# BREAKING CYCLES:

## GENETICS & INTERGENERATIONAL TRAUMA IN EATING DISORDER TREATMENT

**Samantha DeCaro, PsyD (she/her/hers)**
Licensed Clinical Psychologist in PA
Director of Clinical Outreach and Education
The Renfrew Center

# Our Agenda

- FAQs, Interests, & Concerns from Clients & Families
- Genetic Counseling: What Is It?
- Genetic Research: AN, BN, & BED. What's Missing & What's Next?
- Intergenerational Trauma: How it Happens & What We Can Do About It
- EDs & Trauma – What's the Connection?
- Trauma Informed Care & Therapeutic Interventions
- Tools & Visual Aids (Deck of Cards, The Piano, and The Jar Model)
- Protective Factors: Breaking Cycles & Creating a Plan

# FAQs & Concerns in the Therapy Session

"Did I cause my eating disorder? If I didn't cause it, what did?"

"Did I do something to cause my child's eating disorder?"

"Is my this all my fault because I passed on my ED & my trauma to my child?"

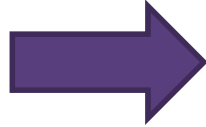
"If I have a child, will they inherit my eating disorder and traumatized genes?"

CAREGIVER ANXIETY/FEAR

CAREGIVER GUILT

CAREGIVER SHAME

CAREGIVER ANGER/ RESENTMENT



**Low Self Efficacy:**
**“Do I know how to help?”**

**Low Empowerment:**
**“Will I be able to help?”**

# What is Genetic Counseling?

- Professional Discipline: formal training dates back to 1960s
- Underutilized in ED care!
- 4000+ Board Certified Genetic Counselors in North America
- Goal is to help clients, couples, and/or families understand & adapt to the ways genes may contribute to medical & psychiatric disorders
- Unearth difficult emotions at the root of their inquiries
- Educate, empower & bolster self-efficacy
- Usually short-term relationship (1-2 appointments)
- Therapists can collaborate with genetic counselors & enlist their services as part of the interdisciplinary team: www.findageneticcounselor.com

Bulik, C.M., Blake, L., Austin, J. (2019). Genetics of Eating Disorders: What the Clinician Needs to Know, *Psychiatric Clinics of North America*, 42(1), pp. 59-73.

# Current State of Genetic Research

- Family Studies, Twin Studies, & Adoption Studies
- The Psychiatric Genomics Consortium (PGC)
- Genome Wide Association Studies (GWAS) What's the purpose?
- Eating Disorders Working Group of PGC (PGC-ED)
- ANGI (Anorexia Nervosa Genetics Initiative)
- EDGI (Eating Disorders Genetics Initiative)
- Genes easier to quantify than environmental factors
- Future Directions for Research

# What Have We Learned About Anorexia?

- Runs in families
- Female relatives 11x more likely to develop AN
- Risk of developing full/partial AN and OSFED elevated for 1st degree relatives of AN
- Twin studies estimate heritability between .28 to .74 (about 60%) and common comorbid diagnoses of MDD and OCD (OCD was the strongest correlation in GWAS studies)
- **PCG-ED reported correlations between AN and psychiatric, metabolic, autoimmune function, & anthropometric traits**
- Positive correlation with physical activity
- AN seems to be a psychiatric **AND** a metabolic condition

# Future Directions for Anorexia Research?

- PGC-ED Phase II includes 16K+ cases and 47K controls from 15 countries
- Larger Sample Sizes
- Goals are to better understand how genetic variation & biological pathways contribute to and are associated with AN risk
- Eventually would like to better predict course of illness & response to treatment, and identify most effective interventions (e.g., therapy, medication)
- Other domains

# What Have We Learned About Bulimia?

- Runs in families – increased risk of BN and other EDs
- Twin Studies estimate heritability around 60%
- AN & BN are genetically correlated (0.46 to 0.79) with higher risk of developing BN
- Correlations between BN symptoms and alcohol abuse (0.33 to 0.61)
- Future Research: PGC-ED searching for genetic variants associated with BN and identify biological pathways shared between BN & AN

# What Have We Learned About Binge Eating Disorder?

- Runs in Families
- Not as much research due to its recent addition to DSM-5
- Twin studies estimate heritability between 0.39 and 0.45
- Genetic associations between BED & alcohol dependence, ADHD, and MDD
- More even sex distribution
- Future research to identify biological pathways associated with BED

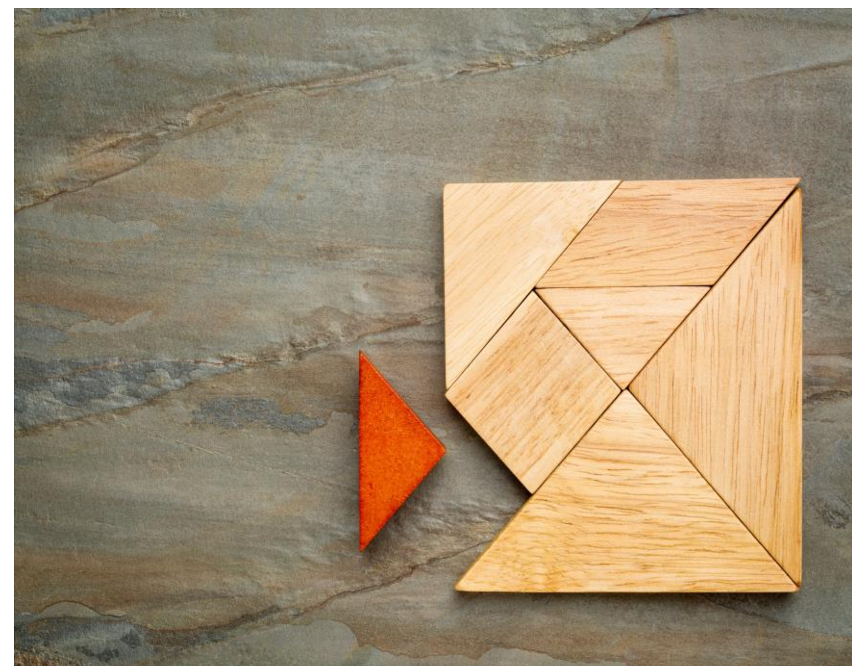
# Yale Study (2023)

- Explored ED genetic risk, brain structures, and ED symptoms
- 4900+ subjects 9-11 years old
- AN risk associated with **reduced caudate volume**
- ED symptoms associated with **greater thickness of visual brain network**
- ED symptoms associated with **reduced thickness in a part of the brain used during a cognitively restful, less vigilant state of mind**

Westwater, M.L., Mallard, T.T., Warrier, V. *et al.* (2023). Assessing a multivariate model of brain-mediated genetic influences on disordered eating in the ABCD cohort. *Nat. Mental Health*

# What's Missing from All This Research?

- Genome-wide association studies (GWAS) with AN did not include atypical AN. Subjects shared strict diagnostic criteria of low weight
- No GWAS for BN or BED
- ARFID, atypical AN, OSFED, and other diagnoses not included in many family, twin, or GWAS.
- Most world populations are under-represented
- Large sample sizes are needed, but difficult to obtain. ***Hundreds of thousands*** required to identify variants.



# “I’m scared to have a child – they’ll inherit my Eating Disorder!”

## 5 Key Messages

- Even if both biological parents have an ED, a child is ***not destined*** to develop one. Genes don’t operate alone
- ***Hundreds of genes*** at play – many are considered common
- Discuss role of ***protective factors*** that will “protect” a child’s mental health
- No parent can “parent” perfectly. Mistakes will be made!
- There is no way for ***any*** parent to completely prevent mental illness

Inglis A., Morris, E., Austin, J. (2017). Prenatal genetic counseling for psychiatric disorders. *Prenatal Diagnostics*, 37, pp. 6-13.

# 3 Important Points to Convey*

1. Eating disorders are complex psychiatric disorders that develop from a ***combination*** of genetics and environmental factors/experiences

2. We inherit ***vulnerability*** to an eating disorder rather than inheriting the eating disorder itself. You are not doomed by your DNA.

3. Currently, there is no known cause that is both ***necessary & sufficient*** for an eating disorder to develop.

*EMOTIONAL REACTIONS will VARY!

Bulik, C.M., Blake, L., Austin, J. (2019). Genetics of Eating Disorders: What the Clinician Needs to Know, *Psychiatric Clinics of North America*, 42(1), pp. 59-73.

# Shifting the Focus: What is ***Maintaining*** the Eating Disorder?

- Effects of Starvation or Altered Nutrition
- Rigidity—Inflexible thinking/limited behavioral repertoire
- Internalized weight stigma & anti-fat biases
- Pro-eating disorder beliefs
- Isolation
- Relational response to ED behavior
- **Experiential Avoidance**
- **Emotional Avoidance**

# Shifting the Focus: *Reducing Risk* & *Supporting Recovery*

- Changing the Home Environment
- Social Support/Community
- Intuitive Eating/Nutrition
- Joyful Movement
- Stress Management
- Adequate Sleep

- Self Compassion
- Confronting & challenging internalized biases
- Acknowledging role of oppression, discrimination, diet culture, & weight stigma (it's not your fault!)
- Embracing imperfection
- Celebrating Victories & Strengths

Photo by Priscilla Du Preez on Unsplash

# The Piano Metaphor

- We inherit ***RISK***
- Genes are only ***PART*** of the picture
- Can be turned ***ON & OFF***
- Environmental & Experiential factors can increase risk
- ***DNA is like a piano***. A key must be ***PRESSED DOWN*** by something in the environment to create a ***SOUND***
- *It's not nature **OR** nurture. It's nature **AND** nurture.*

https://pgc.unc.edu/for-the-public/basic-genetics/

# The Deck of Cards

- **Clubs** = Genetic Risk Factors
- **Spades** = Protective Genetic factors
- **Diamonds** = Environmental Risk Factors
- **Hearts** = Protective Environmental Factors

Photo by Izzy Park on Unsplash

# What's Intergenerational Trauma?

A distinct type of trauma that can develop ***indirectly.***

It can be transmitted across generations and within communities ***without ever being directly exposed to the trauma*** or adversity or ***even knowing*** harmful event ever occurred.

The effects of trauma can be experienced ***in future generations***

Trauma is a ***risk factor and a maintaining factor*** for eating disorders and comorbid mental health conditions

(McCloughen et al., 2021; Phipps & Degges-White, 2014)

# Historical Trauma & Race-based Trauma

- Black communities ***experience traumatic events at a higher rate*** than any other racial group
- Black individuals report a ***higher lifetime prevalence of PTSD*** than their White, Afro-Caribbean, Latinx, and Asian counterparts (Alegría et al., 2013; Roberts et al., 2011)
- **Race-based traumatic stress injury** (RBTSI)
- **Post-traumatic Slave Syndrome** (PTSS) theory
- **Historical Trauma** (e.g., enslavement, family separation, inhumane treatment, segregation, inequalities etc.)

Lee, A. T., Chin, P., Nambiar, A., & Hill Haskins, N. (2023). Addressing intergenerational trauma in Black families: Trauma-informed socioculturally attuned family therapy. *Journal of Marital and Family Therapy*, 49, 447–462.

# Rodent Studies at Emory University

- Mice shocked & developed a fear to a cherry-like scent (i.e., traumatic stress).
- Mice developed fear ***PRIOR*** to mating
- Children & Grandchildren: showed ***increased startle response to the smell***
- In-vitro fertilization (sperm only) resulted in the same neuroanatomical changes to the olfactory system
- Info seemed to be passed down by either egg OR sperm. ***Didn't need both!***
- These children & grandchildren were never exposed to their ***parents***, the ***shock,*** or ***smell.***
- They ***did not learn by watching***

(Dias & Ressler, 2014)

# Intergenerational Trauma Can Be Passed Down? How Does This Happen?

Family Systems Theory

Social Learning Theory

Psychodynamic Model

Collective Re-experiencing & Recollection of Group Traumas

Biological Models

Epigenetics

(Phipps & Degges-White, 2014; Haynes et al., 2020; Bandura, 1986; Roseboom et al., 2011)

# Methylation: Can Shut Genes OFF & Turn Genes ON

- Ample evidence within the field of epigenetics suggests that ***early life stress*** can lead to DNA methylation of the glucocorticoid receptor (GR) gene.

- Replicated in 40 independent investigations, 13 animal studies, and 27 human studies.

- The glucocorticoid receptor's job is to ***turns off*** the stress response, so when methylation happens to that gene, it's later associated with an elevated stress response

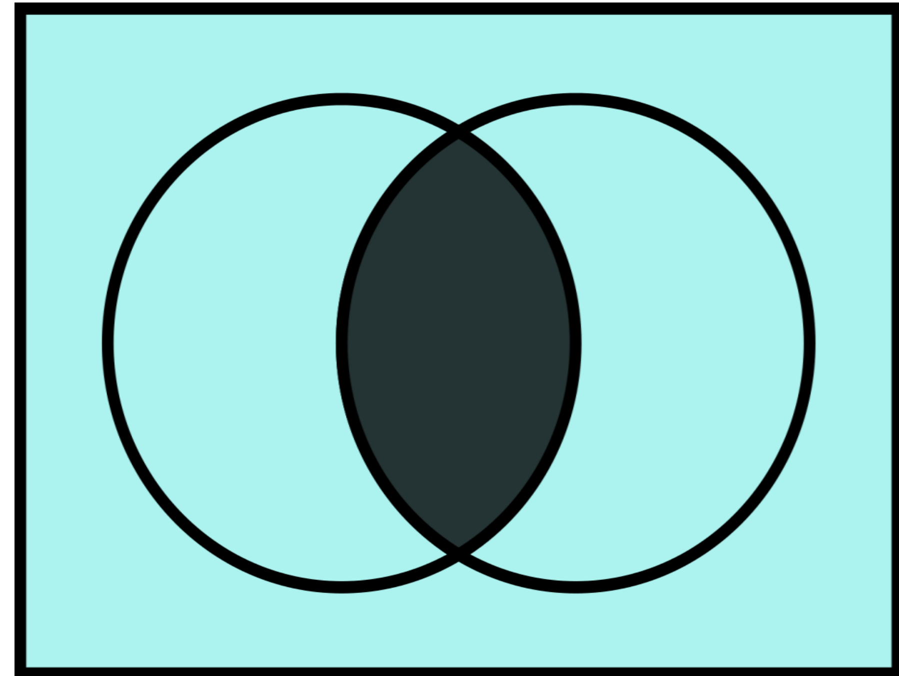
# Remember the Mouse Studies? They Got Therapy

- Mice received ***extinction therapy*** to eliminate the fear of the cherry scent
- Repeated exposure to the scent ***WITHOUT*** shocks
- Epigenetic marks ***not present*** in sperm
- Children of those mice ***were not afraid*** of the cherry scent

Aoued HS, Sannigrahi S, Doshi N, Morrison FG, Linsenbaum H, Hunter SC, et al. (2019). Reversing behavioral, neuroanatomical, and germline influences of intergenerational stress. *Biol Psychiatry*, 85, 3, pp. 248–56.

# Trauma & EDs Commonly Co-Occur

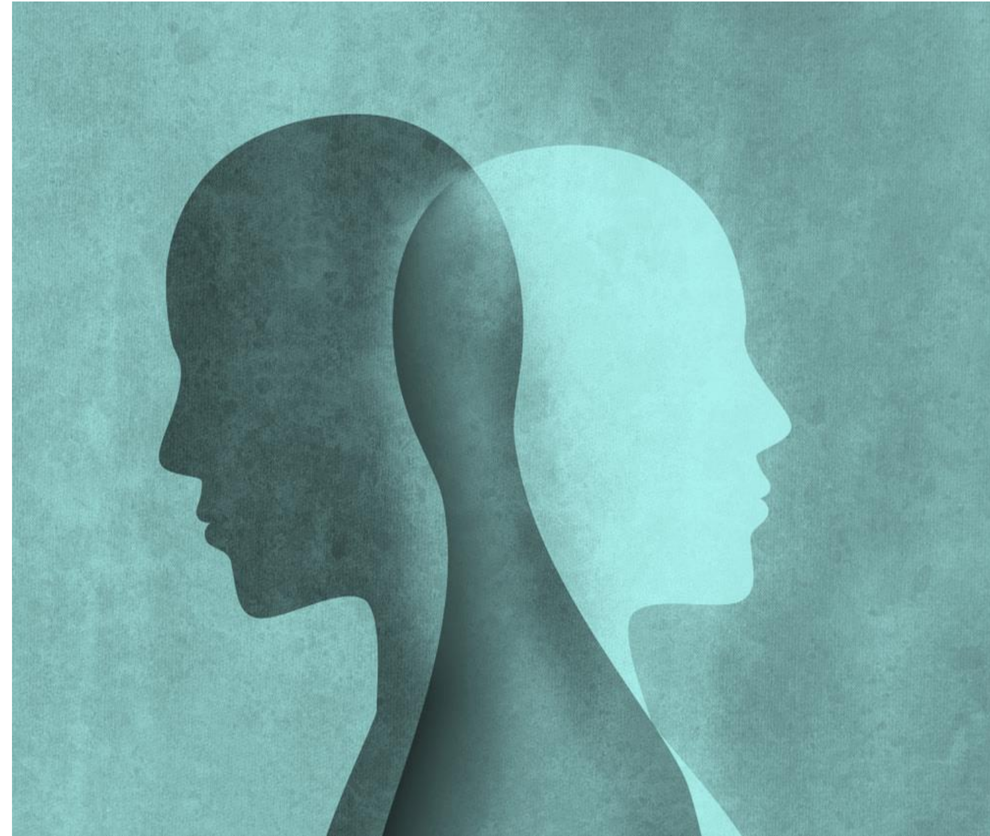
- Trauma History
- Secondary/Vicarious Trauma
- Adverse childhood experiences (ACES)
- Post-traumatic stress disorder (PTSD)
- Complex PTSD
- Sub-threshold PTSD
- Minority Stress



(Brewerton et al., 2020; Rienecke et al., 2022)

# Trauma & EDs Commonly Co-Occur. But Why?

- Emotional Avoidance & Management of Trauma Symptoms
- Biological Impacts of Trauma Increase ED Risk (e.g., stress response system, mental status, metabolism, immune system, hormonal systems)



(Carpenter et al., 2007; Danese, 2012)

# ED Symptoms & Trauma

## *RESTRICT*

- Disappear or dissociate
- Desire to stay small
- Delay/prevent sexual development
- Avoid trauma memories
- Reduce emotional intensity

## *PURGE*

- Purify or cleanse the body (get rid of the event)
- Shameful behavior to reenact trauma in an effort to feel more in control
- Laxatives - feel "empty"

## *BINGE*

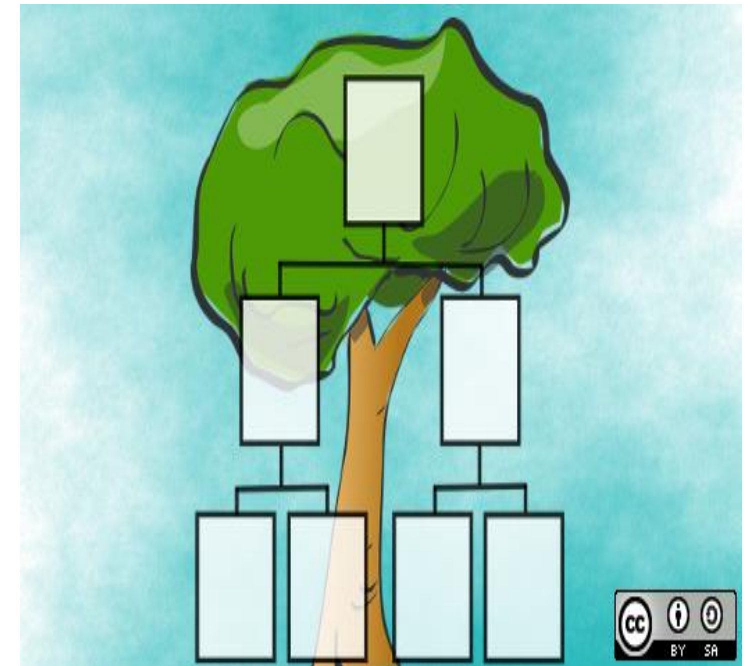
- Isolate/Disconnect
- Avoid Intimacy
- Provide a sense of emotional numbing/comfort/dissociation
- "Stuff down" emotions/food

# Making the Mental Shift: Trauma Informed Conceptualizations

**What's wrong with you?**

**What happened to you?**

**What happened to you,**
**your family, and your ancestors?**



# The Tenets of Trauma Informed Mental Health Care

(a) **Safety** (e.g., physical & psychological; accept & affirm experiences, predictability)

(b) **Trust and Transparency** (e.g., open communication, transparency about clinical background & the therapeutic process. Owning your lack of experience with injustices)

(c) **Power & Empowerment** (e.g., voice & choice, acknowledge power differentials & create a safe space for client to express themselves, strengths & skills)

(d) **Collaboration** (e.g., partnership on goals, objectives, interventions, diagnostic processes; amplifying the voices of the client/family)

(e) **Cultural, Historical, & Gender Issues** (e.g., organization moves past stereotypes/biases, offering culturally responsive services, leveraging therapeutic value of cultural connections, recognizes/addresses historical trauma)

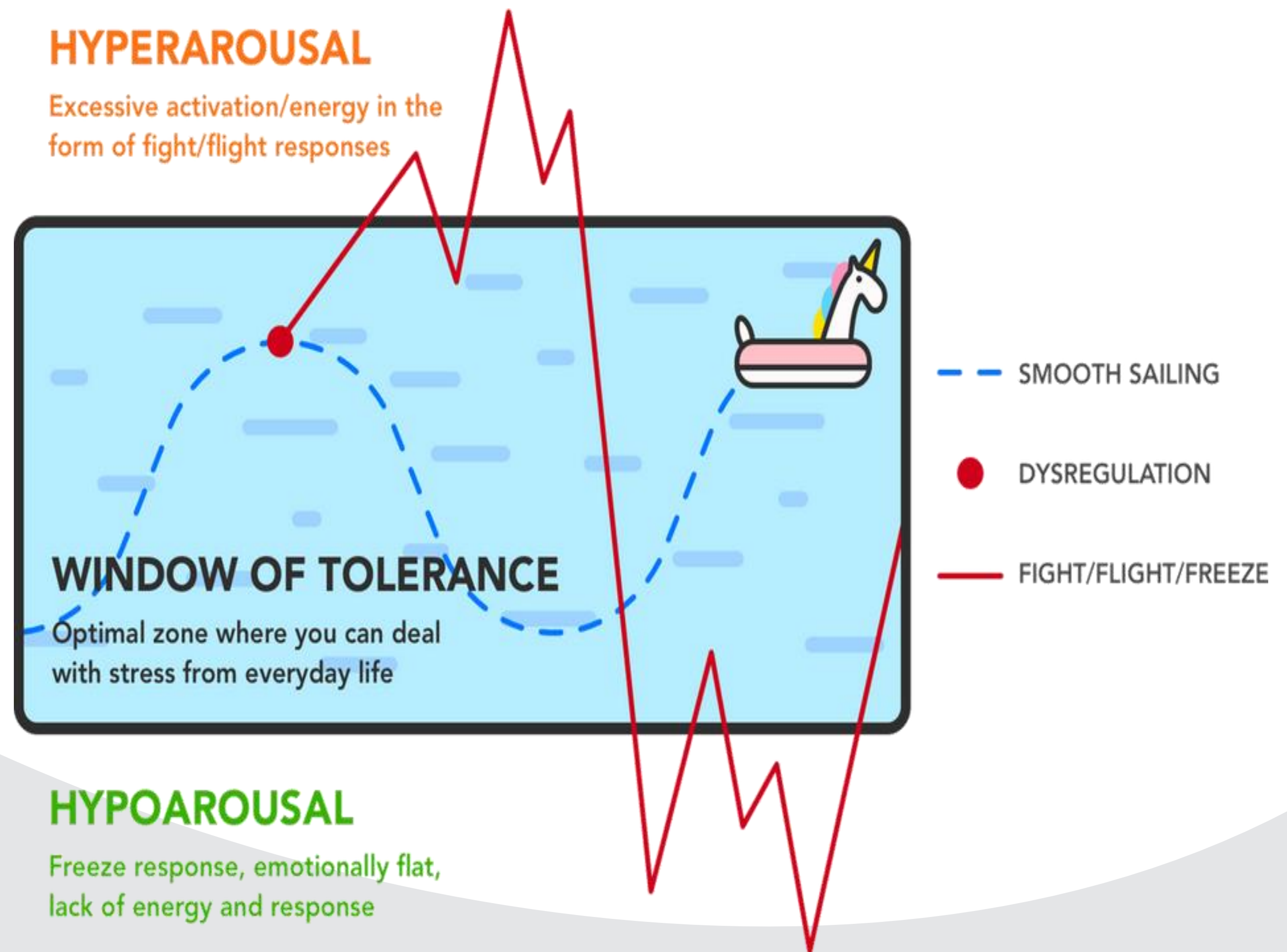
Lee, A. T., Chin, P., Nambiar, A., & Hill Haskins, N. (2023). Addressing intergenerational trauma in Black families: Trauma-informed socioculturally attuned family therapy. *Journal of Marital and Family Therapy*, 49, 447–462.

CDC & SAMHSA

# #1 Improve Awareness of Nervous System States

Questions to ask clients:

- How does it feel in your body when you are above or below your window?
- What ED behaviors do you reach for when in hyperarousal? Hypoarousal?
- How do your eating disorder behaviors help you manage the freeze or fight/flight responses?
- What are other ways of managing your nervous system responses?



# #2 Develop Discrepancy

| Are you… | | | |
|---|---|---|---|
| | refusing to eat due to fear/anxiety/body image? | OR | is a fight/flight response shutting down digestion? |
| | purging due to fear of having had "too many calories"? | OR | Is this an attempt to cool a hyper-aroused nervous system? |
| | exercising to lose weight? | OR | to disrupt a frozen state? |

# #3 Increase Interoceptive Awareness (IA)

Folks who experienced traumatic life events, especially early in life, struggle to cope with intense emotions and overwhelming inner experiences for the following reasons:

- Received little to no help and reassurance from caretakers and therefore don't understand the inner experience
- An inner experience may become symbolic of who they are as a person ("I feel bad therefore I am bad.")
- The internal experience may be a reminder of the trauma, or a signal that something bad will happen

Boon et al., 2011

# #4 Exposure to Discomfort (“Leaning In”)

Identifying and challenging emotion avoidance strategies:

- Subtle behavioral avoidance
- Cognitive avoidance
- Safety signals

Choosing alternative action tendencies

Creating an exposure hierarchy (when ready)

Key maintaining factor for many psychiatric illnesses:

**Drive to avoid negative emotional experiences**

**Recovery requires experiential challenge** (doing things that have been habitually avoided) **and reducing avoidance strategies**

# #5 Increase Growth Fostering Connections

- Trauma can lead to chronic disconnection (remaining stuck in fight/flight/freeze)
- Eating disorders are rooted in disconnection from self & others
- Co-regulation: using another person to calm one's nervous system; shared experience of safety
- Therapist/client relationship as a template for safety and trust
- Growth-fostering relationship (RCT): The "five good things"

# Breaking Cycles & Reducing the Impact of Intergenerational Trauma

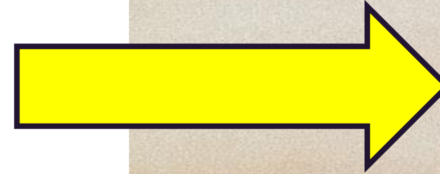
1. Prioritizing Mental Health
2. Trauma Informed Providers
3. Socio-culturally Attuned Providers
4. Culturally Adapted Treatment Modalities & Prevention Programs
5. Education & Support with Parenting
6. Managing Stress
7. Finding Community
8. Improving Sleep
9. Eating & Nourishing Intuitively
10. Resiliency & Post Traumatic Growth

(Substance Abuse and Mental Health Services Administration, 2014)

# The Jar Model

(found at nsgc.org)

Must **be filled to top** with genetic & environmental risk factors to experience a Mental Health Disorder



We all have a jar for mental illness, including one for Eating Disorders!

Photo by Kier in Sight Archives on Unsplash

The ***taller the jar***, the ***more marbles it can hold*** without ever filling up

**Rings** = Protective Factors

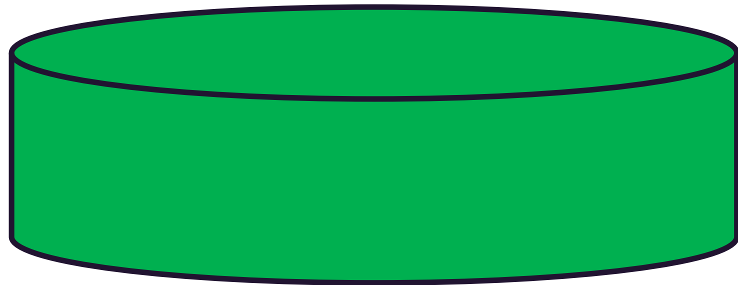


Photo by Kier in Sight Archives on Unsplash

We can even **REMOVE** *some* environmental risk factors by turning the jar upside down and **dumping them out**

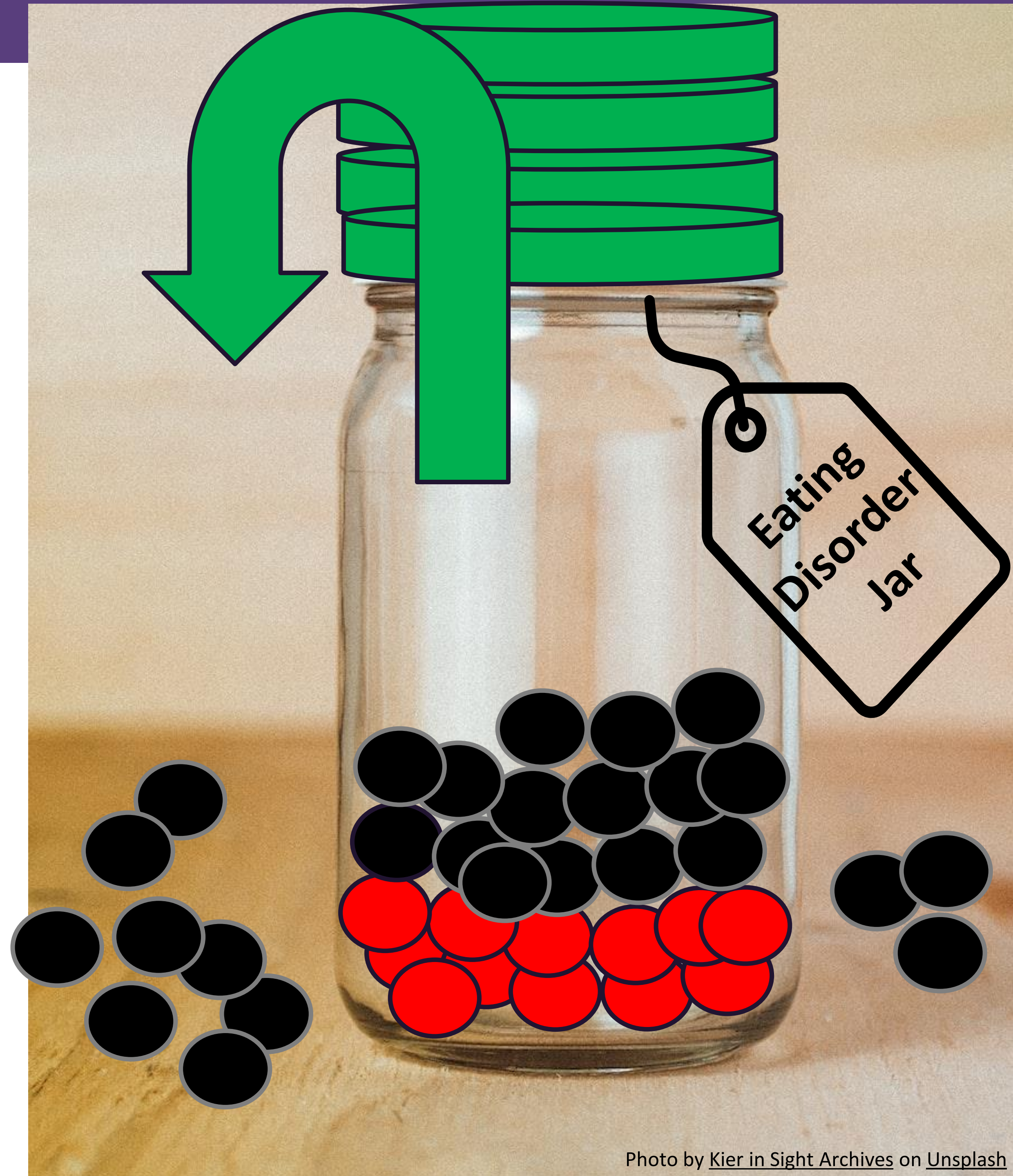



Photo by Kier in Sight Archives on Unsplash

# Protective Factors: Changes in the Home

- Normalize and validate emotions and needs
- Prioritize mental health
- Address internalized stigmas and unlearn beliefs rooted in healthism & diet culture
- No dieting of talk of the intentional pursuit of weight loss
- Redefine what “health” (separate it from weight)
- Repair ruptures between family members
- Eat together & connect
- Limit media exposure & learn about media literacy
- Stop all body comments (self & others)
- Stop moralizing food & labeling food as good/bad
- Be mindful of appearance-based praise/comments of self, child & others. Focus on internal qualities
- Talk openly about values
- If accessible, seek professional support (therapist, dietician, psychiatrist, support groups etc.)

# Contact Information

**Samantha DeCaro, PsyD (she/her/hers)**
Licensed Clinical Psychologist in PA
Director of Clinical Outreach and Education
The Renfrew Center
**Email:** sdecaro@renfrewcenter.com

.