type



The largest varieties of services are provided in outpatient settings, which are closely followed by inpatient care. While the categorizations used were suggested by the granting agency, there is overlap and lack of clarity in the categorizations. For example, how are outpatient services different from community-based services or home based services?

Figure 19 shows the different services available in Idaho. The most common service available is referral. Interestingly, referrals are offered regardless of the setting in which one is seeing service. The second through fourth most common services are Occupational, Physical and Speech and Language therapies along with social work support. The least common services include traditionally under-offered services, mental/behavioral and oral healthcare.

Figure19 Services Available In Various Settings



Prevention

The IDHW's Injury Prevention Program works with agencies, district health offices, individuals, and the state legislature to improve primary prevention services. The program has promoted use of bicycle helmets, child car seats, and seat belts. Idaho does not currently have a mandatory seat belt law as a primary offense for persons over the age of 4 years.

Twenty-four agencies indicated that they provide prevention services. Ten organizations indicated they offer primary prevention services for intentional injuries, and 17 organizations indicated they offer primary prevention services for unintentional injuries. Twelve agencies indicated they offer secondary prevention services.

Table 7 displays the results of the Provider/Agency Needs Assessment for the question asking how many respondents have staff dedicated to a variety of TBI issues. Forty-four respondents indicated they have at least one staff person working with TBI survivors and/or families. This table may be a little misleading because in a separate question from the needs assessment, agencies were asked how many staff members spend 50% or more of their time on TBI issues. The median number of staff at each organization who spend 50% of their time on TBI issues was 1, with a range from 0 – 100 persons.

Table 7 Designated Staff Assigned To Work On TBI Issues

Staff dedicated in each area	**Number of agencies indicating yes**
Agencies with staff dedicated to TBI issues	44 Median staff = <5 (range 0-100)
Specific areas of support for persons/families with TBI	
Alcohol and drug addiction	8
Mental health counseling	13
Family support	17
Employment issues	8
Housing issues	6
Transportation issues	14
Education	24
Assistive technology	20
Other	9

Acute Care Services

Of the 194 Provider/Agency needs assessment surveys returned for analysis, 60 respondents indicated they provided direct services to patients. This was defined as providing treatment, therapy, transportation, housing, etc. In a separate survey question, 47 respondents indicated they provide acute care services. The responses to this question are displayed in Table 8. All 44 Idaho counties had at least one organization that offers some type of services to individuals with TBI. This varies widely; some counties provide only EMS, others rely on school systems, and still others have multiple types of organizations within the county boundary.

One question asked if agencies provide services to individuals or families who have experienced TBI: 95 reported yes and 85 indicated no. Analysis of responses that indicated that such services are not provided found that they were the same types of organizations as those that do provide TBI services, including school districts, acute care hospitals, EMS and ambulance companies, physician offices, long-term care facilities, and others. This suggests a need to educate these organizations about what it means to serve individuals and families with TBI.

Table 8 Acute Care Services For Individuals With TBI

Service	**Number**
Do you provide acute care services?	47
Specific Services	
Acute medical care	24
Discharge planning/service coordination	21
Dental care	7
Emergency medical care	34
Family education, information & training	21
Pre-hospital transport and treatment	17
Discharge protocols at all levels of TBI	9
Family mentoring	10
Referrals to subspecialties	22
Substance abuse screening	10
Telehealth/telemedicine (2-way television)	<5
Trauma systems	13
Psychiatry/psychology	19
Other	9

The Provider/Agency needs assessment also asked respondents to list the types of services they provide in various healthcare settings. Table 9 displays the results for this question. It is clear from examining this table that there are limited services in some specific service areas.

Table 9 Provider/Agency With Specific Inpatient And Skilled Nursing Services

Service	Number providing inpatient services	Number with skilled nursing services
Acute Rehabilitation	14	10
Advocacy Training Services	5	<5
Assistive Technology Services	11	<5
Case Management Services	12	5
Cognitive Therapy Services	12	<5
Community/Agency Referral Services	17	7
Dental Care Services	6	<5
Driver Education Services	7	0
Education/Special Education Services	6	0
Independent Living Skills	14	<5
Neurobehavioral Treatment Services	9	<5
Neuropsychology Services	10	<5
Nursing Services	19	10
Occupational Therapy Services	18	8
Orthodontics/Prosthetics Services	8	<5
Physical Therapy Services	17	8
Pre-Vocational Services	10	0
Psychiatry Services	12	<5
Psychology Services	12	6
Social Work Services	18	9
Speech & Language Therapy Services	18	6
Substance Abuse Assessment & Treatment	8	<5
Swallowing Services	18	8
Telehealth/Telemedicine Services	<5	0
Therapeutic Recreation Services	12	<5

Rehabilitation Services

Rehabilitation services refer to inpatient, outpatient, and community-based services. Acute care rehabilitation is critical immediately following a TBI and it is often necessary for an individual to undergo long-term outpatient or community rehabilitation in order to achieve maximum functional status. Rehabilitation can involve physical activity, such as physical therapy, occupational therapy, etc., or it can involve psychological activities, such as neurobehavioral treatment. Both types of rehabilitation are important. Table 10 displays the results for the residential and day treatment settings. There are limited services in some specific service areas, particularly in the area of residential services.

Table 10 Number Of Provider/Agency Respondents Who Provide Specific Residential And Day Treatment Services

Service	**Number of respondents providing residential services**	**Number of respondents providing day treatment services**
Acute Rehabilitation	<5	8
Advocacy Training Services	<5	<5
Assistive Technology Services	<5	6
Case Management Services	<5	5
Cognitive Therapy Services	<5	6
Community/Agency Referral Services	6	6
Dental Care Services	<5	<5
Driver Education Services	0	5
Education/Special Education Services	<5	<5
Independent Living Skills	<5	8
Neurobehavioral Treatment Services	<5	6
Neuropsychology Services	0	6
Nursing Services	0	<5
Occupational Therapy Services	<5	9
Orthodontics/Prosthetics Services	<5	<5
Physical Therapy Services	<5	10
Pre-Vocational Services	<5	6

Psychiatry Services	v	0
Psychology Services	v	6
Social Work Services	<5	9
Speech & Language Therapy Services	0	11
Substance Abuse Assess./Treatment Services	<5	v
Swallowing Services	0	6
Telehealth/Telemedicine Services	0	<5
Therapeutic Recreation Services	<5	<5

Community Services

Community services provide information, counseling, support, and a chance to locate needed resources. Table 11 below displays the results of the Provider/Agency needs assessment related to services provided in the home-based, community-based, and community re-entry settings. Psychological services seem to be lacking in all three settings. Only a few providers in the state offer neurobehavioral, neuropsychology, or psychiatric services in these settings.

Table 11 Number Of Provider/Agency Respondents Who Provide Specific Home Based, Community Based And Community Re-Entry Services

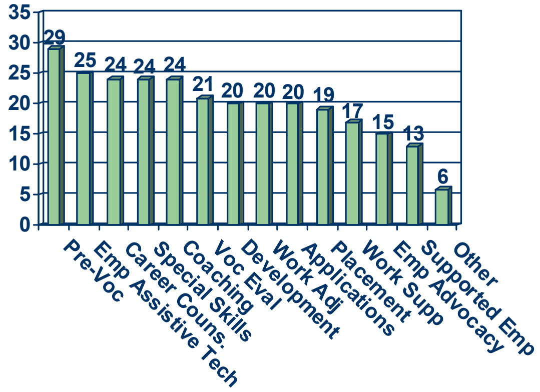
Service	Number providing home-based services	Number providing community-based services	Number providing community re-entry services
Acute Rehabilitation	7	<5	8
Advocacy Training Services	7	6	<5
Assistive Technology Services	7	8	8
Case Management Services	9	13	5
Cognitive Therapy Services	<5	9	<5
Community/Agency Referral Services	11	14	8
Dental Care Services	<5	<5	<5
Driver Education Services	v	6	v
Education/Special Education Services	v	9	<5
Independent Living Skills	6	10	4

Neurobehavioral Treatment Services	<5	5	v
Neuropsychology Services	<5	5	<5
Nursing Services	11	<5	<5
Occupational Therapy Services	10	9	5
Orthodontics/Prosthetics Services	<5	<5	<5
Physical Therapy Services	10	9	5
Pre-Vocational Services	<5	11	<5
Psychiatry Services	0	<5	0
Psychology Services	0	7	<5
Social Work Services	11	8	5
Speech & Language Therapy Services	9	9	5
Substance Abuse Assessment & Treatment Services	<5	7	<5
Swallowing Services	5	<5	<5
Telehealth/Telemedicine Services	0	0	0
Therapeutic Recreation Services	<5	<5	<5

Employment and Vocational Services

People with TBIs are employed at rates lower than the general public and people with TBI and their families consistently request employment assistance; therefore, data regarding employment was selected for analysis (see Figure 20). Approximately one-half of the agencies (29 of 60) offered vocational or employment services. Most services were associated with career advice, although about one-quarter of agencies offered assistance with placement. Less than one-fifth offered any type of actual employment support, such as assistive technology or supported employment. It appears from the data that the majority of services offered are in pre-vocational employment vs. supported employment.

Figure 20 Types Of Employment And Vocational Services Offered



Summary of Needs and Resources Information

Seven life areas were used to collapse the complicated needs of individuals and families into a manageable number of categories. These are self-determination, employment, housing, health information, education, community support, and transportation. Self-determination is defined as people having control, choice, and flexibility in the services and supports they receive. In addition, other areas of concern that will be addressed include the needs for public awareness, referrals, and case management.

Consumer and family/significant other involvement

The table below (Figure 12) sums across all of the surveys, then compares the number of individuals concerned about each of the life areas. The columns are arranged in order of total importance (see row 5). Comparing Row 3 and Row 4 demonstrates the similarities of concerns reported by providers and individuals/family members. One noticeable difference in the data reported shows 115 individuals/family members expressing concerns in the area of health.

Table 12 Individual Concerns About Life Areas

Row	Origin of Data	Community Support	Health	Information/ Education	Housing	Self-determination	Employment
1	BIA-ID Membership (90)	n=70, 78%	n=57, 63%	n=46, 51%	n=5, 6%	n=14, 16%	n=24, 27%
2	BIA-ID I&R database (n=149)	n=77, 52%	n=40, 27%	n=68, 46%	n=5, 6%	n=29, 19%	n=9, 6%
3	Planning Grant Prov/Agency survey (n=104)	n= 28, 27%	<5, <5%	n=9, 9%	n=5, 6%	n=5, 5%	n=5, 5%
4	Planning Grant Indiv/Family survey (n=272)	n=81, 30%	n=115, 42%	n=17, 6%	<5, <5%	n=13, 5%	n=6, 2%
5	Total (N=676)	n=228, 34%	n=212, 31%	n=131, 19%	n=10, 11%	n=56, 8%	n=39, 6%

Life Area—Community Support

Community Support recognizes every individual and family as a valued and participating member of their community. Approximately one-third of individuals indicated Community Support was an area of concern. When coupled with health, or the availability of needed health services in their communities, the number jumped to almost 65% of respondents. Community Support is a complex issue and encompasses many agencies and needs. It can involve transportation, social outlets, and recreational opportunities. It also includes some very basic day-to-day tasks. Respondents indicated community support needs such as help in re-learning skills for daily activities (like shopping), help with money management, and assistance with medical and legal systems.

Life Area—Health

Healthy lifestyles refers to people who are healthy and benefit from the full range of needed health services. This life area has the largest observed gap between the consumers and the providers and agencies who serve them. No provider/agency respondents thought consumers had health concerns relative to the other life areas. Almost one-third of the consumers, however, indicated differently. Consumer comments ranged from general issues, such as the need to locate contact information of specialists, to the feeling that the health care providers working with them were untrained regarding the diagnosis and treatment of TBI. This echoes the Provider/Agency needs assessment that pointed out that there are few professionals within the state who spend at least 50% of their time on TBI issues and that the median number of hours per year for continuing education about TBI was 5 hours. The data point to the fact that there may be valid concerns expressed by consumers with regard to the availability and accessibility of health care providers who are up-to-date on TBI diagnosis and treatment.

Consumers experience different phases of the health care delivery system, including hospitals, rehabilitation, and health care provided in community settings. Respondents were asked to describe their frustrations with the three stages of recovery. They were specifically asked to comment on their experiences in the acute care setting (hospitals), rehabilitation facilities, the community setting, and the transition between the health care settings. Table 13 below highlights these experiences.

Table 13 Respondent Experiences with Health Care Settings

Health care setting or issue	**Number of individuals experiencing concern with each category (N=162)**
Acute care – worker competence	<5
Acute care – overall experience	6
Acute care- avail. needed services	<5
Transition to home/rehab	<5
Rehab. facility – worker competence	5
Rehab. facility – overall experience	8
Rehab. facility – avail. needed services	13
Rehab. facility –transition to home	59
Healthcare competence overall	50
Availability of medical services	<5
Availability of non-medical services	56

It is clear from this table that almost a third of respondents had concerns with three areas: 1) the transition from rehabilitation to home, 2) the overall competence of their health care providers, and 3) the availability of non-medical services in the community. These areas highlight the problems of having complex services available in rural communities in Idaho.

Life Area—Housing

The life area of housing consists of adults choosing where and with whom they live and have services needed to support their choices. Housing appears to be of lesser concern for many respondents. Of 196 respondents to housing questions, 60% indicated they do not need help with housing issues. Twenty-four percent of respondents indicated they were receiving help with housing. Thirty-two individuals (16%) indicated that they would like help with housing. An area of concern is that of the 32 individuals who indicated they need housing assistance, 20 (63%) said they do not know how to get help. This suggests an area for improvement: to make sure all individuals and families are aware that assistance is available to qualifying families and helping them find necessary resources.

Life Area—Information/Education

The Information/Education life area is defined as individuals accessing needed information and reaching their educational potential. This area is dominated by consumers' interest in additional TBI knowledge. Specific areas of knowledge included TBI diagnosis (How do I know what my difficulties are related to a traumatic brain injury?), information about support groups (Where can I get support locally?), and information about specialists in the state in TBI (If I have concerns about the quality of the health care information I am receiving, where can I go for a second opinion?).

Traditional education seemed less important to respondents. They focused on two immediate needs: 1) cognitive retraining and 2) job skills training. Cognitive retraining is a medical specialty that teaches linear thinking and problem solving skills to persons with TBI. These skills are essential for successful work and personal relationships. Out of 189 respondents on the Individual/Family needs assessments, 73 (39%) indicated they want cognitive retraining and 33 (17%) of respondents indicated they are receiving help. Of the 73 individuals who want cognitive training assistance, 41 indicated they do not know how to get help and 18 indicated they cannot afford help or have no insurance.

Life Area—Self-Determination

Self-determination is defined as people having control, choice, and flexibility in the services and supports they receive. This life area was difficult to separate from the other life areas because it is so intertwined. In order to have a choice in the services and supports received, a person needs to know what is possible (information and education), what is available (community support and health), and what is accessible (specific services in their community at a price they can afford).

Life Area—Employment

Employment consists of people getting and keeping employment consistent with their interests, abilities, and needs. Employment is an area of concern for many consumers. It is a complicated issue which involves many aspects, including 1) jobs must be available, 2) the consumer must know about the job, 3) the consumer must be able to perform the job skills (with or without assistive devices), 4) the consumer must have transportation to and from work, 5) the consumer must be able to physically meet the demands of working (full-time versus part-time work), and 6) the job must provide the consumer with a living wage. Re-entry into the job market post-TBI is hampered by a lack of understanding by potential employers regarding hiring an individual with a TBI, the lack of assistive devices at many jobs, and the difficulties individuals may have in adequately identifying and communicating job related problems.

Life Area—Transportation

Transportation is defined as people having access to a range of opportunities in moving from one place to another. The majority of consumers 143 (71%) stated they travel with their own car when asked how they travel on a daily basis. If they needed help with transportation, however, 35 (18%) stated they wanted help with transportation. The respondents were asked if they wanted help with transportation, didn't receive it, and the reason. Fourteen respondents stated they did not know how to get help with transportation and thirteen persons responded by saying they can not afford or were not insured. Eleven percent of family members stated they needed help with transportation. Fourteen agency providers reported that they provide transportation as a community support service. During 2001, two of the focus groups with the three regional advisory councils cited the lack of available, accessible, affordable transportation as a weakness.

Public Awareness

Consumers expressed a great deal of concern over public education of traumatic brain injuries. Areas targeted for public education included prevention, how to accept persons with TBI into a community or work place, the need for assistive technology use by employers, adaptive employment settings, and the effect of public opinion on access to housing, transportation, employment, and education.

Referrals

All 44 Idaho counties provide TBI services but referrals to other providers were the most common service, although it unclear if there are sufficient openings in the state to accommodate the referrals. Consumers indicated frustration with "the run-around," where they are sent to multiple locations to receive a needed service because providers are unaware of the appropriate place to send them. Many consumers and providers suggested compilation of an up-to-date resource manual and for one designated agency to take the role as the statewide repository of service availability. This would give consumers and providers one contact agency in the state and workers in that agency would have up-to-date information about the availability of services throughout the state.

Service Arrangement and Coordination (Case Management)

Little information was collected on case management from consumers or health care providers. However, consistent qualitative and quantitative data suggest people get frustrated when they don't know how to access services. A dedicated case manager might overcome this frustration. A case manager either works with or is closely aligned with the centralized agency. This means the case manager should know what resources are available and help guide individuals to appropriate services and supports within the system.

GOAL 4
COMPLETION OF FINAL REPORT & STATEWIDE ACTION PLAN

The recommendations that are derived from the analyses comprise a statewide action plan that is based upon inter- and intra-agency collaboration to help ensure the success of the primary goal of the project—to develop the comprehensive, community-based system of services and supports. A key to the plan is the need for consideration of the life area variables.

It is worth noting that Goal 4, the completion of a plan, and the implementation submission were intermingled during the final year of the planning grant. The planning grant was funded for two years (2000 and 2001) but continued into 2003 with a no-cost extension for year 2002. During 2002, the implementation grant was also written and subsequently funded in spring of 2003.

The action plan was created in 2002 from the work of the staff and Councils involved in the planning grant. The action plan was disseminated in draft form to members of the Advisory Councils and the Interagency Working group. The plan was further articulated in the implementation grant, which was circulated to individual council members and other agencies for letters of support prior to submission. It was also discussed with members of the State CIC and the Real Choices System Change Grant workgroup members.

The Planning Grant outcomes suggested six strategies for successful implementation of the TBI Action Plan that inform this methodology. These strategies are explained below.

Involve Consumer and Family/Significant Others.

The Virtual Program Center (VPC) gives consumers access to information, and allows them to track their own progress. The information is available from anywhere in the state—whether for health, support services, or employment—and access to a provider is unnecessary. At this point, there are no plans to include confidential patient information at the site, but if the advisory council recommended it after seeing the initial phases, this could be added.

Work Across All Life Areas

The following empty table is an example template of how information will be arranged via the VPC. Life areas are indicated down the left hand column to provide easier access to specific types of information. The categories across the top of the table allow for sorting of information by life area by type of user.

Table 14 Life Areas Organized By User(s)

	Agencies/ Providers and Schools	**Persons with TBIs**	**Family Members/ Significant Others**	**Community Members**
Self-Determination				
Employment				
Housing				
Health				
Information/Education				
Community Support				
Transportation				

Begin With Self Determination, Employment, and Family Supports

The TBI-VPC supports self- determination by giving people information. It aids increased employment by making information available about employment resources. TBI affected people and families can make connections with peers and professionals through the VPC.

Provide Awareness & Education

Educational materials are among the easiest to maintain at a VPC. The site contains downloadable information. It is also a central point for making reservations to attend Virtual Grand Rounds or other activities that can be listed at the site.

Improve Information and Referrals

The core element of the VPC is cataloging and displaying information to support decisions. Professionals and people with TBIs and their family members will therefore have access to information that represents the state's collective repository of knowledge. One of the requests from consumers is for "one-stop-shopping." While it is unlikely that people who live in the far-flung corners of Idaho will have a short drive to all services, VPC makes one-stop service planning an option.

Improve Case Coordination, Management

As the site matures, decisions can be made as to whether or not to archive individual personal information at the site. If the decision is made to use the VPC as an electronic medical record (EMR), it will be designed so that only those with authorization can see what services are being used. Even if the decision is against an EMR, the VPC can still help improve service coordination by helping people know where to get services. As people access information for themselves, it supports self-determination and reduces the demands on overly busy professionals.

Description of Suggested Methodological Approach

The needs and resource assessment identified the availability of core health, social, rehabilitative, and residential services in most communities in Idaho. It also identified that most of the staff of these core services had little or no knowledge and skill with TBI due to the infrequency of contact. This plan chooses to support existing systems of care rather than creating new disability-specific systems. Disability-specific programs do not work because Idaho's low population will not support a disability-specific approach. A more useful approach is to build the knowledge and skills of health, rehabilitation, vocational, and social service providers who currently operate within the state and will continue to operate past the conclusion of the grant.

IDHW maintains a strong commitment to the maintenance and enhancement of community-based services and community integration for all persons, regardless of disability type. Through the Department's efforts with the Planning Grant, the TBI waiver, significant additional expertise on TBI has been developed within the Department of Health and Welfare that enhances sustainability of TBI system change efforts in Idaho. Any future programs should include (a) strategic alliances, (b) anywhere-anytime access to TBI information, (c) ongoing assessment, and (d) policy review and planning. The method of development rests on improving access to services by improving access to information.

Continue and Improve Advisory Councils

The advisory councils have been chartered since 2000. The plan calls for continuing the existing charter and moving toward an executive order by the end of 2004. As noted previously in the report, some aspects of the coordination of the multiple councils were administratively cumbersome. The regional councils should be continued and an alternative structure for the executive committee should be considered. The Intra-Agency Council should be disbanded and replaced by the Community Integration Committee, which is already chartered and functioning. One method for ensuring the long-term success of the Councils would be to use legislation to establish their charter.

Utilize Strategic Alliances

A strategic goal of IDHW is to build leadership and form relationships with the community. Future activities should focus on expansion of leadership capacity across organizations and the innovative use of technology to extend education and information to consumers and providers.

Partnerships such as that with the BIA-ID, an initial partner in the planning grant, should continue as a major partner. The BIA-ID participation strengthened the organization and its continuing involvement is an invaluable resource to assist its growth. Saint Alphonsus

Regional Medical Center, is the leading trauma center in Idaho and the home to the Idaho Neurological Institute, which provides health and rehabilitation care to persons with a TBI. Its involvement strengthens community participation, adds significant resources for the project, and assures sustainability. In addition, partnerships with the State's universities increase access to scholarly and research resources.

Create Anywhere-Anytime access to TBI information: The Virtual Program Center

Based on knowledge gained in the planning grant, the strategic plans for the state, and the growing strength of telehealth in Idaho, we suggest an Internet-based TBI Virtual Program Center (TBI-VPC) for agencies, providers, and people with TBI and their family members. With existing telehealth technology, the system is equally available to all professionals in Idaho and can overcome the obstacles Idaho faces with social and economic boundaries, uneven population distribution, and difficult geography and climate. People without any computer access at all will have difficulty gaining the information, but less difficulty than currently exists as the information will at least be collected and accessible on behalf of those without computer access rather than the current situation where few, if any, people know what is actually available in the way of services and supports for people with TBI and their family members in Idaho.

One section of the TBI-VPC should focus on providers of services and support, with a subsection specifically for schools. It can provide current knowledge of TBI, benchmarks and best practice standards for each stage and type of service, and decision support tools to most appropriately guide the care process. Because many current caregivers have infrequent contact with persons with TBI and because turnover in caregivers is high, making information available on a just-in-time, need-to-know basis is critical. State-of-the-art knowledge can be made available for all facets of services and supports, including emergency, acute, sub-acute, short-term rehabilitation, long-term rehabilitation, housing, vocational, financial, social, and recreational services. Primary providers can be targeted and could include EMS workers, ER staff, Rehabilitation Providers, Vocational Rehabilitation Counselors, teachers, and Independent Living Center staff.

A second section of the TBI-VPC should focus on individuals with TBI and their families. It can provide current knowledge related to TBI, best approaches to treatment at each stage of rehabilitation, information on services, and consumer empowerment guides.

Imbedded in the appropriate sections of the TBI-VPC should be information and access to continuing education available to caregivers, persons with a TBI, and family members. Telehealth can be made available to use the resources of all of the major partners and Advisory Council members, including grand rounds on TBI and other educational presentations. Users of the TBI-VPC should be able to access a wide array of state and national educational presentations.

Ideally, the TBI-VPC should have tools for cognitive screening and assessment. It is unclear as to whether these tools can be incorporated. These tools, some of which are currently being used in one school district in the state, can be especially effective for children state wide. They can enable parents and caregivers to identify otherwise undetected TBI related to athletics or other vigorous activities, and accidents with children. The project should partner with the State Department of Education, Special Education Section to identify the appropriate tools and determine how best to implement them within the TBI-VPC.

The costs of the TBI-VPC should be "front loaded;" maintaining the system is cheaper than building it. While maintenance does require ongoing resources, sustainability is enhanced by building the capacity of the existing health, rehabilitation, vocational, and social service infrastructure rather than an entirely separate, new system of service. Existing TBI specialists in Idaho and the US should be used for some of the continuing education and grand rounds activities. Saint Alphonsus Regional Medical Center can be central to the sustainability process. Because of its current role as a regional trauma center, the strength of its Idaho Neurological Institute, and its commitment to telehealth, the migration and continuation of the TBI-VPC to St. Alphonsus in year three of the grant is a natural fit. The Medical Center has both the program and technical expertise to sustain the TBI-VPC.

Developing TBI-VPC Content

Working with the Advisory Council and Inter-Agency Working Group members, project staff should assemble information on TBI and its effects, diagnosis, assessment, treatment, and rehabilitation. All information should be catalogued and offered based on its appropriateness for agencies/providers (including schools), persons with TBIs and their family members, or the general public. The combination of current knowledge, best practice, and decision support for each major life area can significantly expand the capacity and capability of current providers in serving persons with a TBI and their families.

Several important steps are outlined below:

- The needs and resources assessment data should be reviewed and catalogued to show what agencies provide what services, updated annually with the new survey.
- The Advisory Council should be polled for information on a regular basis.
- BIA-ID should assist in obtaining information from consumers and family members.
- All offices of the State of Idaho should be reviewed for appropriateness of links.
- Schools should be contacted to solicit information.
- Professional Idaho organizations such as the Psychological Association, the Hospital Association, Medical Association, Nurses Association and Social Work Association, etc., should be invited to provide information.
- Radio, print and broadcast news media should be used to solicit submission of information.
- Persons with TBI and their families should be active in helping identify resources.

Dissemination of the VPC

After the VPC is developed, efforts should turn to implementation, marketing, maintenance, and refinement based upon input from the Council and community. The Advisory Council and BIA-ID can assist in educating persons with TBI, family members, and agencies about VPC and how to use it. Information on the TBI-VPC should also be made available to all hospitals, primary care providers, and selected specialists.

Provide Educational Activities

Educational activities should be created for all types of people including (a) professionals, (b) persons with TBIs and their families, and (c) the general public. These activities should improve services and supports, reduce mismatched service and support utilization, and reduce stigma toward people with TBIs and their families. Existing TBI specialists in Idaho and the US can be used for some of the continuing education activities. Ongoing virtual community education programs can be provided through Universities' distance learning network and video streaming for persons in rural areas of the state. In addition professionals should be able to receive continuing education credits.

Complete Ongoing Needs and Resources Assessment

The data gathered in the planning grant led to the development of an improved and shorter version of the assessment that was subsequently used in the Real Choices grant. Data were collected in 2001 and 2002, and should be collected in the future allowing for longitudinal comparison of needs and resources. Data should be analyzed and reported to the Advisory Councils, the State of Idaho, to people with TBI and their families, the BIA-ID, and scientific publications.

Review and Monitor Policy

A key element of sustaining these efforts is understanding the political, economic, and health services aspects of the system of services and supports. There should be ongoing analyses of policies and costs, taking into account the vicissitudes of the state and national economy. Each policy review should be limited in scope and culminate in a white paper available to planners, legislators, and community members.

Coordinate with Injury Control and Prevention

The IDHW Division of Health oversees injury control and prevention activities in the State. Future efforts should dovetail with these existing programs, but not fund them. The goal should be to coordinate activities and expand the capacity of both groups. The ongoing needs and resources assessment can be used as a vehicle to track outcomes of programs and to look for new areas to expand the work of the injury control and prevention services.

Address Reimbursement for Services

There are complex and lingering problems associated with reimbursement of services and supports for people with TBIs and their family members. There should be an annual review of needs and resources to assess the previous year's efforts, and to plan for the coming year's needs. There should be ongoing support of the Medicaid waiver. In recognition that non-state funding is also essential, there should be an active effort to pursue other public and private reimbursement sources.

Work for System Change

TBI is part of the State's commitment to System Change. One activity will be to stimulate institutional support for public and private system change. These efforts include budgeting TBI efforts at administrative levels, assessing legislative feasibility, and assessing trust fund legislation feasibility by October 2005 (month 30 of implementation grant). Additionally, it will be important to seek extramural funding across time, working collaboratively with state, private, university, and non-profit organizations.

CONCLUSION

Idaho is poised to move forward in implementing the action plan for the state. The goals and objectives reflected above seek to address both the strengths and weaknesses identified by the planning grant activities. Overall, the proposed plan should support the knowledge, information, and skill development of all providers in all of Idaho's communities to strengthen their ability to work with persons with a TBI and enable the person with a TBI to live and thrive in their home community. The plan also recognizes the role of self determination and empowers consumers and their families by providing them knowledge of resources and how to access them. The researchers and Advisory Council members recommended that all future projects should focus on capacity building, reducing stigma, meeting needs of people with TBIs and their family, and take a person-centered approach. They urge that future plans work toward an environment that supports consumer choice and actions that support the Supreme Court decision Olmstead vs. LC (1999) which has been interpreted to say that people with disabilities have a right to choices about services and supports in their lives. Finally, the Council and researchers recognize that all activities should include recognition of ethnocultural and other cultural issues that arise based on place of residence (urban/rural/frontier).

APPENDIX A

MAILED STATEWIDE NEEDS AND RESOURCES SURVEY, 2001

INDIVIDUALS WITH TBIS AND THEIR FAMILY MEMBERS

Mailed Statewide Needs and Resources Survey, 2001

Individuals with TBIs and their Family Members

Demographic Information

Surveys were completed from 35 of Idaho's 44 counties (79.5%). Additional surveys were returned from individuals who list their residence as Oregon (3), Washington (1) and California (1). Eighteen surveys did not have county listed. The number of surveys returned from residents of each county is listed below.

One hundred forty nine (65.3%) of the completed surveys specified gender as male, 79 (34.7%) were from females. Forty-four surveys had no gender recorded.

One hundred and forty six (146) surveys were completed by an individual with TBI, 69 were completed for a child with TBI, 29 were completed for a spouse with TBI, 4 were completed for a significant other with TBI, 12 were completed for other with TBI, and 1 was completed for a parent with TBI. Eleven surveys did not specify the relationship.

County of Residence	Number	County of Residence	Number
Ada	62	Gem	1
Adams	2	Gooding	0
Bannock	10	Idaho	5
Bear Lake	0	Jefferson	2
Benewah	1	Jerome	4
Bingham	5	Kootenai	18
Blaine	5	Latah	3
Boise	4	Lemhi	3
Bonner	11	Lewis	0
Bonneville	30	Lincoln	2
Boundary	0	Madison	3
Butte	2	Minidoka	2
Camas	0	Nez Perce	1
Canyon	30	Oneida	1
Caribou	3	Owyhee	3

Cassia	4	Payette	2
Clark	1	Power	0
Clearwater	3	Shoshone	0
Custer	5	Teton	0
Elmore	3	Twin Falls	8
Franklin	3	Valley	0
Fremont	4	Washington	1

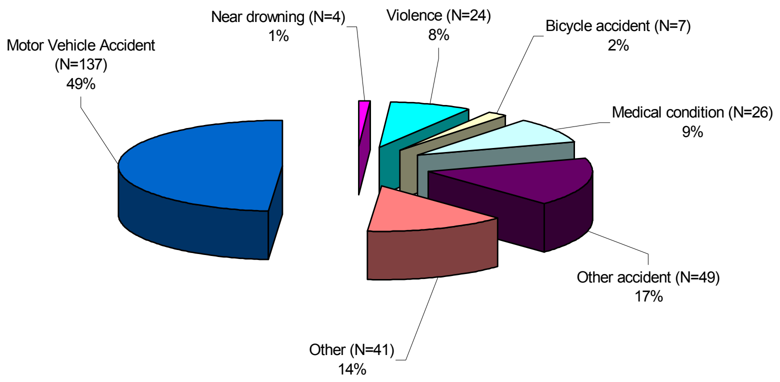
Age of the TBI respondents at the time of completing the survey was assessed. Two hundred and two surveys had current age completed. The mean age was 38.6 years, with a range from 4 years to 75 years. The median age of respondents was 38 years. Respondents were divided into age groups based on their age at the time of the survey. Seventy (70) surveys did not have age information. Another variable assessed was the number of years since the TBI occurred. The average time since the TBI was 12.6 years, the median number of years was 10, and the range was less than a year to 56 years.

Age Group of TBI Respondents	Number (%)
Aged 0 – 4 years	1 (0.5%)
Aged 5 – 17 years	6 (3.0%)
Aged 18 – 64 years	185 (91.5%)
Aged 65+ years	10 (5.0%)

Age at the time of injury was also assessed. Two hundred and fifty-two (252) surveys contained age at the time of the TBI. The mean age was 27 years old, with a range from 0 (less than 1 year) to 72 years. The median age at TBI was 24.

Twenty-five (25) surveys indicated a second TBI. The mean age at injury two was 28 years, with a range from 1 to 72 years. The median age at the second injury was 24 years.

Number and percent by cause of TBI, 272 respondents*



*Because some respondents had more than one TBI, the total exceeds 272.

Cause Of TBI

Another factor we considered, besides the cause of the TBI was where the injury occurred and if safety devices were used. Of the completed surveys, 46 respondents indicated that their injury occurred while at work. Of the 7 individuals with TBI from a bicycle accident, one indicated they had worn a bicycle helmet at the time of the accident. Of the 137 individuals who indicated their TBI occurred as the result of a motor vehicle injury, 37 indicated they had been wearing a seat belt at the time of the injury.

Hospital/Rehabilitation information

Two hundred and thirty (230) respondents indicated they were treated for their TBI in an acute care hospital. Average length of stay in the hospital was 59 days, with a range from 1 day to 730 days. The median length of stay was 30 days.

One hundred and forty (140) respondents indicated they were treated in a rehabilitation facility. The average length of stay in rehabilitation was 102 days, with a range from 1 day to 720 days. The median length of stay in a rehabilitation facility was 60 days.

Twenty-nine (29) respondents indicated they received care in a nursing home. The average length of stay in a nursing home was 274 days, with a range from 1 day to 1,460 days (4 years). The median length of stay in a nursing home was 100 days.

Forty-nine (49) persons indicated they received care in another type of facility, with home being listed as the most common alternate setting. The average length of stay listed for another setting was 364 days, with a range from 1 day to 2,980 days (8 years). The median length of stay in an alternate setting was 60 days.

Education Since TBI

The needs assessment asked individuals about their educational experiences since their TBI. We divided the 272 respondents into persons aged 19 and older at the time of the TBI and those aged 18 and younger. One hundred and eleven (111) surveys contained a response to the question, "Have you attended school since the injury". Of those over 18 years of age, 92/92 (100%) of the respondents indicated that they had not returned to school since the injury. Of the 19 responses from persons less than 18 years of age at the time of the injury, 6/19 (32%) indicated that they had not returned to school after the injury.

The Table Below Summarizes School Attendance Of Survey Respondents By Age.

Education since TBI	Number
Attended elementary school since TBI for those 0 – 17 years at time of injury	17/23 (74%)
Attended middle school since TBI for those 0 – 17 years at time of injury	26/30 (87%)
Attended high school since TBI for those 0 – 17 years at time of injury	39/45 (87%)
Needed special education because of TBI	
0 – 17 years	39/57 (68%)
18 and older	35/125 (28%)
Attended a university since TBI	
0 – 17 years	23/27 (85%)
18 and older	49/57 (86%)
Attended other school since TBI	
0 – 17 years	14/18 (78%)
18 and older	24/32 (75%)

Information About Advice On TBI Services

One area of interest was how individuals and families with TBI are informed about available services. The following table outlines how information on services was obtained by survey respondents. Because a respondent was asked to select all sources of advice, the total is greater than the total number of respondents.

Provided advice on TBI services	Number
Received advice from no one	87
Received advice from hospital staff	92
Received advice from a mental health counselor	14
Received advice from a spiritual leader or minister	7
Received advice from an attorney	17
Received advice from a self-help or support group	60
Received advice from emergency room staff	13
Received advice from family or friends	41
Received advice from primary care provider	24
Received advice from a social worker	48
Received advice from a specialist	50
Received advice from a vocational rehabilitation counselor	23
Received advice from other source	28

Other Issues Associated With TBI

Fourteen (12%) survey respondents indicated they were bothered “very much” by bad dreams or memories of the TBI injury, 30 (27%) respondents indicated they were bothered “somewhat”, 12 (11%) respondents were “neutral”, 23 (21%) respondents indicated they were bothered “not much”, and 33 (29%) respondents indicated they were bothered “not at all”.

Twenty-eight (11%) survey respondents indicated they were bothered “very much” by bad dreams or memories of a person with TBI, 54 (22%) respondents indicated they were bothered “somewhat”, 25 (10%) respondents were “neutral”, 41 (17%) respondents indicated they were bothered “not much”, and 97 (40%) respondents indicated they were bothered “not at all”.

One survey question asked if the person with TBI found meaning or received help from their spiritual beliefs or groups. Two hundred thirty-one (231) individuals responded to this question with 198 (86%) indicating yes.

Quality Of Life Issues

One key issue for persons with TBI is the impact it has on their life. We attempted to assess the quality of life before and after TBI. The following table summarizes these findings.

Quality of life	Number
Quality of life before TBI	
Excellent	100 (40%)
Above average	65 (26%)
Average	67 (28%)
Below average	10 (4%)
Poor	<5 (2%)
Quality of life after TBI	
Excellent	14 (6%)
Above average	36 (14%)
Average	53 (21%)
Below average	78 (32%)
Poor	66 (27%)

Information About Evaluation For Work Potential

One area of interest was how individuals with TBI are evaluated regarding their work potential. The following table outlines how evaluation of work potential was obtained by survey respondents. Because a respondent was asked to select all sources of evaluation, the total is greater than the total number of respondents.

Work Potential Evaluation	Number
Received no work potential evaluation	87
Received evaluation through job counseling	38
Received evaluation through job placement	39
Received evaluation through vocational testing	103
Received evaluation through job training	43

Received other work potential evaluation	41

Information About Work /Volunteer Experience

A critical area of interest was how individuals with TBI are able to perform work and volunteer activities compared to before their injury. The following table outlines how survey respondents compared their work and volunteer experiences before and after their TBI.

Work / Volunteer Experience	Number
Worked for wages before TBI	195
Work for wages now	95
Worked as a volunteer before TBI	38
Work as a volunteer now	34
Worked off and on before TBI	25
Work off and on now	46
Did not work by choice before TBI	23
Do not work by choice now	37
Not able to find work now	22
Not able to get hired now	40
Not able to do any job	65
Not working because they have no VR counselor	14
Not working because no TBI job accommodations	35
Not working because retired	6
Does not want to work	7
Not working because of other reasons	62

Information About Living Arrangements Of Persons With TBI

One area we assessed is the living arrangements of persons with TBI. The following table outlines the living arrangements of persons with TBI as indicated by survey respondents.

Living arrangement	Number (%)
Type of housing (245 responses)	
Currently living in a house / apartment	216 (88%)
Currently living in a group home	11 (4.5%)
Currently living with a professional caregiver	11 (4.5%)
Currently living in a rehabilitation facility	<5 (1.5%)
Currently living in a nursing home	<5 (1%)
Currently homeless	<5 (0.5%)
Household members (296 responses)	
Living with spouse	78 (26%)
Living with parents	67 (23%)
Living alone	58 (20%)
Living with children	53 (18%)
Living with other	40 (13%)

Information About Transportation Issues

The Following Table Outlines How Persons With TBI Access Transportation.

Transportation issues (351 responses)	Number (%)
Travel with own car	143 (41%)
Travel with family / friends	97 (28%)
Travel with public transportation	38 (11%)
Travel with others	36 (10%)
Travel with professional caregiver	29 (8%)
Not able to get transportation	8 (2%)

Information About Drug /Alcohol Use

The Following Table Describes Drug And Alcohol And Legal Trouble By Survey Respondents.

Drug / Alcohol / Legal Issues	**Number (%)**
Legal trouble since TBI (190 responses)	87 (46%)
Use of alcohol or illicit drugs (248 responses)	
Never use	162 (65%)
Use 1-2 times per month	32 (13%)
Use 1–2 times per year	28 (11%)
Use 3-5 times per week	17 (7%)
Use 3-5 times per day	9 (4%)

Information about changes in life issues since TBI

The following table describes changes in life issues since TBI obtained by survey respondents.

Work Potential Evaluation	**Number (%)**
TBI changed employment	190 (98%)
TBI changed living situation	142 (95%)
TBI changed marriage / family	158 (97%)
TBI changed medical health	178 (99%)
TBI changed psychological health	195 (99%)
TBI changed social status	168 (98%)

Information about income

The Following Table Describes The Income Of Survey Respondents.

Income of persons with TBI	**Number (%)**
Less than $7,500	76 (33%)
$7,500 - $14,999	42 (18%)

$15,000 - $24,999	33 (14%)
$25,000 - $34,999	19 (8%)
$35,000 - $49,999	26 (11%)
$50,000 - $74,999	21 (9%)
$75,000 or more	16 (7%)

The Following Table Describes The Sources Of Income For Survey Respondents.

Work Potential Evaluation	Number
Had income from social security or retirement	135
Had income from employment	100
Had income from family / friends	66
Income from a TBI legal settlement	26
Had income from public assistance	18
Had income from other source	16
Had income from worker's compensation	9
Had income from unemployment compensation	<5

Information about current needs

The Following Table Describes Housing Needs Of TBI Survey Respondents.

Housing assistance	Number (%)
Help with housing (196 responses)	
Want help	32 (16%)
Have help	47 (24%)
Do not need help	117 (60%)
Satisfaction with housing services	
Satisfied	64
Not satisfied	16

Why are you not receiving assistance	
Not a problem	14
Do not know how to get help	20
Can not afford / not insured	9
Can not get to it	6
Primary care giver won't approve	6

The Following Table Describes Employment Needs Of TBI Survey Respondents.

Employment assistance	**Number %)**
Help with employment (178 responses)	
Want help	73 (41%)
Have help	31 (17%)
Do not need help	74 (42%)
Satisfaction with employment services	
Satisfied	37
Not satisfied	32
Why are you not receiving assistance	
Not a problem	10
Do not know how to get help	41
Can not afford / not insured	12
Can not get to it	12
Primary care giver won't approve	<5

The Following Table Describes Personal Care Needs Of TBI Survey Respondents.

Personal care assistance	**Number (%)**
Help with personal care (188 responses)	
Want help	12 (6%)

Have help	46 (24%)
Do not need help	130 (70%)
Satisfaction with personal care services	
Satisfied	62
Not satisfied	8
Why are you not receiving assistance	
Not a problem	10
Do not know how to get help	9
Can not afford / not insured	8
Can not get to it	<5
Primary care giver won't approve	<5

The Following Table Describes Chore Help Needs Of TBI Survey Respondents.

Chore assistance	Number (%)
Help with chores (184 responses)	
Want help	24 (13%)
Have help	44 (24%)
Do not need help	116 (63%)
Satisfaction with chore assistance	
Satisfied	55
Not satisfied	11
Why are you not receiving assistance	
Not a problem	12
Do not know how to get help	13
Can not afford / not insured	11
Can not get to it	5
Primary care giver won't approve	<5

The Following Table Describes Transportation Needs Of TBI Survey Respondents.

Transportation assistance	**Number (%)**
Help with transportation (196 responses)	
Want help	35 (18%)
Have help	58 (30%)
Do not need help	103 (52%)
Satisfaction with transportation services	
Satisfied	58
Not satisfied	18
Why are you not receiving assistance	
Not a problem	14
Do not know how to get help	14
Can not afford / not insured	13
Can not get to it	7
Primary care giver won't approve	<5

The Following Table Describes Speech Therapy Needs Of TBI Survey Respondents.

Speech therapy assistance	**Number (%)**
Help with speech therapy (186 responses)	
Want help	34 (18%)
Have help	20 (11%)
Do not need help	132 (71%)
Satisfaction with speech therapy assistance	
Satisfied	42
Not satisfied	11
Why are you not receiving assistance	
Not a problem	12

Do not know how to get help	11
Can not afford / not insured	15
Can not get to it	<5
Primary care giver won't approve	<5

The Following Table Describes Nursing Needs Of TBI Survey Respondents.

Nursing assistance	Number (%)
Help with nursing (184 responses)	
Want help	8 (4%)
Have help	26 (14%)
Do not need help	150 (82%)
Satisfaction with nursing services	
Satisfied	36
Not satisfied	7
Why are you not receiving assistance	
Not a problem	14
Do not know how to get help	7
Can not afford / not insured	5
Can not get to it	<5
Primary care giver won't approve	<5

The Following Table Describes Recreational Needs Of TBI Survey Respondents.

Recreational assistance	Number (%)
Help with recreational needs (186 responses)	
Want help	44 (24%)
Have help	33 (18%)
Do not need help	109 (58%)
Satisfaction with recreation services	
Satisfied	44
Not satisfied	22
Why are you not receiving assistance	
Not a problem	12
Do not know how to get help	19
Can not afford / not insured	11
Can not get to it	6
Primary care giver won’t approve	<5

The Following Table Describes Cognitive Training Needs Of TBI Survey Respondents.

Cognitive training assistance	Number (%)
Help with cognitive training (189 responses)	
Want help	73 (39%)
Have help	33 (17%)
Do not need help	83 (44%)
Satisfaction with cognitive training services	
Satisfied	38
Not satisfied	21
Why are you not receiving assistance	
Not a problem	10

Do not know how to get help	41
Can not afford / not insured	18
Can not get to it	5
Primary care giver won't approve	<5

The Following Table Describes Money Management Needs Of TBI Survey Respondents.

Money management assistance	**Number (%)**
Help with money management (196 responses)	
Want help	44 (22%)
Have help	58 (30%)
Do not need help	94 (48%)
Satisfaction with money management services	
Satisfied	56
Not satisfied	14
Why are you not receiving assistance	
Not a problem	12
Do not know how to get help	23
Can not afford / not insured	9
Can not get to it	<5
Primary care giver won't approve	<5

The Following Table Describes Community Skills Needs Of TBI Survey Respondents.

Community skills assistance	**Number (%)**
Help with community skills (183 responses)	
Want help	48 (26%)
Have help	36 (20%)
Do not need help	99 (54%)
Satisfaction with community skills services	

Satisfied	40
Not satisfied	14
Why are you not receiving assistance	
Not a problem	14
Do not know how to get help	30
Can not afford / not insured	11
Can not get to it	5
Primary care giver won't approve	<5

The Following Table Describes Occupational Therapy Needs Of TBI Survey Respondents.

Occupational therapy assistance	Number (%)
Help with occupational therapy (180 responses)	
Want help	57 (32%)
Have help	30 (17%)
Do not need help	93 (51%)
Satisfaction with occupational therapy services	
Satisfied	37
Not satisfied	15
Why are you not receiving assistance	
Not a problem	12
Do not know how to get help	31
Can not afford / not insured	23
Can not get to it	6
Primary care giver won't approve	<5

The Following Table Describes Physical Therapy Needs Of TBI Survey Respondents.

Physical therapy assistance	**Number (%)**
Help with physical therapy (180 responses)	
Want help	43 (24%)
Have help	39 (22%)
Do not need help	98 (54%)
Satisfaction with physical therapy services	
Satisfied	40
Not satisfied	17
Why are you not receiving assistance	
Not a problem	12
Do not know how to get help	17
Can not afford / not insured	22
Can not get to it	<5
Primary care giver won’t approve	6

The Following Table Describes Mental Health Needs Of TBI Survey Respondents.

Mental health assistance	**Number (%)**
Help with mental health (182 responses)	
Want help	56 (31%)
Have help	54 (30%)
Do not need help	72 (39%)
Satisfaction with mental health services	
Satisfied	48
Not satisfied	21
Why are you not receiving assistance	
Not a problem	10

Do not know how to get help	31
Can not afford / not insured	21
Can not get to it	7
Primary care giver won't approve	<5

The Following Table Describes Financial Assistance Needs Of TBI Survey Respondents.

Financial assistance	**Number (%)**
Help with financial matters (85 responses)	
Want help	24 (28%)
Have help	16 (19%)
Do not need help	45 (53%)
Satisfaction with financial services	
Satisfied	12
Not satisfied	11

The Following Table Describes Respite Care Assistance Needs Of TBI Survey Respondents.

Respite care assistance	**Number (%)**
Help with respite care (87 responses)	
Want help	26 (30%)
Have help	11 (13%)
Do not need help	50 (57%)
Satisfaction with respite services	
Satisfied	12
Not satisfied	7
Why are you not receiving assistance	
Do not know how to get help	11
Can not afford / not insured	5
Can not get to it	<5
Primary care giver won't approve	<5

APPENDIX B

MAILED STATEWIDE NEEDS AND RESOURCES SURVEY, 2001

AGENCY/PROVIDER STATEWIDE TRAUMATIC BRAIN INJURY NEEDS ASSESSMENT SURVEY

Mailed Statewide Needs and Resources Survey, 2001

Agency/Provider Statewide Traumatic Brain Injury Needs Assessment Survey

The next series of questions asked agencies/providers for specific information about the individuals with TBI they served. The median number of individuals with TBI served from January 1 to December 31, 2000 was 5, with a range from 0 to 536.

The Following Table Describes Individuals Treated For TBI

Characteristic	Median number served	Range served
Gender		
Males	3	0 – 356
Females	2	0 – 180
Age Group		
Children	3	0 – 158
Senior citizens	3	0 – 37
Race / Ethnicity		
White	4	0 – 218
Hispanic	1	0 – 62
African American	0	0 – 8
Asian	0	0 – 1
Native American	1	0 – 5

Next, each agency and/or provider was asked to indicate which Idaho counties they served. Seventeen (17) respondents indicated they served all Idaho counties. A breakdown by county is provided in the following table.

County of service	Number	County of service	Number
Ada	12	Gem	4
Adams	3	Gooding	10
Bannock	8	Idaho	5
Bear Lake	6	Jefferson	8
Benewah	2	Jerome	7

Bingham	7	Kootenai	6
Blaine	5	Latah	3
Boise	4	Lemhi	4
Bonner	7	Lewis	4
Bonneville	10	Lincoln	4
Boundary	3	Madison	11
Butte	6	Minidoka	8
Camas	2	Nez Perce	2
Canyon	11	Oneida	1
Caribou	3	Owyhee	4
Cassia	6	Payette	4
Clark	6	Power	4
Clearwater	3	Shoshone	5
Custer	5	Teton	8
Elmore	3	Twin Falls	12
Franklin	3	Valley	3
Fremont	9	Washington	6

Next, respondents were asked if their organization employed designated staff specifically assigned to work on issues related to TBI. The following table shows these results by area of expertise.

Staff dedicated in each area	**Number**
Staff dedicated to TBI issues	44
Specific areas of support for persons/families with TBI	
Alcohol and drug addiction	8
Mental health counseling	13
Family support	17
Employment issues	8

Housing issues	6
Transportation issues	14
Education	24
Assistive technology	20
Other	9

Information on TBI services

Next, agencies and providers were asked if they have programs specifically developed for underserved populations, particularly pediatrics, geriatrics, and/or minority groups. Thirty-six (36) agencies/providers responded that they have special programs developed for underserved groups.

When asked about direct services to affected individuals and families, 60 respondents indicated that they provide direct care, such as treatment, therapy or transportation, to individuals with TBI. The tables below provide information on the types of prevention services provided and information on the types of acute care services provided to individuals with TBI.

Number Of Agencies/Providers Addressing Prevention Of TBI

Prevention Services	Number
Do you provide prevention services?	24
Primary prevention of intentional injuries (shaken baby syndrome, violence, etc.)	10
Primary prevention of unintentional injuries (falls, occupant protections, etc.)	17
Secondary prevention of disabling conditions	12
Other	6

Acute Care Services For Individuals With TBI

Service	Number
Do you provide acute care services?	47
Acute medical care	24
Discharge planning/service coordination	21
Dental care	7

Emergency medical care	34
Family education, information & training	21
Pre-hospital transport and treatment	17
Discharge protocols at all levels of TBI	9
Family mentoring	10
Referrals to subspecialties	22
Substance abuse screening	10
Telehealth/telemedicine (2-way television)	4
Trauma systems	13
Psychiatry/psychology	19
Other	9

Specifics about services and locations provided

Acute Rehabilitation Services And Setting Provided

Acute rehabilitation	Number
Inpatient services	14
Outpatient services	14
Community based services	<5
Community re-entry services	8
Day treatment services	8
Residential services	<5
Skilled nursing services	10
Home based services	7
Other	<5

Advocacy Training Services And Setting Provided

Advocacy training services	Number
Inpatient services	5
Outpatient services	6
Community based services	6
Community re-entry services	<5
Day treatment services	<5
Residential services	<5
Skilled nursing services	<5
Home based services	7
Other	<5

Assistive Technology Services And Setting Provided

Assistive technology services	Number
Inpatient services	11
Outpatient services	15
Community based services	8
Community re-entry services	8
Day treatment services	6
Residential services	<5
Skilled nursing services	<5
Home based services	7
Other	10

Case Management Services And Setting Provided

Case Management Services	Number
Inpatient services	12
Outpatient services	12

Community based services	13
Community re-entry services	5
Day treatment services	5
Residential services	<5
Skilled nursing services	5
Home based services	9
Other	<5

Cognitive Therapy Services And Setting Provided

Cognitive Therapy Services	Number
Inpatient services	12
Outpatient services	17
Community based services	9
Community re-entry services	<5
Day treatment services	6
Residential services	<5
Skilled nursing services	<5
Home based services	<5
Other	5

Community/Agency Referral Services And Setting Provided

Community/Agency Referral Services	Number
Inpatient services	17
Outpatient services	16
Community based services	14
Community re-entry services	8
Day treatment services	6
Residential services	6

Skilled nursing services	7
Home based services	11
Other	<5

Dental Care Services And Setting Provided

Dental Care Services	**Number**
Inpatient services	6
Outpatient services	<5
Community based services	<5
Community re-entry services	<5
Day treatment services	<5
Residential services	<5
Skilled nursing services	<5
Home based services	<5
Other	<5

Driver Education Services And Setting Provided

Driver Education Services	**Number**
Inpatient services	7
Outpatient services	12
Community based services	6
Community re-entry services	<5
Day treatment services	5
Residential services	<5
Skilled nursing services	<5
Home based services	<5
Other	7

Education/Special Education Services And Setting Provided

Education / Special Education Services	Number
Inpatient services	6
Outpatient services	11
Community based services	9
Community re-entry services	<5
Day treatment services	<5
Residential services	<5
Skilled nursing services	<5
Home based services	<5
Other	15

Independent Living Skills And Setting Provided

Independent Living Skills	Number
Inpatient services	14
Outpatient services	14
Community based services	10
Community re-entry services	<5
Day treatment services	8
Residential services	<5
Skilled nursing services	<5
Home based services	6
Other	7

Neurobehavioral Treatment Services And Setting Provided

Neurobehavioral Treatment Services	Number
Inpatient services	9
Outpatient services	7
Community based services	5
Community re-entry services	<5
Day treatment services	6
Residential services	<5
Skilled nursing services	<5
Home based services	<5
Other	<5

Neuropsychology Services And Setting Provided

Neuropsychology Services	Number
Inpatient services	10
Outpatient services	11
Community based services	5
Community re-entry services	<5
Day treatment services	6
Residential services	<5
Skilled nursing services	<5
Home based services	<5
Other	<5

Nursing Services And Setting Provided

Nursing Services	Number
Inpatient services	19
Outpatient services	14

Community based services	<5
Community re-entry services	<5
Day treatment services	<5
Residential services	<5
Skilled nursing services	10
Home based services	11
Other	<5

Occupational Therapy Services And Setting Provided

Occupational Therapy Services	Number
Inpatient services	18
Outpatient services	21
Community based services	9
Community re-entry services	5
Day treatment services	9
Residential services	<5
Skilled nursing services	8
Home based services	10
Other	13

Orthodontics/Prosthetics Services And Setting Provided

Orthodontics/Prosthetics Services	Number
Inpatient services	8
Outpatient services	8
Community based services	<5
Community re-entry services	<5
Day treatment services	4
Residential services	<5

Skilled nursing services	<5
Home based services	<5
Other	<5

Physical Therapy Services And Setting Provided

Physical Therapy Services	Number
Inpatient services	17
Outpatient services	21
Community based services	9
Community re-entry services	5
Day treatment services	10
Residential services	<5
Skilled nursing services	8
Home based services	10
Other	11

Pre-Vocational Services And Setting Provided

Pre-Vocational Services	Number
Inpatient services	10
Outpatient services	11
Community based services	11
Community re-entry services	<5
Day treatment services	6
Residential services	<5
Skilled nursing services	<5
Home based services	<5
Other	8

Psychiatry Services And Setting Provided

Psychiatry Services	**Number**
Inpatient services	12
Outpatient services	8
Community based services	<5
Community re-entry services	<5
Day treatment services	<5
Residential services	<5
Skilled nursing services	<5
Home based services	<5
Other	<5

Psychology Services And Setting Provided

Psychology Services	**Number**
Inpatient services	12
Outpatient services	12
Community based services	7
Community re-entry services	<5
Day treatment services	6
Residential services	<5
Skilled nursing services	6
Home based services	<5
Other	<5

Social Work Services And Setting Provided

Social Work Services	Number
Inpatient services	18
Outpatient services	19
Community based services	8
Community re-entry services	5
Day treatment services	9
Residential services	<5
Skilled nursing services	9
Home based services	11
Other	5

Speech & Language Therapy Services And Setting Provided

Speech & Language Therapy	Number
Inpatient services	18
Outpatient services	21
Community based services	9
Community re-entry services	5
Day treatment services	11
Residential services	<5
Skilled nursing services	6
Home based services	9
Other	16

Substance Abuse Assessment & Treatment Services And Setting Provided

Substance Abuse Assessment & Treatment	Number
Inpatient services	8
Outpatient services	8
Community based services	7
Community re-entry services	<5
Day treatment services	<5
Residential services	<5
Skilled nursing services	<5
Home based services	<5
Other	<5

Swallowing Services And Setting Provided

Swallowing Services	Number
Inpatient services	18
Outpatient services	14
Community based services	<5
Community re-entry services	<5
Day treatment services	6
Residential services	<5
Skilled nursing services	8
Home based services	5
Other	<5

Telehealth/Telemedicine Services And Setting Provided

Telehealth/Telemedicine Services	Number
Inpatient services	<5
Outpatient services	<5
Community based services	<5
Community re-entry services	<5
Day treatment services	<5
Residential services	<5
Skilled nursing services	<5
Home based services	<5
Other	<5

Therapeutic Recreation Services And Setting Provided

Therapeutic Recreation Services	Number
Inpatient services	12
Outpatient services	9
Community based services	<5
Community re-entry services	<5
Day treatment services	<5
Residential services	<5
Skilled nursing services	<5
Home based services	<5
Other	<5

Employment Services

Agencies/providers were asked about the types of employment services they provide. The responses are shown in the table below.

Types Of Employment Services Provided

Employment Services	Number
Are employment services provided?	44
Advocacy for employment	15
Assistive technology for employment	25
Career counseling/guidance	24
Job adaptations	20
Job coaching	24
Job development	20
Job placement	19
Pre-vocational services	29
Special skills training	24
Supported employment	13
Vocational evaluation	21
Work adjustment	20
Work support	17
Other	<5

Long-term Community Support Services

Agencies/providers were asked about the types of long-term community support services they provide. The responses are shown in the table below.

Types Of Long-term Community Support Services Provided

Long-term community support services	Number
Do you provide long-term community support services?	40
Advocacy	8
Assistive technology	9
Case management / services coordination	9
Clubhouse	<5

Coma care	<5
Dental	<5
Durable medical supplies/equipment	<5
Family support, training & education	12
Home care / home support	8
Housing (accessible/affordable)	5
Housing (modifications)	5
Independent living services	8
Information / resources	13
Legal services	<5
Mental health services	8
Nursing care	8
Peer support	11
Personal assistance/attendant services	6
Primary care medical services	<5
Recreation / social programs	9
Respite care	8
Skilled nursing facilities	8
Substance abuse treatment	6
Telehealth / Telemedicine	<5
Transitional living services	5
Transportation	14
Other	8

Financial Resources for Persons with TBI

Agencies/providers were asked about the types of financial resource services they provide. The responses are shown in the table below.

Types Of Financial Resources Provided

Financial Resources	Number
Are financial resources provided for persons with TBI?	31
Assistive technology	17
Education	19
Home care / home support	<5
Medical supplies / equipment	14
Transportation	20
Personal Attendant Services	7
Shelter costs (food, rent, utilities, etc.)	<5
Other	9

Education and/or training programs on traumatic brain injury

Agencies/providers were asked if they provide any education and/or training programs on TBI. The responses are shown in the table below.

Types Of Education And/Or Training Services Provided

Education/Training Services	Number
Are education and/or training services provided?	46
Training for individuals with TBI	32
Training for family/significant others	26
Training for law enforcement	<5
Training for health professionals / rehabilitation providers	30
Training for educators/teachers	28
Other	<5

Miscellaneous Questions

Additional questions were asked of respondents. The first question asked if someone from his or her organization participates on the state TBI Advisory Council. Twenty-four (24) respondents indicated yes, they have a representative on the state TBI Advisory Council. Respondents were also asked if they have TBI representation on their organization's task forces or advisory councils, with 17 respondents indicating yes.

Agencies and providers were also asked if they were interested in learning more about telehealth and/or telemedicine, such as two way television, with 62 respondents indicating yes.

Next, agencies and providers were asked to estimate what percentage of their client payment comes from various payment sources. The results are shown in the following table.

Payment Types Of Individuals Treated For TBI

Insurance Type	Median percent served	Range (percent served)
Medicaid	46%	(0 – 100%)
Medicare	13%	(0 - 80%)
Private Insurance	20%	(0 - 100%)
Other	10%	(0 - 100%)

Agencies/providers that chose other as a payment type were asked for more information. The most common answer was that services are provided at no charge through federal and/or state funding and public support.

The next three questions asked agencies/providers how many staff work in their organization, the number of staff who spend at least 50% of their time working with TBI, and the number of hours per year staff spend at brain injury training, such as conferences and workshops specific to TBI. These responses are shown below.

Median Numbers Of Staff And Educational Hours From Responding Agencies/Providers.

Staff issues	Median Number (range)
Total number of staff	25 (1-2,900)
Number of dedicated TBI staff (spend more than 50% of their time on TBI)	1 (0-100)
Number of annual TBI training hours	5 (0-120 hours)

Individuals and family members with TBI were asked if were interested in receiving telehealth in general or telehealth for TBI. The following table lists survey responses.

Interest in Telehealth

Telehealth Information	Number (%)
Interested in telehealth	
Very much	52 (22%)
Somewhat	45 (19%)
Neutral	47 (20%)
Not much	28 (12%)
Not at all	64 (27%)
Telehealth on TBI	
Very much	27 (25%)
Somewhat	31 (29%)
Neutral	12 (11%)
Not much	11 (10%)
Not at all	25 (24%)

APPENDIX C
IDAHO TBI REGIONAL ADVISORY COUNCIL MEMBERS And INTRA-DEPARTMENT WORK GROUP MEMBERS

IDAHO TBI REGIONAL ADVISORY COUNCIL MEMBERS

State Agency Reps	Service Provider Reps	Persons or Family Member with Traumatic Brain Injury
Eastern		
Bonnie Meyers * 150 Shoup Idaho Falls, Idaho 83402	Howard Harper 392 E. Court Street Blackfoot, Idaho 83221	Thomas Benjamin Welch 1550 Teton View Lane #B-11 Idaho Falls, Idaho 83402
Clayton Pearce * 2040 Dana Pocatello, Idaho 83201	Dr. Diane Neilson * Helping Hand Sanctuary of Idaho 56 Plateau Pocatello, ID 83204	Nikki Doll P.O. Box 154 Challis, Idaho 83226
Denis Freudenthal * Pocatello Women's Correctional Ctr 1287 W. Quinn Road Pocatello, Idaho 83202	Donna Hampton 4954 Mauna Lane Idaho Falls, Idaho 83404	Teresa Rushton 2000 W. 4010 North Rexburg, Idaho 83440
Virginia Galizia, Ph.D. * 838 Spyglass Point Pocatello, Idaho 83204	Jill Schuette Pocatello Regional Medical Center 777 Hospital Way Pocatello, Idaho 83201	Mary Callahan P.O. Box 1456 Blackfoot, Idaho 83221
Northern		
	William Wessling 715 S. Cowley Suite 226 Spokane, Washington 99202	Cheryl Allpress P.O. Box 381 Weippe, Idaho 83553
Chris Puckett P.O. Box 509 Craigmont, Idaho 83523	Charles Bean 2005 Ironwood Parkway, Suite 201 Coeur d' Alene, Idaho 83814	Mary Ellen Denton 1106 N. 12th Coeur d' Alene, Idaho 83814
Jean Ann Walker Department of Health and Welfare 709 Dundee Drive Post Falls, Idaho 83854	Chris Bartalamay * 711 S. Cowley, Suite 1023 Spokane, Washington 99801	Pat Bistline P.O. Box 151 Hope, Idaho 83836

State Agency Reps	Service Provider Reps	Persons or Family Member with Traumatic Brain Injury
	Diane Shriner Harmony House Assisted Living 454 West Lacey Avenue Hayden, Idaho 83835	
	Shari Hendrickson * Kootenai Medical Center 2003 Lincoln Way Coeur d’ Alene, Idaho 83814	
Southwest		
Brenda Grupe * Department of Health and Welfare 803 Harrison Twin Falls, Idaho 83301	Dennis Woody, Ph.D. 310 West Hays Street Boise, Idaho 83702	Gladys Esquibel P.O. Box 835 Burley, Idaho 83318
Cynthia Pilant * 11978 Highlander Road Boise, Idaho 83709	Jeanne O’Connor * STARS 717 N. Liberty Boise, Idaho 83704	Marilyn Hern 1547 E. Holly Street Boise, Idaho 83712
Lisa Marshall Council on Dev Disabilities 802 West Bannock, Suite 308 Boise, Idaho 83702	Kami Gillette 832 Alturus Drive Twin Falls, Idaho 83301	Joyce Koeppen 4321 Bear Lane Caldwell, Idaho 83605
Steve Pearce * Idaho State School and Hospital 3100 11th Avenue North Nampa, Idaho 83687	Weslee Wells 1807 E. Laurelwood Drive Eagle, Idaho 83616	Al Becker P. O. Box 64 New Meadows, ID 83814
Bruce Christopherson 4007 Rose Hill Street Boise, Idaho 83705		

* Persons also consisting of someone with a TBI and/or family member

IDAHO TBI INTRA-DEPARTMENT WORK GROUP MEMBERS

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Boise, Idaho 83702

Ginger Floerchinger-Franks
Bureau of Health Promotion- Injury Prevention
Pete T. Cennarrusa Bldg.
450 West State Street
Boise, Idaho 83720

APPENDIX D
CHARTERS FOR THE IDAHO TBI REGIONAL ADVISORY COUNCIL And INTRA-DEPARTMENT WORK GROUP

TRAUMATIC BRAIN INJURY REGIONAL ADVISORY COUNCIL (S) TBI-RAC

Northern/Southwest/Eastern

CHARTER

December, 2000

Goal: To develop a comprehensive, coordinated, community-based system of support for individuals with a traumatic brain injury and their families that addresses all age groups, levels of acuity, and racial and ethnic groups.

Purpose: To guide and advise the state in developing a system of supports for traumatic brain injury.

OBJECTIVES:

1. Support the completion of a thorough statewide assessment of needs and resources.

2. Support the development of a statewide action plan.

3. Increase both intra and inter-agency collaboration on TBI supports

AUTHORITY: Through the Institute of Rural Health at Idaho State University, the advisory councils report to and receive guidance and resources from the Director of the Department of Health and Welfare

DECISION-MAKING: Advisory council decisions will be made, when possible, by consensus or through the democratic process with a quorum needed to ratify a decision. Split decisions will be reported to the Executive Committee for action.

SCOPE: The advisory councils:

Are chartered until June 30, 2002 (and will at that time review its charter and either disband or revise its charter to reflect its updated purpose and goals);

Will at least bi-annually report its progress or barriers to progress to its authority entities and the advisory council members;

Will meet as necessary, but not less than quarterly to accomplish the scope of work;

Will limit its work effort to the above goal and objectives (as defined under the contract and within the scope of work and the appointing authority); and

May accomplish its tasks in small work groups, sub-committees and/or outside regularly scheduled meetings.

MEMBERSHIP:

A. Members will be recommended for appointment in accordance with the TBI Act (P.L 104-166) and accompanying amendments Sec. 1252 (b) 3 –Advisory Council

B. The Skills/Knowledge/Abilities members need is: knowledge and understanding of traumatic brain injury; ability to make decisions; ability to effectively solve problems; and basic group processing skills.

C. Members' Roles and Responsibilities will be: to attend all scheduled meetings unless excused by the chair; actively participate in a positive and helpful manner; complete assignments on time; seek assistance as needed; seek group consensus; manage conflict effectively; keep effective minutes or notes of advisory council activities and decisions; assist in developing an action plan for the state.

OTHER RESOURCES: These advisory councils will continually seek resources outside the group to advise, guide, assist and otherwise coordinate and partner with, such as: The Governor's Office; legislators; other work groups or committees involved in traumatic brain injury or TBI related services; consumers, customers, clients and advocates; etc.

TBI Statewide Executive Committee: The chairs from each of the three regional advisory councils (3) and one additional person from each council and two members of the intra-department work group for a total of eight individuals will make up the statewide Executive Committee. At least three of these representatives will be individuals with a TBI or family members.

The Statewide Executive Committee shall meet as needed, either in person or via conference call, within budget parameters.

AUTHORITY: The Statewide Executive Committee through the Institute of Rural Health at Idaho State University is responsible for ensuring linkage with the Intra Department work group; provides leadership and direction to other regional advisory council members

DECISION-MAKING: Statewide Executive Committee decisions will be made, when possible, by consensus or through the democratic process with a quorum needed to ratify a decision. Split decisions will be reported to the Institute of Rural Health and Department of Health and Welfare for approval.

Statewide Executive Committee Roles/Responsibilities: Each of the three advisory council chairs along with one representative from each advisory council will work closely with the project manager by assisting in making arrangements for all meetings, developing and circulating an agenda prior to each meeting, arranging as necessary for meeting facilitators, provide all handouts 10 days in advance of scheduled meetings, and otherwise provide the tools and resources to maximize the effectiveness of the business of the advisory council.

Statewide Executive Committee Chairs are responsible for: attending and participating in meetings of the advisory council and committee; developing and implementing a plan for communicating advisory council and committee recommendations back to their respective regional council, organizations or constituencies; developing and implementing a plan for gathering stakeholder comments on the advisory council and committees work and reporting outcomes to those stakeholders; provide the advisory council with information they or their organizations have gathered that affect council/committee decisions.

OTHER GUIDANCE OR CLARIFICATION - ADVISORY COUNCILS WILL:

1. Develop a common lexicon of words or terms that will increase communication effectiveness and minimize misunderstandings and miscommunications.

2. Keep any system design simple without unnecessary layers or complexity.

3. Consider the effectiveness of breaking into smaller workgroups or subcommittees based on priorities in accomplishing work.

4. In conjunction with the Intra-Department work group, and representatives from Inter Departmental agencies examine funding sources (including obtaining accurate data of amounts and sources) and availability for additional funds or other types and kinds of resources and report to the Statewide Executive Committee and make recommendations

5. Actively identify and coordinate/cooperate with other work groups or committees, interagency representatives engaged in similar TBI activities or in other activities that might impact TBI services (e.g., Medicaid, substance abuse, etc.).

6. Make certain the advisory councils products and processes are congruent with current as well as changing policies, procedures and processes of the Department of Health and Welfare’s strategic plan, other state, county and local agencies, the Governor’s Office, the legislature, and the various and involved associations.

7. Resolve issues that may create barriers to developing and implementing an effective comprehensive, coordinated system of supports by fully partnering with persons with TBI and their families toward participatory and inclusive person-centered solutions. Such as: finding ways and means to increase the effectiveness of communication between all involved parties; seek a common clarity of purpose, procedures and processes; challenge assumptions and seek common

understanding; find ways and means to increase coordination and integration of services in order to save resources and maximize services; and challenge statements and attitudes of "we can't do that" and replace them with "how can we?"

I Karl B. Kurtz charter this group effective December 15, 2000.

Karl B. Kurtz, Director Date
Department of Health and Welfare

TRAUMATIC BRAIN INJURY INTRA-DEPARTMENT WORK GROUP (TBI-IDWG)

Charter

December, 2000

Goal: To assess, determine and complete the necessary procedures and guidelines to solidify and institutionalize the role of the Department of Health and Welfare, Division of Family and Community Services, as the lead coordinating agency for a TBI support system and to insure the ongoing operation of the TBI program.

Purpose: To review areas for internal service coordination, identify service needs, determine areas for improved collaboration, explore coordination of resources, participate in the assessment and action planning process in collaboration with the three regional advisory councils.

AUTHORITY: Through the Institute of Rural Health at Idaho State University, the workgroup reports to and receives guidance and resources through the Director of the Department of Health and Welfare.

> *Product/Result: A written collaboration agreement will be developed to assure defining what each party can contribute to the system, how information will be shared, and a defined set of actions to include in the TBI action plan for the state.*

DECISION-MAKING: TBI-IDWG decisions will be made by consensus or through the democratic process with a quorum needed to ratify a decision.

SCOPE: This workgroup:

Is chartered until June 30, 2002 (and will at that time review its charter and either disband or revise its charter to reflect its updated purpose and goals);

Will at least bi-annually report its progress or barriers to progress to its authority entities and the three regional advisory councils through the Executive Committee;

Will meet at least quarterly to accomplish the scope of work;

Will limit its work effort to the above goal and purpose (as defined under the contract and within the scope of work and the appointing authority); and

May over time include representatives consisting of other interagency personnel consisting of agencies that have an interest/responsibility in serving individuals with TBI (e.g. Office of Highway Safety –Transportation Department, Vocational Rehabilitation, Law Enforcement, etc.)

COMPOSITION: The TBI Intra - Department Work Group (TBI-IDWG) will consist of (8) persons representing the following:

Members will consist of representatives from the following Divisions within the Department:

Division of Family and Community Services:
The Chief of the Bureau of Developmental Disabilities or their designee
The Chief of the Bureau of Mental Health and Substance Abuse or their designee
The state's Manager of the Infant Toddler Program
The Administrator of the Idaho State School and Hospital or their designee

Division of Health:
The Chief of the Bureau of Emergency Medical Services or their designee
The state Manager for the Bureau of Health Promotion, Injury Prevention Program
The Chief of the Bureau of Vital Statistics and Health Policy or their designee

Division of Medicaid:
The Administrator of the Division of Medicaid or their designee

D. The **Skills/Knowledge/Abilities** members need is: knowledge and understanding of traumatic brain injury policy within their respective authority; ability to make decisions; ability to effectively solve problems; and basic group processing skills.

E. Members' **Roles and Responsibilities** will be: to attend all scheduled meetings unless excused by the convener of the meeting; actively participate in a positive and helpful manner; complete assignments on time; seek group consensus; manage conflict effectively; keep effective minutes or notes of TBI-IDWG activities and decisions; model effective service coordination and integration principles; assist in developing an action plan for the state.

Members of the Intra-agency group, when practical, may also participate in meetings involving the Northern, Eastern, and Southeast regional advisory councils.

OTHER RESOURCES: This TBI-IDWG will continually seek resources outside the group to advise, guide, assist and otherwise coordinate and partner with, such as: The Governor's Office; legislators; other TBI-IDWGs or committees involved in traumatic brain injury or TBI related services; consumers, customers, clients and advocates; etc.

OTHER GUIDANCE OR CLARIFICATION – TBI INTRA-DEPARTMENT WORK GROUP MEMBERS WILL:

8. Develop a common lexicon of words or terms that will increase communication effectiveness and minimize misunderstandings and miscommunications.

9. Keep any system model simple without unnecessary layers or complexity.

3. In conjunction with the regional advisory councils, examine funding sources (including obtaining accurate data of amounts and sources) and availability for additional funds or other types and kinds of resources for the action plan.

4. Actively identify and coordinate/cooperate with other TBI-IDWGs or committees, interagency representatives engaged in similar TBI activities or in other activities that might impact TBI services (e.g., Medicaid, substance abuse, etc.).

5. Make certain the TBI-IDWGs products and processes are congruent with current as well as changing policies, procedures and processes of the Department of Health and Welfare's strategic plan, other state, county and local agencies, the Governor's Office, the legislature, the regional TBI advisory boards and the various and involved associations.

6. Resolve issues that may create barriers to developing and implementing an effective comprehensive, coordinated system of care for persons with a traumatic brain injury and their families, such as: find ways and means to increase the effectiveness of communication between all involved parties; seek a common clarity of purpose, procedures and processes; challenge assumptions and seek common understanding; find ways and means to increase coordination and integration of services in order to save resources and maximize services; and challenge statements and attitudes of "we can't do that" and replace them with "how can we?"

I Karl B. Kurtz charter this group effective December 15, 2000.

Karl B. Kurtz, Director Date
Department of Health and Welfare