Creating a Community Coalition to Address The Problems of TBI in Persons Who Are Homeless:

The Appleton, WI Project

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2012 NATIONAL HEALTH CARE FOR THE HOMELESS CONFERENCE & POLICY SYMPOSIUM

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Overview

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A Traumatic Brain Injury

Is defined as

- an alteration in brain function,
- or other evidence of brain pathology,
- caused by an external force.

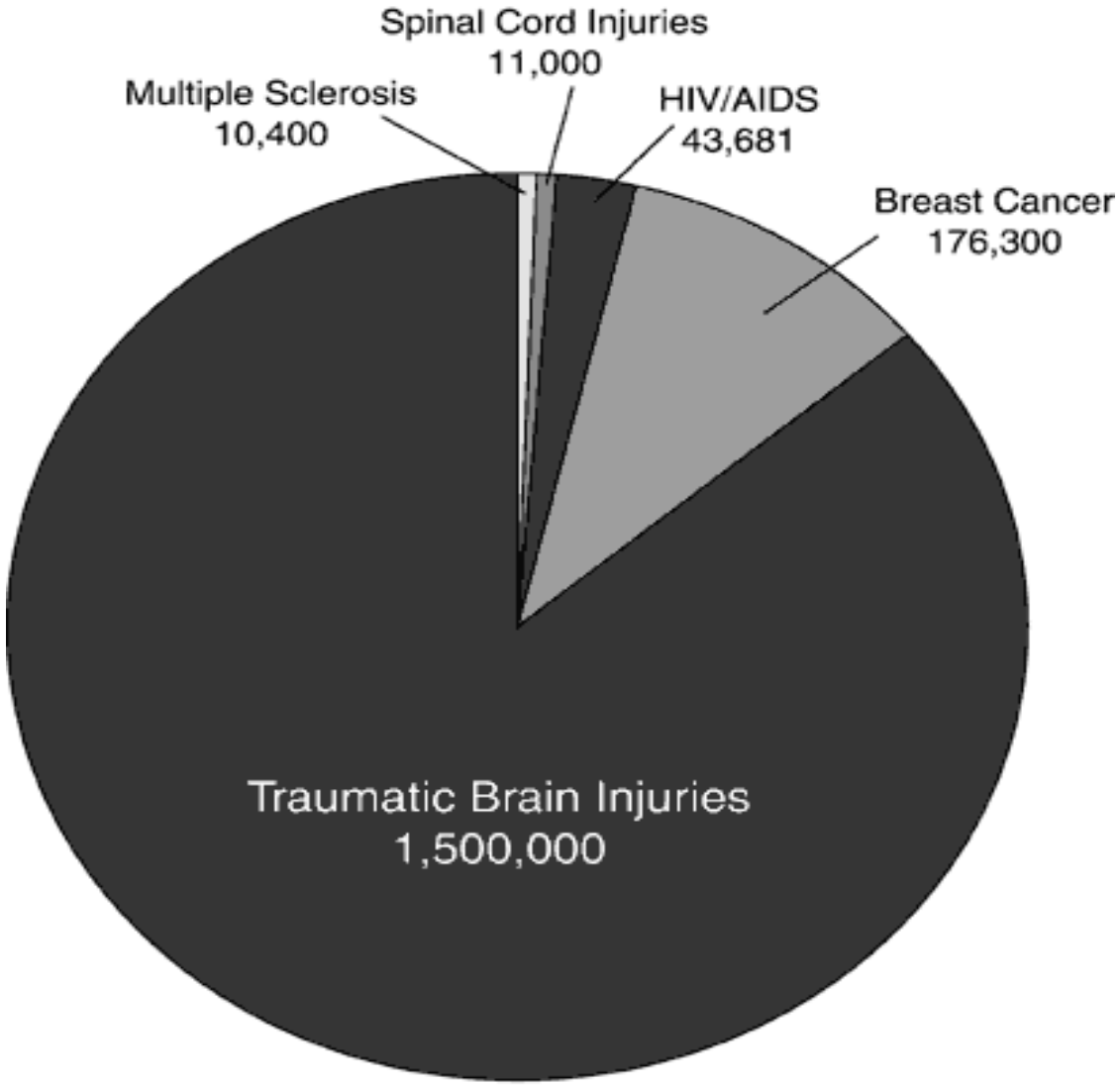
(BIAA)

Scope of the Problem

Each year

- Approximately 1.7 million persons sustain a TBI
- 1.365 million are treated and released from emergency rooms
- 275,000 are hospitalized
- 52,000 die
- Total number of “untreated” is unknown

At the present time 3.7 million Americans
are living with disabilities from TBIs



Comparison of Annual Incidence

Data compiled and arranged by the Brain Injury Association of America
based on data from the Centers for Disease Control and Prevention,
American Cancer Society and National Multiple Sclerosis Society

TBI: Cost to Society

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Higher Risk for TBI

- Special Populations:
  -
  - Homeless ~ 50%
  - Prisoners ~ 27% to 85%
- Males: 1.5 to 2 times risk
- Age: 15-45; < 5years; > 75 years
- **TBI: leading cause of death ages 15-45** (CDC)

TBI Data

- sample of homeless people:

  <u>58% in men, 42% in women</u>

- These rates are
  - **5 times higher** than in the general population
  - are comparable to the rates found among prison inmates
- The first TBI usually happened before the first episode of homelessness

(Hwang)

Boston Study: Data

152 **67%)** subjects in homeless shelters reported at least one head injury.

- 71% reported more than 1 injury.
- 73% reported losing consciousness with the injury.
- 73% reported being hospitalized after the head injury.

  77% of the 73% hospitalized had no follow up treatment
- **Only 23%** reported receiving any type of therapy after the injury (including speech, physical, occupational, language, psychiatric and behavioral).
- 44% reported using alcohol or drugs when the injury occurred.

Toronto Study

- and 18 meal programs over 12 months in 2005
- Data on 904 individuals
- Male-to-female ratio of 2:1
- Homeless families not included

(Hwang)

TBI Screening Question

"Have you ever had an injury to the head which knocked you out or at least left you dazed, confused or disoriented?"

(Hwang)

TBI among the Homeless

- TBI is common in the homeless
  - 50% (Hwang); 30% (Wilder Research)
- TBI often occurs before homelessness
  - 70% (Hwang); 55% (Wilder Research)
- Severity of TBI
  - 66% Mild TBI
  - 23% Moderate or severe

Persons with a TBI

- Became homeless at a younger age
- Experienced more years of homelessness
- Higher prevalence of
  - Seizures (22% v 8%)
  - Mental health problems (43% v 33%)
  - Alcohol problems (42% v 28%)
  - Drug problems (57% v 40%)

TBI Severity Definition

- "Mild"
  - "a head injury that left the person dazed, confused, or disoriented, but resulted in no unconsciousness, or LOC < 30 minutes"
- Moderate or Severe
  - "a head injury that resulted in unconsciousness for more than 30 minutes"

(Hwang)

TBI & Homelessness

- Mean age of first TBI --- 17.8 years
- Severity of the TBI
  - Moderate or severe 23%
  - Mild TBI 66%
  - Unknown 11%

(Hwang)

TBI: A Clinical Challenge

"Homeless persons with significant cognitive deficits can often appear to be very high functioning because of their superior communication and survival skills."

(Highley)

Typical Descriptions….

- “Unmotivated”
- “Unfocused”
- “Poorly organized”
- “Unable to plan ahead”
- “Unable to follow a train of thought”
- “Forgetful”

(Koss 1997, Walker 1991, Warshaw 1993)

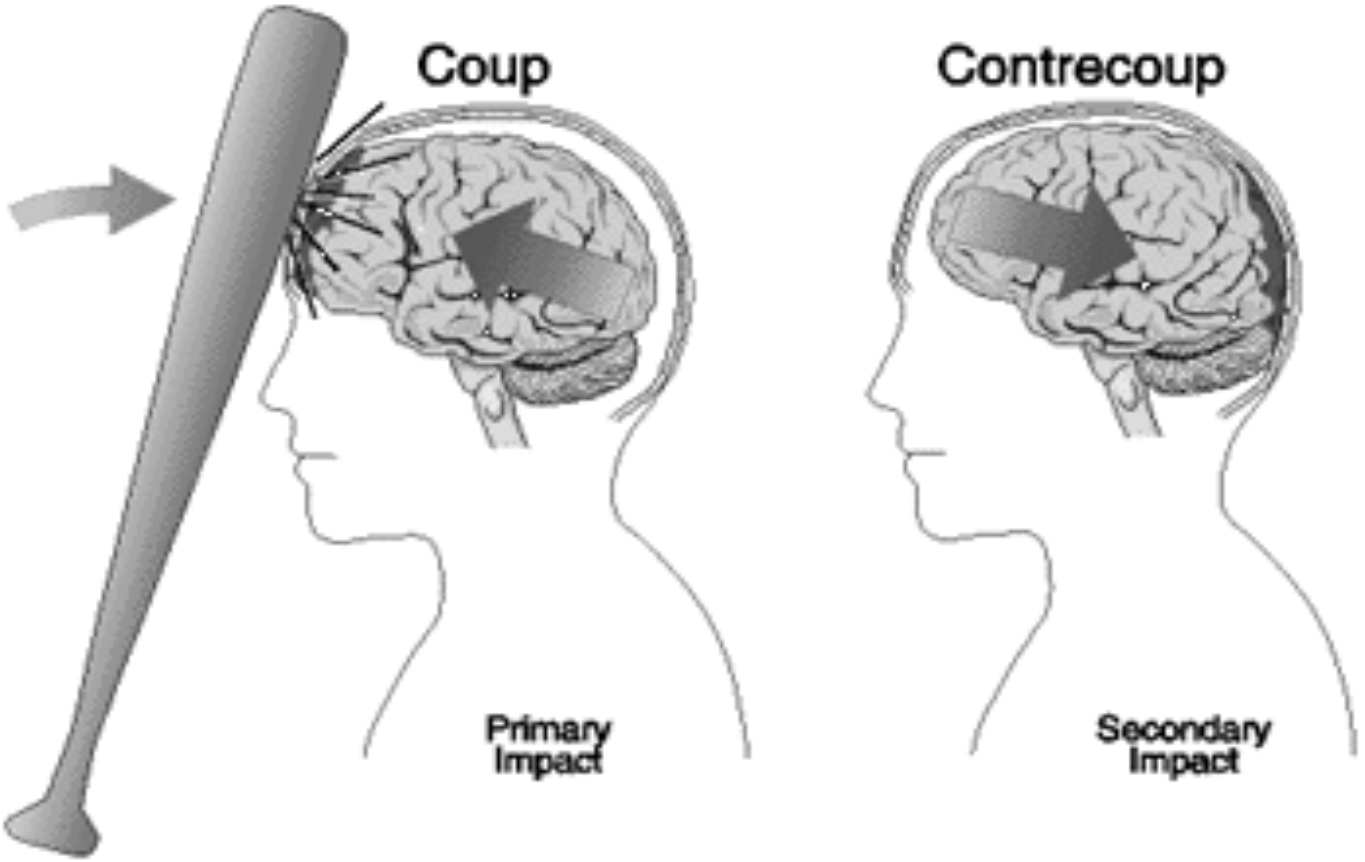
Persons with TBI are often called:

- “Lazy”
- “Poor historian”
- “Uncooperative” or “Non-compliant”
- “Attention seeking”
- “Irresponsible”
- “Unable to benefit from treatment”

What happens in a TBI ?

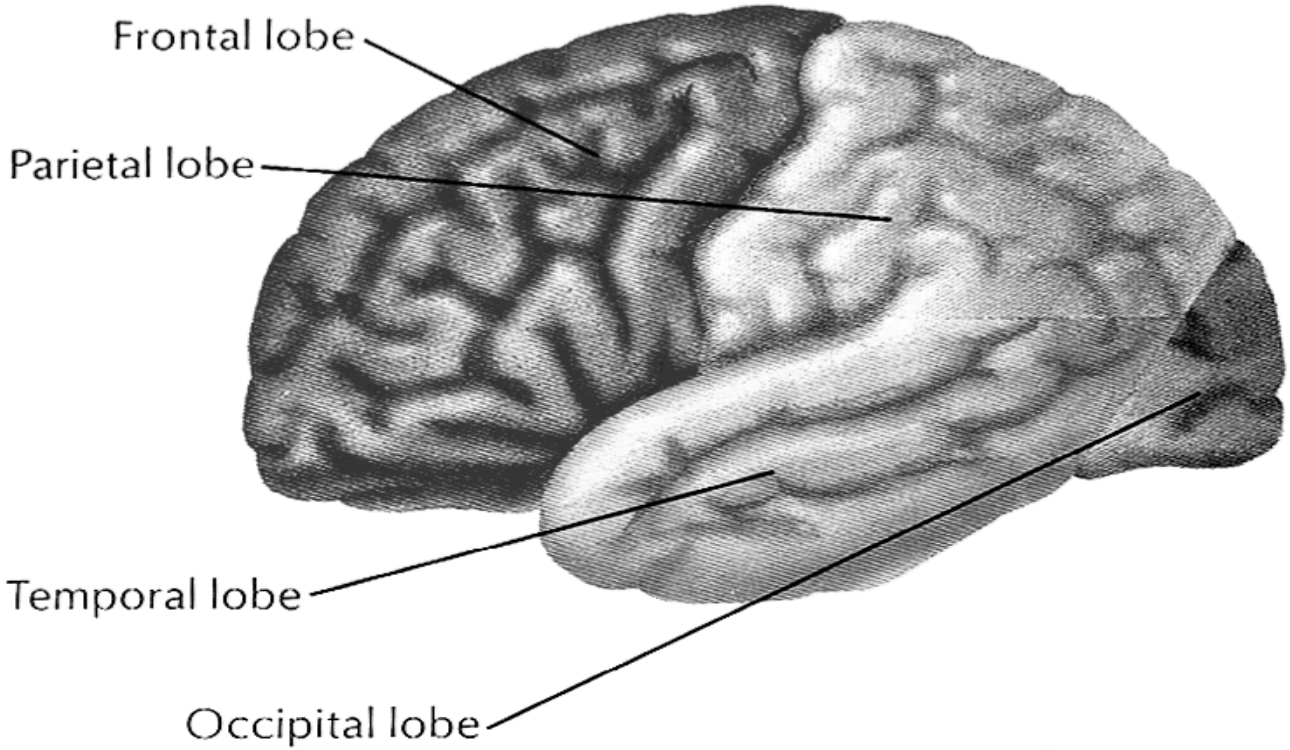
- Nerve fibers within specific areas of the brain are severed … never to be regained
- Nerve fibers are stretched … resulting in inefficient and slowed functioning
- Onset of physical, cognitive and behavioral changes after the TBI reflect impaired functioning due to these broken or stretched nerve fibers

Closed Head Injury



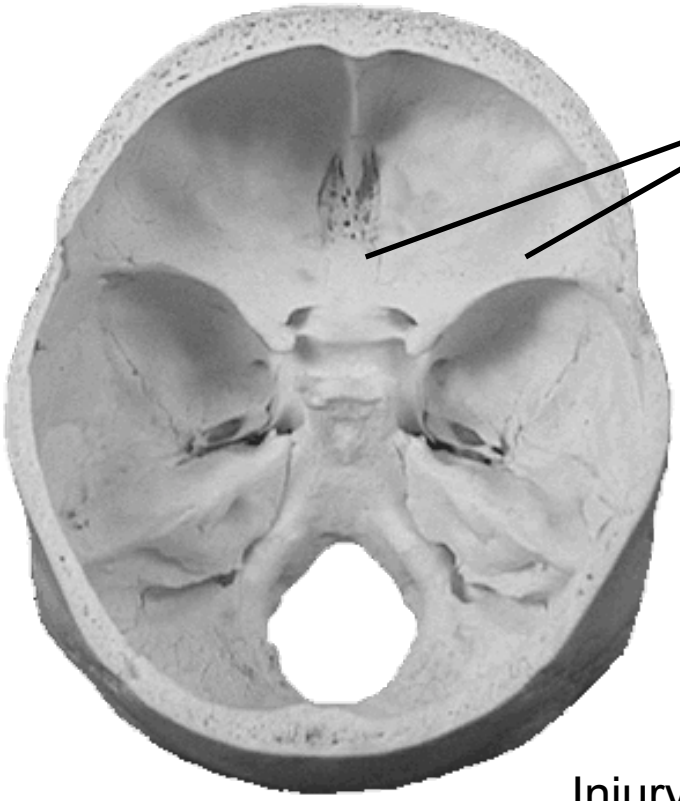
ALL-NET Pediatric Critical Care Textbook Source: LifeART EM Pro (1998) Lippincott Williams & Wilkins. www.med.ub.es/All-Net/english/neuropage/trauma/head-8htm

Areas of the Brain



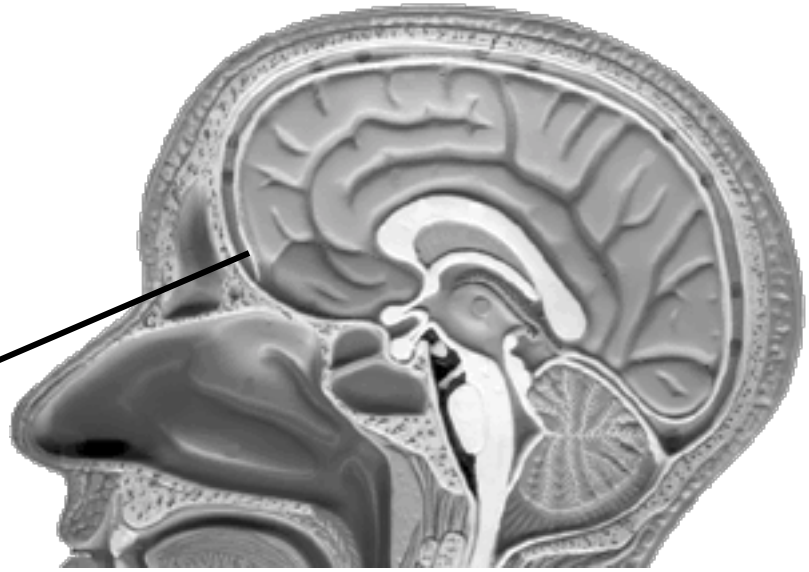
Lobes of the Brain: Frontal, Temporal, Parietal, Occipital

Interior Skull Surface



The base of the skull is rough, with many bony protuberances.

These ridges can result in injury to the temporal lobe of the brain during rapid acceleration.



Frontal Lobe Functions

- Planning/anticipation/initiation
- Problem solving/judgement
- Awareness
- Mental flexibility
- Ability to inhibit responses
- Personality/ emotions

Temporal Lobe Functions

- Memory and learning
- Organizing and sequencing
- Hearing
- Understanding language

Thinking Changes in "Executive Functioning"

Difficulty with

- planning and setting goals
- problem solving
- organizing
- prioritizing
- being flexible
- being aware of thinking changes in self

Thinking Changes

Attention

-
-
-
  tasks

Processing speed

- Slow thinking
- Slow reading
- Slow verbal and written responses

Thinking Changes (2)

Communication

- Difficulty finding the right words, naming objects
- Disorganized in communication

Learning and Memory

- Information before TBI intact
- Reduced ability to remember new information
- Problems with learning new skills

Physical Problems

- Fatigue
- Headaches
- Increased sensitivity to noise/bright lights
- Overall slowing
- Clumsiness
- Decreased vision/hearing/smell
- Dizziness

“The Fall”

- Fall off a ladder on May 19, 1999
- CT scan – small amount of bleeding
- Overnight hospitalization
- “Mild” TBI identification
  - “You’ll be back to your normal self”
- “Wandering in the Wilderness”
- 14 months later, finally TBI treatment

Major Problems for Me

- Ignorance
- Pain
- Automatic behaviors
- Fatigue
- Sensitivity to external stimuli
- “Brain Brown-out”
- “Emotional Isometrics”
- Loss of sense of self

Fatigue

Window of Awareness

0% Least Severe

25%

50%

75%

100% Most Severe

Allure of Alcohol

- Relieves pain from physical symptoms
- Helps to fill the time when I can't really function
- Blocks out emptiness and meaninglessness

General Time Line

- Sustained a “mild” TBI, May 19, 1999
- “Wandering the Wilderness”
- Finding appropriate treatment, 2010
- George Washington University, 2005-07
- Begin educating others, 2006
- TBI & homelessness presentation, 2008
- Creating the Community Coalition: ?

Appleton, Wisconsin

- Northeast Wisconsin community of 78,000
- 30 miles from Green Bay
- 95 miles from Milwaukee and Madison
- Strong tradition of community involvement in addressing the problems of poverty and homelessness

“Point-in-Time” homeless count in the Fox Cities, July 28-29, 2010

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  or living in cars, park shelters, under bridges, in storage units)

333 people Total of Homeless on 1 night

First Presentation on TBI & Persons who are Homeless

- Research and preparation
  - National experts
- Question and answer period
  - Powerful stories and example
  - "Aha" reactions
- Providers educated and inspired me
- Subsequent discussions

"Statistics are people with the tears wiped away”

Prof Irving Selikoff

Building the Coalition

- State conference
- Salvation Army
- Emergency Shelter staff
- Fox Cities Housing Coalition
- Harbor House and county child protection section

Community Groups

- Civic
- Library Lecture series
- “NoonHour” Philosophers
- L.E.A.V.E.N.
- Church groups

Professional Groups

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  Improvement Forum: WREN (Wisconsin Research and Education Network)

Coalition Members:
The Provider Groups

- COTS
- Emergency Shelter of Fox Valley
- Fox Valley Warming Shelter
- Fox Cities Housing Coalition
- Housing Partnership

Coalition Members:
The Provider Groups (2)

- Salvation Army
- Harbor House Domestic Abuse Program
- Christine Ann Domestic Abuse Services

Benefits of Local Funding

- Education of local community
- Education of local leadership
- Discovery of unexpected TBI problems
  - No-shows for Community Clinic
- More coordinated interventions
- “Institutionalization of the issue”

Community Needs to Know:

- TBI is very common in the homeless
  - 50% (Hwang); 30% (Wilder Research)
- TBI often occurs before homelessness
  - 70% (Hwang); 55% (Wilder Research)
- Severity of TBI
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- The symptoms of and the cost of TBI

Perspective on Brain Injury

- No two brain injuries are exactly the same
- The effects of a brain injury depend on such factors as cause, location and severity
- Adjustment is dependent on “before-after” changes in the person

What's next?

What's next?

Screening Tools

- **“HELPS”**
- **BISQ:** Brain Injury Screening Questionnaire
- **OSU TBI-ID-SF**: Ohio State University TBI Identification Method-Short Form
- **RBANS**: Repeatable Battery for the Assessment of Neuropsychological Status
- Other

What do we know?

- Data identifies that some of the homeless population have diagnosed or suspected brain injuries.

- Individuals' awareness or knowledge of history of brain injury is variable

- Knowledge of suspected or definite brain injury can be cause to consider a modification of expectations, approach due to possible cognitve difficulties.

What do we know? (2)

- Cognitive rehabilitation teaching compensation strategies for cognitive difficulties can be effective, especially when systematically taught.

- Environmental modifications can be employed fairly easily and economically to facilitate compensation for those unable to learn strategies themselves.

- Most staff working with the homeless population are not trained to do cognitive rehabilitation.

Is it possible to train staff working with the homeless to teach homeless individuals with brain injuries compensation strategies?

An exercise

Now is the time for you to come to the aid of your countrymen.

lepore

- Verbal instructions
- Discuss results: What did you do to succeed? Or did you?
- Could you do something different?

(Compensation strategies)

LEMSKY, 2011:
"Help clients learn how to think about their thought processes-planning, problem-solving and social interactions.

One of the biggest difficulties for staff may be learning to step back and facilitate progress rather than doing “everything” for client.

- Homeless man, 40s, staying at Salvation Army

- Frequent cell phone contact with ESFV staff person for needs and assistance.

- Agreed to meet with ESFV staff and cognitive therapist.

Results

- Listen to his story
- *Cue
- Give homework
- *Introduce compensation strategies

Cues

- Clues or suggestions to help come up with a solution, answer
- Direct
- Indirect
- Self

COMPENSATION STRATEGIES

- ▲ Stop and Think
- ▲ Double check
- ▲ Ask for help
- ▲ Ask for clarification
- ▲ Ask questions

What's Next?

- Develop Training Manual
- Offer Skype training
- Seek trials

  (If interested, contact Tom Tatlock)

Some Lessons Learned

- Ask national experts
- Ask “to be invited to speak”
- Identifying the right audiences
- Listen to your audiences
- It takes longer than you think

Passion, Preparation, Persistence, Patience, Humor, Hope & Flexibility

Summary

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Bicycling into the Wind

Thank you!

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