Severe TBI after all these years
Unmet needs
Future Challenges

Marilyn Price Spivack, Founder, Past President of the BIAA formerly the National Head Injury Foundation

Neurotrauma Outreach Coordinator
Spaulding Rehabilitation Hospital
Charlestown, MA
Objectives

- Provide current epidemiology and cost burden
- Present long term issues and challenges: aging with a brain injury
- Sharing Resources and funding possibilities
- Consider Brain Injury as a chronic disease
- Encourage increased ADVOCACY and CALL FOR ACTION..NOW!
Objectives: Massachusetts
Accomplishments and Challenges

- Started in 1980
- Birth of the Head Injury Movement (NHIF—BIAA)
- Setting organizational system in place (NHIF)
- Educating State Administration, State Legislature, State agencies, Rehabilitation Hospitals,
- Informing and engaging rehabilitation professionals
- Listening, learning, communicating
- Building a base in Boston and DC
objectives

Massachusetts Experience .. The Birth of our SHIP in 1985

- The Coordination and Collaboration of the Administration, the Legislature, Massachusetts Rehabilitation Commission (MRC) and the Dept of HHS

- Gov. Michael Dukakis, MRC Commissioner Elmer Bartels, and Commissioner of HHS, Phillip Johnson

- Advocacy of the NHIF of Massachusetts
JON  age 18  1974
LISA  age 18  1976
Deborah   age 18    1978
Melissa and Arielle
NHIF first home, Framingham, MA
Resources - 32 yrs in the making

- Research
- Publications
- Conferences, seminars, webinars
- Organizations
- Blogs, Websites, Facebook, LinkedIn
- Federal and State agencies
- Brain Injury providers nationwide
One Voice for Systems Change

- BIAA
- BI Alliance
- NABIS
- NASHIA
- ACRM/ BIISIG
- SJ Foundation
An estimated 1.7 million TBIs occur in the United States each year.

Of the 1.7 million TBIs occurring each year in the United States, 80.7% were ED visits, 16.3% were hospitalizations and 3.0% were deaths.
CDC statistics
1.7 million annually

- 50,000 Deaths
- 276,000 hospitalizations
- 475,000 TBI’s among 1-14 yrs old annually
- Rates higher ..age 0-4yrs old..
- Falls #1 cause ...MV #2
- Cost 60 billion direct and indirect costs
3.1 to 7 million people live with the consequences of TBI or ABI

1.4 million receive treatment in a hospital emergency room and are released

275,000 are hospitalized and survive

80,000 join the ranks of those with disabilities resulting from brain injuries

About 52,000 die

Report to the National Conference of State Legislators, 2001
Facts

- At least 3 TBI’s are sustained every minute
- Males are more likely to die than females
- Estimated cost TBI: 76.5 billion (year 2000 data)
TBI Public Health Burden

- 1.7 million TBI’s occur annually
- 80.7% resulted in ED visits
- 16.3% resulted in Hospitalizations
- 3% resulted in deaths

Faul, M. et al. Center for Disease Control and Prevention, NCIPC, 2010
TBI Act under HHS  1995

- HCFA grants to states
- CDC grants prevention state registries demonstrations projects
- NIH NIDRR....Basic neurosciences
- NCMRR ...rehabilitation research technologies

- Dept of Education NIDRR
- DOD VA research collaborations
TBI Produces Cognitive, Emotional, Behavioral, and Physical Disturbances

Brain Injury

- Cognitive Disturbance
  - Impaired Attention
  - Memory Disturbance
  - Language Impairment
  - Executive Dysfunction
  - Intellectual Loss
  - Irritability
  - Rage
  - Depression
  - Anxiety
  - Agitation
  - Aggression
  - Disinhibition
  - Apathy
  - Sleep Disturbance
  - Headaches
  - Pain
  - Visual Problems
  - Dizziness/Vertigo
  - Seizures

- Emotional Disturbance

- Behavioral Disturbance

- Physical Disturbance

(Silver 1994; Silver 2000; McAllister 1992; McAllister 1994; Kay and Harrington, 1993)
EMT

ER

ICU/Acute Hospital

Acute Rehabilitation

Subacute Rehabilitation
  • Coma management
  • Custodial
  • Restricted

ICU/Acute Hospital

Interdisciplinary rehabilitation assessment identifies goals to reduce disability
  • Cognitive
  • Emotional
  • Behavioral
  • Physical
  • Independent living
  • Vocational
  • Psychosocial

Goals for rehabilitation

No rehabilitation goals

Sufficient self-awareness to participate in realistic goal setting

Impaired self-awareness

Safe in outpatient setting

Unsafe without supervision, or severe behavior problems

Comprehensive (holistic) day treatment

Residential community reintegration

Outpatient community re-entry

No services, or community-based services only

Neuro-behavioral

Outpatient community re-entry

Comprehensive (holistic) day treatment

Residential community reintegration

Neuro-behavioral

Outpatient community re-entry

Comprehensive (holistic) day treatment

Residential community reintegration

Neuro-behavioral
TBI  ........a new understanding

- For many Brain Injury is not an event or an outcome
- Severe Brain Injury may be the start of a chronic condition that is disease causative or disease accelerative
- CBI can manifest itself in varying physical, cognitive, psychosocial, communicative, behavioral deficits at different points across the lifespan resulting in debilitating and disability, poorer quality of life and costly dependence on the family and society
Brain Injury... a causative disease

- Musculoskeletal
- Osteoporosis, osteoarthritis
- Epilepsy
- Cognitive decline
- Parkinson’s disease/ Alzheimer Disease
- Endocrine issues
- Women’s health
“a deviation from or an 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, an whose etiology, pathology and prognosis may be known or unknown,
WHO defines Chronic Disease

One or more:

- Permanent
- Leaves residual disability
- Caused by non-reversible pathological alteration
- Patient requires special rehabilitation training
- May be expected to long period of supervision, observation or/and care

World Health Organization, 2002
Aging with Brain Injury

- Aging deficits + brain injury deficits
  - Impaired cognition, motor control & balance
- Medical, functional, cognitive, social changes
  - Improvement, no change, worsening, new issues
- Impact of inactivity and weight gain
- Effects of trauma
- Does the injured brain respond differently to the aging process than an uninjured brain?
- Programmed neurologic change due to TBI?
- What is the impact of decreased brain tissue reserve?
Prioritized Services for Persons with Physical, Cognitive, & Sensory Impairment

- Advocacy
- Income Support
- Vocational Training
- Personal Assistance Services
- Specialized Medical Services
- Family Support Services
- Assistive Technology
- Basic Needs: Housing
- Basic Needs: Education
- Basic Needs: Transportation
- Basic Needs: Employment
- Basic Needs: Recreation
- Professional Training
- Independent Living Skills
- Case Management
Case Management

- An absolute necessity over a lifetime of needs
- Knowledge and expertise in TBI and long term issues
- Identified agency ..Sustainable ..attachment
- Collaborative... blend or braid funding and services
- Work with Family and advocates
What is *needed* over time

**Service coordination**
- Acute care
- Acute rehabilitation
- Next steps
- lead agency/organization
- insurance/public funding
- workers comp
- FAMILY
- Team building

**Case management**
- Case manager
- Case manager
- Next steps
- lead agency/organization
- insurance/public funding
- workers comp
- FAMILY
- Team building
Restoring Hope After Severe Brain Injury: The Spaulding Rehabilitation Network Disorders of Consciousness Program
The Traumatic Brain Injury Model Systems of Care

A project funded by the US Department of Education
National Institute on Disability and Rehabilitation Research
Mission

- **Clinical**
  Optimize functional recovery through the application of evidence-based assessment and treatment procedures in individuals with severe acquired brain injury (ABI) who have not yet regained the ability to reliably follow instructions, communicate or perform basic self-care activities.

- **Research**
  Conduct an integrated program of research designed to identify injury mechanisms that contribute to impaired consciousness, develop and refine diagnostic and prognostic assessment methods and investigate the effectiveness of existing and novel treatment interventions intended to promote recovery.

- **Education**
  Disseminate knowledge and provide resources to healthcare professionals, family members, caretakers, payers and policy-makers involved in the care and management of individuals with DOC.
Spaulding Brain Injury Program

- Brain injury Program and Disorders of Consciousness (DoC) Program systematic approach to evidenced based clinical care
- Interdisciplinary, trans disciplinary teams
- Adherence to standardized measurement tools
- Goal-oriented rehabilitation
- CARF Specialty Accreditation
- Safety-Care training for all clinical staff
Severe TBI
A broad range of severity and conditions
A hidden neglected population
Health care and HHS system responsible
Where are they in your state?

SNF’S
Families
Group Homes not appropriate
Institutions (facilities for the mentally ill)
Prisons
Homeless
Coma

- Coma is a state of pathologic consciousness in which the eyes remain closed and the patient cannot be aroused (MSTF, 1994)
Vegetative State

The vegetative state is a condition in which there is complete evidence for awareness of self and environment, with preserved capacity for spontaneous or stimulus-induced arousal.

(Aspen Workgroup, 2001)
Minimally Conscious State (MCS)

- The minimally conscious state is a condition of severely altered consciousness in which minimal but definite behavioral evidence of self or environmental awareness is demonstrated

  (Giacino et al., Neurology 2002)
Emergence from MCS occurs when there is reliable demonstration of either a yes-no communication or functional object use. This condition is also referred to an acute confusional state.

Giacino, et al., Neurology 2002)
BI Patients admitted to SRH

- 2012  BI program 448 / DoC program 59  Boston
- 2012  DoC program 65  Cambridge
- 2013  BI program 250 / DoC program 22  Charlestown
- 2013  DoC program 28  Cambridge

Discharge disposition ongoing challenges
Disorders of Consciousness and Disorders of Care: Families, Caregivers, and Narratives of Necessity

From the Division of Medical Ethics, Weill Cornell Medical College and The Rockefeller University, New York, NY
Patients with Disorders of Consciousness: the struggle

- “Patients most often not beneficiaries of advances in the neuro sciences” (1) Fins, J. Archives of PM and R article in press

- “Patients victims of pervasive level of neglect influenced by culture and attitude and lack of health care system which discounts the possibility of recovery despite scientific evidence to the contrary “ (2) Fins, J: Archives of PM and R

- Misdiagnosis all too common
- Impact of reimbursement under “medical necessity”
- Challenges proposed under the ACA
CONSEQUENCES OF Lack of Systems of Care:

- May prevent access to rehabilitation.
- May delay the use of interventions that might otherwise promote recovery.
- May lead to inappropriate or harmful interventions, including withdrawal of care.
- BENEFITS OF INITIAL CARE LOST
- Disability and medical complications increase as does cost.
Challenges to Care

CMS holds the Keys

- Medicare and Medicaid rulings and eligibility criteria
- Medical necessity rulings not working. Behavioral and cognitive issues disregarded impacting acute and post acute rehabilitation
- Reimbursement for needed specialists
- Lack of needed specialists
- Specialized Skilled Nursing Facilities
- Community based services including residential services
- Provider Licensure
- Establish System of Care
Disorders of Consciousness Program
27 Patients

Facility Discharges
2011

<table>
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<tr>
<th>Facility</th>
<th>Discharge Count</th>
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<tr>
<td>Tewksbury</td>
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<tr>
<td>Middleboro</td>
<td>6</td>
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<tr>
<td>Crotched Mt</td>
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<tr>
<td>SHC</td>
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</tr>
<tr>
<td>Other Rehab</td>
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</tbody>
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TBI: An Agency Puzzle: who owns our population????

- Health and Human Services
- National Institutes of Health
- NINCD; NCMRR; NIMH; NIA
- HRSA (Health Research & Services Adm.)
- Numerous agencies under this umbrella
- CDC - Center for Injury Control
- SSA (Social Security Adm.)
- CMS: Centers Medicaid and Medicare ********
- SAMSA: Substance Abuse and Mental Health Services
Federal Agencies INVOLVED

- U.S. Dept of Education /OSERS
- NIDRR: National Institute of Disability and Rehabilitation Research
- RSA: Rehabilitation Services Administration
- OSEP: Office of Special Education Programs
AGENCIES (cont)

- NTSHA: National Traffic Safety Highway Administration
- VA: Veterans Administration
- DOD: Department of Defense
Lifetime Challenges

- Coma To Community...And The Journey Begins!
- Where You Are ...Who You Are...And Who Pays!!!!!!!
- Access
- Adequacy
- Affordability
- Family Involvement
- Community Support
Human and Fiscal Capital

- Expertise, Experience, Energy, Tenacity, Creativity, Risk Taking, Collaboration, Data collection, Registries, Legislation, Funding Streams, .......Advocacy + Desire to Respond

- Consumers (Survivors, Families, Friends)
  Professionals of multiple disciplines
  Providers, Organizations, Business
  Federal and State Agencies
  Research and Training
  Funding.....Multiple Revenue Streams
  Funders
Addressing Needs 1980-2013

- Public Awareness
- Provide Information, Education, Training
- Create Services: Coma to Community
- Identify And Raise Funding Sources
- Create Legislation And Policy
- Research $$$ - Basic to Rehabilitation
- Prevention: Education and Legislation
- Healthcare reform and future of Rehabilitation (research to practice)
Resilience of survivor and family

- Is it a trait or a process
- Is it one’s coping skills
- Is it one’s personal internal and external resources
- Is it one’s life experiences
- Is it one’s upbringing, networks, communities
- Is it one’s ability or desire to communicate, collaborate
- Is it one’s ability to seek resources, to question,
- Is it willingness to learn the art and value of Advocacy
2010: TBI Incidence in the Commonwealth

- 768 Fatalities
  - falls 294; 187 mv; 145 suicide, firearms

- 5,944 Hospitalizations
  - 3,701 falls; 1,039 mv, ped, mcycles; 362 assaults,

- 60,725 ER visits
  - falls 29,210; MV 8,084; struck by 15,579

Data collected from all Massachusetts acute care hospitals
• Thank You for being here

• Pleased to introduce Debra Kamen, Assistant Commissioner of MRC and my good friend and supreme advocate of those who live with TBI and their families
MASSACHUSETTS SUPPORTS

- **STATE HEAD INJURY PROGRAM UNDER MASS REHAB COMMISSION FUNDED BY STATE LEGISLATION** under a defined line item advocated for annually

- **11.2 m 95% ON RESIDENTIAL PROGRAMS**

- HITS funded at 60% . July 1 at 75% at 7.5M

- Conference committee established HITS fully funded in 2014...should bring added revenues

- BIA-MA contract 1.3 m for services
Report of TBI Commission led by Sen Harriet Chandler and Rep Thomas Conroy
- addressing gaps and service needs across the Commonwealth
- recommendations sent to Gov Patrick Dec 2011
- Report available upon request
SHIP SERVICES

Eligible candidates

- Service coordination/CM
- Residential
- Individual skills training and support
- Companion services
- Consultations
- Substance abuse services

Services regardless of eligibility

- I and R
- Social and recreation programs
- General consultations schools, agencies and programs
- Outreach to homeless
- Outreach to Veterans
What do People Need?

- Assessment/Evaluation
- Behavioral Services
- Community/Family Education
- Companion Services
- Durable Medical Equipment
- Emotional Support
- Financial Assistance
- Housing
- Individual/Family Counseling
- Legal Advice
- Life Skills Training

- Long-term Residential
- Personal Care
- Recreation/Socialization
- Respite
- Special Education
- Supported Employment
- Substance Abuse Treatment
- Rehabilitative Therapies
- Transportation
- Vocational Services
Resources and Information

- BIAA and State Associations
- The United States Brain Injury Alliance
- ACRM (American Congress of Rehab Medicine)
- NABIS (National Association of BI Specialists)
- TBIMS (Traumatic BI Model Systems)
- NASHIA (National Assoc. State Head Injury Administrators)
- Brain Trauma Foundation
Severe TBI/ABI After all these years...Still a Civilian Silent Epidemic

Marilyn Price Spivak, Neurotrauma Outreach Coordinator
Spaulding Rehabilitation Hospital
&
Debra S. Kamen, Assistant Commissioner
Massachusetts Rehabilitation Commission (MRC)

National Home and Community Based Services Conference
September 12, 2013
Development of the Statewide Head Injury Program (SHIP)

- First state-operated program for those with TBI
- Part of the MA Rehabilitation Commission
- Initial funding sources & resources
- Service coordination vs. Case management
- Hx of the development of services in MA

Out-of-state placements
Priority categories for applicants (P1 - high risk population)
Development of a secure Neurobehavioral Unit (NBU)
Development of SHIP (cont’d)

- Shifting focus to the needs of those living in the community
- Development of a community-based system of services statewide
- Range of programs & supports based on need
- Collaboration with community-based providers & capacity development
- Critical training needs
Development of SHIP (cont’d)

- Expanded funding streams:
  - Trust Fund
  - Grants & Underserved Populations
    - Multicultural outreach
    - Veterans
Community First Initiatives in MA

Acquired Brain Injury Waivers

- Hutchinson Class Action Law Suit
- Focus on those in facilities and their desire to return to the community
- ABI Waivers -
  - Non-Residential and ResHab
  - Eligibility criteria
  - Clinical criteria
  - Cost caps
  - Waiver Services
Acquired Brain Injury Waivers Eligibility Criteria

- MassHealth member or eligible for MassHealth Standard once in the community
- Sustained an ABI at the age of 22 or older
- Currently residing in a nursing facility, chronic disease or rehabilitation hospital for at least 90 days when applying for the waiver
- Expected annual care costs do not exceed the individual cost cap limits
- In need of waiver services, and can be safely served in the community with the services available in the waiver
- There are open slots in the waiver
Money Follows the Person

- Community First focus in MA
- Response to Olmstead
- Demonstration services
- MFP-CL and MFP-RS Waivers
  - Eligibility criteria -
    - Disability or elderly
    - Qualified facilities from & to
    - Expanded services
- State plan only option
MFP Waivers Eligibility Criteria

1. Residing in an inpatient facility for 90 or more **consecutive** days
   - Nursing facility
   - Chronic or rehabilitation hospitals
   - State psychiatric hospitals (for specific age group)
   - ICF/MR

2. Resident of Massachusetts

3. Eligible for Medicaid + at least 1 Medicaid-paid inpatient day

4. Consented to the program

5. Transitioning to an eligible residence
   - Home / apartment owned or leased
   - Community-based residential setting
MFP Waivers
Eligibility Criteria (cont’d)

6. Adults age 18 and over with disabilities
   - Frail Elders
   - People with intellectual and developmental disabilities
   - People with physical disabilities including acquired brain injury
   - People with mental illness
ABI-RH Waiver Services

ABI Residential Habilitation

- ResHab
- Supported Employment
- Assisted Living Services
- Day Services
- Occupational Therapy
- Physical Therapy
- Shared Living-24 Hour Supports
- Specialized Medical Equipment
- Speech Therapy
- Transitional Assistance - RH
- Transportation
ABI-N Waiver Services (cont’d)

ABI Non Residential

- Homemaker
- Personal Care
- Respite
- Supported Employment
- Adult Companion
- Chore
- Day Services
- Home Accessibility Adaptations
- Individual Support and Community Habilitation
- Occupational Therapy
- Physical Therapy
- Specialized Medical Equipment
- Speech Therapy
- Transitional Assistance
- Transportation
MFP Community Living

- Home Health Aide
- Homemaker
- Personal Care
- Prevocational Services
- Respite
- Supported Employment
- Addiction Services
- Adult Companion
- Chore Service
- Community Crisis Stabilization
- Community Family Training
- Community Psychiatric Support and Treatment (CPST)
- Day Services
- Home Accessibility Adaptations
MFP-CL Waiver Services (cont’d)

- Independent Living Supports
- Individual Support and Community Habilitation
- Medication Administration
- Occupational Therapy
- Peer Support
- Physical Therapy
- Shared Home Supports
- Skilled Nursing
- Specialized Medical Equipment
- Speech Therapy
- Supportive Home Care Aide
- Transportation
- Vehicle Modification
MFP Residential Supports

- Prevocational Services
- Residential Habilitation
- Supported Employment
- Addiction Services
- Assisted Living Services
- Community Crisis Stabilization
- Community Psychiatric Support and Treatment
- Day Services
- Home Accessibility Adaptations
- Individual Support and Community Habilitation
MFP-RS Waiver Services (cont’d)

- Medication Administration
- Occupational Therapy Peer Support
- Physical Therapy
- Residential Family Training
- Shared Living - 24 Hour Supports
- Skilled Nursing
- Specialized Medical Equipment
- Speech Therapy
- Transportation
MFP Demonstration Services for MFP Enrollees

- Transitional Assistance & Services
  - Identifying transitional support and service needs
  - Community re-integration activities
  - One time set up expenses
  - Arranging necessary services & supports
  - Housing Search
  - Home Adaptations
  - Specialized Assessments

- Case Management
  - Person Centered Service Planning
  - Ongoing oversight and monitoring of services including consumer satisfaction

- 24/7 on-call back-up

- Assistive Technology & Specialized Medical Equipment

- Orientation & Mobility Services
The MA Experience Today

- Although MA has accomplished a great deal in 30 years of focused efforts on people with brain injuries and their families, we have yet to design and implement a fully comprehensive and integrated system.

- Funding availability, (e.g. state, federal & private), and state priorities, (e.g. public, political & legal), have driven systems development and services.
1. In MA and nationally the pendulum has swung from providing necessary extended inpatient rehabilitation services critical to successful outcomes for those who sustain brain injuries to premature discharges.

2. In MA and nationally the pendulum has swung from providing necessary extended outpatient rehabilitation services critical to those who sustain brain injuries and their success at community re-entry to limits and caps on hours of rehabilitation.

3. In MA the pendulum has swung from serving those at highest risk in high cost placements out of state to bringing individuals back to MA & developing services closer to home, e.g. NBU & 24/7 community residences.
The MA Experience Today (cont’d)

4. In MA the pendulum has swung from serving those more complex and challenging individuals needing 24/7 services & structure due to high risks to those living in the community without supports.

5. In MA the pendulum has swung from serving and supporting those in the community to assisting those in institutional settings to transition to the community.

6. In MA there are no funds to support diversion from long term institutional settings.
Lessons for the Future

- This approach is short-sighted & costs the state more in the long run because the care/services & related spending is not flexibly managed and cannot be changed or reallocated as individuals' needs change.

- A truly comprehensive system for ABI needs to provide:
  * the right service/intervention
  * at the right time
  * for the right amount of time
  * in the right place
  * by the right people
  with the understanding that those needs are constantly in motion.

- There is a need for case managers with knowledge and expertise in ABI to assist the individual/family to access what they need, when they need it, from a flexibly designed system - optimally that case manager stays with the individual regardless of their journey and place of service.
Lessons for the Future (cont’d)

- State and federal officials need to recognize that there is a need for different locations of “care” at different times and for different people.

- To create such a system, states must include clinical expertise to help design and develop what is needed (e.g. neurology, physiatry, rehab professionals, clinical nurses, neuropsychology, or those who know how to provide community services).

- In order to stand the test of time, what is built must include management, finance and clinical leaders equally at the table to obtain the necessary balance.
Where do we go from here?

Advocacy

Policy Change

Necessary Funding

Systems Development/Re-design/Expansion

Comprehensive Community-Based Services

Availability, Flexibility, Quality & Choice for those with ABI & their Families