WORKING WITH MEDICAL PROFESSIONALS TO ENHANCE PATBI AVOCACY

A Training for The Nationwide Network of Protection and Advocacy Traumatic Brain Injury Programs

August 4, 2004

AGENDA

1-1:10 – Elizabeth Priaulx, National Association of Protection and Advocacy Systems-
Web cast procedures and overview of presentation

1:10 – 1:25 - Dr Warren Lux, Medical Director, Defense and Veterans Brain Injury Center –
improving PATBI advocacy by understanding typical TBI medical characteristics

Agenda Continued

1:25 – 1:45 – Brian Hartman, Director, Delaware Community Legal Aid (the P&A)
Collaboration to bring about policy change

1:45 – 2:05 Julia Freeman Woolpert, PATBI Advocate, Disability Rights Center (NH)
Collaboration with State TBI Coordinators and university medical centers

AGENDA CONTINUED

2:05 - 2:20 Amy Messner, Attorney, Disability Rights Center (NH P&A)

Medical experts in ABI waiver Litigation

2:20 – 2:35 – Kenneth Currier, Director, TBI Technical Assistance Center

Funding Sources for TBI Supports

2:35 – 3:00 – Questions for Presenters

Dr Warren Lux – Characteristics (CDC Fact sheet)

- Every brain injury is different.
- Some symptoms may appear right away. Other symptoms may not show up for days or weeks.
- Sometimes the injury makes it hard for people to recognize or to admit that they are having problems.
- People may look fine even though they may act or feel differently.

Dr Lux – Characteristics (CDC Fact Sheet)

- TBI may cause problems with
- Cognition (concentration, memory, judgment, and mood).
- Movement abilities (strength, coordination, and balance).
- Sensation (tactile sensation and special senses such as vision).
- Emotion (instability and impulsivity).

Dr Lux – Consequences NASHIA Fact Sheet

- Can appear as lack of motivation or resistance to help
- Professionals not aware of neurobehavioral issues may prepare ineffective treatment plans
- Assessment requires an interdisciplinary team e.g. neurologist, neuropsychiatrist, neuropsychologist, physiatrist, OT, PT, speech, Behavioral therapy, VR

Mr. Hartman - Establishment of State Council for Persons with Disabilities Brain Injury Committee

A. Need

B. Membership (includes health care representatives)

C. Minutes: www2.state.de.us/scpd

Mr. Hartman – Prevention Legislation

1. Airbag Safety [S.B. No. 260]
2. DUI [H.B. No. 111]
3. Learner's Permit Driving Restrictions [S.B. No. 244]
4. Dram Shop Liability [S.B. No. 51]
5. Child Car Seats [H.B. No. 365; H.B. No. 481]
6. Electric Scooters & Bicycles [S.B. No. 234; H.B. No. 336; H.B. No. 439]

Mr. Hartman – Services Legislation

A. Special Education Identification [S.B. No. 105]

B. Nurse Practice Act Exemption [S.B. No. 261]

C. Domestic Violence Victim Compensation [H.B. No. 421]

D. Money Follows the Person [H.B. No. 373]

Mr. Hartman - Regulations

[www.delregs.state.de.us/index/html]

A. Child Abuse/Neglect “Shaken Baby” Reg. [7 DE Reg. 787 (December 1, 2003)]

B. Day Care Helmet Reg. [7 DE Reg. 911, §194 (January 1, 2004)]

Mr. Hartman - Training

- A. Special Education (May 6, 2004): Dr. Wayne Gordon, Chief of Rehabilitation Psychology & Neuropsychology Service, Mt. Sinai School of Medicine [www.mssm.edu.tbinet]
- B. Proposed School Psychologist Materials [www.lapublishing.com]

Service Delivery System Enhancement

A. Division of Developmental Disabilities Services [“DDDS”] Eligibility Regulation

B. ABI Medicaid Waiver

C. Attendant Services Waiver

D. DDDS Family Support Waiver

Delaware Initiatives Continued

VI. “Think First” Delaware Plan [www.thinkfirst.org]

VII. Individual Cases

A. N.T.: Medicaid Denial of “Experimental” Treatment

B. S.W.: Residential Placement

Disabilities Rights Center: PATBI in New Hampshire

Amy B. Messer,
Senior Staff Attorney
Julia Freeman-Woolpert,
Outreach Advocacy Specialist

Presenters:

Project RESPONSE: Collaborative effort of:

- **NH Division of Developmental Services**
- **NH Division of Behavioral Health**
- **Brain Injury Association of NH**
- **Dartmouth Medical School**

Developing capacity to assist people with neurobehavioral consequences of TBI

Collaboration with State TBI Grant Program, Project RESPONSE

- Julia is former coordinator
- On each others' advisory groups
- Training to DRC from Project RESPONSE about TBI neurobehavioral issues
- Postdemonstration Grant to develop family/survivor course: DRC to do a unit on advocacy
- SIG "Sliver" Grant, training for educators in Manchester, Londonderry School Districts

Collaboration with BIANH

- DRC Legal Director is on BIANH Board
- Referrals to and from BIANH Resource Facilitators
- Legislative Committee participation
  - DRC reports on mental health rules that could affect individuals with TBI; status of ABD Waiver case
  - Keep updated on legislation of interest to TBI community

Individual Casework

- PATBI calls since Jan 1, 2004: 54
- Survey of special education intakes for:
  - Suspension/Expulsion
  - Unidentified TBI

PATBI intakes: same issues as other intakes

- Housing, such as landlord problems
- Employment discrimination
- Benefits or Financial problems
- Special Education
- Health Insurance/Medicaid
- Abuse/Neglect
- Access to Services
- Guardianship

Outreach to TBI Community

- Headway, BIANH Newsletter
- BIANH conference
- BIA Professional Provider Council
- TBI page on website

All of the above reach medical professionals

Priority Setting Process

- Input Survey
- 2 Public Forums
- Meetings with 4 Brain Injury Support groups
- Needs Assessment from TBI Planning Grant

TOP 3 TBI PRIORITIES WERE SAME AS ALL RESPONDENTS

- Education/Special Education: Quality of Instruction, Supports, Services, Accommodations
- Access to Health Care
- Access to Medicaid and Medicare

People with TBI told us that…

- The ABD waiver eligibility criteria needs to be expanded.
- The special education TBI coding needs to be broadened to include other acquired brain disorders.
- There need to be better accommodations in school, employment, and public agencies.

People with TBI told us that…

- Medical personnel do not have enough knowledge about TBI, especially in post-acute care.
- There is a lack of re-entry transition from acute rehabilitation settings.
- Accessibility issues at places like AOL, UPS, and FedEx – the phone systems are confusing and difficult for people with memory problems.
- Applying for benefits, especially social security, is confusing, and inadequate help is given with the application process and with understanding notices.

Home and Community Based Care ABD Waiver

Who is eligible?

•Any Medicaid eligible New Hampshire resident;
•With an acquired brain disorder or traumatic brain injury
•Who requires a skilled nursing or skilled rehabilitation facility level of care

What Services are Available under the ABD Waiver?

Case Management
Personal Care Services
Respite Care
Day Habilitation
Supported Employment
Environmental Accessibility Adaptations
Crisis Services

Advocating for Services for people with TBI/ABD

- Advocating for Eligibility
- Advocating for Enhanced Services

Advocating for Eligibility

- Focus on specific eligibility criteria
- Work with doctors to focus their attention on specific criteria
- Work with doctors to gather information on ability to perform daily living skills, intellectual functioning, judgment, behavior, disinhibitions, hygiene, ability to manage money, ability to monitor medications, physical limitations and needs. Get beyond test data with physicians.

Advocating for Enhanced Services- The ABD Wait list

- Physicians can be extremely helpful in looking at ADA and Olmstead issues
- Many people with are unnecessarily institutionalized
- Have an independent doctor evaluate an institutionalized individual's ability to live in an integrated community setting.

Advocating for Enhanced Services- The ABD Wait list

- Have a physician complete a tour of the individual's facility, review records, speak to the individual and guardian if the individual has one, speak with staff members.
- Have the physician determine the level of treatment or services necessary.
- Have the physician determine the consequences of the absence of community-based care, ie- physical deterioration, declining mood, depression, lack of access to peers, increasing passivity or increasing aggression, etc.

Mr. Currier – Federal Funding

- Block Grants
- Vocational Rehabilitation
- Special Education

Mr. Currier – Federal/State Funding

- Medicaid
- Medicaid Waivers
- TBI Waivers

Mr. Currier – State Funding

- General Revenue
- Special Revenue
- Trust Funds

Questions & Answers

Please fill out the evaluation at the end of this webcast.

Please visit www.mchcom.com for an archive of this event and others.