Traumatic Brain Injury (TBI):

Symptoms, Systems, & Person-Centered Care

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UCLA Health
STEVE TISCH BrainSPORT PROGRAM
St. Jude Brain Injury Network
A program of St. Jude Medical Center
TBIOC tbioc.org
DOR DEPARTMENT of REHABILITATION
Employment, Independence & Equality

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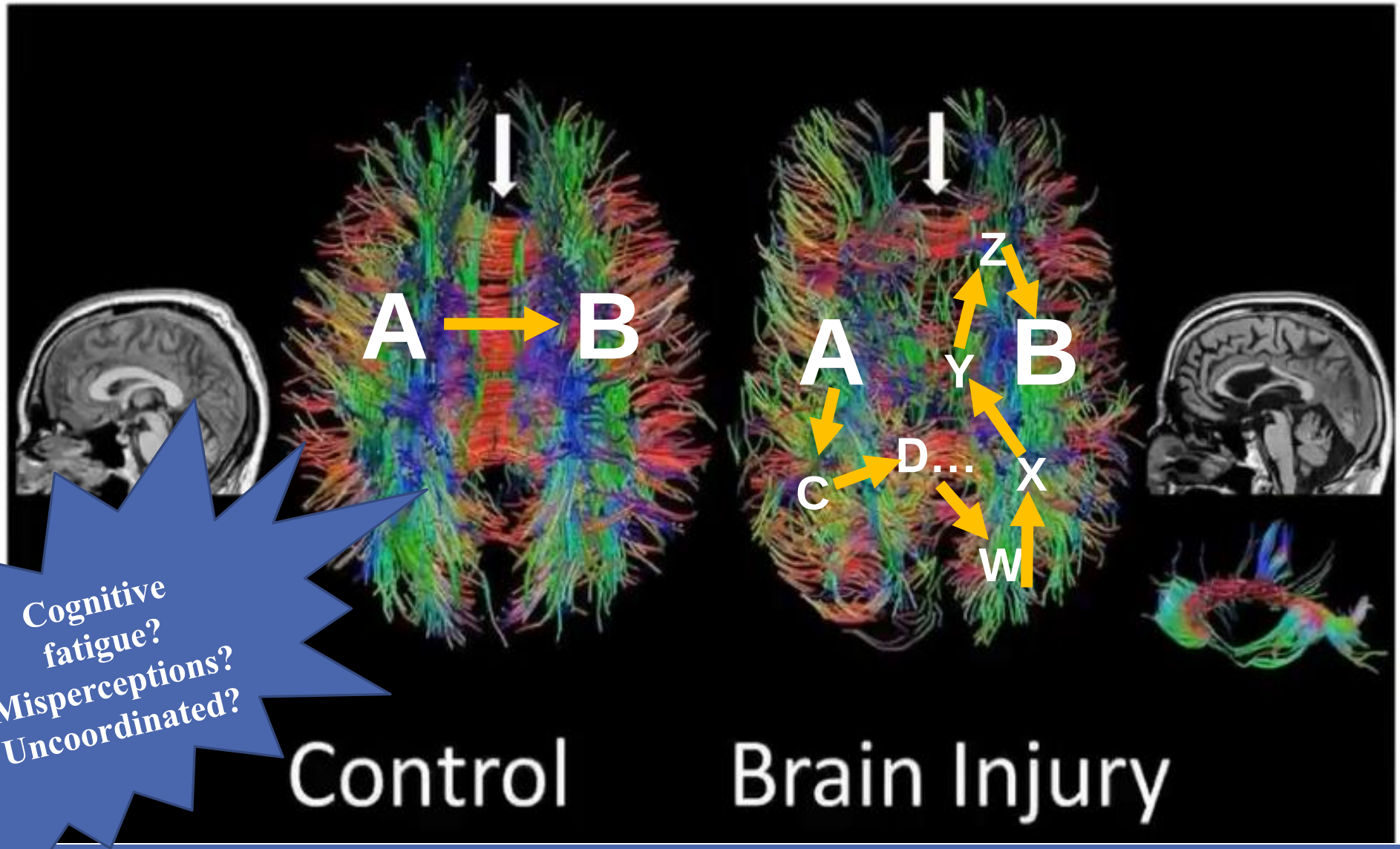
What happens in TBI?

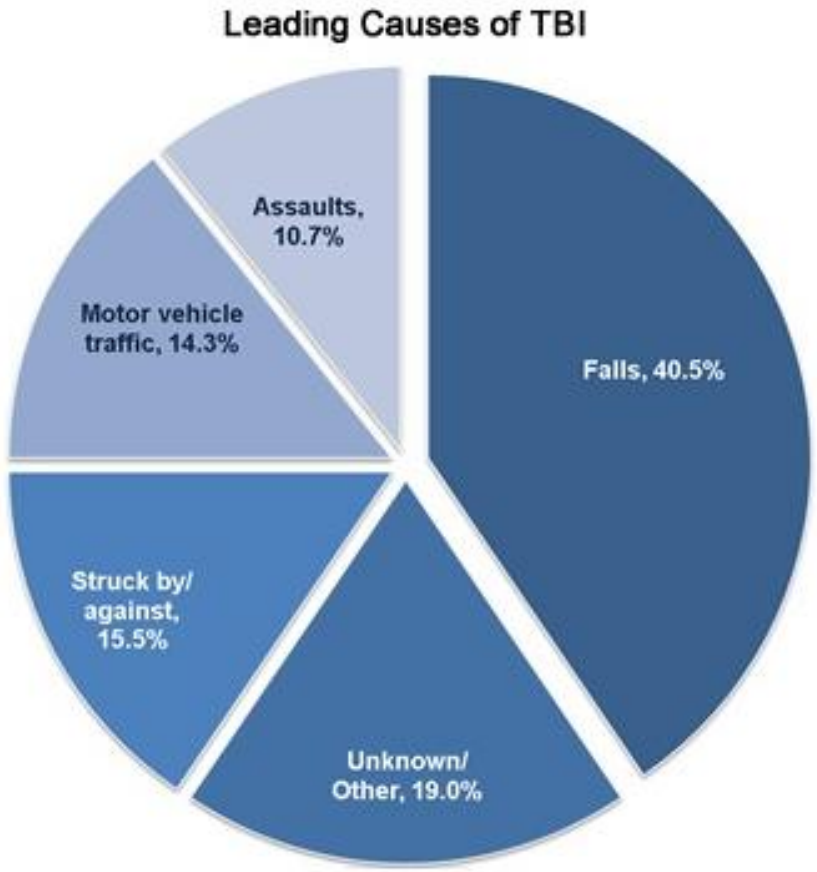
TBI is a disorder of disrupted brain connectivity



Zooming Out: United States Prevalence

- **2.87+ million TBIs occur annually**
  - **837,000+ in children**
  - **64k TBI-related deaths**

(APA, 2022; CDC, 2022)



- TBI Sequela that impacts community reintegration can include, but is not limited to:
  1. Memory loss, headaches, seizures, fatigue, vision difficulties, anxiety, depression, emotional dysregulation, anosognosia, apathy

"Medical Severity" for TBI

CRITERIA	Mild	Moderate	Severe
Glasgow Coma Scale (3-15) (best available in 24 hours)	13–15	9–12	3–8
Duration of unconsciousness	< 30 minutes	30 min to 24 hours	>24 hours
Post-traumatic Amnesia	< 24 hours	>1 day to 1 week	> 1 week
Alteration of Consciousness/Mental State	< 24 hours	>24 hours	>24 hours
Structural Imaging	Normal/Abnormal UN/COMPLICATED	Normal/abnormal	Normal/ abnormal

***Please Note:**

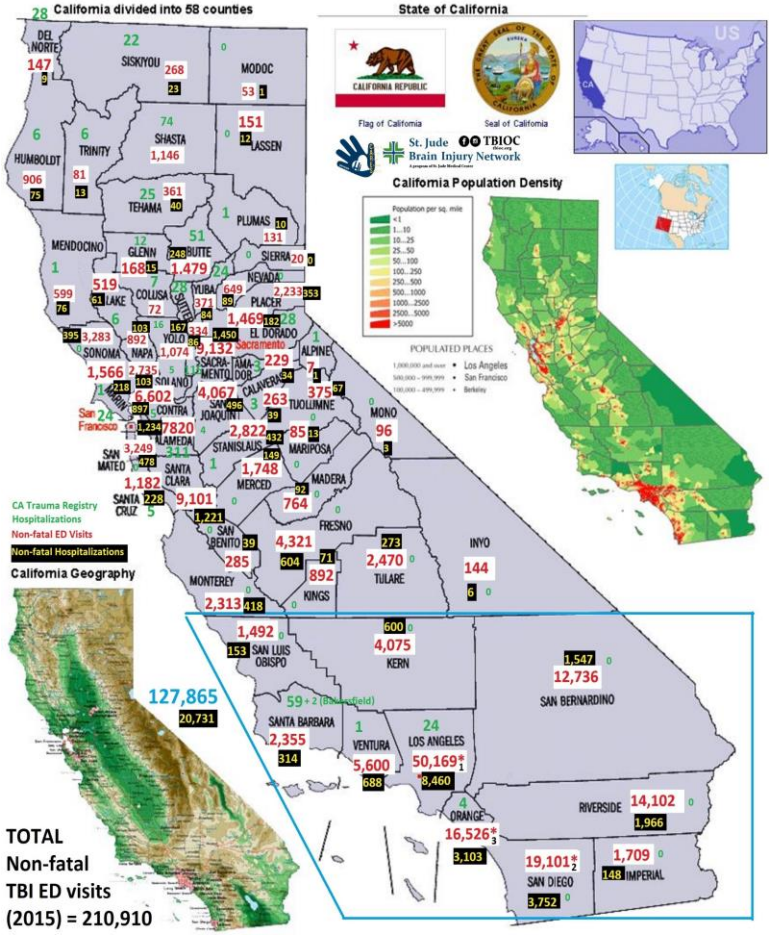
These designations do not necessarily reflect the impact of the symptoms on survivors' lives

According to CDPH (2016-2020):

N = 1,228,634 (ages 0 to 85+)
from 570 hospitals in CA

Yearly Average (2016-2020):

1. Nonfatal TBI <u>CDC Definition</u> ED visits (*M* = 73,761)
2. Nonfatal <u>Unspecified Head Injury</u> S09 (*M* = 171,966)
3. TBI-related Deaths in California (*M* = 5,122)
4. 40.5% revisit ED within 1 year (Hsia et al., 2018) (13.4% revisits resulted in hospitalization)
5. 46.7% accessed another hospital ED



Problem Statement:

1. **5.3 million U.S. citizens =** TBI related disability (Rao et al., 2020)
2. 40% have 2+ chronic neuropsychiatric diagnosis (Rao et al., 2020)
3. U.S. **unemployment rates for survivors** two years post: (Cuthbert et al., 2015)
    1. As high as 60% for full-time unemployment
    2. 35% for part-time employment.
4. **Associated outcomes such as:**
    1. homelessness (Stubbs et al., 2019)
    2. incarceration (Durand et al., 2017; Schofield et al., 2015)
    3. substance abuse (Center for Substance Abuse Treatment, 2010; Corrigan et al., 2012)

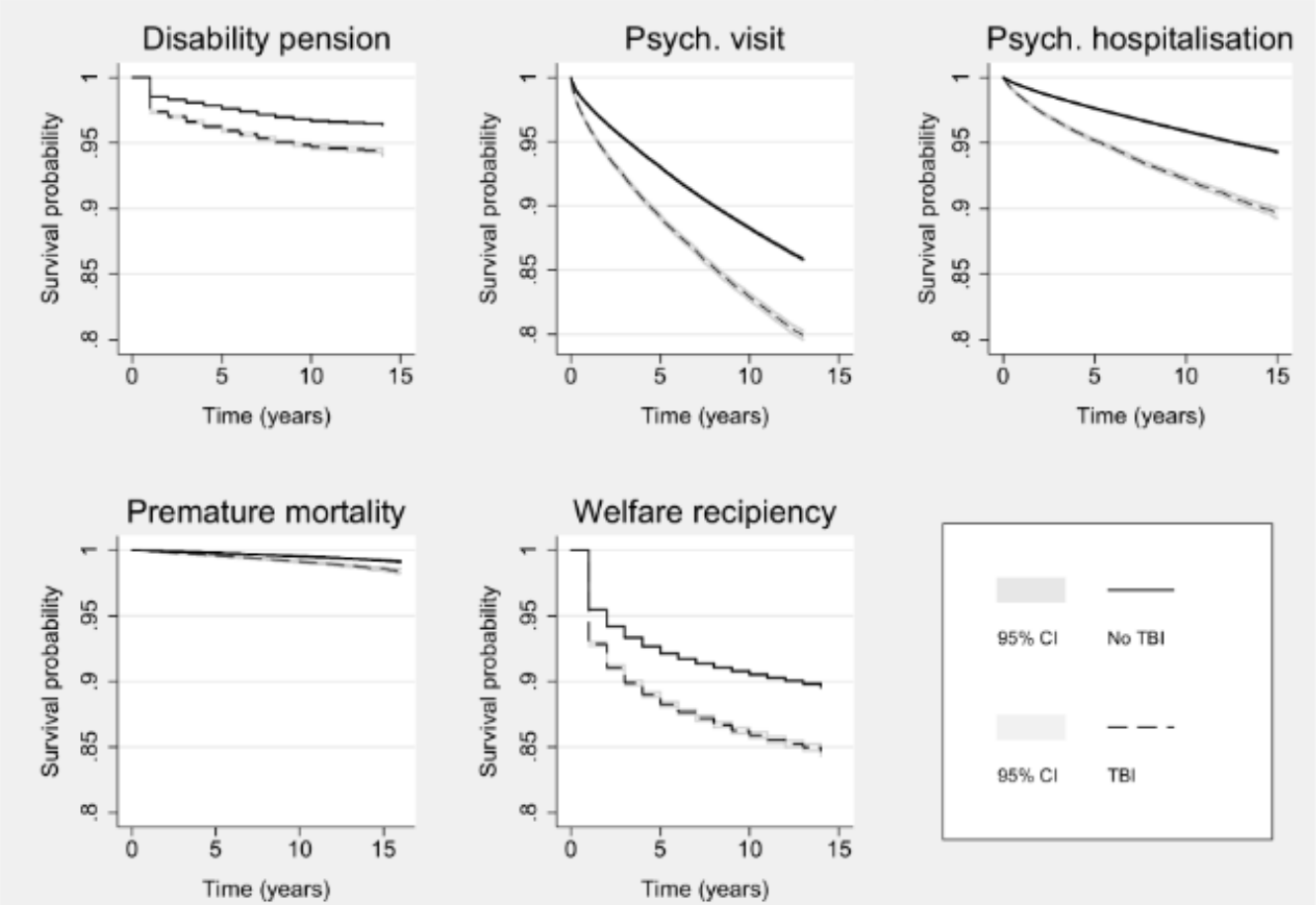


Fig 1. Kaplan-Meier survival curves for all right-censored outcomes across TBI exposure before age 25 y.

doi:10.1371/journal.pmed.1002103.g001

(Sariaslan et al., 2016)

Table 4. Population-attributable fractions, expressed as percentages, for TBI before age 25 y on poor functioning in adulthood.

	Model I	Model II	Model III
	PAF [95% CI]	PAF [95% CI]	PAF [95% CI]
Disability pension	5.9% [5.7%; 6.2%]	4,5% [4.2%; 4.8%]	4.6% [3.8%; 5.3%]
Psychiatric visit	4.4% [4.2%; 4.5%]	3.4% [3.3%; 3.6%]	3.1% [2.7%; 3.4%]
Psychiatric hospitalisation	7.4% [7.3%; 7.7%]	6.4% [6.1%; 6.6%]	5.5% [4.9%; 6.1%]
Premature mortality	6.1% [5.5%; 6.8%]	5.0% [4.2%; 5.7%]	4.7% [2.9%; 6.5%]
Low education	5.0% [4.8%; 5.1%]	4.1% [3.9%; 4.3%]	2.8% [2.4%; 3.3%]
Welfare recipiency	4.7% [4.5%; 4.8%]	3.2% [3.0%; 3.4%]	2.4% [1.9%; 2.9%]

Notes: Model I: Full sample, adjusted for sex, birth order, and birth year; Model II: Additional adjustments for individual and parental highest achieved education levels, parental income, parental lifetime criminal and psychiatric histories, and maternal single status; Model III: Within-family estimates that are additionally adjusted for individual educational attainment at age 26 y.

doi:10.1371/journal.pmed.1002103.t004

The **population attributable fraction** is the proportional reduction in population disease or mortality would occur if exposure to a risk factor were reduced to an alternative ideal exposure scenario.

(Sariaslan et al., 2016)

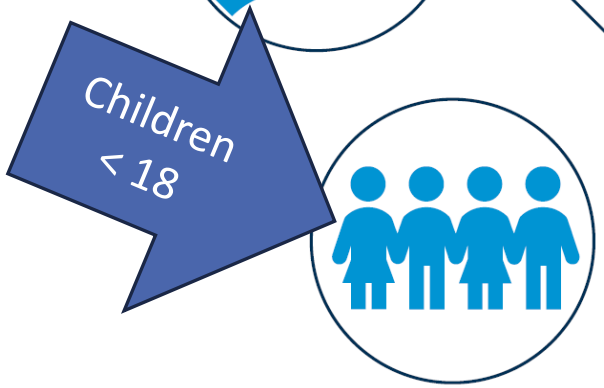
Populations of Focus (POFs)

January 1, 2022

- Individuals and families experiencing homelessness
- Adult high utilizers
- Adults with Serious Mental Illness (SMI) or Substance Use Disorder (SUD)
- Adults transitioning from incarceration

January 1, 2023

- Adults eligible for Long-Term Care
- Adult nursing facility residents



July 1, 2023

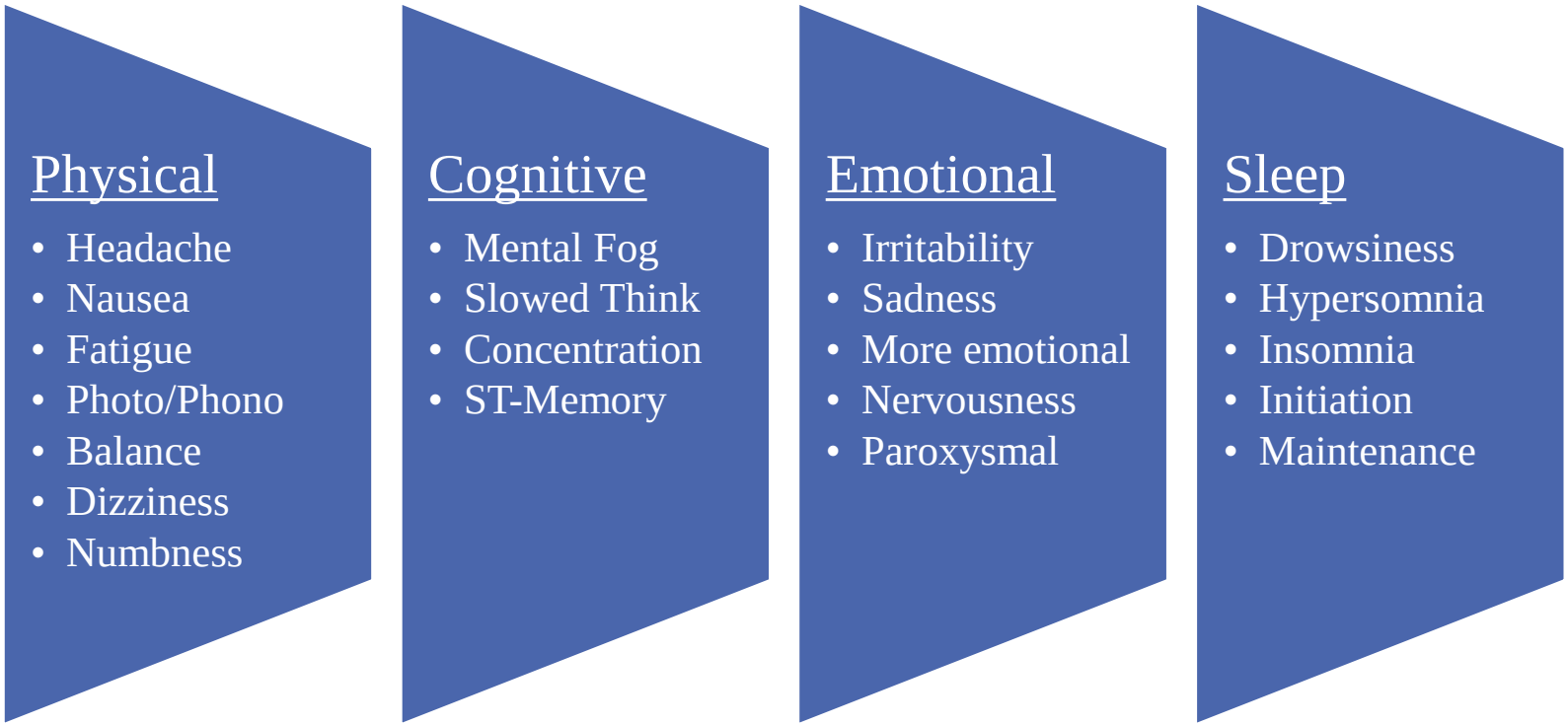
- Children with special conditions: high utilizers, Serious Emotional Disturbance (SED), California Children's Services (CCS), Whole-Child Model (WCM), child welfare and transitioning from incarceration

(Belanger et al., 2005; Theadom et al., 2019)

Impact of Post Concussive Symptoms (PCS)

Symptom Clusters of PCS: physical, emotional, cognitive, sleep

https://www.cdc.gov/headsup/pdfs/providers/ace-a.pdf



PCS are expected to resolve in **three months to a year, but half still experience** PCS for years following (persistent post concussive symptoms; PPCS) (Viegel at al., 2021; Stein et al., 2019)

II. Model of Functional Disability after Brain Injury (Kay et al., 1992)

https://drive.google.com/file/d/1Ci-Sp0qWup5_yRSxsX8FoyrarOVbXedM/view?usp=sharing

Rusk Institute of Rehabilitation Medicine
New York University Medical Center

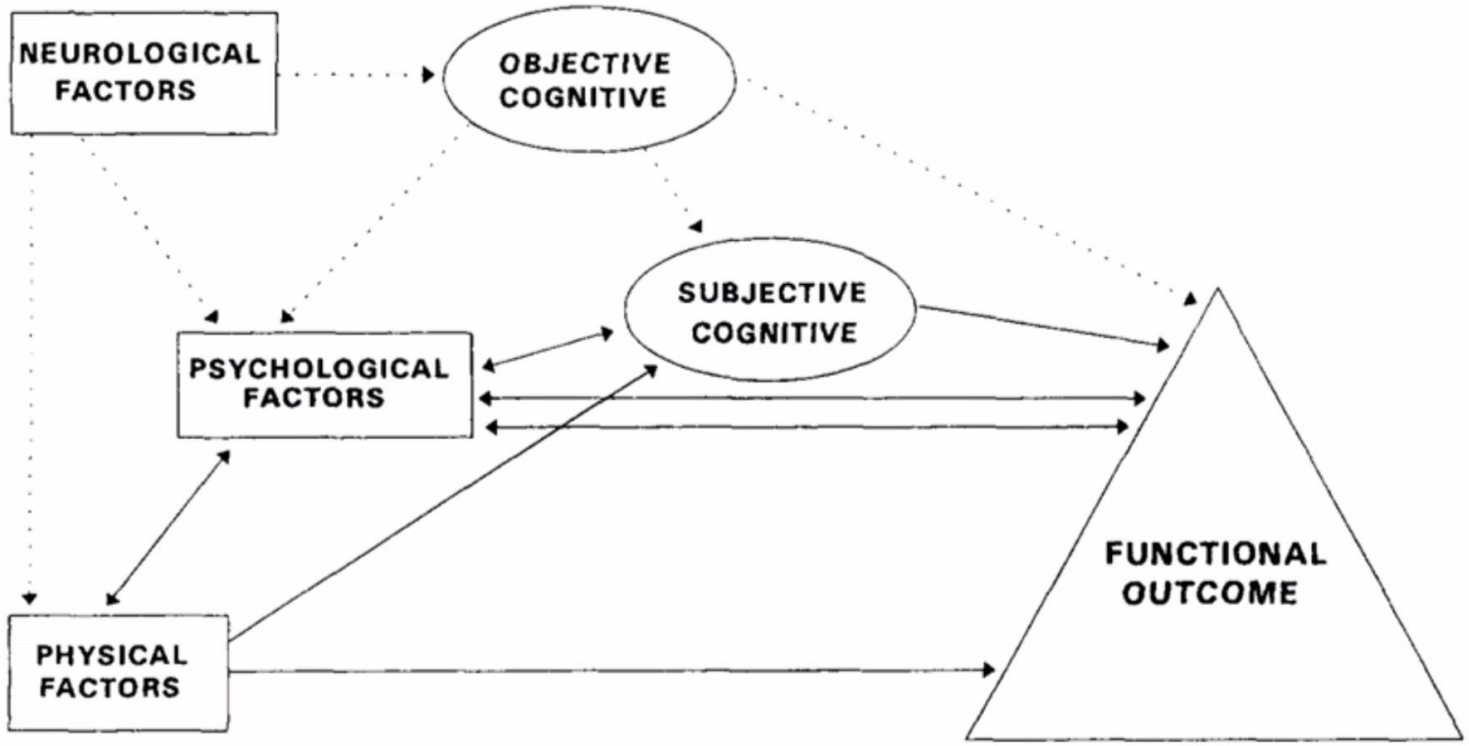


Figure 1. A neuropsychological model of functional outcome after mild traumatic brain injury.

II. Model of Functional Disability after Brain Injury (Kay et al., 1992)

***Functional outcome* =**

1. Neurologic Factors (medical rule out/in): e.g., neurologist, DO/MD
   - E.g., congenital, genetic, infections, nerve injury, neuroimaging
2. Physical Factors (medical rule out/in): e.g., PCP, physiatry, DO/MD
   - E.g., cardiovascular, digestive, respiratory, diabetes, cancer, muscular injury, cervicogenic
3. Objective Cognitive: e.g., Clinical [Neuro]Psychologist, PhD, ABPP
   - E.g., neuropsychological battery/assessments, cognitive testing, https://abpp.org/directory/
4. Subjective Cognitive (cognitive training): e.g., Speech, occupational
   - E.g., support with compensatory strategies (e.g., journal, calendar), restorative cognitive training
5. Psychological Factors (mental health): LMFT, LPCC, PsyD, CBIS
   - E.g., individual/couples counseling, case management, peer support programming https://www.emdria.org/find-an-emdr-therapist/

"The Injury Context"

Rusk Institute of Rehabilitation Medicine
New York University Medical Center

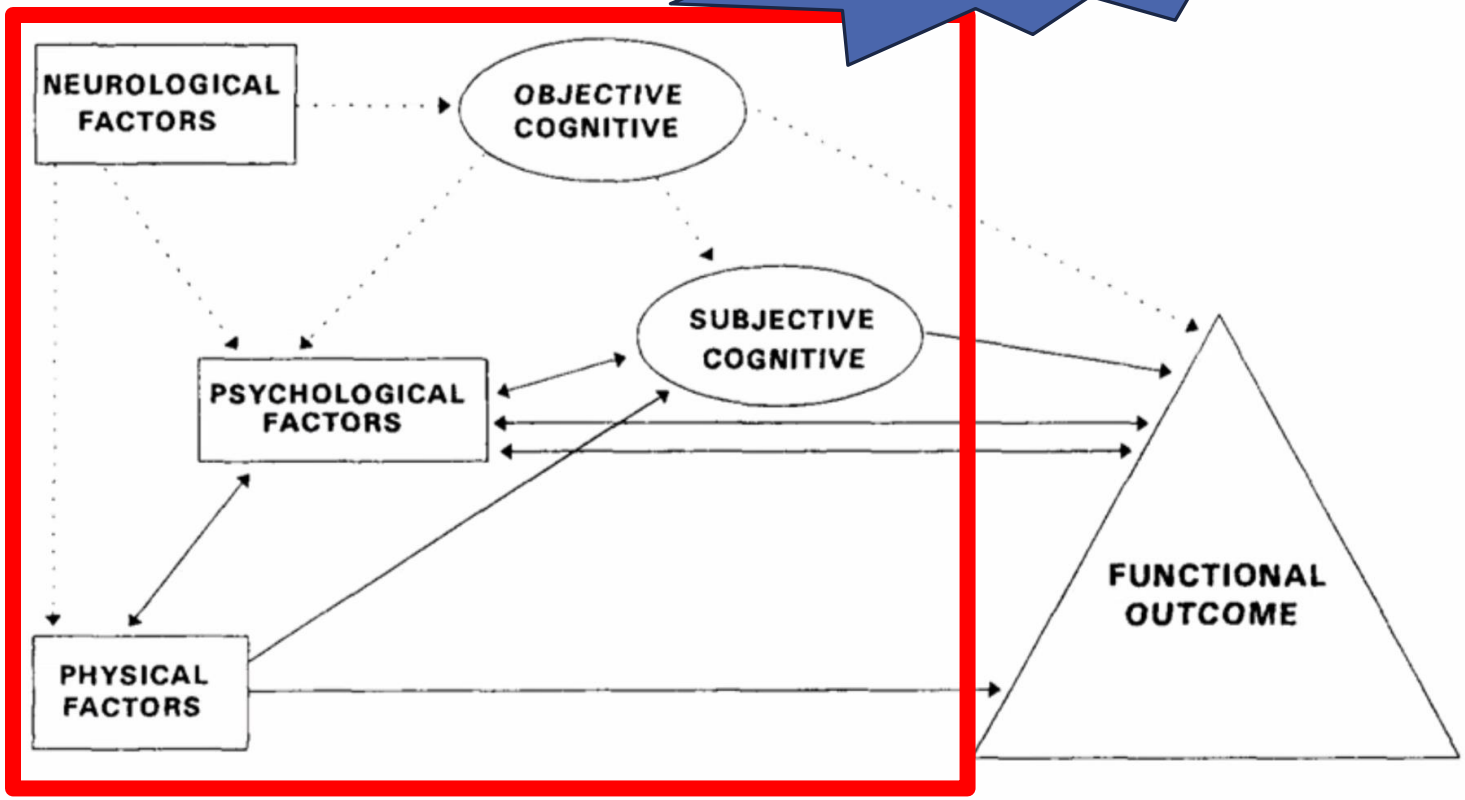
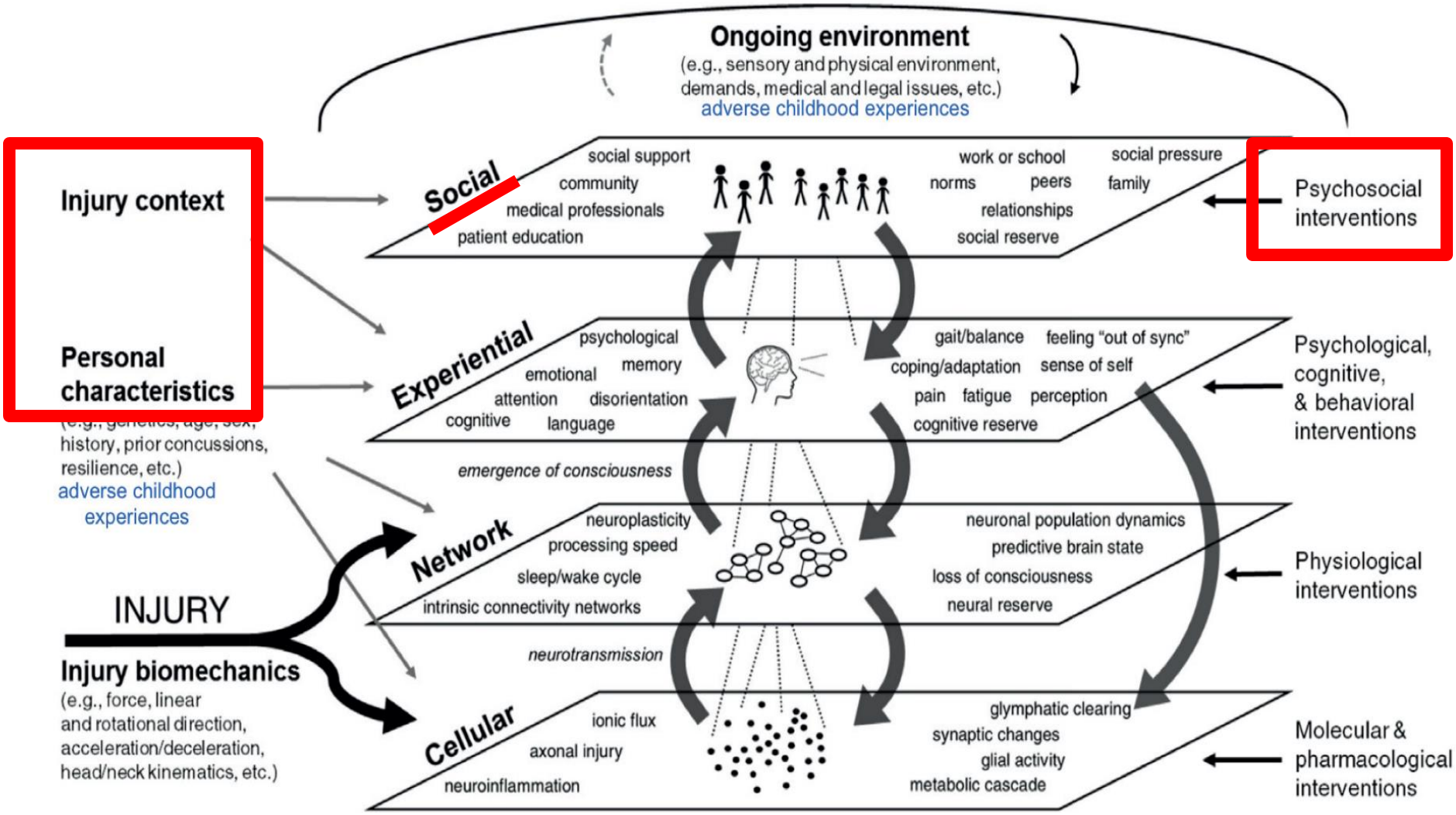


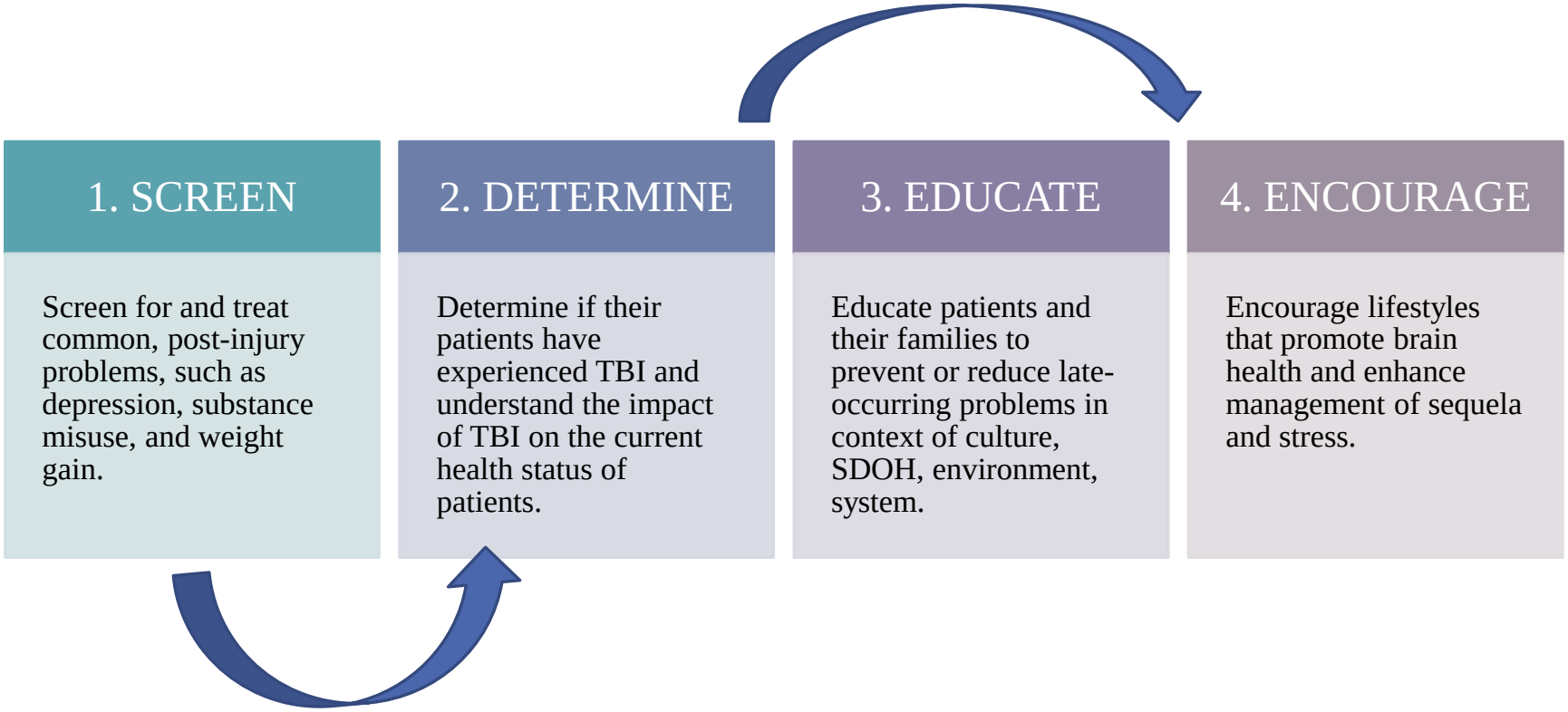
Figure 1. A neuropsychological model of functional outcome after mild traumatic brain injury.


Ongoing environment
(e.g., sensory and physical environment, demands, medical and legal issues, etc.)
adverse childhood experiences
Injury context
Personal characteristics
(e.g., genetics, age, sex, history, prior concussions, resilience, etc.)
adverse childhood experiences
INJURY
Injury biomechanics
(e.g., force, linear and rotational direction, acceleration/deceleration, head/neck kinematics, etc.)
Social
social support
community
medical professionals
patient education
work or school
social pressure
norms
peers
family
relationships
social reserve
Psychosocial interventions
Experiential
psychological
memory
emotional
attention
disorientation
cognitive
language
gait/balance
feeling "out of sync"
coping/adaptation
sense of self
pain
fatigue
perception
cognitive reserve
Psychological, cognitive, & behavioral interventions
emergence of consciousness
Network
neuroplasticity
processing speed
sleep/wake cycle
intrinsic connectivity networks
neuronal population dynamics
predictive brain state
loss of consciousness
neural reserve
Physiological interventions
neurotransmission
Cellular
ionic flux
axonal injury
neuroinflammation
glymphatic clearing
synaptic changes
glial activity
metabolic cascade
Molecular & pharmacological interventions

III. Screening & Diagnosis

RELATED CONDITIONS AND SYMPTOMS

At the local level, health care providers can:



1. SCREENING FOR TBI:
Craig Hospital TBI Model System & CDC BRFSS

Thinking about any injuries you have had in your lifetime:

1. How many times have you hurt or hit your head or neck?
2. How many times were you ever knocked out or lost consciousness?
3. If you have lost consciousness, for how long (minutes/hours)?

CDC's Acute Concussion Evaluation

B. Symptom Check List* Since the injury, has the person experienced any of these symptoms any more than usual today or in the past day?

Indicate presence of each symptom (0=No, 1=Yes). ***Lovell & Collins, 1998 JHTR***

PHYSICAL (10)		COGNITIVE (4)		SLEEP (4)	
Headache	0 1	Feeling mentally foggy	0 1	Drowsiness	0 1
Nausea	0 1	Feeling slowed down	0 1	Sleeping less than usual	0 1 N/A
Vomiting	0 1	Difficulty concentrating	0 1	Sleeping more than usual	0 1 N/A
Balance problems	0 1	Difficulty remembering	0 1	Trouble falling asleep	0 1 N/A
Dizziness	0 1	**COGNITIVE Total (0-4)** _____		**SLEEP Total (0-4)** _____	
Visual problems	0 1	**EMOTIONAL (4)**			
Fatigue	0 1	Irritability	0 1		
Sensitivity to light	0 1	Sadness	0 1		
Sensitivity to noise	0 1	More emotional	0 1		
Numbness/Tingling	0 1	Nervousness	0 1		
PHYSICAL Total (0-10) _____		**EMOTIONAL Total (0-4)** _____			
(Add Physical, Cognitive, Emotion, Sleep totals) Total Symptom Score (0-22)			_____		

Exertion: Do these symptoms worsen with:

Physical Activity __Yes __No __N/A

Cognitive Activity __Yes __No __N/A

Overall Rating: How different is the person acting compared to his/her usual self? (circle)

Normal 0 1 2 3 4 5 6 Very Different

MHS Military Health System
health.mil

MACE 2

Military Acute Concussion Evaluation

Use MACE 2 as close to time of injury as possible.

Service Member Name: _____

DoDI/EDIPI/SSN: _____ Branch of Service & Unit: _____

Date of Injury: _____ Time of Injury: _____

Examiner: _____

Date of Evaluation: _____ Time of Evaluation: _____

Purpose: MACE 2 is a multimodal tool that assists providers in the assessment and diagnosis of concussion. The scoring, coding and steps to take after completion are found at the end of the MACE 2.

Timing: MACE 2 is most effective when used as close to the time of injury as possible. The MACE 2 may be repeated to evaluate recovery.

SCAT5©

SPORT CONCUSSION ASSESSMENT TOOL – 5TH EDITION

DEVELOPED BY THE CONCUSSION IN SPORT GROUP

FOR USE BY MEDICAL PROFESSIONALS ONLY

supported by

SCAT 6 Just completed!

ONLINE @ https://scat5.cattonline.com/

Patient details

Name: _____

DOB: _____

Address: _____

ID number: _____

Examiner: _____

Date of Injury: _____ Time: _____

WHAT IS THE SCAT5?

The SCAT5 is a standardized tool for evaluating concussions designed for use by physicians and licensed healthcare professionals[1]. The SCAT5 cannot be performed correctly in less than 10 minutes.

Key points

- Any athlete with suspected concussion should be REMOVED FROM PLAY, medically assessed and monitored for deterioration. No athlete diagnosed with concussion should be returned to play on the day of injury.

2. Determine TBI History to:
Understand Impact on Current Health Status

The Community Integration Questionnaire- **R)**

Name: _____

Personal Assistant/Care Services

1	Who usually does the shopping for groceries or oth			?
	☐ Yourself alone	☐ Yourself and someone else	☐ Someone else	
2	Who usually prepares meals in your household?			
	☐ Yourself alone	☐ Yourself and someone else	☐ Someone else	
3	In your home who usually does normal everyday housework?			
	☐ Yourself alone	☐ Yourself and someone else	☐ Someone else	

Mayo Portland Adaptability Inventory-4 (MPAI 4): Participation Index (M2PI)

Part C. Participation

22. Initiation: Problems getting started on activities without prompting

0 None	1 Mild problem but does not interfere with activities; may use assistive device or medication	2 Mild problem; interferes with activities 5-24% of the time	3 Moderate problem; interferes with activities 25-75% of the time	4 Severe problem; interferes with activities more than 75% of the time

23. Social contact with friends, work associates, and other people who are not family, significant others, or professionals

0 Normal involvement with others	1 Mild difficulty in social situations but maintains normal involvement with others	2 Mildly limited involvement with others (75-95% of normal interaction for age)	3 Moderately limited involvement with others (25-74% of normal interaction for age)	4 No or rare involvement with others (less than 25% of normal interaction for age)

24. Leisure and recreational activities

0 Normal participation in leisure activities for age	1 Mild difficulty in these activities but maintains normal participation	2 Mildly limited participation (75-95% of normal participation for age)	3 Moderately limited participation (25-74% of normal participation for age)	

25. Self-care: Eating, dressing, bathing, hygiene

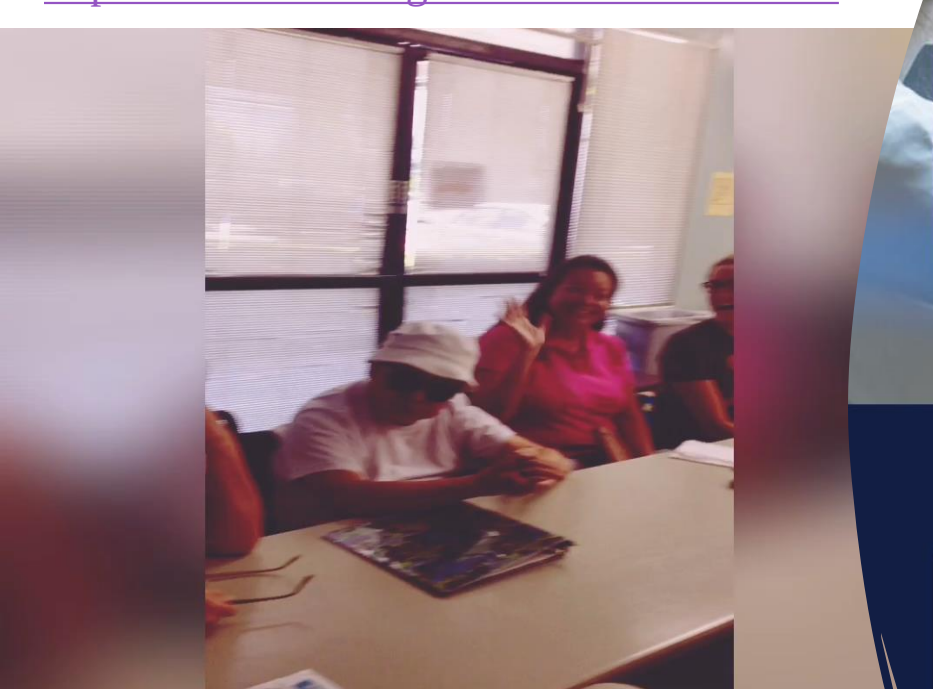
0 Independent completion of self-care activities	1 Mild difficulty, occasional omissions or mildly slowed completion of self-care; may use assistive device or require occasional	2 Requires a little assistance or supervision from others (5-24% of the time) including frequent prompting	3 Requires assistance or supervision from others (25-75% of the time)	4 Extensive assistance or supervision from others (more than 75% of the time)

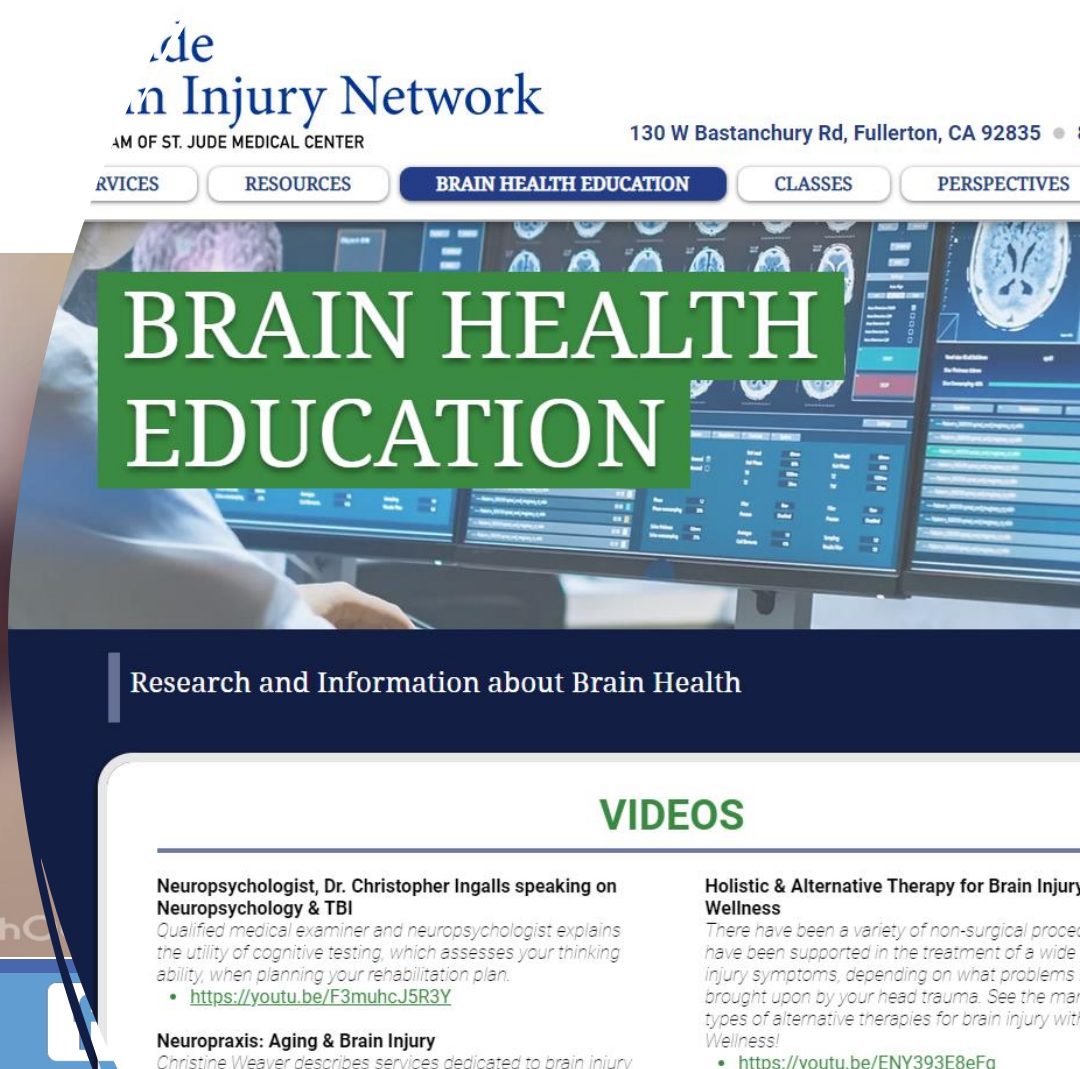
Independent Living Skills Training/Classes

3. Educate Patients & **Family Caregivers**:
to prevent/reduce problems

St. Jude Brain Injury Network: Orange County

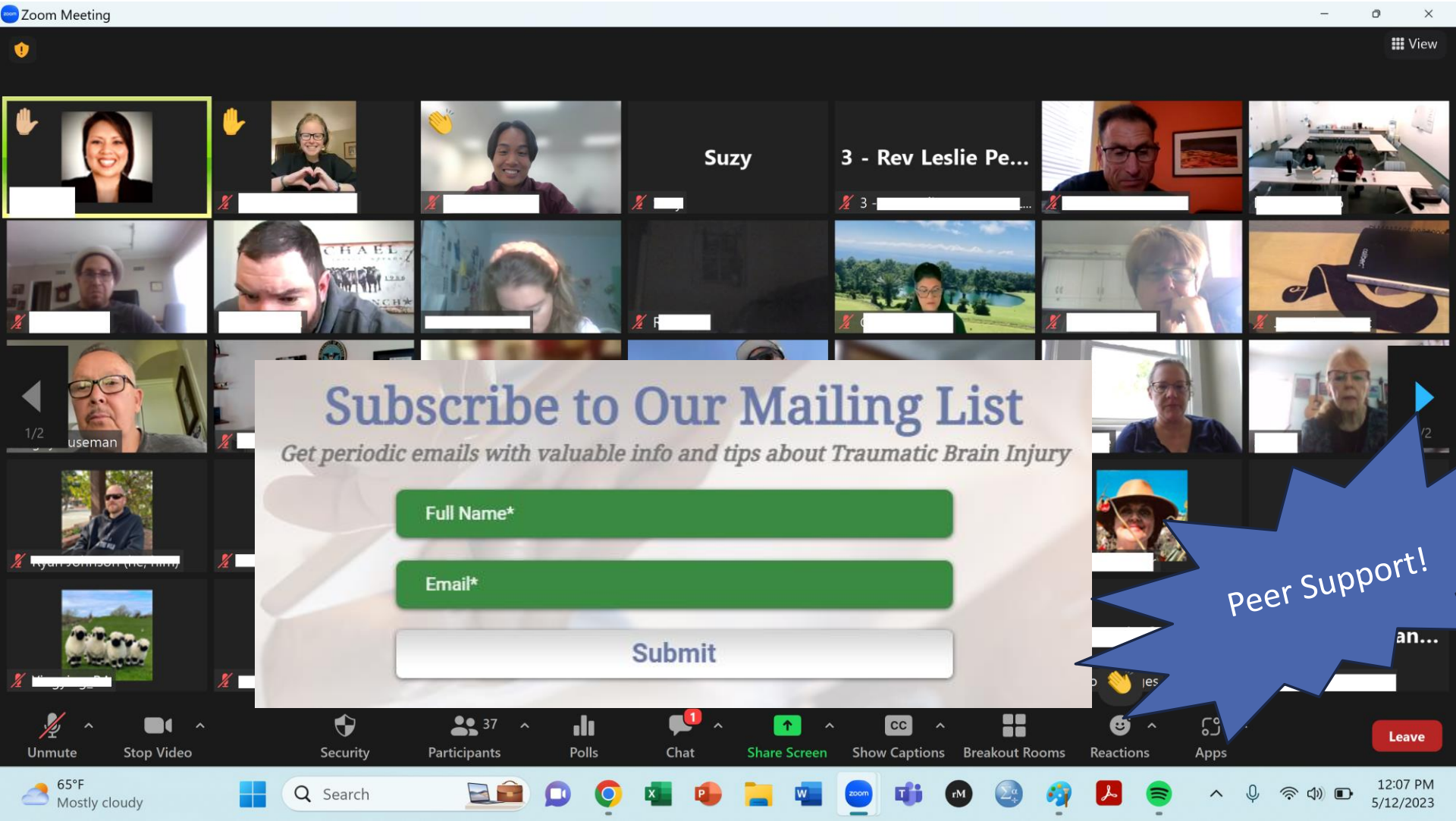
https://www.tbioc.org/brain-health-education





Weekly Peer Support Programming (Tu, W, F, Sat) & Weekly Newsletter that Summarizes Groups

(resources, referrals, education; subscribe at the bottom www.tbioc.org) email: Daniel.Ignacio@stjoe.org



4. Encourage Lifestyle to Promote Brain Health

Five Pillars of Brain Health:

I. Exercise/Physical Activity/Aerobic vs. Weight Training

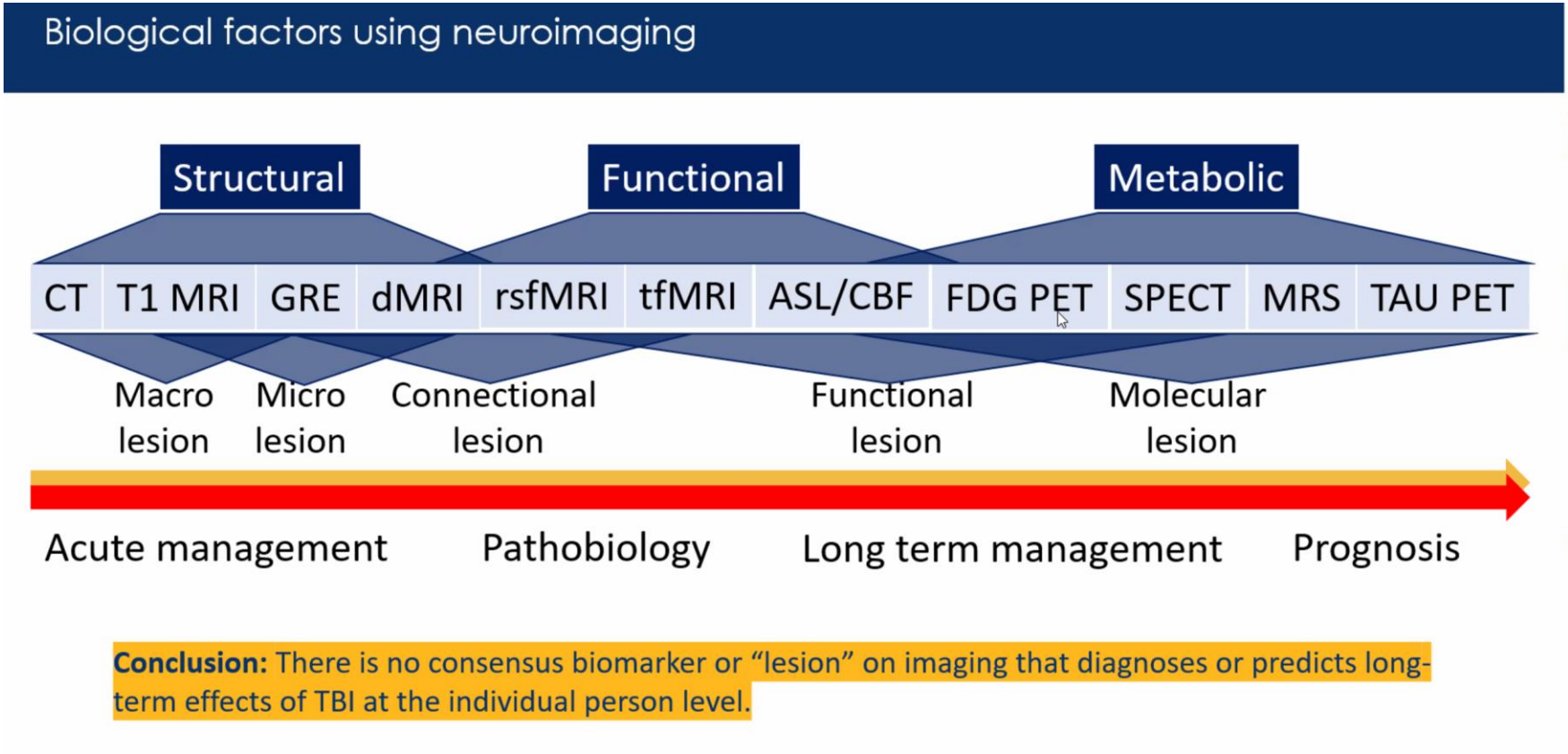
II. Diet/Nutrition

III. Sleep/Sleep Hygiene/Initiation vs. Maintenance

IV. Cognitive Stimulation (e.g., learning, reading)

V. Social Connectedness (e.g., social brain hypothesis)

Diagnosis through "Brain Scans"



Conclusion: There is no consensus biomarker or "lesion" on imaging that diagnoses or predicts long-term effects of TBI at the individual person level.

Don't get caught up in trying to "find" your brain injury!
We can't say what will lead to better or worse outcomes – just not there yet!

Examples of Diagnostic Processes for TBI

1. **Rule out medical complications**
    1. Physician: PCP, neurologist, physiatrist (physical medicine & rehabilitation)
    2. If they say exam/assessment is within expected ranges/normal/unremarkable, then there may not be a medical problem/a solution may not be with a medical provider
2. **What could it be then?**
    1. Functional condition (e.g., chronic pain, FND)?
    2. Integrated difficulties (e.g., neuropsychiatry, neuro-optometry https://nora.memberclicks.net/find-a-provider#/ , social, vocational rehabilitation, executive dysfunction, interdisciplinary clinics https://www.reactivept.com/services)
    3. Neurocognitive Disorder due to… (DSM-5 TR versus ICD-10/11 G31.84)
3. **Treating with Therapy & Working backwards**
    1. Physical therapy (e.g., vestibular, neuro PT) www.neuropt.org/consumer-info/what-is-a-neurologic-physical-therapist
    2. Occupational Therapy (acute rehab versus lifestyle medicine – UCLA BrainSPORT)
    3. Speech Therapy (traditional cognitive rehab)
    4. Community or Home-based Neurorehabitation

Model of Functional Disability after Brain Injury (Kay et al., 1992)

Functional outcome =

1. Neurologic Factors
2. Physical Factors
3. Objective Cognitive
4. Subjective Cognitive
5. Psychological Factors

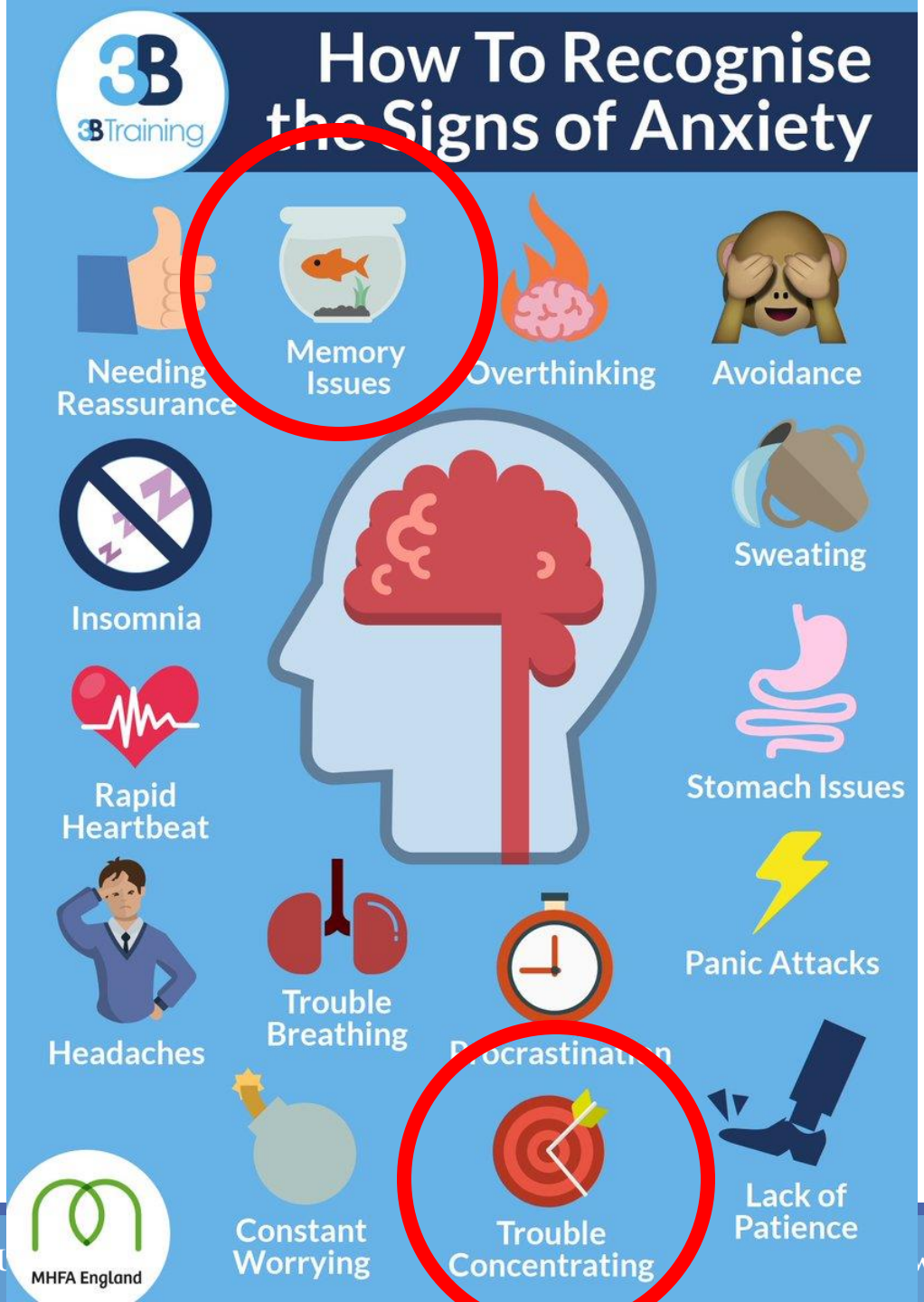
Psychological Factors

and the environment. First, the person experiences cognitive breakdowns in information processing, attention and concentration, learning and memory, and problem solving as a direct result of the primary neurological injury. Second, when these symptoms persist into the period of return to functioning, the person begins to experience failure, frustration, and the inability to perform as usual for reasons unknown to him or her. If medical consultation fails to adequately explain and manage the symptoms, the person develops a "shaken sense of self"; that is, his or her sense of predictability and control over self and environment begins to disintegrate, and the disparity between external appearances of normality and internal but nonvalidated convictions of dysfunction result in the feeling of "going crazy." Third, anxiety builds and the person begins to avoid situations in which he or she may fail. Fourth, depression deepens. Fifth, both the anxiety and the depression begin to feed back into the cognitive weak links; anxiety and depression cause further cognitive breakdowns, which in turn fuels more anxiety and depression. Sixth, this psychological overlay begins to accumulate over time and eventually may become more functionally disabling than the underlying primary deficits themselves. The extent of the disintegration of the self will depend on both personality characteristics of the person and the adequacy of the environmental response.

Personality factors may influence the extent of the disintegration of self, and thus help determine functional outcome, in at least three different ways. First, there are individual

Common Symptoms between Depressed mood and TBI

Apathy	• May range from mild (trouble getting started) to needing direction for all behavior
Blunted or Labile affect	• Frontal Lobe and underlying structures
Changes in Appetite	• Hypothalamus
Sleep Disturbance	• Areas of the brain stem responsible for sleep initiation and maintenance.
Fatigue	• Both mental and physical fatigue
Cognitive Impairment	• Memory, poor problem-solving, attention and concentration


3B
3B Training
How To Recognise the Signs of Anxiety
Needing Reassurance
Memory Issues
Overthinking
Avoidance
Insomnia
Sweating
Rapid Heartbeat
Stomach Issues
Panic Attacks
Headaches
Trouble Breathing
Procrastination
Lack of Patience
Constant Worrying
Trouble Concentrating
MHFA England

HOW STRESS AFFECTS THE BODY

BRAIN

Difficulty concentrating, anxiety, depression, irritability, mood, mind fog

CARDIOVASCULAR

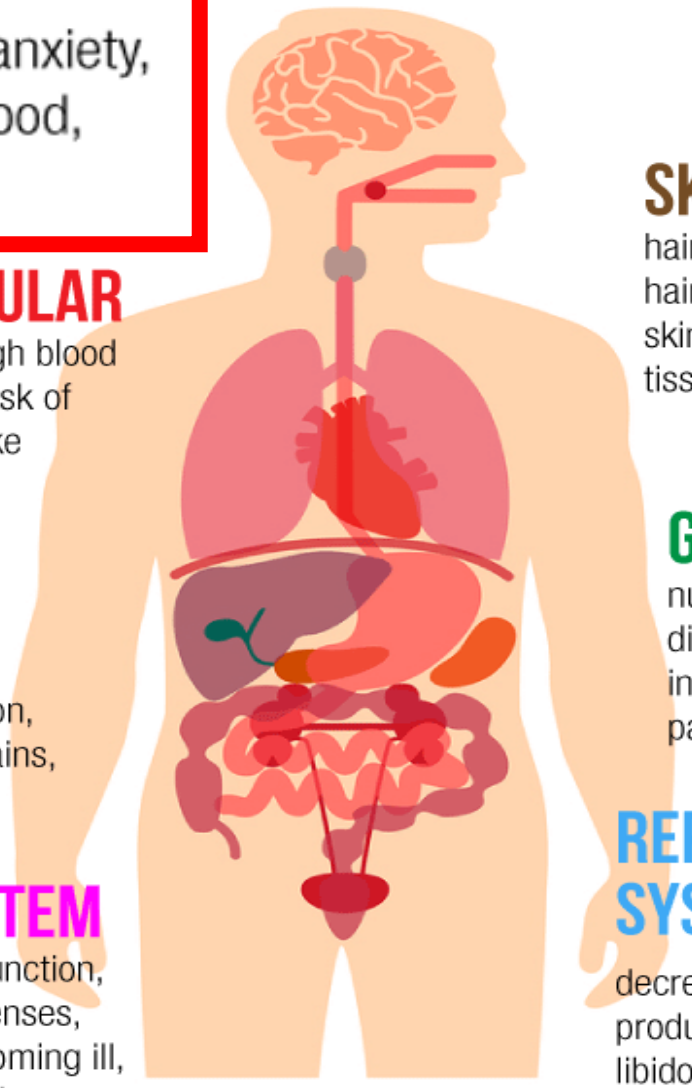
higher cholesterol, high blood pressure, increased risk of heart attack and stroke

JOINTS AND MUSCLES

increased inflammation, tension, aches and pains, muscle tightness

IMMUNE SYSTEM

decreased immune function, lowered immune defenses, increased risk of becoming ill, increase in recovery time



SKIN

hair loss, dull/brittle hair, brittle nails, dry skin, acne, delayed tissue repair

GUT

nutrient absorption, diarrhea, constipation, indigestion, bloating, pain and discomfort

REPRODUCTIVE SYSTEM

decreased hormone production, decrease in libido, increase in PMS symptoms

Neuropsychiatric Symptoms

1. Depression, Anxiety, & Stress can cause **cognitive symptoms**

2. Brain injury can also cause **cognitive symptoms**

3. The Brain manages **depression, anxiety, & stress…**

So, what happens when the thing that deals with problems, is the thing with the problem??

The environment must respond by accommodating to survivor deficits.

"Person-Environment Fit"

Help Survivors with Referrals to Connect to Resources

- Survivors need a "surrogate brain"
  – assistance with thinking, regulating, motivation, awareness, guidance
  - This is where direct service providers come in
  - Start building referral base for county services
- An injury to an organ as comprehensive as the Brain REQUIRES interdisciplinary care coordination and support!
- Examples of Needed Service Coordination:
  - Directory of Community Resources (information & referral) based on symptoms!
  - Work Incentives Planning & Assistance (WIPA) – vocational rehabilitation
  - Disability Income Advocacy/Benefits Advising

Accommodating cognitive impairment

Showing up

Paying attention

Remembering What to do

Deciding what to do

Planning

Starting

Evaluating

Reducing cognitive load

Slow down

Break down tasks

Use routines

Create reminders and teach clients to use them

Set clear goals and agendas

Remove Distractions

Other Potential Neurorehabilitation Models:

1. *learn to participate* model **Rehabilitation Facilities** (Carlson et al., 2006)
    1. involve teacher to acquire proficiency in sheltered
    2. Then generalize to real-world environments
2. *participate to learn* model **Community settings** (Carlson et al., 2006)
    1. involves 1st experience in real-life roles for proficiency
    2. No need to generalize since learning is natural
3. **Community-based Neuropsychological Rehabilitation (CBNPR)**
    1. Person-environment-symptom fit to maximize success (Judd & DeBoard, 2009)

***NOT suggesting to replace medical model**
…BASED ON TIME/PLACE/CIRCUMSTANCE/NEEDS!

Accessing Neurorehabilitation

1. **Medical insurance** (e.g., Medicaid, MediCare, Private/Commercial, PPO)
2. **Legal coverage** (e.g., worker's compensation, personal injury)
    1. California State Bar Lawyer Referral Service (866) 442-2529
    2. DRC Employment Law Resources by County: https://docs.google.com/document/d/1NwgzuJmFkfy1JT09H4-gLvbkZSjfWGrt2/edit?pli=1
    3. Find a Certified Bar Lawyer tool: https://www.calbar.ca.gov/Public/Need-Legal-Help/Using-a-Certified-Lawyer-Referral-Service/Certified-Lawyer-Referral-Services-Directory
3. National survey by the U.S. Department of Health and Human Services (SAMHSA, 2018):
    1. 2018, 16% of Americans did not receive mental health services because limited coverage, compared to 9% in 2008.

Legislation & Public Policy

- **01/01/2021:**
  In California, SB 855
  was enacted

- **03/11/2021:**
  President Biden American Rescue Plan Act (Pub. L. 117-2)
- HCBS Waivers allow Medicaid states to develop creative alternatives

- **10/01/2021:**
  SB 48 Medi-Cal annual cognitive evals (65+)

Legislation & Public Policy

- ARPA resulted in federal funding to HHS
  - CA Department of Rehabilitation TBI Program:
  - $5M for 3 years as enhanced Federal funding
- Home Community Based Services Waiver
  - TBI Expansion (2022)
  - 07/01/22: 6 sites to receive enhanced funds
- Advocacy with SB 855 to insurance payor for DSM-5 TR diagnosis: neurocognitive disorders due to TBI (F02.80-1)

Intervention at the Social & Experiential Levels – what do you think is needed??

PRIMARY (preventing occurrence)

1. CDC's CORE SIPP
2. Wearing helmet, seatbelt, protective gear
3. Limiting risky behaviors (e.g., DUI, unhealthy lifestyles)
4. Identifying At-Risk populations (e.g., ACEs, correctional facilities "San Quentin Rehabilitation"

SECONDARY (acute, subacute, post-acute care)

1. Enhance Community Awareness and Medical Literacy about TBI (1st identifying, then manage)
2. Subthreshold aerobic exercise (recommendation following concussion)
3. TBI Model System Sites (PT, OT, ST)

TERTIARY (community reintegration)

1. Medicaid HCBS TBI Waiver (e.g., CATBI)
2. Compensatory Cognitive Strategies (e.g., calendar, journal, social skills retraining)
3. Individual Therapy (e.g., counseling, vocational rehabilitation)
4. Incorporating direct Family Caregivers

Questions?

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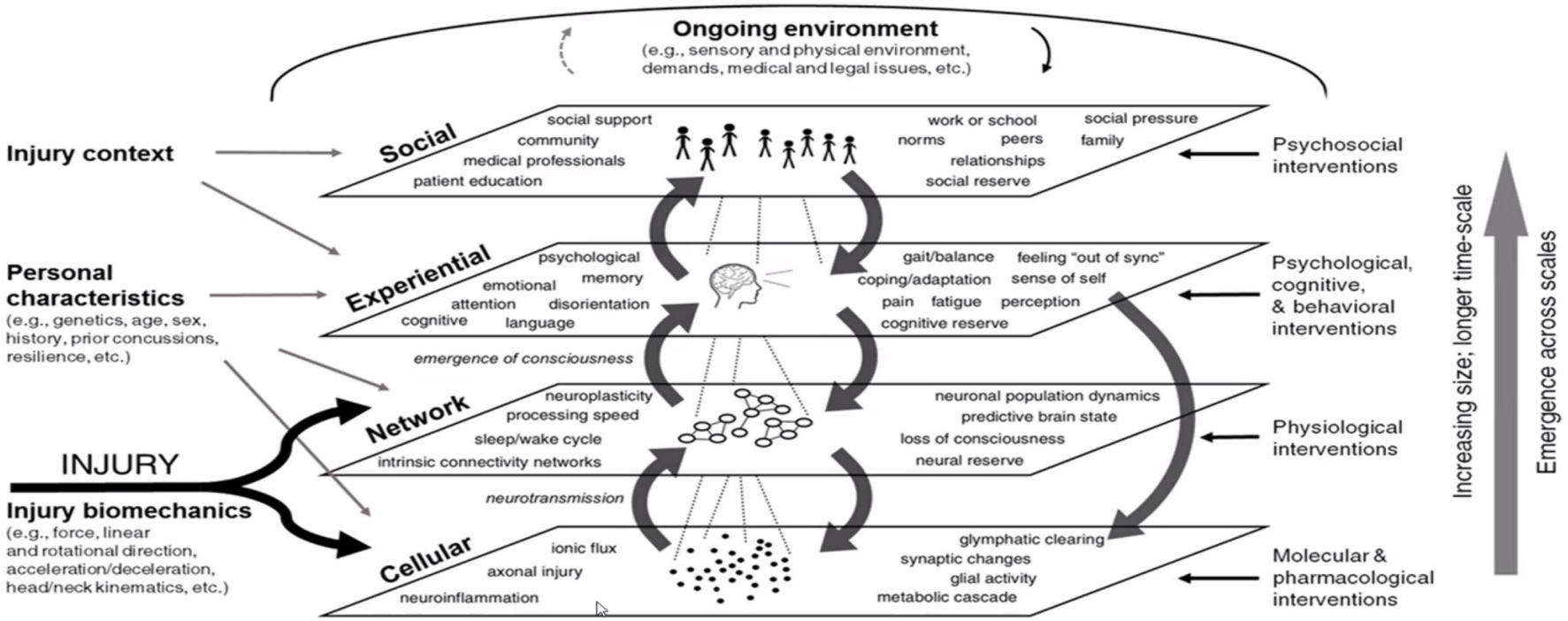
: TBIOC

St. Jude Brain Injury Network:
www.tbioc.org

Multidimensional approach



Kenzie et al., 2017, Frontiers

REFERENCES

https://drive.google.com/file/d/1G7Nd9WO8R5iFyz4sKapPGmr74NsE8y0p/view?usp=sharing

Neuroplasticity

1. https://www.youtube.com/watch?v=ELpfYCZa87g
2. https://www.youtube.com/watch?v=kWIagHUqD8A&t=34s

Your brain is going to get used to whatever you put it in…

NEUROPLASTICITY – can be good & BAD