

# **Life After Severe Brain Injury: the Restoration of Self and Social Role Return**

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## **Disclosure**

**Rolf B. Gainer, PhD has business relationships with Rehabilitation Institutes of America, Brookhaven Hospital, Community NeuroRehab of Iowa and their related companies.**

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**No commercial interest is related to this presentation.**

# **Objectives:**

**To understand the  
process of recovery  
of self in relation to  
social role return**

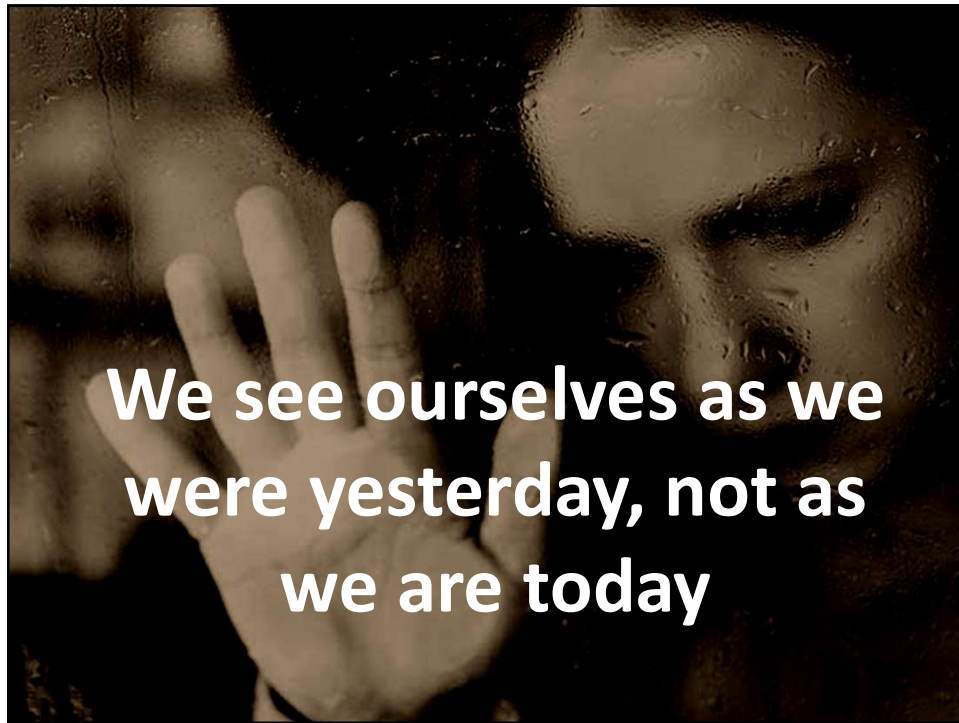
**To consider the  
changes in social  
relationships after  
brain injury**

**To identify the  
barriers faced by the  
person in addressing  
loss**

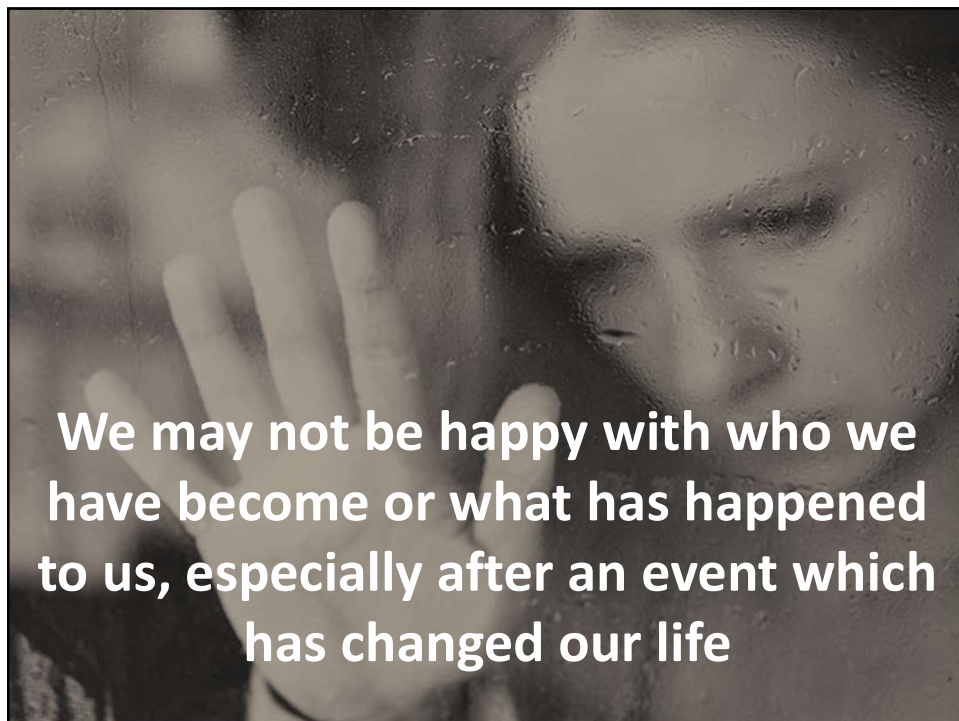
**To understand what can  
facilitate change**

**How does  
the person  
perceive  
what  
happened?**

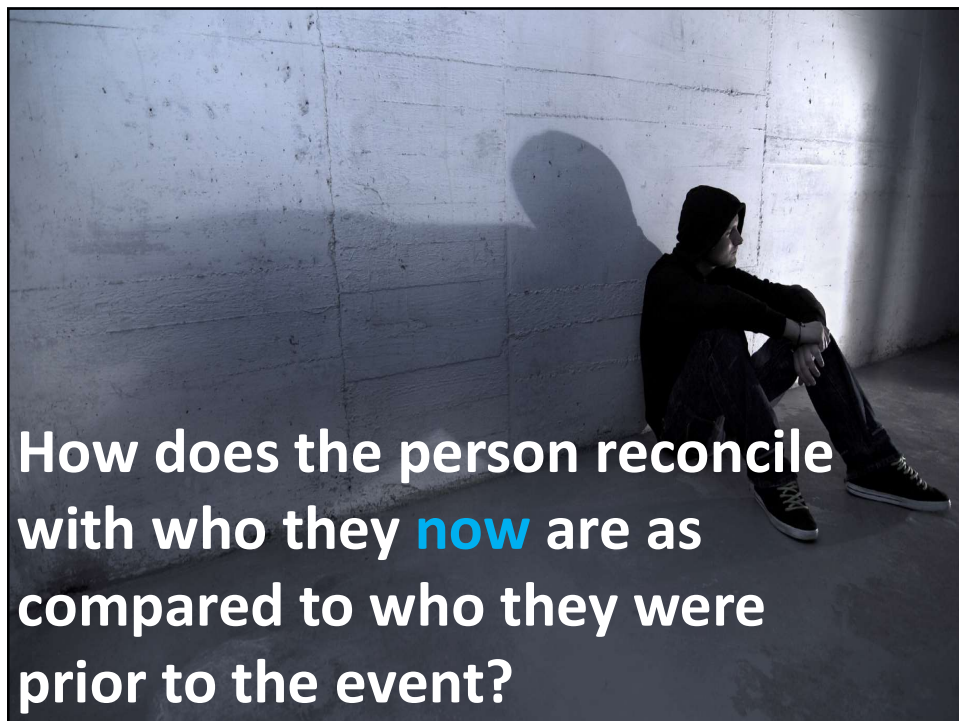




**We see ourselves as we  
were yesterday, not as  
we are today**



**We may not be happy with who we  
have become or what has happened  
to us, especially after an event which  
has changed our life**



# **disability**shift

**“The most devastating  
loss of all becomes a loss  
of the meeting of the  
minds”**

Paula Freed, 2002

**“Our only truths are narrative truths, the stories we tell each other and ourselves- the stories we continually recategorize and refine”**

**Oliver Sacks, The River of Consciousness, 2017**

**Psychological health is dependent on our ability to change and revise memory.**

**What happens when the person's ability to access memory is impaired?**



**Brain injury can change a person's self-awareness and ability to express emotion making it difficult to describe who they are now**

**The person faces loss of self and loss of social role**





**What happens  
as life goes on?**

## Three categories of loss

Nochi, 1998

## Loss of clear self knowledge



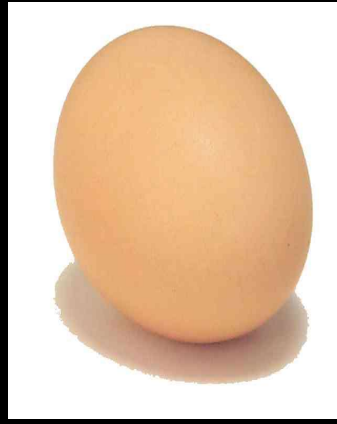
## Depression and loss disrupt the person's sense of social stability

Source: Frank, et al. (2005)

Grief for the **loss** of the healthy self

Frank, E et al (2005)

**which came first?**

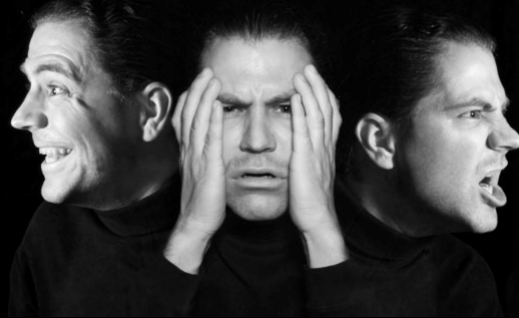


**Loss of sense of  
self**

**or**

**Relationships**

**What do people see  
when they see  
themselves?**



**Is the view of self  
consistent with what  
other people see?**





**How do we recognize  
what we see vs. what  
others see?**



**are they linked?**





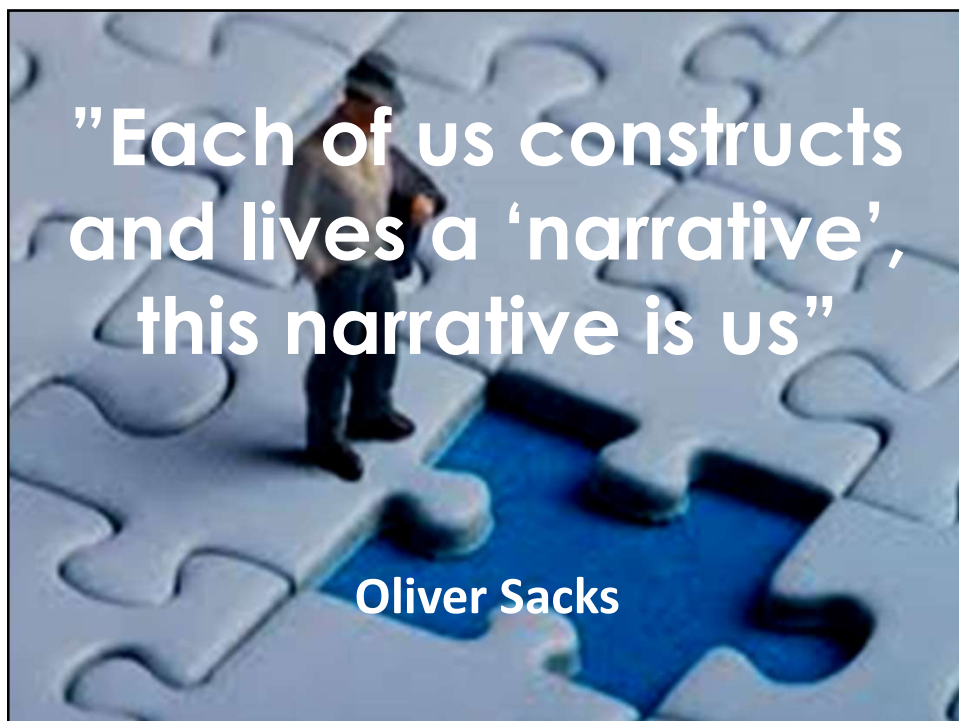
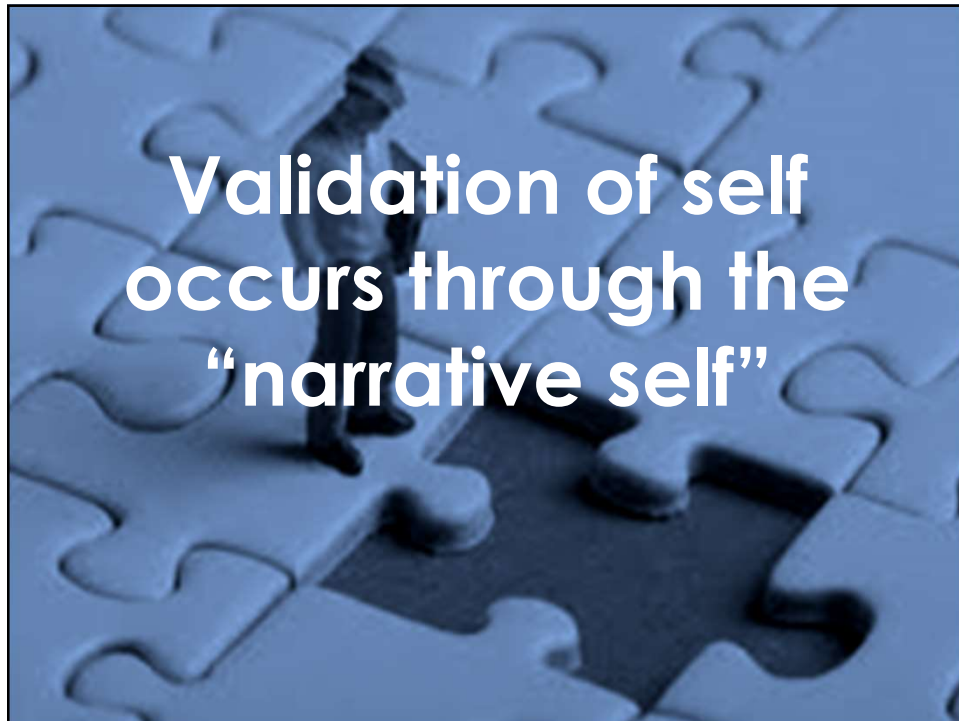
**Which must be  
addressed first?**

**Which aspects are  
the work of the  
person to  
accomplish?**

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

**The  
person:**







**Our lives become a  
story about ourselves**

**What happens to our  
story after disability  
from brain injury?**

**Does the narrative  
end or shift to what  
the person  
remembers?**

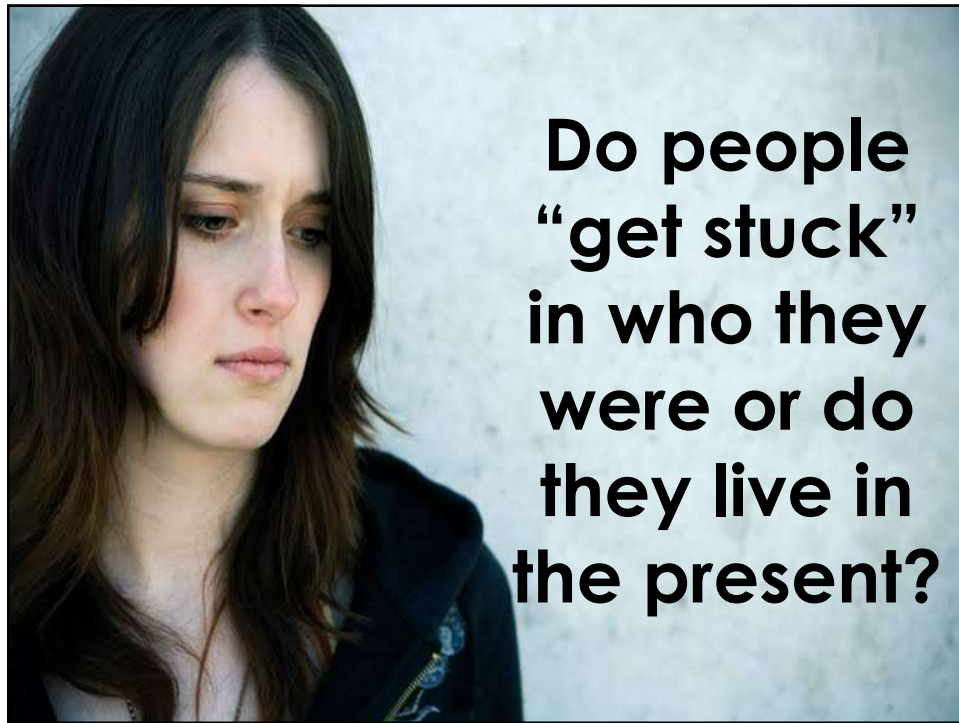
**Is this the point where  
the story we built  
becomes one of  
living in the here and  
now?**

**How does the person  
begin to construct a  
new self?**

**Or, do they deny that  
anything has changed?**

“Each day, we wake slightly  
altered, and the person we  
were yesterday is dead.”

John Updike, BrainPickings.org



**How can we better understand the impact of the event and its aftermath on the person?**

# **Memory and attention impairments effect the quality of relationships**



**“Events are not traumatic until we experience them as traumatic”**

George Bonanno, 2016  
Loss, Trauma and Emotion Lab, Columbia University



**“Events are not predictive  
until there is a negative  
response”**

George Bonanno, 2016

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

Source: Condelucci, A. (2008)



Is this the point where  
we encounter isolation  
and withdrawal?



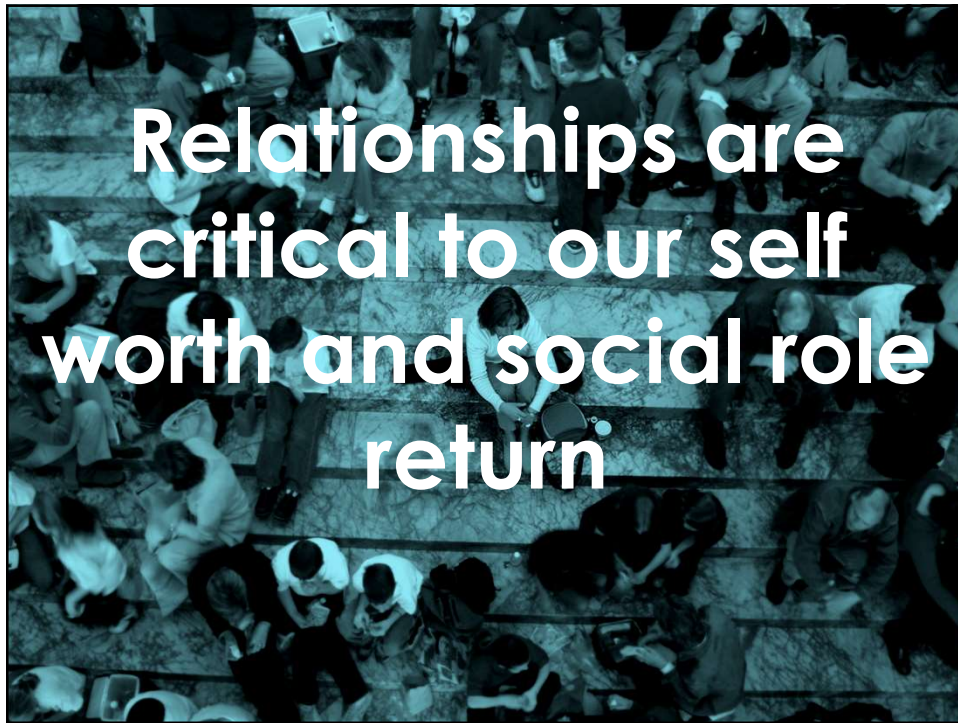


## **“connectedness”**

**The perception of relationships  
The recognition of emotion and  
affect**

**The ability to exercise decision  
making over behavior**

Yeates G, et al, 2013



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



**Let's return to what George Bonanno addressed in defining response. How does resilience impact on personal response and social participation?**

**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**

**There is no measure for resilience, it is the person's response to adversity, obstacles and threat which determines how the person will fare with each event**

Emmy Werner, 1989

**Resilience is a constant recalculation of factors relating to multiple stressors over time**

Emmy Werner, 1989

**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

**“Events are not predictive  
until there is a negative  
response”**

George Bonanno, 2016



Brian Little refers to “our multiple selves” made up of our “fixed” or biogenic traits and our “free” or sociogenic traits

How does injury exert change on the person’s biogenic traits and their sociogenic traits?

Brian Little, 2014

**Brain injury impacts both  
the “fixed” and the “free”  
aspects**

**Understanding the process  
of recovery of self may  
help us to understand  
resilience**

**Do people have different  
“susceptibility” factors?**

**And, can those factors  
change over time?**

**Can we enhance a person’s  
likelihood of a positive  
response to an adverse  
event?**

## **Core Traits Associated with Resilience**

**Even Tempered, Stable Emotionally**  
**Positive Outlook, Optimism**  
**Self-regulatory skills**  
**Social Perception, “Liked” by others**  
**Insightful modification of behavior**  
**Good problem-solving skills**  
**Effective communication**

**Many of these traits are  
affected by brain injury**

**Let's shift from the  
person to their  
relationships with  
others.**

**social role:**

**the characteristic or expected social  
function of a person or thing, especially in  
a particular situation or environment;**

**a collection of behaviors, attitudes,  
responsibilities, and expectations related  
to a particular niche a person fills.**

**Establishing the scope  
of the problem:**



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



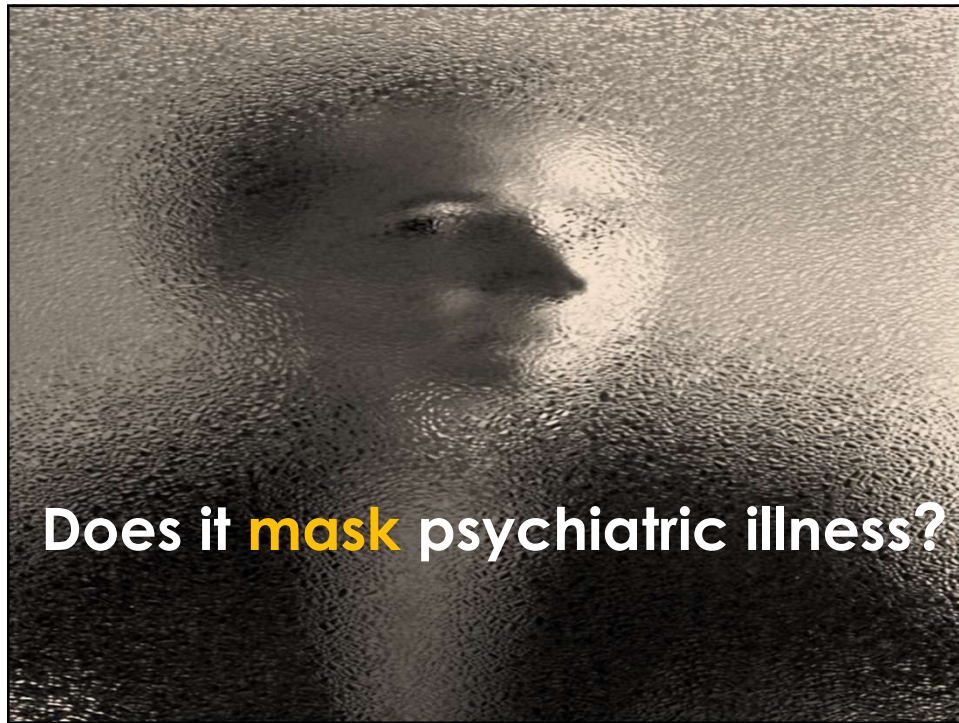
**Let's focus on aspects of  
mutuality and participation**



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

Source: Frank, et al. (2005)

Does it mimic psychiatric illness?  
Does it mimic psychiatric illness?



Does it **mask** psychiatric illness?

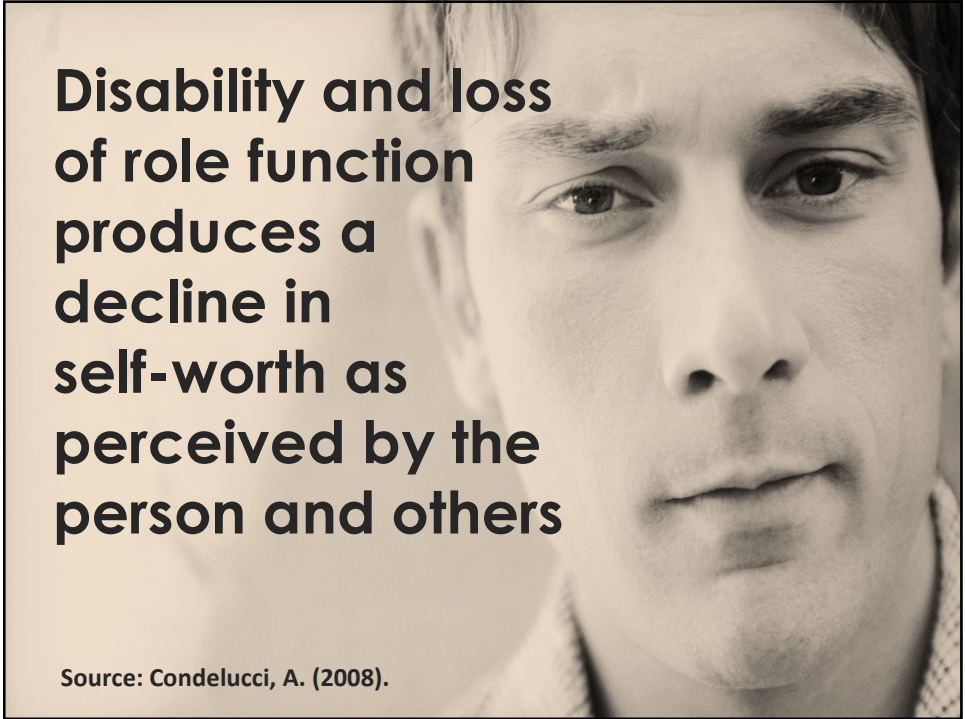
Is the person with a  
**brain injury**  
and  
**a dual diagnosis**  
more likely to experience  
**social role return**  
**problems?**



# How do we measure self-worth?



job, profession, skills  
relationships, family, friends  
life activities  
home/residence ownership  
positive feedback  
participation with others



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

Source: Condelucci, A. (2008).

**self-worth**

**=**

**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**?



**Resilience  
requires social  
capital**

**Social capital relates to  
other capital...**

**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?**

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





## **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**

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

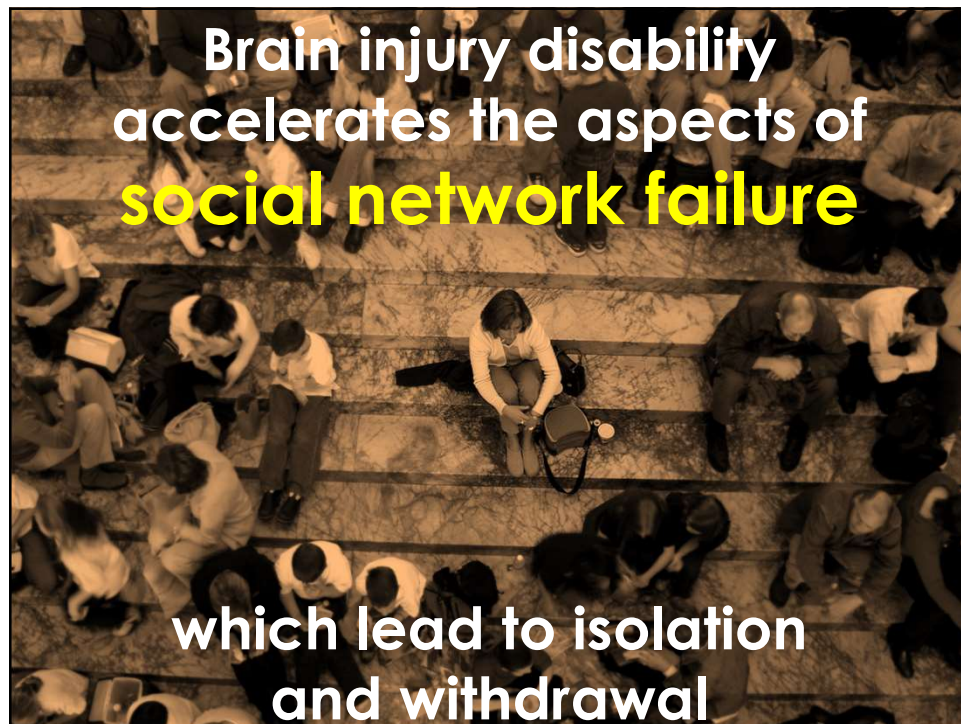
**Can we look through the lens used by Christakis and Fowler and see the reduction in social network activity?**

**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).



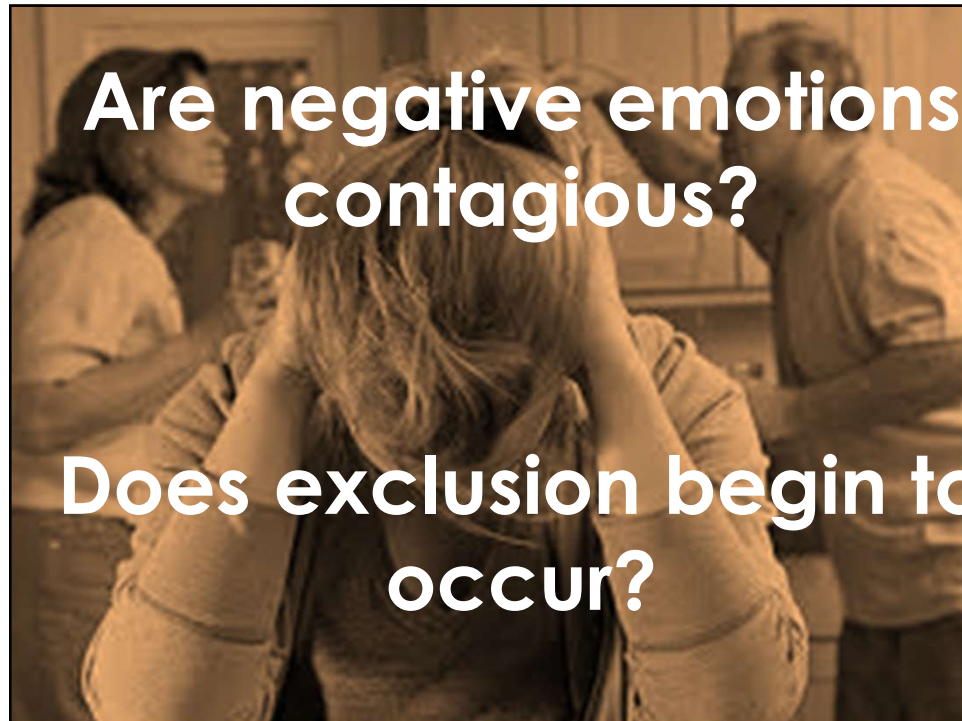


A brain injury will effect  
others in the person's social  
network

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**



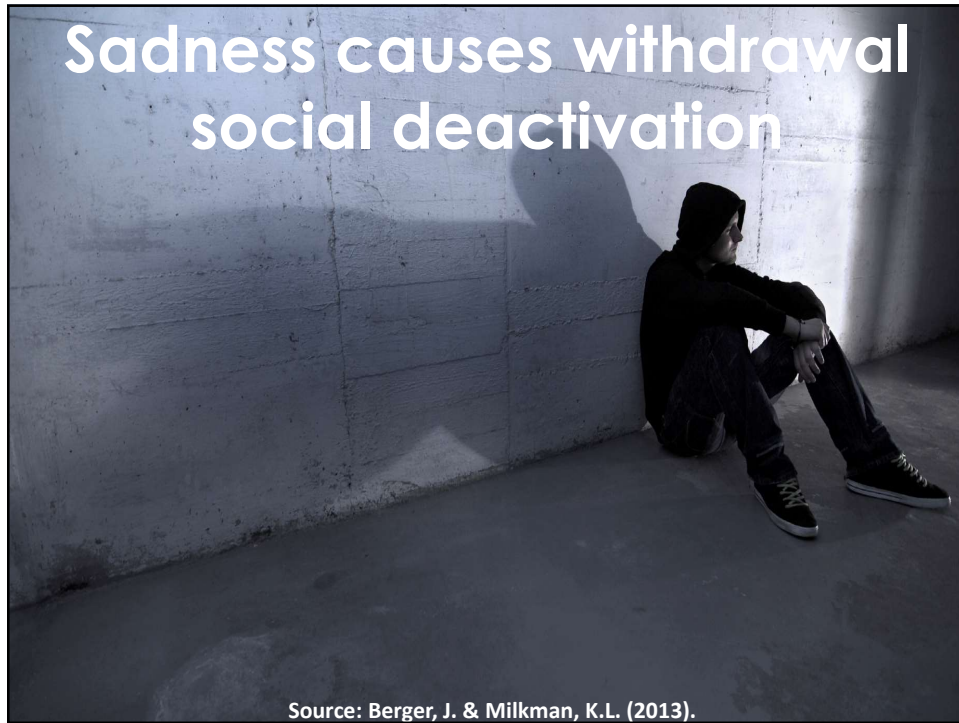
**Are negative emotions  
contagious?**

**Does exclusion begin to  
occur?**

**What about looking  
outside of rehab?**

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

## Sadness causes withdrawal social deactivation



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

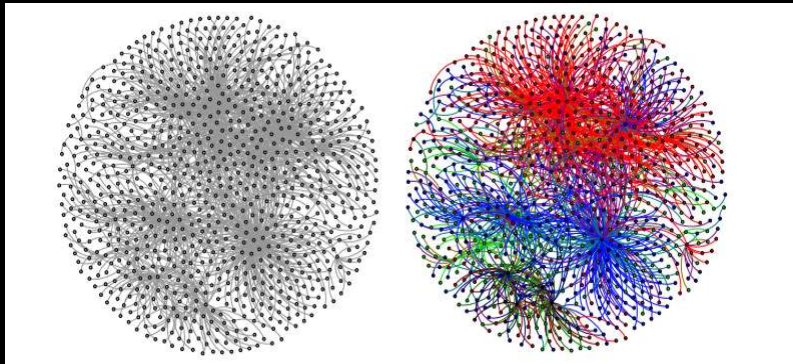
How do other people react when a  
person is sad and depressed?

I HATE  
LIFE!

Can they sustain the relationship?



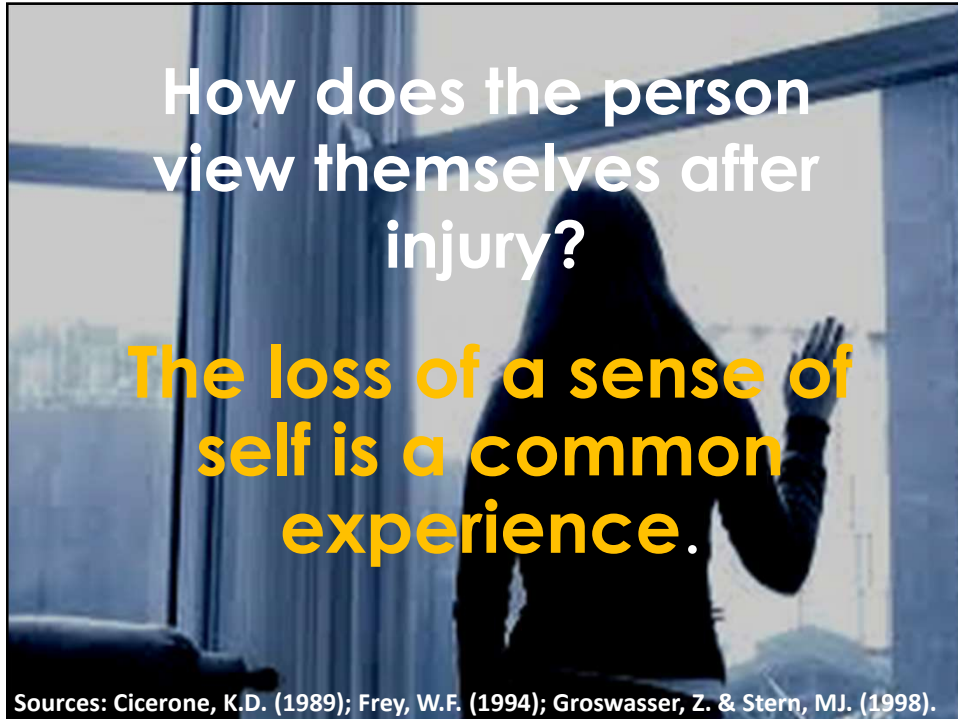
**Rage and anger are transmitted  
faster through social networks,  
triggering a chain reaction**



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

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

**What happens when  
they disconnect?**

A person is seen from behind, standing in front of a large window. They are looking out at a cityscape. The text is overlaid on the image.

**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, M.J. (1998).

A person is seen from behind, standing in front of a large window. They are looking out at a cityscape. The text is overlaid on the image.

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

Source: Myles, S. (2004).



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

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



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

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

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



**What causes social withdrawal?**

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

**What are the effects  
of isolation?**

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

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

**Jerry M.**

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

**“The better I got, the more aware I became of my deficits which made me even more depressed about my prospects of the future”**

**Laurie Rippon**

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

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

**Melissa Felteau**

**“When life was turned upside down I began to focus on what really mattered to me. That set me on the way to a new life-one I could be proud of”**

**Laurie Rippon**

**“ I learned to feel good about each small step of progress, which gave me the confidence to look to the next step... until I felt more whole”**

**Laurie Rippon**

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

# **degrees of separation**

**brain injury**  
**impacts on  
social role**

# **The NRIO Study**

**1997-2017**

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

**751 tracked from 1995-2017**

**Average age: 32.1**

**Age Range: 21.1 to 78.7**

**100% Severe TBI**

**90.3% MVA**



## **the NRIO cohort**

- **age at injury      27.8**
- **GCS <9              83.1%**
- **male/female        61.3% / 38.7%**
- **period from injury to post-acute:    27.8 months**
- **months in prior rehabilitation: 94.55 days**
- **% MVA related        90.3%**

## **the NRIO Study:**

### **Social Role Return**

### **Independence/Support Level**

### **Vocational/Avocational Activities**

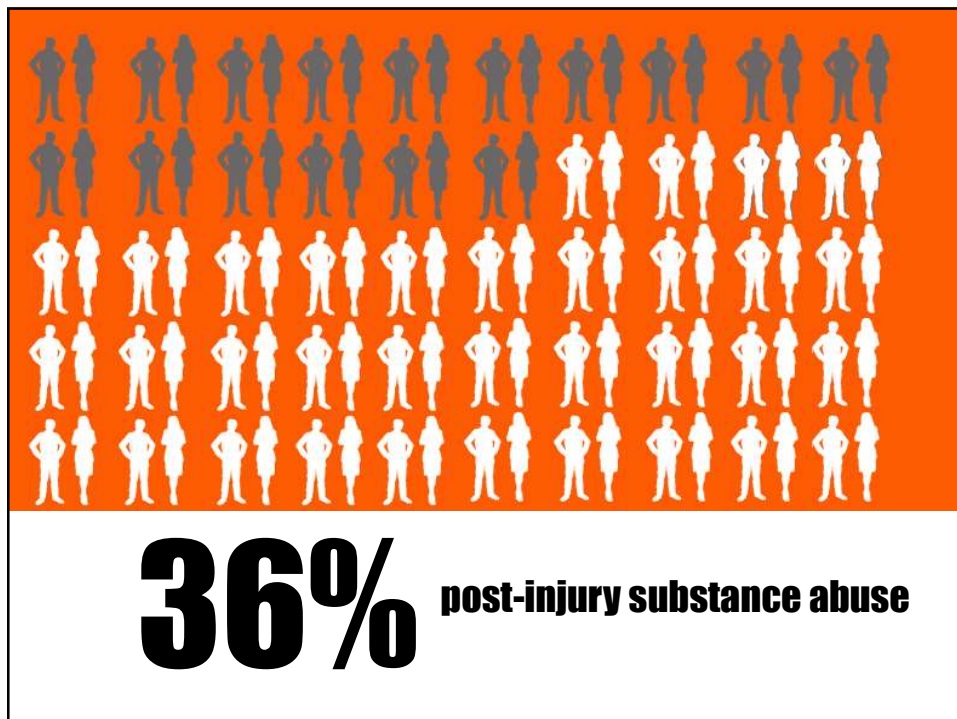
### **Mental Health and Substance Abuse Issues**

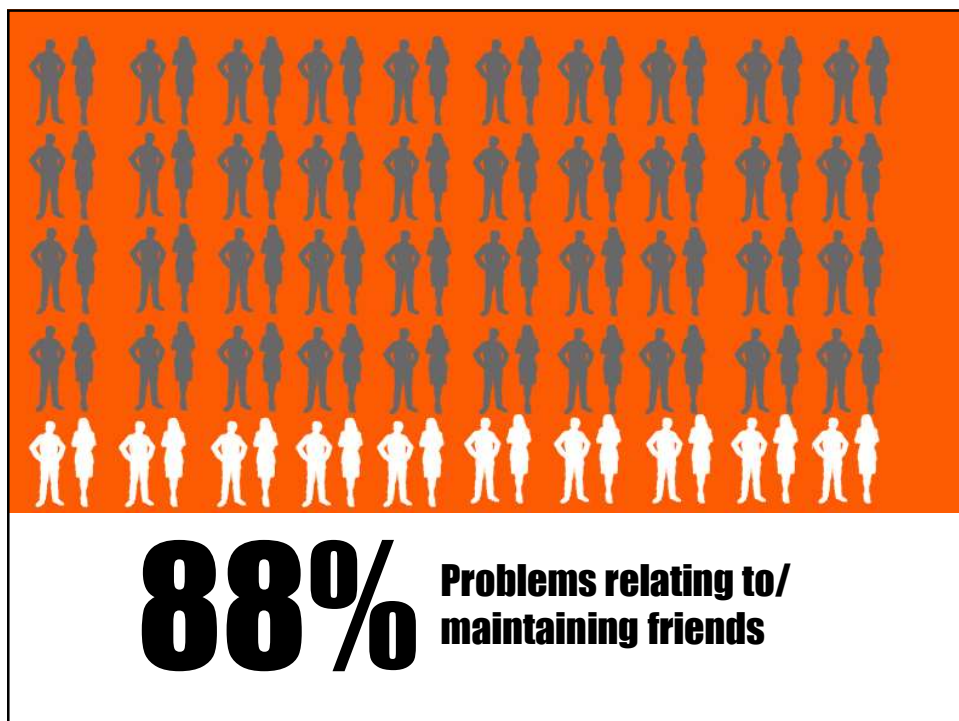
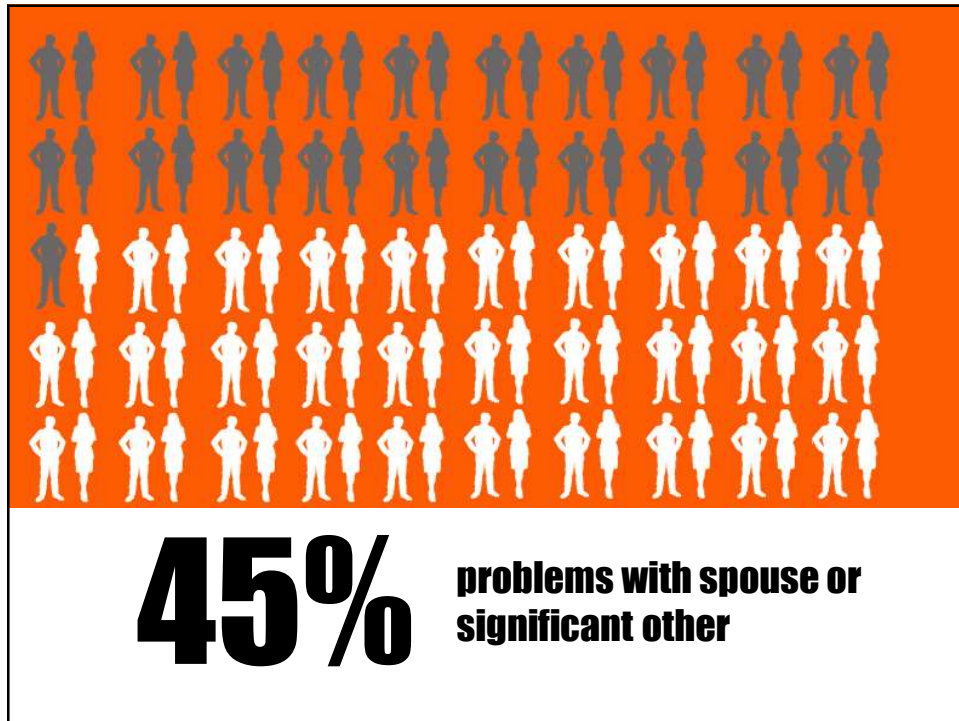
### **Durability of Outcome**

**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  
1997-2017

**pre-admission  
characteristics**





**2.5 years post injury  
prior to admission**



**1 to 5 years after the injury**

**nrio outcome study, adult cohort  
1997-2017**

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

**36.40%**

**Returned to pre-injury  
social role without  
modifications**



**55.45%**

**Required modified pre-injury  
social role**



**8.15%**

**Required extensive support by paid  
or family caregivers**



**55.45%**

**Required minimal to moderate  
mental health care  
to support social role  
return**



**24.1%**

experienced significant  
psychological problems  
requiring intervention



**24.1%**

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



**Let's look at a study with five  
years of operation and a similar  
population**

**CNR Study  
2011-2016**

## **the CNR cohort**

**age at injury: 17.33**

**50% of discharges injured prior to age 10**

**male/female :83.33%/16.67%**

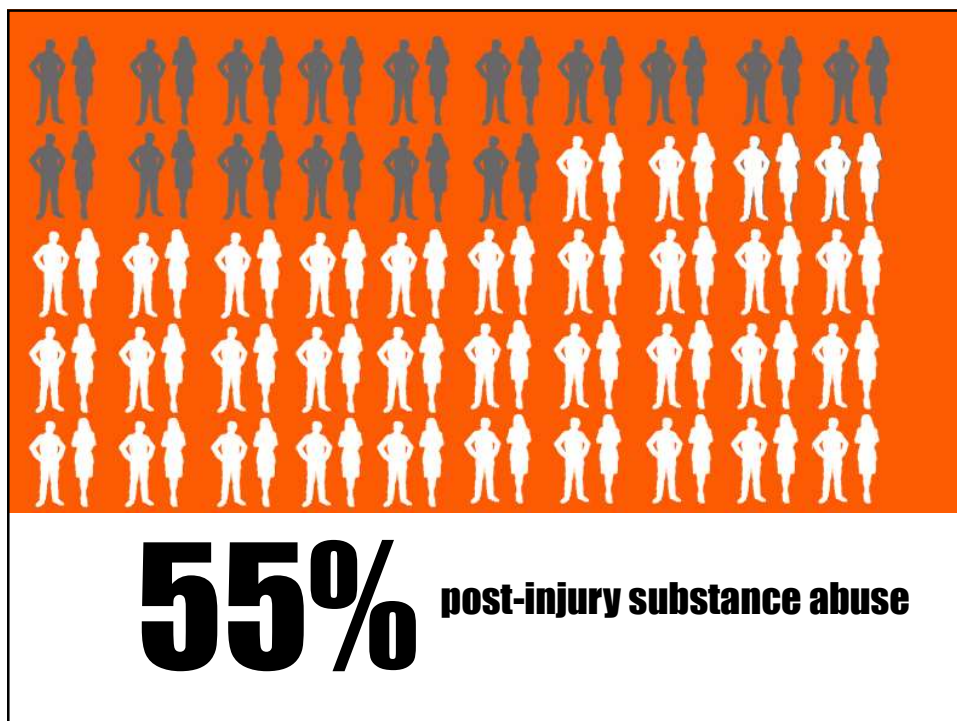
**period from injury to post-acute: 11.0 –  
15.5 years**

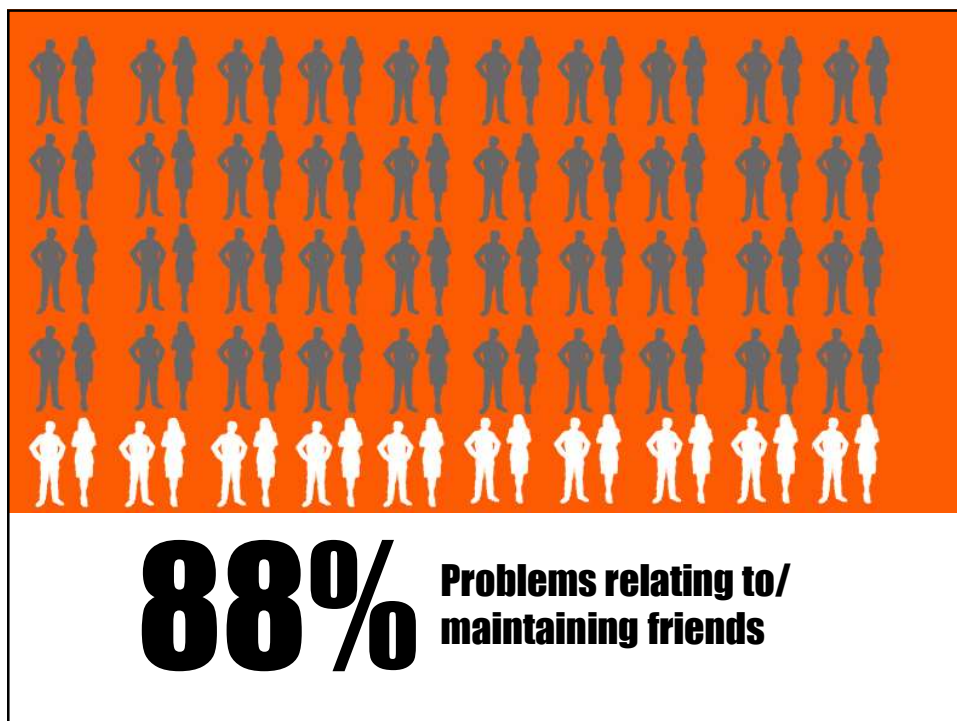
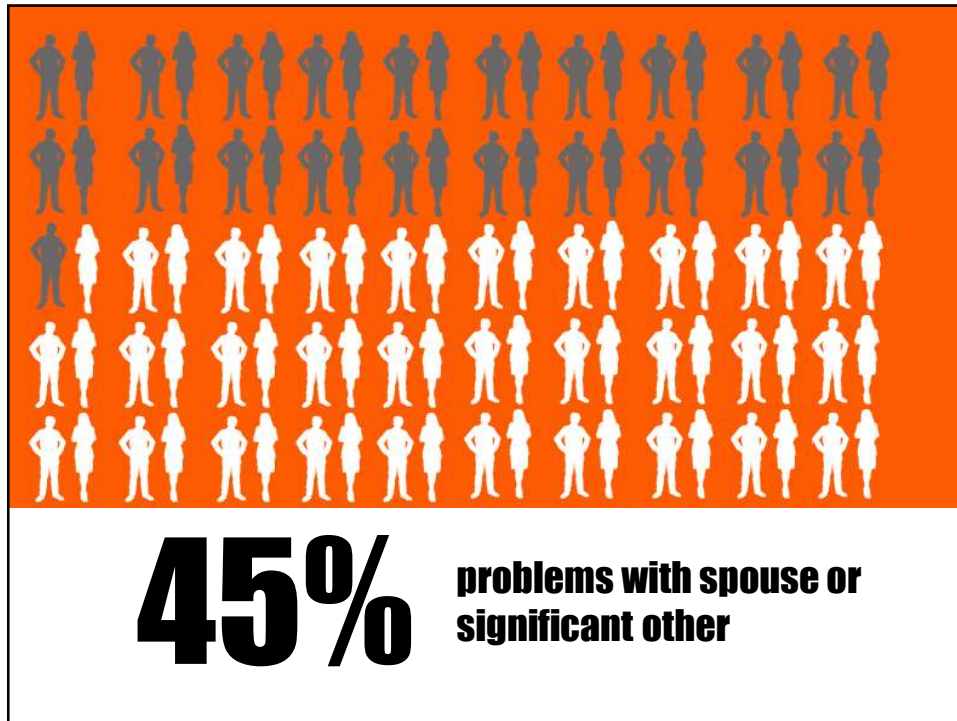
**Pre-injury psychological problems: 77%**

**Pre-injury substance abuse: 33%**

**Pre-injury legal problems: 44%**

## **pre-admission characteristics**





## **Returning to pre-injury social role in 2016**

**16.7%**

**Returned to pre-injury  
social role without  
modifications**



**0%**

**Returned to pre-injury role with  
modifications/supports**



**83.3%**

**Interfering psychiatric problems and/  
or substance abuse problems  
affecting social role**



**0%**

**Returned to pre-injury role with  
Minimal modifications/supports**



**83.3%**

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

**The search for answers:  
why are there differences in  
outcome attainment?**

**NRIO and CNR: Essential Differences**

**Age at time of injury**

**Length of time from initial  
injury to treatment**

**Number of “failed”  
treatment events**



## **NRIO and CNR: Essential Differences**

**Pre-injury mental health and substance abuse issues**

**Post-injury mental health and substance abuse issues**

**Availability of post-injury and post-treatment supports**

**The search for answers:  
why are there differences in  
outcome attainment?**

**A person's history is  
key to  
understanding how  
they will react to  
their brain injury**

Prigatano G, 1986, 2008

**How can change be  
facilitated?**

**What are the key  
elements of change?**

**Self knowledge comes  
in bits and pieces...**

**The trick is how we  
assemble them?**

**Or, maybe re-assemble  
them.**

**“...Identity is a growing and changeable thing ... the tragedy which occurred can be inserted into one’s narrative and shape their identity...”**

McAdams, 1993, 1994

**“ I learned to feel good about each small step of progress, which gave me the confidence to look to the next step... until I felt more whole”**

**Laurie Rippon**

**“We create ourselves as  
a work of art”**

Michael Foucault, “On the Genealogy  
of Ethics”, 1983

**“Being the same person over time  
is not about holding on to every  
aspect of our current selves;  
instead it is about changing  
purposefully”**

M. Foucault, 1983

**Brain injury disability may  
prevent the person from access  
to their abilities to change...**

**How can we facilitate  
positive change?**

**Thank you!**

**Questions?**

This presentation may be  
accessed at

[traumaticbraininjury.net](http://traumaticbraininjury.net)

under “Resources”, then  
“Community Presentations”

## Resources and References

## Resources and References

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