STUDY OF TRAUMATIC HEAD INJURIES

Bulletin No 91-3

LEGISLATIVE COMMISSION
OF THE
LEGISLATIVE COUNSEL BUREAU
STATE OF NEVADA

SEPTEMBER 1990

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LEGISLATIVE COMMISSION

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LEGISLATIVE COUNSEL BUREAU

CARSON CITY, NEVADA

SEPTEMBER 1990

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Senate Concurrent Resolution No 41—Committee on Finance

FILE NUMBER 193

SENATE CONCURRENT RESOLUTION—Directing the Legislative Commission to conduct an interim study of traumatic head injuries

WHEREAS There are people in the state who have suffered traumatic head injuries and who do not receive support from any source and

WHEREAS There would be a significant cost to the establishment of a program for the treatment of traumatic head injuries and

WHEREAS The coordination of services and available resources is necessary to ensure the success of a program for the treatment of traumatic head injuries now therefore be it

RESOLVED BY THE SENATE OF THE STATE OF NEVADA THE ASSEMBLY CONCURRING That the Legislative Commission is hereby directed to conduct an interim study of the treatment of traumatic head injuries and be it further

RESOLVED That the Legislative Commission report the results of the study and any recommended legislation to the 66th session of the Nevada Legislature

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REPORT OF THE LEGISLATIVE COMMISSION

TO THE MEMBERS OF THE 66TH SESSION

OF THE NEVADA LEGISLATURE

This report is submitted in compliance with Senate Concurrent Resolution No 41 of the 65th session of the Nevada Legislature which directed the Legislative Commission to study traumatic head injuries in Nevada

The members of the subcommittee appointed by the Legislative Commission to conduct the study were

Senator Mike Malone, Chairman
Assemblyman Bob L Kerns Vice Chairman
Senator Dean A Rhoads
Assemblywoman Vivian L Freeman

Legislative Counsel Bureau staff services for the subcommittee were provided by H Pepper Sturm of the Research Division (principal staff), Tom Linden of the Legal Division (legal counsel) and Kay Graves of the Research Division (subcommittee secretary)

In this report, the subcommittee has attempted to concisely present its findings and recommendations All of the supporting documents and the minutes of the subcommittee are on file in the Research Library of the Legislative Counsel Bureau and are available for review

This report is transmitted to the members of the 66th session of the Nevada Legislature for their consideration and appropriate action

Respectfully Submitted,

Legislative Commission
Legislative Counsel Bureau
State of Nevada

Carson City, Nevada
September 1990

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LEGISLATIVE COMMISSION

Assemblyman John E Jeffrey, Chairman
Assemblyman Robert M Sader Vice Chairman

Senator Charles W Joerg	Assemblyman Louis W Bergevin
Senator William R O'Donnell	Assemblyman Joseph E Dini, Jr
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Senator Randolph J Townsend	Assemblyman Danny L Thompson
Senator John M Vergiels	

SUMMARY OF RECOMMENDATIONS

The Legislative Commission s Subcommittee to Study Traumatic Head Injuries recommends that the 66th session of the Nevada Legislature

1 Provide, by statute, that the Rehabilitation Division of the Department of Human Resources (DHR) establish a specific program designed to address the specialized requirements of traumatic brain injury (TBI) patients and their families Subject to the availability of funds, the program shall include

   a Direct services such as attendant care, case management, day treatment, independent living skills training, supported employment for survivors of TBI and transitional residential care,

   b A preventative/educational component

   c A substance abuse intervention and treatment component and

   d Support services, such as respite care, for families of TBI victims

   The division shall monitor the incidence of head injuries in Nevada and evaluate the effectiveness of programs established within the state The agency shall report the results of these evaluations at each regular session of the Legislature (BDR 38-163)

2 Define, within statute, TBI as a distinct disability to be served by specific state programs such as those for alcohol and drug abuse, Medicaid, and vocational rehabilitation, among others These services would be subject to eligibility and budget constraints existing under current federal and state law (BDR 38-163)

3 Urge, by resolution, substance abuse self-help support groups, such as Alcoholics Anonymous, to address the special needs of TBI patients (BDR R-374)

4 Require, by statute, that the Rehabilitation Division establish standards of care for TBI patients based upon the criteria established by the national Commission on Accreditation of Rehabilitation Facilities (BDR 38-165)

5 Encourage mental health therapy programs for TBI patients to use a behavioral component to ameliorate the psychological symptoms often associated with this injury

6 Establish that funding for state-administered programs for TBI patients and their families shall be accomplished with funds from Nevada's State Industrial Insurance System existing federal and state programs, such as Medicaid, Supplemental Security Income and Title I and the state general fund through revenues developed by increasing certain alcohol taxes It is estimated that an appropriation of $919,467 is needed for fiscal year (FY) 1991-1992 and $928,224 is required for FY 1992-1993 (BDR S-168)

7 Encourage Nevada s Medicaid program to include coverage for psychological services rendered in acute-care hospitals

8 Increase the state tax on beer by 4 cents per gallon, and recommend that the Legislature consider adequately funding the TBI program (BDR 32-166)

9 Encourage the Insurance Commissioner in Nevada's Department of Commerce to support adequate disclosure, under current statutes (Assembly Bill 114 of the 1989 legislative session [Chapter 586, Statutes of Nevada 1989, pages 1248-1255]), to consumers or health care beneficiaries of the extent and types of coverage for TBI, including policy provisions for catastrophic and long-term care

10 Provide, by statute, that the state maintain a central registry for TBI Such a registry shall be administered by the Division for Review of Health Resources and Costs in DHR in cooperation with the Rehabilitation Division The Division for Review of Health Resources and Costs shall make a statistical report concerning TBI to the Legislature on an annual basis (BDR 38-167)

11 Establish, by statute, a head-injury advisory committee The committee shall be appointed by the Administrator of the Rehabilitation Division to study issues related to TBI, and will advise the division concerning operation

of any TBI program The committee shall study and recommend to the administrator any necessary action concerning existing and potential programs for TBI patients and their families Members shall consist of representatives from family support groups, appropriate state agencies, and other interested parties and will serve without compensation An annual report shall be made by the committee to the Administrator of the Rehabilitation Division, the Nevada Legislature's Committee on Health Care (Nevada Revised Statutes 439B 200), and the Legislative Commission (BDR 38-164)

12 Encourage the Rehabilitation Division to provide training opportunities for the special needs of TBI patients to parents of TBI victims and providers of acute-care and rehabilitative services

13 Continue support of existing educational programs designed to prevent disabling injuries

REPORT TO THE 66TH SESSION OF THE NEVADA LEGISLATURE BY THE LEGISLATIVE COMMISSION S SUBCOMMITTEE TO STUDY HEAD TRAUMA

I INTRODUCTION

The 65th session of the Nevada Legislature adopted Senate Concurrent Resolution No 41 of the 1989 legislative session (File No 193, Statutes of Nevada 1989, page 2371) which directed the Legislative Commission to study the treatment of traumatic head injuries To fulfill this mandate, the Legislative Commission appointed a subcommittee to conduct the study and report its recommendations The subcommittee consisted of four members

Senator Mike Malone, Chairman
Assemblyman Bob L Kerns, Vice Chairman
Senator Dean A Rhoads
Assemblywoman Vivian L Freeman

The subcommittee which conducted the study adopted a total of 13 recommendations addressing specific issues associated with victims of traumatic head injuries, commonly called traumatic brain injuries (TBI)

A total of two meetings were held Testimony was taken from state agencies including the Rehabilitation Division of the Department of Human Resources (DHR) Nevada Medicaid the State Department of Education and the State Industrial Insurance System Other presentations were made by medical experts and by TBI patients and their families

The first meeting of the subcommittee was held on November 30, 1989, at McCarran International Airport in Las Vegas, Nevada At this hearing, the subcommittee heard testimony regarding the incidence of TBI in Nevada the fiscal impact upon various state agencies, medical and care issues and services available in Nevada for TBI victims and their families The members also reviewed personal accounts of the impact of TBI upon patients and family members

The second meeting was held April 30 1990 at the Washoe County Commission Chambers in Reno Nevada The initial part of this hearing was dedicated to receiving additional testimony regarding suggestions for legislative action The remainder of the second meeting was a work session, devoted to the consideration of suggestions previously received, and the adoption of legislative recommendations

The subcommittee s activities focused upon two tasks first, reviewing the extent and nature of TBI in Nevada as well as problems concerning the availability of programs and services for patients and their families second, proposing the appropriate policies by which the State of Nevada could address these problems

II BACKGROUND

Traumatic brain injury has grown dramatically in the past 25 years as a source of functional impairment and disability This increase may be attributed to faster and more sophisticated emergency medical treatment for trauma victims at the scene of an accident thus resulting in fewer deaths but more survivors with short-term and long-term problems

Traumatic brain injury, has been defined as, * * * damage to the brain, either temporary or permanent, that results when the head is hit, strikes a stationary object or is shaken violently Not included in the definition of TBI is brain damage caused by genetic abnormalities, birth defects, stroke, tumors, or degenerative processes associated with substance abuse or Alzheimer s disease

A INCIDENCE OF INJURY

National estimates of annual incidence of TBI vary widely--some studies estimate the rate at 600 per 100 000 population while others place the figure at around 70 per 100,000 The federal Interagency Head Injury Task Force Report (1989) estimates an incidence rate of 200 per 100,000 population or about 500,000 head injuries per year, severe enough to require admission to a hospital By extrapolation, Nevada is estimated to have over 2 000 such cases a year

Statistics from various studies include the following

1 Males are twice as likely as females to sustain TBI

2 The highest incidence occurs in the 15 to 25 year age group and

3 The incidence among black and Hispanic minorities is 30 to 70 percent higher when compared to whites

These statistics are of special concern since the demographic groupings are similar to those identified as that part of the work force that typically does not have medical insurance

B MEDICAL AND BEHAVIORAL CONCERNS

In general terms a typical head trauma injured person requires four phases of medical and support care depending upon the severity of the injury

1 Acute care within the hospital environment

2 Post-acute care, requiring special rehabilitation therapies within a residential care environment

3 Transitional rehabilitation directed at resuming reentry into the community and

4 Community-based rehabilitation by way of a case management system

Directed rehabilitation and careful case management are important for TBI patients and their families Following hospitalization for acute care medical problems the injured person and his family may have to endure memory loss as well as emotional, language, behavioral and physical problems various subjective symptoms and a continuing need for supervision

Typically, family members complain about the changed personality of the person with TBI They note such disorders as

Slowness of thinking
Loss of memory
Lack of energy
Impatience
Loss of temper
Aggression
Depression
Mood swings

The incidence of significant disorders varies according to the severity of the injury and the progress made during rehabilitation Some disorders and problem behaviors emerge months after the injury

A common request from advocates and family members is the availability of supervised community residences for those individuals whose uncontrolled behavior will draw the attention of law enforcement officials with subsequent confinement in jail or prison There is also concern that the family will be held liable for any civil damages incurred

Several recent studies indicate a number of violent criminals currently within the Nation s prison system have histories of severe head injuries A recent survey of TBI families living in western New York state disclosed that one-third of the families had a TBI member whose supervisory requirements were sufficiently high to justify placement in a well-supervised community residence with a structured program for modifying problem behaviors

C ECONOMIC CONSEQUENCES

The economic consequences of TBI for individuals and their families are enormous One study estimated the total lifetime cost of care for an individual with TBI at $4 6 million A national study completed in 1989 estimates that the total direct and indirect costs of medical treatment, rehabilitative/support services, and lost income approaches $25 billion annually in the United States The same study estimates the service costs of a typical survivor of a head injury to exceed $4 million during 5 to 10 years of intensive services

Actual expenses vary according to the severity of injury A Maryland study completed in 1988 estimated the first-year TBI costs by severity of injury, as follows

Minor	$ 8 416
Low Moderate	$ 23,708
High Moderate	$ 56,858
Severe	$105,570

Preliminary Nevada data confirms this information According to the Division for Review of Health Resources and Costs in the DHR, 651 persons with severe brain injuries were admitted to Nevada hospitals in 1988 These individuals accounted for more than 6,000 days of hospital care at a cost of over $7 million About half (328) of these claims were paid by private, industrial or Medicaid insurance

According to Nevada s State Industrial Insurance System, Nevada employers have paid over $16 5 million in compensatory and medical benefits to employees who suffered an industrial head injury over the past 5 years

During that same period, 194 Nevada TBI patients were approved for federal Supplemental Security Income and/or Social Security Disability Insurance benefits at about

$1 million dollars annually The majority of these 194 will receive Medicaid benefits ranging from $10 thousand to $70 thousand per year averaging about $35 thousand each (approximately $6 8 million for all 194)

According to the Rehabilitation Division the great majority of these individuals are relatively young (averaging between 15 and 24 years of age) If their rehabilitation needs are not adequately addressed the state may pay for their care in institutions for the rest of their lives That translates to over $3 million across the individual s lifetime

D HEAD TRAUMA ACTIVITIES BY THE FEDERAL GOVERNMENT

In response to a United States Congressional mandate in 1988 the federal Department of Health and Human Services (HHS) established the Interagency Head Injury Task Force The group consisted of key government administrators and was organized to identify problems and formulate solutions to meet the needs of persons with TBI

The report of the task force was released early in 1989 and contains an analysis and recommendations for a national strategy to cope with TBI Primary prevention at the community level is identified as a key issue requiring national leadership and coordination of actions by government agencies professional associations, private voluntary organizations and private sector entities The report implies that any national strategy will center around the involvement and cooperation of state and local governments

Of particular interest to state legislatures is the report s analysis of proposed methods to address financing issues within the current health care system Many of these suggestions fall within the jurisdiction of state government The full report and recommendations of the task force may be found in Appendix A of this bulletin

E HEAD TRAUMA ACTIVITIES IN OTHER STATES

Dealing with TBI and its consequences is a relatively new phenomenon The number of those suffering from TBI was relatively small until medical technology improved the survival rates In response to increasing numbers of those suffering from TBI, several states recently have passed legislation to help individuals and their families cope with TBI

Legislative activities include establishing TBI registries, initiating various demonstration projects and implementing statewide integrated head injury programs The following chart summarizes these legislative efforts

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STATE LEGISLATIVE INITIATIVES FOR TRAUMATIC HEAD-INJURED PERSONS

Create Central Registry (13 states)

Florida	Montana
Georgia	Pennsylvania
Iowa	Rhode Island
Maine	Virginia
Maryland	West Virginia
Michigan	Wisconsin
Missouri	

Define TBI as a Distinct Disability for Funding Purposes (10 states)

California	Illinois
Georgia	Maryland
Florida	Maine
Iowa	New Jersey
Indiana	Rhode Island

Establish Demonstration Projects (1 state)

California

Create Special Trust Fund (2 states)

Florida	Pennsylvania

Create Integrated System of Care (4 states)

California	Maine
Massachusetts	Pennsylvania

Sources National Head Injury Foundation and John H Noble, Jr , "Forward Looking State Legislation for Persons with Traumatic Brain Injury and Their Families" National Conference of State Legislatures/Assembly on the Legislature, October 1989

As medical technology continues to save the lives of persons with TBI each year, increasing numbers of families from every socioeconomic strata of society will experience the cost, burden and stress of caring for a head-injured member Nevada recently began the process of creating its own statewide trauma system--as a result the state can expect the number of persons surviving traumatic head injuries to grow

An increasing number of states are beginning to address TBI issues through a variety of initiatives It also appears that the federal strategy, as it is currently being formulated will rely heavily upon state and local government to carry out its goals At the present time and for the foreseeable future, assistance for persons with traumatic head injuries and their families will be focused at the state level

F SERVICES AVAILABLE IN NEVADA

As noted earlier, a typical brain-injured person requires four phases of medical and support care--emergency/acute care residential rehabilitation, transitional rehabilitation and community based care

Nevada s trauma system provides excellent care and services during the first phase of care At the other end of the treatment spectrum, the state has vocational rehabilitation, supported employment and independent living skills training available However, services associated with the middle portion of that spectrum are absent or marginal

The recent completion of a full scale rehabilitation hospital in Las Vegas, Nevada, completes another part of the care spectrum The state now requires supervised residential living and day treatment facilities to complete the missing component in the TBI continuum of care

III ISSUES AND RECOMMENDATIONS

Nevada has grown in population to the point where the number of its citizens with TBI provides justification for the development of specialized programs

In view of this growing number of persons suffering from traumatic brain injury, the subcommittee determined that it is necessary for the State of Nevada to take a larger and more active role in providing appropriate care and services Suggestions were solicited from health care providers state agencies, as well as TBI patients and their families

The final recommendations of the subcommittee represent those policies which the members of the subcommittee have determined would be most effective The background for each of these recommendations is summarized in the following sections

A SERVICES FOR TRAUMATIC BRAIN INJURED PATIENTS AND THEIR FAMILIES

The centerpiece of the subcommittee s recommendations is the proposal to designate a lead agency responsible for coordination and leadership in developing a statewide program specifically for TBI

1 Existing Programs And New Services

As part of a national program for the brain injured, the federal Interagency Head Injury Task Force recommends that each state establish a lead agency to coordinate activities and services for TBI patients and their families

In Nevada, several state agencies share responsibility for TBI-related services, including the State Department of Education Nevada Medicaid the Rehabilitation Division and the State Industrial Insurance System The Mental Hygiene and Mental Retardation Division of DHR also provides care for some TBI patients to a limited extent A TBI patient may need services from more than one agency requiring multiple applications and as many case managers The lead agency would be responsible for coordinating care for TBI patients for identifying and addressing any service gaps and for keeping decisionmakers, state agencies and the public informed

The lead agency would support appropriate programs with both fiscal resources and technical assistance and ensure that necessary services for TBI patients are available within the state The subcommittee determined that the Rehabilitation Division would be the appropriate lead agency for Nevada

The subcommittee recommends therefore that the Legislature

> **Provide, by statute that the Rehabilitation Division of the Department of Human Resources establish a specific program designed to address the specialized requirements of traumatic brain injury patients and their families Subject to the availability of funds, the program shall include**

a Direct services such as day treatment transitional residential care attendant care, case management, independent living skills training and supported employment for survivors of TBI

b A preventative/educational component

c A substance abuse intervention and treatment component and

d Support services, such as respite care for families of TBI victims

The division shall monitor the incidence of head injuries in Nevada and evaluate the effectiveness of programs established within the state The agency shall report the results of these evaluations at each regular session of the Legislature (BDR 38-163)

To assist in the identification and monitoring of TBI as a distinct disability and to assist in establishing programs and services the subcommittee determined that a statutory definition is necessary for traumatic brain injury

The subcommittee recommends, therefore that the Legislature

Define, within statute TBI as a distinct disability to be served by specific state programs such as those for alcohol and drug abuse Medicaid, and vocational rehabilitation, among others These services would be subject to eligibility and budget constraints existing under current federal and state law (BDR 38-163)

In addition to establishing a new program and the coordination of existing ones, the subcommittee recognized the role of various substance abuse self-help groups in addressing preexisting and injury-related substance abuse problems among TBI patients Members were informed that many of these groups are not prepared to address the special needs of TBI patients Specific areas requiring attention include injury-related behavioral and communication problems, as well as transportation difficulties among others

The subcommittee recommends therefore that the Legislature

Urge, by resolution, substance abuse self-help support groups, such as Alcoholics Anonymous, to address the special needs of TBI patients (BDR R-374)

2 Standards of Care

Persons suffering from a traumatic brain injury often require a continuum of care which includes a wide range of services The major stages of treatment for a TBI patient includes the following components

1 Emergency services and prehospital care

2 Acute trauma care in a hospital setting

3 Post-acute clinical care and rehabilitation and

4 Community-based services

Although standards exist for the treatment of all types of patients in the associated facilities the subcommittee wishes to ensure that the appropriate standards are adopted for TBI rehabilitation programs

The subcommittee recommends therefore that the Legislature

Require, by statute, that the Rehabilitation Division establish standards of care for TBI patients based upon the criteria established by the national Commission on Accreditation of Rehabilitation Facilities (BDR 38-165)

While the subcommittee determined that the Mental Hygiene and Mental Retardation Division is not the appropriate agency for treating TBI patients mental health treatment programs are often required Experience has demonstrated that behavior modification is the basis for all successful treatment and rehabilitation programs for TBI patients Such therapy should be part of any integrated treatment system mentioned previously in this report

The subcommittee recommends, therefore, that the Legislature

Encourage mental health therapy programs for TBI patients to use a behavioral component to ameliorate the psychological symptoms often associated with this injury

B FINANCING ISSUES

The subcommittee recognizes that the fiscal impact of the proposed new program is significant However coordination of existing funding sources combined with any savings realized by treating citizens within the state will provide a long-term benefit to Nevadans

1 Funding

The subcommittee noted that most of the potential savings and economies of scale will be realized by keeping Nevadans within the state However close coordination of existing funding sources, especially through Medicaid, federal education funds, and the State Industrial Insurance System need to be taken into account when computing program costs

In addition to savings realized by the coordination of agencies and funding sources, an additional appropriation is necessary to establish one of two planned rehabilitation facilities, and to implement other program requirements from the subcommittee s initial comprehensive recommendation

The subcommittee recommends, therefore that the Legislature

> **Establish that funding for state-administered programs for TBI patients and their families shall be accomplished with funds from Nevada s State Industrial Insurance System existing federal and state programs, such as Medicaid, Supplemental Security Income and Title I and the state general fund through revenues developed by increasing certain alcohol taxes It is estimated that an appropriation of $919,467 is required for fiscal year 1991-1992 and $928,224 is required for FY 1992-1993 (BDR S-168)**

The subcommittee also reviewed eligibility requirements for rehabilitation services through Nevada Medicaid Testimony indicated past difficulties in obtaining coverage for psychological services rendered during a TBI patient s time in an acute care hospital While such coverage is currently available to TBI patients undergoing an overall rehabilitation program, Nevada Medicaid indicated that it would make internal adjustments to extend eligibility to other TBI patients The subcommittee noted that early psychological intervention for TBI patients is highly desirable and supports such a change

The subcommittee recommends, therefore that the Legislature

Encourage Nevada's Medicaid program to include coverage for psychological services rendered in acute-care hospitals

2 Revenue Source

According to testimony, at least half of all traumatic brain injuries are alcohol-related Although the subcommittee did not wish to link a specific increase in revenue to funding for the proposed TBI program it was concluded that an increase in the state tax on beer would be appropriate to offset the costs of the new program

The subcommittee recommends therefore that the Legislature

Increase the state tax on beer by 4 cents per gallon, and recommend that the Legislature consider adequately funding the TBI program (BDR 32-166)

3 Insurance Policy Disclosures

Few families can afford the high cost of care unless they are covered by medical insurance or are eligible for Medicare or Medicaid

Many insurance plans, however place maximum limits on their liability so that funds for catastrophic medical conditions may fall short of the amount needed to pay for the cost of care

Existing statutes require insurance companies to disclose significant exclusions and policy limits The subcommittee was informed that no consumer complaints have been registered with the Insurance Division in the Department of Commerce concerning limited coverage for TBI however concern existed regarding specific insurance problems that might be encountered by TBI patients

The subcommittee recommends, therefore, that the Legislature

Encourage the Insurance Commissioner in Nevada's Department of Commerce to support adequate disclosure, under current statutes (Assembly Bill 114 of the 1989 legislative session [Chapter 586, Statutes of Nevada 1989 pages 1248-1255]) to consumers or health care beneficiaries of the extent and types of coverage for

TBI, including policy provisions for catastrophic and long-term care

C MONITORING OF TRAUMATIC BRAIN INJURIES

In Nevada, an exact figure for brain injuries is not known Based upon extrapolations from national estimates about 2 000 head injuries occur in Nevada each year Due to the high cost of treatment required by most TBI patients program estimates need to be as accurate as possible In addition, early notification and referral of TBI patients and family members may help speed recovery and decrease overall expenses

As previously noted, many states have adopted legislation establishing central registries of traumatic brain injuries These statutes usually require that the administering agency refer affected individuals to appropriate private or public agencies where rehabilitations services may be obtained At a minimum, registries document the dimensions of TBI within a state and provide the necessary data for public policy decisions and budgeting for state TBI programs

The subcommittee recommends therefore that the Legislature

Provide, by statute that the state maintain a central registry for TBI Such a registry shall be maintained by the Division for Review of Health Resources and Costs in cooperation with the Rehabilitation Division The Division for Review of Health Resources and Costs shall make a statistical report concerning TBI to the Legislature on an annual basis (BDR 38-167)

D HEAD INJURY ADVISORY COMMITTEE

The subcommittee received extensive testimony concerning the special requirements of TBI patients and their families Often these needs are not appropriately addressed by the services provided by state and local agencies In addition agencies associated with TBI require a forum for resolving interagency problems and for program coordination It is the subcommittee s determination that this process should be accomplished within the context of a interagency committee to include persons representing the practical concerns of patients and affected family members

The subcommittee recommends therefore that the Legislature

Establish, by statute, a head-injury advisory committee The committee shall be appointed by the Administrator of the Rehabilitation Division to study issues related to TBI and will advise the division concerning operation of any TBI program The committee shall study and recommend to the administrator any necessary action concerning existing and potential programs for TBI patients and their families Members shall consist of representatives from family support groups, appropriate state agencies, and other interested parties and will serve without compensation An annual report shall be made by the committee to the Administrator of the Rehabilitation Division, the Nevada Legislature s Committee on Health Care (Nevada Revised Statutes 439B 200), and the Legislative Commission (BDR 38-164)

E EDUCATION AND TRAINING

The survival and rehabilitation of TBI patients is a relatively new phenomenon, and the specific skills required by health professional and others in the care of TBI is often inadequate Also, the general public should be educated about TBI, the magnitude of the problem the effect upon individuals and families methods of prevention and costs Public education is needed to ensure that the behavioral and physical changes associated with TBI are understood

1 Training Needs for Families and Health Providers

Families of TBI patients suffer with members exhibiting high levels of depression and anxiety over the daily care needs of an afflicted family member Several studies document levels of anxiety likely to require psychiatric treatment in 40 percent of relatives of persons with severe injuries, and in 19 percent of relatives of persons with minor injuries Significant social dysfunction, such as marital difficulties tend to emerge 6 months and later after the injury Many family members turn to special head trauma support groups for assistance

In addition, families commonly complain about dealing with health care systems that are not equipped to address either the immediate or long-term consequences of TBI Key groups for specific education include criminal justice workers emergency medical personnel employers other health care providers health insurance companies and mental health and social services professionals

The subcommittee recommends therefore that the Legislature

Encourage the Rehabilitation Division to provide training opportunities for the special needs of TBI patients to parents of TBI victims and providers of acute-care and rehabilitative services

2 Prevention Programs

Often the accidents associated with TBI are not chance or random events injuries occur with regularity to predictable segments of the population As a result prevention programs can focus upon specific changes needed to avoid brain injury

Important advances have been made in the prevention of TBI in motor vehicle accidents through seat belt and helmet use Nevada has existing laws requiring helmets for motorcyclists and seat belts for persons riding in motor vehicles along with public education programs encouraging the use of these safety devices In addition, federal and state programs are in place designed to reduce high risk behavior such as alcohol use, drug abuse, motor vehicle speeding, and seat belt nonuse Community-based projects such as the use of protective head devices in athletic events and bicycle helmet campaigns, should continue to be encouraged

The subcommittee recommends, therefore that the Legislature

Continue support for existing educational programs designed to prevent disabling injuries

IV BIBLIOGRAPHY

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Head Trauma in Nevada An Overview a document prepared by the Rehabilitation Division, Nevada s Department of Human Resources, Revised November 1988

Interagency Head Injury Task Force Report, United States Department of Health and Human Services February 1989

Noble John H , Jr Forward Looking State Legislation For Persons With Traumatic Brain Injuries And Their Families, remarks delivered to the National Conference of State Legislatures, Assembly on the Legislature, October 20 1989

V APPENDICES

APPENDIX A

Executive Summary Of Document Titled
Interagency Head Injury Task Force Report,
United States Department of Health and
Human Services, February 1989

INTERAGENCY
HEAD INJURY TASK FORCE

REPORT

February 1989

DEPARTMENT OF HEALTH AND HUMAN SERVICES

Public Health Service

National Institutes of Health

National Institute of Neurological Disorders and Stroke

INTERAGENCY

HEAD INJURY TASK FORCE

REPORT

February 1989

DEPARTMENT OF HEALTH AND HUMAN SERVICES

Public Health Service

National Institutes of Health

National Institute of Neurological Disorders and Stroke

For Administrative Use Only

INTERAGENCY HEAD INJURY TASK FORCE REPORT

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INTERAGENCY HEAD INJURY TASK FORCE REPORT

Executive Summary

The House Committee on Appropriations encouraged the establishment of an Interagency Head Injury Task Force which would identify the gaps in research training and service delivery and recommend solutions in meeting the needs of the traumatic head injured At the same time, the Senate Committee on Appropriations encouraged increased efforts among Government agencies in these areas

The Task Force was established by the Secretary, Department of Health and Human Services in early 1988 He appointed as its chairman, the Director of the National Institute of Neurological Disorders and Stroke National Institutes of Health and included representatives from thirteen Federal agencies In carrying out its activities the Task Force defined head injury as traumatic brain injury (TBI) Its knowledge and understanding of TBI were enhanced through the solicitation of public comments during a two day public hearing These findings, along with the activities of its three subcommittees provided the background and framework for examining the problems and addressing their solution

Current data indicate that someone receives a head injury every fifteen seconds in the United States A conservative estimate puts the total number of such injuries at over two million per year with 500 000 severe enough to require hospital admission 75 000 to 100 000 die each year as a result of TBI and it is the leading killer and cause of disability in children and young adults Among those who survive TBI results in 5 000 new cases of epilepsy each year and is the principal cause of permanent brain damage in young adults Related medical and legal bills can become astronomical often leaving families with near or total financial ruin The economic costs alone approach $25 billion per year

There are no words to express the fear, anguish and despair of TBI victims and their families The problems resulting from severe impairment of a family member are compounded by the frustrations of trying to work within medical, legal and social systems that for the most part are not equipped to deal with either the immediate or long term consequences of TBI Indeed many patients and their families find that the present system discourages efforts toward self sufficiency and provides no support for the family as a unit

The most important of all the activities needed to improve the prognosis of the traumatic brain injured is the establishment of regional centers of excellence linked to a network of local facilities Additional research is needed in every aspect of the problem prevention basic biology clinical and rehabilitation intervention and community services Specific measures need to be aimed at increasing local community programs of emergency care acute care rehabilitation and long term care Financial and legal reforms are also essential to ensure availability and access to TBI care Importantly the Federal role should be that of providing coordination and assistance

NATIONAL STRATEGY

The complex and pervasive barriers to effective treatment and rehabilitation of TBI victims and the need for research and primary prevention led the Task Force to identify a broad range of issues These are listed below and discussed more fully in the report The Task Force believes that all of these points must be addressed in order to carry out the national strategy and have an impact on the problems of TBI thus it is not possible to set priorities among individual recommendations or issues for implementation It is clear however that a framework for action must include certain minimal elements in order to succeed The Task Force views the following six recommendations as representing a national strategy for TBI

Recommendation 1 Establish "traumatic brain injury' as a category in reporting systems (page 11)

Recommendation 2 Designate a lead Federal agency with responsibility for overall coordination and planning for Federal state and private sector activities and establish a government private sector advisory group to assist the effort (page 11)

Recommendation 3 Encourage the establishment of working groups at the state and local level to provide leadership and coordination (page 12)

Recommendation 4 Create a national network of fifteen comprehensive regional head injury research centers beginning with the immediate establishment of five centers and adding five additional centers per year for the next two years (page 12)

Recommendation 5 Organize a decentralized system of care networked with regional head injury research centers to ensure accessibility to appropriate care Inform TBI victims and their families about the availability of such service facilities (page 12)

Recommendation 6 Study and document the financial issues relevant to patient and family services societal cost and related economic impact of TBI (page 13)

IMPLEMENTATION ISSUES

The Task Force recommends that the following issues be addressed in implementing the national strategy

A Primary Prevention

A1 Developing behavioral and environmental interventions aimed at reducing the frequency or severity of TBI (page 13)

A2 Encouraging the use of both innovative and proven model prevention programs with provisions to evaluate their results (page 14)

A3 Encouraging activities that minimize head injury risk in athletics and stimulate the use of helmets (or other head protective device) by boxers bicyclists motorcyclists and other high risk groups (page 14)

A4 Evaluating existing societal barriers to the effective implementation of prevention strategies (page 14)

A5 Improving community level access to existing database systems to assist in designing and developing prevention programs (page 15)

B Clinical and Community Service Settings

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B7 Encouraging appropriate local and state agencies to mount special efforts to provide counseling for TBI survivors and their families supportive resources such as day care TBI vocational counseling and training and specialized treatment in the case of the TBI with mental health alcohol and substance abuse problems (page 17)

B8 Utilizing for TBI care appropriate mental health mental retardation and special education facilities and programs (page 17)

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G6 Developing modifying and evaluating therapies that retard prevent or reverse brain damage after acute head injury arrest further deterioration during the subacute phase and provide for restitution of function for patients with long term injury (page 26)

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INTERAGENCY HEAD INJURY TASK FORCE REPORT

Introduction

This report has been prepared by the Interagency Head Injury Task Force in response to congressional concerns regarding the traumatic brain injured

MAGNITUDE OF PROBLEM

Every fifteen seconds someone receives a head injury in the United States, every five minutes, one of those people will die and another will become permanently disabled Each year, head injuries claim the life of 75,000 to 100,000 Americans, with most of the deaths occurring at the time of the injury or within the first two hours of hospitalization Of those who survive, each year approximately 70,000 to 90,000 will endure life long debilitating loss of function, 5,000 new cases of epilepsy will result, and 2,000 will exist in a persistent vegetative state

A conservative estimate puts the total number of head injuries at over two million per year with 500,000 injuries severe enough to require admission to a hospital Motor vehicle crashes cause one half of all traumatic brain injuries with falls accounting for 21 percent assaults and violence 12 percent and sports and recreation 10 percent Males are more likely to suffer serious head injuries than females and young males between 15 and 24 years have the highest rate of injury Traumatic brain injury is the leading killer and cause of disability in children and young adults Child abuse accounts for 64 percent of infant head injuries Juxtapose the fact that over the past 12 years mortality from head injury has exceeded the cumulative number of American battle deaths inclusive of all wars from the founding of the republic and the enormity of the problem begins to emerge

Primarily a disability of the young traumatic brain injury takes a tremendous toll on society The economic costs alone approach $25 billion per year This figure includes the total direct and indirect costs of medical treatment rehabilitative and support services and lost income A survivor of a severe brain injury typically faces 5 to 10 years of intensive services at an estimated cost in excess of $4 million Paradoxically, research into the control and treatment of traumatic brain injury receives less than one penny of every Federal dollar spent on medical research

OVERVIEW

Injuries that preclude head trauma victims from participating fully in society are as varied as the functions of the brain Depending upon which areas of the brain are damaged a head injury can produce losses in movement sensation intellect behavior and memory Head injuries may lead to death coma or long lasting disabilities such as paralysis epilepsy dementia or loss of hearing or vision

Emergency treatment before and after the patient reaches the hospital is critical Proper immediate care can prevent additional damage to brain tissue due to inadequate blood flow or insufficient oxygen supply Once the patient is stabilized and not in immediate danger of death the physician can then determine the extent of damage and take steps to protect and restore function Computerized tomography (CT) scanning provides three dimensional information about the brain and has proven critical to early and accurate diagnosis and treatment of head injury patients

Severe head injuries often require surgical intervention to repair tissue damage and control bleeding while concomitant drug therapies are administered to limit and reduce brain swelling After initial management, new brain imaging tools such as positron emission tomography (PET) and magnetic resonance imaging (MRI) allow scientists to study the changes in brain function following injury Rehabilitation and psychological therapies are optimally begun during hospitalization in order to begin the long process of restitution of brain and body function

Following discharge from the hospital the injured patient is often sent home to complete the recovery process Outpatient therapy may be provided at a rehabilitation center or in a hospital with a rehabilitation program People who suffer severe brain injuries may be institutionalized at a rehabilitation center for an extended period during which they participate in an intensive program of specialized physical and psychological therapy Experts including psychologists and speech physical and occupational therapists offer a variety of services to the patient These include instruction in basic living skills such as bathing dressing cooking and reading Cognitive therapy may also be used to teach patients to respond appropriately in a wide variety of situations and improve attention span self awareness, and flexibility of thought

The patient s physical limitations often complicate early stages of rehabilitation The more severe the injury, the greater likelihood of serious and enduring physical problems Loss of muscle control and muscle weakness interfering with leg and arm movement- can occur as a result of head injury Posttraumatic epilepsy may develop from scarred brain tissue Blood clots and skull fractures that exert pressure on the brain can cause facial paralysis, deafness disorders in muscles controlling eye movement and loss of the senses of smell and taste Therapy can enhance the plasticity of the brain restoring old skills to damaged parts of the brain and teaching new skills to brain areas that were not injured

Improvements in emergency room practice diagnosis and surgery allow more head injured patients to survive However the effort to improve intensive care immediately after the injury may be wasted if subsequent follow up therapy and community support are inadequate

Although a large proportion of head injured survivors are able to return to their families and communities and with minimal assistance resume an active life a significant subgroup of these individuals may need years of care and habilitation services These may include extended rehabilitation (daily therapies medical care and multisensory stimulation) ambulatory services (multidisciplinary outpatient therapy/services and evaluation) and homebound services Unfortunately the compounding effect of extremely high institutional costs and the overall inadequacy of insurance coverage has severely limited the availability of these kinds of facilities thereby depriving a vast majority of those who need this service Progress can be slow and may require years perhaps a lifetime Some of the most difficult problems surface during the period when individuals and their families begin the adjustment to post injury life Medical follow up and integrated community services are critical needs at this time

Society does not always focus on the value and dignity of some of its more vulnerable members The enormous overall dollar costs of head injury represent only one dimension of its impact The costs of pain grief and disruption in family and social activities are more difficult to measure as are the social and psychological effects of long term disability limitations of mobility behavior alteration and severe

reduction in mental function Medical and related legal bills can become astronomical With insurance coverage often inadequate, families are frequently faced with near or total financial ruin There are no words to express the fear anguish and despair of the families as well as the victims themselves

Research on head injury has advanced significantly over the past decade both in the clinical and basic sciences Traditionally scientists believed that damaged nerve cells in the brain were incapable of repair However recent results demonstrate that damaged nerve cells may be able to function again Scientists have shown that nerve cells from the mammalian central nervous system sprout new branches when they are in contact with supporting cells thereby showing that adult brain cells have the capacity for repair and growth Whether this property can be used to repair the injured brain with its billions of nerve cell connections is being creatively investigated Research opportunities need to be capitalized upon if improved methods of brain cell repair and restitution of function are to be developed

While vigorous intensive care monitoring and early treatment of structural and biochemical dysfunction in patients with head injuries have led to improved survival too many of these patients are not returned to useful lives The challenge of understanding the mechanisms that lead to improved survival now includes understanding the biochemical activities that will lead to improved brain function Although the work is still at early stages of investigation and development promising leads have been obtained in the experimental use of brain implants to aid in the recovery of the injured nervous system In coming years, it may be possible to replace tissues damaged by injury and restore the functions for which the damaged tissues were responsible

Despite research advances a fundamental shift in the approach to the problem of head injury is imperative It must be grounded in a commitment to primary prevention and strengthened research efforts Equally importantly it must address public health medical financial, legal and social issues affecting TBI victims their families and society as a whole

CONGRESSIONAL CONCERNS

In its report on the Fiscal Year 1988 budget for the Department of Health and Human Services the House Committee on Appropriations states

> "The Committee encourages the Secretary to consider the establishment of an Interagency Head Injury Task Force to be made up of key government administrators whose purpose would be to identify the gaps in research training and service delivery and to recommend solutions in addressing the needs of the traumatic head injured In addition attention should be directed to research which could develop a system of care from acute trauma management to extended rehabilitation programs that would provide individuals an opportunity to return to an optimum level of function
>
> The Committee also would urge that the Task Force address the development of a well coordinated national data base system for traumatic brain injury that will address epidemiology research neural recovery acute medical management and rehabilitation extended rehabilitation services and needs assessment for

> community reentry support services The Committee urges the Department of Health and Human Services and Department of Education to develop basic and applied research in rehabilitation and technology (House Report No 100 256 page 71)

In addition in its report on the Fiscal Year 1988 budget for the Department of Health and Human Services the Senate Committee on Appropriations states

> "The Committee encourages the National Institutes of Health to increase efforts to coordinate with other Government agencies in identifying gaps in research including service delivery research and national data in the area of traumatic head injury " (Senate Report No 100 189 page 103)

CREATION/COMPOSITION OF TASK FORCE

The Secretary of Health and Human Services established the Task Force and appointed as its Chairman the Director National Institute of Neurological Disorders and Stroke National Institutes of Health (NIH) Representatives from the following organizations served on the Task Force Department of Defense Department of Education (National Institute on Disability and Rehabilitation Research) Department of Transportation Veterans Administration National Science Foundation National Institute of Mental Health National Center for Health Statistics Food and Drug Administration Centers for Disease Control Health Resources and Services Administration National Center for Health Services Research/Health Care Technology Health Care Financing Administration and the National Institute of Neurological Disorders and Stroke, NIH

ACTIVITIES OF THE TASK FORCE

In keeping with the intent of the congressional request head injury was defined by the Task Force as traumatic brain injury (TBI) The Task Force Chairman appointed three subcommittees (research clinical care and community services) from among the members and directed each to conduct an indepth review and assessment of the problems and needs in its area of assigned responsibility

To enhance its knowledge and understanding of TBI needs the Task Force solicited public comments during a two day public hearing on September 8 and 9 1988 in Washington D C Notice of the public hearing was announced in the Federal Register on June 1 1988 (Volume 53 number 105 page 20024) Concurrently the same information was communicated by letter to thirty five relevant organizations to ensure their awareness of the hearing Oral statements presented at the hearing and written testimony submitted to the Task Force by those unable to attend have been assembled in the public testimony addendum (Addendum I)

The knowledge and insight gathered through the solicitation of public comments and the efforts of the three subcommittees are reflected in this report In addition background documentation describing head injury research and research opportunities (Addenda II and III) served as adjunct resources to the Task Force

INTERAGENCY HEAD INJURY TASK FORCE REPORT

NATIONAL STRATEGY

The acute and long term care rehabilitation and community reintegration of traumatic brain injury (TBI) survivors pose unique problems that overlap with many neurologic disabilities but that are distinct and different These range from the acute response of the brain to trauma to the long term consequences of frontal or temporal lobe damage in a child or adult The gaps in understanding the problem of TBI among health care providers and the community often result in counterproductive long term management in existing care systems designed not for TBI but rather for the paralyzed the mentally retarded or the mentally ill In addition, TBI poses its own unique problems in children and the aged For these reasons the Task Force recommends a series of actions that would represent the core of a national strategy for dealing with TBI In addition the Task Force has identified issues to be addressed in the implementation of a national strategy

Recommendation 1 Establish "traumatic brain injury" as a category in reporting systems

TBI should be specifically identified as a reportable condition or disability in Federal systems, hospitals and state and local health related agencies should be encouraged to do likewise This will ensure the identification and epidemiological assessment of victims, document the relative priority of TBI as an area of research, training and services allow accurate assessment of insurance needs, and provide a basis for the allocation of resources

Recommendation 2 Designate a lead Federal agency with responsibility to foster overall coordination and planning for Federal, state and private sector activities and establish a government private sector advisory group to assist the effort.

A Federal agency should be designated as the national focal point to coordinate encourage and assist in the development of mutually advantageous collaborations between industry (e g insurance, health care pharmaceutical, athletic and automobile) labor head injury citizen groups academia, and government to establish and support model TBI prevention, research and care systems A three pronged action plan should be developed by using the fundamentals of education legislation and environmental change outlined in 'Injury in America' (published by the National Academy of Sciences and the Department of Transportation in 1985)

In order to further encourage collaborative efforts in TBI the Federal lead agency should establish an advisory group that includes representatives from the Federal Government industry labor the Council of State Governments citizen groups and other private sector organizations The advisory group would encourage collaborative efforts such as the development and evaluation of model systems which are particularly important at the local level

Recommendation 3 **Encourage the establishment of working groups at the state and local level to provide leadership and coordination**

Lead agencies are needed at state and local levels to provide essential leadership and coordination of activities to identify and assist the TBI These entities must assume responsibility for ensuring that surveillance and service coordination occurs Major objectives would be to define and continuously monitor TBI issues and availability of resources ensure that important service gaps are identified and addressed and keep the public collaborating entities and decision makers informed The lead agency must ensure that necessary services for TBI patients are available within the community

State agencies can support community programs with fiscal resources technical assistance and consultation and guidance appropriate for the priorities of the community Such programs could help develop more targeted TBI guidance for state agencies in their technical assistance activities Existing examples of coordination at a state level have proven to be highly productive in injury control

Recommendation 4 **Create a national network of fifteen comprehensive regional head injury research centers, beginning with the immediate establishment of five centers and adding five additional centers per year for the next two years**

Multidisciplinary research requiring the collaboration of scientists and clinicians from a wide variety of fields is essential if further progress in research on TBI is to occur Individual comprehensive research centers should be affiliated with inpatient and outpatient clinical facilities as a basis for clinical research These regional "hubs would provide specialized care in complex cases as well as education training and consultation to other service providers and collaboration in multicenter clinical research studies Each center would be prepared to conduct basic clinical behavioral and community research However each center would not need to address the full national agenda since collectively the national network would pursue the comprehensive research program One example of this is the National Institute of Neurological Disorders and Stroke program of Huntington s Disease Centers Without Walls

Clinical research would foster the development and evaluation of new forms of surgical and medical treatment and rehabilitative modalities It would also address available information on diagnosis treatment pathophysiological consequences and behavioral and psychiatric sequelae thereby enabling evaluation of existing approaches to acute and long range management of patients with injury to the nervous system Research in areas such as epidemiology biomechanics injury prevention rehabilitation and community reentry should be incorporated in the agenda of selected centers Collaborative efforts between regional comprehensive centers and local trauma units would be a productive and efficient mechanism for performing timely research enhancing access to treatment and providing an efficient means for disseminating emerging knowledge for community use

Recommendation 5 **Organize a decentralized system of care networked with regional head injury research centers to ensure accessibility to appropriate care Inform TBI victims and their families about the availability of such service facilities**

For a variety of reasons (e g organizational financial legal and geographic) optimal TBI care in all phases is not available to a large proportion of the population In addition to the TBI network system existing facilities should be enhanced to ensure the availability of local properly accredited trauma care facilities readily accessible in every part of the United States Service delivery would continue to be managed at the local level however local trauma facilities and private or government rehabilitation or specialized nursing facilities would be networked with regional TBI research centers Financial incentives to local institutions and the research centers should be structured to foster collaboration This system would stimulate and facilitate dissemination of "state of the art' care to the local level The ability to deliver care at the local level is particularly important and must include the prehospital immediate acute and long term community reintegration phases of care Federal matching funds to states should be contingent upon the development and maintenance of regional trauma systems throughout the state

Recommendation 6 Study and document the financial issues relevant to patient and family services, societal cost and related economic impact of TBI

Society s establishment of priorities is a reflection of its perception of the relative magnitude of problems Accurate measurement of the financial burden related to patient and family services, the full cost of TBI and the related impact of TBI on American society is needed to elevate awareness of the scope of TBI

IMPLEMENTATION ISSUES

A Primary Prevention

"Accidents" are often not chance or random events, instead TBI generally occurs with great regularity to predictable portions of the population within specific settings As a result primary prevention efforts can focus on discrete changes needed to avoid brain injury Important advances have been made in the prevention of TBI in motor vehicle accidents through seat belt and helmet use and installation of air bags However adoption of these and other equally effective methodologies is far less than optimal Paradoxically, although TBI is both a predictable and often preventable problem the development of prevention technology is an endeavor still in its infancy

Prevention efforts should target the unique problems of each specific population (e g athletes motor vehicle operators and passengers children and the aged) or setting (industrial sites and high crime areas) integrating activities which include educational regulatory and environmental changes At the community level prevention activities are often not coordinated and lack a focus for health status improvements Additional resources can often be mobilized by involving private sector and citizen groups Nationally mechanisms must be developed to provide for coordination and leadership facilitating cooperative actions by governmental agencies professional associations private voluntary organizations and private entities Specific prevention issues to be addressed include

A1 Developing behavioral and environmental interventions aimed at reducing the frequency or severity of TBI

A substantial portion of TBI could be prevented or decreased in severity with appropriate changes in the transportation occupational and recreational

environment Passive preventive measures such as physical restraints and helmets deserve increased emphasis Research is needed to evaluate apparently effective interventions to ensure practicality and cost effectiveness Additional research is needed to develop new interventions

Human error inappropriate behavior lack of understanding and impaired performance are all major contributors to TBI Programs that concentrate on altering high risk behaviors such as alcohol use drug abuse seat belt nonuse and motor vehicle speeding are designed to affect related knowledge and attitudes Careful evaluation of these and other behavioral intervention strategies is imperative

A2 Encouraging the use of both innovative and proven model prevention programs with provisions to evaluate their results

Increased collaboration among public agencies academic institutions, voluntary organizations media private industry and professional groups could lead to increased effectiveness in prevention Model programs should focus on stimulating increased use of seat belts helmets and other prevention technologies (including air bags in automobiles) The bicycle helmet campaign is an excellent example of a community based citizen collaborative endeavor seeking to decrease TBI in young bicyclists

Program evaluation must be built into the implementation plan of model prevention programs Adoption of such programs by other locales or high risk groups will require modifications to adapt them for each unique setting

A3 Encourage activities that minimize head injury risk in athletics and stimulate the use of helmets (or other head protective device) by boxers, bicyclists, motorcyclists, and other high risk groups

Efforts are needed to stimulate the development and utilization of improved protection devices for the head and neck and to require their use in professional and amateur athletics particularly boxing Rules of play for physically aggressive sports that threaten head and neck safety require study and probably revision

Despite the fact that helmets greatly reduce TBI associated with crashes of bicyclists and motorcyclists helmet use by both groups is distressingly low A national coalition led by the American Academy of Pediatrics the National Head Injury Foundation Inc and the Bicycle Federation of America have taken important initial steps targeted on increasing use of helmets among children 5 14 years of age Motorcyclist helmet use laws have been the focus of advocacy efforts several states are considering reinstating laws which were repealed in the late 1970s Nationwide use of helmets by motorcyclists remains much lower than when state laws were widespread TBI has increased as a result

A4 Evaluating existing societal barriers to the effective implementation of prevention strategies

Many interventions have already been developed that irrefutably reduce the frequency and/or severity of TBI yet they are not systematically applied These include environmental interventions behavioral interventions or both

Research in prevention should focus on understanding why apparently effective strategies are not implemented or if adopted why they are later discarded

A5 Improving community level access to existing database systems to assist in designing and developing prevention programs

The causes of TBI vary in individual communities each community also has varying resources and diverse interests Community prevention programs must develop relevant database systems in order to identify the unique problems in their community define the priorities for intervention activities and evaluate their effectiveness Prevention programs at the community level should be able to provide this information to their coalition members to use for educating decision makers and the public about the effectiveness of specific interventions

B Clinical and Community Service Settings

Issues involved in clinical and community services are addressed in four components (1) emergency services and prehospital care (2) acute trauma facility access (3) postacute clinical care and rehabilitation and (4) community services

Emergency Services and Prehospital Care

Prehospital care represents an opportunity to reduce significantly the mortality and morbidity of TBI Two thirds of TBI fatalities occur before hospitalization a major preventable cause of mortality and long term disability is directly related to early respiratory problems and shock Model systems already functioning in a few communities demonstrate the enormous value of enhancing prehospital care through appropriate training and support of local emergency care personnel

B1 Enhancing the provision of emergency services through training, improved communications and availability of rapid transportation of the injured

Intensive training and certification courses for police firemen paramedics and other emergency medical personnel are needed emergency personnel need authority to administer certain drugs under appropriately supervised conditions emergency medical transport systems which will allow rapid transportation (less than four hours) to a local acute care trauma facility need to be developed further Improved communications are essential to speed the dispatch of transportation of the injured

Acute Trauma Facility Access

The fundamental resource in acute trauma care is the local hospital trauma facility Although the basic concept of the trauma unit remains valid many hospitals are now being forced to close their trauma facilities due to financial losses (from uncompensated care) legal liability/malpractice litigation threats and lack of health care workers skilled in trauma care

B2 Ensuring adequate geographical distribution of local acute care trauma facilities

The local trauma facility represents an essential element of TBI care As with school districts an acute care facility which meets national accreditation standards should be established in each district to provide the availability and expertise essential to saving lives and preventing complications Legal and health care financing reforms (as addressed in the Financial Issues section of this report) will help to ensure the cost effectiveness of accredited trauma programs in local hospitals

Postacute Clinical Care and Rehabilitation

TBI has an economic impact on thousands of victims left partially or totally disabled unemployable or dependent on their families or on state or Federal sources, this includes both civilian and military populations While great strides have been made serious gaps remain particularly in the postacute period where optimal care is either unavailable or inaccessible to a large portion of the population Patients are too often forced to travel great distances from their homes to obtain postacute care This usually increases the overall costs and complicates attempts at community reintegration Inpatient rehabilitation in the private sector has become prohibitively expensive and outpatient rehabilitation often suffers from lack of organization or coordination

Nationally accepted measures of physical and psychosocial outcome with which to assess the value of various therapies are lacking Most current programs lack a coherent plan for coordinating the different phases of treatment and fail to allocate resources efficiently for the patient during recovery Consequently, many patients and families end up "hopping in desperation from program to program

B3 Encouraging the continuing review of standards of service for TBI clinical care and rehabilitation by appropriate public and private organizations

Establish standards of clinical care and rehabilitation services with provisions for continuing review by appropriate public and private institutions such as the American College of Surgeons Committee on Trauma the American Association of Neurological Surgeons Joint Section on Trauma and the American Academy of Physical Medicine and Rehabilitation Provision should be made for periodic reaccreditation of TBI health care facilities by appropriate public and private organizations

B4 Emphasizing outpatient rather than inpatient services for noncritical care and rely on outpatient services at the local level

B5 Encouraging the use of "care manager" systems that operate throughout all stages of care, from acute care through community reentry

The care manager is an accredited health care professional who is responsible for the integration of acute subacute and long term care into a coherent scheme for the delivery of services and expenditure of resources based on the patient s neurological and behavioral diagnoses The care manager is responsible for ensuring that the resources of the facility community and region are made available to the TBI patient in a coordinated efficient and effective manner

B6 Focusing on the ultimate goal of independent function in the community, including training in problem solving and incorporating proven behavior and educational therapies

B7 Encouraging appropriate local and state agencies to mount special efforts to provide counseling for TBI survivors and their families, supportive resources such as day care, TBI vocational counseling and training, and specialized treatment in the case of the TBI with mental health, alcohol, and substance abuse problems

B8 Utilizing for TBI care appropriate mental health, mental retardation and special education facilities and programs

TBI can result in mental health problems requiring special facilities for housing therapy and special education Although facilities and programs already exist that can be useful in meeting these needs they will typically require modification to meet the special needs of the head injured

Community Services

Lack of local trauma care and rehabilitation facilities excessive geographic distances to facilities resulting in disruption of the family/support unit insurance limitations and financial burdens are all common problems of TBI survivors and their families Programs for reentry of TBI survivors into the community are lacking because of the absence of coordination and resources at local and state levels Some TBI survivors require long term specialized care and comprehensive life long support services

B9 Facilitating community reentry by the provision of transitional and supervised residential facilities and programs For those TBI survivors whose recovery is delayed or incomplete, a wide range of residential settings is needed, from skilled nursing units to domiciliaries and semi independent group living facilities

C Minor Head Injury

In so called minor head injury or cerebral concussion there is brief or undetected loss of consciousness and no recognizable major acute complications However the lack of overt symptoms may prove deceptive Permanent structural brain damage has been documented after minor concussion in laboratory experiments Further brain imaging technologies including magnetic resonance imaging (MRI) and positron emission tomography (PET) have revealed structural and metabolic changes in humans after concussion These changes correlate with documented neurobehavioral changes after even extremely minor head injury without loss of consciousness Owing in part to these studies the post concussion syndrome is increasingly being recognized by clinicians as resulting primarily from organic brain damage The failure to diagnose this syndrome and to institute management is likely to prolong the resulting incapacitation and complicate subsequent treatment Given the fact that the annual incidence of minor head injury is extraordinarily high (approximately 1 5 million each year) the social and economic impact is considerable Significantly minor head injury can lead to a permanent deficit of

brain function repeated minor head injuries often do cause permanent brain damage

There is a growing body of evidence that repeated TBI regularly suffered in certain sports particularly observed in boxing and football poses not only an acute risk to the athlete but may also result in long term organic brain damage This includes learning disabilities in children and premature dementia in adults The popularity of a given sport should not interfere with an effort to develop new or improved protective equipment and to explore changes in rules or regulations that will diminish the probability of TBI

C1 Defining anatomic, physiologic and behavioral criteria for measuring the severity of minor head injury

Quantification of the degree of minor head injury should include sensitive diagnostic testing such as evoked sensory and motor potentials MRI and neuropsychological evaluation Screening tests that can be used by the local physician must be developed for assessing minor head injury Such tests would serve to alert the physician to the possibility of organic brain damage and to guide patient management

C2 Encouraging academic and professional institutions to include in primary and continuing education programs for health care providers the recognition and management of minor head injuries Encouraging the inclusion of minor head injury management in community based TBI educational programs

C3 Stimulating high risk industries and union groups to establish model acute and subacute management programs for workers recovering from minor head injury

These programs should include gradual restitution of normal work demands combined with specific job assessment/modification and counseling based on objective testing (i e evoked potentials MRI neuropsychological studies etc) Insurers should be encouraged to support these programs

C4 Developing early follow up and intervention programs for patients and family members that emphasize maintenance of established role relationships and dynamics of family adjustment.

These programs should identify personal and family adjustment problems early in the clinical course of minor head injury and provide family oriented therapy and other appropriate intervention strategies to maintain and enhance the family unit These family oriented services should be developed in conjunction with other management programs for workers recovering from minor head injury

C5 Creating in service training programs for educators and counselors designed to make them aware that minor head injuries can result in behavioral changes and learning difficulties which interfere with the activities of daily living

Continuing education that addresses the unique deficiencies of the head injured population should be stressed Families counselors and individuals

involved in all parts of the educational system should coordinate their efforts to ensure that intervention is available when necessary

C6 Increasing the support for research on minor head injury, particularly in athletics

In addition to prevention and educational efforts research into the acute and long term neurological and neurobehavioral effects of repeated minor head injury should be pursued further using sports such as boxing and football at the professional amateur and school competition levels as models Studies should encompass the broad array of research topics including epidemiology prevention therapy and rehabilitation

D Financial Issues

There is no national plan for financing the acute and long term care of the TBI patient At this time existing financial resources available to such patients may include coverage through Medicare/Medicaid standard health insurance companies health maintenance organizations (HMOs) governmental health care programs as well as insurance contracts Yet often to the surprise of the consumer the policies of these providers fail to address adequately the catastrophic costs associated with TBI health care particularly long term care needs Such costs have spiraled Many new modalities of care are very expensive but too often they are neither of proven value nor cost effective Frequently the end result is that the financial resources of patient and family are exhausted

From the perspective of health care providers, the sizeable proportion of inadequately insured TBI patients with no other means of health care support creates a substantial recurring financial burden to health care institutions of all sizes As a result institutions are often forced to either curtail or close their trauma services or restrict them only to paying patients

The system of cost sharing as a mechanism for covering underinsured or indigent patient care (especially postacute) has been seriously curtailed by prospective payment systems This has been further influenced by a shifting of paying patients to more modern facilities where nonpaying patients are often not accepted

The following items address selected financial issues within the present system of health care

D1 Exploring needed improvements in personal injury insurance for motorists and work related injuries

Given that over one half of all TBI results from motor vehicle crashes motorists nationwide should bear the responsibility for adequate personal injury insurance that covers acute postacute and long term care This is inherent in the privilege of operating a motor vehicle (automobile truck motorcycle moped etc)

Insurance payments for health care should be automatic in all motor vehicle and organized sports related injuries and independent of litigation for compensation Programs exist that serve as models of this type of payment system A properly designed and implemented system can raise patient benefits without increasing insurance premiums Employee health insurance

and military and other governmental programs should also contain provisions for postacute and long term care for traumatic head injury

D2 Requiring full health insurance disclosure and including options for long term or catastrophic care coverage

Adequate disclosure to consumers or health care beneficiaries of the extent and types of coverage for long term care by insurers (including HMOs and governmental health care providers) should be subject to continuing review by appropriate state or national agencies

Although the cost of offering blanket chronic care coverage is high model health insurance programs providing postacute care coverage for accident victims should be encouraged in conjunction with cost control measures

D3 Encouraging the use of prospective payment systems

Gradual institution of flexible prospective payment systems in well defined settings may be the most efficacious approach to controlling costs These systems must be responsive to the long term needs of the TBI patient tailored to individual dynamic prognosis and should require scientific validation of approved therapies Universally accepted criteria for the diagnosis and quantification or measurement of patient outcome are requisite to these research evaluations

Interaction should be encouraged by Federal and state payers and the private insurance industry for the determination of compensable acute and postacute therapies

D4 Encouraging adoption of the "care manager" approach

As with implementation issue B5 the "care manager approach emphasizes a judicious allocation of resources among acute and subacute treatments and facilitates resolution of the more obstinate longer term problems of community reintegration and independent living Periodic oversight of care managers by the appropriate public or private agencies includes medical as well as financial issues Federal state and health industry insurers should be stimulated to adopt this efficient, integrated approach to care and payment

D5 Establishing reserves or trust funds for acute and long term care for uninsured accident victims

There is a need for the establishment of state government reserves (with matching Federal funds) insurance "risk pools or trust funds to cover payment of TBI acute and long term medical expenses for underinsured persons These costs can be moderated significantly through the previously described insurance and cost control reforms Study of this process should be part of the agenda of the study group addressed in implementation issue D8 While outlays from the Federal government should be capped existence of an adequate trust fund or reserve is crucial to the maintenance of a viable trauma care network

D6 Identifying and publicizing financial resources for community services

Educate community leaders and relevant public information offices about sources of financing to cover costs of TBI community services Community data should supplement national information serving the needs of the patient and his/her family the general public decision makers and third party payers responsible for care long term follow up and community services

D7 Fostering insurance industry efforts to reward safe practices among policyholders and publicizing the results

The insurance industry has offered rebates and other financial incentives to policyholders to defray costs of air bag installation use of residential smoke detectors and other safety practices The expectation is a reduction in company costs Foreign companies have developed financial incentives which encourage motorists to use seat belts and air bags and motorcyclists to wear helmets and protective suits These premium reductions have been more than offset by reduced claims costs Insurance organizations should be encouraged to report and publicize their findings to stimulate wider adoption of similar programs

D8 Supporting legislation to allow for automatic release of accident insurance funds for acute and long term trauma care, independent of the tort system Exploring the liability issues surrounding trauma incidents

Expensive and time consuming litigation not only increases costs but often delays use of desperately needed insurance funds in the early subacute and postacute phases of care This results in unneeded financial and emotional stress on families who are already trying to cope with a threat to the life of a family member

There is also a disturbingly high rate of medical malpractice litigation arising from acute trauma cases In many locations fear of malpractice litigation is a major underlying deterrent to the development of acute trauma care services acute therapeutic clinical trials and recruitment of personnel into the field of TBI

One approach would be the establishment of a national study group to recommend solutions to the liability issues surrounding the trauma situation the study group could function as a committee of the government-private sector advisory group (Recommendation 2) Target issues to be included are medical malpractice insurance trust funds to cover acute trauma care application of "Good Samaritan" or deferred consent concepts in specific settings that permit prompt emergency treatment of TBI victims liability caps, contingency fee limitations and binding arbitration panels

E Training and Education

The training of professionals and paraprofessionals in the care of TBI remains inadequate Similarly there is a paucity of focused attention on TBI among health care and special education workers and scientists The problem of "burn out among health care workers is particularly severe in the field of TBI owing to the relative lack of effective treatments and the frustrations of dealing with the irregular compensation and legal ramifications of TBI

The general public should be educated about TBI the magnitude of the problem its effect on individuals and families its prevention and its costs Public education is needed to ensure that the functional and behavioral alterations associated with TBI are understood Key groups for specific education include emergency medical and criminal justice personnel health care mental health and social services personnel teachers and special education personnel employers and third party payers

E1 Encouraging and funding training programs in TBI research, clinical care and rehabilitation

Increase the attraction to the TBI field by raising awareness of the problem and by increasing incentives to enter the field This effort encompasses both primary medical and other clinical care education offered by academic institutions and continuing clinical care education managed by regional centers in a regional network Training in clinical research methodologies should be emphasized at all levels

E2 Incorporating model programs for TBI care in the training and accreditation of parame lics, police and firemen

Often the first to arrive at the scene of a head injury paramedics police and firemen assume a vital diagnostic and management role (including early resuscitation and airway maintenance) which prevents death and/or subsequent brain damage Training programs should be developed by and administered through individual regional trauma networks to make certain that such personnel are prepared to provide these services with expertise

E3 Enhancing public and professional awareness of TBI

A variety of established educational approaches exist through which public and professional awareness of TBI can be increased including public health announcements (e g the Surgeon General s Report a Public Health Service publication) marketing models professional organizations citizen organizations and formal training programs

F <u>Public Health Surveillance</u>

Planning of model systems for the care of TBI victims entails deriving information from diverse databases and epidemiological studies The true incidence and prevalence of TBI disability of all degrees remains unknown Similarly clinical studies are often noncomparable because of the lack of universally accepted measures especially for the psychosocial dimensions of outcome

Each community (local and state) must be able to characterize the magnitude of its TBI problem and to identify victims severity causes (e g motor vehicle crashes bicycle accidents sports injuries violence etc) consequent disabilities and costs Such information should be available in a manner that is readily usable by community region state and Federal interests This information is also necessary to evaluate prevention and control activities

F1 Initiating field investigations of the incidence and prevalence of TBI

Efforts in the area of another aspect of nervous system trauma spinal cord injury have led to the field investigation by the Centers for Disease Control DHHS of the occurrence of that injury TBI should be investigated in a similar fashion A nationwide reporting system is necessary for providing reliable data on TBI incidence and prevalence

F2 Improving the coding of TBI in existing database systems

Although the International Classification of Disease 9th Revision Clinical Modification (ICD 9 CM) provides general codes for TBI records often lack sufficient detail to permit accurate coding of the diagnosis or external causes of injury (E codes) Most care providers do not enter the E code into hospital discharge summaries Several states including New York California Washington and Wisconsin have recognized the importance of this information and the limited costs to collect the data by incorporating E coding This practice should be expanded to a national basis

The ICD 9 CM codes for the nature of the injury (N codes) or diagnosis provide a general classification system for TBI, however, improved TBI codes and coding training could be added to enhance the classification process In addition, a review of the ICD 10 should be undertaken, without delay to ensure useful TBI codes for the future Endorsement/training by the American Medical Association American Hospital Association American Medical Records Association and the Joint Committee on the Accreditation of Health Care Organizations could foster the accomplishment of this goal

F3 Conducting population based epidemiologic studies to identify the risk factors associated with TBI and to better identify causative factors that are amenable to intervention

The growing literature on brain injury is mostly clinical in nature and rarely involves representative groups of individuals Consequently, there is limited ability to accurately define the risk factors that influence the prevalence of TBI in the population or the incidence of TBI in various population groups In order to make informed decisions about prevention it is necessary to identify the high risk populations, what types of TBI are sustained and when where and under what circumstances is TBI likely to occur Epidemiologic research of TBI is essential as well as development of methods to assess the effectiveness of prevention

F4 Fostering the development of model community and state surveillance of TBI, drawing on public health, clinical care and rehabilitation perspectives and expertise

Public health clinical care rehabilitation and local service providers should become involved in the development and/or use of existing surveillance databases utilizing standardized nomenclature for describing the types severity and outcomes of TBI Model programs should be developed which lead to guidelines for surveillance in other communities and states

F5 Encouraging the use of the existing and well functioning National Library of Medicine MEDLINE database for retrieval of basic and clinical research information on TBI Establishing clinical and

rehabilitation care directories on a regional basis linked to regional networks

The National Library of Medicine (NLM) MEDLINE database provides excellent coverage of the world literature on TBI inclusive of the basic and clinical research areas specified within the congressional appropriation language This information has been published reviewed evaluated indexed and stored Access to MEDLINE is readily available to individuals and institutions at minimal cost The information can be obtained through NLM's Regional Medical Library Network by contacting any local health sciences library The availability of this rich source of information should be widely communicated to scientists and health care providers

Some information about TBI may not be available to the research community because it was conducted as proprietary research and not submitted to peer review journals Research pursued by the military government regulatory bodies and the private sector comprise this "fugitive literature It is conceivable that making such findings available to the research community at large might avoid unnecessary duplication of expensive time consuming research However the scope and quality of research and clinical care information in this literature are unknown the repositories are unlisted and their availability is usually not publicly known The cost of finding reviewing evaluating and making this information available makes the endeavor cost-ineffective Those who sponsor or perform research should be encouraged to seek publication of results in refereed journals, leading to the availability of this information to the world community through MEDLINE

With respect to information about clinical and community care resources the establishment of regional centers networked with local facilities will provide the most efficient and appropriate base for this information Each regional center should be required to establish a patient service directory to provide for the needs of the region, the pooling of data from the regional clinical care directories will provide the information for needed national planning and monitoring

G Research Priorities

Research directed toward understanding and altering the course of the head injury process encompasses the development of prevention strategies that reduce the frequency and severity of TBI technical interventions that directly alter or mitigate the mechanical biochemical and metabolic events eliminating or reducing the severity of the injury efficacious acute care treatment modes to enhance the recovery process following TBI and medical and rehabilitative interventions that alter the long term outcome

The critical factors that contribute to the occurrence of a head injury include the mechanical conditions that produce the initial brain lesions and the subsequent sequence of molecular cellular and clinical events that determine the outcome Examination of the interrelationships between these events and the development of their phenomenological explanations will lead to prevention strategies that limit the mechanical biochemical and metabolic insults to the brain and clinical strategies for the treatment of TBI victims This would lead to minimizing the extent severity and progression of resulting dysfunction

The primary research resource identified by the Head Injury Task Force involves the establishment of a national network of regional head injury research centers (Recommendation 4) This network of centers has been alluded to throughout the document and should serve as the central thrust of any proposal addressing head injury clinical care and research

The full research agenda encompasses elements that overlap with previously addressed issues including prevention minor head injury economic (financial) impact and public health surveillance (including epidemiologic research) Discussions of the research aspects of these issues are found in the relevant sections of this document The following section elaborates on research issues of immediate priority, it is divided into three components basic mechanisms of TBI, clinical research and rehabilitation and habilitation research

Basic Mechanisms of TBI

G1 Elucidating the biomechanics of brain injury

Research in this area entails the development of more effective estimates of the biomechanical origins of head injury quantification of the resulting injury and prognostic assessment of TBI in the acute and long term phases of care Subsequently an evaluation is needed of the essential relationships that characterize the mechanical response and failure both physical and functional of neural and vascular brain tissues experiencing impact conditions Enhancement of the analytic capabilities of simulation technologies will lead to improved ability to interpret and predict the effect of impacts to the head Experimental controlled studies should be initiated to determine characterize and quantify the relationship of translational and rotational motion impact to the head and the resultant functional alterations of the brain This information is critical to the design of effective environmental interventions Both computer based and experimental animal research are essential if these objectives are to be achieved

G2 Defining the molecular and cellular characteristics of primary and secondary injury to the brain and their relation to outcome

A cascade of time related biochemical and physiological events occur, beginning immediately after the head injury There is a possibility these events will continue for several months Traditionally circumscribed as acute intermediate and prolonged effects of injury these events may be conceptualized as the sequential reactions of injured neural tissue The ontological approach includes identification of the sequences and their interrelationship and characterization of the substrates and time dependencies at the molecular and cellular level A significant portion of traumatic brain damage may be due to secondary events the ability to develop treatments that ameliorate or halt the progression of sequelae is contingent upon a rational understanding of these biochemical events Experimental animal and clinical research in humans as well as basic biochemical and tissue culture research are essential to the achievement of these objectives

G3 Defining the molecular and cellular characteristics that lead to acute and prolonged 'coma' and developing methods to restore wakefulness

Coma is an extremely grave indicator of profound brain damage Patients in coma require total and continuous support The more prolonged the coma the less the chance of emergence coupled with a greater likelihood of permanent serious brain deficits An understanding of the mechanisms that cause coma and of the means by which coma may be managed reversed and recovery achieved are vital components of brain injury research Both human clinical and experimental animal research are essential if these objectives are to be achieved

G4 Seeking and developing improved experimental brain injury models

The mainstay of head injury research is based on realistic models that mimic essential elements of injury to the brain There is an urgent need to develop improved models that address individually and collectively, the full range of pathology that occurs in head injury Humanely designed animal experiments must be included in the research agenda to define and explore important research parameters without such experiments critical areas of clinical significance cannot be addressed Such efforts require additional public education owing to the sensitive overtones associated with animal research particularly experimental head injury

Clinical Research

G5 Developing new methods and modalities for more effective measurement of diagnosis, degree of injury, post injury monitoring, and prognostic assessment of head injury for the acute and prolonged phases of care

Evaluating the extent of head injury severity and determining the appropriate sequence of intervention are complicated processes Physiologically based quantification of severity will lead to more efficacious intervention Improved measurement techniques using biomechanical and engineering principles need to be coupled with assessment of clinical physiological and pathological responses Prognostic accuracy is dependent upon a qualified knowledge of the degree and severity of the brain injury The specific differences in the pediatric adolescent and adult age groups need to be defined and the neurological neuropsychological and psychiatric sequelae identified and measured Experimental animal and human clinical research are essential to the achievement of these objectives

G6 Developing, modifying and evaluating therapies that retard, prevent, or reverse brain damage after acute head injury, arrest further deterioration during the subacute phase, and provide for restitution of function for patients with long term injury

Few controlled prospective randomized clinical trials related to the management of head injury in children and in adults have been conducted Study designs and methodologies for this application involve highly complex medical issues that are not well defined Rigorous research efforts should be directed into evaluation and further development of this methodology With the improvement of these methodologies there needs to be a serial implementation of clinical trials for testing current and novel treatments and for examination of rehabilitative modalities and methods to optimize outcome

Inherent in each system is the development and understanding of the measurement techniques required to determine a "significant" result and of the barriers which impede such research

G7 Integrating clinical brain injury research into clinical care settings

Management strategies used in the acute stages of care as well as in rehabilitation and community reintegration are still largely unproven While many "accepted" treatment practices may appear efficacious, most have not been subjected to proper scientific validation of effectiveness, indications and cost efficiency Some treatments, while making the patient, family and provider "feel good" in the short run, may actually be counterproductive by fostering continued dependence in the patient Due to the remarkable ability of the young adult brain to compensate for injury naturally with minimal intervention, patient improvement under a given regimen is not sufficient to establish efficacy Only properly controlled and conducted, reproducible clinical research studies will resolve this issue

Clinical care and clinical outcomes research must be integrated to ensure that government and health insurance dollars spent on care also help lead to advances in the knowledge of TBI New and existing rehabilitation techniques, including vocational and special education, should be subject to the same scientific scrutiny for determining efficacy, indications, and efficiency as are other aspects of care Training in clinical research methodologies should be further encouraged throughout the field of TBI

As an incentive to the integrative effort, hospitals and long term care institutions should expect selected aspects of the cost of clinical care of patients enrolled in approved clinical and rehabilitative outcome research studies to be covered by governmental or private insurance Funds for this purpose derived from governmental and private agencies under guidance from the DHHS, and/or the National Institute of Disability and Rehabilitation Research, Department of Education, could be managed at the state level These clinical care funds utilized in research would be in addition to the research budgets already administered through traditional governmental or private agencies

An essential link in the system of incentives is a network of regional research centers with close ties to regional specialized clinical care facilities, local trauma units and private or public rehabilitation institutions While projects might be initiated at any level, the regional research centers would be expected to be responsible for the development and coordination of clinical studies that include the local facilities This would allow local facilities to become eligible for the financial incentives suggested above, enabling certain innovative "state of the art" therapies to become available also at the local level

G8 Addressing informed consent issues in the management of traumatic brain injured patients who cannot provide consent.

Effective patient management from the moment of impact is sometimes compromised by excessive and counterproductive requirements for informed consent Therapeutic trials, particularly in life threatening situations are severely handicapped by the difficulty of locating family for immediate consultation in a highly mobile society "Patient Advocate" concepts with

appropriate safeguards should be extended to provide for properly approved and monitored therapeutic studies, thereby reducing the time to treatment.

Rehabilitation and Habilitation Research

G9 Conducting additional research on TBI rehabilitation and habilitation, using modern methods of experimental design

Emphasis should be placed on research leading to the acquisition and dissemination of new knowledge to improve the independence, self sufficiency, and quality of life for persons with physical, psychological, vocational, and social handicaps resulting from a brain injury This goal can be accomplished through the refinement and evaluation of new and existing therapeutic techniques and rehabilitation modalities, the identification of those segments of the TBI population who will benefit from specific rehabilitation methodologies, and by maintaining and maximizing all aspects of functioning, including the prevention of progressive complications Emphasis should also be placed on the development and critical evaluation of community based services including transitional and independent living models, enhancement of social participation and other approaches to meet the long term rehabilitation and adjustment needs of brain injured persons

G10 Establishing and developing an understanding of the dysfunctional, behavioral, cognitive, and emotional responses and sequelae of brain injury

Regardless of the degree of brain injury (including minor concussion), subtle to extensive neuropsychological and psychiatric consequences may ensue Both short-term and long term effects need to be carefully elucidated using available techniques for measuring brain structure and function and by the more modern methodologies for brain imaging and evaluating neurotransmitter and neuroendocrine status The utility of commonly used psychiatric clinical indicators and experimental neuropsychological tests needs to be assessed Research should also address the long term processes of coping, adjustment, and independent functioning, as well as the effects on education, employment and family life

G11 Conducting research on community service issues of TBI with an emphasis on progressive rehabilitation, independent living, and family participation and support.

The advent of a suddenly brain injured person has an immense impact throughout the extended family and the community The emotional and financial burden is immediate and long lasting Areas of research deserving particular attention include the identification and demonstration of innovative transitional living and day programs, organization and delivery of community based rehabilitation services, and strategies for active participation in productive social recreational, and avocational programs

INTERAGENCY HEAD INJURY TASK FORCE

Member	Agency
Dr Murray Goldstein (Chairperson)	National Institutes of Health, Department of Health and Human Services
Dr Stuart T Brown	Centers for Disease Control, Department of Health and Human Services
Dr Karen C Carlson	Health Resources and Services Administration, Department of Health and Human Services
Dr Enrique D Carter	National Center for Health Services Research/ Health Care Technology Assessment, Department of Health and Human Services
Mr Michael M Finkelstein	National Highway Traffic Safety Administration, Department of Transportation
Dr Joseph B Green	Veterans Administration
Dr Robert M A Hirschfeld	National Institute of Mental Health, Alcohol, Drug Abuse and Mental Health Administration, Department of Health and Human Services
Dr Gordon C Johnson	Food and Drug Administration, Department of Health and Human Services
Mrs Mary A. Moien	National Center for Health Statistics, Department of Health and Human Services
Dr Nathaniel G Pitts	National Science Foundation
COL Andres M Salazar	Uniformed Services University of the Health Sciences, Department of Defense
Ms Ellen Shillinglaw	Health Care Financing Administration, Department of Health and Human Services
Dr J Paul Thomas	National Institute of Disability and Rehabilitation Research, Department of Education
Dr Michael D Walker	National Institute of Neurological Disorders and Stroke, National Institutes of Health, Department of Health and Human Services
Mr Joseph J Culhane (Executive Secretary)	National Institute of Neurological Disorders and Stroke, National Institutes of Health Department of Health and Human Services
Mrs Cheryl A Seaman (Editorial Assistant)	National Institute of Neurological Disorders and Stroke National Institutes of Health Department of Health and Human Services

APPENDIX B

Suggested Legislation

SUMMARY Requires rehabilitation division of department of human resources to establish program for persons with traumatic brain injuries (BDR 38 163)

FISCAL NOTE Effect on Local Government No

Effect on the State or on Industrial Insurance Yes

AN ACT relating to traumatic brain injuries requiring the rehabilitation division of the department ot human resources to establish a program for persons with traumatic brain injuries and providing other matters properly relating thereto

THE PEOPLE OF THE STATE OF NEVADA REPRESENTED IN SENATE AND ASSEMBLY DO ENACT AS FOLLOWS

Section 1 Title 38 of NRS is hereby amended by adding thereto a new chapter to consist of a new section to read as follows

1 The rehabilitation division of the department of human resources shall establish a program for persons with traumatic brain injuries

2 The program may subject to legislative appropriation provide

(a) The following services to persons with traumatic brain injuries

(1) Treatment during the day on an outpatient basis

(2) Care provided in a facility operated and maintained to furnish food shelter assistance and limited supervision

(3) Care provided in the home

(4) Instruction in the skills required for independent living

(5) Placement for jobs and

(6) Counseling and treatment for the abuse of drugs or alcohol

(b) Support services for families of persons with traumatic brain injuries

(c) For the dissemination of information for the prevention of traumatic brain injuries

3 The rehabilitation division shall evaluate the program and submit a report containing the evaluation and any recommended legislation to each regular session of the legislature

4 As used in this section traumatic brain injury means a sudden shock or damage to the brain or its coverings which is not of a degenerative nature and which produces an altered state of consciousness or temporarily or permanently impairs the mental cognitive behavioral or physical functioning of the brain The term does not include

(a) A cerebral vascular accident

(b) An aneurism or

(c) A congenital defect

SUMMARY Creates advisory committee on traumatic brain injuries (BDR 38 164)

FISCAL NOTE Effect on Local Government No

Effect on the State or on Industrial Insurance No

AN ACT relating to traumatic brain injuries creating the advisory committee on traumatic brain injuries and providing other matters properly relating thereto

THE PEOPLE OF THE STATE OF NEVADA REPRESENTED IN SENATE AND ASSEMBLY DO ENACT AS FOLLOWS

Section 1 Title 38 of NRS is hereby amended by adding thereto a new chapter to consist of a new section to read as follows

1 The advisory committee on traumatic brain injuries consisting of five members is hereby created

2 The administrator shall appoint to the committee

(a) Two members from the Nevada chapter of the National Head Injury Foundation

(b) Two members who are employees of providers of health care located in this state

(c) One member who is an employee of the rehabilitation division of the department of human resources

3 After the initial appointments each member of the committee serves a term of 3 years

4 The committee shall elect one of its members to serve as chairman

5 Members of the committee serve without compensation and are not entitled to receive the per diem allowance or travel expenses provided for state officers and employees generally

6 The committee may

(a) Make recommendations to the administrator relating to the establishment and operation of any program for persons with traumatic brain injuries

(b) Make recommendations to the administrator concerning proposed legislation relating to traumatic brain injuries

(c) Collect information relating to traumatic brain injuries

7 The committee shall prepare a report of its activities and recommendations each year and submit a copy to the

(a) Administrator

(b) Legislative committee on health care and

(c) Legislative commission

8 As used in this section

(a) Administrator means the administrator of the rehabilitation division of the department of human resources

(b) Provider of health care has the meaning ascribed to it in NRS 629.031.

(c) Traumatic brain injury means a sudden shock or damage to the brain or its coverings which is not of a degenerative nature and produces an altered state of consciousness or temporarily or permanently impairs the mental, cognitive, behavioral or physical functioning of the brain. The term does not include:

(1) A cerebral vascular accident;

(2) An aneurism; or

(3) A congenital defect.

Sec. 2. As soon as practicable after October 1, 1991, the administrator of the rehabilitation division of the department of human resources shall appoint to the advisory commission on traumatic brain injuries:

1. Two members whose terms expire on September 30, 1994.

2. Two members whose terms expire on September 30, 1993.

3. One member whose term expires on September 30, 1992.

SUMMARY Requires rehabilitation division of department of human resources to adopt regulations concerning care of persons with traumatic brain injuries (BDR 38 165)

FISCAL NOTE Effect on Local Government No

Effect on the State or on Industrial Insurance No

AN ACT relating to traumatic brain injuries requiring the rehabilitation division of the department of human resources to adopt regulations concerning the care of persons with traumatic brain injuries and providing other matters properly relating thereto

THE PEOPLE OF THE STATE OF NEVADA REPRESENTED IN SENATE AND ASSEMBLY DO ENACT AS FOLLOWS

Section 1 Title 38 of NRS is hereby amended by adding thereto a new chapter to consist of a new section to read as follows

1 The rehabilitation division of the department of human resources shall adopt regulations concerning the care of persons with traumatic brain injuries The division shall in adopting the regulations consider the criteria established by the Commission on Accreditation of Rehabilitation Facilities for the care of such persons

2 As used in this section traumatic brain injury means a sudden shock or damage to the brain or its coverings which is not of a degenerative nature and produces an altered state of consciousness or temporarily or permanently impairs the mental cognitive behavioral or physical functioning of the brain The term does not include

(a) A cerebral vascular accident

(b) An aneurism or

(c) A congenital defect

SUMMARY Increases rate of tax on malt beverage liquor (BDR 32 166)

FISCAL NOTE Effect on Local Government No

Effect on the State or on Industrial Insurance No

AN ACT relating to malt beverage liquor increasing the rate of tax on malt beverage liquor and providing other matters properly relating thereto

THE PEOPLE OF THE STATE OF NEVADA REPRESENTED IN SENATE AND ASSEMBLY DO ENACT AS FOLLOWS

Section 1 NRS 369 330 is hereby amended to read as follows

369 330 Except as otherwise provided in this chapter an excise tax is hereby levied and must be collected respecting all liquor and upon the privilege of importing possessing storing or selling liquor according to the following rates and classifications

1 On liquor containing more than 22 percent of alcohol by volume $2 05 per wine gallon or proportionate part thereof

2 On liquor containing more than 14 percent up to and including 22 percent of alcohol by volume 75 cents per wine gallon or proportionate part thereof

3 On liquor containing from one half of 1 percent up to and including 14 percent of alcohol by volume 40 cents per wine gallon or proportionate part thereof

4 On all malt beverage liquor brewed or fermented and bottled in or outside this state [9] *13* cents per gallon

SUMMARY Requires division for review of health resources and costs of department of human resources to establish system for reporting information relating to persons with traumatic brain injuries (BDR 38 167)

FISCAL NOTE Effect on Local Government Yes

Effect on the State or on Industrial Insurance Yes

AN ACT relating to traumatic brain injuries requiring the division for review of health resources and costs of the department of human resources to establish a system for the reporting of information relating to persons with traumatic brain injuries requiring each hospital to report certain information relating to persons with traumatic brain injuries providing a penalty and providing other matters properly relating thereto

THE PEOPLE OF THE STATE OF NEVADA REPRESENTED IN SENATE AND ASSEMBLY DO ENACT AS FOLLOWS

Section 1 Title 38 of NRS is hereby amended by adding thereto a new chapter to consist of the provisions set forth as sections 2 to 6 inclusive of this act

Sec 2 As used in this chapter

1 Division means the division for review of health resources and costs of the department of human resources

2 Traumatic brain injury means a sudden shock or damage to the brain or its coverings which is not of a degenerative nature and produces an altered state of consciousness or temporarily or permanently impairs the mental cognitive behavioral or physical functioning of the brain The term does not include

(a) A cerebral vascular accident

(b) An aneurism or

(c) A congenital defect

Sec 3 The division shall

1 Establish and maintain a system for the reporting of information relating to persons with traumatic brain injuries and

2 Adopt regulations which prescribe the information which must be reported to the division and the procedure for reporting that information

Sec 4 1 The chief administrative officer of each hospital in this state shall submit to the division the information required by the regulations adopted pursuant to section 3 of this act

2 Any person who violates this section is guilty of a misdemeanor

Sec 5 Each year the division shall prepare and submit to the legislative commission a statistical report which summarizes and interprets the information obtained pursuant to section 3 of this act

Sec 6 A person who provides information to the division pursuant to section 3 of this act may not be held liable in a civil or criminal action for disclosing confidential information unless he has done so in bad faith or with malicious purpose

SUMMARY Makes appropriation to rehabilitation division of department of human resources to establish program for persons with traumatic brain injuries (BDR S 168)

FISCAL NOTE Effect on Local Government No

Effect on the State or on Industrial Insurance Contains Appropriation

AN ACT making an appropriation to the rehabilitation division of the department of human resources to establish a program for persons with traumatic brain injuries and providing other matters properly relating thereto

THE PEOPLE OF THE STATE OF NEVADA REPRESENTED IN SENATE AND ASSEMBLY DO ENACT AS FOLLOWS

Section 1 There is hereby appropriated from the state general fund to the rehabilitation division of the department of human resources to establish a program for persons with traumatic brain injuries

For the fiscal year 1991 92	$919 467
For the fiscal vear 1992 93	$928 224

Sec 2 Any balance of the sums appropriated by section 1 of this act remaining at the end of the respective fiscal years must not be committed for

expenditure after June 30 and reverts to the state general fund as soon as all payments of money committed have been made

Sec 3 This act becomes effective on July 1 1991

SUMMARY Urges certain self help groups in Nevada to develop programs to address special needs of persons with traumatic brain injuries (BDR R 374)

CONCURRENT RESOLUTION Urging certain self help groups in this state to develop programs to address the special needs of persons with traumatic brain injuries

WHEREAS Each year approximately 2 000 persons in this state sustain traumatic brain injuries and

WHEREAS Some persons who suffer the emotional and physical effects of traumatic brain injuries often develop or exacerbate problems relating to the abuse of drugs or alcohol and

WHEREAS Many of those persons would benefit greatly from the services of certain self help groups and

WHEREAS Self help groups such as Alcoholics Anonymous Narcotics Anonymous and Al Anon Family Groups have not developed programs to address the special needs of persons with traumatic brain injuries now therefore be it

RESOLVED BY THE OF THE STATE OF NEVADA THE CONCURRING That the Nevada Legislature urges Alcoholics Anonymous Narcotics Anonymous and Al Anon Family Groups and any other self help groups which provide services which would benefit persons

with traumatic brain injuries to develop programs to address the special needs of those persons and be it further

RESOLVED That copies of this resolution be prepared and transmitted forthwith by the of the to the chief officer in Nevada of Alcoholics Anonymous Narcotics Anonymous Al Anon Family Groups and any other self help groups in this state of which she is aware that provide services which would benefit persons with traumatic brain injuries