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

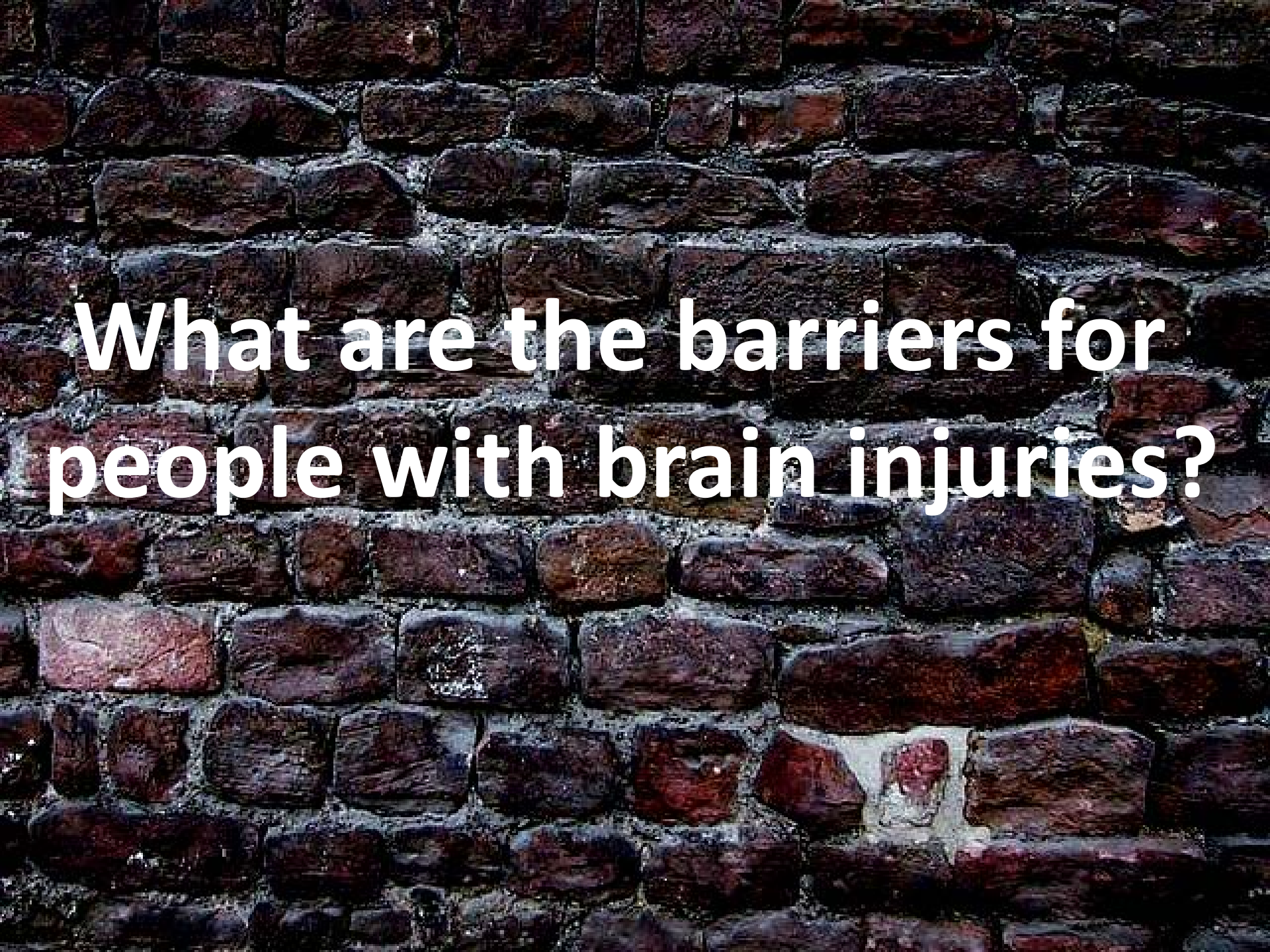
You never change things by fighting the existing reality. To change something, build a new model that makes the existing model obsolete.

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

Source: Masel, B. & Dewitt, D. (2010)

When do barriers emerge following brain injury?

And, how do they change?

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

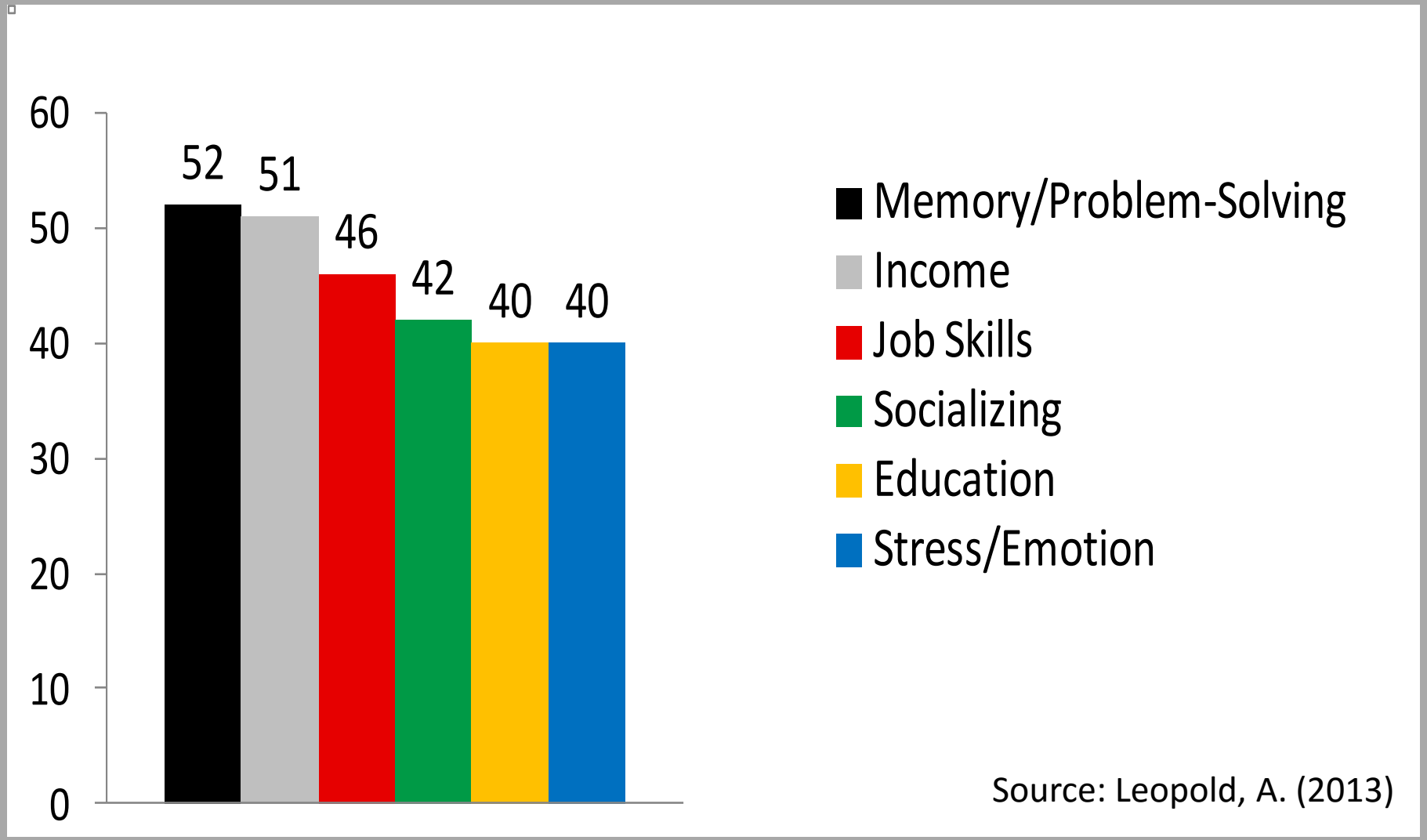
Resources = Outcomes

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

Source: Leopold, A. (2013).

Medicaid recipients reporting "unmet needs"



Source: Leopold, A. (2013)

Do people with unmet needs find themselves in crisis situations?

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

Stability in housing is vital to community living

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

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

emergency placements

at hospital's
psychiatric units…

nursing homes…

jails…

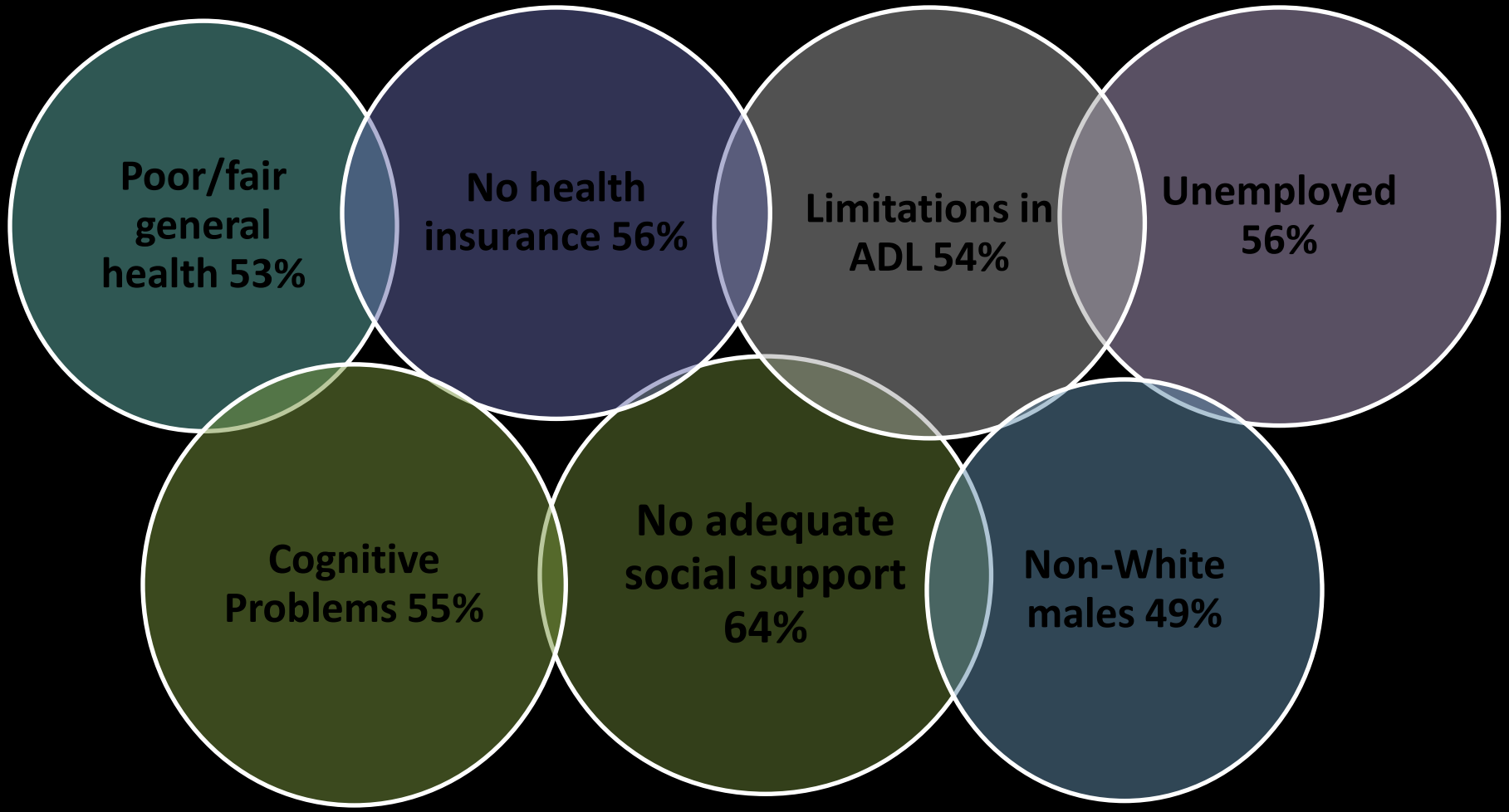
homeless shelters

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

…and, certainly do not offer realistic long term solutions

What are the barriers?

Defining the barriers



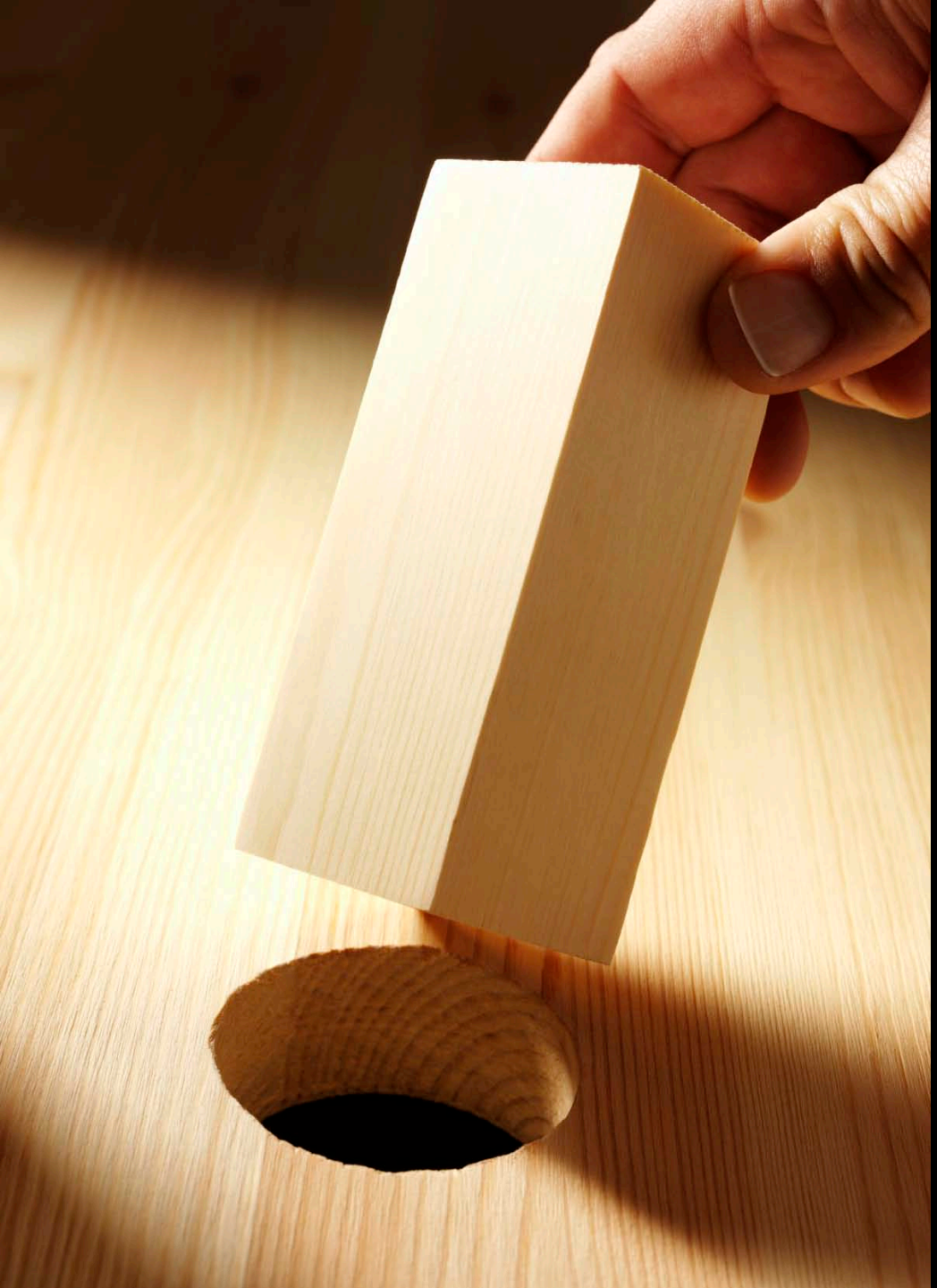
Source: Leopold, A. (2013)

The lack of access to services creates barriers

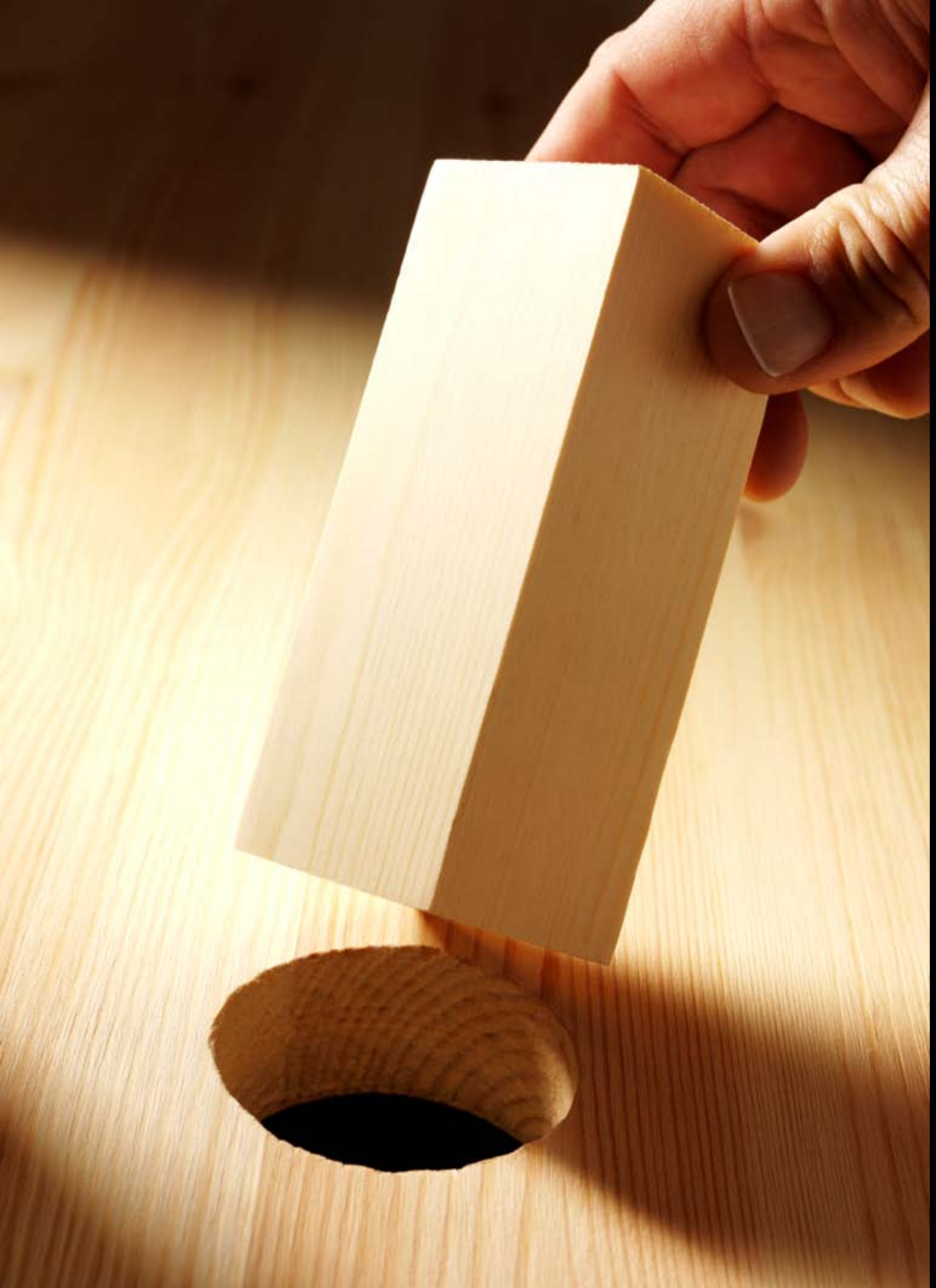
Would Sarah's outcome

be different without barriers?

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



What about the person who doesn't fit?



Or, is it “one size fits all”?

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

Inappropriate services result in poorer outcomes over time…

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

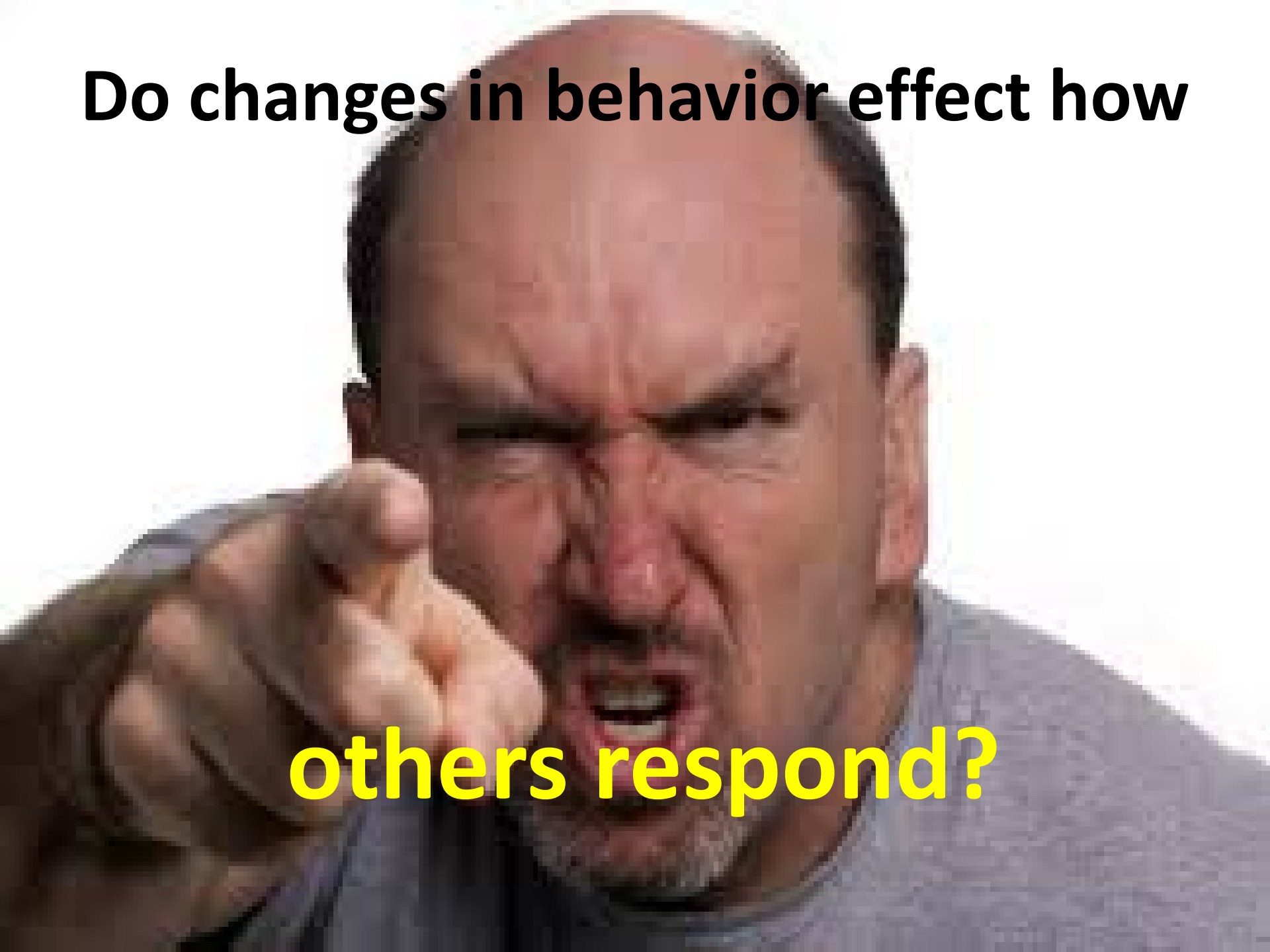
What about services after rehabilitation?

To sustain the gains made in rehab

To deal with new problems

Do changes in behavior effect relationships?

Do changes in behavior effect how



others respond?

Can we expect caregivers to work without supports?

What supports?

Social

Psychological

Health

Financial

Changes in relationships
create barriers

Does aging with a brain injury create new barriers?

What do the studies tell us?

Age and sex-specific life expectancy were lower than the U.S. general population

Brooks, J et al. Long-Term Survival After Traumatic Brain Injury. Part I and II. Arch Phy Med and Rehab, V.96, N.6, June 2015. pp994-1005

Age, male gender, injury severity and degree of disability in walking and self-feeding relate to increased mortality

Brooks, J et al. Long-Term Survival After Traumatic Brain Injury. Part I and II. Arch Phy Med and Rehab, V.96, N.6, June 2015. pp994-1005

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

The aging process in the increasing years since injury

Declines in physical and cognitive functioning

Declines in societal participation

Source: Sendroy-Terrill, et al, 2010


Let’s look at the story of
Mitchell and David…

to see how these two brothers involved in the same accident had different outcomes…


A Tale of Two Brothers
Mitchell & David were in a severe
MVA 20 years ago


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

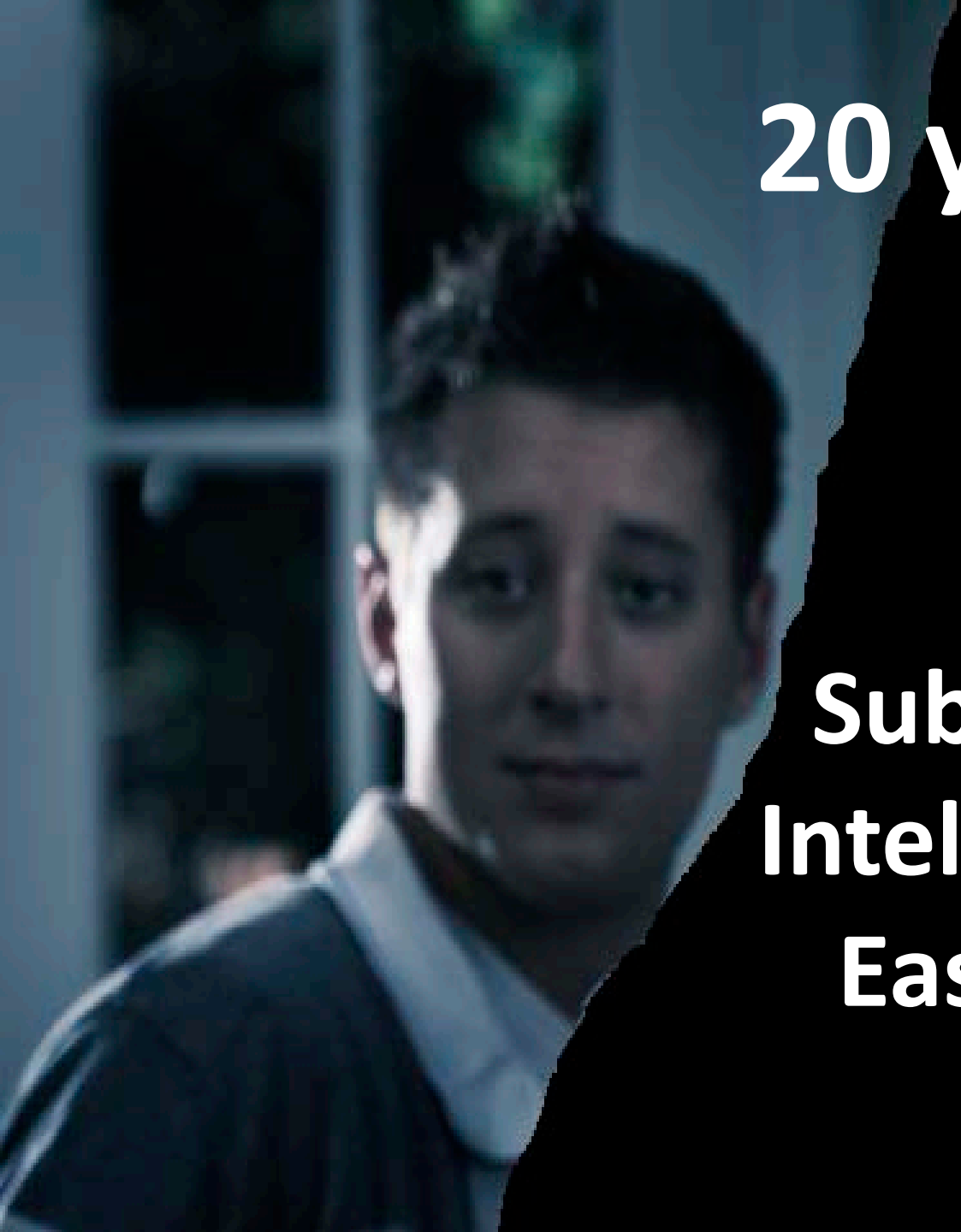
- 90 days of acute rehab
- Depression

Both received the same services, with very different outcomes

20 years later…

Mitchell

Intermittent Explosive Disorder
Intact Intellect
Impulsivity



20 years later…

David

Substance abuse
Intellectual deficits
Easily exploited

Mitchell

Isolated due to the fearful reactions of those around him

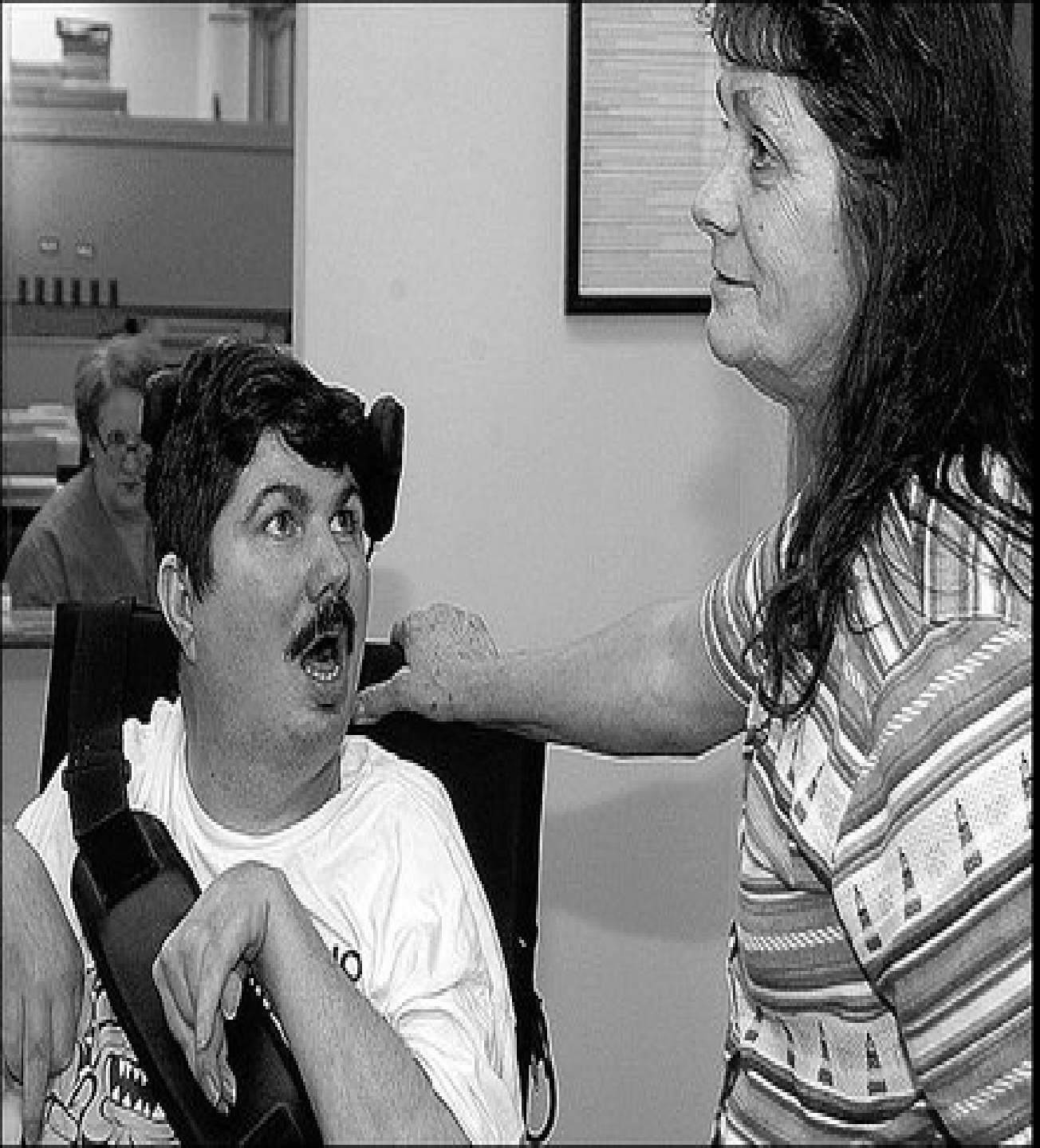
David

Had more relationships…
but was vulnerable.

Can attitudes be a barrier to rehabilitation?

Whose attitudes?

The person?



Their family?

The rehabilitation provider?

The community?

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?

Long-term functional status

Health status

Their perception of life after brain injury

The amount of support needed throughout their lifetime

Let’s look at these factors in terms of long-term issues

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

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

Source: Frank, et al. (2005)

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

Source: Condelucci, A. (2008)

Disengagement from naturally occurring social units

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

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

Source: Silver, J., Kramer R., Greewald., Weissman, M. (2001)

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

Source: Kaponen, S. , et al. (2002)

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

Source: Ponsford ,J .et al. (2008)

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

Source: Whelan-Goodinson, R., Ponsford, J., Johnston, L., Grant, F.J. (2009)

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

Source: Fann, J., et al. (2004).

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

Source: Geurtsen, G.et al. (2010)

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?

Is loneliness a component of social network failure?

What are the effects of isolation?

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).

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?

What's needed as people age with a brain injury?

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

Life expectancy after TBI

- **Twice as likely to die as age, gender and race matched peers**

- **Estimated life reduction of 7 years**

Source: Harrison-Felix, C., et al. (2004); Harrison-Felix, C., et al. (2006).

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).

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

Source: Brooks, et al ACRM V96, N.6, June 2015

The people living with brain injuries in the shadows…

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

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?

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

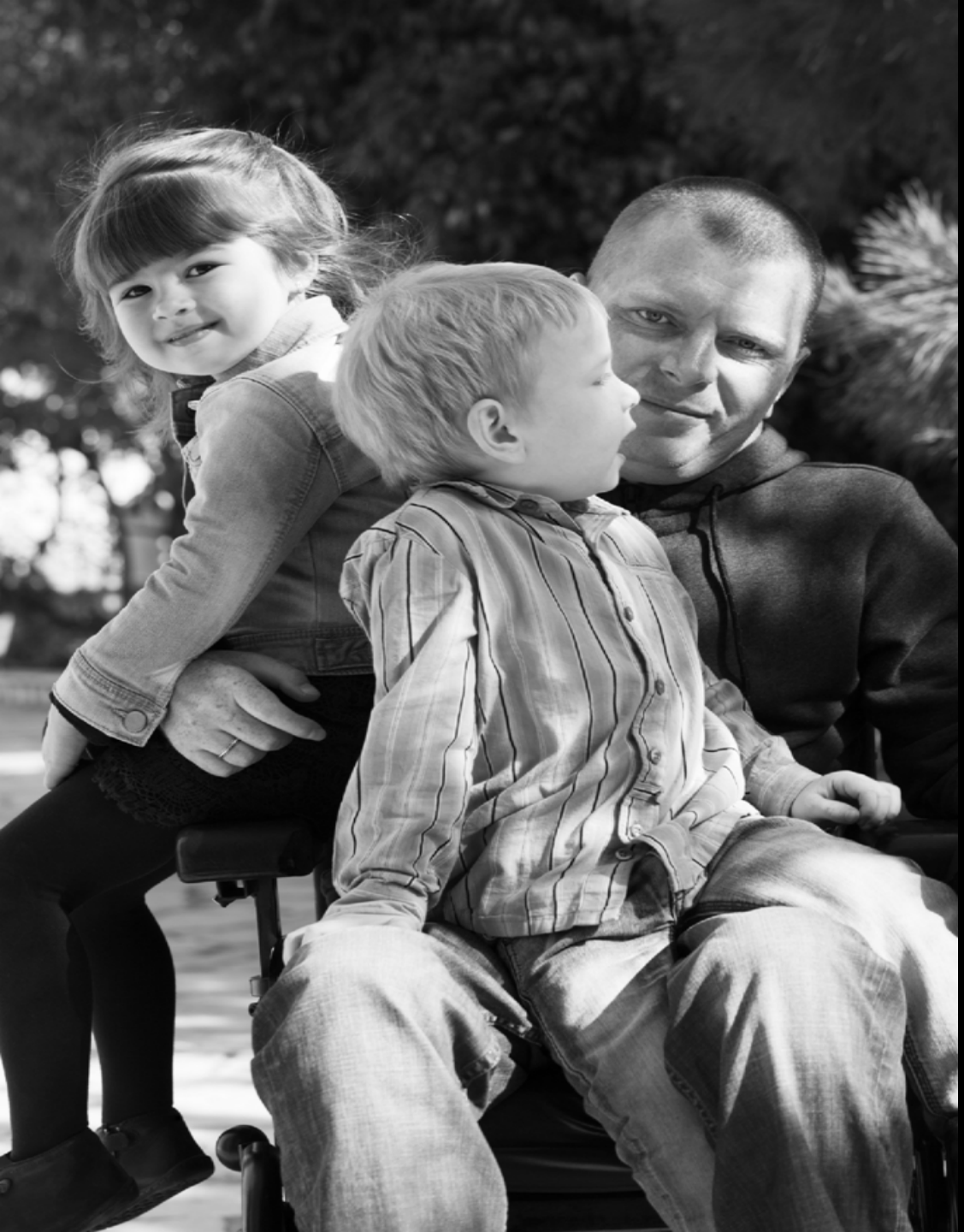
Resources for mental health and substance abuse

Support for caregivers

Preventing caregiver burnout

Housing

Transportation



Meaningful life activities

Resources to accommodate aging with a brain injury

Preventing Disability-related poverty

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.


Let’s take another look
at the brothers…

Today…

Mitchell

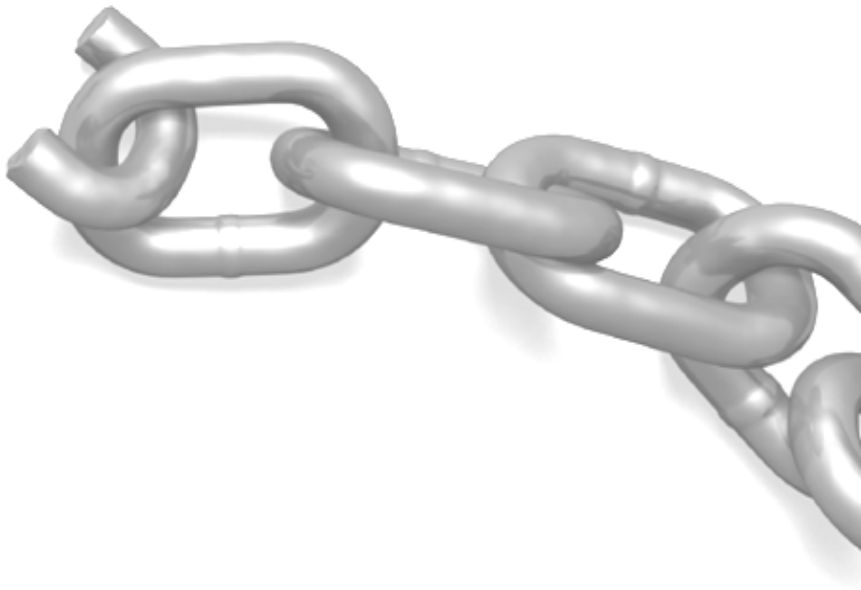
- Living on the streets

David

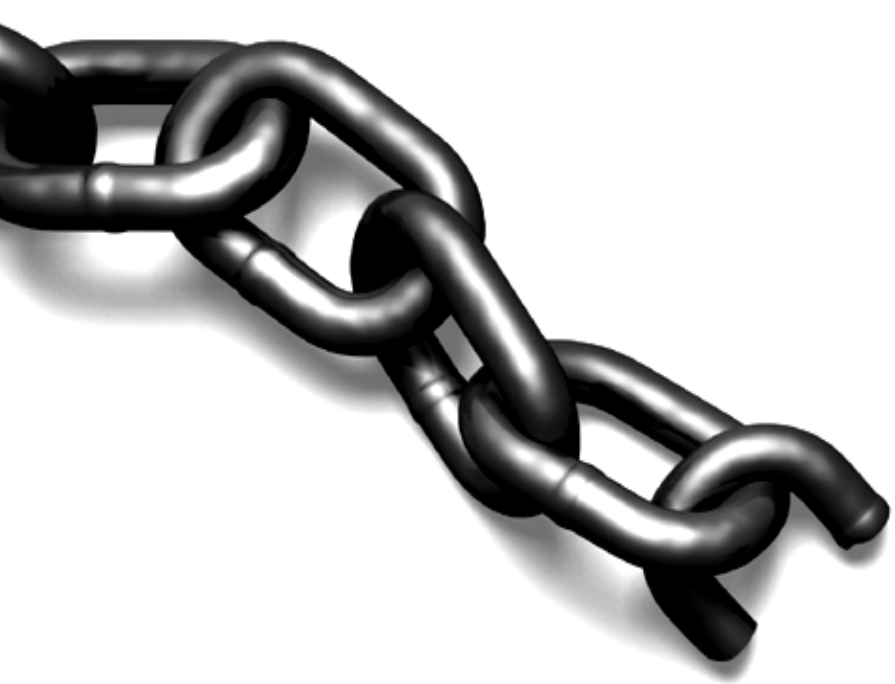
- Intensive rehab
- Living in a group home

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

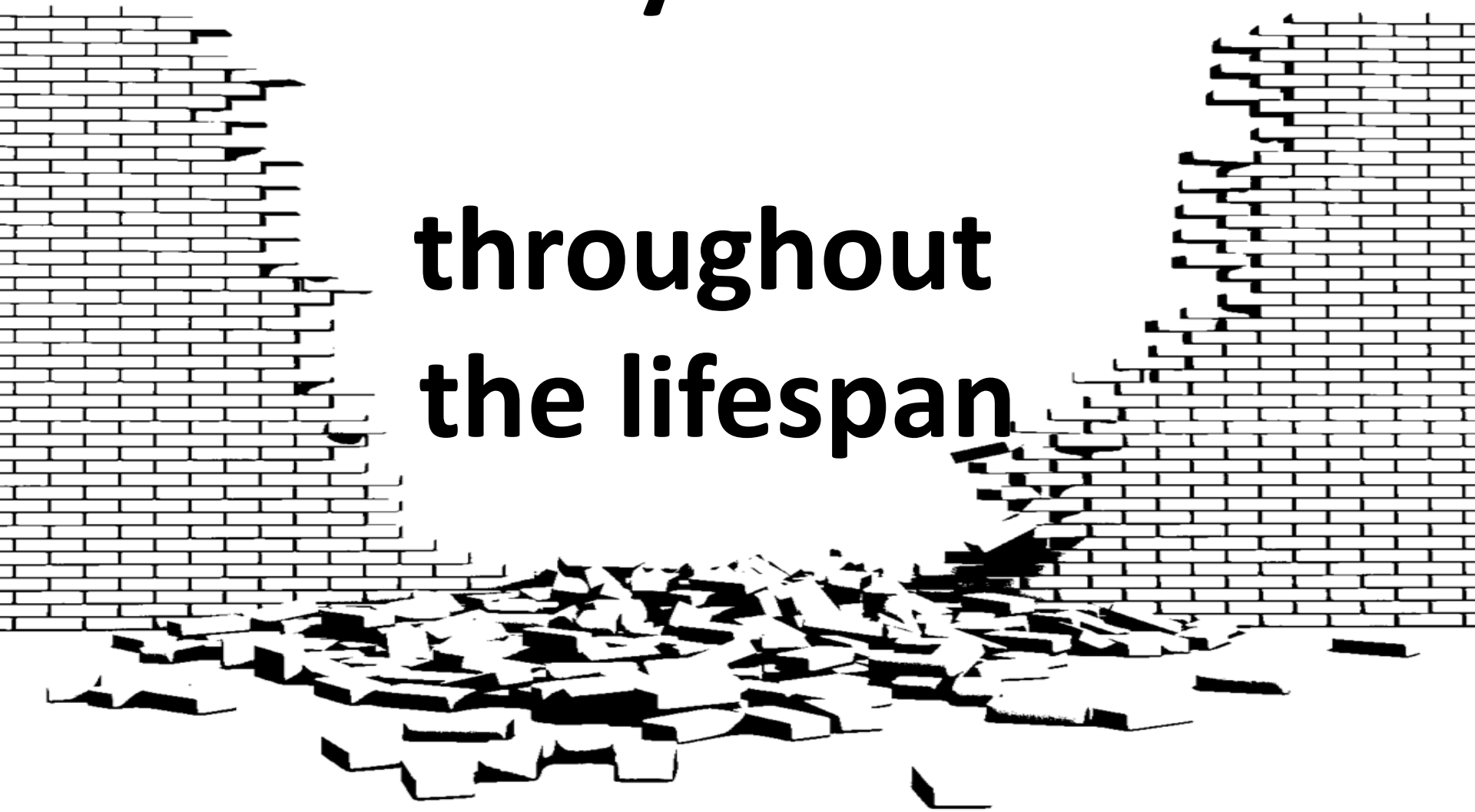
Who Pays for Treatment After a Severe Brain Injury?

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?

Eliminating barriers as they occur….



throughout the lifespan

What do you think is needed?


Let’s Brainstorm!

What about financial barriers?

What about social supports?

What about housing?

What about access to services?

What do you think would work?

This presentation can be found at traumaticbraininjury.net Look under "Resources" and then "Community Presentations"

Resources

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Yeo, R., Moore, K. Including disabled people in poverty reduction work: “Nothing about us, without us”, World Development, 2003 V 31 (3): 571-90

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