## Resilience after Brain Injury Disability

### Rolf B. Gainer, PhD

Rehabilitation Institutes of America, Novato, California; Neurologic Rehabilitation Institute at Brookhaven Hospital, Tulsa, Oklahoma; Community NeuroRehab, Des Moines Iowa

## Resilience after Brain Injury Disability

Rolf B. Gainer, PhD

Rehabilitation Institutes of America, Novato, California; Neurologic Rehabilitation Institute at Brookhaven Hospital, Tulsa, Oklahoma; Community NeuroRehab, Des Moines, Iowa

#### Disclosure

Rolf B. Gainer, PhD has business relationships with Rehabilitation Institutes of America, Brookhaven Hospital, Community NeuroRehab of Iowa and their related companies.

No commercial interest is related to this presentation.

### Objectives

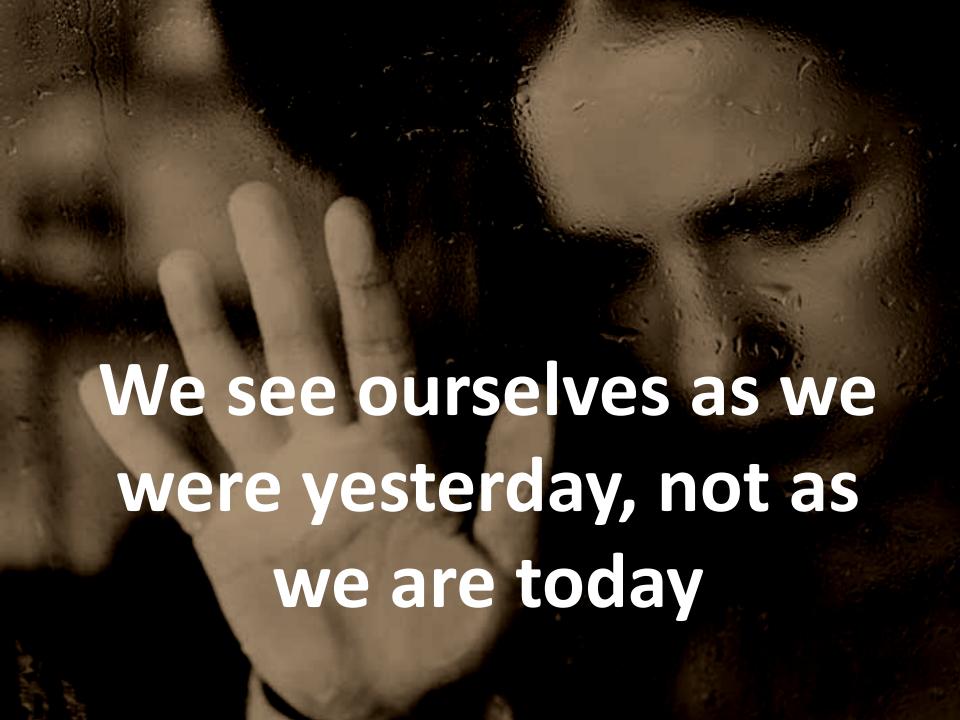
# To examine the concept of psychological resiliency in relation to disability

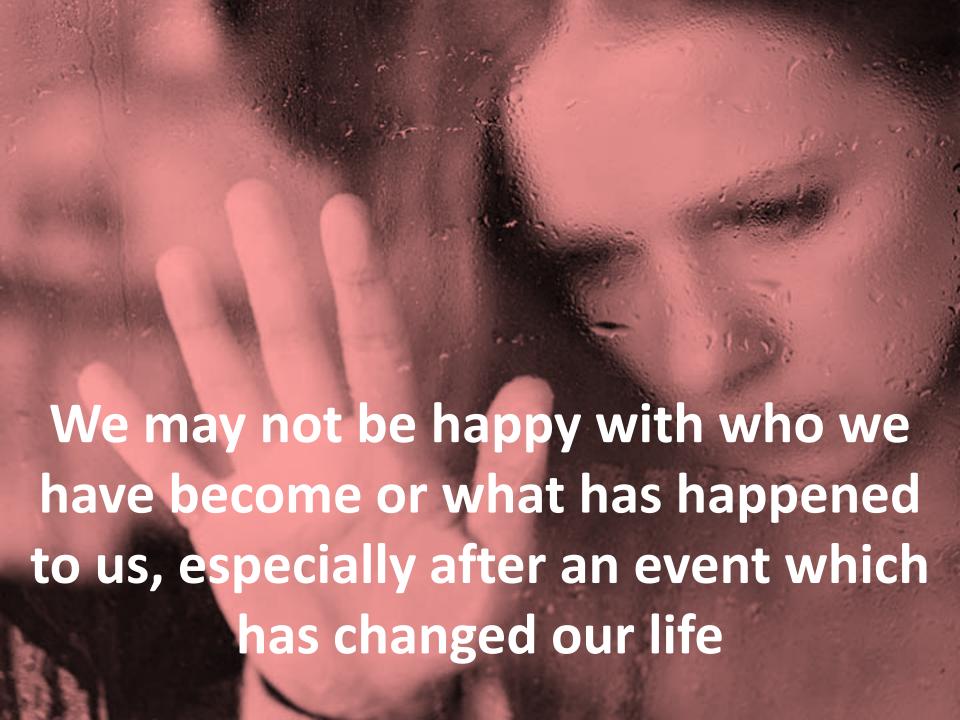
# To identify the processes of change associated with resiliency

# To understand the significance of personal narrative in relationship to resiliency

### Resilience:

- 1. The capability of a strained body to recover its size and shape after deformation caused especially by compressive stress;
- 2. an ability to recover from or adjust easily to misfortune or change











### Loss of clear self knowledge





# Loss of self in the eyes of others

## Everybody has a plan... until they get punched in the face



How does a person deal with the changes in their life created by brain injury disability?

Fundamental changes following TBI result in feelings of: Pessimism Hopelessness **Generalized Anxiety** 

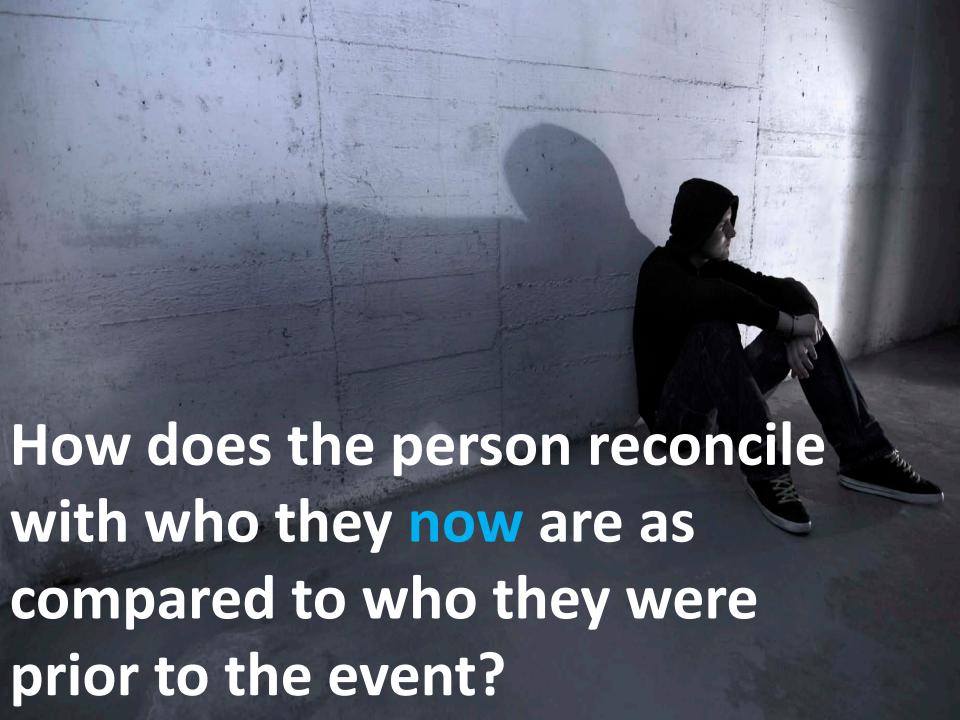
Kreutzer, J. et al 2001 Reeves, R and Laizer, J. 2012

"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







There is no measure for resilience, it is the person's response to adversity, obstacles and threat which determines how the person will fare with each event

Resilience is a constant recalculation of factors relating to multiple stressors over time

## "Events are not traumatic until we experience them as traumatic"

George Bonanno, 2016 Loss, Trauma and Emotion Lab, Columbia University

# "Events are not predictive until there is a negative response"

## Does brain injury disability create "a cloak of competence"?

For the person?

And, in the perception of others?

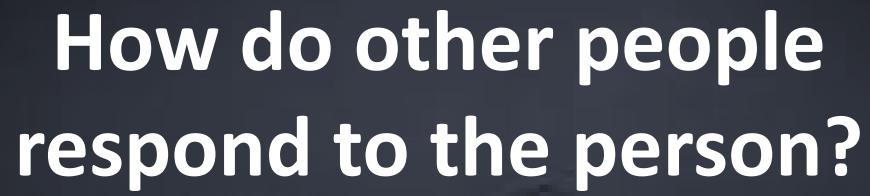
How does the person deal with the changes in their perception of self?

## How does the person perceive the control of their life after an adverse event?

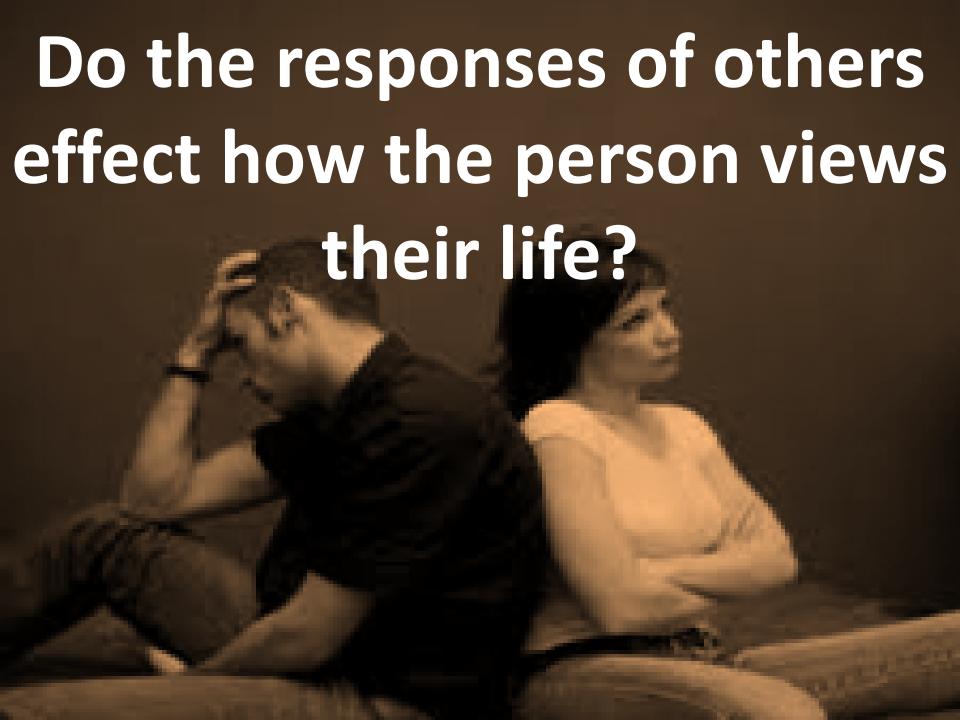
Internal or External?

## Shifting to internal control can lead to positive responses and changes

Externalizing control prevents the person from addressing the changes in their life







# 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

### Relatives' 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





"I felt I was different, couldn't put my finger on it... absorbing it internally, it was something wrong with me"

Craig Phillips, 2015

### Why do some people lose their sense of self?

### Why do some people "bounce back"?

## Are people inherently different in their psychological resiliency?

## What can we learn from people with psychological resilience?

## Can we teach or enhance the skills associated with psychological resilience?

## Laurie Rippon commented on "changes"

#### Defining "loss of self"

"How could I accept the changes from my 'before' life?"

#### "What can I actually do? I felt useless with no purpose... I was depressed"

"The better I got, the more aware I became of my deficits which made me even more depressed about my prospects of the future"

# Understanding the process of recovery of self may help us to understand resilience

### Do people have different "susceptibility" factors?

And, can those factors change over time?

# Can we enhance a person's likelihood of a positive response to an adverse event?



## Resilience Theory: resilience is a positive adaption in the face of a traumatic event

Newman, R., 2005

### Core Skills Associated with Resilience

**Even Tempered, Stable Emotionally** Positive Outlook, Optimism **Self-regulatory skills** Social Perception, "Liked" by others Insightful modification of behavior **Good problem-solving skills Effective communication** 

#### Resilient

or

#### dysfunctional reintegration

#### Traits vs. Skills

## We can't learn new "traits" but we can learn new "skills"



## Attitude or personal belief?

Trait or skill?

### How does a person change their narrative?

#### "If there is no change...

...nothing changes"

## "Every day passes whether you participate or not"

**Deng Ming-Dao** 

The tasks for the person are defining what they can change and making the changes

### Which skills are "teachable"?

## Can others assist in the process of redefinition?

### Do some people "catastrophize" barriers?

The perception of personal and environmental obstacles affects resilience and ability to participate

Ravesloot, et al. Can people catastrophize barriers?, Disability and Health Journal, (2017), 10, Elsevier, NY, pp 65-72



#### Ray

Ray, was a promising middleweight boxer who started his career at age 14. By his early 20's he had experienced multiple concussions and left boxing. At age 44 he was diagnosed with **Parkinson Syndrome and Dementia Pugilistica** 

"...I had my first concussion at 16 in Buffalo, New York when I took a right hook to the back of my head..."

"one week later I was scheduled to fight in Syracuse. I knew something was wrong- I got my "bell rung" in the first round..."

"...I vomited in my water bucket but stayed in the fight. I didn't even remember that I lost the fight in the post-fight interview...."

"...the fog lingered. I started having problems in school, trouble concentrating, headaches, sleeping excessively and resenting authority..."

"...I battled through and asked a trainer about the headaches and fatigue. He told me to "gut it out".

"...In 1971 I failed the required **EEG for the New York State Boxing Commission license. I** fought in places were no license was required. I returned in 1973 for a re-test and my EEG was grossly abnormal...."

"....In 1974 I took a break from boxing-the symptoms didn't go away. I threw out my boxing memorabilia . I went into a mental health facility and was diagnosed with severe depression..."

"... I took to the road for a while and avoided everybody. I took refuge in the National Parks...."

"...14 years later I couldn't continue working at my job due to tremors. I was diagnosed with Parkinson Syndrome and Dementia Pugilistica..."

# "...The only thing I could do was prevent another athlete from going down my path..."

Now, at 63, Ray is the founder of The Second Impact, a not-for-profit brain injury prevention program. He provides talks to athletes-amateurs, university and professional teams about concussion recognition and prevention. He has turned his losses from brain injury into a way to help others.

#### Melissa

Melissa was injured at 30 in a motor vehicle accident while at work. She was the Director of Public Relations at a large teaching hospital. A selfdefined "workaholic" and she enjoyed an active social life with friends and family and participated in sports.

"...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..."

"...my parents replaced my functions in the home. They took care of everything..."

### "...l 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..."

## "...we weren't "people withdrew from me, too"

# "...I felt vulnerable due to my brain injury..."

"...I started to feel OK about myself when I started volunteering and getting involved in peer counseling..."

### "...l started to develop self-compassion..."

#### "I began to explore myself through meditation"

"... I started going back to school... its been over 10 years since my brain injury"

# "...the third hurdle was getting my master's degree..."

Now, 24+ years since her injury, Melissa is an accomplished researcher in Mindfulness, a published journal author, a sought after conference speaker and teacher. She can reflect back on her journey and share the process she went through to find herself.

#### Jerry

I met Jerry when he was a 20year old university student, injured at 19. Following a short period of acute rehabilitation he experienced a deep depression which didn't clear

## "I tried to go back to school, but I couldn't concentrate"

# "getting C's and B's just wasn't me. I was used to getting straight A's"

"It was hard to hang out with my friends. Somehow we weren't the same anymore. It was easier to be alone"

"I thought about killing myself a lot. I went up to the roof and thought about jumping, or taking an overdose. It was impossible to tell my family about how I felt"

"I stole Sherri's car and I thought today was the day. I looked into the back seat and I saw the baby's car seat. I had to bring the car back"

Jerry ended his life by driving his car into a bridge abutment about 3 years after he left our program. He was finishing university. I see his mother often. She has become very involved in advocacy work

#### All hit bottom...

One stayed there

Two came back

#### Why?

#### Laurie Rippon

addressed that process

"When life was turned upside down I began to focus on what really mattered to me. That set me on the way to a new lifeone I could be proud of"

Laurie Rippon

"I always look forward – setting aside regrets of the past and instead, imagining a future, I still love to learn, grow and move"

Laurie Rippon

" I learned to feel good about each small step of progress, which gave me the confidence to look to the next step... until I felt more whole"

Laurie Rippon

# Changing the narrative is vital to defining "self" after injury

### Psychotherapy and Change

## Can we help the person change their narrative?

"Focus on discovering the meaning of their lives in the face of, not despite, the brain injury"

## "Teaching the person to behave in their own self-interest"

## Helping the person in viewing their life as meaningful

Ben-Yishay, Daniels-Zide, 2000. Examined Lives: Outcomes After Holistic Rehabilitation

These strategies create a safe place to experience the changes from injury and identify a new self

## Rational Frame Theory Developing a new self-concept

Myles S. 2004, Intl. J of Psychology and Psych Therapy, 2004 V.4, N.3. 487-504

### **Redefining Self** Conceptualized Self Self as an ongoing process of verbal knowledge Self as context

Experiencing loss in the context of perceived loss of competencies- the "then and now"

Working through the anger, depression, anxiety, grief: aspects of distress over the loss of competency

### Acceptance and Commitment Therapy (ACT)

Assisting the person in recognizing being "stuck" due to fear vs. relearning to "act"

### Accept your reactions

### Choose a valued direction

### Take action

Myles S., 2004

Working through the experience of intense anxiety post-injury Conceptualized as a defense of pre-injury self-concept

## Teaching the person to become non-judgmental and accepting of self

"...Identity is a growing and changeable thing ... the tragedy which occurred can be inserted into one's narrative and shape their identity..."

Helping survivors of a traumatic event see the positive and assist the survivor in de-victimizing themselves- creating opportunities for positive thinking and growth

Taylor, Wood, Lichtman, 1983

# Emotion-focused Therapy helps the person make sense of their internal experience after trauma

Greenberg, LS, Clin Psychology and Psychotherapy, 11, 3-16, 2004, John Wiley and Sons, Ltd.

# A person cannot leave a place until they have arrived at it

The process of Emotion Awareness, Emotional Regulation and Emotion **Transformation** is key to that process

# Change occurs through arriving and leaving



## Assist the person in attempting an alternative to "failure"

Reframing negative reactions to real situations:

You can do it!

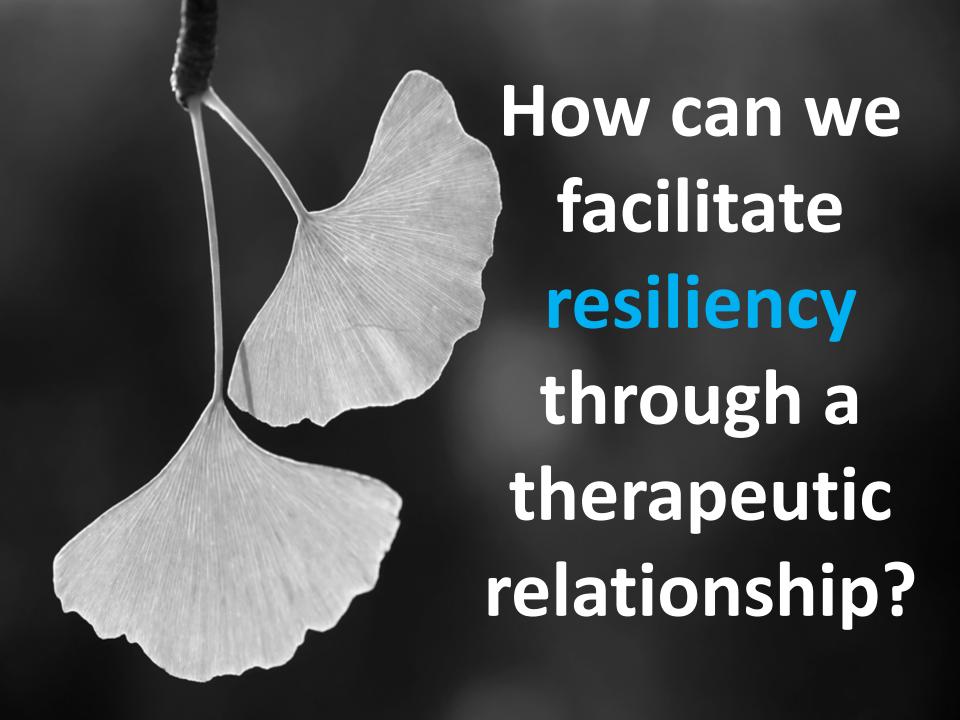
## As we look at the models of treatment, there is a commonality:

## Acceptance of the new self is critical to adjustment

### Moving beyond therapy

"I could replace perfectionism with the pursuit of excellence. I had to get to a place where I could move beyond the pain of denial and not accepting my reality, before I could grieve my reality."

How can we help people in this process of finding themselves and, in a way, reinventing themselves?



### How can a person start the process of rewriting their narrative?

## "The longest way round is the shortest way home"

James Joyce

"The only way to make sense out of change is to plunge into it, move with it, and join the dance."

Alan Watts

"We all have two lives. The second one begins when you realize you only have one."

Confucius





## CHANGE

# Maybe more than one person is involved





### How can we help the person and their system to mobilize and change?



### Thanks

### Questions?

### This presentation can be found at TraumaticBrainInjury.net

under "Resources" and "Community

Presentations"

#### Resources and References

- Lukow, H et al. Relationship Between Resilience, Adjustment and Psychological Functioning After Traumatic Brain Injury: A Preliminary Report. 2015, Wolters Kluwer Health, Inc. Journal of Head Trauma Rehabilitation
- Hart, T et al. Prevalence, Risk Factors and Correlates of Anxiety at 1 Year After Moderate to Severe Traumatic Brain Injury, 2016, American Congress of Rehabilitation Medicine (ACRM), Archives of Physical Medicine and Rehabilitation, 2016;97:701-7
- Lukow, H. 2015 Workbook for Promoting Resilience to Enhance Recovery from Brain Injury, Virginia Traumatic Brain Injury Model System, presented at the OBIA Conference, Niagara, Ontario, 2015
- Greenberg, L. 2004 John Wiley and Sons, Ltd., **Emotion-focused Therapy**, Clinical Psychology and Psychotherapy. 11, 3-16
- Gagnon, J. et al. 2006, Taylor and Francis, Inhibition and Object Relations in Borderline Personality Traits after Traumatic Brain Injury, 2006, 20 (1), 67-81

#### Resources and References

- Ravesloot, C. et al. 2016 Elsevier Inc., Can people catastrophize barriers? An exploratory analysis of the association between pain catastrophizing and perceptions of environmental factors, Disability and Health Journal, 10 (2017) 65-72
- Konnikova, M. 2016, Conde Nast, How People Learn to Become Resilient, New Yorker, February 11, 2016
- Gainer, R. 2015, Neurologic Rehabilitation Institute of Ontario.
   Outcome Validation Study of Individuals with Severe Brain Injury and Co-existing Conditions, 1997-2015, nrio.com
- Connor, K. and Davidson, J. 2003, Wiley-Liss, Inc.
   Development of a new Resilience Scale: The Connor-Davidson Resilience Scale (CD-RISC) Depression and Anxiety, 18:76-82 (2003)