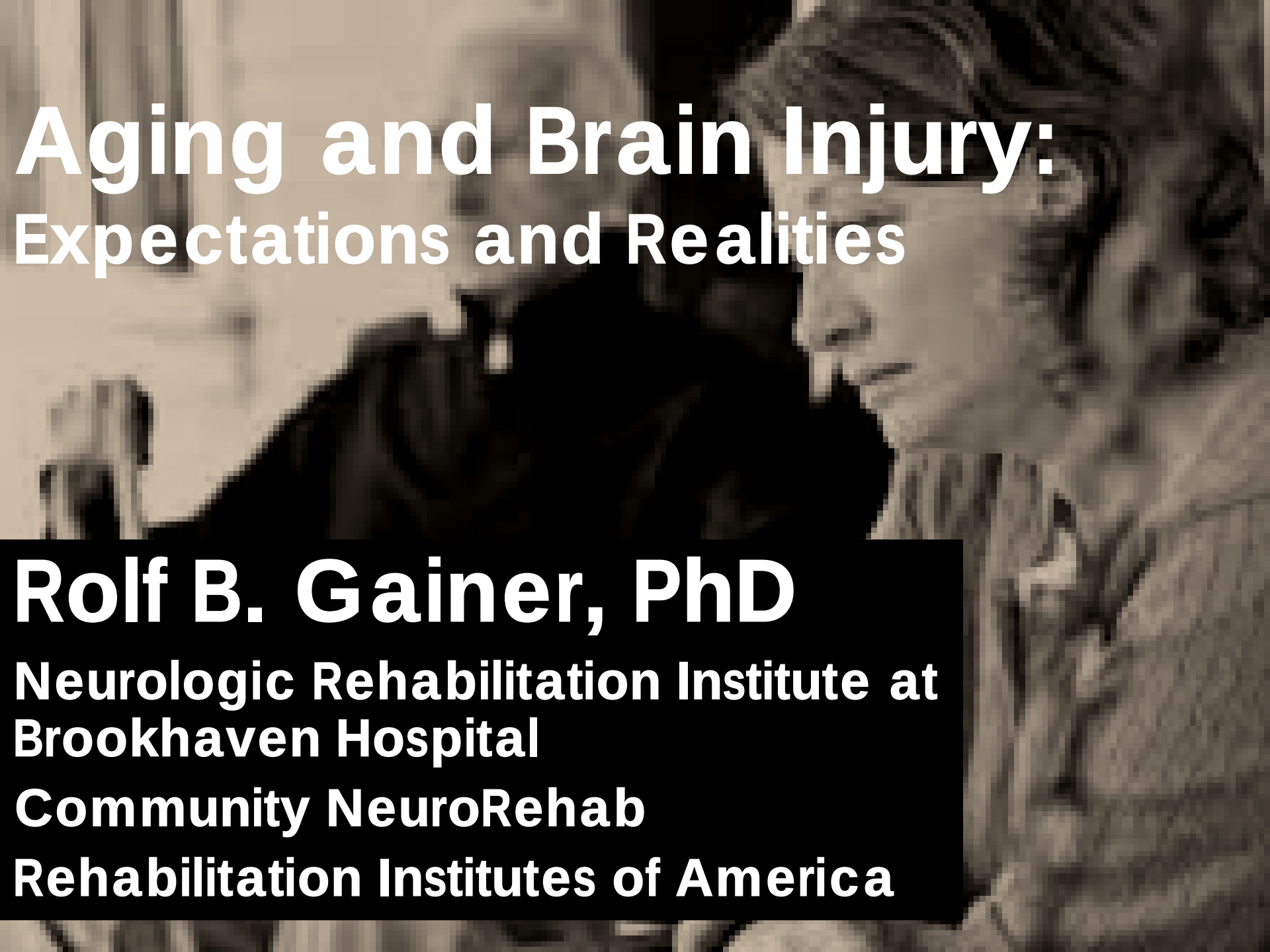

Aging and Brain Injury:
Expectations and Realities

Rolf B. Gainer, PhD

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Community NeuroRehab

Rehabilitation Institutes of America

Disclosure

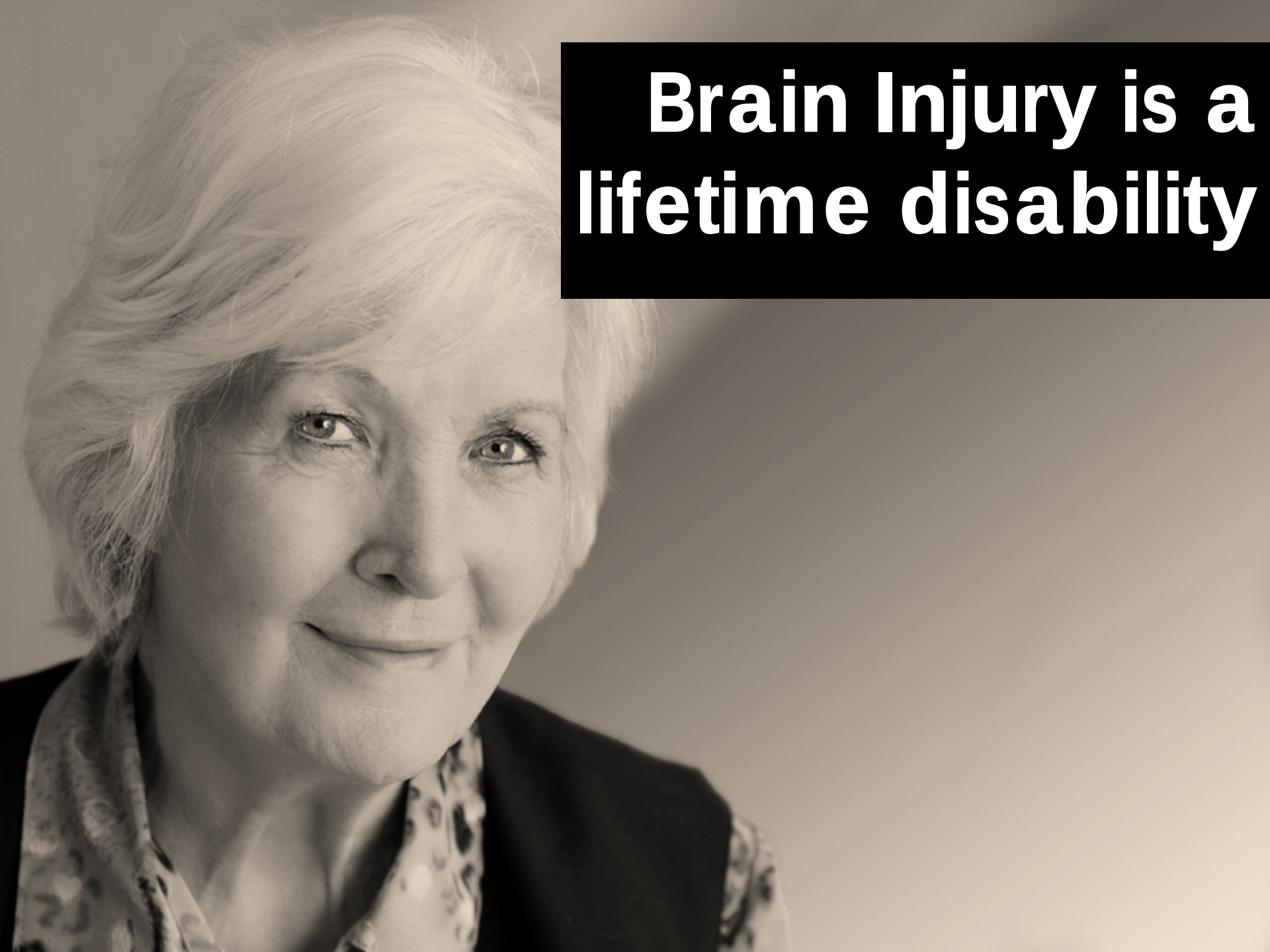
- Rolf B. Gainer, PhD has business relationships with Brookhaven Hospital, the Neurologic Rehabilitation Institute of Ontario, Community NeuroRehab of Iowa and Rehabilitation Institutes of America
- The studies conducted by Brookhaven Hospital , Community Neuro Rehab and the Neurologic Rehabilitation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

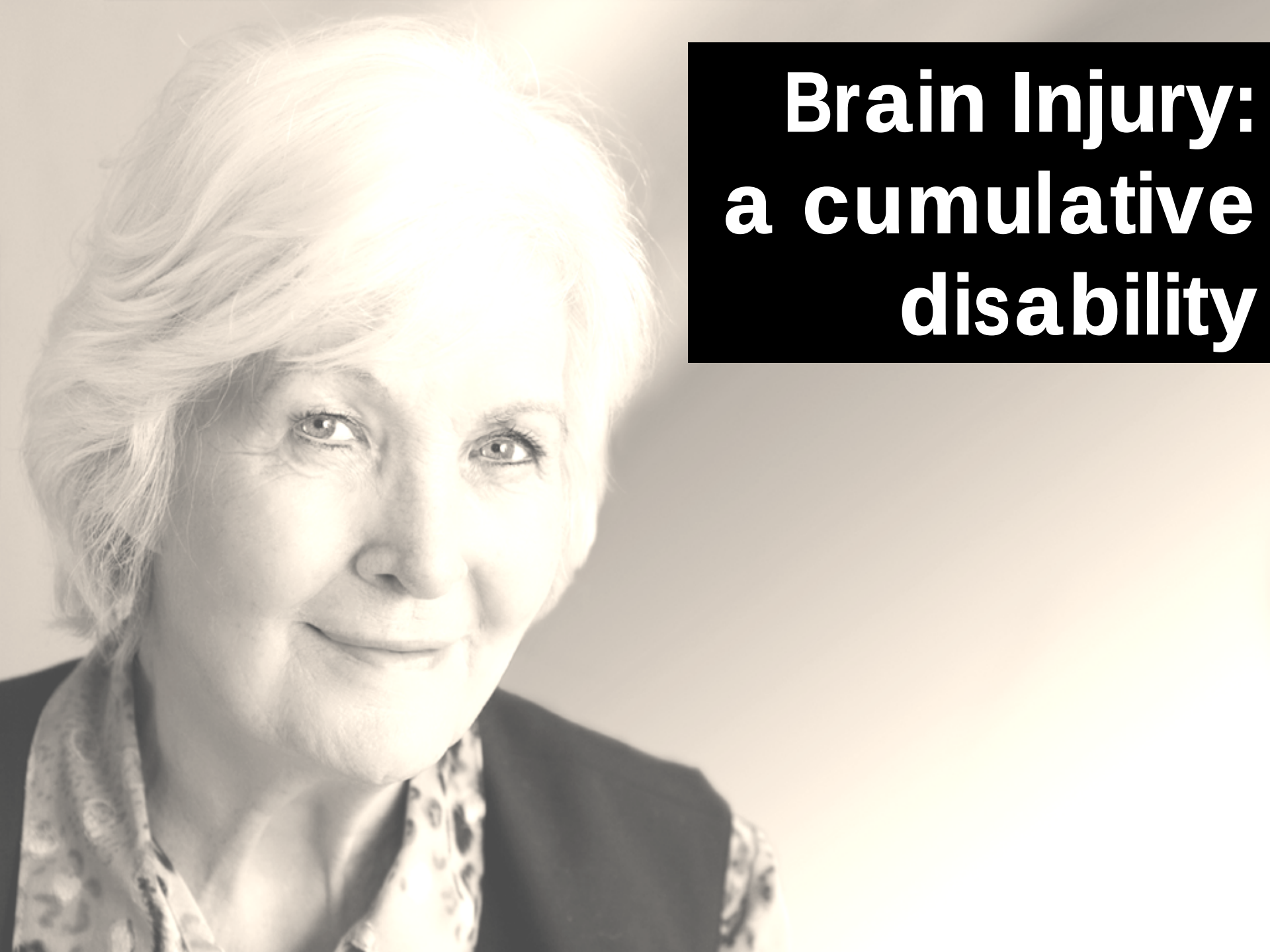
objectives:

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 is a
lifetime disability



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

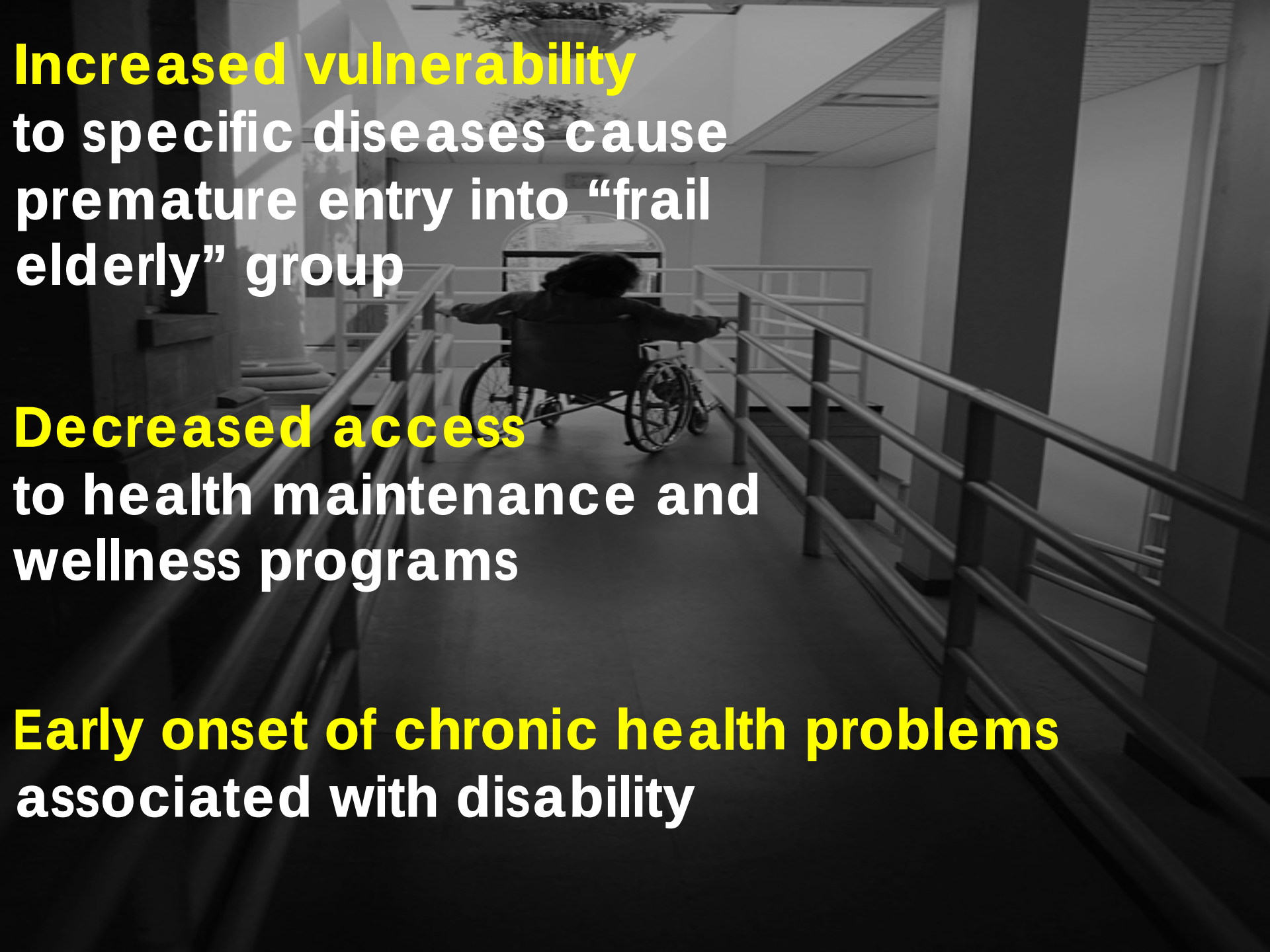
Atrophy increases with age

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

Same problems

Different timeframe for onset

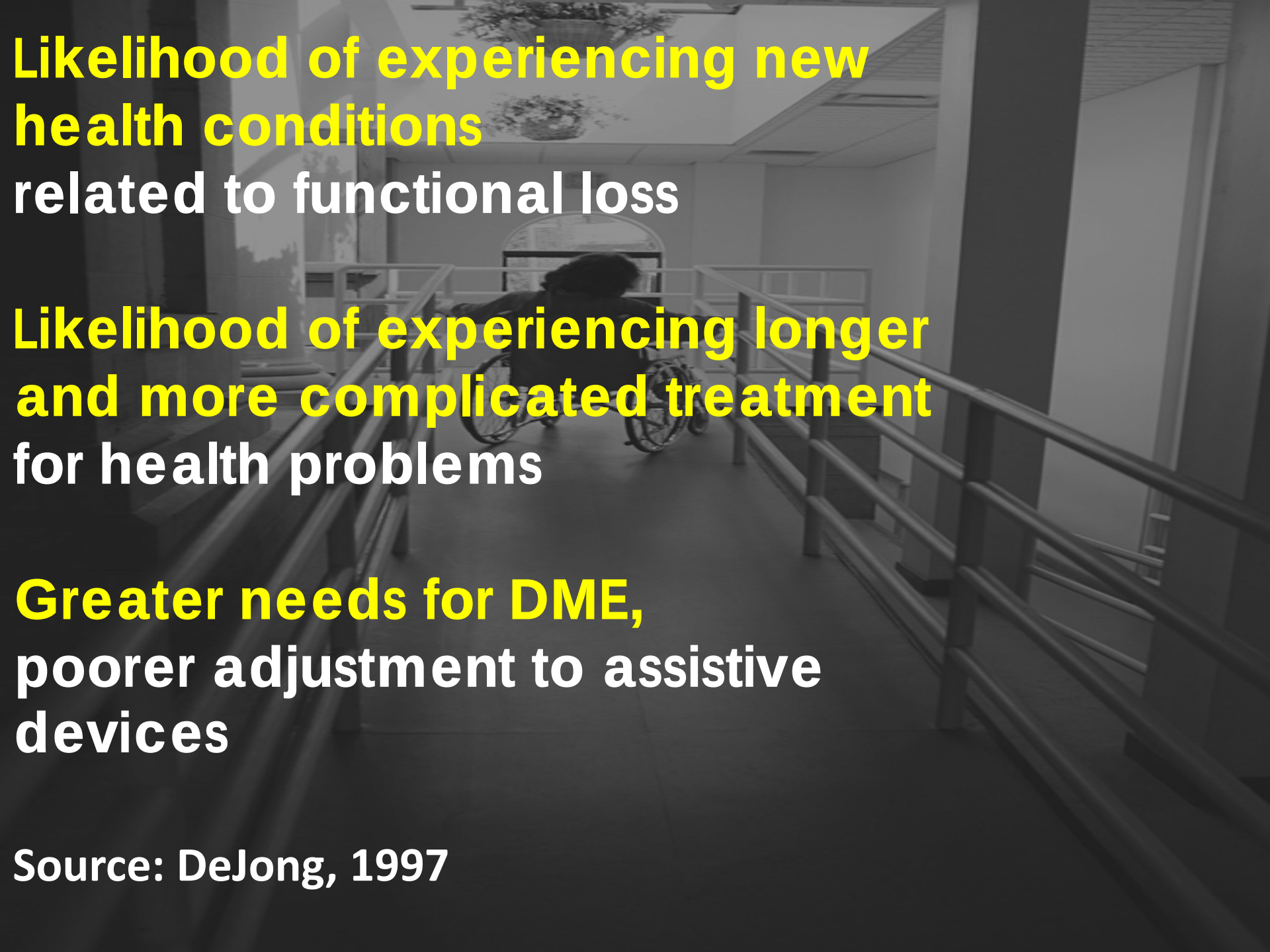
Disability and Future Healthcare Needs



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?

Pro-inflammatory and anti-inflammatory processes

Endocrine and immune system changes

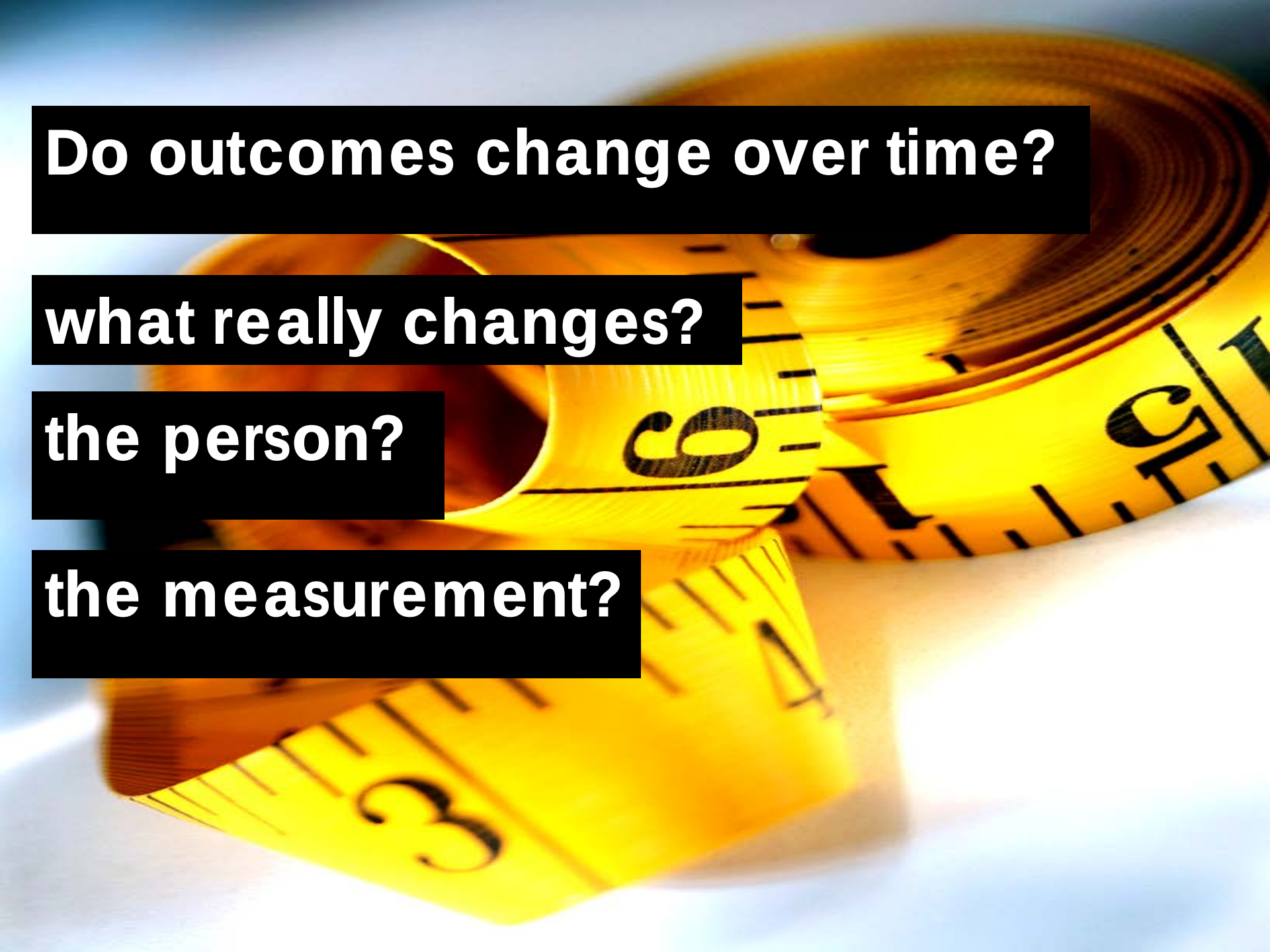
Do these processes affect how the will person age?

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?

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

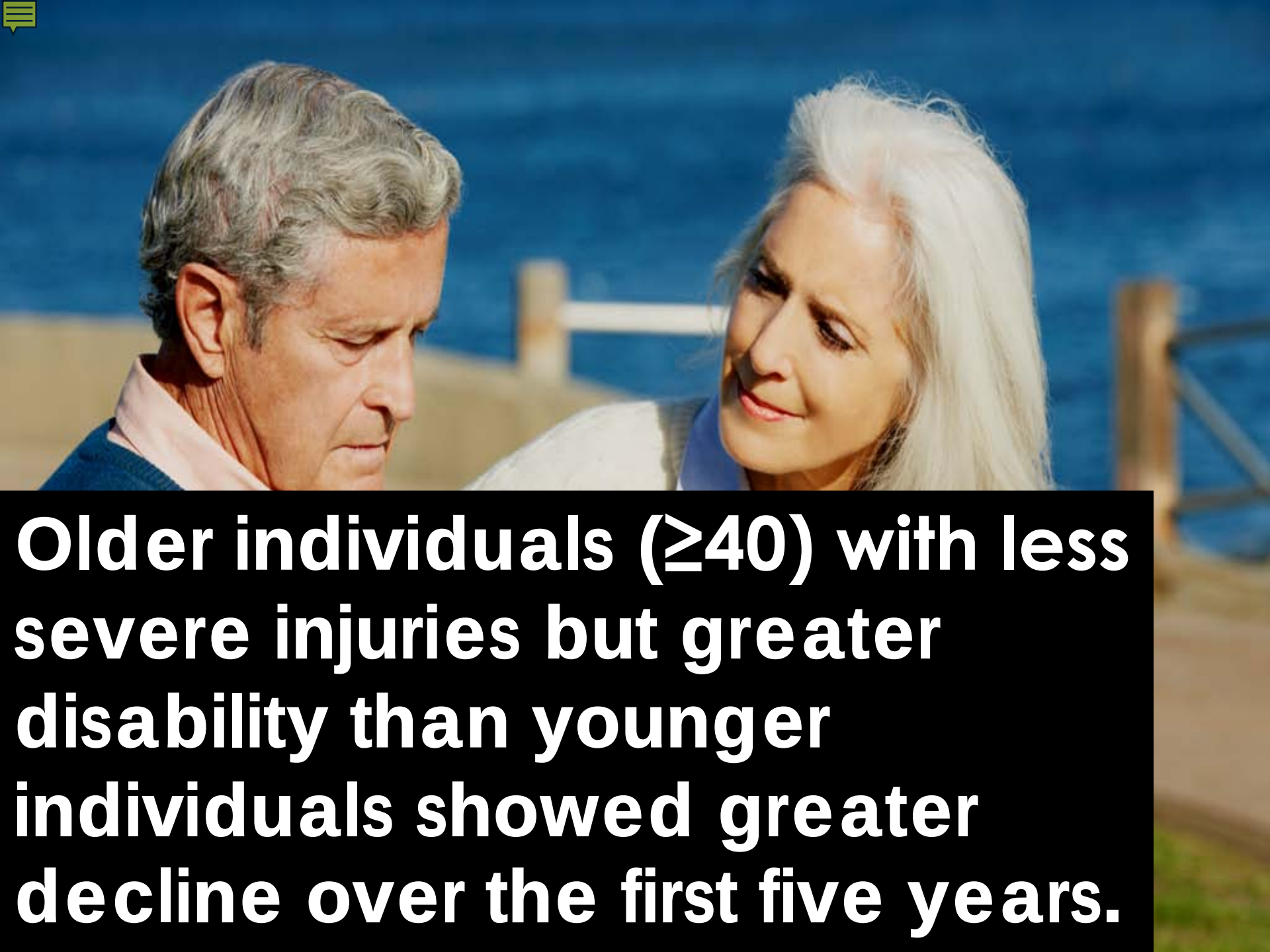
Creating a more vulnerable and fragile population of people aging with a brain injury

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

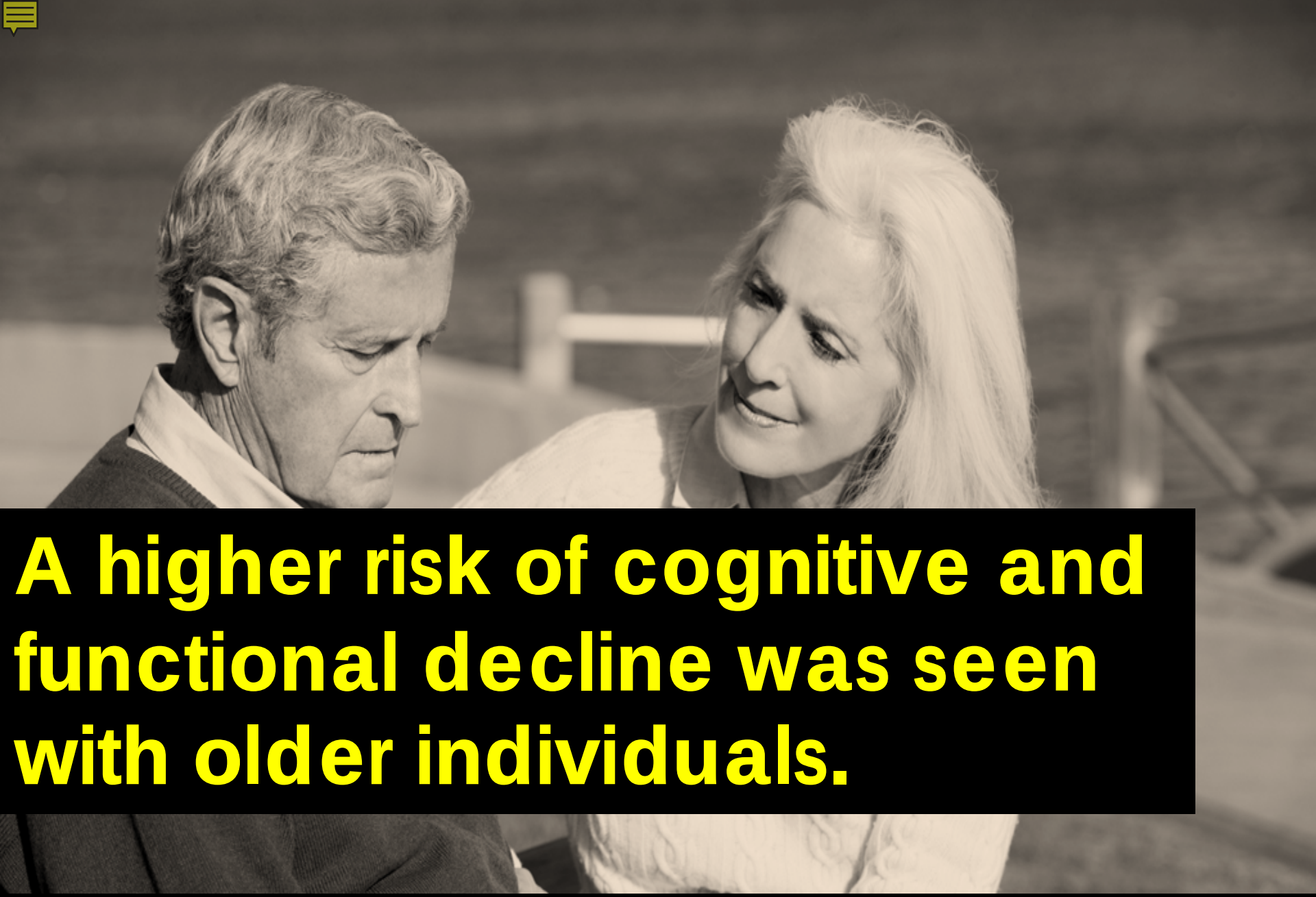
Brooks, J et al. Long-Term Survival After Traumatic Brain Injury. Part I and II. Arch Phy Med and Rehab, V.96, N.6, June 2015. pp994-1005

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



Older individuals (≥40) with less severe injuries but greater disability than younger individuals showed greater decline over the first five years.



A higher risk of cognitive and functional decline was seen with older individuals.

Marques de la Plata C, Hart T, Hammond F et al: Impact of Age on Long Term Recovery from Brain Injury. Arch of Phys Med Rehabilitation V 89, May 2008

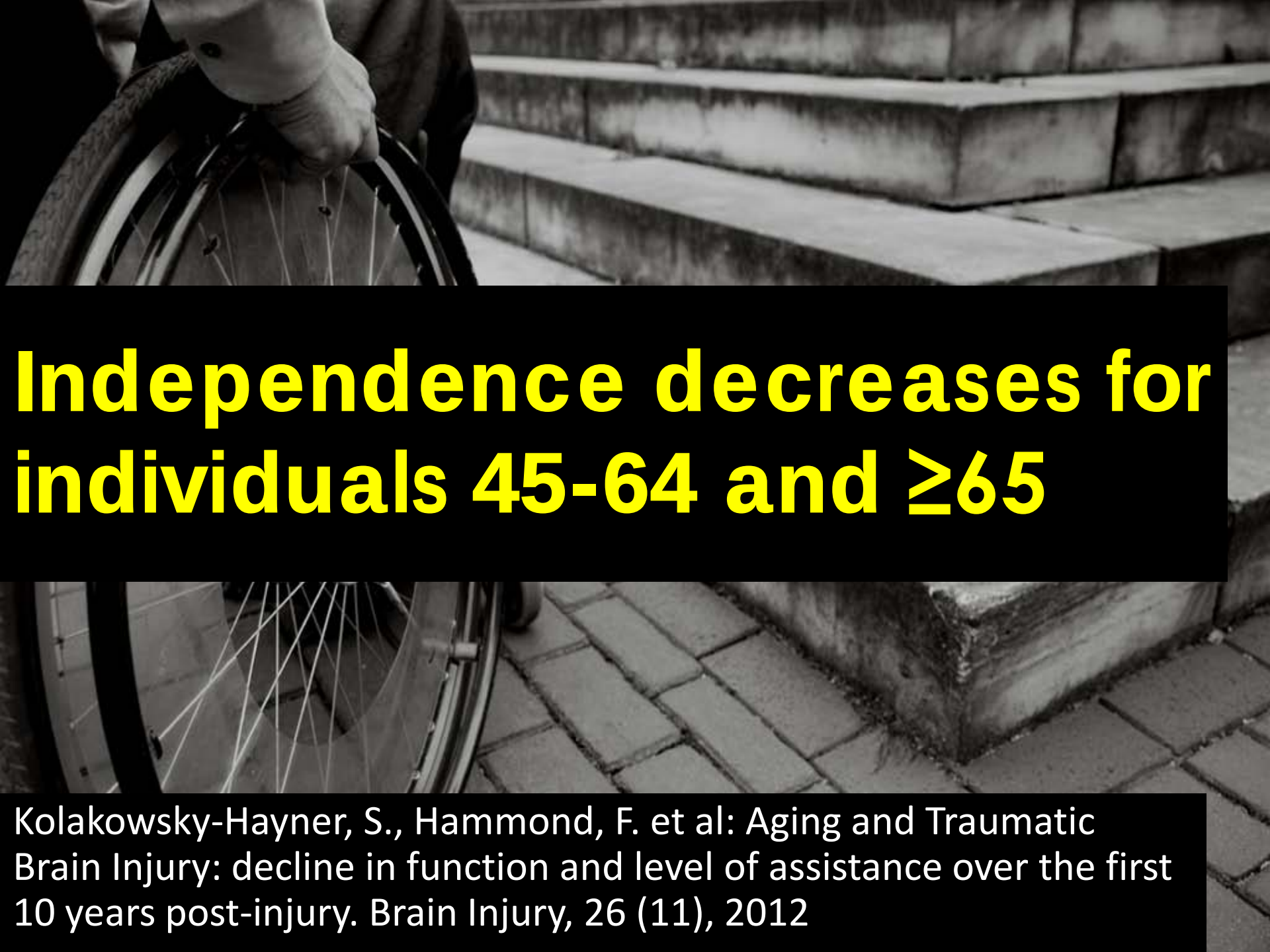
History of traumatic brain injury associated with increased risk for dementia and Parkinsonism, cognitive impairments and decline, seizure, hormonal disorders…

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

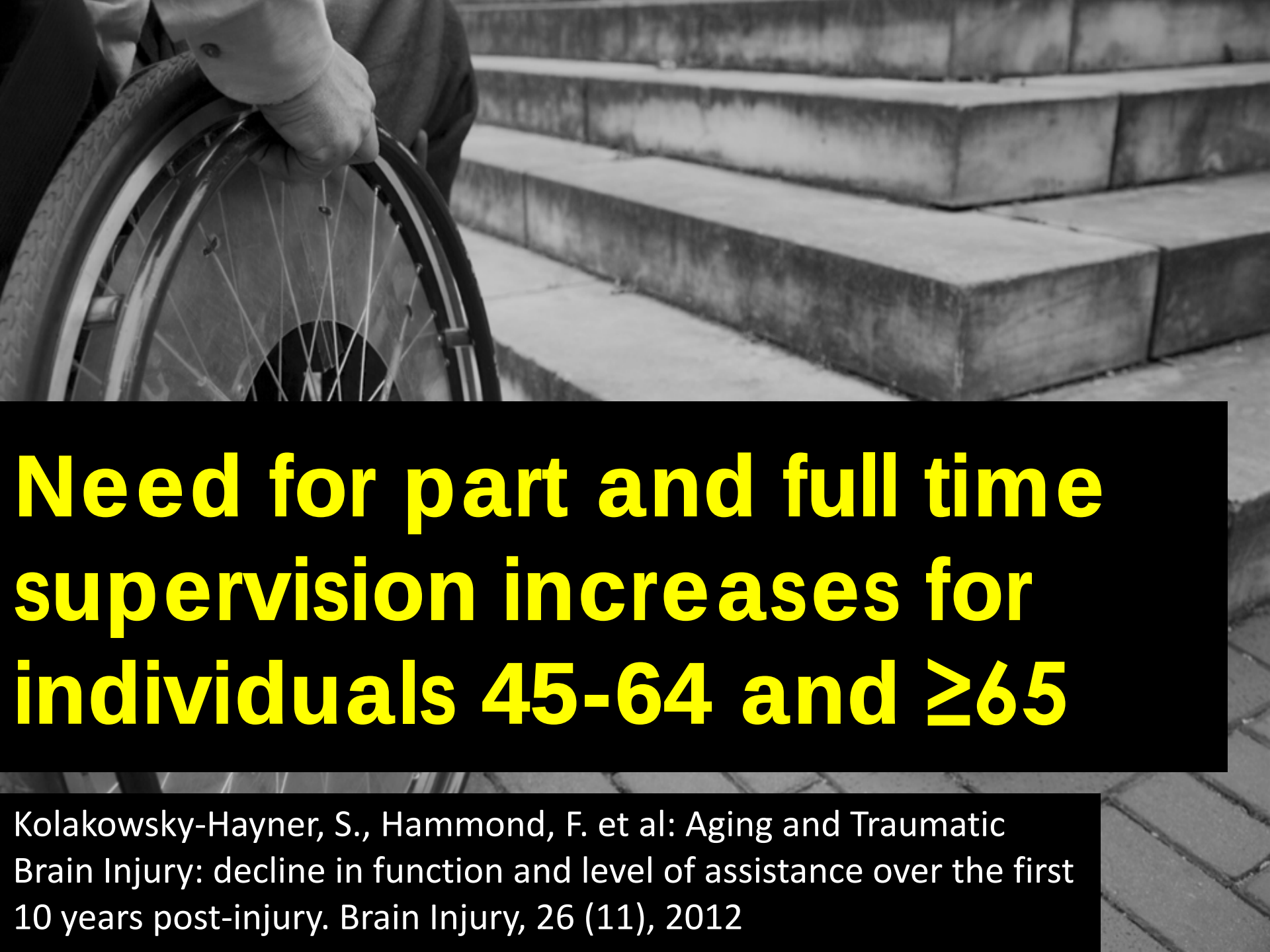
Ishibe N, et al, Long Term Consequences of BI, a Report to the Institute of Medicine, 2009


Loss of independence
creates increased needs



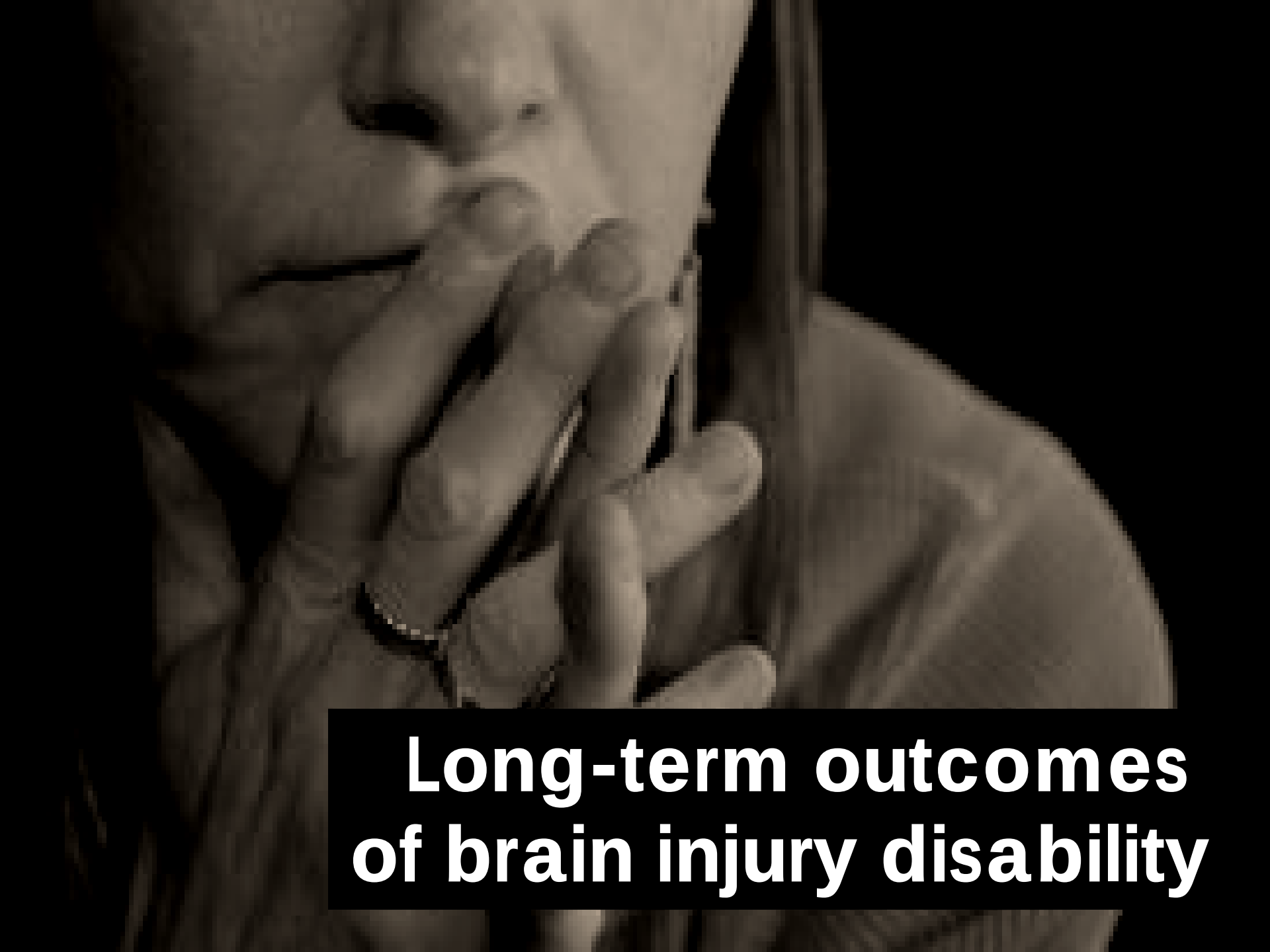
Independence decreases for individuals 45-64 and ≥65

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 illusive 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

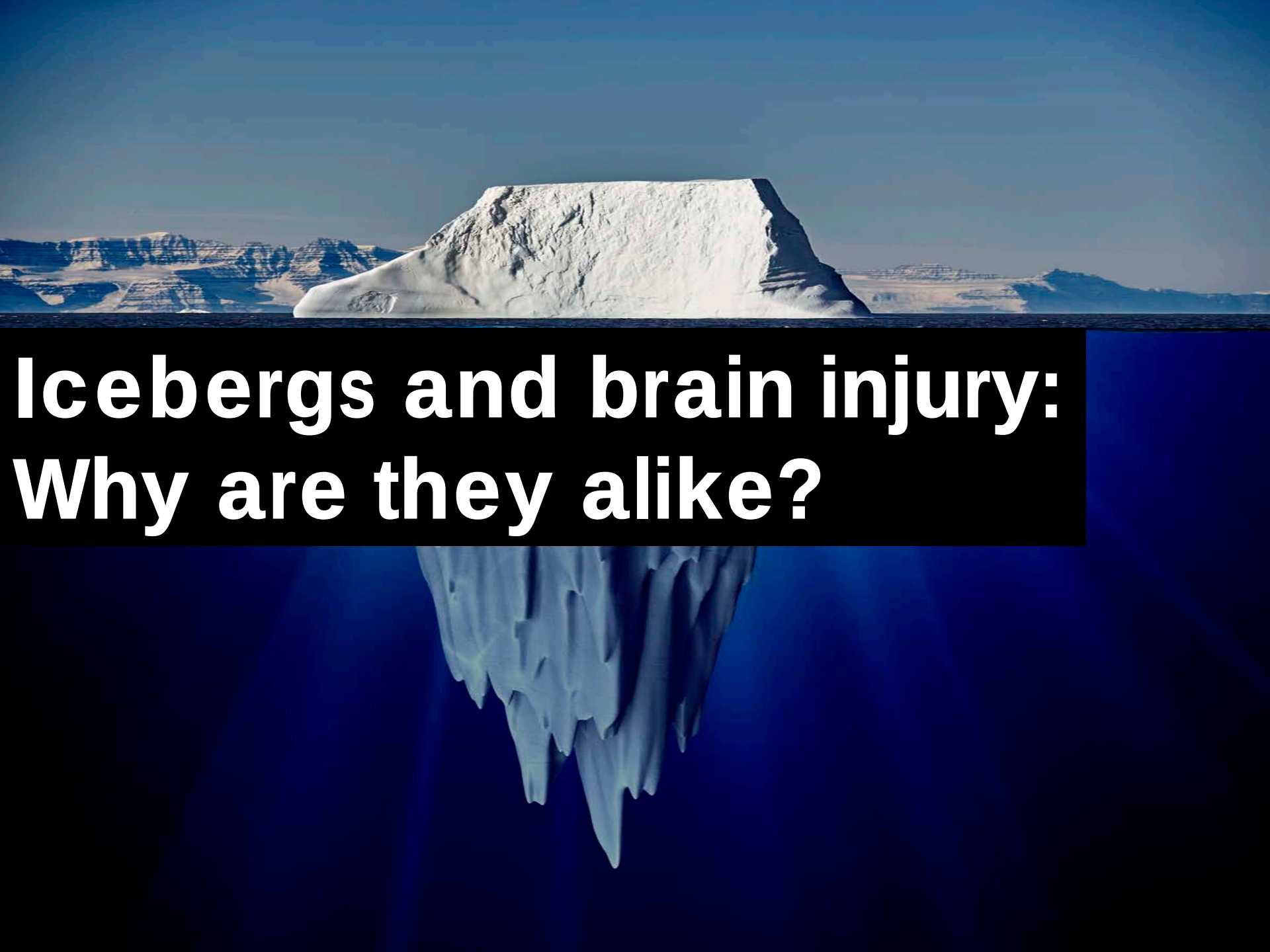
- ✓ **Permanent**
- ✓ **Leaves a residual disability**
- ✓ **Caused by a non-reversible pathological alteration**
- ✓ **Requires special training of the person**
- ✓ **May be expected to require a long period of supervision, observation and care**

Brain injury: an illness?

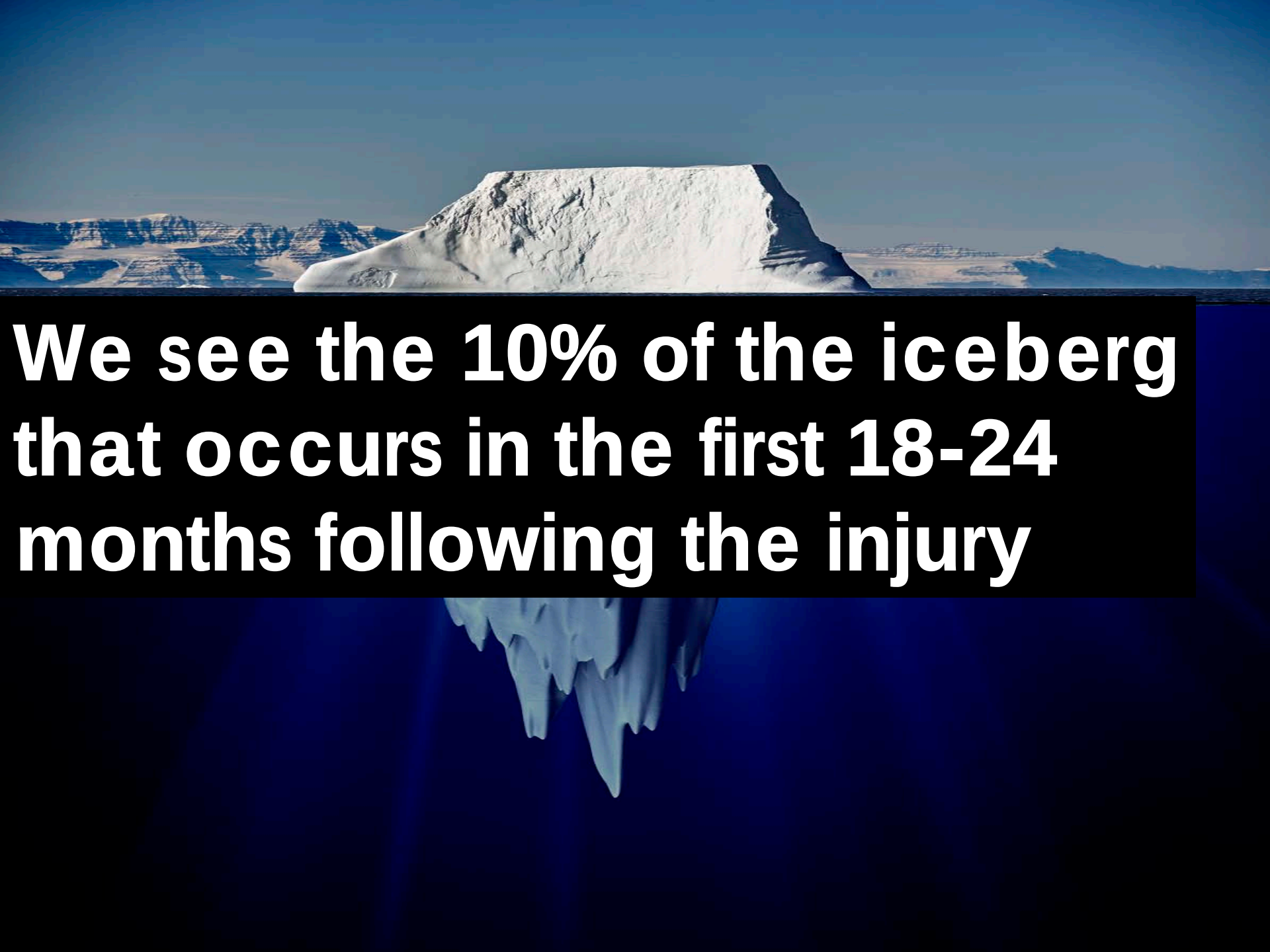
this view isolates the impact of the injury on the entire person

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…



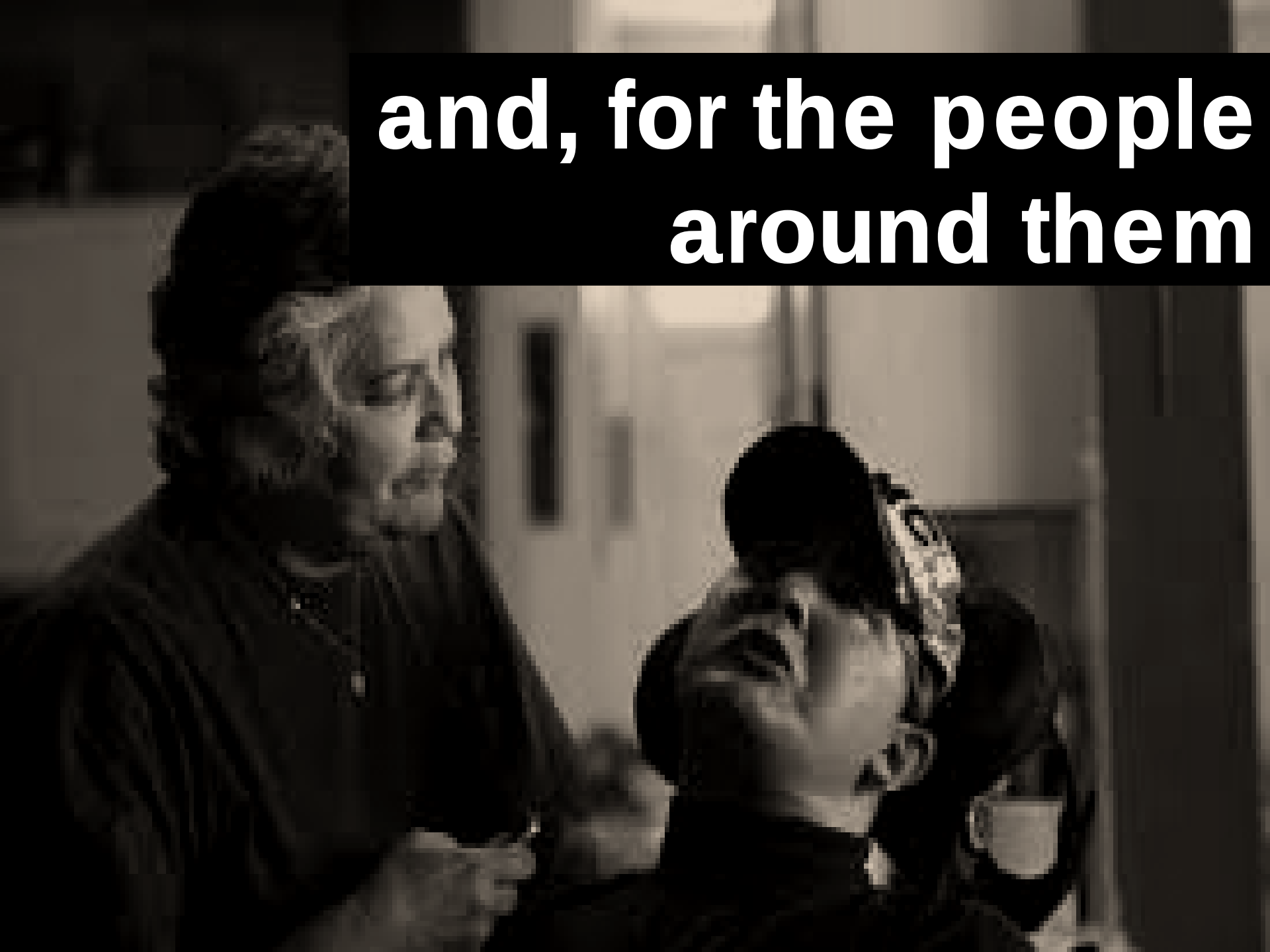
Icebergs and brain injury: Why are they alike?

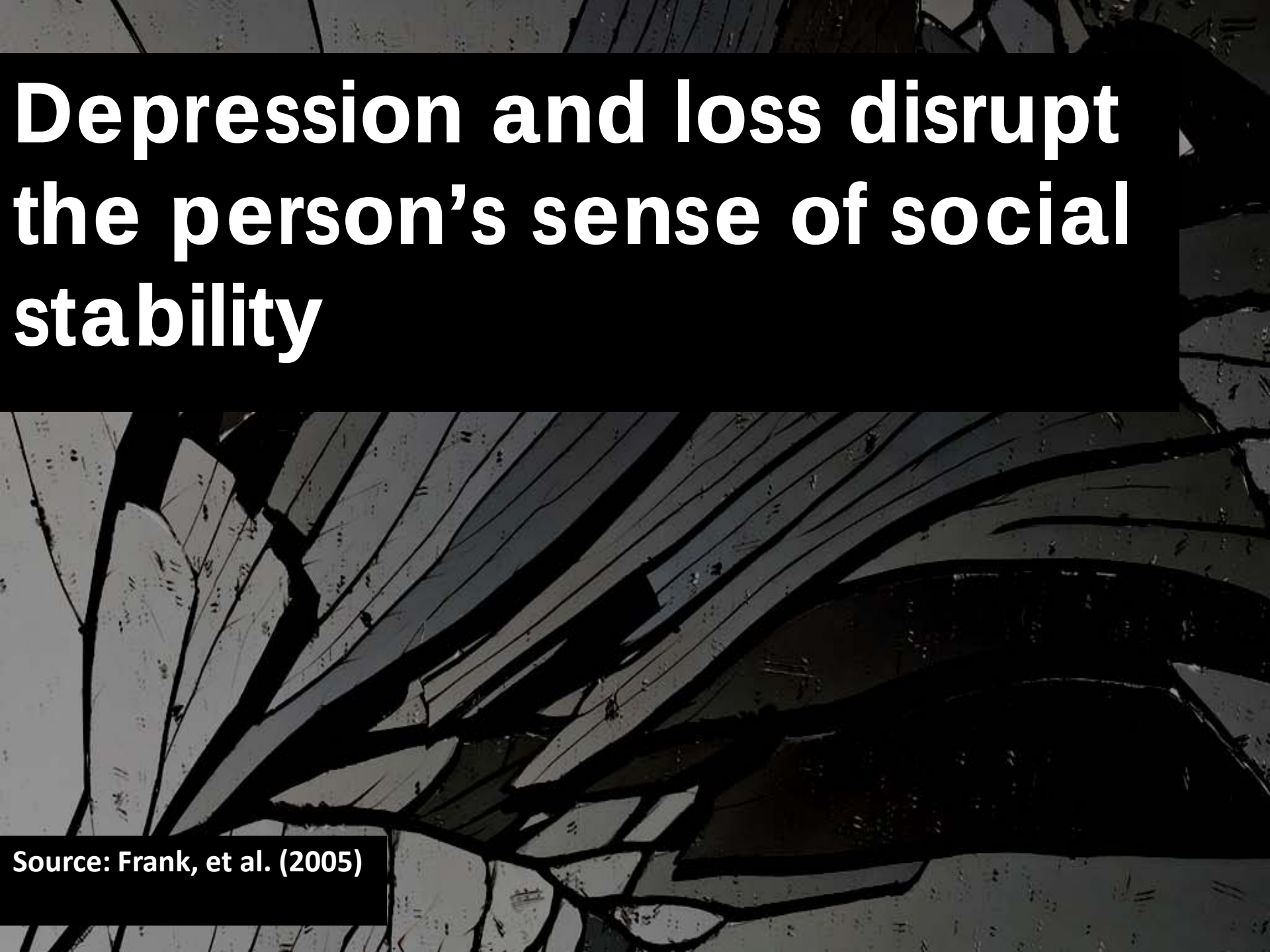

We see the 10% of the iceberg that occurs in the first 18-24 months following the injury

10% of an iceberg is visible,
90% is below the surface

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?

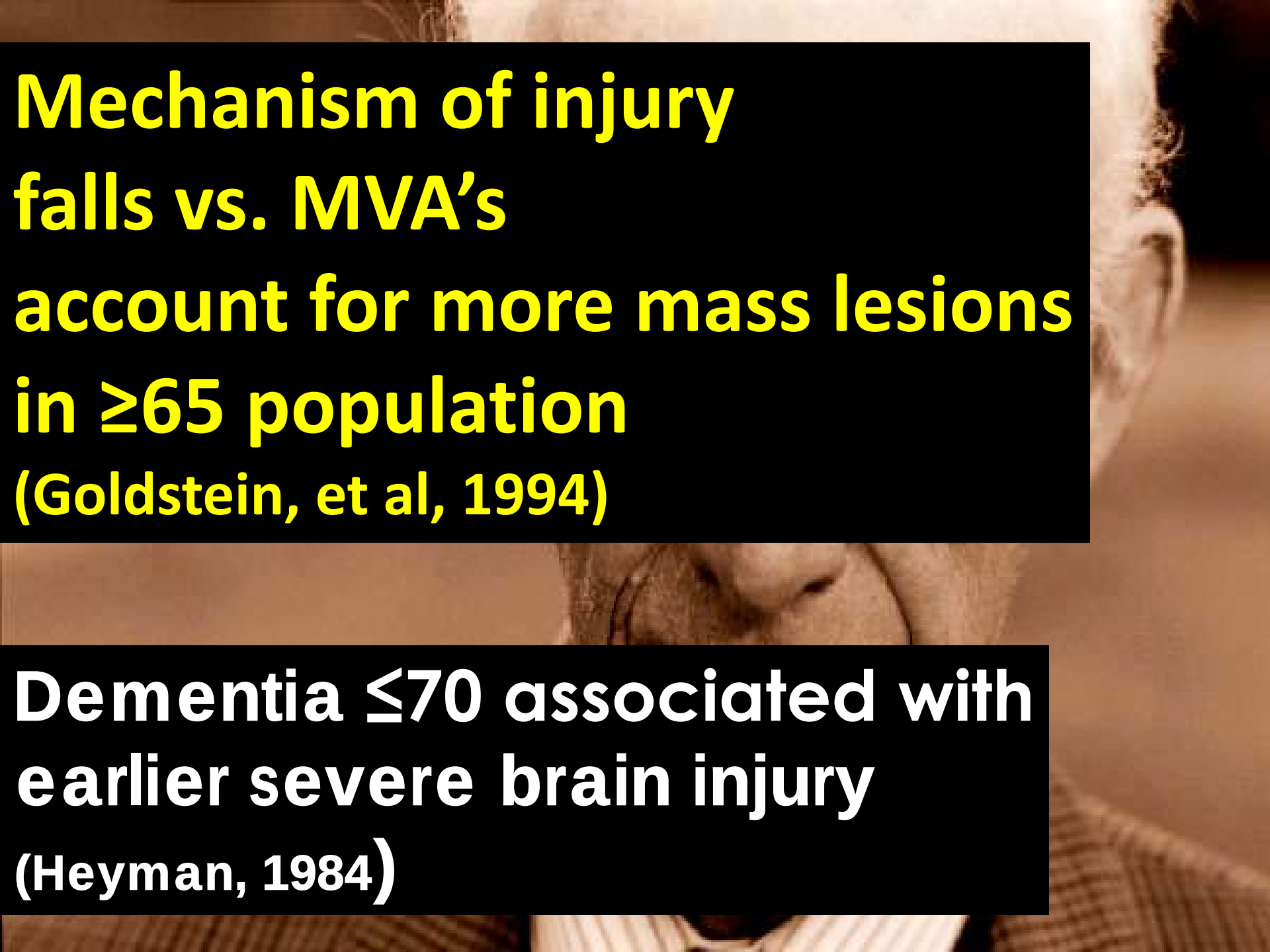
Age and Brain Injury: Outcomes of Injury

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)

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)



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

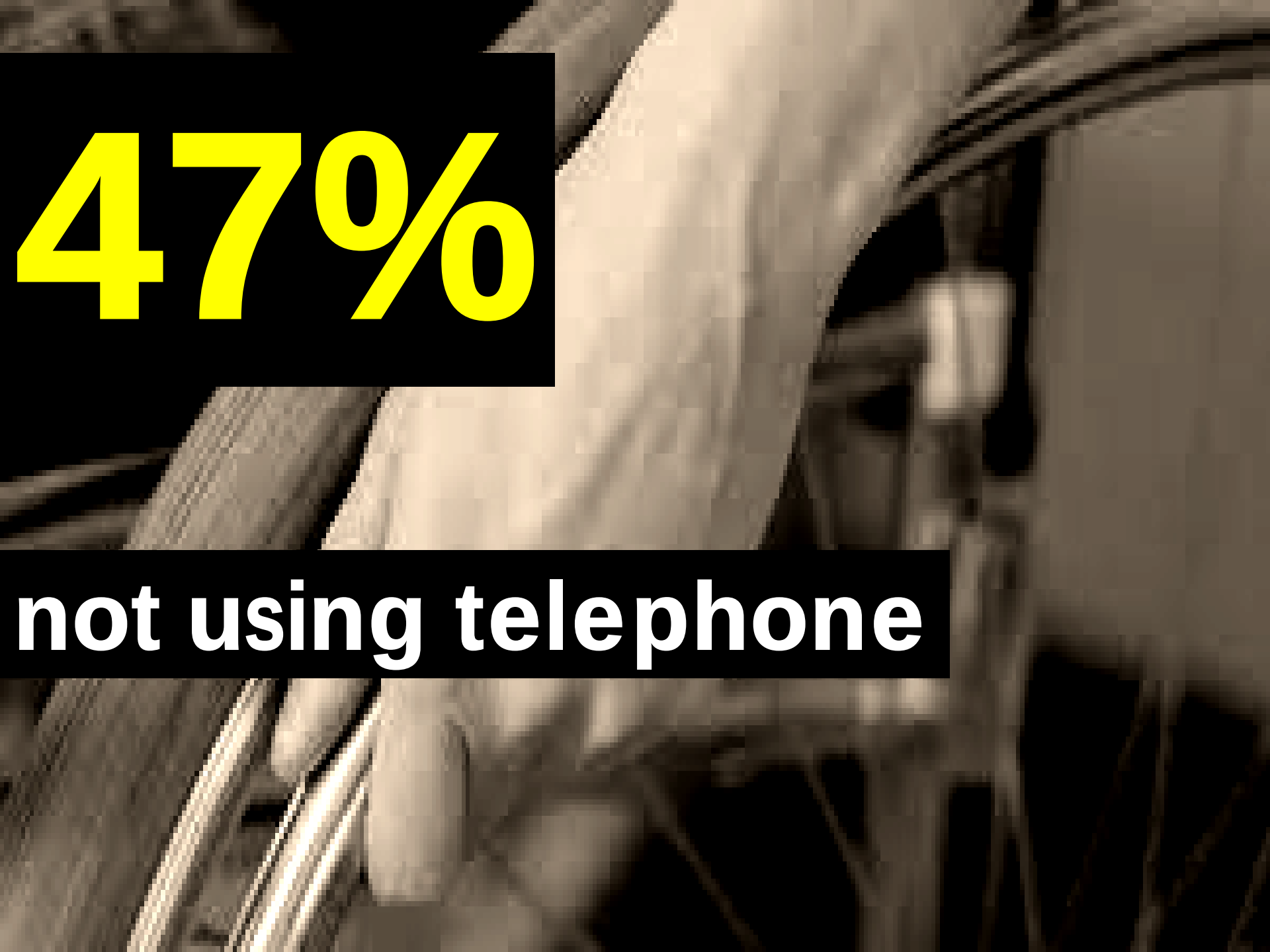
Dementia ≤70 associated with earlier severe brain injury
(Heyman, 1984)


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

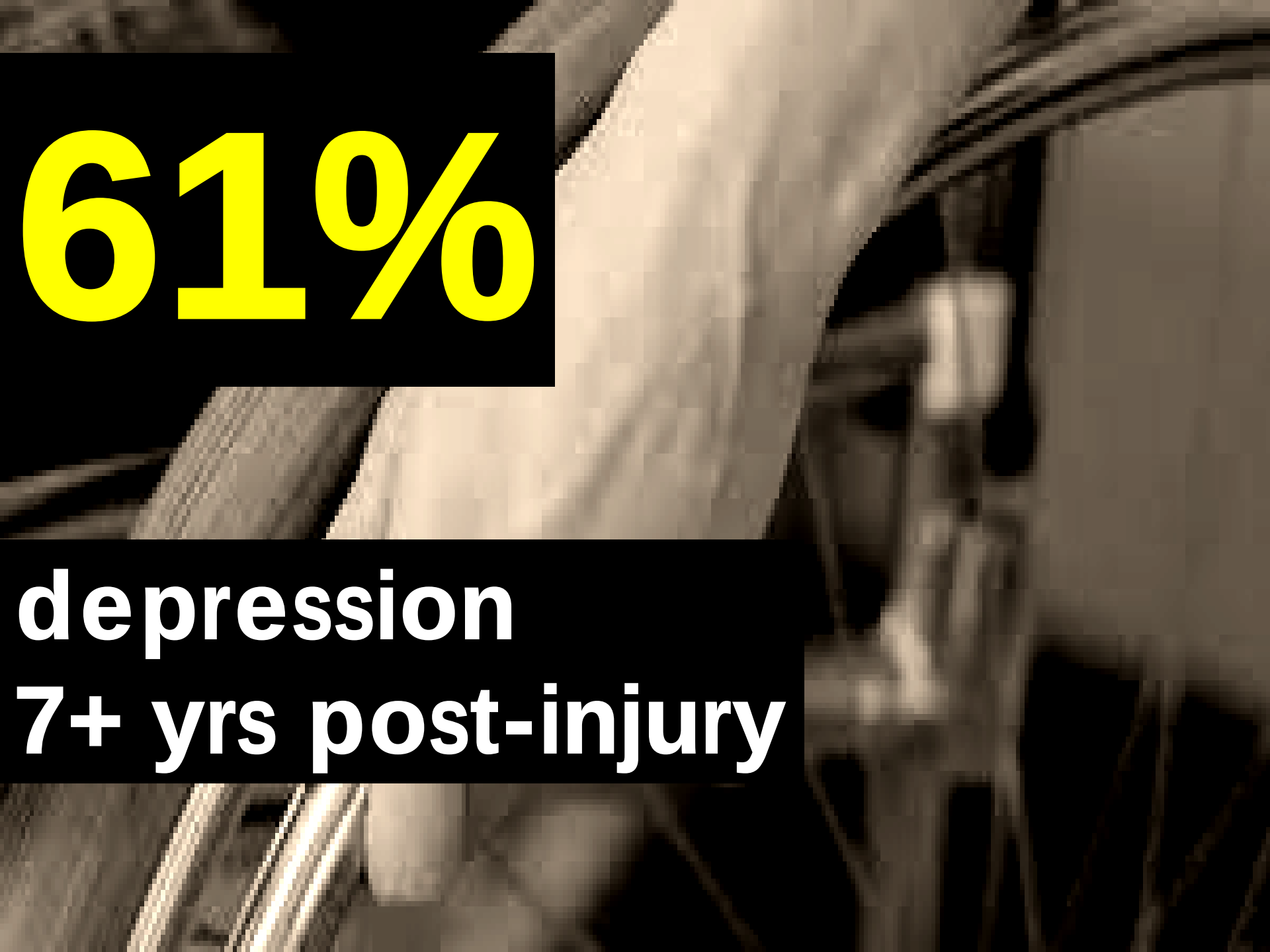
Dawson and Chipman's study

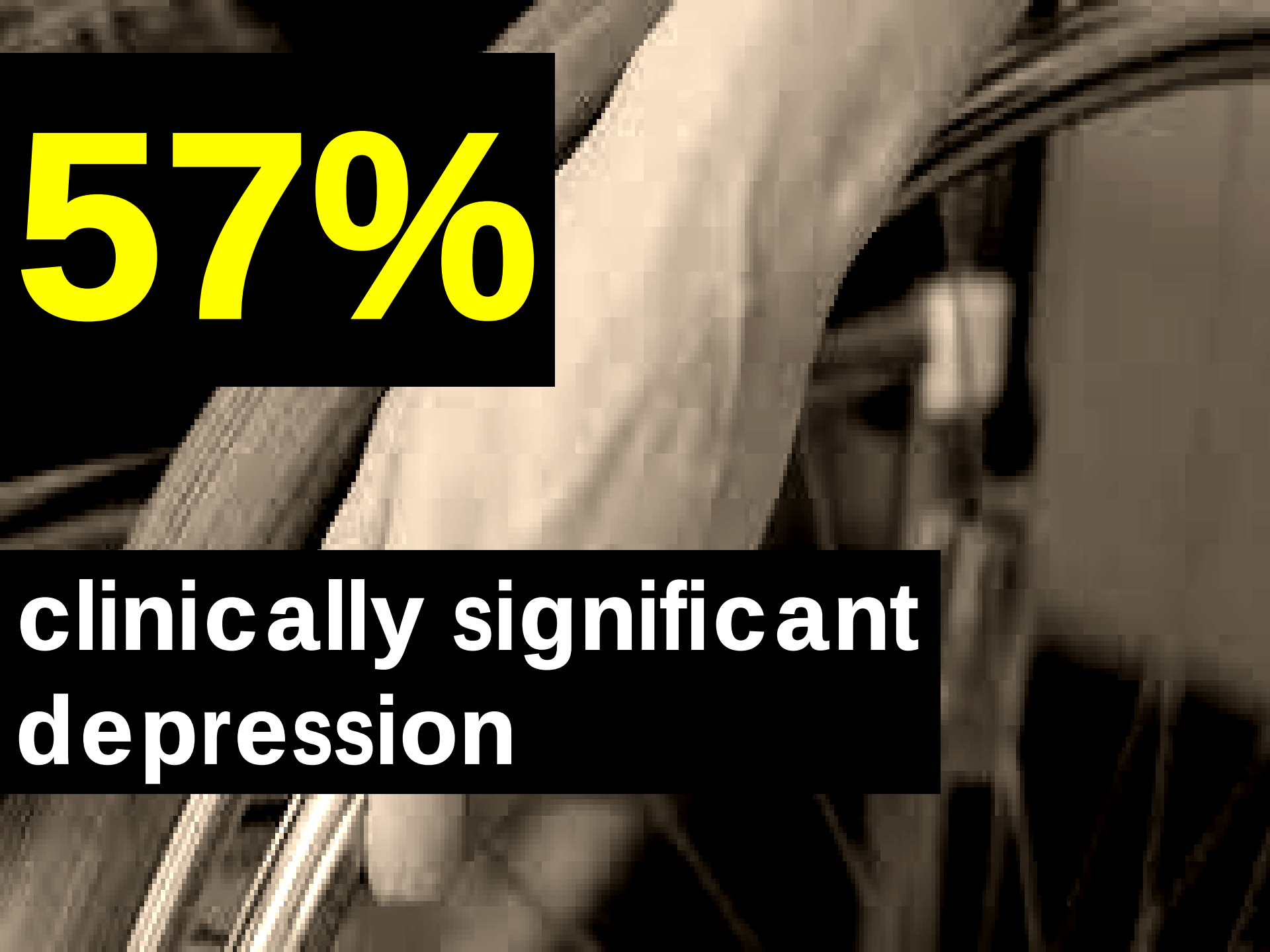
Quality of Life for individuals with severe and high moderate brain injuries ≥15 years post-injury, living in urban and rural settings

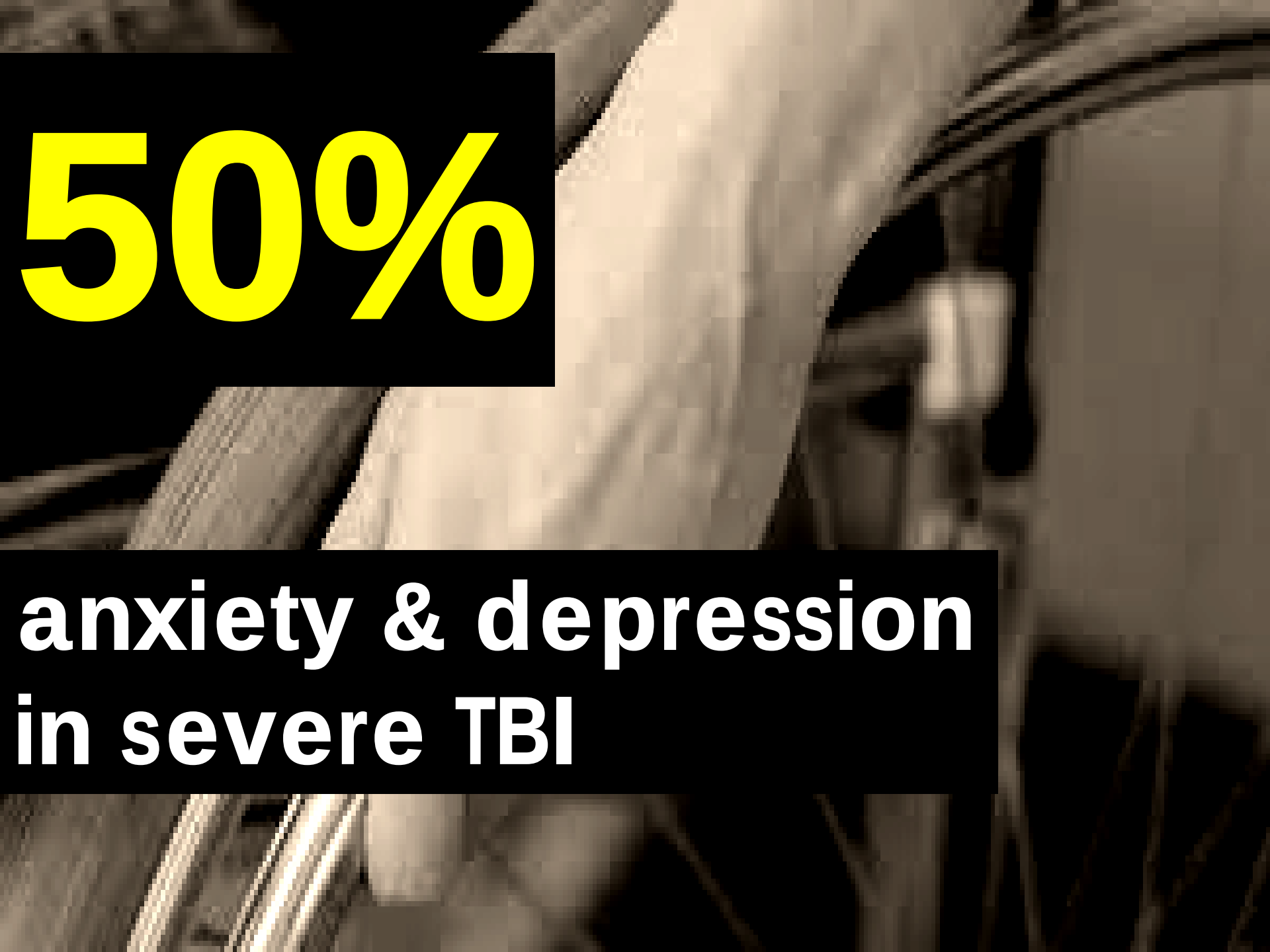

47%
not using telephone


66%
need ADL assistance


75%
unemployed


61%
depression
7+ yrs post-injury


57%
clinically significant
depression


50%
anxiety & depression
in severe TBI

Why ?

interference of symptoms

ability to self-manage

cognitive ability

physical functions

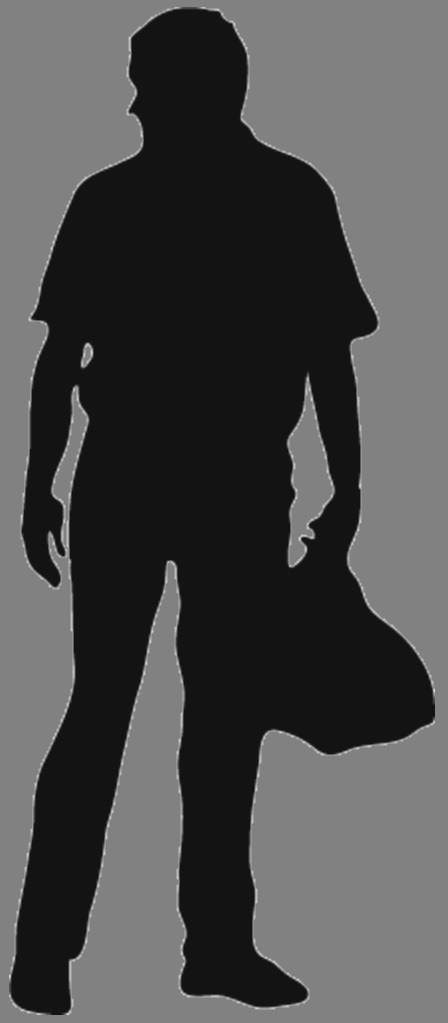
How does that appear over the course of time?

son

father

wife

daughter



Meet Walter at 55

Walter at 65

Walter at 55

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):

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


aging hides TBI

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

(Bilmes,L ,2007)

and $8 to 17 million

(Livneh and Antonak, 1997)


$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

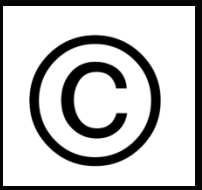
Address critical transition events which trigger crises and problems

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)

Emerson, E. Poverty and people with intellectual disabilities, Mental Retardation and Development Disabilities Research Review, 2007, 13 (2): 107-113

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, July 8, 2014 (live broadcast date)

Resources

Gainer, R., et al., (1997 – ongoing). NRIO outcome validation study. NRIO, Etobicoke, Ontario.

Geurtsen, G., et al. (2010). Comprehensive rehabilitation programmes in the chronic phase after severe brain injury: A systematic review Journal of Rehabilitation Medicine, 42, 97-110

Harrison-Felix, C.L., Whiteneck, G.G., Jha, A. (2004). Mortality following rehabilitation in the Traumatic Brain Injury Model Systems of Care. Neurorehabiliation. 19(1), 45-54.

Harrison-Felix, C.L., Whiteneck, G.G., Jha, A. (2006). Causes of death following 1 year postinjury among individuals with traumatic brain injury. Journal of Head Trauma Rehabilitation, 21(1), 22-33.

Harrison-Felix, C.L., Whiteneck, G.G., Jha, A., Devivo, M.J., Hammond, F.M., Hart, D.M. (2009). Mortality over four decades after traumatic brain injury rehabilitation: a retrospective cohort study. Archives Physical Medical Rehabilitation. (9), 1506-1513.

Harrison-Felix, C.L., Whiteneck, G.G., Jha, A., Devivo, M.J., Hammond, F.M., Hart, D.M. (2009). Mortality over four decades after traumatic brain injury rehabilitation: a retrospective cohort study. Archives Physical Medical Rehabilitation. (9), 1506-1513.

Resources

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

Kaponen, S., Taiminen, T., Portin, R., Himanen, L., Isoniemi, H., Heinonen, H., Hinkka, S., Tenovuo, O. Axis I and Axis II Psychiatric Disorders After Traumatic Brain Injury: A 30-Year Follow-Up Study (2002) American J Psychiatry. August 2002;159,82: 1315-1321

Kim, E. et al. Neuropsychiatric Complications of Traumatic Brain Injury: A critical review of the literature. J. Neuropsychiatry and Neurosciences, V 19 (2) Spring 2007

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

Leopold, A. Post Acute Rehabilitation of Adults with TBI: Receipt of Services, Unmet Needs and Barriers to Receiving Services, JBS International Inc., Washington, D.C. October 9, 2013 (Southwest Disability Conference)

Marques de la Plata C, Hart T, Hammond F et al: Impact of Age on Long Term Recovery from Brain Injury. Arch of Phys Med Rehabil V 89, May 2008

Masel, B., DeWitt, D. (2010). Traumatic brain injury: A disease process, not an event. Journal of Neurotrauma., 27(8), 1529-1540.

Resources

Ponsford, J, Draper, K, Schonberger, M. Functional outcome 10 years after traumatic brain injury: its relationship with demographic, injury severity, and cognitive and emotional status. J of the Intl Neuropsych Society 2008; 14: 233-242

Rao, V, Lyketsos, C., Neuropsychiatric Sequelae of Traumatic Brain Injury, Psychosomatics, V 41 (2) March-April 2000: 95-103

Sanders, A. Family Response to TBI, Baylor College of Medicine Press, Dallas, TX, 2003 (monograph)

Sendroy-Terrill M, Whiteneck G, Brooks C. Aging with Traumatic Brain Injury: Cross-Sectional Follow-Up of People Receiving Inpatient Rehabilitation Over More Than 3 Decades. Arch Phy Med Rehabil, V 91, March 2010 pp489-497

Silver J, Kramer R, Greenwald S, Weissman M. The association between head injuries and psychiatric disorders: findings from the New Haven NIMH Epidemiologic Catchment Area Study, Brain Injury, 2001, V. 15, No. 11: 935-945. Reproduced with permission from Informa Healthcare.

van Reekum, R., Boago, I., Finlayson, M.A., Garner, S., et al. (1996). Psychiatric disorders after traumatic brain injury. Brain Injury, 10 (5), 319-27.

Resources

van Reekum R, Cohen T, Wong J. Can Traumatic Brain Injury Cause Psychiatric Disease, J. Neuropsychiatry. 2000; 12: 316-327

van Reekum R., Stuss, D.T., Ostrander, L. (2005). Apathy: why care? *Journal of Neuropsychiatry and Clinical Neurosciences* 17(1):7-19.

Yeo, R., Moore, K. Including disabled people in poverty reduction work: “Nothing about us, without us”, World Development, 2003 V 31 (3): 571-90

Whelan-Goodinson, R, Ponsford, J, Johnston, L, Grant, F. J of Head Trauma Rehabilitation. Psychiatric Disorders Following Traumatic Brain Injury: Their Nature and Frequency. 2009 Vol 24 (5): 324-332