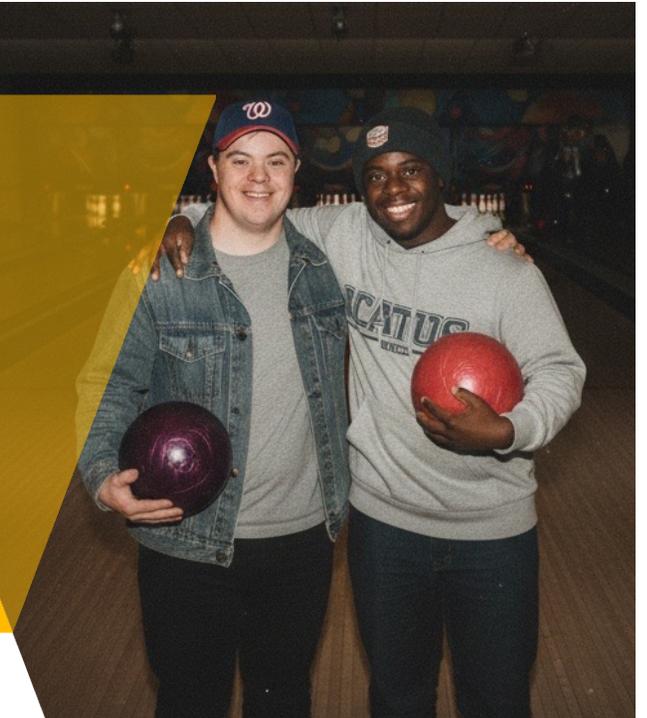




# Supporting Resilience: Helping Adults with Down Syndrome Cope with Life's Challenges

Ruth Brown, PhD, LCP



## About the HOPE Lab



<https://hope.lab.vcu.edu>

### About me:

Clinical Psychologist

- Psychometrics, measure development
- Stress and trauma
- Treatment outcome research

Assistant Professor

Virginia Institute for Psychiatric and Behavioral Genetics



# Agenda

- 1** Understanding Stress and Trauma
- 2** Understanding the Effects of Stress and Trauma on Adults with Down syndrome
- 3** Supporting Adults with Down Syndrome
- 4** Self Care

## Self Care

**Step out and take a break if you need to.  
Talk to someone you trust.  
Do something relaxing.**



# Understanding Stress and Trauma

1

## What is Stress?



**Feeling of pressure, worry, or tension caused by a difficult or challenging situation.**



**Short term, manageable stress can help us grow and develop greater stress tolerance.**



**Chronic, unmanageable stress can cause wear and tear on our bodies and minds.**

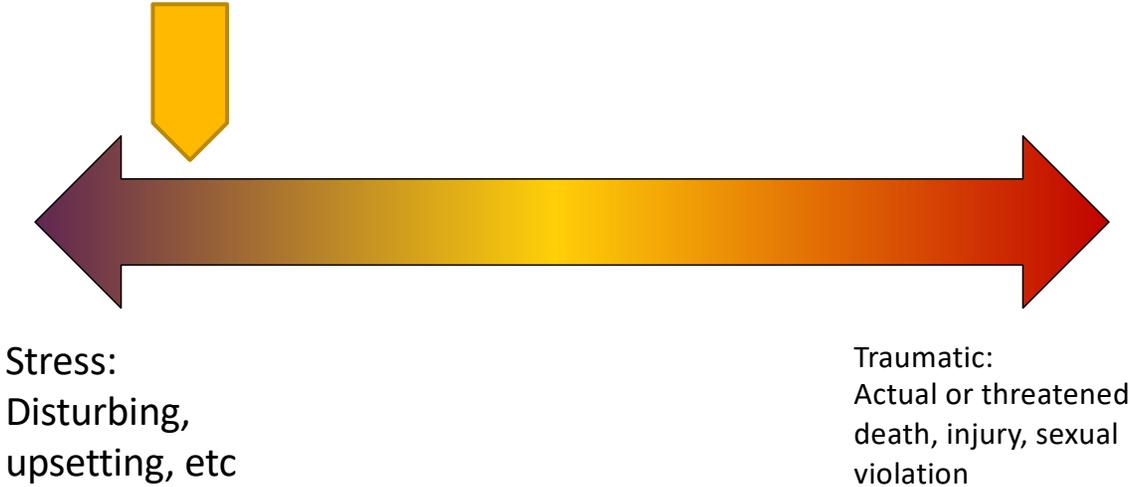
What is Trauma?

A traumatic event is an event **perceived** as frightening, dangerous, or violent that **poses a threat to a person's life or bodily integrity**.

Can involve witnessing a traumatic event of another person, especially a loved one.

The greater the **perception of threat** (to life, body), the greater the trauma experienced.

# One Person's Stress is Another Person's Trauma



Understanding the Impact of Stress  
and Trauma on Adults with Down  
Syndrome

2

## People with Developmental Disabilities Experience Stress and Trauma

### More likely to experience:

Social exclusion

Institutionalization

Bullying

Abuse

Sexual abuse

Loneliness

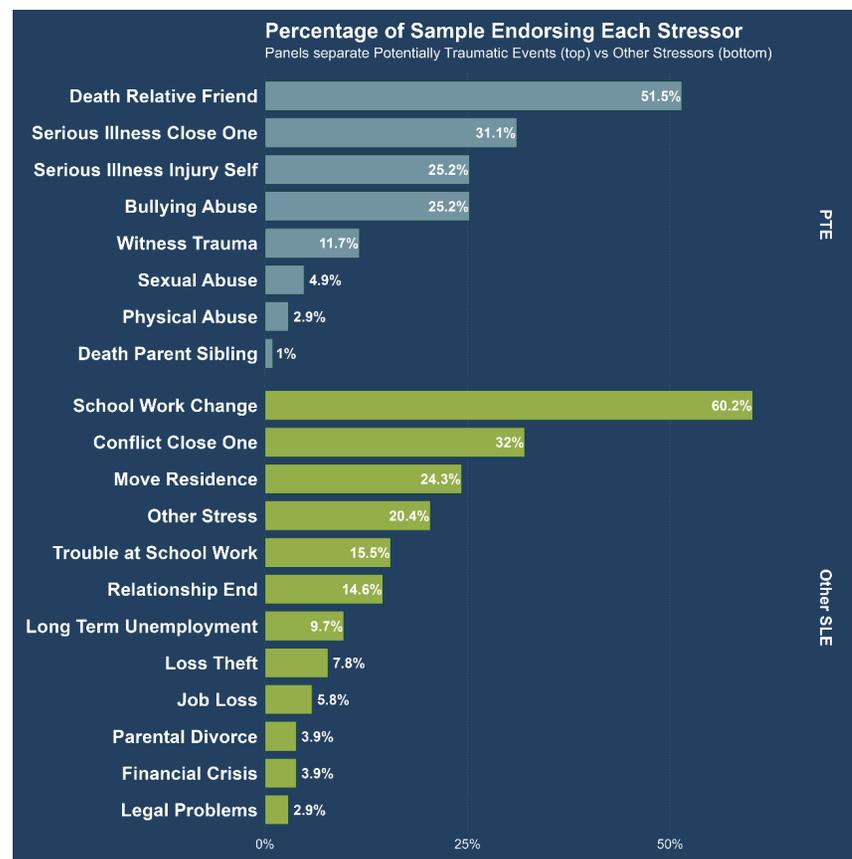
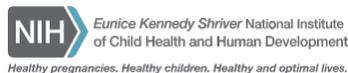
Few studies about people with Down syndrome



## People with Down Syndrome Experience Stress and Trauma



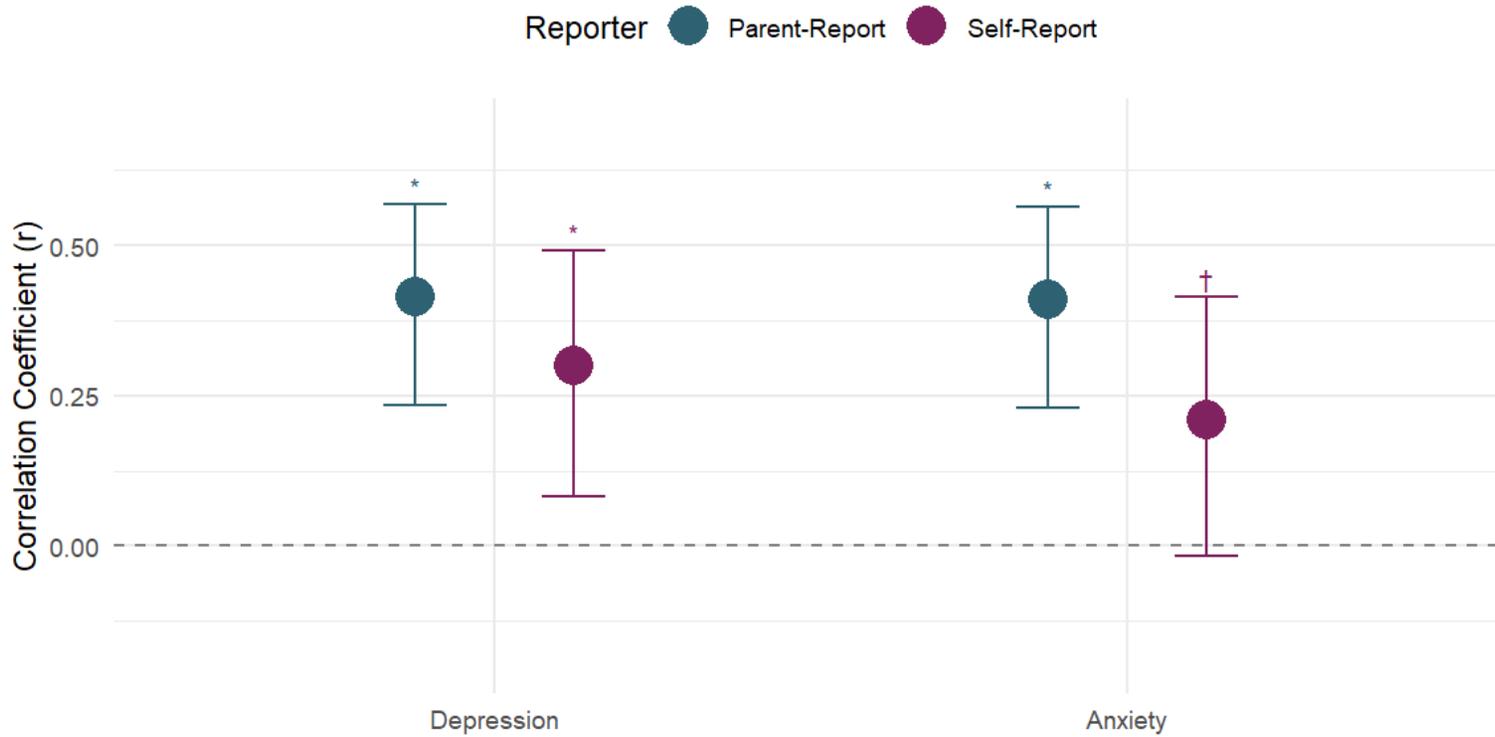
- **127 children, parents, or self advocates with Down syndrome and mosaic Down syndrome**
  - Recruited through IMDSA, Down syndrome organizations, NIH DS-Connect registry
- **Aged 12-45 years**
- **Which life events did the person experience in the last 2 years?**



## Stressful Life Events and Mental Health Symptoms

Correlation with total stressful life events (SLE)

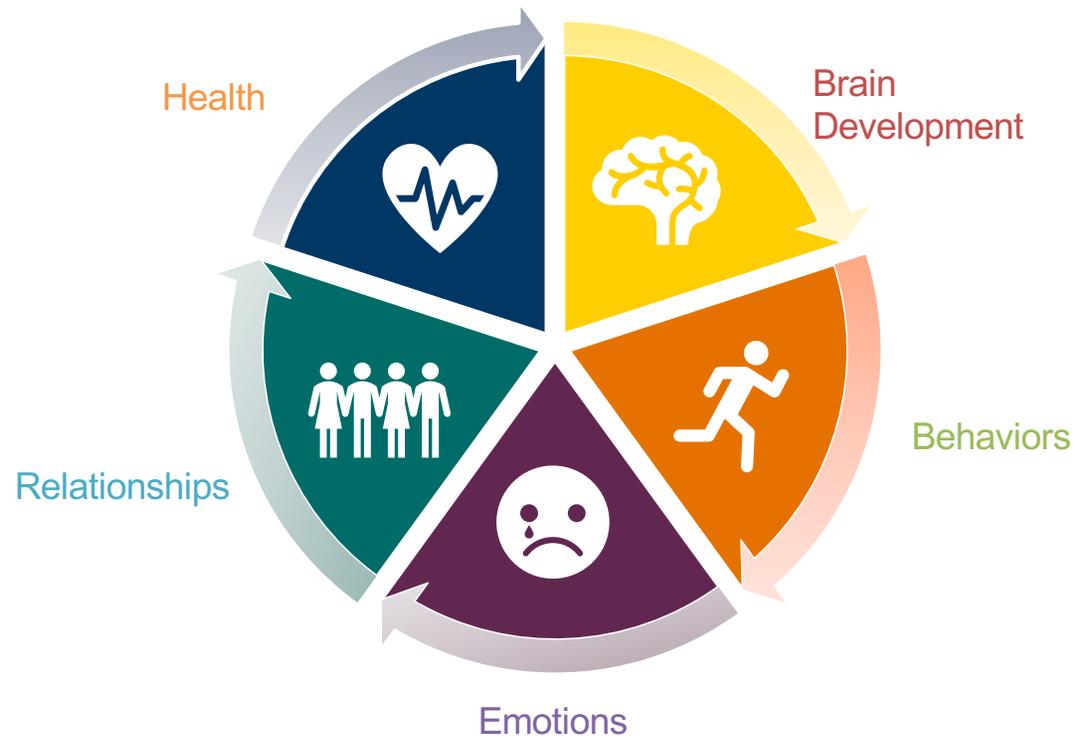
\*  $p < 0.05$ , †  $p < 0.1$



## Myths about People with Intellectual and Developmental Disabilities

- ⊗ People with intellectual disabilities do not experience trauma
- ⊗ People with IDD cannot engage in treatment
- ⊗ Behavior modification is the only option
- ⊗ A challenging behavior is explained by an intellectual disability
- ⊗ Their behaviors are just to get attention or something they want

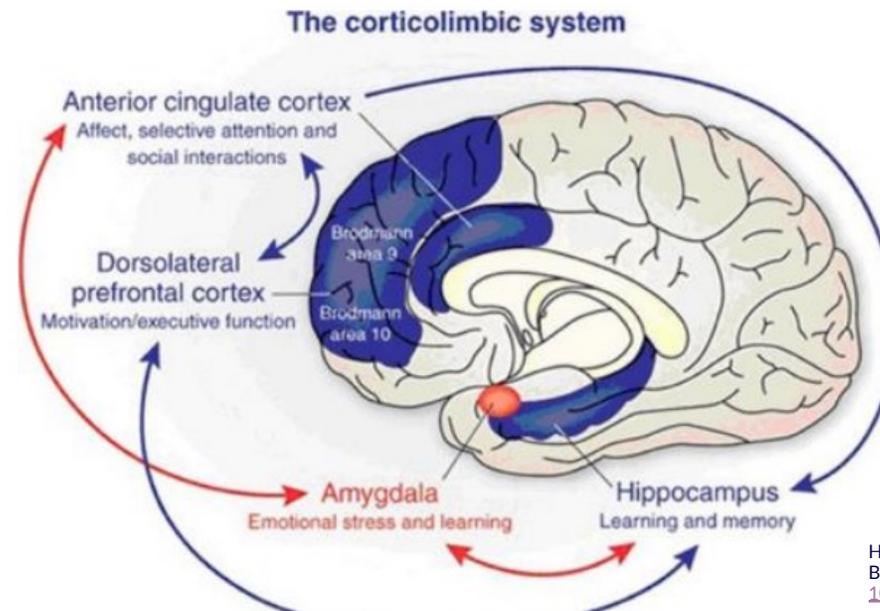
# The Reality is that Stress and Trauma Impact the Whole Person





## Trauma and Chronic Stress Can Effect the Brain

Biologically driven changes in thinking, feeling, and behavior

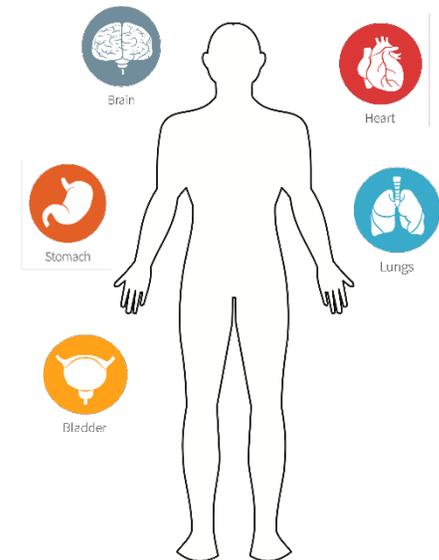


Herrington, R.J. Trauma, PTSD, and the Developing Brain. *Current Psychiatry Reports*, 19, 69 (2017). doi: [10.1007/s11920-017-0825-3](https://doi.org/10.1007/s11920-017-0825-3)

## Trauma and Chronic Stress Can Effect Health

### Chronic Stress and Trauma are associated with:

Cardiovascular disease  
Chronic pain, headaches  
Inflammatory diseases  
Metabolic disorders  
Immune disorders





## Trauma Can Impact Behaviors

### **Avoidance:**

- Actively avoiding people, places, or activities that are reminders of the trauma.
- May look like stubbornness or opposition/defiance

### **Changes in routine:**

- Sudden changes in eating or sleeping patterns (e.g., nightmares, difficulty falling asleep).

### **Regression:**

- Loss of previously learned skills, such as toileting, communication, or daily living skills.

### **Increased self-stimulatory behavior:**

- Rocking, pacing, or other repetitive movements may increase as a way to self-soothe.

### **Externalizing behaviors:**

- An increase in aggression, agitation, or self-injurious behaviors can be a sign of internal distress.



## Trauma and Stress Can Impact Thoughts and Emotions

### Intense and overwhelming emotions:

- Increased fear, anxiety, sadness, anger, or irritability
- Sudden unexplained crying
- May seem out of proportion to the current situation

### Hypervigilance:

- Constantly on alert, as if searching for danger
- They may be easily startled
- Pacing, difficulty sitting still
- Locking doors, windows, etc.
- Increased sensory sensitivities, overwhelm



## Trauma and Stress Can Impact Thoughts and Emotions

### **Negative thoughts about self and the world:**

- They may blame themselves for what happened
- May express feelings of worthlessness
- Feel the world is a dangerous place and no one can be trusted.

### **Difficulty concentrating:**

- Trouble focusing on tasks at work, home, or in a day program.

### **Confusion or disorientation:**

- Especially when reminded of a stressful or traumatic event.



## Trauma and Stress Can Impact Relationships

### Difficulty trusting

**Needing more reassurance, support, behavior management**

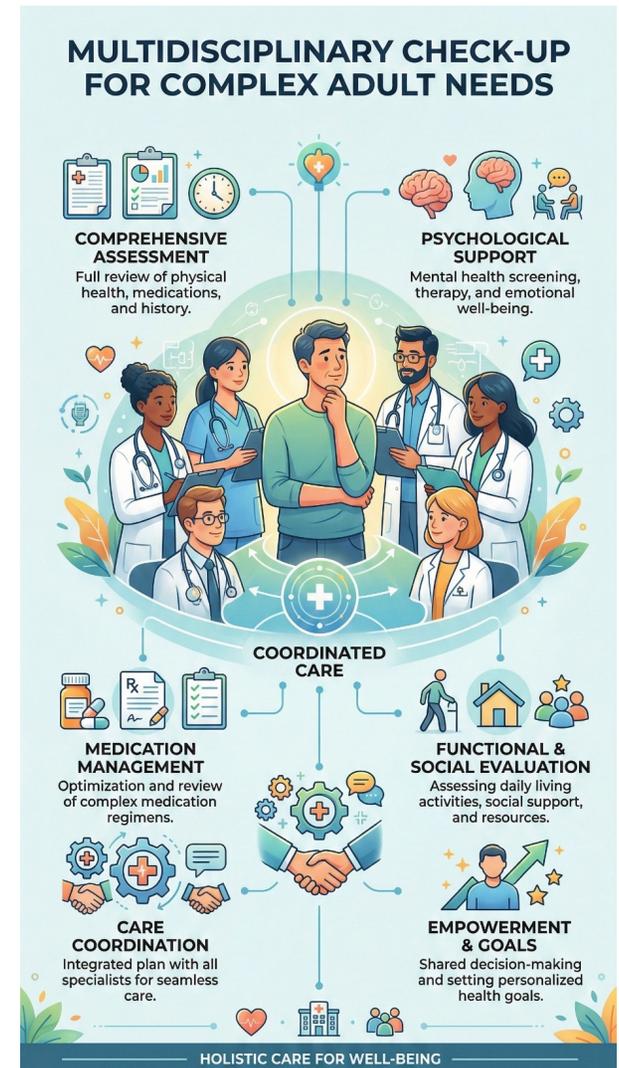
**Emotional dysregulation can take it's toll on friends, family, caregivers**

**Caregivers or family may have also experienced trauma**

- The same event (e.g., car crash, fire, natural disaster)
- Secondary traumatic stress from learning about the trauma
- Unrelated traumas that impact their own wellbeing and window of tolerance

## Is it because of trauma?

- Could be underlying medical issues
  - Sleep apnea
  - GI distress
  - Dental pain
- Could be general emotional dysregulation
- Could be general lack of communication/coping strategies
- Could be serving another function
- Could be a combination of trauma and any of these!



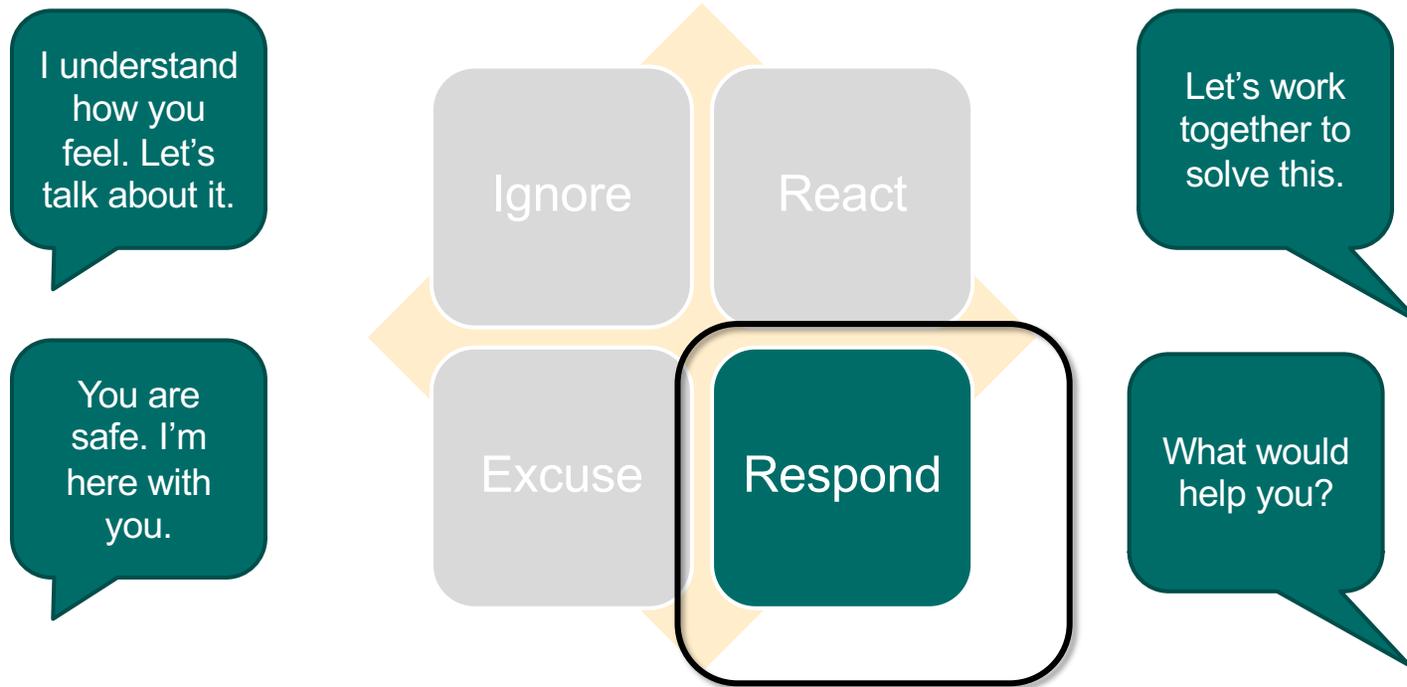
Supporting Adults with Down  
Syndrome Who Have Experiences  
Trauma or Chronic Stress

3

## Common Reactions to Symptoms of Traumatic Stress



## Trauma-Responsive is Where We Want to Be



# Responsive Strategies

## Create a sense of safety

- Safe places
- Safe people
- If these are ongoing threats – create “Islands of safety”

## Addressing thoughts

- Addressing negative thoughts about self, others, world

## Addressing behaviors through a trauma-informed lens

- Emotion coaching, person-centered, skill building

## Addressing emotion regulation needs

- Co-Regulation
- Building coping skills

**TRAUMA-RESPONSIVE STRATEGIES:  
A GUIDE FOR CAREGIVERS OF ADULTS**

**CREATE A SENSE OF SAFETY**  
Build predictability & trust

- **SAFE PLACES**  
(e.g., Calm environment, structured routines)
- **SAFE PEOPLE**  
(e.g., Consistent, reliable interactions, supportive relationships)
- **IF ONGOING THREATS**  
(e.g., Establish 'Islands of Safety'—reliable moments, spaces, or people)

**ADDRESSING THOUGHTS**  
Challenge negative self-talk & beliefs about self, others, the world

- Listen without dismissal, explore assumptions, offer alternative perspectives

'I'm bad' → 'I am resilient'  
'People are dangerous' → 'Some people are safe'

**ADDRESSING BEHAVIORS through a trauma-informed lens**  
View challenging behaviors as communication

- **EMOTION COACHING**  
Validate feelings, label emotions like anger, fear, or sadness
- **PERSON-CENTERED**  
Collaborate, give choices, respect autonomy
- **SKILL BUILDING**  
Teach healthy coping, communication skills, problem-solving

**ADDRESSING EMOTION REGULATION NEEDS**  
Help manage intense emotions

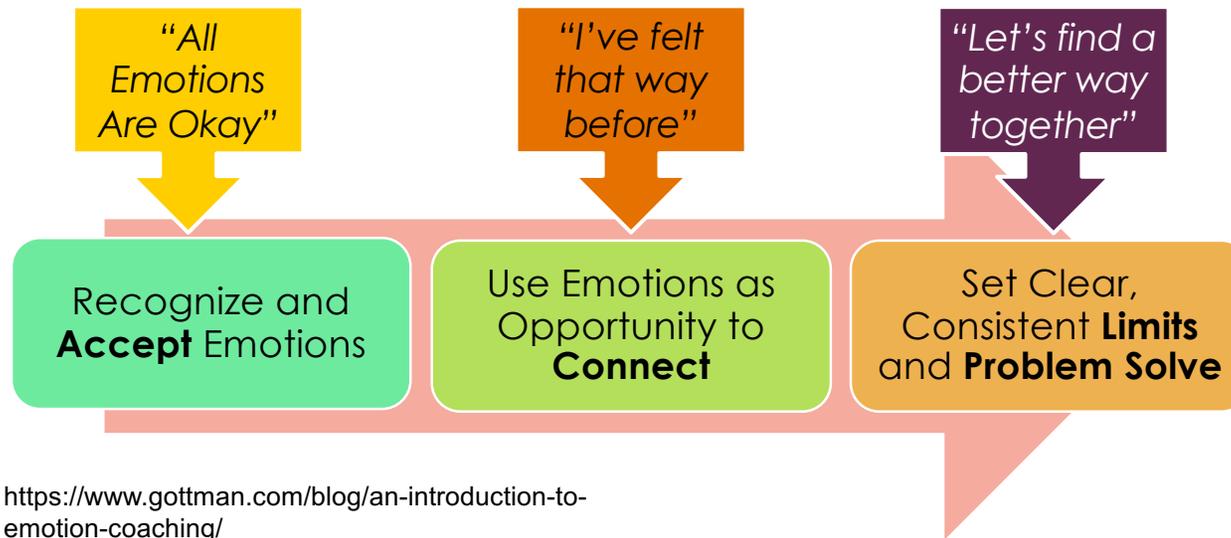
- **CO-REGULATION**  
Stay calm yourself, model regulation, share calm
- **BUILDING COPING SKILLS**  
Develop personalized tools: deep breathing, grounding, exercise, creative outlets

**Coping Toolkit**  
Music, Reading, Walking, Walking

SUPPORTING HEALING & RESILIENCE

# Addressing Behaviors with Emotion Coaching

Trauma-informed and sets limits



## Trauma-Responsive Communication

- Use simple, clear language. Avoid jargon or complex explanations.
- **Validate their feelings:** "I can see that you're scared. That must have been very frightening." This shows you understand and are not judging them.
- **Be a "Feelings Detective":** Pay attention to non-verbal cues. If they seem agitated, you can say, "You look upset. Can you show me what's wrong?"
- **Offer choices, not demands:** Instead of "You need to calm down," try "Would you like to listen to music or sit in the quiet corner for a few minutes?" This returns a sense of control.
- **Practice active listening:** Be patient and give them plenty of time to communicate their thoughts and feelings, in whatever way they can.
- **Correct negative beliefs** about blame or danger.
  - "A bad thing happened to you, but you are safe now."
  - "It wasn't your fault. No one deserves to get hurt."

## Trauma-Responsive Co-Regulation:

- **Co-regulation is the process of helping someone return to a calm state by being a calm, supportive presence.**
- **Model calmness:** Your calm presence is contagious. Lower your voice, slow your breathing, and use relaxed body language.
- **Create a safe space:** Reduce sensory input. Dim the lights, lower the noise, and move to a less crowded area.
- **Use sensory tools:** Offer a weighted blanket, a stress ball, or soft music. Find what is soothing for that individual.
- **Practice grounding techniques together:**
  - 5-4-3-2-1 Game: Name 5 things you can see, 4 things you can feel, 3 things you can hear, 2 things you can smell, and 1 thing you can taste.
  - Deep breathing: "Let's pretend to blow up a big balloon. Breathe in deep... and now blow it all out slowly."
- **Make it a regular enjoyable activity you do together (e.g., before bed)**



## Proactively Building Coping Skills

- **Create a "Calm Down" Kit:** Work together to create a box of items they find soothing (e.g., favorite photos, a soft object, scented lotion). Practice using it when they are calm, so it's familiar during times of stress.
- **Role-play difficult situations:** Practice how to handle situations that might be stressful, like going to the doctor or meeting a new person.
- **Celebrate small successes:** Acknowledge and praise them when they use a coping skill, no matter how small the step.



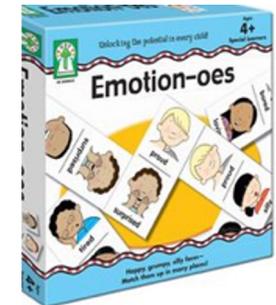
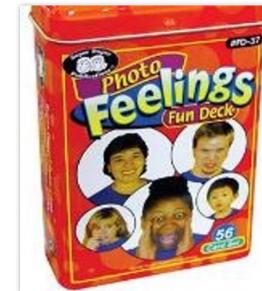
## Building an Emotion Vocabulary

**Name emotions:** Help them build an emotional vocabulary. Use pictures, feeling charts, or social stories to identify different feelings.

Talk about and normalize emotions of TV characters.

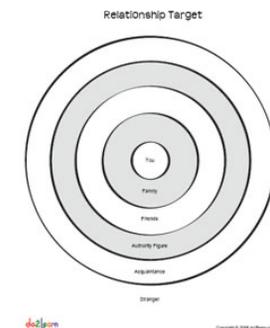
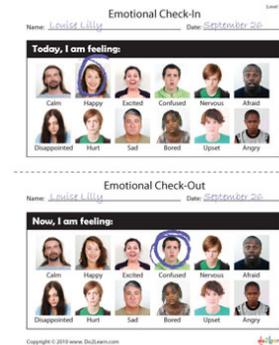
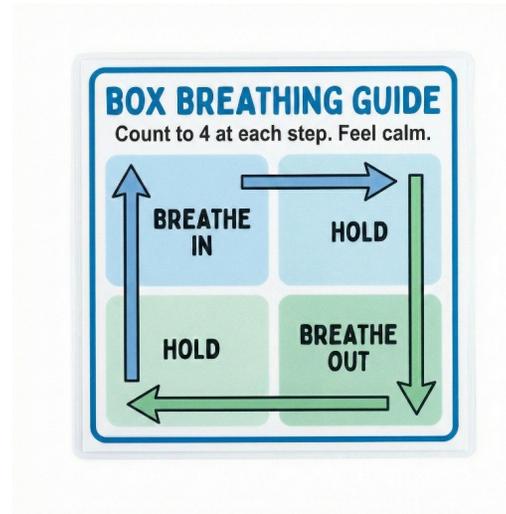
### Emotion Charades.

- Take turns acting out emotions on the cards and guessing the emotion.
- Ask follow-up questions:
  - Tell me about a time you felt that way.
  - What can you do when you feel that way?



## Visual Supports

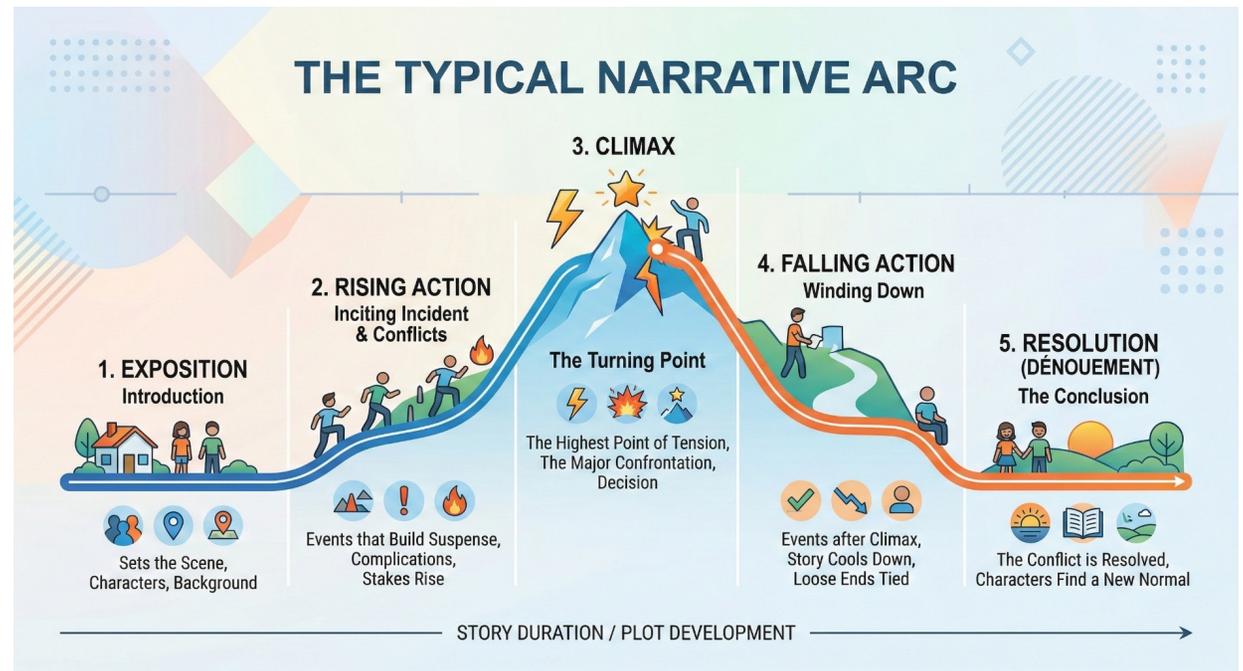
- Improve memory retention.
- Supports comprehension for struggling readers.
- Provide cues when “flipped lid”.
- Help to make abstract concepts more concrete.



<https://www.teacherspayteachers.com/Product/Social-Skills-Scripts-Self-Advocacy-Social-Story-Behavior-Saying-Sorry-SPED-10662419>

## Narratives and Meaning-Making

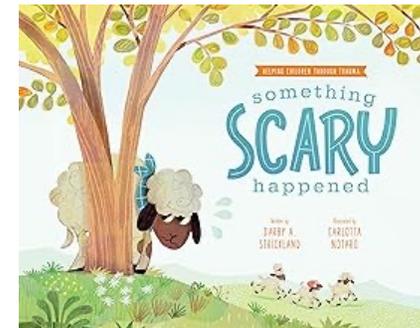
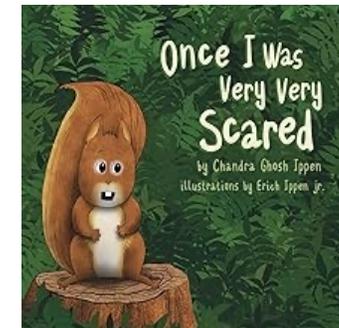
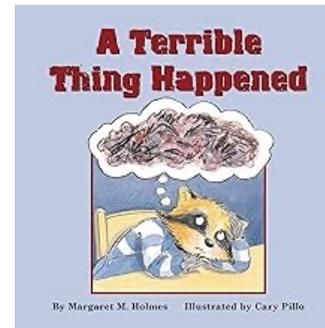
- One of the oldest and most effective forms of trauma therapy.
- Viktor Frankl's Logotherapy
- Helps turn scattered, frightening memories into a coherent story with a **beginning**, **middle**, and **end**.
- Provides gentle exposure to feared thoughts and memories.
- This reduces the memory's emotional power and helps the person regain a sense of control.



## Ready Made Books about Trauma and Coping

### Books

- Nonconfrontational
- Normalize feelings of being scared or experiencing scary situations
- Model resilience
- May open the door to talk about what happened
  - Follow their lead – Don't push if they aren't ready



## Making a Personalized Narrative

- Create a Storybook or Timeline. Use drawing, photos, or simple sentences to map out what happened.
- A visual story can make the event feel more manageable and less chaotic.
  - **The story must always end with the present moment, emphasizing that they are safe now.**
- Focus on **Survival and Strength**. Help them identify what they did to get through the experience. Even small actions count. Frame them as a survivor, not a victim.
  - "You were so brave when you held my hand."
  - "You were strong when you told me you were scared."

## Making a Personalized Narrative

- **Let them take the lead.** The story must be theirs. Listen patiently and don't push for details they aren't ready to share. Let them tell it in their own way, whether through words, gestures, or pictures.
- **Separate the Event from Their Identity.** The traumatic event is something that happened to them; it is not who they are. Use language that reinforces this separation. "That was a scary time" instead of "You're a scared person."
- **Validate, Don't Trivialize.** This is not about finding a "silver lining." Avoid saying things like "Everything happens for a reason." Instead, validate their feelings: "That was not fair, and it's okay to be angry about it."

If I could draw a picture of what happened, it might look like this:

A drawing or picture



I felt it in my body like this:  
My heart was beating SO fast. My wrist hurt really bad. I was shaking and I could not stop shaking even when people put a blanket on me. I kept crying and I could not stop. My ears were ringing from the loud crash.

Draw a picture of how you felt:

A drawing of my feelings



I got in the ambulance even though I was very scared and had never been in one before. I also let the doctor look at my wrist even though it hurt. The doctor said I was very brave and cooperative. Mom said she was proud of me.

Draw or paste a picture of something that helped you:

Something that helped me



## New Resource

### Step-by-step workbook to create a narrative.

- Includes instructions for caregivers and a completed example narrative.
- Work on it gradually and don't push.
- The goal is gradual and safe exposure to the upsetting memories.
- In the case of significant traumatic stress, this should be done with the help of a therapist.



## When to Seek Professional Help

It may be time to seek professional support if you notice:

- Symptoms are persistent and are not improving over several weeks.
- Symptoms are disrupting daily life, work, relationships, or general wellbeing.
- Behaviors are posing a safety risk to themselves or others.
- You feel overwhelmed or are unsure how to provide support.
- Asking for help is not a failure.



## How to Find a Therapist

**Look for therapists or counselors who specialize in working with individuals with intellectual and developmental disabilities (IDD) if available in your area.**

- Ask primary care for referral
  - Ask local DSA, ARC, or Special Olympics programs for recommendations
  - Ask your state's University Centers for Excellence in Developmental Disabilities (UCEDD)
    - <https://www.aucd.org/about-ucedds>
  - Check with other parent support groups such as Parent to Parent USA <https://www.p2pusa.org/>
- Specialists are very hard to find. You may need to find a therapist who is *willing to help*.**
- NDSS Guide for Providers

<https://ndss.org/resources/practicing-inclusive-mental-healthcare-individuals-down-syndrome>

### Practicing Inclusive Mental Healthcare of Individuals with Down Syndrome

This resource is provided to equip mental health professionals with tools, resources, and strategies to better serve individuals with Down syndrome and other intellectual and developmental disabilities, taking into consideration their unique mental health needs.



Self-Care

4

## Self-Care for Parents and Caregivers

### The Oxygen Mask Rule

**You must put on your own oxygen mask before you can help others.**

**You cannot pour from an empty cup.**

**Caring for someone who has experienced trauma can be exhausting and can lead to compassion fatigue or burnout.**

**Taking care of yourself is not selfish—it is essential for being an effective and resilient caregiver.**



## What Does Caregiver Burnout Look Like?

### Recognizing it in yourself or someone else

**Emotional Exhaustion:** Feeling drained, depleted, and having a short fuse.

**Depersonalization:** Becoming cynical or detached from the person you are caring for.

**Reduced Sense of Accomplishment:** Feeling like your efforts don't make a difference.

**Physical Symptoms:** Headaches, stomach issues, changes in sleep, and lower immunity.

## Practical Self-Care Strategies

### The Basics

**Protect your sleep:** Aim for 7-8 hours per night. A well-rested mind and body are more resilient.

**Nourish your body:** Eat regular, balanced meals. Stress can deplete your body of key nutrients.

**Move your body:** Even 15 minutes of walking can reduce stress hormones and improve your mood.

**Schedule regular health check-ups:** Don't neglect your own medical and dental appointments.

## Practical Self-Care Strategies

### Taking Care of Your Mind

**Practice mindfulness:** Use apps like Calm, Headspace, or simply take 5 minutes to focus on your breath. This can help you stay grounded in the present.

**Set boundaries:** It's okay to say "no." You don't have to attend every event or take on every task.

**Engage in hobbies:** Make time for activities that you enjoy and that are just for you.

**Limit news and social media:** Constant exposure to negative information can increase anxiety. Use an app or wifi blocker to set specific windows of time if you have a hard time limiting yourself, especially before bedtime.

## Practical Self-Care Strategies

### Building Your Support System

**Connect with other caregivers:** Join a local or online support group. Talking with others who "get it" is incredibly validating.

**Ask for and accept help:** Be specific. "Could you sit with my son for an hour on Tuesday so I can go to the grocery store?"

**Consider respite care:** Professional services can provide temporary relief, giving you a much-needed break.

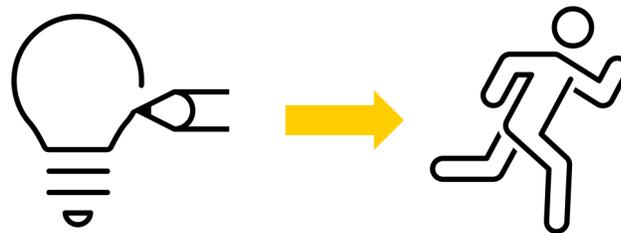
• <https://archrespice.org/caregiver-resources/respitelocator/>

**Talk to a professional:** A therapist can provide a safe space to process your own feelings and develop coping strategies.

## Create Your Own Self-Care Plan

Take a moment to think:

- What recharges me? (e.g., reading a book, walking in nature, coffee with a friend)
- Who can I call for support? (List 3 people)
- What is one small self-care activity I can do this week?
- Write it down and commit to it. A plan makes it more likely to happen!



## Key Takeaways

- Trauma is a response to a perceived threat and it impacts the brain, body, and behavior.
- People with Down syndrome experience trauma, and behaviors are often a form of communication about their internal distress.
- The goal is to provide support and teach skills while maintaining structure.
- Focus on creating Safety, Predictability, and Control to foster a healing environment.
- Caregiver self-care is not a luxury, it is a necessity.

## Questions?

**Ruth Brown, PhD**

[Ruth.brown@vcuhealth.org](mailto:Ruth.brown@vcuhealth.org)





# Project HOPE

*Down Syndrome Parent Perspectives Survey*

## What's Involved

- 30-60 minute survey questions about your loved one's mental health, development, and behavior.
- Participate online or over the phone.

## Who's Eligible

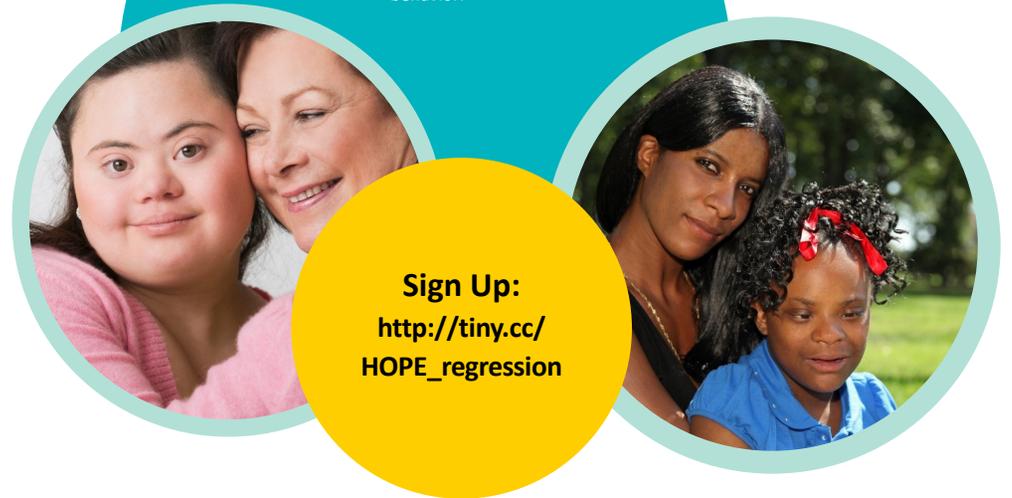
Parents or legal guardians of a person with Down syndrome aged 10-30.

Contact Ruth Brown, PhD at [ruth.brown@vcuhealth.org](mailto:ruth.brown@vcuhealth.org) for questions.



## Volunteers Needed

For an online research study to develop a new screening measure of health and behavior.



**Sign Up:**

[http://tiny.cc/  
HOPE\\_regression](http://tiny.cc/HOPE_regression)

