



**5 Priorities in 5 Years:
Strategic Plan for 2009 to 2013**

Introduction

In August 2008 the Brain Injury Association of America's Board of Directors and staff met with members of the State Affiliate Assembly's Strategy and Long Term Planning Committee to identify five strategic priorities to pursue during the next five years.

Prior to the meeting, BIAA leaders reviewed input from more than 650 individuals with brain injury, family caregivers, clinicians and others who responded to an online survey conducted from July 21 to August 15, 2008 (for results, please see http://biausa.org/elements/strategic_planning_survey_responses_081608.pdf). Meeting participants also gained insight from an environmental scan prepared by BIAA staff and volunteers.

During the 2-day meeting, BIAA's leaders set out to create priorities that are ambitious but achievable over the next five years. They recognized that the Association must invest in its infrastructure and nurture growth and unity across its nationwide network of state affiliates. The leaders also understood that no strategic plan could address the work of an entire organization.

The priorities selected for the next five years represent key initiatives, but they are not the sum of all of BIAA's parts. This document does not attempt to specify how each priority will be implemented; instead, it lists objectives—and in some cases strategies or tactics—that can be incorporated into the annual work plans of BIAA's committees and staff.

BIAA operates in a dynamic environment. Scientific breakthroughs, a growing public awareness of brain injury, a fluctuating national economy, and changes in the healthcare delivery system will present new opportunities and challenges for the organization and the people it serves. Thus, BIAA's leaders are committed to annual evaluation and adjustment of the priorities to ensure they remain evergreen.

Mission

Our mission is to be the voice of brain injury.

Core Belief

Brain injury is a misdiagnosed, misunderstood, under-funded neurological disease. Until there is a cure, people who sustain brain injuries must have timely and equal access to expert trauma care, specialized rehabilitation, lifelong disease management and individualized services and supports in order to live healthy, independent and satisfying lives.

Guiding Principles

1. We value strong leadership.

We expect Board members to be fully engaged in BIAA's mission. We set high standards for management and staff. State affiliate leaders are an integral part of our organization; we value their "on-the-ground" experience in shaping plans and policy decisions.

2. We serve the entire field.

We respect the dignity and worth of all people. We encourage individuals with brain injury and their family members to participate in BIAA in meaningful ways while simultaneously welcoming the perspectives of researchers, clinicians and other professionals. We value the accomplishments of those who came before us and embrace the next generation of leaders who will pursue BIAA's mission with urgency and excellence.

3. We act with integrity while functioning as a business.

We seek transparency in our communications and agility in our operations. At all times, we strive to be a growth-oriented, metrics-driven organization employing technology and entrepreneurial approaches to achieve BIAA's mission. We foster mutually-beneficial relationships with other organizations that share our goals.

Strategic Priorities

The Brain Injury Association of America's strategic priorities for 2009 to 2013 are to:

- Increase access to brain injury treatment and care.
- Unify BIAA and state affiliates.
- Embrace technology in all aspects of our work.
- Secure adequate resources to accomplish the mission.
- Influence awareness and understanding of brain injury.

1. Increase Access to Brain Injury Treatment and Care

"BIAA's first priority should be enabling people who have suffered a brain injury to get medical treatment and rehab by mandating insurance coverage—private as well as Medicare and Medicaid."

--Family caregiver of less than 2 years from Indiana

Every day, hundreds – perhaps thousands – of patients are deprived of the acute care, rehabilitation and related services they need to regain maximum function and quality of life after their brain injury. Inconsistent pre-admission policies, arbitrary limits on scope and duration of care, outright coverage denials, unreasonable payment rates, and questionable post-treatment audits are just a few of the tactics used in today's healthcare environment.

By delaying and denying access to care, our nation is needlessly increasing permanent disability among people who sustain brain injuries. Consumer choice is being reduced or eliminated as specialty hospitals, rehabilitation facilities, and community-based long-term care providers are driven out of business. As a result, "subprime" insurance carriers and their policies are privatizing profit and socializing cost by transferring the burden of care to federal and state governments, and thus, American taxpayers.

To reverse these dangerous trends, BIAA will pursue the following objectives:

- 1.1 Lead the adoption, promotion and use of universally-accepted standards for the treatment, rehabilitation and long-term management of neurological disease.
 - A. Work with the Brain Trauma Foundation to circulate notices to hospital administrators and relevant agencies and organizations promoting the *Guidelines for Surgical Management of TBI and Medical Management of Severe TBI in Infants, Children and Adolescents*
 - B. Work with the Brain Injury Business & Professional Council to review, revise (if necessary), adopt and promote the *Colorado Guidelines for Medical Treatment of Brain Injury*
 - C. Work with state affiliates to circulate and enact model legislation (see New York) tying Medicare and Medicaid reimbursement to accepted standards of care
 - D. Support and promote federally-funded and private sector-developed disability and rehabilitation research demonstrating the efficacy of therapeutic treatment/return on investment

- 1.2 Collect evidence of questionable practices by insurers and payers.
 - A. Conduct gap analysis between standards of care and coverage policies of the nation's leading public and private payers and widely disseminate results
 - B. Create insurance company rating database containing testimonials from patients who are denied care
 - C. Publish handbook(s) for consumers and professionals on insurance policy language that is commonly used to delay or deny treatment and step-by-step instructions for redress, including appeal strategies and sample letters
 - D. Pursue Government Accountability Office (GAO) Report demonstrating why/how the burden of care is transferred to taxpayers

- 1.3 Develop and pursue legal strategies to expand access to care.
 - A. Work with state affiliates to circulate and pursue lawsuits and settlements (see Massachusetts) against state government payers
 - B. Research tobacco litigation and similar endeavors to identify parallels and lessons learned

- 1.4 Amend state and federal laws and regulations to mandate comprehensive treatment, rehabilitation and long-term management after neurological disease.
 - A. Amend TBI Act to authorize the Health Resources and Services Administration's State Grant Program to include direct services as an approved use of funding and increase funding
 - B. Publish position statements/policy platform on barriers in access to care and circulate to relevant federal and state agencies, organizations and election campaigns
 - C. Identify potential partners and coalesce with them to reform the Employee Retirement Income Security Act (ERISA)
 - D. Work with state affiliates to circulate and enact model legislation (see Texas HB 1919) mandating brain injury coverage

2. Unify BIAA and State Affiliates

BIAA should establish a single "branded" identity, nationally recognizable and adopted by each state affiliate without dissent.

--Professional of more than 15 years from New Hampshire

Data extrapolated from the 2007 Benchmarking Study of State Brain Injury Associations indicate BIAA and state affiliates answer 100,000 individual requests for help and welcome 2 million website visitors each year. The data also show BIAA and state affiliate budgets represent a \$15+ million advocacy network with a 25-year track record of state and federal policy achievement that annually

generates millions of dollars for brain injury awareness, research, treatment, and long-term services.

BIAA and state affiliates will undertake the following strategies to capitalize on their shared position as the largest and *only* nationwide voice in brain injury:

- 2.1 Adopt a uniform look and message in all communications and materials.
 - A. Complete branding campaign and circulate style manual to affiliates
 - B. Develop standardized fact sheets and information materials
 - C. Build website that interfaces with and supports uniform state pages that are easily modified by affiliate staff and volunteers
 - D. Create standardized “issue briefs” and “talking points” for media inquiries
 - E. Annually produce and disseminate standard Brain Injury Awareness Month theme and materials

- 2.2 Align state and federal public policy goals.
 - A. Create federal legislative platform
 - B. Create handbook with step-by-step instructions for pursuing state legislation and/or regulations that improve access to care (see Texas, New York, Massachusetts and others)
 - C. Develop model “Returning Servicemembers with TBI Act” to expand availability of I&R, education and support to military families

- 2.3 Build consistency in programs and services across states.
 - A. Enroll each state affiliate in the National Brain Injury Information Center over the next 5 years
 - B. Increase the number of state affiliates providing NeuroResource Facilitation to 25
 - C. Establish state affiliates as group administrators for the Academy of Certified Brain Injury Specialists
 - D. Encourage and facilitate standardized caregiver training nationwide

- E. Create standardized peer-to-peer mentoring program
- F. Create standardized support group materials

2.4 Ensure long-term sustainability and growth.

- A. Negotiate group buying initiatives for equipment, software, materials, supplies, employee benefits, and insurance
- B. Develop nationwide fundraiser, such as “Walk for Thought”

2.5 Maximize effectiveness through ongoing organizational development.

- A. Pursue Better Business Bureau or similar “gold seal of approval” designation
- B. Revise affiliation agreement and bi-annual review process to strengthen program and service outcome and quality measures

3. Embrace Technology in All Aspects of Our Work

“BIAA must have top-notch technology, including the website.”

--BIAA Board Member of 2-5 years

Providing rapid, reliable brain injury information that is relevant to individual needs and accessible on a 24/7 basis is foundational to BIAA’s mission. Gone are the days that resources can be filed away in cabinets or that learning can take place only in classroom settings. Today’s highly competitive, fast-paced environment demands that customers be able to transact business electronically and that employees and affiliates have the equipment, software, training and access to work efficiently and effectively from locations across the country.

As good stewards of the limited resources available nationwide, it is incumbent upon BIAA to invest in technology as follows:

- 3.1 Establish and maintain a robust information management system that integrates key functions across BIAA.
 - A. Establish an up-to-date, multi-use database capturing the range of BIAA contacts and resources with user-friendly access
 - B. Utilize software that seamlessly connects the different aspects of BIAA's administrative, financial, and consumer services including ACBIS initiatives
 - C. Make components of the software accessible to state affiliates for greater efficiency and consistency of service

- 3.2 Identify and implement a website interface that serves as the nationwide platform for user-friendly brain injury information, continuing education and networking.
 - A. Fully integrate state affiliate websites into nationwide site
 - B. Transact as much business as possible online (e.g., certification application/testing; product sales; conference registrations, donations, etc.)
 - C. Deliver on-demand educational programming
 - D. Conduct online polls and consumer service rating opportunities
 - E. Ensure website is fully accessible to all constituents including those with visual disabilities

- 3.3 Continually elevate technology fluency among BIAA employees and state affiliates.
 - A. Identify and correct technology bottlenecks and obstacles within BIAA and across affiliate network
 - B. Negotiate group purchasing of technology solutions
 - C. Furnish technology training and networking opportunities to BIAA and state affiliate employees
 - D. Progressively modify departmental work plans and affiliation agreements to embed technology-related standards and goals

3.4 Form a technology committee.

A. Cultivate a patron saint for technology advice and support

IV. Secure Adequate Resources to Accomplish Mission

“The first priority should be to increase the money available to BIA and state organizations for lobbying and political awareness, to improve outreach and community educational efforts, and for financial assistance for research.”

--Survivor of 2-5 years from Wisconsin

Since its inception, BIAA has struggled to secure adequate resources to meet organizational goals. Whether narrow or wide, the gap between revenue and expense in any given year has led the organization to rely heavily on an industry in which profits are dwindling; to pursue federal grants that can present conflicts of interest and be costly to administer; and to engage in futile efforts to save its way to prosperity.

Pulitzer-Prize winning novelist Edith Wharton who died of a stroke in 1937 once said, “The only way not to think about money is to have a great deal of it.” With that in mind, BIAA’s goal is to grow its annual budget from \$1.5 million to \$5 million over the next five years. The specific objectives are to:

- 4.1 Achieve annual growth of 2-5% in existing individual and corporate contributions and in current advertising and product sales.
- 4.2 Establish new direct mail and e-solicitation programs.
- 4.3 Aggressively market valued programs and services, such as the Academy of Certified Brain Injury Specialists (ACBIS).

- 4.4 Launch new initiatives for the professional community, including the Brain Injury Business & Professional Council and the preferred attorneys program.
- 4.5 Secure up to 20% of total revenue in corporate, foundation and federal grants.
- 4.6 Identify one or more national sponsors for a nationwide fundraising event to benefit state affiliates.

V. Influence Awareness & Understanding of Brain Injury

“BIAA’s priority should be to position itself as the first organization that comes to mind when discussing brain injury and as a logical and valued partner in anything brain related.”

--State Affiliate Leader of 5 to 15 years

For 25 years, brain injury was labeled a “silent epidemic,” garnering only nominal attention from media outlets, policy makers and the general public. Almost overnight, the wars in Iraq and Afghanistan brought a sharp rise in public awareness. BIAA and state affiliates benefitted from the attention with an unprecedented 250% increase in media mentions in 2007.

Although the craze has now subsided, the onslaught of new players it ushered into the field continues to increase. Ensuring that BIAA and state affiliates remain the preeminent voice in brain injury will be a challenge in the coming years. Thus, the following strategies are envisioned:

- 5.1 Position BIAA as a research organization that passionately pursues a cure.
 - A. Form Research Council to create BIAA-endorsed research agenda

- B. Launch capital campaign and direct mail campaign to establish Research Endowment
 - C. Cultivate the nation's leading researchers for Board service, newsletter articles
 - D. Launch and expand partnerships with relevant organizations and publications (e.g., adoption of JHTR)
- 5.2 Analyze opportunities to position BIAA as voice for individuals with mild brain injury.
- A. Produce information explaining why a "mild" injury is not mild
 - B. Examine positions, materials, and activities to ensure inclusiveness
 - C. Explore viability of "Mild TBI Council"
- 5.3 Promote awareness of and involvement in BIAA's mission among core constituents.
- A. Circulate frequent notices of activities and accomplishments
 - B. Establish volunteer opportunities that are "one time only" assignments as well as progressively more responsible assignments of longer duration
- 5.4 Promote awareness of and involvement in BIAA's mission among external audiences.
- A. Identify and partner with a leading national public relations agency to create a multi-media ad campaign involving celebrities, athletes and community leaders as honorary spokespersons
 - B. Use awards programs and other methods to continuously position BIAA in media
 - C. Use social networking and other methods to outreach to next generation

- 5.5 Partner with a wide variety of industries and associations to develop co-branded programs and products that are profitable and ethical.
 - A. Establish a BIAA “gold seal of approval” for workplace safety practices
 - B. Work with biomedical and pharmaceutical industries to promote awareness of useful products and services
 - C. Link with financial planners and companies that offer life care products (e.g., METDesk) for persons with special needs

- 5.6 Actively recruit business leaders and persons of influence and affluence to serve on BIAA’s Board of Directors.
 - A. Provide training and collateral materials to encourage Board members to engage friends and associates in BIAA’s mission