



# The Double Whammy: Living with a Brain Injury and a Psychiatric Disorder

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# Disclosure Statement

Rolf B. Gainer, PhD has business relationships with Brookhaven Hospital, the Neurologic Rehabilitation Institute of Ontario, Community NeuroRehab and Rehabilitation Institutes of America.

Any of the outcome studies conducted by those organizations and referenced in this presentation are funded by the respective organizations without grants or other research supports.

addressing the  
realities of a co-  
occurring diagnosis



# today's goals

- **1. Review**
- **2. Review**
- **3. Review**
- **4. Review**
- **5. Review**
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- **99. Review**
- **100. Review**

# today's goals

**To develop an understanding  
of the problems faced by an  
individual with a brain injury  
and psychiatric problems in  
their long term return**

# today's goals

**To understand the community-based resources which are needed by the person with a brain injury and a psychiatric disorder**

# today's goals

**To consider how an amalgam of strategies  
and interventions are needed to sustain  
participation and involvement**

# today's goals

**To understand the role of brain injury in  
the mental health population**

**what do we know  
about TBI?**

**1.5+ million new cases a  
year**

**what about severity?**

**75-80% of the brain injuries in the U.S. civilian population are “Mild”**

**“Mild” Brain Injuries can  
have significant long-term  
consequences**

**there is nothing “mild”  
about Mild Brain  
Injuries**

**Moderate and Severe Brain  
Injuries cause significant  
disability with  
physiological, cognitive,  
psychological and  
behavioral changes.**

Brain Injury can create  
a lifetime of disability

we could fill **six cities the size  
of Detroit** with people living with  
the effects of brain injury in  
America today.

# **what groups contain individuals with brain injury?**

- Mental Health 25%**
- Substance Abuse 40%**
- Prison population 65-70%**
- Homeless 80%**

# what about returning veterans?

- Estimated 150,000 – 300,000 have a TBI (2000-2010)
- Nearly 10% of all service members
- 30% of all Walter Reed AMC admissions
- 18.5% of all service members have PTSD = 472,000 diagnosed with PTSD
- 25% are experiencing mental health problems
- 17.5- 22.00/100,000 have attempted suicide

# TBI

THE INDEX EVENT

psychosisdepres  
sionanxietydisor  
dersmaniaaffecti  
vedisordposttrau  
maticstressor  
deraggression



**every page of the DSM**



**where do we find the roots of  
mental health issues?**



**let's consider brain injury and  
mental health issues in the  
context of social  
relationships and social  
network participation**

**what about social role  
return?**

**is it a determinant of  
potential mental health  
problems?**

**by addressing the  
realities of a co-occurring  
diagnosis**

**life changes.**

**changes**  
**injury-based changes**  
**changes**

**every aspect**

**each relationship**

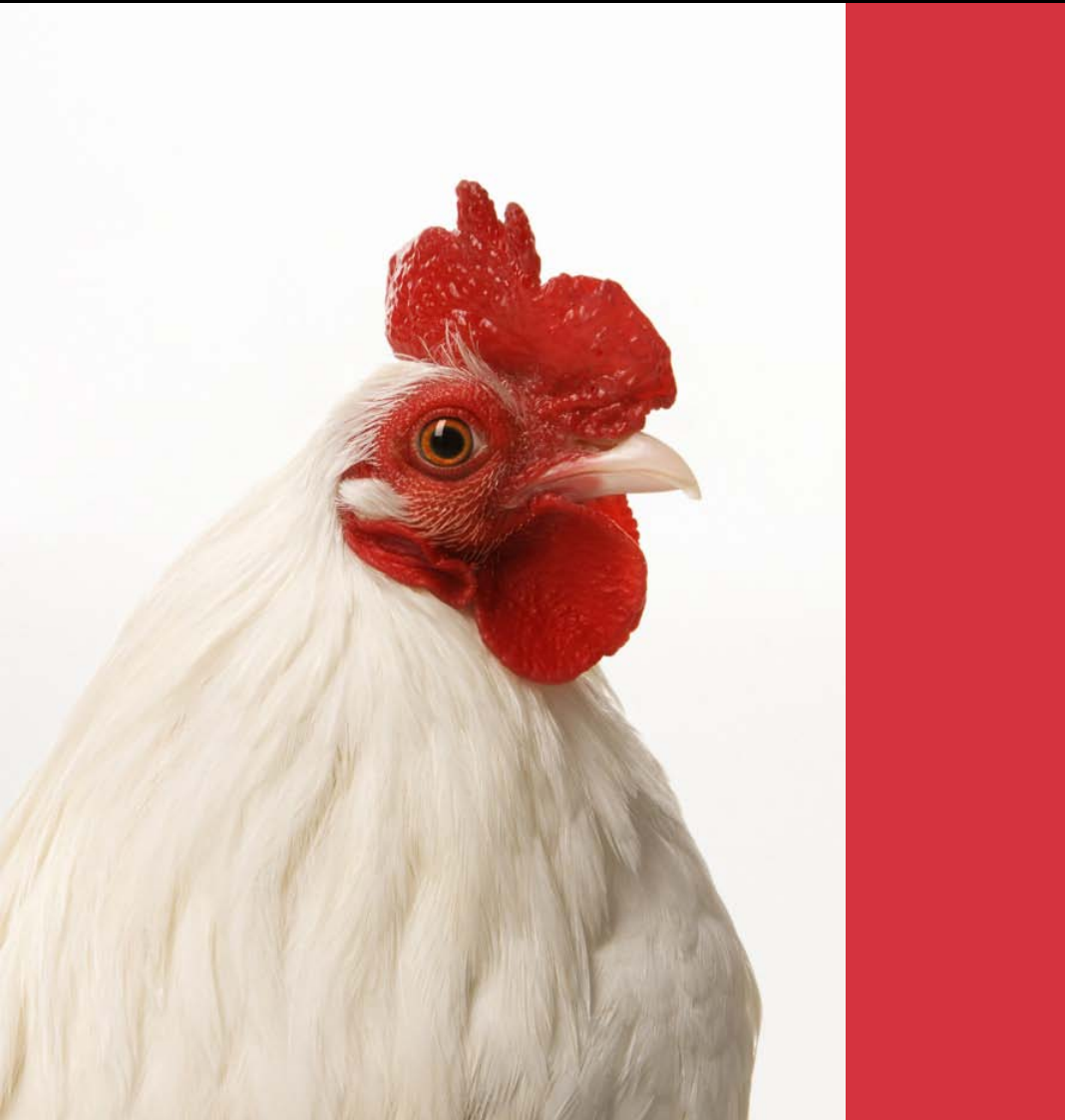


**In the early phases of recovery,  
some behaviors can resemble a  
psychiatric illness**

**pre-injury mental health problems  
can be exacerbated by a brain injury**



# what came first?



psychopathology ?

or

neuropathology ?

**Does it ~~mask~~ psychiatric illness?**

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

what is it?

**the NRIO study**

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

**614 tracked from 1995-2012**

**Average age: 31.6**

**Age Range: 2.11 to 78.7**

**100% Severe TBI**

**89.05% MVA**

**the NRIO Study:**

**Social Role Return**

**Independence/Support Level**

**Vocational/Avocational Activities**

**Mental Health and Substance Abuse  
Issues**

**Durability of Outcome**

# the NRIO cohort

- **age at injury** 31.6
- **GCS <9** 83.5%
- **male/female** 67.4% / 32.6%
- **period from injury to post-acute** 21.00 months
- **% MVA related** 89.5%

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  
1997-2012

2.5 years post injury  
prior to admission



***substance  
abuse***

# 36%

**Pre- and post- injury substances abuse problems**



***substance  
abuse***



# 45%

**problems with significant other**



***substance  
abuse***

# 45%

**trouble maintaining relationships with friends**



***substance  
abuse***



**family members perception of  
problems post-injury**

Functional Physical Limitations  
**Chronic Medical Care Needs**  
Reliance Upon Others for Basic Care  
**Transportation**  
Depression  
**Cognitive Problems**  
Behavior and Anger Management Problems



**what our participants saw  
as key changes in their  
lives post-injury**

**1 to 5 years after the injury**

**nrio outcome study, adult cohort  
1997-2010**

# perception of post-injury changes

- cognition
- behavior
- emotions
- physical abilities
- relationships
- level of participation
- level of independence



why are the participants  
perceptions of post-injury  
changes different from those  
of family members ?

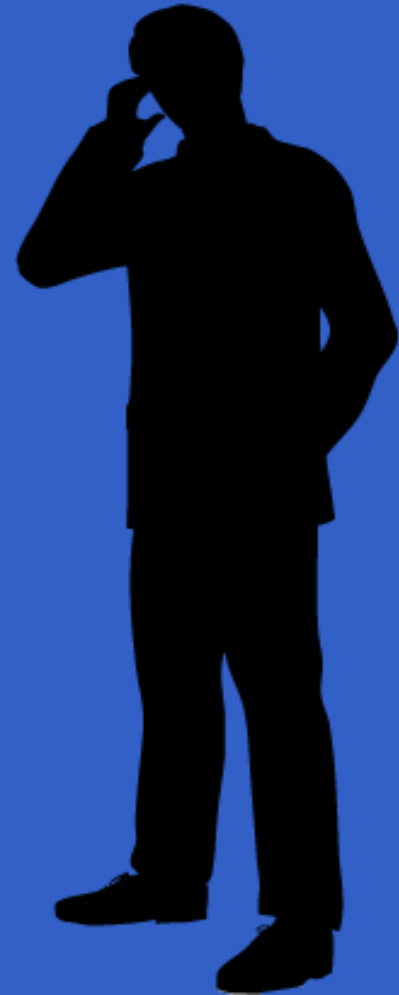
relationships  
participation  
independence

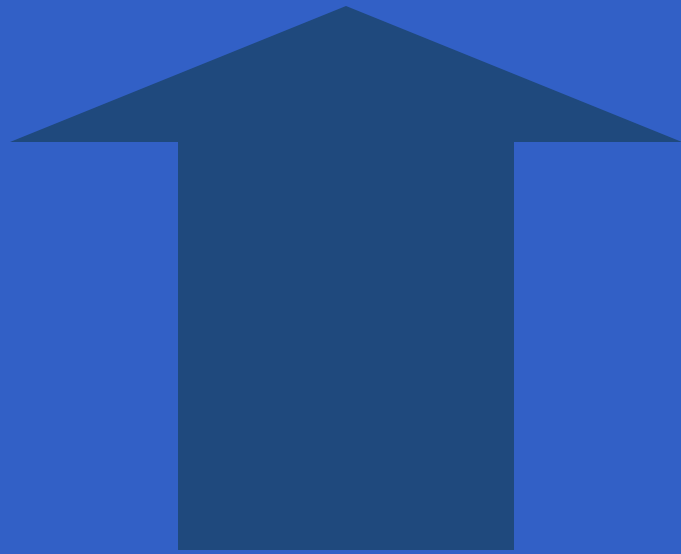
**perception = reality**

# mental health and TBI

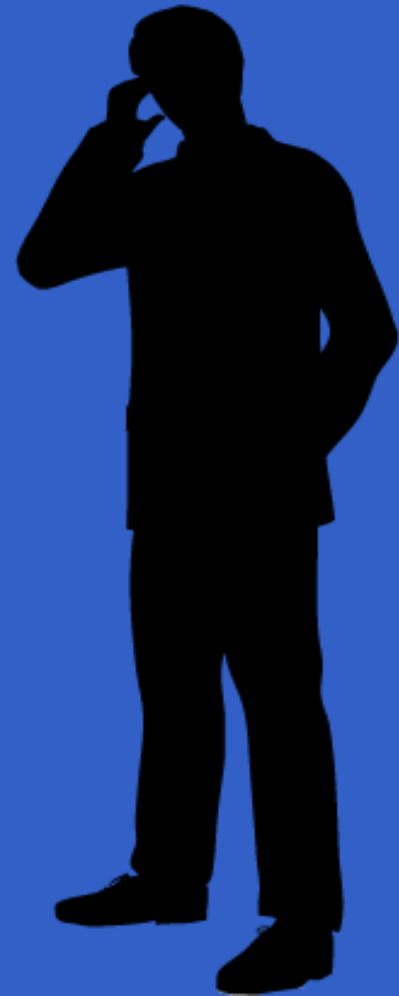


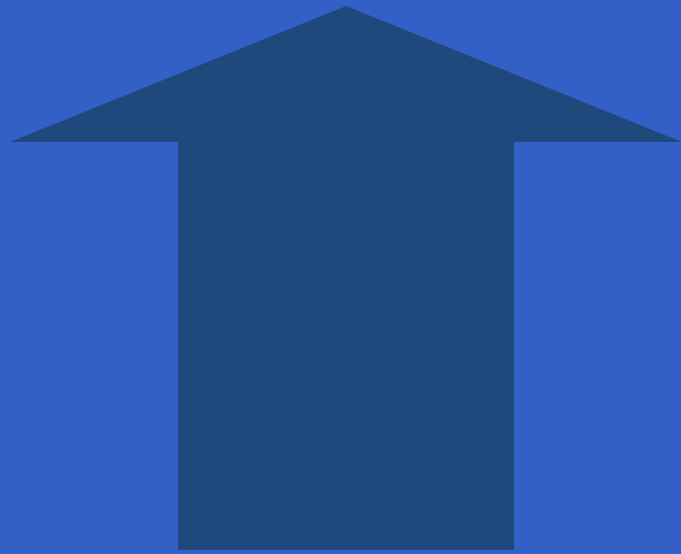
Unemployment +  
depression +  
anxiety



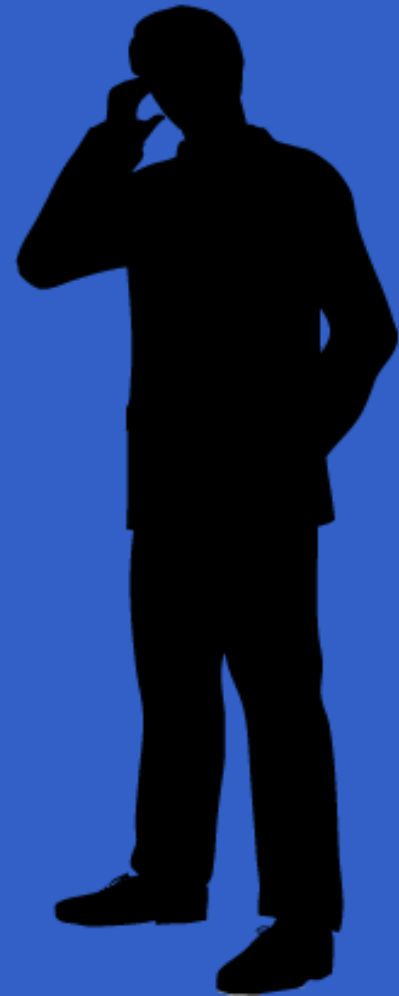


substance  
abuse





risk for  
suicide





why?

# long term outcomes

employment problems

decreased sense of well-being

suicidality

risk of seizures



***substance  
abuse***

# TBI: Pervasive Effects

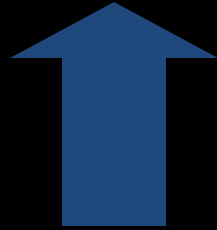


**cognitive  
changes**

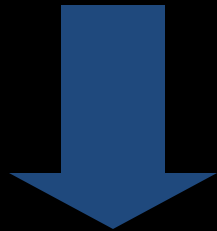
**underlie**

**behavioral  
responses**

cognitive deficits



interaction



post-injury behavioral  
disturbances

**behavioral responses  
contribute to risks**

How  
do we  
measure  
self-worth?

job, profession, skills

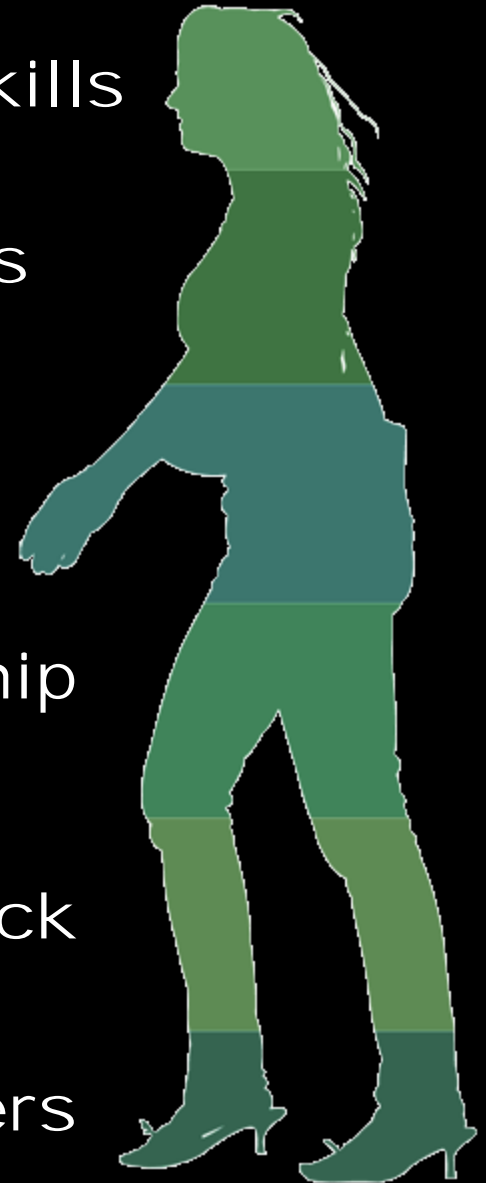
relationships, family, friends

life activities

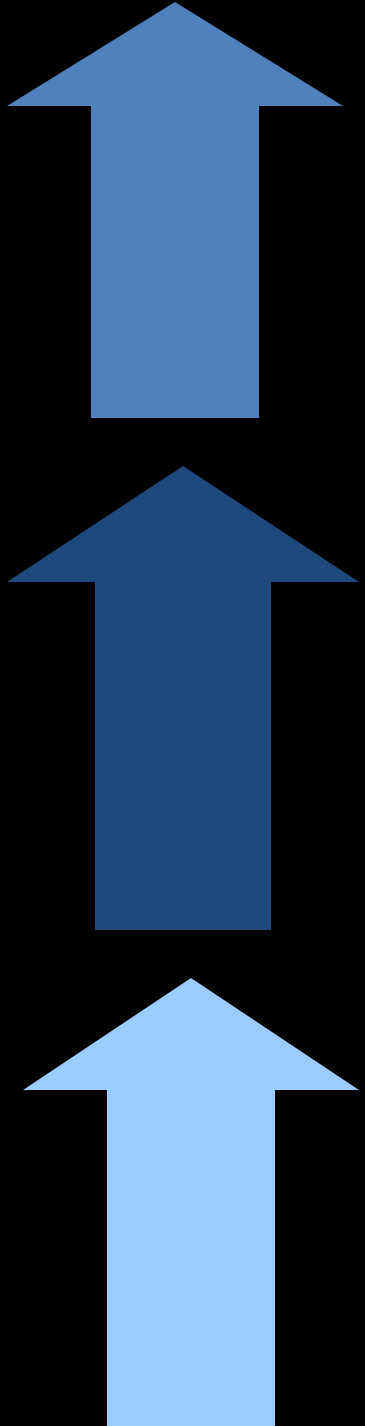
home/residence ownership

positive feedback

participation with others



What parts of  
me will  
adjust after  
a brain injury?

Three upward-pointing arrows are positioned on the left side of the slide. The bottom arrow is a light blue, the middle arrow is a medium blue, and the top arrow is a dark blue. They are arranged vertically, pointing upwards.

**aspects of brain  
injury increase  
psychological  
problems over time**

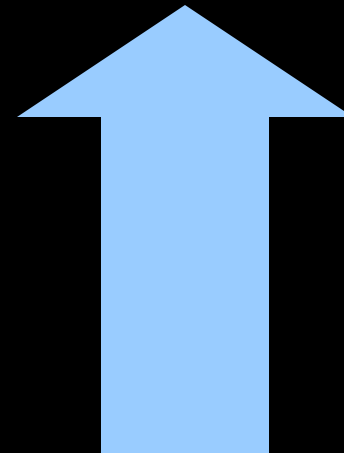
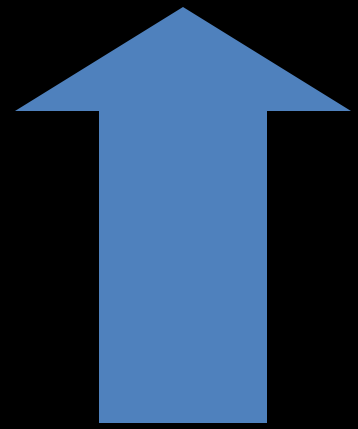
# **RISK FACTORS**

related to the onset of mental health problems

- **age**
- **pre-injury psychiatric problems**
- **pre-injury substance abuse**
- **poor work/social adjustment history**
- **problems in support networks**

degrees of  
separation

the risk for behavioral  
health problems  
**increases** in the years  
following an injury



brain injury

impacts on

social role



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

what happens

1yr 5yrs 10yrs

after rehab?

**10 years after the injury and  
rehab**

**nrio outcome study 1997-2012**

# 37.3%

**return to their  
primary social role  
without modifications**



# 43.1%

**experience a change  
requiring support and  
role modification**



0%

regression



# 19.6%

**experienced significant  
psychological problems  
requiring intervention**



are these the people with a  
“Dual Diagnosis”?

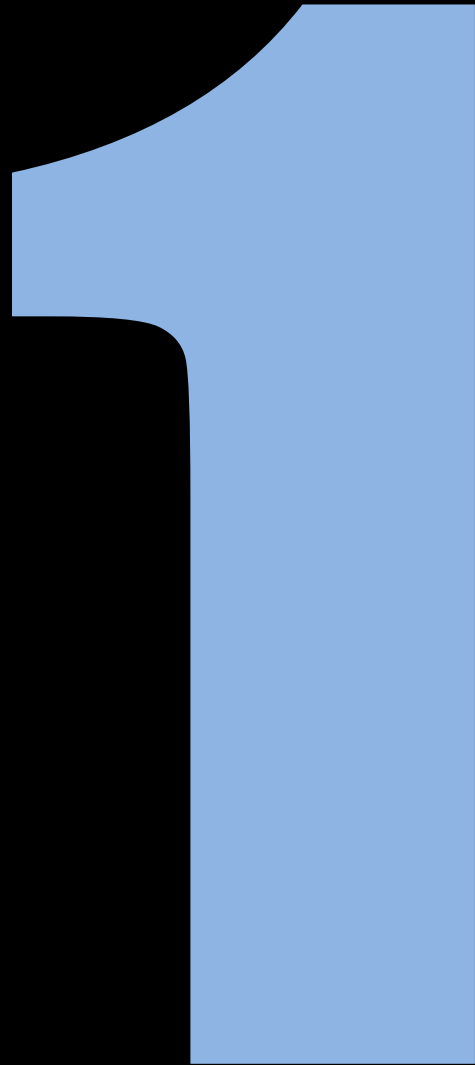
# 2 coping styles

**avoidance**

**worry**

**blame**

**drugs**

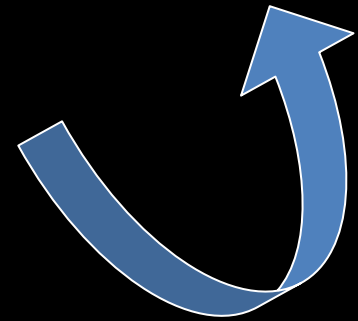


**humor  
relaxation  
problem-  
solving**

**2**

disability  
shift

# brain injury creates a risk for a mental health trajectory



- age at onset of disability
- male vs. female
- low/reduced social supports
- financial hardships

an increase to the risk  
for crisis...

requiring emergency  
mental health services

crisis events increased  
isolation and  
withdrawal

**will neurobehavioral  
problems be  
misunderstood?...**

...during a **crisis** event

**the response to mental  
health emergencies**

**where do I go in a  
crisis?**

**does social isolation  
contribute to the  
development of  
neuropsychiatric  
symptoms?**

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

is loneliness  
contagious?



mother



best friend



art school

Meet Rick  
at 22



# Richard at 37

art school



best friend



mother



# Rick at 22



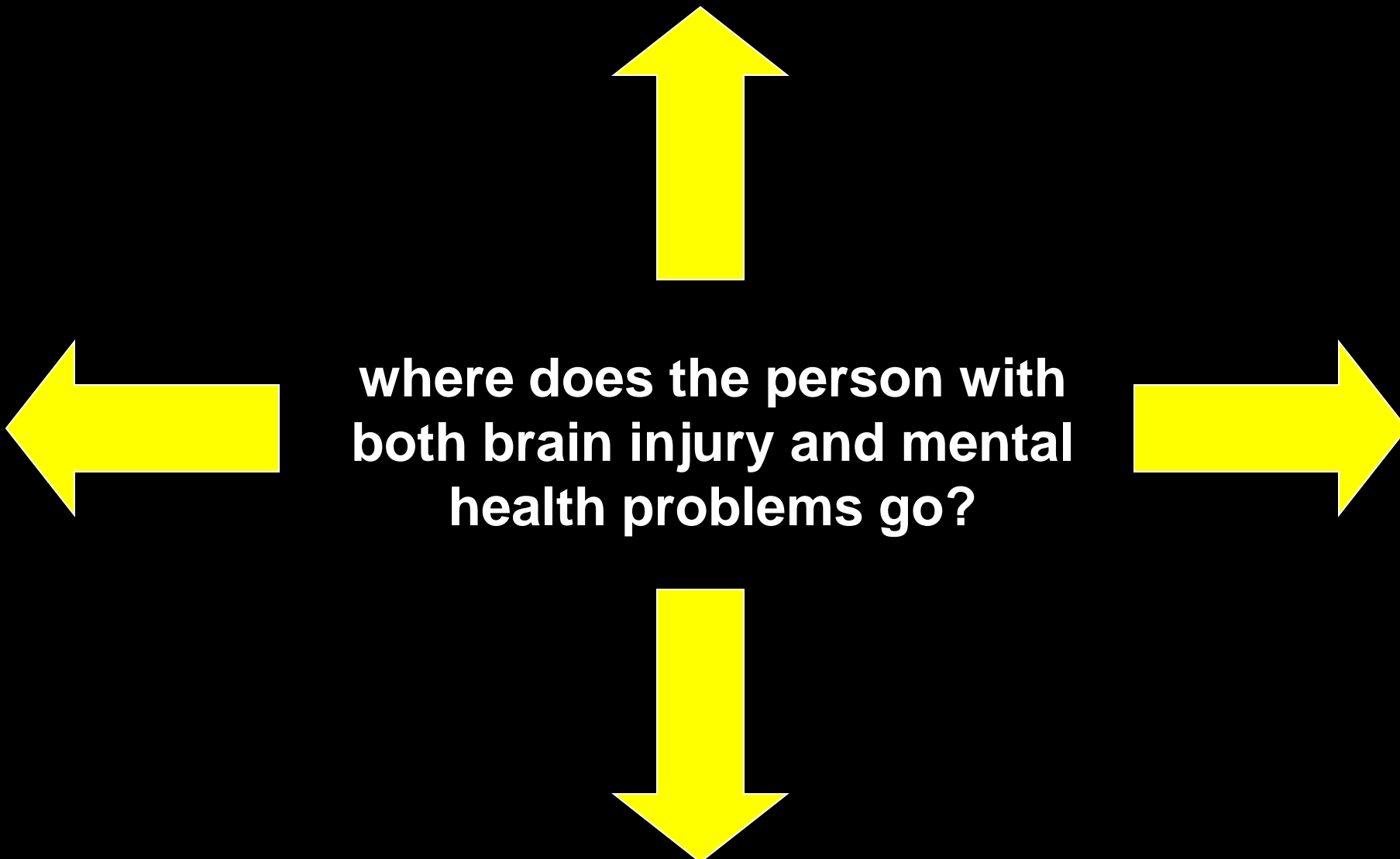
# Brain Injury and Mental Health

- 93.7% of BI providers reported working with dual diagnosis clients
- 48% estimated more than 26% of clients had a mental health diagnosis
- 20% estimated more than 50% of clients had a mental health diagnosis
- 23.1% of mental health providers indicated that clients with BI were not eligible for services
- Source: Toronto Acquired Brain Injury Network newsletter, Spring 2011

**does the person with a brain  
injury fit the mental health  
network?**

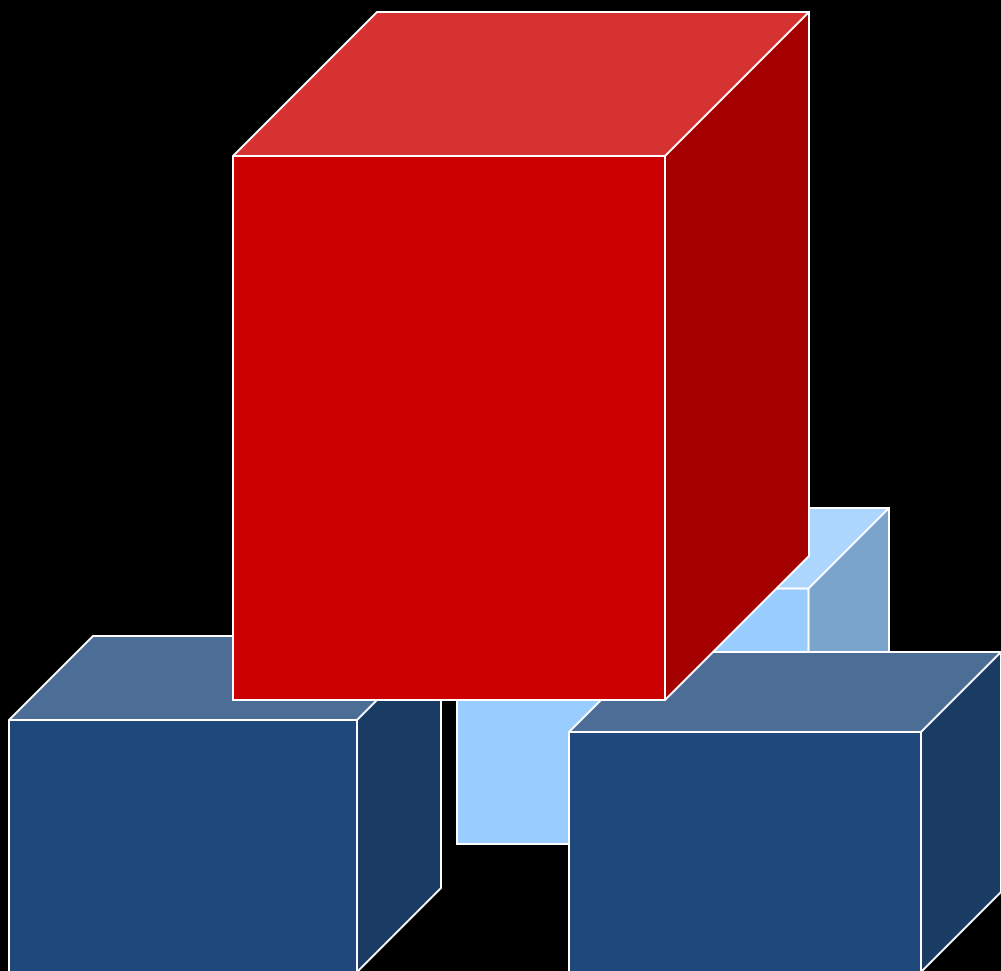
**or**

**does the person with mental  
health issues fit the brain  
injury network?**

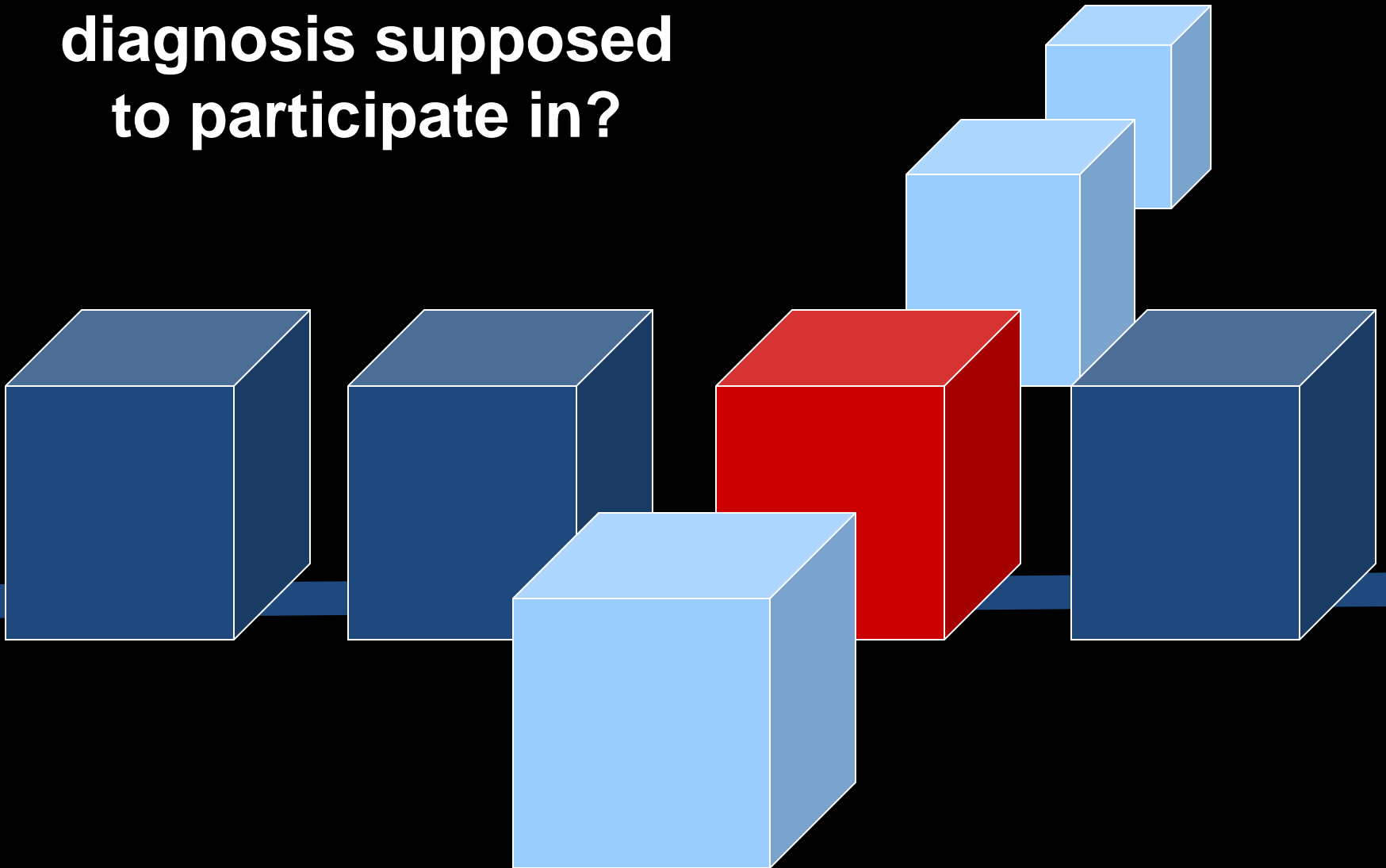


**where does the person with  
both brain injury and mental  
health problems go?**

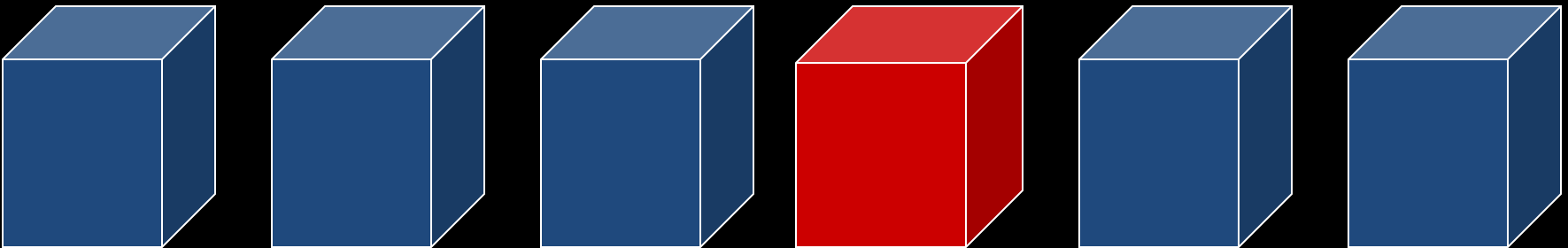
**or, will they be on  
the edge of two  
networks?**

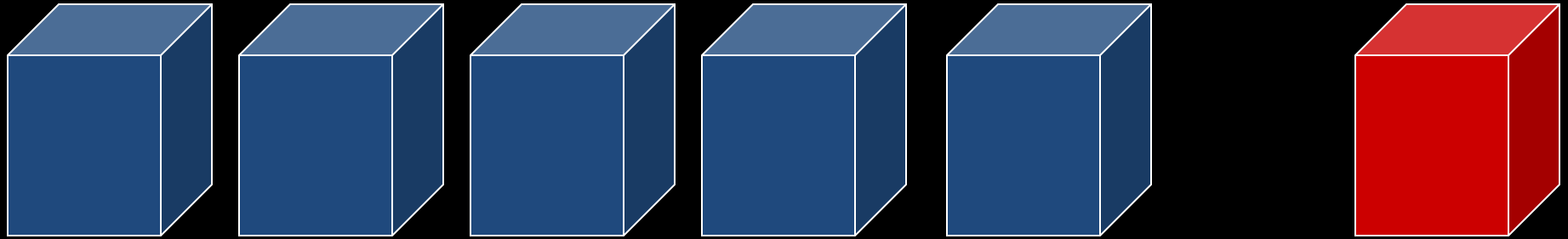


**What network is the  
person with a dual  
diagnosis supposed  
to participate in?**



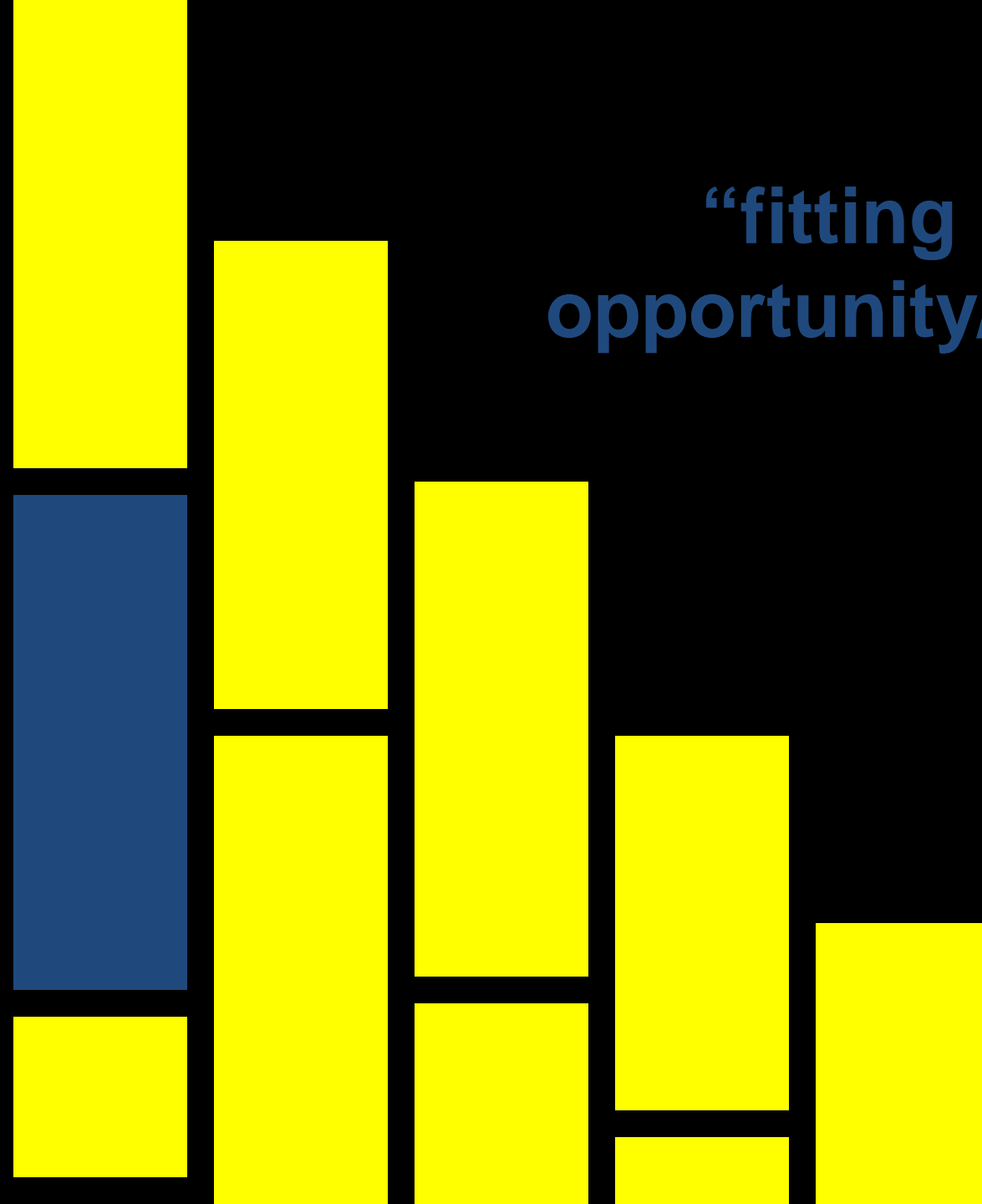
**isolation occurs when the person  
can't participate...**






they are moved to  
the edge of the network

**“fitting in” increases  
opportunity/participation**





social networks  
affect our lives

---

**we operate in clusters**



but, how much relates  
to the person?



# each network has relationship effects

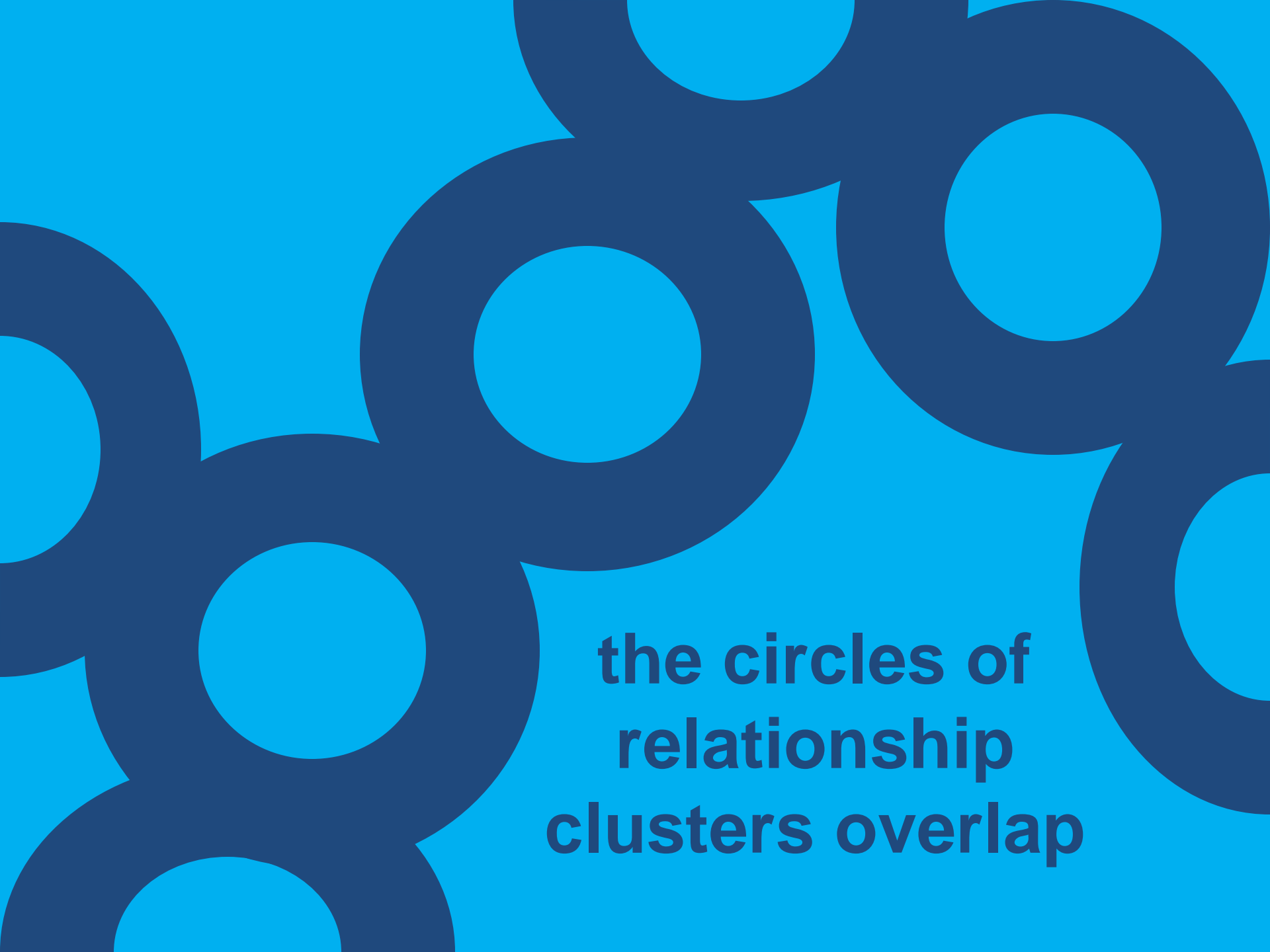


induction

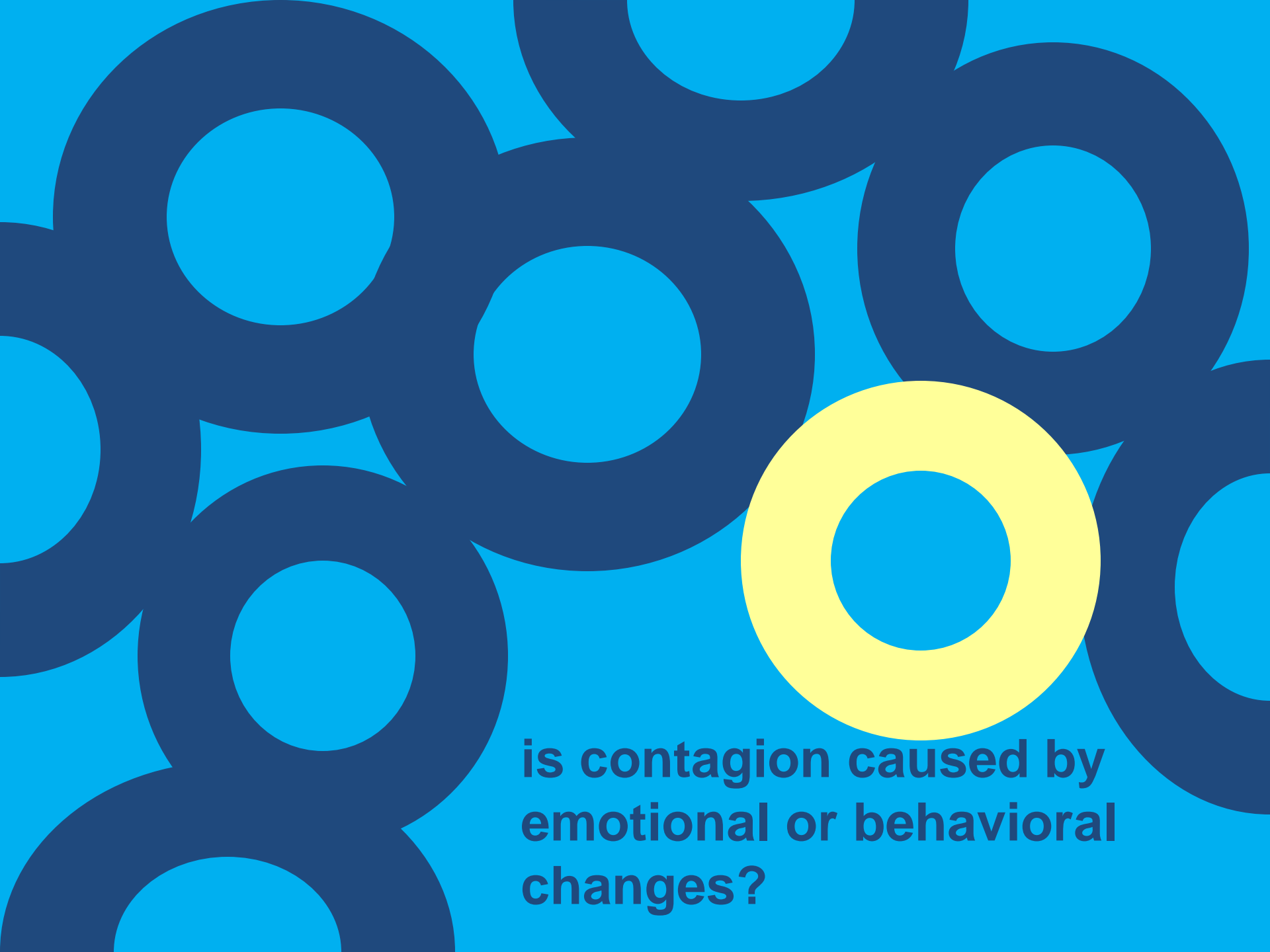
homophily

confounding

contagion

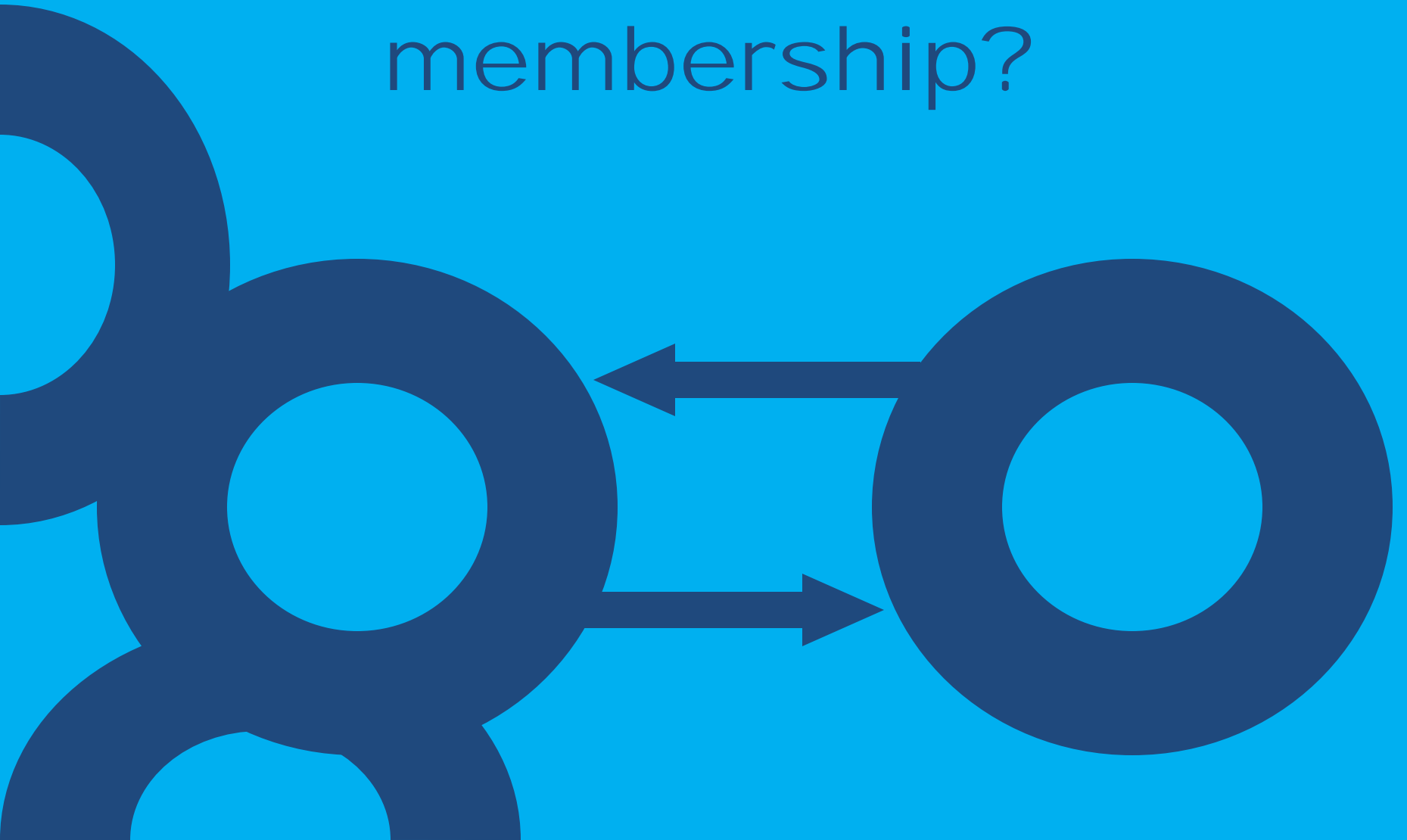


**the circles of  
relationship  
clusters overlap**

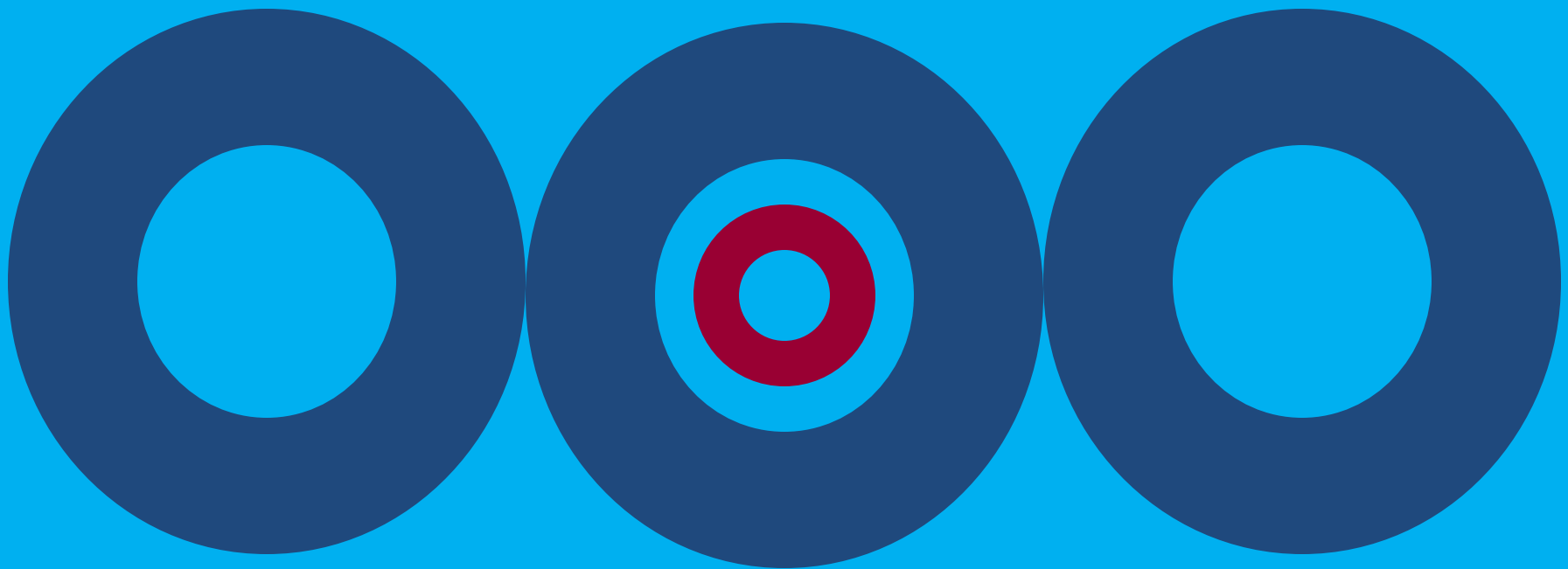


**is contagion caused by  
emotional or behavioral  
changes?**

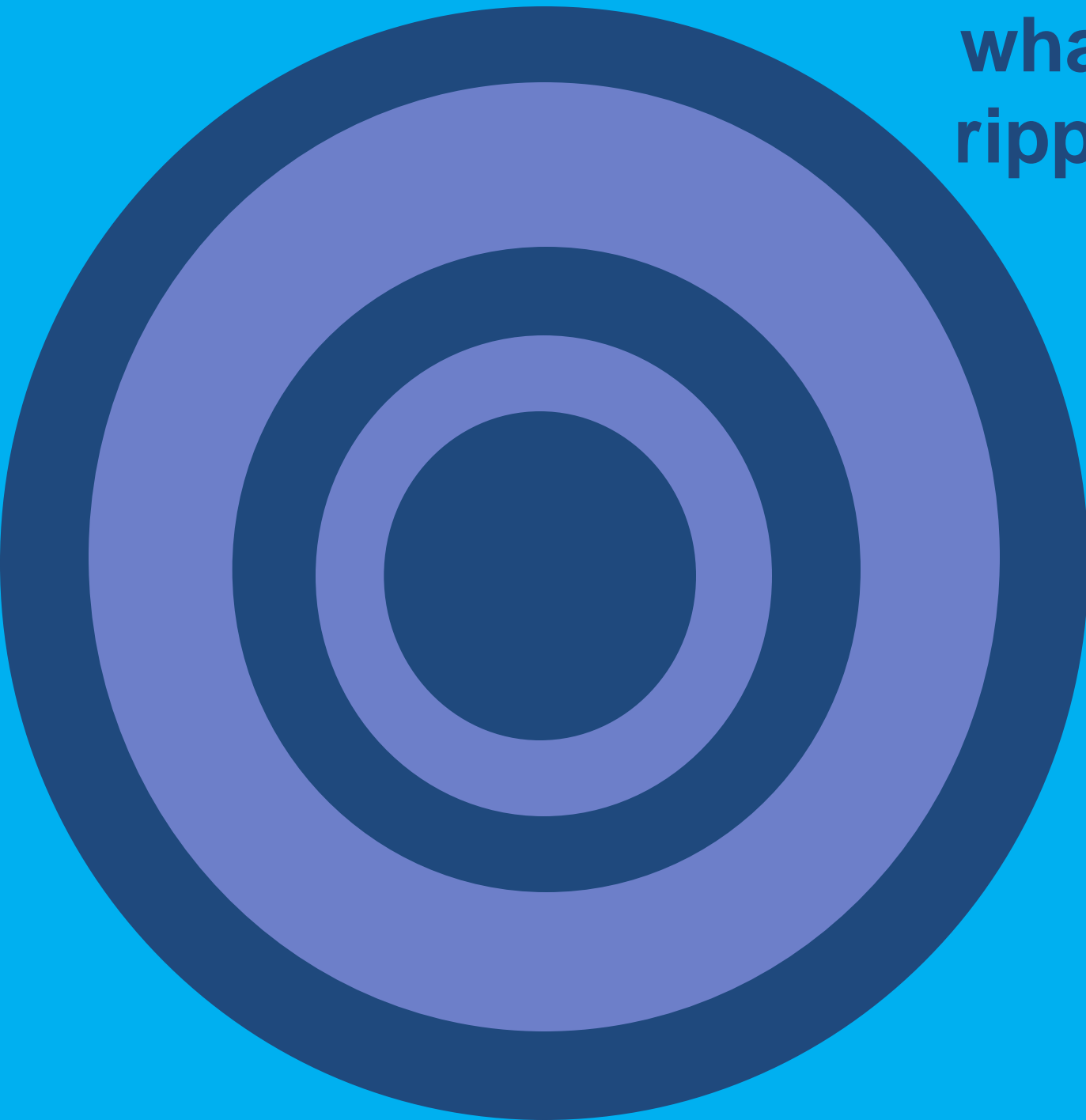
and, what part comes  
from social network  
membership?



do networks move  
people within the  
network?



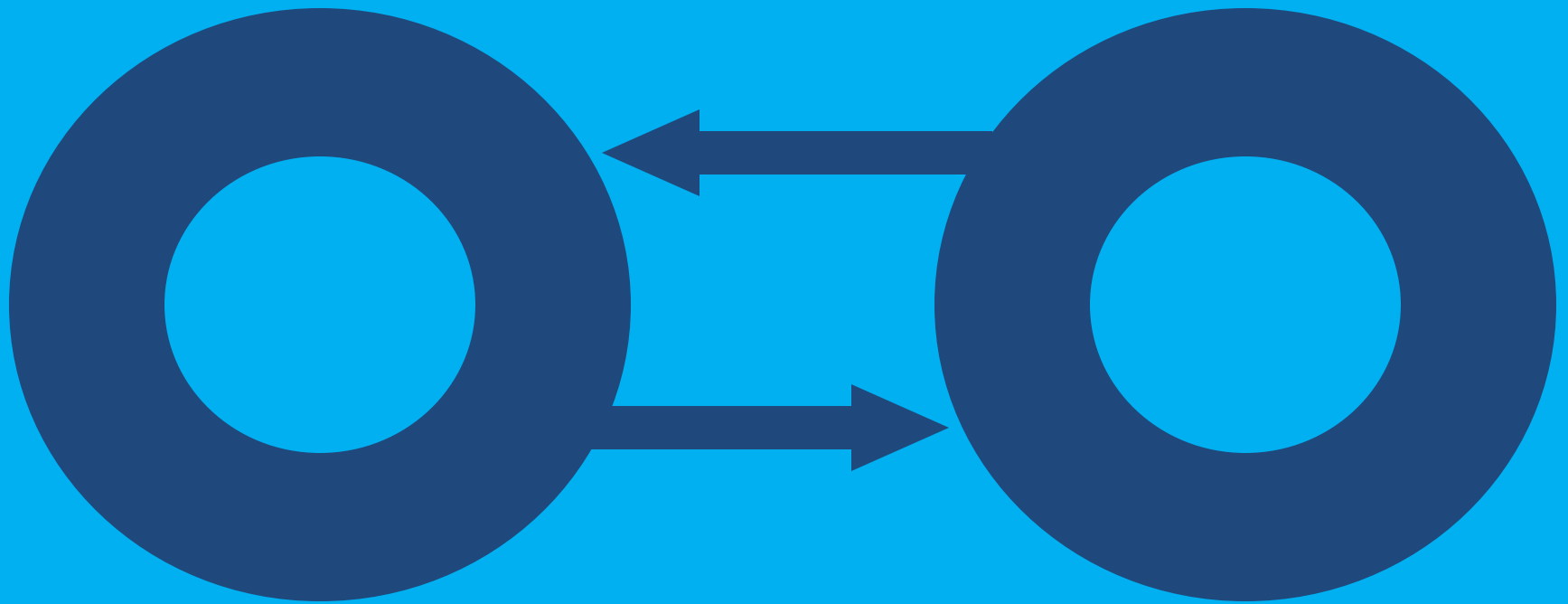
**what about the  
rippling effect?**





**...people who don't fit are  
found at the edges**

does the social network theory  
help us understand what  
happens to relationships?



social networks  
change size and  
complicate over time.

Social network  
membership requires  
certain behaviors

**where are the answers?**

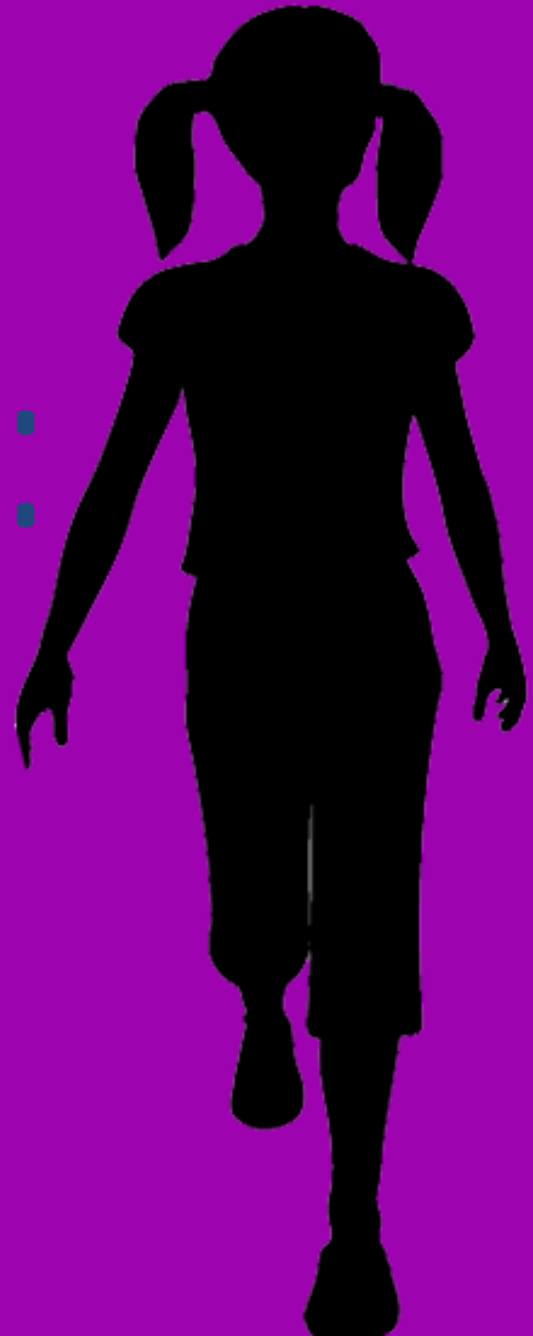
let's start

small

**what can we learn from  
children with TBI?**

**about the issues faced in  
adulthood?**

brain injury  
in childhood :  
the lifespan  
issues



high survival rate for moderate to severe

risk of future mental health issues

problems 5-8 years post-injury

social isolation due to  
functional and behavioral issues

need for extended family  
supports

Long Term Implications



**brain injury in childhood will effect the  
person throughout their lifetime, increasing  
the risk of mental health problems**

**two years later**

1997-2009, nrio outcome validation study, pediatric and youth cohort



20%

**returned to grade level**



40%

**required program changes**



40%

**required psychological supports**

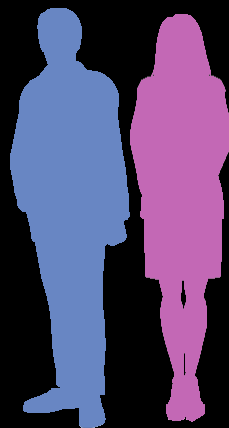


60%  
returned with modified social role

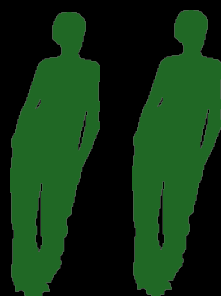


today's  
child with  
TBI is  
tomorrow's  
adult

**can we see the roots of  
problems in adulthood  
when we look at children  
with a severe brain injury?**



father mother



siblings

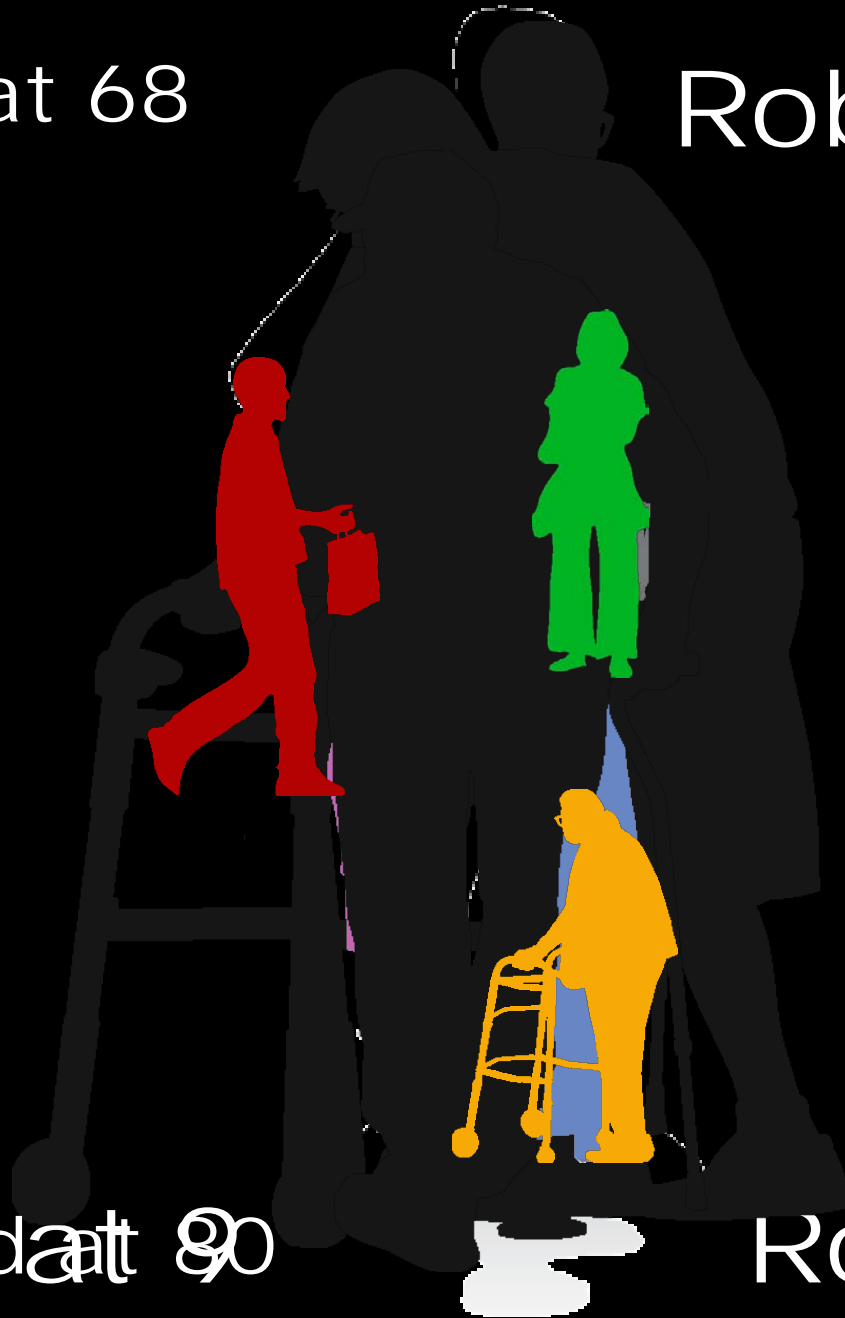


school

Meet Bobby at 9

Mr. Ford at 68

Robert at 40



Bob Ford at 80

Rob at 20

children

**grow**

parents  
**age**

participation  
declines

community  
**fades**

does rehab ever

**end?**

how does  
TBI  
impact  
social role?

**“fit  
problems”**

**Cognitive  
Behavioral  
Emotional  
Physical**



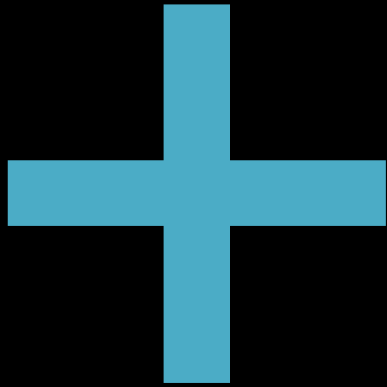
family  
friends  
work  
community

4 components of a social network

as changes to the  
person's social network  
occur and functional  
problems increase with  
age, what happens?

**neuropsychiatric and  
neurological features**

**brain injury: a**  
**STARTLING**  
**reality**



positive and negative roles



Helper

Worker

Friend

Caregiver



helpless  
unemployed  
patient

**what happens to the  
person who isn't  
able to give?**



son



father



wife

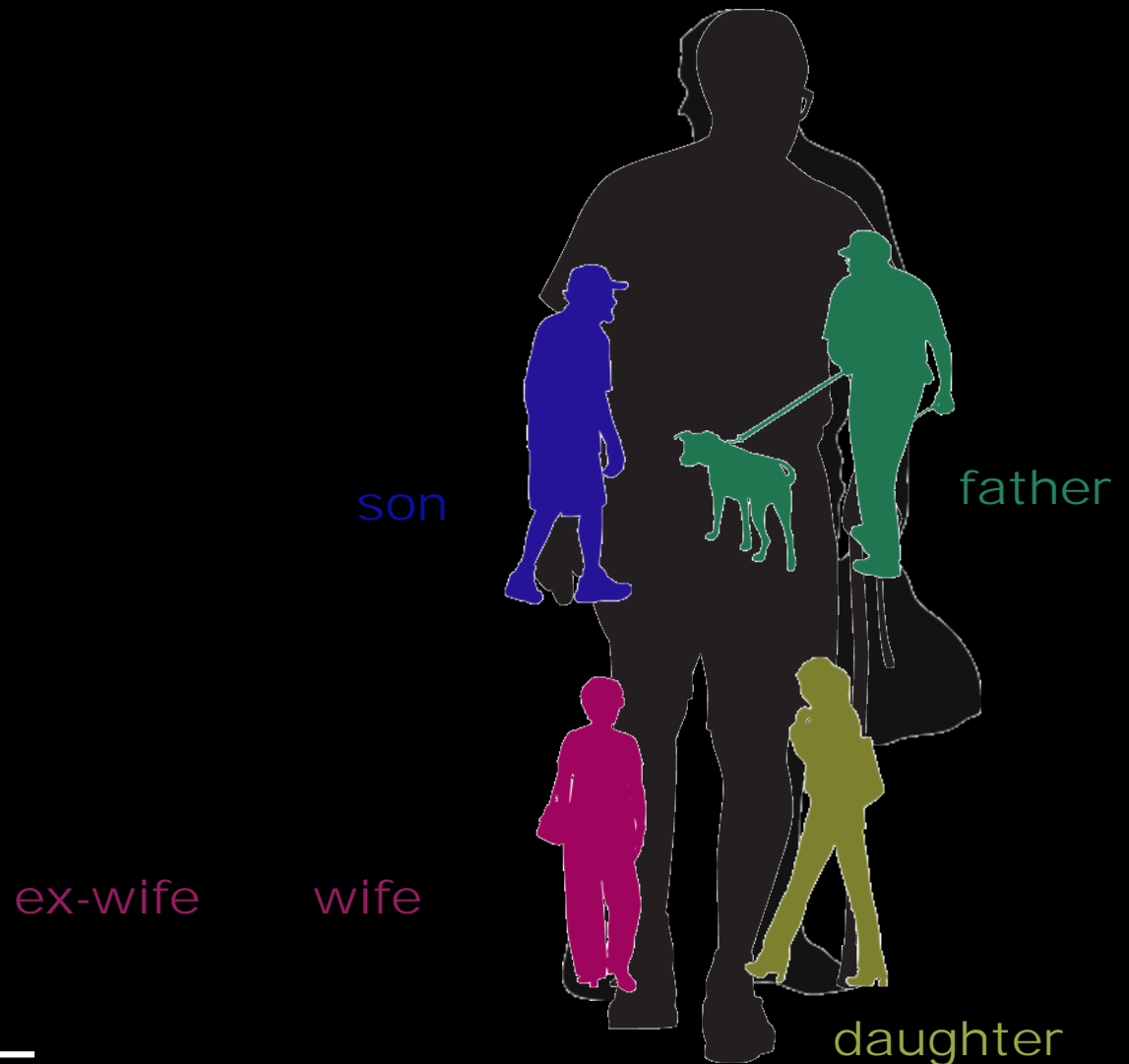


daughter



Meet Walter  
at 55

# Walter at 65



# Walter at 55

the  
distancing  
effect

loss of  
interpersonal  
connectivity

# social role adjustment

it's complicated.

**the TBI Bias: one year  
later an elevated risk**



**are these the people with a  
“Dual Diagnosis”?**

# neuropsychiatric features of brain injury



unemployment

depression

family strain

**lasting psychological and  
social functioning problems**

aggressive behaviors

diminished  
relationships

dependence

# cognitive problems

executive dysfunction

impulse control

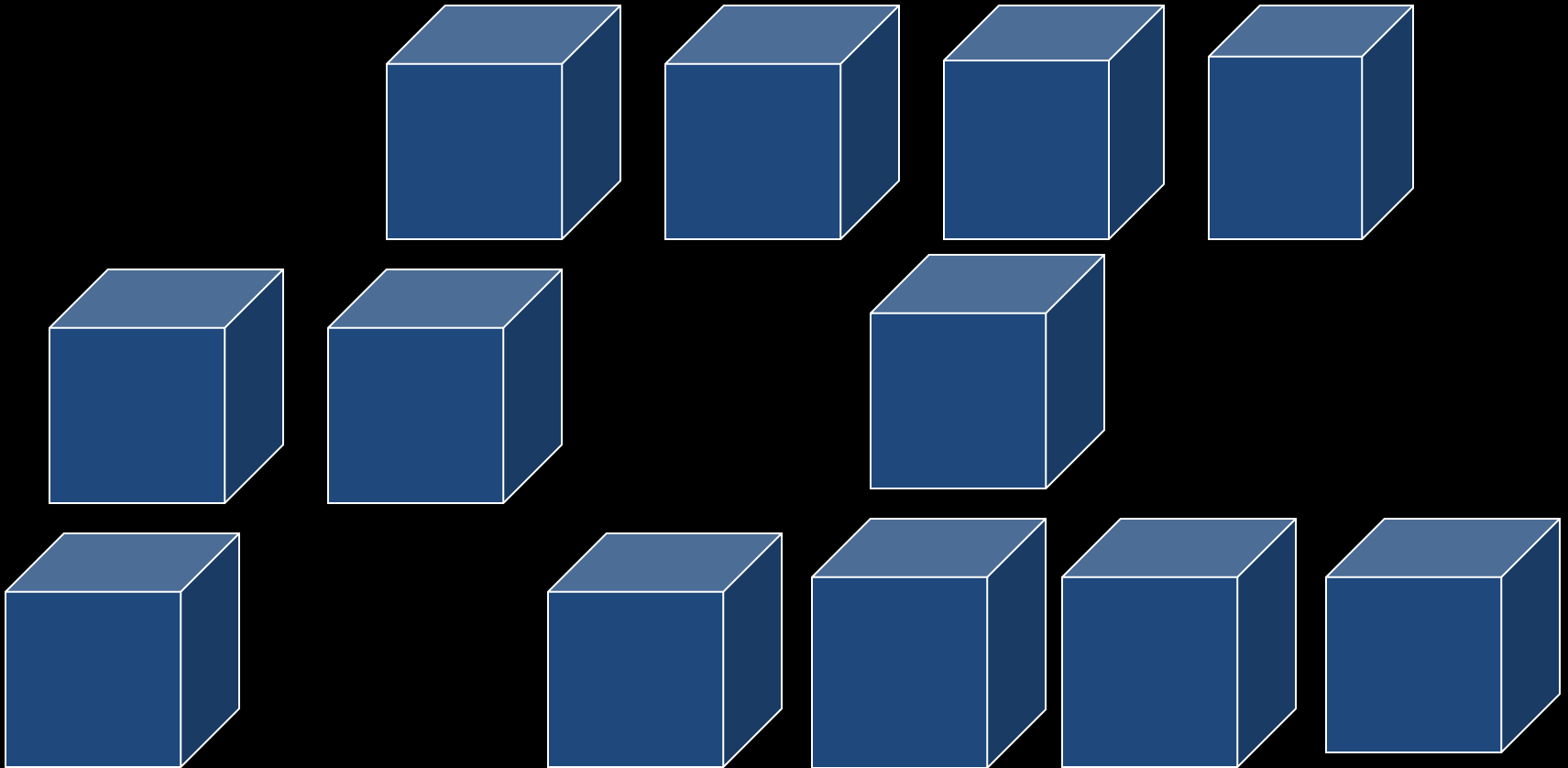
memory problems

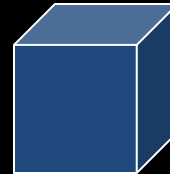
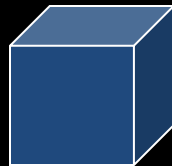
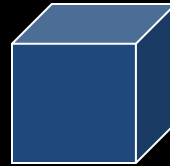
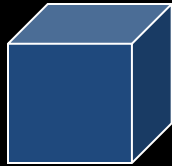
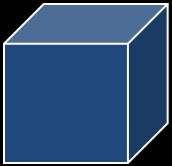
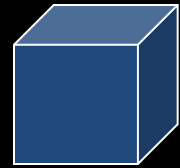
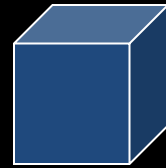
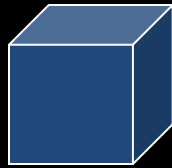
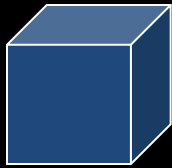
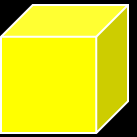
social withdrawal

emotional  
response  
to injury



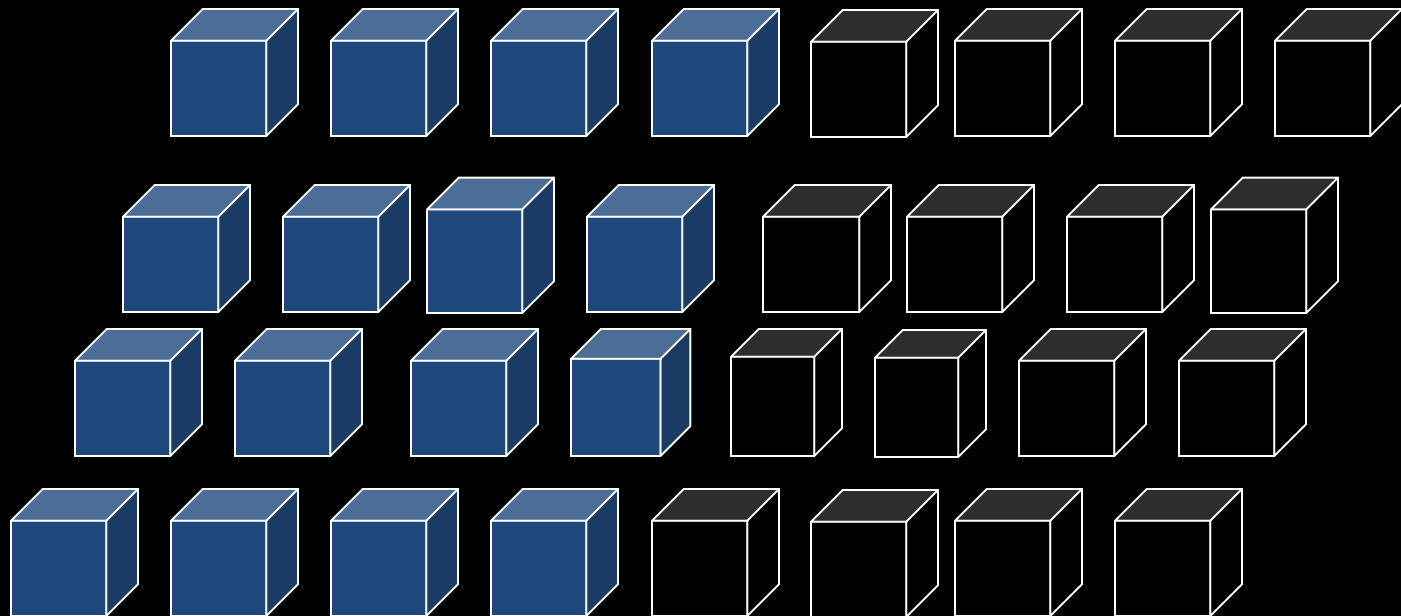
**brain injury and mental health problems reduce  
the number of available connections...**





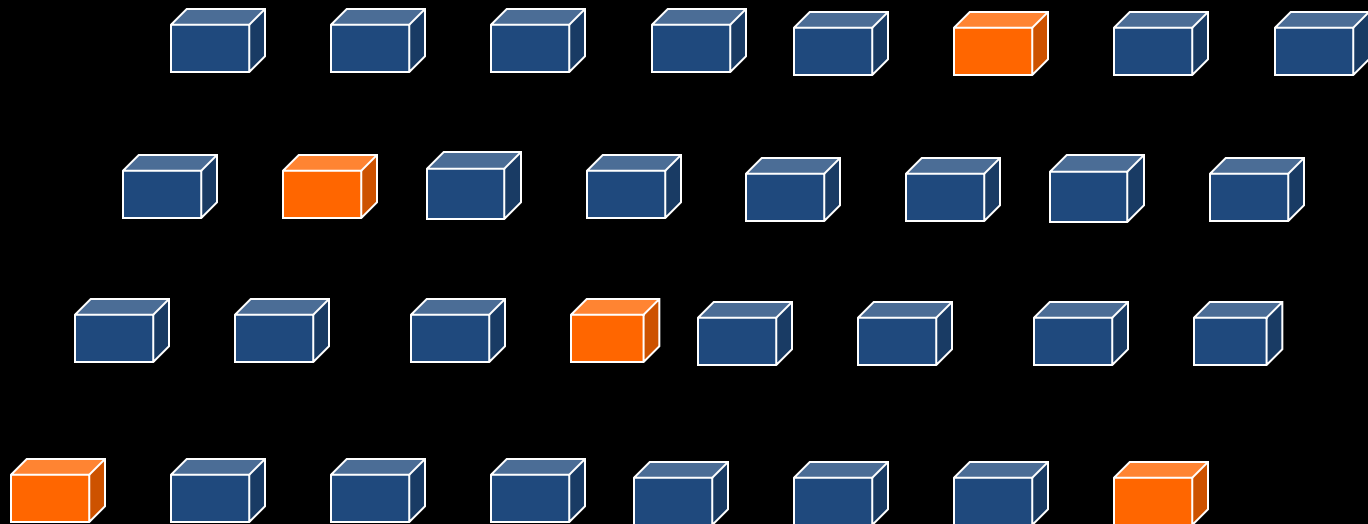
**people move towards the fringe where  
there are fewer connections to make**

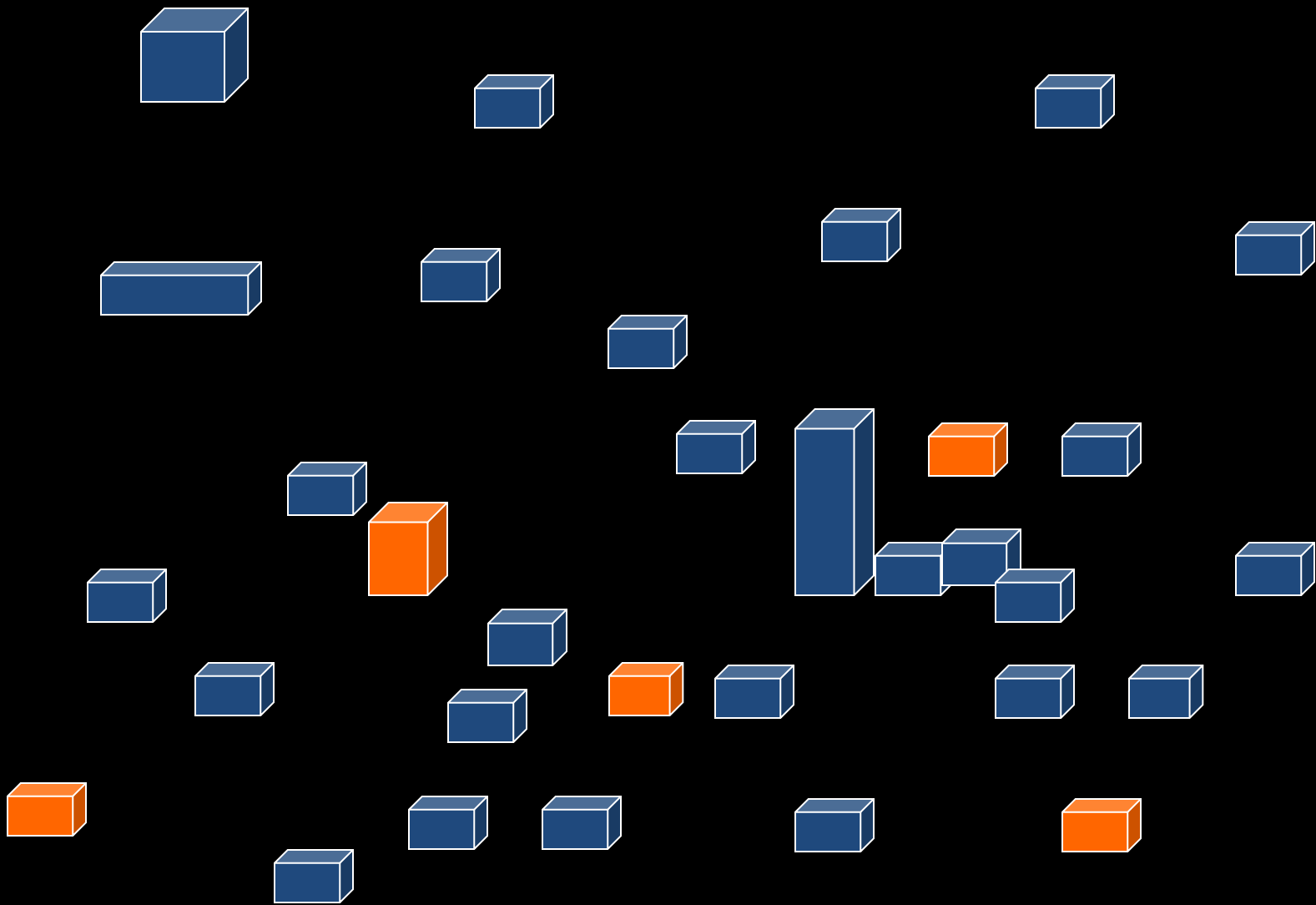
# living on the fringe of two networks:



Brain Injury or Mental Health

**and an increased separation from the  
center of pre-injury networks of family,  
friends, work and community.....**





**how do TBI and Mental Health  
problems impact on social networks?**



A close-up photograph of a person's hand holding a white rectangular sign. The person is wearing a dark suit jacket, a light-colored shirt, and a striped tie. The background is blurred. The sign has the text '76%' in a large, bold, black font, and 'unemployed' in a smaller, bold, black font below it.

**76%**  
**unemployed**

**what about  
severe brain injury?**

**what factors prevent  
participation?**



# **The Canadian Study by Dawson and Chipman**



61%

depression  
7+ yrs  
post-injury

apathy



66%

need ADL  
assist



90%

dissatisfied  
with social life



75%

unemployed



47%

not using  
telephone



27%

not socializing  
at home

# 35%

**unmet needs**



# 43%

**concerned with the  
realities of a long-  
term disability**



# dissatisfied



isolation

isolation &  
social withdrawal  
stifle interaction

does  
apathy +  
isolation =  
depression?

**Let's look at a study involving people  
with TBI living in nursing homes**

**staff report that  
50% could be living  
elsewhere**

but, where?







80°

40°

0°

40°

80°

Greenland

Arctic Circle

EUROPE

ATLANTIC

Equator

AFRICA

OCEAN

Antarctic Circle

ANTARCTICA

ARCTIC OCEAN

ASIA

PACIFIC OCEAN

INDIAN OCEAN

AUSTRALIA

NORTH AMERICA

SOUTH AMERICA

Tropic of Cancer

Tropic of Capricorn

160° 120° 80° 40° 0° 40° 80° 120° 160° © H. L.



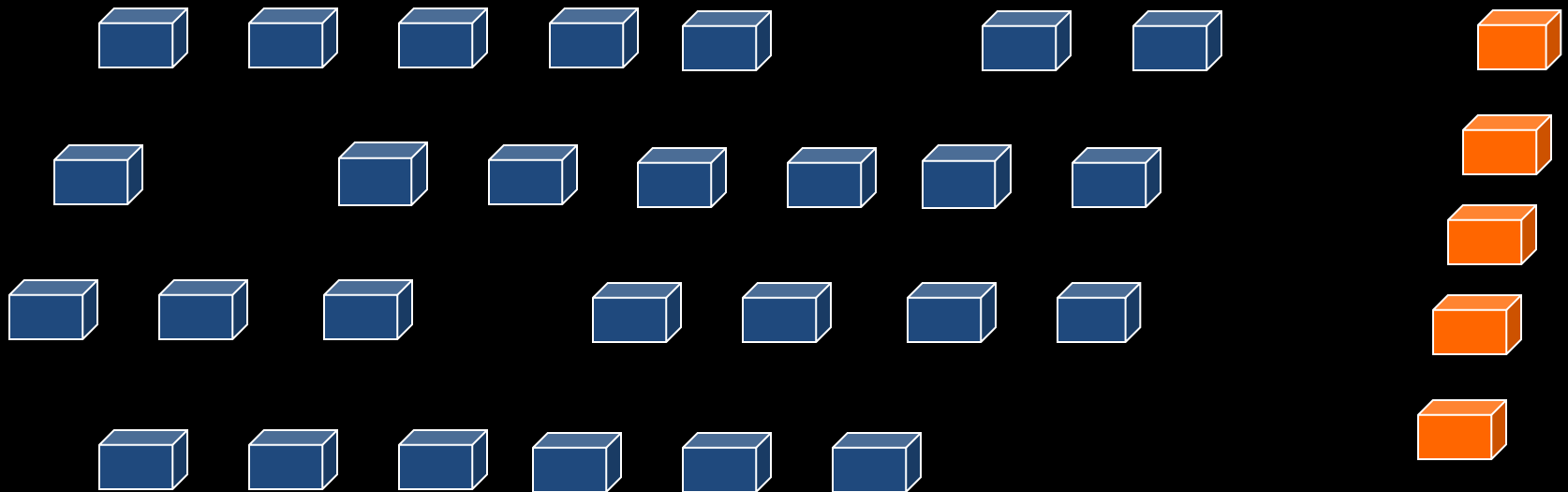
A close-up photograph of a person's hand holding a small white bowl filled with coins. Another hand is reaching out towards the bowl. The background is blurred, showing more of the person's arm and clothing.

**where you live can make  
you depressed**

**neighborhoods with poor social  
cohesion increase likelihood of  
stressful events**

Ahern and Gales, Collective Efficacy and Major Depression in Urban  
Neighborhoods. Am J Epidemiol 2011 April 28

**does TBI disability create a forced choice...**



**by moving people away from social networks?**

does **marginalization** set  
the person up for mental  
health problems?

**or does the person's  
mental health problems set  
them up for  
marginalization?**

# another chicken or egg problem?



Where's the data?

few resources that support independence



what about  
mental health and aging  
with a severe brain injury?

what are the barriers?

brain injury

accelerates

psych conditions

**the TBI Bias: one year  
later an elevated risk**



# aging

with a brain injury



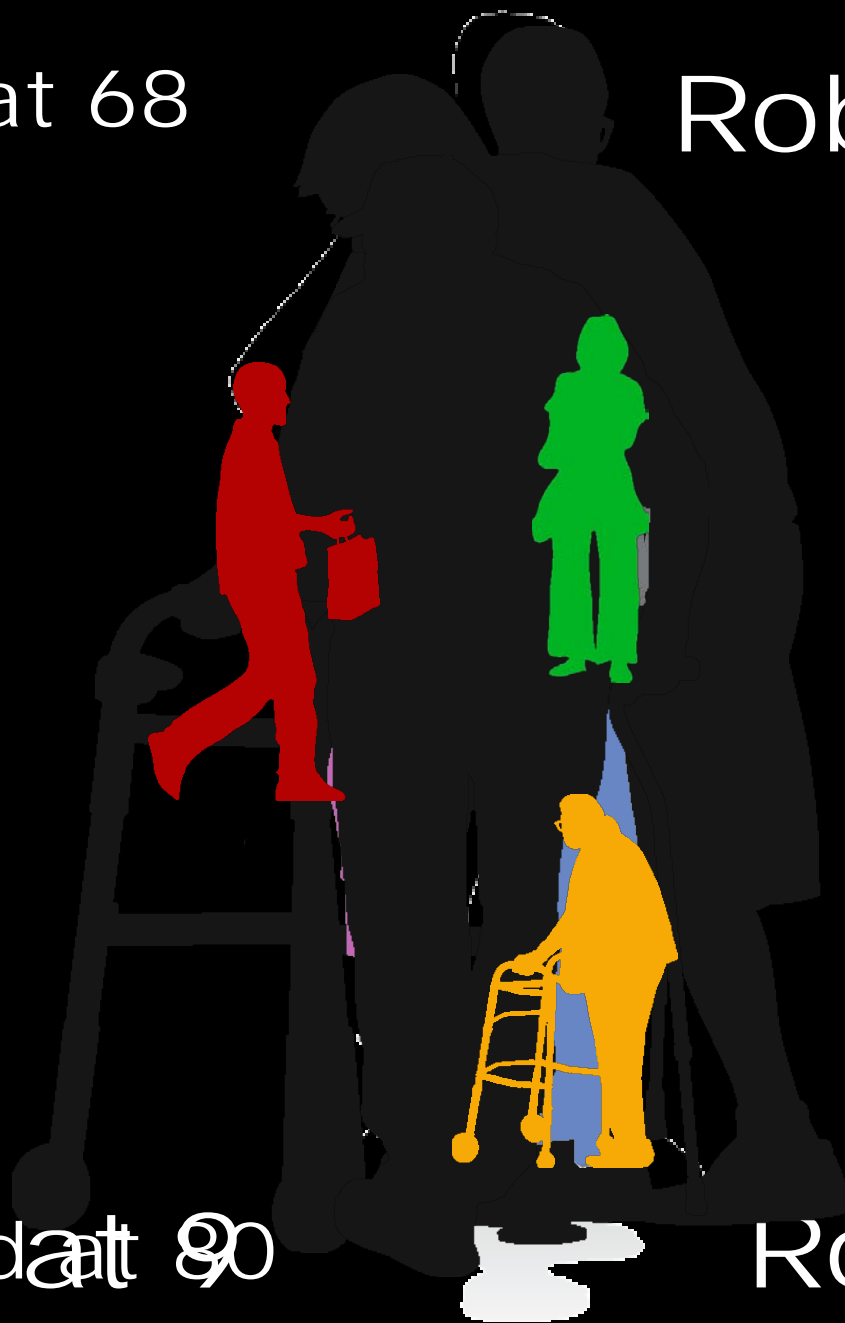
by 80 the average  
person has 3  
disabling  
conditions...



Remember Bobby?

Mr. Ford at 68

Robert at 40



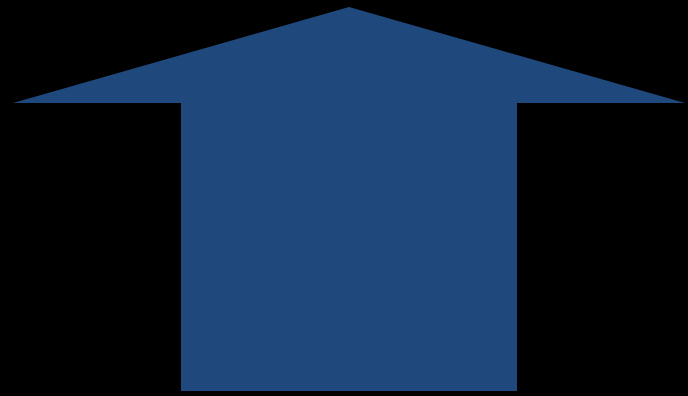
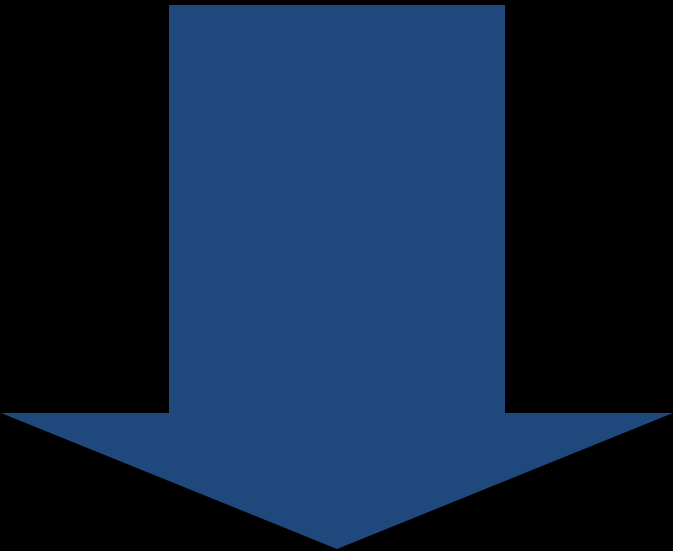
Bobby at 90

Rob at 20

support & care  
needs increase



functional  
abilities



required  
supports



what happens when a  
caregiver dies?

where does the person go?

# change in routines

problems associated with loss of a loved one

search for other caregivers

# economic upheaval



# social network and aging



why don't we ever talk  
about the real costs?

disability

+ aging



\$\$\$\$\$\$\$\$

\$15 million  
projected over the  
person's lifetime

# TBI: The Ultimate Stressor



barriers to  
reintegration  
increase



# lack of resources



# restrictive settings



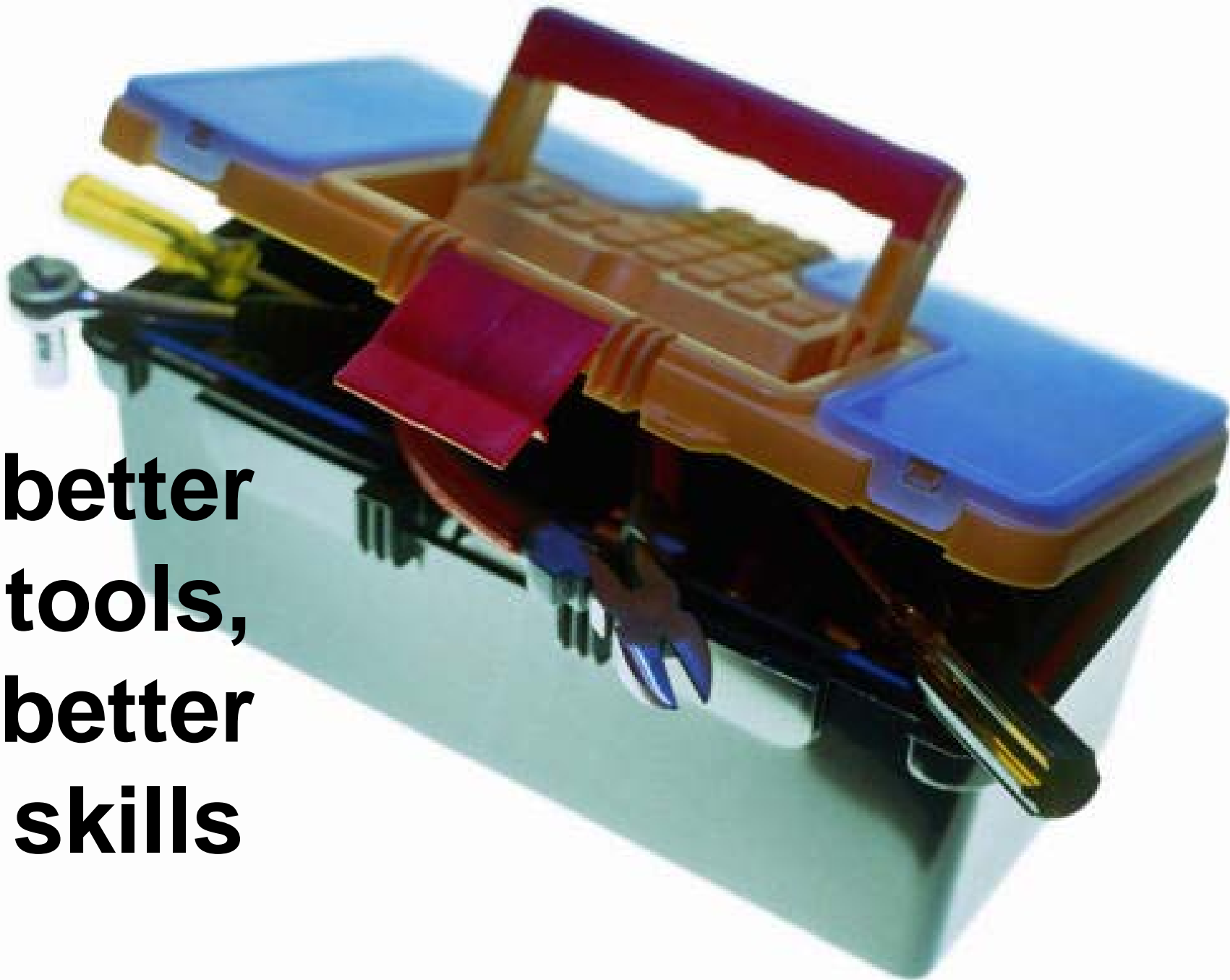
# divergent treatment



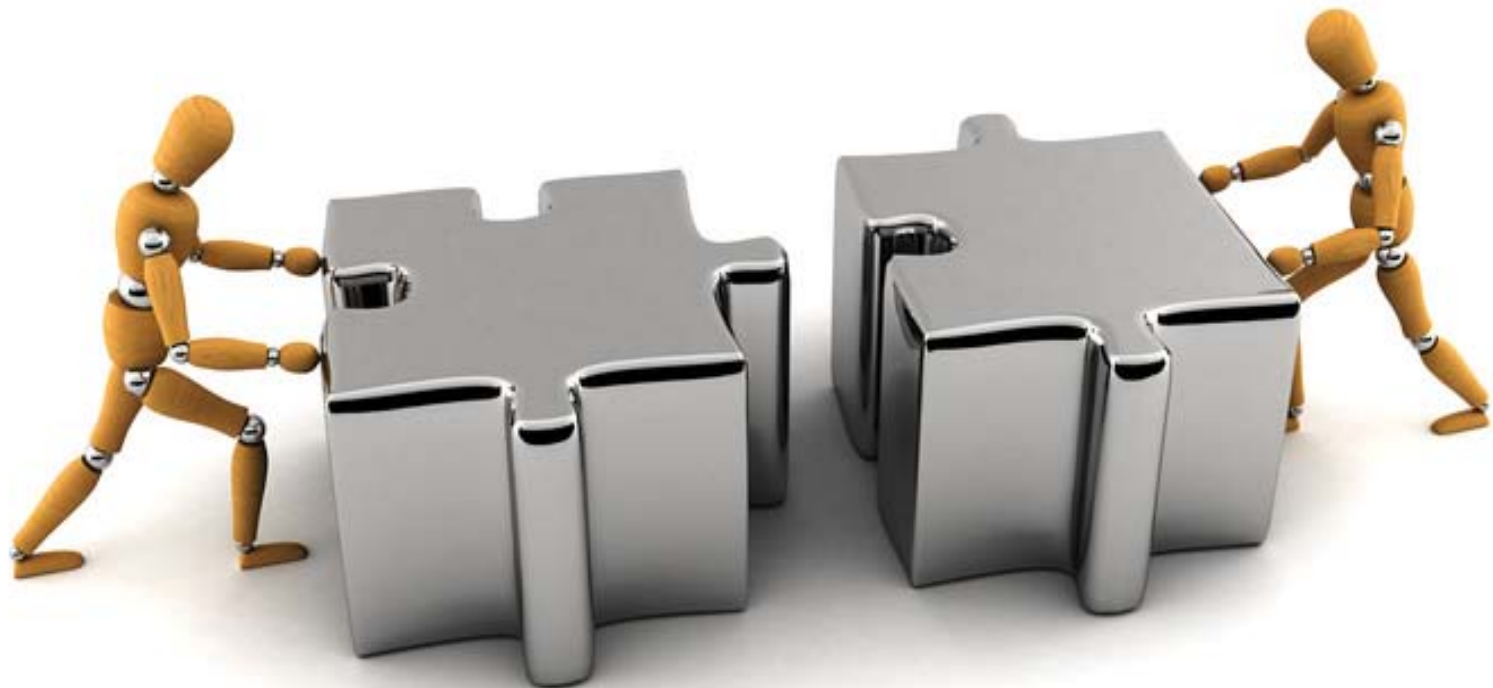
what about the people?

how can we reach out to  
the person better?

**better  
tools,  
better  
skills**



# building relationships between service providers



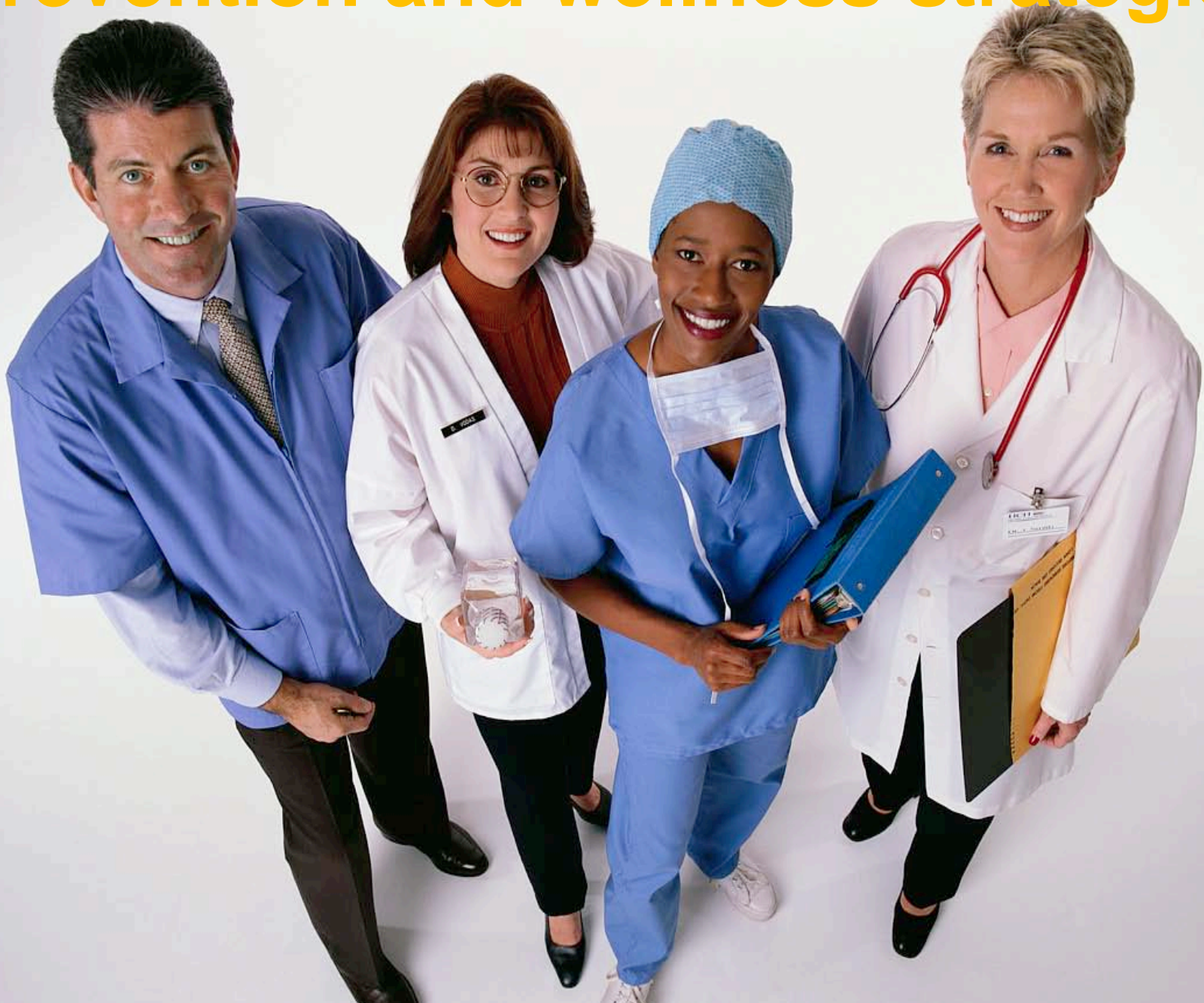
# making supports work through integration



helping the person return  
to their lifestyle



# prevention and wellness strategies




supporting  
caregivers  
to sustain  
the person



enhancing  
participation





responding  
to costs of  
lifetime  
disability with  
real \$'s



creating the  
right  
resources and  
expertise

plan and  
measure



what's important?

- Early identification and intervention
- Development of mental health resources with TBI expertise
- Understanding risk factors
- Creating a capacity to respond to crisis
- Providing ongoing supports in the home and community
- Providing caregiver support

can we fix  
what is broken?

are we committed?



nri at brookhaven hospital

201 South Garnett Road  
Tulsa, Oklahoma 74128

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

918-438-4257

888-298-HOPE (4673)

**nrrio**

**59 Beaver Bend Crescent  
Etobicoke, Ontario M9B 5R2**

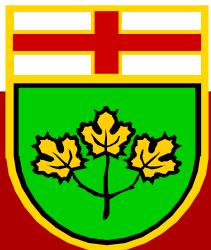
**416-231-4358**

**nrrio.com**

This presentation can be  
found at:  
[traumaticbraininjury.net](http://traumaticbraininjury.net)  
under “Resources”

Disclaimer: Rolf B. Gainer, Ph.D. has business relationships with the Neurologic Rehabilitation Institute of Ontario, the Neurologic Rehabilitation Institute at Brookhaven Hospital, Community Neuro Rehabilitation of Iowa and Rehabilitation Institutes of America. The NRIO Outcome Validation Study is supported by the Neurologic Rehabilitation Institute of Ontario





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