

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 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

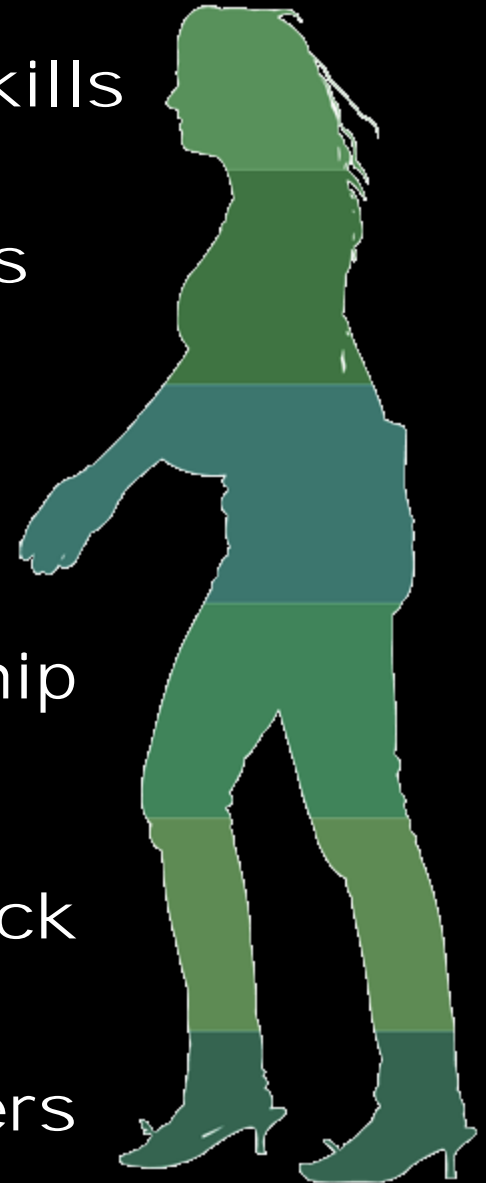
relationships, family, friends

life activities

home/residence ownership

positive feedback

participation with others



self-worth

=

social capital

A large stack of US dollar bills, with several bundles of \$5,000 bills visible in the foreground. The bills are fanned out, showing the edges of many pages. The text "SOCIAL CAPITAL ?" is overlaid in large, bold, yellow letters.

SOCIAL CAPITAL ?

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

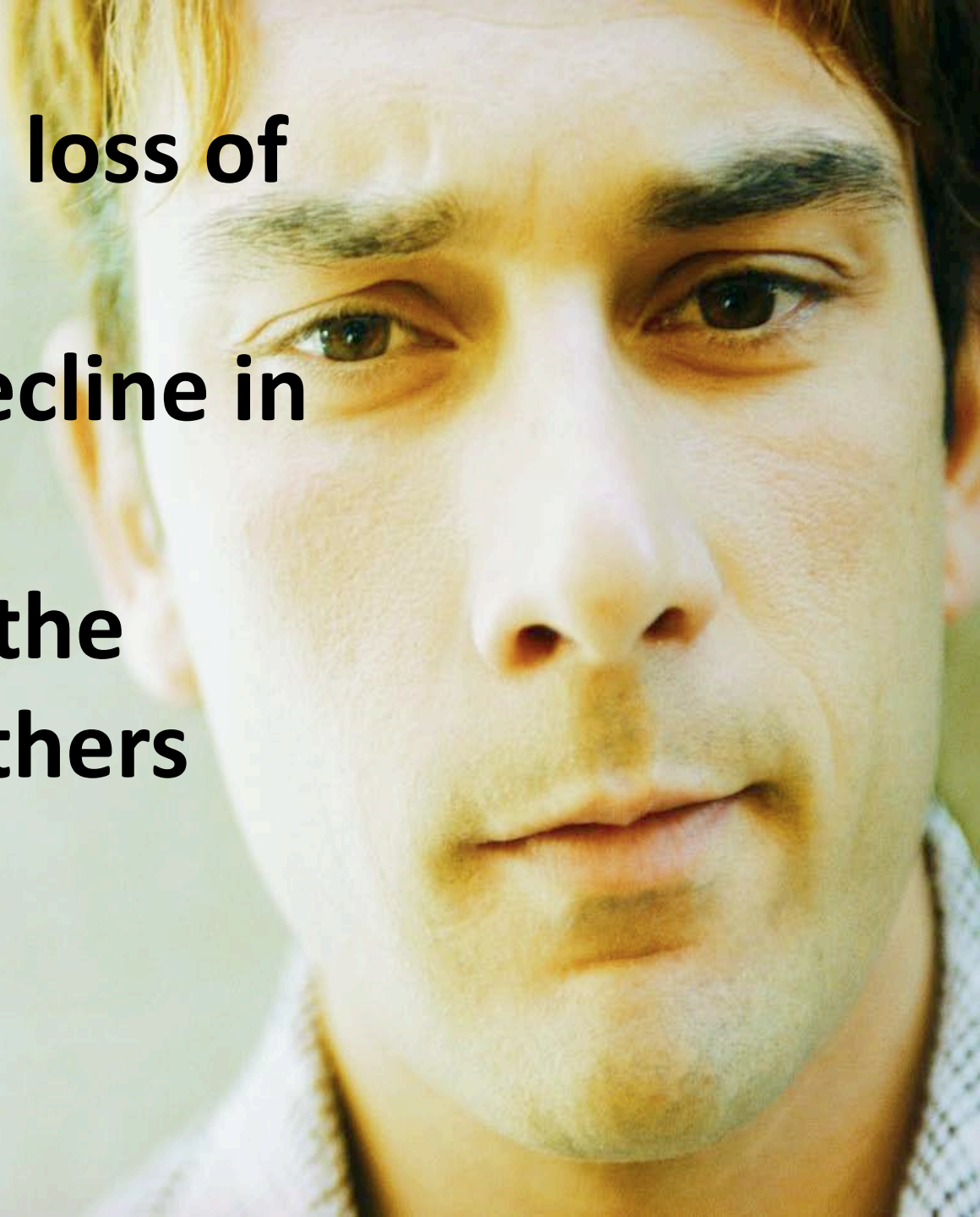
- The value of a person is created by the individual and their society
- The roles a person occupies and their effectiveness in those roles creates value


**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 of a person in profile, looking down with their hand to their face in a gesture of grief or contemplation. The person's face is partially obscured by their hand, and the lighting is dramatic, highlighting the contours of their head and hand against a dark background.

Frank, E et al (2005)



life changes.

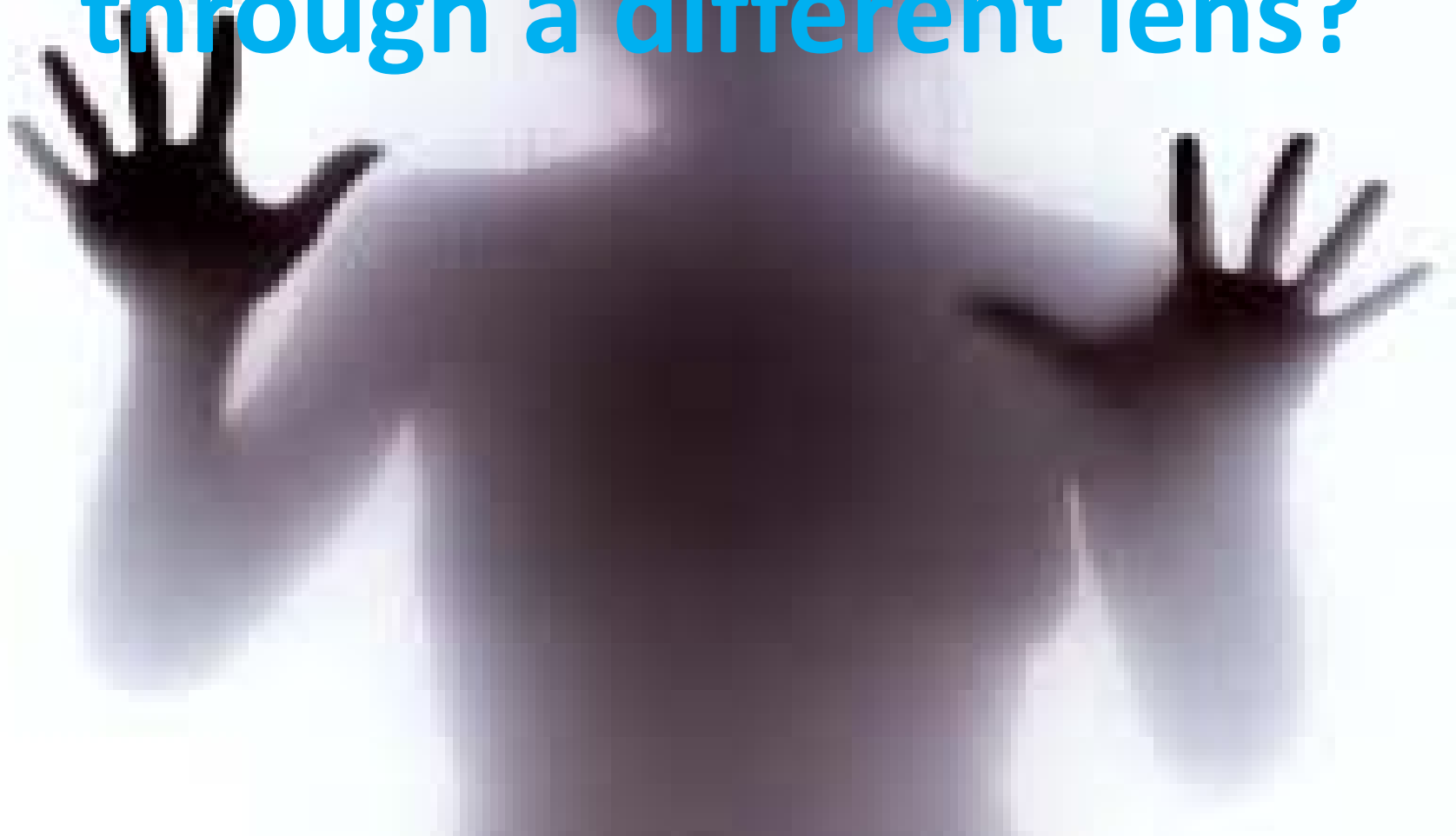


changes
injury-based changes
changes

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**

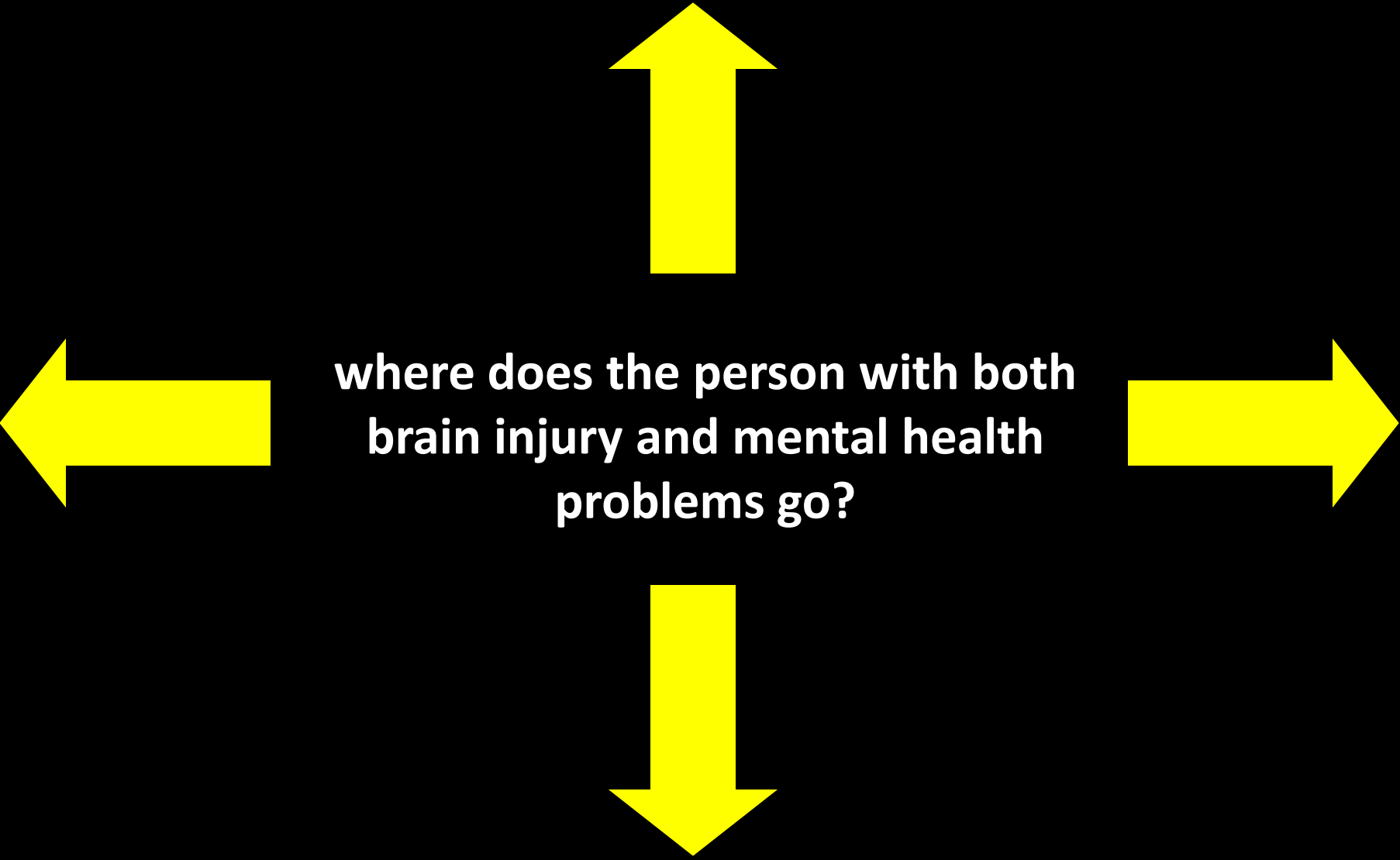
Source: Dawson, J. & Chipman, L. (1995).

**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

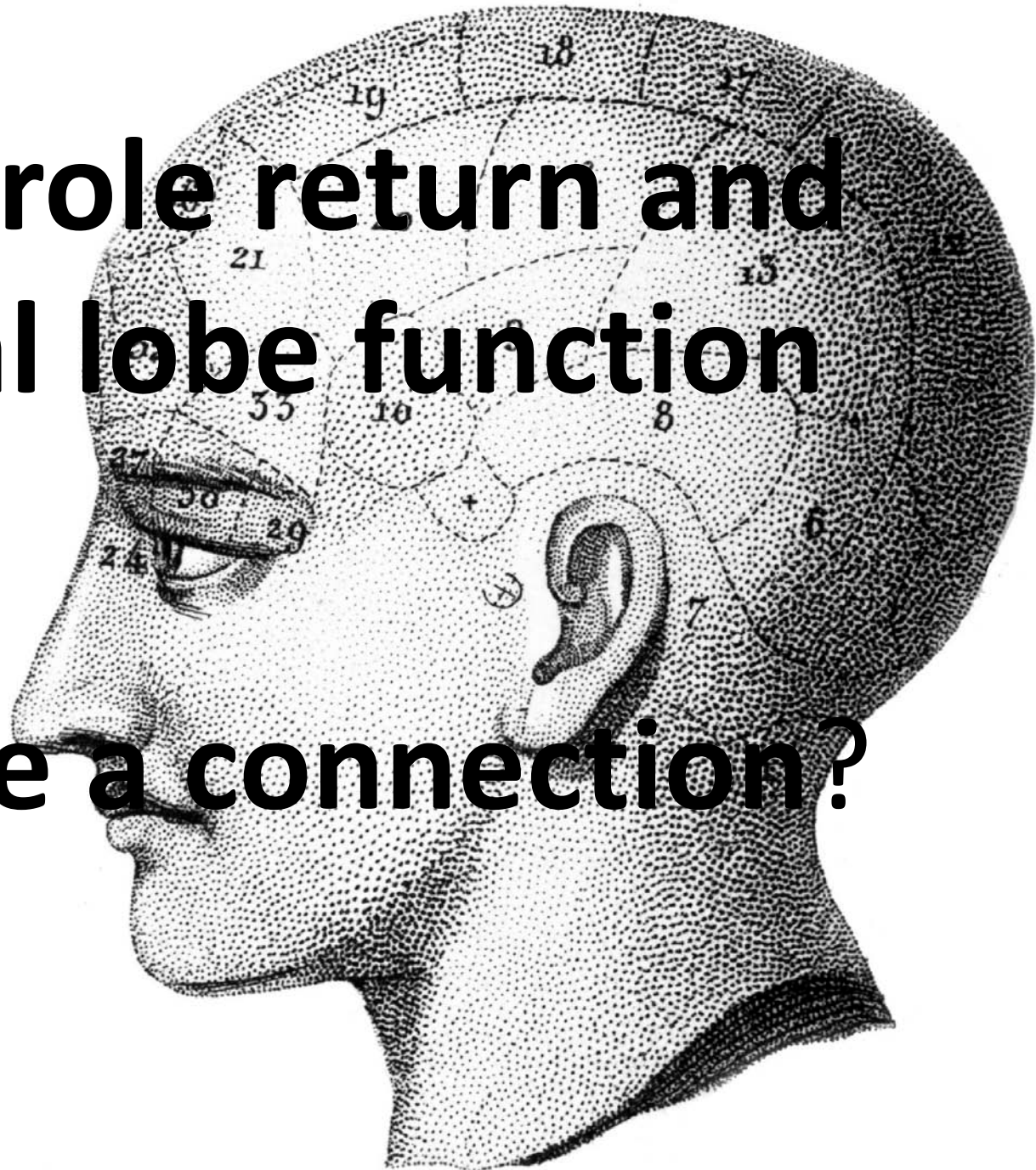


**where does the person with both
brain injury and mental health
problems go?**

**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

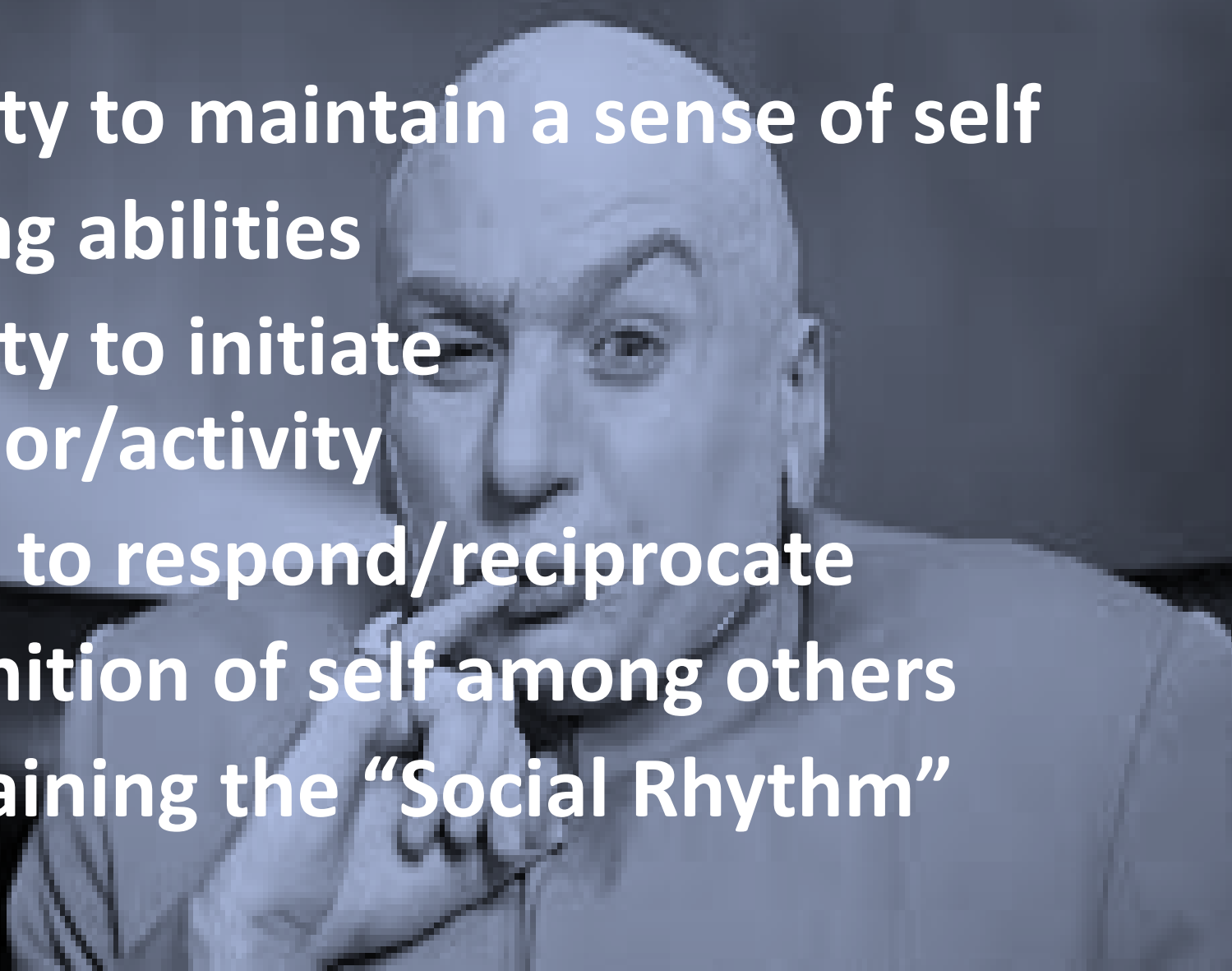
**How does the person's ability to
perceive others impact on their
social role?**

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

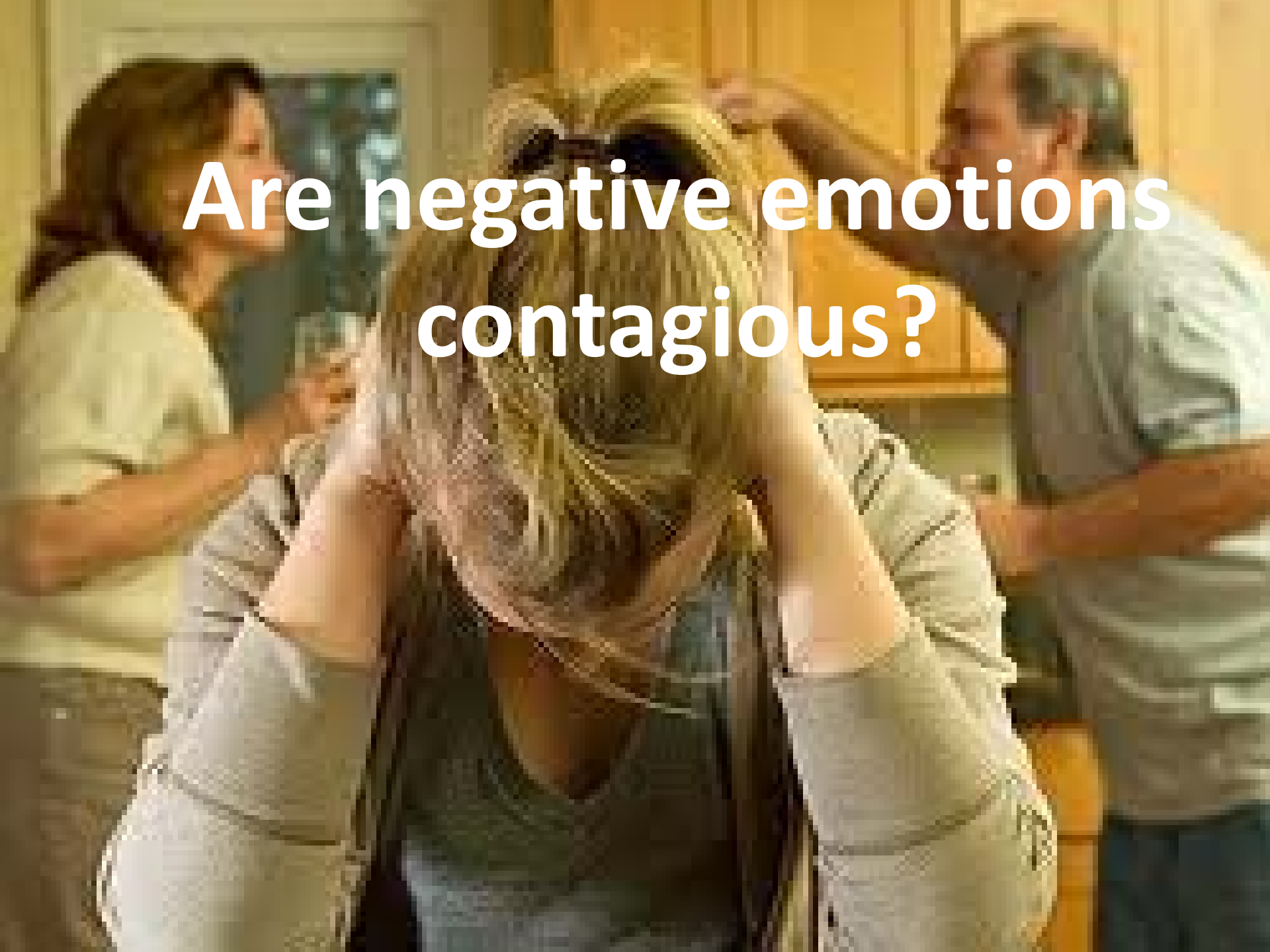
Apathy may exist as subtypes defined by frontal-subcortical loops (Apathy Syndromes)

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, low-angle photograph of a crowd of people, mostly seen from behind, looking upwards towards the top of the frame. The image has a soft, out-of-focus quality with a warm, slightly yellowish tint. The people are wearing various casual clothing, and their heads are scattered across the frame, creating a sense of a large gathering.

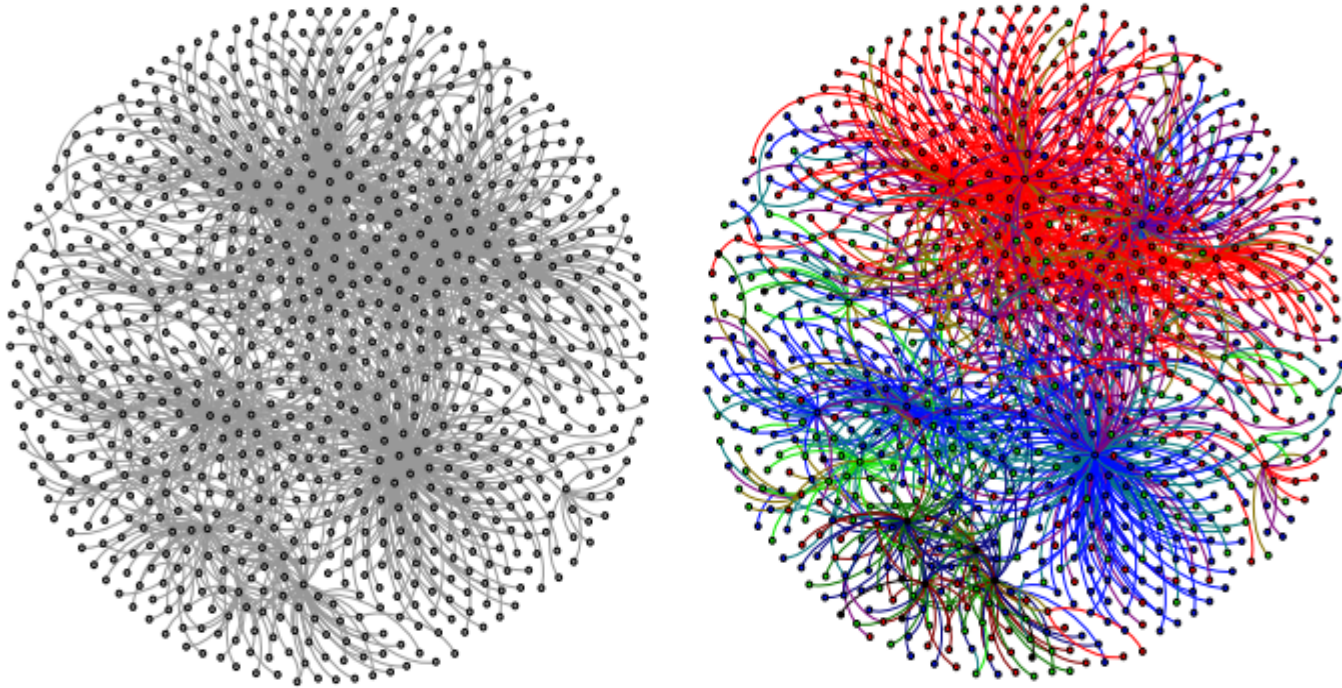
**What about looking
outside of rehab?**

**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

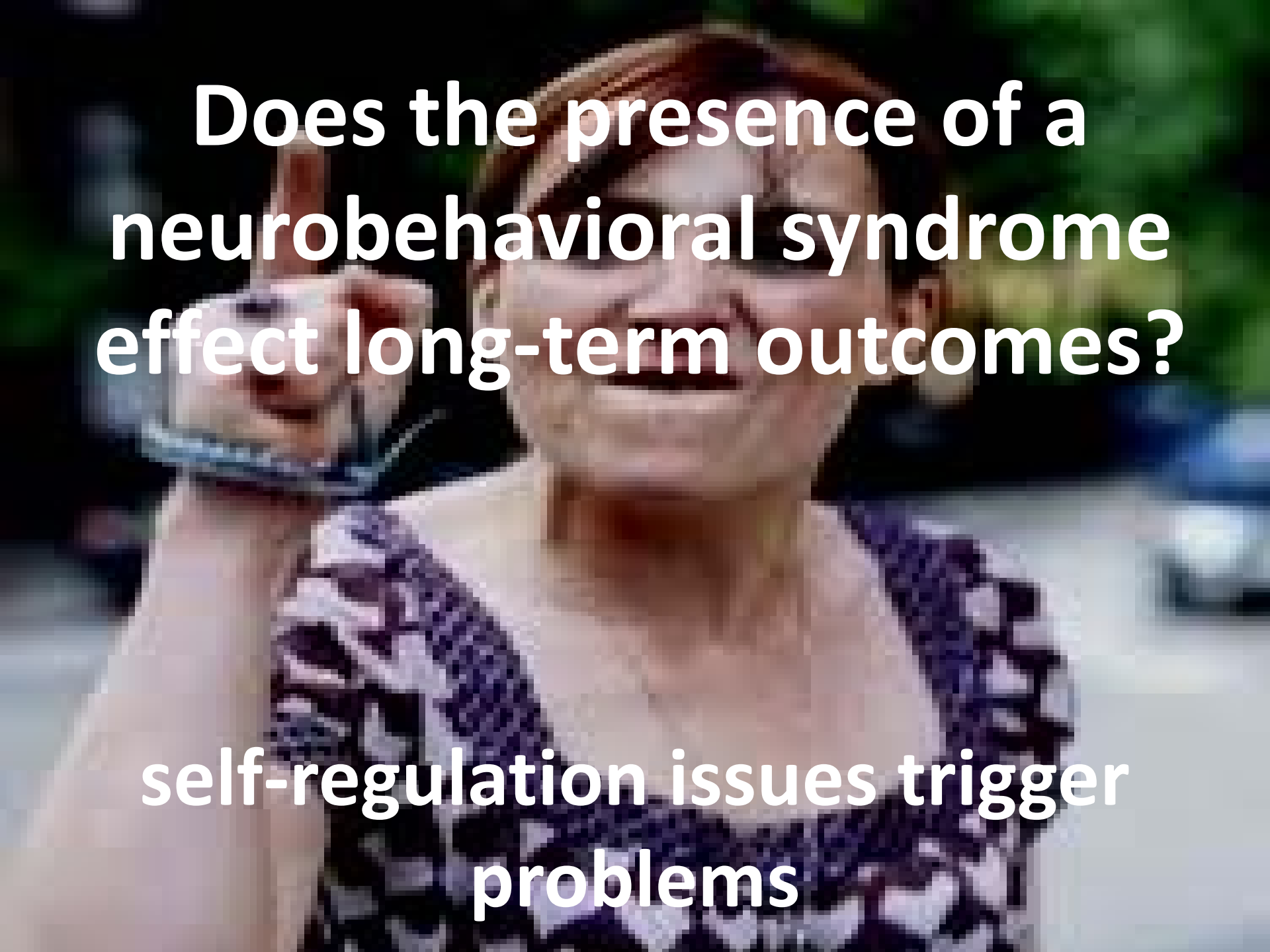


Sources: Rui Fan, et al., (2013); Berger, J. & Milkman, K.L. (2013).



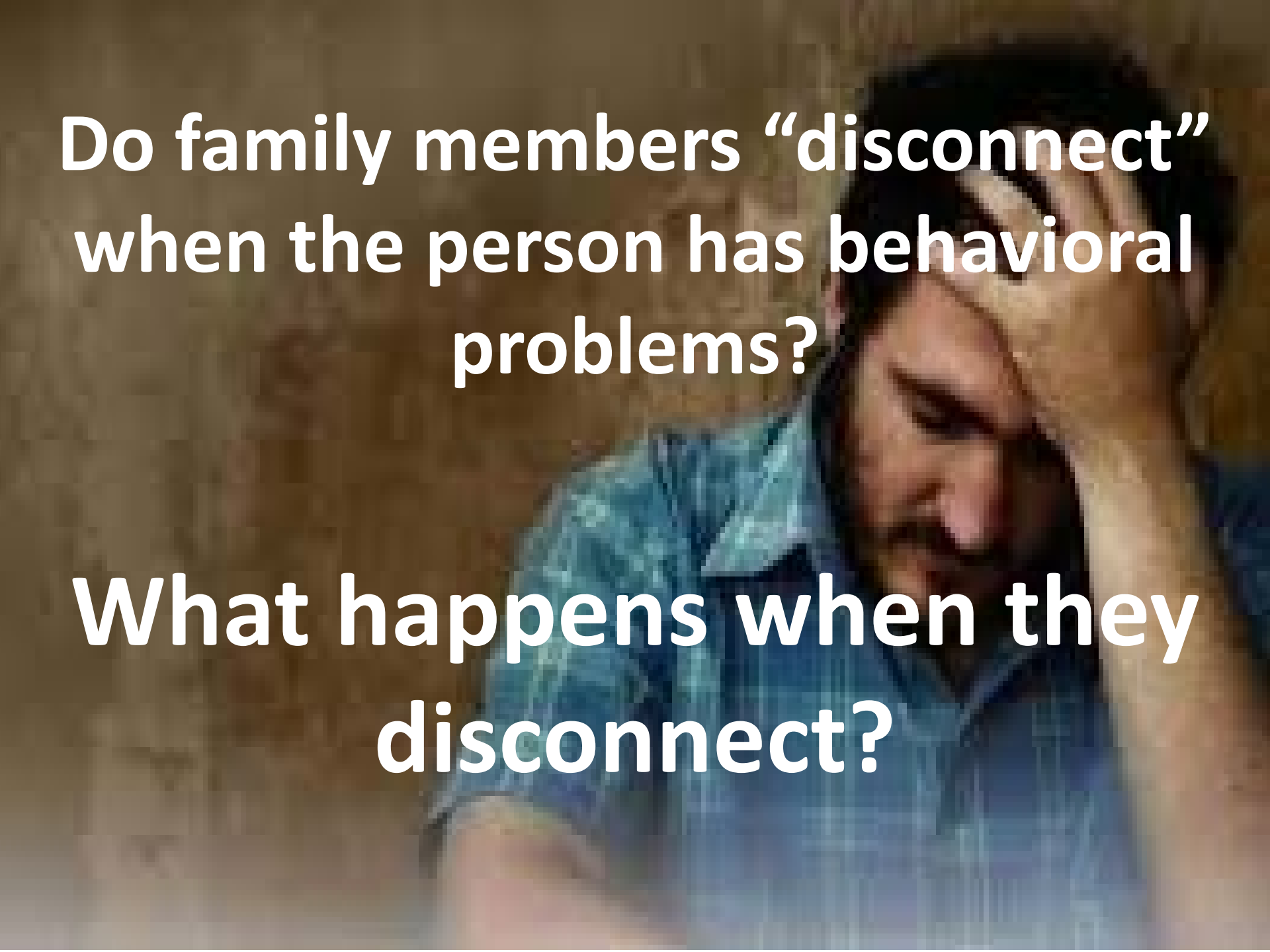
**Similar to past studies involving
the families of individuals with
brain injuries**

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

A young girl with a wide, toothy smile, wearing a purple patterned shirt, with her hand near her face. The background is blurred, showing green foliage and a blue car.

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

**self-regulation issues trigger
problems**

A man with dark hair, 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 blurred, warm-toned interior.

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

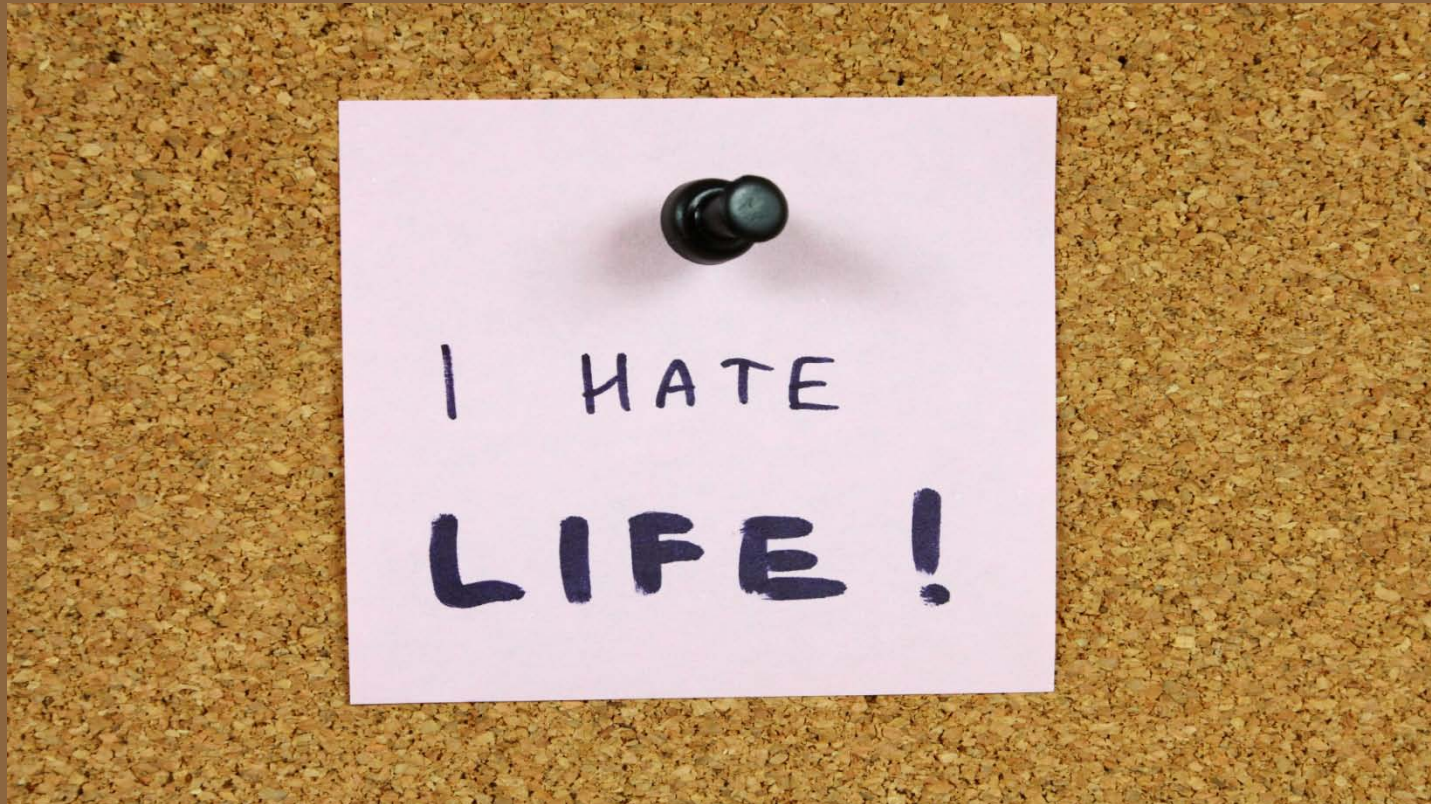
**What happens when they
disconnect?**

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 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 view outside the window is a bright, hazy landscape, possibly a beach or a coastal area. 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 in a dark, long-sleeved shirt is standing by a window, looking out. Their right hand is resting on the window frame. 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**

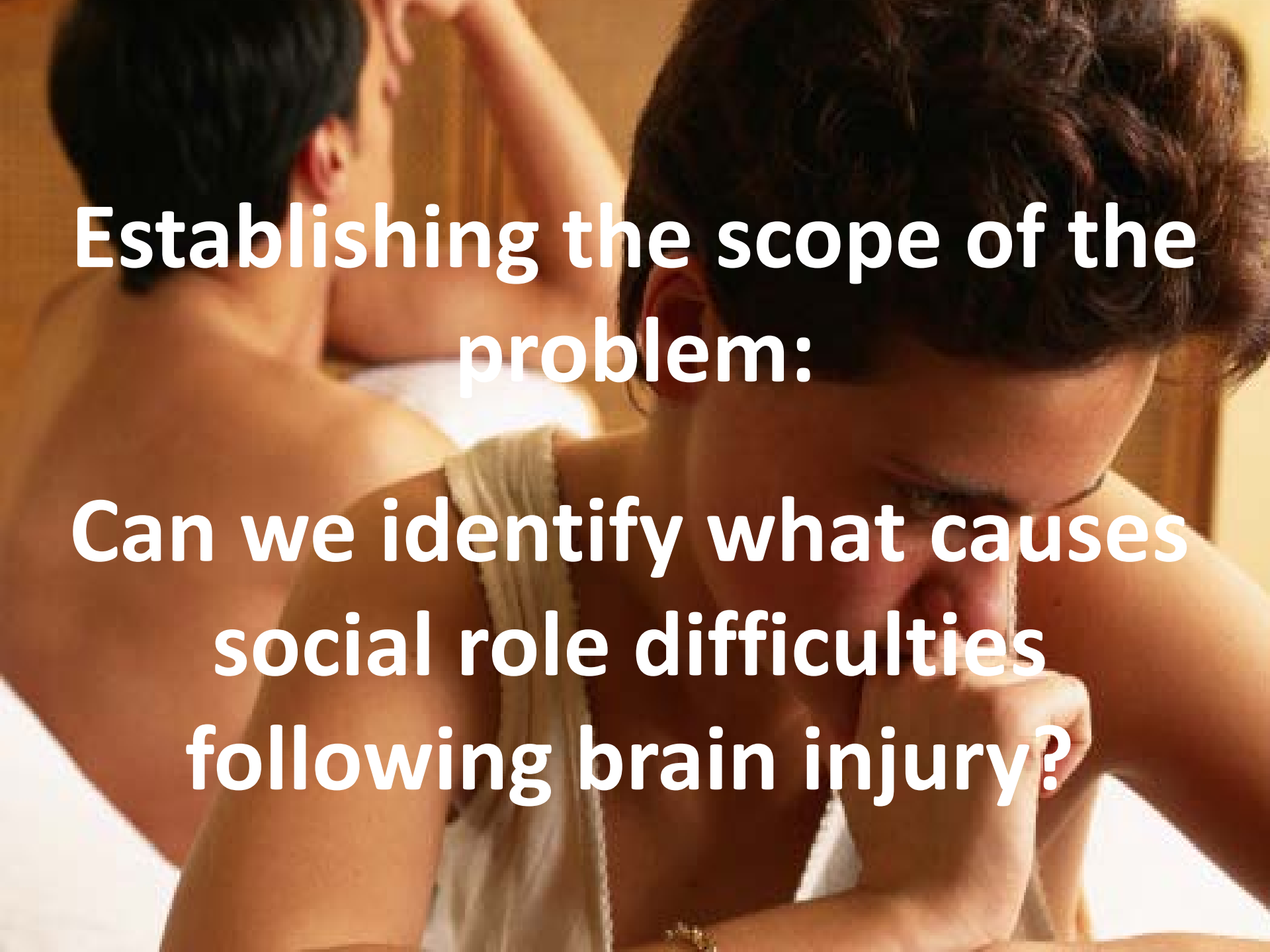
View of self as “not the same person”

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

A close-up photograph of a person's face, heavily tinted with a teal or cyan color. The person has dark hair and is looking directly at the camera with a wide, intense eye. Their right hand is raised, with fingers spread, covering their mouth and nose. The lighting is dramatic, with strong highlights and deep shadows, emphasizing the texture of the skin and the fabric of their clothing. The overall mood is one of shock, fear, or emotional distress.

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

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

A close-up, warm-toned photograph of a man and a woman in an intimate embrace. The man, with dark curly hair, is leaning his head against the woman's shoulder. The woman has dark hair and is looking down. The background is softly blurred, showing what appears to be a wooden headboard.

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”**

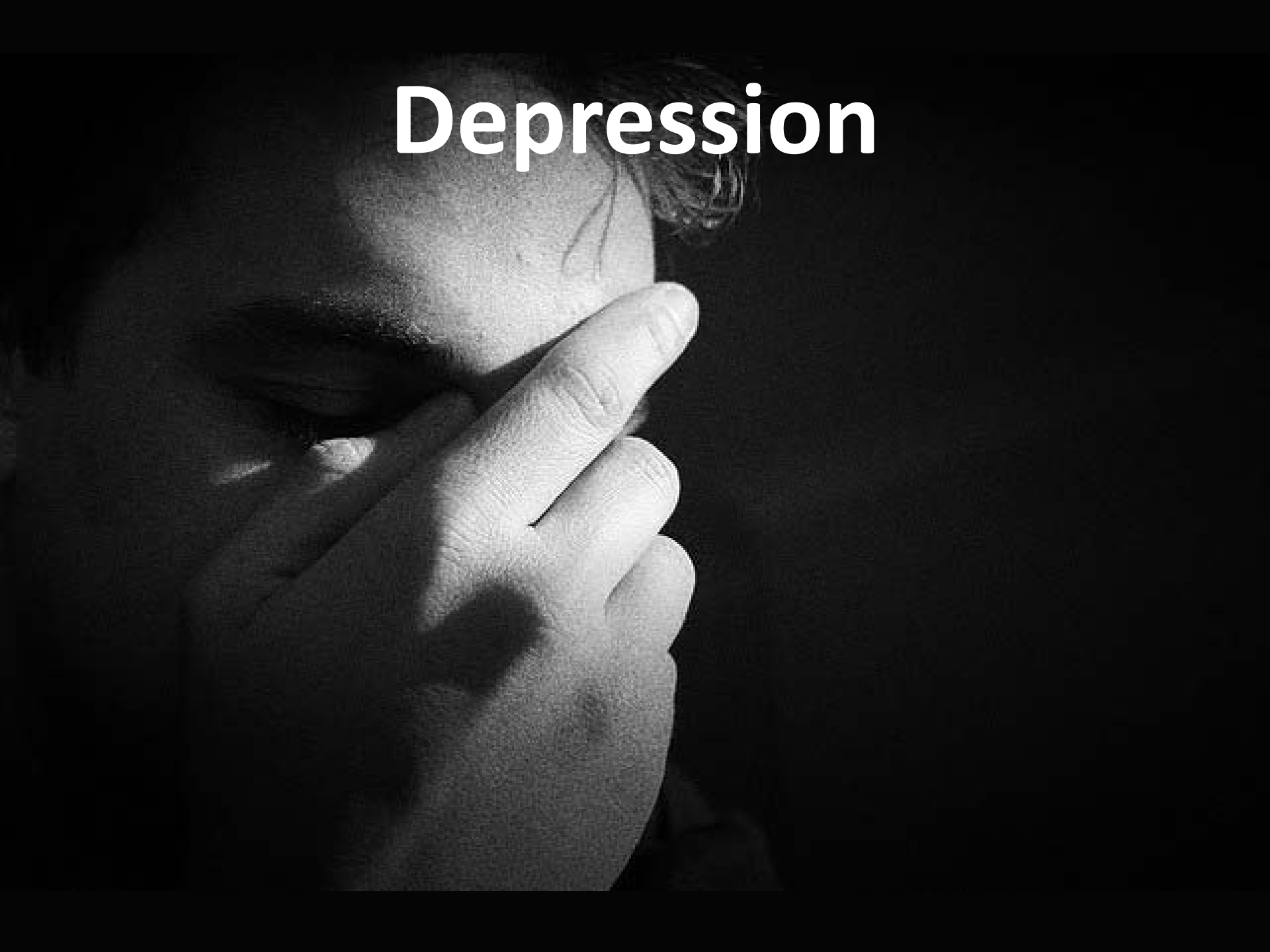
Walter Mosley, “When the Thrill is Gone”, 2011

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

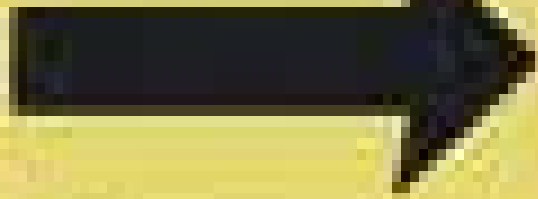


Healthy Life

NEXT EXIT



Brain Injury

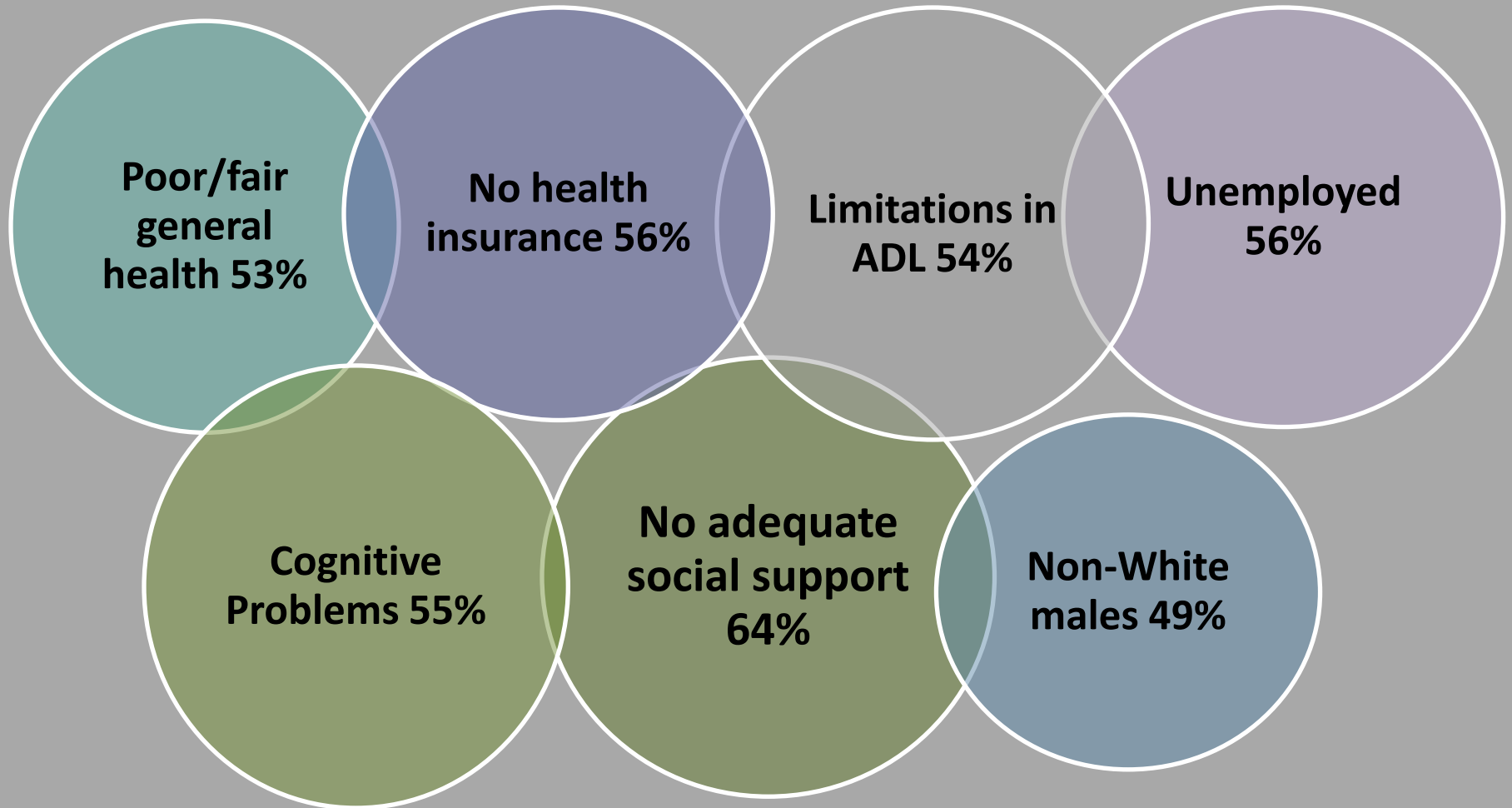


The image features three strands of barbed wire running diagonally from the bottom left towards the top right. The wire is dark and silhouetted against a clear, bright blue sky. The sharp, twisted points of the wire are clearly visible. In the bottom right corner, a portion of a metallic structure, possibly a fence post or gate, is visible, showing some rust and a red stripe.

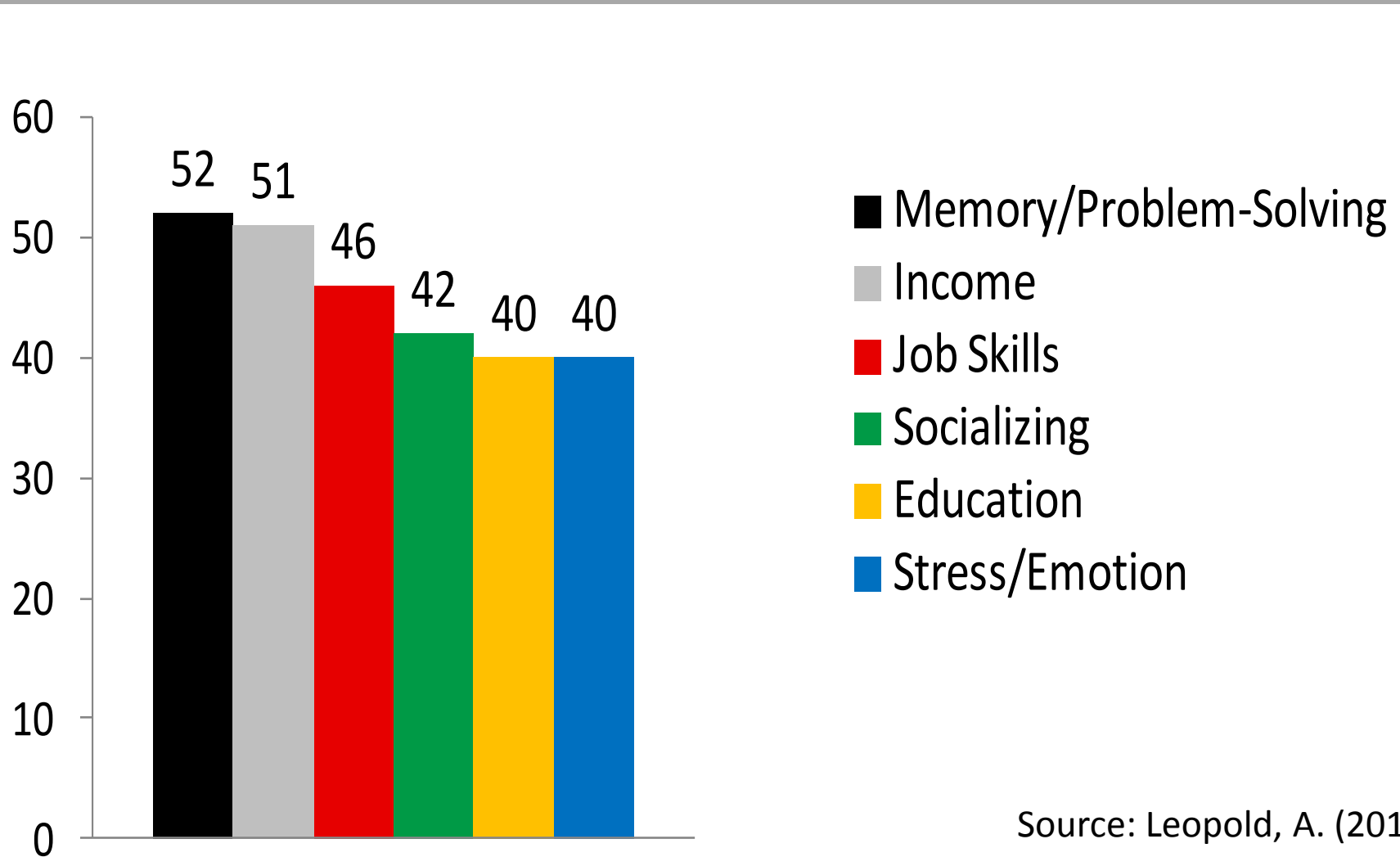
What are the barriers?

**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?



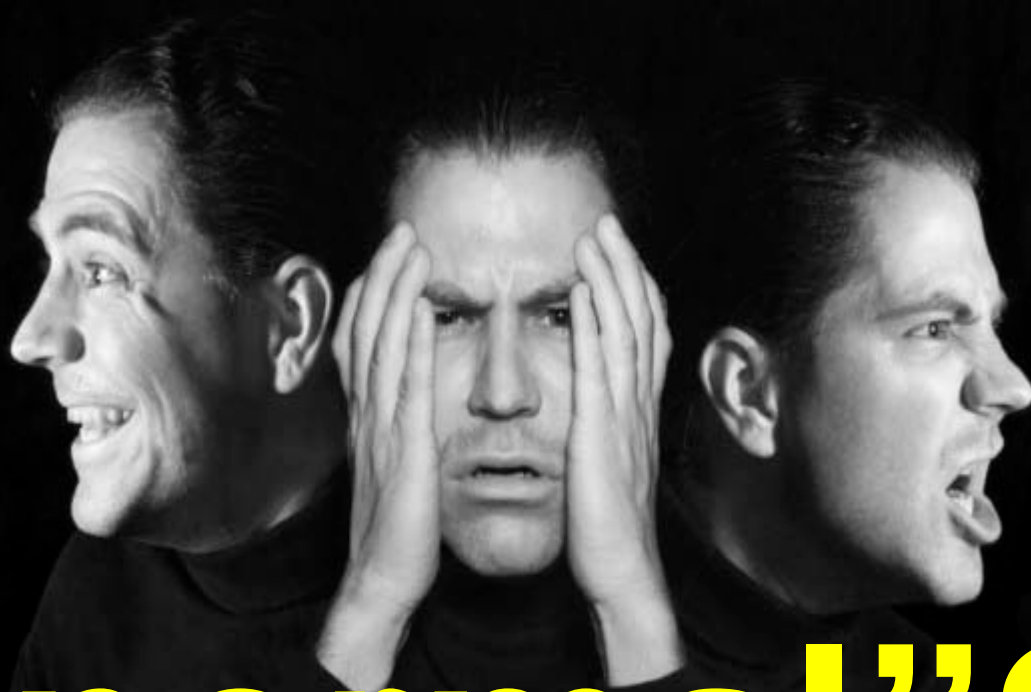
**what about social role
return?**

**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?

A man in a dark jacket is standing in a kitchen, looking up and measuring a window frame with a yellow tape measure. He has a yellow pencil in his mouth. The kitchen has wooden cabinets and a large window. The text "how can we expand the domains we measure" is overlaid on the image in white and yellow. The text "to be more relevant to the person and their life?" is overlaid on the image in blue.

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**



the NRIO study

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

641 tracked from 1995-2013

Average age: 32.0

Age Range: 2.11 to 78.7

100% 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).

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).

2.5 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
1997-2013

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**



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

18 tracked from 2010-2013

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%

CNR Outcomes

Employed: 11%

Not working: 89%

**Independent Living with 0 to 4/hrs day of
support: 33%**

**Living with family 0-4/hrs day of support:
11%**

Living in care situation: 44%

post-injury psychiatric diagnosis: 88%

post-injury substance abuse: 55%

Substance Abuse Issues

Pre-injury substance abuse: 33%

**Post-injury substance abuse:
55%**

Maintaining abstinence: 78%


Minimal substance use: 11%

Moderate substance use: 11%

Legal involvement

Pre-injury legal problems: 44%

Post-injury legal problems: 44%



Returning to pre-injury social role

Returned to pre-injury social role: 33%

Returned to pre-injury role with
modifications/supports: 22%

Interfering psychiatric and substance
abuse problems affecting social role:
44%

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

Weekly counseling: 11%

Occasional counseling: 55%

Attending self-help/support group: 22%

**Not receiving psychological/psychiatric services:
11%**

Requiring 24 hr placement: 56%



44%

**experienced significant psychological
problems requiring intervention**



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

44%

**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

**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



**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
nrio.com

It can be found under “Resources”

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

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

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