

# **Long-term Social Role Difficulties for the Person with Brain Injury and a Psychiatric Diagnosis**

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# Disclosure

- **Rolf B. Gainer, PhD has business relationships with Brookhaven Hospital, the Neurologic Rehabilitation Institute of Ontario, Community NeuroRehab 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 review the key studies involving people living with brain injury and co-occurring mental health disorders**

- **To consider the dynamics involved in social role in the years post-injury**

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

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

**Advisement: Some slides may contain images  
which could be disturbing**



**social role**, n., (səʊʃl rōl ): a network  
of mutuality based on participation.

**Let's look at the process which  
this woman went through 20-  
years ago**

**Can we better understand the  
social role issues through her  
story?**

**“...I received 64 floral  
arrangements from my  
friends... nobody came to visit  
me after my discharge...”**

**“...right after the accident  
my parents, younger sister  
and brother were my  
support network...”**

**“...my parents replaced my functions in the home. They took care of everything...”**

**“...I tried to go back to  
work...”**

**“...my job could not  
accommodate post-injury  
needs...”**

**“...my social relationships  
fell off as people recognized  
my deficits...”**



**“...they didn’t know how to  
make it comfortable...”**

**“...we weren’t  
operating in the  
same social circles  
anymore...”**

**“...I felt vulnerable  
due to my brain  
injury...”**

**Can we identify the  
mileposts in her journey?**

**How does injury severity  
and residual deficits impact  
on long-term social  
integration?**

**What is the role of  
psychological resilience in  
adjustment?**

**What causes social  
withdrawal?**

**What are the dynamics  
of social withdrawal?**



**What is the relationship  
of cognitive flexibility to  
post-injury adjustment?**

**Is social participation an  
aspect of the person's  
measure of post-injury  
adaptation?**

**What are the effects of  
isolation?**

**Is loneliness a  
component of social  
network failure?**

**Could the outcome have  
been different?**

**Examining mental health  
supports: what is needed?**

**Can we effectively  
intervene to support  
social role return?**

**How  
do we  
measure  
self-worth?**



**job, profession, skills**

**relationships, family, friends**

**life activities**

**home/residence ownership**

**positive feedback**

**participation with others**



**self-worth**

**=**

**social capital**



**SOCIAL CAPITAL ?**

# **Self-worth:** a factor of “**social capital**”?

- The value of a person is created by the individual and their society
- The roles a person occupies and their effectiveness in those roles creates value

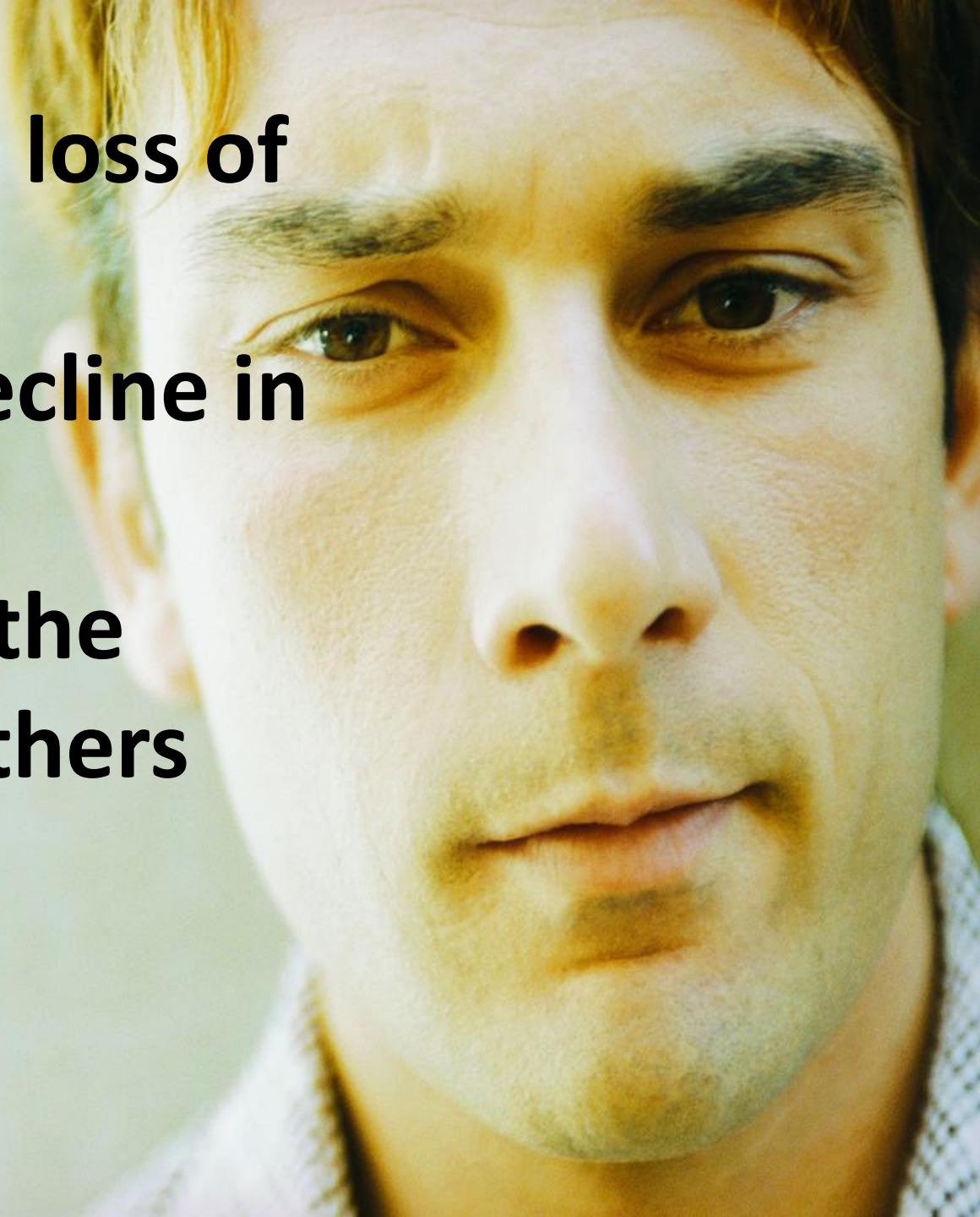
**What is the effect of  
social capital?**


**What happens for the  
person?**



**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

A black and white photograph showing the silhouette of a person, likely a woman, with her head bowed and hands clasped near her face, suggesting a state of deep grief or distress. The background is a soft, out-of-focus light source, possibly a window or a lamp, creating a somber and contemplative mood.

Frank, E et al (2005)



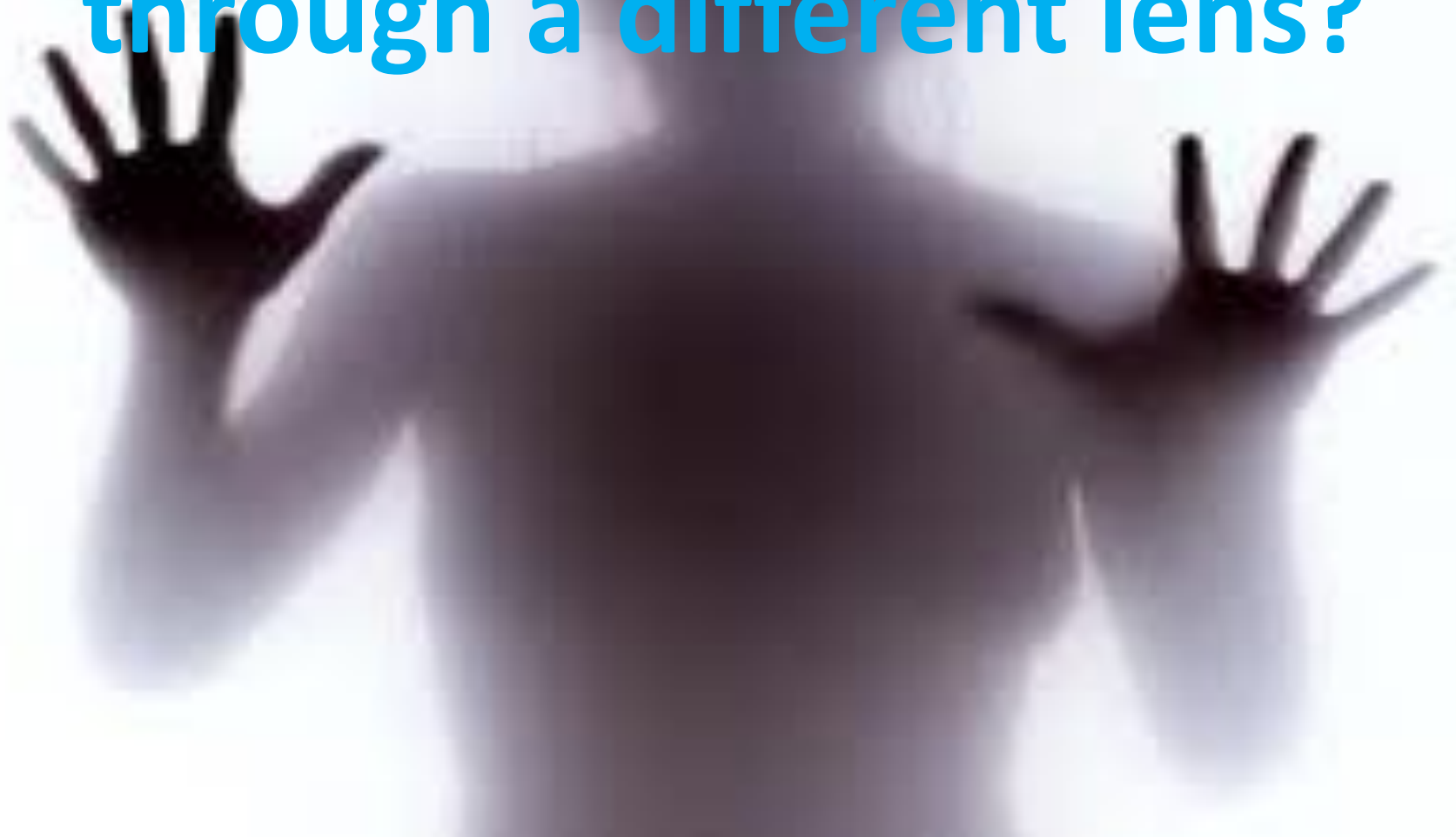
**life changes.**

**changes**  
**injury-based changes**  
**changes**

**every aspect**

**each relationship**

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



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

**Let's examine the sociogram  
of a 22-year old with a  
severe brain injury**



**mother**



**best friend**



**art school**

**Meet Rick  
at 22**



# Richard at 42

art school



best friend



mother

# Rick at 22





What has **happened** over the  
course of time to his

**social network?**

**family?**

**friends ?**

**The challenge of today's  
survivor:**

**“Sicker and Quicker”**

Mark Ashley's study

**17 days of acute medical  
care in 2012 vs. 57 days in  
1990 for high moderate to  
severe injuries**

Source: Ashley, M. Santa Clara Valley Brain  
Injury Conference, 2012

**Home quicker, but at  
what cost?**

**Will shortened  
rehabilitation impact on  
long-term social role  
return?**

How will the **person**,  
**family** and **social**  
**network** deal with **the**  
**stressors?**

**Can we look through the lens used by  
Christakis and Fowler and see the  
reduction in social network activity?**



# **Social network Theory: Christakis and Fowler**



**Can we better understand the social impact of brain injury on long-term outcomes?**

**Source: Fowler, J. & Christakis, N. (2010); Fowler, J., Dawes, C. & Christakis, N. (2009).**





# **Social Network participation: the impact of disability**

# **Our social network: degrees of separation occur over the lifespan**

**Primary Relationships**

**Children grow up**

**Friendships**

**Parents age/death**

**Social participation declines**

**Community participation fades**

**Ability to work changes**

**Brain injury disability accelerates the aspects of social network failure which lead to isolation and withdrawal**



# The Dawson and Chipman study

- Study involved 454 Canadians, average 13 years post TBI
- 66% required ADL assistance
- **75% not working**
- **90% dissatisfied with social interaction**
- **47% not talking with others by telephone**
- **27% never socialize at home**
- **20% never visit others**

Source: Dawson, J. & Chipman, L. (1995).

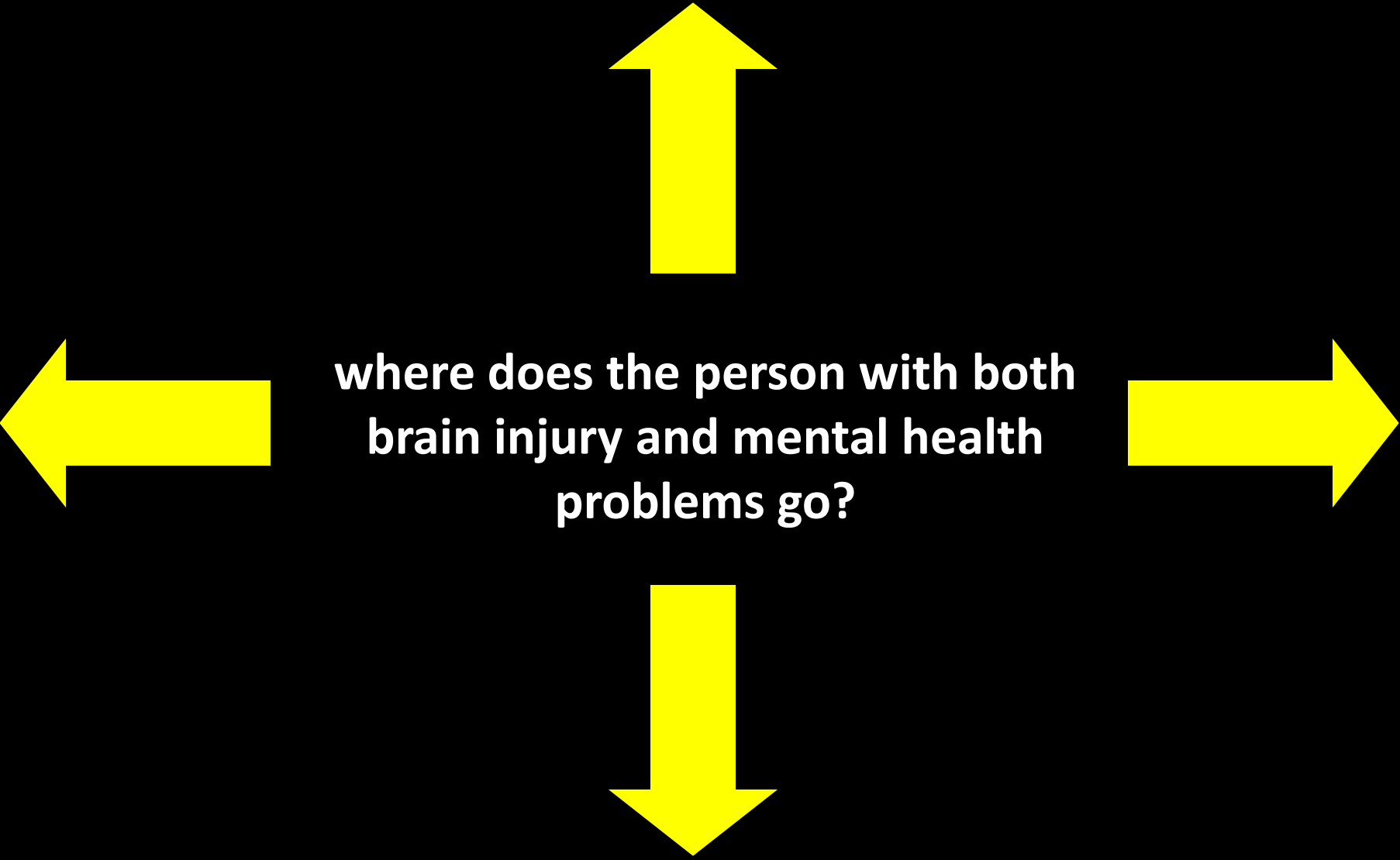


**A brain injury will effect others  
in the person's social network**

**It will create changes in the  
quality and quantity of  
relationships**

**The person's ability to  
adhere to rules of social  
membership can cause  
exclusion**

**Exclusion = Isolation**



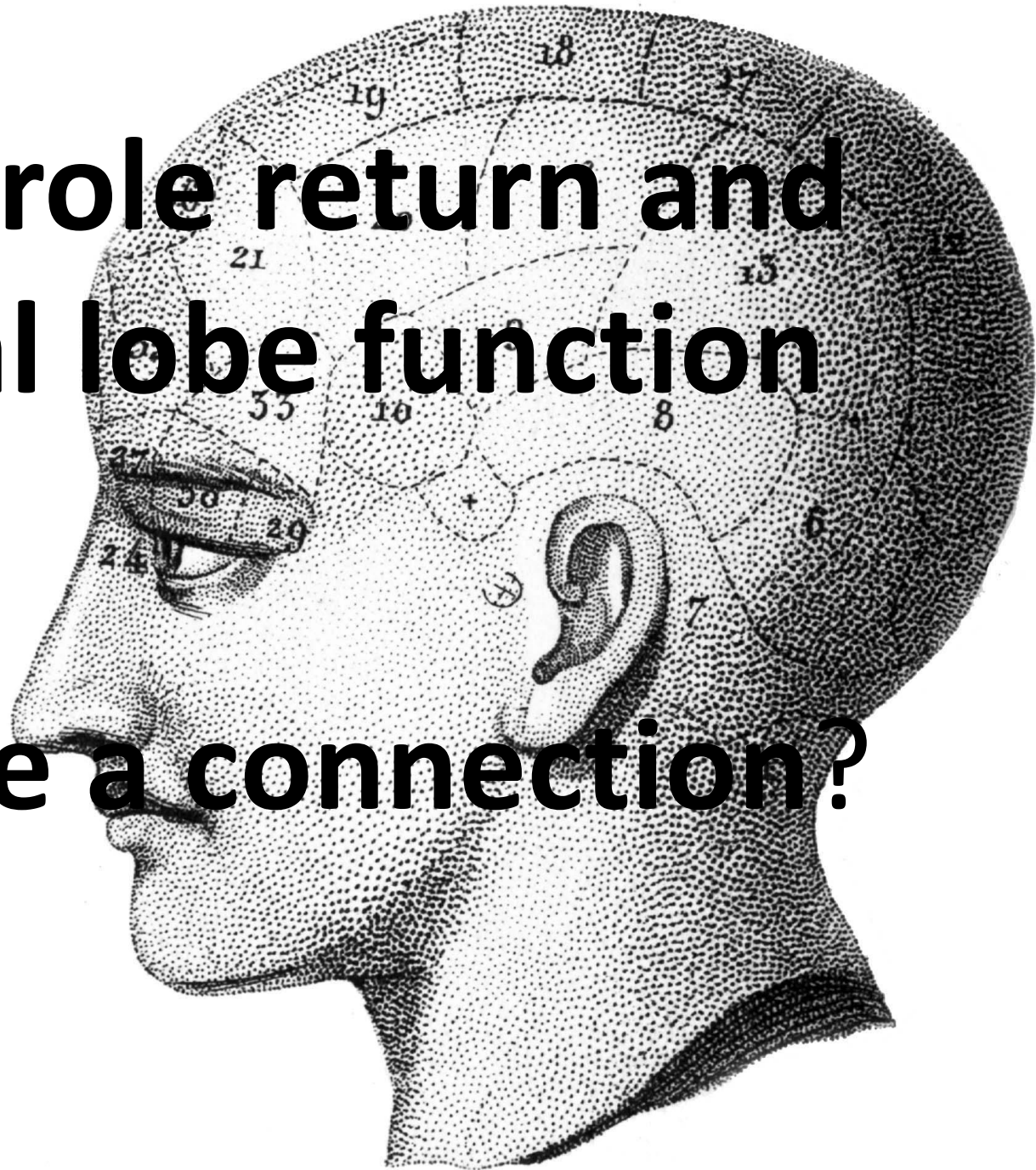
**where does the person with both  
brain injury and mental health  
problems go?**



**Do specific aspects of brain  
injury relate to social role  
return?**

**Social role return and  
frontal lobe function**

**Is there a connection?**



# **Theory of Mind applied to social network integration**

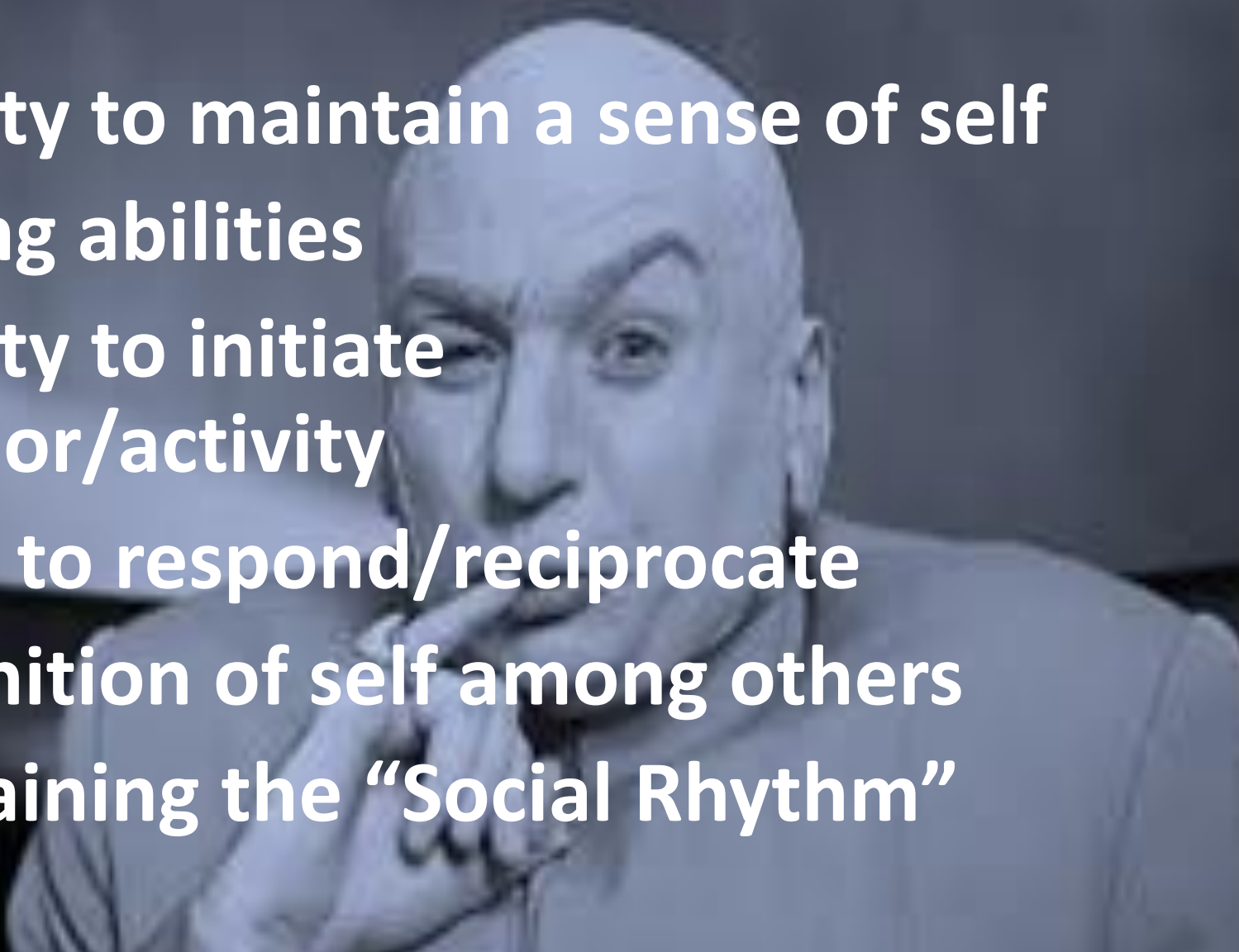
**How does the person's ability to  
perceive others impact on their  
social role?**

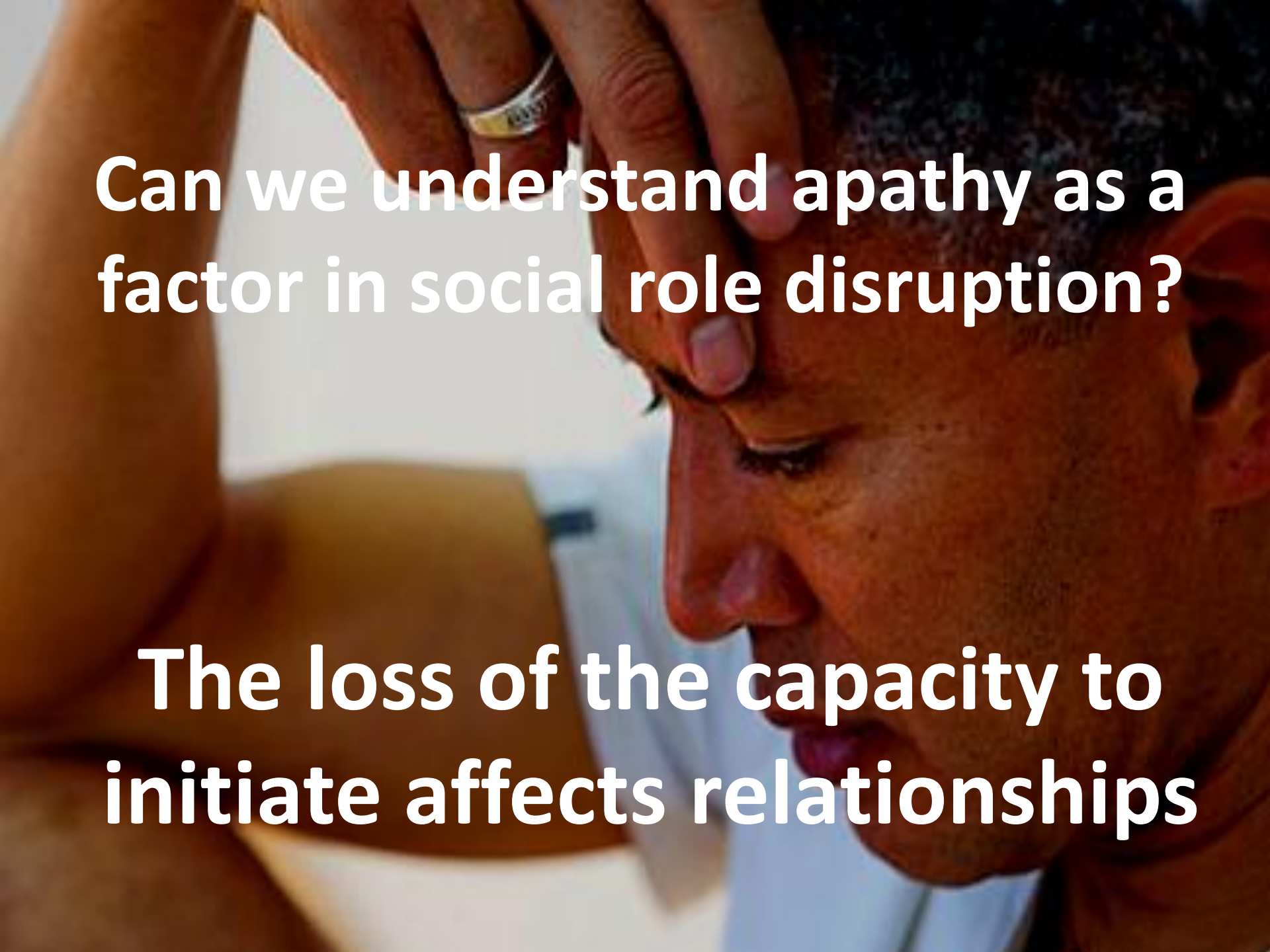
# Is our social role functioning determined by frontal lobe function?

- Emotional recognition
- Infer mental states of others
- Social Cognition
- Cognitive Flexibility
- Executive Functioning

Source: Bibby , H. & McDonald, S. (2005); Henry, J.D., et al. (2006); Stuss, D.T. & Gow, C.A. (1997).

# The “I” function and social role return

- Capacity to maintain a sense of self
  - Relating abilities
  - Capacity to initiate behavior/activity
  - Ability to respond/reciprocate
  - Recognition of self among others
  - Maintaining the “Social Rhythm”
- 



**Can we understand apathy as a  
factor in social role disruption?**

**The loss of the capacity to  
initiate affects relationships**

# Apathy and Social Role Return

- Individual may not fully sense their altered role behaviors and performance
- Ability to participate in relationships is reduced
- Significant response by others to changes in functional status “...not the same person...”
- Loss of responsiveness to requirements of role
- Lack of initiation of behaviors integral to role





**Apathy is associated with a reduced emotional and physical response**

**83% of TBI cases with apathy had comorbid depression**

**Differentiation of “social apathy” an altered sense of self and social awareness related anterior frontal lesions**

**Apathy may exist as subtypes defined by frontal-subcortical loops (Apathy Syndromes)**

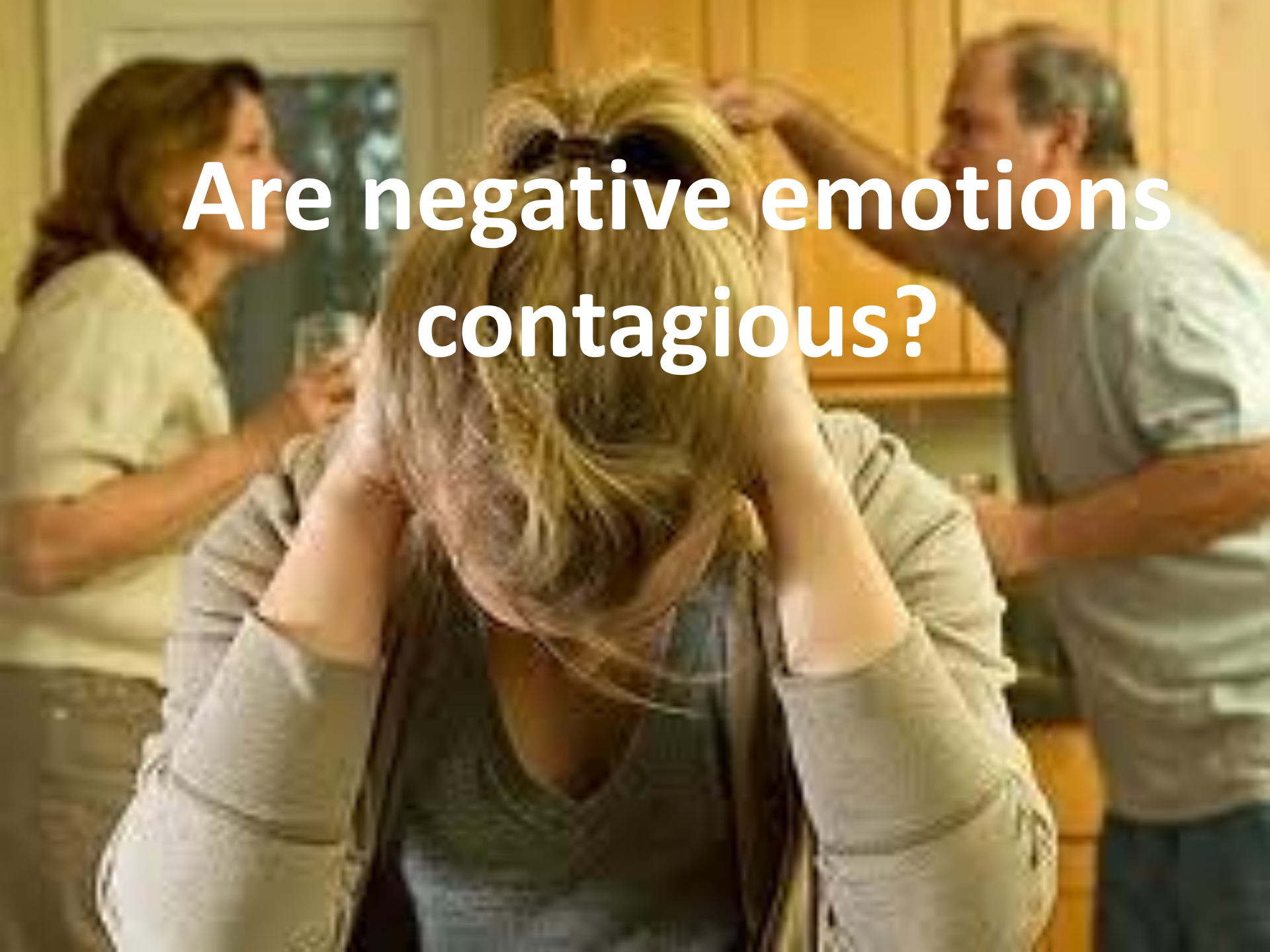



# Apathy: Who Cares?

## Is social role function determined by injury location?

- Apathy found in adult TBI at a prevalence range of 46.4% to 71.1%, average of 61.4%
- Loss of role and hopelessness found in most individuals with apathy
- Apathy may not be concern to the individual due to a loss of self-observation
- Caregivers rate apathy as the third most difficult neurobehavioral problem

**Are negative emotions  
contagious?**



A blurred background image showing a group of people standing in a circle, possibly in a meeting or workshop setting. The people are out of focus, with some appearing in shades of blue and others in more natural colors. The overall scene suggests a collaborative environment.

**What about looking  
outside of rehab?**

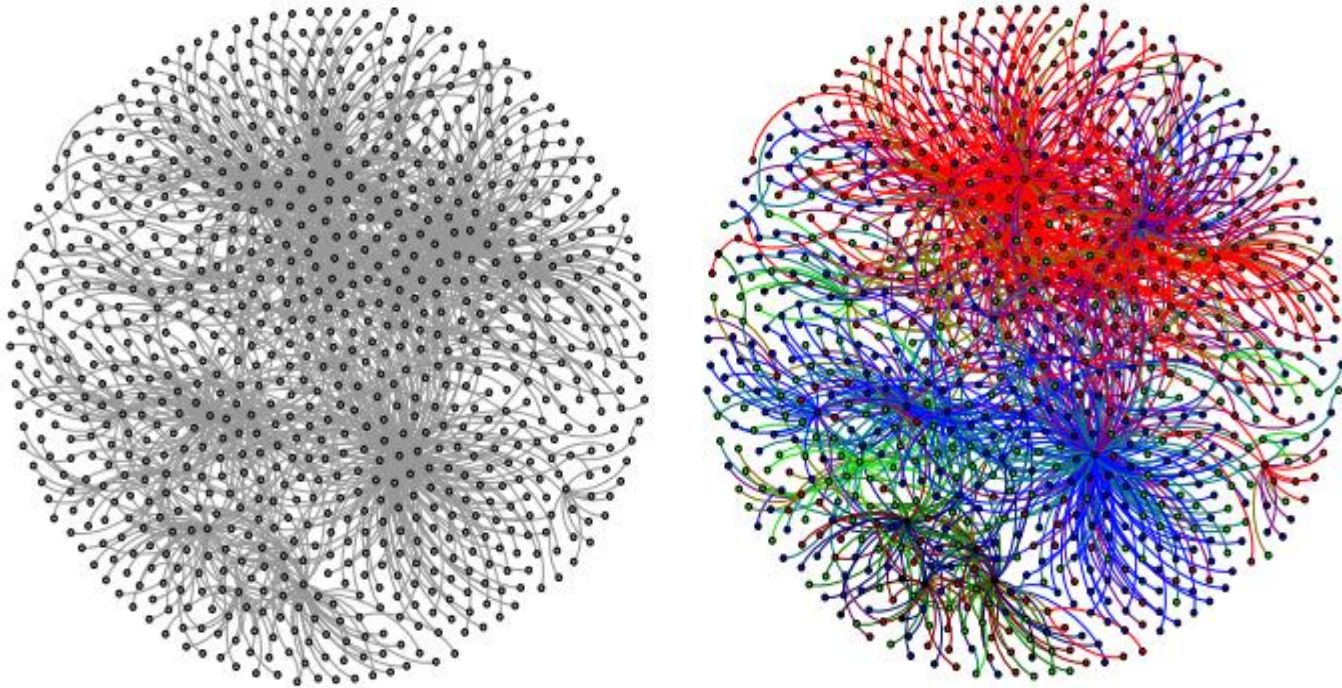
**Does the research on emotions  
and social media offer an  
understanding?**

# **“The Fast and the Furious”**

**Does the strength of the emotional  
and behavioral content speed  
communication?**



Rage and anger are transmitted faster  
through social networks,  
triggering a chain reaction

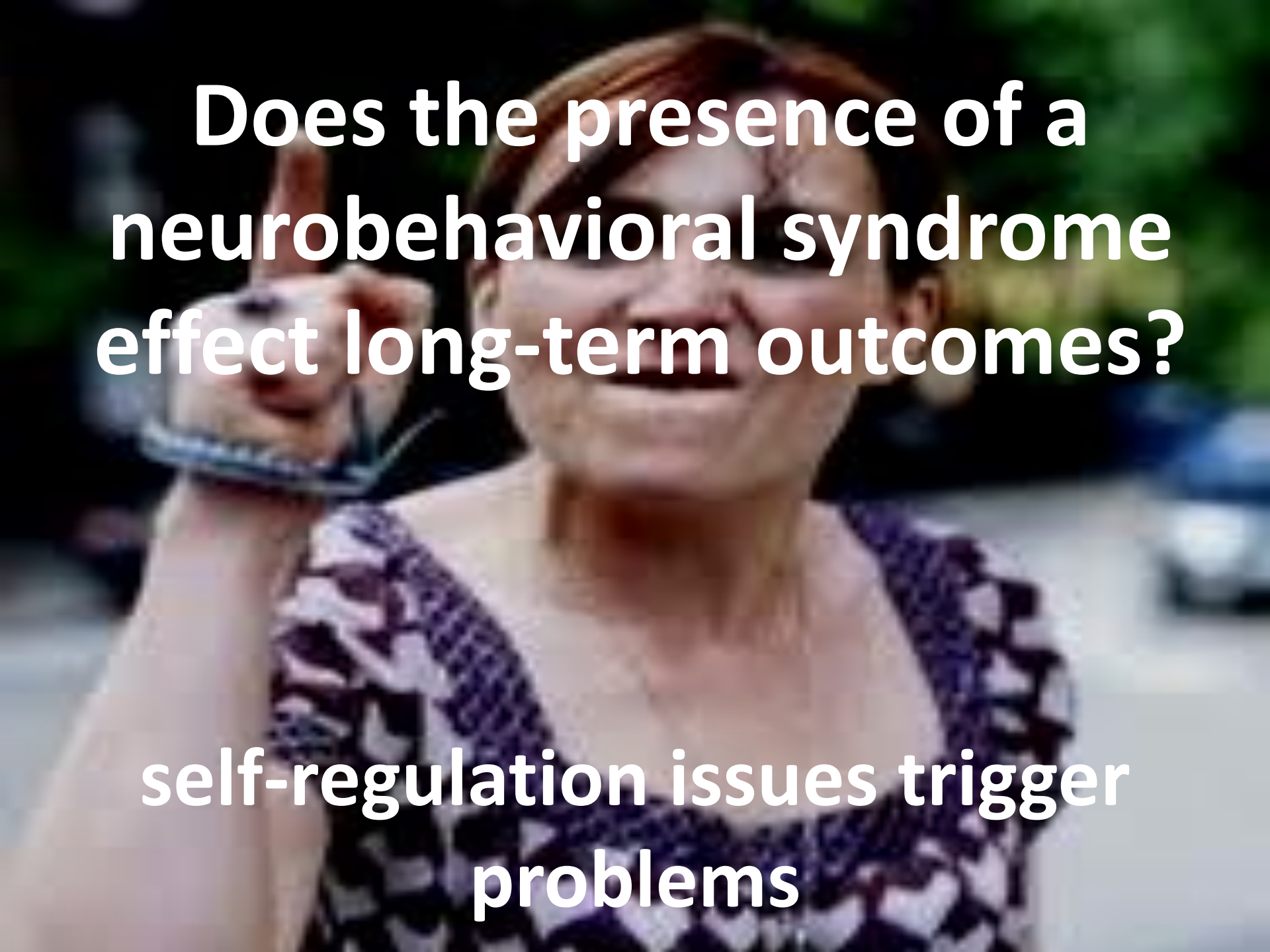


Sources: Rui Fan, et al., (2013); Berger, J. & Milkman, K.L. (2013).



**Similar to past studies involving  
the families of individuals with  
brain injuries**

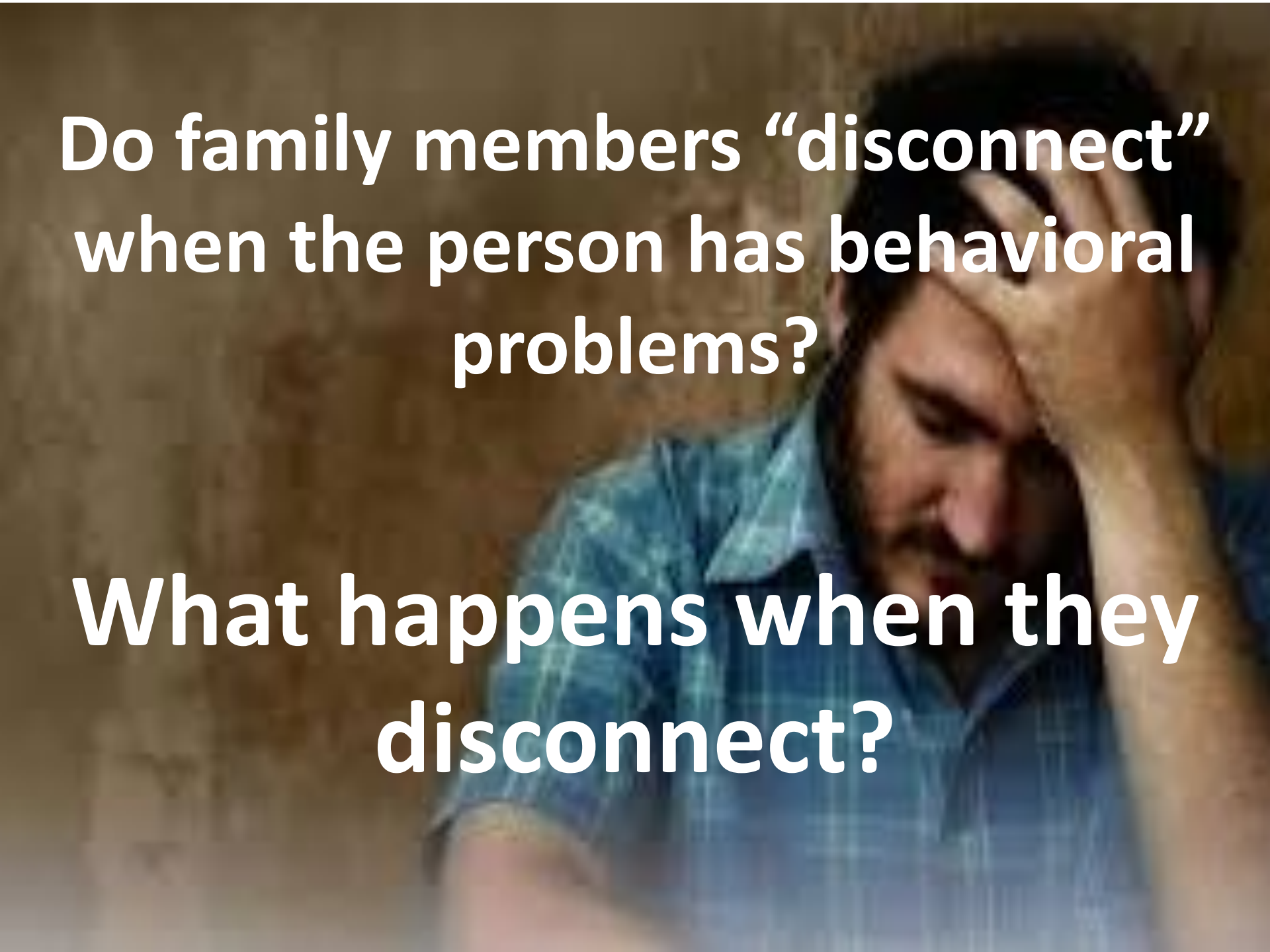
**Behavioral dyscontrol is the  
hardest for family members**



**Does the presence of a  
neurobehavioral syndrome  
effect long-term outcomes?**

**self-regulation issues trigger  
problems**



A man with dark hair and a beard, wearing a blue plaid shirt, is shown from the chest up. He has his right hand pressed against his forehead and eyes, with his fingers spread, suggesting a state of distress, frustration, or despair. The background is a plain, light-colored wall.

**Do family members “disconnect”  
when the person has behavioral  
problems?**

**What happens when they  
disconnect?**

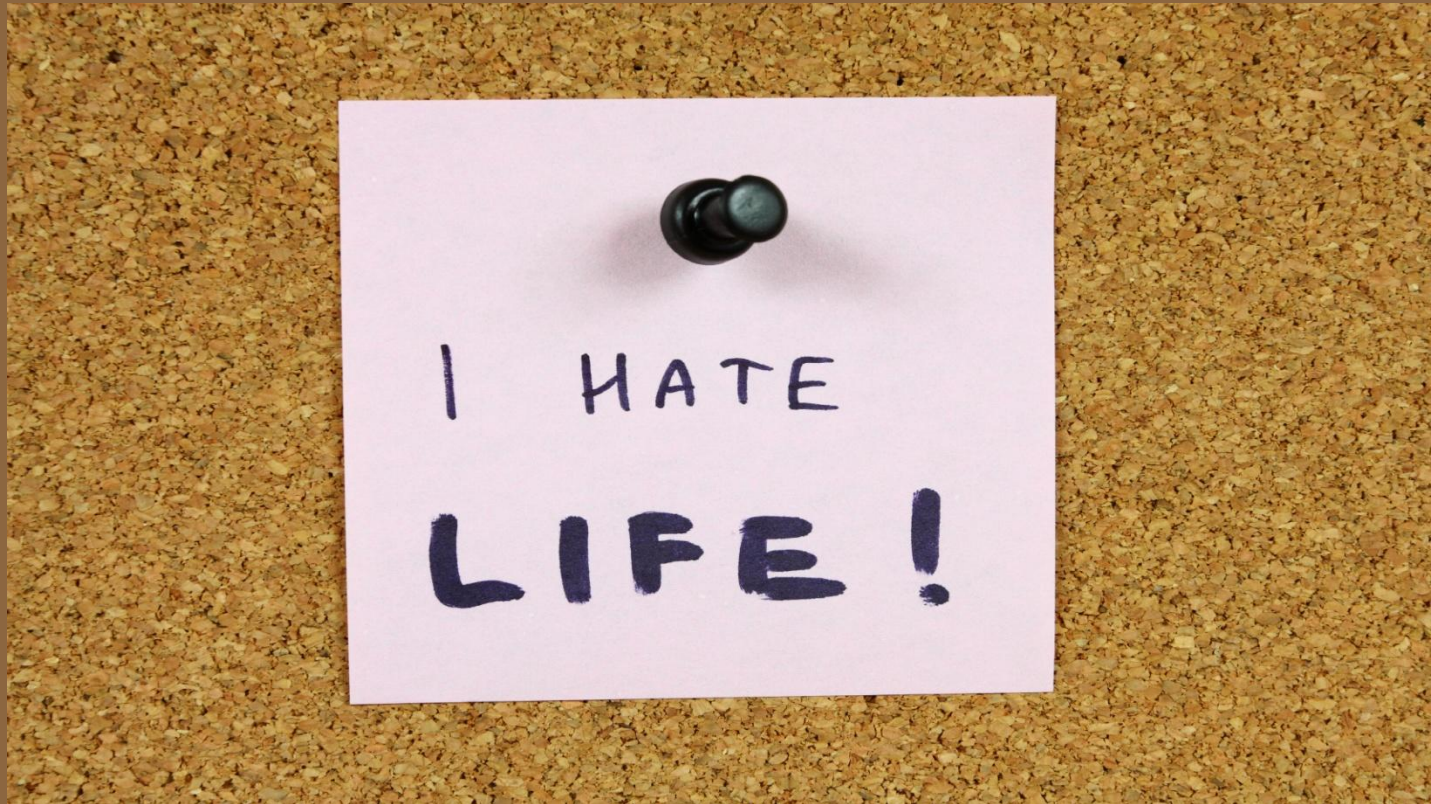


# Sadness causes withdrawal and social deactivation



**Source: Berger, J. & Milkman, K.L. (2013).**

**How do other people react when a person is sad and depressed?**




**Can they sustain the relationship?**

A person is shown in silhouette, standing in front of a large window. Their right hand is pressed against the glass. The view outside the window is a bright, hazy cityscape. The overall mood is contemplative and somber.

**How does the person view  
themselves after injury?**

**The loss of a sense of self is a  
common experience.**

**Sources: Cicerone, K.D. (1989); Frey, W.F. (1994); Groswasser, Z. & Stern, MJ. (1998).**

A person with long dark hair, wearing a dark long-sleeved top, stands with their back to the camera, looking out of a large window. Their right hand is pressed against the glass. The scene is brightly lit, suggesting a sunny day outside. The text is overlaid on the upper half of the image.

**Self-estrangement, negative  
self-evaluation, emotional  
distress and denial of changes in  
functioning**



**View of self as “not the same person”**

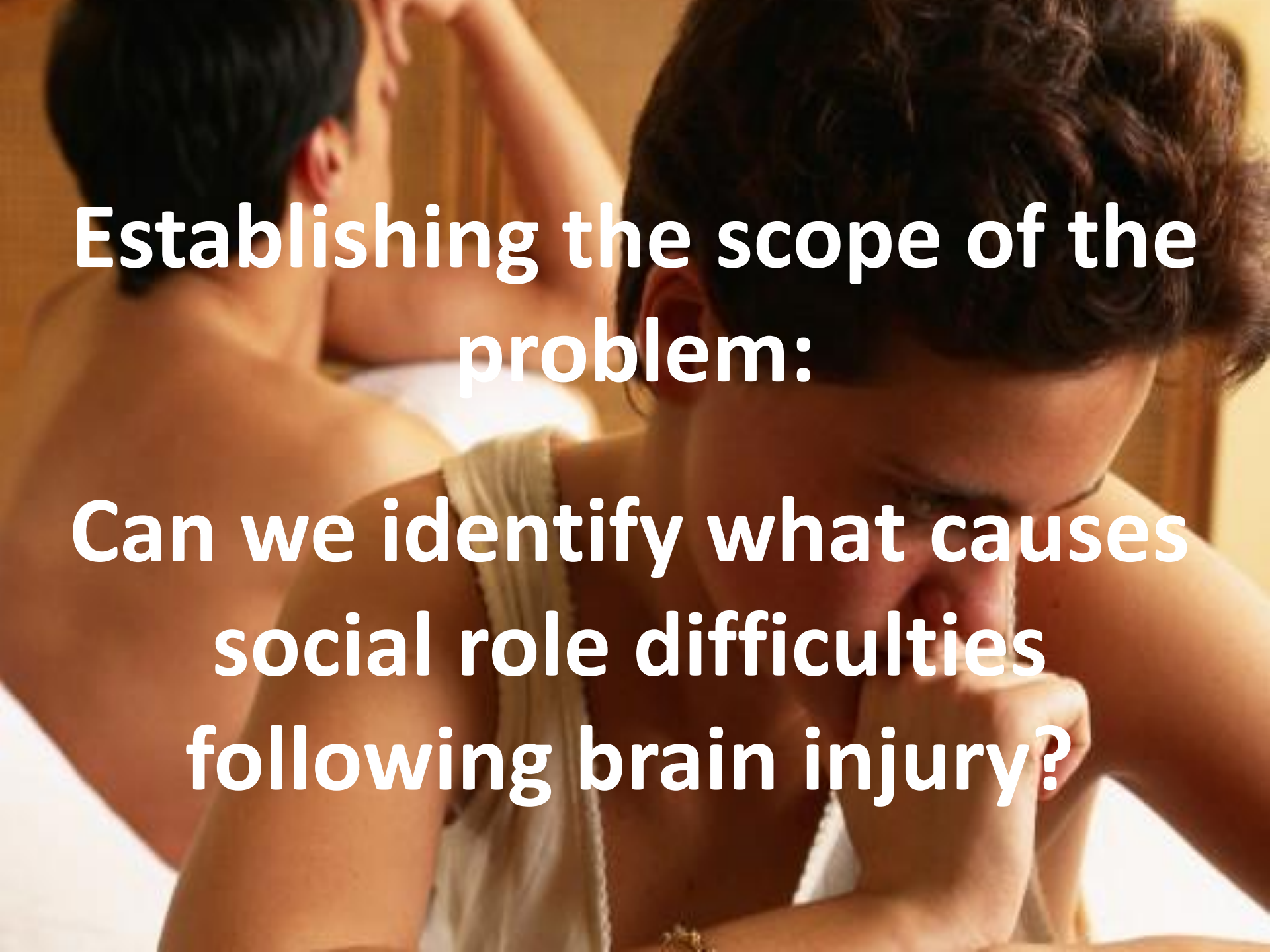
**Loss of sense of competency and effectiveness at work, home and in social relationships**



A close-up photograph of a person's face, heavily shadowed and tinted with a dark teal or blue color. The person's right hand is raised, with fingers spread, covering their eyes and the upper part of their face. Only their left eye is visible, looking directly at the camera with a wide, intense, and somewhat fearful or desperate expression. The lighting is dramatic, with deep shadows on the right side of the face and under the hand. The overall mood is one of emotional distress, shame, or a desire to hide.

**Does the loss of sense of self  
drive withdrawal?**

what's the difference between  
**isolation** and **withdrawal**?

A photograph of a man and a woman in a close embrace. The man, with dark curly hair, is resting his head on the woman's shoulder. The woman has dark hair and is wearing a light-colored top. The background is softly blurred, showing what appears to be a wooden headboard. The overall mood is intimate and supportive.

**Establishing the scope of the problem:**

**Can we identify what causes social role difficulties following brain injury?**



# Defining the duration of the problem



**Does the problem change over the course of time?**

**“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”**

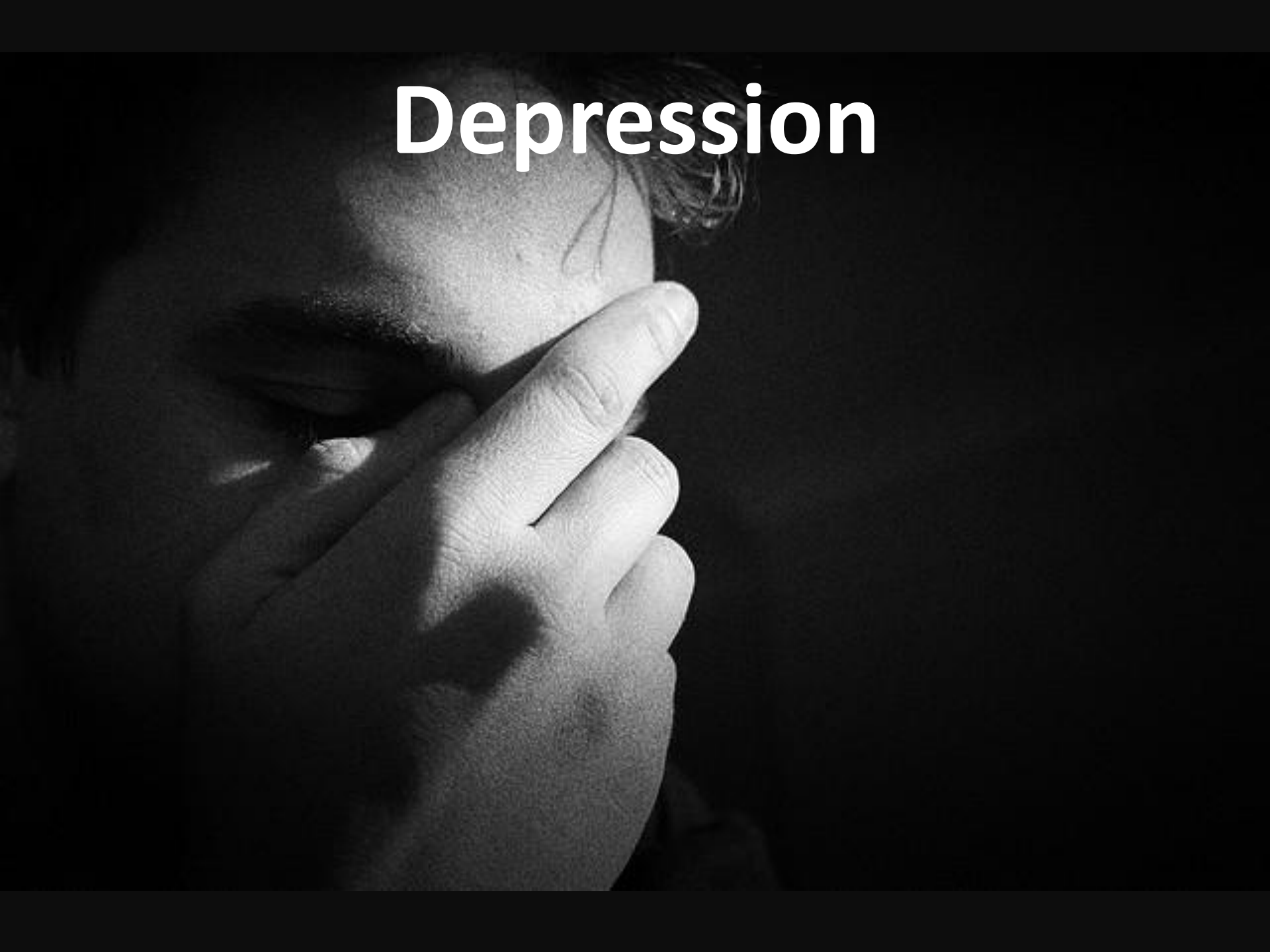
Walter Mosley, “When the Thrill is Gone”, 2011

# What are the risk issues?



**What are the mental  
health issues?**

# Depression



**Anxiety**



# Mood state problems

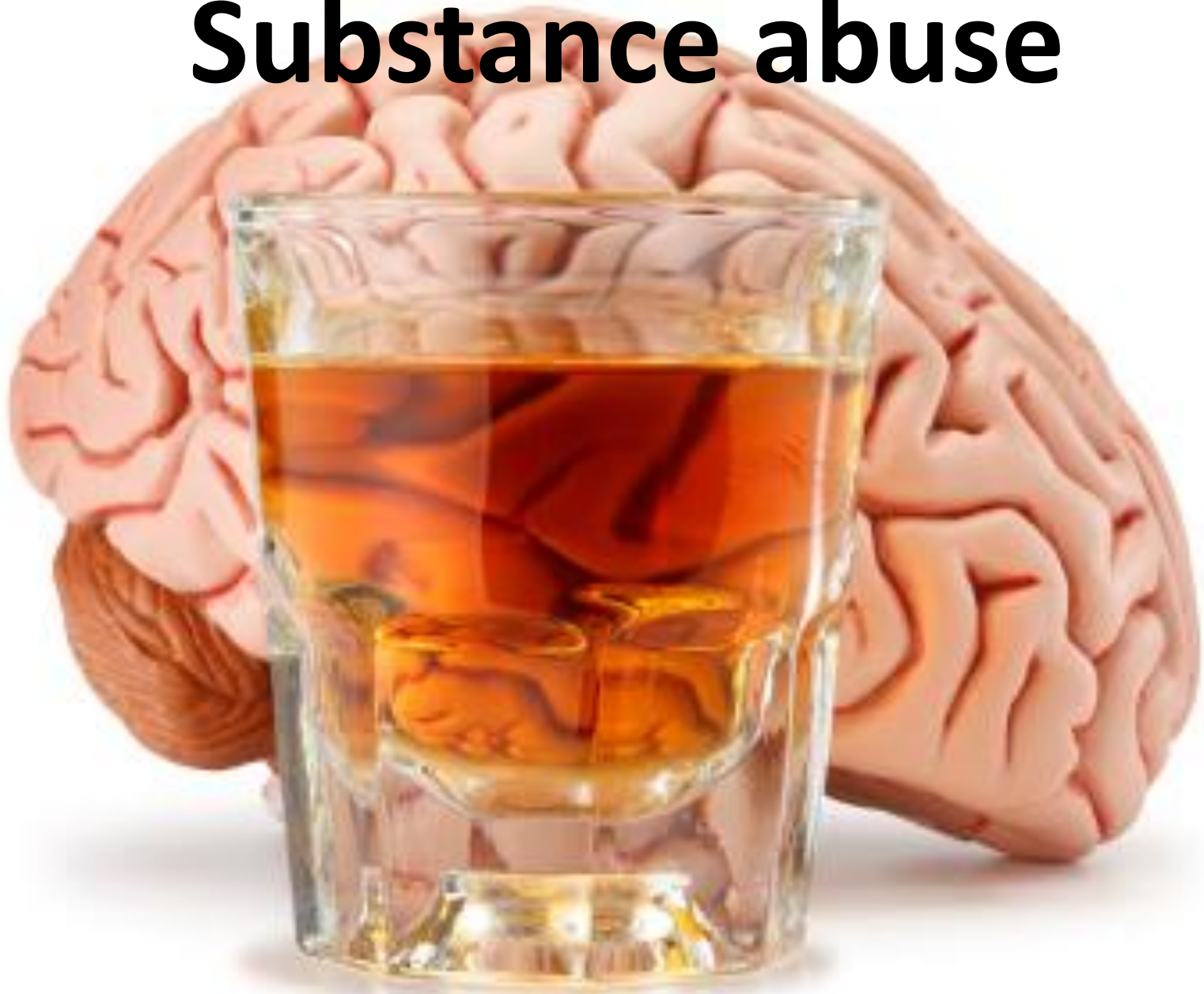


# Risk for Suicide





# Substance abuse





**Irritability, anger and  
aggression**



# High risk behaviors



# **Other Mental Health Problems**

**Does it mimic psychiatric illness?**

**Does it mimic psychiatric illness?**

**Does it ~~mask~~ psychiatric illness?**

**and, the relationship to  
physical health and  
wellness**







**DETOUR  
AHEAD**

**Brain Injury**

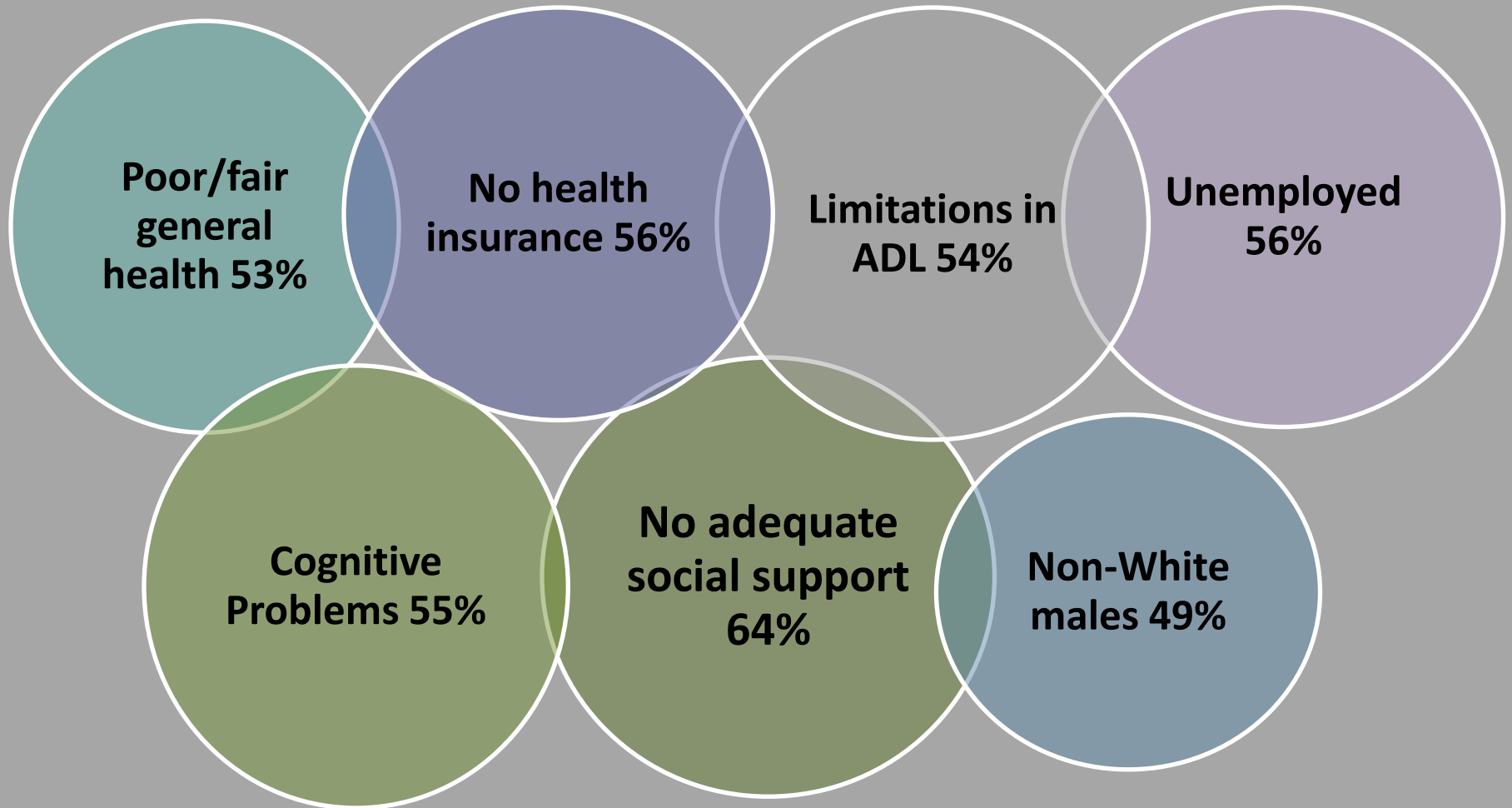


# What are the barriers?

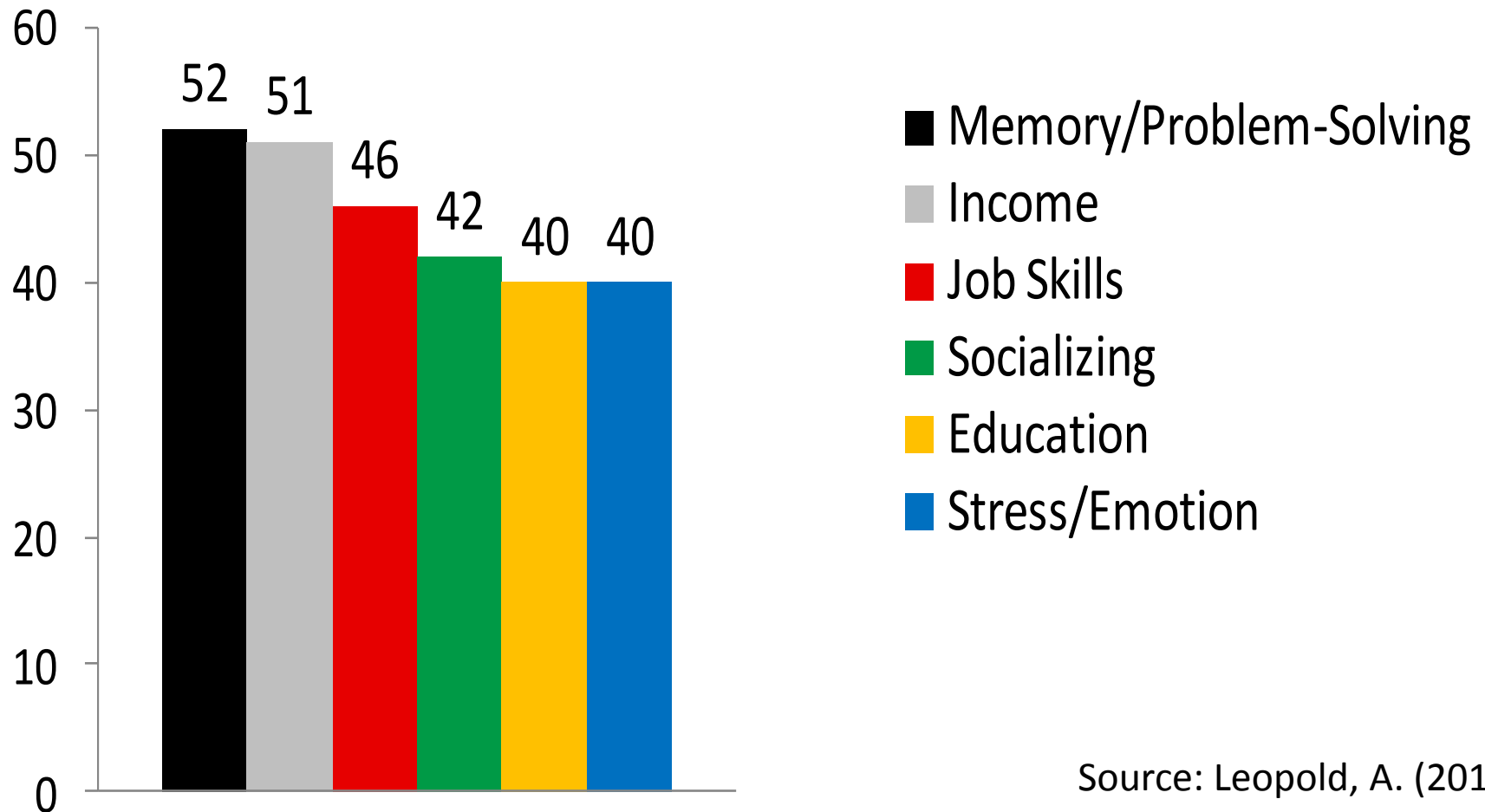


**Financial, structural, individual,  
and attitudinal barriers directly  
impede individuals' abilities to  
access rehabilitation services  
even though these services  
could greatly improve their  
recovery from TBI**

# Defining the barriers



# Medicaid recipients reporting “unmet needs”



Source: Leopold, A. (2013)

**Does limited rehab increase  
problems in social role  
return?**

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

**Can those studies help  
define the issues related  
to social role return?**

# Geurtsen's study on sustaining outcomes



# 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

# **J. Ponsford's study**

# 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

# **The Monash University Study**

# **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**

# Kaponen's 30-year study

# **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**

# 30-year study of mental health issues and brain injury

- 61.7 had an Axis 1 (DSM-IV) diagnosis in their life time
- 48.8% had an Axis 1 diagnosis following their injury
- 40.0% had a current, post-injury Axis 1 diagnosis
- Depression (MDD) was the most common diagnosis



# J. Silver's HMO Study

# 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

**R. van Reekum's studies**

# **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).**

# **Meichenbaum's Study of Resilience**

- **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.**

**Fann, et al**

# **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**



What do the **long-term**  
studies tell us?

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

**Dawson and Chipman's  
study of living in the  
community with a brain  
injury**

**Reviewed the quality of life,  
assistance needs and level of  
socialization experienced by  
individuals 13+ years post  
moderate-severe brain injury  
living in both rural and urban  
environments**

## **Dawson and Chipman: quality of life, support needs and socialization**

- **66% need ADL assistance**
- **75% unemployed**
- **90% dissatisfied with social life**
- **47% not using telephone**
- **27% not socializing at home**

# **Health and Aging 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**

# 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**
- **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).

What are the **economic**  
**aspects** of brain injury  
disability which **effect social**  
**role return?**

**People with disabilities**  
experience  
disproportionally **high**  
**rates of poverty**

Source: Yeo, R. & Moore, K. (2003); Hughes, C. & Avoke, S.K. (2010); Emerson, E. (2007); Fremstad, S. (2009).

Does disability related  
poverty increase social  
exclusion and social  
network failure?

**What happens when rehab is over?**

**What happens as life goes on?**

**what about social role  
return?**

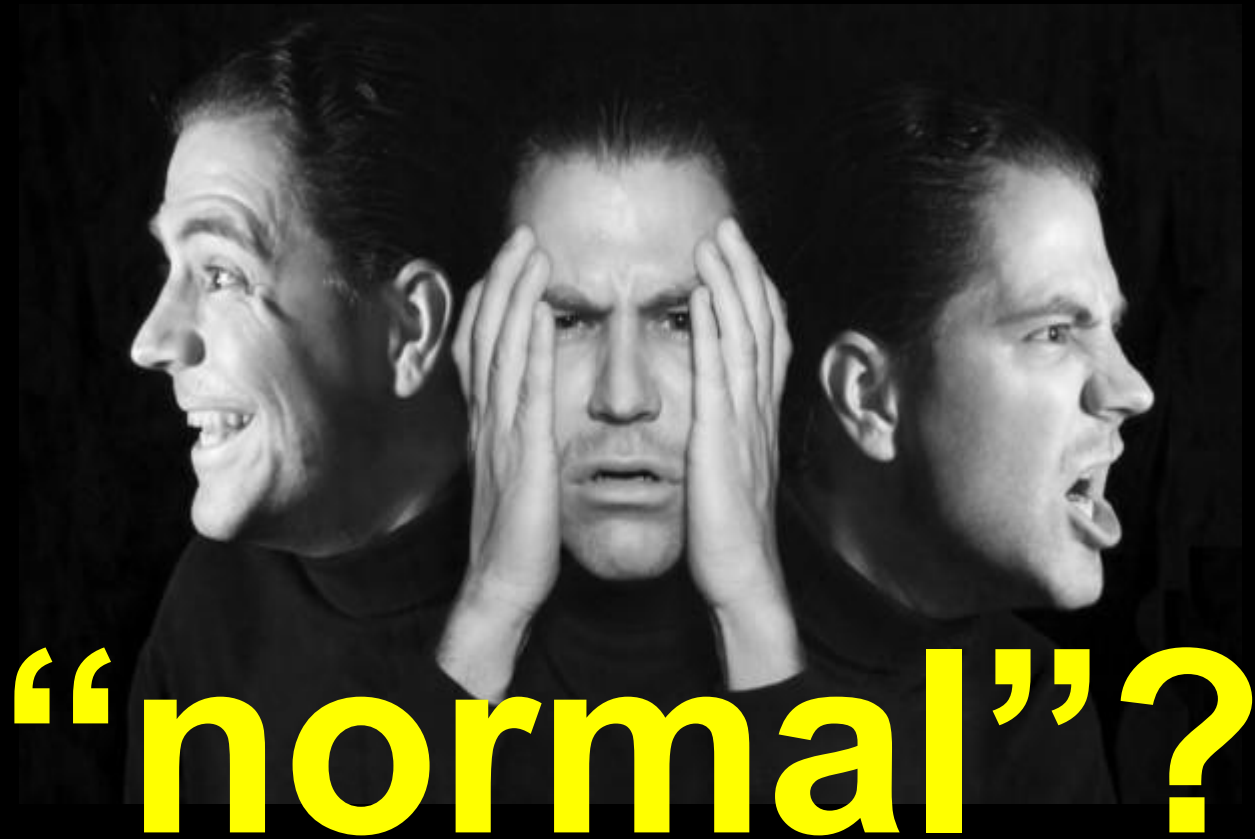
**is it a determinant of  
potential mental  
health problems?**



What is **related** to  
the **person's** brain  
injury **disability**?

What is **related** to the  
**responses** of people  
and groups **external**  
**to the person?**

# 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?



**how can we expand  
the domains we  
measure**

**to be more relevant  
to the person and their life?**



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

**Alya Reeve, MD,**

**“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**

# 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

# **A. Condelucci's view of living with a brain injury disability**

**What are the life outcomes?**

**Work?**

**76% are unemployed**

# Home ownership?

6.1% own their home

# Transportation?

The majority are not  
driving

# **Friendships and personal relationships**

**Many people experience  
the loss of relationships**

**Let's look at outcome data  
from two community-based  
programs**



**the NRIO study**

**the people over the course of the  
study:**

**641 tracked from 1995-2014**

**Average age: 32.0**

**Age Range: 2.11 to 78.7**

**83.3% Severe TBI**

**90.5% MVA**

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

**the NRIO Study:**

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).**

# the NRIO cohort in 2014

- **age at injury** **36.2** vs. 32.0 study average
- **GCS <9** **85.5%** vs. 83.3%
- **male/female** 68.3% / 31.7%
- **period from injury to post-acute** **35.5** vs. 25.00 months
- **% MVA related** 90.5%

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

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  
1997-2013

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

# **3.4 years post injury prior to admission**



***substance  
abuse***



**33%**

**legal problems due to social  
behavior & judgment**





**36%** post-injury substance abuse



**45%**

**problems with spouse or  
significant other**



**88%**

**Problems relating to/  
maintaining friends**

1 to 5 years after the injury

**nrio** outcome study, adult cohort  
1997-2014

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

# perception of post-injury changes

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



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

# 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?**

**Is there a commonality of  
problems for the individuals  
in this group?**

**What are the mental  
health issues?**

**How does substance abuse  
impact on social role  
return?**

**What factors prevent  
returning to their pre-injury  
social role?**

**What happens to  
individuals who don't  
return to their pre-injury  
social role?**

**What supports are needed  
to sustain outcomes over  
the course of time?**

**What can we learn from  
individuals who make a  
successful return?**



**What can we expect as  
changes in outcomes over  
the course of time?**

**Let's look at a study with three  
years of operation and a similar  
population with different  
outcome results**

# CNR Study

# **the CNR Study:**

**Social Role Return**

**Independence/Support Level**

**Vocational/Avocational Activities**

**Mental Health and Substance Abuse  
Issues**

**Durability of Outcome**

# the people over the course of the study

28 tracked from 2010-2014

Average age: 39.21

Age Range: 34.10-60.00

Age at injury: 31.90

100% Severe TBI

33% MVA

22% Aneurysm

22% Assault

22% Anoxic Injury/Toxic Encephalopathy

**the CNR cohort**

**age: 39.21**

**male/female :72%/27%**

**period from injury to post-acute: 1.0 –  
20.0 years**

**Average from injury to post-acute  
admission 8.0 years**

# **Post-injury, pre-admission problems**

**Pre-injury psychological  
problems: 77%**

**Pre-injury substance  
abuse: 70%**

**Pre-injury legal problems:  
57%**

# CNR Outcomes

Employed: 10%

Not working/unable to work: 90%

Independent Living with 0 to 4/hrs day of support: 20%

Independent Living with 6-10/hrs day of support: 20%

Living with family 0-4/hrs day of support: 20%

Living in care situation: 40%



# **Substance Abuse Issues**

**Post-discharge substance abuse:  
40%**

**Maintaining abstinence: 60%**

**Minimal substance use: 10%**

**Moderate substance use: 30%**

**Returning to pre-injury social role**

**Returned to pre-injury social role:  
20%**

**Returned to pre-injury role with  
modifications/supports: 40%**

**Interfering psychiatric and  
substance abuse problems  
affecting social role: 40%**

# Individuals who don't return to their pre-injury social role

Weekly counseling: 0%

Occasional counseling: 30%

Receiving daily support 2-6/ hrs day: 10%

Attending self-help/support group: 0%

Not receiving psychological/psychiatric services:  
30%

Requiring 24 hr placement: 40%

# 40%

**experienced significant psychological  
problems requiring intervention**



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

**40%**

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

# Why?

The length of time from  
injury to rehabilitation  
creates persistent problems

# Why?

**The development of chronic  
mental health and substance  
abuse problems which effect  
participation and engagement**

# Why?

**The loss of personal, family and social network supports over time resulting from psychiatric and substance abuse problems related to brain injury**



**Let's take another look at  
Cathy...**

**“...I started going back to  
school...”**

**“...I started to feel OK about myself when I started volunteering and getting involved in peer counseling...”**

**“...it took me six years to  
integrate...”**

**“...I started to develop  
self-compassion...”**

**“...the third hurdle was  
getting my master’s  
degree...”**

**now, 20-years since her injury,  
an accomplished researcher in  
Mindfulness, a published  
journal author, conference  
speaker and teacher.**

# The search for answers



**What can we learn from  
people who don't succeed  
in social role return?**

**What can we learn from  
durability?**

**What are the factors associated  
with sustained long term  
outcomes?**

**Where do we need to look  
to make meaningful  
changes?**

# **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**

# **Supports for social integration**



**Programs for the person...**

**unique, person centered  
programs**

# Targeting loneliness and isolation

**Can we establish strategies  
and interventions for  
individuals with a dual  
diagnosis?**

**Where will funding  
come from?**

**Eliminating barriers  
as they occur....**

**throughout  
the lifespan**



“you can observe  
a lot by watching”

Yogi Berra



*That's all Folks!*

# Thank you!

## Questions?

This presentation may be downloaded at  
[www.traumaticbraininjury.net](http://www.traumaticbraininjury.net)  
[nrio.com](http://nrio.com)

It can be found under “Resources”

The presentation cannot be copied, used or distributed without the consent of the author





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# **The Psychometrics of Social Role Return for the Person with Brain Injury**

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