

Long Term Outcomes in TBI

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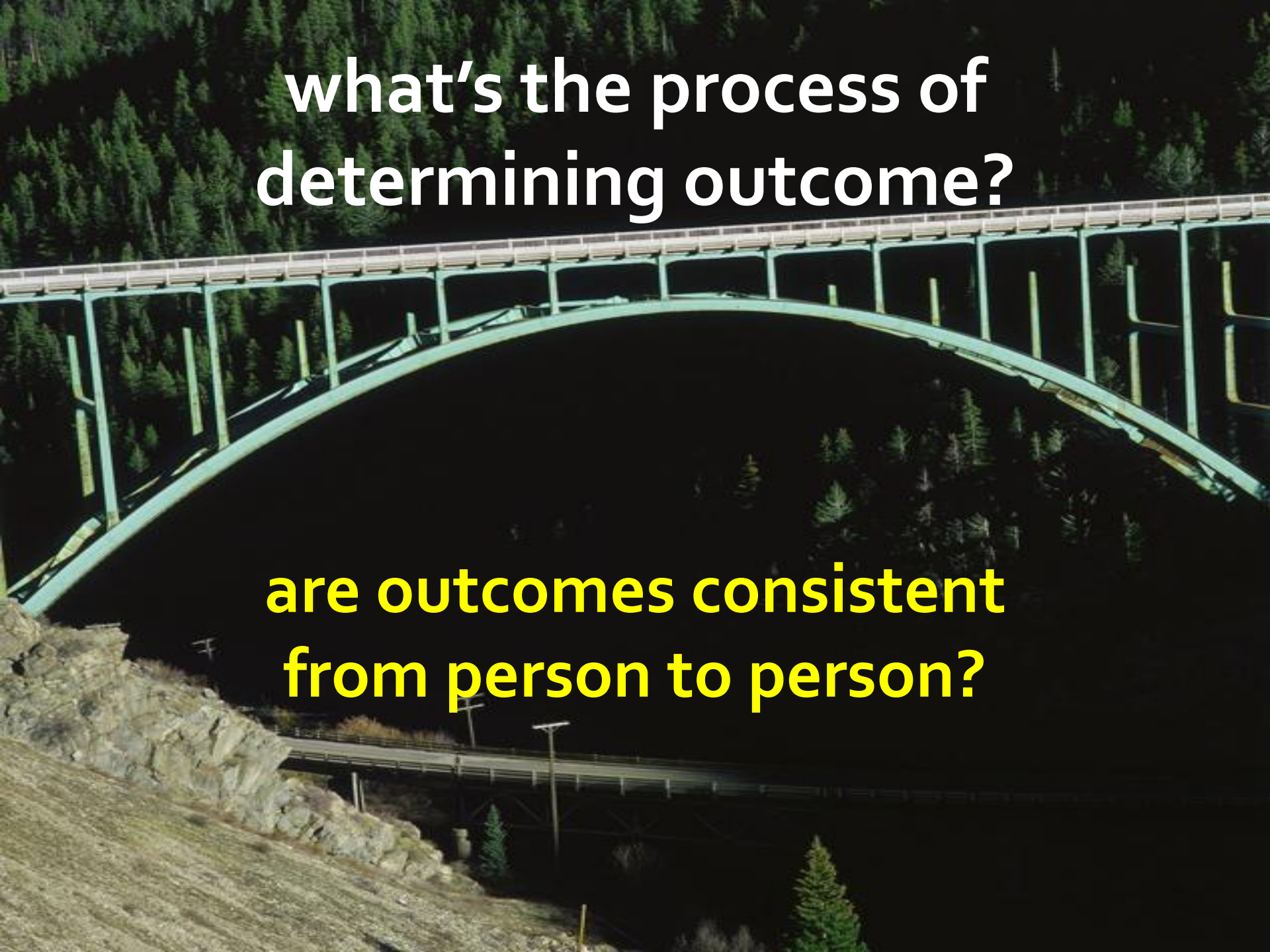
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“The New Normal” What Really is an Outcome from Brain Injury ?

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A large steel arch bridge with a green-painted structure spans a deep valley. The bridge has multiple lanes of traffic. Below the arch, a smaller bridge or road is visible in the distance. The background is a dense forest of evergreen trees. The foreground shows a rocky, grassy slope.

**what's the process of
determining outcome?**

**are outcomes consistent
from person to person?**

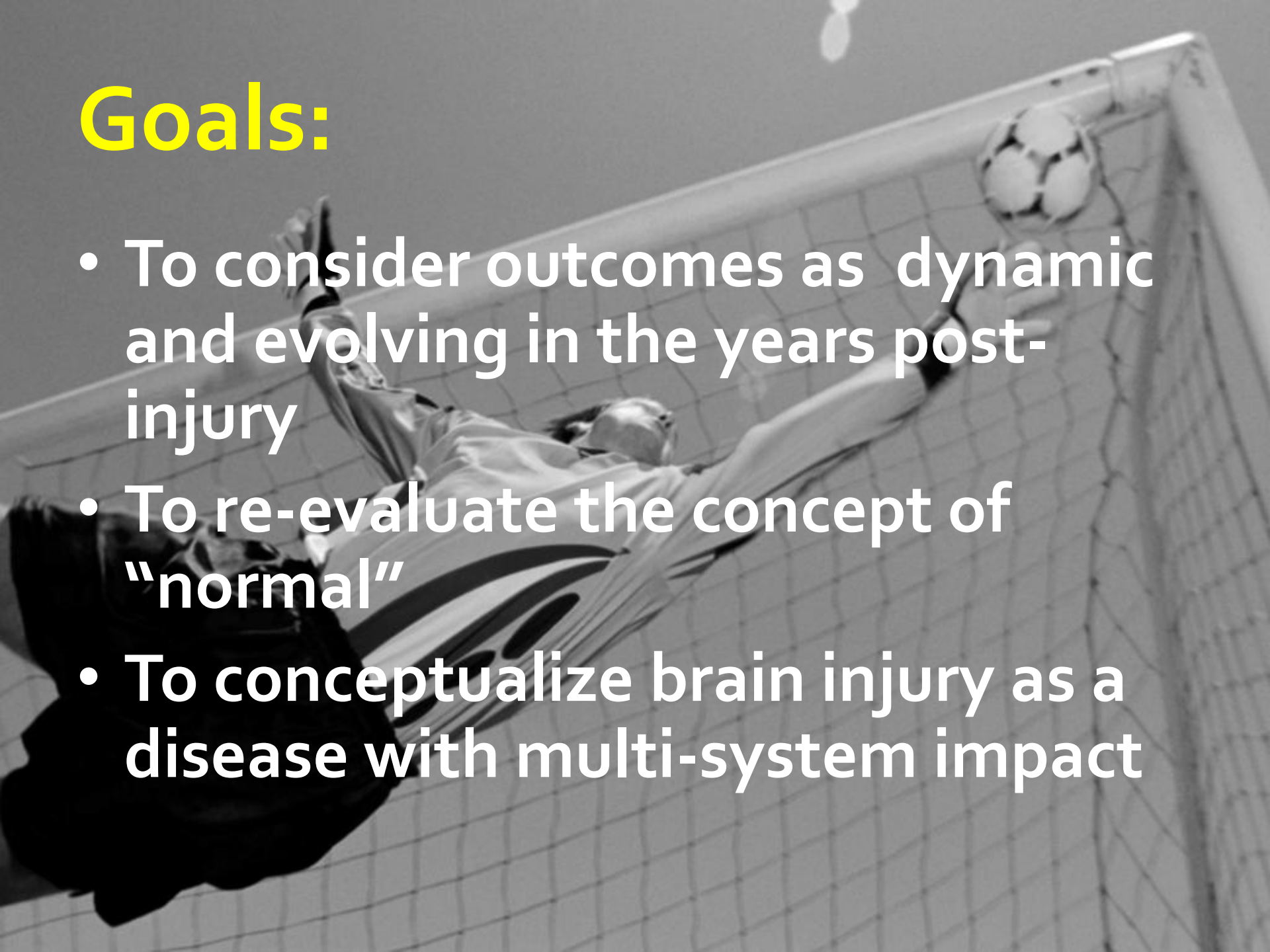
“create a new baseline and not
go back to where they were”

Alya Reeve, MD, University of New Mexico Hospital
From: “Every 21 Seconds or why I scream at the
refrigerator”

A film by Laura Napier and Doug Claybourne, New
Mexico Brain Injury Advisory Council, 2006

Goals:

- To consider outcomes as dynamic and evolving in the years post-injury
- To re-evaluate the concept of “normal”
- To conceptualize brain injury as a disease with multi-system impact



A close-up photograph of a man with light-colored hair and glasses, looking directly at the camera with a thoughtful expression. His hand is resting on his chin, and his teeth are slightly visible. The background is a plain, light color.

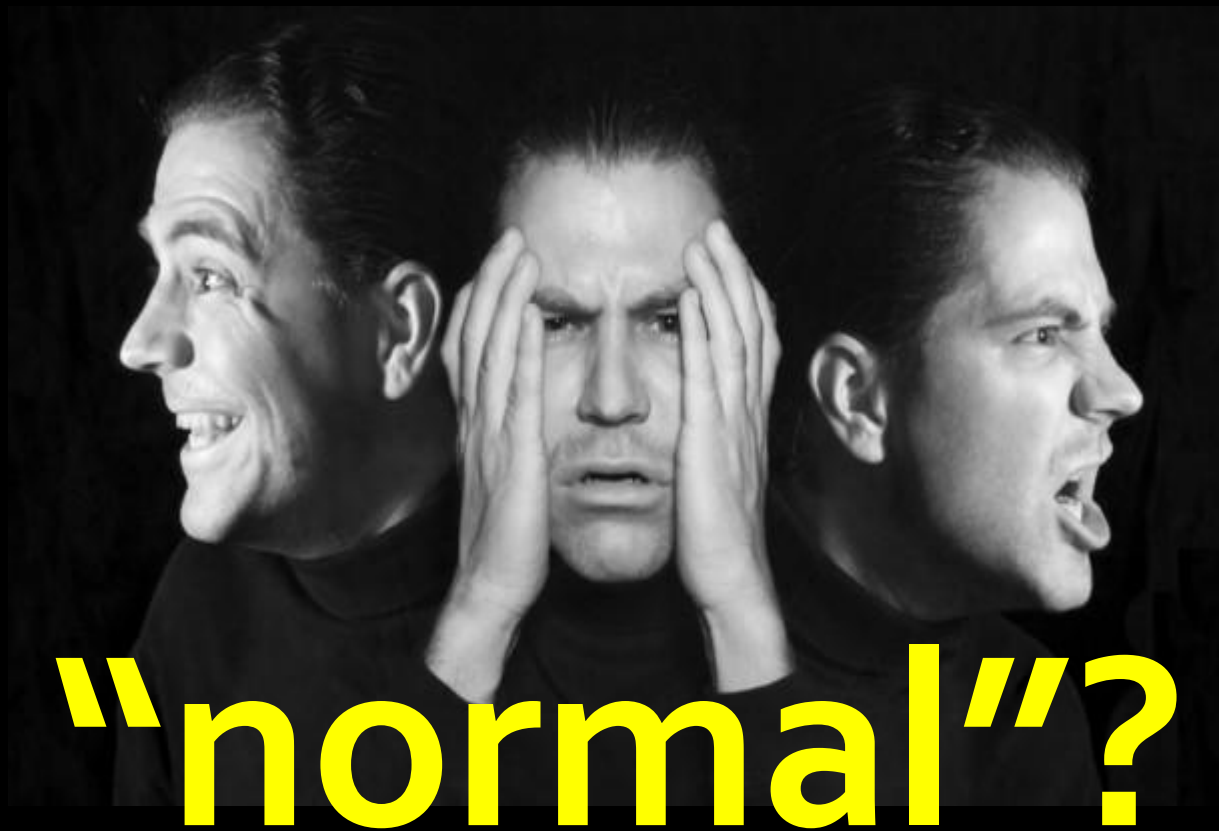
What are outcomes?

**When do
outcomes occur?**

outcome:

- something that follows as a result or sequence
- Synonyms: aftereffect; aftermath; backwash; conclusion; consequence; corollary; development; fate; effect; outgrowth; product; result; sequel; sequence; upshot

what's



"normal"?

normal:

- according with, constituting or not deviating from a norm, role or principle occurring naturally

what's **normal**
after a brain
injury?

who determines
what's "normal"?

When is “normal”
reached?

is there a **typical** brain
injury?

no more likely than
there is a **typical** person!

let's consider:

what's happened
to the person?

what's going to
happen to them in
the future?

what is realistic?

how do we get there?

From	Belt	Time	Status
Minneapolis	8	7:35 PM	Now 7:35 PM
Detroit	2	7:40 PM	On Time
Atlanta	6	7:41 PM	On Time
Washington-IAD	3	7:42 PM	On Time
Milwaukee	8	7:45 PM	On Time
Chicago-Midway	3	7:50 PM	On Time
Fort Worth	7	8:00 PM	On Time
Hare	8	8:20 PM	On Time
	2	8:50 PM	On Time
	8	9:15 PM	On Time
	9	9:30 PM	On Time
	2	9:40 PM	On Time
	8	9:55 PM	On Time
	5	10:15 PM	On Time
		10:19 PM	On Time
		5:55 PM	

life changes.

Are outcomes fact or expectations?



what time table



are they on??



**tomorrow? next week?
next month? next year?**

**exactly when will
things go back to
normal?**

but, what's **normal** ?

**when should we
measure
outcomes?**



A close-up, warm-toned photograph of a coiled measuring tape. The tape is yellow with black markings and numbers. The text "what are we really measuring?" is overlaid in white, bold, sans-serif font. The background is a soft, out-of-focus orange and yellow light.

**what are we really
measuring?**

at the time of the injury?





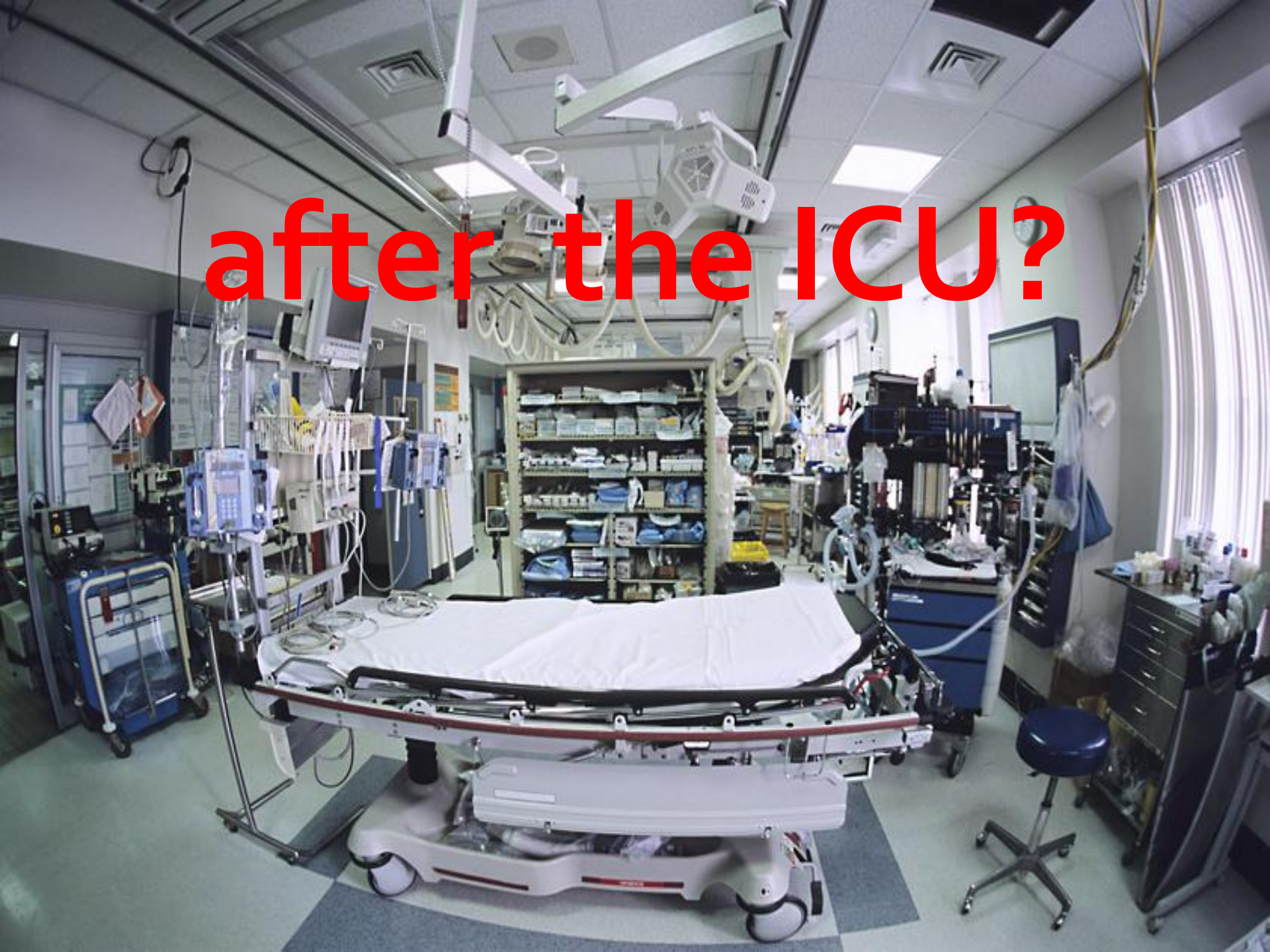
**at the beginning of
emergency medical
treatment?**



**“heaven and hell
existing within”**

from: Every 21 Seconds or Why I scream at the Refrigerator

after the ICU?



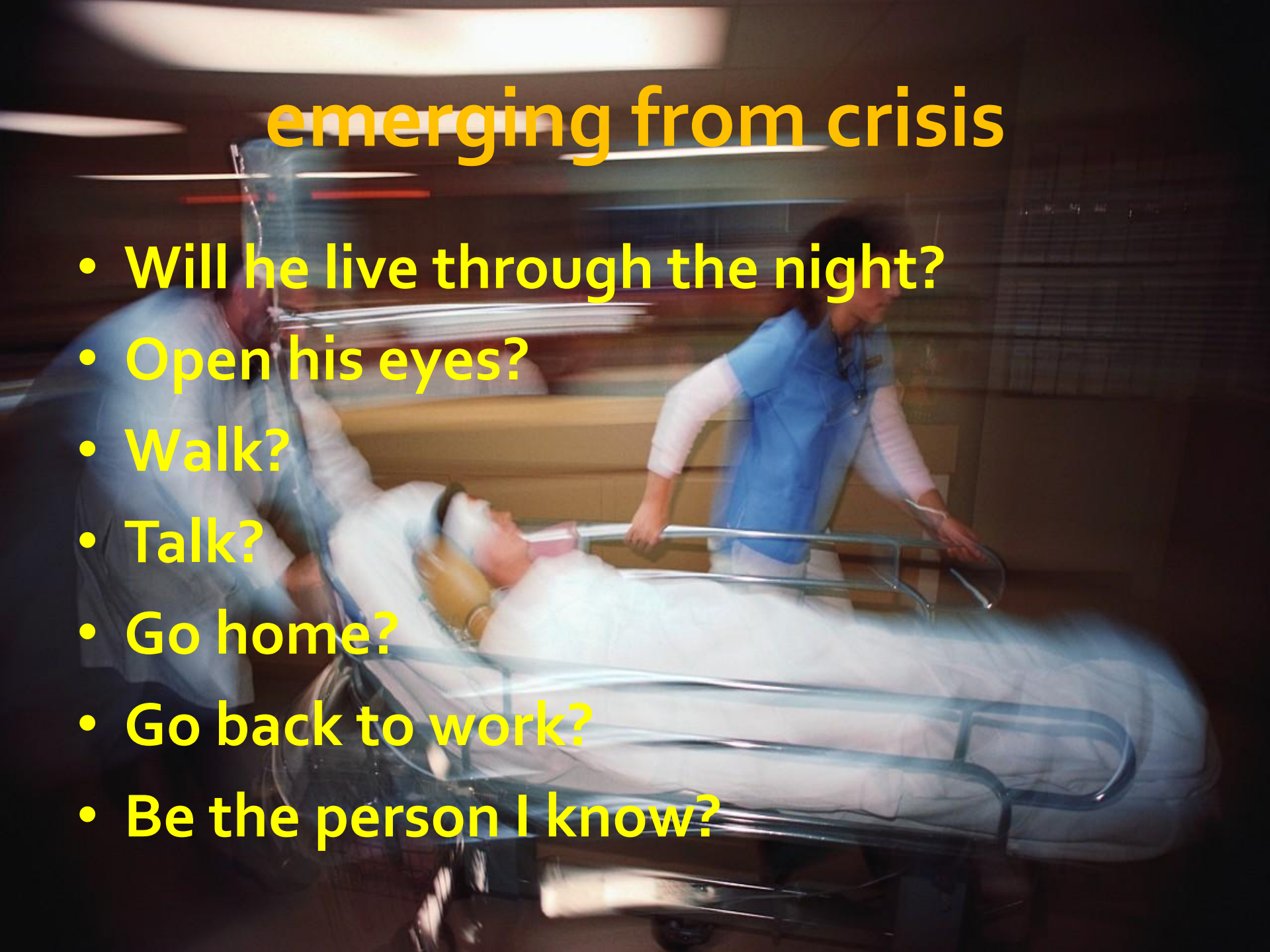
A photograph of two paramedics, a woman on the left and a man on the right, loading a patient into the back of an ambulance at night. The patient is lying on a stretcher, secured with straps. The ambulance's rear doors are open, revealing medical equipment inside. The number '71' is visible on the back of the ambulance. The scene is illuminated by the bright, glowing emergency lights on top of the vehicle, which create a strong contrast and some lens flare. The paramedics are wearing dark uniforms; the man's uniform has a 'PARAMEDIC' patch on the chest. The overall mood is urgent and professional.

what about “the chain of
miracles”?

does that effect our
perception of reality?

emerging from crisis


- Will he live through the night?
- Open his eyes?
- Walk?
- Talk?
- Go home?
- Go back to work?
- Be the person I know?





“waking up different”

from: Every 21 seconds or why I
scream at the refrigerator

A blurred photograph of a hospital corridor. In the foreground, a patient with dark hair lies in a gurney, covered with a white sheet. A nurse in a pink shirt is pushing the gurney from behind. In the background, another nurse in a blue shirt is visible, also pushing a gurney. The image is intentionally blurred to convey a sense of motion and urgency. Overlaid on the image is the text "could that be too early?" in a bold, sans-serif font. The words "could that be" are in black, while "too early?" is in red.

could that be too
early?

A photograph of two medical professionals, a man and a woman, both wearing white lab coats and stethoscopes, pushing a gurney through a hospital hallway. The patient on the gurney is lying down, covered with a white sheet, and has a blue oxygen mask over their face. The hallway is brightly lit with overhead fluorescent lights. The text "do we start making decisions about the person's 'return to normal' while they are in the acute medical phase?" is overlaid on the image in white and blue font.

do we start making decisions
about the person's "return to
normal" while they are in the
acute medical phase?

why not **wait?**

but, **when?**

...at the start of
rehabilitation?



at the end of medical
rehabilitation?



...at the end of post-
acute rehabilitation?



...on the return to home?



...or at.... 6?.... 12

months?

1 year..... 5 years.....

10 years?

do outcomes change over time?



what really changes? the person?
or, the measurement?

maybe changes continue to
occur....

..just like in everyone's life

what's **normal** can
change, too

over the course of
time

how can we learn to measure at
multiple points in the lifespan?

to accurately address
changes over time



**What parts of
me will
adjust after
a brain injury?**

**What parts of
me will
change after
a brain injury?**

A man in a dark jacket is measuring a window frame with a yellow tape measure. He is looking up at the tape. The background shows a kitchen with wooden cabinets and a window. The text is overlaid on the image.

how can we expand
the domains we measure

to be more relevant to the
person and their life?

1 to 5 years after the injury

client perception of post-injury changes

nrio outcome study, adult cohort

1997-2010

perception of post-injury changes

- cognition
- behavior
- emotions
- physical abilities
- relationships
- level of participation
- level of independence



**family members perception of
problems post-injury**

Functional Physical Limitations
Chronic Medical Care Needs
Reliance Upon Others for Basic Care
Transportation
Depression
Cognitive Problems
Behavior and Anger Management Problems



the person and their loved
ones have a different
understanding of changes

why are there **variances** in the
perception of changes and
problems?

do the differences
represent what is
important to the person
vs. their family's view?

are aspects of outcome
dependent on the person's
capacity to return to their
pre-injury social roles?

are aspects of
“outcome” dependent
on

**social network
participation?**

**are outcomes
determined by the
perception of deficits?
whose perception?**



**is there an identity of
disability?**

**can a person change that
identity?**

A man and a woman are lying in bed, looking at each other. The woman is on the left, with her back to the camera, and the man is on the right, looking towards her. They are both wearing white clothing. The background is a white pillow and a white blanket.

**Or, does society make the
rules about who gets to
play?**

**are outcomes influenced by
expectations of change?**

whose expectations?

A grayscale background image showing a close-up of a hand holding a pencil, poised to draw on a piece of paper. A ruler is visible in the lower right corner. The text is overlaid on this image.

how can we extend our view
of outcome to encompass
social role and participation?

how would we measure
that?



mother



grandparents



best friend



art school

**Meet Rick
at 22**



Richard at 37

art school



grandparents



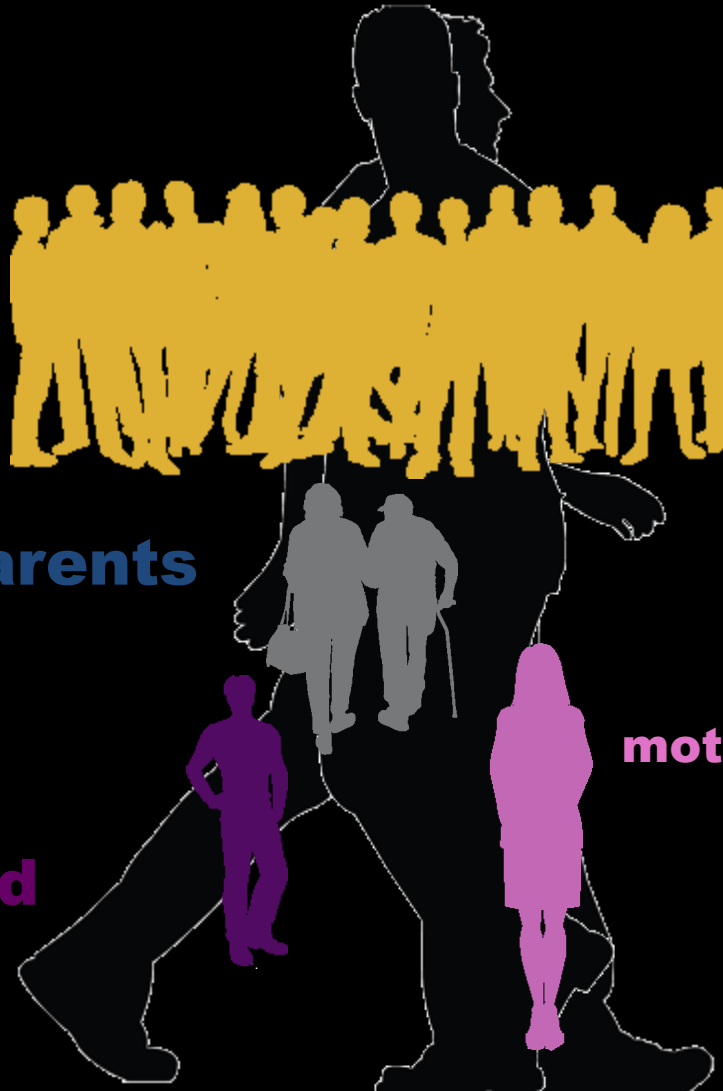
mother



best friend



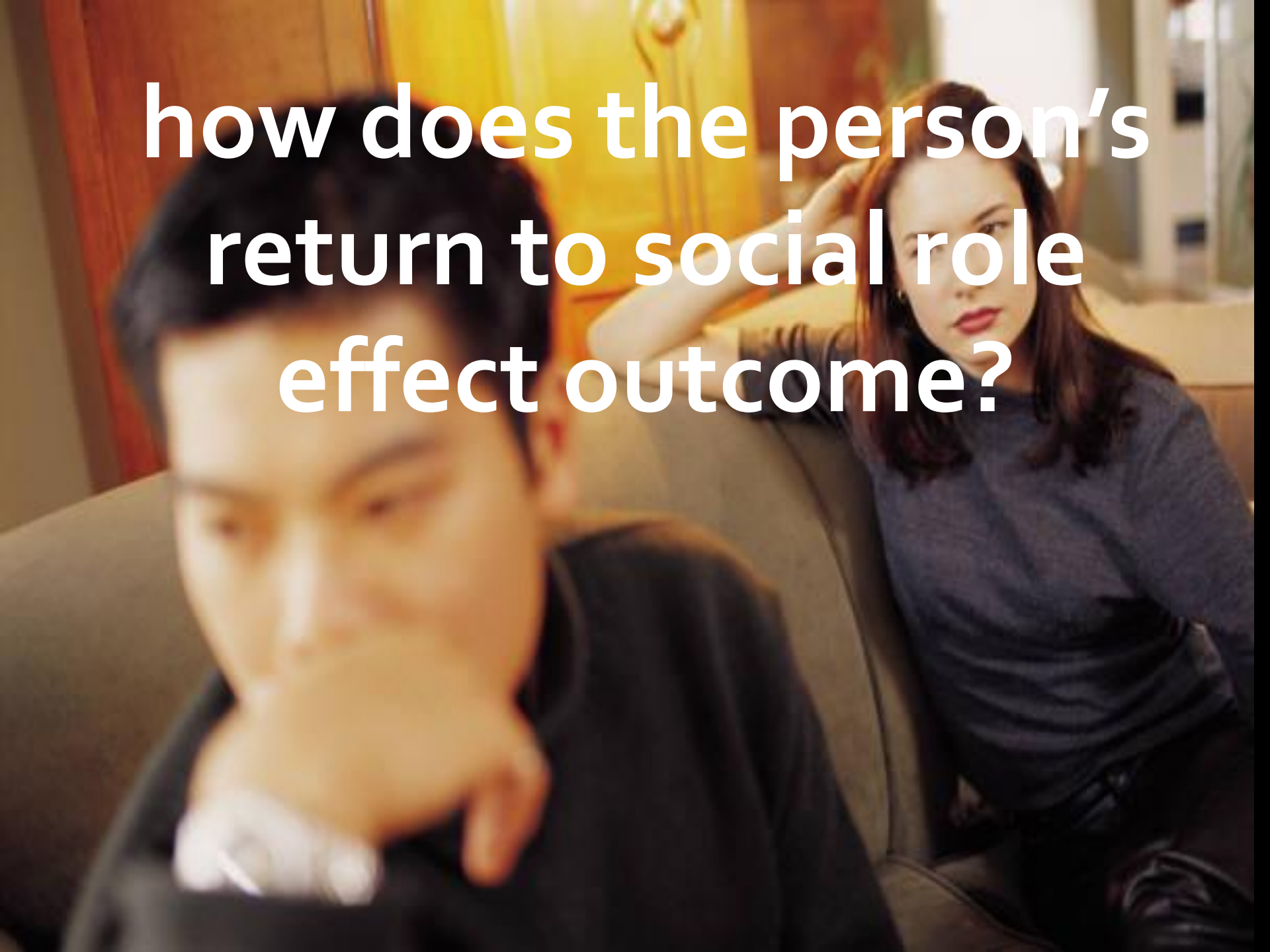
Rick at 22



**social role: its bigger
than we thought?**



how does the person's
return to social role
effect outcome?



**does the return to social network
participation determine
outcome?**





what if
you don't
fit?

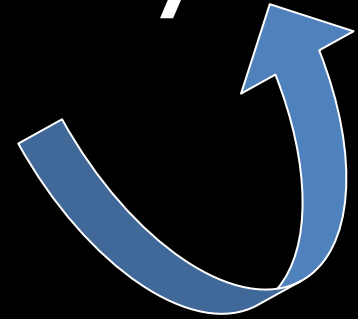
where do
you go?



what about social role return?

**is it a determinant of future health
and mental health problems?**

brain injury creates a risk for a mental health trajectory



- age at onset of disability
- male vs. female
- low/reduced social supports
- financial hardships

**does age at injury relate to
long term emotional
outcomes?**

**are people injured as
children at a greater risk for
problems later in life?**

does aging change
outcomes?



**does
stress
impact on
outcome?**





**What are
we really
measuring?**

**are we
measuring
against the
pre-injury
person?**



**against
societal norms
and
expectations?**





or the
person post-
injury?



or our
personal bias
and
expectations?

but, before we get to measuring
outcomes, we need to consider a
basic question.....

Is Brain Injury a:

Sickness or disease?

does it ever go away?

a broken arm **heals**.....

but, a **brain injury** impacts
for life

WHO definition of chronic disease

- **Permanent**
- **Leaves a residual disability**
- **Caused by non-reversible pathological alteration**
- **Requires special training of the person**
- **May be expected to require a long period of supervision, observation care**
- World Health Organization, 2002

different outcomes.....

are based on many factors

person-focused factors

- type of injury
- severity
- location
- the person's recovery
- their psychological make-up

external factors

- **treatment and rehabilitation received**
- **resources made available**
- **support network**
- **economic and financial**
- **community**

Brain Injury: a disease process

TBI is not solely “an event”.....

...but, a process which
continues to exert
changes over the course
of a person's life

Brain Injury: as a sickness

**this view isolates the injury
from the entire person**

it creates **expectations** of a
return to the person's pre-
injury status

TBI: not a static process

- Impact on organ systems
- Disease causative and disease accelerative
- Impacts on the person over the course of time

TBI: Mortality and Death

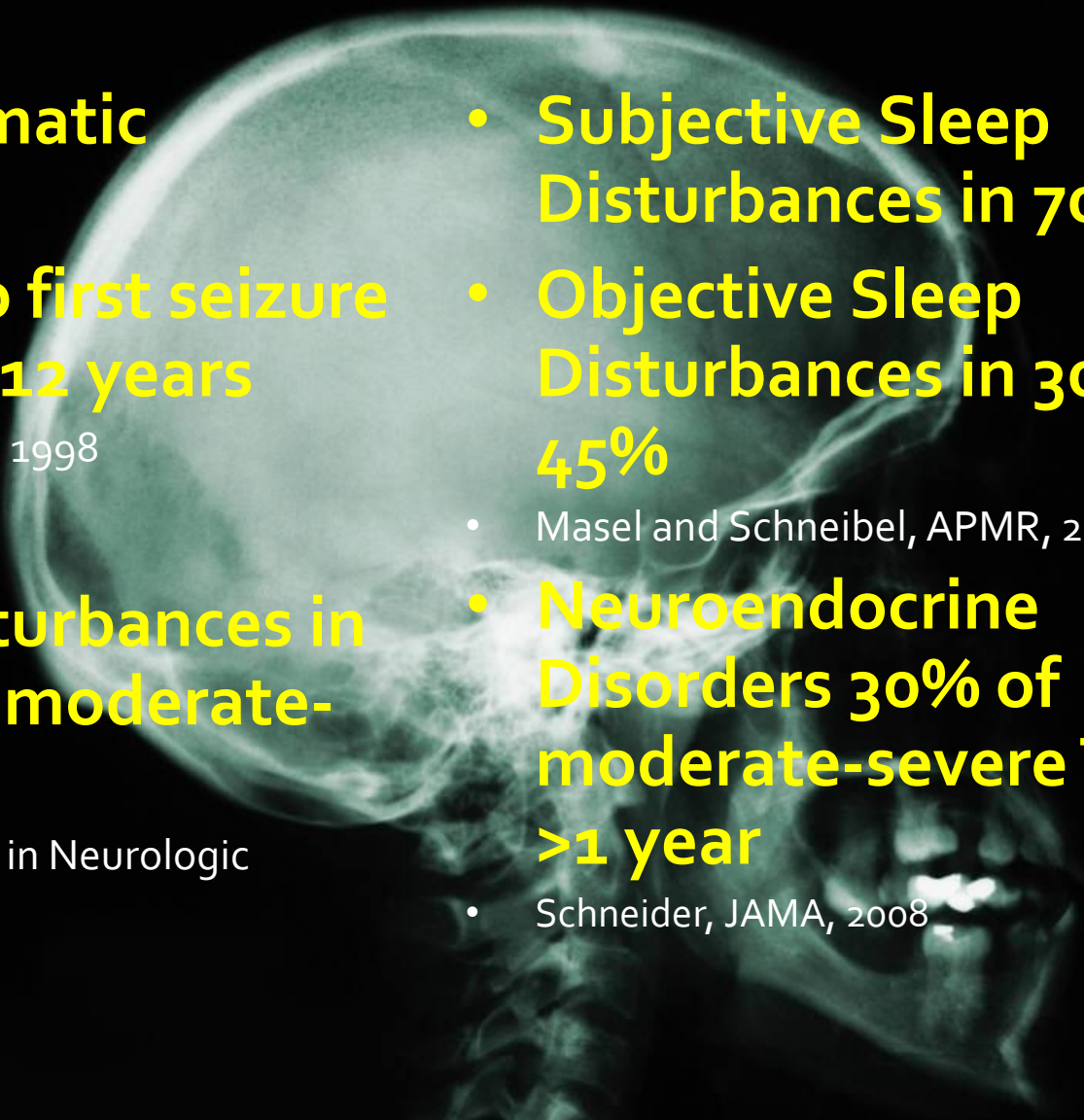
- **Moderate to Severe: Twice as likely to die**
- **Average reduction of life expectancy of 7 years**
- Harrison-Felix, JHTR, 2006
- Savelle, AmJPhysMedRehab, 2001

Death from many causes:

Individuals more than 1 year post-TBI

- **37X more likely to die from seizures**
- **12X more likely to die from septicemia**
- **4X more likely to die from pneumonia**
- **3X more likely to die from other respiratory conditions**
- Harrison-Felix JHTR, 2006

Neurologic Disorders

- 
- **Post-traumatic epilepsy**
 - **Latency to first seizure as long as 12 years**
 - Annegans, NEJM, 1998
 - **Visual Disturbances in 30-45% of moderate-severe TBI**
 - Atkins E, Reviews in Neurologic Disease, 2008
 - **Subjective Sleep Disturbances in 70%**
 - **Objective Sleep Disturbances in 30-45%**
 - Masel and Schneibel, APMR, 2001
 - **Neuroendocrine Disorders 30% of moderate-severe TBI's >1 year**
 - Schneider, JAMA, 2008

Musculoskeletal Dysfunction

- Spasticity
- Muscle contractures
- Tissue Breakdown
- Skin ulceration
- Heterotopic ossification, included delayed onset and ankylosis
- TBI Medical Treatment Guidelines, Colorado Department of Labor, 2006



Incontinence

- Of 1000 individuals 5% at 1 year post injury
- Of 116 moderate-severe TBI's >1 year 14% incontinent of bowel
- Cause of skin infections and decubitus ulcers
- Fox-Orenstein, APMR, Feb 2003
- Safaz, Brain Injury 2008
- **Increases care needs**
- **Interferes with independence**
- **Interferes with community mobility and access**

Psychiatric Disease with long term TBI

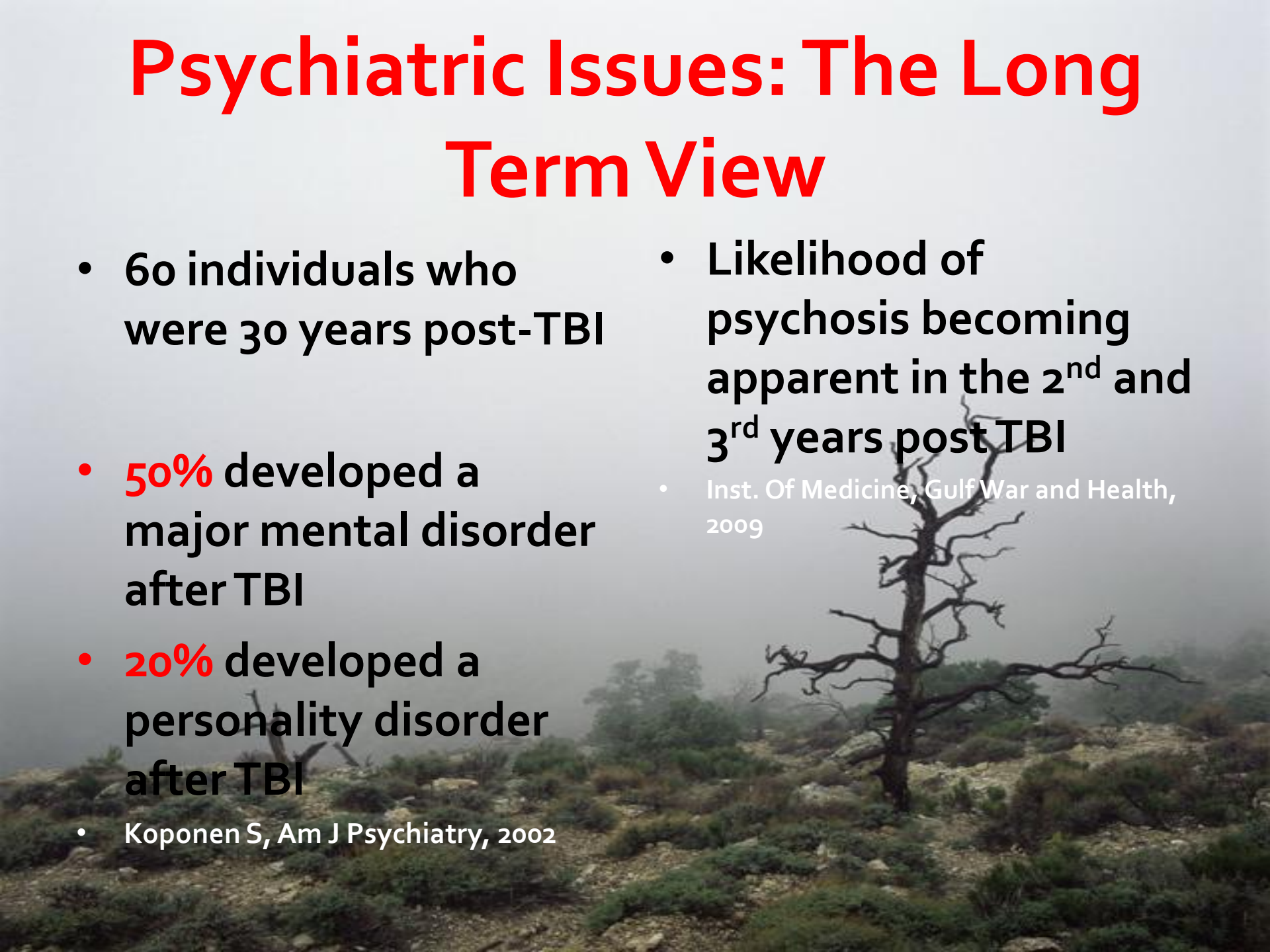


- Psychosis 20%
- Depression 18-61%
- Mania 1-22%
- PTSD 3-59%
- Aggression 20-40%
- Kim E, JNeuropsychiatry, 2007

- TBI is associated with high rates of suicide ideation, suicide attempts and completed suicide

Psychiatric Issues: The Long Term View

- 60 individuals who were 30 years post-TBI
- **50%** developed a major mental disorder after TBI
- **20%** developed a personality disorder after TBI
- Koponen S, Am J Psychiatry, 2002
- Likelihood of psychosis becoming apparent in the 2nd and 3rd years post TBI
- Inst. Of Medicine, Gulf War and Health, 2009



Risk of Neurodegenerative Disease

- Increased risk of Alzheimer's type Dementia- risk increases to 4X at the severe range
 - Gottleib, S, BMJ, 2000
 - Consentino, Arch Neurolm 2010
- Post-recovery cognitive decline-27% showed cognitive decline from baseline to 2-5 year interval
 - Till, APMR, 2008
 - Greenberg, APMR, 2008
- Other risks include Chronic Traumatic Encephalopathy (CTE)
- Parkinsonism
 - Bowers, Neurology, 2008

Cognitive, behavioral and emotional changes

- Higher incidence of cognitive, behavioral and emotional changes at 5 years than 2 years
- 32% of those working at 2 years were unemployed at 5 years
- Olver J, Brain Injury, 1996



“The tragedy of the human brain is
that it is aware of what it has lost
and where it is headed-both at the
same time”

Walter Mosley, “When the Thrill is
Gone”, 2011

WHO World Report on Disability

- Relationship between disability and poverty
- Increased vulnerability of women, children and persons with mental health disabilities
- Increased risk for poor health
- Barriers to care
- World report on disability, 2011. World Health Organization www.who.int



vulnerabilities create
barriers to outcome

factors **external** to the
person influence outcome

are caregivers a factor
to consider in
outcomes?

A photograph of a man and a woman sitting outdoors. The man, in the foreground, is wearing a blue ribbed sweater and has a serious, contemplative expression. The woman, slightly behind him, is wearing a red turtleneck and also looks thoughtful. The background is a soft-focus outdoor setting with warm, golden light.

Caregiver Stress: Factors in Long Term Outcomes



greater stigma
associated with
caregivers of
persons with
visible physical or
neurobehavioral
problems

increased
caregiver strain
leads to **social
isolation,
depression and
anxiety**



A photograph of a woman and a man sitting outdoors on a rocky or sandy surface. The woman, in the foreground, has curly brown hair and is wearing a red ribbed sweater over a white top. She is looking down and to the side with a sad expression, her hand resting on her head. The man, in the background, has short dark hair and is wearing a blue ribbed sweater. He is looking away from the camera towards the right. The background is a blurred natural setting with warm, golden light.

Perceived discrimination against the person with TBI associated with increased caregiver strain and isolation

Perceived stigma, strain and mental health among caregivers of veterans with traumatic brain injury. Phelan, S. et al, Disability and Health Journal 4 (2011) 177-184

caregiver stress and community integration

greater caregiver perceived social
support was associated with better
outcomes in social integration

**how does
money
impact on
outcome?**



is money a factor to
consider in outcomes?



\$15 million over the
course of a person's
lifetime

who really pays?

**what happens over the
course of time?**

10 years after the injury and rehab

nrio outcome study 1997-2010

37.3%

return to their
primary social role
without modifications



43.1%

experience a change
requiring support and role
modification



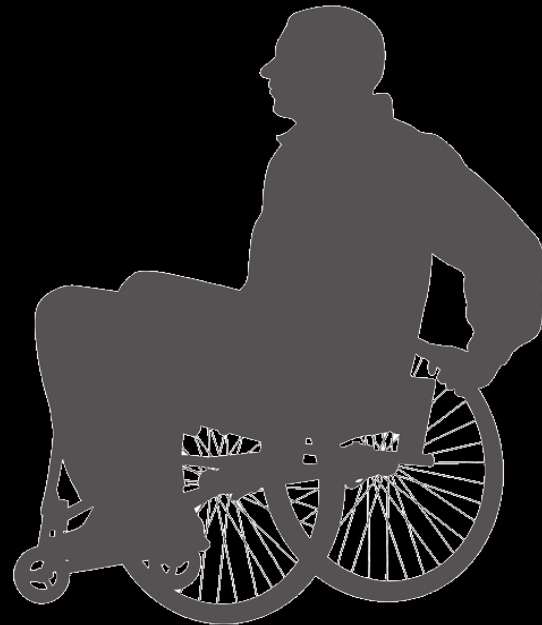
0%

regression



19.6%

experienced significant
psychological problems requiring
intervention



19.6%

is this the cohort where we
see the long term
problems with social
network return?



**is this the group where
outcomes don't meet
expectations?**

whose expectations?



do **psychological** issues
prevent social membership
participation?



does brain injury create the perfect
storm for loneliness?



loneliness: not a single entity

- **Social loneliness**: absence of involvement in a social network
- **Emotional loneliness**: absence of an important attachment or the loss of a relationship (Weisz, 1973)
- **Life transitions** can provoke loneliness (Marangoni & Ickes, 1989)

is loneliness contagious?

- Average person experiences loneliness 48 days a year
- Having a lonely friend can add 17 days of loneliness
- When feelings of loneliness emerge, those feelings are transmitted to others
- Loneliness can destabilize a social network before the individual moves towards the fringe
- Source: Alone in the Crowd: The Structure and Spread of Loneliness in a Large Social Network, J. Personality and Social Psychology, December 2009.

Predictors of loneliness in disability

- **Physical dependence**
 - **Anxiety in social situations**
 - **Impaired social skills**
-
- Source: Begin, G. Disability Related Variables Associated with Loneliness Among People with Disabilities. J. Rehabilitation, July 2001

Social isolation: a predictor of mortality similar to clinical risk factors

Pantell M. et al. Social Isolation: A predictor of mortality compared to clinical risk factors. Am J Public Health, 2013 September 12. (Epub) PMID: 24028260

Is **isolation** a bigger
factor than disability?



factors related to loneliness

- Depression, anxiety, low self esteem (DiTomaso & Spinner, 1997)
- Suicide, suicide fantasies, alcohol and drug use (WcWhirter, 1990)
- Poor social skills (Morier, Boisvert, Loranger & Arcand, 1996)
- Poor health (Hojat & Vogel, 1987)
- Heavy users of Emergency Departments (Andren & Rosenquist, 1985)

A close-up photograph of two people's faces. The person on the left is a woman with light brown hair, her mouth wide open in a gasp or shout, eyes wide. The person on the right is a man with dark hair, also with a shocked expression, eyes wide and mouth slightly open. The background is blurred.

**do difficult behaviors
become the person's way of
creating social engagement?**

**do we respond to the behavior
rather than the person?**

isolation,
withdrawal and
loneliness
impact on the
potential
outcomes?



old questions:

derived from Frederick A. Fay, Ph.D.

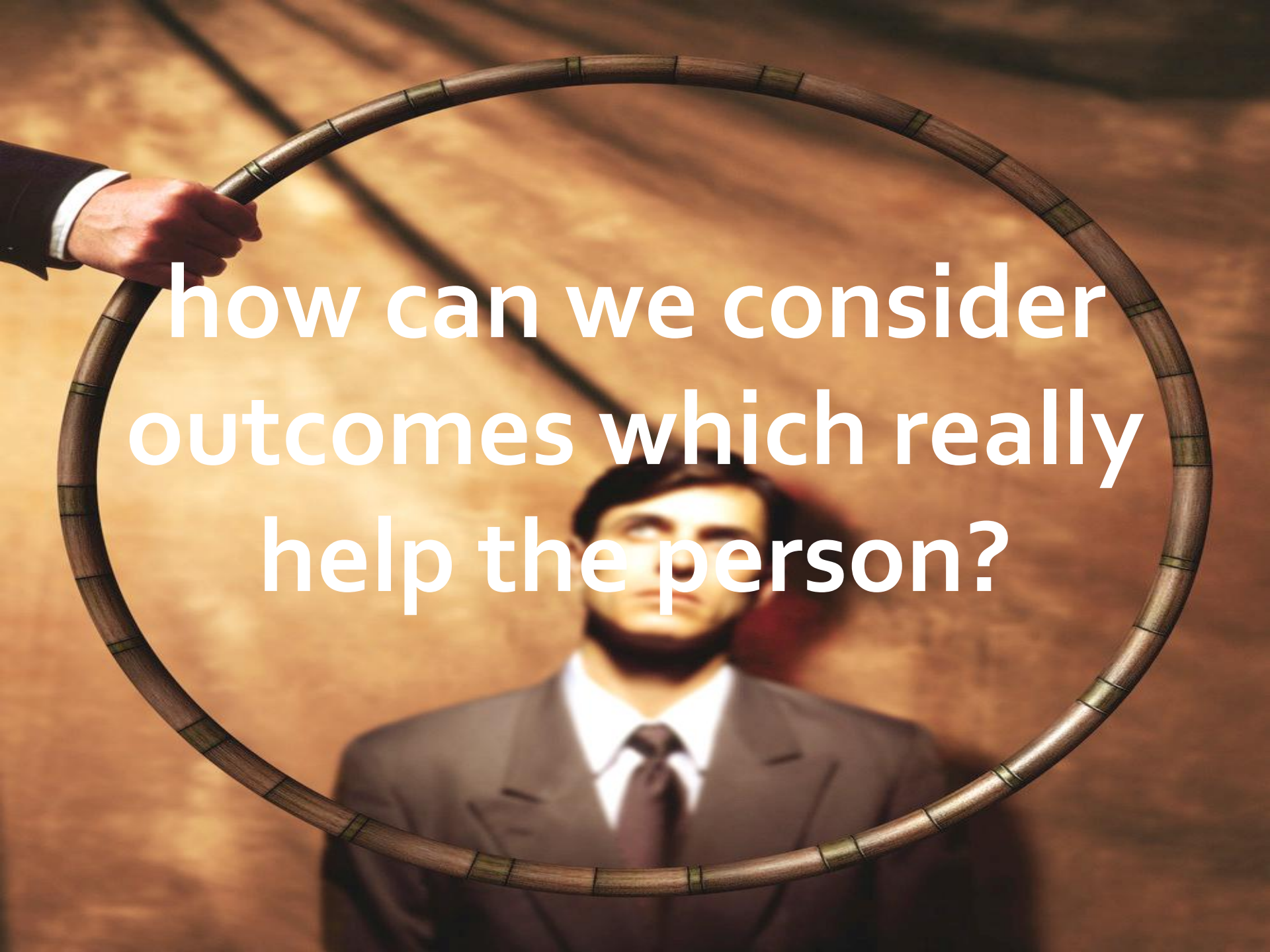
what is wrong with you?

how do we fix you?

**what can we do with you if
we can't fix you?**

do the old questions
increase the likelihood
of **negative outcomes**?

**can we change how we
perceive outcomes by
examining the questions
we ask?**

A man in a grey suit and dark tie is looking upwards with a contemplative expression. He is positioned behind a large, circular wooden hoop that is held by a hand in a dark suit jacket on the left side. The background is a warm, textured brown with diagonal lines, suggesting a wooden wall or a similar material. The overall tone is thoughtful and professional.

how can we consider
outcomes which really
help the person?

**how did we get stuck in the
medical model of disability
from the 1960's?**



**what would we say in the
new questions?**

**how do we help define
real outcomes?**

**how can outcomes reflect
the person's goals?
values? personal choices?**

**can better connections
improve outcomes?**

**how can we help facilitate
social network
membership?**

**do we allow outcomes to
evolve with the person over
the course of time?**

**or, do we get stuck with
the measurement that was
made following the injury?**

**can we learn to measure at
multiple intervals throughout
the person's lifetime?**


**to accurately address changes
which occur over the course of
time**

maybe we should stop
measuring with old
tools?



A large, green-painted steel arch bridge spans a deep valley. The bridge has a prominent arch and is supported by a series of vertical steel beams. Below the main arch, a smaller, simpler bridge is visible, crossing a lower part of the valley. The background is filled with a dense forest of evergreen trees. The foreground shows a rocky, grassy slope. The text "can new questions improve outcomes?" is overlaid on the image in white and green font.

can **new questions** improve
outcomes?

A wooden suspension bridge with chain-link railings stretches into a forest. The bridge is made of wooden planks and is surrounded by lush green trees. The perspective is from the front of the bridge, looking down its length towards the vanishing point.

**how can we help the person
discover and move towards a
better future?**

A diverse group of five young adults (three men and two women) are sitting outdoors under a large tree. They are all smiling and looking towards the camera. The group includes a man with a beard in a plaid shirt, a man in a light blue shirt, a man in a red and white striped shirt, a woman in a white shirt, a woman in a light green shirt, and a woman in a bright green shirt. The background shows green foliage and a clear sky.

how can we offer
assistance that promotes
valued experiences for the
person?



how can we offer needed
assistance in ways that
**support and sustain
community participation?**

**How can we identify
outcomes which really
help the person?**

Questions..... Comments?

Thank you!



“The New Normal” Outcomes of Brain Injury and the Lifespan

Rolf B. Gainer, Ph.D.

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this presentation can be accessed on
traumaticbraininjury.net
look under resources

Disclaimer:

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The author is affiliated with the Neurologic Rehabilitation Institute of Ontario,
Brookhaven Hospital, Community NeuroRehab of Iowa and Rehabilitation
Institutes of America