NASHIA’s Role in the Evolution of TBI Service Delivery

Susan L. Vaughn
Director of Public Policy

Monday, October 7th, 2013
3:45– 4:45 pm
Purpose

• Evolution of TBI Programs/Policies
• Evolution of NASHIA
• NASHIA’s Future
In the beginning . . .

If you would understand anything, observe its beginning and its development.

Aristotle
National Head Injury Foundation (NHIF) -- BIAA

1980’s . . .

• Public awareness
• Family and professional support
• Education on TBI
• Public policy: federal and state
Mr. Marilyn Price Espenshade
Executive Secretary
National Head Injury Foundation
P.O. Box 147
Lexington, MA 02173

Dear Marilyn,

I am pleased to have this opportunity to thank the members of the National Head Injury Foundation for their efforts to help head injury survivors across the country.

As much progress as we have made, there is always room for improvement. Although we have reached many milestones, we still face many challenges. The NHIF has played a crucial role in raising awareness of head injuries and the importance of research.

I am particularly proud to be associated with the NHIF and to have been a part of the public service announcement that will be broadcast on television and radio in Washington, D.C., to raise awareness of head injuries and the efforts of the NHIF to prevent and reduce the impact of head injuries.

The work of the NHIF has made it an important resource for persons with head injuries and their families. Keep up the good work.

Sincerely,

Jim Brady
Press Secretary to the President
"Injury is a public health problem whose toll is unacceptable"

Committee on Trauma Research, IOM, National Research Council
Federal Interagency Task Force

• Establish "traumatic brain injury" as a category in reporting systems

• Designate a lead Federal agency

• State and local “working groups”

-- Federal Interagency Task Force 1989 Report

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Federal Initiatives

- NIDRR Research Training Centers (1987)
State Initiatives -- 1980’s

- Legislative studies
- Appointed councils/committees
  - Executive Branch; Legislation
- Prevention
  - Traffic Safety Legislation (i.e. seat belts, child seats, motorcycle helmets)
State Initiatives

- Registries (surveillance, linkage)
- Trauma Systems
- Funding for programs & services
  - State funding
  - Trust funds (dedicated funding)
  - State rehab facilities
Expanded Existing Programs

- Developmental Disabilities
- Designated VR TBI Counselors
- Special Education Support
- Medicaid State Plan Services
Federal Legislation – 1990’s

- Nat’l Center for Injury Prevention and Control (1992)
- IDEA, added TBI as disability for reporting purposes (1990)
  - Defined TBI
- DVBIC (1992) – Gulf War
TBI Act

• TBI Act of 1996, as amended
  – HRSA State Grants, CDC TBI Prevention, Data, Public Education, NIH Research

• 2000 Amendments, added P&A

• 2008 Reauthorization
Military-Related TBI

Iraq & Afghanistan Wars:

- NICoE (2008)
  (National Intrepid Center of Excellence)
State Initiatives -- 1990’s

- Medicaid TBI HCBS Waivers -- Kansas (1991)
- Expanding services and supports; “benchmark” and infrastructure
- Prevention
  - Sports-Related Concussions
  - Distracted Driving
Alone we can do so little; together we can do so much.

... Helen Keller
1st National SOS

New Orleans, 1990
Organization

- Organizational Meeting (1993)
- First President (1993)
- By-laws (1995)
- Incorporated (1995)
Our Mission

Assist State government in promoting partnerships and building systems to meet the needs of individuals with brain injury and their families.
NASHIA Structure

• Officers – 2 yr. terms
• Executive Committee
• Board of Directors
• Committees
Leadership

Amy Flaherty (PA), President
Lorraine Wargo, RN, Executive Director

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Support Team

- Donna Huckekestein, Bookkeeper
- Paul Walsh, Webmaster
- Susan Vaughn, Director of Public Policy
- Rebeccah Wolfkiehl, Government Relations
Support Team

Rebeccah “Becky” Wolfkiel, Government Relations and Susan Vaughn, Director of Public Policy

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Membership

- State Agency
- Full Membership (State Employees)
- Associate
- Supporting
- Retiree
- Student Membership
Committees

- Education & Training
- Finance/Audit
- Membership
- Public Policy
- SOS Planning Committee
Special Interest Groups

- Neurobehavioral Health
- Employment
- Children/Youth
- Veterans
- Substance Abuse
- Prevention
- Medicaid Working Group
Contributions to the Field

Publications:

• *What Legislators Need To Know About TBI* (NCSL, 1993)
• JHTR (1990, 1994)
• *USA Today, GAO Report on TBI*
• IOM Report on HRSA Program
• NABIS BIP Professional
NASHIA Member Services

- SOS Annual Conference
- Information, newsletters
- Collective representation
- Technical assistance
- Web page
- Webinars – NEW!

www.nashia.org
Recognitions

Presented to a State Member who contributes significantly to NASHIA’s achievements and growth...
Awards

• **Friend of NASHIA** -- recognizes an individual who has consistently provided professional expertise and assistance to NASHIA

• **Partnership** – recognizes organizations and agencies who partner, collaborate and provide invaluable assistance to NASHIA

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Public Policy Committee

- Recommends policy positions
- Develops Policy Platform
- Responds to proposed federal regulations
- Liaison with federal agencies

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Primary Priorities

• Funding for TBI Act Programs
  ✓ Federal Interagency Work Group
  ✓ National Strategic Plan

• TBI Act Reauthorization (H.R. 1098)
  ✓ Elevating TBI Program within HHS
  ✓ Extend authority for appropriations
Primary Priorities

• Resources for returning troops/veterans
• Vocational rehab/Employment
• Children and youth with TBI, including education
• Dual diagnosis/co-occurring
Support

• Appropriations for array of public assistance, disability/health programs
• EMS/Trauma care
• Health care, Medicaid, Medicare Research
Support

• Disability and TBI Research
  ✓ Funding for Model TBI Centers, RR&T Centers (NIDRR)
  ✓ NIH – i.e. Project Brain, MTBI
  ✓ DoD, VA
  ✓ CDC

• DD Act Reauthorization

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Support

• Aging and TBI
• Prevention
• Community living services and supports
Congressional Brain Injury Task Force

- Founded in 2001
- Awareness Day
- Public awareness
- Promotes funding and legislation

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NASHIA Public Policy

Co-chairs: Cong. Bill Pascrell, Jr. (D-NJ)

Cong. Tom Rooney (R-FL)

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CBITF Awareness Day

NASHIA Co-Sponsors Annual Awareness Day Reception; Participates in Fair and Briefing

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NASHIA Public Policy

• Publications
  – *Capitol News, Action Alert, Washington Weekly*
  – Informational Packets
  – Position Papers

• Testimony, Support Letters

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Coalitions

- Consortium for Citizens with Disabilities (CCD)
- American Brain Coalition
- Disability & Rehabilitation Research Coalition
- Injury and Violence Prevention Network
Federal Stakeholders

- CDC
- CMS
- DCoE
- HRSA
- NIH

- NIDRR
- RSA
- SAMHSA
- VA
- ACL

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National Associations

• States United in Aging & Disabilities (NASUAD)
• State Directors of Developmental Disabilities Services (NSDDDS)
• State of Alcohol and Drug Abuse Dir.
• State Mental Health Directors
• Safe States Alliance

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NASHIA Funding Support

- Dues
- Donations
- Conference Income
- Volunteers
HRSA Contracts

- Partnership for Information and Communication Cooperative Agreement (PIC) – 2001-2002
- TAC Contract (2003-09)
Strategic Plan

• Sound financial organization
• Resource for Members and assist States in keeping with our Mission
• Representation/Influence federal policies
• Maintain and expand partnerships
We respect the past and embrace the future, we value diversity, creativity, innovation, and individuality in people and systems, we are goal-directed and hold ourselves accountable, and we strive to learn from others and ourselves.
Have You Joined NASHIA Yet?

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