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Dr. Rolf B. Gainer is the Vice President of Rehabilitation Institutes of America and the founder of the Neurologic Rehabilitation Institute of Ontario (Canada), serves as the Chief Executive Officer at Brookhaven Hospital and is a founding Board member of Community NeuroRehab (CNR). Dr. Gainer has been involved in the design and operation of brain injury rehabilitation programs since 1978. He has a PhD in Clinical Psychology (Union University) and a MEd in Counseling Psychology (Antioch University). He has published numerous articles on brain injury rehabilitation and has presented at many national and international conferences. He is the author of the chapter on Psychosocial Complications of Brain Injury in The Essential Brain Injury Guide. He is involved in three outcome studies related to brain injury and social role return.



Aging and Brain Injury: **Expectations and Realities**

Rolf B. Gainer, PhD

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Rehabilitation Institutes of America

Disclosure

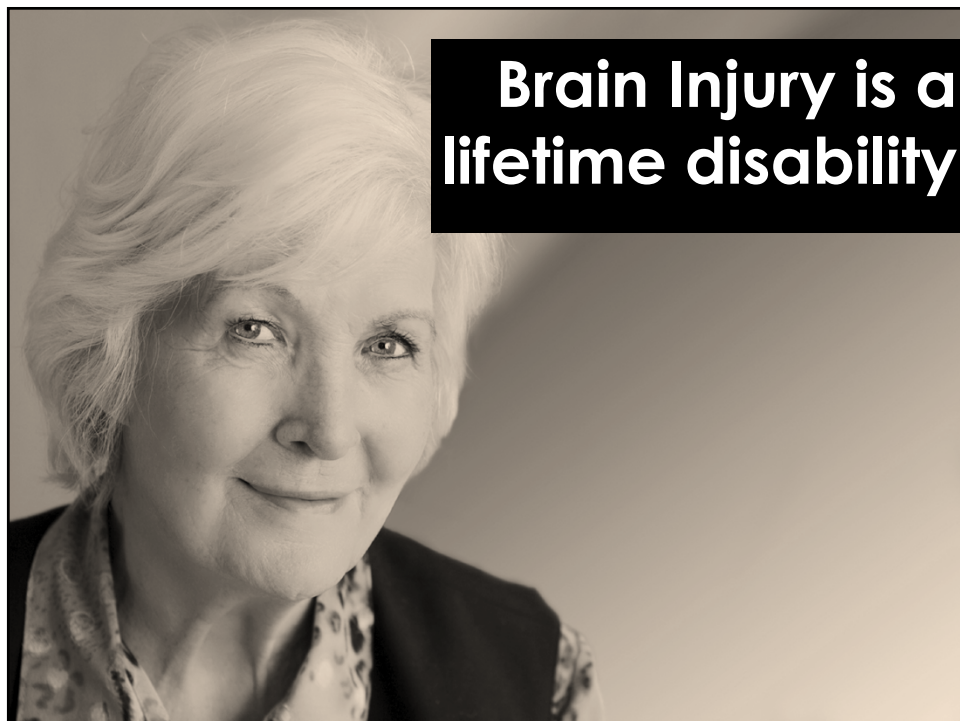
- **Rolf B. Gainer, PhD has business relationships with Brookhaven Hospital, the Neurologic Rehabilitation Institute of Ontario, Community NeuroRehab of Iowa and Rehabilitation Institutes of America**
- **The studies conducted by Brookhaven Hospital , Community Neuro Rehab and the Neurologic Rehabilitation Institute are self-supporting and receive no public or private grant monies.**

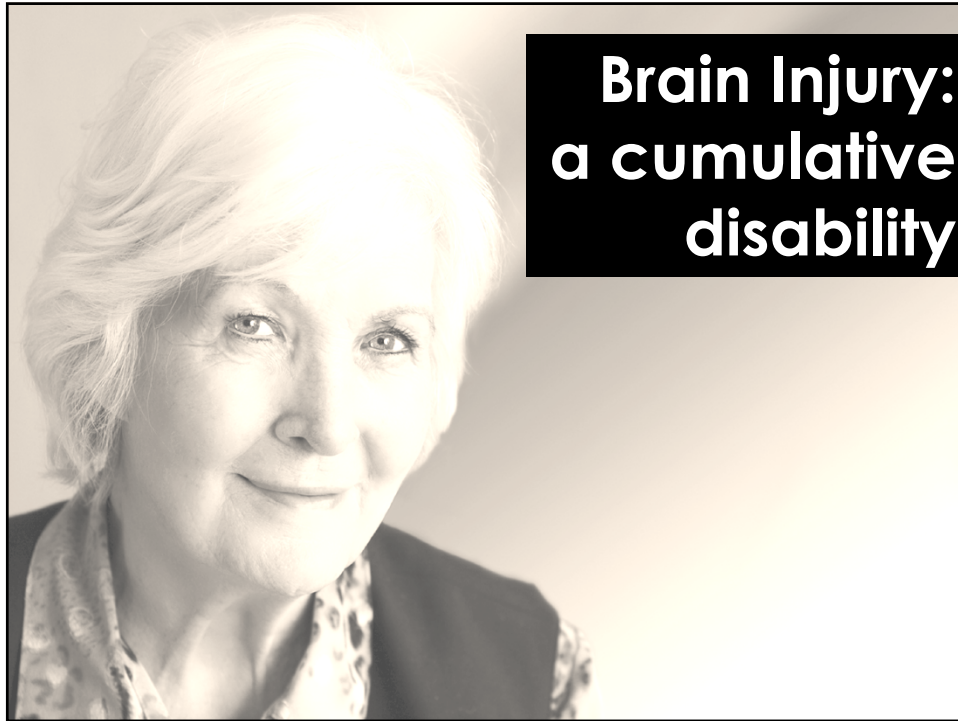
objectives:

To understand brain injury as a chronic disease which affects the person throughout their lifetime

To consider co-morbid conditions which affect the process of aging with a brain injury

**To understand the
accelerated process
of aging related to
people living with a
brain injury**





**Brain Injury:
a cumulative
disability**

**Age and Disability:
Shared Issues, Different
Timing**

Age and Disability: Shared Issues

TBI Disability Based **Age Based**

Mobility problems

Functional losses

Memory and cognitive problems

Sensory impairments

Health problems

Loss of independence

Reduced income

Depression

Loss of peers/ social withdrawal

Aging

Neuroplasticity decreases with age

Atrophy increases with age

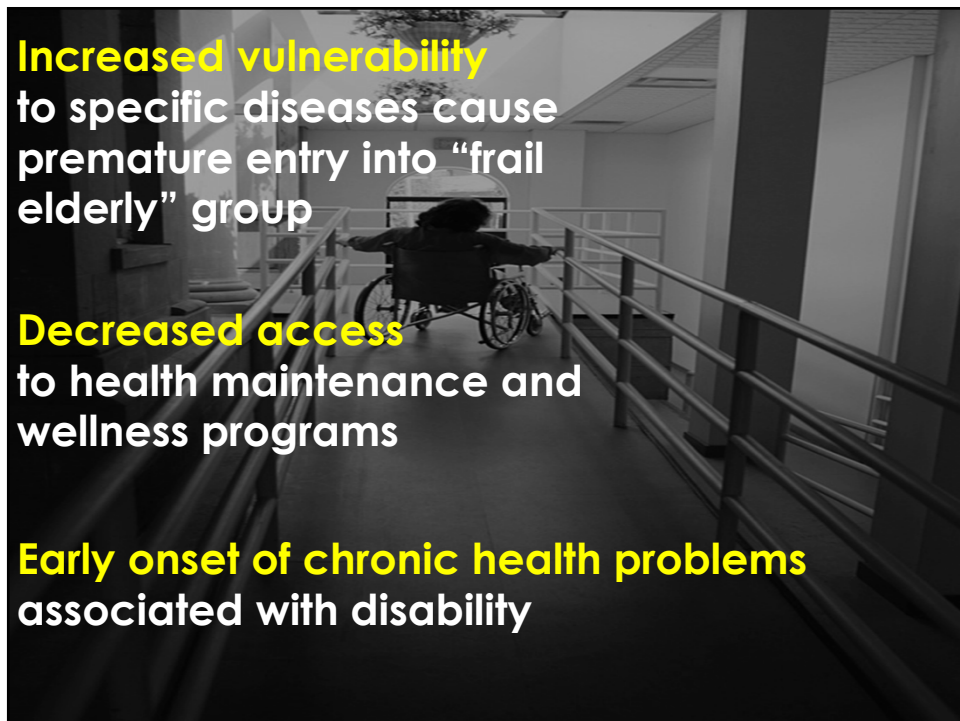
The process of aging can have a greater effect on a person with a brain injury

Same problems

Different timeframe
for onset



Disability and Future Healthcare Needs



Increased vulnerability
to specific diseases cause
premature entry into “frail
elderly” group

Decreased access
to health maintenance and
wellness programs

Early onset of chronic health problems
associated with disability



Likelihood of experiencing new health conditions
related to functional loss

Likelihood of experiencing longer and more complicated treatment
for health problems

Greater needs for DME,
poorer adjustment to assistive devices

Source: DeJong, 1997

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

to accurately address
changes over time

**Health disparities effect
quality of life
and, the relationship to
physical health and
*wellness***



**Creates a change
in direction**

how can we understand
the ***sequence of life
changes*** following brain
injury?

we need to start by looking
at ***changes within the brain
at the time of injury:***

are there ***biomarkers*** other
than outward function?

The incidence of Acute Ischemic Stroke (AIS) is 10 times higher in the days and weeks following moderate to severe TBI for <40

Haarbauer-Kruppa J, Kowalski R, et al. 2017

**Pro-inflammatory and anti-inflammatory processes
Endocrine and immune system changes**

Do these processes affect how the will person age?

How do behavioral influences like **diet, sleep and exercise** impact on these functions?

Can we intervene to stall the neurodegenerative process?

Will that exert change on how a person ages with a brain injury?

How does **social isolation** effect health after disability?

Lack of social contact leads to early death

29-32% of increased likelihood of mortality

Social deficits more predictive of death in <65

Steptoe, Shankar, Demakakos and Wardle, 2013

The more severe a brain injury the higher the risk for dementia among middle aged men

Raj, Kaprio et al, PLOS Medicine, 2017

We hear about outcomes...



Do outcomes change over time?

what really changes?

the person?

the measurement?



**maybe changes continue
to occur**

just like in everyone's life

We also hear about
“normal”

Who determines
what's **“normal”**?

When is “normal”
reached?

Is there a typical
brain injury?

How does that relate to
the aging process?

Let's look at some research to identify issues that we see beyond the original injury

Does this research help us to understand the process of living with a brain injury?

Life expectancy after TBI

**Twice as likely to die as age,
gender and race matched peers**

Estimated life reduction of 7 years

Source: Harrison-Felix, C., et al. (2004); Harrison-Felix, C., et al. (2006)

Health disparities

Increase in health issues post-TBI

15 times more likely to die from seizures

**5 times more likely to have mental
health or behavioral problems**

Health disparities

3 times more likely to die from aspiration pneumonia, sepsis, nervous system disorders, digestive problems and assaults

2 times more likely to die from suicide, circulatory conditions and unintentional injuries

Source: Harrison-Felix, C., et al. (2009)

Health disparities and increased disease likelihood affects longevity

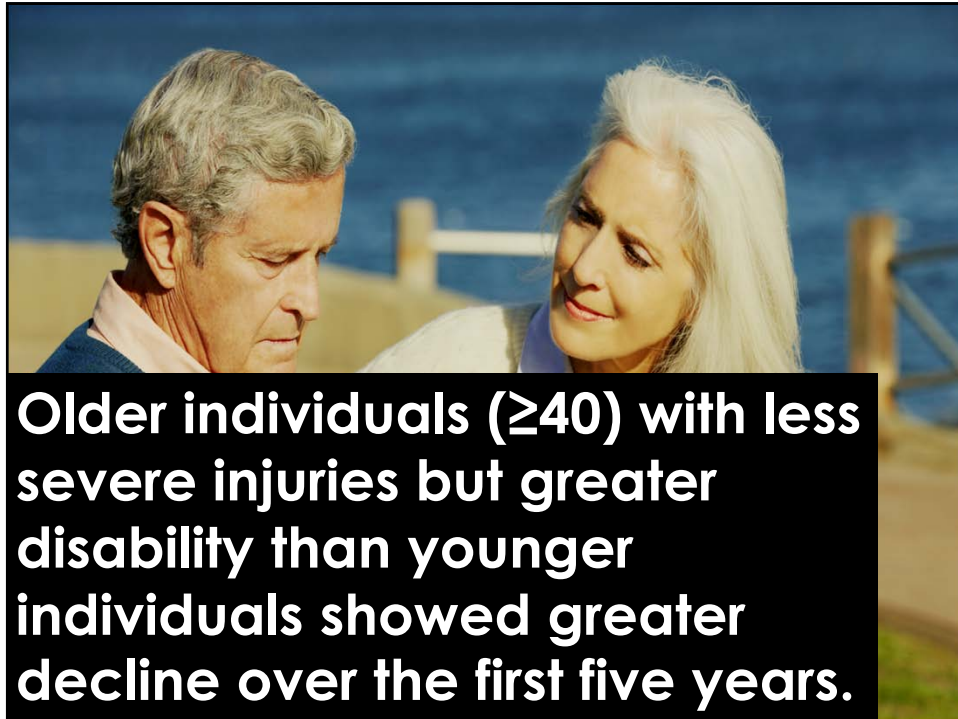
Creating a more vulnerable and fragile population of people aging with a brain injury

Age and sex-specific life expectancy were lower than the U.S. general population

Brooks, J et al. Long-Term Survival After Traumatic Brain Injury. Part I and II. Arch Phy Med and Rehab, V.96, N.6, June 2015. pp994-1005

Age, male gender, injury severity and degree of disability in walking and self-feeding relate to increased mortality

Brooks, J et al. Long-Term Survival After Traumatic Brain Injury. Part I and II. Arch Phy Med and Rehab, V.96, N.6, June 2015. pp994-1005



**History of traumatic brain
injury associated with
increased risk for dementia
and Parkinsonism, cognitive
impairments and decline,
seizure, hormonal disorders...**

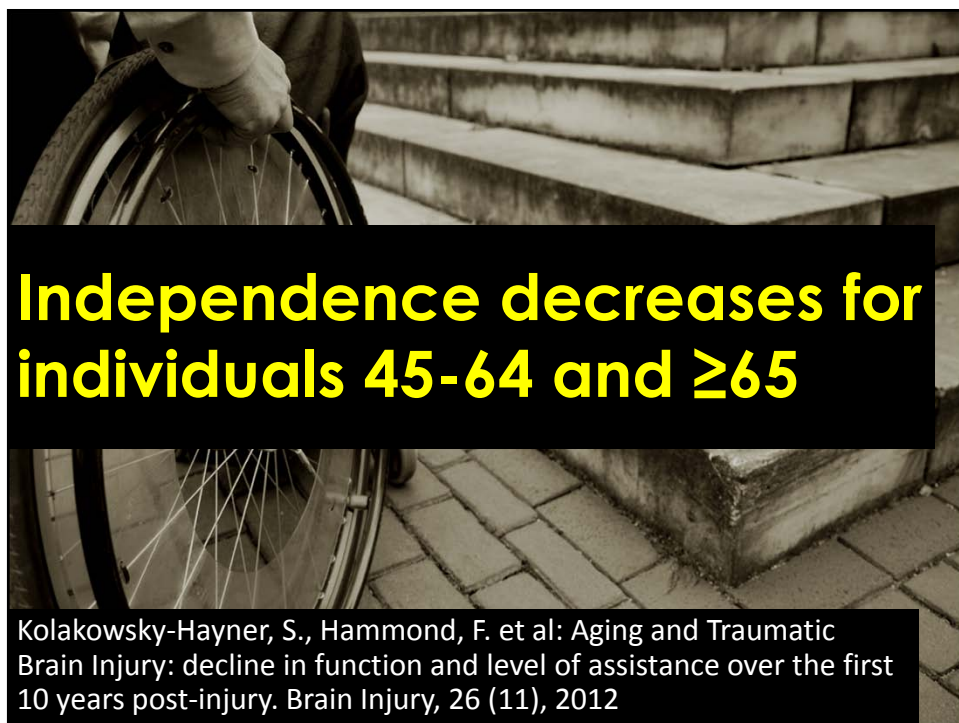
Ishibe N, et al, Long Term Consequences of BI, a report to
the Institute of Medicine, 2009

**...and long term emotional
and social problems and
unemployment**

Ishibe N, et al, Long Term Consequences of BI, a Report to
the Institute of Medicine, 2009



**Loss of independence
creates increased needs**



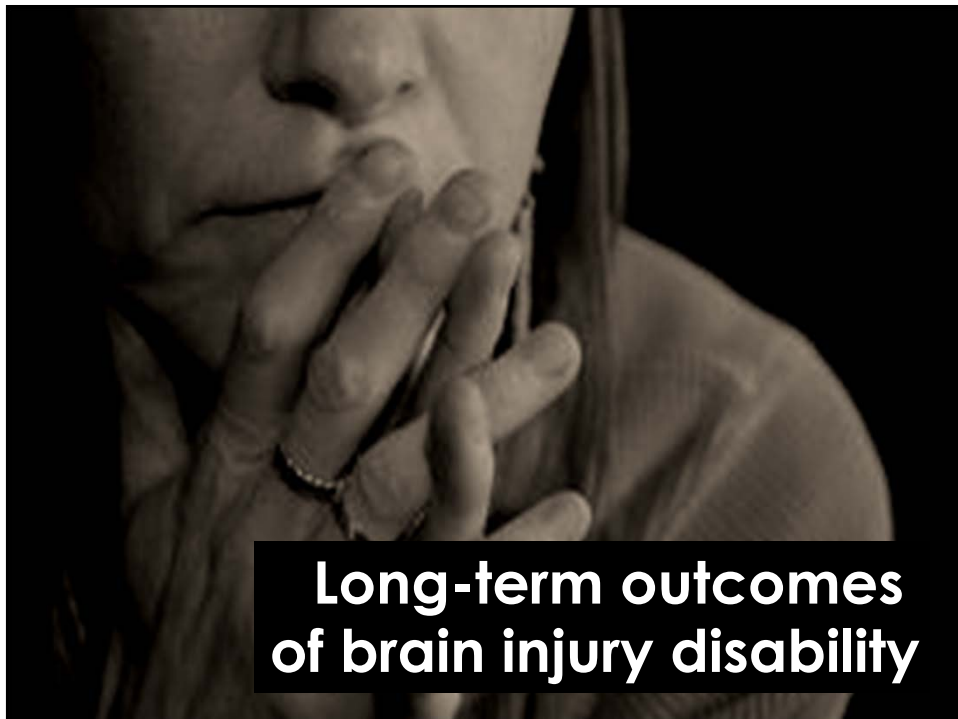
**Independence decreases for
individuals 45-64 and ≥ 65**

Kolakowsky-Hayner, S., Hammond, F. et al: Aging and Traumatic Brain Injury: decline in function and level of assistance over the first 10 years post-injury. Brain Injury, 26 (11), 2012



Need for part and full time supervision increases for individuals 45-64 and ≥ 65

Kolakowsky-Hayner, S., Hammond, F. et al: Aging and Traumatic Brain Injury: decline in function and level of assistance over the first 10 years post-injury. *Brain Injury*, 26 (11), 2012



**Long-term outcomes
of brain injury disability**

Disengagement from naturally occurring social units



The aging process in the
increasing years since injury

**Declines in physical and
cognitive functioning**

**Declines in societal
participation**

Source: Sendroy-Terrill, et al, 2010

Cognitive, physical and societal functioning are influenced by the severity of the injury

Source: Sendroy-Terrill, et al, 2010



Fatigue identified as a key factor in functioning and participation

**Fewer environmental
barriers reported as people
age with a brain injury**

**Adaptation or reduced
societal participation?**

Source: Sendroy-Terrill, et al, 2010

**Increased age at injury
predicts decline in
functional independence**

**Creating increased care
needs**

Source: Sendroy-Terrill, et al, 2010

Can rehabilitation outcomes be sustained?

Life functioning and community integration gains can be sustained after rehabilitation

Areas studied included:

Living accommodations

Employment

Hours of care needed

Source: Geurtsen, G.et al. (2010)

How do psychological changes impact on a person's return to living their life?

Functional Outcomes 10 years after injury

High levels of anxiety and depression = poorer outcome attainment

Level of ability to participate = poorer outcomes

Social isolation related to functional deficits

Psychiatric diagnosis and cognitive deficits are best regarded as components rather than outcomes

Source: Ponsford, J. et al. (2008)

Monash University Study: Likelihood of post-injury psychiatric disorders

Psychiatric disorders occurring in 60% of the post-injury population in a 5.5 year period

Greater likelihood of psychiatric disorder found in relationship to pre-injury substance abuse, major depressive and anxiety disorders

Source: Whelan-Goodinson, R., Ponsford, J., Johnston, L., Grant, F.J. (2009)

30-year study of mental health issues and brain injury

Temporary disruption of brain function leading to the development of psychiatric symptoms

Increased, long-standing vulnerability and even permanent psychiatric disorder

Source: Kaponen, S. , et al. (2002)

HMO Study of mental health issues

Severe TBI related to higher rates of depression (MDD), dysthymia, OCD, phobias, panic disorders, substance abuse/ dependence, bipolar disorders as compared to the non-TBI group

Source: Silver, J., Kramer R., Greewald., Weissman, M. (2001)

HMO Study of mental health issues

“Poorer physical or emotional health and higher likelihood of receiving welfare for the TBI cohort”

Negative symptoms of psychiatric disorders enforce social isolation and social network failure

Source: Silver, J., Kramer R., Greewald., Weissman, M. (2001)

Fann et al: Self perception

Individuals with both depression and anxiety perceived themselves as more ill and demonstrated reduced function as compared to cohort with anxiety without depression

Source: Fann, J., et al. (2004).

The onset of health issues
and functional
impairments **reduce the
person's ability to
participate** in activities
which support
independence

Resilience: an
illusory factor in aging
with a disability

Resilience and long-term functional outcomes

Resilience may protect mood and **prevent depression**

Resilience may increase **social participation**

Resilience may change
from pre-injury baseline
as a **person ages with a
brain injury disability**

Source: Silverman A et al Arch Phys Med Rehabil
2015;96:1262-1268

Let's look at a cohort of 10
individuals in a
community-based
supported living
environment to consider
the problems they are
experiencing.

The demographics

9 males, 1 female, ≥ 20 years post-injury

100% Severe Brain Injury

55-69 years of age

88% Motor Vehicle Accidents

100% were employed pre-injury

Changes to their family support systems since their injury

12% have no contact with family

50% have experienced the death of one or both parents

75% have reduced contact with family members

What health problems are they facing now that they are ≥ 20 years post injury?

Decreased mobility

25% using walkers

25% using wheelchairs

Development of medical problems post-injury

Diabetes in 33%

Skin integrity problems 25%

Circulatory problems 25%

Seizure disorder 12%

Swallowing problems 50%

Sleep apnea 25%

Parkinson's Disease 25%

Hearing, vision problems 75%

Psychological/Psychiatric Problems

50% report ongoing depressed mood

50% report problems with anxiety

100% report problems with fatigue

Mortality 20%

Male 62- Massive MI

**Female 69- Bowel
obstruction, sepsis**

**100% requiring medical,
nursing and attendant
care to manage health,
living and mobility.**

Brain Injury: Not a Single Disability

Severity related factors

Increased survivability with greater functional deficits

Increased comorbidity

Caregiver stress

Mobility and access issues

Reduced income, onset of disability related poverty



**Brain injury: a
disease process**

TBI is not solely an event

when we look at the
**effects of a brain injury on
a person**, we need to
regard **the chronic nature
of the disabling conditions**

What defines a chronic disease?

World Health Organization, 2002

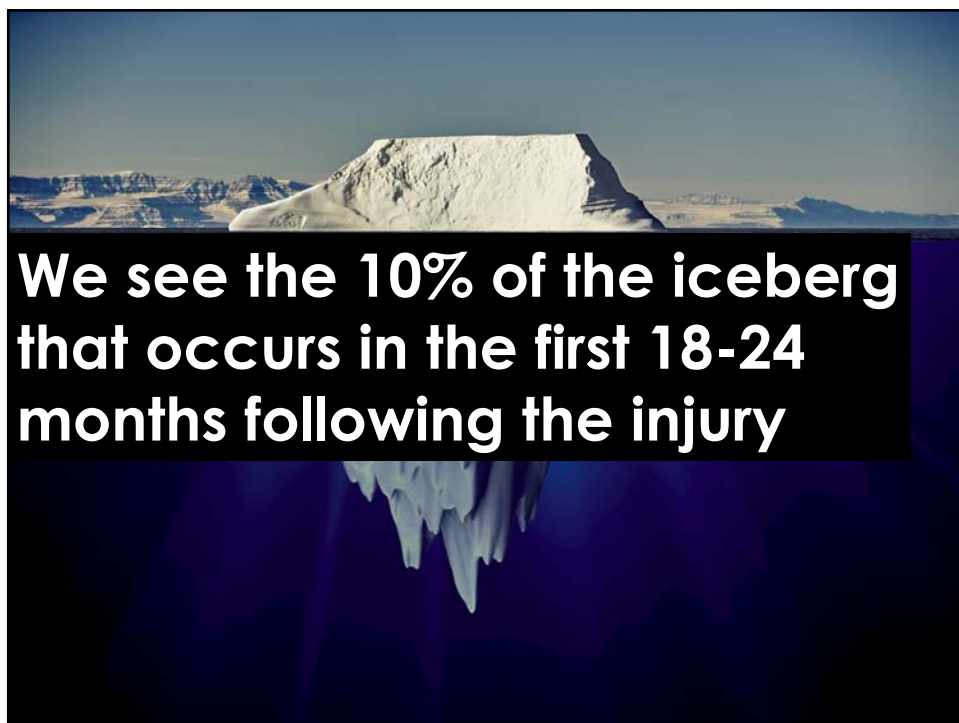
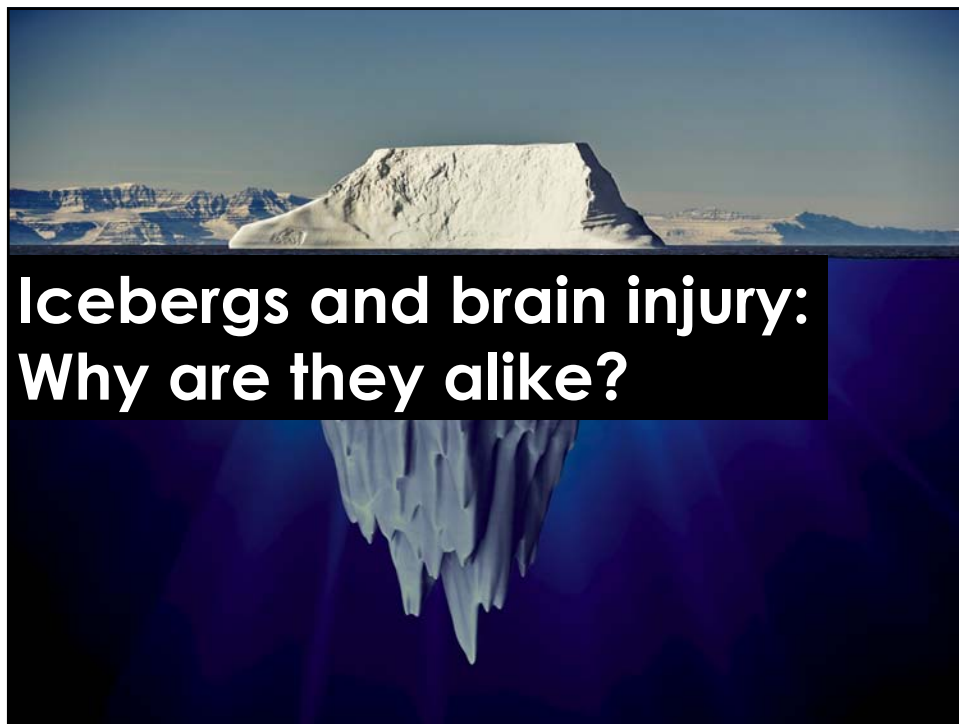
- ✓ **Permanent**
- ✓ **Leaves a residual disability**
- ✓ **Caused by a non-reversible pathological alteration**
- ✓ **Requires special training of the person**
- ✓ **May be expected to require a long period of supervision, observation and care**

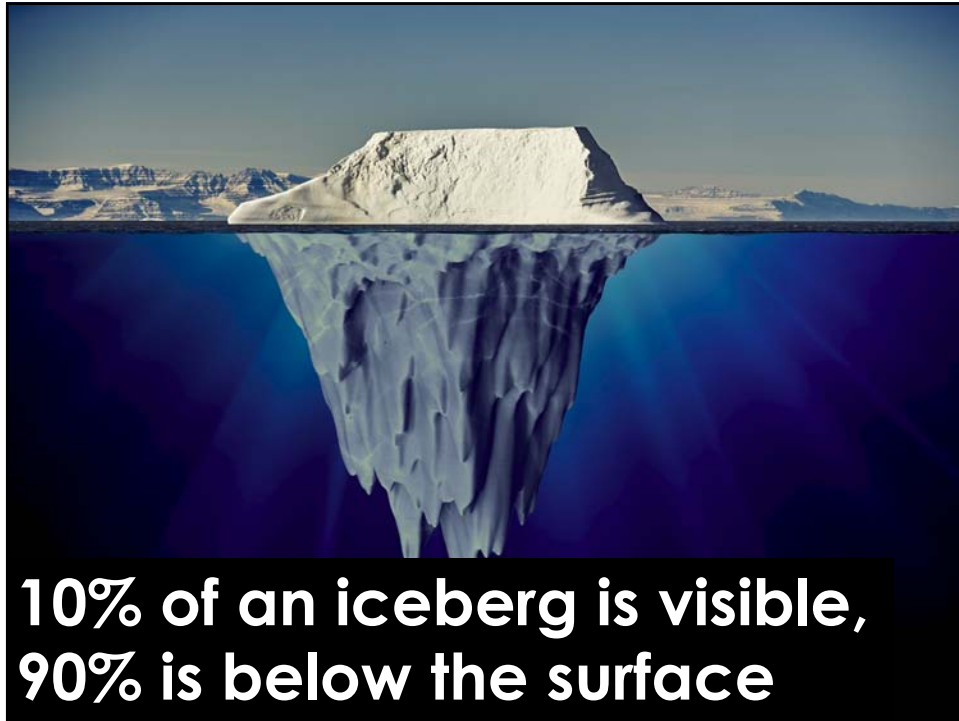
Brain injury: an illness?

this view isolates the impact of the injury on the entire person

**it creates expectations
of a person's return to
their pre-injury status
without problems**

**...but brain injury is a
process which
continues to exert
changes over the
course of a person's
life...**

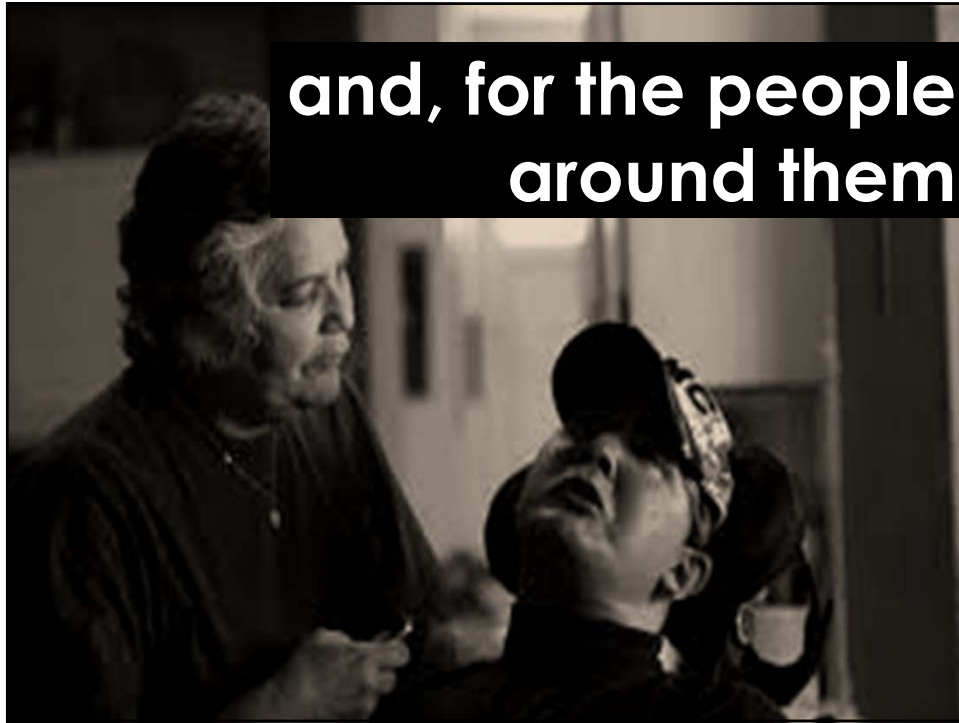




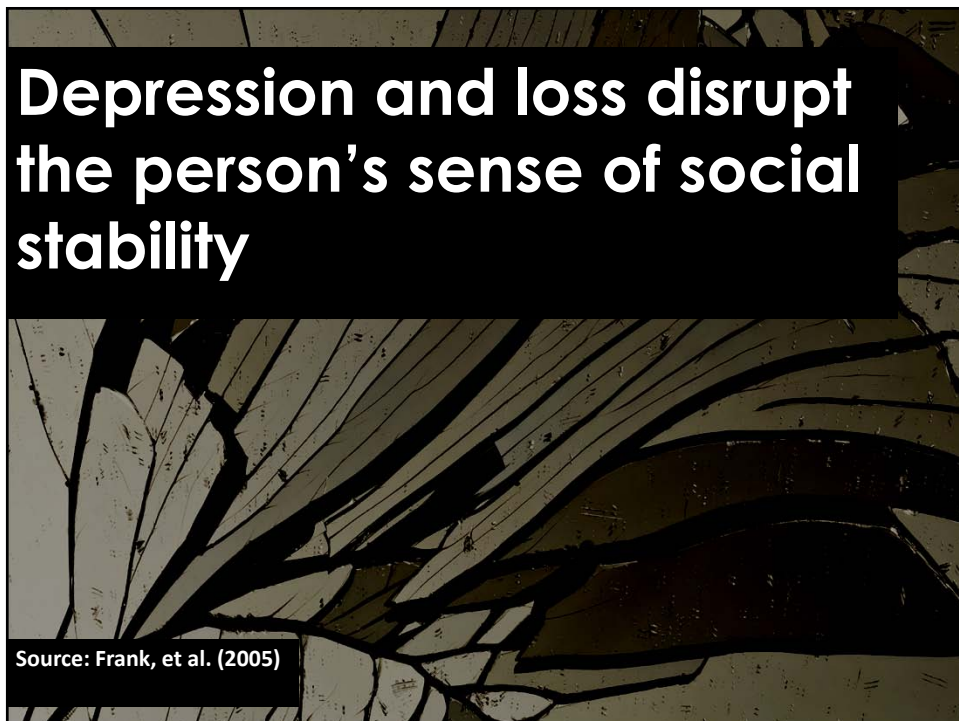
**The chronic nature of
brain injury related
disability effects the
person throughout their
lifetime**

Source: Masel, B. & Dewitt, D. (2010)

**and, for the people
around them**



**Depression and loss disrupt
the person's sense of social
stability**



Source: Frank, et al. (2005)

**Mental health and
substance abuse
issues change
outcome potential**

1 to 5 years after the injury

**nrio outcome study,
adult cohort**

1997-2014

Source: Gainer, R., et al. (1997-Ongoing)

Person's perception of post-injury changes

cognition

behavior

emotions


physical disabilities

relationships

level of participation

level of independence

family members
perception of problems
post-injury



Functional Physical Limitations
Chronic Medical Care Needs

Reliance on Others for Basic Care
Behavior and
Anger Management
Problems
Cognitive Problems
Depression
Transportation

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?

37.3%

return to their
primary social role
without modifications

Source: Gainer, R., et al. (1997-Ongoing)

43.1%

experience a change
requiring support and
role modification

Source: Gainer, R., et al. (1997-Ongoing)

19.6%

experienced significant
psychological problems
requiring intervention

Source: Gainer, R., et al. (1997-Ongoing)

What can we **expect**
of these cohorts as they
age?

Age and Brain Injury: Outcomes of Injury

**11-15 years post injury
Medical Problems**

**CNR Study
2011-2016**

CNR Demographics

Age at Injury	27 years
Age at Admission	36 years
Male/Female	68%/32%
Mechanism of Injury : MVA	42.86%
Assault/Fight	14.29%
Aneurysm	28.57%
Fall	7.14%
Anoxic/hypoxic Injury	7.14%

CNR Study Medical Problems 11-15 years post-injury

Seizure Disorder	64.29%
Hemiparesis/Mobility Issues/ Movement/contracture/spasticity	64.59%
Vision	21.43%
Type 2 Diabetes	21.45%
Heart disease/angina/hypertension	28.57%
Bowel/Bladder/Digestive	28.57%
Fatigue/Muscle Weakness/Insomnia	21.43
Aphasia	14.29%

CNR Study: Discharge Care Needs

Independent Living/ 0 support needs	13.11%
Independent Living/ Low support 2-4 hrs/day	6.22%
Independent Living/ Moderate support 6-10 hrs/day	2.00%
Independent Living/ High support 11-24 hrs/day	23.56%
Living with Family/ Requiring unpaid support	20.89%
24-hour Support outside of home	34.89%



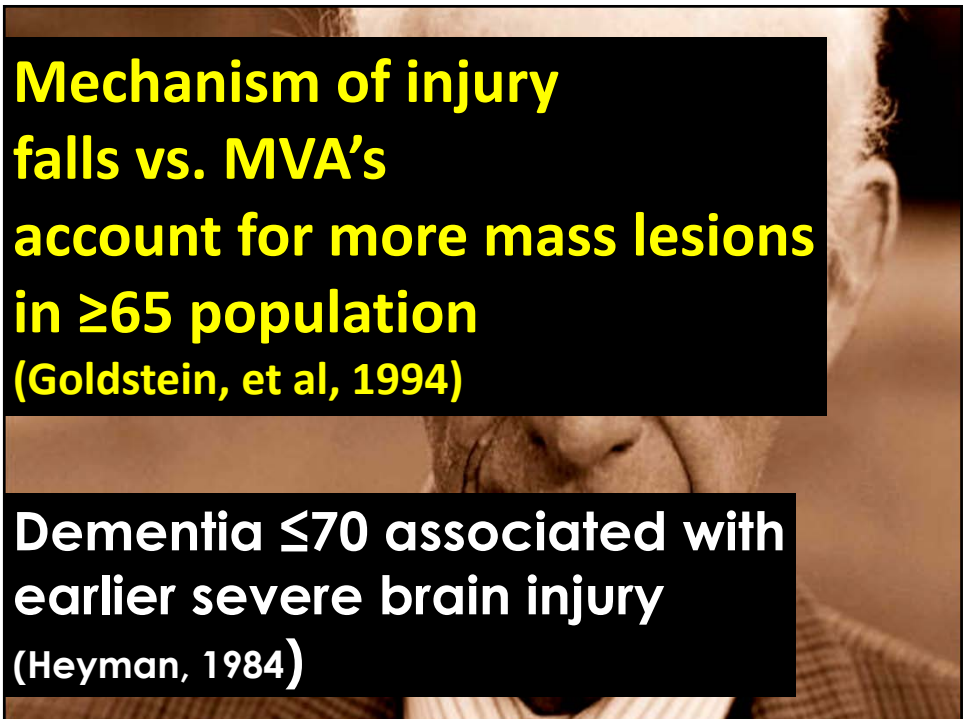
Facts: Age, Severity and Outcome

55% of individuals injured >65 were severely disabled or died vs. 86% of moderately injured <65 had good recoveries or required ADL assistance (Pentland, 1986)

A close-up photograph of an elderly man's face, showing wrinkles and a serious expression. The image is used as a background for the text.

Age Severity and Outcome

**Two to five year post injury:
>50 had longer hospital stays
and were more dependent in ADL's
and less likely to be working than <25
(Davis and Acton, 1988)**

A close-up photograph of an elderly man's face, showing wrinkles and a serious expression. The image is used as a background for the text.

**Mechanism of injury
falls vs. MVA's
account for more mass lesions
in ≥ 65 population
(Goldstein, et al, 1994)**

**Dementia ≤ 70 associated with
earlier severe brain injury
(Heyman, 1984)**

Observation: Age at the time of injury is a significant factor in outcome



Now, let's review a study involving individuals at the 15 year point post- moderate to severe brain injury and consider issues of participation and perception of quality of life

Dawson and Chipman's study

Quality of Life for individuals with severe and high moderate brain injuries ≥ 15 years post-injury, living in urban and rural settings



47%

not using telephone

A close-up, sepia-toned photograph of a person's hand resting on the metal rim of a wheelchair wheel. The background is blurred, showing parts of the wheelchair and some foliage.

66%

need ADL assistance

A close-up, sepia-toned photograph of a person's hand resting on the metal rim of a wheelchair wheel. The background is blurred, showing parts of the wheelchair and some foliage.

75%

unemployed

A close-up, sepia-toned photograph of a person's hand resting on a bicycle handlebar. The hand is positioned on the left side of the frame, with the fingers gripping the handlebar. The background is blurred, showing the spokes of a bicycle wheel and some foliage.

61%

**depression
7+ yrs post-injury**

A close-up, sepia-toned photograph of a person's hand resting on a bicycle handlebar. The hand is positioned on the left side of the frame, with the fingers gripping the handlebar. The background is blurred, showing the spokes of a bicycle wheel and some foliage.

57%

**clinically significant
depression**

A photograph of a person in a wheelchair, with a focus on their hand resting on the wheel. The image is dark and grainy, with text overlays.

50%

**anxiety & depression
in severe TBI**

Why ?

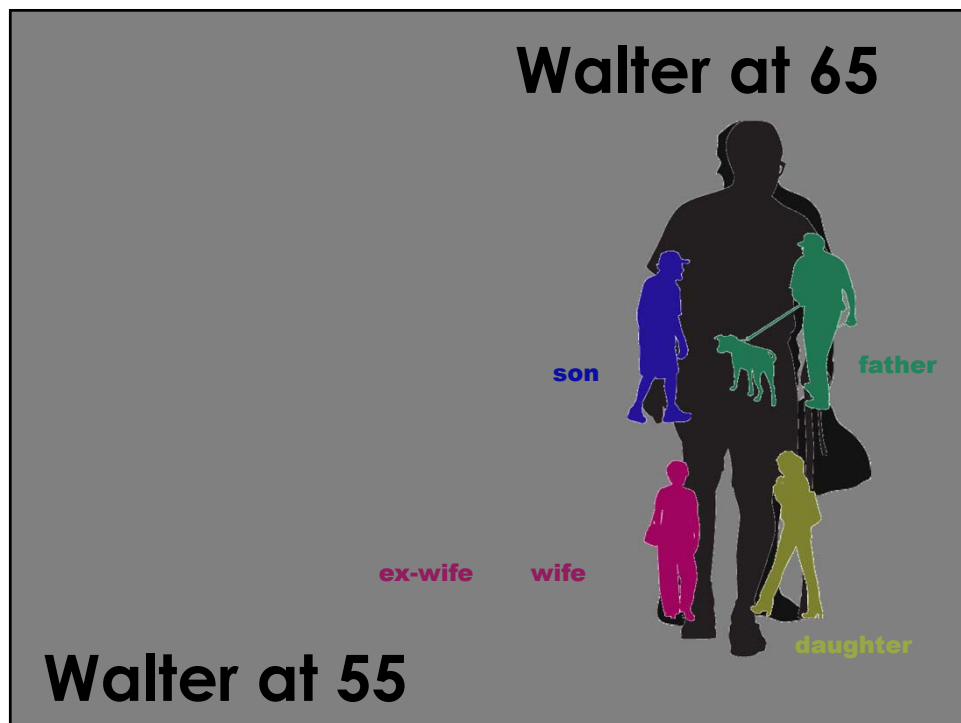
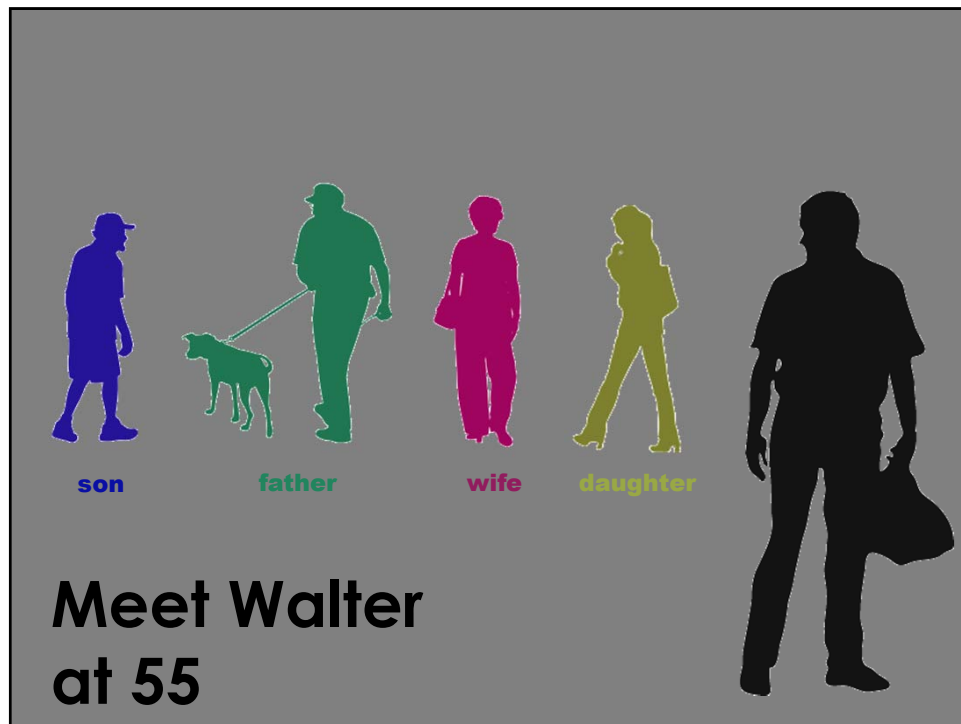
interference of symptoms

ability to self-manage

cognitive ability

physical functions

**How does that appear
over the course of
time?**



**care and support
needs
increase over time**

**fewer supports
to provide them**

What about “Caregivers”?

Age/gender of caregivers

**Health problems of
caregivers**

**Physical capacity of
caregivers**

Financial Issues

Limited resources

According to Caregiver Action Network

([http://caregiveraction.org/statistics/#Caregiving Population](http://caregiveraction.org/statistics/#Caregiving%20Population)):

More than 65 million people, 29% of the U.S. population, provide care for a chronically ill, disabled or aged family member or friend during any given year and spend an average of 20 hours per week providing care for their loved one

(Source: Caregiving in the United States; National Alliance for Caregiving in collaboration with AARP; November 2009)

The value of the services family caregivers provide for "free," when caring for older adults, is estimated to be \$375 billion a year

(Source: Evercare Survey of the Economic Downturn and Its Impact on Family Caregiving; National Alliance for Caregiving and Evercare. March 2009)

That is almost **twice as much** as is actually spent on homecare and nursing home services combined (**\$158 billion**)

(Source: Evercare Survey of the Economic Downturn and Its Impact on Family Caregiving; National Alliance for Caregiving and Evercare. March 2009)

47% of working caregivers indicate an increase in caregiving expenses has **caused them to use up ALL or MOST of their savings**

(Source: Evercare Survey of the Economic Downturn and Its Impact on Family Caregiving; National Alliance for Caregiving and Evercare. March 2009)

**Family caregivers
experiencing extreme
stress have been shown to
age prematurely**

**This level of stress can take
as much as 10 years off a
family caregiver's life**

*(Source: Elissa S. Epel, Dept of Psychiatry, Univ of Calif, SF, et al,
From the Proceedings of the National Academy of Sciences, Dec
7, 2004. Vol 101. No. 49.)*

**Loss of independence is
costly**

Housing Choice

**Returning to live with parents
or family in a dependent status**

**Difficulty in accessing services
outside of the home**

Source: NRIO Outcome Study, 1993-2014

Loss of independence is costly

Difficulty in obtaining TBI support services

Finding resources with brain injury expertise

Economic changes

Source: NRIO Outcome Study, 1993-2014

Disability and loss of role function produces a decline in self-worth as perceived by the person and others

Source: Condelucci, A. (2008)



**isolation and
social
withdrawal
stifle
interaction**



**Health risks
increase
with age**



**Individuals living with a
brain injury disability and
have **limited financial
resources** are more likely
to experience **health
problems****

Hospitalizations

Admission issues change over time

Long term healthcare resource utilization

Severity of injury, physical/cognitive and psychosocial disability all predict service utilization

Individuals 6-48 months post injury used services related to restoration of function

Individuals 72- 204 months post injury used services in response to life changes such as loss of relationship or caregiver

Hodgkinson, 2000

TBI and Re-hospitalization

3 Years Post Injury

50% of admissions for orthopedic and reconstructive surgery

15% for seizures

Psychiatric hospitalizations doubled in years 1-2, leveling off in year 3

Cifu, 1999

TBI and Re-hospitalization

5 Years Post Injury

Orthopedic and reconstructive surgery admissions declined

Incidence rate for seizures and psychiatric admissions increased

Marwitz, 2001

Costs of Care Increases With Age

TBI costs associated with acute care increased at **twice the rate for general medical care**

(Kreutzer, 2001)

Increased motor disability associated with total charges

(Vangel, 2005)



Costs of Care Increases With Age

Coping and adaptive strategies learned in rehabilitation **fail as individuals become middle aged and senior citizens** for mild to moderate injuries

(Klein, 1996)





What are the barriers?

Financial, structural, individual, and attitudinal barriers directly impede individuals' abilities to access rehabilitation services even though these services could greatly improve their recovery from TBI

Source: Leopold, A. 2013

**few resources that
support
independence**

**Does *limited* access
to adequate
financial resources
accelerate
problems?**

The high cost of a bump on the head

**Highest rate among 15-19
year old Males:
550/100,000 vs 115/100,000**

The high cost of a bump on the head

**Increased survivability for
younger individuals**

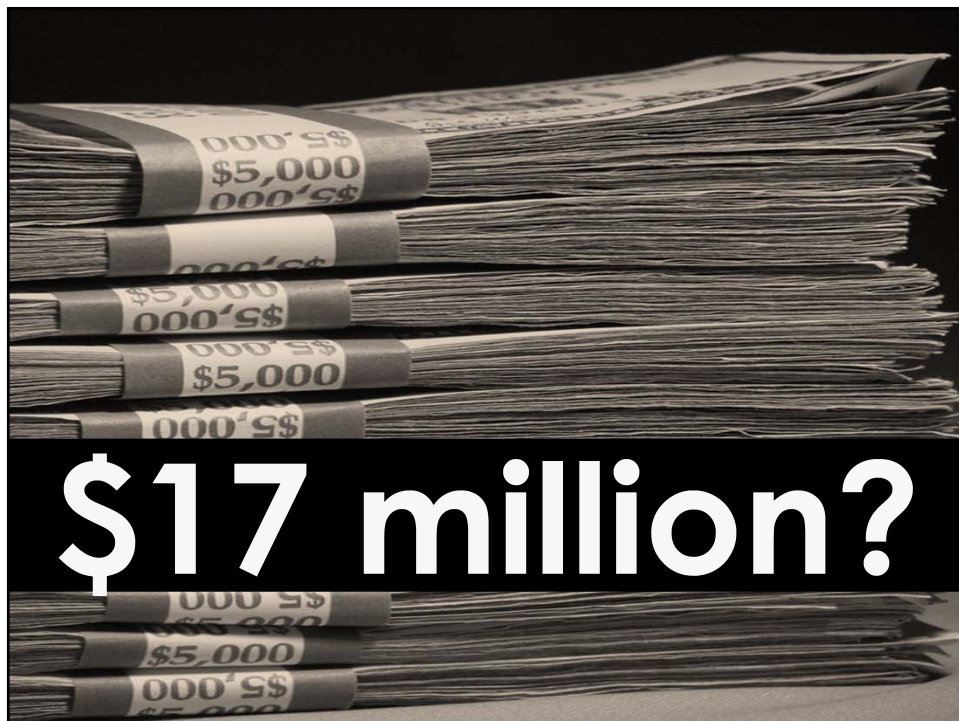
The high cost of a bump on the head

**Lifetime costs projected
\$4.5 to 5 million**

(Livneh and Antonak, 1997)

and \$8 to 17 million

(Bilmes, L, 2007)



\$17 million?

**Will outcomes
change in the future?**

**The challenge of today's
survivor**

**“Sicker and
Quicker”**

Source: Ashley, M. (2012)

17 days of acute
medical care in 2012
vs.

57 days in 1990 for
high moderate to
severe injuries

Source: Ashley, M. (2012)

The Future
Problems and Planning

Today's injuries
**tomorrow's aging
with a disability**

More People Survive, Less Resources to Share

“Sicker and Quicker” reduced stays in acute medical care

More survivors with greater disability levels and comorbidities

Increased lifetime costs associated with severity and longevity

Source: NRIO Outcome Study 1997-2014; NRI Outcome Study 1993-2014

Today's Injuries Tomorrow's Disabilities

Increase in medical technology preserves life for individuals with severe injuries

Increase in survivorship increases the extent and level of disabilities experienced by people

Improvements in healthcare **extends the lifespan** of people living with disability

Are the resources
available to **support**
people as they age with a
brain injury?

**What resources are
needed?**

Aging and Brain Injury: Addressing Long Term Needs

Increase availability of
accessible housing,
transportation and
community supports

Eliminate healthcare
disparities

Aging and Brain Injury: Addressing Long Term Needs

Provide economic supports and income supplements to avoid disability based poverty

Provide lifetime supports for caregivers and family members

Aging and Brain Injury: Addressing Long Term Needs

Address critical transition events which trigger crises and problems

Make available professional healthcare resources who can address the issues of aging with a brain injury

How do you address the problems associated with aging with a brain injury?

Thank you!

This presentation can be
downloaded at
traumaticbraininjury.net
Look under “Resources”
on the header, then
“Community
Presentations”



Resources

Dawson J, Chipman, L. (1995). The Disablement Experienced by Traumatically Brain Injured Adults Living in the Community, *Brain Injury*, (4): 339-354

DeJong, G. Disability and Future Healthcare Needs, *Archives of Physical Medicine*, May-June 1997, V76 (3)

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Fann J, Burington B, Leonetti A, Jaffe K, Katon W, Thompson R. Psychiatric Illness Following Traumatic Brain Injury in an Adult Health Maintenance Organization, *Arch of General Psychiatry*. 2004; V 61, Jan 2004: 53-61

Fremstad, S. Half in ten: Why taking disability into account is essential in reducing poverty and expanding economic inclusion, Center for Economics and Policy Research, Washington, DC 2009

Gainer, PhD, Rolf B. “What Family Caregivers Face in Years Following Severe Brain Injury” interview with Dr. Gordon Atherley, Episode 328, Family Caregivers Unite, VoiceAmerica, [familycaregiversunite.org](http://ow.ly/r84EZ), <http://ow.ly/r84EZ>, July 8, 2014 (live broadcast date)

Resources

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