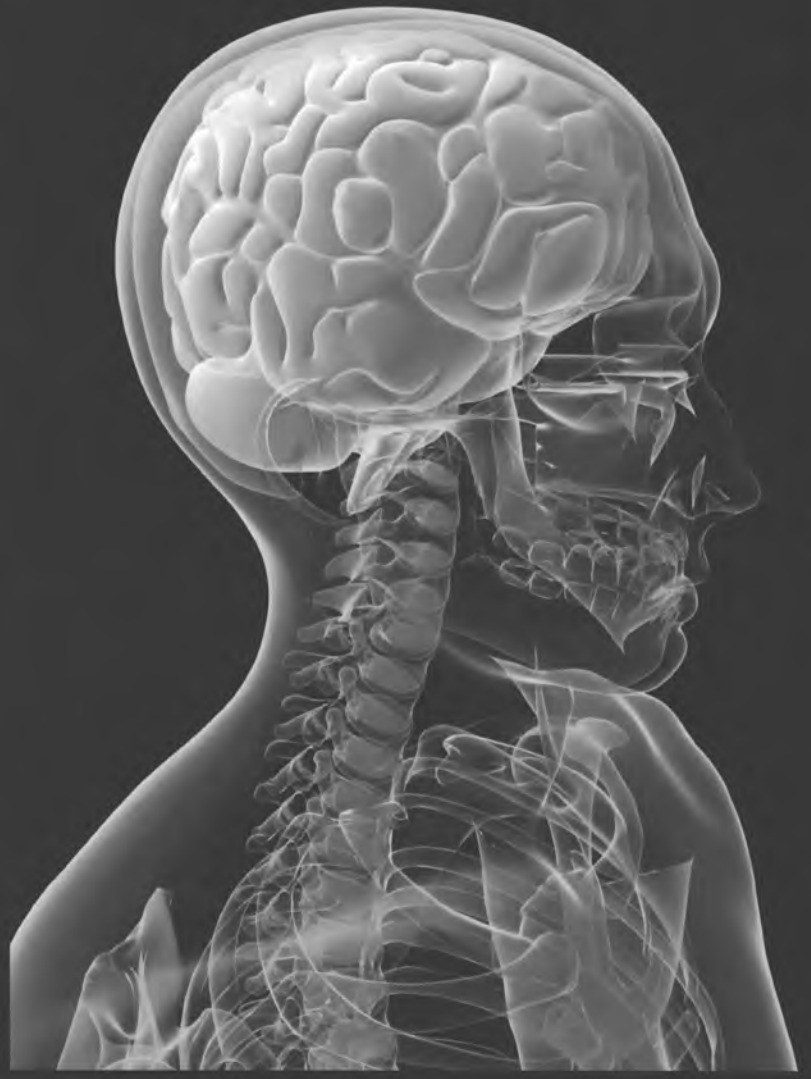
02/21/13 PRESENTATION: ALASKA BRAIN INJURY NETWORK

<TARGET><BILL></BILL><SUBJECT>02-21-13 PRESENTATION ALASKA BRAIN INJURY NETWORK</SUBJECT><COMM>HHSS28</COMM></TARGET>

TRAUMATIC BRAIN INJURY

Evidence-Based Management



Roland Torres, MD, FAANS, FACS

Chairman

Dept. of Neurosurgery

Alaska Native Medical Center

ALASKA NATIVE MEDICAL CENTER

TRAUMATIC BRAIN INJURY

*Neuro***Trauma** ***Stanford's Level I Trauma Center &*** ***Life Flight Emergency Transport***

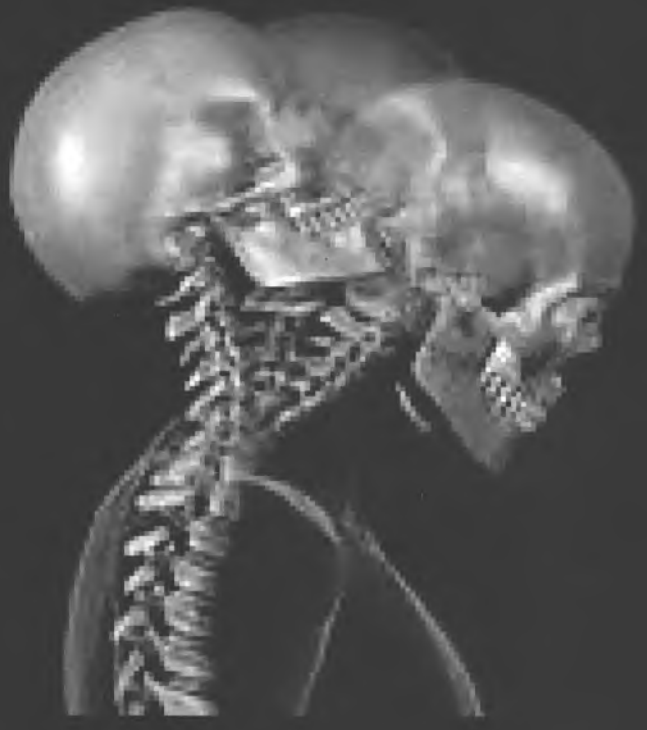
Each Support Stanford's
Traumatic Brain Injury Program,
Providing State-of-the-Art Acute Interventions and Transport for Neuro Trauma Patients

Traumatic brain injury (TBI) is a national health problem accounting for 40% of all deaths from acute injuries in the U.S. For those 200,000 victims who survive annually, hospitalization is required and many are left permanently disabled. Each year, 1 out of 1,000 Americans sustain a TBI, including 1.7 million people who suffer mild TBI, like brain concussions. The detrimental cumulative effect on neuropsychological function and brain pathology following repetitive concussions is now being recognized, with important implications for many sports and athletes. The direct cost of TBIs in the U.S. is estimated at $4 billion annually, with indirect costs reaching ten times greater.

The Stanford Traumatic Brain Injury Program delivers state-of-the art Neuro-Intensive care for acutely brain injured patients at Stanford, Santa Clara Valley Medical Center (SCVMC) and the Veterans Affairs Palo Alto Health Care System (VAPHCS), with SCVMC and VAPHCS providing anationally recognized Centers of Excellence for brain trauma rehabilitation. New methods are being developed to monitor severe brain injury using chemical analysis of brain tissue, cerebrospinal fluid and blood, as well as novel brain imaging techniques such as magnetic resonance (MR) diffusion tensor imaging (DTI). Current research is also identifying specific blood biomarkers that predict future neurological and psychological sequelae following mild and severe brain trauma, allowing earlier targeted intervention. A major effort currently, is to improve the outcome from this devastating condition by applying therapeutic advances pioneered at Stanford such as mild brain hypothermia for patients and investigating new pharmacologic treatments, as part of NIH supported clinical trials.

INTRODUCTION

- DEFINITION
- DIAGNOSIS
  - EVALUATION
  - GRADING
- MANAGEMENT
- RETURN TO PLAY
- REFERRAL CRITERIA
- CURRENT GUIDELINES
  - PRAGUE 2004
- BOARD QUESTIONS



ALASKA NATIVE MEDICAL CENTER

TRAUMA CARE FUND:
ALASKA NATIVE MEDICAL CENTER
LEVEL II TRAUMA CENTER

Working together to promote and protect the health and well-being of Alaskans through an Inclusive Trauma System

The **Trauma Care Fund** (HB 168) was signed into law by Governor Parnell in 2010 to sustain existing trauma centers, support development of new trauma centers, and develop a statewide trauma system. The Trauma Care Fund partially offsets increased costs of optimal care to critically injured Alaskans.

With the third highest rate of injury deaths in the nation, only 55.2% of Alaskans are within 60 minutes of a Level I (Harborview, Seattle) or Level II (ANMC) trauma center. Yet, because of their experience, staff, and equipment, patients have up to a 25% better chance of survival at a trauma center.

The Trauma Care Fund is administered by the Department of Health & Social Services **Trauma Program** with recommendations by the **Alaska Trauma System Review Committee.**

RETURN ON

TRAUMA ACTIVITIES	TRAUMA COSTS
PERSONNEL	$1,355,806
REVERIFICATION	$13,000
EQUIPMENT	$85,289
EDUCATION	$46,138
REGISTRY / QI	$14,000
OUTREACH	$25,250
TOTAL ANMC COSTS	**$1,539,483**
TCF PAYOUT	$337,500
RETURN ON INVESTMENT	**456%**

ACTIVITIES THAT ENHANCED TRAUMA CARE AT ANMC IN 2012:

Pending Redesignation: Level II Trauma Center November 19, 2012

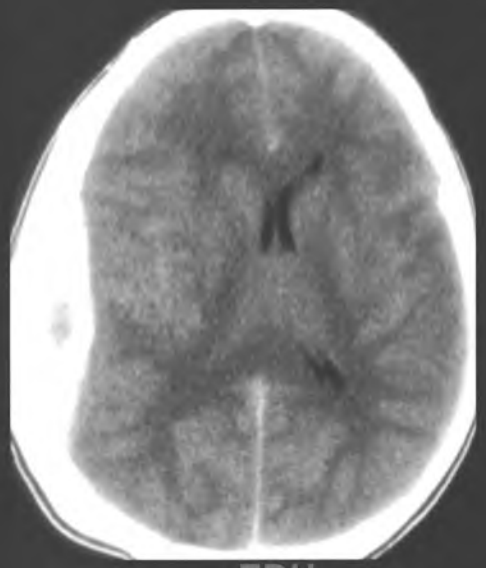
- **24/7 Trauma Care Coverage** with enhanced neurosurgery capacity, with new staff neurosurgeon from Stanford University.
- **Acquisition of Cell Saver Equipment** training and support personnel. The Cell Saver is an intraoperative cell salvage machine that suctions, washes and filters the patient's blood, reducing the need for, and risk of, blood donation.
- **Advanced Trauma Life Support (ATLS) Training**: A systematic, concise approach to early care of the trauma patient. Simulation provides a common language, enhancing team communication and coordination for rapid, effective, life-saving patient treatment.
- **Trauma Nurse Care Course (TNCC)** provided enhanced clinical knowledge and psychomotor skills related to trauma.
- **Trauma Quality Improvement**: Collection of data through the Trauma Quality Improvement Program allows ANMC to use the National Trauma Data Bank (NTDB) to collect valid, reliable data that identifies characteristics associated with improved outcomes.
- **Trauma Center Association of American (TCAA)** utilization for up-to-date information on resources and sustainability.
- **Outreach and P**

ANMC

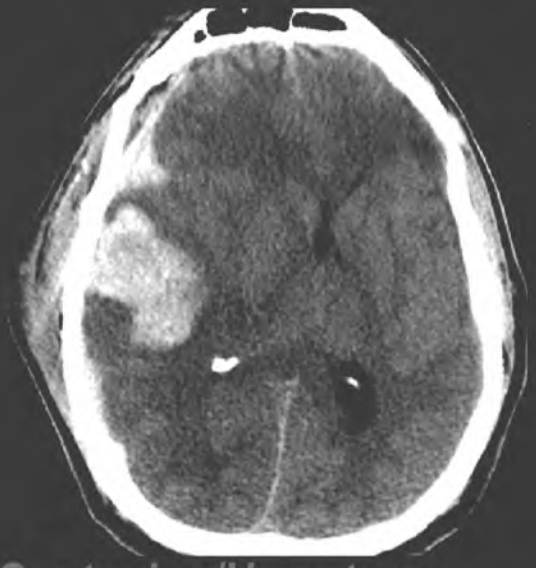
.Established a ***THINKFIRST Chapter*** to provide educational programs to schools and community groups on head injuries.

- Provided education in Neurotrauma to Critical Care Nurses at ANMC for clinical expertise.
- Upgraded angiography equipment for diagnosis and treatment of vascular injuries.
- Addition of 1 full time trauma registrar as recommended by the American College of Surgeons Committee on Trauma.
- Reverification visit successfully completed for Level II Trauma Center by the American College of Surgeons Committee on Trauma.
- Trauma Quality Improvement Program through the ACS-COT provides quarterly reports, external data validation, and annual training.

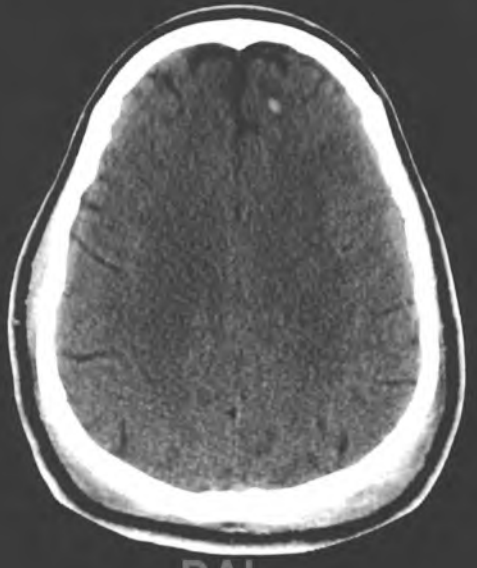
6 different examples of "Severe" TBI ?!?



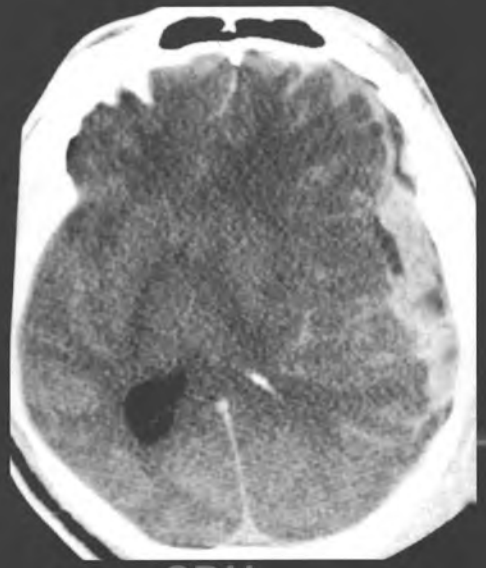
EDH



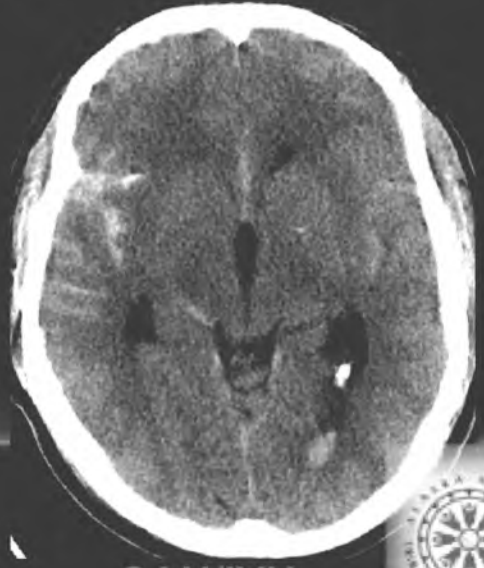
Contusion/Hematoma



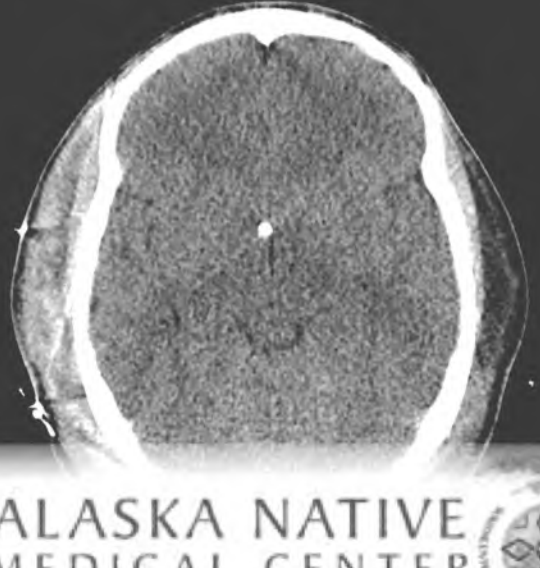
DAI



SDH



SAH/IVH



ALASKA NATIVE MEDICAL CENTER

BURDEN OF NEUROLOGICAL EMERGENCIES

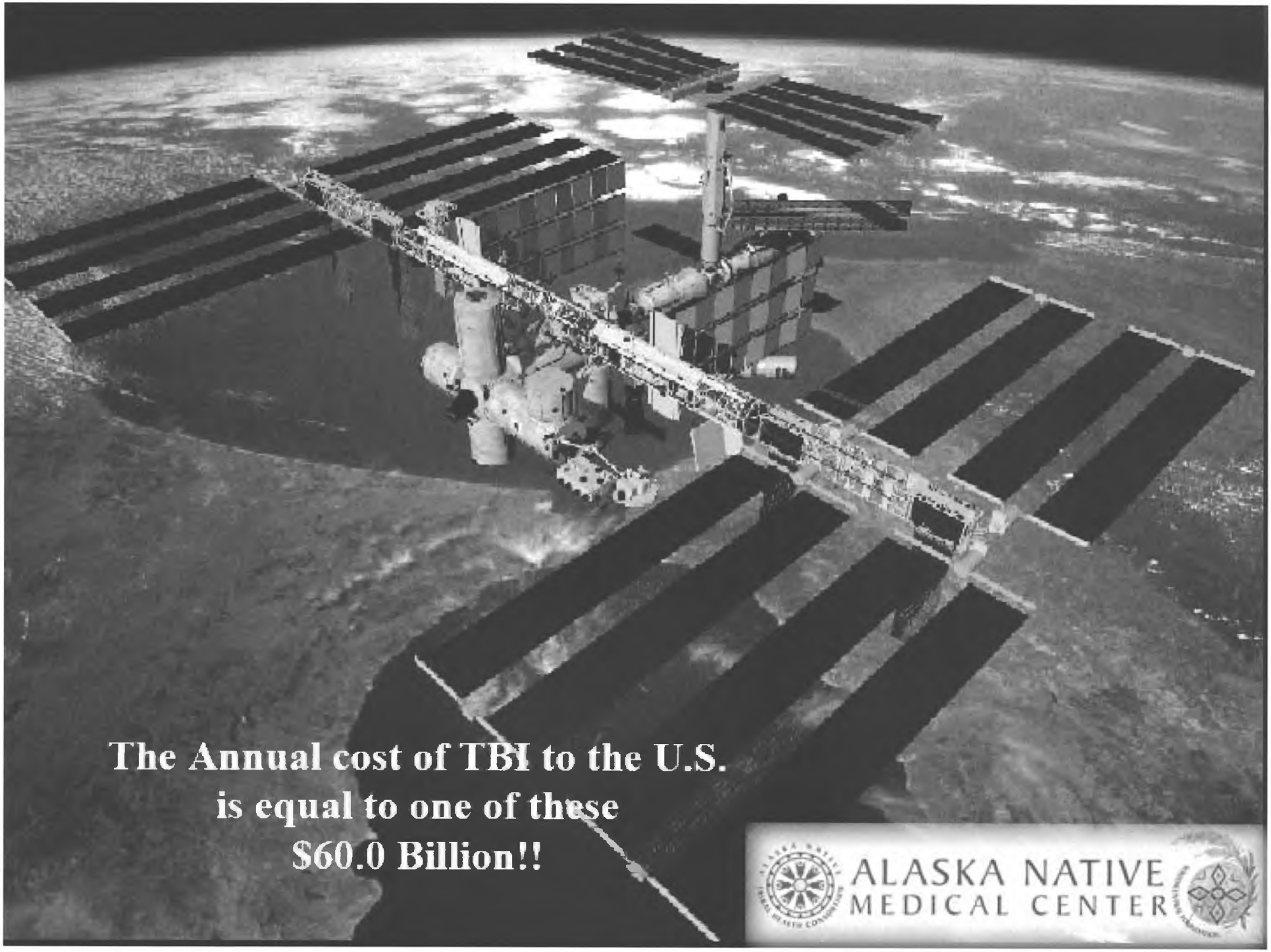
Disorder	**Incidence** per 100,000	**Mortality** 30-day	%**Cost*** thousands $
Acute Ischemic Stroke	200	17	$91
Intracerebral hemorrhage	15	50	$124
Subarachnoid hemorrhage	6	50	$228
Traumatic brain injury	100	29	$136
Spinal cord injury	4	20	$200
Bacterial meningitis	1.5	12	$8
Status epilepticus	40	22	$40
Anoxic brain injury	7.5	80	$50**

*Per patient in first year, **Rehabilitation only

ALASKA NATIVE MEDICAL CENTER

PAYERS FOR TRAUMATIC BRAIN INJURY HOSPITALIZATIONS, 2007-2011, ALL RACES, ALASKA

Payer	Number of Cases paid	Total Charges
Self-Pay	650	$31,622,615
Private	669	$26,692,287
Medicare	570	$24,515,213
Medicaid	404	$16,251,949
Automotive	196	$10,556,986
Military/VA	195	$9,430,418
CHAMPUS	71	$4,880,163
Workers	110	$4,575,387
IHS	264	$4,177,991
PPO	11	$627,655
Victims	30	$359,374
Welfare	4	$285,085
Fisherman's	12	$204,143
Other or unknown	210	$10,811,730
Total	**3396**	**$144,990,996**


The Annual cost of TBI to the U.S.
is equal to one of these
$60.0 Billion!!
ALASKA NATIVE
MEDICAL CENTER

HIGH RISK POPULATIONS

Young people

Low-income individuals

Unmarried individuals

Members of ethnic minority groups

Residents of inner cities

Men (2:1 vs. women)

Individuals with previous history of substance abuse

Individuals with previous TBI

ALASKA NATIVE MEDICAL CENTER

TRAUMA IN ALASKA

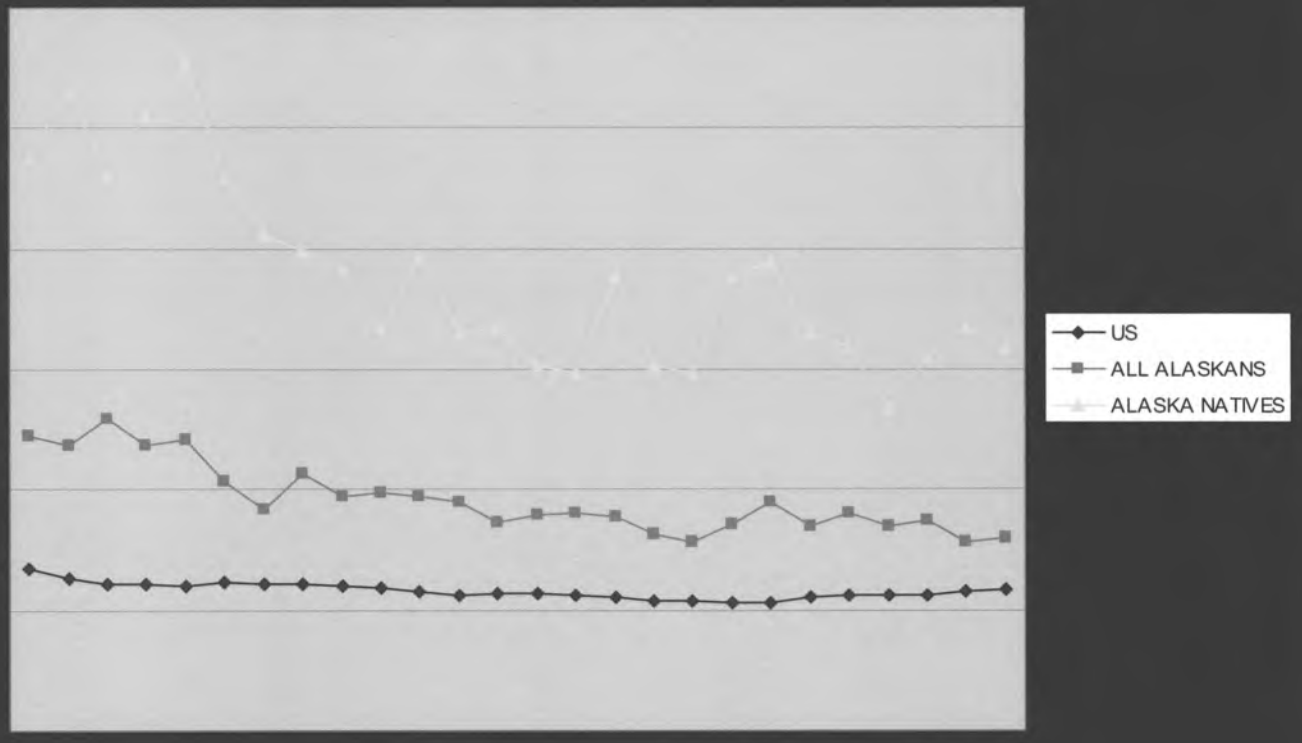
The leading cause of death under age 44.

- Alaska- 2nd highest trauma mortality in the US.

  400-500 alaskans die each year.
  Over 1000 with permanent disabilty.

- Approximately 5000 admissions

TRAUMA MORTALITY IN ALASKA



TRAUMATIC BRAIN INJURY

- **"the incidence rate of identified Traumatic Brain Injuries (TBI's)** in Alaska is 28% higher than the national rate"

Alaska Department of Health and Social Services
Division of Behavioral Health

TRAUMATIC BRAIN INJURY

Each year, 244 people are hospitalized for Traumatic Brain Injury (TBI) in the Anchorage and Mat-Su region.

One out of four injured was under the influence of alcohol.

Almost half are under 30 years old.

if have organization

TRAUMA SYSTEMS

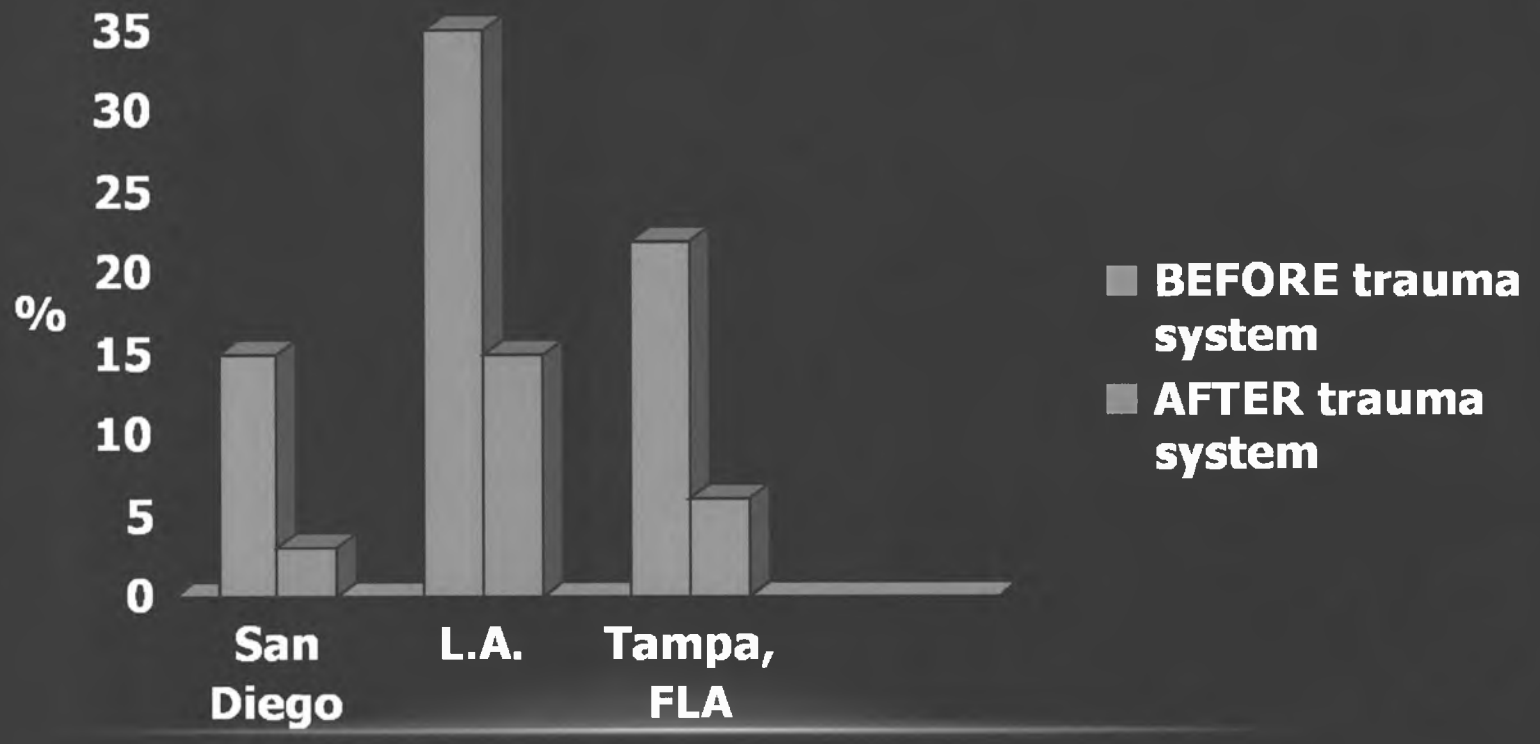
- "15-20% improvement in survival of the seriously injured." NEJM 1999
- Inclusive systems -best

Increase productive working years

Improve statewide disaster preparedness.

PREVENTABLE DEATHS: THE IMPACT OF TRAUMA SYSTEMS

NATHENS ET AL. 2000



The Impact of Volume on Outcome in Seriously Injured Trauma Patients: Two Years' Experience of the Chicago Trauma System

ROBERT F. SMITH, M.D., M.P.H.*†, LAWRENCE FRATESCHI, M.A.†, EDWARD P. SLOAN, M.D.*, LURENE CAMPBELL, R.N., M.S.N.†, RICHARD KRIEG, PH.D.†, LONNIE C. EDWARDS, M.D.*†, AND JOHN A. BARRETT, M.D.*

1643 trauma patients treated at seven trauma centers with differing annual volumes of trauma patients.

Patients taken to a low volume trauma center had a 30% greater chance of dying.

J. Trauma 30: 1066-1076, 1990

ALASKA NATIVE MEDICAL CENTER

Traumatic Brain Injury
Evidence-Based Management

The NEW ENGLAND JOURNAL of MEDICINE

SPECIAL ARTICLE

A National Evaluation of the Effect of Trauma-Center Care on Mortality

Ellen J. MacKenzie, Ph.D., Frederick P. Rivara, M.D., M.P.H., Gregory J. Jurkovich, M.D., Avery B. Nathens, M.D., Ph.D., Katherine P. Frey, M.P.H., Brian L. Egleston, M.P.P., David S. Salkever, Ph.D., and Daniel O. Scharfstein, Sc.D.

ALASKA NATIVE MEDICAL CENTER

TRAUMATIC BRAIN INJURY
EVIDENCE-BASED MANAGEMENT

Direct Transport Within An Organized State Trauma System Reduces Mortality in Patients With Severe Traumatic Brain Injury

Roger Härtl, MD, Linda M. Gerber, PhD, Laura Iacono, RN, MSN, Quanhong Ni, MS, Kerry Lyons, MS, and Jamshid Ghajar, MD, PhD

Background: Prehospital management of traumatic brain injury (TBI) and trauma system development and organization are aspects of TBI care that have the potential to significantly impact patient outcome. This multi-center study was conducted to explore the effect of prehospital management decisions on early mortality after severe TBI.

Methods: This report is based on 1449 patients with severe TBI (GCS <9) treated at 22 trauma centers enrolled in a New York State quality improvement (QI) program between 2000 and 2004. The prehospital data collected on these patients include time of injury, time of arrival to the trauma center, mode of transport, type of EMS provider, direct or indirect transport, blood pressure and pulse oximetry values, GCS score, pupillary assessment, and airway management procedures.

Results: After exclusion criteria were applied, a total of 1,123 patients were eligible for analysis. The majority of patients were male (75%) with a mean age of 36 years. After controlling for arterial hypotension, age, pupillary status, and initial GCS score, direct transport was found to result in significantly lower mortality than indirect transport. Transport mode, time to admission, and prehospital intubation were not found to be related to 2-week mortality.

Conclusions: The present study provides class II evidence that demonstrates a 50% increase in mortality associated with indirect transfer of TBI patients. Patients with severe TBI should be transported directly to a Level I or Level II trauma center with capabilities as delineated in the *Guidelines for the Prehospital Management of Traumatic Brain Injury*, even if this center may not be the closest hospital.

Key Words: Traumatic brain injury, Transport, Mortality, Prehospital.

J Trauma. 2006;60:1250–1256.

Transport

Impact of a Trauma System on Outcome of Severely Injured Patients

Steven R. Shackford, MD; Robert C. Mackersie, MD; David B. Hoyt, MD; William G. Baxt, MD; A. Brent Eastman, MD; Fred N. Hammill, MD; F. Barry Knotts, MD; Richard W. Virgilio, MD

- 189 severely injured patients
- Compared with a model for predicting survival from a cohort study
- Predicted survival was 18%
- Actual survival was 29% utilizing a trauma system
- Improved survival was attributed to the integration of prehospital and hospital care and access to expeditious surgery

Shackford SR, Mackersie RC, Hoyt DB, et al: Impact of a trauma
outcome of severely injured patients. Arch Surg 122:523-527, 198

ALASKA NATIVE MEDICAL CENTER

Transport

Interhospital versus Direct Scene Transfer of Major Trauma Patients in a Rural Trauma System

JEFFREY S. YOUNG, M.D.,* DEENI BASSAM, B.S.,* GERALD A. CEPHAS, M.D.,* WILLIAM J. BRADY, M.D.,† KATHY BUTLER, R.N.,* AND MICHELLE POMPHREY, R.N.*

From the University of Virginia Trauma Center, Departments of Surgery and Emergency Medicine,† University of Virginia Health System, Charlottesville, Virginia*

- Prospective, observational cohort study
- Trauma patients with ISS >15 presenting to UVA
- Patients transported directly to the trauma center were compared with those who were first taken to a rural hospital and later transferred.
- Directly transported patients had shorter ICU and shorter total hospital stays although mortality was not different

Young JS, Bassam D, Cephas GA, et al: Interhospital versus direct scene
of major trauma patients in a rural trauma system. Am Surg 64:88-92, 199

ALASKA NATIVE MEDICAL CENTER

IMPACT OF TBI GUIDELINES

The Journal of **TRAUMA**® *Injury, Infection, and Critical Care*

Using a Cost-Benefit Analysis to Estimate Outcomes of a Clinical Treatment Guideline: Testing the Brain Trauma Foundation Guidelines for the Treatment of Severe Traumatic Brain Injury

Mark Faul, PhD, Marlena M. Wald, MLS, MPH, Wesley Rutland-Brown, MPH, Ernest E. Sullivent, MD, and Richard W. Sattin, MD

ALASKA NATIVE MEDICAL CENTER

IMPACT OF TBI GUIDELINES

Table 2 Overall Cost Savings and Lives Saved Resulting From Adoption of BTF Guidelines—Total Costs

	Deaths	Direct Medical Costs	Rehabilitation Costs	Societal Costs	Implementation Costs	Total Costs
BTF adoption	3,466	$ 1,154,116,956	$ 64,008,683	$ 3,859,102,789	$ 60,906,282	$ 5,138,134,710
Current state	7,073	$ 1,416,538,024	$ 107,428,632	$ 7,696,680,328	$ 0	$ 9,220,646,983
Difference	3,607	$ 262,421,068	$ 43,419,949	$ 3,837,577,538	$ 60,906,282	$ 4,082,512,273

Calculated medical costs probabilities are subject to rounding errors.

per hypothetical study

ALASKA NATIVE MEDICAL CENTER

CASE PRESENTATION. NO.1

- 34 M Found down.
- Dx: Subdural Hematoma, Severe TBI
- Surgical intervention: Decompressive Craniotomy
- Bone flap replaced 12 day ago.
- Length of stay: 40 days+.
- Ready for discharge
- Hometown: Wainwright, Alaska
- Problems: 1.) Funding 2.) Availability in Alaska

CASE PRESENTATION. NO. 2

- 59 F brought in by EMS after family found her with confused speech and right sided weakness.
- Dx: Severe brainstem hemorrhagic stroke, Hydrocephalus, Severe TBI
- Surgical Intervention: Evacuation of hematoma, placement of External Ventricular Drain
- Stabilized, beginning to speak
- Length of stay: 88 days+
- Ready for discharge. Her husband is at her bedside almost daily.
- Hometown: Fairbanks, Alaska
- Problems: 1.) Funding 2.) Availability of Neuro-Rehabilitation Center in Alaska

CASE PRESENTATION. NO.3

- 66 M Flown from Bethel with Right sided Dense Hemiparesis and Expressive Aphasia.
- Dx: Subarachnoid Hemorrhage from an anterior communicating ruptured aneurysm, Hunt Hess Grade 4. Severe TBI
- Subarachnoid Hemorrhage and ruptured aneurysm 10-15% die before reaching medical care. 46% mortality rate in the first 30 days.[1]
- Surgical Intervention: Craniotomy to evacuate the hematoma
- Extubated and Stabilized
- Length of stay: 73 days
- Finally discharged after over a month of waiting.
- Hometown: Kwethluk, Alaska
- Problems: Availability of Neuro-Rehabilitation Center in Alaska

CASE PRESENTATION.NO.4

- 50 F Flown from Juneau with new onset of seizures
- Dx: Chronic Subdural hematoma, Severe TBI
- Surgical Intervention: Burr hole evacuation
- Stabilized with improving Receptive and Expressive Aphasia and Post-Concussive Amnesia. Is at 80% of normal cognitive faculties.
- Length of Stay: 26 days
- Discharge to Assisted Living Facility as she was deemed too “High Functioning” for Rehabilitation.
- Problem: No Neuro-Rehabilitation Center in Alaska

CASE PRESENTATION. NO.5

- 20 F Fell from a 3 story building, ETOH and hx of suicide attempts
- Dx: R Frontal Subdural Hematoma, Moderate Traumatic Brain Injury
- Surgical intervention: Craniotomy
- Stabilized and Psychiatric Evaluation
- Length of Stay: 7 days
- Discharge to API
- Problems: 1.) Lack of availibility of inpatient psychiatric care 2.) Lack of Multidisciplinary treatment collaboration

CASE PRESENTATION. NO.6

- 39 M Self-inflicted Gun Shot Wound to the Head
- Dx: Self inflicted GSW with retained fragments, Concussion, Several facial fracture, Severe TBI
- Surgical Intervention: Craniotomy to remove bone fragments
- Stabilized and Psychiatric Evaluation
- Length of Stay: 19 days
- Discharged to API. Length of stay at API: 1 week.
- Problems: 1.) Limited inpatient psychiatric support 2.) Lack of Multidisciplinary treatment collaboration

CASE PRESENTATION.NO.7

- 3 M Non-traumatic Injuries, Suspected Child Abuse
- Dx: Bilateral Subdural Hematoma, Refractory ICP, and Severe Traumatic Brain Injury
- Surgical Intervention: Hemicraniectomy
- Barbiturate Coma. Later Stabilized and Condition Improved. Attempting verbal. Moving all 4 extremities. Not able to walk upon discharge.
- Length of Stay: 32 days
- Discharged to Pediatric Rehabilitation Center in Seattle. No pediatric rehabilitation is Alaska. Has been placed in foster care system.
- Problems: 1.) Long term support physical and financial support 2.) Outpatient rehabilitation

Common Methods for Funding Trauma Care Services

State	Traffic & Legal Fines	Car & Driver Charges	Taxes	State Funds
California	✔		✔	
Illinois	✔			✔
Maryland		✔	✔	
Pennsylvania	✔			✔
Texas			✔	✔
Mississippi	✔		✔	
Washington	✔	✔		✔

Government Trauma Funding

Source	Description
Tobacco Settlements	A number of states use the funds and interest earned from tobacco lawsuit settlements to help finance their trauma care systems.
Federal Medicaid Fund	Washington provides supplemental payments for trauma services provided to Medicaid clients for Level I, II, or III trauma service facilities. These facilities receive Medicaid payments based on the relative amount of trauma care provided per quarter to Medicaid recipients.
Block Grants	Block grants are made available by both state and federal agencies. Most grants are specifically designated for emergency and trauma program research, improvement, expansion and implementation.
State Funding	A number of states designate a portion of the state budget specifically for the development, implementation and maintenance of their trauma programs. State funding ranges from $5 million to $25 million.

Comparison of Different State Trauma Programs

State	Funding Sources	Total Fund Pool	Eligibility Requirements	Payment Methodology	Fund Administration
Pennsylvania	Traffic fines, criminal fines	Varies; 75 percent trauma funds, 25 percent catastrophic care funds	Certified Trauma Centers Levels I, II and III	Of the total Medicaid disproportional share hospital payment funds allocated to trauma care, the state pays 90 percent to Level I and II trauma centers; the state pays the remaining 10 percent to Level III trauma centers. For all levels, the state divides 50 percent of the total funds equally among providers and divides the remaining 50 percent proportionally based on number of trauma patients and outstanding costs not covered by the lump sum distribution.	Department of Public Welfare
Florida	Sales tax, additional surcharges to all traffic fines	$18.4 M FYs 2002-2003	Certified Trauma Centers Level I and II, and Pediatric Referral Trauma Center	Funds distributed proportionately to the level of uncompensated care by service areas	Department of Health
California	Traffic fines, property tax, state general fund	$25 M FY 2002-2003	Certified Trauma Centers Levels I, II and III	Level I-II $150,000 minimum Level III $50,000 minimum Any facility with costs exceeding the minimum payment may then be awarded additional funds if available to cover outstanding costs, plus 1 percent of the total payment for administrative costs.	Department of Health
Illinois	Traffic fines, civil fines, federal match	$13 M FY 2002	Certified Trauma Centers Levels I and II	50 percent of total fund proportionately to providers; the remaining 50 percent is distributed proportionately by dividing a Hospital Distribution Factor by a Regional Distribution Factor.	Department of Health
Maryland	Vehicle registration fee, traffic fines, block grants	Varies	Certified Trauma Centers Levels I to IV and Physicians	Grants awarded to centers based on need; fines and fees pooled for emergency services	The Maryland Institute for Emergency Medical Services Systems
Washington	Traffic fines, vehicle registration, state funds, federal match	$32 M SFYs 2002-2003	Certified Trauma Centers Levels I, II and III and Physicians	Funds paid proportionately based on injury index system	Department of Health – Office of EMS and Trauma Prevention

BIBLIOGRAPHY

- 1. Greenburg

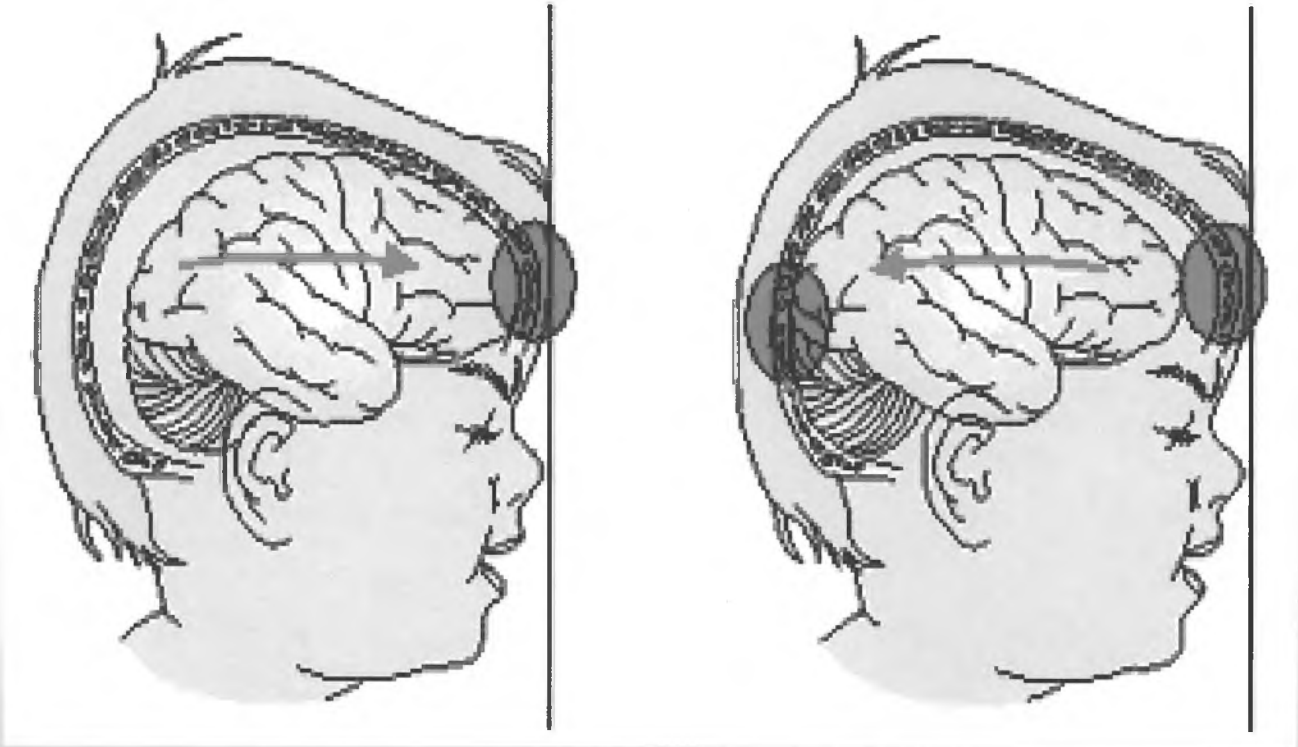
"Brain Injury Care (or Lack Thereof) in Alaska. Implications. Possible Solutions"

House Health Social Services Committee
February 21, 2013

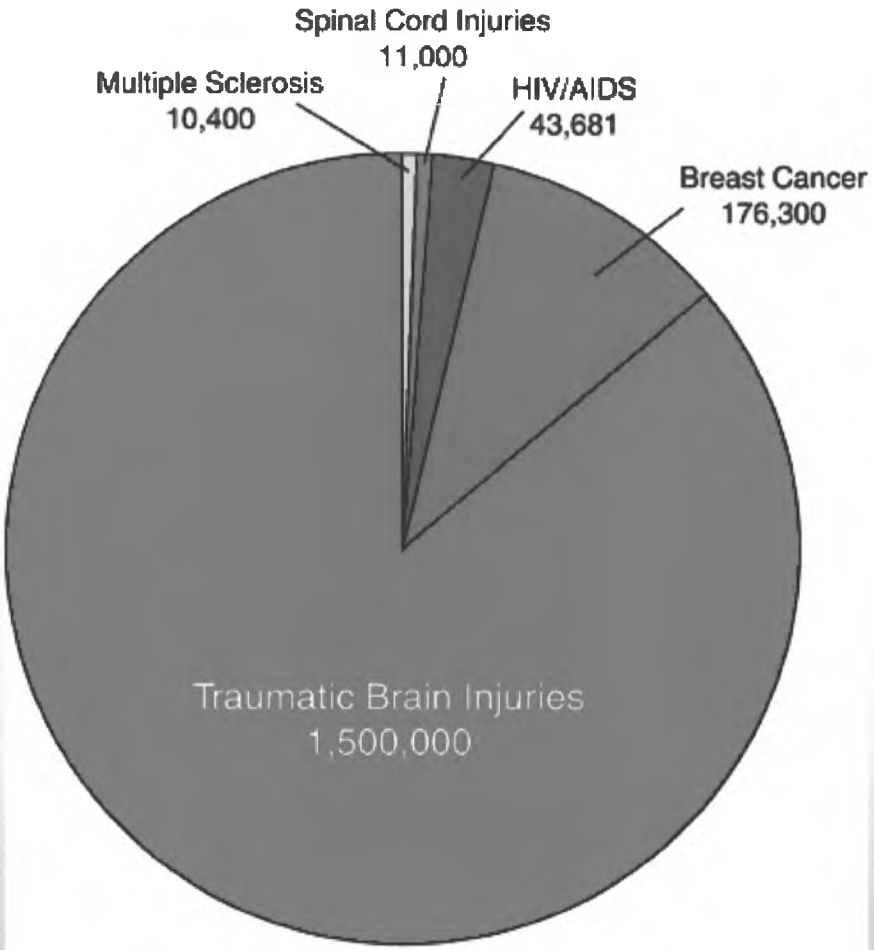
ALASKA NATIVE MEDICAL CENTER

alaska brain injury network

Why Worry About Brain Injury?



Because it Happens a LOT!

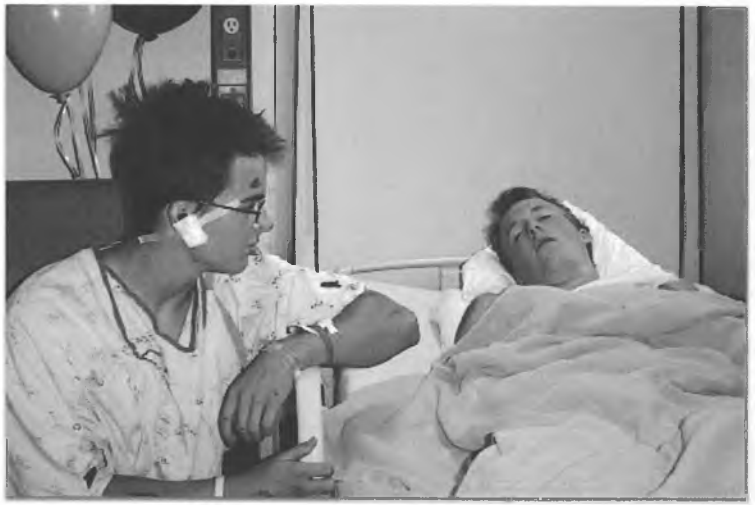


Comparison of Annual Incidence

Data compiled and arranged by the Brain Injury Association of America based on data from the Centers for Disease Control and Prevention, American Cancer Society and National Multiple Sclerosis Society

What is Traumatic Brain Injury (TBI)?

TBI is a non-degenerative, non-congenital insult to the brain from an external mechanical force, possibly leading to permanent or temporary impairment of cognitive, physical, and psychosocial functions, with an associated diminished or altered state of consciousness

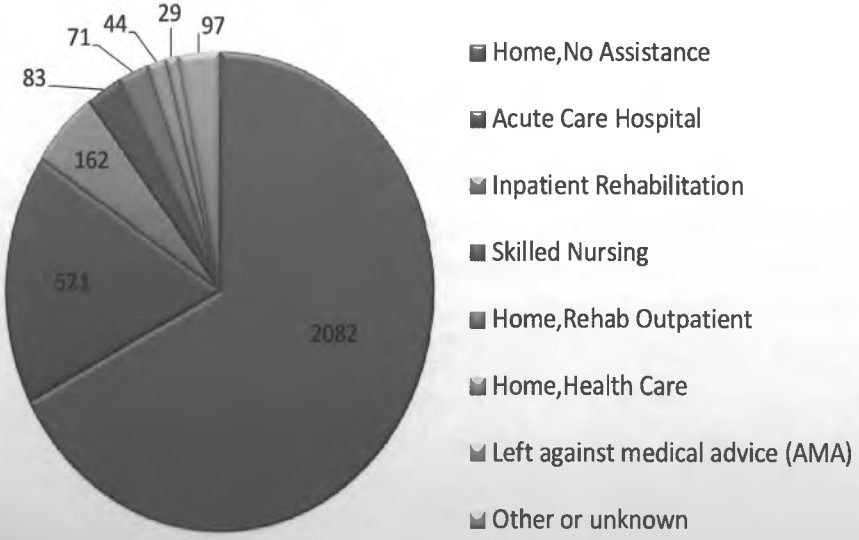


What we know

- On average **680** Alaskans hospitalized annually[1]
- Est. **3,000** Alaskans visit the emergency room and go home the same day[2]

Total acute care costs is about $29 million per year (five year period = $145,000,000)[1]

Highest hospitalization cost for one patient: $1,010,000[1]

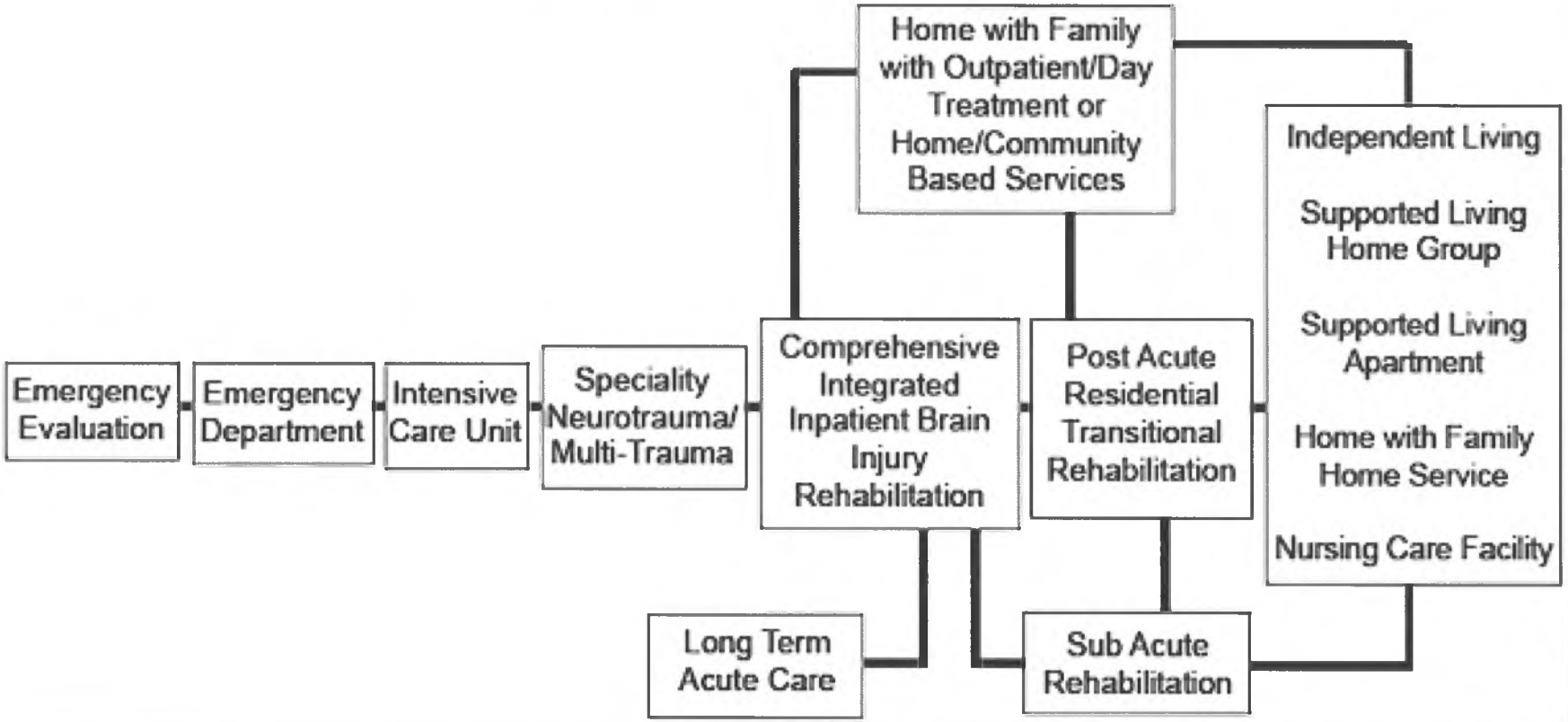


- 34% of Alaska behavioral health clients are screening positive for head injury[3]
- Anchorage and Juneau Homeless Coalitions are finding "possible brain injury" in interview[4]
- National meta-analysis, 60% of inmates screen positive for TBI[5]
- Texas, New Jersey, others looking at Juvenile Justice and how many kids have history of TBI[6]

1. Alaska Trauma Registry 2007-20011, Alaska Native Tribal Health Consortium
2. Centers for Disease Control estimates
3. Alaska's Automated Information Management System (AKAIMS)
4. Alaska Mental Health Trust Authority, presentation to House Finance, Feb. 2013
5. J Correct Health Care. 2010 Apr;16(2):147-59
6. http://www.nashia.org/pdf/sos2012/pres-beckworth-2012-sos.pdf

Traumatic Brain Injury Continuum of Care

Adapted from the Rocky Mountain Regional Brain Injury System to depict the continuum of care for individuals with moderate and severe TBI



"Classification of TBI not as an event, not as the final outcome, but rather as the beginning of a disease process."

(Brain Injury Association of America, "Conceptualizing Brian Injury as a Chronic Disease Position Paper", March 2009)

Problem:

Comprehensive Neurological Rehabilitation and Long-term support services **do not exist** in Alaska

OPPORTUNITY

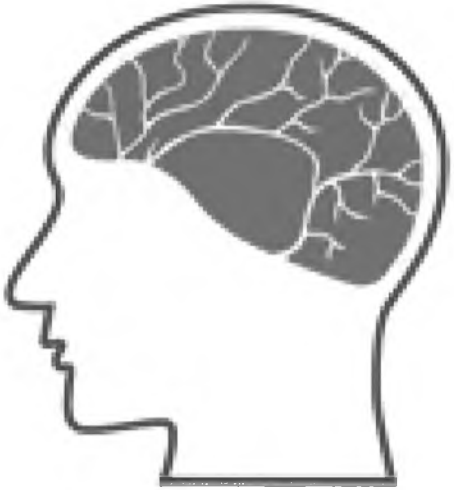
Create a TBI model system that includes Brain Injury Rehabilitation/Treatment in Alaska

Using the latest discoveries in Neuroscience, we can build a state of the art **system** which is incredibly effective.

CATCH

Policy and **Payment** is **ESSENTIAL!**

Educate. Plan. Coordinate. Advocate.



alaska
brain injury
network

Working to prevent traumatic brain injuries and promote wellness for Alaskans with all brain injuries.

Statewide Partners

- State of Alaska
  - Senior and Disabilities Services
  - Division of Behavioral Health
- Alaska Mental Health Trust Authority
  - Governor's Council on Disabilities and Special Education
  - Alaska Mental Health Board/Advisory Board on Alcohol and Drug Abuse
  - Alaska Commission on Aging
- Alaska Native Medical Center, Neurosurgery Dept.
- Alaska Native Tribal Health Consortium Injury Prevention
- Statewide Independent Living Council
- Disability Law Center
- Veterans Affairs
- Elmendorf TBI Clinic
- Several private/public agencies statewide

alaska brain injury network

Brain injury
HURTS
Alaska.

Policy and Funding that supports brain injury care will help Alaskans help themselves!

Jessi Chapman, Ketchikan

Dr. Roland Torres

Dr. Torres is a nationally recognized neurotrauma expert and one of the few neurosurgeons in the United States who is certified as an Advanced Trauma Life Support provider and instructor.

ALASKA NATIVE MEDICAL CENTER

Key Points

- TBI is a silent epidemic that has HUGE public health implications
- ABIN 10 Year Plan for TBI in Alaska has comprehensive list of recommendations:
  - Prevention and Identification
  - Improved trauma care: TBI Model Systems
  - Post-acute rehabilitation and long-term community supports
- **Policy** and **Payment** is **ESSENTIAL** to developing this care in Alaska
- Developing state-of-the-art brain injury care will require commitment from many players (and PAYORS)
- Brain Injury Care is an industry
  - Employs many different professionals
- FY14 Budget recommendations:
  - $350,000 GF/MH Operating Traumatic/Acquired Brain Injury Program
  - Continued funding for the Complex Behaviors Collaborative
  - $250,000 capital for "Research and Information Analysis"
- Brain Injury as a Chronic Disease
- Alaska Brain Injury Network appreciates your continued support

Policy and Funding that supports brain injury care will help Alaskans help themselves!

CONTACT INFORMATION

Jill Hodges, Executive Director
jill@alaskabraininjury.net

3745 Community Park Loop, #140
Anchorage, AK 99508

Toll-free: (888) 574-2824
Direct: (907) 274-2824

www.alaskabraininjury.net

Roland Torres, MD,FAANS,FACS
Chairman, Dept. of Neurosurgery
Alaska Native Medical Center
739-2520
ratorres@anthc.org

Background: Alaska's Response To This Growing Public Health Issue

- State of Alaska, Centers for Disease Control TBI Surveillance Study, 1996
- Department of Health and Social, Division of Mental Health Developmental Disabilities (DBH) apply for Federal Health Resources and Services Administration (HRSA) TBI Act funds, 1999
  - Alaska Mental Health Trust Authority Authorized Receipts were used for the state match.

alaska brain injury network

Background: Alaska's Response (cont.)

- HRSA Grant Requirements (1999)
  - Identify State lead agency (Division of Behavioral Health, moved to Senior and Disabilities Services)
  - Develop TBI advisory board (Alaska Traumatic Brain Injury Advisory Board, now Alaska Brain Injury Network (ABIN))
  - Needs assessment (consumer satisfaction surveys, now ABIN Resource Navigation Program)
  - Action plan (most recent, 10 Year Plan for Brain Injury in Alaska)

alaska brain injury network

2000-2010 Progress and Needs

System and Funding Progress

- Screen Behavioral Health (34% new BH clients screen positive)
- Alaska Mental Health Trust Authority funds:
  - TBI Advisory Board (ABIN)
  - Information and Referral (ABIN)
  - Brain Injury training (pilot)
  - Case Management (pilot)
  - Mini-grant program (pilot)
  - ImPACT testing/Concussion Management (pilot)
- Analysis of Alaska Trauma Registry data (ABIN partners with Alaska Native Tribal Health Consortium 2010)

Needs

- Statewide Case Management
- Post-acute treatment/rehabilitation
  - TBI Waiver
- Vocation/Education Programs
- Long-term support services
- Outreach/Identification
- Public Awareness
- Workforce development/training
- System's Planning Leadership (State, Trust, Veterans, Tribal, Public/Private)

2010 to today
Progress and Needs

System Progress

- SB 219, an act establishing a Traumatic/Acquired Brain Injury Program and Registry within Department of Health and Social Services passes unanimously in the 2010 session (Sen. McGuire and Rep. Johnson sponsored respective bills)
  - Collect, analyze and maintain databases on information related to longitudinal data on traumatic/acquired brain injury
  - Implement targeted case management (Medicaid-eligible)
  - Provide T/ABI services under a waiver if the department has received approval from federal government and dept. has appropriations allocated for the purpose
  - Establish a T/ABI Program (purpose of evaluating the effectiveness and availability of informational and services for the prevention and treatment of T/ABI in the state. Must partner with state agencies, non profits and other organizations in the state
- Trauma Bill (SB 168 Sen. Coghill sponsored)
- Student Athlete/Concussion Management Bill passes unanimously in 2011 (Rep. Doogan sponsored)

Needs

- Statewide Case Management
  - $300,000 GF/MH Operating
- Post-acute treatment/rehabilitation
- Vocation/Education Programs
- Long-term support services
  - Complex Behaviors Collaborative
- Outreach/Identification
- Public Awareness
- Workforce development/training
- System's Planning Leadership (State, Trust, Veterans, Tribal, Public/Private)

Cognitive Rehabilitation:

The Evidence, Funding and Case for Advocacy in Brain Injury

A Position Paper of the Brain Injury Association of America

November 2006

Brain Injury Association of America

Acknowledgements

The Brain Injury Association of America gratefully acknowledges the authors of this position paper: Douglas I. Katz, MD; Mark J. Ashley, ScD; Gregory J. O'Shanick, MD; and Susan H. Connors. The authors thank Caroline Feller, OTR, for her assistance.

Volunteer reviewers provided unique insight and thoughtful comments. The Association is deeply appreciative of their expertise and effort:

Keith D. Cicerone, PhD, ABPP/Cn
JFK-Johnson Rehabilitation Institute

Cindy Dahlberg, MA, CCC, CPHQ
Craig Hospital

Roberta DePompei, PhD
University of Akron

Wayne A. Gordon, PhD, ABPP/Cn
Mount Sinai School of Medicine

Tessa Hart, PhD
Moss Rehabilitation Research Institute

Donna Langenbahn, PhD
NYU Medical Center

Ronald C. Savage, EdD
North American Brain Injury Society

The Board of Directors of the Brain Injury Association of America adopted this position statement in November 2006. The Association will continue to review the topic of cognitive dysfunction and cognitive rehabilitation following brain injury as scientific and public policy progress dictates.

Electronic copies of this statement may be obtained from the Brain Injury Association of America's website: http://www.biausa.org/policyissues.htm.

The paper may be cited as follows:
Katz, DI; Ashley MJ, O'Shanick GJ, Connors, SH. *Cognitive rehabilitation: the evidence, funding and case for advocacy in brain injury.* McLean, VA: Brain Injury Association of America, 2006.

Executive Summary

Individuals who sustain brain injuries frequently acquire cognitive impairments, or thinking problems, that interfere with their safety, productivity, independence and interpersonal relationships. These impairments create lifelong burdens for the individuals who are injured and their caregivers. Physicians, scientists and allied health professionals have developed a systematically applied set of medical and therapeutic services to improve cognitive functioning. These treatment methods, known as cognitive rehabilitation, are designed to reduce cognitive dysfunction and/or assist individuals in compensating for its impact on daily living.

The need for cognitive rehabilitation should be identified and therapeutic services should be delivered by clinicians who have fulfilled the requirements for professional training and certification in their respective disciplines. Such diagnosis and treatment should be initiated when the individual is capable of benefiting from the intervention and may be performed in a variety of settings where there is effective quality control and adequate supervision by trained professionals.

The benefits of cognitive rehabilitation have been discussed in more than 700 published research studies and are evident in positron emission tomography (PET) scans and other neuroimaging techniques in both human beings and animal models. Numerous scientific organizations and professional associations have adopted treatment guidelines or position statements in support of cognitive rehabilitation for individuals with brain injury. Federal and state governments have acknowledged the value of cognitive rehabilitation by allocating taxpayer funds for services. Lawmakers in selected states have required private insurance companies to include cognitive rehabilitation and related therapies in their accident and health insurance policies.

Despite individual testimonials, evidence-based literature and public sector endorsement, only a small number of private insurers include cognitive rehabilitation as a covered service. Most often, these payers have long-term responsibility for the health and welfare of the individual who has been injured. Many third-party payers as well as Medicare and Medicaid restrict scope, duration, timing and intensity of service and make no provision for cognitive treatment as life circumstances change. Some insurers disallow claims for cognitive rehabilitation while others have specifically excluded such treatment from their policies.

The Brain Injury Association of America (BIAA) adopted this position paper in November 2006 to call attention to the need for treatment of cognitive dysfunction. The paper provides definitions and principles for the application of cognitive rehabilitation, discusses research evidence for the efficacy of treatment and highlights the burden on individuals and their caregivers resulting from limitations and denials of service coverage.

BIAA acknowledges the need for additional research, further development of clinical guidelines and modification to public systems of care and private sector insurance policies. The fact that research questions remain about cognitive rehabilitation and that techniques are constantly being improved should not be an excuse to withhold payer support for treatment. Individuals with brain injury must have access to cognitive rehabilitation that is of sufficient scope, duration and intensity and is available as cognitive skills and related problems change over time. Availability, accessibility and ease of movement among services in systems of care for persons with brain injury must be improved.

The Brain Injury Association of America offers ten recommendations to reduce the barriers in accessing and delivering cognitive rehabilitation treatments as follows:

1. Cognitive rehabilitation should be a covered benefit for persons with brain injury, supported by all public and private payers.

2. Cognitive rehabilitation should be based on sound scientific theoretical constructs and, when available, evidence for best practices, with clearly stated goals and quantifiable outcomes.

3. Cognitive rehabilitation should be provided by qualified practitioners. Qualified practitioners are clinicians who have fulfilled the requirements for professional certification and licensure in their respective medical and allied health disciplines.

4. Cognitive rehabilitation treatment strategies and goals, and the duration, scope, intensity, and interval of treatment should be determined based on appropriate diagnosis and prognosis, the individual functional needs of the person with brain injury and reasonable expectations of continued progress with treatment.

5. Treatment planning, case management and health insurance coverage for cognitive rehabilitation should respect the long-term scope and changing needs of persons with brain injury. Necessary treatment for cognitive problems should not be constrained by arbitrary time limits or caps on the number of treatment sessions. Improved longer-term systems of treatment should be developed, supported by public and private payers, employing disease management models, to support persons with brain injury with extended needs.

6. There should be an increase in priority for public and private research funding of questions related to cognitive rehabilitation to achieve better understanding of cognitive disorders after brain injury and how cognitive rehabilitation interventions improve recovery and functioning. Specific priorities should include questions about what interventions are effective for what particular problems, at what intensities and intervals post-injury.

7. There should be an increased emphasis on proper education, training, certification and continuing education for professionals and support staff involved in cognitive rehabilitation.

8. The particular needs of children with brain injury and their families, including developmental and educational implications of cognitive rehabilitation, and issues pertaining to transition to adulthood, have to be addressed by providers, payers and the entire health care system.

9. Cognitive rehabilitation should be integrated into and coordinated with vocational services, special education, and community based programming such as supported living, support networks, and recreation groups so that individuals move seamlessly within a comprehensive, coordinated system of care that is adequately funded.

10. All states should have an external review process for medical claims, and individuals who have been denied coverage for cognitive rehabilitation should fully avail themselves of all internal and external processes.

The Board of Directors of the Brain Injury Association of America adopted this position statement in November 2006. The Association will continue to review the topic of cognitive dysfunction and cognitive rehabilitation following brain injury as scientific and public policy progress dictates.

Cognitive Rehabilitation: The Evidence, Funding and Case for Advocacy in Brain Injury

Impairments of cognitive function are among the most common and important problems that lead to disability after acquired brain injury. Treatment of cognitive dysfunction is central to the treatment and recovery of individuals with brain injury because of the widespread impact of cognitive rehabilitation deficits on safety, functional independence, productive living, and social interaction. Yet, individuals with brain injury often have difficulty obtaining treatment for cognitive dysfunction, termed "cognitive rehabilitation."

The Brain Injury Association of America (BIAA) authored this position paper to address the need for medical and allied health treatment of cognitive dysfunction among persons with brain injury, the limitations and denials of service coverage by payers and the research evidence for the efficacy of treatments. BIAA offers recommendations to reduce the barriers in accessing and delivering cognitive rehabilitation treatments.

INTRODUCTION

Individuals who sustain brain injuries frequently have difficulties in arousal, attention, concentration, memory, problem solving, decision making, insight and other areas of cognition that impede their ability to function in everyday activities. Alterations in perception, motor control, balance, emotional functioning, social interaction and control of behavior are also common after brain injury and are closely linked and intertwined with cognitive issues. Cognitive abilities and disabilities must be considered in addressing all areas of functioning including communication, mobility, self-care, social interaction, recreational pursuits, and productive activities such as school or work.

Cognitive rehabilitation of children with brain injuries presents some additional complications. The cognitive rehabilitation of children with brain injuries is crucial for their ongoing learning and development. Children with brain injuries have a two-fold problem. First, their brains are still developing and new cognitive skills are built upon previously learned cognitive skills (e.g., learning division skills). Thus, a brain injury early in life interrupts the child's learning and development as he or she gets older. Second, injuries to the frontal-temporal regions of the brain, which control many cognitive abilities and new learning will often create new cognitive and behavioral problems for children at each new developmental milestone (i.e., ages 1-6 years, 7-10 years, 11-13 years, 14-17 years, and 18-21 years). Therefore, it is not uncommon to see children with brain injuries worsen cognitively and behaviorally as they grow into the late adolescence and young adulthood unless they receive cognitive rehabilitation therapy throughout their developmental years.

Cognitive problems change over time for adults too. Early in recovery, arousal, attention and memory encoding problems may be the issues that are the most obvious; later, difficulties with divided attention, memory retrieval, and executive functioning (cognitive control mechanisms) may be most prominent. Cognitive recovery evolves at a different pace for each person, with many interacting factors affecting recovery. Some individuals with brain injury recover relatively well and return to previous levels of functioning. After more severe injuries, however, recovery may extend over a long period of time with some cognitive problems persisting and becoming permanent. Even after returning to daily life activities, individuals with brain injury frequently experience reduced cognitive efficiency and inconsistency of performance, and persistent difficulty dealing with novel, complex, or stressful situations. These problems may, in turn, lead to emotional difficulties such as frustration, depression and anxiety disorders. In some cases of cognitive dysfunction, individuals can engage in unsafe activities or unwittingly re-injure themselves. Cognitive disorders make it difficult for some people to monitor changes in their daily health or to reliably comply with medication or medical treatment regimens.

Continuing advances in cognitive neuroscience have broadened our understanding of the anatomy and neurophysiology of cognitive function and its disruption after brain injury. Recent work in basic neuroscience has also enhanced knowledge of learning and brain reorganization after injury, especially in response to the highly structured treatment provided in rehabilitation. Further research will continue to provide the underpinnings for theory and design of effective rehabilitation, including treatment for cognitive dysfunction.

DEFINITIONS AND PRINICPLES OF COGNITIVE REHABILITATION

Cognitive rehabilitation is a systematically applied set of medical and therapeutic services designed to improve cognitive functioning and participation in activities that may be affected by difficulties in one or more cognitive domains. Diagnosis and treatment of cognitive dysfunction may be conducted in a variety of settings throughout the continuum of medical care. Cognitive rehabilitation is often part of comprehensive interdisciplinary programs. When properly applied, it is based upon sound scientific theoretical constructs and strategic approaches drawn from numerous disciplines in neuroscience, neurophysiology, neurobiology, neuropsychology, neurolinguistics and language development, cognitive development and cognitive neuroscience.

Treatment goals vary depending on the etiology, extent, and severity of injury to the brain, the timing of treatment, individual differences in cognitive capacity and personality, academic and vocational achievement, phase of recovery and prospects for restoration or compensation of a problem with remedial interventions. Diagnosis and treatment of cognitive dysfunction[1] should be undertaken by clinicians who have fulfilled

[1] The Society for Cognitive Rehabilitation recommends a standard battery of assessments sufficient to form hypotheses about the underlying cognitive impairments and deficits that interfere with cognitive

the requirements for professional training and certification in their respective medical or allied health disciplines, such as speech/language pathology, clinical neuropsychology or occupational therapy. Collaboration between disciplines is advised and encouraged.[2] Surveys indicate cognitive rehabilitation is frequently performed by numerous disciplines within the allied health fields, most often by speech pathologists, neuropsychologists, and occupational therapists.[3,4] Wellmark BlueCross BlueShield of Iowa concludes that cognitive rehabilitation may be performed by a physician, psychologist, or a physical, occupational or speech therapist.[5]

Theoretical models of cognitive rehabilitation vary along several different dimensions. Treatments may be process specific, focused on improving a particular cognitive domain such as attention, memory, language, or executive functions. Alternatively, treatments may be skill-based, aimed at improving performance of particular activities. The overall goal may be restoring function in a cognitive domain or set of domains or teaching compensatory strategies to overcome domain specific problems, improving performance of a specific activity, or generalizing to multiple activities.

Some compensatory treatments employ internalized procedures while some require orthotic devices, such as books, pagers, alarms or PDAs. Other treatments involve re-establishing previous skills and behavior patterns and some involve establishing new skills or enabling adaptation to adjust to problems that are not modifiable. Some cognitive rehabilitation treatments are directly applied using actual functional activities in real-world settings while others improve a specific cognitive process or an activity in a clinical setting that is intended to generalize to actual performance in real-life situations.

Persons with brain injury may also engage in services aimed at improving emotional, behavioral and psychosocial functioning because these problems are often closely linked

---

functioning. The battery should be sufficient as to enable decision making about which treatments are necessary. In rehabilitation settings, standardized psychometric assessments, questionnaires, structured interviews and behavioral observations across a range of functional settings with equal emphasis should be used. Results of various measures should be cross-referenced with each other and across environments and testing times and dates. Results should be shared with the person being tested and that person should participate in design of the treatment program where possible. Reassessment should be undertaken at regular intervals to monitor and report progress. Evaluative results and treatment plans should also be reviewed with the caregiver. Evaluative results should be used to make prognostic statements which should also be shared with the brain injured person. Treatment goals should be created arising from the assessment and should include outcome goals, long-term goals and short-term goals. All goals should be shared with and agreed to be the person with a brain injury. {From: Mailia K, Law P, Sidebottom L, Bewick K, Danziger S, Schold-Davis E, Martin-Scull R, Murphy K, & Vaidya A. Recommendations for best practice in cognitive rehabilitation therapy: acquired brain injury. Society for Cognitive Rehabilitation, 2004.}

[2] Paul Brown, D & Ricker, JH. Evaluating and treating communication and cognitive disorders: approaches to referral and collaboration for speech-language pathology and clinical neurospychology. Technical Report. *ASHA Supplement.* 2003; 23:47-57.

[3] Ashley, MJ, Persel, CS, Cognitive rehabilitation for brain injury: A survey of clinical practice. *Journal of Cognitive Rehabilitation.* 2003; 21(2):20-27.

[4] Mazmanian, PE, Kreutzer, JS, Devany, CW, Martin, KO, A survey of accredited and other rehabilitation facilities: Education, training and cognitive rehabilitation in brain injury programmes. *Brain injury.* 1993; 7:319-331.

[5] http://www.wellmark.com/e business/provider/medical policies/policies/cognitive rehabilitation.htm.

to neurocognitive functions. Such services are appropriately delivered by neuropsychologists, speech pathologists and others. Family members and other caregivers also play an important role in reinforcing the consistent use of strategies. Other agents, such as computers, may be useful in supplementing clinical therapies.

BIAA recognizes that a number of different labels and definitions are used to describe the mix of services and supports that assist individuals in overcoming cognitive impairments that interfere with productive living, healthy relationships and functional independence. BIAA supports cognitive evaluation and treatment methods that are driven by proper theoretical models and planned, administered and monitored under the supervision of professionals with recognized expertise in cognitive rehabilitation.

COGNITIVE REHABILITATION AND REALITIES OF THE MARKETPLACE

Americans mistakenly believe that employer health plans, individual insurance policies or Medicare/Medicaid will pay for needed services when serious accidents or illnesses occur. In reality, many of today's health plans are geared toward wellness and routine care. Very few insurance companies bear the full lifetime costs, which are estimated at $600,000 to $1.8 million for an individual with a severe brain injury.[6] Policies that adequately cover acute care and comprehensive rehabilitation for individuals with brain injuries do so to minimize the company's exposure to costly long-term services. More often, payers simply deny coverage for cognitive rehabilitation or enact reimbursement policies that may yield short-term gains, but leave lifelong burdens on injured individuals and their caregivers. In response to consumer demand and the evidence-based literature, public policymakers have begun to acknowledge the value of cognitive rehabilitation and are helping to expand its availability in the public and private sector.

Private Sector Approaches to Cognitive Rehabilitation Coverage

Health insurance companies operate under different legal and contractual obligations as to the inclusion or denial of cognitive rehabilitation benefits. Approaches vary based on the payer's long-term financial responsibility for the individual who is injured. Payers with lifelong responsibility, such as workers' compensation insurers, are highly motivated to invest in treatments that reduce care requirements, promote return to work or school, and restore individuals to the highest level of independence possible.

Many workers' compensation insurance companies manage lifetime costs by pursuing effective acute medical care and comprehensive rehabilitation for maximal long-term outcomes. For example, personal care attendant (PCA) expenses account for a significant

[6] National Institutes of Health. *Report of the Consensus Development Conference on the Rehabilitation of Persons with Traumatic Brain Injury.* NIH: Bethesda, MD. 1999.

portion of the lifelong costs for individuals who sustain catastrophic brain injuries. Workers' compensation carriers attempt to mitigate PCA expenses by resolving cognitive deficits early thereby reducing disability and dependence in the long term. Liability carriers have a similar motivation for long-term cost management; however, they often have less opportunity to influence the early medical treatment of individuals who sustain brain injuries.

The contractual liability of accident and health carriers is limited to the term during which premiums are being paid or to the period during which COBRA[7] protection is extended. Individuals who sustain moderate or severe brain injuries are often unable to continue paying health insurance premiums. Hence, the long-term contractual liability is more limited, and accident and health carriers have less motivation to minimize permanent disability. In fact, many carriers favor short-term cost containment. One such strategy is the automatic denial of coverage for any cognitive rehabilitation service. The denial may generalize to treatment of cognitive goals even if those goals are imbedded in physical rehabilitation therapies involving ADLs or gait training.

Some accident and health payers restrict coverage by limiting the number of sessions or reducing the time period for treatment. Although the phenomenon of attaining a plateau in functional restoration prior to entering a secondary recovery phase is a well-documented occurrence, reimbursement policies tend to treat recovery as a linear event. In that paradigm, "plateau" is synonymous with termination of benefits, often with no subsequent provision to re-evaluate and reinitiate rehabilitation efforts after a given interval.

A variation on this theme is seen in the context of triaging an individual who fails to meet prerequisites for therapy participation and is consigned to a low intensity program, such as a nursing home, with the implication of returning to aggressive intervention at some future date. Such triaging, however, especially among individuals with severe injuries, often becomes a terminal placement with no further option or hope for comprehensive treatment. The implied promise to family members to re-evaluate the patient is often unrealized due to limitations in available treatment intensity and sometimes expertise in the treatment environment itself. Thus, the individual with brain injury encounters a "Catch-22" when he/she fails to achieve rehabilitative progress thereby making it impossible to meet a requirement for demonstrated improvement to warrant further treatment. In other instances, established financial reserves for such endeavors are

[7] Congress passed the landmark Consolidated Omnibus Budget Reconciliation Act (COBRA) health benefit provisions in 1986. The law amends the Employee Retirement Income Security Act, the Internal Revenue Code and the Public Health Service Act to provide continuation of group health coverage that otherwise might be terminated. COBRA provides certain former employees, retirees, spouses, former spouses, and dependent children the right to temporary continuation of health coverage at group rates. Group health coverage for COBRA participants is usually more expensive than health coverage for active employees, although it tends to be less expensive individual health plans. Generally health benefits may be continued for 18 months or longer depending on the employer's plan and other circumstances. {From: http://www.dol.gov/ebsa/faqs/faq_consumer_cobra.html; May 12, 2006.}

exhausted in the low intensity setting precluding a return to treatment of higher intensity and greater professional expertise.

Occasionally, treatment for cognitive rehabilitation is covered only in acute or post-acute settings. Such policy restrictions are based on the flawed assumption that an individual with brain injury has "recovered" when he or she is discharged from structured treatment. No provisions are made for the dynamic challenges of living with brain injury and the necessity for additional cognitive treatment or strategy development as life circumstances change. Indeed, models from other chronic illnesses, such as diabetes mellitus, are more relevant to brain injury treatment than models based on emergency care, as the former contain contractual provisions for continuing case monitoring, patient education and relapse prevention.

The operational definition of cognitive rehabilitation, whether narrow or broad, affects covered services and can lead to coverage denial depending on how a service is labeled. Moreover, adaptation of rehabilitation policy standards intended for treatment of physically-based disorders has mixed results because recovery periods for such disorders are typically much shorter than for brain injury.

Because of limitations in coverage, professionals are sometimes forced to have basic and limited goals within the time frame allowed and are unable to address restorative approaches or more complex compensatory procedural treatments that have longer-lasting effects. As a consequence, immediate concerns, such as safety awareness, may be alleviated, but learning is seldom generalized to other situations or useful in meeting future needs. While a short-term focus can attain rapid outcomes that satisfy payers, these approaches lack long-term utility and flexibility needed in an evolving chronic condition.

The Blue Cross and Blue Shield Association Technology Evaluation Center (TEC) report[8] concludes that the efficacy of cognitive rehabilitation has not been adequately demonstrated; therefore, cognitive rehabilitation does not meet the TEC criteria for covered services. In many states, the Blue Companies® do not support cognitive rehabilitation. Recently, however, an independent external review organization overturned a BlueCross BlueShield of Montana denial for cognitive rehabilitation services, requiring the company to pay for treatment after a year of denials and appeals.[9,10]

Wellmark BlueCross BlueShield of Iowa revised its policy to include coverage of cognitive rehabilitation. The revised policy states:

---

[8] Blue Cross and Blue Shield Association Technology Evaluation Center. Cognitive rehabilitation for traumatic brain injury in adults. *TEC Assessment Program*. 2002; 17(20).

[9] McCarty, J. Cognitive rehabilitation denial overturned. *The ASHA Leader*. 2006; 11(9):1-22.

[10] Commercial insurance companies have an established protocol for internal appeals and reviews. In 42 states, insurance companies are subject to an external review process; see www.healthinsuranceinfo.net for each state's procedure and contact points.

"Cognitive rehabilitation may be considered medically necessary following a stroke or brain injury when the plan of care documents specific diagnosis-related goals for a patient who has a reasonable expectation of achieving measurable improvements in a reasonable and predictable period of time."[11]

Aetna also reversed a previously restrictive policy and provides the following language pertaining coverage of cognitive rehabilitation:

"I. Aetna considers cognitive rehabilitation as adjunctive treatment of cognitive deficits (e.g., attention, language, memory, reasoning, executive functions, problem solving, and visual processing) medically necessary when *all* of the following are met:

A. The cognitive deficits have been acquired as a result of neurological impairment due to trauma, stroke, or encephalopathy, *and*
B. The member has been seen and evaluated by a neuropsychiatrist or neuropsychologist, *and*
C. Neuropsychological testing has been performed and neuropsychological results will be used in treatment-planning and directing rehabilitation strategies, *and*
D. The member is expected to make significant cognitive improvement, e.g., is not in a vegetative or custodial state.[12]

Individual and Family Perspectives

Calls to the Brain Injury Association of America from individuals and family members consistently report frustration and dissatisfaction with delays and denials of coverage for cognitive rehabilitation and other services. Research demonstrates that the emotional disturbances and disorders of executive function contribute distinctively to family burden[13]. The emotional and financial toll of cognitive deficits following brain injury cannot be overstated.

Brain injuries also exact an enormous cost from society at large. The Centers for Disease Control and Prevention reports the annual cost of medical care and lost productivity was nearly $60 billion across the U.S. in 1995.[14] As individuals are left with disabling cognitive impairment following brain injury, they are often unable to return to the workforce, may draw SSI or SSDI, may access public housing or other public assistance benefits, and may require another family member to leave the workforce to provide for their cognitive supervision. The injured person and other family members may become

[11] http://www.wellmark.com/e business/provider/medical policies/policies/cognitive rehabilitation.htm
[12] http://www.aetna.com/cpb/data/CPBA0214.html
[13] Lezak, MD. Brain damage is a family affair. *Journal of Clinical & Experimental Neuropsychology.* 1988; 10(1):111-123.
[14] Thurman D. The epidemiology and economics of head trauma. In: miller L, Hayes R, Editors. Head trauma: basic, preclinical, and clinical directions. New York (NY): Wiley and Sons. 2001.

uninsured/medically indigent. For these reasons, the public has a stake in all aspects of brain injury rehabilitation.

Public Responsibility

Federal, state and territorial governments provide medical assistance to children, individuals who are aged, blind, and/or disabled and those with low incomes through the Medicare, Medicaid and State Children's Health Insurance Programs as authorized by the Social Security Act. Many individuals with brain injury are eligible for medical care and related services under these programs as well as other programs administered by state and local governments.

Using Medicaid Home and Community-Based Services Waivers, states may target services to certain age groups, geographic areas, and/or functional abilities by selecting a mix of services that best meet the needs of the population. As of 2004, 25 states have established brain injury-specific Medicaid Waivers to fund case management, home health care, personal care attendants, respite care and other services for individuals with brain injuries. In 14 of the 25 states, cognitive rehabilitation is included among the menu of services offered. Cognitive rehabilitation is offered in two additional states whose Medicaid Waiver programs are not limited to individuals with brain injury.[15]

Individuals with brain injuries who meet eligibility requirements may access health and other services via public programs financed by income taxes and other fees and fines assessed in the state. As of 2004, 18 states have legislation in place to support funding for brain injury-specific services. Cognitive rehabilitation is funded in 12 of these programs. Legislators in five other states annually appropriate general or special revenue to cover cognitive therapies for individuals with brain injury who meet eligibility criteria.[16] Public payers limit the scope, duration and intensity of cognitive rehabilitation services.

In addition to allocating taxpayer funds, in 2002, policymakers began responding to constituent demands for expanded availability of cognitive rehabilitation. The Texas State Legislature enacted House Bill 1676 to prohibit carriers that write accident and health insurance policies in the state from excluding "coverage for cognitive rehabilitation therapy, cognitive-communication therapy, neurocognitive therapy and rehabilitation neurobehavioral, neuropsychological, and psychophysiological testing or treatment, neurofeedback therapy, remediation, post-acute transition services, or community reintegration services necessary as a result of and related to an acquired brain injury."[17]

In January 2006, Senate Bill 6563 was introduced in the New York State legislature and referred to the committee on insurance. The legislation would require the inclusion of

---

[15] King, A & Vaughn, S. *Guide to state government brain injury policies, funding and services, 2nd ed.* Bethesda, MD: National Association of State Head Injury Administrators, 2005.
[16] Ibid.
[17] http://www.captital.state.tx.us/cgi-bin/tlo/textframe.cmd?LEG=77&SESS=R&CHAMBER

cognitive rehabilitation in every medical or major medical health policy at a level that meets or exceeds Medicare's standard of care.[18] Given the caps for reimbursement and the cost for treatment by a registered occupational therapist or speech/language pathologist with the highest level of professional certification services, Medicare's standard of care provides a maximum of 18 hours of therapeutic services on annual basis.[19]

EVIDENCE FOR EFFICACY

Inconsistent coverage for cognitive rehabilitation is usually attributed to the paucity of definitive evidence for efficacy. In fact, the body of literature on cognitive rehabilitation has been growing and now includes more than 770 studies of varying quality that support the benefit of various types of cognitive rehabilitation.

In the medical community, treatment guidelines are established through a consensus process that entails a review of relevant literature in peer-reviewed publications. Stringent procedures are used for identification and inclusion of published studies. The search results are scrutinized and relevant studies are then stratified into classes based on the rigor of the methodology, design, and statistical power of the research conducted. Results of the literature review are combined with input from expert peer groups convened for the purpose of subject review. Input from patient advocates groups may also be invited. From this exhaustive process, treatment guidelines emerge and are updated regularly to reflect advances in research and clinical practice. In this manner, both the art and science of medicine are integrated into treatment guidelines.

As of 2005, more than ten scientific organizations or professional associations[20] had adopted treatment guidelines or position statements that provide strong and convincing support for general rehabilitation of people with brain injury; specific guidelines for general rehabilitation and for cognitive rehabilitation; requisite training and preparation for professionals undertaking cognitive rehabilitation; and specificity pertaining to

---

[18] State of New York 229th Annual Legislative Session, Senate Bill 6563, Introduced by Sen. Bonacic, January 31, 2006.

[19] Current Medicare reimbursement schedules provide a cap for occupational therapy services at $1,740 per year and a cap of $1,740 per year for physical therapy or speech/language pathology services combined. As both occupational therapists and speech language pathologists with the highest level of professional certification provide cognitive rehabilitation services at the rate of $196 per hour. Therefore, the maximum number of hours per year available for cognitive rehabilitation would be 18 as follows: $3480 divided by $196 equals 18 hours.

[20] Treatment guidelines and position statements have been adopted by the Academy of Neurologic Communication Disorders and Sciences; American Congress of Rehabilitation Medicine; American Speech/Language/Hearing Association in conjunction with Division 40 (Clinical Neuropsychology) of the American Psychological Association; British Society of Rehabilitation Medicine in collaboration with the Royal College of Physicians (2003); European Federation of Neurological Societies; National Academy of Neuropsychology; Society for Cognitive Rehabilitation; and the State of Colorado Department of Labor and Employment's Division of Workers' Compensation (2005). It should be noted that the Cochrane Collaboration Reviews (Cochrane Database of Systematic Reviews), although supportive in the majority, are limited in their scope as cited literature is greater than 5 to 8 years old.

treatment interventions and techniques that have demonstrable efficacy in cognitive rehabilitation.

Evidence from Literature Reviews

The National Institutes of Health (NIH) convened a consensus development conference in 1998 to report on the scientific basis of therapeutic interventions for sequelae of brain injury.[21] An independent panel reviewed the literature for cognitive rehabilitation published through August 1998 and concluded that the data were limited by heterogeneity of the subjects of the studies, the interventions applied and the outcome measures used. These problems point out the exceptional challenges in studying these treatments in this population.

Although comprehensive conclusions about the effectiveness of cognitive rehabilitation could not be reached, the NIH panel noted good evidence for effectiveness of specific interventions using compensatory devices, such as memory books. Further, the panel noted the evidence supported the probable effectiveness of interventions to improve specific cognitive processes, such as attention, memory and executive skills. The consensus report concluded:

> "Evidence supports the use of certain cognitive and behavioral rehabilitation strategies for individuals with brain injury in particular circumstances. These interventions share certain characteristics in that they are structured, systematic, goal-directed, and individualized and they involve learning, practice, social contact, and a relevant context."[22]

As part of the NIH Consensus Development Conference, Chesnut and colleagues reviewed 32 studies based on highly restricted criteria, such as limiting the study participants to individuals with traumatic brain injury. They found limited evidence to support certain forms of cognitive rehabilitation in treating memory and anxiety and in improving self-concept and interpersonal relationships. They cautioned that long-term benefit and clinical relevance were not well established.

Experts from the Brain Injury Interdisciplinary Special Interest Group of the American Congress of Rehabilitation Medicine published an evidence-based review of the cognitive rehabilitation literature in 2000[23] and a comprehensive updated review in 2005 that included articles not available in the 1998 and 2001 Cochrane Reviews.[24] The review encompassed 171 articles in the first report and an additional 87 studies in the update.

---

[21] National Institutes of Health. *Report of the Consensus Development Conference on the Rehabilitation of Persons with Traumatic Brain Injury*. Bethesda, MD. September 1999.
[22] Ibid.
[23] Cicerone KD, Dahlberg C, Kalmar K, et al. Evidence-based cognitive rehabilitation: recommendations for clinical practice. *Arch Phys Med Rehabil*. 2000; 1596-1615.
[24] Cicerone KD, Dahlberg C, Malec JF, et al. Evidence-based cognitive rehabilitation: updated review of the literature from 1998 through 2002. *Arch Phys Med* Rehabil. 2005; 1681-1692.

The reviews were not restricted to traumatic brain injury, but also included treatments studied in stroke survivors. Overall, there were 46 Class I studies (prospective, randomized controlled methodology) and 43 Class II studies (prospective cohort studies, retrospective case-controlled studies or series with well-designed controls). For Class I studies involving both patients with stroke and patients with brain injury, 78.7% of the comparisons demonstrated a benefit of cognitive rehabilitation over the alternative treatment. They concluded that "there is substantial evidence to support cognitive rehabilitation for people with brain injury."[25] An additional 28 studies were reviewed by Gordon et al., 2006,[26] and it was found that the research reviewed provided further evidence for the efficacy of cognitive rehabilitation. Similarly, positive conclusions were drawn in a recent volume devoted to the effectiveness of cognitive rehabilitation that was based on an international conference convened in 2002, which included the world's top researchers in the area of rehabilitation for attention, memory, language and executive deficits.[27]

Clearly a growing body of evidence exists that supports the effectiveness of cognitive rehabilitation for persons with brain injury. Whether more positive or negative in their conclusions, all of these reviews emphasize that more research is needed to strengthen the evidence and better answer specific questions about what methods of rehabilitation are effective, for whom, and at what time post-injury.

Evidence from Basic Science

Cognitive function is broadly represented throughout the brain. Cognitive domains, such as attention, memory, language, spatial and executive functions are subserved by widely distributed neural networks with nodal centers in particular cortical and subcortical regions. For instance, executive function is primarily ascribed to frontal lobe cortices and associated subcortical pathways. These pathways are comprised of both open and closed loop circuits that project to subcortical structures, including the striatum, globus pallidus and thalamus, and other parts of the cortex, receiving and modulating neural activity throughout the brain. In all, there are virtually no areas of the brain that do not impact cognitive function.

Brain injuries affect the neural pathways for cognitive functioning in a number of ways.[28] Brain injuries that are focal in nature, such as focal contusions, disrupt relatively localized cortical or subcortical areas when compared to the broadly distributed and multi-focal effects of diffuse injuries, such as diffuse axonal injury. Recent evidence demonstrates that even focal lesions can result in damage to remote structures in the

---

[25] Ibid.

[26] Gordon WA, Zafonte R, Cicerone K, Cantor J, Brown M, Lombard L, Goldsmith R, Chandna T. Traumatic brain injury rehabilitation state of the science. *Amer J Phys Med Rehabi.* 2006; 85(4):343-82.

[27] Halligan PW, Wade DT, (Eds.) *Effectiveness of rehabilitation for cognitive deficits.* Oxford University Press, 2005.

[28] Povlishock JT, Katz DI. Update of neuropathology and neurological recovery after traumatic brain injury. *J Head Trauma Rehabi.* 2005; 20:76-94.

brain, potentially causing more widespread disruption of cognitive networks. Focal and diffuse brain injury are often combined and usually associated with secondary injury from a variety of other processes, such as nerve cell loss from surges of excitatory neurotransmitters. In general, the degree of cortical and subcortical damage can be expected to correlate with the degree of impairment of cognitive function.

Brain recovery after injury has been ascribed to at least three mechanisms: reduction of diaschisis, compensation and adaptive plasticity.[29] Diaschisis, the reduction in function of remote areas of brain connected to the damaged areas, begins to reverse during early stages of recovery. Compensation, the attempt to use alternate strategies to substitute impaired functions, and adaptive neuroplasticity are mechanisms that begin early and continue long after the injury. Neuroplasticity, use-dependent modulation of the functional organization of cortical brain representations is a normal brain capacity that facilitates learning of motor and cognitive skills over a lifetime. The same capacity that is necessary for experience-based learning in the uninjured brain appears to be an important mechanism for brain reorganization and recovery of function after brain injury. The molecular and cellular mechanisms of neuroplasticity are being intensively investigated.

In the last 20 years, animal models have clearly demonstrated modulation and reorganization of cortical representations of motor, somatosensory and visual functions in response to new behavioral requirements and skill acquisition in normal and injured animals. Similar processes have been demonstrated in humans using functional neuroimaging (see below). These adaptive changes in brain organization do not occur passively but require the individual to be actively engaged in skill acquisition. Repetitive activity alone in the absence of skill acquisition is not sufficient to induce these changes.[30] Further, changes in brain organization do not occur immediately, but improve with longer interactions and require a minimal period of training.[31] There are clear implications of these findings for the role of rehabilitation in cognitive and motor recovery after brain injury. Rehabilitative efforts that lead to improvement in function after brain injury can be associated with lasting changes in brain structure and physiology. Such adaptive plasticity and learned compensations require directed training and practice, and likely have minimal time periods necessary to assure durable improvements.

Evidence from Imaging Studies

Functional neuroimaging techniques are being used to study the normal patterns of brain activity in numerous perceptual, motor and cognitive activities. Evidence from human

---

[29] Nudo RJ, Dancause N. Neuroscientific basis for occupational and physical therapy interventions. In Zasler ND, Katz DI, Zafonte RD. *Brain injury medicine*. New York: Demos, 2006.

[30] Plautz, EJ, Milliken, GW, and Nudo, RJ. Effects of repetitive motor training on movement representations in adult squirrel monkeys: role of use versus learning, *Neurobiol Learn Mem.* 2000; 74(1):27-55.

[31] Kleim JA, Hogg TM, VandenBerg PM, Cooper NR, Bruneau R, Remple, M. Cortical synaptogenesis and motor map reorganization occur during late, but not early, phase of motor skill learning, *J Neurosci.* 2004; 24(3):628-33.

studies employing functional neuroimaging demonstrates the injured brain is capable of rapid and long-term physiologic and structural reorganization in response to learning and experience. A number of studies using functional neuroimaging of persons with brain injury demonstrate changes in brain activation toward more normal patterns of activity correlated with improving function after rehabilitative treatment. For example, in a study of a visuospatial working memory task, practice led to improvement in performance that was associated with decreasing levels of activation of frontal and parietal cortex as the task was learned.[32]

In a study of patients with left neglect after right hemisphere brain injury, PET scan studies before and after a 2 month rehabilitative intervention showed greater activation of right hemisphere areas associated with attention in conjunction with improvement in tests of neglect and spatial skills.[33] Laastch and colleagues recently demonstrated cortical reorganization following cognitive rehabilitation in five patients who showed marked enhancement in fMRI activity in brain areas related to the tasks being trained.[34]

It is clear that the injured brain can react and can be facilitated through medical and rehabilitative treatment in a variety of ways that contribute to the return of function. Improved function is associated with changes in brain organization that can be tracked with functional imaging. Behavioral interventions and skill-based activities are perhaps the most powerful modulators of post-injury brain plasticity.

SUMMARY AND CONCLUSIONS

Impairments of cognitive function are common and important problems that lead to disability after acquired brain injury. Cognitive rehabilitation is central to the treatment and recovery of individuals with brain injury because it impacts many problems that interfere with productive living, appropriate social interaction and functional independence. Yet, individuals with brain injury often have difficulty obtaining cognitive rehabilitation services and undue burdens are often placed on caregivers to find proper care and support. Cognitive disability following brain injury poses a major public health problem and a serious economic burden to the private and public sectors.

Cognition is a neurophysiologically-based function that is modifiable by medical and rehabilitative treatments. Cognitive rehabilitation has been demonstrated to be effective in reducing cognitive disability following brain injury and should be covered by public and private medical insurance. The Centers for Medicare and Medicaid Services (CMS) should take the lead and incorporate public comment in developing a national standard of care for cognitive dysfunction following brain injury and should provide ongoing

---

[32] Garavan H, Kelley D, Rosen A, et al. Practice-related functional activation changes in a working memory task. *Microsc Res Tech.* 2000; 51:54-63.

[33] Pizzamiglio L, Perani D, Cappa S, et al. Recovery of neglect after right hemisphere damage. *Arch Neurol.* 1998; 55:561-568.

[34] Laatsch LK, Thulborn KR, Krisky CM, Shobat DM, Sweeney. Investigating the neurobiological basis of cognitive rehabilitation therapy with fMRI. *Brain Injury.* 2004; 18:957-974.

payment for medically necessary services in the treatment of cognitive dysfunction following brain injury.

Systems of care for persons with brain injury must recognize that many persons with brain injury have long-term and, sometimes, lifelong needs because of cognitive dysfunction. The present health care system often only supports the early care of persons with brain injury. Support for cognitive rehabilitation must extend beyond hospitalization and the immediate post-hospitalization period. Cost-effective care and support must be developed for persons with brain injury and their families who have longer-term needs. The disease management models that have been developed for other chronic disorders, such as heart disease, diabetes and kidney disease may offer insights for developing better long-term systems of care for persons with brain injury.

The provision of cognitive rehabilitation should be effective and cost-conscious. In order to achieve these goals, providers must recognize their responsibilities in maintaining professional standards and monitoring delivery of treatment. Cognitive rehabilitation should be provided and supervised by qualified practitioners, and applied in the context of accurate diagnosis of the brain injury and subsequent cognitive impairments. Treatment plans should be formulated with respect to prognosis and natural history, targeting problems that are not expected to resolve spontaneously.

Cognitive rehabilitation should be based upon sound scientific theoretical constructs with clearly stated goals and measurable outcomes. Medical and allied health professional education programs should enhance training in cognitive neuroscience and diagnosis and treatment of cognitive dysfunction. Case management professionals should receive similar training and recognize and exercise the responsibility to advocate for those who are unable to advocate fully for themselves due to cognitive dysfunction.

Federal and private research funding and projects targeting the study of cognitive neuroscience and the diagnosis and treatment of cognitive dysfunction following brain injury should be substantially increased. The public would also be served by development of better standards and systems of care for brain injury and systems to monitor the provision and payment of services.

The fact that research questions remain about cognitive rehabilitation should not be an excuse to withhold payer support for treatment, any more than heart surgery should be withheld because surgical techniques are being continuously refined through clinical research. Persons with brain injury must have treatment services for cognitive problems and best practices must be based on the available body of knowledge at any given time. Persons with brain injury and their families must have available services and payer support for treatment of cognitive and related problems over the time period necessary. Availability, accessibility and ease of movement among services in systems of care for persons with brain injury must be improved.

RECOMMENDATIONS

Based on the foregoing, the Brain Injury Association of America offers the following recommendations:

1. **Cognitive rehabilitation should be a covered benefit for persons with brain injury, supported by all public and private payers.**

2. **Cognitive rehabilitation should be based on sound scientific theoretical constructs and, when available, evidence for best practices, with clearly stated goals and quantifiable outcomes.**

3. **Cognitive rehabilitation should be provided by qualified practitioners. Qualified practitioners are clinicians who have fulfilled the requirements for professional certification and licensure in their respective medical and allied health disciplines.**

4. **Cognitive rehabilitation treatment strategies and goals, and the duration, scope, intensity, and interval of treatment should be determined based on appropriate diagnosis and prognosis, the individual functional needs of the person with brain injury and reasonable expectations of continued progress with treatment.**

5. **Treatment planning, case management and health insurance coverage for cognitive rehabilitation should respect the long-term scope and changing needs of persons with brain injury. Necessary treatment for cognitive problems should not be constrained by arbitrary time limits or caps on the number of treatment sessions. Improved longer-term systems of treatment should be developed, supported by public and private payers, employing disease management models, to support persons with brain injury with extended needs.**

6. **There should be an increase in priority for public and private research funding of questions related to cognitive rehabilitation to achieve better understanding of cognitive disorders after brain injury and how cognitive rehabilitation interventions improve recovery and functioning. Specific priorities should include questions about what interventions are effective for what particular problems, at what intensities and intervals post-injury.**

7. **There should be an increased emphasis on proper education, training, certification and continuing education for professionals and support staff involved in cognitive rehabilitation.**

8. **The particular needs of children with brain injury and their families, including developmental and educational implications of cognitive rehabilitation, and issues pertaining to transition to adulthood, have to be addressed by providers, payers and the entire health care system.**

9. **Cognitive rehabilitation should be integrated into and coordinated with vocational services, special education, and community based programming such as supported living, support networks, and recreation groups so that individuals move seamlessly within a comprehensive, coordinated system of care that is adequately funded.**

10. **All states should have an external review process for medical claims, and individuals who have been denied coverage for cognitive rehabilitation should fully avail themselves of all internal and external processes.**

The Board of Directors of the Brain Injury Association of America adopted this position statement in November 2006. The Association will continue to review the topic of cognitive dysfunction and cognitive rehabilitation following brain injury as scientific and public policy progress dictates.

Conceptualizing Brain Injury as a Chronic Disease

A position paper of the Brain Injury Association of America

March 2009

Brain Injury Association of America

CONCEPTUALIZING BRAIN INJURY AS A CHRONIC DISEASE

HISTORY

Disease is defined in the *Free Online Dictionary* as representing a "deviation from or interruption of the normal structure or function of any body part, organ or system that is manifested by a characteristic set of symptoms and signs and whose etiology, pathology and prognosis may be known or unknown."

In general, the insurance industry uses the term "sickness" rather than disease. Sickness is defined by one medical insurance provider as: "illness, disease of condition of a covered person which first manifests itself after the effective date of the policy and which this policy is in force for such person. Sickness includes any complications of recurrences that relate to such sickness while the policy is in force of the person." (H. Kelso, personal communication, June 30, 2008).

Historically, the medical definition and approach to most, if not all diseases, has evolved over time. Certainly, any student of science has been exposed to the humor theory, which was the most commonly held view of the human body from the age of Hippocrates until the beginning of modern medicine in the nineteenth century. The approach to traumatic brain injury (TBI) has changed as well. In 1927, the Supreme Court of the United States upheld the right of states to sterilize persons with mental disabilities, and yet, only 20 years later, Howard Rusk began providing neurorehabilitation to pilots injured in World War II.

As the TBI continuum of care evolved, acute rehabilitation was hospital-based and followed a strict medical model. The medical model dictated treatment to the patient/family, as most survivors in the acute phase of rehabilitation were incapacitated and unable to participate in decisions made about their treatment. The physicians, nurses, neuropsychologists and allied healthcare professionals were regarded as the experts and very little was negotiable with regard to treatment. As post-acute programs began to develop and carve out a specialty niche in the evolving continuum, there was a push to differentiate post-acute care from acute rehabilitation.

Post-acute rehabilitation defined itself as non-hospital based treatment with an interdependent model of care. Despite the fact that the Latin root of the word means "suffering or sick person," individuals were no longer referred to as patients. Rather, family members and individuals with a TBI, now called clients, (which interestingly has its Latin origin meaning "follower") were seen as experts with regard to the pre-injury history and function of the individual. Treatment at the post-acute level was often provided by non-professionals under the direction of a team of professional consultants (i.e., doctor, nurse, SLP, PT, OT and neuropsychologist). Treatment goals and other aspects of the services delivered were negotiated between the staff delivering the service(s) and the individual receiving the service. The individual and his/her family were considered team members and an important resource for the staff delivering service(s).

Unfortunately, post-acute rehabilitation succeeded in separating itself from the medical model—so much so that it was cut off from most medical funding streams. The science at the post-acute

level was not strong—outcomes not adequately tracked, therapies not evidenced-based, etc. Activities offered to individuals at this level of care were considered to be not much more than therapeutic hand holding by many in the business, and community integration and life satisfaction were not considered covered benefits by most funding sources.

The *American Heritage Dictionary* defines an event as "the final result; the outcome." The *Webster's New World Dictionary* defines an injury as "harm or damage." Traumatic damage to the brain was therefore seen by the industry as an "event." A broken brain was the equivalent of a broken bone—the final outcome to an insult in an isolated body system. Once it was fixed and given some therapy, no further treatment would be necessary in the near or distant future, and certainly, there would be no effect on other organs of the body.

PURPOSE

The purpose of this paper is to encourage the classification of a TBI not as an event, not as the final outcome, but rather as the beginning of a disease process. The paper presents the scientific data supporting the fact that neither an acute TBI nor a chronic TBI is a static process—that a TBI impacts multiple organ systems, is disease causative and disease accelerative, and as such, should be paid for and managed on a par with other diseases.

Despite the fact that patients with a TBI who survive the acute event do not die of their brain injury per se, a TBI is a disease. There are many similar examples in the field of medicine. Chronic kidney disease is an independent risk factor for cardiovascular disease (Sarnak et al., 2003). Patients with chronic kidney disease are more likely to die of cardiovascular disease than end stage renal failure (Sarnak et al., 2003). Patients do not succumb to AIDS. They die from other diseases, such as pneumonia, caused by the AIDS disease. And indeed, diseases can be caused by external forces such as injuries. An individual sustaining a severe chemical burn to the lungs will develop chronic lung disease that may then cause or accelerate cardiac disease. Although the phenomenon is not clearly understood, following chemotherapy, many patients may develop disabling problems with memory, attention, multi-tasking and other domains of cognitive function, known as "chemo brain" (Tannock et al., 2004).

MORTALITY

In a 2004 study on mortality one year post injury among 2,178 individuals with a moderate to severe TBI, it was reported that individuals with a TBI were twice as likely to die as a similar non-brain injured cohort and had a life expectancy reduction of seven years (Harrison-Felix et al., 2006). Follow-up studies on causes of death revealed that individuals surviving *more* than one year with a TBI are 37 times more likely to die from seizures, 12 times more likely to die from septicemia, four times more likely to die from pneumonia and three times more likely to die from other respiratory conditions than a matched cohort from the general population. The greatest proportion of deaths in the study—29 percent—was from circulatory problems. Although this number was not significantly greater than that of the general population, there was still a 34 percent increase over the expected number of circulatory-related deaths (Harrison-Felix

et al., 2006). Shavelle and colleagues found that individuals with a TBI were three times more likely to die of circulatory conditions (Shavelle et al., 2001). Although it is somewhat intuitive that individuals with moderate to severe TBIs would have a higher mortality rate than the normal population, even individuals with mild TBIs have been found to have a small but statistically significant reduction in long-term survival (Brown et al., 2004).

ETIOLOGY

The nature by which a brain injury can impact other organs is not known, but clearly there is an indirect effect. Mirzayan and colleagues (Mirzayan et al., 2008) subjected mice to a controlled brain injury, and sacrificed them at 96 hours. Histopathologic changes were found in the liver and lungs, suggesting that an isolated TBI can lead to the migration of immuno-incompetent cells to the peripheral organs, and thus potentially lead to their dysfunction. Heterotopic ossification (H.O.) is an appropriate disease model for this theory. Ectopic bone formation, most often at the elbows, knees and shoulders occurs in 3-20 percent of TBIs (Mital et al., 1987, Hoffer and Brink, 1975). Generally, the more severe the TBI, the more likely that individual will develop H.O. The immune response is significantly impaired acutely following a TBI ("post-traumatic immune paralysis") and may be associated with the high prevalence of infections in these patients (Kox et al., 2008).

Age is clearly a factor in brain injury disease. Older patients show a greater decline over the first five years following a TBI than younger patients (Marquez de la Plata et al., 2008). Also, the greatest amount of improvement in disability has been noted in the youngest group of survivors.

MORBIDITY

NEUROLOGIC DISORDERS

Epilepsy

Traumatic brain injuries are a major cause of epilepsy, accounting for 5 percent of all epilepsy in the general population (Hauser et al., 1991). Individuals with a TBI are 1.5-17 times (depending on the severity of the TBI) more likely than the general population to develop seizures (Annegers et al., 1998). TBI is the leading cause of epilepsy in the young adult population. Seizures will be observed over a week after a penetrating TBI in 35-65 percent of individuals. In a study of 309 individuals with moderate-severe TBI followed as long as 24 years post injury, 9 percent were being treated for epilepsy (Yasseen et al., 2008). As the time from injury to the time of the first post TBI seizure may be as long as 12 years (Aarabi et al., 2000), there is a need for heightened awareness of the development of epilepsy on the part of the patient, family and treating medical personnel.

Vision

Visual disturbances are common after a TBI, occurring in 30-45 percent of individuals (Sabates et al., 1991). In a review of 254 individuals, two and five years post injury, 42 percent continued to complain of visual difficulties at five years (Olver et al., 1996). Optic atrophy can begin shortly after the brain injury and lead to a marked decreased acuity and blindness. Persistent

visual field deficits also pose a significant safety risk due to the inability to see to the side. High flow carotid cavernous fistulas causing the direct flow from the internal carotid artery system into the cavernous venous sinus may develop weeks after a TBI. If not recognized and treated, permanent visual loss may progressively develop (Atkins et al., 2008).

Sleep

Sleep complaints are common following TBI. Subjective complaints of sleep disturbances have been reported in 70 percent of TBI outpatients (Chesnut et al., 1999, Max et al., 1991, McLean et al., 1984). Disturbed sleep, as measured by polysomnogram, was reported in 45 percent of a group of 71 individuals averaging three years post injury (Masel et al., 2001). Hypersomnia is associated with decreased cognition and decreased productivity, and certainly with a greater risk for accidents. National Highway Traffic Safety Administration data showed that approximately 56,000 auto crashes annually were cited by police officers where driver drowsiness was a factor (Strohl et al., 2005).

Alzheimer's Disease

Alzheimer's disease (AD) is an enormous public health problem in the United States where 5.2 million Americans are living with that disease. The direct and indirect cost of this disease is estimated to be $148 billion annually. (http://www.alz.org/index.asp). Although the cause of Alzheimer's is unknown, numerous studies have shown that a brain injury may well be a risk factor for the development of Alzheimer's disease (Jellinger et al., 2001, Plassman et al., 2000). In a large study of World War II veterans, Plassman and colleagues found that any history of head injury more than doubled the risk of developing AD, as well as the chances of developing non-Alzheimer's dementia. They also found that the worse the head injury, the higher the risk for AD. A moderate head injury was associated with a 2.3 fold increase in the risk, and a severe head injury more than quadrupled that risk (Plassman et al., 2000). In their excellent review on this issue, Lye and Shores (Lye and Shores, 2000) suggested many possible etiologies for this connection: damage to the blood brain barrier causing leakage of plasma proteins into the brain, liberation of free oxygen radicals, loss of brain reserve capacity, as well as the deposition of beta amyloid plaque (present in Alzheimer's disease). Even individuals with no known cognitive impairment after their TBI have a risk of an earlier onset of dementia due to Alzheimer's disease (Schofield et al., 1997).

Chronic Traumatic Encephalopathy (CTE) has recently garnered the attention of both the medical and lay press. At one time referred to as *dementia pugilistica* or "punch drunk," CTE is a distinct neuropathological entity caused by repetitive blows to the head and was at one time deemed to be a disease seen only in old retired professional boxers. CTE is an insidious disease beginning with deterioration in concentration, memory and attention, eventually affecting the pyramidal tract resulting in disturbed gait, coordination, slurred speech and tremors (McCrory et al., 2007). The sporting world has recently been shaken by autopsy-confirmed findings of CTE in retired professional football players (Omalu et al., 2006). As repetitive head injuries occur in a wide variety of contact sports beginning at the high school level, there is a pressing need for further study of this entity.

Neuroendocrine

A TBI is associated with a host of neuroendocrine disorders. Hypopituitarism is found in approximately 30 percent of individuals, over a year post injury, with moderate to severe TBIs (Schneider et al., 2007). Although individuals who develop post-traumatic hypopituitarism acutely may have resolution of that problem over time (Aimaretti et al., 2004), 5 percent of those patients in that study had normal pituitary functioning at three months but developed deficits at one year (Aimaretti et al., 2005).

Growth hormone (GH) deficiency/insufficiency is found in approximately 20 percent of moderate to severe TBIs (Agha and Thompson, 2006). GH deficiency is associated with an increased risk of osteoporosis, hypercholesterolemia and atherosclerosis. These patients have a significant increase in mortality from vascular disease (Rosén and Bengtsson, 1990).

Hypothyroidism is found in approximately 5 percent of individuals post TBI (Agha and Thompson, 2006). Associated signs and symptoms are weight gain, dyspnea, bradycardia and intellectual impairment (Agha and Thompson, 2007). A recent study has shown a connection between hypothyroidism in females and the development of Alzheimer's disease (Tan et al., 2008).

Gonadotropin deficiency is found in approximately 10-15 percent of individuals post TBI (Agha and Thompson, 2006). Adult males will note decreased libido, muscle mass and strength. A correlation has been found between low free testosterone levels and cognitive function, although there is no clear consensus on testosterone supplementation therapy and cognition (Papaliagkas et al., 2008). Hypogonadal women will develop secondary amenorrhea and increased risk for osteopenia.

INCONTINENCE

A TBI frequently affects the cerebral structures that control bladder storage and emptying functions, resulting in a neurogenic bladder. Fox-Orenstein and colleagues reviewed the records of more than 1,000 individuals admitted to rehabilitation centers after a TBI. One-third of the individuals were incontinent of bowel. Twelve percent were incontinent at discharge, but 5 percent were still incontinent at the one year follow-up. In their review of medical complications in 116 individuals with moderate to severe TBI, Safaz and colleagues found that 14 percent had fecal incontinence over one year post injury (Safaz et al., 2008). Fecal incontinence is not only socially devastating, but it will have medical consequences, including skin breakdown, pressure ulcers and skin infections (Foxx-Orenstein et al., 2003).

Urinary incontinence is also an enormous social and medical problem. Chua, et al., (Chua et al., 2003) reviewed the records on 84 patients admitted to a rehabilitation unit within six weeks of injury. Sixty-two percent were incontinent. This improved to 36 percent at discharge; however, 18 percent remained incontinent at six months. Safaz and colleagues found urinary incontinence in 14 percent of their cohort over a year post injury (Safaz et al., 2008). Urinary incontinence is associated with the development of frequent urinary tract infections and decubitus ulcers.

PSYCHIATRIC DISEASE

The impact and cost to society by psychiatric disorders is among the most important healthcare issues of today. Current estimates in the U.S. suggest that the collective cost of psychiatric diseases could be one-third of the total healthcare budget (Voshol et al., 2003). It is critical to note that psychiatric and psychological deficits are among the most disabling consequences of a TBI.

Many individuals with a mild TBI, and the overwhelming majority of those who survive a moderate to severe TBI, are left with significant long-term neurobehavioral sequelae. The costs to society in terms of lost productivity, as well as the costs for medical treatment are enormous. In addition to the aggression, confusion and agitation seen in the acute stages, a TBI is associated with an increased risk of developing numerous psychiatric diseases, including obsessive compulsive disorders, anxiety disorders, psychotic disorders, mood disorders and major depression (Zasler et al., 2007b).

Individuals with a TBI appear to have higher rates of depressive disorders, anxiety disorders and substance abuse or dependence (Hibbard et al., 1998, Holsinger et al., 2002, Koponen et al., 2002, Silver et al., 2001) and often have suicidal plans or suicidal behavior in the context of these illnesses (Kishi et al., 2001). TBI is associated with high rates of suicidal ideation, (Kishi et al., 2001, León-Carrión et al., 2001) suicide, (Silver et al., 2001) and completed suicide (Teasdale and Engberg, 2001). In chronic TBI, the incidence of psychosis is 20 percent. The prevalence of depression is 18-61 percent, mania is 1-22 percent, PTSD is 3-59 percent and post TBI aggression is 20-40 percent (Kim et al., 2007).

Koponen, et al, (Koponen et al., 2002) studied 60 individuals, 30 years post injury. Fifty percent developed a major mental disorder that began *after* their TBI. Another 11 percent developed a major mental disorder later on in their lifetime. Twenty-three percent had developed a personality disorder. In a long-term follow-up study of 254 individuals at two and five years post TBI, it was found that there was a higher incidence of cognitive, behavioral and emotional changes at five years than at two years post TBI. Thirty-two percent of those working at two years were unemployed at five years (Olver et al., 1996). A traumatic brain injury clearly may cause decades long, and possibly permanent, vulnerability to psychiatric illness.

SEXUAL DYSFUNCTION

Sexuality, both physiological and functional, plays an enormous role in our lives. Sexual dysfunction is a large issue in the general population and is a major ongoing problem in the TBI population. Studies have shown 40-60 percent of individuals complain of sexual dysfunction after a TBI (Zasler et al., 2007a). Transient hypogonadism is common acutely following a TBI, yet it persists in 10-17 percent of long-term survivors. Beyond just the fertility and psychosocial issues presented by hypogonadism, muscle weakness and osteoporosis may have a significant impact on long-term function and health with consequences exacerbated by immobility of long durations following a TBI (Agha and Thompson, 2005).

MUSCULOSKELETAL DYSFUNCTION

Muscular dysfunction

Spasticity is characterized by an increase in muscle tone that will result in abnormal motor patterns. This spasticity may well interfere with an individual's general functioning, and limit self care, mobility and independence in the activities of daily living. Spasticity requires life long treatment. Untreated, spasticity will eventually lead to muscle contractures, tissue breakdown and skin ulceration.

Skeletal dysfunction

The incidence of fractures in a TBI is approximately 30 percent. TBI patients with fractures, especially fractures of the long bones, are at risk for heterotopic ossification (HO), which may not develop for as long as three months post injury. HO is defined as "the development of new bone formation in soft tissue planes surrounding neurologically affected joints," and has an incidence of 10-20 percent following a TBI (Colorado, 2006). Safaz and colleagues found HO in 17 percent of their cohort over a year post injury (Safaz et al., 2008). If left untreated, HO will eventually lead to abnormal bony fusions (ankylosis) and subsequent functional limitations.

SUMMARY

Historically, individuals living with a brain injury have been referred to as brain injury *survivors*. No one knows how that term came to be used in this situation. Perhaps the concept of merely staying alive was used because as little as 30 years ago, the majority of individuals with a moderate to severe TBI succumbed soon after their injury. Perhaps it was used to imply that the individual *outlived* their injury and persevered despite the hardship of the trauma.

This term, however, does not address the reality of brain injury. Cancer *survivors* are survivors because it is believed they are cured—and they indeed have outlived their disease. Many individuals who sustain a TBI recover 100 percent. They have truly survived their injury. However, in the U.S. alone, every year, over 125,000 individuals who sustain a TBI become disabled. This paper discusses only a small percentage of the causes of disability and the ongoing and developing medical conditions individuals with TBI face. Presently, more than 3 million individuals in the U.S. are disabled due to the myriad of sequelae of a TBI (Zaloshnja E, Miller T, Langlois JA, Selassie AW. Prevalence of long-term disability from traumatic brain injury in the civilian population of the United States, 2005.*The Journal of Head Trauma Rehabilitation 2008*;23(6):394-400.) Their brain trauma has resulted in a condition that is disease causative and disease accelerative. As a result of their brain trauma, these individuals now have life-long brain injury disease.

Their disease should be reimbursed and managed on a par with all other diseases. Only then will the individuals with this disease get the medical surveillance, support and treatment they deserve. Only then will brain injury research receive the funding it requires. Only then, will we be able to truly talk about a cure.

ACKNOWLEDGEMENTS

The Brain Injury Association of America gratefully acknowledges Brent Masel, M.D., as the author of this position paper. The Association also thanks Mark J. Ashley, Sc.D., Gregory J. O'Shanick, M.D., and Christopher Nowinski for their contributions.

The Board of Directors of the Brain Injury Association of America adopted this position paper at its meeting on February 27, 2009, in Washington, D.C. The Association will continue to review the topic of brain injury as a disease as scientific and public policy progress dictates.

Electronic copies of this statement may be obtained from the Brain Injury Association of America's website: http://www.biausa.org.

The paper may be cited as follows:
Masel, B. *Conceptualizing Brain Injury as a Chronic Disease.* Vienna, VA: Brain Injury Association of America, 2009.

REFERENCES

Aarabi, B., Taghipour, M., Haghnegahdar, A., Farokhi, M. and Mobley, L. (2000) *Neurosurg Focus* **8,** el.

Agha, A. and Thompson, C. (2005) *Pituitary,* **8,** 245-9.

Agha, A. and Thompson, C. J. (2006) *Clin Endocrinol (Oxf),* **64,** 481-8.

Agha, A. and Thompson, C. J. (2007) *Pituitary,* **8,** 245-9.

Aimaretti, G., Ambrosio, M. R., Di Somma, C., Fusco, A., Cannavò, S., Gasperi, M., Scaroni, C., De Marinis, L., Benvenga, S., degli Uberti, E. C., Lombardi, G., Mantero, F., Martino, E., Giordano, G. and Ghigo, E. (2004) *Clin Endocrinol (Oxf),* **61,** 230-6.

Aimaretti, G., Ambrosio, M. R., Di Somma, C., Gasperi, M., Cannavò, S., Scaroni, C., Fusco, A., Del Monte, P., De Menis, E., Faustini-Fustini, M., Grimaldi, F., Logoluso, F., Razzore, P., Rovere, S., Benvenga, S., Degli Uberti, E. C., De Marinis, L., Lombardi, G., Mantero, F., Martino, E., Giordano, G. and Ghigo, E. (2005) *J Clin Endocrinol Metab,* **90,** 6085-92.

Annegers, J. F., Hauser, W. A., Coan, S. P. and Rocca, W. A. (1998) *N Engl J Med.,* **338,** 20-4.

Atkins, E. J., Newman, N. J. and Biousse, V. (2008) *Rev Neurol Dis.* , **5,** 73-81.

Brown, A. W., Leibson, C. L., Malec, J. F., Perkins, P. K., Diehl, N. N. and **Larson, D. R.** (2004) *NeuroRehabilitation,* **19,** 37-43.

Chesnut, R. M., Carney, N., Maynard, H., Patterson, P., Mann, N. C. and Helfand, M. (1999) (Ed, Services, D. o. H. a. H.) Agency for Health Care Policy and Research Publication

Chua, K., Chuo, A. and Kong, K. H. (2003) *Brain Inj,* **17,** 469-78.

Colorado, S. o. (2006), Vol. RULE 17 EXHIBIT 10 (Ed, Employment, D. o. L. a.) State of Colorado, Colorado, pp. 46.

Foxx-Orenstein, A., Kolakowsky-Hayner, S., Marwitz, J. H., Cifu, D. X., Dunbar, A., Englander, J. and Francisco, G. (2003) *Arch Phys Med Rehabil,* **84,** 231-7.

Harrison-Felix, C., Whiteneck, G., Devivo, M. J., Hammond, F. M. and Jha, A. (2006) *J Head Trauma Rehabil,* **21,** 22-33.
Hauser, W. A., Annegers, J. F. and Kurland, L. T. (1991) *Epilepsia,* **32,** 429-445.
Hibbard, M. R., Uysal, S., Kepler, K., Bogdany, J. and Silver, J. (1998) *J Head Trauma Rehabil,* **13,** 24-39.
Hoffer, M. M. and Brink, J. (1975) *Clin Orthop Rel Res,* **110,** 224-8.
Holsinger, T., Steffens, D. C., Phillips, C., Helms, M. J., Havlik, R. J., Breitner, J. C., Guralnik, J. M. and Plassman, B. L. (2002) *Arch Gen Psychiatry,* **59,** 17-22.
Jellinger, K. A., Paulus, W., Wrocklage, C. and Litvan, I. (2001) *BMC Neurol,* **1,** 1:3.
Kim, E., Lauterbach, E. C., Reeve, A., Arciniegas, D. B., Coburn, K. L., Mendez, M. F., Rummans, T. A., Coffey, E. C. and Research., A. C. o. (2007) *J Neuropsychiatry Clin Neurosci,* **19,** 106-27.
Kishi, Y., Robinson, R. G. and Kosier, J. T. (2001) *Psychosomatics,* **42,** 382-90.
Koponen, S., Taiminen, T., Portin, R., Himanen, L., Isoniemi, H., Heinonen, H., Hinkka, S. and Tenovuo, O. (2002) *Am J Psychiatry,* **159,** 1315-21.
Kox, M., Pompe, J. C., Pickkers, P., Hoedemaekers, C. W., van Vugt, A. B. and van der Hoeven, J. G. (2008) *Neurology,* **70,** 480-5.
León-Carrión, J., De Serdio-Arias, M. L., Cabezas, F. M., Roldán, J. M., Domínguez-Morales, R., Martín, J. M. and Sanchez, M. A. (2001) *Brain Inj,* **15,** 175-81.
Lye, T. C. and Shores, E. A. (2000) *Neuropsychology Review,* **10,** 115-29.
O'Neil-Pirozzi, T. M., Whyte, J., Carlile, M. and Diaz-Arrastia, R. (2008) *Arch Phys Med Rehabil,* **89,** 896-903.
Masel, B. E., Scheibel, R. S., Kimbark, T. and Kuna, S. T. (2001) *Arch Phys Med Rehabil,* **82,** 1526-32.
Max, W., Mackenzie, E. J. and Rice, C. P. (1991) *J Head Trauma Rehabil,* **6,** 76-91.
McCrory, P., Zazryn, T., Cameron, P., (2007) *Sports Medicine*, Vol 37 (6), 467-476.
McLean, A., Dikmen, S., Temkin, N. R., Wyler, A. R. and Gale, J. L. (1984) *Neurosurgery,* **14,** 393-399.
Mirzayan, M. J., Probst, C., Krettek, C., Samii, M., Pape, H. C., van Griensven, M. and Samii, A. (2008) *Neurological Research,* **30,** 457-460.
Mital, M. A., Garber, J. E. and Stinson, J. T. (1987) *J Ped Ortho,* **7,** 83-90.
Olver, J. H., Ponsford, J. L. and Curran, C. A. (1996) *Brain Inj,* **10,** 841-8.
Omalu, B., DeKosky, S., Hamilton, R., Minster,R., Kamboh, M., Shakir, A., Wecht, C. (2006) *Neurosurgery,* **59** (5) 1086-1093.
Papaliagkas, V. T., Anogianakis, G. A. and Tsolaki, M. N. (2008) *J Neurodegeneration and Regeneration,* **1,** 35-42.
Plassman, B. L., Havlik, R. J., Steffens, D. C., Helms, M. J., Newman, T. N., Drosdick, D., Phillips, C., Gau, B. A., Welsh-Bohmer, K. A., Burke, J. R., Guralnik, J. M. and Breitner, J. C. (2000) *Neurology,* **55,** 1158-66.
Rosén, T. and Bengtsson, B. A. (1990) *Lancet,* **336,** 285-8.
Sabates, N., Grouce, M. and Farris, B. (1991) *J of Clinical Neuro-Ophthalology,* **11,** 273-277.
Safaz, I., Alaca, R., Yasar, E., Tok, F. and Yilmaz, B. (2008) *Brain Inj,* **22,** 733-9.
Sarnak, M. J., Levey, A. S., Schoolwerth, A. C., Coresh, J., Culleton, B., Hamm, L. L., McCullough, P. A., Kasiske, B. L., Kelepouris, E., Klag, M. J., Parfrey, P., Pfeffer, M., Raij, L., Spinosa, D. J. and Wilson, P. W. (2003) *Circulation,* **108,** 2154-69.

Schneider, H. J., Kreitschmann-Andermahr, I., Ghigo, E., Stalla, G. K. and Agha, A. (2007) *JAMA,* **298,** 1429-38.

Schofield, P. W., Tang, M., Marder, K., Bell, K., Dooneief, G., Chun, M., Sano, M., Stern, Y. and Mayeux, R. (1997) *J Neurol Neurosurg Psychiatry,* **62,** 119-24.

Shavelle, R. M., Strauss, D., Whyte, J., Day, S. M. and Yu, Y. L. (2001) *Am J Phys Med Rehabil,* **80,** 510-6.

Silver, J. M., Kramer, R., Greenwald, S. and Weissman, M. (2001) *Brain Inj,* **15,** 935-45.

Strohl, K., Blatt, J., Council, F., Georges, K., Kiley, J., Kurrus, R., McCartt, A. T., Merritt, S. L., Pack, A. I., Rogus, S., Roth, T., Stutts, J., Waller, P. and Willis, D. (2005) (Ed, Administration, N. H. T. S.) Washington, D.C.

Tan, Z. S., Beiser, A., Vasan, R. S., Au, R., Auerbach, S., Kiel, D. P., Wolf, P. A. and Seshadri, S. (2008) *Arch Intern Med. ,* **168,** 1514-20.

Tannock, I. F., Ahles, T. A., Ganz, P. A. and van Dam, F. S. (2004) *J Clin Oncol,* **22,** 2233-9.

Teasdale, T. W. and Engberg, A. W. (2001) *J Neurol Neurosurg Psychiatry,* **71,** 436-40.

Voshol, H., Glucksman, M. J. and van Oostrum, J. (2003) *Curr Mol Med. ,* **3,** 447-58.

Yasseen, B., Colantonio, A. and Ratcliff, G. (2008) *Brain Inj,* **22,** 752-7.

Zaloshnja E, Miller T, Langlois JA, Selassie AW. Prevalence of long-term disability from traumatic brain injury in the civilian population of the United States, 2005.*The Journal of Head Trauma Rehabilitation* **23**(6), 394-400.

Zasler, N. D., Katz, D. I. and Zafonte, R. D. (2007a) In *Brain Injury Medicine: Principles and Practice* (Eds, Zasler, N. D., Katz, D. I. and Zafonte, R. D.) Demos Medical Publishing, LLC, New York City, pp. 667.

Zasler, N. D., Katz, D. I. and Zafonte, R. D. (2007b) In *Brain Injury Medicine: Principles and Practice*(Eds, Zasler, N. D., Katz, D. I. and Zafonte, R. D.) Demos Medical Publishing, LLC, New York City, pp. 835.

Traumatic Brain Injury in the United States: A Call for Public/Private Cooperation

Executive Summary

Traumatic Brain Injury (TBI) is a growing public health problem in U.S. military and civilian populations.

The standard of care is early, intensive acute treatment and rehabilitation followed by timely post acute rehabilitation of sufficient scope, duration and intensity to restore maximum function and accommodate residual disability. To optimize their independence and maintain good health throughout their lives, individuals with brain injury need access to a full continuum of care as well as intermittent or lifelong community-based information, resources, services and supports.

The complex nature of TBI necessitates treatment by an interdisciplinary team of highly experienced and specialized clinicians. In the past, the Department of Defense and the Department of Veterans Affairs have contracted with private sector clinicians rather than attempt to replicate the many and varied programs and services that make up the TBI continuum of care.

Now is the time to expand those cooperative relationships to avoid treatment delays, unnecessarily high levels of disability, and greater taxpayer burden in the years to come.

The Brain Injury Association of America urges Congress to facilitate greater public and private cooperation in all aspects of brain injury: awareness, education, treatment and research. America's service members with TBI and the millions of children and adults who are injured in the U.S. each year deserve no less.

Acknowledgements

The Board of Directors of the Brain Injury Association of America adopted this position statement in April 2007. The Association gratefully acknowledges Mark J. Ashley, ScD; Debra Braunling-McMorrow, PhD; Susan H. Connors; Wayne A. Gordon, PhD; and Tina M. Trudel, PhD for their work in preparing this statement.

The American Congress of Rehabilitation Medicine has endorsed this position statement.

A Growing Public Health Crisis

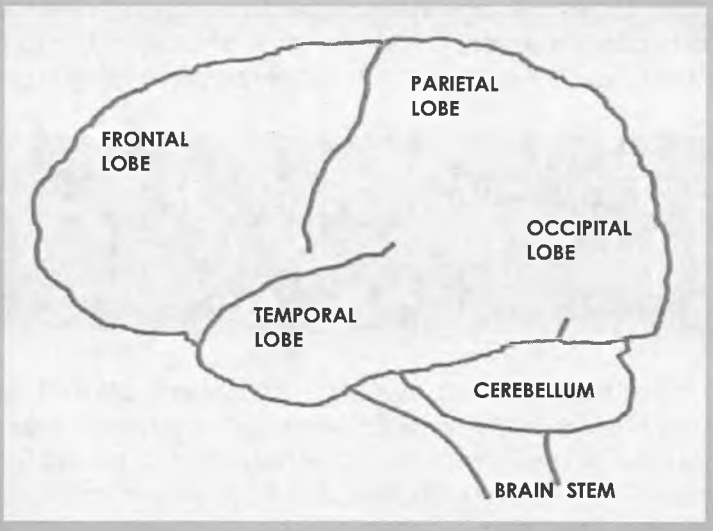
The human brain controls physical, cognitive and behavioral functions. A traumatic brain injury (TBI), which is a blow or jolt to the head or a penetrating head injury, can impact one or more parts of the brain, thereby temporarily or permanently disrupting normal function.

Simplified Brain Behavior Relationships

(Adapted from D. Brooks & L. Meinert, American Academy for the Certification of Brain Injury Specialists, Level I Training Manual, 2nd Ed. 1998)

Frontal Lobe
Initiation
Problem Solving
Judgment
Planning
Behavior
Self-monitoring
Personality
Emotions
Awareness of abilities
Organization
Concentration
Mental Flexibility
Expressive Language

Temporal Lobe
Memory
Hearing
Receptive Language
Organization
Sequencing



Parietal Lobe
Sense of touch
Differentiation in size, shape and color
Spatial perception
Visual perception

Occipital Lobe
Vision

Cerebellum
Balance
Coordination
Skilled motor activity

Brain Stem
Breathing
Heart rate
Arousal/Consciousness
Sleep/Wake Functions
Attention
Concentration

TBIs are caused by falls, motor vehicle crashes, assaults and other incidents. Shock wave blasts from improvised explosive devices, rocket propelled grenades and land mines are the leading cause of TBI for active duty military personnel in combat zones.

In prior military conflicts, TBI was present in 14-20 percent of surviving casualties.[1] Reports indicate 12,274 service members have sustained a TBI in Operation Iraqi Freedom (OIF) and Operation Enduring Freedom (OEF) as of March 24, 2007,[2] but that number could grow as high as 150,000[3]. In peacetime, more than 7,000 persons are admitted to military and Veterans hospitals for TBI each year.[1]

The Centers for Disease Control and Prevention (CDC) estimates that 1.4 million TBIs annually occur among civilians. Of these, TBI results in 50,000 deaths and leaves 80,000 to 90,000 citizens with a disability.[4] At least 5.3 million children and adults live with a long-term disability resulting from TBI.[5]

The effects of brain injury are cumulative, and individuals with TBI may be predisposed to re-injury and the onset of disability with subsequent injury. In the civilian population the re-injury rate is 14 percent and the severity increases with recurrent injury.[6] Given the added risks for military personnel, it is estimated that the re-injury rate is higher.

For civilians, direct medical expenses and indirect costs such as lost earning potential and caregiver burden annually exceed $60 billion in 2001 dollars.[7] Although costs for OIF and OEF Veterans with TBI are unknown, the medical and disability expenses for all Iraq and Afghanistan War casualties are estimated at $349 to $662 billion.[8]

Cost estimates may under-represent the true burden on society. TBI has been linked to respiratory, circulatory, digestive, and neurological diseases such as epilepsy, Alzheimer's and Parkinson's disease, but awareness of brain injury as a disease, disease-causative and disease-accelerative is only slowly emerging.[9]

Heterogeneity in TBI Diagnosis and Treatment

No two brains are alike; therefore, no two brain injuries are alike. The same force applied to the brains of different individuals will result in different injury severity. The impairments caused by TBI are heterogeneous and are not predictable. This makes TBI unlike other medical diagnoses. In addition, some symptoms or impairments may emerge soon after the injury while others manifest after weeks or months.

In a 2005 descriptive analysis of 433 patients with TBI seen at the Walter Reed Army Medical Center, moderate and severe injuries accounted for 56 percent of those diagnosed with TBI.[10] In the civilian population, up to 20 percent of all TBIs are moderate to severe. Thus, although each year more civilians are injured, the injuries sustained by service members are more severe.

Mild TBI, sometimes called Hidden TBI, is often undiagnosed or misdiagnosed because patients present with what appear to be more critical physical injuries or may have co-occurring disorders such as depression, substance abuse or post traumatic stress disorder. Any brain injury -- whether mild, moderate or severe -- can temporarily or permanently diminish a person's physical abilities, impair cognitive skills, and interfere with emotional and behavioral well-being.

Common Changes After TBI

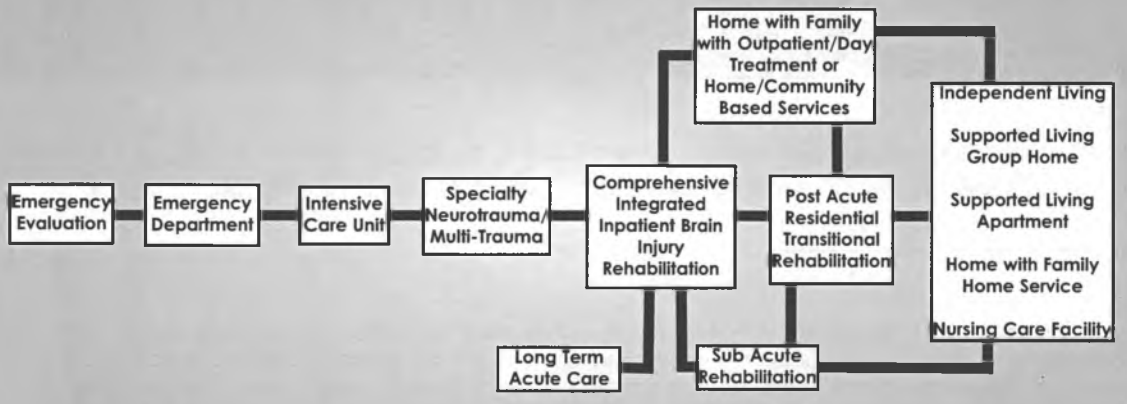
Physical Challenges	Cognitive Challenges	Behavior Challenges
Balance, Mobility	Memory	Depression
Motor Coordination	Problem Solving, Sequencing	Anxiety, Stress
Persistent Headaches	Decision Making, Judgment	Disinhibition, Aggression
Fatigue or Weakness	Processing Speed	Failed Response to Social Cueing
Hearing or Vision Impairment	Planning, Organization	Lack of Emotional Control
Sensory Loss	Attention, Concentration	Frustration, Mood Swings
Seizures	Initiation	Difficulty Relating to Others
Sexual Dysfunction	Speech, Language	Reduced Self-Esteem

There is no single pathway or course of recovery from TBI. Advances in emergency medicine and improvements in diagnostic procedures, monitoring devices and treatment methods have evolved into a complex continuum of TBI care that includes acute hospitalization, acute rehabilitation, post acute rehabilitation, and community support services.

In the private sector, the TBI continuum of care is comprised of specific facility and specialty program types, many of which have earned accreditation as acute care hospitals by the Joint Commission and accreditation as specialized brain injury programs by the Commission on Accreditation of Rehabilitation Facilities (CARF). Every level of the TBI continuum of care in the private sector is enriched by clinical experience, protocols, and extensive operational management knowledge acquired during the last 30 years.

Traumatic Brain Injury Continuum of Care

(Adapted from the Rocky Mountain Regional Brain Injury System to depict the continuum of care for individuals with moderate and severe TBI. See Appendix A for a description of each component.)



A patient's length of stay at any level of the TBI continuum of care should be based on the nature of the neurological injuries and the degree to which additional, measurable functional improvement within specific time frames is anticipated. Such judgments, and the scope, intensity and duration of medical, rehabilitative and long-term treatment and service plans should be developed by a highly specialized and experienced interdisciplinary team† in concert with the patient and family.

As Douglas Gentlemen aptly noted in a 2001 article,

> **"Clinical and political responses to the worldwide epidemic of traumatic brain injury need to recognize that the quality of outcome depends on both phases of treatment: acute care and rehabilitation."** [11]

The value of effective rehabilitative treatment is demonstrated through peer-reviewed scientific research.[11-16] A 2005 Cochrane review of multi-disciplinary rehabilitation for acquired brain injury in adults of working age examining all relevant studies meeting rigorous methodological criteria published since 1966 found:

> **For individuals with moderate to severe brain injury, there is 'strong evidence' of benefit from formal intervention... for individuals with moderate to severe brain injury who are already in rehabilitation, there is 'strong evidence' that more intensive programs are associated with earlier functional gains.**[17]

Research demonstrates the relationships among provision of rehabilitation therapies, increased functioning, improved test scores and changes in cortical organization on fMRI, as well as an improved rate of recovery and functional independence from more intensive therapies.[15, 16]

Barriers to Accessing Treatment

Americans mistakenly believe Veterans benefits, employer health plans, or individual insurance policies will provide for all needed services when serious injuries or illnesses

---

†The interdisciplinary brain injury team is comprised of medical and allied health professionals with specialized experience in TBI including: behavioral specialist, case manager, clinical psychologist, neurologist, neuro-ophthalmologist, neuropsychologist, neuroscience nurse, neurosurgeon, nurse, occupational therapist, neuro-optometrist, physical therapist, physiatrist, psychiatrist, rehabilitation counselor, social worker, speech/language pathologist, therapeutic recreation specialist, vocational rehabilitation counselor, and paraprofessional support staff such as medical technician, rehabilitation technician, rehabilitation assistant, life skills trainer, job coach and certified nursing assistant.

occur. In reality, most insurance polices are geared toward wellness and routine care with very few supporting best practices in acute and post acute care and rehabilitation.

> **Some insurance policies still allow patients to substitute skilled nursing benefits for rehabilitative care, but many insurance companies have eliminated this option. One insurance company eliminated rehabilitation benefits altogether.**

Insurance companies' reimbursement policies have driven down the average length of stay for acute hospitalization and rehabilitation of TBI patients from 77 days in 1990 to a current average of only 46 days.[18, 19] Nearly two-thirds of all individuals hospitalized with brain injury return to their homes with no further medical rehabilitative treatment.[20]

Public funding sources, such as Medicare and Medicaid, support only minimal medical rehabilitation in acute hospitals and post acute rehabilitation settings. The long-held institutional bias among public payers often consigns individuals with brain injury to inappropriate placements such as nursing homes and psychiatric facilities. Depending on the state in which the civilian lives, access to publicly funded services may be limited by age, cause of injury, or injury severity.

Barriers to Accessing Treatment	Military		Civilian	
	DoD Medicine	Veterans Hospitals	Insurance Policies	Public Funding
Limitations on service scope, duration and intensity	X		X	X
Shortage of TBI specialty personnel		X		
Age restrictions				X
Injury severity restrictions				X
Cause of injury restrictions				X
Institutional bias toward nursing homes		X		X
Shortage of community-based options	X	X		
Lack of information, resources, advocacy and support	X	X	X	X
Lack of federally-funded basic and applied research	X	X	X	X
Bureaucracy and/or paperwork burdens		X	X	X

The Armed Forces Epidemiological Board acknowledged the Department of Defense lacks "a system-wide approach for proper identification, management and surveillance of individuals who sustain a TBI."[21] Servicemen and women with severe brain injuries are treated at military hospitals where they are covered by an active duty military insurance policy that in some cases pays for private care, if needed. After acute treatment, the Department of Defense shifts service member healthcare to the Department of Veterans Affairs.

The needs of individuals with TBI are urgent and the complexity of the injury is not conducive to accelerated training of heath care providers. Personnel shortages are a substantial barrier to appropriate care for our Armed Forces.

Service member access to the full TBI continuum of care is also limited by extended travel distances to centralized Veterans hospitals. Just like other payers, TriCare limits access to comprehensive rehabilitation by negotiating contracts that only allow for minimal service provision.

Payers of all types point to the need for additional evidence-based research on health outcomes as a reason for denial of medically-necessary inpatient and outpatient rehabilitative treatment for individuals with TBI, particularly for those who require behavioral health services and cognitive rehabilitation.

The federal government has made a modest investment in applied TBI research within the Department of Education's National Institute on Disability and Rehabilitation Research (NIDRR). The agency awards a total of $6 million to 16 geographically disbursed TBI Model Systems of Care Centers to develop and test practice parameters, innovative treatment interventions, and novel diagnostic procedures as well as identify adverse outcomes and associated risk factors of TBI.

The Model Systems are a vital component of quality TBI care and a national resource. They furnish technical assistance to local Veterans hospitals and prepare private sector researchers and clinicians for TBI specialty care. NIDRR's Model Systems maintain the only non-proprietary longitudinal database on the recovery and outcomes of patients with TBI.

As has been identified by Model Systems investigators and other leaders in the brain injury field, comprehensive, validated outcome measures applicable to both military and civilian populations must be developed. To that end, treatment must be accurately characterized for therapeutic intensity, duration and content, and measures must encompass immediate, short-term and long-term gains from admission to discharge. The stability of achieved outcomes and the cost/benefit relationship between dollars expended for treatment and lifetime dollars saved by disability reduction must be documented.

The influx of TBI survivors returning home from war emphasizes the need to leverage the existing civilian TBI research and treatment capacity to address the outcomes measurement issue and to augment the care systems being developed at both the Department of Defense and the Department of Veterans Affairs. The public and private sectors must come together to meet this mutual need.

In both the military and civilian populations, there is a nationwide shortage of TBI information, resources, advocacy and support for patients and family caregivers. Information requests to the Brain Injury Association's National Brain Injury Information Center indicate the areas in which help is needed most.

Information & Resource Needs		
Information/Resource Topic	**Military Requests**	**All Requests**
Basic Packet	27%	32%
Medical	20%	11%
Behavior	20%	3%
Programs/Providers	12%	20%
Concussion	10%	7%
Finance	4%	7%
Specific Publication	2%	7%
Support Group	2%	6%
Legal	2%	3%
Rehabilitation	<1%	3%
Coma	<1%	2%

Data From the Brain Injury Association of America's National Brain Injury Information Center Database of callers, Oct 2004 to Mar 2007.

Consequences of Inadequate Treatment

Barriers to accessing the TBI continuum of care result in enormous medical, social and economic consequences for the individual who is injured, his or her family members, and the nation as a whole.

> **Delayed treatment results in higher levels of disability, an increased reliance on pharmacological interventions, greater durable medical equipment needs, and higher long-term care costs.**

People who experience a TBI report poorer physical and emotional health as compared to those with other disabilities and those without disabilities.[22] Individuals with brain injury who live with residual disability often fail when they attempt to return to active military duty, productive work, previous social roles, familial responsibilities and pre-injury lifestyles.[22] People with TBI are 66 percent more likely to receive welfare or disability payments and are four times more likely to attempt suicide than people without disabilities.[22]

Depression, substance abuse, and family dysfunction are just a few of the personal consequences of inadequate access to the TBI continuum of care. Societal costs for both military and civilian populations include transference of burden to federal, state and municipal taxpayers through homelessness, psychiatric placements and correctional sentences.

The Right Treatment, Right Now

America's Armed Forces and millions of children and adults with TBI are harmed when they cannot access immediate medical treatment, comprehensive rehabilitation, and community-based information, resources, services and supports.

The system of care and expertise that is needed to deliver TBI services to all exists in the private sector. Replicating such a system in the Department of Defense or the Department of Veterans Affairs for an unknown number of service members with brain injury would be cost prohibitive and delays in treatment would result in higher levels of disability and poorer health outcomes.

The Brain Injury Association of America urges Congress to improve the systems of care for all Americans with brain injury by adopting the following recommendations:

1. Require all allied health professionals, including case managers and support staff, working with service members with TBI to obtain brain injury specialty training and certification.

2. Provide confidential information, resources and service system navigation to assist individuals with TBI and military families to understand brain injury, cope with its aftermath, and access the many and varied program types within the TBI continuum of care.

3. Revise Department of Defense and Department of Veterans Affairs policies and procedures to ensure records are transferred from the operational environment to Germany and then U.S. facilities without a loss of information.

4. Revise Department of Defense and Department of Veterans Affairs policies to broaden the number of eligible private sector rehabilitation providers by:

   (a) ensuring access to hospital and less costly non-hospital facilities for comprehensive post acute inpatient and outpatient rehabilitation. Current requirements for Medicare certification and Comprehensive Outpatient Rehabilitation Facility licensing are not appropriate for non-hospital-based rehabilitation programs with specialized populations such as TBI and should be substituted with requirements for specialized CARF Brain Injury accreditation and/or Joint Commission accreditation;

   (b) evaluating the benefits of a one-year moratorium on medical retirement so that service members can remain on active duty status with insurance coverage allowing for care in the private sector. If this approach is adopted, military families should be fully informed of the retirement moratorium; and

(c) accelerating the pace at which contracts are negotiated and executed.

5. Enact and fully fund the Heroes At Home Act of 2007 and provide full funding for the Heroes At Home Act of 2006, which together provide for:

   (a) implementation of an objective assessment protocol to measure cognitive functioning both prior to and after deployment to improve the screening process for TBI in service members;

   (b) establishment of a Traumatic Brain Injury Family Caregiver Personal Care Attendant Training and Certification Program to train, certify and compensate family caregivers as personal care attendants for service members with TBI; and

   (c) grant awards to community-based organizations to meet employment and emotional adjustment needs of members of the National Guard and Reserve with TBI.

6. Reauthorize the Traumatic Brain Injury Act and fund the measure at $30 million in FY 2008. The TBI Act charges agencies within the Department of Health and Human Services with epidemiological research, public awareness, and administration of grants to state agencies and protection and advocacy organizations to improve coordination of and access to public services.

7. Intensify and accelerate research efforts research by:

   (a) supporting specialized research on the mechanisms and recovery pathways for blast injury survivors as well as other treatment and education initiatives of the Defense and Veterans Brain Injury Center with funding of $19.5 million in FY 2008;

   (b) augmenting existing research programs of the National Institute on Disability and Rehabilitation Research TBI Model Systems and allocating line-item funding of $30 million in FY 2008 to continue and expand NIDRR's applied research results;

   (c) elevating the National Center for Medical Rehabilitation Research to full Institute status within NIH; and

   (d) enhancing collaboration between military and civillian trauma entities to conduct clinical research and establish a National Trauma Institute that will benefit both the military and civilian populations.

References

[1] Defense and Veterans Brain Injury Center. Frequently Asked Questions page. Available at http://www.dvbic.org/cms.php?p=FAQ. Accessed March 31, 2007.

[2] Glaser R. A shock wave of brain injuries. *The Washington Post*. April 8, 2007; B1, B5.

[3] ABC News. Bob Woodruff Reports. Available at http://www.abcnews.go.com/wnt/woodruffreports/story?id+2908676&page=1. Accessed March 31, 2007.

[4] Langlois JA, Rutland-Brown W, Thomas KE. *Traumatic brain injury in the United States: emergency department visits, hospitalizations, and deaths*. Atlanta, GA: Centers for Disease Control and Prevention, National Center for Injury Prevention and Control; 2003.

[5] Thurman D, et al. Traumatic brain injury in the United States: a public health perspective. *Journal of Head Trauma Rehabilitation*. 1999;14(6):602-615.

[6] Guskiewicz KM, Weaver NL, Padua DA, et al. Epidemiology of concussion in collegiate and high school football players. *American Journal of Sports Medicine*. (28)5:643-650.

[7] Finkelstein E, Corso P, Miller T, et al. *The Incidence and Economic Burden of Injuries in the United States*. NY: Oxford University Press; 2006.

[8] Bilmes L. *Soldiers Returning from Iraq and Afghanistan: The Long-term Costs of Providing Veterans Medical Care and Disability Benefits* (RWP07-001). Unpublished manuscript in the Harvard University John F. Kennedy School of Government KSG Faculty Research Working Paper Series; January 2007.

[9] National Institute of Neurological Disorders and Stroke. *Traumatic Brain Injury: Hope through Research. NIH Publication No.*: 02–158. Bethesda, MD: National Institutes of Health; 2002.

[10] Warden DL, Ryan LM, Helmick KM, et al. War neuro-trauma: the Defense and Veterans Brain Injury Center (DVBIC) experience at Walter Reed Army Medical Center (WRAMC). J *Neurotrauma*. 2005;22(10):1178.

[11] Gentleman D. Rehabilitation after traumatic brain injury. *Trauma*. 2001;3:193-204.

[12] Gray DS. Slow-to-recover severe traumatic brain injury: a review of outcome and rehabilitation effectiveness. *Brain Injury*. 2000;14(11):1003-1014.

[13] Turner-Stokes L. The evidence for the cost-effectiveness of rehabilitation following acquired brain injury. *Clinical Medicine*. 2004;4(1):10-12.

[14] Turner-Stokes L, Disler P, Nair A, Wade D. Multi-disciplinary rehabilitation for acquired brain injury in adults of working age. *The Cochrane Database of Systematic Reviews*. 2005;3.

[15] Laatsch L, Little D, Thulborn, K. Changes in fMRI following cognitive rehabilitation in severe traumatic brain injury: a case study. *Rehabilitation Psychology*. 2004;49(3):262-267.

[16] Shiel A, et al. The effects of increased rehabilitation therapy after brain injury: results of a prospective controlled trial. *Clinical Rehabilitation*. 2001;15:501-514.

[17] Cicerone KD, Dahlberg C, Malec JF, et al. Evidence-based cognitive rehabilitation: updated review of the literature from 1998 through 2002. *Arch Phys Med Rehabil.* 2005:1681-1692.

[18] Kreutzer JS, Kolakowsky-Hayner SA, Ripley D, et al. Charges and lengths of stay for acute and inpatient rehabilitation treatment of traumatic brain injury 1990-1996. *Brain Injury*. 2001;15:763-774.

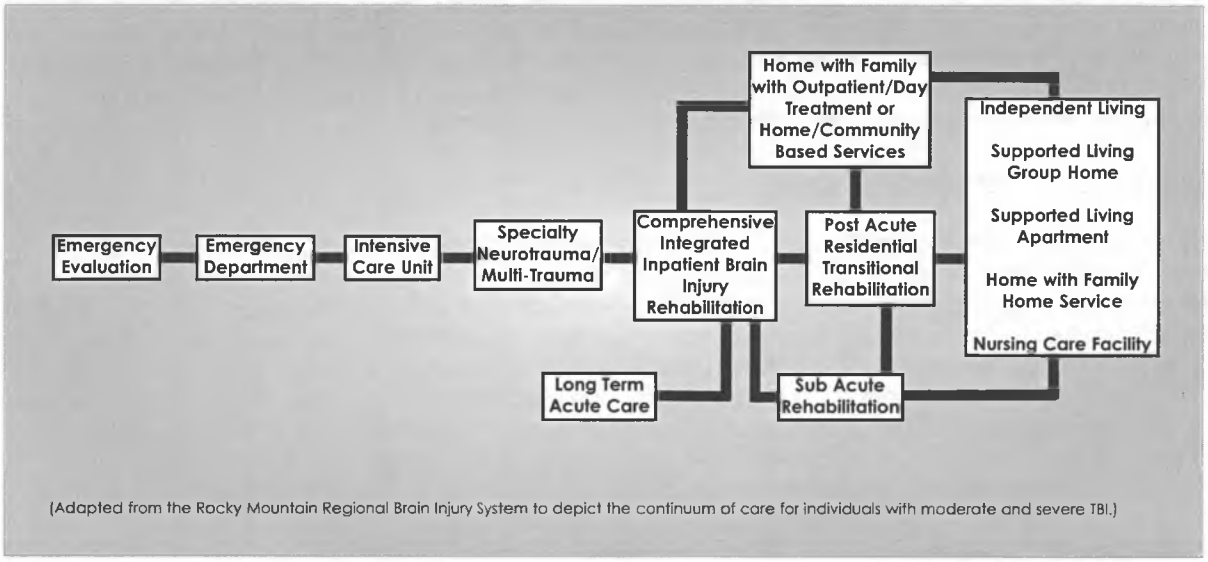
[19] Gordon W. Personal communication on April 10, 2007 regarding TBI Model Systems Uniform Data Collection Report for 2004.

[20] Mellick D, Gerhart KA, Whiteneck GG. Understanding outcomes based on the post-acute hospitalization pathways followed by persons with traumatic brain injury. *Brain Injury*. 2003;17(1):55-71.

[21] Armed Forces Epidemiological Board. Memorandum dated August 11, 2006, on Traumatic Brain Injury in Military Service Members 2006-02 to The Honorable William Winkenwerder, Jr, MD.

[22] Silver J, Kramer R, Greenwald S, et al. The association between head injuries and psychiatric disorders: findings from the New Haven NIMH Epidemiologic Catchment Area Study. *Brain Injury*. 2001;15(11):935-945.

Appendix A
TBI Continuum of Care



(Adapted from the Rocky Mountain Regional Brain Injury System to depict the continuum of care for individuals with moderate and severe TBI.)

Acute Care

Established Emergency Medical Services (EMS) triage guidelines and organized pre-hospital trauma systems improve the delivery of trauma care and should be utilized. Trauma systems with identified regionally-designated neuro-trauma centers (preferably Level I or Level II Trauma Centers) should be utilized for the acute care of individuals with traumatic brain injury. Neuro-trauma centers should have a multidisciplinary trauma team, an in-house trauma surgeon, promptly available neurosurgeon, a continuously staffed operating room, neuroscience nurses, neuro-intensive care unit, lab, and a CT immediately available at all times. Other team members should include orthopedists, radiologists and anesthesiologists. Rehabilitation therapies should be initiated in this phase of care as soon as the patient is stable.

Acute Rehabilitation

Following medical stability, individuals with moderate/severe brain injury should be transferred from acute hospital care to a comprehensive integrated inpatient brain injury rehabilitation program. Acute brain injury rehabilitation hospitals should have a designated specialty program, with therapy programs, equipment, and a sufficient number of individuals with TBI to constitute a peer and family milieu. Acute rehabilitation hospitals should be accredited by the Commission on Acceditation of Facilities (CARF) as a specialized Brain Injury Comprehensive Integrated Inpatient Rehabilitation Program and/or as a general rehabilitation hospital by the Joint Commission.

Long-Term Acute Care (LTAC)

Some individuals will be unable to participate in a full inpatient program immediately following acute care and may need long-term acute care for a period of time prior to entering a comprehensive program. LTAC is a recognized designation (by the Centers for Medicare and Medicaid Services) for acute care hospitals whose average length of stay is at least 25 days. LTAC hospitals provide specialized care services, including skilled nursing care to manage medical conditions so that individuals with catastrophic or acute illnesses/injuries may progress toward entry into comprehensive brain injury inpatient rehabilitation. LTAC programs should be accredited by the Joint Commission and/or CARF as a Brain Injury Comprehensive Integrated Inpatient Rehabilitation Program in an LTAC. LTAC rehabilitation is generally accepted, but should not be used in lieu of categorical inpatient rehabilitation.

Sub-acute Rehabilitation Programs

These programs are located on separate and specially licensed units of hospitals or nursing homes. Individuals who are appropriate for sub-acute care typically are medically stable, require skilled nursing care, and have ether completed comprehensive inpatient rehabilitation or are judged to not be able to benefit from inpatient rehabilitation. Sub-acute rehabilitation is generally accepted, but should not be used in lieu of categorical inpatient rehabilitation for individuals who may benefit from a comprehensive inpatient rehabilitation program. Sub-acute rehabilitation programs should be accredited by the Joint Commission as a Skilled Nursing Facility- Sub-acute services and CARF as a Brain Injury Comprehensive Integrated Inpatient Rehabilitation Program – Skilled Nursing Facility or a Brain Injury Long Term Residential Program.

Post Acute Rehabilitation

Post acute rehabilitation describes programs following inpatient rehabilitation, including outpatient or day treatment rehabilitation, residential transitional rehabilitation, home- and/or community based programs and vocational programs. The most appropriate post acute rehabilitation depends on the individual's needs following inpatient rehabilitation, as well as proximity and availability of services, family dynamics, and projected long-term outcomes. Individuals with significant deficits or who require behavioral treatment or supervision for safety may require brain injury residential transitional rehabilitation. Other individuals may be able to use a combination of home and community-based rehabilitation and outpatient or day treatment rehabilitation as well as vocational programs. Post acute rehabilitation programs should be accredited by CARF. CARF accreditation as a specialized Brain Injury program implies that programs meet specific standards that require personnel competency in ABI and measurement of performance in effectiveness, efficiency, access and satisfaction of the person served.

Long-Term Care

The range of long-term outcomes following TBI is diverse from virtually complete independence and function to severe and permanent disability. Therefore, the range of needed services is complex and individualized. Some individuals with moderate/severe brain injury will require significant care and supervision, either at home by family or attendant care, in a nursing care facility, or in a long-term assisted or supported living program. Individuals may benefit from periodic re-evaluations, based on condition and needs. Long-term care programs should be accredited by the Joint Commission or CARF. CARF accreditation as a Specialized Brain Injury program implies that programs meet specific standards that require personnel competency in ABI and measurement of performance in effectiveness, efficiency, access and satisfaction of the person served.

Appendix B
TBI Resource Facilitation

Military personnel and their families have difficulty understanding traumatic brain injury (TBI), coping with the changes following TBI, and accessing appropriate and local information, resources, services and supports. The Brain Injury Association of America, which has more than 25 years of experience in the field and a nationwide network of chartered state affiliates, is uniquely positioned to meet service members' care coordination needs through Resource Facilitation.

Resource Facilitation is a person-centered, community-based initiative linking individuals with TBI and their families to local information, resources, service providers and natural supports. It is a collaborative process that respects and encourages the involvement and choices of individuals with brain injury and their family members. The model includes: 1) identifying needs, problem-solving, planning, negotiating, referral to services and monitoring; 2) on-going assessment of goals, emotional support and self-advocacy training; and 3) education and awareness, outreach to service professionals and support providers within the community, and resource development. The outcome of Resource Facilitation is timely and appropriate receipt of services and support that meets the unique needs of participants and their families to ensure a seamless transition back to their communities, family responsibilities, and social roles.

The Brain Injury Association of America (BIAA) is ready to provide Resource Facilitation for returning service members using its existing infrastructure. Working cooperatively with the VA's polytrauma centers, network sites, and the Defense and Veterans Brain Injury Center, the Association can adapt data-driven outreach initiatives, intake procedures, data collection and analysis methods, and program models for the military population. The Association can also create a national standardized outcome assessment to evaluate access and linkage to services and supports in the community, monitor lifespan changes, family supports, natural supports and customer satisfaction. The Brain Injury Association of America can implement TBI Resource Facilitation on a nationwide basis for all service members.

The Brain Injury Association of America was founded in 1980 to improve the quality of life for individuals with brain injury and their family members. Today, the Association is headquartered near Washington, D.C., and encompasses a nationwide network of state affiliates that offer resource facilitation programs, support groups, peer mentoring activities, family caregiver training and more.

Annually, the Brain Injury Association of America and its affiliates respond to 100,000 individual requests for help through toll-free information centers that include Spanish language services. The Association's comprehensive website receives more than 2 million hits per year. The Brain Injury Association of America publishes the only National Directory of Brain Injury Service Providers and has expanded the number of certified professional and paraprofessional brain injury specialists/trainers to nearly 2,000. The Association is administering the newly created Bob Woodruff Family Fund for TBI to assist service members and their families affected by the war in Iraq and Afghanistan.

Brain Injury Association of America

Brain Injury Association of America
8201 Greensboro Drive, Suite 611
McLean, VA 22102
703-761-0750
www.biausa.org

The Brain Injury Data Project: One Soldier's Story

FEB 6 2013, 8:04 AM ET

http://www.theatlantic.com/health/archive/2013/02/the-brain-injury-data-project-one-soldiers-story/272806/#

Data from more than 10,000 brain injury patients -- including hundreds of variables and outcomes -- is being tracked in an ongoing government project that began 26 years ago. A Palo Alto veterans' hospital shows how important this information has become in helping patients establish and meet expectations for recovery.

Cpl. Toran Gaal on "stubbies" for the first time since his injury.

"You've been blown up, dude."

Those were the first words Corporal Toran Gaal heard upon awaking from a coma in a hospital bed in Walter Reed National Military Medical Center. Gaal was grateful that his brother, a former Marine, was so blunt.

A month earlier, right before dawn on June 26, 2011, the 24-year-old Marine squad leader had stepped on an improvised explosive device in Sangin, Afghanistan. When he opened his eyes at Walter Reed, Gaal wondered why he wasn't in country. Who was leading his men?

He says his limbs were an afterthought. The left leg would be amputated above the knee. Doctors would unsuccessfully try to salvage the right above the ankle, but it would eventually be taken at the hip. His

brain's left frontal lobe was severely damaged. In less than a second, the trajectory of Gaal's life had changed. The infantryman, the college basketball player, the man always in control -- that person now lived in the past.

Gaal in Afghanistan, 2011

Gaal somehow manages not to dwell there. Still in recovery at the Naval Medical Center San Diego, he walks on prosthetics, rows, drives a car, and has plans to become an emergency services dispatcher. "I can't go back," he says. "I can't say what if, what if, what if. I'm happy with what I have. I'm alive."

Gaal's resilience can seem miraculous. He thinks of it as a trait he earned on the basketball court in adolescence and one that the military further "refined." Either way, his grit was a force that Gaal's doctors at the VA Palo Alto Polytrauma Rehabilitation Center, where he spent the first five months of his recovery, did not take for granted. Instead, it became leverage in their mission to see that Gaal's healing surpassed the average outcome for his injuries.

This was no wishful thinking; his doctors could compare Gaal's case to datasets based on thousands of civilian patients with brain trauma and other catastrophic injuries. Every day, Gaal's doctor, physical therapist, nurse, and case manager tapped into his urgent need to thrive, and pushed him just a little harder. Gaal knew they cared deeply, but it was hard to see that it was science.

***

Dr. Odette Harris, a neurosurgeon and associate chief of staff of polytrauma at the Palo Alto center, is a data hound. To her, resilience can be a "nebulous" term.

What she wants to know is how recovery might be measured in outcomes: how long will a patient stay in the hospital; will he be able to walk again; might she regain the ability to speak? Even the strongest willed patient is tied in some way to the fate of others who came before, demonstrating what the human body is capable of under a certain set of circumstances.

For a polytrauma physician, creating a treatment plan is more than an educated guess; it's built on decades of data known as the Traumatic Brain Injury Model Systems (TBIMS). Started in 1987 by the federal government, TBIMS is a prospective study that has tracked the recovery of more than 10,000

brain-injured patients using hundreds of variables and outcomes, including length of stay and what's known as a functional independence measure.

Gaal in Palo Alto, 2011

The patients recorded in TBIMS are mostly civilians. Three-quarters of them are male and half were injured in car accidents. A small but important subset also suffers spinal cord injuries, burns, and other life-altering wounds.

The database has become the gold standard for clinically describing the variations and possibilities in these patients' outcomes. Two years ago, the Department of Veterans Affairs aligned all of the data for its five national polytrauma centers so that staff could compare themselves to private sector facilities. These facilities treat the gravely wounded: Each patient has an injury to more than one organ system.

The VA also began its own research study to create a parallel database that reflected the difference between civilian and combat injuries, accounting for things like embedded shrapnel and infections born of bacteria unique to Afghanistan. Of the more than 50,000 service members wounded in Iraq and Afghanistan who are considered polytrauma patients, 1,600 have moderate to severe brain injuries, 1,400 are amputees, and 900 were severely burned. So far, there are 303 veterans in the new database.

Though Harris and her team are armed with data to benchmark the recovery of their patients, they deploy it judiciously among themselves.

"I don't actually stand at the bedside and say to the family, 'You know, your family member is on the higher end of traumatic brain injury patients, therefore I'm a little less optimistic,'" Harris says. Instead, it's about guiding expectations and directing staff to focus on an evidence-based treatment plan that will, for example, keep a patient on target to recover at the appropriate pace or make measurable improvements in cognition and speech.

Gaal did not know that this data from the experiences of thousands of patients was guiding his recovery, and it's a realization that doesn't make a difference to him. "I knew they were going to give me the help I needed," he says. "They don't need to be up front about it."

***

Dr. David X. Cifu, the VA's director of the physical medicine and rehabilitation program likes to think of the acute and long-term TBIMS data as a roadmap for recovery.

Staff at polytrauma centers, for example, can plug in seven factors and get a patient's expected length of stay at a rate that Cifu says is about 50 percent accurate. Those might seem like lousy odds, but for a patient with a TBI, an amputation and severe burns, knowing how you compare to 10,000 people who have had similar injuries is something tangible.

It also allows hospital staff and families to begin immediately planning for that projection. If there's a setback, like a seizure or an infection, both groups can rally around the road map, using it as motivation for realigning the patient with his treatment plan. Cifu says the staff will remind a service member whose confidence or determination has flagged that pain brings recovery: "If you struggle harder, tomorrow will be better, and we're going to keep laying on more struggle."

Gaal knows this well. He was motivated, privately setting goals outside of physical therapy sessions and exercising in the gym or his room. He drew on old basketball workouts to improve his core strength. He remained a fighter, but there were often moments of despair.

One day he refused to attend a groundbreaking ceremony attended by VA Secretary Eric Shineski on the hospital's grounds. Gaal couldn't yet independently move himself from the bed to a wheelchair and cited that as part of his reluctance. The center's program director, Pawan Galhotra, and social work supervisor, Scott Skiles, safely transferred him by the sheet of the bed to his wheelchair and escorted him out. "They pushed me," Gaal says. "They wouldn't allow me to sit around in my room and sulk about anything."

Galhotra, who came to the VA from the private sector, says this diligence is necessary: "It's very important to emphasize that because we have resources doesn't mean we can sit back and say we're resource rich. I constantly challenge the team to say how are we pushing this individual forward."

***

Gaal with John Elway at a San Diego Chargers game during an event for wounded warriors in 2012

In the last fiscal year, 92 percent of the patients at the Palo Alto center were discharged to a non-institutional setting, outpacing the national average by nine points. The typical length of stay is longer

than for TBIMS patients, but the VA's charges have unique injuries and also are covered by government insurance that does not set arbitrary limits on hospitalization. (The average cost of the first year's care for a polytrauma patient is $136,000.)

Where the center really shines, Harris says, is its functional independence measure (FIM) at discharge, an 18-item scale that measures rehab progress. Palo Alto's FIM is 120 compared to an average TBIMS score of 93.

Cifu acknowledges that the Palo Alto center is "ahead of the curve," thanks in part to Harris' intimate knowledge of the data. The goal, he says, is to use these means and help driven patients and their families create a new normal.

"Even when they can climb mountains, they're not exactly the same as they were before," he says. "This is not Hollywood. If you've lost a limb, you've lost a limb."

Gaal is energized by the possibilities of his future. He could play wheelchair basketball, but prefers to focus on his new passion for rowing. Though he's heartbroken at the prospect of never again leading a crew of men into combat, as an emergency services dispatcher, he'd be responsible for people's lives -- a duty he relishes.

If he's held onto anything of his former life, it's the sense of mission that guided his recovery: "My Marines have been a huge part of my way of getting through this. If I quit, what does that show them? They know me as this person before, so they're not going to see me give up."

Early vs. Late Treatment of Traumatic Brain Injury

A position paper of the
Brain Injury Association of America

August 2009

Brain Injury Association of America

Acknowledgements

The Brain Injury Association of America gratefully acknowledges the authors of this position paper: Mark J. Ashley, Sc.D., CCC-SLP, CCM, CBIS, Gregory J. O'Shanick, M.D., and Lisa A. Kreber, Ph.D., CBIS.

The Board of Directors of the Brain Injury Association of America adopted this position paper at its meeting on August 28, 2009, in Chicago, IL. The Association will continue to review the topic of early versus late treatment as medical and public policy progress dictate.

Electronic copies of this statement may be obtained from the Brain Injury Association of America's Web site: http://www.biausa.org.

The paper may be cited as follows:
Ashley, M, O'Shanick, G, Kreber, L. *Early vs. Late Treatment of Traumatic Brain Injury.* Vienna, VA: Brain Injury Association of America, 2009.

Early vs. Late Treatment of Traumatic Brain Injury

Anecdotal case reports regarding the dramatic effectiveness of rehabilitation following brain injury have largely centered on those few individuals where financial constraints were not an issue. The phenomenal return to broadcast journalism by Bob Woodruff of ABC News following a severe brain injury reflects the medical rehabilitation outcomes possible in the 21st century when seamless and timely acute neurotrauma care and medical rehabilitation is provided to the individual. For the vast majority of U.S. citizens, this opportunity does not exist. Financial and access to treatment constraints imposed by third party payers preclude best outcomes from being realized. The existence of "Bob Woodruffs" in the world represents the recovery of outcome attainable in today's system of brain injury treatment as a result of decades of neuroscientific research.

In a healthcare environment focused on cost containment, treatment following brain injury face time and intensity constraints imposed by third party payers. A clear trend toward earlier discharge from any phase of rehabilitation intervention currently exists, whether hospital or non-hospital based. Existing outcome literature reflects these disturbing trends. Re-hospitalization rates increased from 14.8% in 1994 to 18% in 1998 for people with disabilities most likely reflecting such treatment constraints.[1] More significantly, mortality rates at 80 to 180 day follow-up increased more than fivefold in the seven year period from 1994 (0.9%) to 2001 (4.7%).[1]

Significant financial investment beginning in the late 1970s by the Federal government and private foundations improved mortality rates from severe brain injuries through aggressive acute neurotrauma management and physiologic stabilization. With that increase in survivability came the need for a more comprehensive approach to neurorehabilitation. The field of postacute rehabilitation for brain injury had its origins during that period of time when the length of stay in acute rehabilitation settings for patients with brain injury lasted months. While clinical wisdom at the time was that recovery was complete at 6 months post injury, data mined from the Traumatic Coma Bank in the 1980s defined a window of opportunity for recovery that was far longer.

Despite advances in the acute salvaging of lives and neuroscientific understanding of the potential for neurogenesis and repair following brain injury, trends to reduce lengths of stay for acute hospitalization and rehabilitation continued. Early data from the TBI Model Systems project placed acute hospital LOS in 1990 at 29 days and rehabilitation hospitalization LOS at 48 days.[2] By 1995, acute LOS was reduced to 20 days and one year later reduced again to an average of 16 days while the average LOS for rehabilitation hospitalization decreased to 29.49 days.[2] Over that time period, brain injury severity and incidence remained constant.

Commercial and government sponsored health insurance coverage provide inadequate and restrictive access to treatment following brain injury. The projected financial risk of an insurer for the lifetime care of a person disabled by brain injury impacts treatment benefits provided for the insured. If no long-term responsibility for care exists, acute care and rehabilitation benefits are more limited. For example, a full continuum of rehabilitation exists across the country to provide the workers' compensation insurance sector a mechanism to maximally reduce long-

term financial risk arising from the fact that due to disability these carriers have a contractual liability for lifetime care costs. Conversely, the absence of similar long-term contractual liability in the health insurance sector incentivizes this sector to prohibit access to treatment.

Approximately, two-thirds of all individuals who are hospitalized for their brain injury, are discharged home with no further medical rehabilitative treatment.[3] As patients are discharged from hospital care to home settings, most policies prohibit admission to intensive residential rehabilitation once the patient is discharged to home. Thus, the intensity and less specialization of expertise is not made available to these patients, leaving them with much less intense and specialized outpatient services or no treatment at all, resulting in greater long-term disability and less functional independence. In some instances, policies further restrict access to rehabilitation by arbitrary limits averaging LOS of 30 or 60 days, and/or disallow payment to non-hospital based facilities. As a consequence, patients are denied treatment, do not recover as completely or as rapidly resulting in a lower likelihood of achieving their maximum potential for independence and vocational or academic return. The long-term financial liability of this needlessly heightened disability is transferred to the public sector in the form of medical, housing, income or other assistance.[4]

The vast majority of individuals discharged from the hospital following brain injury are discharged home with no further rehabilitative treatment. [3] Unfortunately, these individuals are at a greater risk for re-injury and re-hospitalization due to unresolved physical and cognitive deficits. Additionally, caregivers may not be educated or equipped enough to provide the level of supervision and care that is necessary following brain injury.

Outcome studies have measured the impact of comprehensive rehabilitation by comparing patient independence as a function of early versus later access to medical treatment and postacute residential rehabilitation for brain injury. In one study, Ashley and Persel [5] longitudinally followed 511 patients with closed (89%) or open (11%) head injuries, ranging in age from 6 to 77 years. The sample was comprised of 83% males and 17% females with time from injury to admission to postacute residential rehabilitation (chronicity) ranging from 5 days to 24.4 years. Mechanism of injury was as follows: MVA: 51%; falls: 40.1%; gunshot wounds: 3.8%; and other: 4.4%. Treatment consisted of physical, occupational, speech, counseling and educational therapies up to 6 hours per day, 5 days per week on a one-to-one therapist to patient basis. Additional inpatient structured therapy was conducted in the residential setting during the mornings, evenings, and weekends with therapy initially conducted on a one-to-one basis until sufficient self care skills developed to enable a lesser level of intervention.

Retrospective analyses of differences in cost, length of stay (LOS) and Disability Rating Scale (DRS) score changes from admission to discharge were calculated for patients grouped by chronicity: less than 6 months, 6-18 months and greater than 18 months. While no statistically significant differences existed across groups for age, the early group (less than 6 months) had statistically significant lower LOS and program costs than the other two groups. The later two groups were not significantly different from each other for age, LOS or program cost. All groups showed statistically significant improvement in the DRS, level of supervision required and occupational status from admission to discharge. Between group differences were not found on admission DRS or occupational status. However, there were differences between the three

groups for admission level of supervision. Supervision decreased with chronicity. Discharge differences between the groups were found for DRS, level of supervision and occupational status between the shortest chronicity group and the later two groups only.

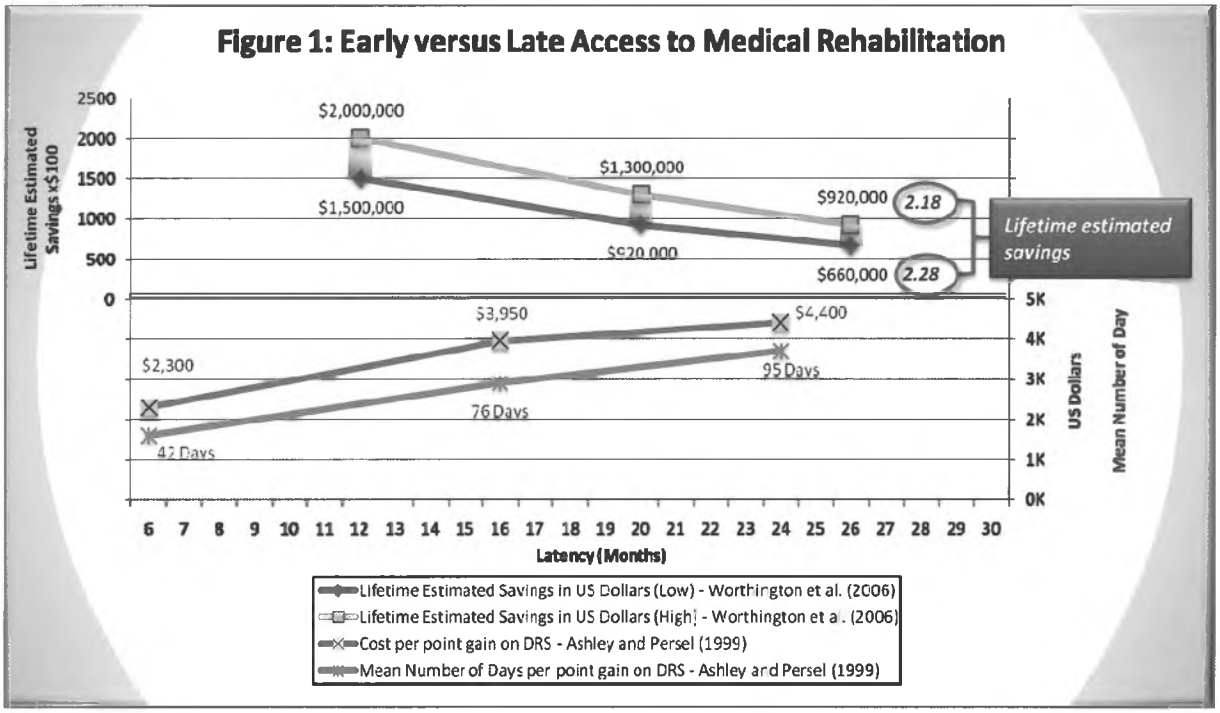
The authors reported the actual cost of increasing level of independence at discharge as reflected by number points of improvement on the DRS. The mean number of days per point improvement on the DRS was 41.87 days (<6 months), 76.32 days (6-18 months) and 95.30 days (18 months). Our analysis of this data showed that the later treatment group required 2.28 times more time per point improvement on the DRS than the less than 6 months group. The cost per point improvement on the DRS was $23, 283.78 for the less than 6 months group, $34,499.14 for the 6-18 months group and $44,175.00 for the greater than 18 months group. Our analysis of the data showed that delaying treatment for more than 18 months resulted in a 1.89 fold greater expense when compared to those receiving rehabilitation less than 6 months post-injury. Ashley and Persel [5] further provided data showing change in ranked level of required supervision from admission to discharge for the three groups: less than 6 months experienced as change of 4.53; 6-18 month had a change of 2.6 and the greater than 18 months group had a change of 1.67. Our analysis of this data showed the early group achieved 2.7 times greater reduction in ranked levels of required supervision than the latest group.

Wood et al [6] reviewed the clinical and cost effectiveness of postacute neurobehavioral rehabilitation for 76 patients with brain injury who had spent at least 6 months in rehabilitation prior to the study. The average age of the group was 27 years, 57 were male and 19 were female. Causes of brain injury included motor vehicle accident (N=48); fall (N=7); assault (N=3); intracranial haemorrhage (N=12); hypoxia (N=1); encephalitis (N=1) and other (N=4). Time since injury averaged 72.83 months and length of rehabilitation delivered after the initial 6 months of rehabilitation was 14.32 months. Patients were grouped by time since injury into three groups: 0 to 2 years; 2 to 5 years; and more than 5 years. Retrospective analysis compared mean hours of care required per day pre-admission versus that needed at follow-up post discharge. A reduction in mean pre-admission to follow-up care requirements was noted across all groups: 22.8 versus 10.39 hours (0-2 years group); 19.88 versus 13.25 hours (2-5 years group); and 21.25 versus. 16.67 hours (over 5 years group). When determining if a proportion exists between the hours of care per day and the time from injury to admission into rehabilitation, it was discovered that when the early group (0-2 years) is compared to the average of the other groups (2-5 years and over 5 years), 1.88 times more hours of care per day were required in these groups than in the early group (0-2 years). Comparison of the latest group (over 5 years post injury) to the earliest group (0-2 years post-injury) demonstrated that the latest group required 2.71 times more hours of care than the early group.

Worthington et al [7] reviewed cost-benefits associated with neurobehavioral rehabilitation following brain injury for 133 patients of whom 101 were male. Etiology of injury was comprised of 33.8% MVA, 9% falls, 8.3% assault, 18% intracranial hemorrhage/CVA, 16.6% hypoxia/hypoglycemia, 8.3% encephalitis, 3% neoplasm and 3% other. Average age was 26.4 years, coma duration averaged 14 days, time since injury averaged 96 weeks, and rehabilitation length of stay averaged 20 weeks. The patients were grouped according to time since injury at the time of admission to rehabilitation into three groups: less than 1 year, less than 2 years, and greater than 3 years. When the influence of early versus later access to rehabilitation was

compared to the estimated lifetime care cost savings following rehabilitation, our analysis showed that while all groups realized substantial lifetime cost savings, the earlier groups (less than one year and less than 2 years) saved more than the latest group (greater than 3 years). Lifetime savings costs were 2.2 times greater for the less than one year group than the greater than three years group.

Figure 1: Early versus Late Access to Medical Rehabilitation



Discussion

Indisputable evidence exists as outlined above that early rehabilitation interventions following brain injury are less expensive and more time efficient when compared to rehabilitation that is delayed. Measurement improvement is obtained regardless of how long after the injury the rehabilitation is received, but earlier intervention is less expensive, of higher value and more rapid. A remarkable proportionality emerges upon comparison of the findings of the three primary studies reviewed: Ashley and Persel [5] provide insight into cost per unit of recovery and rate of recovery in the mean cost per point improvement on the DRS and days to achieve one point improvement on the DRS, respectively. Early to late treatment ratios of 1.88 are seen for cost per unit of recovery and 2.28 for rate of recovery, where early treatment is 1.88 to 2.28 times more efficient than late treatment. Further analysis of the Ashley and Persel [5] data revealed an early to late treatment ratio of 2.7 in ranked level of supervision.

The data from Wood et al [6] demonstrate similar proportionality in mean hours of care per day requirements with early treatment being 1.88 times more efficient than late treatment when comparing less than and greater than 2 years time since injury groups. When comparing less than 2 years to greater than 5 years, the efficiency soared to 2.71 times. This ratio compares favorably with that found in the Ashley and Persel [5] data of ranked level of required supervision at 2.7.

Further analysis of the Worthington et al [7] study found remarkably consistent proportionality of efficiency comparing the lifetime cost savings between early and late treatment groups where the early treatment group realized 2.2 times more lifetime cost savings than the late treatment group. Remarkably, three independent studies of different patient groups by unrelated authors show a proportionality in strikingly different outcome measures of cost per unit of recovery, rate of recovery, level of required supervision, required hours of care per day and lifetime cost savings. These data taken together strongly suggest that early rehabilitation can be conducted for essentially two times (1.88) less cost, can achieve roughly twice the rate of recovery (2.28), can reduce level of required supervision and hours of care per day by half or more (1.88 to 2.71), and can produce approximately two times (2.2) more lifetime cost savings than late rehabilitation.

The implications for these findings are striking. First, these studies provide objective evidence that rehabilitation provided more than 2 years post injury is effective in reducing disability, reducing care and supervision needs and achieving substantial lifetime cost savings. Turner-Stokes et al [8] reviewed this specific issue and demonstrated that rehabilitation with patients longer than 2 years post injury could not only achieve these improvements but that the cost of rehabilitation could be reliably recouped in annual cost of care savings within the first two years post treatment.

Second, the current practice of severely truncated lengths of stay at hospital and non-hospital based rehabilitation venues has no scientific basis and represents misguided clinical and cost containment practice. It is clear that early intervention of sufficient duration provides significant benefits in rate of recovery, cost per unit of recovery, care requirements and reduction of lifetime costs. To that end, payer practices that truncate lengths of stay are ill informed and detrimental to the public welfare as, financial liability is transferred to the public sector, unnecessarily burdening that system with substantially higher long-term costs. Turner-Stokes et al [8] conclude that policies that arbitrarily restrict treatment to specific time periods likely increase the overall cost of care rather than contain costs.

These findings provide convincing support for policy change relative to the manner by which rehabilitation treatment following brain injury is approached, authorized, and delivered. True cost efficiency has been and remains founded in early, intensive and effective rehabilitation following brain injury.

References

1. Ottenbacher K, Smith P, Illig S, Linn R, Ostir G, Granger C. Trends in length of stay, living setting, functional outcome, and mortality following medical rehabilitation. JAMA; 292: 1687-1695.

2. Kreutzer J, Kolakowsky-Hayner S. Charges and lengths of stay for acute and inpatient rehabilitation treatment of traumatic brain injury 1990-1996. Brain Injury 2001; 15: 763-74.
3. Mellick D, Gerhart K, Whiteneck G. Understanding outcomes based on the post-acute hospitalization pathways followed by persons with traumatic brain injury. Brain Injury 2003; 17 (1): 55-71.

4. Brain Injury Association of America. TBI in the U.S.: A Call for Public/Private Cooperation; 2007.

5. Ashley M, Persel C. Traumatic brain injury recovery rates in post-acute rehabilitation of traumatic brain injury: Spontaneous recovery or treatment? Journal of Rehabilitation Outcomes and Measurement 1999; 3 (4): 15-21.

6. Wood R, McCrea J, Wood L, Merrriam R. Clinical and cost effectiveness of post-acute neurobehavioural rehabilitation. Brain Injury 1999; 13 (2) 69-88.

7. Worthington A, Matthews S, Melia Y, Oddy M. Cost-benefits associated with social outcome from neurobehavioural rehabilitation. Brain Injury 2006; 20 (9): 947-57.

8. Turner-Stokes L. Cost-efficiency of longer-stay rehabilitation programmes: Can they provide value for the money? Brain Injury 2007; 21 (10): 1015-21.

ResCare Premier
Dedicated to persons with acquired brain injury

ResCare Premier Texas

Press Release

Marcos' Success Story

Marcos is a 28 year old male who suffered a brain injury following an assault on January 13, 2012. He sustained a right occipital skull fracture and multiple hemorrhagic contusions but after 5 days of hospitalization his vital signs were stable and he was neurologically intact so he was discharged home.

At home, Marcos complained of headaches, dizziness, and weakness, in addition to experiencing severe insomnia. His mother began to witness distinct personality changes. Prior to the attack, Marcos had been hard working and easy going but was now hyper vigilant, withdrawn, and angry. He experienced paranoia, particularly in crowded spaces, became anxious in unfamiliar territory, and isolated to avoid these situations. The effect of the trauma was overwhelming his ability to cope, causing significant impairment in his social and occupational areas of functioning. Marcos was exhibiting the classic symptoms of PTSD.

Marcos was admitted to ResCare Premier's cognitive behavioral program in September, 2012. In addition to medication and individual counseling, exposure therapy/desensitization was utilized as a psychotherapeutic intervention. Without any danger, Marcos was carefully and gradually exposed to the very situations he feared in order to overcome his anxiety. Relaxation techniques were taught to help him manage his stress effectively. He was given a self rating scale to monitor his level of anxiety before, during, and after activities and was encouraged to use the various coping mechanisms he had learned to calm himself. Once Marcos became comfortable in one scenario, he would identify a more challenging situation in which to engage. Upon admission, Marcos experienced extreme anxiety in any circumstance involving more than a handful of people. His final triumphant was attending a Spurs basketball game with thousands of people in attendance.

Today Marcos is back in his home community, has returned to his former job, and he and his fiancée have joy in their life again and hope for the future.

About ResCare Premier Texas
ResCare Premier Texas is a unique group of interrelated treatment facilities that together form a comprehensive continuum of care for individuals with brain injury and other neurological disorders. Our programs specialize in behavioral management, community-based rehabilitation, and long-term support services. Since 1978, ResCare Premier Texas has served over 2000

individuals with brain injury and other neurological disorders from across the United States, Canada and Guam.

ResCare Premier is an in-network provider for Paradigm, BC/BS of Texas, and many other national health care insurance companies and Workers' Compensation insurers, as well as the Department of Labor. In addition, ResCare Premier Texas is among the programs selected by the Veterans Administration (VA) to participate in the Assisted Living Pilot Program for Veterans with Traumatic Brain Injury.

ResCare Premier Texas
800.28.BRAIN
www.rescarepremiertexas.com

Beth Hearne
Director of Admissions
bethmhearne@rescare.com

Forward email

BRAIN INJURY ASSOCIATION OF AMERICA

1608 Spring Hill Road | Suite 110 | Vienna, VA 22182
Phone: (703) 761-0750 | Fax: (703) 761-0755
www.biausa.org

THE VOICE OF BRAIN INJURY

Determining an Essential Benefits Plan for Rehabilitation and Habilitation Services and Devices: A Value-Based Approach

Rehabilitation, habilitation services and devices were included in the essential benefits package because they are consistent with the Affordable Care Act's focus on value, namely, achieving better outcomes at less overall cost.

The outcomes of rehabilitation and habilitation services and devices are consistent with core American values because they enable people to:

- Maximize independence in the least restrictive environment;
- Live active and productive lifestyles that embrace family, work, education, and community; and
- Avert medical complications and minimize hospital readmissions.

These outcomes are important to individuals, families, and society. By promoting these outcomes, overall health care costs can be reduced, and thus provide significant value to American taxpayers.

The organizations listed below have developed and unanimously support this document and believe that, in order to achieve these outcomes, a number of guiding principles need to be incorporated into rehabilitation and habilitation services and devices benefits design. They include:

1. Medically necessary services in habilitation and rehabilitation services and devices (1) promote medical recovery, (2) enhance and maintain function, (3) promote participation in life roles and activities, (4) avert medical complications, and (5) assist in learning, improving and acquiring skills. Enhancing and maintaining function is essential to maintaining health and averting medical complications.
2. Rehabilitation, habilitation, and prosthetic/orthotic, assistive and adaptive devices should be provided by qualified professionals as defined by State and/or National standards for their respective professions.
3. There should be no arbitrary limits or caps on medically necessary services.
4. Services may be delivered across a variety of care settings based on the individual needs and may include inpatient, outpatient, post-acute, day program, and residential settings. These services may also include the use of durable medical equipment, prosthetics, orthotics, supplies and assistive and adaptive devices that improve or maintain function.
5. Each Exchange Plan should develop an objective appeal process to address the denial of care determined to be appropriate by qualified professionals. The appeal should be reviewed by individuals with demonstrated expertise in rehabilitation, habilitation services and devices.
6. Essential benefits should reflect an appropriate range and balance of care from a variety of professions as indicated by patient need.
7. Benefit design should not discriminate against any individual due to disability, age, gender, religion, race, veteran's status, sexual orientation/gender identity or for any arbitrary reason.

8. Benefits and services should be informed by the best available evidence, professional expertise and consensus, and patient values and preferences.

9. There should be mechanisms to update the coverage of rehabilitation and habilitation services and devices based on new clinical evidence.

The following organizations, representing a broad consensus in the field of rehabilitation, developed and support these guidelines.

Academy of Spinal Cord Injury Professionals
American Academy of Orthotists and Prosthetists
American Congress of Rehabilitation Medicine
American Music Therapy Association
American Occupational Therapy Association
American Physical Therapy Association
American Psychological Association (Division 22) (Rehabilitation Psychology)
American Speech-Language-Hearing Association
American Spinal Injury Association
American Therapeutic Recreation Association
Amputee Coalition of America
Association of Rehabilitation Nurses
Brain Injury Association of America
CARF International
Insurance Rehabilitation Study Group
National Association of Social Workers
National Association of State Head Injury Administrators
North American Brain Injury Society
United Spinal Association

DEFINING "REHABILITATIVE AND HABILITATIVE SERVICES AND DEVICES" IN THE ESSENTIAL HEALTH BENEFITS PACKAGE PURSUANT TO CONGRESSIONAL INTENT UNDER THE AFFORDABLE CARE ACT

On March 23, 2010, President Obama signed into law the Patient Protection and Affordable Care Act (ACA—H.R. 3590, also known as Pub. L. No. 111-148). One week later, on March 30th, he signed a reconciliation bill, the Health Care and Education Reconciliation Act of 2010 (HCERA—H.R. 4972, also known as Pub. L. No. 111-152) that modifies Pub. L. No. 111-148. *The law provides for the implementation of an essential health benefits package that must be offered through new state insurance exchanges.*

This package of benefits was designed by Congress to meet the needs of all Americans, including people with disabilities and chronic conditions, by guaranteeing access to medically necessary treatment. A critical aspect of this overarching policy is the inclusion of "rehabilitative and habilitative services and devices" in the statute as a category of essential health benefits. This category of benefits has profound implications on the ability of the private insurance system to meet the needs of people with disabilities and chronic conditions and, therefore, appropriate regulations related to this provision in the new law are critically important.

Congressional intent can be clearly identified in the legislative history with respect to the meaning of the term, "rehabilitative and habilitative services and devices." Although there are no committee reports associated with passage of health care reform, there are floor statements by members of Congress that are helpful in examining the meaning of the terms in the statute. This white paper comprises suggested recommendations from the American Academy of Physical Medicine and Rehabilitation (AAPM&R) regarding what must be included in the essential benefits package as it relates to rehabilitation and habilitation services and devices.

AAPM&R's Approach

As specialists in physical medicine and rehabilitation (PM&R) we must play a pivotal role in advocating for an essential benefits package that includes quality patient care and represents the interests of all patients with, or at risk for, temporary and/or permanent disabilities and/or functional impairments.

AAPM&R has been actively monitoring the current national dialogue on an essential benefits package. This document specifically addresses the issues of critical importance for the medical rehabilitation provisions of the package that are reflective of the uniqueness of the specialty and

aaPM&R
American Academy of
Physical Medicine and Rehabilitation
Physicians Adding Quality to Life®
9700 W. Bryn Mawr Ave., Suite 200
Rosemont, Illinois 60018
phone 877/AAPMR 99
info@aapmr.org www.aapmr.org

the patients we serve. For guidance with this process, we looked to our Academy mission statement and core purpose.

Mission Statement

The American Academy of Physical Medicine and Rehabilitation (AAPM&R) serves its member physicians by advancing the specialty of physical medicine and rehabilitation, promoting excellence in physiatric practice, and advocating on public policy issues related to persons with disabling conditions.

Core Purpose

To advance our members' ability to serve patients

AAPM&R is pleased to offer its support and recommendations to the U.S. Department of Health and Human Services on the essential benefit package as it relates to medical rehabilitation and habilitation services and devices.

As a preface to our recommendations, it should be noted that the benefits herein are geared toward the goal of making Americans as healthy, functional, and independent as possible. In the long run, this decreases the dependence on government subsidies, helps to keep people in the workforce, and decreases the need for further medical interventions. In addition, we respect the Americans with Disabilities Act and its goal to provide access and prevent discrimination against people with disabilities.

We recognize that there must be a determination made as to when services are necessary as all patients with certain diagnoses may not require all services. There must be a review process for any services/treatments/procedures/devices the treating physician deems necessary that may be denied by a payer. While criteria (guidelines) need to be developed, the limitations of an ICD-9 (or ICD-10) type of numeric coding system must be recognized. Two patients with the same diagnosis code may require vastly different treatments and services and for that reason, any diagnosis code-based guidelines must only be guidelines, preserving the physician's ability and judgment to deviate in the best interests of the patient (and society which has a stake in the successful rehabilitation and return to work/productivity). AAPM&R stands ready to assist the Department by providing medical experts to help review cases as well as review related guidelines.

aaPM&R
American Academy of
Physical Medicine and Rehabilitation

Physicians Adding Quality to Life®

9700 W. Bryn Mawr Ave., Suite 200
Rosemont, Illinois 60018
phone 877/AAPMR 99
info@aapmr.org www.aapmr.org

This white paper specifically addresses the following areas:

- The importance of rehabilitative and habilitative services and devices to people with disabilities and chronic conditions, and society as a whole;
- The scope of the definition of rehabilitative and habilitative *services*;
- The scope of the definition of rehabilitative and habilitative *devices*;
- Required elements for consideration in defining the essential health benefit package; and
- Patient protections, the treatment continuum, and the provision of health care benefits in the appropriate setting by qualified providers and suppliers.

I. The importance of rehabilitative and habilitative services and devices to people with disabilities and chronic conditions, and society at large.

In 1998, the President's Commission on Consumer Protection and Quality in the Health Care Industry issued its final report where it defined the purpose of the health care system. The report stated:

> "The purpose of the health care system must be to continuously reduce the impact and burden of illness, injury, and ***disability***, and to improve the health ***and functioning*** of the people of the United States."

For many people with disabilities and chronic conditions, rehabilitative and habilitative services and devices are equivalent to the provision of antibiotics to a person with an infection—both are essential medical interventions. Thus, rehabilitative and habilitative services and devices are an integral component of health care, especially for persons with disabilities and chronic conditions. With respect to an individual with a disability or chronic condition, rehabilitative and habilitative services and devices:

- Speed recovery (better outcomes and enhanced likelihood of discharge to one's home, living longer and retaining a higher level of function post injury or illness);
- Improve long-term functional and health status and improve the likelihood of independent living and high quality of life;
- Reduce the likelihood of relapse and rehospitalization;

- Halt or slow the progression of primary and secondary disabilities (maintain functioning and prevent further deterioration); and
- Facilitate return to work in appropriate circumstances.

For example, medically necessary rehabilitative and habilitative services and devices:

- Enable persons with spinal cord injuries to recover and regain functions through intensive rehabilitation services and the use of appropriate wheeled mobility;
- Enable persons born with congenital conditions or developmental disabilities to acquire skills and the ability to function through habilitation therapies and assistive devices;
- Enable amputees to walk, run, work and fully function using an artificial limb;
- Enable persons with a traumatic brain injury to improve cognition and functioning through appropriate therapies and assistive devices.

Evidence-based literature and individual testimonials demonstrate that when people with disabilities and chronic conditions have access to a continuum of medically necessary and appropriate treatments, including rehabilitative and habilitative services and devices, their health and quality of life are substantially improved and both patients and insurers, as well as taxpayers, save significant dollars of future health care costs. According to the Brain Injury Association of America, The consequences of inadequate rehabilitative and habilitative services and devices for individuals with disabilities and chronic conditions and society are also well known. Inadequate rehabilitative and habilitative services and devices often result in higher levels of medical complications, permanent disability, family dysfunction, job loss, homelessness, impoverishment, medical indigence, suicide and involvement with the criminal or juvenile justice system. Inadequate treatment also leads to lost productivity and greater utilization of publicly-funded income maintenance programs (such as SSI and SSDI), publicly financed health care programs (such as Medicare and Medicaid), long-term care, and institutionalization."

Covered health benefits should enable individuals to be healthy, functional, live as independently as possible, and participate in the community. Essential rehabilitation and habilitation services must include services and devices that improve, maintain, and lessen the deterioration of a person's functional status over a lifetime and on a treatment continuum.

aaPM&R
American Academy of
Physical Medicine and Rehabilitation

Physicians Adding Quality to Life®

9700 W. Bryn Mawr Ave., Suite 200
Rosemont, Illinois 60018
phone 877/AAPMR 99
info@aapmr.org www.aapmr.org

II. The Scope of the Definition of Rehabilitative and Habilitative *Services*.

The ACA specifies that the term "essential benefits package" means coverage that provides for the essential health benefits defined by the Secretary. [See Section 1302(a) of the ACA.] The Secretary must define essential health benefits to include a list of statutorily-mandated general categories. One category listed in the statute is "rehabilitative and habilitative services and devices." This general category implies coverage of a full spectrum of rehabilitation care, including services such as immediate post-operative, intensive, inpatient hospital rehabilitation to outpatient rehabilitation therapies provided in a variety of settings. It also includes under the term "habilitation," which means ongoing, medically necessary, therapies provided to children with developmental disabilities and similar conditions who need habilitation therapies to achieve functions and skills never before acquired.

Congressional intent involving the definition of the term "rehabilitation and habilitation services and devices" can be seen in a floor statement offered by Congressman George Miller, the Chairman of the House Committee on Education and Labor during the passage of the Affordable Care Act. He explained that the term rehabilitative and habilitative services "includes items and services used to restore functional capacity, minimize limitations on physical and cognitive functions, and maintain or prevent deterioration of functioning. Such services also include training of individuals with mental and physical disabilities to enhance functional development." [Congressional Record, H1882 (March 21, 2010).]

Similarly, Congressman Pascrell, co-chair of the Congressional Brain Injury Task Force, included the following in his House floor statement: "The term rehabilitative and habilitative services includes items and services used to restore functional capacity, minimize limitations on physical and cognitive functions, and maintain or prevent deterioration of functioning as a result of an illness, injury, disorder or other health condition. Such services also include training of individuals with mental and physical disabilities to enhance functional development." [Congressional Record, E462 (March 23, 2010).]:

These statements of congressional intent reflect an evidence-based understanding of the medical necessity of rehabilitative and habilitative services for individuals with disabilities and chronic conditions. Evidence indicates the need to focus on services that are designed to assist people with disabilities acquire self-help, socialization, and adaptive skills, and to restore function, maintain functioning as well as prevent deterioration in functioning. For example, rehabilitative services for degenerative conditions such as multiple sclerosis may have an outcome of slowing the

progression of the effects of the condition. A child with cerebral palsy may need ongoing physical therapy to prevent muscle contractures (i.e., functional deterioration) in his arm that is used to operate the joy stick on his electric wheelchair. Absent therapies, he may lose completely the use of his arm and, therefore, his ability to be independently mobile.

Consistent with congressional intent, it is inappropriate to deny coverage merely because rehabilitative services may not lead to immediate and consistent results, or prevent a condition from worsening. Recovery is not necessarily a linear process. It may appear that progress toward an outcome is not being made, when in fact, a plateau or relapse may be part of the natural progression of recovery. This is particularly indicative of traumatic brain injury and relapsing and remitting neuromuscular conditions.

III. The Scope of the Definition of Rehabilitative and Habilitative *Devices*.

Congressman George Miller, the Chair of the Committee on Education and Labor, also explained in his House floor statement during passage of the Affordable Care Act that the term rehabilitative and habilitative devices "include durable medical equipment, prosthetics, orthotics, and related supplies." "It is my expectation," he further stated, "that 'prosthetics, orthotics, and related supplies' will be defined separately from 'durable medical equipment.' I also expect that durable medical equipment will not be limited to 'in-home' use only." [Congressional Record, H1882 (March 21, 2010)]; See also a similar statement by Congressman Pascrell, Co-chair of the Congressional Brain Injury Task Force [Congressional Record, E462 (March 23, 2010)].

Chairman Miller went on record to state his belief that "rehabilitation services and devices" includes durable medical equipment, prosthetics, orthotics and related supplies ("DMEPOS") because that is the specific language that was adopted in the House bill. House staff at the time confirmed that the Congressional Budget Office did not view this more specific language as "costing" any more than coverage of "rehabilitation and habilitation services and devices" would have cost because the benefit package models being used by CBO to calculate the bill's cost included these services and devices anyway. Because of this, Chairman Miller went on record to state that even though the Senate language on rehabilitation services and devices was ultimately adopted in the final negotiations on the ACA, DMEPOS was clearly intended to be covered in the essential benefits package.

Chairman Miller's statement that "I expect that durable medical equipment will not be limited to 'in-home' use only" is important because currently CMS defines durable medical equipment for Medicare purposes with a phrase that has been misinterpreted for years, i.e., that DME coverage is

limited to use "in the patient's home." This phrase was originally intended to establish separate payment under Part B of the program for DME covered outside of an institution such as a hospital reimbursable under Part A. This misinterpretation of the Medicare statutory provisions currently restricts Medicare coverage of wheelchairs and other mobility devices that are also necessary for use outside of the patient's home.

Beneficiaries with disabilities that would primarily utilize a wheelchair outside the home are prevented from receiving the most appropriate medical equipment to meet their needs under the Medicare program. For example, the "in the home" restriction prevents Medicare beneficiaries from receiving wheelchairs to be able to access medical appointments, the pharmacy, places of worship, schools, and even to vote or go to work and be employed taxpayers. Policies such as these contradict President Obama's community integration initiative and other public policies such as the most integrated setting provisions of the Americans with Disabilities Act, as interpreted by the Supreme Court in the Olmstead decision. The definition of durable medical equipment under the Medicare program or covered by the essential benefits package should not refer to "in home" use in any manner.

Chairman Miller's floor statement also demonstrated explicit Congressional intent that the terms "durable medical equipment" and "prosthetics and orthotics" should be defined separately in health plan benefit policies. This is because these benefits are separate and distinct, use different treatment models, and are two completely separate fields of health care. Prosthetics and orthotics are highly customized and clinically intensive and should be distinguished from DME for purposes of comparing benefit package components within private health insurance plans.

"Prosthetics" are comprised of artificial legs, arms, and eyes while "orthotics" includes leg, arm, back and neck braces. Prosthetic devices include devices which replace all or part of the function of an internal body organ and include devices that are surgically inserted, devices that are physically attached to the body such as colostomy bags and supplies directly related to colostomy care, and external devices, including replacement of such devices.

"Supplies" include accessories and supplies which are used directly with equipment or devices to achieve the therapeutic benefits of such equipment or devices or to as assure the proper functioning of such equipment or devices.

The category of rehabilitative and habilitative devices also includes replacement of such equipment or devices when required in cases of loss, irreparable damage, wear, or because of a change in the patient's condition; repair and maintenance of such equipment and devices; and fitting (including adjustments) and training for use of these items is also included. Of course, a

aaPM&R
American Academy of
Physical Medicine and Rehabilitation

Physicians Advancing Quality of Life

9700 W. Bryn Mawr Ave., Suite 200
Rosemont, Illinois 60018
phone 877/AAPMR 99
info@aapmr.org www.aapmr.org

rehabilitative or habilitative device is covered only if it improves functional ability or prevents or minimizes deterioration in function.

IV. Required Elements for Consideration in Defining Essential Health Benefits.

Extending life, reducing disability, improving functioning, decreasing pain and savings to the community should all be considered when evaluating essential benefit mandates.

The provisions in the ACA specify that in defining essential health benefits, the Secretary must ensure that such essential benefits reflect an "appropriate balance" among the categories so that benefits are not unduly weighted toward any category. This provision also requires parity in the provision of all categories of benefits. [See Section 1302(b) (4) (A) of the ACA.] Thus, those with disabilities and chronic conditions who need rehabilitative and habilitative services and devices should not be hampered by unreasonably restrictive coverage policies in their ability to access appropriate treatment.

In addition, the Secretary may not make coverage decisions, determine reimbursement rates, establish incentive programs, or design benefits in ways that discriminate against individuals because of, among other things, disability. [See Section 1302(b) (4) (B) of the ACA.] Further, the Secretary must take into account the health care needs of persons with disabilities, among other segments of the population. [See Section 1302(b) (4) (C) of the ACA.] In addition, the Secretary must ensure that health benefits established as essential are not subject to denial to individuals against their wishes on the basis of the individual's present or predicted disability, degree of medical dependency or quality of life. [See Section 1302(b) (4) (D) of the ACA.]

As Congressman Pascrell explained the impact of these provisions on persons with brain injury and other disabilities and chronic conditions, "Taken together, these are strong protections that will help ensure that the essential health benefits package—that must be offered by all health plans that participate in the new Health Insurance Exchanges—will take into account the needs of people with brain injury and other disabilities and chronic conditions and not impose value judgments about disability and quality of life. The legislative language makes clear that Congress understands the subtle discrimination that can occur against people with brain injury and other disabilities in the area of benefit design." [Congressional Record E462 (March 23, 2010).]

Thus, under the ACA it is inappropriate (i.e., discriminatory) to limit rehabilitative and habilitative services and devices to persons from whom full restoration of functioning is expected; rather these services and devices must be defined so as to provide an opportunity for a patient born with a

congenital condition to acquire functioning and for others to improve, maintain, or prevent deterioration of functioning.

The Secretary must not promulgate a regulation on the essential benefits package that violates existing federal civil rights laws. In addition, federal and state oversight must ensure that health plans are aware of the ADA requirements and do not create plans that violate existing law.

In addition, under the Affordable Care Act's provisions, the Secretary may not make coverage decisions, determine reimbursement rates, establish incentive programs, or design benefits in ways that discriminate against individuals because of, among other things, disability. [See Section 1302(b) (4) (B) of the ACA.] The Secretary must take into account the health care needs of persons with disabilities, among other segments of the population. [See Section 1302(b) (4) (C) of the ACA.] The Secretary must ensure that health benefits established as essential are not subject to denial to individuals against their wishes on the basis of the individual's present or predicted disability, degree of medical dependency or quality of life. [See Section 1302(b) (4) (D) of the ACA.] This is very powerful language that is designed to ensure that normative judgments about the quality of life of a person with a disability are not used against people with disabilities when decision makers determine the essential benefits package.

Prohibiting denial of benefits based on these factors is critical to creating a health care system that meets the needs of people with disabilities and chronic health conditions. Implementing these provisions will help ensure that value judgments about disability and quality of life are not used against people with disabilities in terms of benefit design or access to covered benefits.Benefits should not disproportionately impact people with disabilities because nondisabled persons tend to view services for people with disabilities as less valuable than services for people without disabilities.

Specifically, the rehabilitation and habilitation services and devices category in the essential benefits package must include:

- Rehabilitation therapies and other treatments such as pain management that improve, maintain, and prevent deterioration of function;

- Habilitation therapies or other treatments that enable a person (*e.g.*, a child) with a disability to attain functional abilities or lessen the deterioration of function over time;

- Intensive inpatient hospital rehabilitation that includes conditions other than those comprising Medicare's "60 percent rule." The current rule states that 60 percent of all admissions to an acute inpatient rehabilitation facility must include 13 prescribed

diagnoses. This restriction precludes many patients who could benefit from acute rehabilitation, but do not fall into a specific diagnosis. A qualified rehabilitation physician should make the determination as to who would benefit from acute rehabilitation. This may include cardiac rehabilitation, pulmonary rehabilitation, acute pain management, debility, and other conditions that a physician determines as reasonable or likely to result in functional improvement. Currently, many patients with these diagnoses are excluded from receiving the benefits of acute rehabilitation.

- Outpatient rehabilitation services without an arbitrary cap on benefits that is unrelated to medical necessity. This should include maintenance services (to prevent deterioration), cognitive retraining, adaptive skills training, and other services as determined by a physician to be reasonable and necessary.

- Durable medical equipment, prosthetics, orthotics, mobility equipment, supplies, assistive and adaptive devices that improve or maintain function and do not include arbitrary limits on access to these devices and related services.

- Interventions that are reasonable and when possible, evidence based. It must be recognized, however, that as more patients survive longer and with more medical conditions that become chronic, it becomes increasingly difficult to produce reliable data that supports specific interventions for specific conditions. As more conditions are layered onto each patient, the predictability of the prognosis becomes more challenging and the complex interplay of pathologies can only be fully appreciated by physicians dealing with these situations on a daily basis. When it has been determined that evidence-based interventions have failed or would be inappropriate or harmful and the circumstances of a particular patient are so unique as to not apply to standard policy, with a description of likely consequences if the requested intervention is not undertaken, serious consideration should be given to approving non-evidence based interventions.

These include future technologies that may be developed to assist in the functioning of disabled individuals. Therefore, such equipment, prosthetics, orthotics, mobility equipment, supplies, assistive and adaptive devices should not be limited to "in-home" use only. Maintenance on such devices and equipment as well as replacements (without a lifetime cap) should also be included so as to ensure that the patient will continue to receive the benefits that have been ordered.

Additionally, the following should be considered:

- Updates to the essential benefits package as medical treatments, advances, or scientific achievements are made;

aaPM&R
American Academy of
Physical Medicine and Rehabilitation

Physicians Adding Quality to Life®

9700 W. Bryn Mawr Ave., Suite 200
Rosemont, Illinois 60018
phone 877/AAPMR 99
info@aapmr.org www.aapmr.org

- Appropriate access to medical care, facilities and programs "at a level of intensity that is consistent with the needs of the patient" (Congressman Pascrell Statement for the Congressional Record, March 23, 2010.) This would include acute care hospitals, inpatient rehabilitation hospitals and units, post-acute rehabilitation, residential rehabilitation facilities, day treatment programs, outpatient clinics, home health agencies, and ongoing medical management;

- Since pain has been identified as a major impediment to functioning, the essential benefits package must ensure that all patients have access to appropriate pain interventions, including medication, physical and occupational therapy, psychological and behavioral services, and interventional procedures, as well as payment for physician care, medical procedures, and tests necessary to diagnose the cause of such pain.

V. Patient Protections, Treatment Continuum, and Provision of Benefits in the Appropriate Setting by Qualified Providers and Suppliers.

The ACA includes important patient protections that are designed to permit providers to fully discuss treatment options with patients and their families and permit the patient to render an informed choice as to their course of treatment, including rehabilitative and habilitative services and devices. These patient protections are designed to ensure that the patient receives appropriate medical care and that the health care treatment is available for the full duration of the patient's medical needs. [See Statement by Congressman Pascrell, Congressional Record E463 (March 23, 2010).] Specifically, the Secretary may not promulgate any regulation that:

- Impedes timely access to health care services;

- Interferes with communications regarding the full range of treatment options between patient and the provider;

- Restricts the ability of health care providers to provide full disclosure of all relevant information to patients making health care decisions;

- Violates the principle of informed consent and the ethical standards of health care professionals; or

aaPM&R
American Academy of
Physical Medicine and Rehabilitation

Physicians Adding Quality to Life®

9700 W. Bryn Mawr Ave., Suite 200
Rosemont, Illinois 60018
phone 877/AAPMR 99
info@aapmr.org www.aapmr.org

- Limits the availability of health care treatment for the full duration of a patient's medical needs. [See Section 1554 of the ACA]

In addition, the ACA specifies that a group health plan and a health insurance issuer shall not discriminate with respect to participation in the group or individual health insurance plan or coverage against any health care provider who is acting within the scope of that provider's license or certification under applicable state law. ACA also specifies that health plans to be considered "qualified" by the Secretary must ensure "a sufficient choice of providers (in a manner consistent with applicable network adequacy provisions under section 2702(c) of the Public Health Services Act) and provide information to enrollees and prospective enrollees on the availability of in-network and out-of-network providers" in order to ensure enrollee access to covered benefits, treatments and services under a qualified health benefits plan. [See Section 1311(c) (1) (B) of the ACA.]

Thus, according to Congressman Pascrell "rehabilitative and habilitative services and chronic disease management services must be available from a full continuum of accredited programs and treatment settings at a level of intensity that is consistent with the needs of the patient." [Congressman Pascrell, Congressional Record E463 (March 23, 2010).]

The treatment continuum is comprised of specific facility and specialty program types. Program types include acute care hospitals, inpatient rehabilitation hospitals and units, residential rehabilitation facilities, day treatment programs, outpatient clinics and home health agencies. Acute care hospitals provide acute medical treatment to arrest disease progression in the early minutes and hours after an injury. Acute treatment may be provided in the emergency room, trauma unit, intensive care unit, medical/surgical floor or similar hospital-based location.

Post-acute treatment includes intensive medical rehabilitation services provided in inpatient rehabilitation hospitals and units. Residential rehabilitation and day treatment programs are critical components of this treatment continuum depending on the injury or illness involved. In all of these settings, high quality care should be provided by fully accredited programs. Accreditation (provided by CARF, JCAHO, and other appropriate accreditors) is an important mechanism to measure quality and accountability of health care providers and the services and devices they provide.

Ongoing medical management is also required to achieve lasting medical outcomes, mitigate disease progression and optimize health and function. These services are offered in community-based settings such as medical offices but can also be provided in group homes, supported apartments, or similar living arrangements. It is also critical to recognize that recovery for many

persons with chronic conditions is not necessarily a linear event. For example, brain injury, cancer, asthma, and diabetes may be stable for a period of time and then may become unstable. Persons with brain injury, for example, may attain a plateau in functional restoration prior to entering a secondary recovery phase. For this reason, individuals with certain chronic conditions may need renewed access at any point along the treatment continuum throughout their lives.

Many of the assistive devices, technologies, and therapies used by persons with disabilities to be functional and live independent and fulfilling lives have widespread application and are generally accepted by physicians and other health care professionals. Many of these services and devices do not have a robust evidence base in the traditional sense, especially with respect to treatments for children.

Evidenced Based Practice:

With respect to health coverage, it is important to recognize that disability conditions vary widely in severity and complexity. There are often multiple co-morbid conditions in play and many disabilities are low prevalence, making specific and meaningful clinical effectiveness studies challenging to pursue. Even well-grounded research on the general population can be easily misapplied to the disability and chronic illness populations, especially to persons with intellectual, behavioral and cognitive disabilities. It is critical that the outcomes of such research are not misapplied or used to broadly establish coverage rules that trump an individual's circumstances and specific needs.

Comparative effectiveness and evidence-based medicine should ultimately provide information to doctors and patients that will help guide real-world clinical treatment decisions for the individual patient at the point of care. Such research should be a tool for practitioners, patients and caregivers, not a bright-line decision applied across the board to the "average" patient as a final decision on coverage.

In private plans and public programs that do take these factors into account, the plans ultimately tend to save money by reducing negative health outcomes while meeting the individual patient's unique healthcare needs.

Medical Necessity Definition:

The definition of medical necessity is critical if the essential benefits package is going to be meaningful. Medical necessity does not necessarily mean that the patient's health or function will improve. Even if the intervention of services slows the deterioration of health status or is useful in maintaining health status, services should be considered medically necessary. Medical necessity

aaPM&R
American Academy of
Physical Medicine and Rehabilitation
Physicians Adding Quality to Life®
9700 W. Bryn Mawr Ave., Suite 200
Rosemont, Illinois 60018
phone 877/AAPMR 99
info@aapmr.org www.aapmr.org

should not be a mechanism to intrude upon the patient and physician relationship or interfere with communications regarding the treatment options between the patient and provider.

"Medically Necessary" or "Medical Necessity" should mean health care services that a physician, exercising prudent clinical judgment, would provide to a patient for the purpose of preventing, evaluating, diagnosing or treating an illness, injury, disease or its symptoms, and that are:

(a) in accordance with generally accepted standards of medical practice;

(b) clinically appropriate, in terms of type, frequency, extent, site and duration, and considered effective for the patient's illness, injury or disease;

(c) not primarily for the convenience of the patient, physician, or other health care provider; and

(d) not more costly than an alternative service or sequence of services at least as likely to produce equivalent therapeutic or diagnostic results as to the diagnosis or treatment of that patient's illness, injury or disease.

Medical necessity reviews and appeals should include the following:

- Medical necessity reviews and appeals of rehabilitation and habilitation services and devices should be conducted by a board-certified physiatrist.
- A qualified (board-certified) physiatrist should make the determination as to who would benefit from rehabilitation care. In addition, coverage decisions about durable medical equipment, prosthetics, orthotics, mobility equipment, supplies, assistive and adaptive devices or rehabilitation care should be reviewed by a board certified physiatrist.
- Board-certified physiatrists should be involved in policy development that determines the medical necessity of rehabilitation and habilitation services, and in rendering appeal decisions.

Finally, whatever definition of medical necessity that is used by health plans, it is critically important that the definition does not trump the physician-patient relationship. Deference to the determination of medical necessity should be given to the physician actually treating the patient and such deference should only be overridden if there is evidence that such deference is not appropriate in a given instance. Decisions that challenge this deference and limit health care services based on a lack of medical necessity must be clearly explained in writing to the patient

aaPM&R
American Academy of
Physical Medicine and Rehabilitation

Physicians Adding Quality to Life®

9700 W. Bryn Mawr Ave., Suite 200
Rosemont, Illinois 60018
phone 877/AAPMR 99
info@aapmr.org www.aapmr.org

and must be subject to a timely internal appeal as well as an external, independent review with decisions being binding upon the health plan.

Updating Essential Benefits:
In order to ensure that beneficiaries have access to the most effective and appropriate treatments, services, and devices, the Secretary of HHS should establish an open, public process for the regular review and update of the essential benefits package. The review and update should be performed on a schedule adequate to ensure timely beneficiary access to new interventions without unnecessary delay. The specific schedule for review should be established by the Secretary with provision for making immediate updates to the essential benefits package when important breakthroughs in interventions are developed that promise significantly improved preventive, health, rehabilitative, wellness or functional outcomes for beneficiaries.

This public process should be transparent, unbiased and should be established by formal regulation. It should allow for public comment and permit stakeholder input from consumer and provider organizations and individuals. Official comment periods should be offered for proposed changes to this process that allow for transparency and comment before implementation of any changes that would potentially reduce or limit access to established benefits. Congress would continue to have the ability to amend the ACA statute and provide guidance to the Secretary with respect to implementation of health policy, including policies related to updating the essential benefits package. Finally, an appeals mechanism for essential benefit decisions should be established to ensure due process.

Oversight and Compliance:
To ensure that health plans are complying with this and other requirements related to the essential benefits requirements, the Secretary should establish an oversight system for receiving consumer and provider feedback, collecting and analyzing data, and evaluating plan performance. Collecting information about who is being denied services, what types of services are being denied, and other information will help determine if unacceptable patterns of service denials are developing. The state and federal government need to ensure that a meaningful and independent external appeals program is established. Information about internal appeals and external appeals must be part of the data collection efforts as well. This information will be crucial to evaluating plan performance and ensuring that the plans are meeting the high standards for access, nondiscrimination, comprehensiveness and quality that the ACA establishes.

Extra-Contractual Services:
Insurance policies occasionally use contractual provisions known as "extra contractual services" to cover benefits that may not be explicitly listed in the benefit package, but that are reasonable to

aaPM&R
American Academy of
Physical Medicine and Rehabilitation

Physicians Adding Quality to Life®

9700 W. Bryn Mawr Ave., Suite 200
Rosemont, Illinois 60018
phone 877/AAPMR 99
info@aapmr.org www.aapmr.org

treat a person's condition. The key element of this language is that such services are only covered if they would obviate the need for more expensive benefits that *are* explicitly included in the benefit package. An example might be where a health plan covers safety devices in the bathroom of a person with a history of falling. If coverage of these safety device benefits on an extra-contractual basis would eliminate the need to place that person in a nursing home, the plan may in fact cover that benefit. AAPM&R believes this is an important clause that should be included in the essential benefits package to ensure such flexibility in meeting patients' needs.

People with disabilities of all ages and their families must have access to health care that responds to their needs over their lifetimes, and provides continuity of care that helps treat and prevent chronic conditions. It is critical for all patients to have access to services to address their functional status.

ABOUT AAPM&R

The American Academy of Physical Medicine and Rehabilitation (AAPM&R) is the national medical society representing more than 8,000 physiatrists, physicians who are specialists in the field of physical medicine and rehabilitation. With a focus on restoring function, physiatrists treat adults and children with acute and chronic pain, persons who have experienced catastrophic events resulting in paraplegia, quadriplegia, or traumatic brain injury, rheumatologic conditions, musculoskeletal injuries, and individuals with neurologic disorders such as stroke, multiple sclerosis, polio, amyotrophic lateral sclerosis (ALS) or any other disease process that results in impairment and/or disability. Medicare patients constitute a very large portion of the patients of this specialty and services are furnished in rehabilitation hospitals, skilled nursing facilities, outpatient facilities, and in the physicians' offices. AAPM&R serves its member physicians by advancing the specialty of physical medicine and rehabilitation, promoting excellence in physiatric practice, and advocating on public policy issues related to disabling conditions.

aaPM&R
American Academy of
Physical Medicine and Rehabilitation

Physicians Adding Quality to Life®

9700 W. Bryn Mawr Ave., Suite 200
Rosemont, Illinois 60018
phone 877/AAPMR 99
info@aapmr.org www.aapmr.org

List of References

January 13, 2011 Testimony of Peter W. Thomas, J.D.; Co-Chair, Health Task Force, Consortium for Citizens with Disabilities, Principal, Powers Pyles Sutter & Verville, PC, Washington, DC.

Patient Protection and Affordable Care Act (PPACA—H.R. 3590, also known as Pub. L. No. 111-148); Sections 1554, 1311, 1302 and 1001, March 23, 2010.

The Public Health Services Act (implemented by 45 CFR 144.103), Section 2702(c)

Congressional Record, E462 (March 23, 2010).

Health Care and Education Reconciliation Act of 2010 (HCERA—H.R. 4972, also known as Pub. L. No. 111-152) that modifies Pub. L. No. 111-148, March 30, 2010.

Congressional Record, H1882 (March 21, 2010).

January 14, 2010, AAPM&R Health Reform Conference Letter.

AAPM&R Position on National Health Care Reform; October 21, 2009.

October 21, 2009, AAPM&R Letter to President Obama on Health Reform Legislation.

B. Giap, Training module: Brain Injury Rehabilitation Services Background Information. January 3, 2011.

B. Giap, Training module: Acquired Brain Injury Rehabilitation Services Medical Necessity Criteria, January 3, 2011.

December 17, 2010, Powers, Pyles, Sutter & Verville (P. Thomas and T. Morgan), Update on Establishment of Essential Health Benefits as Mandated by ACA; December 17, 2010.

Amednews.com; August 10, 2009. Debate flares over what 'essential' benefits include.

The Essential Benefits Package in the House Health Reform Bill (HR 3200), Families USA, September 2009.

P. L. 101-336, the Americans with Disabilities Act of 1990.

November 10, 2009 United Healthcare's Essential Benefits Guide (Mixed).

October 10, 2010 United Healthcare's Essential Benefits Guide (Self Insured).

aaPM&R
American Academy of
Physical Medicine and Rehabilitation

Physicians Adding Quality to Life®

9700 W. Bryn Mawr Ave., Suite 200
Rosemont, Illinois 60018
phone 877/AAPMR 99
info@aapmr.org www.aapmr.org

October 10, 2010 United Healthcare's Essential Benefits Guide (Fully Insured).

The Council for Affordable Health Insurance, Health Insurance Mandates in the States, 2010.

Brain Injury Association of America - Covering the Treatment Continuum for Persons with Brain Injury

Brain Injury Association of America – December 6, 2010 IOM Survey Questions

1998 President's Commission on Consumer Protection and Quality in the Health Care Industry Final Report

Olmstead v L.C., 119 S. Ct. 212187 (1999).

In *Re Managed Care* (2006 multidistrict litigation).

J. L. Kaminski; Defining Medical Necessity, http://www.cga.ct.gov/2007/rpt/2007-r-0055.htm]

Approve by BOG 4/10/11
Executive Committee 5/17/11

aaPM&R
American Academy of
Physical Medicine and Rehabilitation

Physicians Adding Quality to Life®

9700 W. Bryn Mawr Ave., Suite 200
Rosemont, Illinois 60018
phone 877/AAPMR 99
info@aapmr.org www.aapmr.org

Payers for Traumatic Brain Injury Hospitalizations, 2007-2011, All Races, Alaska

Data source: Alaska Trauma Registry

Costs do not include Medevac Transport costs or post-hospitalization care

Hillary Strayer, Alask Native Tribal Health Consortium, 2/19/2013

Payor	Number of Cases paid	Sum of Charges	Percentage
Self Pay	650	$31,622,615	21.81%
Private	669	$26,692,287	18.41%
Medicare	570	$24,515,213	16.91%
Medicaid	404	$16,251,949	11.21%
Other or unknown	210	$10,811,730	7.46%
Automotive	196	$10,556,986	7.28%
Military/VA	195	$9,430,418	6.50%
CHAMPUS	71	$4,880,163	3.37%
Workers	110	$4,575,387	3.16%
IHS	264	$4,177,991	2.88%
PPO	11	$627,655	0.43%
Victims	30	$359,374	0.25%
Welfare	4	$285,085	0.20%
Fisherman's	12	$204,143	0.14%
Total	3396	$144,990,996	100.00%