

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

**Rolf B. Gainer, PhD**

The Neurologic Rehabilitation Institute at  
Brookhaven Hospital, Tulsa, Oklahoma

Neurologic Rehabilitation Institute of Ontario,  
Etobicoke, Ontario

Community NeuroRehab, Des Moines, Iowa  
Rehabilitation Institutes of America

# 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 the Neurologic Rehabilitation Institute of Ontario and Community NeuroRehab 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**

**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...”**

How  
do we  
measure  
self-worth?



job, profession, skills

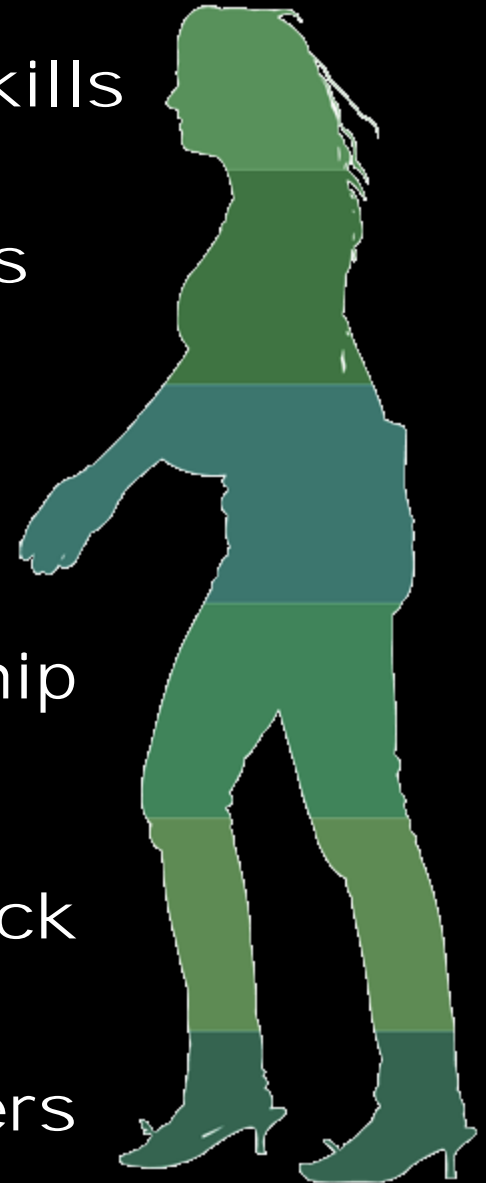
relationships, family, friends

life activities

home/residence ownership

positive feedback


participation with others



A person wearing a dark hoodie is seen from behind, looking out of a large window. The person's right hand is pressed against the glass. The scene is dimly lit, with light coming from the window, creating a contemplative and somewhat somber atmosphere. The background outside the window is blurred, suggesting an urban or industrial setting.

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

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

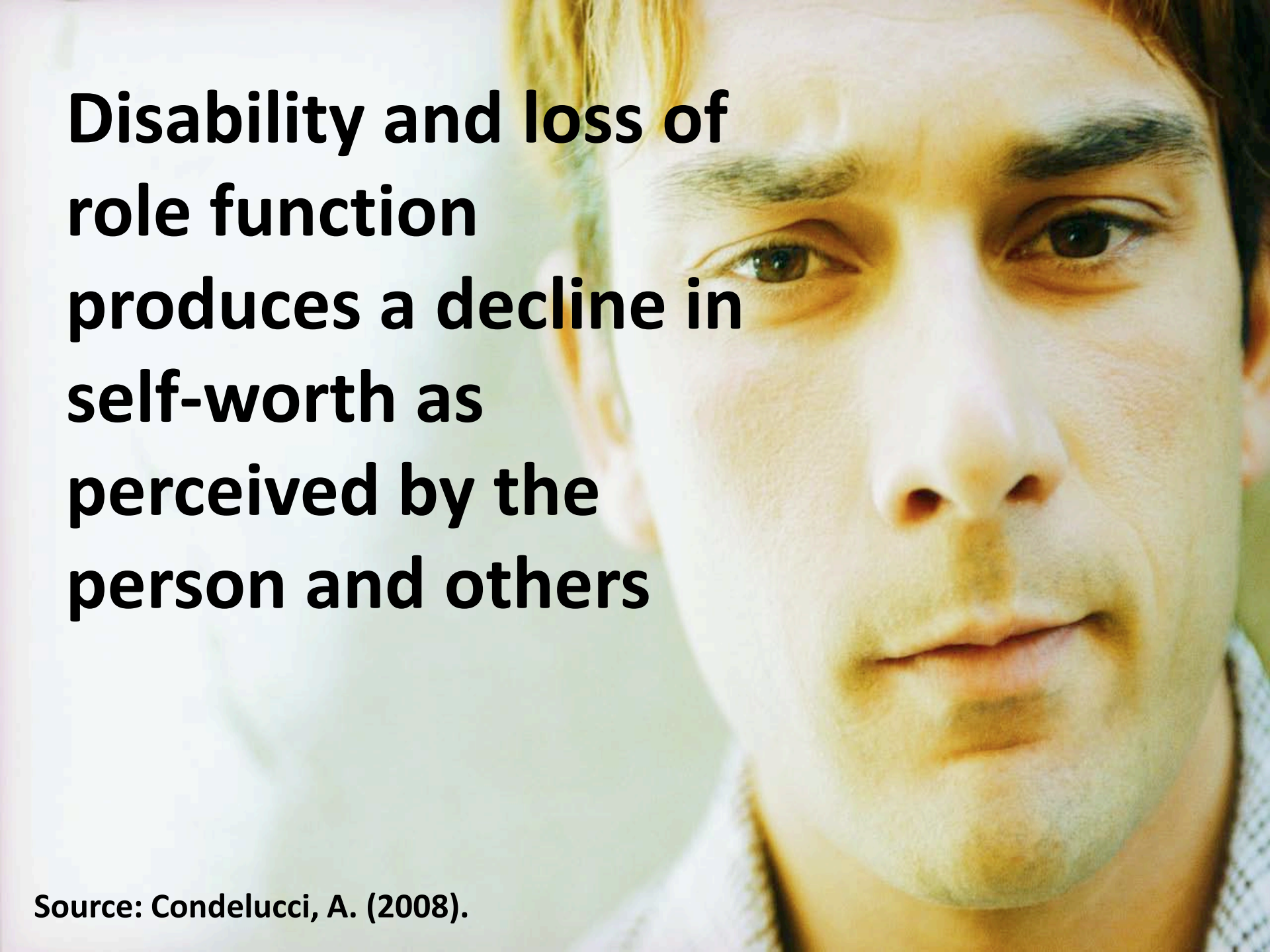
A person wearing a dark hoodie is seen from behind, looking out a window. The person's right hand is raised, touching the window frame. The background outside the window is bright and overexposed, suggesting a sunny day. The overall mood is contemplative or somber.

**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**



**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

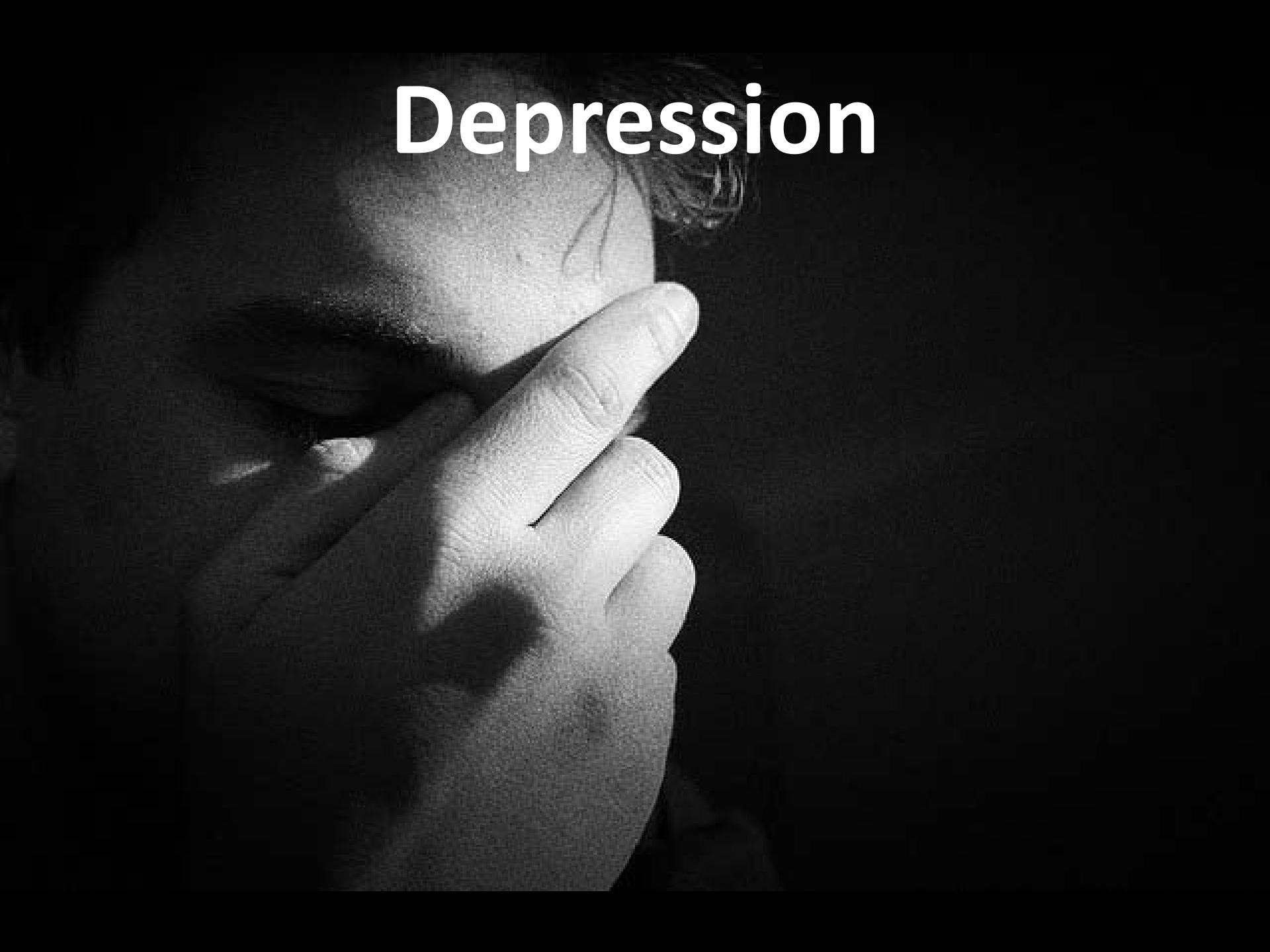


Frank, E et al (2005)

**What are the mental health and risk issues?**



# Depression



**Anxiety**



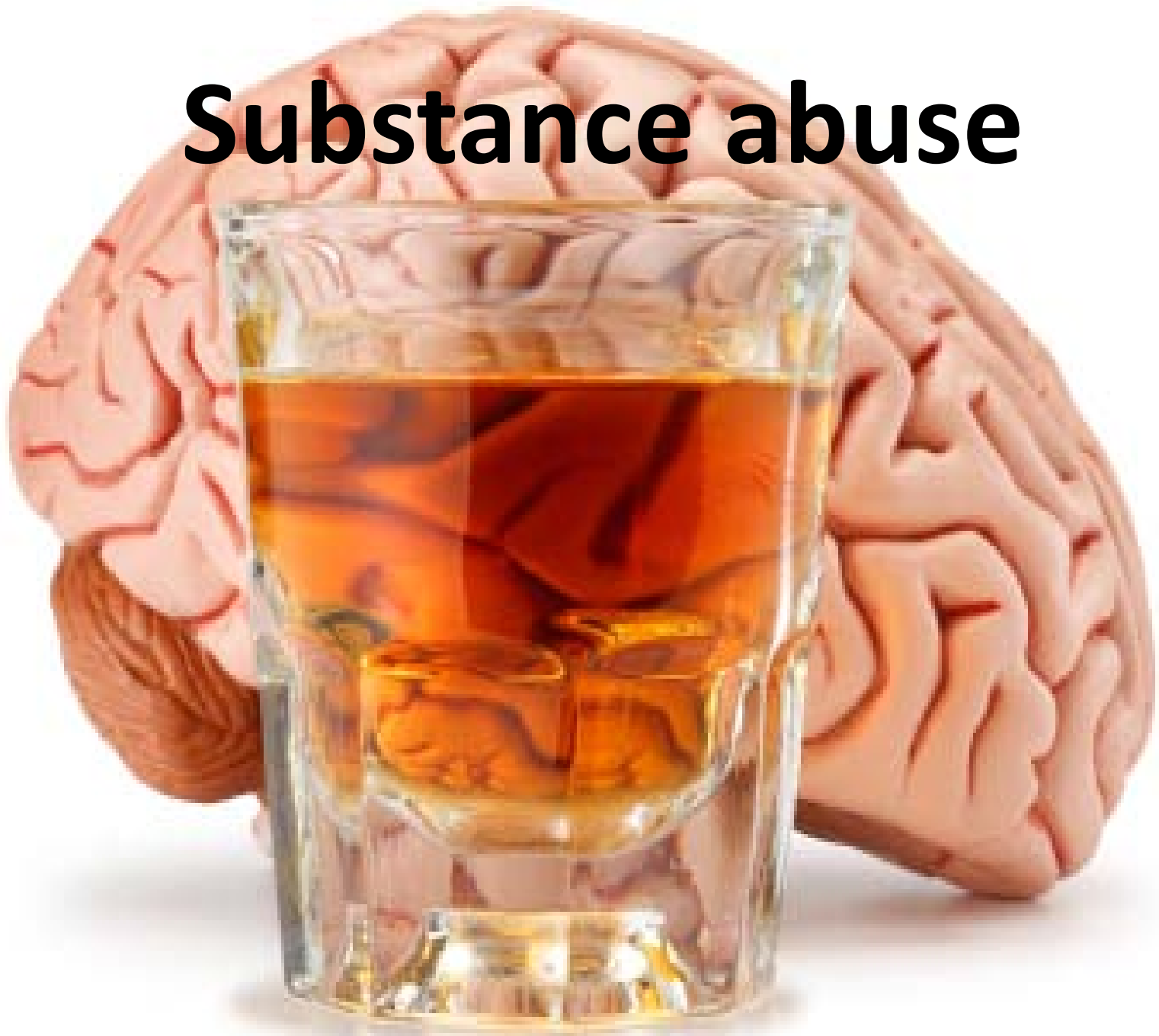
# Mood state problems



# Risk for Suicide



# Substance abuse



A man with a mustache is driving a car, looking stressed and gesturing with his hands. The text "Irritability, anger and aggression" is overlaid on the image.

**Irritability, anger and aggression**



# High risk behaviors



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

# 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**

# 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**

# 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**

# 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 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



# 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



# Meichenbaum: 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.**

# Life expectancy after TBI

- Twice as likely to die as age, gender and race matched peers
- **Estimated life reduction of 7 years**

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

**Dawson & Chipman's study 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**

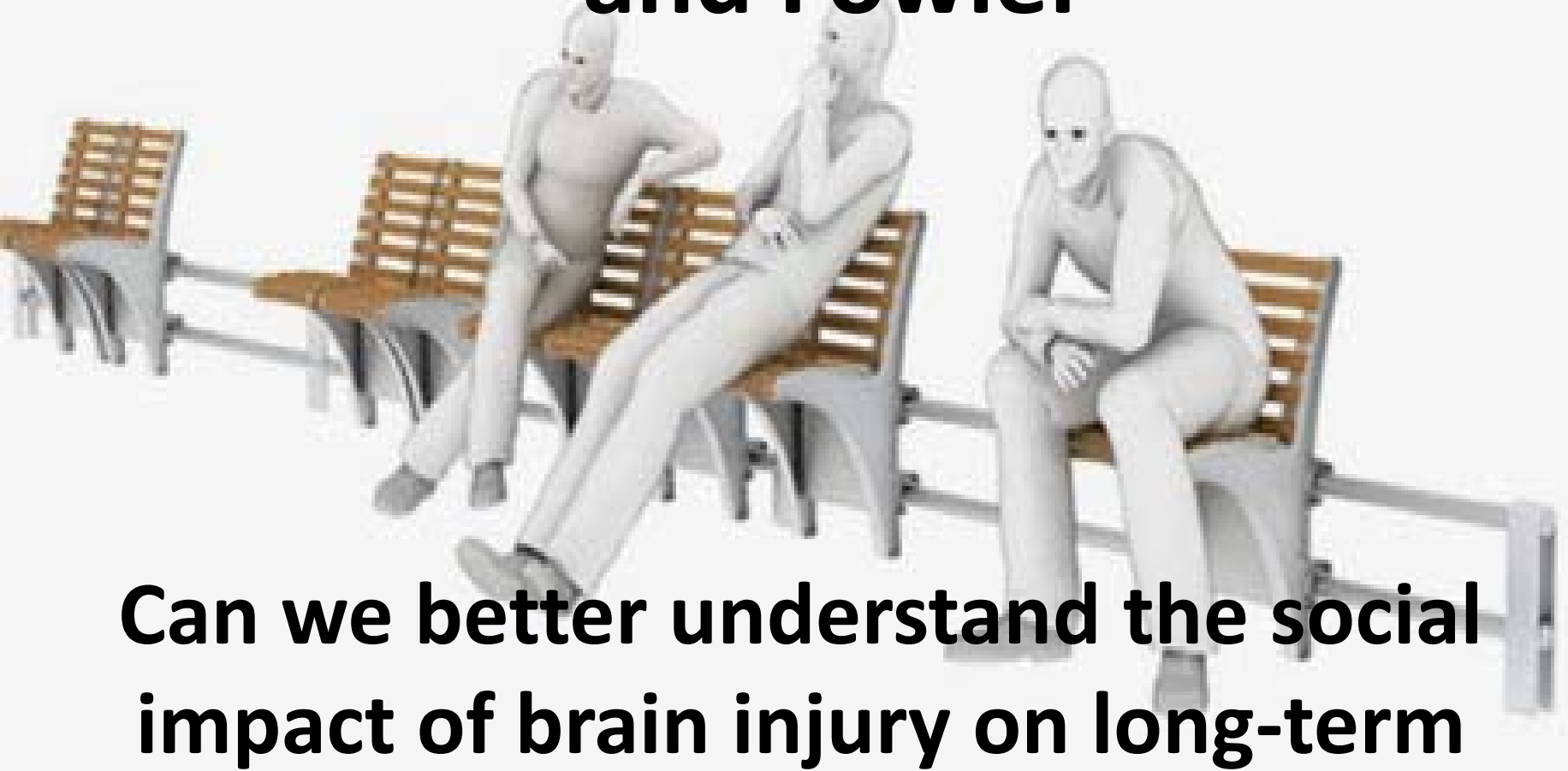
# Dawson and Chipman's quality of life, support needs and socialization

- 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).

**Does isolation and  
loneliness create social  
network failure?**

# **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).

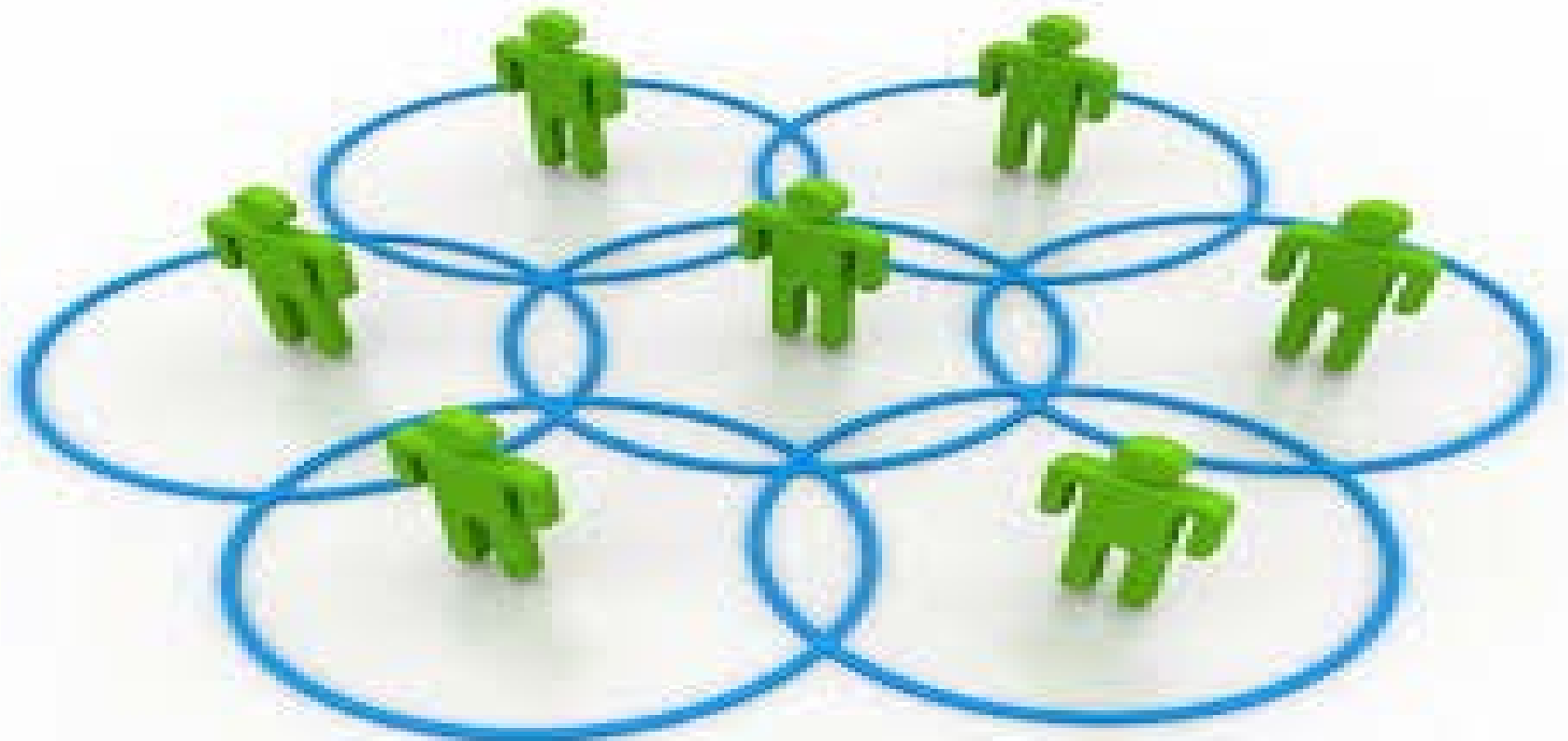


# Sadness causes withdrawal and social deactivation



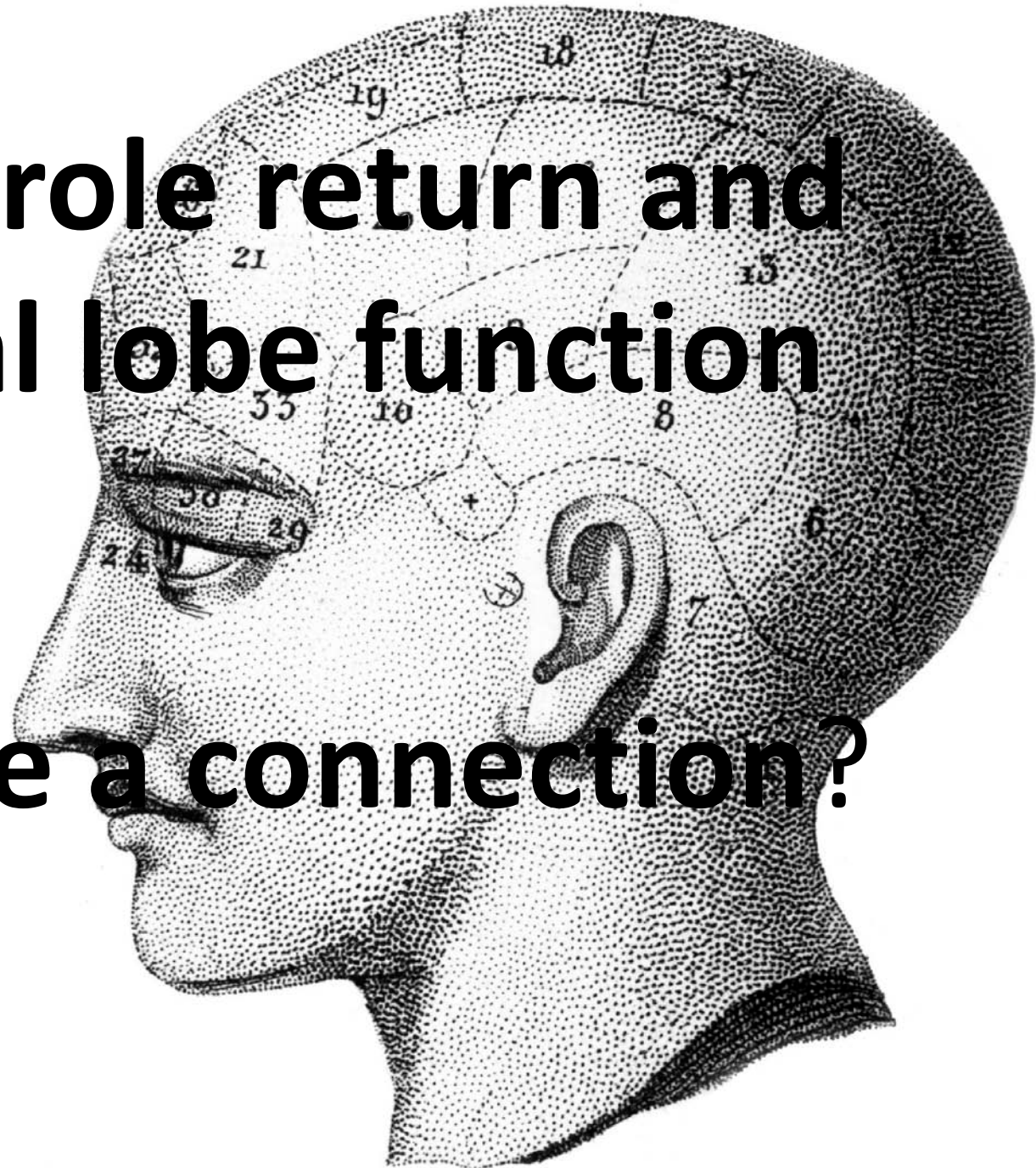
- Source: Berger, J. & Milkman, K.L. (2013).

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



**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?**

**Does apathy separate the  
person from relationships  
because of loss of role  
function and ability to  
reciprocate?**

**Or, do others separate from  
the person because of their  
perception of the changes  
in the person's ability to  
relate to them?**

# a chicken or egg problem?



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



**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 (ongoing)**

# the NRIO Study:

Social Role Return

Independence/Support Level

Vocational/Avocational Activities

Mental Health and Substance Abuse Issues

Durability of Outcome

# 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%**



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**

**Outcomes and Stability**



# 37.3%

**return to their  
primary social role  
without modifications**



# 43.1%

**experience a change  
requiring support and role  
modification**





19.6%

problems requiring intervention



**19.6%**

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



# CNR Study

**2010-2013 (ongoing)**

# **the CNR Study:**

**Social Role Return**

**Independence/Support Level**

**Vocational/Avocational Activities**

**Mental Health and Substance Abuse  
Issues**

**Durability of Outcome**

# **the CNR cohort**

**age at injury: 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%**

# 33.3%

**return to their  
primary social role  
without modifications**





# 22.0%

**experience a change  
requiring support and role  
modification**





44.0%

problems requiring intervention



**44.0%**

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

**What is the major  
difference between the  
NRIO and CNR cohorts?**

**25 months vs. 11-15.5  
years post injury**

**Is the time between  
injury and treatment a  
factor to consider in the  
development of social  
role return problems?**

**Let's take another look at  
Cathy, 10 years later...**

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

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



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

**now, 22-years since her injury,  
an accomplished researcher in  
Mindfulness, a published  
journal author, conference  
speaker and teacher.**

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

**Can we facilitate the  
process of change?**



*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 authors

# Resources

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