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MCHB/TBI

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Unidentified TBI:

The Importance of Screening to Find Those Who "Get Lost" and Those "Not Found"

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Moderator:

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Unidentified TBI:

The Importance of Screening to Find Those Who "Get Lost" and Those "Not Found"

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The Challenge

- Unidentified TBI is a major unrecognized cause of social, vocational and educational failure.
- Barriers prevent those with mild TBI from:
  - Self-identifying as having a brain injury
  - Gaining access to help
  - Addressing long-term TBI-related difficulties that affect their quality of life.

TBI Statistics: Incidence

- 180-250/100,000 per year
- 1.5 million per year
- 4,000 per day

(Bruns & Hauser, 2003)

How Does TBI Happen?

Each year:

- 398,000 people sustain a TBI in falls
- 280,000 people sustain a TBI in crashes
- 156,000 people sustain a TBI in an assault

Consequences of TBI

- 80,000 discharged from acute care and rehabilitation per year with significant disability.

  (Thurman, 1999)

- 50,000 deaths occur each year.

  (Langlois, 2004)

About 5.3 million individuals live with identified TBI in the United States.

TBI in the Medical System

- TBI accounts for 1 million visits to ERs per year.
- TBI accounts for about 10% of all calls to EMS in NYC.

  (Hayes, 2000)

TBI and Children

- TBI is the leading cause of death and disability in children.
- More than half of TBIs occur before age 25.

These are the numbers:
the count of identified TBIs.

Who remains uncounted?

The unidentified.

Who Remains Uncounted?

- Data do not include:
  - 425,000 people treated by MDs in office visits
  - 90,000 people treated in other types of outpatient settings
  - 320,000 soldiers returning from Iraq and Afghanistan who report a "probable" TBI; this is 20% of all who have served
- There are others (back to that later).

(Langlois et al., 2004; Rand Corporation, 2008)

In Sum:

Those identified as having a TBI:

Only the tip of the iceberg!

Failure to Identify TBI

- Those who “get lost”
- Those who are “not found” in the first place

“Getting Lost” after TBI

Many people with TBI are:

- Sent home from the ER without follow-up
- Sent home from acute care hospitalization without follow-up
- Sent home from rehabilitation without follow-up
- Sent home from war, often with other injuries, but with their brain injury unidentified

“Not Found” after TBI

Many individuals who sustain a mild TBI do not seek medical help; they may be:

- People who have been assaulted
- Soldiers exposed to blasts/explosions
- Women and children who are victims of domestic abuse and domestic violence
- People who get into bar-room brawls
- People who fall down stairs
- Children injured during sports or at the playground

Those who “get lost” or are “not found” in these ways are individuals with unidentified TBI.

Failure to Identify: How Does This Happen? (1)

- Injured individuals may have no immediate symptoms; people:
  - in accidents,
  - who fall
  - who are abused
- Soldiers who are “dazed” may not have any overt physical injuries.
- Children who are injured may not be observed by a responsible adult.

Failure to Identify: How Does This Happen? (2)

- Many physicians do not equate a concussion with a mild TBI and discount the symptoms of their patients.
- Many primary care physicians are not aware that a concussion or mild TBI may have long-term effects … they mistakenly believe that time heals all symptoms.

Failure to Identify: The Consequences

- Many people do not link the changes in function they experience to the blow to the head that they sustained, so they fail to recognize cause and effect.
- This is similarly seen with parents and teachers who fail to see the link between head injury and subsequent problems in children.
- People with unidentified TBI do not receive services that may be helpful for individuals with TBI.

Three Groups with TBI

- Those identified and receiving needed services
- Those identified but not receiving needed services
- Those unidentified (typically with mild TBI)

What is Mild TBI?

At least one of the following:

- Loss of consciousness (LOC)
- Loss of memory for events immediately before or after the injury (PTA)
- Altered mental status at the time of injury, i.e., dazed and confused, disoriented

(JHTR, 1993, 86-87)

What is Mild TBI?

Any period of observed or self-reported:

- Transient confusion, disorientation or impaired consciousness
- Dysfunction of memory around the time of injury (PTA)
- Loss of consciousness (LOC) lasting less than 30 minutes

(Report to Congress on Mild Traumatic Brain Injury in the US: Steps to Prevent a Serious Public Health Problem, CDC, 2003)

Mild TBI: Indicators

- LOC $\leq$ 30 minutes
- Glasgow Coma Scale score of 15, 30 minutes after injury
- PTA $\leq$ 24 hours

Mild TBI: Immediate Symptoms

- Seizures acutely following injury
- Among infants and young children: irritability, lethargy, vomiting
- Among older children and adults: headache, dizziness, irritability, fatigue, poor concentration

Mild TBI: "Two Types"

- Identified
- Unidentified

Mild TBI: Identified

- Of all identified TBIs, only 15% are moderate to severe injuries.
- Thus, 85% are "mild" injuries.
- That's a huge number, but . . .

Mild TBI: Identified

- But, only 15% have disabling symptoms one year post injury.
  (Alexander, 1995)
- Thus, most such injuries have no long-term consequences.

Mild TBI: Symptomatic

CDC estimates that:

- The incidence of symptomatic mild TBI is: 25-50 per 100,000 in the population.
- The unidentified group is about 25% of those who are identified.

Unidentified Mild TBI

Other estimates are larger:

- In non-disabled samples, 7-8% have experienced a mild TBI and persistent symptoms.
  (Gordon et al., 1998; Gordon, 1992)
- 7% in the New Haven catchment area study reported a LOC.
  (Silver et al., 2001)

Unidentified Mild TBI

If one extrapolates these percentages to the U.S. population: up to 21 million people have a TBI with persisting symptoms.

Most are unidentified.

Consequences

- Years of unnecessary anxiety and disability
- New Haven Study
  - 1/3 more health difficulties
  - 2/3 more emotional difficulties
  - 2/3 more on welfare or receiving disability payments
  - 4 times more likely to attempt suicide

(Silver, et al., 2001)

Consequences

- Sports Concussions
- Children

Sports Concussions

Between 1997 and 2000:

- 40,547 reportable injuries
- Concussions: 62% of all injuries

Sports Concussions

Most frequent:

- Women's lacrosse
- Women's soccer
- Men's ice hockey
- Men's lacrosse
- Men's football
- Women's basketball

(Corassin et al., 2003)

Sports Concussions

- 50% of a sample of soccer players (age 11-14) had signs of a concussion.
- 54% of high school football players had a concussion.
- 175,000 head hits per year in high school football. *(Powell, 1997)*
- 51% of NFL players have had 1 concussion; 30% had more than 3. *(New York Times, 5/17/01)*

Concussion: Consequences

- We do not know how many concussions a person can sustain before they become symptomatic.
- Concussion may have long-term effects on neurocognitive functions.

(Janada, 1999; Collins et al., 1999)

- In general, 12% of those with a TBI have a second injury.

TBI in Children

- On average 475,000 TBIs per year are experienced by American children age 0-14.
- 91.5% are released from hospital ERs.
- There are 75% more ER visits by children with TBI than by adults with TBI.

TBI in Children: USDOE

- Almost 6 million children are receiving special education.
- Very few children with TBIs are currently identified in our schools, only 5% of children predicted.
  - 24,000 identified
  - 500,000 predicted

(USDOE, 2006)

TBI in Children

- In our work in NYC schools
  - A lag of 5 years between injury and identification is the average.
  - 10% of those in regular education had a TBI.
- Data from Denver: about 40% of those referred to Special Ed have a TBI.

Why Are Kids Not Identified? (1)

- Most concussions go unnoticed.
- When noticed, there may be no follow-up.
- Some sequelae are delayed in their emergence; kids “grow into” brain injury .
- No connection is made between a blow to the head and the child’s school record.

Why Are Kids Not Identified? (2)

- Given the pressures on special education...there is a reluctance to acknowledge a new disability group.
- School personnel are not adequately trained to either assess or identify.
- This results in a high rate of misdiagnosis.
- If it “looks like LD or ADHD”, it does not mean that it is ADHD or LD.

(3)

Why Are Kids Not Identified?

BIGGEST REASON:

NO SCREENING!

Long-term Consequences of Unidentified TBI

- TBI is often co-morbid with other diagnoses:
  - Substance abuse
  - Depression
  - Criminal behavior
  - Homelessness
- TBI often initiates a pathway to social failure.

TBI and Substance Abuse

- More admissions = more failures
- More DSM-IV diagnoses
- More complex diagnoses
- Many with multiple injuries
- An example: first injury at age 14, not identified until age 35

TBI and Depression

- 60% of those with TBI are depressed at some point after injury.
- At any given time, about 20% are depressed and/or anxious.
- Those who are depressed don't function as well.

(Hibbard,2003; Ashman, 2004)

TBI and Criminal Behavior

- 87% of those incarcerated have experienced a TBI.

  (Slaughter, et al, 2003)

- 82% of those incarcerated have had at least one TBI, 65% with a LOC.

  (Schofield, et al, 2006)

TBI and the Homeless

- Co-morbidity is about 50% (or much higher).
- Those with TBI have severe cognitive impairments.

TBI and War

- About 10% of wounded soldiers returning from Iraq and Afghanistan have had a TBI.
- If asked, about 70% report a jolt or blow to the head; 20% a "probable" TBI.
- Long-term consequences of TBI caused by blast injuries are unknown.

(1)

TBI and Domestic Violence

- 30% of battered women who are seen in the ER have had at least 1 prior LOC.
- 67% reported symptoms that could be TBI-related.

(Corrigan, 2003)

(2)

TBI and Domestic Violence

- Of 99 abused women interviewed, 75% had sustained at least 1 brain injury.
- 50% had sustained multiple partner-related and partner-inflicted brain injuries.

(Valera, 2003)

(3)

TBI and Domestic Violence

- In 53 abused women, average of 5 brain injuries in the prior year, with almost 30% reporting 10 brain injuries in previous year.

(Jackson & Phillips, 1998)

- Many partner-abusing men have sustained a TBI.

(Turkstra, et al, 2003)

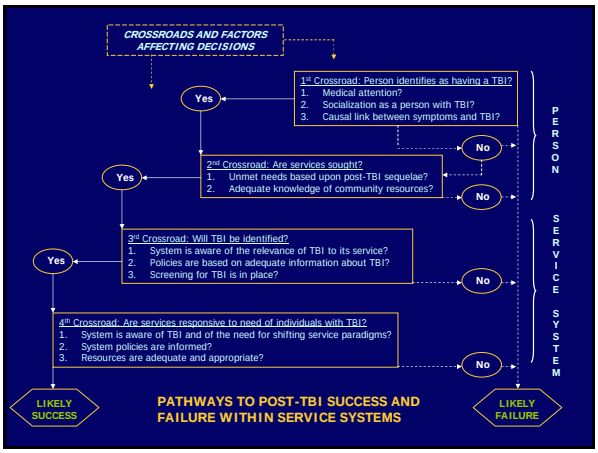
Lack of Identification

Consequences for all:

- Leads to misdiagnosis
- Leads to inappropriate treatment
- Results in mismatch between treatment and cognitive impairment
- Leads to failure

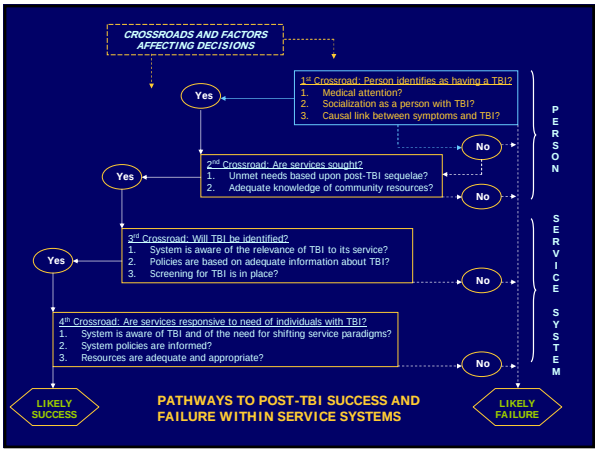
Pathways to Failure and Success

- For some with mild TBI, the challenges are brief and resolve quickly.
- Others with mild injuries face life-long challenges that require intervention from multiple service systems.
- Some succeed…some become social failures.



Crossroads to Success or Failure

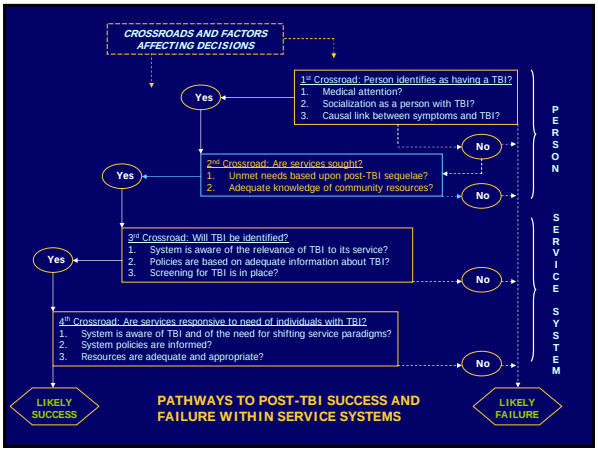
Four crossroads that pave the way to success or failure are traversed by people with TBI with persistent symptoms.



Crossroad #1 to Success or Failure

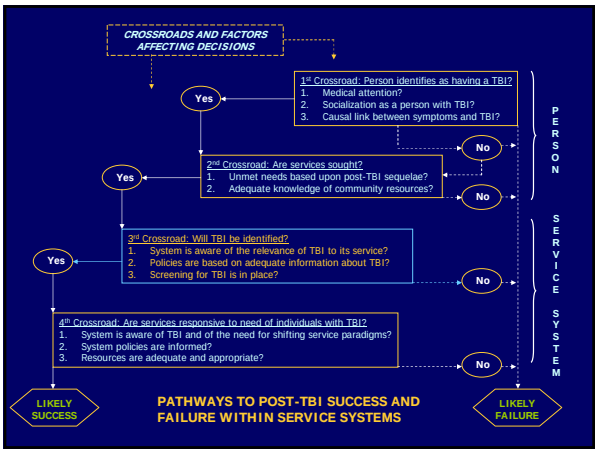
Self-identification by the person

- Those who seek medical attention are more likely to self-identify
- Those with greater awareness are more likely to self-identify



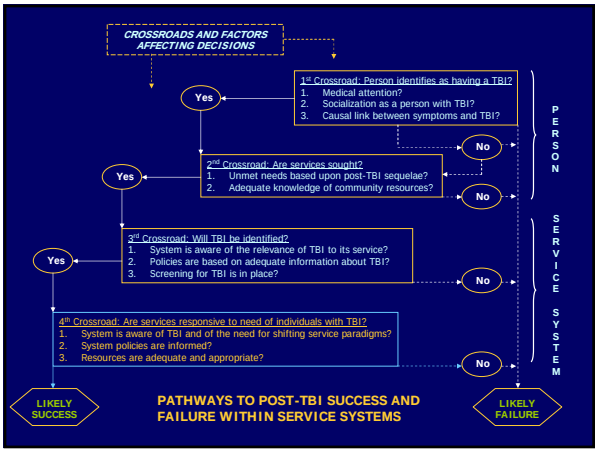
Crossroad #2 to Success or Failure

The person must seek out post-ER services.



Crossroad #3 to Success or Failure

The service system must correctly identify the person with a TBI.



Crossroad #4 to Success or Failure

TBI-appropriate services must be available. In order for these services to be available the system must recognize the complexity of TBI and the consequent diversity of needed services.

Achieving Post-TBI Success

- Thus, success depends upon the person self-identifying as a person who has experienced a TBI and upon him/her seeking services.
- And, a service system is needed that identifies the person and provides services that are responsive to the person's needs.

Achieving Post-TBI Success

- How can we identify the unidentified -- both those who "get lost" and those "not found" (yet!)
- We need to screen. But, how?
- The Brain Injury Screening Questionnaire (BISQ)

Brain Injury Screening Questionnaire

The BISQ is based on the *HELPS Card*, developed by Picard, Scarisbrick and Paluck (1991), and on the *Symptoms Checklist* developed by Lehmkuhl (1988) at TIRR (Houston) and a symptom list developed by Kreutzer and colleagues (undated) at the Medical College of Virginia.

Brain Injury Screening Questionnaire

- Step 1: Identify events associated with LOC or being dazed and confused after a blow to the head
- Step 2: Does the person experience persisting symptoms associated with one or more events consistent with TBI? Are these symptoms unique to TBI?
- Step 3: Rule out other potential conditions

Brain Injury Screening Questionnaire

- Symptoms unique to TBI:
  - A specific cluster of symptoms is more commonly found in people with TBI than in those with no TBI
  - Cognitive symptoms are the differentiators
  - Physical and behavioral symptoms are not sensitive to TBI
- Gordon, W.A., et al. (2000). The sensitivity and specificity of self-reported symptoms in individuals with traumatic brain injury. *Brain Injury, 14,* 21-33.

How Is BISQ Screening Done?

- Step 1
  - A list of ways a person might sustain a brain injury, e.g., while on the playground, car crashes, high fever
  - Determination if loss of consciousness or a period of being dazed and confused occurred
- If the person is negative, the BISQ is complete

How Is BISQ Screening Done?

- Step 1
- If the person is positive, we have documented in Step 1:
  - Number of blows to the head, as well as etiology
  - Duration of loss of consciousness or duration of being dazed and confused
  - Age of "onset"

How Is BISQ Screening Done?

- Step 2
  - A list of 100 symptoms commonly or sometimes reported after a TBI, including the 25 that we found to be sensitive and specific to TBI
  - Identifies symptoms by type and total
  - Identifies symptoms that are unique to TBI

How Is BISQ Screening Done?

- Step 3
  - Ruling out other conditions that could account for the symptoms, e.g., premature birth, psychiatric condition, learning disability, substance abuse

What Happens Next?

- Refer the person for neurocognitive testing to determine the nature of the specific impairments
- Is the pattern of test data consistent with TBI?
- Develop an intervention plan, based on this information

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Questions and Answers

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