

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

Rolf B. Gainer, PhD

Rehabilitation Institutes of America, Novato, CA
Neurological Rehabilitation Institute at Brookhaven Hospital,
Tulsa, OK
Community NeuroRehab, Des Moines, IA

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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Objectives:

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

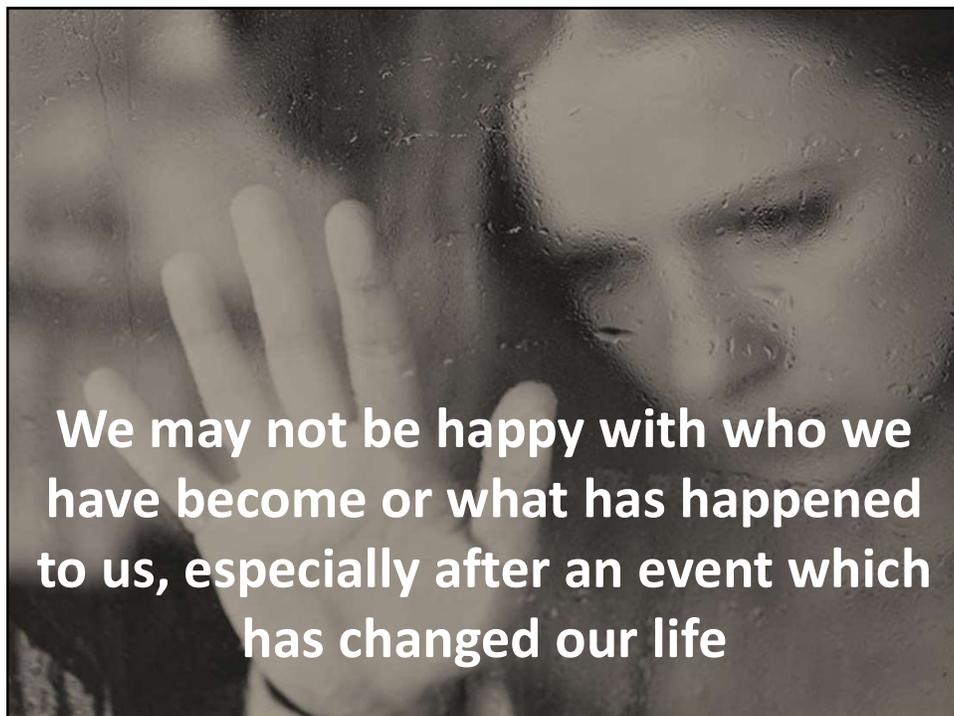
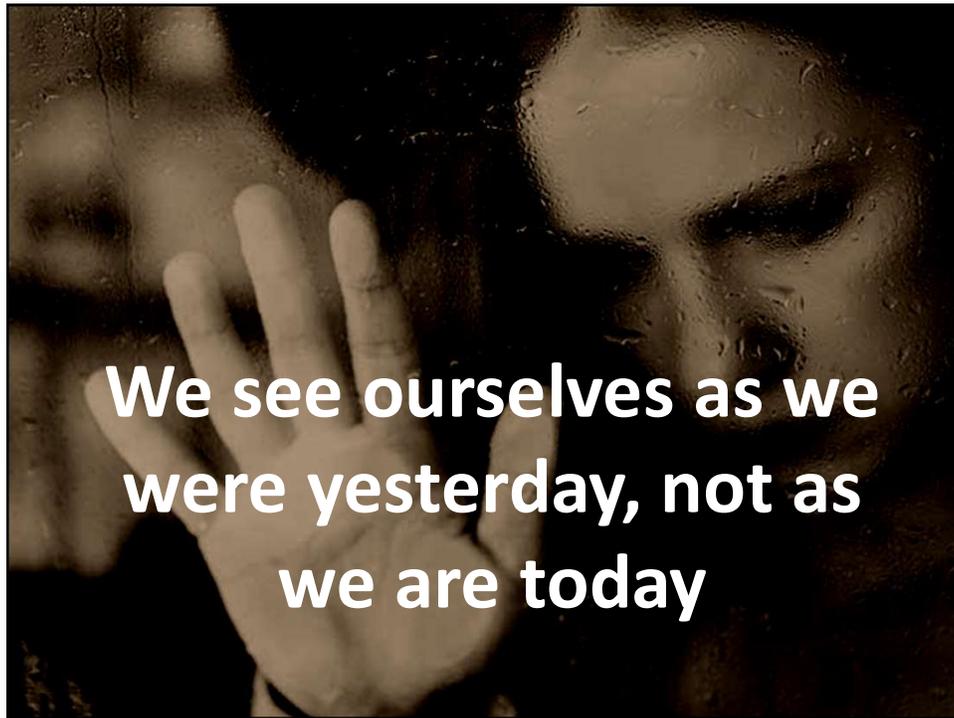
**To consider the
changes in social
relationships after
brain injury**

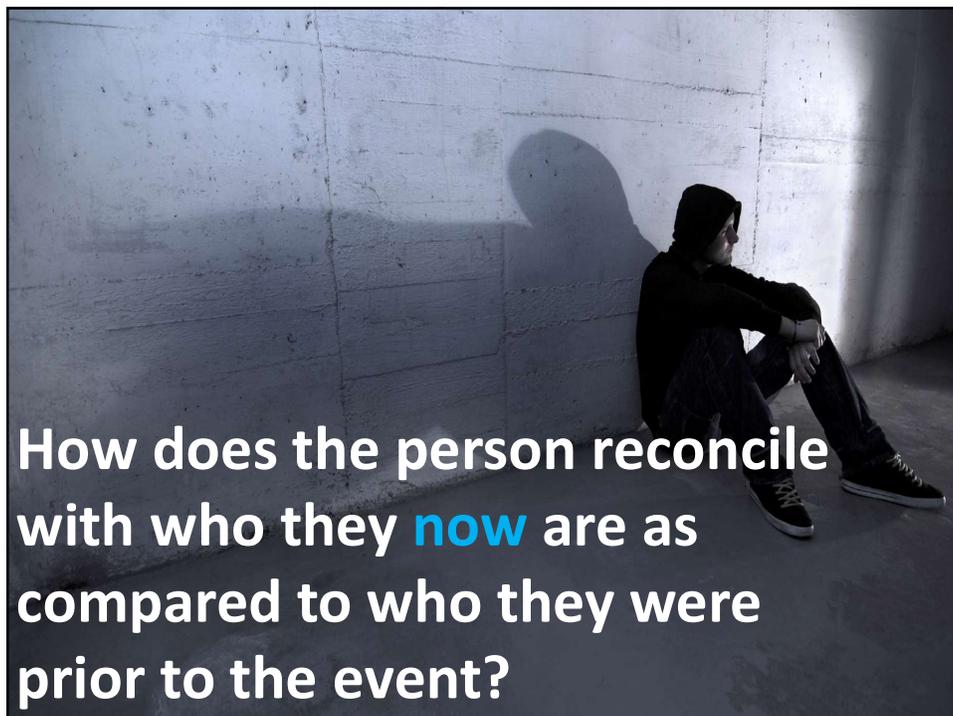
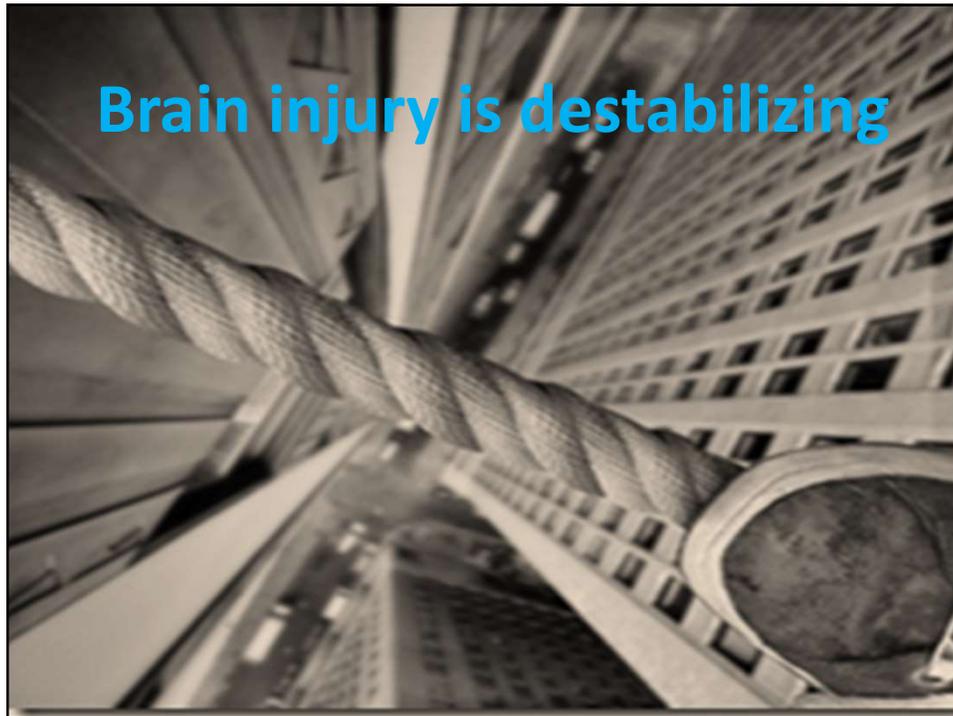
**To identify the
barriers faced by the
person in addressing
loss**

**To understand what can
facilitate change**

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







disabilityshift

**“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

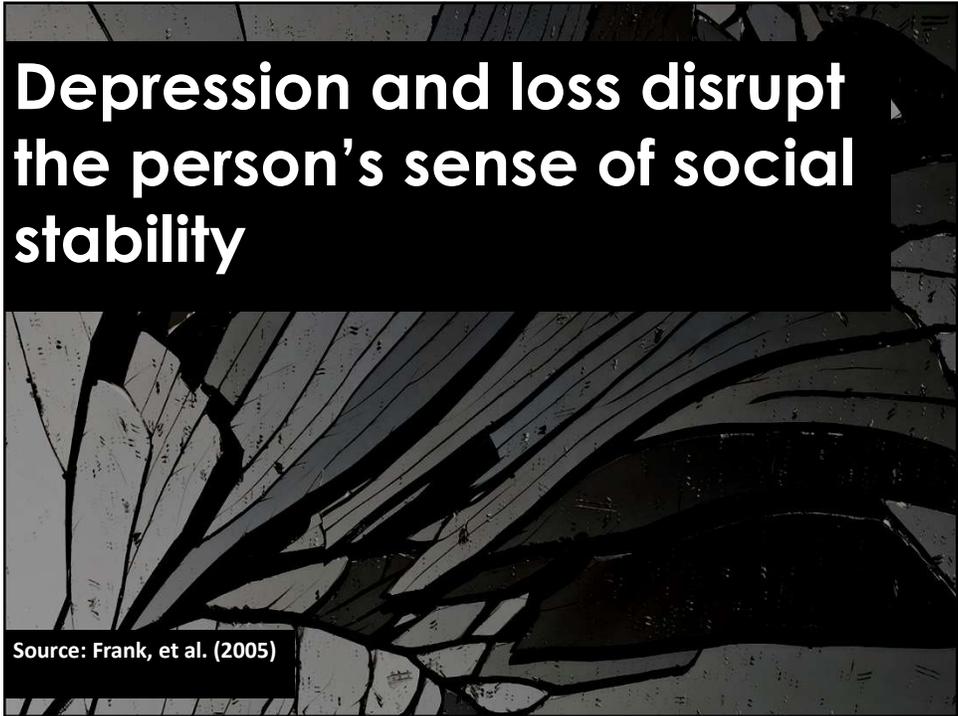


Nochi, 1998

Loss of clear self knowledge







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

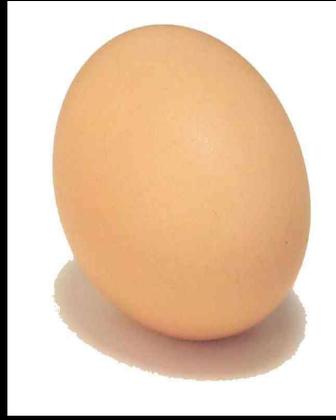
Source: Frank, et al. (2005)



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?



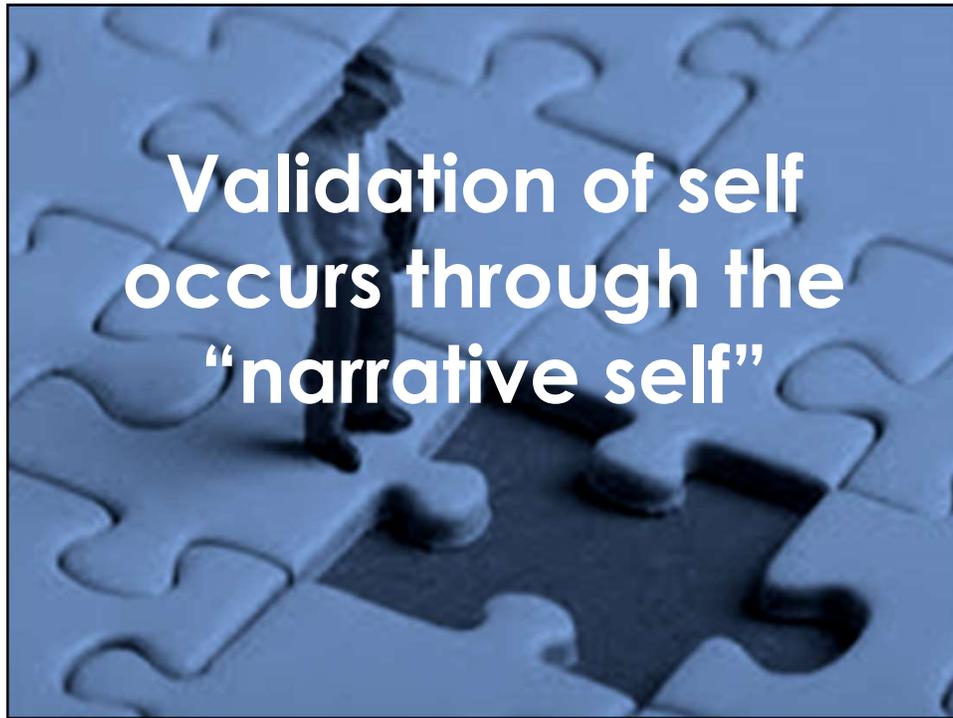
**Which must be
addressed first?**

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

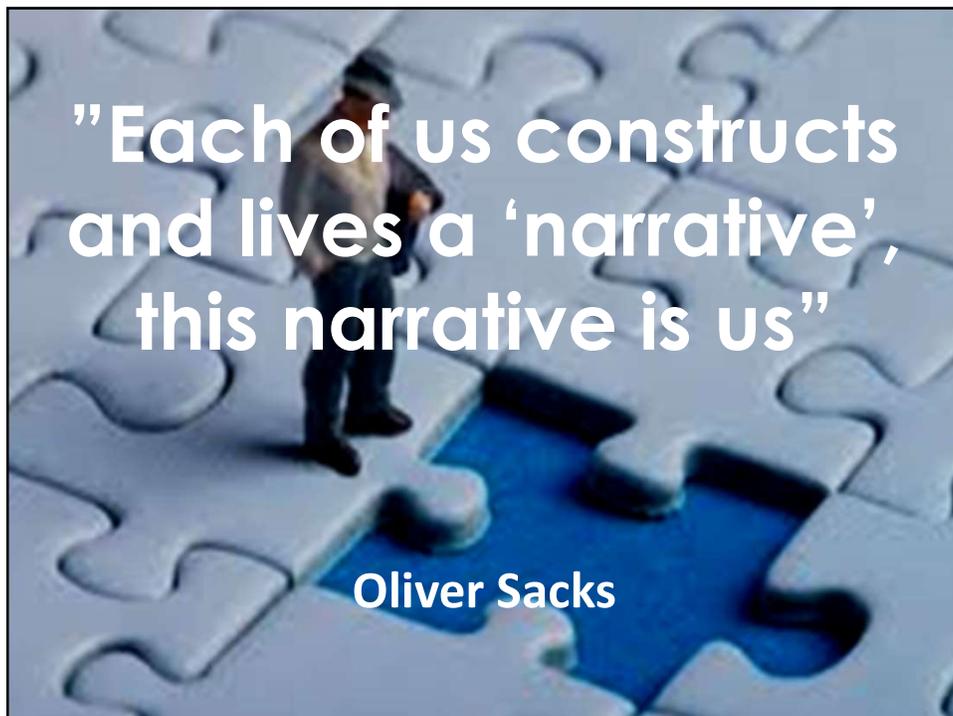
What is related to the responses of people and groups external to the person?

The person:



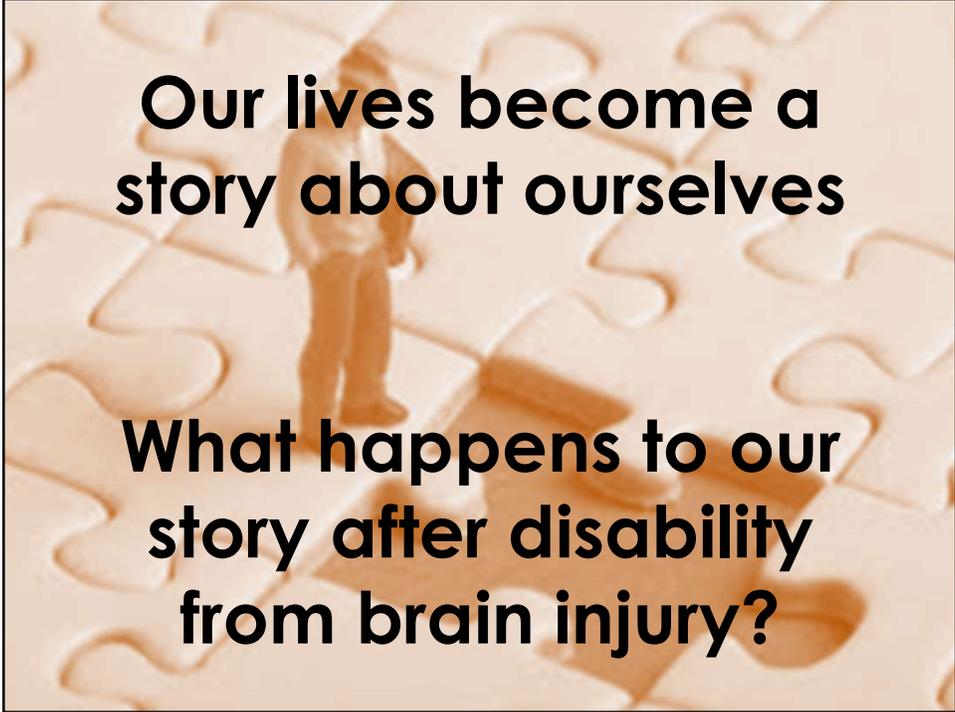


**Validation of self
occurs through the
“narrative self”**



**“Each of us constructs
and lives a ‘narrative’,
this narrative is us”**

Oliver Sacks



**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?**

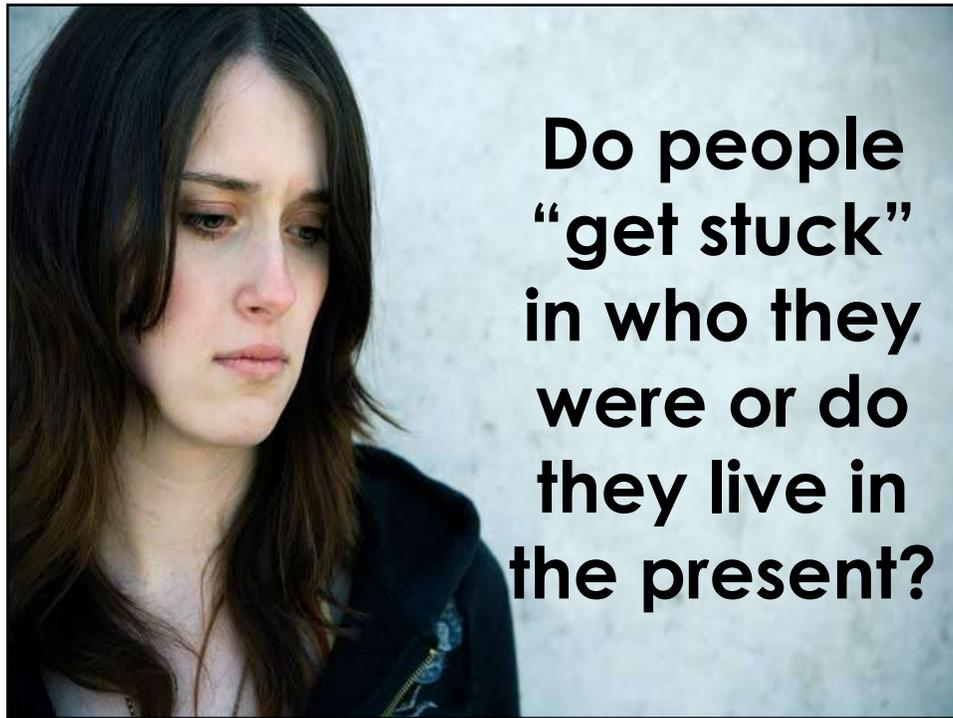
**Is this the point where
the story we built
becomes one of
living in the here and
now?**

**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



**Do people
“get stuck”
in who they
were or do
they live in
the present?**

**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?

How does **social
isolation** effect health
after disability?



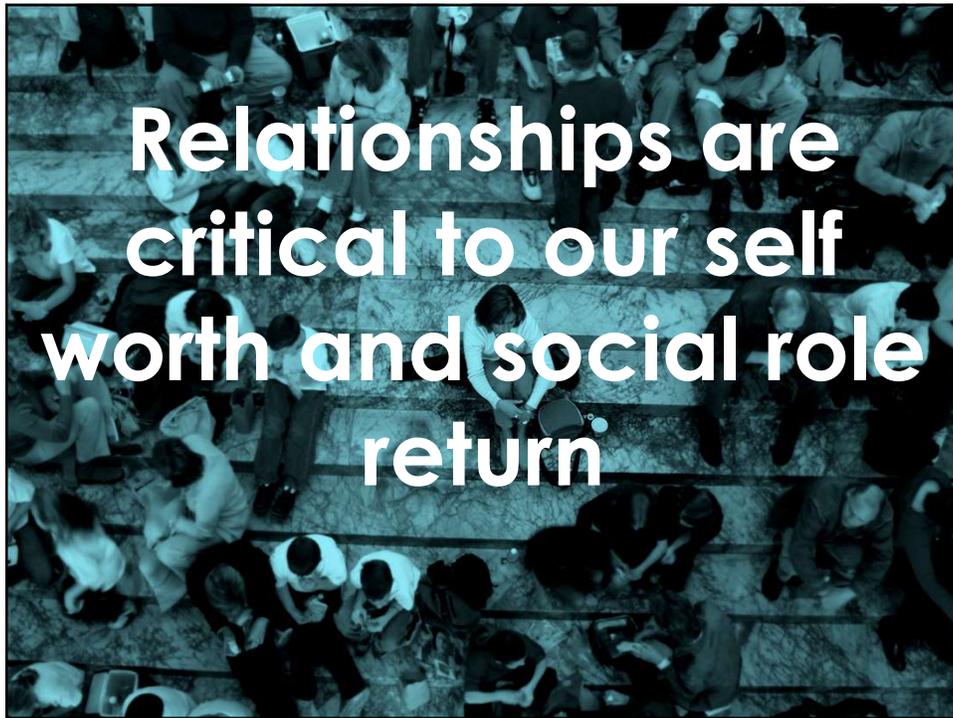
Disengagement from naturally occurring social units



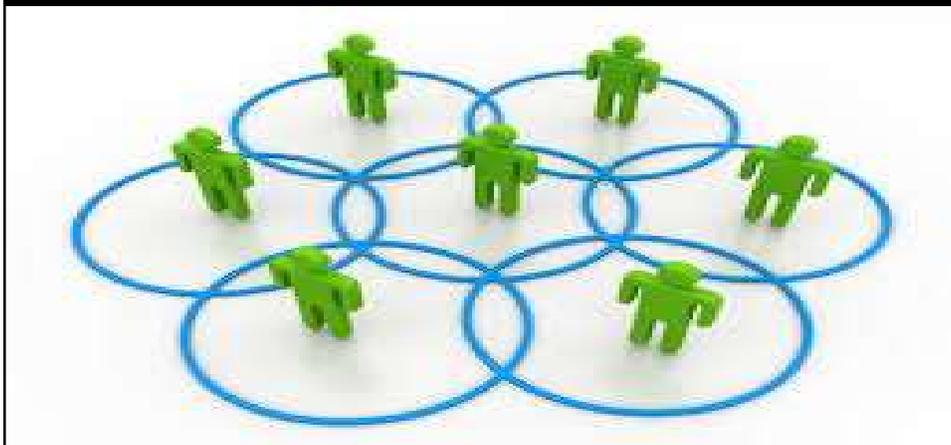
“connectedness”

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:

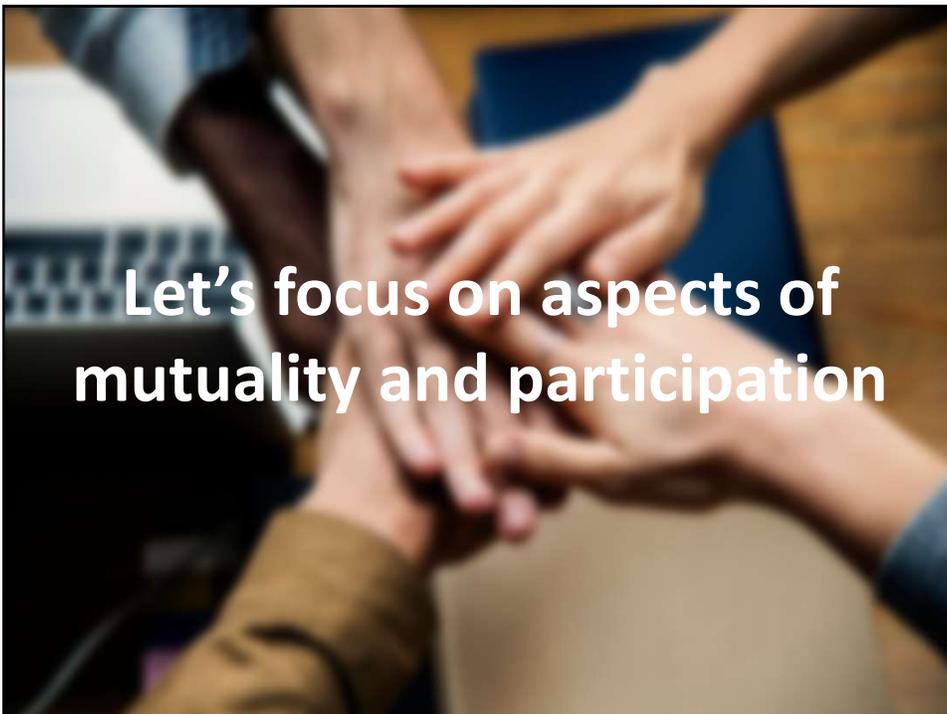
**the characteristic or expected social
function of a person or thing, especially in
a particular situation or environment;**

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

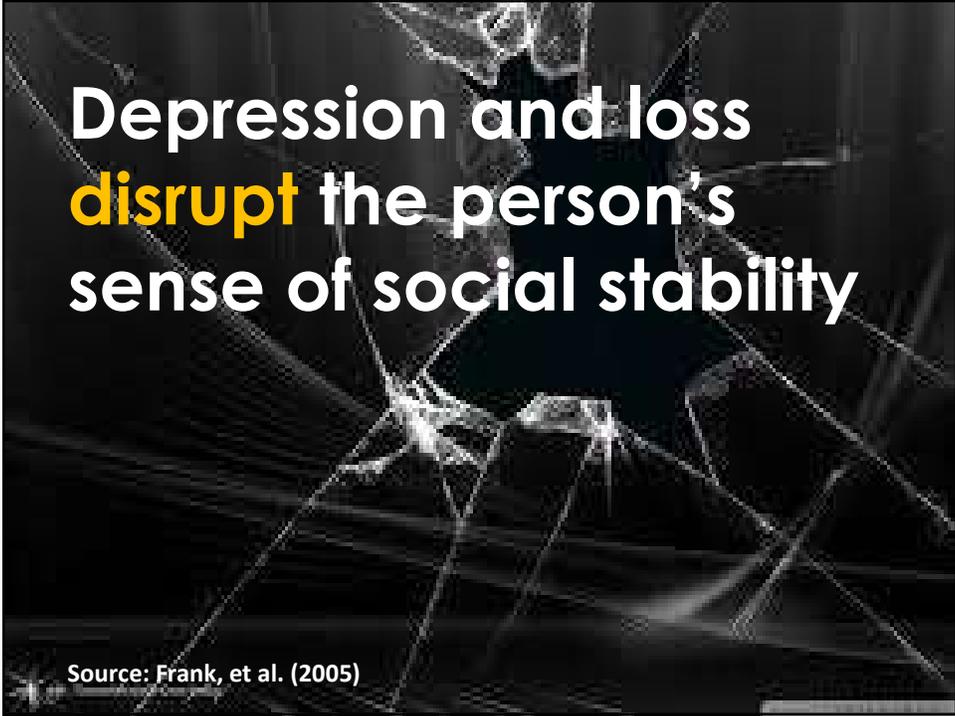
**Establishing the scope
of the problem:**



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



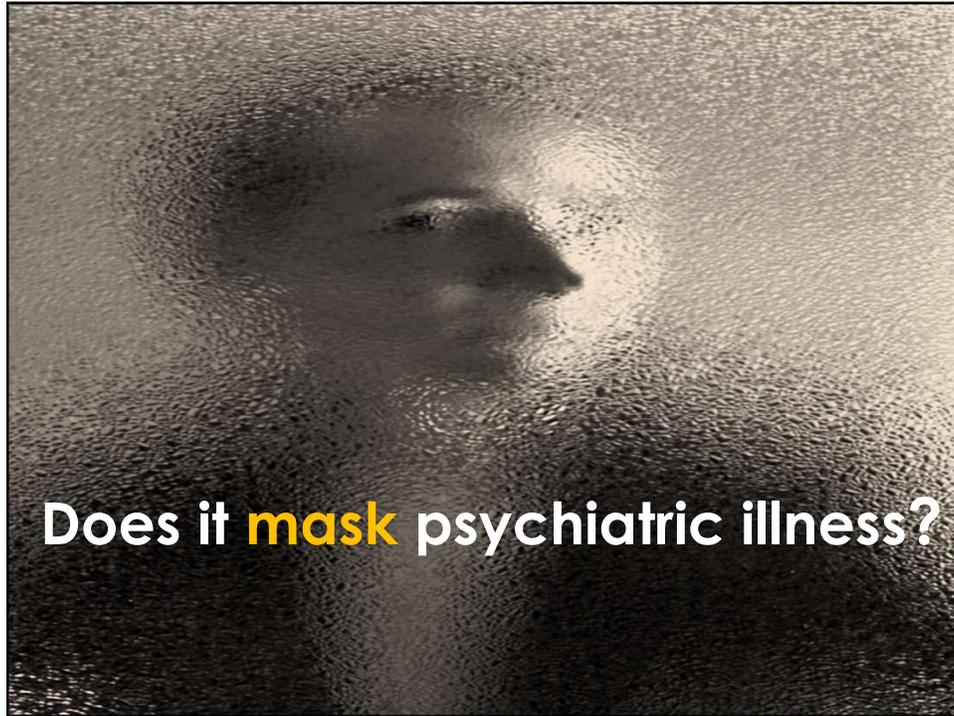
**Let's focus on aspects of
mutuality and participation**



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?

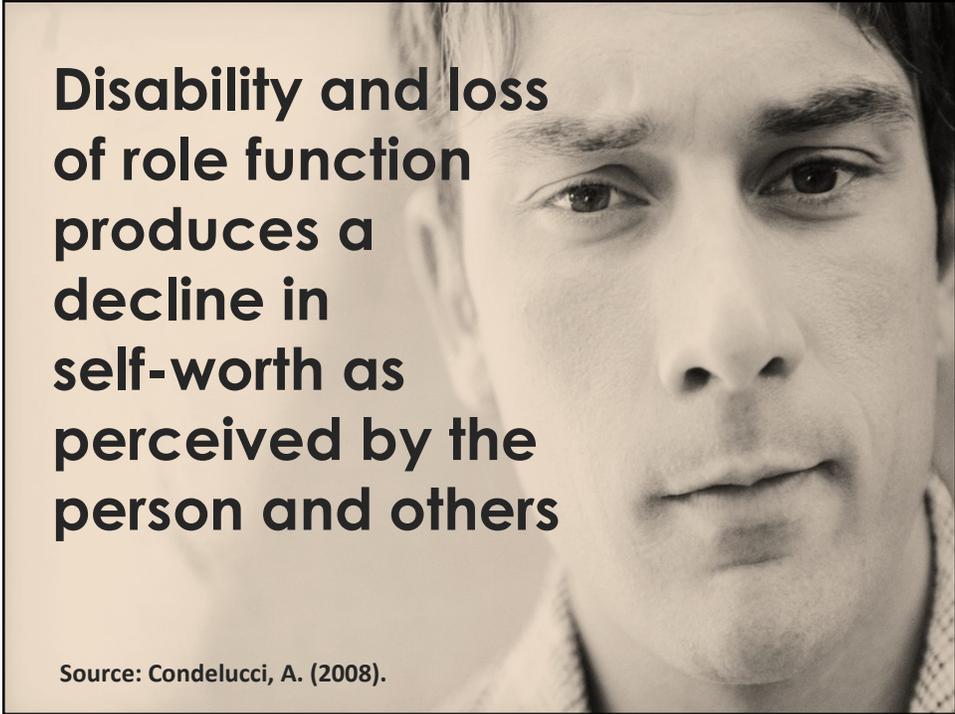


Is the person with a
brain injury
and
a dual diagnosis
more likely to experience
social role return
problems?

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?

**As social capital
decreases, stress
increases**



Kawachi Ichiro

**Resilience
requires social
capital**

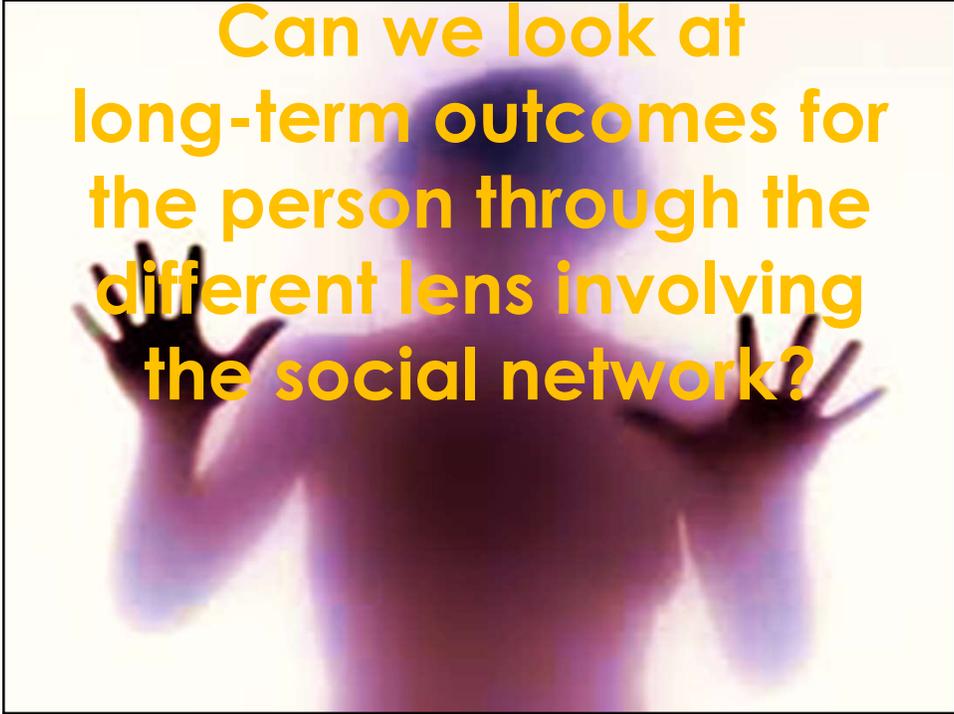
**Social capital relates to
other capital...**

**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?**

A blurred image of a person's back and hands, with the text overlaid. The person appears to be standing with their hands raised, possibly in a gesture of surprise or confusion. The image is out of focus, emphasizing the text.



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

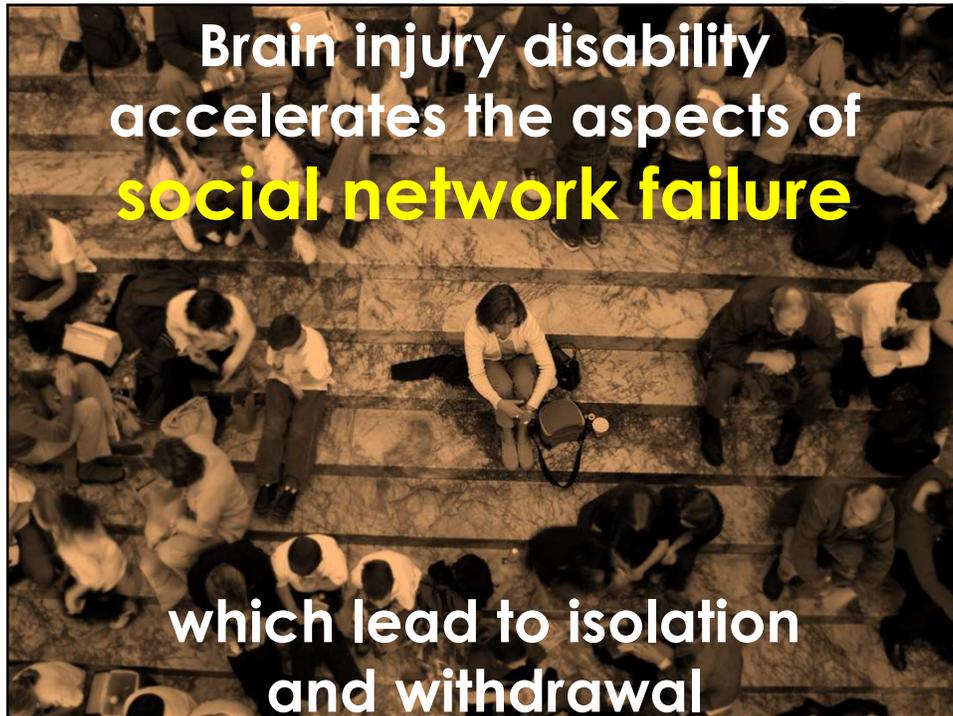
Source: Fowler, J. & Christakis, N. (2010); Fowler, J., Dawes, C. & Christakis, N. (2009).

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).

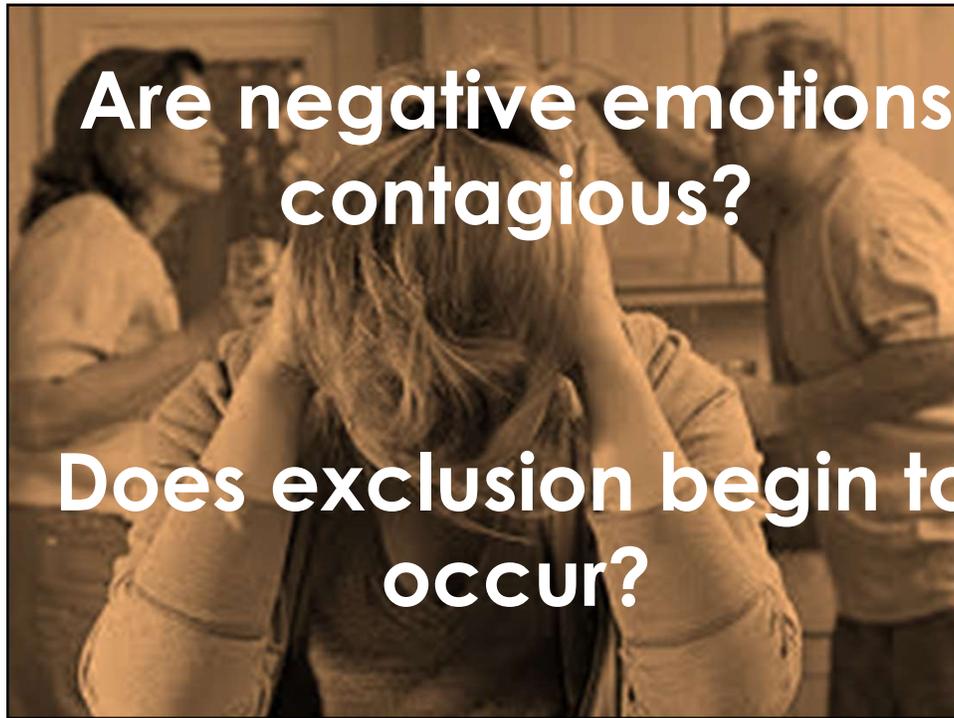


A brain injury will effect
others in the person's social
network

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



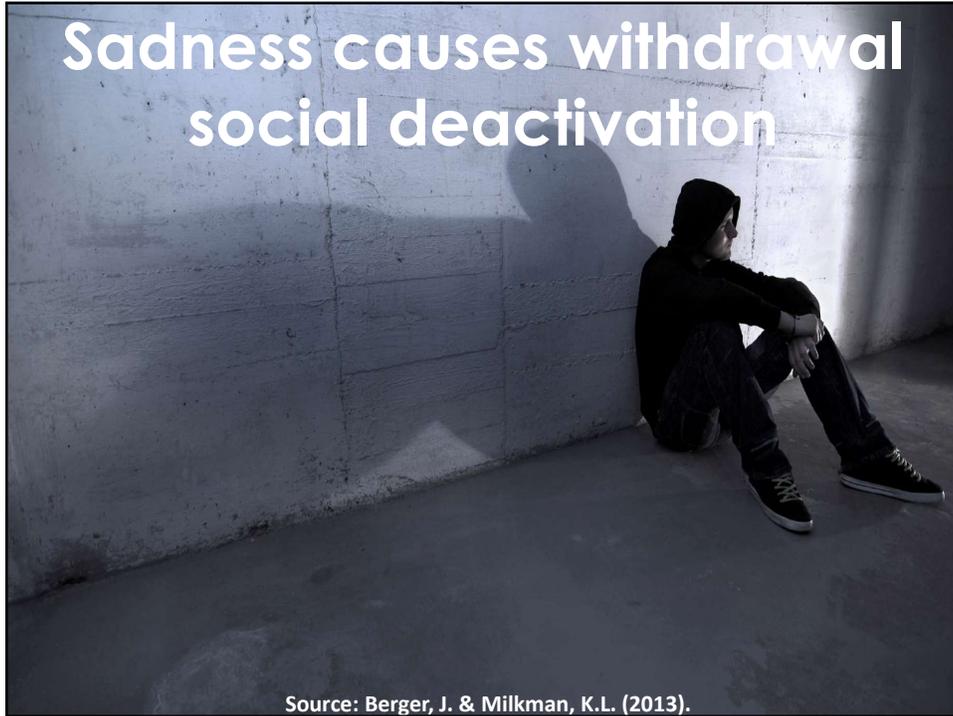
Are negative emotions contagious?

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



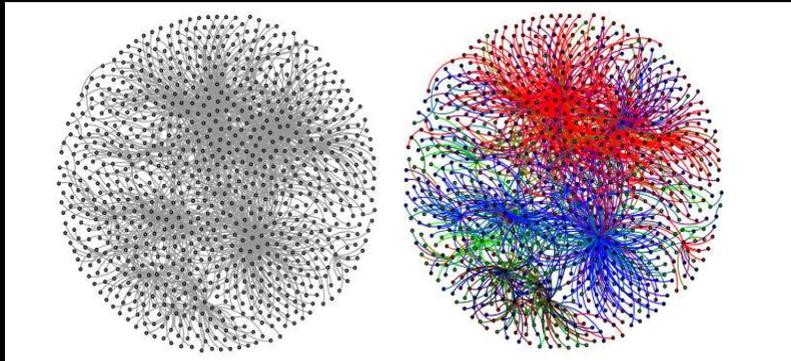
Source: Berger, J. & Milkman, K.L. (2013).

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

I HATE
LIFE!

Can they sustain the relationship?

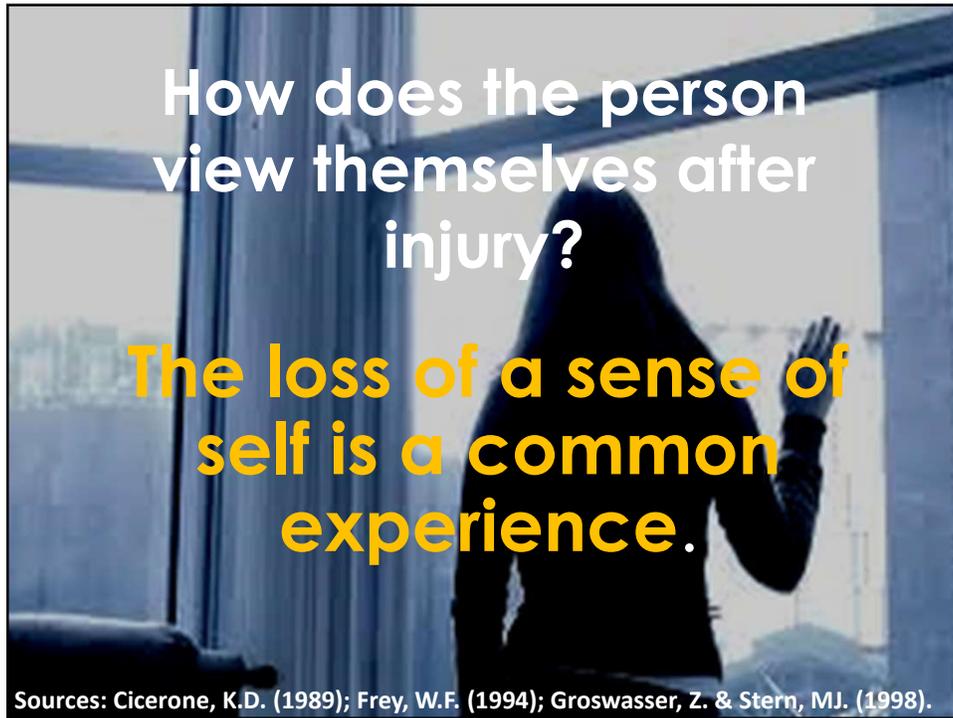
Rage and anger are transmitted faster through social networks, triggering a chain reaction



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 shown in silhouette, standing in front of a large window. The person's right hand is raised, touching the window pane. The scene is dimly lit, with light coming from the window, creating a contemplative or somber mood.

**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 shown in silhouette, standing in front of a large window. The person's right hand is raised, touching the window pane. The scene is dimly lit, with light coming from the window, creating a contemplative or somber mood.

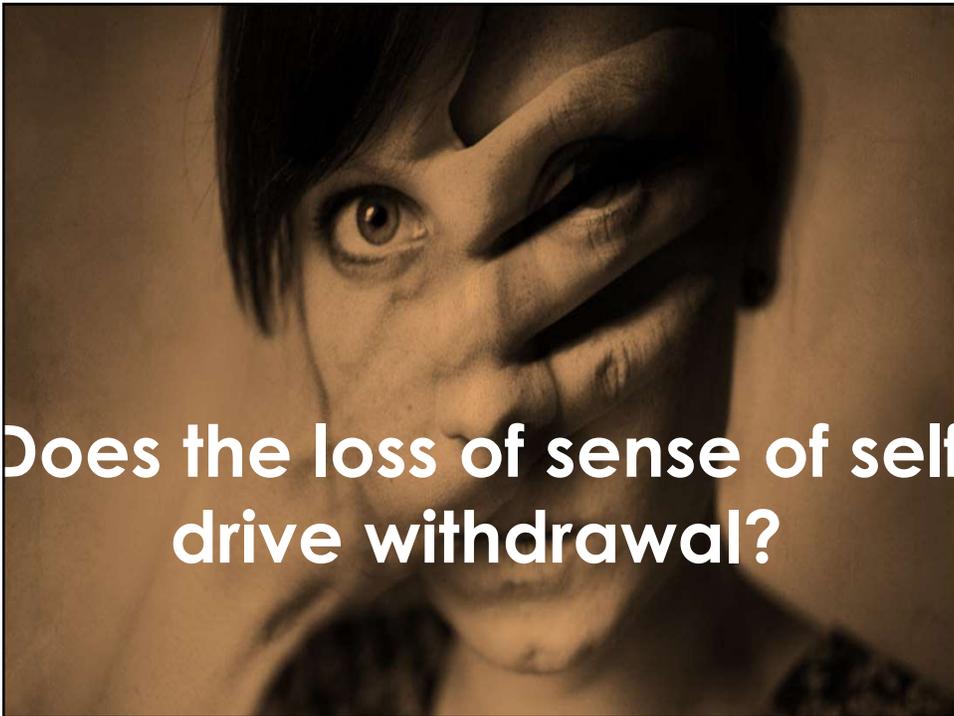
**Self-estrangement, negative
self-evaluation, emotional
distress and denial of changes
in functioning**

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

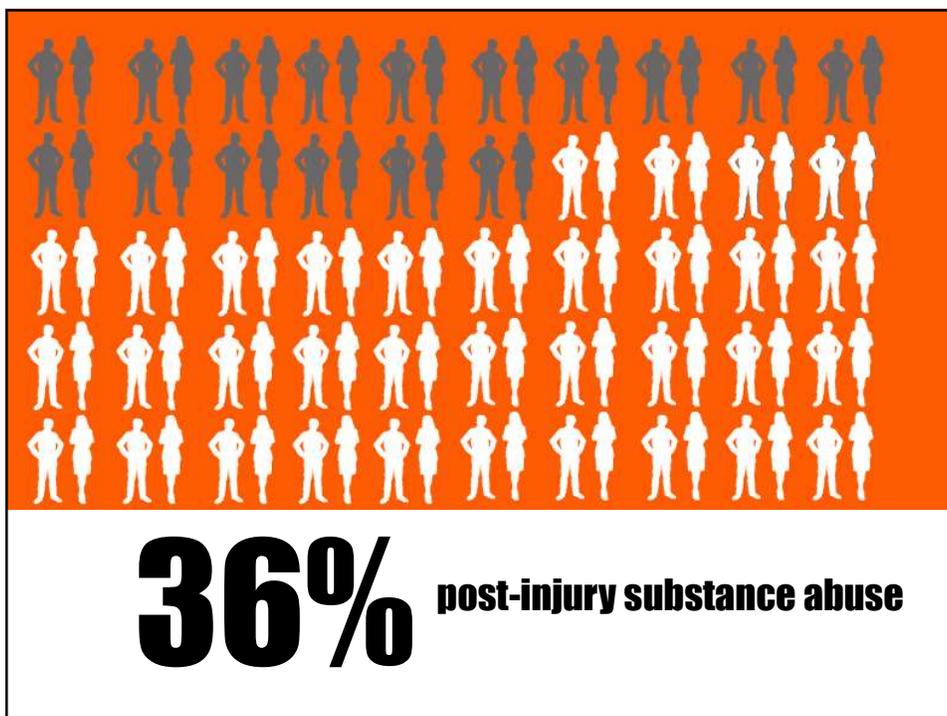
Mental Health and Substance Abuse
Issues

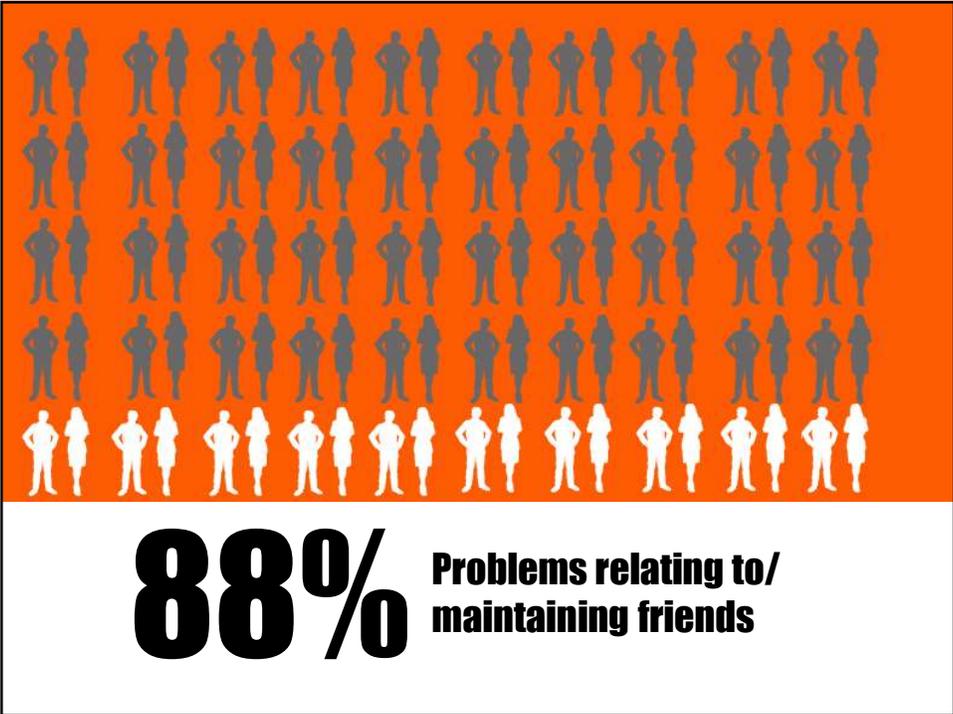
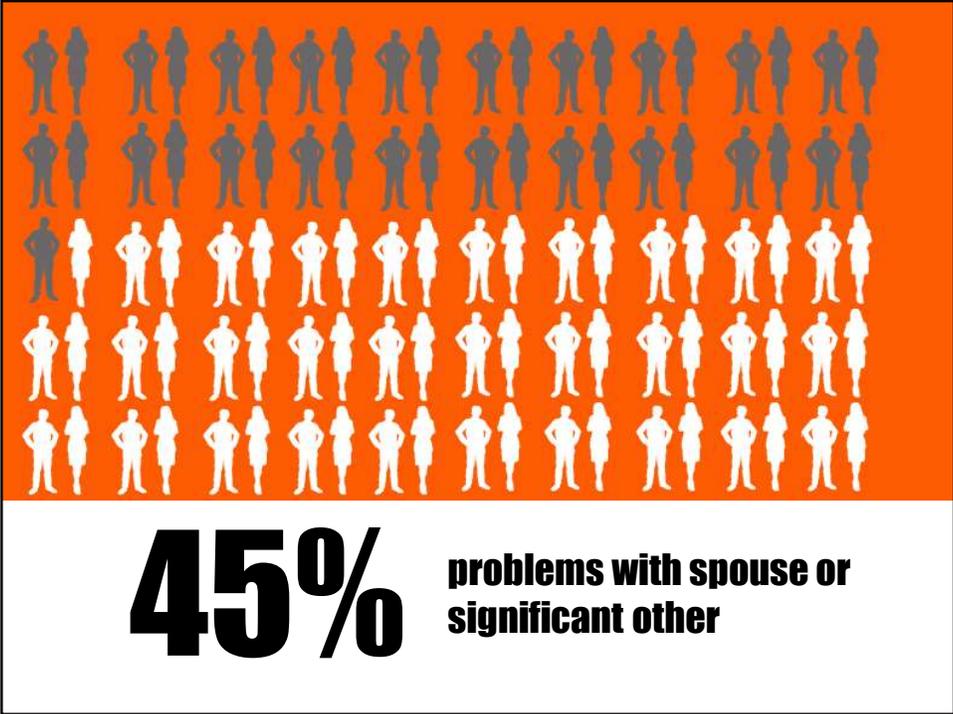
Durability of Outcome

**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

**primary 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%

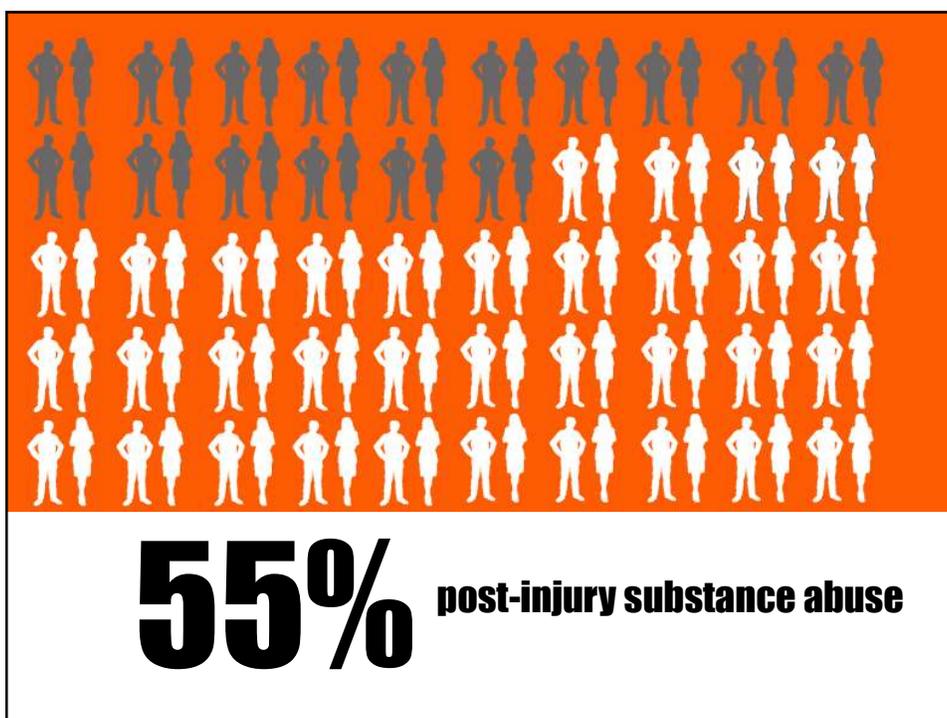
**period from injury to post-acute: 11.0 –
15.5 years**

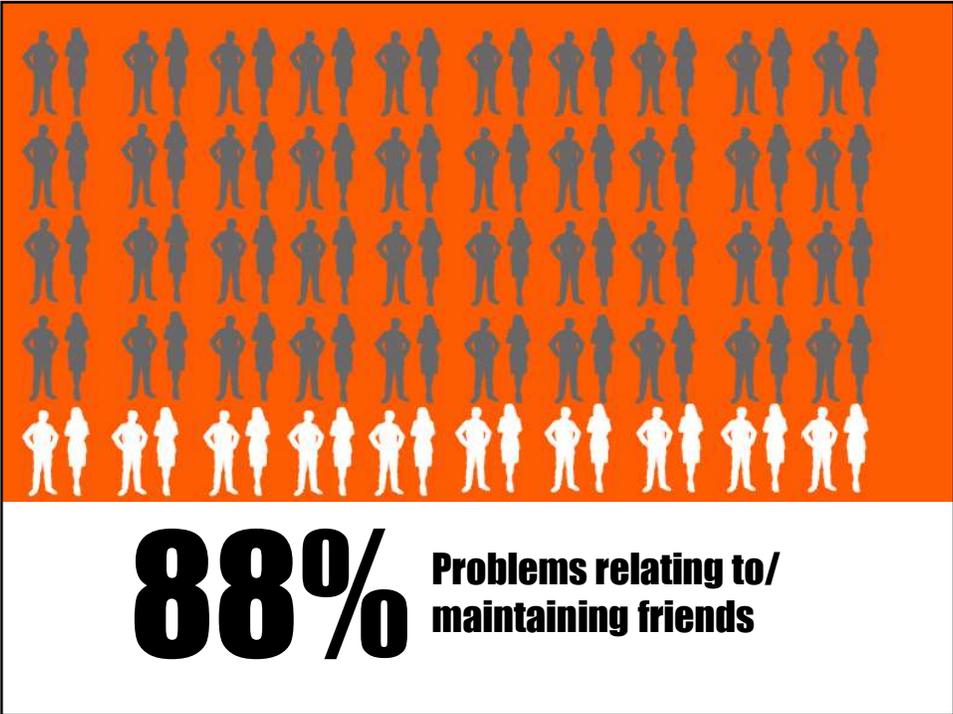
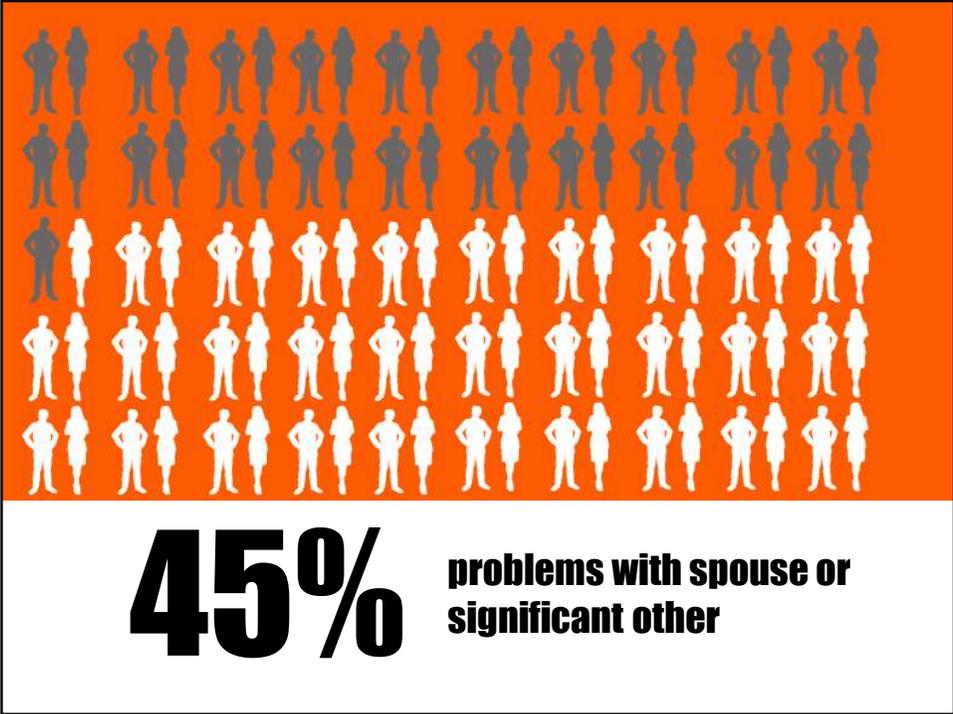
Pre-injury psychological problems: 77%

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

under "Resources", then "Community Presentations"

Resources and References

Resources and References

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