



**Midwest Genetics
Network**

Region 4



Trauma-Informed Care *in the* Medical Genetics Clinic *Workbook*

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PRE-ASSESSMENT

The Center for Health Care Strategies has identified 10 key ingredients for Trauma Informed Care. These ingredients are split into Organizational practices and Clinical practices.

Take a few minutes to reflect on your clinic's current practices thinking about areas of strength and areas of opportunity. Then, on the subsequent pages, rank your clinic in each area on a scale of 1-10.



1. Lead and communicate about being trauma-informed



6. Build a trauma-informed workforce



2. Engage patients in organizing and planning



7. Involve patients in the treatment process



3. Train both clinical and non-clinical staff



8. Screen for trauma



4. Create a safe physical and emotional environment



9. Train staff in trauma-specific treatments



5. Prevent secondary traumatic stress in staff



10. Engage referral source and partner organizations

Area of
Opportunity



Area of
Strength



1

2

3

4

5

6

7

8

9

10

Organizational Ingredients

Lead and Communicate

Clinic Ranking



Engage Patients

Clinic Ranking



Train All Staff

Clinic Ranking



Create Safe Environment

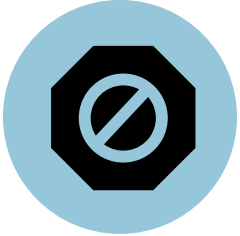
Clinic Ranking



Organizational Ingredients, Cont'd

Prevent Secondary Stress in Staff

Clinic Ranking



Build a Trauma-Informed Workforce

Clinic Ranking



“Trauma-informed care can transform the caregiving experience of providers from being treaters to being healers.”

~Eddy Machtinger, MD, UCSF

Clinical Ingredients

Involve Patients in Treatment Process

Clinic Ranking



Screen for Trauma

Clinic Ranking



Train Staff in Trauma Treatments

Clinic Ranking



Engage Referral & Partner Organizations

Clinic Ranking



Additional Reflections

The image below illustrates some examples of trauma experienced by patients and families with genetic conditions. Which of these have you seen in your patients and families? Are there others that are missing?

Experiencing the loss of a child/almost losing a child

Fear of decompensation/permanent disability or death with common illness

Watching a child endure painful/frequent medical procedures

Medical gaslighting

Navigating complex medical systems & insurance coverage

Enduring a diagnostic odyssey

Potential Trauma Experiences Specific to Genetic Conditions

Difficult, Uncertain, or Painful Treatment Plan

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

History of genetics and its misuse

Difficulties with access to care and treatment

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

Guilt/stigma in passing on genetic conditions

Story Reflections

“That first conversation set the tone for our journey as a rare disease family, causing us to be tentative and aloof with each member of our child’s healthcare team...”

“When I go to an appointment for myself, my daughter or any loved one, I feel like I am always on ten. I feel like nothing that I say will be taken into consideration as it pertains to my diagnosis and/or treatment.”

“He dismissed all of my concerns, and caused me to second-guess my own observations. It left me wondering if I could trust my own instincts.”

Story Reflections

Consider the family stories presented during the webinar and the quotes provided on the previous page. What words and descriptions of the families' experiences stood out to you? Have you seen patients with similar experiences and emotions? How might trauma-informed care have mitigated or changed these family stories?

Additional Reflections

Trauma can present in a number of ways and throughout an individual's development. In what other ways might trauma manifest in patients and caregivers who have experienced trauma? What signs of trauma have you seen in your patients and their caregivers? How can your clinic implement better practices to address patient and caregiver needs?

Physical health difficulties

- Increased rates of disease
- Premature death
- Sleep difficulties
- Weight gain or loss

Emotional & mental health difficulties

- Increased depression, anxiety, stress, anger
- Emotion regulation difficulties
- Substance use

Behavioral difficulties

- Daily functioning
- Risk-taking behaviors
- Aggression
- Withdrawal from people/interests

Social difficulties

- Lack of trust
- Poor boundaries
- Isolation
- Difficulties forming or maintaining relationships

Cognitive difficulties

- Attention/concentration
- Learning difficulties
- "brain fog"

Functional difficulties

- Employment
- Education
- Hobbies/interests
- Not meeting developmental milestones

Pause and Think

How could the effects of trauma show up in the patients and families I treat?

How may past trauma impact how patients & families engage in care?

How may patients and families experience trauma WITHIN healthcare?

What could happen if a provider does not understand trauma or its impact?

Additional Reflections

S

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

A

AVAILABILITY: Includes practical and emotional availability. Take time to connect with patients and caregivers to talk about their feelings.

M

MIND IN MIND: Being aware of and acknowledging the emotions of the caregiver and patient.

E

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

A healthcare provider has an opportunity to offer families ways as to how they can create secure relationships, especially for families dealing with trauma. One method healthcare providers can use to promote trauma recovery is by using the SAME acronym. How might you use the SAME method while implementing trauma-informed care in your clinic?

Next Steps & Actions

Now that you've learned some of the basics around trauma-informed care and its role in the medical genetics clinic, what do you see as your next steps in implementing these tools in your clinic?

CLINIC GOALS

Define three tasks that you will complete to reach your goal

Task One

Task Two

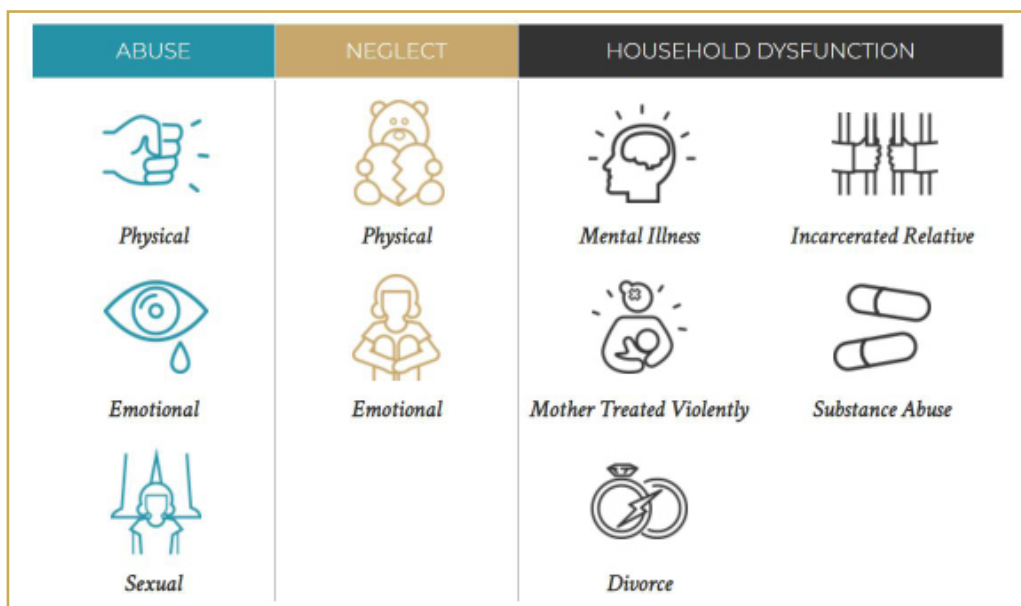
Task Three

Additional Action Items:

Glossary

ADVERSE CHILDHOOD EXPERIENCES

Term that originated in a study conducted in 1995 by the Centers for Disease Control and the Kaiser Permanente health care organization in California. In that study, “ACEs” referred to three specific kinds of adversity children faced in the home environment and ten core ACEs. See Figure. There are other types of adverse childhood experiences not included in the list of 10 ACEs below, including community and environmental ACEs such as racism, bullying and community violence. Researchers have begun to include these experiences as ACEs, too, because they create the same biologic changes as the original 10 ACEs.



TOXIC STRESS

In the early 2000s, the National Scientific Council on the Developing Child coined the term “toxic stress” to describe extensive, scientific knowledge about the effects of excessive activation of stress response systems on a child’s developing brain, as well as the immune system, metabolic regulatory systems, and cardiovascular system. Toxic stress is the physiological wear and tear on the body due to being in a prolonged or chronic state of physiological arousal/ stress response caused by on going on cumulative exposure to trauma or adversity without necessary supports.

Glossary

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.

TRAUMA-INFORMED CARE

A trauma-informed approach to care acknowledges that health care organizations and care teams need to have a complete picture of a patient's life situation — past and present — in order to provide effective health care services with a healing orientation. A program, organization, or system that is trauma-informed **realizes** the widespread impact of trauma and understands potential paths for recovery; **recognizes** the signs and symptoms of trauma in clients, families, staff, and others involved with the system; and **responds** by fully integrating knowledge about trauma into policies, procedures, and practices, and seeks to actively **resist re-traumatization**.

TRAUMATIC STRESS

The stress of any individual who has had a traumatic experience and is having difficulties moving forward with his or her life. Individuals who suffer from traumatic stress are those individuals who have been exposed to one or more traumas over the course of their lives and develop reactions that persist and affect their daily lives after the traumatic events have ended. Traumatic reactions can include a variety of responses, including intense and ongoing emotional upset, depressive symptoms, anxiety, behavioral changes, difficulties with attention, academic difficulties, nightmares, physical symptoms such as difficulty sleeping and eating, and aches and pains, among others. Individuals who suffer from traumatic stress often have these types of symptoms when reminded in some way of the traumatic event. Although many of us may experience these reactions from time to time, when a person is experiencing traumatic stress, they interfere with the individual's daily life and ability to function and interact with others.

Resources

Midwest Genetics Network: <https://midwestgenetics.org/>

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)

Trauma-Informed Needs in Rare Disease:

[National Economic Burden of Rare Disease Study](#). Kan K, Gupta R, Davis MM, Heard-Garris N, Garfield C. Adverse Experiences and Special Health Care Needs Among Children. *Matern Child Health J.* 2020 May;24(5):552-560.

Belzer LT, Wright SM, Goodwin EJ, Singh MN, Carter BS.

[Psychosocial Considerations for the Child with Rare Disease](#): A Review with Recommendations and Calls to Action. *Children.* 2022; 9(7):933.

[Common Themes and Characteristics of Trauma](#) in the Healthcare Experiences of Patients with Rare Disease: A Literature Analysis

RareMinds.org

