

POSITION PAPER

**JUDGES' BENCH BOOK - TIME FOR CHANGE:
STOP BEHAVIORAL HEALTH INVOLVEMENT &
DIVERT SURVIVORS TO BRAIN INJURY REHABILITATION**

"Brain injury" - When 1) a specific event in the past 2) has injured neurons & neuronal networks 3) resulting in compromised functional domains, 4) compromised future brain maturation (under age 23), and 5) diminished brain reserves, then 6) time, 7) protection, 8) funding sources, and 9) rehabilitation are needed.

1. Specific event (screen for a life history that includes such an event)
 - a. external trauma (fall, gunshot, whiplash, punch, explosion, blast, near suffocation, near drowning, falling object, concussion, sports concussion, shaken baby, freezing, excess heat, difficult birth, etc.)
 - b. internal trauma (fetal alcohol, poisoning, smoke inhalation, carbon monoxide, drug reaction, anesthesia, heart bypass, brain tumor, brain surgery, cardiac arrest, drug abuse, alcoholism, high fever, repeated epileptic seizures, infection, meningitis, etc.).
2. Injury to neurons/neuronal networks
 - a. death, wounded or dormant state of individual brain cells (neurons) prevents signaling
 - (1) lack of oxygen (anoxia)
 - (2) mechanical injury - shearing, twisting, crushing, penetration
 - (3) metabolic injury - inflammation, poisoning, heat
 - b. death/ silence/absence of individual neurons disrupts neural networks
 - (1) 10,000 million neurons in overlapping networks
 - (2) neuronal networks control all mental, emotional, sensory, & physical functions
3. Compromised functional domains (neuropsychological evaluation for deficits specific to brain injury)
 - a. impaired cognitive function is revealed by neuropsychological testing that identifies difficulties with memory (creation, storage, retrieval, short/medium/working/longterm, aphasia), judgment, attention, concentration, multi-tasking, anosognosia (loss of the ability to observe the self), apathy, loss of initiation (inability to start an activity), perseverance (inability to stop an activity), decision-making, planning, organization, visual comprehension/processing, and auditory comprehension/processing. Professionals that may be useful include a neuropsychologist specializing in brain injury, a physician specializing in rehabilitation (physiatrist), a speech & language therapist specializing in brain injury, etc.
 - b. impaired physical function is revealed by medical evaluation for difficulties with balance, gait, swallowing, vision (accommodation, tracking, blindness, one-sided neglect), hearing (background/foreground, deafness), paralysis, spasticity, coordination, slurred speech, seizures (40-60%), loss of taste/smell, fatigue, etc. Professionals that may be useful include a medical doctor who has specialized in rehabilitation (physiatrist), a behavioral optometrist, a neuro-ophthamologist, an audiologist, a speech pathologist, an ear/nose/throat physician, etc.)
 - c. impaired emotional function is revealed by neuropsychological testing that identifies difficulties with impulsivity, easy irritability, anxiety, mood swings, egocentric behavior, accommodating others, age appropriate behavior, violence and depression
 - d. IMPACT - at all times following a brain injury, individuals may be easily overwhelmed by an inappropriate environment (motion, flashing lights, noise, crowds, unfamiliar, complex), demands (loud, quick, more than one step, unfamiliar), stressful interactions (more than one person, more than one variable), unrealistic expectations (due to loss of prior habits, memory, academic skills, social skills, etc.). Most often, each individual has multiple deficits in all three functional domains, and will be progressively overwhelmed if their comfort zone is transgressed. This "overwhelm" is known as the catastrophic stress reaction - a meltdown, shutdown, walk away situation which one would want to avoid to preserve the energy of the brain for self-

healing. This comfort zone normally rises and falls moment by moment depending on fatigue, stage in recovery, last meal, dehydration, other illness, other stressors (grief, divorce, intensity of effort, duration of effort, move, birth) - and this is a normal part of brain injury recovery. Recovery includes recognizing and avoiding situations which may lead to a catastrophic stress reaction, re-learning skills, compensating for permanently lost skills, and learning to use assistive technology.

e. competence must be assessed by a neuropsychologist to allow for diversion into the CommCare Waiver or the PA Head Injury Program for rehabilitation.

4. Compromised brain maturation (prior to age 23 - age at each brain injury affects brain development)

a. 30% of children labeled seriously emotionally disturbed in the Chicago school system were actually brain injured. These children were noted as being more difficult in the classroom, than those without injury.

b. 85% of 1,000 consecutive male admissions to Minnesota's state prison system were found to have a history of brain injury. 200 had just one brain injury, while 650 had two or more brain injuries. Those with earlier injuries from birth to age 5 were more compromised.

c. injuries prior to age 23 will cause behaviors to be retained indefinitely that were normal for the chronological age at the time of injury.

d. interference with brain maturation may prevent the subsequent development of age appropriate milestones such as delaying gratification, understanding cause and effect, abstract reasoning, etc.

5. Diminished brain reserves

a. inefficient mental processing requires more energy and involves more neurons, leading to fatigue.

b. illness, emotional reactions, hunger, thirst, etc. will diminish the capacity for mental processing.

c. the damaged brain will show accelerated aging (sometimes 20 years) as capacity is already limited.

d. the risk of dementia and Alzheimers' may be greater.

6. Time needed for healing

a. the brain repairs at its own speed - and repair proceeds indefinitely

b. the medical severity of each separate injury does not predict outcome

c. basing expectations on 6 - 12 month progress is outdated by studies proving neuron repair/rerouting

d. five to ten years will generally be required to assess recovery potential

e. time is required to appreciate that there was an injury, grieve the losses as they are discovered, relearn walking/swallowing/speaking, relearn fundamental concepts such as gravity/volume/time/heat/cold/wind, relearn activities of daily living such as showering/dressing/cooking/opening doors, relearn skills such as telling time/reading/ arithmetic/making change/writing checks, learn to use compensatory strategies such as a date book/reminder watch/lists/wheelchair, adjust to improving capabilities, work out family relationships as independence increases, find another career, make new friends, etc.

7. Protection allows healing

a. brain reserves are limited at best, and there is little capacity to deal with any additional stress

b. all available energy must be reserved for the self-repair of the brain

c. unnecessary activities which lead to stress should be postponed until the brain is more efficient.

d. activities which create stress must be handled when functioning is optimal (rested, fed, calm, etc.)

e. suicidality increases for at least 15 years post injury to a rate 5 times normal, as the survivor gradually realizes losses, watches colleagues move ahead in life, and foresees the struggles that lie ahead.

f. the use of pharmaceuticals must be minimized and compatible with brain injury recovery.

8. Rehabilitation funding sources - not well known

a. Department of Public Welfare - provides adult brain injury rehabilitation under two Medicaid Waivers

(1) CommCare Waiver - 800-757-5042 - requires a brain injury caused by trauma

(2) OBRA Waiver - 800-757-5042 - requires a disability that began prior to age 22

b. Department of Health - provides one year of brain injury rehabilitation to adults under the PA Head Injury Program - call the DOH Brain Injury Help Line at 866-412-4755.

c. Medical Access - physical healthcare plan - capitation for brain injury does not include adult rehabilitation but occupational, physical, and speech & language therapy should be available - neurologists, psychiatrists, and other physicians (except physiatrists) lack training in the diagnosis and rehabilitation of chronic brain injury (thus the current traumatic brain injury physician education campaign by the Centers for Disease Control and Prevention) - BUT all disabled children under age 21 are Medicaid-eligible, and the Special Needs Coordinator should arrange rehabilitation (call Eric Ulsh, 717-705-8259, Special Needs Unit, Harrisburg)

- the general absence of an automatic brain injury rehabilitation protocol for disabled children violates the Medicaid Act at 42 U.S.C., Section 1396(d)(r)(5), Early & Periodic Screening, Diagnosis & Treatment:

(5) *Such other necessary health care, diagnostic services, treatment, and other measures described in subsection (a) of this section to correct or ameliorate defects and physical and mental illnesses and conditions discovered by the screening services, whether or not such services are covered under the State plan.*

d. Medical Access - behavioral healthcare plan - state model behavioral health contracts prohibit brain injury services - psychiatrists are not trained to assess or treat chronic brain injury - children's behaviors will trigger a mental health diagnosis and mental health medication with entrapment and warehousing in mental health facilities, to their great detriment, as years are lost, self-repair of the brain is prevented by drugging, treatment is geared to the wrong diagnosis, and drug side effects accumulate.

e. Medicare - begins 24 months after approval for Social Security Disability - no brain injury rehabilitation

f. the PA Auto CAT Fund provided brain injury rehabilitation but ended in 1989.

g. Workers' Compensation will provide but not routine - requires assertive worker/attorney.

h. Office of Vocational Rehabilitation - only 18 months - rejects those who need more help

i. Private/employer/commercial insurance - not required to cover brain injury rehabilitation - loss of job ends coverage - while spouse may have coverage, the divorce rate is over 90%.

9. Rehabilitation is essential

a. for brain injury rehabilitation providers, go to www.abin-pa.org, Resources, Resources, Rehabilitation

b. neuropsychological evaluations performed under optimal conditions of awareness are essential for determining competency, identifying deficits and strengths, and planning treatment.

c. these brain injury rehabilitation providers offer neuropsychological evaluations plus inpatient and outpatient care, including detoxification:

(1) Bryn Mawr Rehabilitation Hospital, Malvern, Dr. Edward Murphy, 610-251-5430.

(2) MossRehab at Elkins Park (part of Einstein), Tom Smith, 215-663-6690.

(3) Magee Rehabilitation Hospital, Philadelphia, Dr. Kelli Williams, 215-587-3000.

(4) Good Shepherd Rehabilitation Hospital, Allentown, Maria Labi, MD, PhD, 610-776-3278.

d. fortunately, under optimal conditions, the brain continues to repair and refine itself from the time of injury to the present as experienced by our members - some having been injured 50 years ago and some having been pronounced dead several times.

e. treatment providers and families will identify simple strategies to minimize stress and allow the brain to heal - including modifying the environment, simplifying requirements, providing for predictability, identifying calming strategies, and working together while the brain repairs itself.

f. substance abuse is likely before and more likely after an injury to the brain. Substance abuse further damages the brain, and increases the risk of another brain injury due to poor judgment. Treatment is essential but must be designed around the unique deficits and strengths of the survivor.

g. hyperbaric oxygen therapy will restore brain volume, definition & function - for case studies, SPECT scans, Curt Allen video, go to www.abin-pa.org, Education, Hyperbaric.

h. children with a history of brain injury should not be placed in the behavioral health, mental retardation, or juvenile justice systems without specific orders that compel neuropsychological services and brain injury rehabilitation. Unfortunately, there are no billing codes or rate structures for neuropsychologists within physical or behavioral healthcare contracts. Further, the state has set up contracting to prevent denial letters, thus parents can not appeal when services are refused. Using statistics on the Pennsylvania Department of Health website for 1995-1999, the total number of children under age 21 with a history of hospital admission for traumatic brain injury was almost 33,000 in 2004. Using the multiple of 5.6 there would be a total of approximately 180,000 children with a history of emergency room discharge for traumatic brain injury. All of these children should be monitored to age 21 so that the cognitive, physical and behavioral sequelae of brain injury can be recognized and addressed to prevent a lifetime of dependency or delinquency.

Contact us for customized training from the perspective of survivors and families.

Brochures and PowerPoints are available on our website www.abin-pa.org.