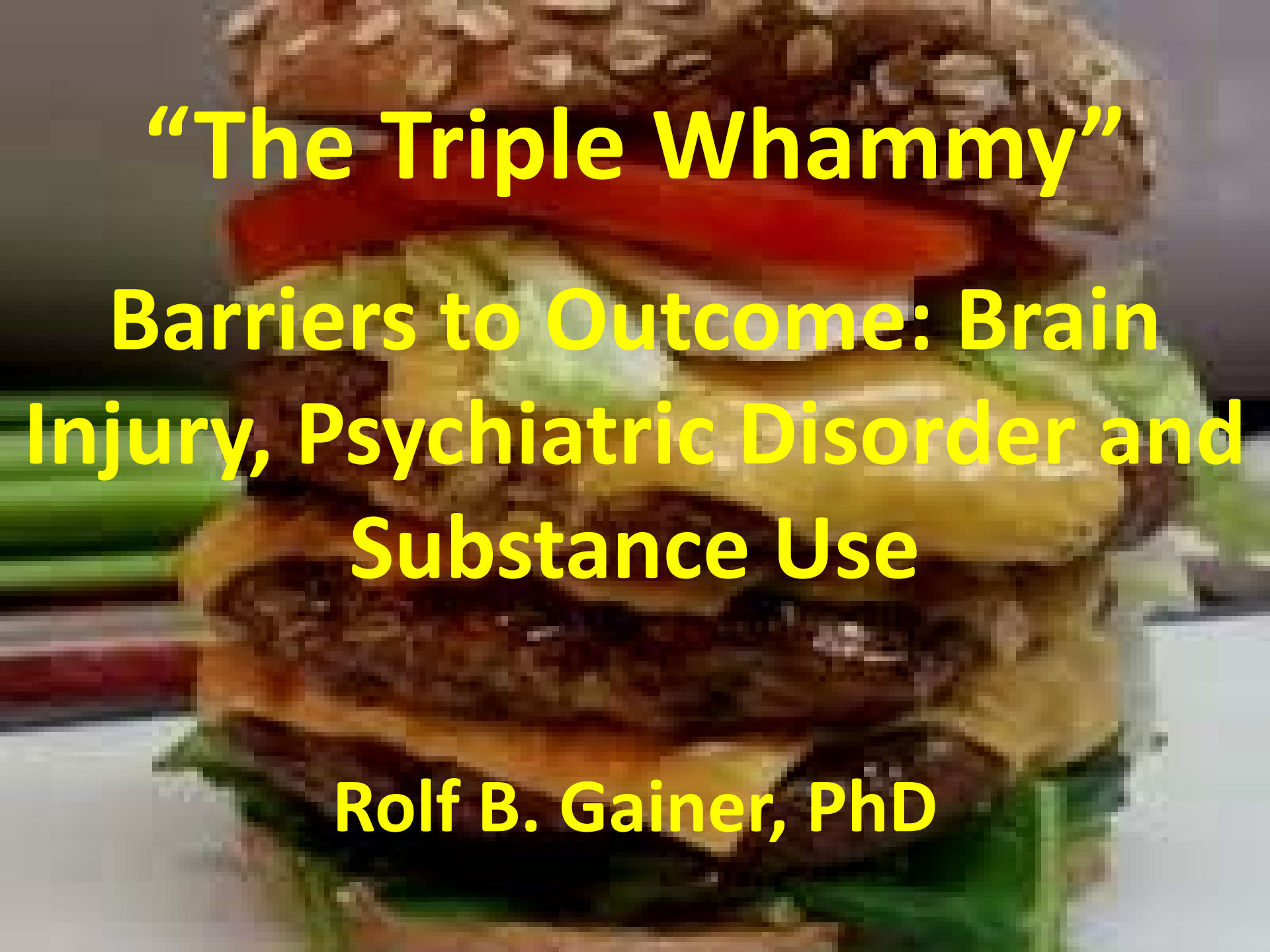
“The Triple Whammy” Barriers to Outcome: Brain Injury, Psychiatric Disorder and Substance Use

Rolf B. Gainer, PhD,

Rehabilitation Institutes of America, Novato, CA; Neurologic Rehabilitation Institute at Brookhaven Hospital, Tulsa, OK; Neurologic Rehabilitation Institute of Ontario, Etobicoke, ON; Community NeuroRehab of Iowa, Des Moines, IA



"The Triple Whammy"

Barriers to Outcome: Brain Injury, Psychiatric Disorder and Substance Use

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Disclosure

- Rolf B. Gainer, PhD, is the Founder of NRIO and its Chief Executive Officer from September 1993 until September 2016.

- He thanks Bayshore Healthcare, the operator of NRIO, for their support of his participation at this conference.

- Dr. Gainer is the Vice President of Rehabilitation Institutes of America and has served as the Chief Executive Officer of Brookhaven Hospital since 1993. Dr. Gainer is a Founding Board Member of Community NeuroRehab.
- Rolf B. Gainer, PhD, has business relationships with Brookhaven Hospital, Community NeuroRehab of Iowa and companies related to those organizations. Dr. Gainer is a shareholder in companies related to the non-clinical operation of NRIO.
- The Outcome Studies conducted by NRIO, Community NeuroRehab of Iowa and Brookhaven Hospital are supported by those organizations and receive no other public or private grants or funding.

- To review the key studies involving people living with brain injury and co-occurring mental health disorders

- To understand the significance of social role return in long-term outcomes from brain injury

- To identify resources needed to prevent aspects of psychosocial problems which effect quality of life and health

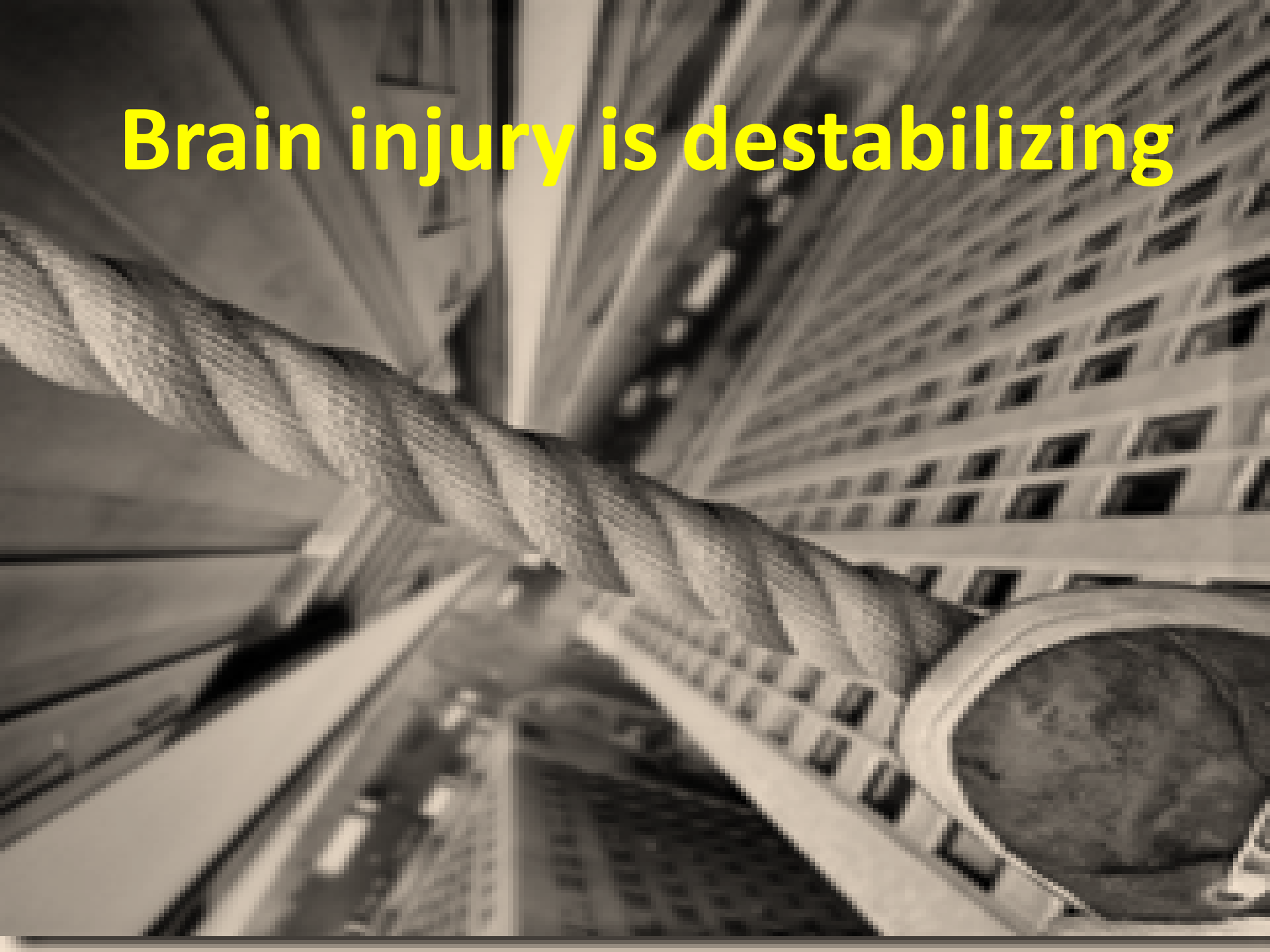

What's in the Triple Whammy?

Brain Injury

Psychiatric Issues

Substance Abuse Problems

all three serve as risk factors


Brain injury is destabilizing

“I felt I was different, couldn’t put my finger on it… absorbing it internally, it was something wrong with me”

“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


Defining the
post-injury
experience

Ambiguous loss creates stress and defies closure

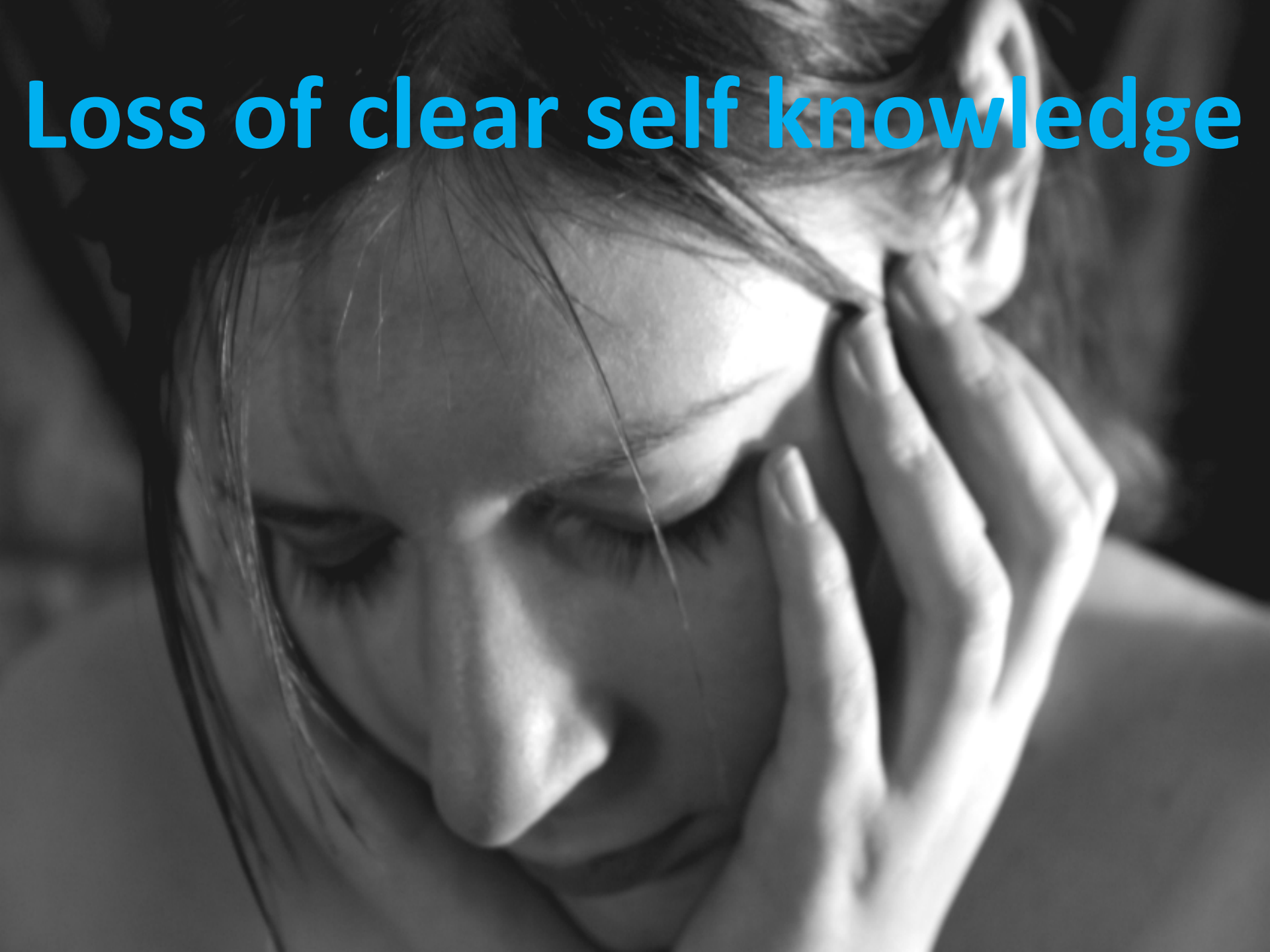

Uncertainty
about self


The erosion
of sense
of
competency
and self
worth


Struggling
with issues
of post-
injury
identity

Three categories of loss

Nochi, 1998

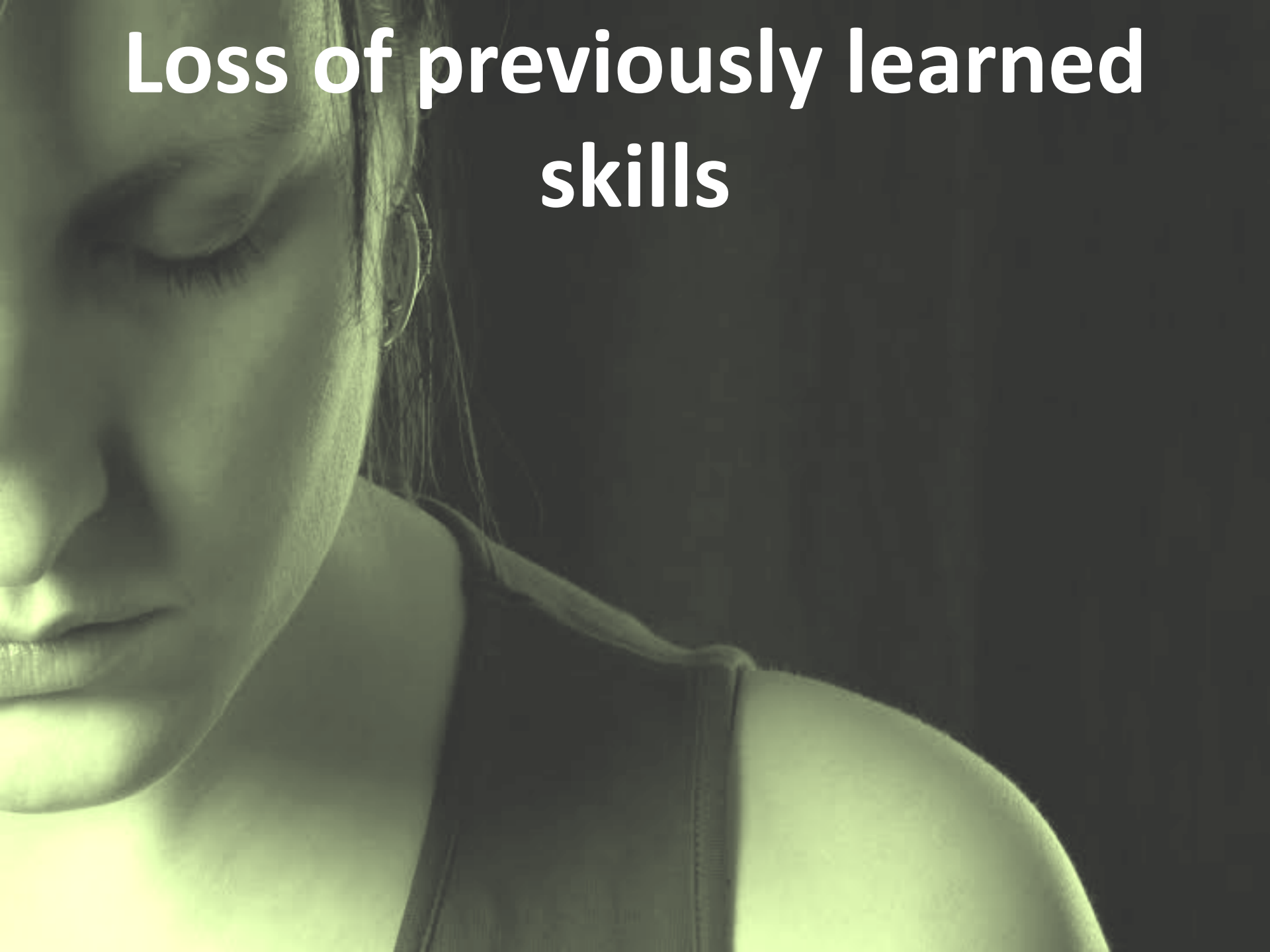

Loss of clear self knowledge


Loss of self by comparison

Loss of self in the eyes of others

Loss of one's sense of competency

Loss of previously learned skills

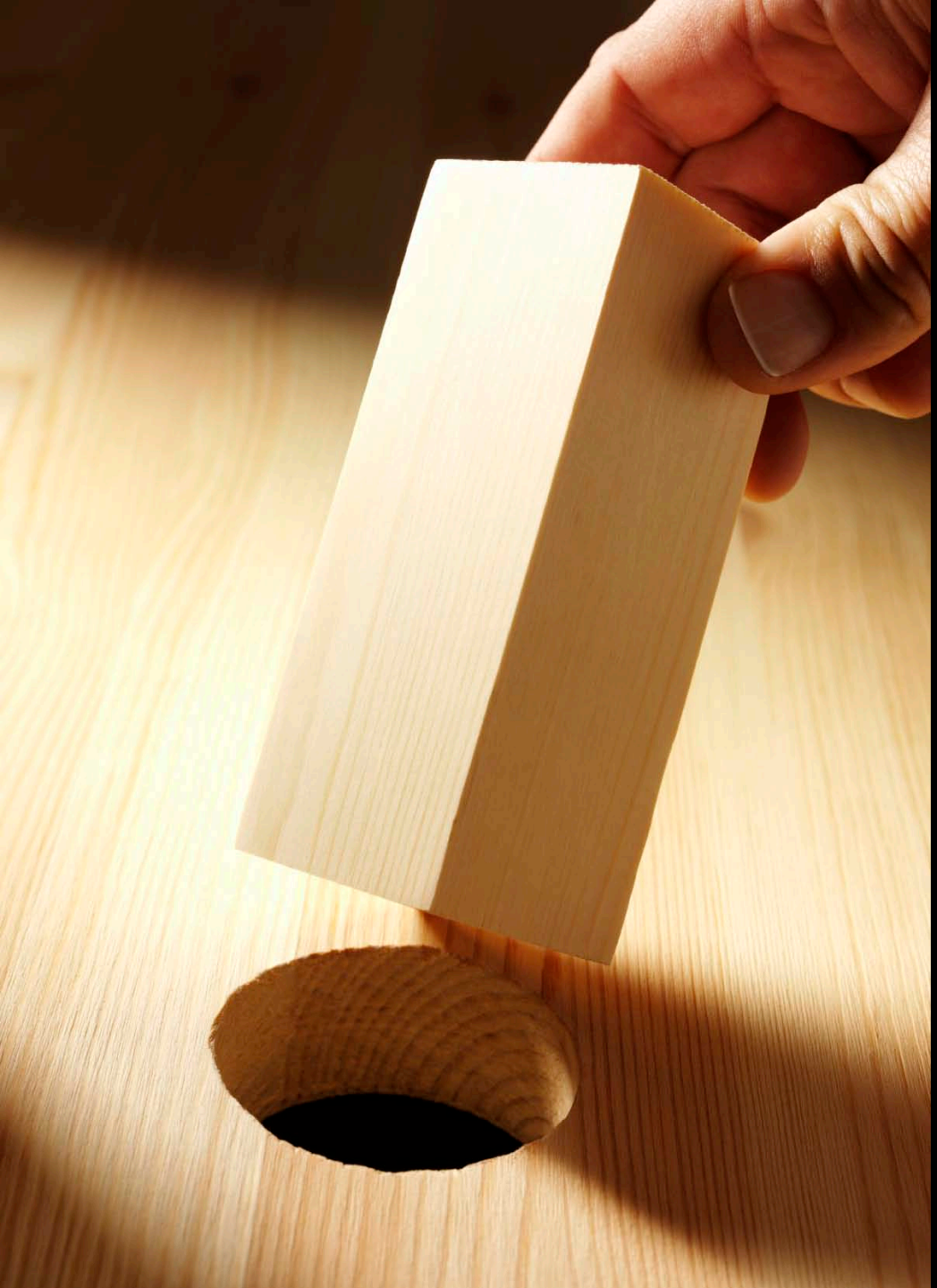



Loss of life focus

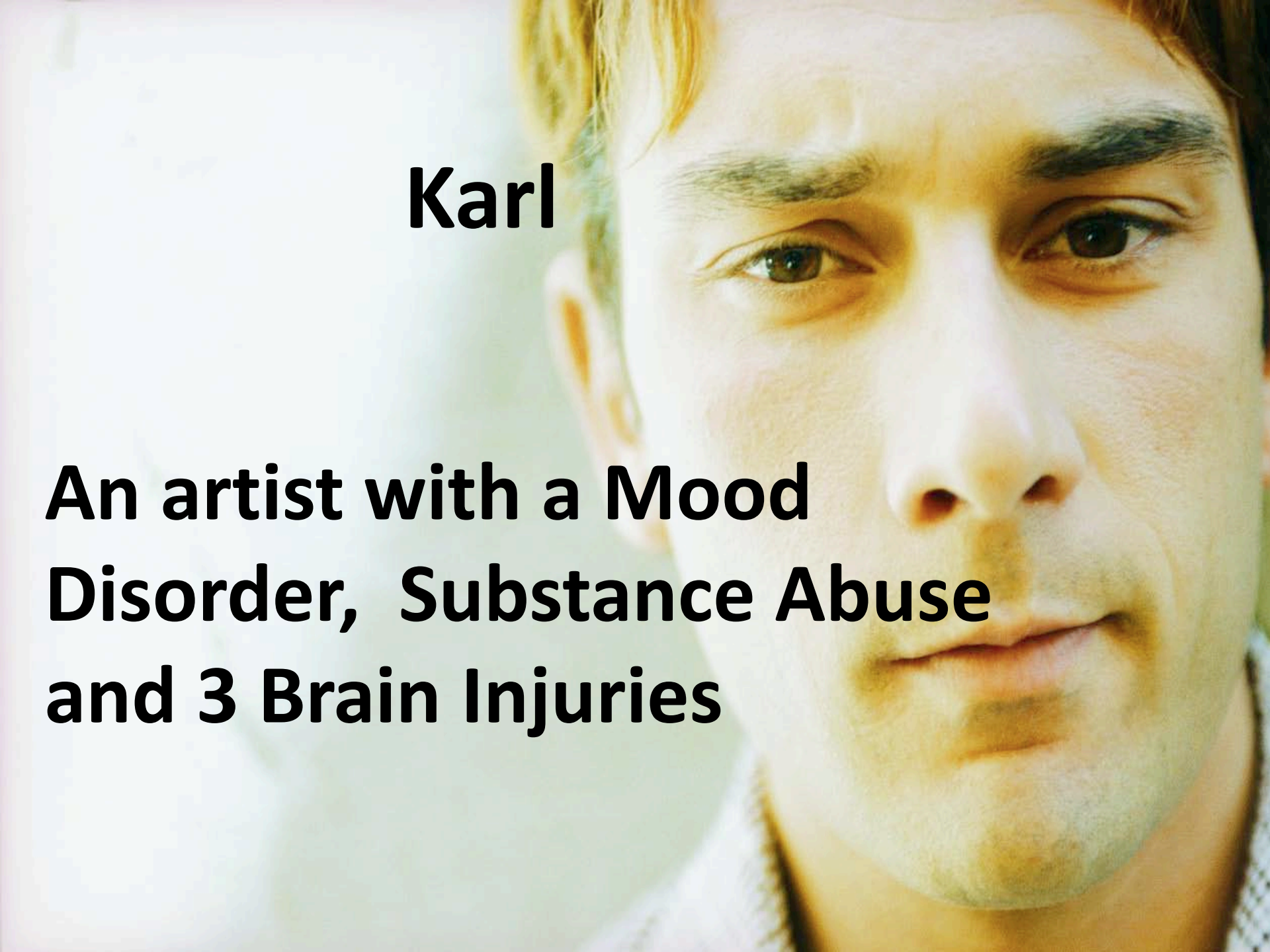
The Chicken or the Egg: which comes first

Brain injury increases the risk for homelessness

Homelessness increases the risk for brain injury



What about the person who doesn't fit?

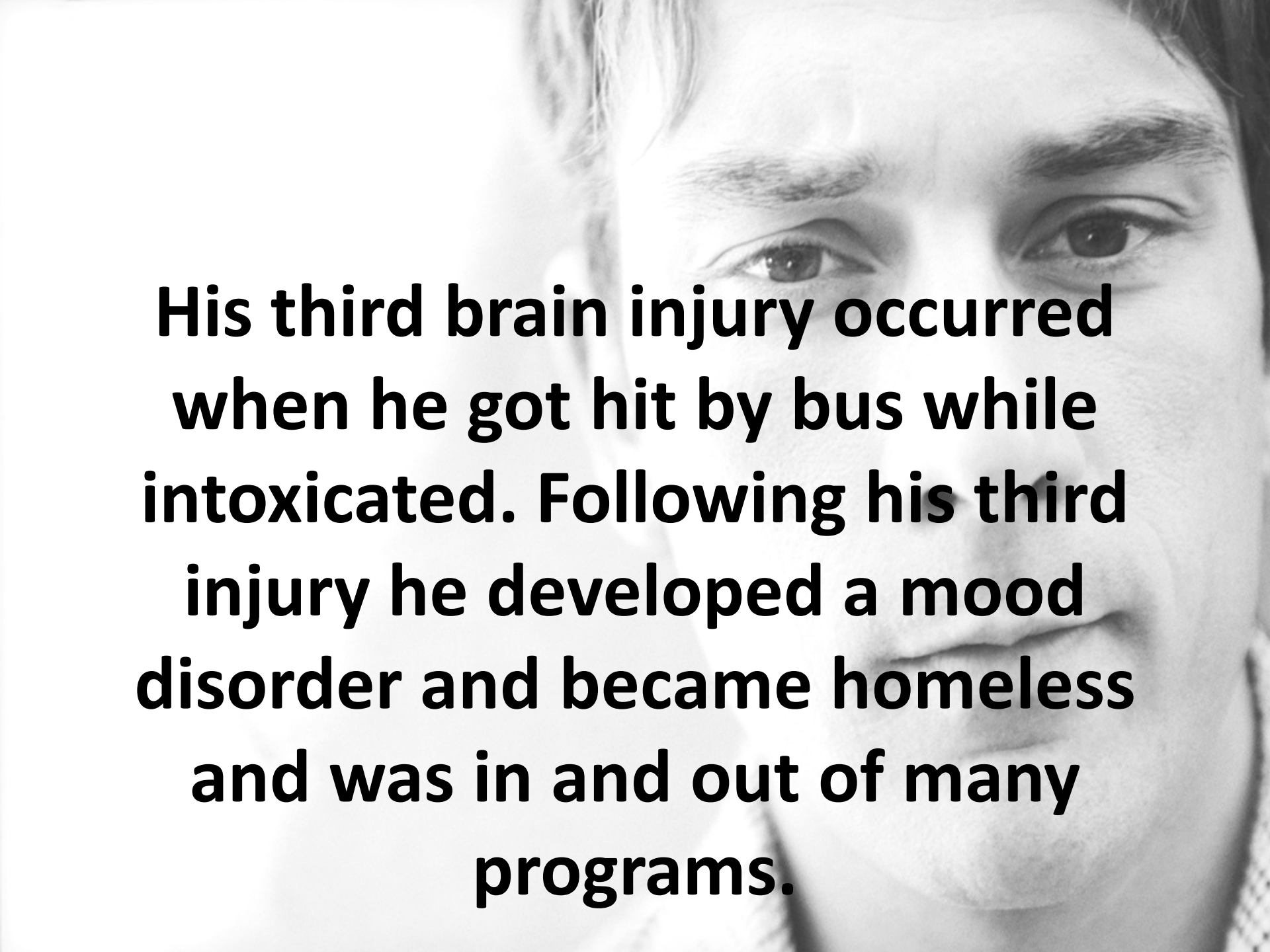


Karl

An artist with a Mood Disorder, Substance Abuse and 3 Brain Injuries

Karl's story

A long standing "drinker". Karl's first two brain injuries came from beatings which caused memory and concentration problems. He has digestive problems and doesn't remember to take his medications.



His third brain injury occurred when he got hit by bus while intoxicated. Following his third injury he developed a mood disorder and became homeless and was in and out of many programs.

The problem of the Triple Whammy

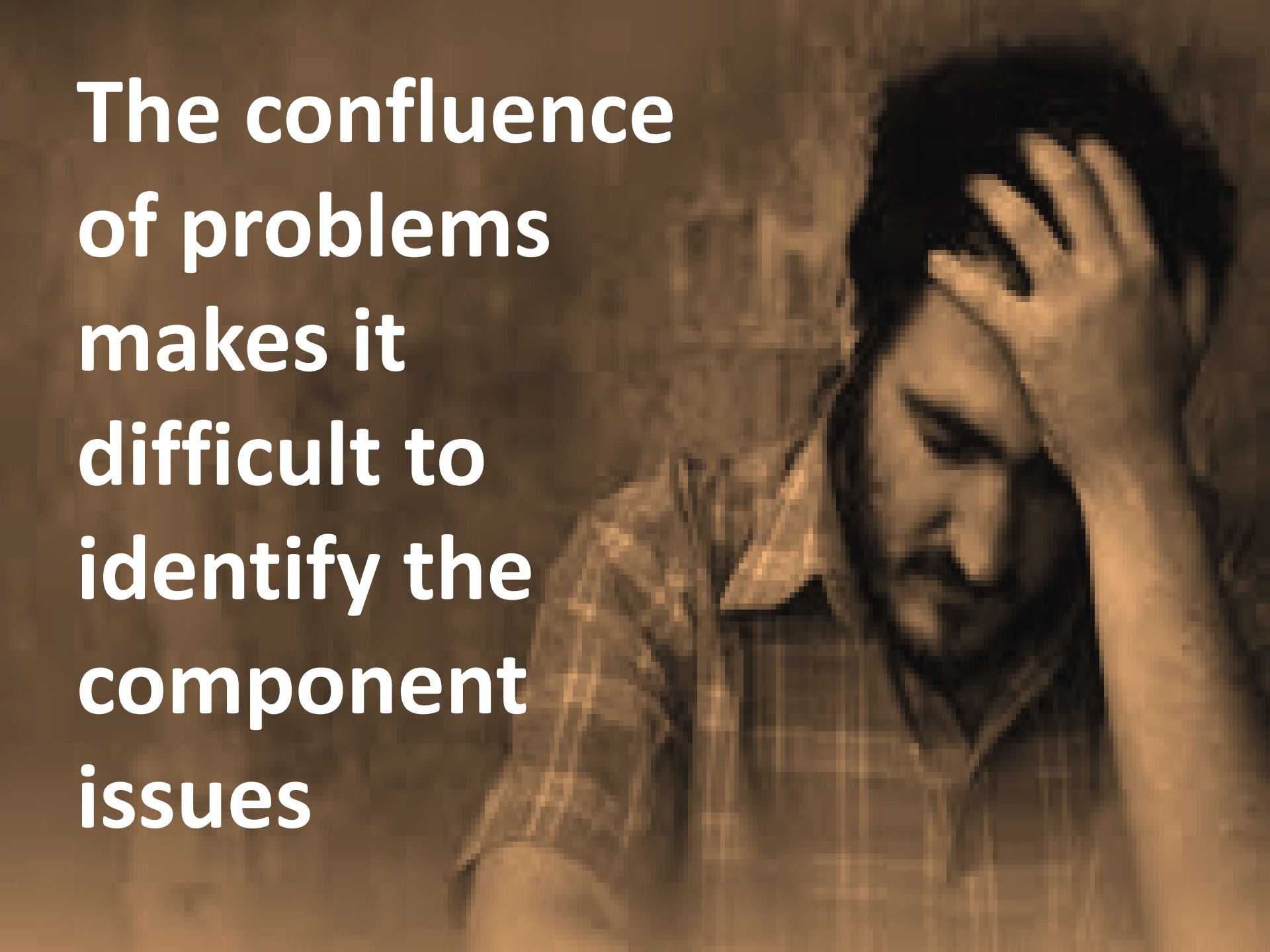
Karl is in the minority. His brain injuries, mood problems and substance abuse put him outside of the reach of many programs

One problem exacerbates the other

Alcohol use is frequently seen in people with brain injuries

Pre-injury alcohol use increases the likelihood of post-injury mood disorders

Arch of General Psychiatry, 2005


The confluence of problems makes it difficult to identify the component issues

Mental health and brain injury share common problems

Memory, difficulty with concentration, anger control problems and initiating activity

Brain injury may take three times longer to treat than mental health and substance abuse issues

Adding to the potential for dropping out

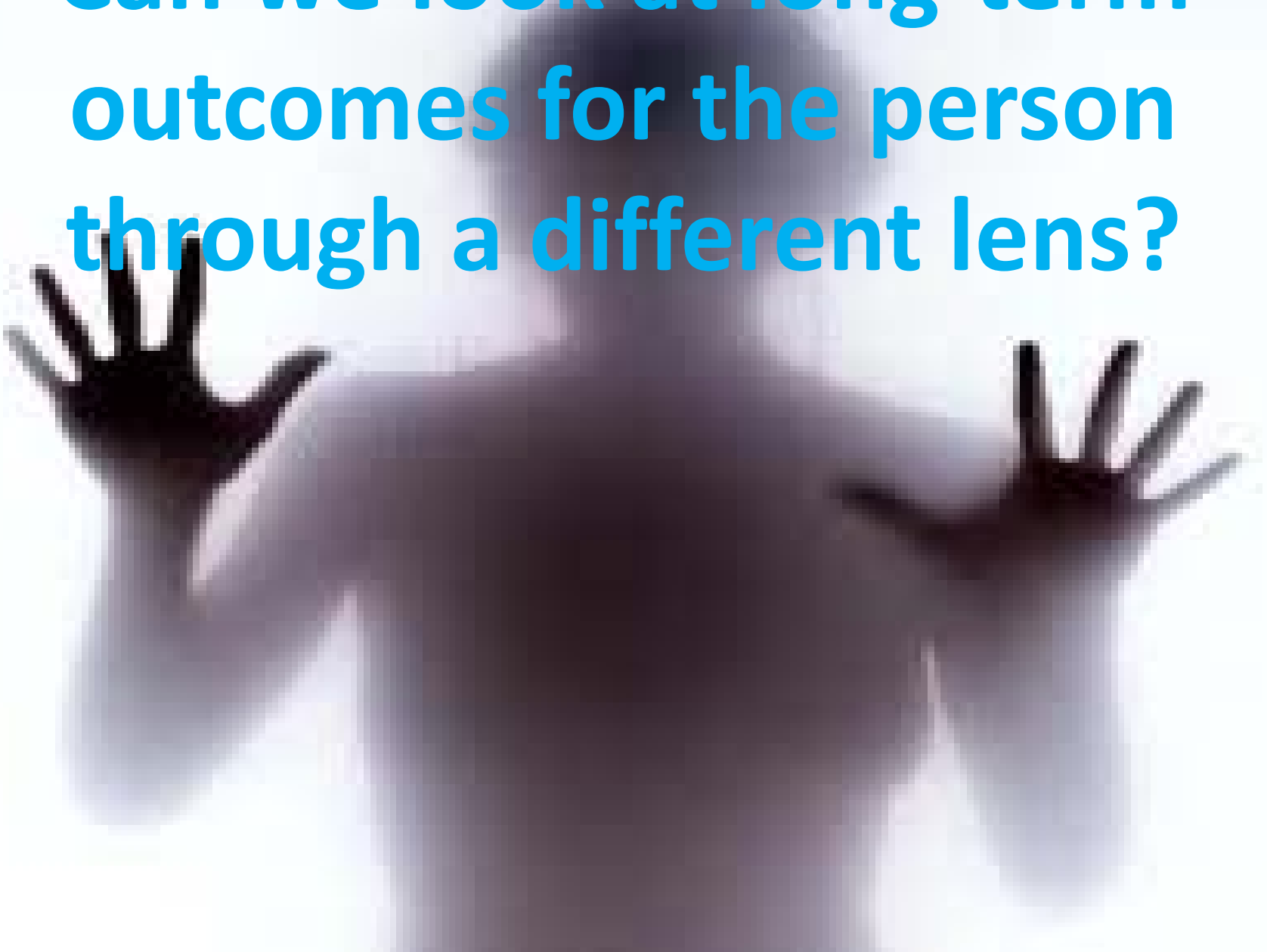
People with brain injury fail in mental health and substance abuse settings

Cognitive problems interfere with selecting and maintaining alternative behaviors.

The cycle of treatment may take five years

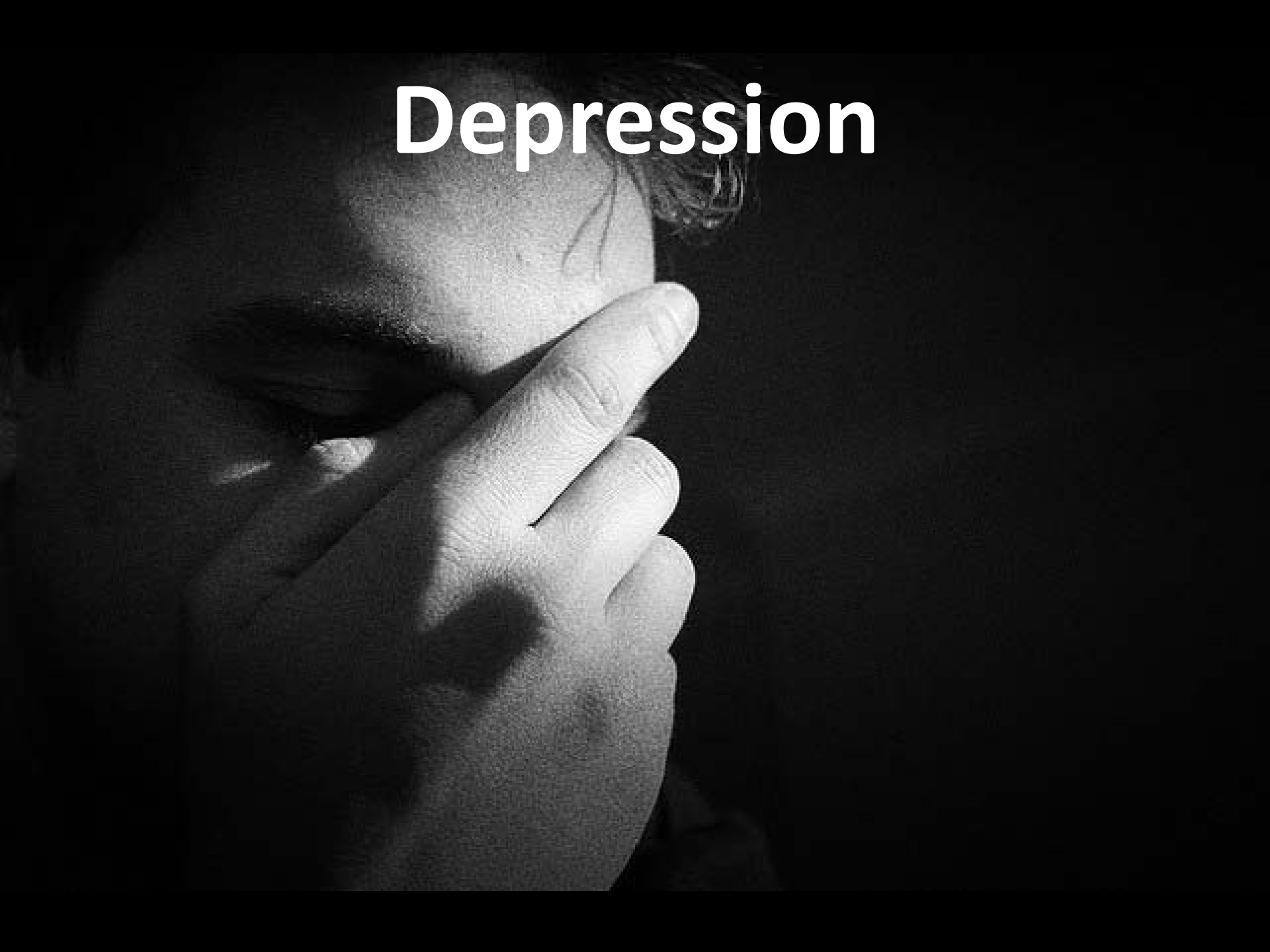
Ample time for people to fall through the cracks

Can we look at long-term outcomes for the person through a different lens?



What are the mental health issues?

Depression

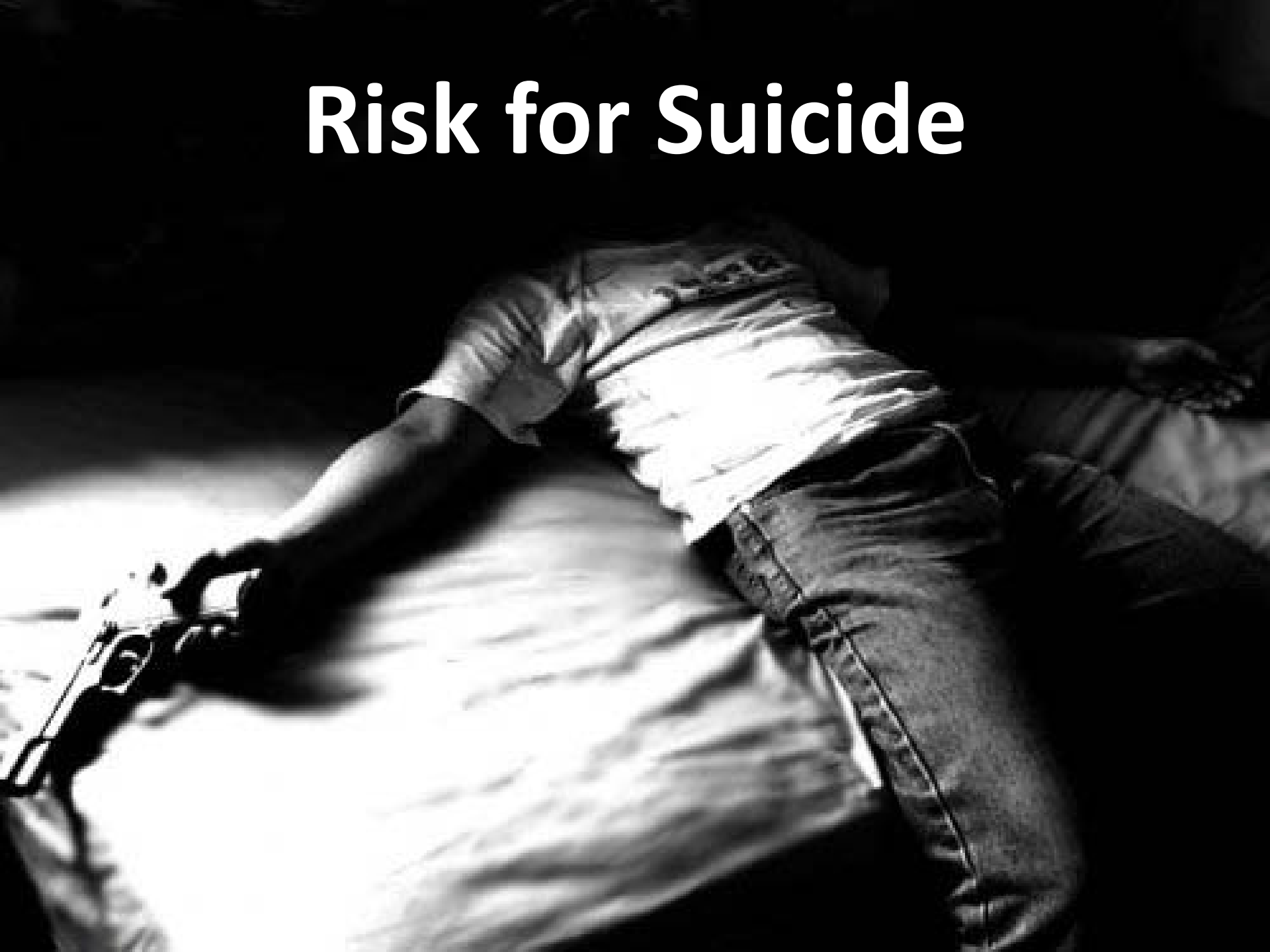



Hopelessness

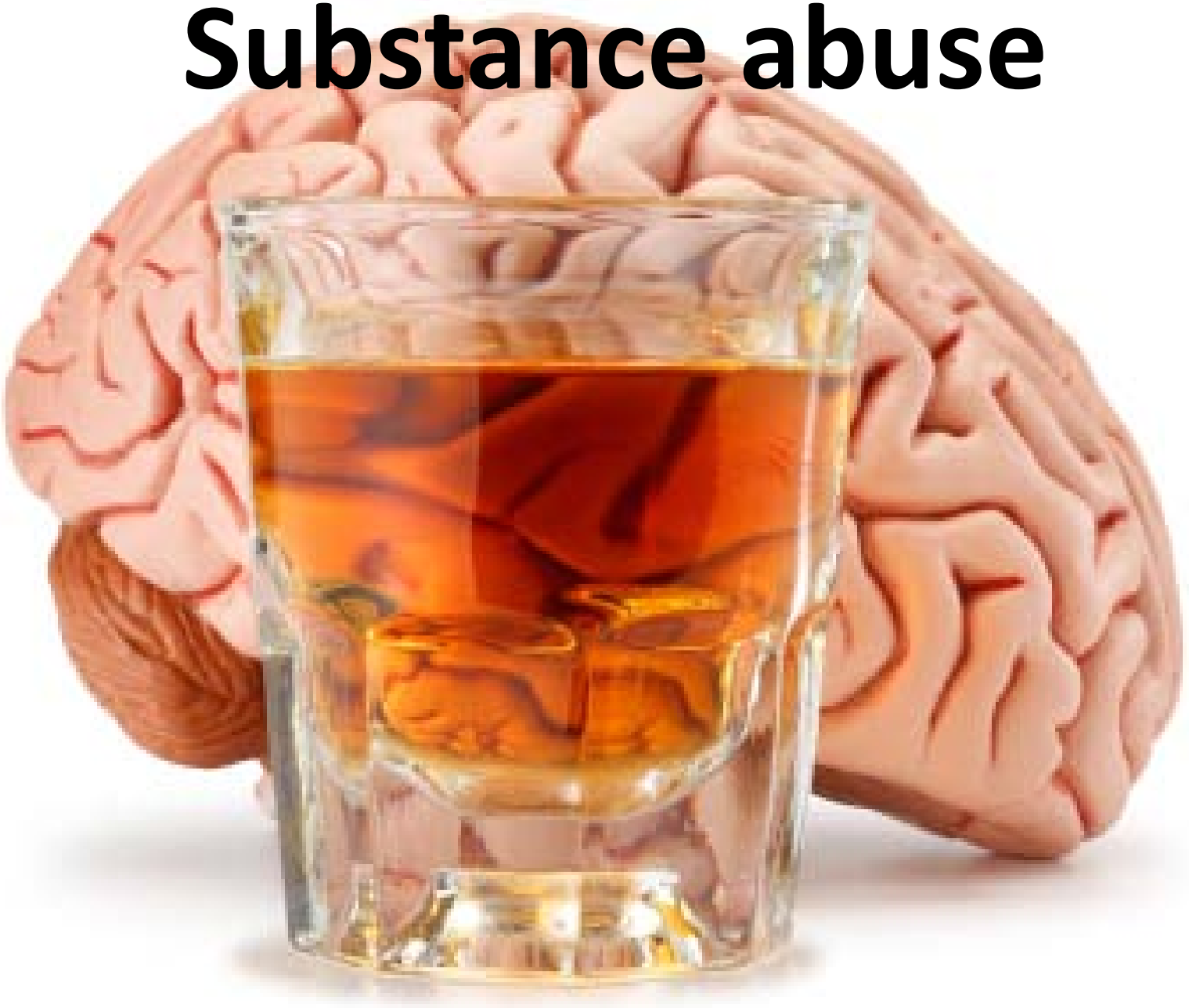
Anxiety

Mood state problems

Risk for Suicide



Substance abuse




Irritability, anger and aggression

High risk behaviors

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

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

What do the research studies tell us about brain injury and future mental health problems?

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
- “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)

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)

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)

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)

R. Van Reekum's Study

- Depression found in 44.3% - 50.0% of cases over a 7.5 year period
- Anxiety Disorders found in 9.1% - 16.6%
- Substance abuse in 27.7%
- Personality Disorders in 12.7%
- Denial of symptoms could prevent an understanding of cognitive, emotional and behavioral difficulties

Source: van Reekum, R. et al. (1996); van Reekum, R., Cohen, T., Wong, J. (2000).

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).

Meichenbaum's Study

- 70-80% of people exposed to trauma recover successfully
- 20-30% continue to experience lingering clinical disorders and adjustment problems such as PTSD, anxiety, depressive and substance abuse disorders that can result in suicidal acts, aggressive behavior and divorce.

Source: Meichenbaum, M. (2012)

Is the person with a brain injury and a dual diagnosis more likely to experience psychosocial and social role return problems?

What about social role return?

Is it a determinant of potential mental health problems?

Brain injury with psychiatric and/or substance abuse problems will impact on the person's long-term outcomes

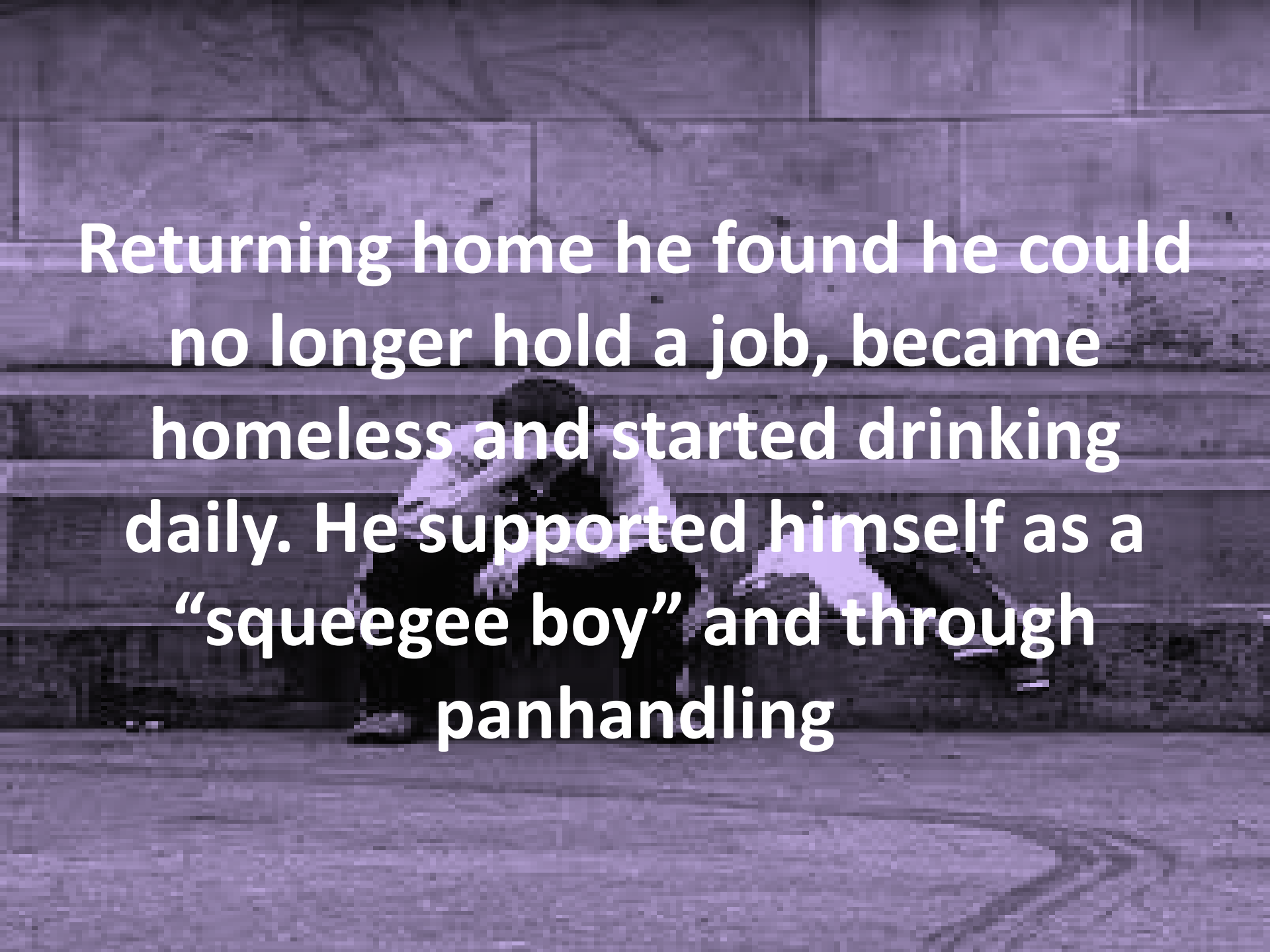
Let’s look at another person with the Triple Whammy…

Dan

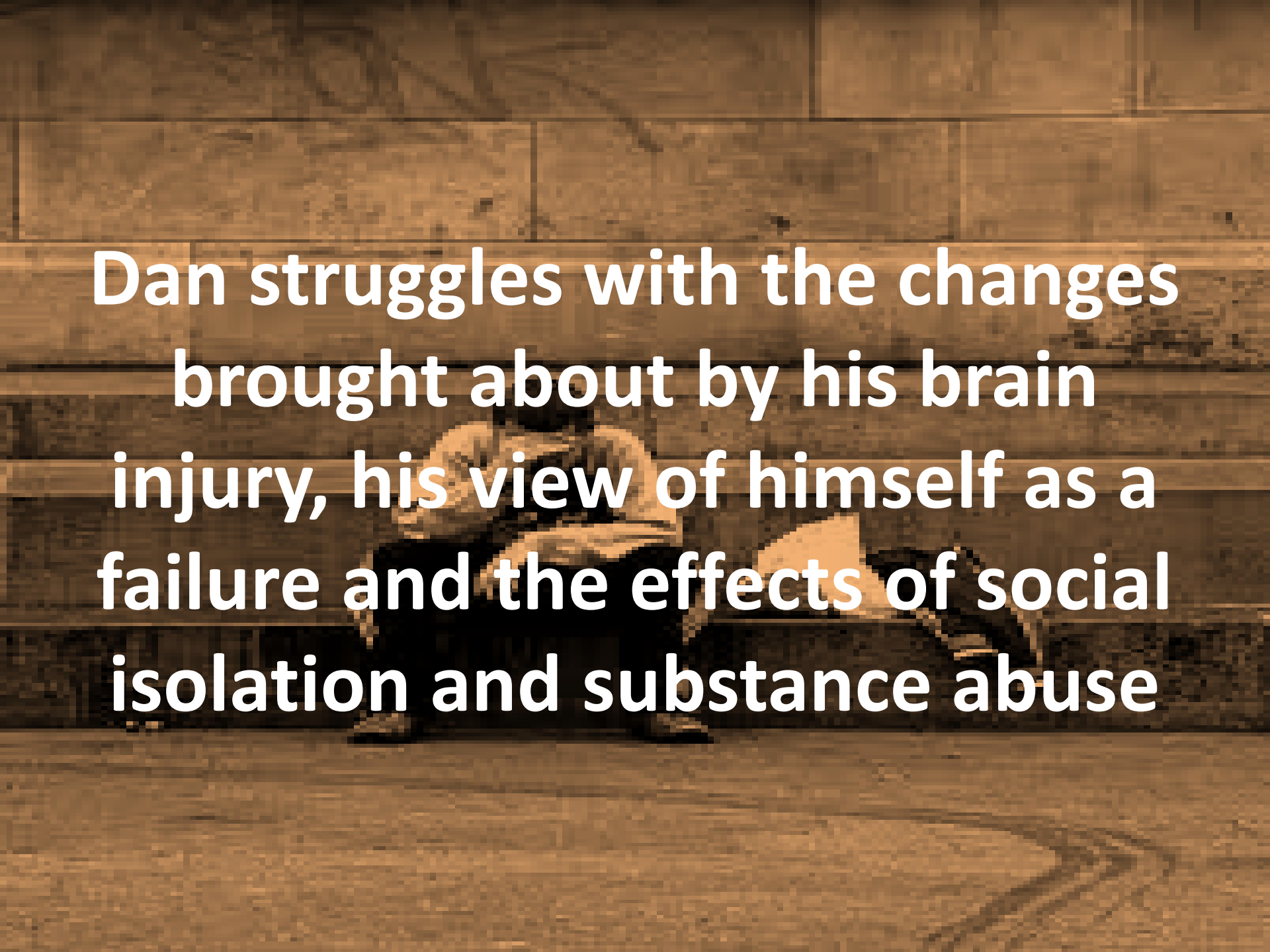
A skilled carpenter, Dan could no longer sustain employment after his brain injury

Dan's story

Prior to his TBI Dan worked in construction as a finish carpenter. After the accident he left the hospital prior to entering brain injury rehabilitation.


Returning home he found he could no longer hold a job, became homeless and started drinking daily. He supported himself as a “squeegee boy” and through panhandling

When he entered into a specialized program for people with TBI and addiction he did well until he moved into the independent living phase when he began drinking again and moved out of program housing.
Dan said that he “didn’t fit” with the program.


Dan struggles with the changes brought about by his brain injury, his view of himself as a failure and the effects of social isolation and substance abuse

Does brain injury disability create

“a cloak of competence”?

For the person ?

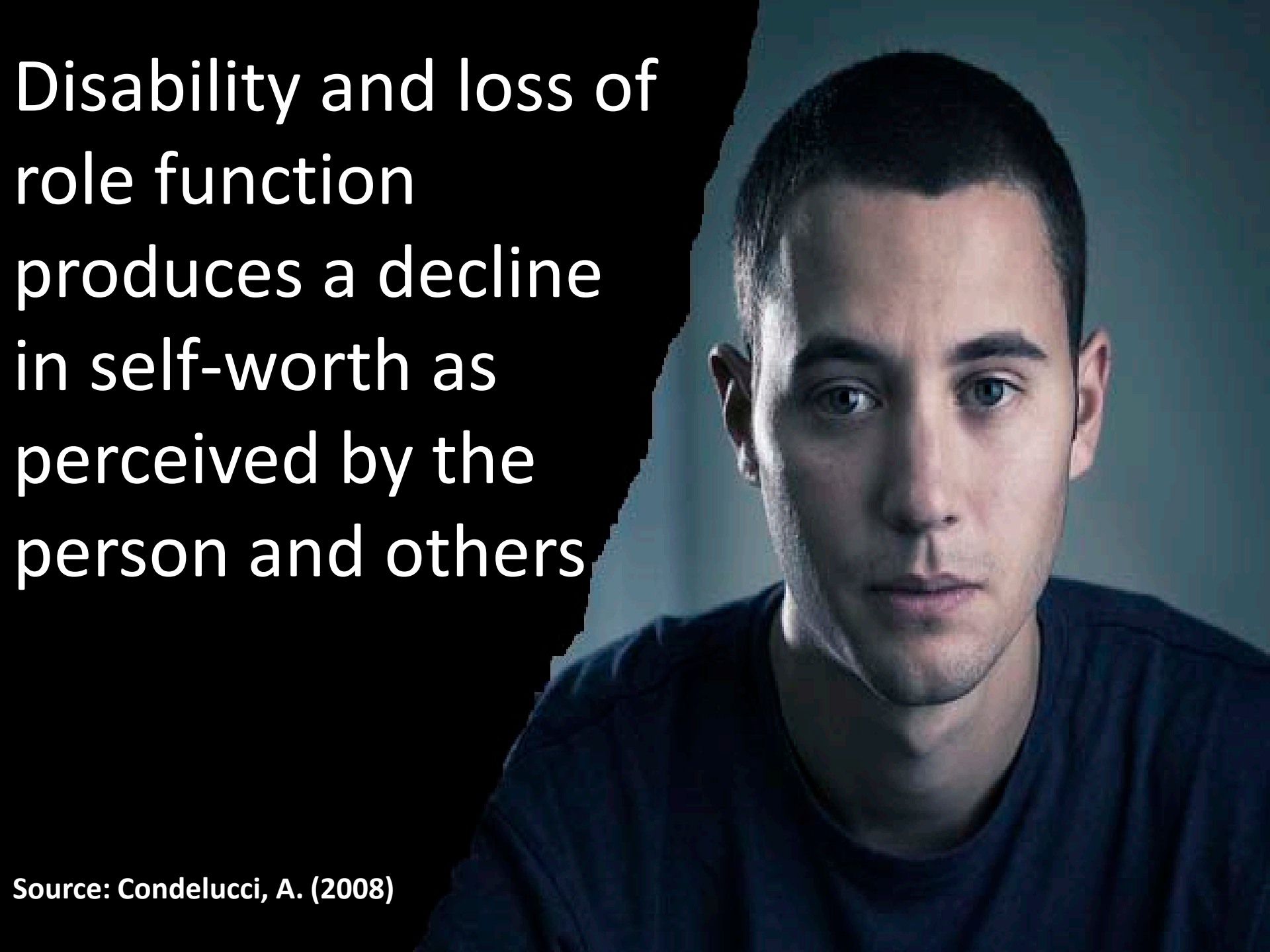
And, in the perception of others?

“I had to struggle with living with an invisible disability. Once the external wounds heal-brain injury is never considered to be an issue”

“It was hard to hang out with my friends. Somehow we weren’t the same anymore. It was easier to be alone”

“ I thought about killing myself a lot. I went up to the roof and thought about jumping, or taking an overdose. It was impossible to tell my family about how I felt”

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



Source: Condelucci, A. (2008)

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

Source: Frank, et al. (2005)

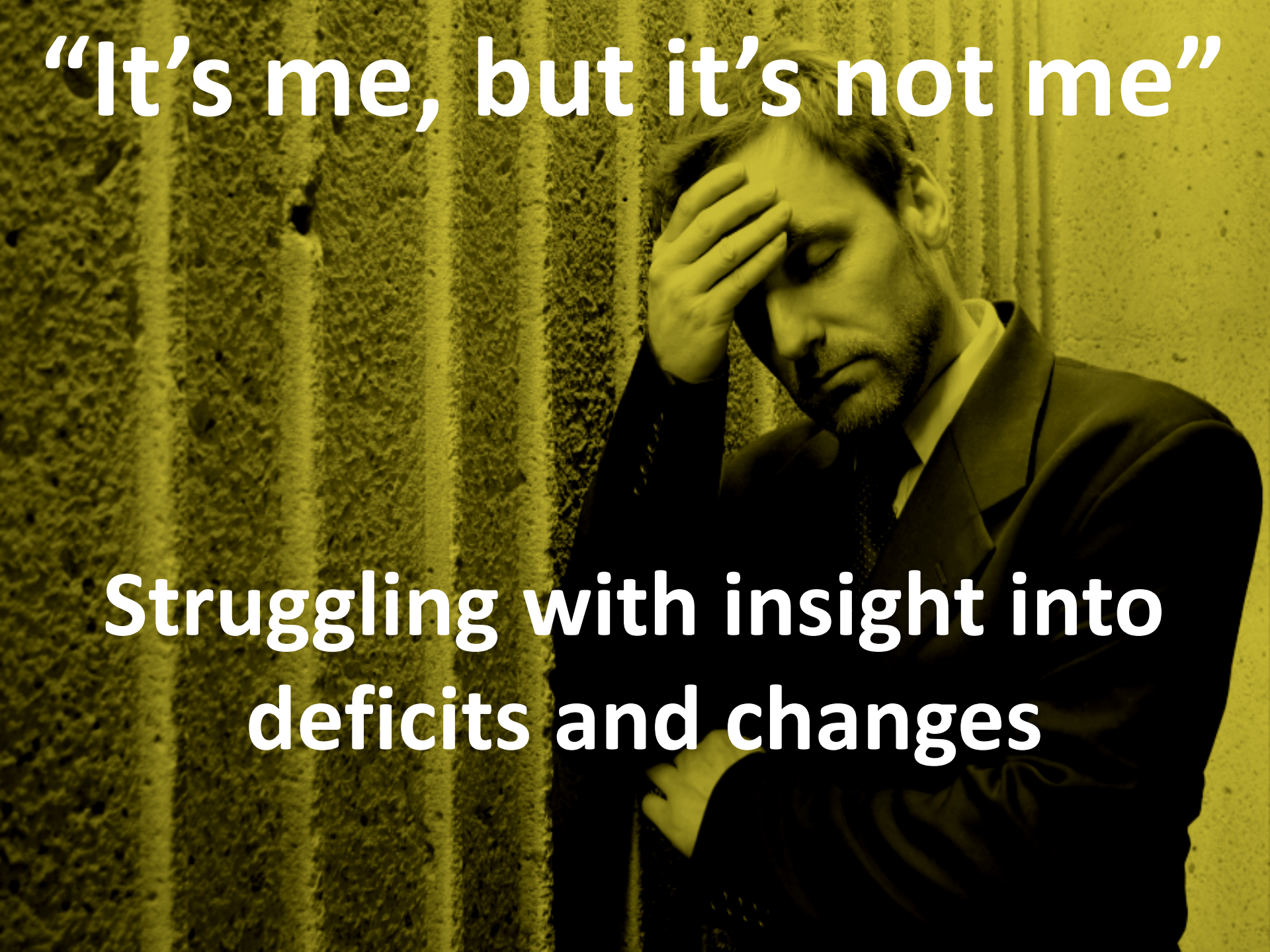
Grief for the loss of the healthy self

Frank, E et al (2005)

What has happened to me?

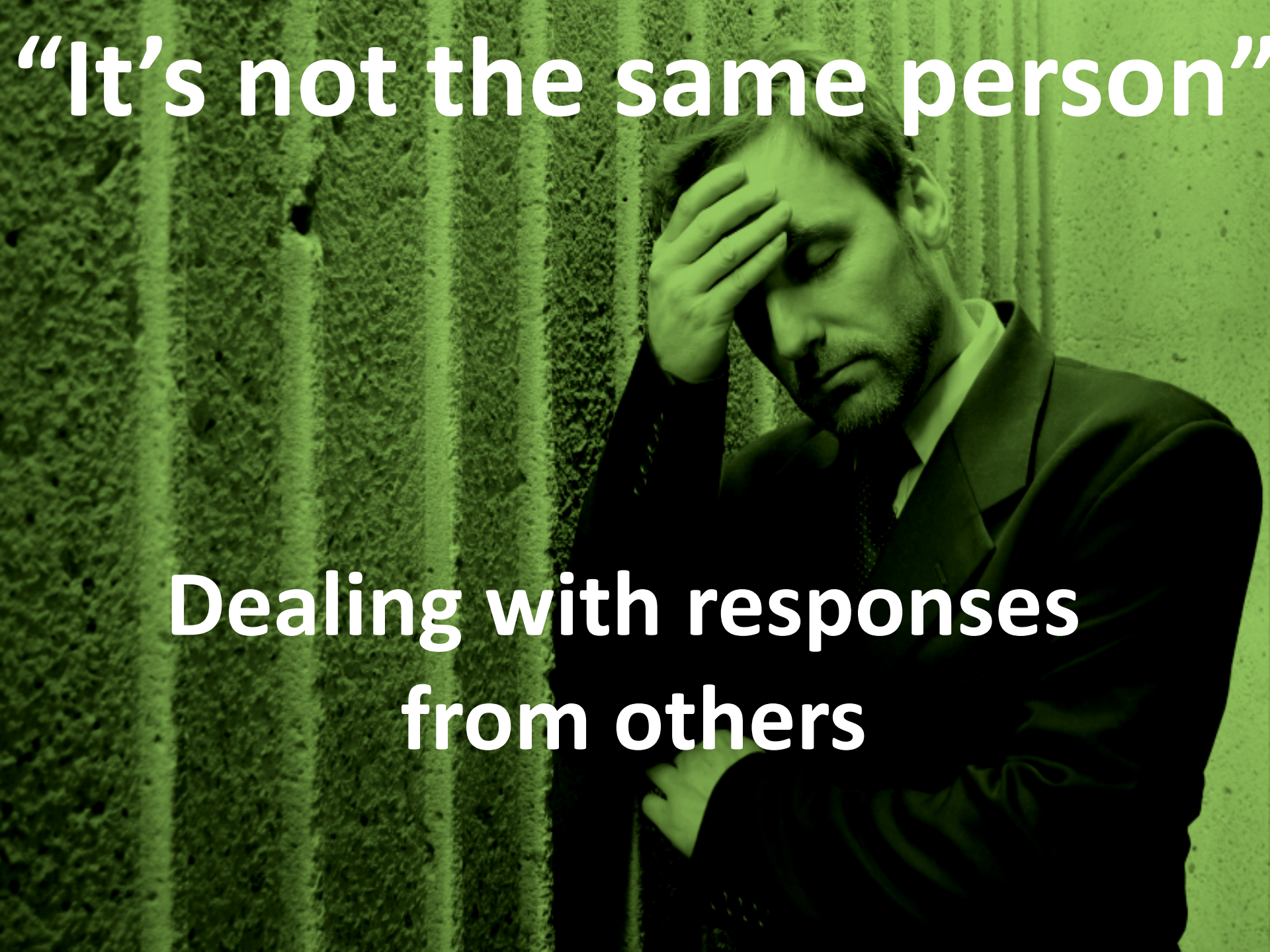
Recognizing the changes to competencies and capacities

“It’s me, but it’s not me”



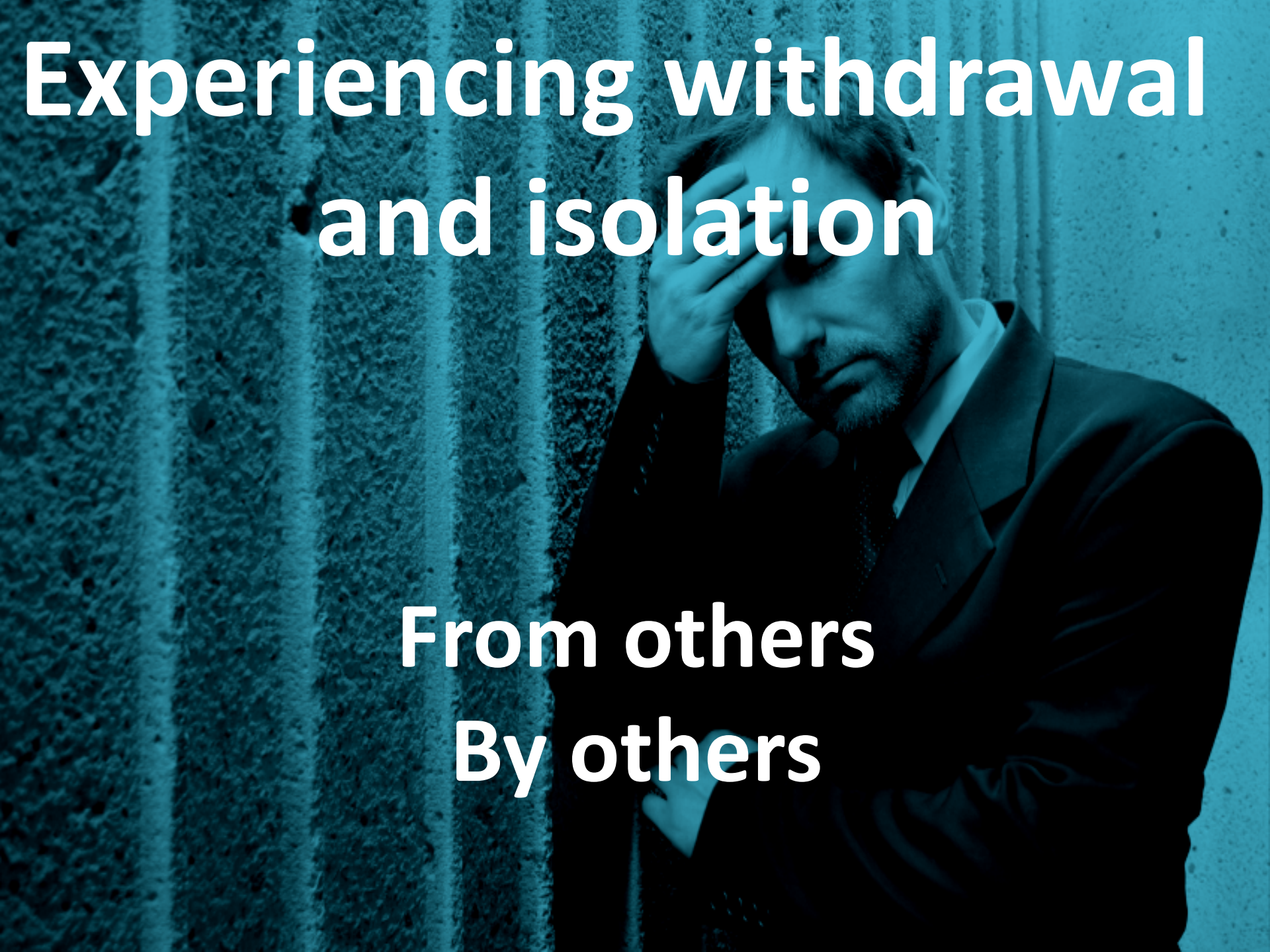
Struggling with insight into deficits and changes

“It’s not the same person”



Dealing with responses from others

Experiencing withdrawal and isolation



From others
By others

Travis

Travis came from a troubled family and had long standing learning problems. He drifted into substance use at an early age and experienced a severe brain injury at 19.

Travis' Story

Travis had difficulty in school and with learning. He was diagnosed with ADHD in elementary school and by 6th grade was missing school and started using drugs. By 18, Travis was living on the streets and engaged in sex work. His meth and alcohol use was daily.

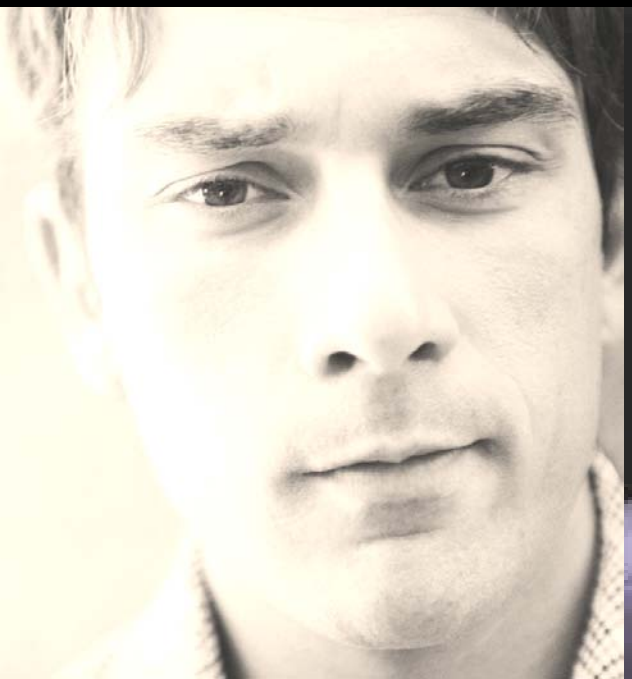
At 19, Travis had a Traumatic Brain Injury when he was struck by a city bus when he slipped from his skateboard . He resisted rehab and continued to use meth and alcohol to manage his fluctuating mood states.

Travis didn’t fit the substance abuse programs and his non-compliance affected his participation in brain injury rehabilitation.

Karl, Dan and Travis represent a group of individuals with brain injury, substance use/abuse and psychiatric issues who “don’t fit” the traditional models.

Once homeless, all three men were caught in a cycle of failed treatment

By creating a stable living situation with supports knowledgeable in TBI, mental health and addictions the cycle can be stopped.



Dan, Karl and Travis illustrate the problems with TBI, homeless and mental health issues and inadequate treatment and intervention

Is it “one size fits all”?

How can we think about the problem differently?

Resources = Outcomes

Karl found an apartment with supports for his mental health and alcohol problems. He began to paint and sculpt again.

Dan never was comfortable with programs and services. He chose to remain on the streets where he survives by panhandling

A Case Manager realized Travis' complex problems and found him a place for treatment which could address his substance abuse, psychological problems and brain injury.

Their problems represent barriers to positive outcomes

What are the barriers?

Can the system accommodate the complex needs of the person post-injury?

Is there access to Brain Injury Rehabilitation?
Mental health services?
Substance Abuse Treatment?
Housing?

Are there adequate resources to meet the real needs of the person living with a dual diagnosis?

Do the resources include:

appropriate healthcare

extended rehab

accessible housing

transportation

community supports

adequate income

Inappropriate services result in poorer outcomes over time…

including an increase in psychiatric disorders, chemical dependency and increased vulnerability and risk

And, can cause the person to experience frequent crisis events and re-hospitalization, incarceration or injury

What about services after rehabilitation?

To sustain the gains made in rehab

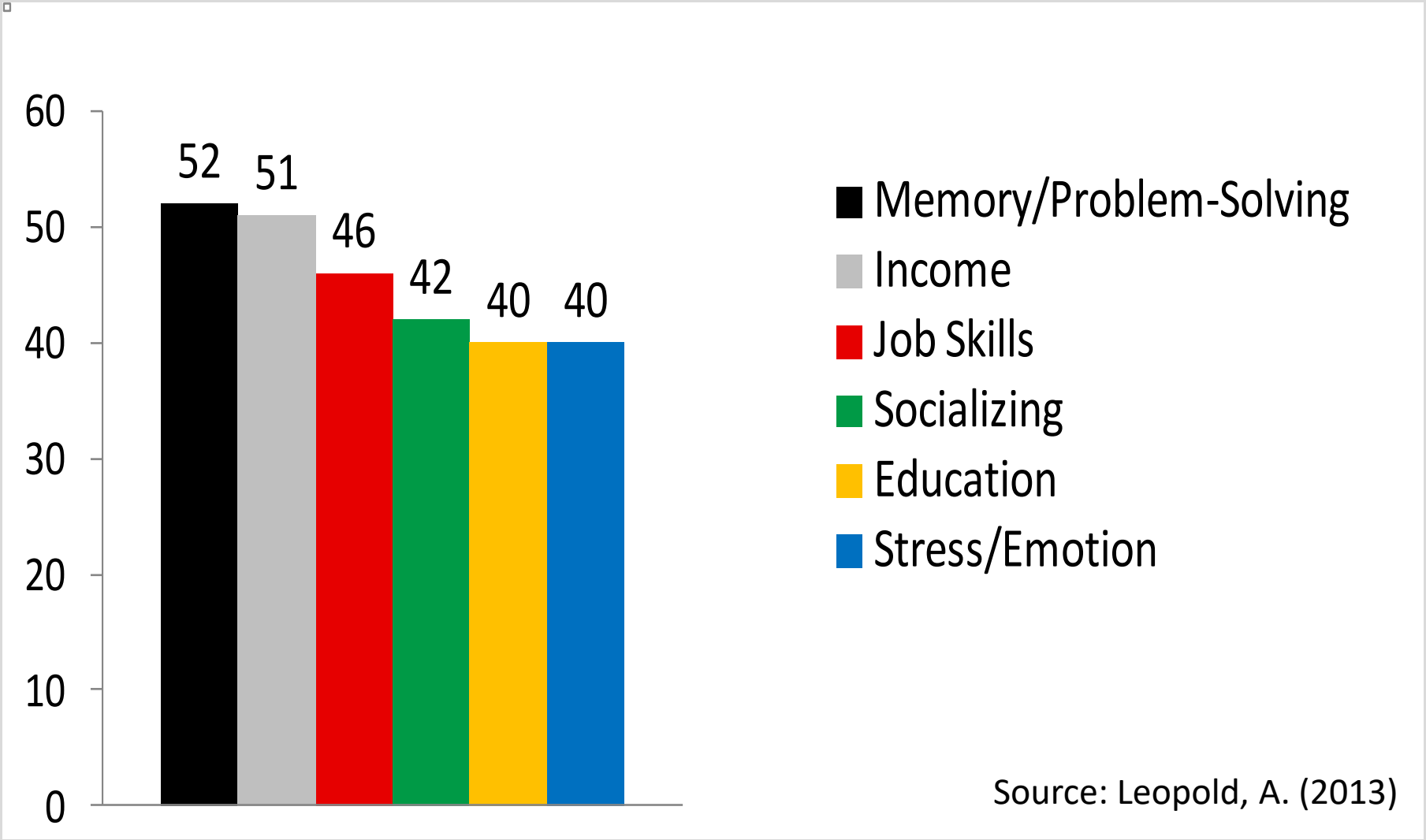
To deal with new problems

What can we learn from the research studies which identify 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).

Medicaid recipients reporting "unmet needs"



Source: Leopold, A. (2013)

Do people with unmet needs find themselves in crisis situations?

Housing

There is "an unrelenting rental housing crisis for extremely low-income people with disabilities in every single one of the nation's 2,557 housing market areas."

Source: Cooper, Emily, L. Knott, et al. 2014

Stability in housing is vital to community living

Services in the home and community can prevent a loss of independence

The gap in services between hospital and home can result in…

emergency placements

in hospitals'
psychiatric units…

nursing homes…

jails…

homeless shelters

None of these are equipped to recognize and/or treat Brain Injury…

…and, certainly do not offer realistic long term solutions

Let’s look at outcome data from two organizations which serve individuals with complex needs and high risk for psychosocial complications

the NRIO study

let's look at the issues with adults with a TBI and a psychiatric disorder prior to post-acute rehabilitation

NRIO Outcome Study, Adult Cohort

1997-2014

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

the people over the course of the study:

641 tracked from 1995-2014

Average age: 32.0

Age Range: 2.11 to 78.7

100% Severe TBI
90.5% MVA

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

Social Role Return

Independence/Support Level

Vocational/Avocational Activities

Mental Health and Substance Abuse Issues

Durability of Outcome

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

the NRIO cohort

- age at injury 32.0
- GCS <9 83.3%
- male/female 68.3% / 31.7%
- period from injury to post-acute 25.00 months
- % MVA related 90.5%

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

2.5 years post injury

prior to admission

33% legal problems due to social behavior & judgment

45% problems with spouse or significant other

88% Problems relating to/ maintaining friends

36% post-injury substance abuse

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)

19.6%

Is this the group in which we will observe social role return problems?

Let’s look at a study with three years of operation and a similar population

CNR Study

the people over the course of the study

18 tracked from 2010-2014

Average age: 37.72

Age Range:34.10-40.50

Age at injury: 31.00

100% Severe TBI

33% MVA

22% Aneurysm

22% Assault

22% Anoxic Injury/Toxic Encephalopathy

the CNR cohort

age: 37.72

male/female :72%/27%

period from injury to post-acute: 11.0 – 15.5 years

Pre-injury psychological problems: 77%

Pre-injury substance abuse: 33%

Pre-injury legal problems: 44%

post-injury psychiatric diagnosis: 88%

post-injury substance abuse: 55%

Returning to pre-injury social role

33%

Returned to pre-injury social role

22%

Returned to pre-injury role with modifications/supports

44%

Interfering psychiatric and substance abuse problems affecting social role

The search for answers

NRIO and CNR: Essential Differences

- Pre-injury mental health and substance abuse issues
- Post-injury mental health and substance abuse issues
- Length of time from initial injury to treatment
- Number of “failed” treatment events
- Availability of post-injury and post-treatment supports

What can we learn from durability?

What are the factors associated with sustained long term outcomes?

Are the answers in front of us?

Where can we find the solutions?

Where do we need to look to make meaningful changes?

Integration of mental health and substance abuse treatment into the early phases of rehabilitation

Mental health screenings need to include brain injury and neurological diseases

Sustaining caregivers

What resources are needed by caregivers to maintain their healthy roles?

Can housing be healthcare?

How can we integrate sustained supports in the home?

Eliminating health disparities

Mental health services across the lifespan

Active Case Management Services

Supports for social integration

Consumer directed information for people living with TBI and homelessness

Programs for the person…

unique, person centered programs


Eliminating barriers as they occur….
throughout the lifespan


That's all Folks!

This presentation can be found on www.traumaticbraininjury.net under “Resources” and then “Community Presentations”

Resources

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