

About the HOPE Lab



About me:

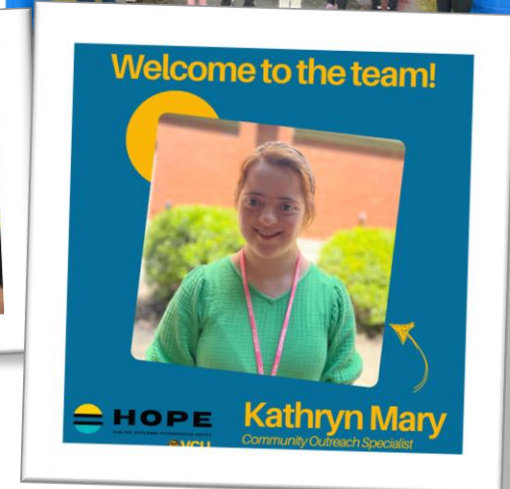
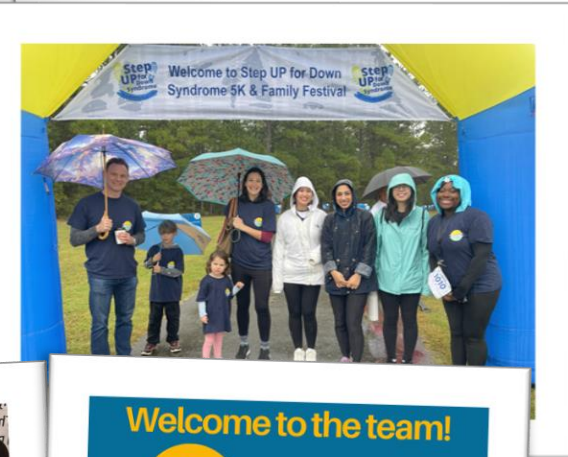
Clinical Psychologist

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

Assistant Professor

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Webinar Content

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

This can be a difficult topic.

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





Understanding Stress and Trauma

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

People with Developmental Disabilities Experience Stress and Trauma

People with Intellectual and/or Developmental Disabilities (IDD) are more likely to experience:

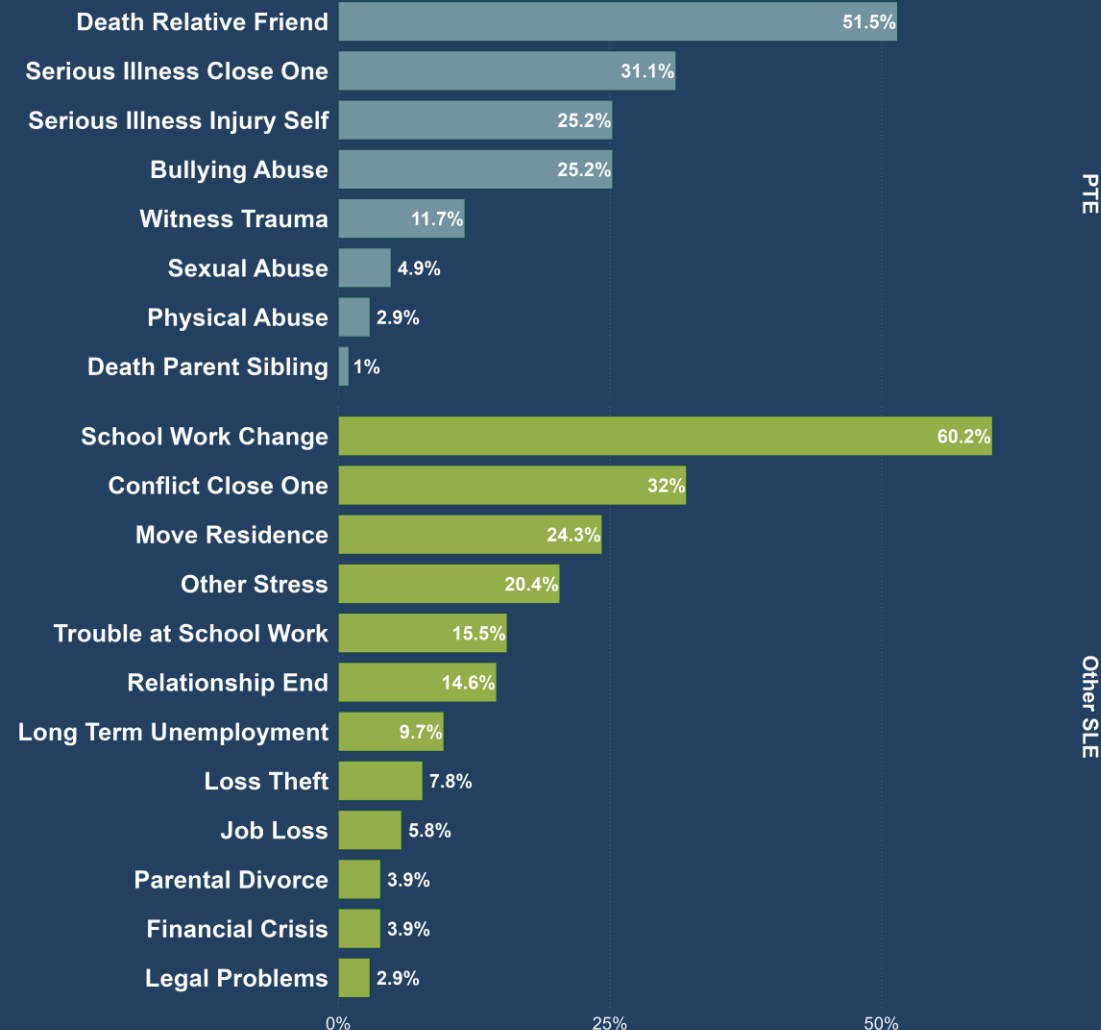
- Social exclusion
- Institutionalization
- Bullying
- Abuse
- Sexual abuse
- Loneliness
- Few studies about people with Down syndrome



People with Down Syndrome Experience Stress and Trauma

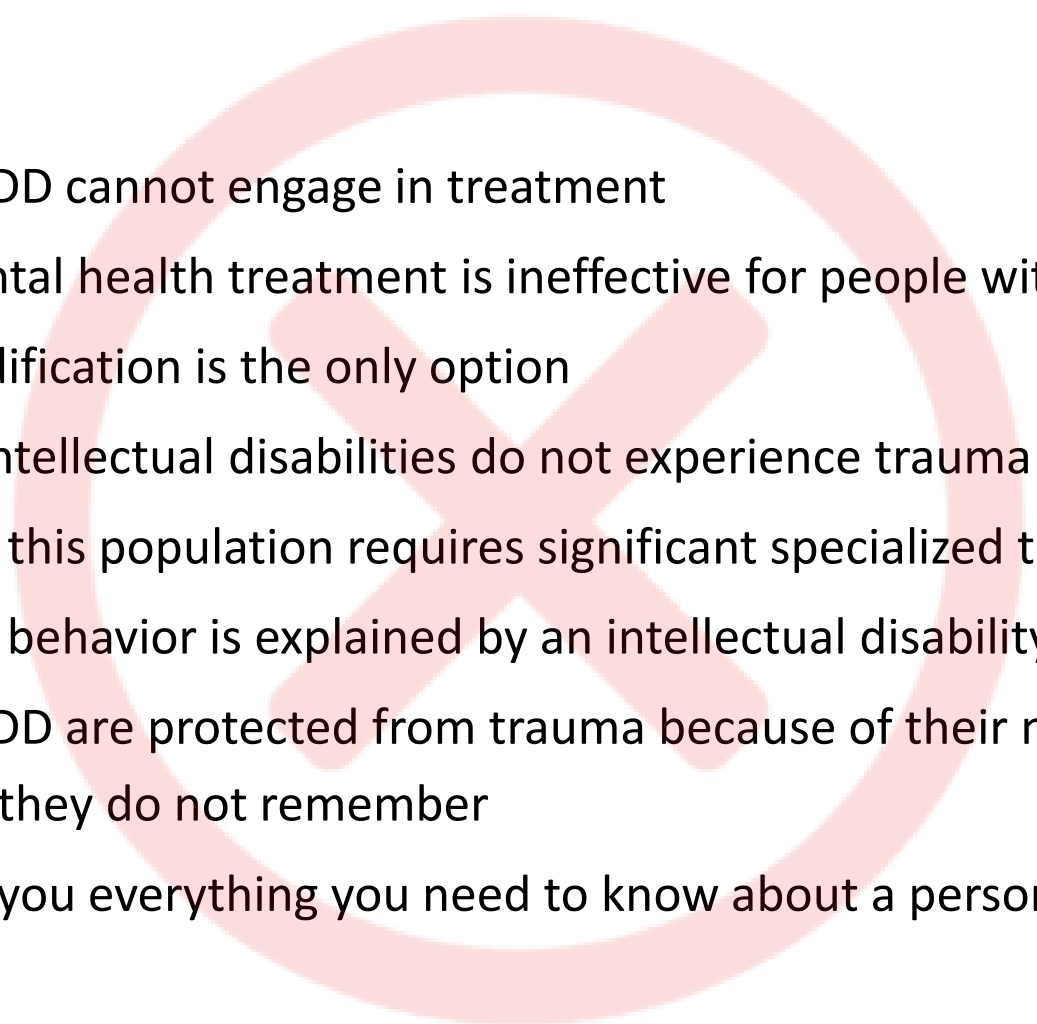
Percentage of Sample Endorsing Each Stressor

Panels separate Potentially Traumatic Events (top) vs Other Stressors (bottom)

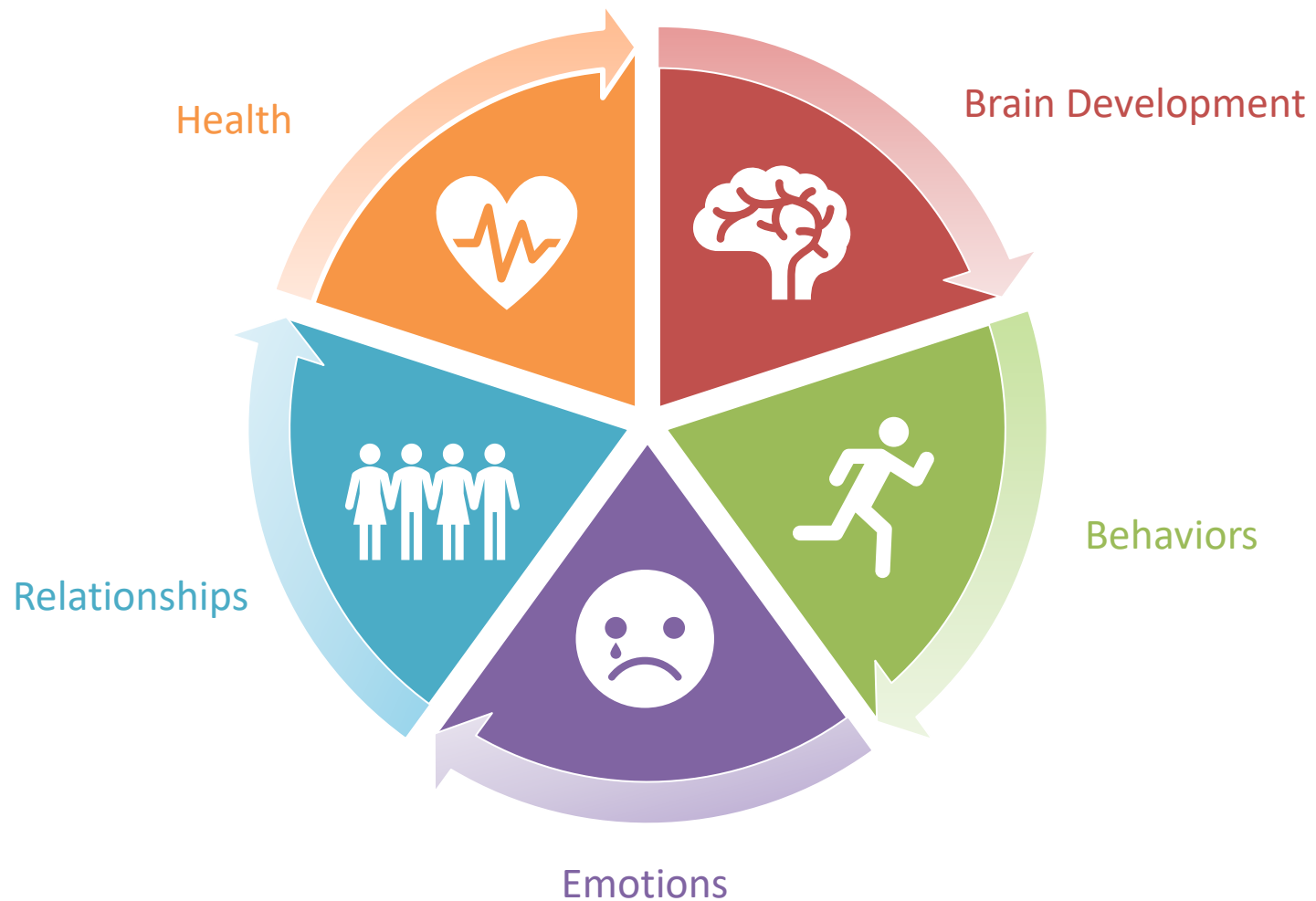


- NIH K08 Career Development Award
- 127 children, parents, or self advocates with Down syndrome and mosaic Down syndrome
 - Recruited through IMDSA, Down syndrome organizations, NIH DS-Connect registry
- Aged 12-45 years
- Past-two-year stressors

Myths about People with IDD

- 
- People with IDD cannot engage in treatment
 - Standard mental health treatment is ineffective for people with IDD
 - Behavior modification is the only option
 - People with intellectual disabilities do not experience trauma
 - Working with this population requires significant specialized training
 - A challenging behavior is explained by an intellectual disability
 - People with IDD are protected from trauma because of their mental age (i.e., babies); they do not remember
 - IQ scores tell you everything you need to know about a person

Impacts of Stress and Trauma

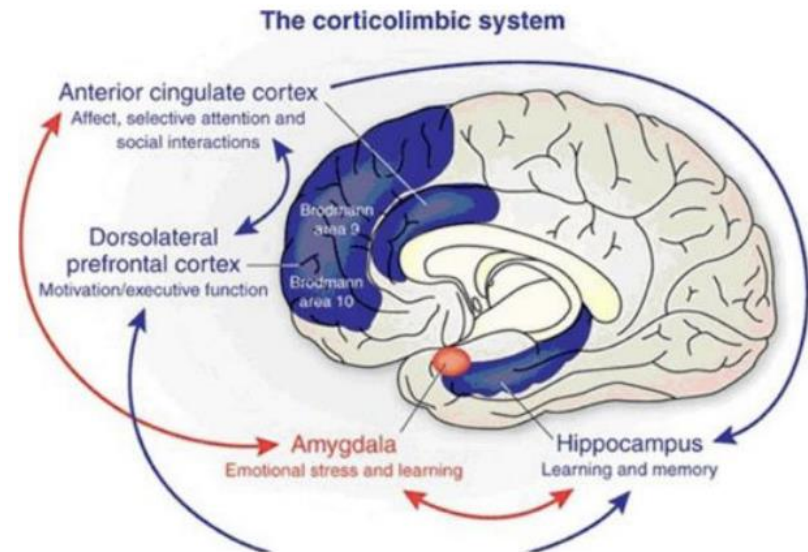


Trauma and Chronic Stress Can Affect the Brain



Biologically driven changes in thinking, feeling, and behavior

- Smaller anterior cingulate cortex
 - Poor rational decision making
- Smaller hippocampus
 - Increased difficulty with learning and memory (learning academics or coping strategies)
- More amygdala reactivity
 - Heightened sense of threat
- Decreased communication between amygdala <-> hippocampus
 - Impaired ability to regulate the threat response.



Herringa, 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 Can Impact Behaviors



- **Avoidance:**
 - Actively avoiding people, places, or activities that are reminders of the trauma.
- **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:**
 - Fear, anxiety, sadness, anger, or irritability that may seem out of proportion to the current situation.
- **Hypervigilance:**
 - A state of being constantly on alert, as if searching for danger. They may be easily startled.
- **Negative thoughts about self and the world:**
 - May express feelings of worthlessness, or that 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



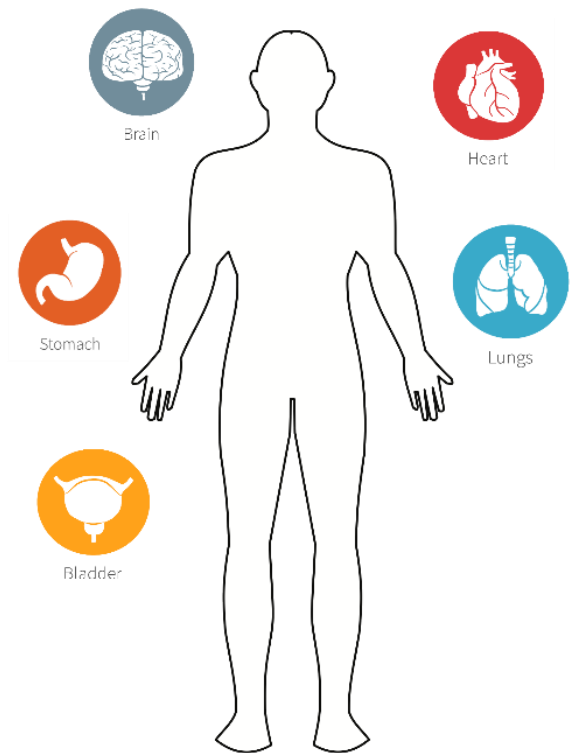
- Difficulty trusting
- Needing more reassurance, support, behavior management
- Emotional dysregulation can take its toll on friends, family, caregivers
- Caregivers or family may have also experienced trauma
 - The same event (e.g., car crash, fire, natural disaster)
 - Secondary traumatic stress from learning about the trauma
 - Unrelated traumas that impact their own wellbeing and window of tolerance

Trauma and Chronic Stress Can Affect Health



Chronic Stress and Trauma are associated with:

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



<https://www.apa.org/topics/stress/body>

Neelakantan S. Psychology: Mind over myocardium. *Nature*. 2013.

Levine GN, et al. Psychological Health, Well-Being, and the Mind-Heart-Body Connection: A Scientific Statement From the American Heart Association. *Circulation*. 2021.

Is It Because of Trauma?

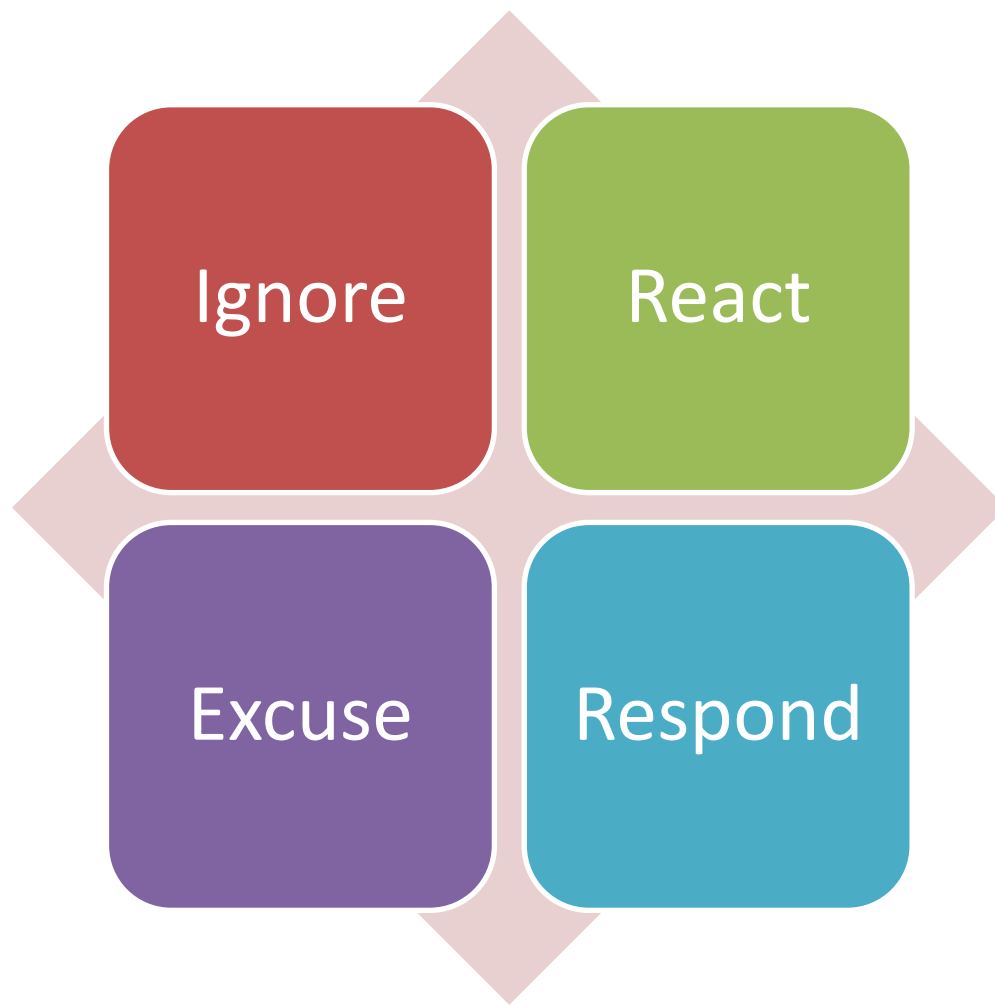
Not necessarily...

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

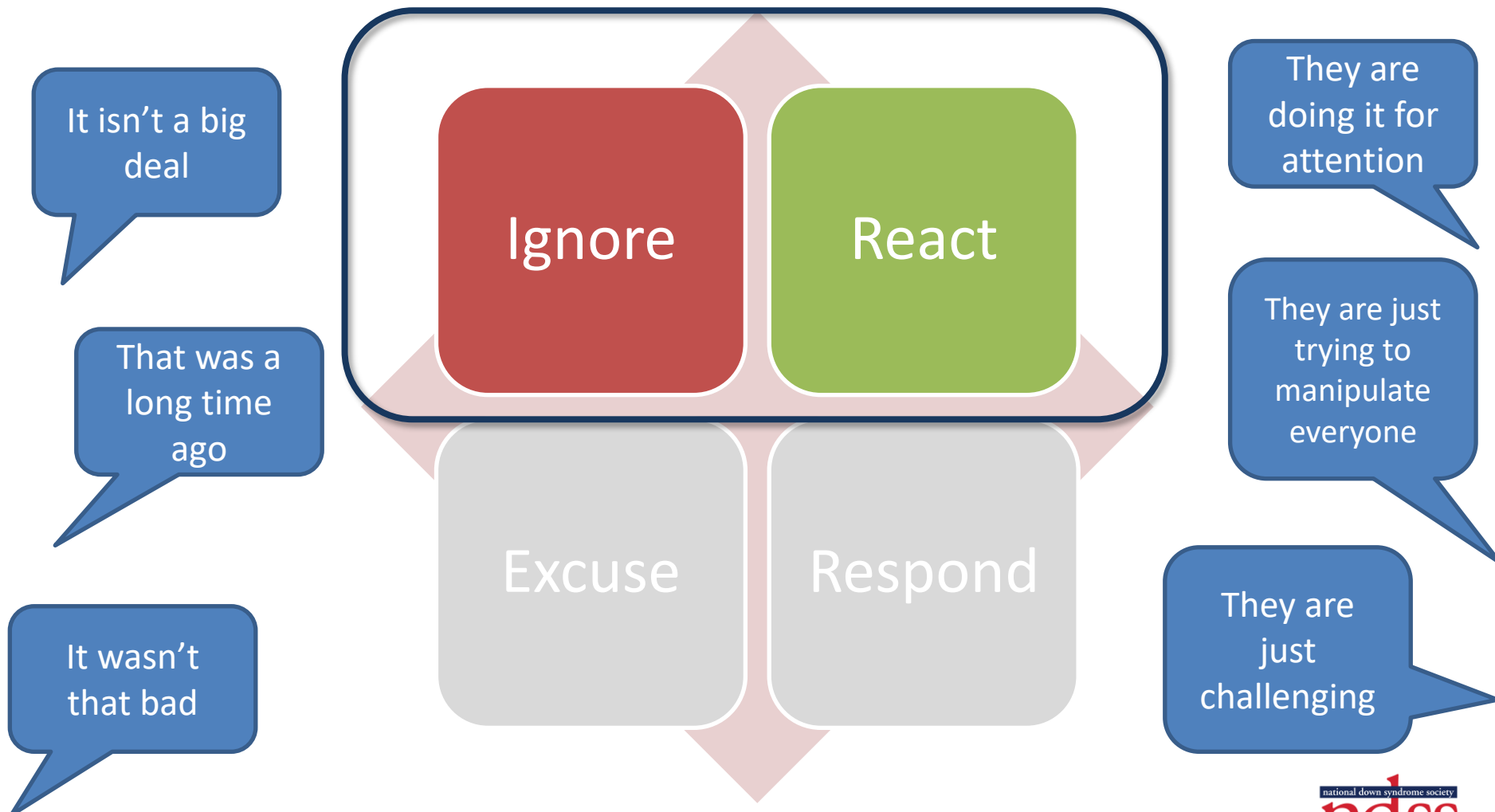


Supporting Adults with Down Syndrome Who Have Experiences Trauma or Chronic Stress

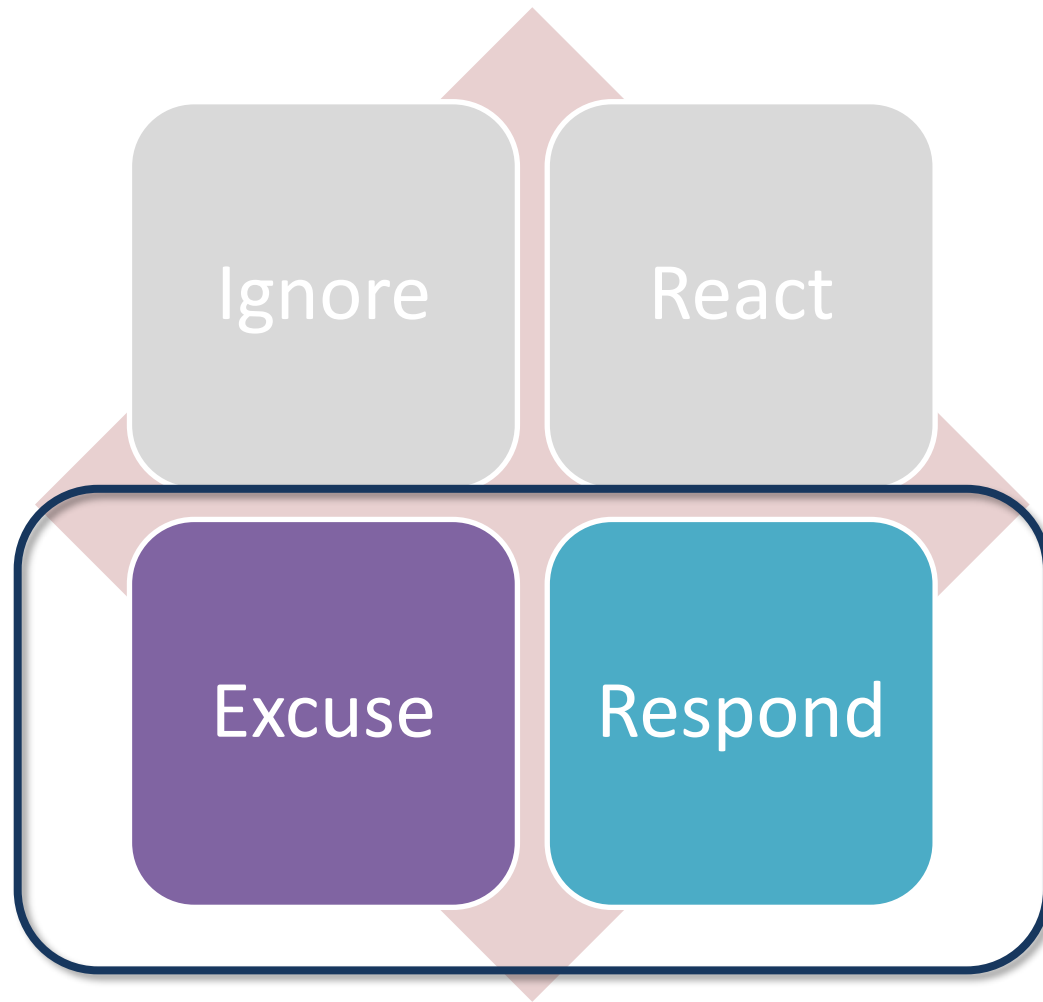
Common Reactions to Symptoms of Traumatic Stress



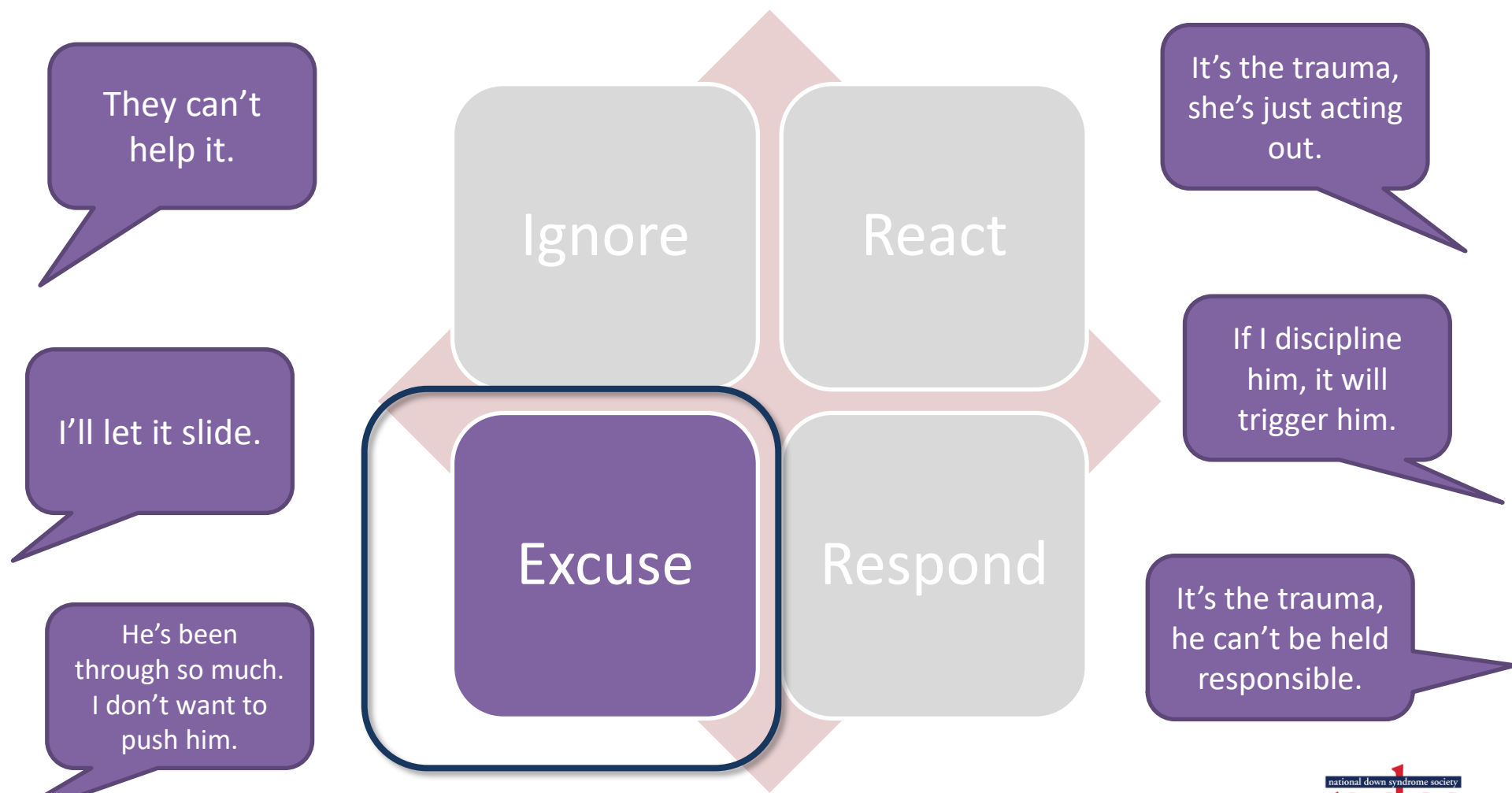
When People Don't Understand the Impacts of Stress and Trauma



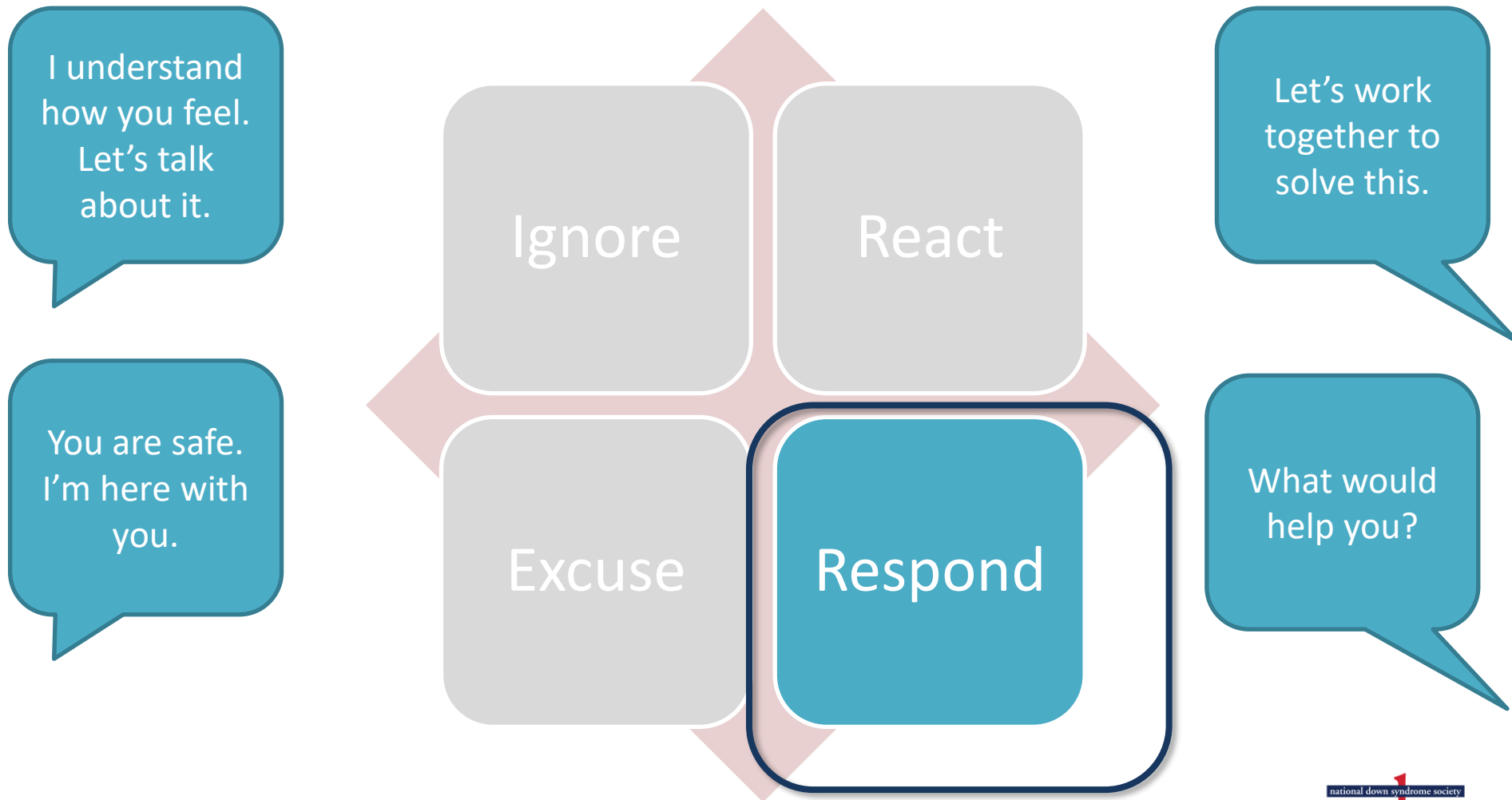
When People Understand Trauma



When People Understand Trauma

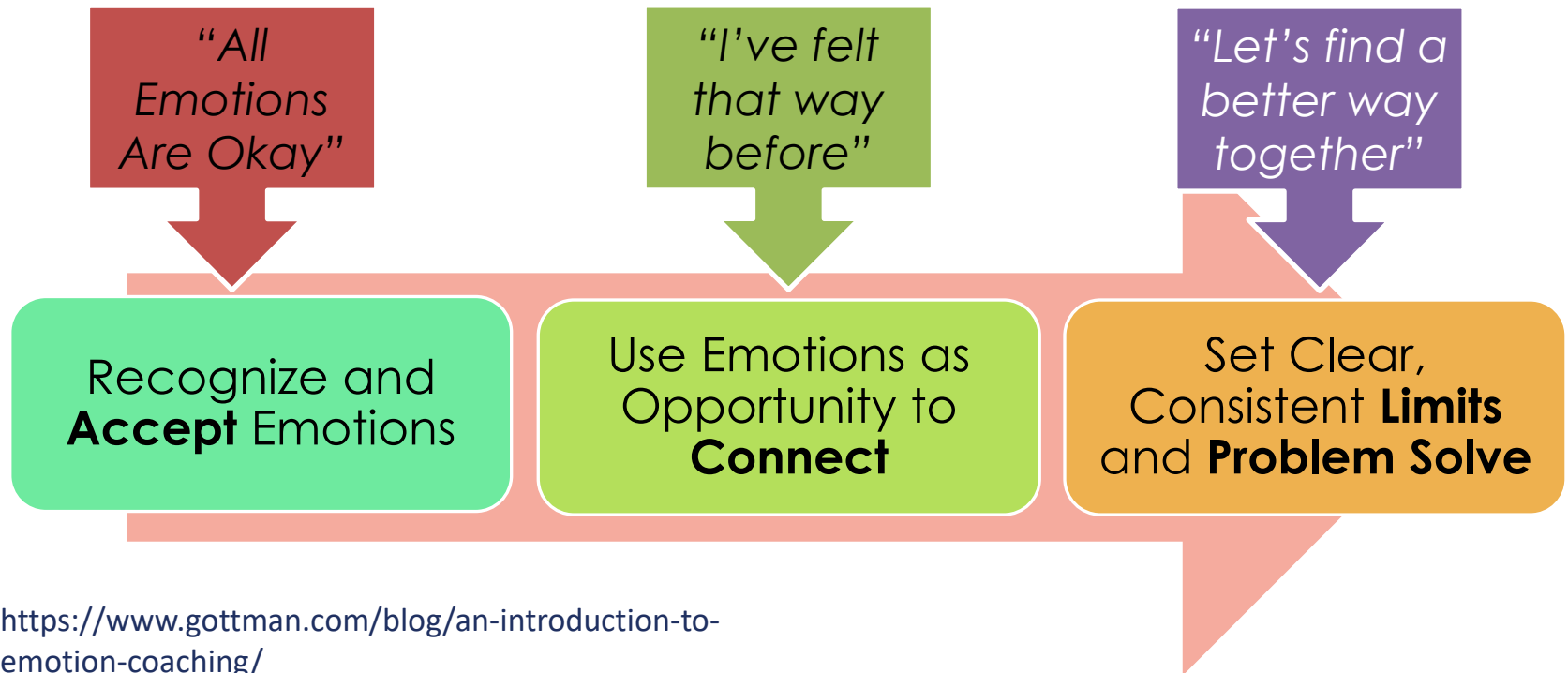


Trauma-Responsive is Where We Want to Be



Emotion Coaching

Trauma-informed and sets limits



How to Be 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.

How to Be Trauma-Responsive:

Co-Regulation

Co-regulation is the process of helping someone return to a calm state by being a calm, supportive presence.

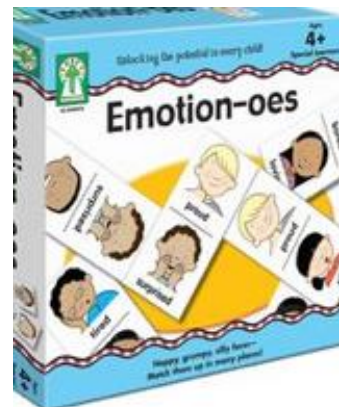
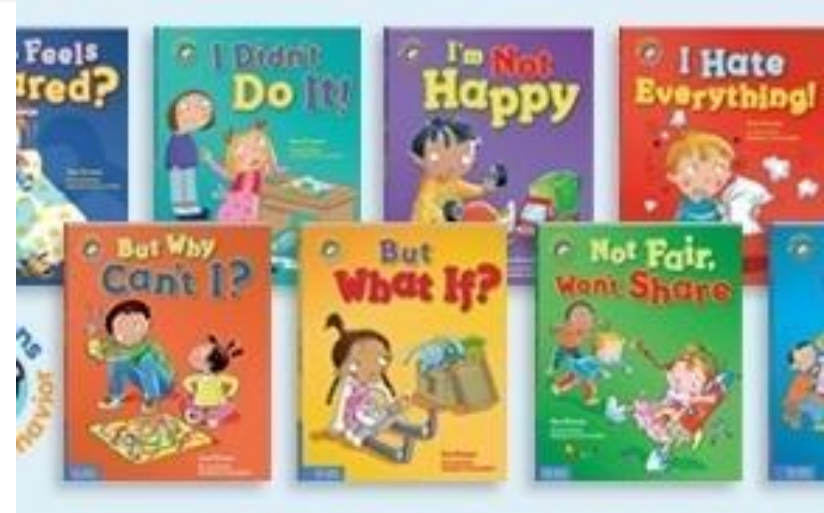
- **Model calmness:** Your calm presence is contagious. Lower your voice, slow your breathing, and use relaxed body language.
- **Create a safe space:** Reduce sensory input. Dim the lights, lower the noise, and move to a less crowded area.
- **Use sensory tools:** Offer a weighted blanket, a stress 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."

Proactively Building Coping Skills

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

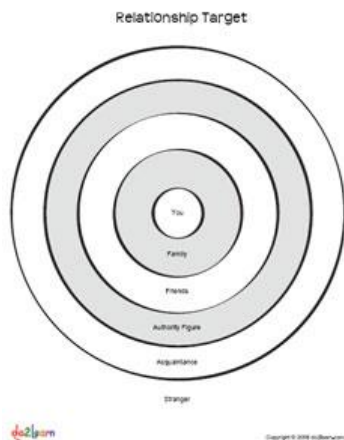
Building an Emotion Vocabulary

- Emotions coloring pages.
- 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.



Emotional Check-In

Name: Louise Lilly Date: September 26

Today, I am feeling:

Emotional Check-Out

Name: Louise Lilly Date: September 26

Now, I am feeling:

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Behavior Rule	point
Reminders	
Be a good friend.	
Quiet voice	
Safe hands and body	
Take turns	
Listen	
Use kind words.	

Social Stories and Role-Play



<https://autismlittlelearners.com/behavior-related-stories/>



40 Social Stories Self Control Regulation Behavior Lessons SEL Emotions Feelings

Created by
My Nerdy Teacher

40 Social Stories MEGA BUNDLE Looking for stories that explain the "why" behind good behavior and the "how" of making better choices. These mini-stories are here to help! It addresses common behavioral issues, making it a perfect tool for teaching.

Not Grade Specific Classroom Management, Life Skills, Social Emotional Learning

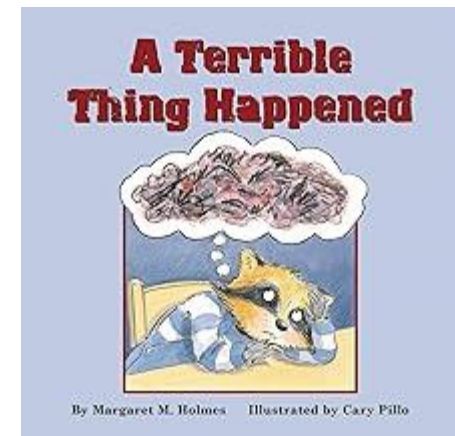
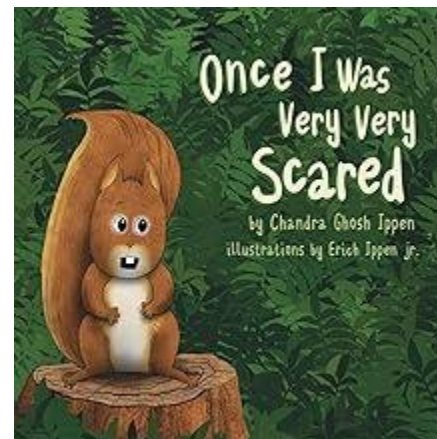
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- **Key Elements of an Effective Social Story**
- Explain the situation factually (e.g., "When I go to the cafeteria, it's noisy").
- Include others' feelings or thoughts (e.g., "My teacher is happy when I sit quietly").
- Offer clear, positive actions (e.g., "I can take three deep breaths if I feel upset").
- Use words and visuals matched to the student's comprehension level.
- Focus on **what to do**, not what to avoid, to encourage success (e.g., "I can ask for a break" vs. "Don't run away").

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



Helping Make Meaning

Goal: To help turn scattered, frightening memories into a coherent story with a beginning, middle, and end. This reduces the memory's emotional power and helps the person regain a sense of control.

- **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.
- **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."
- **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."

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.
- Behaviors are **disrupting** daily life, work, or relationships.
- Behaviors are posing a **safety risk** to themselves or others.
- You feel **overwhelmed** and are unsure how to provide support.

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

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 or 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 blocker to set specific windows of time (not before bed) if you have a hard time limiting yourself.

Practical Self-Care Strategies

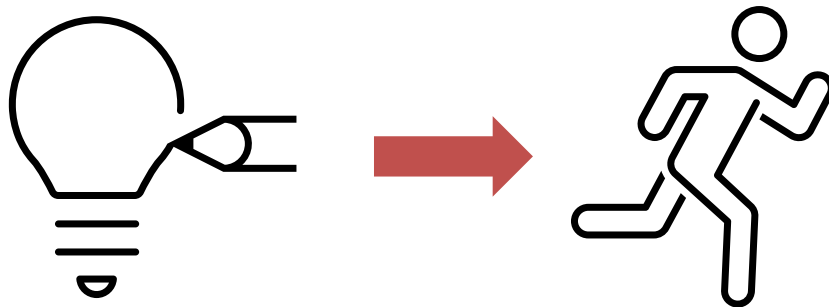
Building Your Support System

- **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.
- **Be trauma-responsive, not permissive.** 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?



Thank you!

Head to www.ndss.org for more
information and additional resources.