Trauma-Informed Care in the Genetics Clinic

Mountain States REGIONAL GENETICS NETWORK

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MGN's geneTIC Workgroup - *Genetics Care (gene) that is Trauma Informed (TIC)*

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Today's Objectives

1. Understanding how trauma, stress and adversity impacts children and families with genetic conditions.
2. Integrate skills in genetics clinic to support children and families with or at-risk for trauma

What is trauma?

"Trauma refers to ***experiences that cause intense physical & psychological stress reactions***. It can refer to a single event, multiple events, or a set of circumstances that is experienced by an individual and ***perceived as physically & emotionally harmful or threatening***, and that has lasting adverse effects on the individual's physical, social, emotional, or spiritual well-being."

SAMSHA, 2014; SAMSHA; 2012

Trauma is complex

- It is not only the traumatic event(s) to consider, but also the context of the event and surrounding circumstances.
  - Event - intensity, severity, frequency, duration of exposure or developmental timing
  - Number of trauma events/experiences
  - Risk factors
  - Protective factors

- People react differently to traumatic events. Experiencing a traumatic event(s) may or may not lead to adverse effects for an individual.

Multiple Types of Trauma

Acute events

- Unexpected death of a loved one
- Serious accidents
- Life-threatening illness
- Ongoing medical treatments

Interpersonal trauma

- Abuse and neglect
- Witnessing or experiencing domestic violence
- Sexual violence
- Stalking

Community and school trauma

- Shootings
- Bullying
- Bombings

Collective trauma

- Covid-19
- Mass shootings
- Terror attacks
- Natural disasters
- Refugee or War experience

Societal trauma

- Racism
- Sexism
- Homophobia
- Any type of discrimination (based on age, ability, religion, gender identity)

Historical trauma

- Slavery
- Killing, abuse, exploitation, & oppression of Native communities

Traumatic events are common

The national average of child abuse and neglect victims in 2013 was **679,000, or 9.1 victims** per **1,000 children.**[2]

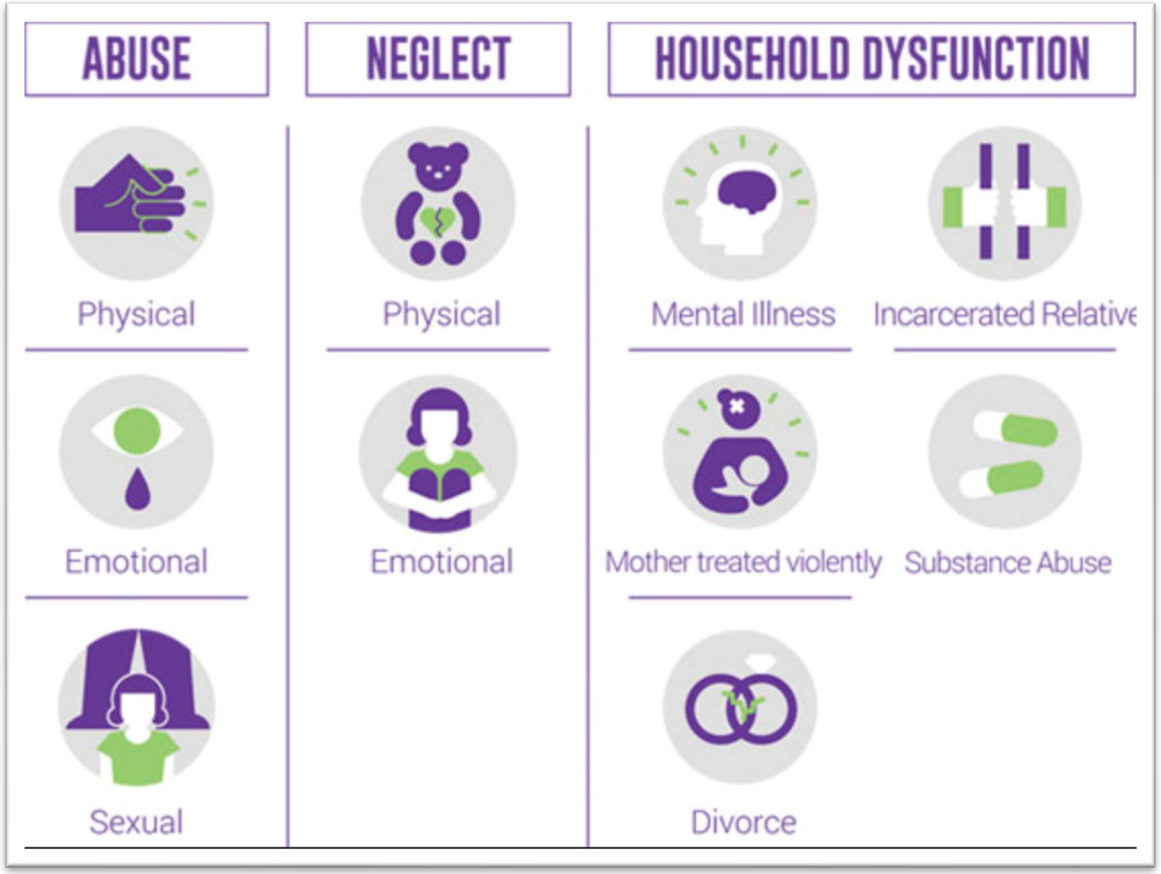
1 IN 4 HIGH SCHOOL STUDENTS was in at least **1 PHYSICAL FIGHT.**[4]

1 in 5 high school students was bullied at school; **1 IN 6 EXPERIENCED CYBERBULLYING.**[5]

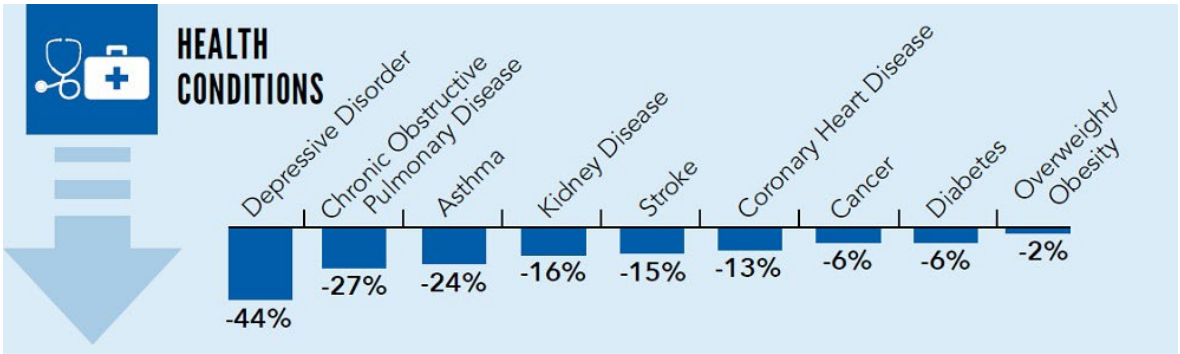
19% of injured and 12% of physically ill youth have post-traumatic stress disorder.[6]

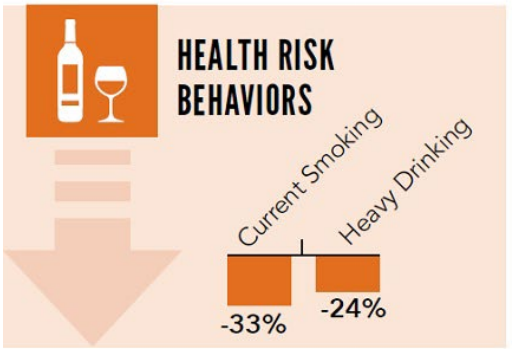
More than half of U.S. families have been affected by some type of disaster (**54%**).[7]

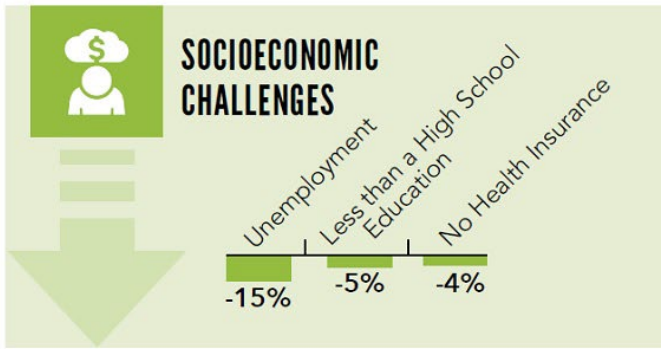
Adverse Childhood Experiences (ACEs)



Data on adverse childhood experiences (ACEs) shows that these experiences impact population health







Infographics by the Robert Wood Johnson Foundation

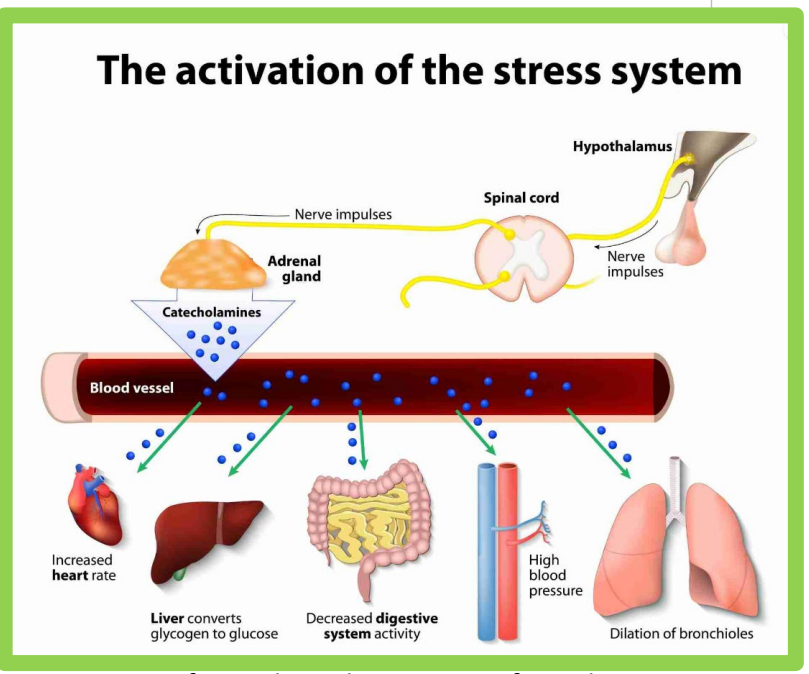
Center for Disease Control (2021, August 23) Adverse Childhood Expereinces.

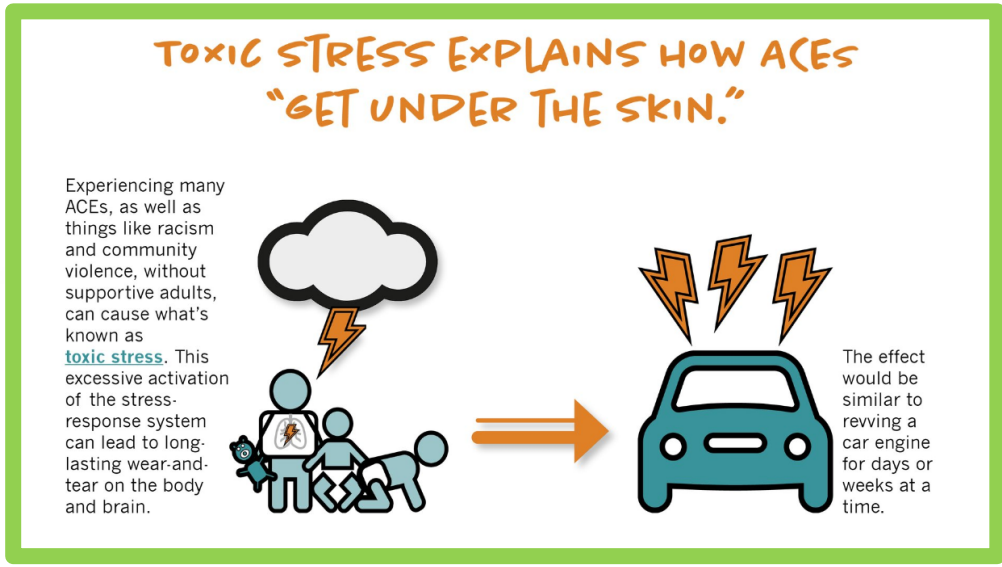
Cumulative Effects of Trauma and Toxic Stress

Brief increases in heart rate, mild elevations in stress hormone levels.

Serious, temporary stress responses, buffered by supportive relationships.

Prolonged activation of stress response systems in the absence of protective relationships.





Trauma Informed Teaching Part 3 of 4: Adverse Childhood Experiences - Social Emotional Learning Curriculum | SEL Lesson Plans (empoweringeducation.org)

Harvard Center for the Developing Child

Experiencing the loss of a child/almost losing a child

Fear of decompensation/permanent disability or death with common illness

Watching your child endure painful/frequent medical procedures

Medical gaslighting

When HCP dismiss or minimize your health concerns, making you doubt your own reality

Navigating complex medical systems & insurance coverage

Potential Trauma experiences specific to genetic conditions

Difficult or painful treatment plan

- Low-protein diet
- Frequent blood draws
- Frequent procedures or hospitalizations

History of genetics and its use

Eugenics, HeLa cells

Difficulties with access to care and treatment

No treatment or only treatment from clinical trials, cost of treatment

Guilt/stigma in genetic conditions

geneTIC workgroup; McBain, 2020; Chrivoli JA. (2021).

Thriving after Trauma

Exposure to trauma does not mean anyone is predetermined to experience health problems

Many experience resilience

- Adapting in the face of stressors/traumatic experiences
- No one way or trait to demonstrate resilience
- Dynamic process utilizing many different potential protective factors

Some experience posttraumatic growth

- Positive psychological change after trauma
- Finding a sense of meaning or personal growth from the events & the ensuing psychological struggle

Healing after trauma

- Many evidence-based treatments and services for trauma-related mental health difficulties

Trauma-Informed Care and the Role of Genetics Providers

Potential Effects of Trauma Exposure

Physical health difficulties	Emotional & mental health difficulties	Behavioral difficulties	Social difficulties	Cognitive difficulties	Functional difficulties
• Increased rates of disease • Premature death	• Increased depression, anxiety, stress, anger • Emotion regulation difficulties • Substance use	• Daily functioning • Risk-taking behaviors • Aggression • Withdrawal from people/ interests	• Lack of trust • Poor boundaries	• Attention/ concentration • Learning difficulties	• Employment • Education • Hobbies/ interests

Symptoms of Medical Post Traumatic Stress

- **Re-experiencing**
  - Intrusive thoughts about the illness, injury or procedure
  - Feeling distressed at thoughts or reminders of it
  - Nightmares, flashbacks
- **Avoidance**
  - Physically avoiding locations
  - Not thinking or talking about hospital, illness or things associated with it
  - Emotionally numb or detached from others
- **Hyperarousal**
  - Increased irritability
  - Trouble concentrating
  - Exaggerated startle response
  - On edge, hypervigilant, always expecting danger
- **Other symptoms**
  - New fears related to medical event
  - Unexplained somatic complaints
  - Feeling “spacey,” “foggy” or in a daze

NCTSN, 2014

Trauma-Informed Care Principles

Realize the widespread impact of trauma and understand potential paths for recovery

Recognize the signs and symptoms of trauma in people using services, their families, staff, & others involved with the system

Respond by fully integrating knowledge about trauma into policies, procedures, and practices

Resist re-traumatization

Relationship is key

SAMSHA; 2014; SAMSHA; 2017 Aap.org/PATTeR

Implementing Comprehensive Trauma-Informed Care

Need to implement both organizational *and* clinical practices to reflect core principles of trauma-informed care

https://www.chcs.org/media/Brief-Key-Ingredients-for-TIC-Implementation.pdf

10 KEY INGREDIENTS FOR TRAUMA-INFORMED CARE

LEAD AND COMMUNICATE

ENGAGE PATIENTS IN PLANNING

TRAIN ALL STAFF

CREATE A SAFE ENVIRONMENT

PREVENT SECONDARY TRAUMA

BUILD AN INFORMED WORKFORCE

INVOLVE PATIENT IN TREATMENT

SCREEN FOR TRAUMA

USE TRAUMA-SPECIFIC TREATMENT

ENGAGE PARTNERS

www.chcs.org

@CHCShealth

https://www.chcs.org/resource/10-key-ingredients-trauma-informed-care/

Role of Genetics Providers

- Creating a trauma-informed healthcare environment
  - Reducing potentially traumatic events and re-traumatization
- Increase access to trauma care and other behavioral health and support services
- Improve case conceptualization, clinical decision-making and quality of care provided

CDC, 2022; NCTSN, 2015

Key Trauma-Informed Practices to Implement

- Organization wide training (all providers, staff, leaders)
- Physical environment
- Language, active listening and body language
- Initial contact, scheduling

Clinical Interaction

- Consent
- Preparation
- Assessment
- Brief intervention
- Referral
- Follow up

Physical Environment

- Consider clinic environment
  - Photos on walls
  - Materials in multiple languages
  - Child friendly (toys, books)
- Be aware that physical environments may re-traumatize families
  - “Bad news rooms”
  - Procedure rooms
- Clearly available exits

Language and Body Language

Language

Use patient preferred language

Avoid Jargon

Avoid pejorative or blaming language

- “What happened” vs “Why didn’t you”

Use respectful language

- “Mom” – used to demean

Active Listening

Pay attention

Withhold judgement

Reflect

Clarify

Summarize

Share

Body Language

Make eye contact

Face family with both shoulders

Do not spend entire meeting typing on computer

Engage with child

S **AFETY:** Use body language and empathy to let parents know they are safe to share their feelings.

A **VAILABILITY:** Includes practical and emotional availability. Take time to connect with caregivers to talk about their feelings.

M **IND IN MIND:** Being aware of and acknowledging the emotions of the caregiver and patient

E **MOTIONAL CONTAINER:** Allows the child or caregiver to express their emotions so that they can find release and comfort and promote psychological healing.

Initial Contact and Scheduling Appointments

Initial Contact

- Explain who you are and what your role is
- Provide information on what is going to happen at an appointment up front
  - Before session if possible
- Setting Expectations – clinician priorities/patient priorities
- Establish team with clinicians and family
- Leave time for questions
- Honor experience/story of family

Scheduling

- Give multiple options if possible
  - Different days and times of day
- Consider commute time, difficulties in transportation
- Get insurance information ahead of time

"Say what you'll do. Do what you say"

–Ocean & Ratzlaff, 2020

SAMSHA; 2014; SAMSHA; 2017

Support for Providers and Staff

Secondary traumatic stress	Compassion fatigue
• Trauma reaction similar to PTSD • when an individual hears firsthand about the trauma experiences of another (Stamm, Figley)	• Stress resulting from caring for individuals exposed to trauma, not the trauma itself • Often characterized by a decreased sense of empathy or increased exhaustion, anger, irritability, negative coping behaviors

Build in protocols to support providers and staff

- Reflective supervision
  - Trauma skills
  - Reflection/processing time
- Staff support/process groups
- Mental health days; break times

How can we implement trauma-informed approaches into newborn screening?

The Newborn Screening Journey: Considerations for Trauma and Trust

Prenatal Period → Newborn Screening → Positive Screening Results → First Follow-Up Visit → Diagnosis or False Positive Result → Treatment

Potential Considerations:

- Previous pregnancy losses/difficult deliveries
- Lack of access
- Inequitable care
- Lack of insurance
- Lack of education/awareness
- Lack of support system
- Stress/Anxiety
- Etc., etc., etc.

Potential Considerations:

- Lack of education/awareness (by family and physician)
- Lack of access
- Fear/stigma/guilt
- Misinformation
- Mistrust in medical system
- Cultural differences
- Lack of support
- Stress/Anxiety
- Etc., etc., etc.

Potential Considerations:

- Lack of access/insurance
- Fear/stigma/guilt
- Lack of information on options
- Mistrust in medical system
- Cultural differences
- Numerous tests
- Ambiguity/Uncertainty
- Stress/Anxiety
- Etc., etc., etc.

Assessing for Trauma in a Genetics Clinic

- Comprehensive Medical History
  - Ensure thorough history is collected at initial assessment
  - Ask patient about potential symptoms that are upsetting or impacting them
  - Parent/caregiver report for minor patients
- Behavioral cues (for adults or children)
  - Agitation, tantrums
  - Lack of trust
  - Hypervigilance, on edge
  - Bed wetting
  - Unexplained physical symptoms (headaches, stomachs)
  - Sleep problems
  - “ADHD” like symptoms
  - School or healthcare avoidance
- Implement universal, standardized screening and assessment measures

Implementing Universal Screening Protocols

- Use at every visit, with every family
  - Consider how this is going to be implemented in your clinic setting
- Consider what specifically you are wanting to screen for and why
  - Trauma experiences (ACEs)
  - Trauma symptoms
  - Other common behavioral health symptoms
- Consider child vs. parent report
- Language translation
- Has it been validated in the population you serve?
- **Once you have the information, what will you do with it?**

Brief Interventions in Session

- Educate and **relationship build**
- Brief meditation, relaxation exercises
- Teach the parent/child co-regulation activities to do at home
- Have other resources, toys, skills books ready

Patient/Community-Specific Referrals

- Familiarize yourself with supports in your communities
  - Tailor recommendations for family needs
  - Cultural considerations
  - Barriers to access
- Look for behavioral health providers with training in evidenced based trauma-informed services for children
  - Trauma-Informed Cognitive Behavioral Therapy
  - Attachment Regulation and Competency Framework

- Look for other evidence based, trauma-informed services
  - Home Visiting
  - Family Therapy
  - Wraparound Services
  - Parent Training
- Consider other needs of family that can reduce stress and increase protective factors
  - Receipt care
  - Support groups
  - Extra curricular actives
  - Case management,
  - Housing and economic supports
  - Healthy food

Place holder for video

Family Quotes

Conway, M., Vuong, T. T., Hart, K., Rohrwasser, A., & Eilbeck, K. (2022). Pain points in parents' interactions with newborn screening systems: a qualitative study. *BMC pediatrics*, *22*(1), 167.

Bani, M., et al. (2023). Parents' experience of the communication process of positivity at newborn screening for metabolic diseases: A qualitative study. *Child: Care, Health and Development*, 1– 11.

"We were left to ourselves and so we went on Google, which I know is wrong, and on the Internet I obviously found unpleasant things, therefore I had a moment of discomfort."

"… the individual who communicated the results was the receptionist from the pediatrician's office … [She] said that there had been a positive for PKU. My wife asked what that was and the receptionist replied that she didn't know, but it meant that our baby could be retarded. So that was obviously traumatic."

"It was very difficult. One of the things I did, being we live in the middle of nowhere and there was such little knowledge from everyone, is I called almost daily for a week until I got someone who would actually talk to me. I called constantly to find someone to talk to because no one else knew anything."

"The communication was fully verbal. As a parent, you feel anxious, and because of that, I missed some pieces of what was being said, I also wish I could record them. If I had that information written on paper, I could return to it afterwards with a clearer mind."

Why Is This Important?

- 91% of health care providers perceived delivering bad news as a very important skill, but only 40% felt they had the training to effectively deliver such news.

- Among physicians, only 31.2% mentioned having learned adequate communication skills. Almost all physicians stated that communication with patients has a significant impact on their employee satisfaction.

Monden KR, Gentry L, Cox TR. Delivering bad news to patients. *Proc (Bayl Univ Med Cent)*. 2016;29(1):101–102.

Sehouli J, Pirmorady A, Boz S, et al. International Journal of Gynecologic Cancer 2021;31:A183.

Place holder for video

Thank you!

Questions or connections? Please email: Kelsey Sala-Hamrick at ksalaham@mphi.org

RESOURCES

Midwest Genetics Collaborative – Midwest Genetics Collaborative

Trauma-Informed Care Basics:

The National Child Traumatic Stress Network | (nctsn.org)
Trauma-Informed Care (aap.org)
Trauma, Treatment and Resilience (aap.org)
Trauma-Informed Care - Center for Health Care Strategies (chcs.org)

Slides not needed

Cautions of Assessing (and not diagnosing) Trauma

- Experiencing something that is potentially traumatic does not mean someone will develop symptoms
- Children do not experience or report mental health symptoms in the same way as adults do
- Common pediatric conditions may be caused or complicated by trauma
- Utilize evidenced based screening and assessment tools, refer to a psychologist for full diagnostic assessment and treatments
- **ALWAYS highlight that there are effective treatments for trauma, many resources available for support etc.**

Common Differential Diagnoses to Trauma

Trauma is often misdiagnosed or may present differently than one may expect. Some examples of this may be:

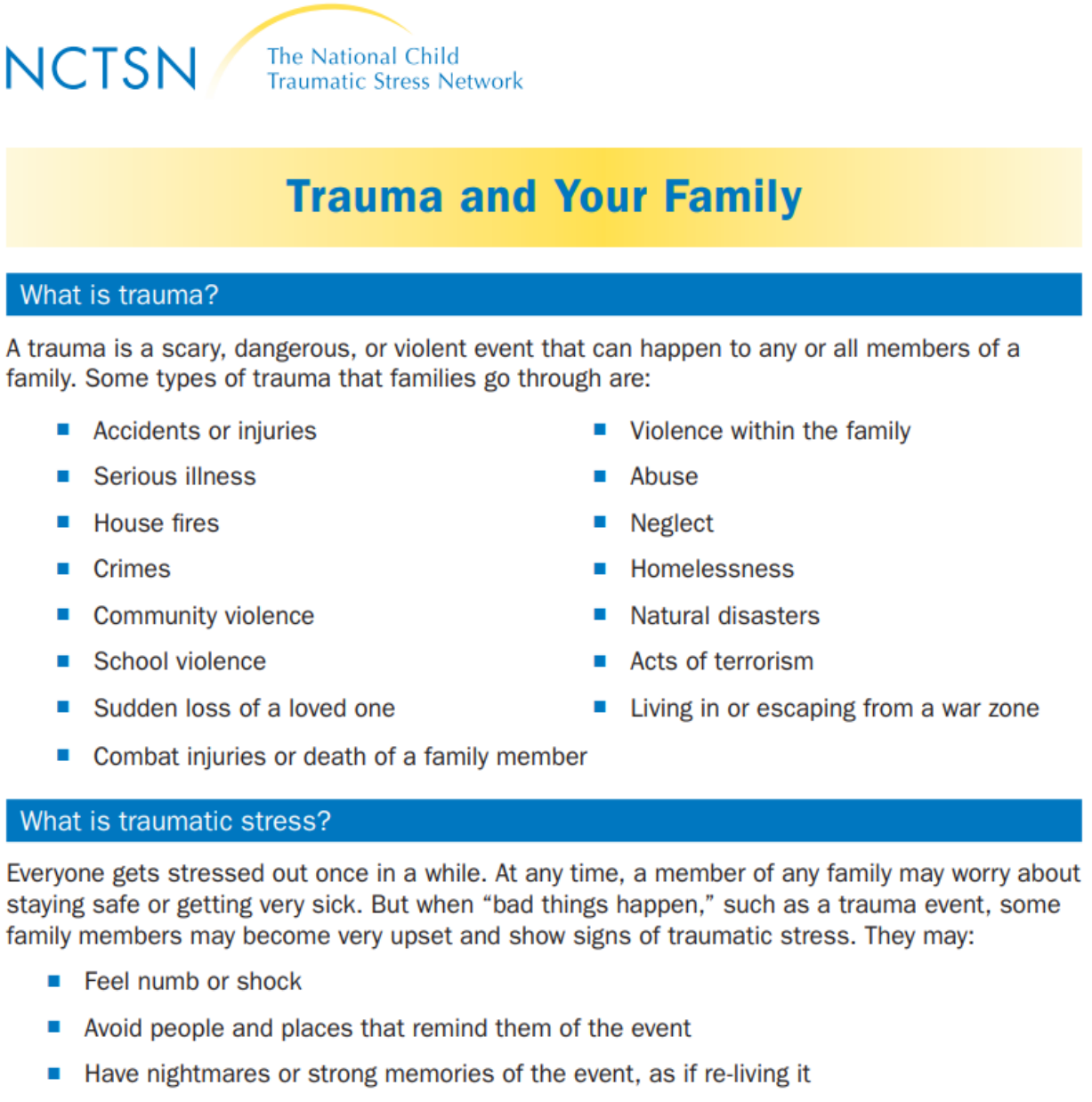
- ADHD
- Insomnia
- Behavioral Difficulties/Regression
- Anxiety
- Learning Disabilities
- School refusal
- Enuresis/encopresis
- Other developmental delays or regressions

Clinically Diagnosed Trauma Conditions

- Trauma Conditions in the DSM-5
  - Post-Traumatic Stress Disorder (PTSD)
  - Acute Stress Disorder (ASD)
  - Other reactions to severe stress
- Not every reaction to trauma fits within a diagnostic condition
- Conditions are not limited to the above disorders

Provide Psychoeducation

- Share with parent that what they or their child is experiencing may be related to experiencing scary or potentially traumatic events
- Provide a straightforward, easy to read resource
- Talk the family through what trauma and traumatic stress are
- ALWAYS emphasize HOPE
  - Family strengths
  - Lots of trauma treatments that work
  - Make referrals to appropriate sources



NCTSN The National Child Traumatic Stress Network

Trauma and Your Family

What is trauma?

A trauma is a scary, dangerous, or violent event that can happen to any or all members of a family. Some types of trauma that families go through are:

- Accidents or injuries
- Serious illness
- House fires
- Crimes
- Community violence
- School violence
- Sudden loss of a loved one
- Combat injuries or death of a family member
- Violence within the family
- Abuse
- Neglect
- Homelessness
- Natural disasters
- Acts of terrorism
- Living in or escaping from a war zone

What is traumatic stress?

Everyone gets stressed out once in a while. At any time, a member of any family may worry about staying safe or getting very sick. But when "bad things happen," such as a trauma event, some family members may become very upset and show signs of traumatic stress. They may:

- Feel numb or shock
- Avoid people and places that remind them of the event
- Have nightmares or strong memories of the event, as if re-living it