

California Brain Injury Association wishes to improve the quality of care, quality of life, and reduce the fiscal impact to the State of California for people with Brain Injury by improving prevention, awareness, and access to medical and rehabilitation treatment across a continuum of treatment settings.



# Brain Injury Overview: How Many Californian's Are Affected?

#### Epidemiology and Brain Injury

Panelists:

David McArthur, Ph.D., UCLA
David Hovda, Ph.D., UCLA
Mark J. Ashley, Sc.D., CCC-SLP, CCM, CBIS, Centre for Neuro Skills



# **Epidemiological Estimates of Brain Injury in California**

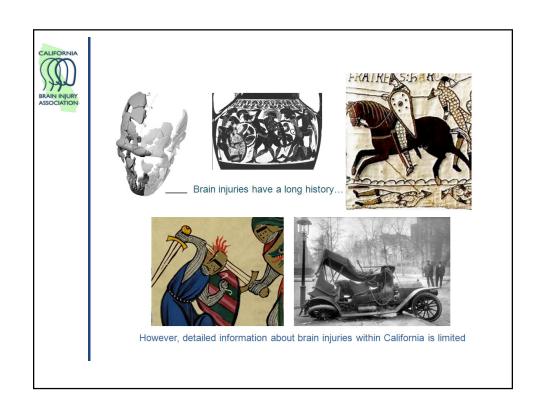
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Estimate: Incidence of TBI in the United States

= 538.2 per 100,000 population per year

source: Rutland-Brown, Langlois, Thomas, Xi. J Head Trauma Rehabil 2006;21:544-8

...... California incidence of TBI thus may be: 205,000

Estimate: ED visits with some form of TBI

= 444 per 100,000 persons per year

source: Jager, Weiss, Coben, Pepe, Academic Emergency Medicine 2000; 7: 134-140

...... California ED visits for TBI thus may be: 169,000

Estimate: Hospital admissions with some form of TBI

= 90 per 100,000 persons per year

source: <u>Jager</u>, Weiss, <u>Coben</u>, <u>Pepe</u>, <u>Academic Emergency Medicine 2000; 7: 134-140</u>

..... California hospital admissions for TBI thus may be: 34,000

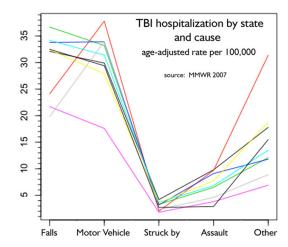
Estimate: | Prevalence of adults with ABI-related disabilities

= 183 per 100,000 population

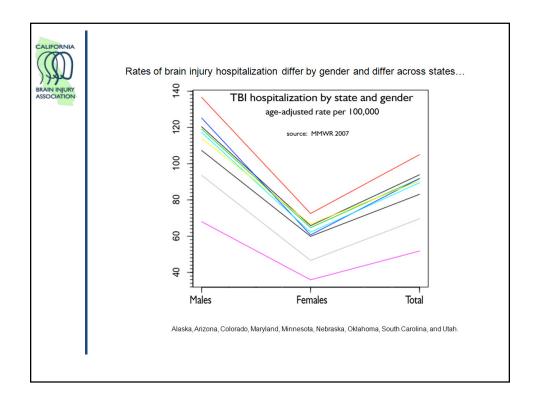
source: <u>Lannoo, Brusselmans</u>, van <u>Evnde, var Laere</u>, Stephens. Brain Injury, 2004; 18: 203–211

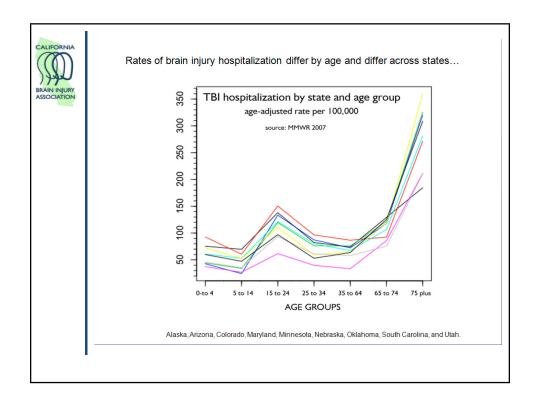


Rates of brain injury hospitalization differ by cause and differ across states...



Alaska, Arizona, Colorado, Maryland, Minnesota, Nebraska, Oklahoma, South Carolina, and Utah.





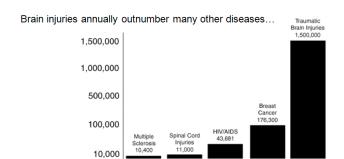


#### Estimates of concussion from the Canadian National Population Health Survey...

- Annual prevalence of persons reporting a concussion as most serious injury
   110 per 100,000 population
- California incidence thus may be: 41,800
   or by other estimates as high as: 300,000
- Those reporting concussion are statistically more likely to be younger and male.
- Males are significantly overrepresented in the 16-34 year-old group.
- More than 54 % of all concussions occur at a place for recreation or sport, with sport having a role in more than 85 % of concussions in the 16-34 year-old group.

source: Gordon, Dooley, Wood. Pediatric Neurology 2006: 34: 376-378

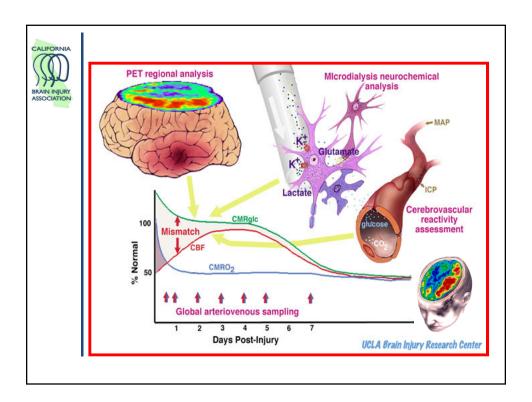




Cost estimates:

TBI nationally in 2000 = \$60 billion source: Finkelstein, Corso, Miller and associates. The Incidence and Economic Burden of Injuries in the United States. New York: Oxford University Press; 2006.

...... California estimate for 2010 = \$ 7.54 billion





# **Brain Injury and Disease**

- The event of brain injury begins a lifelong disease process.
- TBI can cause epilepsy and increase the risk for conditions such as Alzheimer's disease, Parkinson's disease, and other brain disorders that become more prevalent with age.

National Institute of Neurological Disorders and Stroke. Traumatic brain injury: hope through research. Bethesda (MD): National Institutes of Health; 2002 Feb. NIH Publication No.: 02–158.



### **Epidemiology**

- The California Brain Injury Trust Fund is funded by DMV fines.
- Other states have similar trust funds.
  - Colorado \$6 million per year
  - Florida \$30 million per year
    - Florida has as many brain injuries per year as California.
- Funds from the Brain Injury Trust Fund are slightly above \$1 million per year in California.



# **Epidemiology & Surveillance**

- Recommendations
  - The State must understand the prevalence of brain injury, its causes, current courses of treatment, complication rates, and life-long issues pertaining to medical and social needs.
  - Establish a California Brain Injury Registry and Surveillance Project



## **Epidemiology**

- Recommendations
  - Brain Injury Trust Fund monies are utilized to fund 7 regional traumatic brain injury services centers around the state.
  - Investigate funding mechanisms utilized for Brain Injury Trust Funds in other states and adopt similar funding vehicles to cover the total Epidemiology investment and to increase funding to the 7 regional traumatic brain injury services centers.
  - Increase DMV penalty fund fines commensurate with other States' penalty funds and allocations to provide at least \$30 million in novel funding to be distributed between the University of California Brain Injury Research sites (\$15 million), Department of Health (\$10 million) and the Traumatic Brain Injury Services of California sites (\$5 million).



#### **Prevention**

- Recommendations
  - Require mandatory training of school athletic coaches, trainers, PE teachers, nurses, team physicians, and students in brain injury prevention.
  - Require adoption of the CDC Guidelines for Concussion by all organized athletic groups and activities.



#### **Prevention**

- Recommendations
  - Require purchase of catastrophic injury protection insurance for all student athletes that provides \$5 million coverage for brain injury, spinal cord injury, and amputation.
  - Allow for recovery relief for school districts that purchase the coverage for the student.



# Standards of Care: Access To Treatment, Long Term Issues & Pediatric Brain Injury

#### Panelists:

Mark J. Ashley, Sc.D., CCC-SLP, CCM, CBIS, Centre for Neuro Skills Nathan Cope, M.D., Paradigm Corporation Sharon Grandinette, M.S., CBIST, Exceptional Educational Services



#### **Access to Treatment**

- Brain Injury poses a significant health threat in the State of California.
- Public and private health payers restrict access medical treatment, medical rehabilitation and disease management following brain injury.
  - Some carriers exclude rehabilitation.
  - Some carriers allow 30 to 100 days of rehabilitation under duress.
  - No payers routinely cover non-hospital based treatment, though this is the standard of treatment following brain injury.



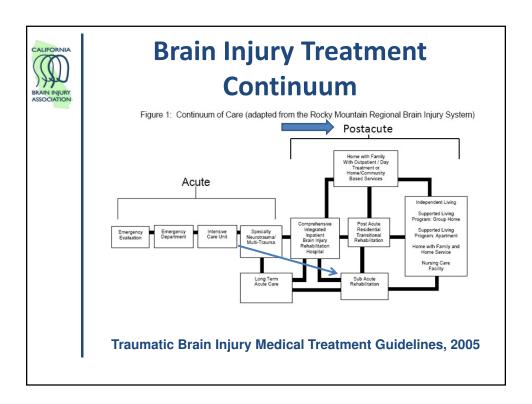
- Private health carriers currently impose severe restrictions on access to medical treatment and rehabilitation following a brain injury.
- Medical rehabilitation is the single most effective treatment following brain injury.
- No other organ system, similarly injured, is managed outside major medical benefits provisions or with arbitrary time constraints on medical treatment.
- Contract language has not changed to keep pace with the evolution and provision of medical treatment outside traditional hospital settings, though the insurance industry promoted the development of such less expensive treatment options.



- Access to postacute medical treatment and rehabilitation is disallowed by most insurance plans as a stated benefit and must be individually negotiated per patient.
- Limited coverage is provided via a "Substitution of Benefits" clause allowing for an arbitrary number of days of treatment that is not predicated by the patient's needs or condition, rather uses a skilled nursing benefit.
- Insurance carriers aggressively restrict hospital lengths of stay and promote discharge home. This practice triggers availability of outpatient treatment benefits only, usually 20 to 26 visits per year.



- Some carriers have eliminated benefits for any rehabilitation in their policies altogether.
- Some carriers have eliminated the ability to allow utilization of "Substitution of Benefits".
- The result is a systematic transfer of the financial liability associated with the brain injury, its treatment, and all costs of ongoing disability and disease management from the private sector to the public sector.





- Much of the postacute medical treatment and rehabilitation is not Medicare eligible.
- MediCal does not provide adequate coverage for outpatient-based services for brain injury rehabilitation.
- MediCal does not recognize non-Medicare services providers.



- Restrictions in access to treatment result in:
  - High levels of disability
  - Job loss
  - Medical indigence
  - Poverty
  - Homelessness
  - Incarceration
  - Public school burden



#### **Financial Access to Treatment**

- Delays in treatment cause more disability and increase the lifetime cost of care.
  - Lifetime cost of care for moderate to severe brain injury can range from \$1 million to well over \$10 million per person.
  - Proper medical treatment, medical rehabilitation and disease management following brain injury can save millions of dollars per lifetime per person.

Turner-Stokes L. Journal of Rehabilitation Medicine 2008;40:691-701.
Ashley MJ, Krych DK. Journal of Insurance Medicine 1990;22(2):156-61.
Ashley MJ, Schultz JD, Bryan UV, Krych DK, Hosys DR. Journal of Rehabilitation Outcomes Measurement 1997;1(5):33-41.
Ashley, M, O'Shanick, G, Kreber, L. Early vs. Late Treatment of Traumatic Brain Injury. Vienna, VA: Brain Injury Association



### **Cost Burden**

- Costs for brain injury treatment and disability are currently borne by the:
  - Department of Health
  - Department of Corrections
  - Department of Education
  - Department of Rehabilitation
  - Department of Developmental Disabilities
  - others



#### **Standards of Care**

- Proven standards of treatment for the disease of brain injury are not being used consistently in the State of California.
- Adherence to these standards will reduce mortality, morbidity and cost of brain injury.
  - Standards for emergency management
    - Guidelines for Pre-hospital Management of Traumatic Brain Injury.
  - Standards for neurological management
    - Guidelines for Management of Severe Traumatic Brain Injury.
  - Standards for surgical management
    - Guidelines for the Surgical Management of Traumatic Brain Injury.
  - Standards for pediatric management
    - Guidelines for the Acute Medical Management of Severe Traumatic Brain Injury in Infants, Children, and Adolescents.
  - Standards for medical treatment
    - Traumatic Brain Injury Medical Treatment Guidelines



#### **Standards of Care**

- Substantial variations in treatment exist across the State. These variations are in part due to facility availability. However, much of the variation is due to lack of adherence to accepted standards of care.
- Standards have been developed by national and state organizations and are in place in other parts of the country.



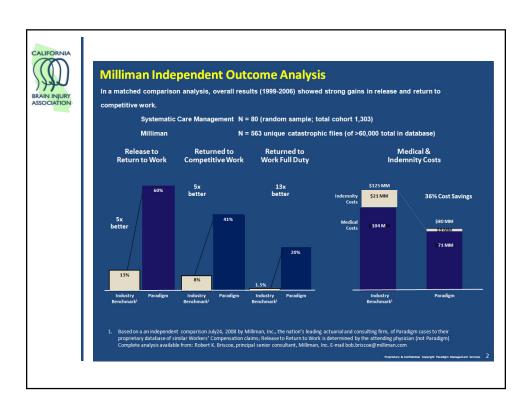
### **Private Sector Experience**

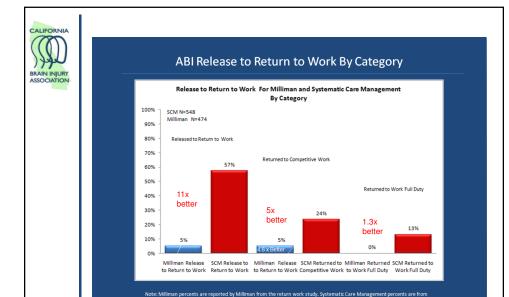
 Workers' compensation and liability insurance sectors have proven the effectiveness of utilization of the continuum of care, expert treatment, utilization of the TBI Medical Treatment Guidelines and the cost effectiveness of disability reduction through intensive medical rehabilitation of appropriate duration.



### **Private Sector Experience**

- Evidence-based medicine provides strong evidence that comprehensive rehabilitation performed by expert clinical personnel with adequate social supports makes an incredible difference in outcomes via
  - Economic gain to society
  - Lessened dependency
  - Lessened institutional and supportive care
  - Increased productivity.







#### **Conclusions**

- The core element of this approach is total, but expertly directed, commitment to the complete continuum of appropriate health services:
  - Acute and post-acute rehabilitation
    - Including inpatient, outpatient, community and in-home based care
- These data demonstrate the feasibility of both significantly improving the health and functional outcomes of TBI Survivors with appropriate comprehensive acute and rehabilitation care.



# Long-Term Issues After Brain Injury



# **Postacute Pathways**

- N = 1059 individuals with TBI
- Pathways identified
  - Rehab, then to home/community 7.7%
  - Rehab, then outpatient services 8.2%
  - Rehab, then LTC 2.6%
  - LTC 3.4%
    Home 64.5%
    Home w/outpatient services 13.6%

Mellick D, Gerhart KA, Whiteneck GG. Brain Injury 2003;17(1):55-71.



#### **Long-Term Issues After Brain Injury**

- Disease initiation.
- Disease acceleration.
- Job loss.
- Insurance loss.
- Medical indigence.
- Educational failure.
- Educational system burden.
- · Social isolation.
- Mental Health and neurobehavioral issues

- Cognitive/memory deficits
- Family system disruption.
- Impoverishment.
- Homelessness.
- Involvement in criminal justice system.
- Lifelong dependence.
- Increased taxpayer cost.



#### **Disease Initiation & Acceleration**

- Brain injury not as an event, but rather the beginning of a disease process.
- Neither an acute brain injury nor a chronic brain injury is a static process
- Brain injury impacts multiple organ systems, is disease causative and disease accelerative

 $Masel, B.\ \textit{Conceptualizing Brain Injury as a Chronic Disease}.\ \textit{Vienna, VA: Brain Injury}\ Association\ of\ America,\ 2009.$ 



#### **Job Separation and Brain Injury**

- 2/3 of job separations come within 6 months of employment.
- Interpersonal relationship difficulties
  - Anger.
  - Inappropriate social interaction.
  - Over-familiarity.
- Economic layoffs
- Substance abuse
- Criminal activity
- Mental health problems

Sale et al 1991, Journal of Head Trauma Rehabilitation 6:1-11



# **Department of Rehabilitation**

- The CA Department of Rehabilitation assists with:
  - Obtaining/retaining employment
    - Transportation
    - Training
    - Supported employment
  - Rehabilitation assistive technology
  - Maximization of independent living
- Appropriate rehabilitation would lessen the longterm financial burden to DOR
- Access to services from DOR is often problematic



# Department of Health Care Services

- Services include:
  - Medi-Cal
  - California Children's Services-CCS
    - Children with health care issues eligible until age 21
  - Child Health & Disability Program
  - Office of Long Term Care
- Appropriate and timely access to rehabilitation would lessen the long-term financial burden on DHCS



# **Neurobehavioral Complications**

- Threats of violence.
  - 15% year 1 54% year 5
- Physical assault of a family member.
  - 10% year 1 20% year 5

Brooks N, Campsie L, Symington C, Beattie A, McKinlay W. Journal of Neurology, Neurosurgery and Psychiatry



### **Criminal Justice System**

- Between 25 87% of inmates report having experienced a head injury or TBI, compared to 8.5% of the general population.
- Prisoners may experience neurobehavioral problems such as severe depression and anxiety, substance abuse, difficulty controlling anger, or suicidal thoughts and/or attempts.

Schofield PW, Butler TG, Hollis SJ, Smith NE, Lee SJ, Kelso WM. Brain Injury 2006;20(5):499-506. Slaughter B, Fann IR, Ehde D. Brain Injury 2003;17(9):731-41. Morrell RF, Merbitz CT, Jain S, Jain, S. Journal of Offender Rehabilitation 1998;27(3-4):1-8. Sliver JM, Kramer R, Greenwald S, Weissman M. Brain Injury 2001;15:935-45. Walker R, Hiller M, Staton M, Leukefeld CG. Journal of Psychoactive Drugs 2003;35(3):343-53. Barnfield TV, Leathem JM. Brain Injury 1998;12(11):951-62. Barnfield TV, Leathem JM. Brain Injury 1998;12(6):455-66. Blaauw E, Arensman E, Kraaji V, Winkel FW, Bout R. Journal of Traumatic Stress 2002;15(1):9-16.



# Addressing Neurobehavioral Complications/Avoiding Criminal Justice System

- CA Department of Mental Health Services provides
  - Assessment/identification
  - Dual diagnosis/substance abuse
  - Counseling
  - Medication Management
  - Supported living
  - Residential treatment
- Appropriate rehabilitation would lessen the longterm financial burden to both systems.
- Access to mental health services is often problematic



#### **Rehabilitation for Children**

- National Pediatric Trauma Registry data indicates many children with TBI discharged from acute hospitalization:
  - with 1-3 impairments are sent home
  - with 4 or more impairments may be sent to a rehabilitation facility.
- Poor funding, limited rehabilitation facilities/distances to them force families to take child home, causing a lapse in rehabilitation services/delay in educational services.
- Rehabilitation becomes the burden of the school system, significantly increasing need for funding for special education services from the CDE

Discala, C., & Savage, R.C., (2003). Epidemiology of children with TBI requiring hospitalization. Brain Injury Source: 6(3), 8-13.



# Schools and Students with Brain Injury

- Limited training of school staff in brain injury and poor implementation of special education services cause families to file for due process under the Individuals with Disabilities Education Act
- School districts bear burden of time/cost of due process and hearing officers decision for brain injury training/provision of outside services
- Appropriate rehabilitation of these students would significantly decrease the costs of serving these students in special education programs



# Department of Developmental Services

- Children who sustain brain injury before age 18 qualify for and are served by the Developmental Disability (Regional Centers) system.
- Services can include
  - Assessment
  - Advocacy
  - Lifelong planning/service coordination
  - Family support/training
  - In home/out of home care
- Appropriate rehabilitation of these children will lessen the long-term financial burden to this system.
- Access to this system is often problematic.



# Lifelong Dependence and Aging Caregivers

- · Caregivers face serious difficulties with:
  - Respite care
  - Community transportation
  - Community engagement/Social isolation
    - Work
    - School
    - Volunteering
  - Housing
  - Securing medical treatment
  - Household finances
  - Depression
  - Family dissolution
  - Quality of life



### **Aging with Brain Injury**

- Decrease in long term productive activity
- Accelerated aging
- · Physical and sensory changes
- Worsening cognitive abilities/possible link to early Alzheimer's Disease
- · Problems of mobility

Colantonio, A., Ratcliff, G., Chase, S., Vernich, L. (2005). Aging with traumatic brain injury: long term outcomes. Brain Injury Professional 2 (2). (30-33).



#### **Standards of Care**

- Recommendations
  - Require adoption of treatment standards for various levels of care:
    - Standards for emergency management
      - Guidelines for Pre-hospital Management of Traumatic Brain Injury.
    - Standards for neurological management
      - Guidelines for Management of Severe Traumatic Brain Injury.
    - Standards for surgical management
      - Guidelines for the Surgical Management of Traumatic Brain Injury.
    - Standards for pediatric management
      - Guidelines for the Acute Medical Management of Severe Traumatic Brain Injury in Infants, Children, and Adolescents.
    - Standards for medical treatment
      - Traumatic Brain Injury Medical Treatment Guidelines

Brain Trauma Foundation



#### **Standards of Care**

- Recommendations
  - Require certification of State employees working with Brain Injury by the American Academy for the Certification of Brain Injury Specialists.



# Brain Injury Identification and Cost Determination

- Recommendations
  - Require the State to identify all costs associated with persons with brain injury, including identification projects including, but not limited to:
    - Department of Health
    - Department of Corrections
    - Department of Education
    - Department of Rehabilitation
    - Department of Developmental Disabilities
    - Skilled Nursing Facilities



- Recommendations
  - Require all private accident & health and workers' compensation insurance carriers and public payers to provide coverage for treatment as outlined in the Traumatic Brain Injury Medical Treatment Guidelines
    - Adopted by the Department of Labor and Employment, Division of Workers' Compensation of the State of Colorado since 1998.
    - Endorsed by the Brain Injury Association of America and the California Brain Injury Association.
  - Disallow arbitrary timeframes that constrain medical rehabilitation treatment to periods of 30 to 100 days and are based rather on patient status and condition.



- Recommendations
  - Adopt a bill similar to HB1919 in Texas which requires that all accident and health insurers provide coverage for postacute medical treatment, rehabilitation, and disease management following brain injury.



# Appropriate Medi-Cal Waiver Design

- Recommendations
  - Establish a Medi-Cal waiver program that provides specifically for care that enables community placement and is not considered a substitute for medical treatment, medical rehabilitation, and disease management following brain injury as outlined in the Traumatic Brain Injury Medical Treatment Guidelines as adopted by the Department of Labor and Employment, Division of Workers' Compensation of the State of Colorado.



# **Medi-Cal Pilot Projects**

- Recommendations
  - Require that Medi-Cal adopt and engage in Aggressive Disability Reduction pilot projects that seek to reduce disability and/or reduce long-term care costs through medical rehabilitation demonstration projects at both the acute and postacute treatment levels.



# Veterans' Issues: Are We Doing Enough

#### Panelists:

David Woodruff, Co-founder, Bob Woodruff Foundation Mark J. Ashley, Sc.D., CCC-SLP, CCM, CBIS, Centre for Neuro Skills













### **California's Returning Veterans**

- California has one of our nation's largest service member and veteran population.
- In Afghanistan and Iraq our service members are engaged in *asymmetrical warfare*.
  - Asymmetrical warfare has no "front" lines.
    - Crude yet effective blast weaponry is used by insurgents to gain an advantage against US forces.
    - IEDs are the signature weapon in these conflicts.
    - Combat circumstances create hypersensitivity and severe injuries in the "rear."





#### **California's Returning Veterans**

- Signature Injuries of the wars in Afghanistan and Iraq (OIF/OEF) are typically "hidden" from view. Signature injuries are TBI, and Combat Operational Stress (COS) resulting in Post Traumatic Stress Disorder (PTSD), depression, anxiety, and substance abuse.
  - Hidden injuries are frequently undiagnosed, misdiagnosed and over-layed.
  - Stigmas in the military culture frequently delay or prevent service members from seeking screening and treatment.





### **California's Returning Veterans**

- Departments of Defense and Veterans Affairs have not screened every returning veteran for TBI and COS.
  - Federal Programs to prevent, screen, diagnose and treat the hidden injuries have been created and improved however:
    - All volunteer services require multiple combat deployments.
    - There is not consensus on when to remove a service member from the "fight."
    - Treatment for injured service members is often not executed close to the service member's home of record.
    - Attempts at reducing stigma are still not as effective as needed.
    - Suicides continue to increase in the Services, especially the Army and Marine Corps.
    - Follow-up to track and ensure successful reintegration for service members and their families is inadequate.





### **Veterans' Injury Statistics**

- As of January 5, 2010, 36,364 service members have been wounded in action and 4,141 killed in action in OIF/OEF.
- Of the patients who require medical evacuation for battlerelated injuries from theater to Walter Reed Army Medical Center (WRAMC), 33% had TBI (01/03-03/31/09).
- Cumulatively, DVBIC sites have seen 9,609 patients with TBI.
   Some patients are seen at a Military Treatment Facility (MTF) and later referred to a Veterans Affairs (VA) site and/or to the DVBIC community reentry program at Lakeview Virginia NeuroCare and Laurel Highlands Neuro-Rehabilitation. (01/03 03/31/09).

Operation Iraqi Freedom (OIF)/Operation Enduring Freedom (OIF) Fact Sheet: March 2009 and Operation Iraqi Freedom (OIF)/Operation Enduring Freedom (OEF) U.S. Casualty Status Fatalities as of January 5, 2010.





# **Veterans' Injury Statistics**

- The Defense and Veterans Brain Injury Center (DVBIC) at WRAMC has evaluated and treated 1,893 TBI patients from the conflicts in Iraq and Afghanistan between January 2003 and March 31, 2009.
- The DVBIC lead VA centers (Minneapolis, Palo Alto, Richmond, and Tampa), have seen a total of 1,676 OIF/OEF TBI patients (1/03 – 03/31/09).
- Over 90% of combat-related TBIs are closed head injuries, with most service members sustaining a mild TBI/concussion (01/03 – 03/31/09).
- Majority of service members receiving treatment for TBI are in their early 20's and male (01/03 03/31/09).

Operation Iraqi Freedom (OIF)/Operation Enduring Freedom (OEF) Fact Sheet: March 2009





#### **California's Returning Veterans**

#### **Reintegration Issues**

- Veterans with these hidden injuries experience substantial difficulties returning to their communities, work and school.
  - Already seeing increases in unemployment, homelessness, divorce, and suicide with OIF/OEF Vets.
- Veterans and their families who have not been properly screened, diagnosed and treated while in the service or who have been disciplined or discharged from service will constitute a large proportion of individuals needing State assistance.





#### **California's Returning Veterans**

- The burdens of responsibility to ensure that our service members, veterans, and their families have successful futures is shared by the federal, state, and local government, as well as the private sector.
- The federal government alone is inadequate in addressing all of the needs of reintegrating service members, especially those with the hidden injuries of war.



# **California's Returning Veterans**





- Legislatively require that all California military service men and women returning from combat zones throughout the world be comprehensively assessed and treated for the cognitive, psychological, physical, social, and medical complications associated with the hidden injuries of war.
- Establish and fund a formal reintegration program at the State level to address the needs of injured service members, veterans, and their families to ensure successful futures and empower communities to take action to assist.
  - Program should specifically address the following issues:
    - Housing
    - Education
    - Employment
    - Healthcare
    - Recreation/Socialization



### **California's Returning Veterans**

- Recommendations
  - Establish a clearinghouse of State and Federal resource availability through a single source to enable all with brain injury and/or their families to gain rapid access to services such as housing, transportation, food assistance, return to work, return to school, respite care, and ongoing medical treatment and access.



# Legislative Caucus/Task Force on Brain Injury

- Recommendations
  - Given that over 55,000 Californians sustain brain injury each year that will result in long-term disability, brain injury constitutes a major health and economic threat.
  - Establish a Legislative Caucus/Task Force on Brain Injury to further study the issue in depth and make ongoing recommendations.