



Mental Health and its Impact on IBD Care: Challenges for patients and clinicians

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Objectives

- Examine how early life events may impact a patient's life journey with IBD
- Discuss how strategies such as trauma-based care can overcome barriers caused by mental health issues

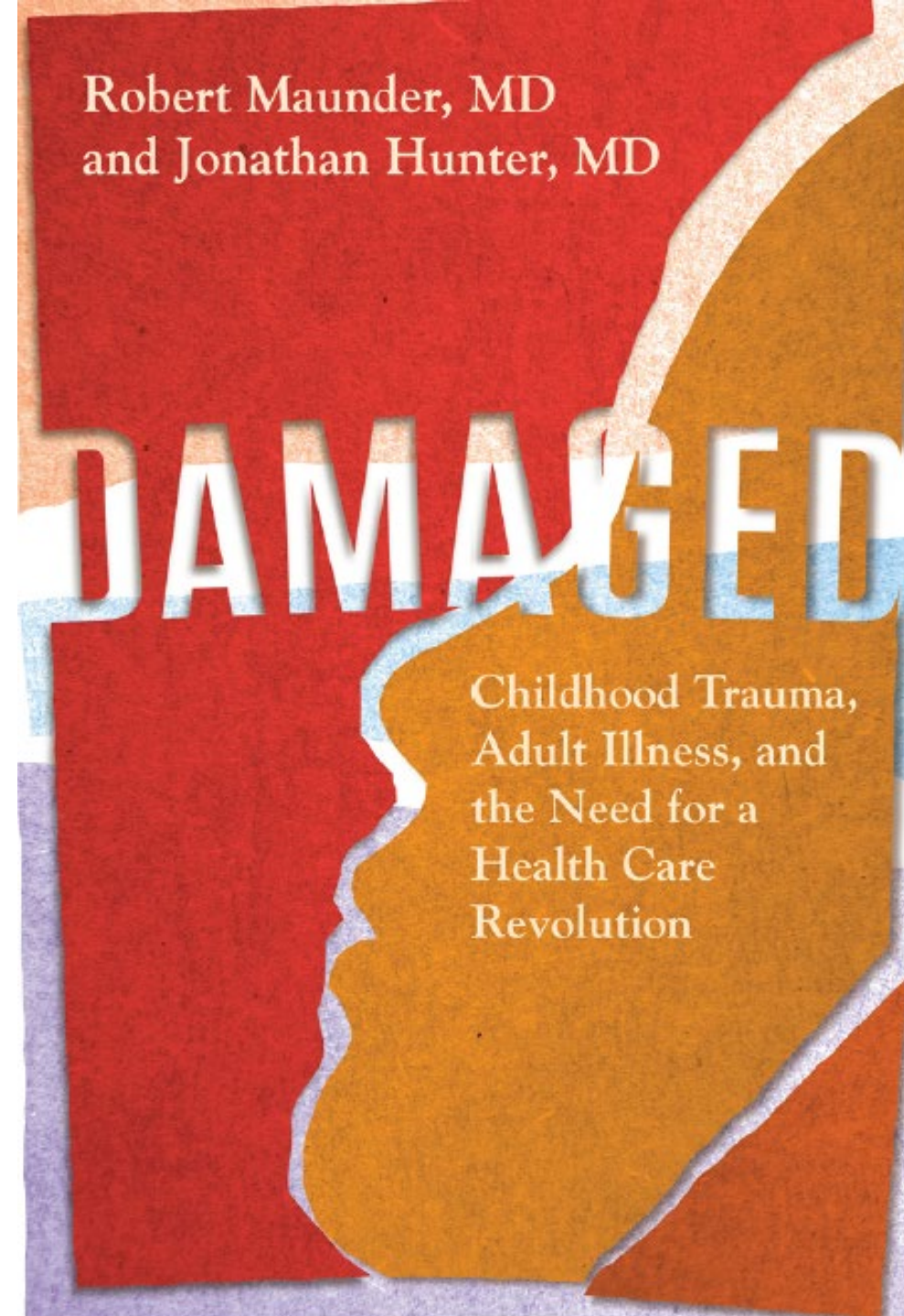
Content warning

We will be discussing childhood trauma, including referring to physical and sexual abuse.

Consent

“Isaac” has given repeated, explicit consent for his case to be described in depth in the book, *Damaged*.

Case vignettes in this presentation are summarized from events described in the book



Isaac

- Isaac is a middle aged man who has had Crohn's disease since his early teens
- He experienced repeated, severe sexual abuse in the years prior to the onset of his disease
- He has had numerous surgical resections and is currently treated with Humira

Vignette: My first consultation with Isaac

- Isaac tells me he will treat his CD with repeated resections and not accept medical treatment
- “Each time they operate, they take out 8 or 10 inches of intestine. The operations have been 5 to 7 years apart. My small intestine is 20 feet long. I’m 45. I have more intestine than I have years. Why take the drugs?”

Context:

- Isaac is fiercely self-reliant. He leads with strength; rejects dependency & takes his own counsel regarding medical options.
- Compulsive self-reliance is an adaptive response to early trauma that forced objective helplessness and compliance

Childhood adversity (ACEs) & child abuse

Research Article

Relationship of Childhood Abuse and Household Dysfunction to Many of the Leading Causes of Death in Adults

The Adverse Childhood Experiences (ACE) Study

Vincent J. Felitti, MD, FACP, Robert F. Anda, MD, MS, Dale Nordenberg, MD, David F. Williamson, MS, PhD, Alison M. Spitz, MS, MPH, Valerie Edwards, BA, Mary P. Koss, PhD, James S. Marks, MD, MPH

Types of Adverse Childhood Experience

	Before the age of eighteen
Physical abuse	An adult in your home often pushed, grabbed, shoved, slapped or threw something at you, or ever hit you so hard that you had marks or were injured.
Sexual abuse	A person at least five years older touched or fondled you, or had you touch their body in a sexual way, or attempted or actually had oral, anal, or vaginal intercourse with you.
Emotional abuse	An adult in your home often swore at or insulted you, or put you down, or acted in a way that made you afraid that you would be physically hurt.
Emotional neglect	Often feeling that no one in your family loved you or thought you were important or special, or that your family didn't look out for each other, feel close to each other, or support each other.
Material deprivation	Often not having enough to eat, or having to wear dirty clothes, or having no one to protect you, or your parents being too drunk or high to take care of you or take you to the doctor if you needed it.
Parental Separation	Parents separating permanently or divorcing.
Family member with mental illness	Living with someone who was depressed or mentally ill or attempted suicide.
Family member with substance abuse	Living with someone who was a problem drinker or alcoholic or who used street drugs.
Family violence	Witnessing violence against your mother or stepmother who was often pushed, grabbed, slapped, or had something thrown at her, or sometimes kicked, bitten, hit with a fist, or hit with something hard, or ever repeatedly hit for a few minutes or threatened with a knife or gun.
Family member jailed	Having a family member go to jail.

Additional evidence-supported types of childhood adversity

Being treated badly or unfairly because of your race or ethnicity; not feeling safe in your neighborhood; being bullied often; living in foster care; experiencing the death of a parent; having low-socioeconomic status; having someone close experience a bad accident or illness; having parents who frequently argued; having no good friends.

Prevalence of multiple ACES

None	41%
One to three	44%
Four to six	13%
Seven or more	3%

59%

Felitti et al, *AM J Prev Med*, 1998
D Finkelhor, A Shattuck, H Turner, S Hamby. *JAMA Pediatr.* 2013;167(1):70–75
Cronholm et al. *Am J Prev Med* 2015;49(3):354–361

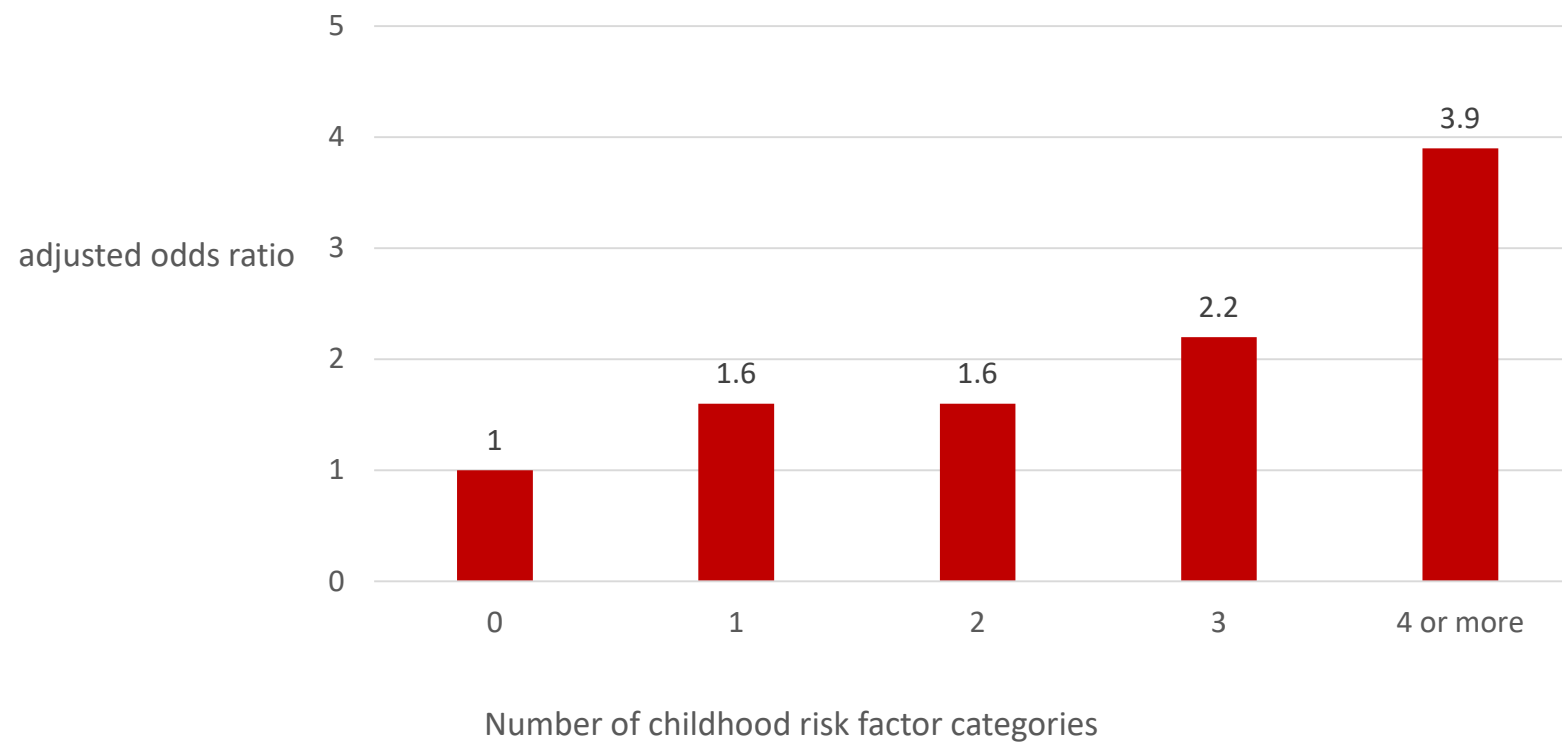
Gilbert et al, *Am J Prev Med*, 2015, 48(3):345-9

1 in 3 Kids Experiences Child Abuse

	Men	Women	All
Physical abuse	31%	21%	26%
Sexual Abuse	6%	14%	10%
Exposure to Intimate Partner Violence	7%	9%	8%
Any of these	34%	30%	32%

Physical disease

Number of ACEs & Odds of COPD



Felitti et al, *AM J Prev Med*, 14, 245-58, 1998

Population attributable risk due to ACEs

COPD - 33%

Asthma - 27%

Kidney disease – 16%

Stroke – 15%

Coronary heart disease – 13%

Cancer (excluding skin) – 6%

Diabetes – 6%

Merrick et al, Morbidity and Mortality Weekly Reports, 68(44). Nov 2019
US Dept of Health and Human Services/CDC

Other physical diseases linked to ACEs or childhood abuse

Hypertension

Arthritis

HIV

Hepatitis C

Chronic liver disease

Felitti et al, *AM J Prev Med*, 14, 245-58, 1998
Afifi et al, Health Reports, Vol. 27, no. 3, pp. 10-18, March 2016 • Statistics Canada
Brezing et al, *Psychosomatics*, 2015-03-01, 56 (2), 107-118



AHA SCIENTIFIC STATEMENT

Childhood and Adolescent Adversity and Cardiometabolic Outcomes

A Scientific Statement From the American Heart Association

“Substantial evidence links childhood adversity to
cardiometabolic disease later in life”

ACEs kill

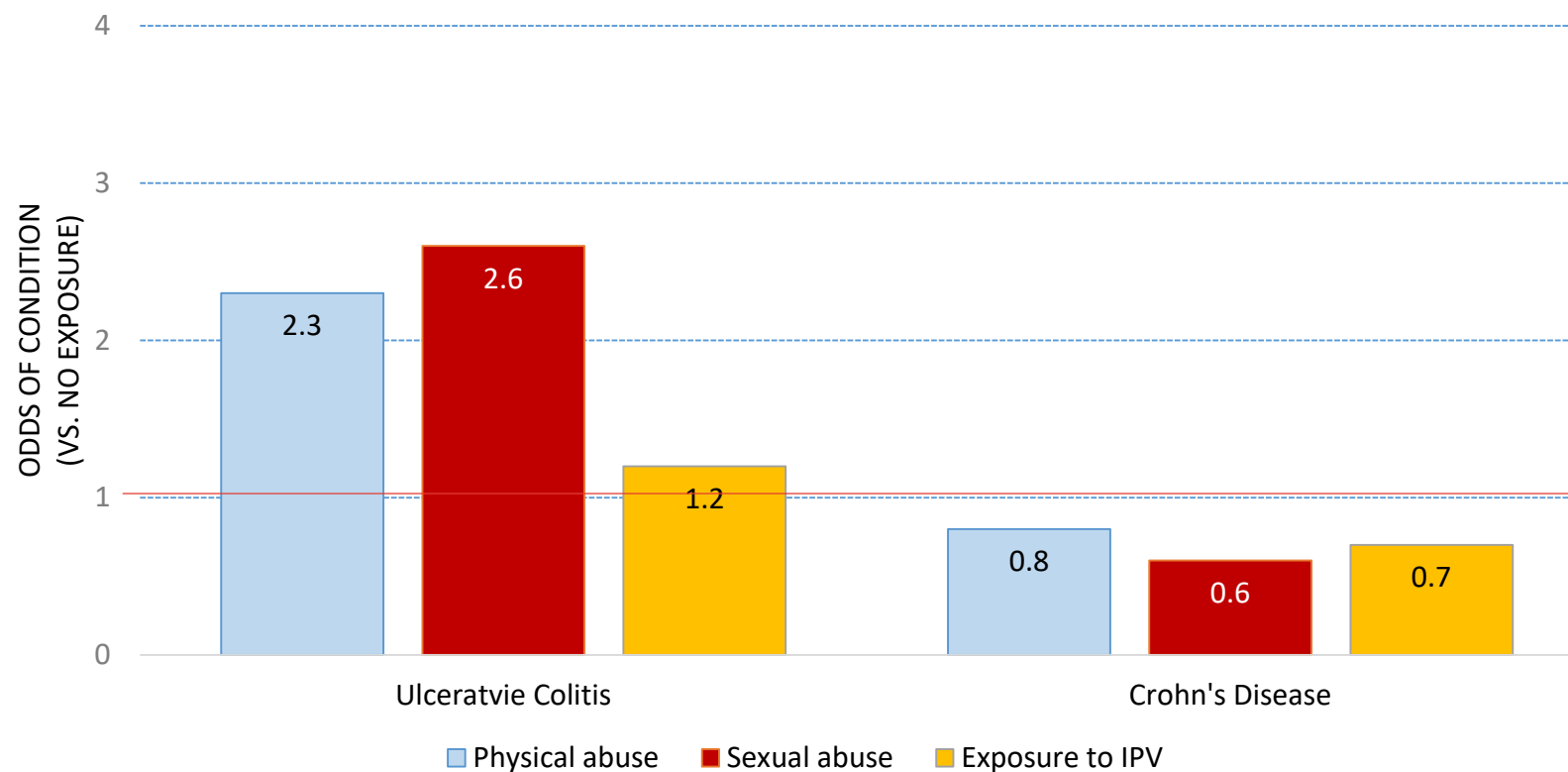
“People with six or more ACEs died nearly 20 years earlier on average than those without ACEs”

Brown et al, Am J Prev Med, 37(5), 389-96, 2009

“mortality was strongly linked to ACEs... Radically different life-course trajectories are associated with exposure to increased ACEs”

Bellis et al, J Public Health, 37(3), 445-454, 2015

Are ACEs associated with IBD risk?

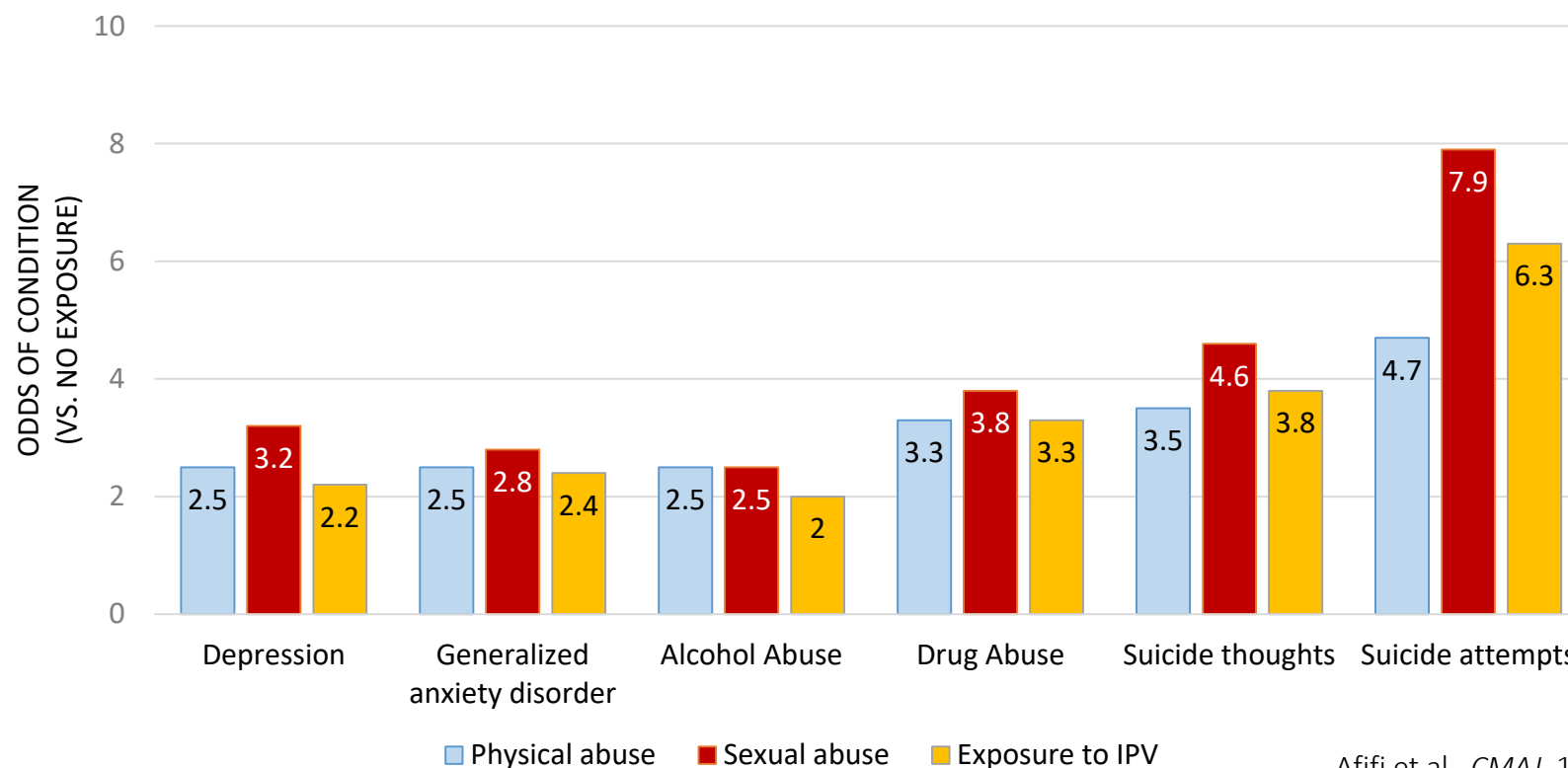


2012 Canadian Community Health Survey—Mental Health
 UC n = 154; CD n = 110 (self-report of MD diagnosis)
 Vs neither n = 21,588

Fuller-Thomson E, West KJ, Sulman J, Baird SL. Childhood Maltreatment Is Associated with Ulcerative Colitis but Not Crohn's Disease: Findings from a Population-based Study. *Inflamm Bowel Dis*. 2015 Nov;21(11):2640-8.

Mental health

Risk of mental health problems more than doubles with exposure to childhood abuse



Afifi et al., *CMAJ*, 186(9), E324-32, 2014

Vignette: A forged prescription

- Isaac reports that he has been caught trying to fill a forged prescription for Fiorinal and is concerned his physician will “fire” him

Context:

- Substance use is a common consequence of early adversity, often starting in teen years as “self-medication” of distress
- Pain out of proportion to objective pathology is very common
- Isaac reports that as a child, his neglectful mother used to give him her Fiorinal for headaches. “It felt great. It was the closest thing to love she ever gave me.”

Mental health problems linked to ACEs or childhood abuse

Depression

Bipolar disorder

Substance use disorder (alcohol, other drugs)

Suicidal thoughts

Suicide attempts

Generalized anxiety disorder

Obsessive-compulsive disorder

Panic disorder

Phobias

Posttraumatic stress disorder

Attention-deficit disorder

Eating disorders

Learning disabilities

Functional syndromes

Figure 2. Odds Ratio for the Association of Sexual Abuse and Somatic Disorders

Chronic pain

Fibromyalgia

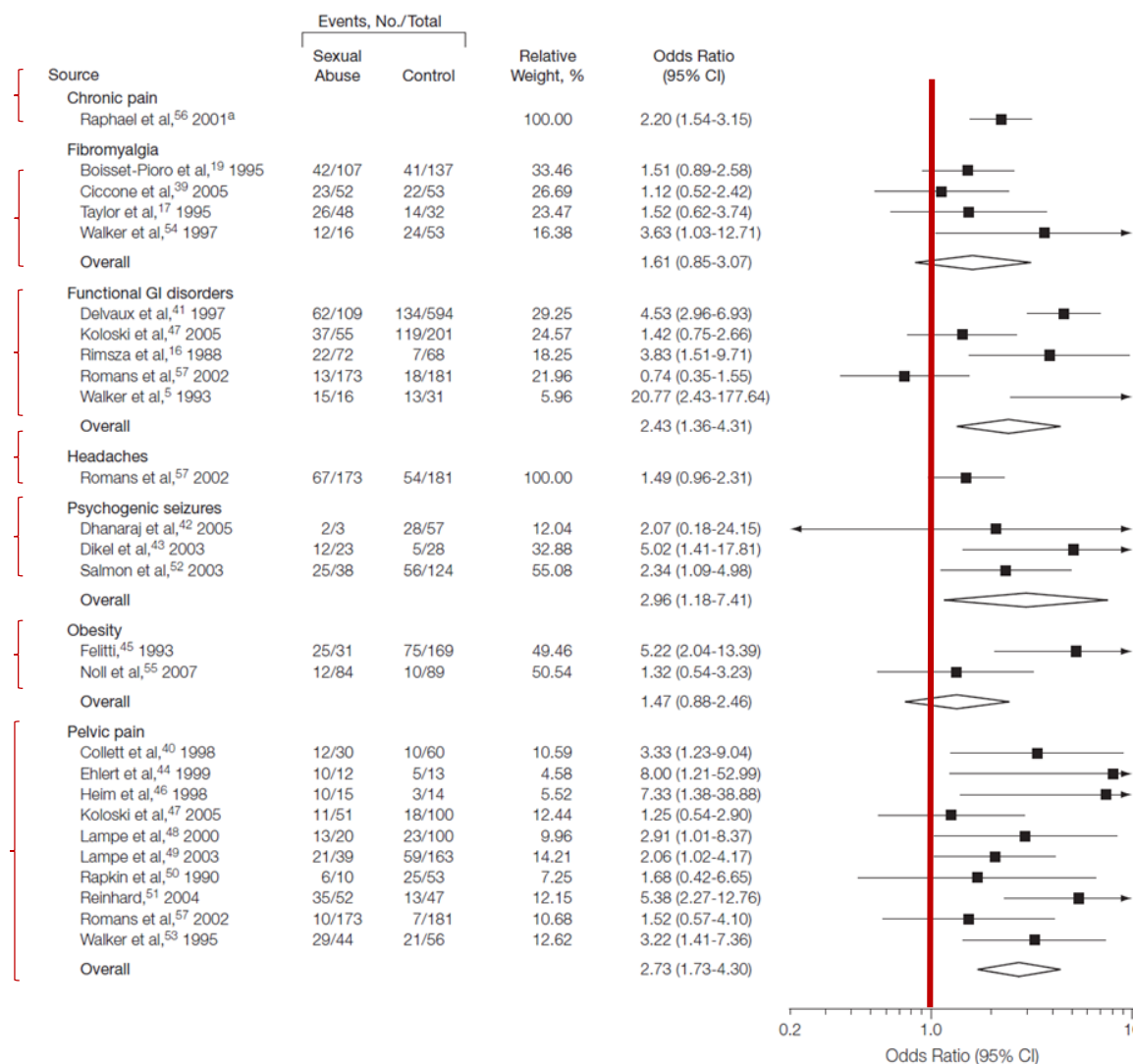
Functional GI disorders

Headaches

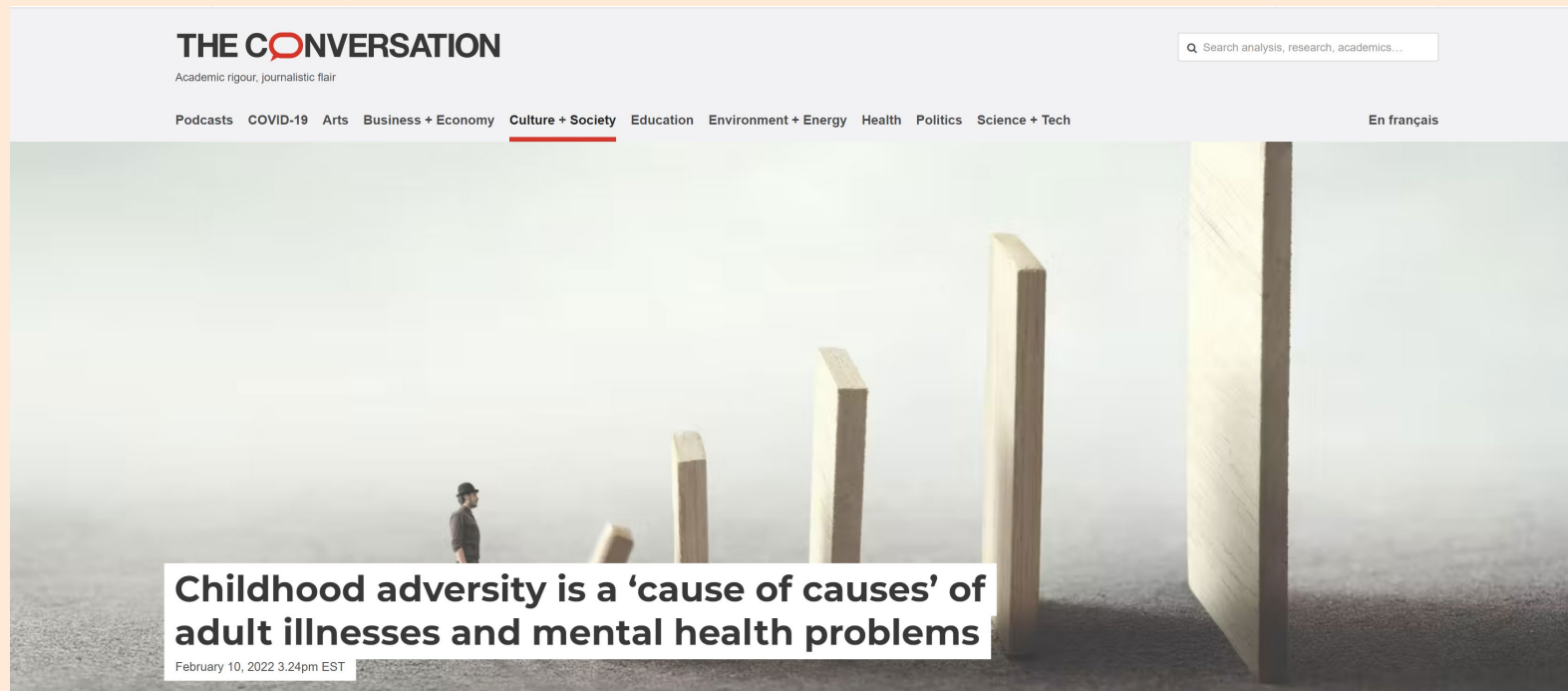
Non-epileptic seizures

Obesity

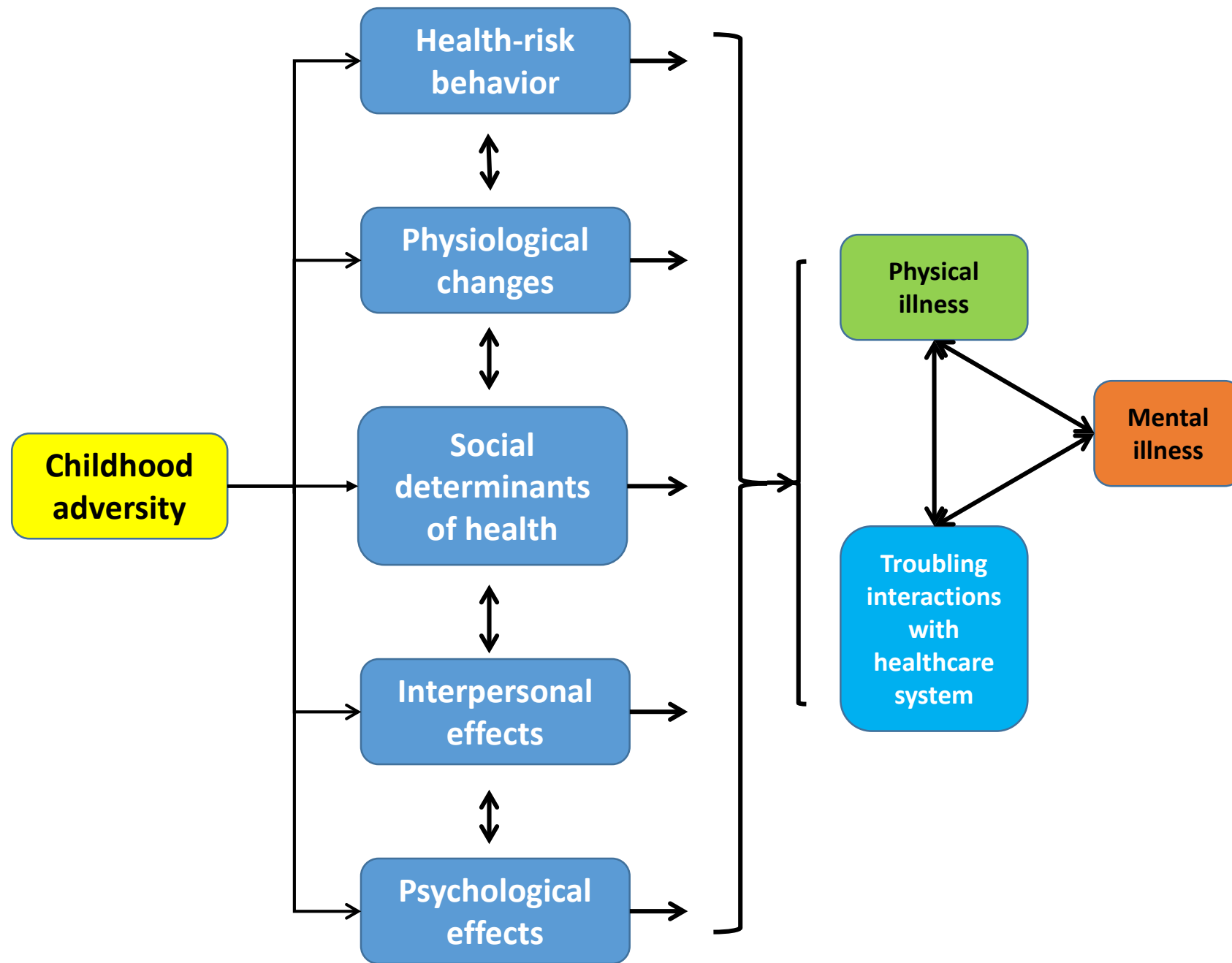
Pelvic pain



Cause of causes



www.theconversation.com



Vignette: At the Remicade infusion clinic

- Isaac experiences an allergic reaction to a Remicade infusion conducted at a clinic, with sudden and severe shortness of breath
- He becomes enraged at the gastroenterologist who prescribed the medication but was not present and plans to confront him for being “completely irresponsible.”

Context:

- The allergic reaction made Isaac feel as if he was drowning.
- It is the same terrifying feeling he has as a child when he was sexually assaulted in a bathtub, while his mother was elsewhere in the house, oblivious.
- Recognizing the connection allows him to work through his reaction and plan a more constructive meeting with his gastroenterologist.

Vignette: What happened to me?

- Although Isaac is intelligent and usually articulate, he is prone to periods in which he becomes perplexed about himself and his past experiences. In these moments, he is hard to understand.
- In the emergency department, Isaac is prone to tell staff what to do, and “doesn’t suffer fools” when he finds a doctor’s line of questioning misses the point. It is difficult to get a history

Context:

Medical care often depends on getting a clear story. Early adversity is often associated with “narrative incoherence.”

Anxious type: Excessive detail, disorganization, strong affect, no clarity

Avoidant type: Minimal detail, conclusions rather than evidence, clichés and pat answers that keep an interviewer at an interpersonal distance.

The Health Care Revolution

Photo by Jon Hunter



Doctors and other Health Care Professionals

If you don't know about a patient's experiences, you can't understand why they act and feel the way they do

Childhood adversity complicates all relationships, including between health care professionals and patients

- Finding interactions aversive

- Experiencing unrecognized triggers

- Complications due to needing more support OR more autonomy than expected

- Symptoms and disability that can't be easily explained

Doctors and other Health Care Professionals

Most doctors don't ask about childhood adversity

Psychiatrists: 91% routinely ask

Family doctors: 66% ask "when indicated"

Other specialists: 77% never ask

Reasons

Not enough mental health resources, not enough time, don't want to cause distress, not confident about how to ask, irrelevant.

Doctors and other Health Care Professionals

Change

- Learn how to ask (The CARE Method) => improves alliance

1. **C**ONSENT
2. **A**SKING
3. **R**EFLECTING
4. **E**NGAGING

Youtube: Maunder Hunter CARE method

- It isn't always appropriate to ask => universal precautions

How and Why to Ask Patients about Childhood Adversity: The C.A.R.E. Method

Talking about adverse childhood experiences, or ACEs, could improve your relationship with patients.



Simply providing a safe environment to talk about ACEs, listening to what patients say, and believing them, is often beneficial.

CARE METHOD

The CARE method is a way to ask about ACEs respectfully and efficiently.

CONSENT

C is for Consent. You could ask "Some childhood and young adult experiences, that are pretty common, but difficult, can affect your health later in life. I'd like to ask you about things that may have happened when you were younger. Is that okay?"

1. **C**ONSENT
2. **A**SK
3. **R**EFLECT
4. **E**NGAGE



ASK

A is for Asking. You don't have to be precise. It may be better to give a little list that conveys the general idea. The list sort of gives your patient permission to describe other similar things. You might say: "When you were young, did you have experiences that were frightening, or that made you feel unsafe?"

**FRIGHTENING?
UNSAFE?
HIT?
TOUCHED?
BULLIED?**



REFLECT

R is for Reflecting. Validate what your patient has told you and indicate that you're willing to think and talk about it together. You can say: "Thank you for sharing that. Sometimes experiences like that have an impact on how you respond to stress later in life. I wonder if you draw any connection between those events and your current situation."



ENGAGE

E is for Engaging. Defer to your patient about what comes next. You can say: "Are you comfortable sharing more with me?" Or "Is this something you would like to talk more about at another time?" Listen to what your patient says and follow their lead.



CARE

Asking about ACEs is a good investment in understanding your patients and improving your treatment relationship.

Vignette: Isaac refuses surgery

- At a time when recurrent partial bowel obstructions are increasing in frequency and duration, surgery is recommended
- Isaac agrees and then as the date approaches, refuses
- Although he has had surgery many times, he is suddenly too frightened to proceed.

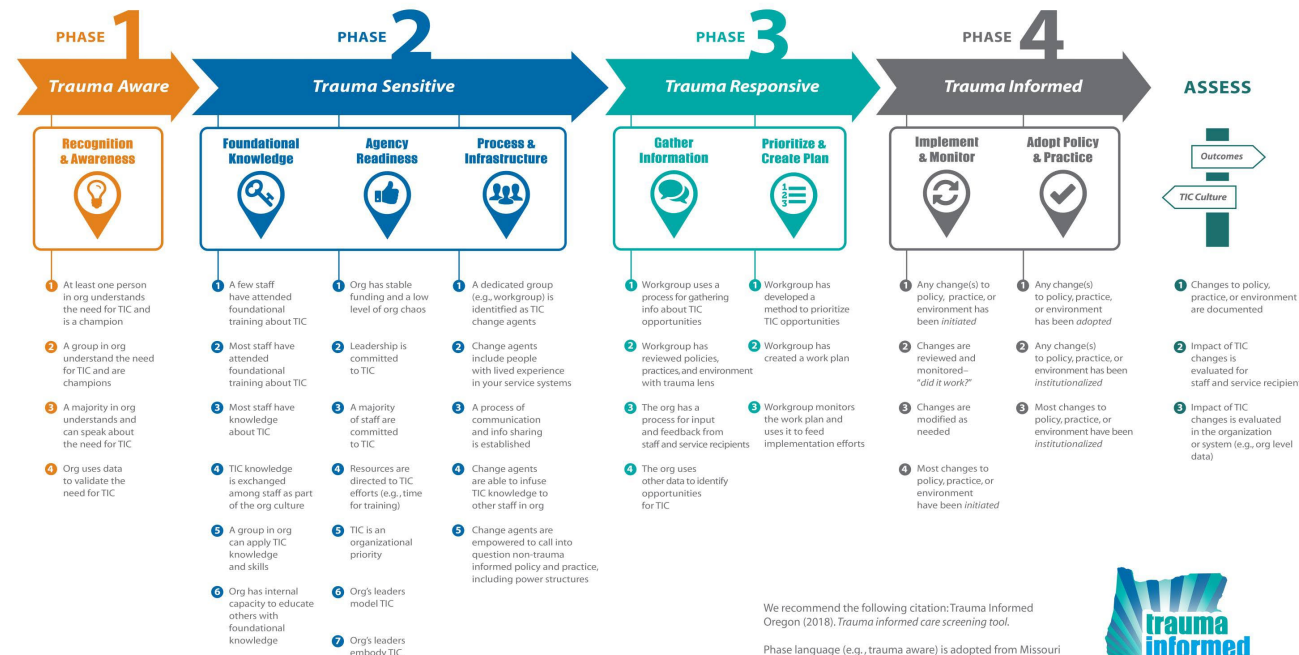
Context:

Isaac is having nightmares and irrational fears of what will happen in the OR when he is unconscious. The idea of being tied down and having no control over what others do to his body is extremely provocative.

Appointments with his surgeon and the anesthetist are arranged in which they describe procedures clearly and reassure him about **what will not happen**. Reassured, he elects to proceed with surgery.

Health Care Organizations: The Long Road to Trauma-Informed Care

Trauma Informed Care Screening Tool



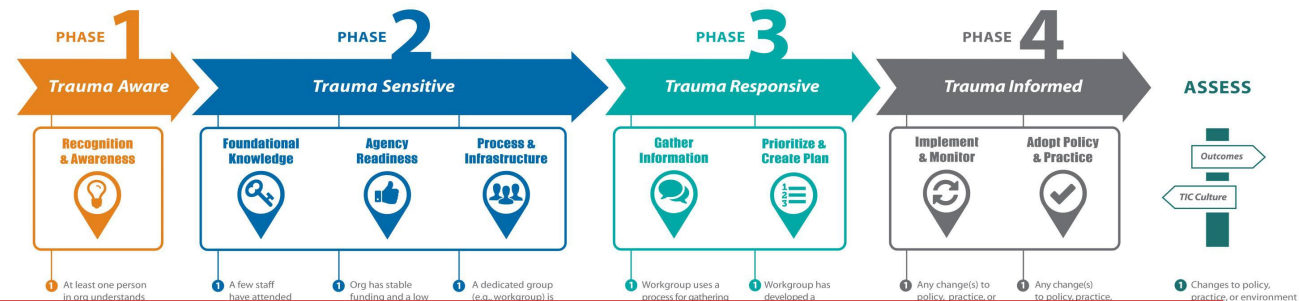
We recommend the following citation: Trauma Informed Oregon (2018). *Trauma informed care screening tool*.

Phase language (e.g., trauma aware) is adopted from Missouri Department of Health and Parnters (2014). *Missouri Model: A developmental framework for trauma-informed*.



Health Care Organizations: The Long Road to Trauma-Informed Care

Trauma Informed Care Screening Tool



1 Trauma Aware

e.g. at least 1 person understands the need for TIC and is a champion

4 Org uses data to validate the need for TIC

4 TIC knowledge is exchanged among staff as part of the org culture
5 A group in org can apply TIC knowledge and skills
6 Org has internal capacity to educate others with foundational knowledge

4 Resources are directed to TIC efforts (e.g., time for training)
5 TIC is an organizational priority
6 Org's leaders model TIC
7 Org's leaders embody TIC

4 Change agents are able to infuse TIC knowledge to other staff in org
5 Change agents are empowered to call into question non-trauma informed policy and practice, including power structures

4 The org uses other data to identify opportunities for TIC

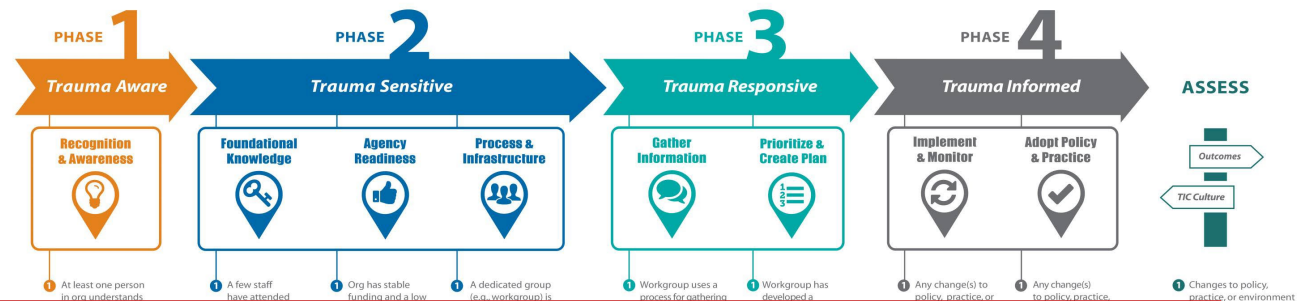
4 Most changes to policy, practice, or environment have been initiated

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Trauma Informed Care Screening Tool



2 Trauma Sensitive

e.g. at a few staff have attended foundational training about TIC
e.g. a dedicated workgroup has been identified as change agents

- knowledge and skills
- Org has internal capacity to educate others with foundational knowledge
- Org's leaders model TIC
- Org's leaders embody TIC
- priority
- question non-trauma informed policy and practice, including power structures

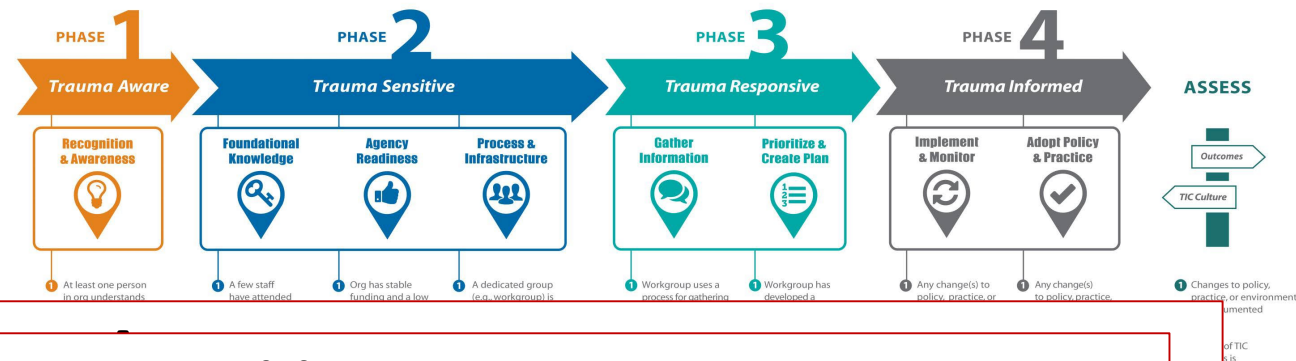
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Trauma Informed Care Screening Tool



3 Trauma Responsive

- e.g. the organization has a process for input from staff, patients and families
- e.g. the workgroup has developed a method to prioritize TIC initiatives

- 6 Org has internal capacity to educate others with foundational knowledge
- 6 Org's leaders model TIC
- 7 Org's leaders embody TIC

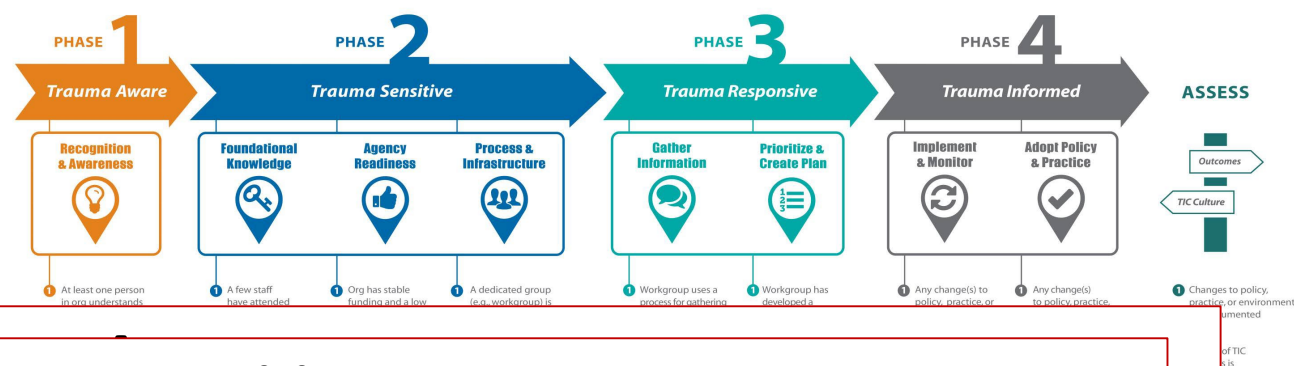
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Health Care Organizations: The Long Road to Trauma-Informed Care

Trauma Informed Care Screening Tool



4 Trauma Informed

e.g. changes to policy, practice and environment are initiated, monitored, modified, adopted & institutionalized

others with foundational knowledge

2 Org's leaders embody TIC

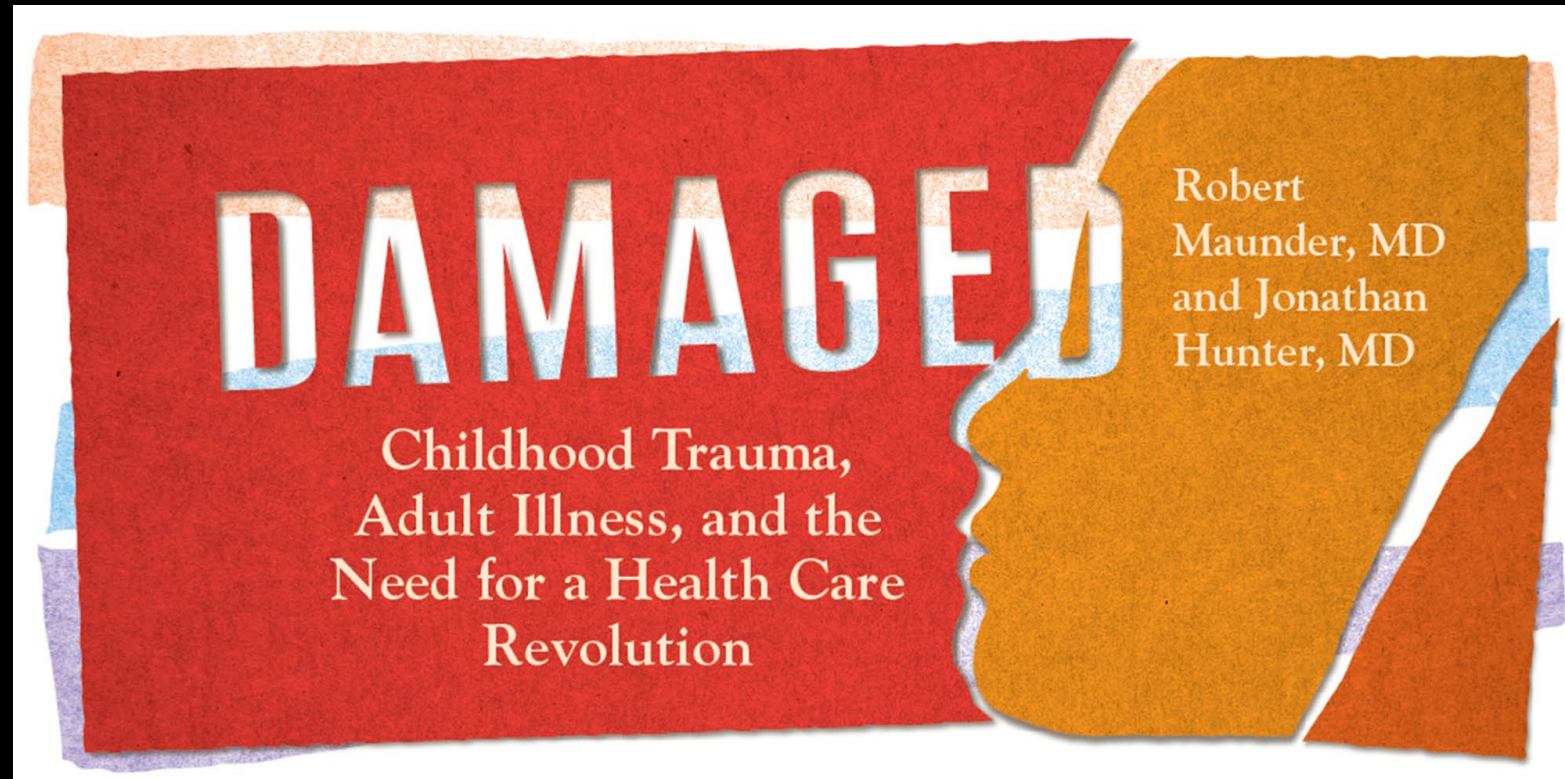
Oregon (2018). Trauma informed care screening tool.

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The Health Care Revolution

- **Health Care Providers**
- **Parents**
- **Citizens & Public Policy**
- **Health Care Organizations**
- **Patients & Families**

To treat, one needs be trusted
To trust, one needs to be safe
To be safe, one needs to be heard



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