

Detours, road closings and potholes: assessing the barriers after brain injury



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Disclosure

- Rolf B. Gainer has business relationships with Rehabilitation Institutes of America, Brookhaven Hospital, the Neurologic Rehabilitation Institute of Ontario and Community NeuroRehab.
- Nancy Weber is a Brain Injury Case Manager/Clinical Evaluator for NRI at Brookhaven Hospital

**You never change things by
fighting the existing reality. To
change something, build a new
model that makes the existing
model obsolete.**

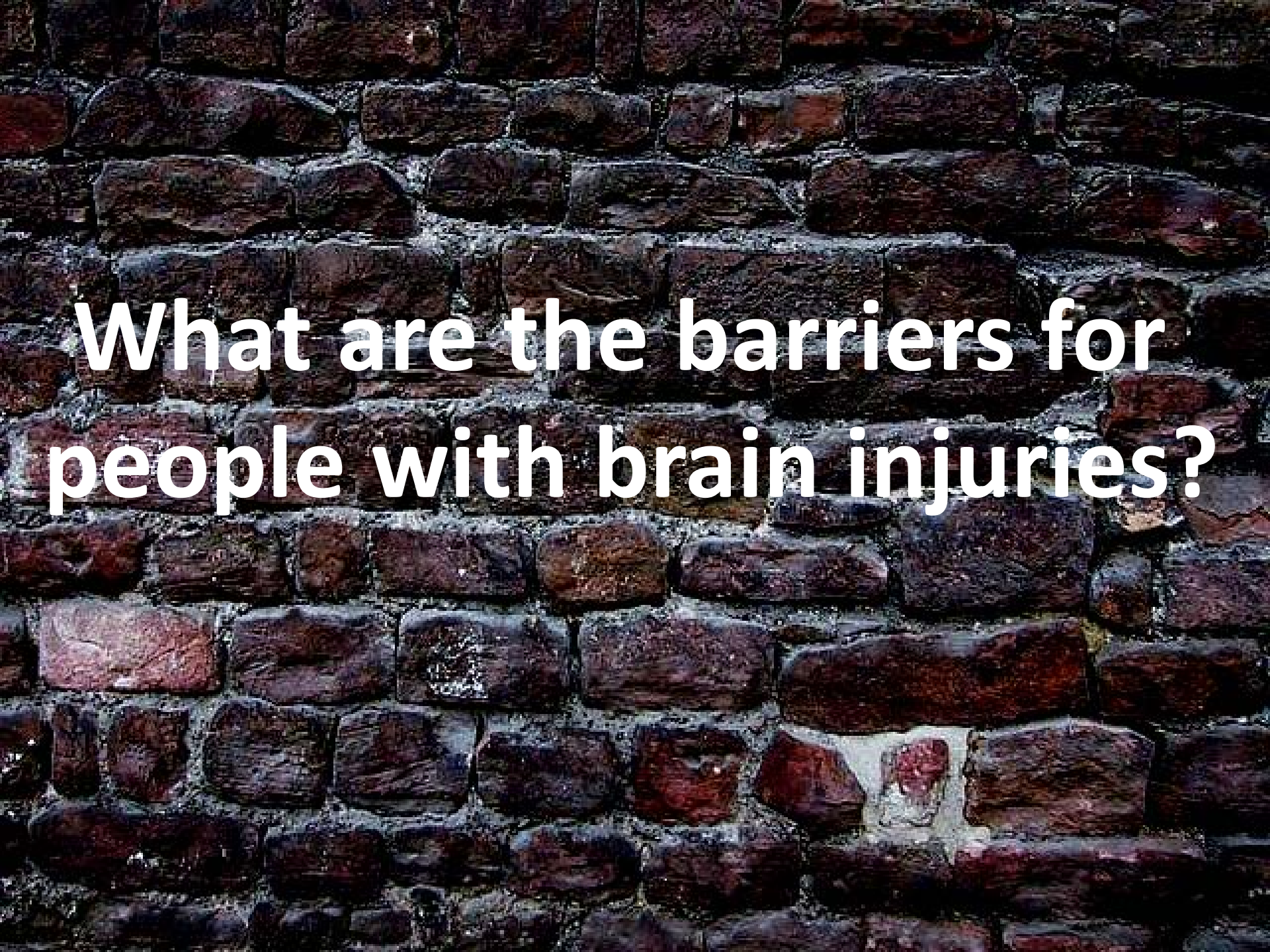
*R. Buckminster Fuller, American Inventor
1895-1983*

Objectives:

**Let's ask the following questions
through the examination of three
case studies
of individuals with brain injury**

**How can we identify what
needs to change?**





**What are the barriers for
people with brain injuries?**

**Are new barriers added
throughout the lifespan?**



**Do those barriers change
over time?**



**What about the person
with complex needs?**



Are the barriers more complex?

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

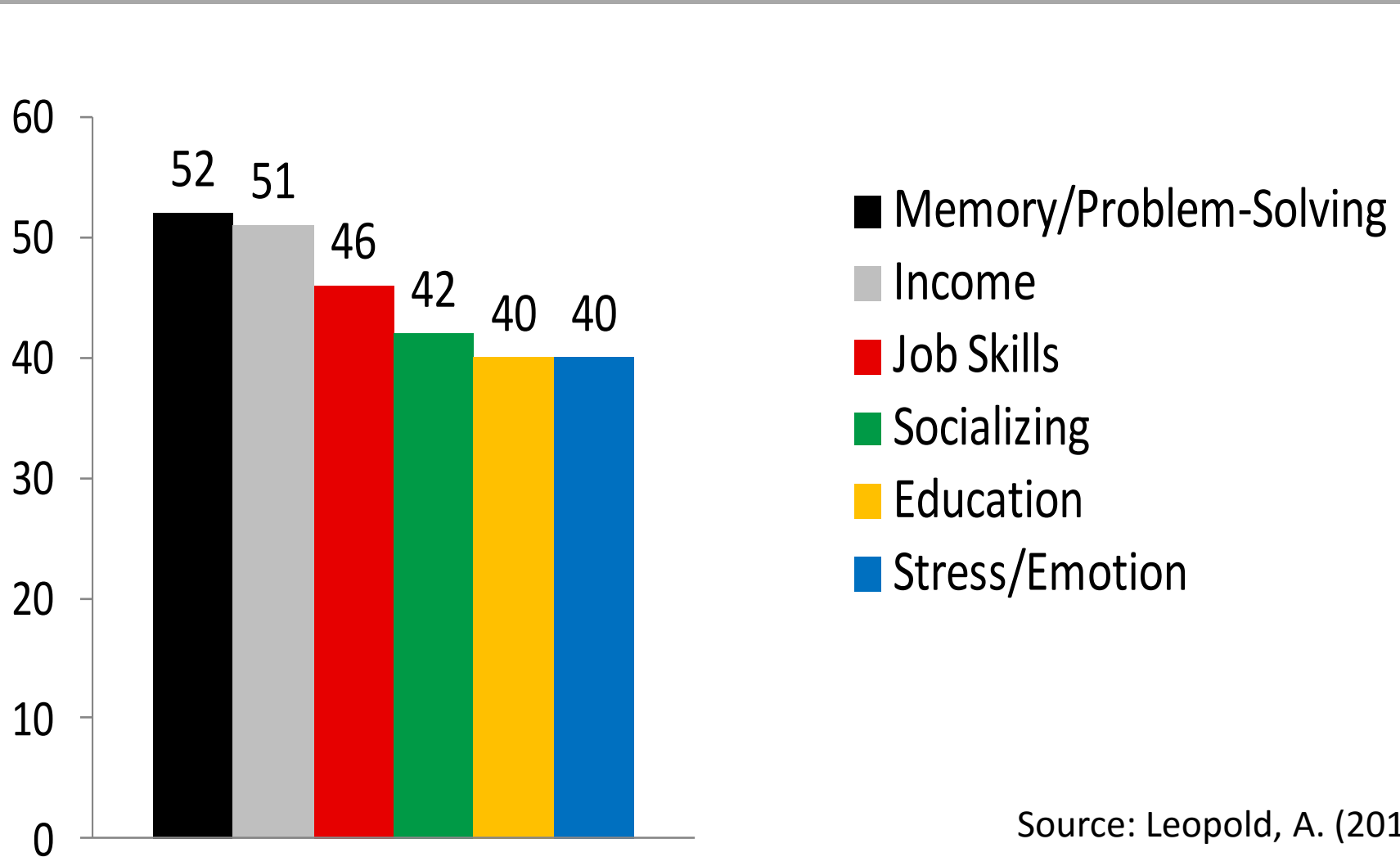
**When do barriers emerge
following brain injury?**

**And, how do they
change?**

**What can we learn from the
research studies which
identify barriers?**

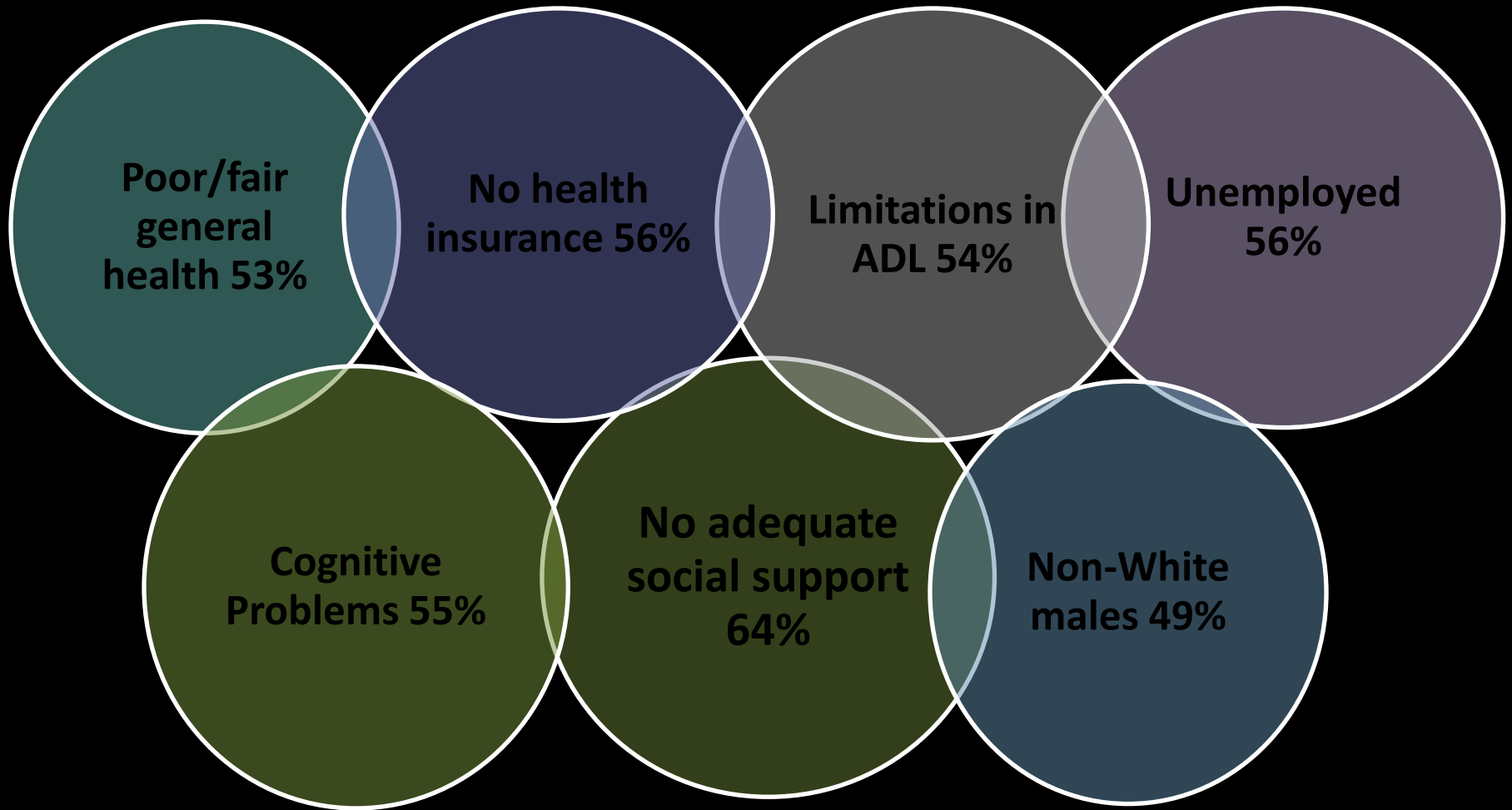
**Financial, structural, individual,
and attitudinal barriers directly
impede individuals' abilities to
access rehabilitation services
even though these services
could greatly improve their
recovery from TBI**

Medicaid recipients reporting “unmet needs”




Source: Leopold, A. (2013)

Defining the barriers




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

A close-up, high-contrast photograph of a person's face, focusing on the right side. The person has light-colored eyes and a mustache. The lighting is dramatic, with deep shadows on the left side of the face and bright highlights on the right. The person's expression is somber and contemplative, with a slight frown and heavy-lidded eyes. The background is a soft, out-of-focus grey.

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

Source: Frank, et al. (2005)

A close-up, high-contrast photograph of a man's face, focusing on his eyes and mustache. The lighting is bright, creating a strong highlight on his nose and cheek. The background is a soft, out-of-focus blue.

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

Source: Condelucci, A. (2008)

A close-up, high-contrast photograph of a person's face, focusing on the eye and nose. The person has light-colored eyes and a mustache. The lighting is dramatic, with one side of the face in shadow. The background is a soft, out-of-focus blue.

Disengagement from naturally occurring social units

**Lewin K. Field Theory in Social Science.
Oxford: Harpers; 1951 Christakis C, Fowler J., 2008**

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

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

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).

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

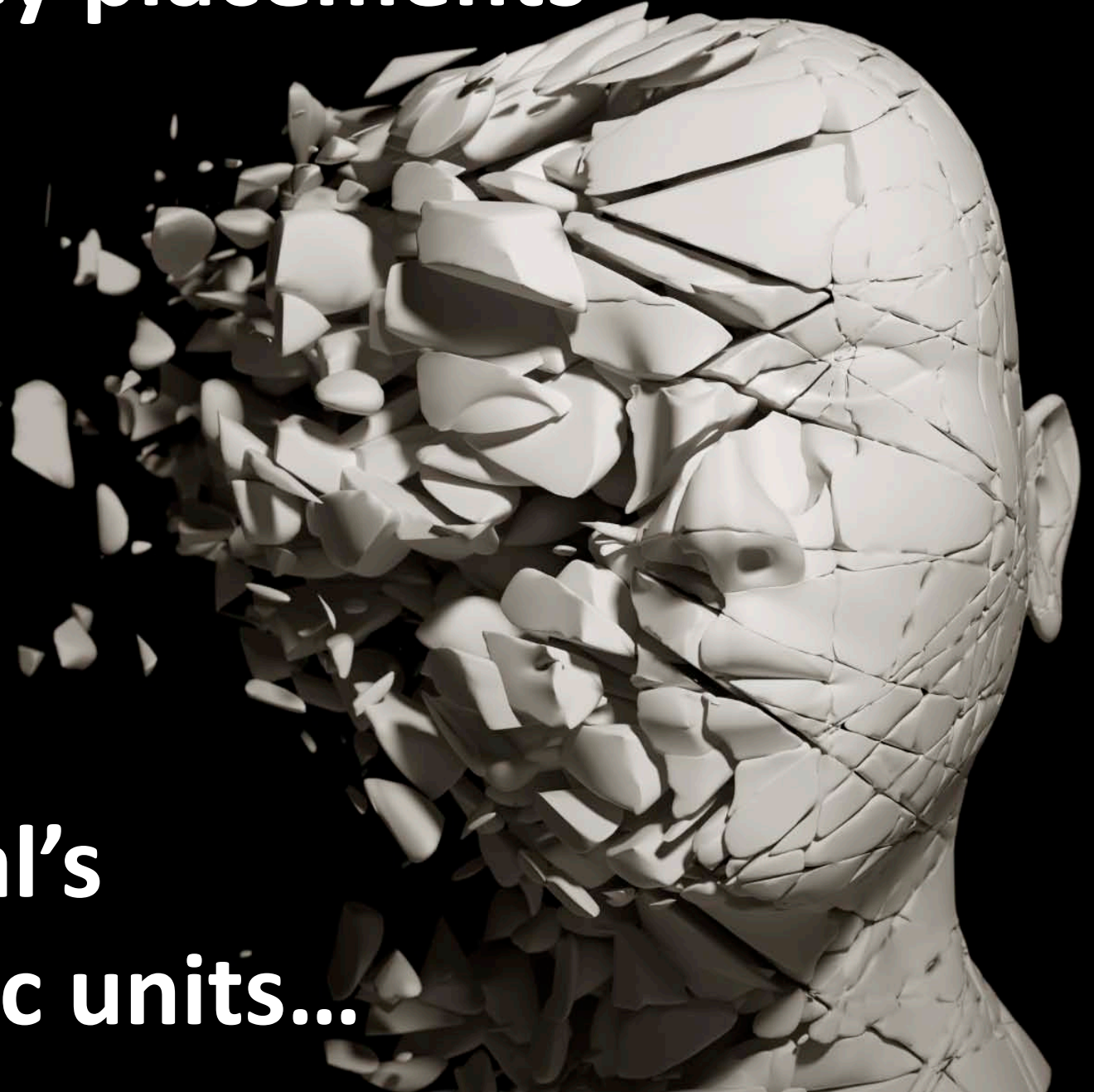
Fann et al: Self perception

- **Individuals with both depression and anxiety perceived themselves as more ill** and demonstrated reduced function as compared to cohort with anxiety without depression

**Do people with unmet needs
find themselves
in crisis situations?**

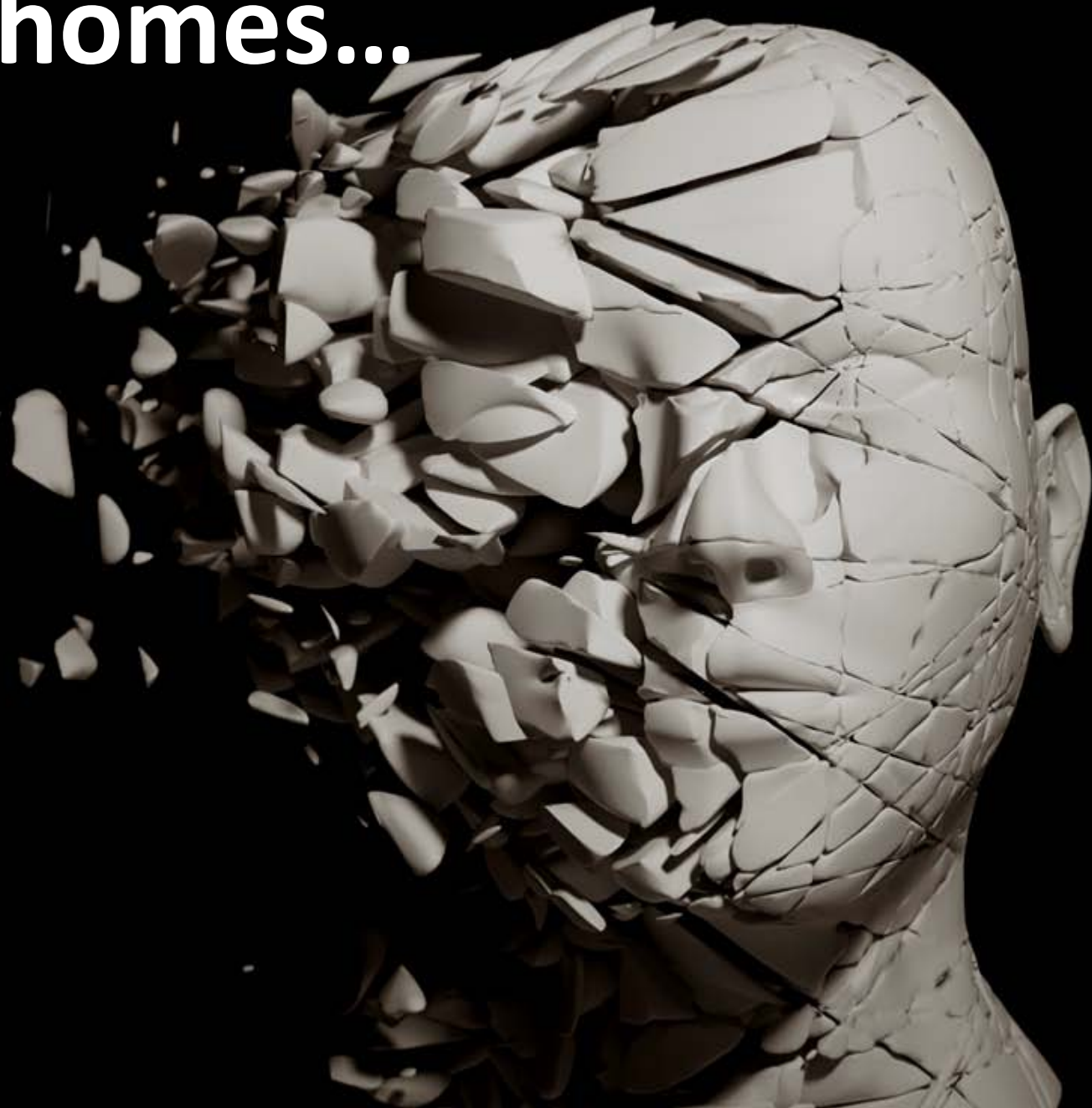
The gap in services
between hospital and home
can result in...

emergency placements



**at hospital's
psychiatric units...**

nursing homes...



jails...



homeless shelters



**None of these are equipped
to recognize and/or treat
Brain Injury...**

**...and, certainly do not offer
realistic long term solutions**

**Functional status and
lifespan issues affects the
person's ability to remain
independent**

**Fatigue identified as a key factor
in functioning and participation**

Source: Sendroy-Terrill, et al, 2010

**Cognitive, physical and
societal functioning are
influenced by the severity of
the injury**

Source: Sendroy-Terrill, et al, 2010

**Stability in housing is vital
to community living**

Housing

There is “an unrelenting rental **housing crisis** for extremely low-income **people with disabilities** in every single one of the nation’s 2,557 housing market areas.”

Source: Cooper, Emily, L. Knott, et al. 2014

**Services in the home and
community can prevent a loss
of independence**

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

Can **the system**
accommodate the **complex**
needs of the **person**
post-injury?



**Let's look
at
Sarah's
story...**



Sarah's Story

- **32 Years Old**
- **Mother of 2 young children**
- **Anoxic Brain Injury from Cardiac Arrest**
- **3 weeks in a coma**
- **90 days acute rehab**

Status at Discharge from Acute Rehab

Physical

- **Limited Mobility of Arms & Legs**
- **Limited Verbal Communication**
- **Swallowing Difficulties**

Psychological

- **Depression**
- **Suicidal Ideation & Self-Harming Behaviors**

Caregiver

- **Caregiver = Mother who is a
BI Survivor with No Training**
- **No Social Supports**

Negative Impact from Limited Rehab

Loss of Progress after Acute Rehab

**Did Sarah need extended
rehab to improve?**

New Financial Barrier

- **Continued Care Denied by MCO
for 2 years**
- **Fixed income limits options**
- **Living in inaccessible, bedbug-
infested apartment**

Caregiver and Environmental Stress

- Caregiver burnout
- Borderline abuse by caregiver
who also has a TBI

What are the Barriers?

**Access to Services due to
Limited Medicaid Coverage**

For Sarah...

- **OT, PT, SLP, Psychological
are needed**
- **No Social Supports**

For Sarah's Caregiver...

- **Lack of Caregiver Support**
- **No Transportation**
- **Fixed Income**

**Lack of funding prevents
access to rehab for Sarah**

Would Sarah's outcome



be different without barriers?



**What about the
person who
doesn't fit?**



Or, is it “one size
fits all”?

**What about services
after rehabilitation?**

**Is there access to
rehabilitation?**

**Are there adequate
resources to meet the real
lifetime needs?**

Do the resources include:

appropriate healthcare

extended rehab

accessible housing

transportation

community supports

adequate income

**To sustain the gains made in
rehab**

Inappropriate services
result in poorer outcomes
over time...

including an increase in
psychiatric disorders,
chemical dependency and
**increased vulnerability and
risk**

Let's look at the story of
Mitchell and David...



**to see how these two brothers
involved in motor vehicle
accidents one year apart and
had different outcomes...**

A Tale of Two Brothers

Mitchell was in a severe
MVA 8 years ago & David
was in a severe
MVA 7 years ago

A photograph of two men. The man in the foreground is a young man with short dark hair, looking directly at the camera with a neutral expression. He is wearing a dark blue t-shirt. The man in the background is slightly out of focus, also looking forward. He has dark hair and is wearing a light-colored collared shirt under a dark jacket. The background is a blurred indoor setting with some greenery visible on the left.

Before the injury

**Both had friends and lived
independently**

Both had full-time jobs



Following the Accident...

Mitchell

- 90 days of acute rehab
- Depression

David

- 90 days of acute rehab
- Depression

**Both received the same
services, with very different
outcomes**



8 years later...

Mitchell

**Intermittent Explosive
Disorder
Intact Intellect
Impulsivity**





7 years later...

David

**Substance abuse
Intellectual deficits
Easily exploited**



Mitchell

**Isolated due to the fearful
reactions of those around
him**

David

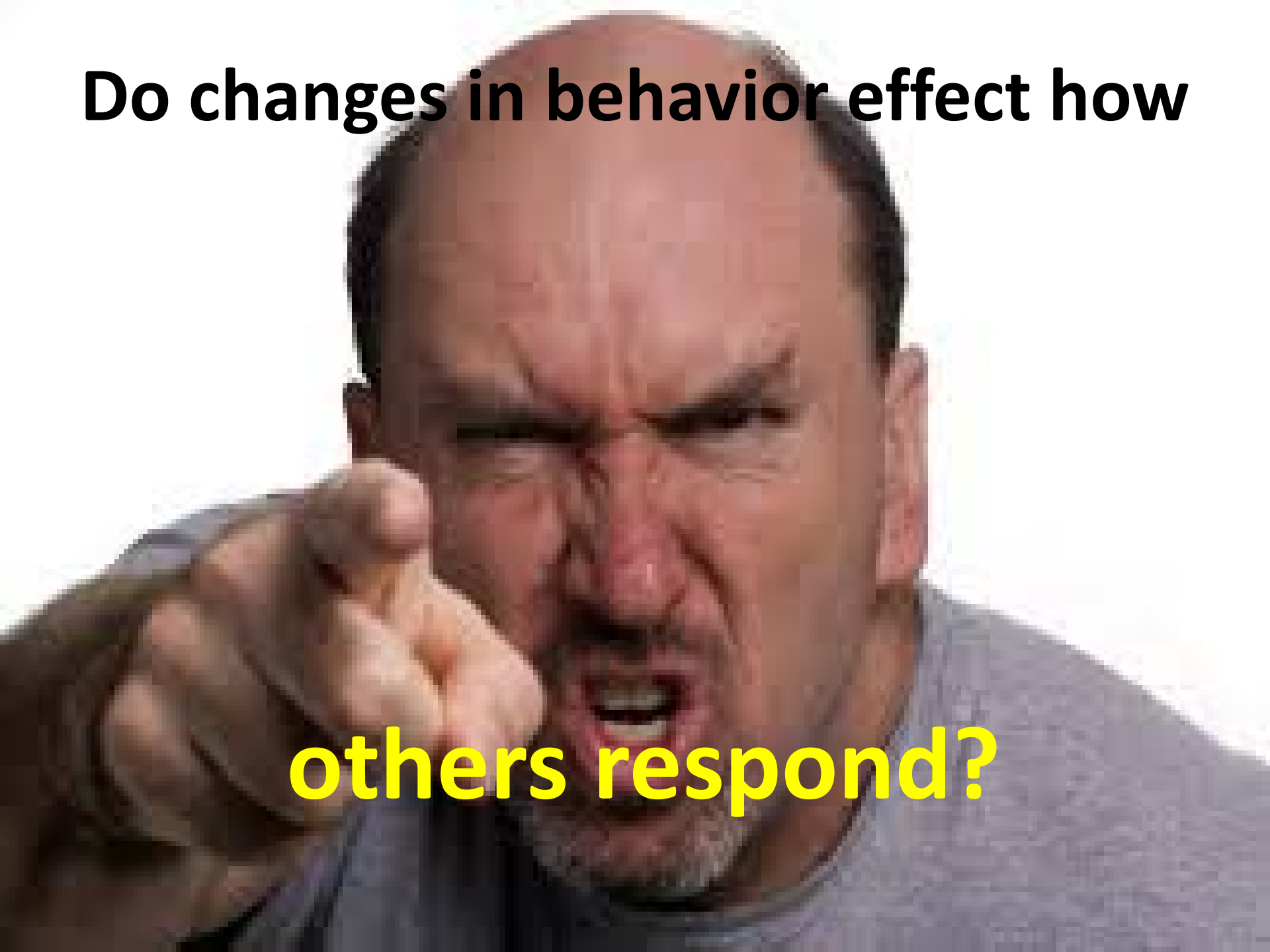
**Had more relationships...
but was vulnerable.**

**Do changes in behavior effect
relationships?**



Do changes in behavior effect how

others respond?



**Can we expect caregivers to
work without supports?**



**Can attitudes be a barrier to
rehabilitation?**

Whose attitudes?

**The
person?**

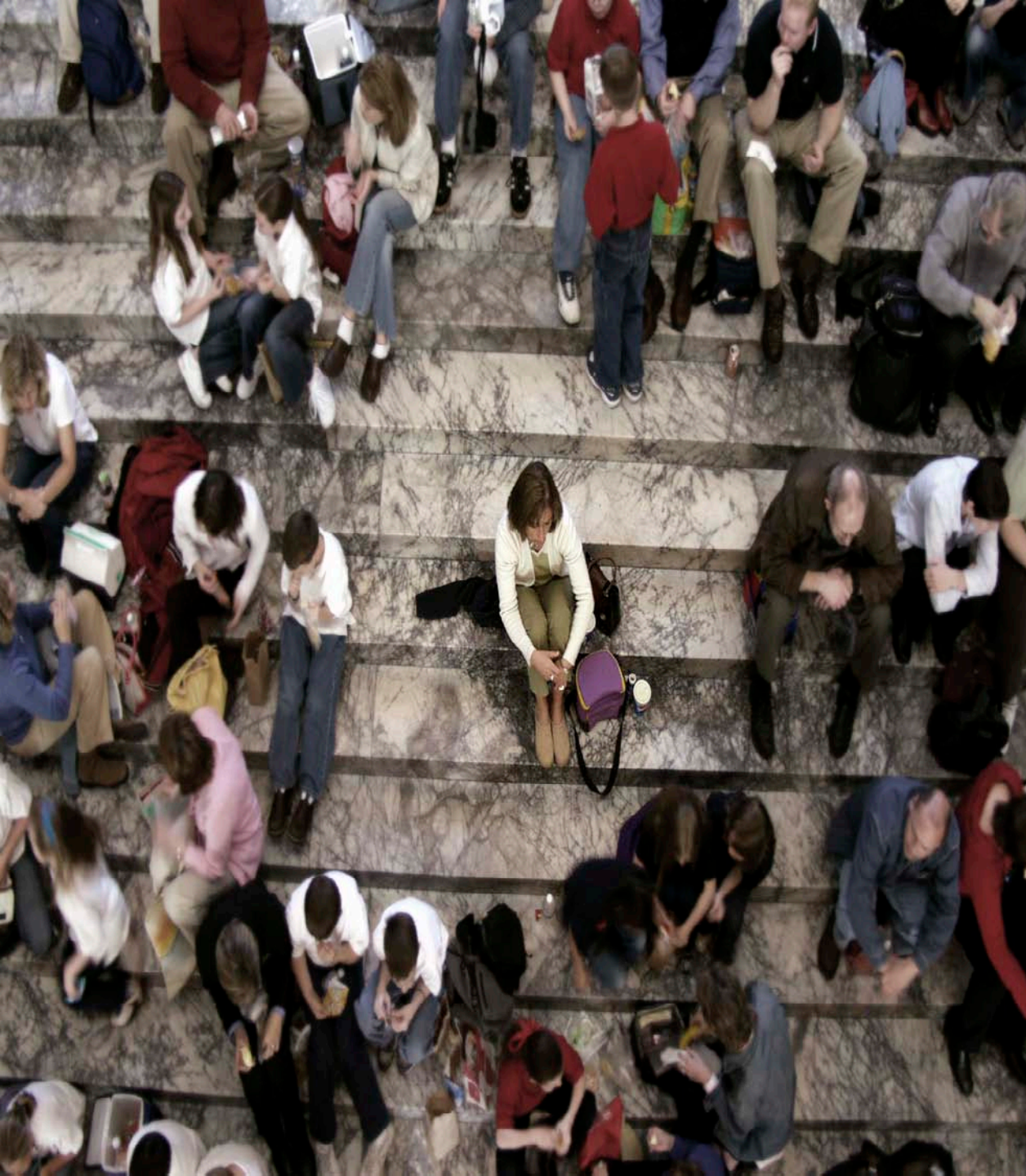




**Their
family?**

The rehabilitation provider?





**The
community?**

**Changes in relationships
create barriers**



**The lack of access to
services creates barriers**



How **adequate** are the
resources in the
community?

Can those resources
produce **good and durable**
outcomes for people with
brain injury?

Factors to consider

The person

Age at Injury

Injury Severity

**How much rehab was
available?**

The impact of barriers...

on support systems...

**on the availability and
access to services...**

**on a way to pay for
services...**

The lack of financial
resources for rehabilitation
changes potential outcomes

**Systems and policies which
provide for or remove
needed resources effect
outcomes**

Resources = Outcomes





**The people living with brain
injuries in the shadows...**

Their perception of life after brain injury

**The amount of support needed
throughout their lifetime**

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

**What are the effects of
isolation?**

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

**What is the relationship of
social relationships to long-
term outcome?**

**Understanding that happiness is
a property of groups of people.**

**A person with brain injury and
those around them may be
unhappy**

Christakis, N, Fowler, J: Dynamic Spread of
Happiness in a large social network. BJM 2008;
337: a2338, 2008

The “cascade” effect occurs in illness and disability as a source of unhappiness for the person and others

Christakis, N, Fowler, J: Dynamic Spread of Happiness in a large social network. BJM 2008; 337: a2338, 2008

**Relative's criticism influences
adjustment and outcome after
brain injury:**

**Association between distress,
coping and recovery**

Weddell R. Arch Phys Med Rehab. Vol 91, June
2010, 897-904

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

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

Economic resources to support living and participation

Hammel J, et al Environmental Barriers and Supports to
Everyday Participation: A Qualitative Insider Perspective
from People with Disabilities, ACRM, Arch of Phys Med
and Reh. Reston VA. Elsevier April 2015 578-588

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).

The reality of living on a
fixed income with
decisions to make and
problems making them

**Brain Injury leads to loss of
financial independence
and creates dependence
on public funding**

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



Let's take another look
at the brothers...





Today...

Mitchell

- Living on the streets

David

- Intensive rehab
- Living independently

Could it have been different?

**What do you think would
work?**

Let's take another look at Sarah...



Overcoming Sarah's Barriers:

Sarah became eligible for Medicare after 2 years and was able to switch her MCO Medicaid to a traditional state-run Medicaid. Sarah is currently receiving the treatment she needs.

**Brain injury rehabilitation can
quickly exhaust a person's
commercial insurance policy**

**Due to forced changes in
economic circumstances they
enroll in Medicaid**

The **impact** of Medicaid and privatization of Medicaid...

**Many state and federal
funding services have been
privatized...**

**which reduce tax burdens
on the states...**

**but leave insurance
companies in charge of
determining eligibility of
services.**

**Insurance companies are
accustomed to addressing
the initial medical costs
incurred...**

**not the long- and short-
term cognitive and
behavioral components of
Brain Injury.**

Insurance companies use the term “**medical necessity**” which may lead to a loss of funding

**39 states now contract
with MCOs to serve some of their
beneficiaries and over half of all
Medicaid beneficiaries get their
care through MCOs.**

Source: KFF Medicaid Care Market Tracker, September 2014

**Services which extend
beyond acute medical
rehabilitation are needed**

**Can the resources be flexible
to meet these needs?**

**Can we create solutions to
problems?**

**Can we work with MCO's to
address the problems
experienced by people living
with brain injury?**

**Can we together develop
solutions which produce
durable outcomes and are cost-
effective?**

**Remember what Buckminster
Fuller said about change?**

Can the **system change** or is a
new system needed?

What needs to be addressed?



Supports for social return



Returning to work



**Resources for mental health
and substance abuse**

Support for caregivers



Preventing caregiver burnout



Housing





Transportation

Preventing Disability-related poverty





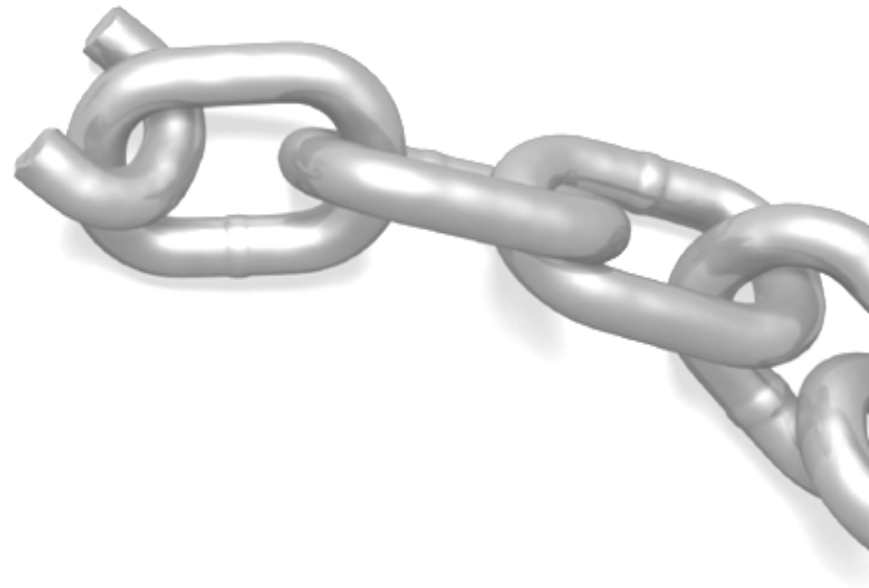
**Meaningful
life activities**

**What about access to
services?**

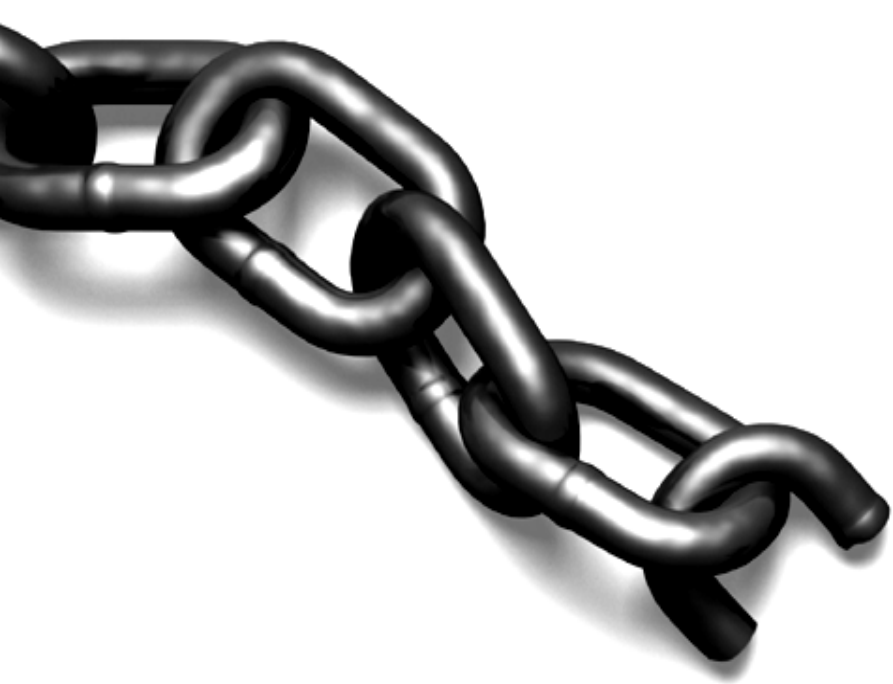


**Is our current model
working?**

How did it get broken?



Is it repairable?



**Or, do we need a new
approach?**

**What would be in the
new model?**

**Considering a New
Approach to the Cost**

**Who Pays for Treatment
After a Severe Brain Injury?**

**How long would treatment
and supports be available?**

Can we consider a model which
integrates care, housing and
supports to address the **long-**
term needs of people with
brain injury?

How would it **work?**

**What do you think
is needed?**



Let's Brainstorm!

**This presentation can be found
at**

traumaticbraininjury.net

**Look under “Resources” and
then**

“Community Presentations”

Resources

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Emerson, E. Poverty and people with intellectual disabilities, Mental Retardation and Development Disabilities Research Review, 2007, 13 (2): 107-113

Fann J, Burington B, Leonetti A, Jaffe K, Katon W, Thompson R. Psychiatric Illness Following Traumatic Brain Injury in an Adult Health Maintenance Organization, Arch of General Psychiatry. 2004; V 61, Jan 2004: 53-61

Fremstad, S. Half in ten: Why taking disability into account is essential in reducing poverty and expanding economic inclusion, Center for Economics and Policy Research, Washington, DC 2009

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Resources

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Silver J, Kramer R, Greenwald S, Weissman M. The association between head injuries and psychiatric disorders: findings from the New Haven NIMH Epidemiologic Catchment Area Study, Brain Injury, 2001, V. 15, No. 11: 935-945. Reproduced with permission from Informa Healthcare.

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Whelan-Goodinson, R, Ponsford, J, Johnston, L, Grant, F. J of Head Trauma Rehabilitation. Psychiatric Disorders Following Traumatic Brain Injury: Their Nature and Frequency. 2009 Vol 24 (5): 324-332