Trauma & Developmental Disabilities:
Identifying victims, advocating for families, and supporting staff.

Amy Bernardoni, Ph.D.

University of Rochester Medical Center

Developmental and Behavioral Pediatrics

October 22nd, 2024

Overview

1. Trauma, risk factors, and its impact on children with disabilities.
2. Importance of understanding and addressing trauma in practice
3. Trauma Screeners and Tools
4. Adapting for trauma-informed care
5. Creating an environment that is trauma-informed.

ACEs = Adverse Childhood Experiences

Nadine Burke Harris, Center for Youth Wellness

The Impact of ACEs

Across 50 States, **50%** of children's ACEs are acquired by the age of 3.[20]

If left untreated, children with a high ACE score face a **20-year decrease** in life expectancy.[21]

Physical & Behavioral Health
Children who experience four or more ACEs are **7.4x** as likely to suffer from alcoholism and **12.2x** as likely to attempt suicide.[22]

Education
Children who experience two or more ACEs are nearly **3x** more likely to repeat a grade.[23]

Criminal Justice
Juvenile offenders are **4x** more likely to have experienced four or more ACEs than those in the CDC-Kaiser ACEs study.[24]

Risk Factors for children and families with disabilities.

Child Risk Factors

- Social communication and language impairment
- Increased reliance on adults
- Risk for exploitation/coercion

Parental Risk Factors

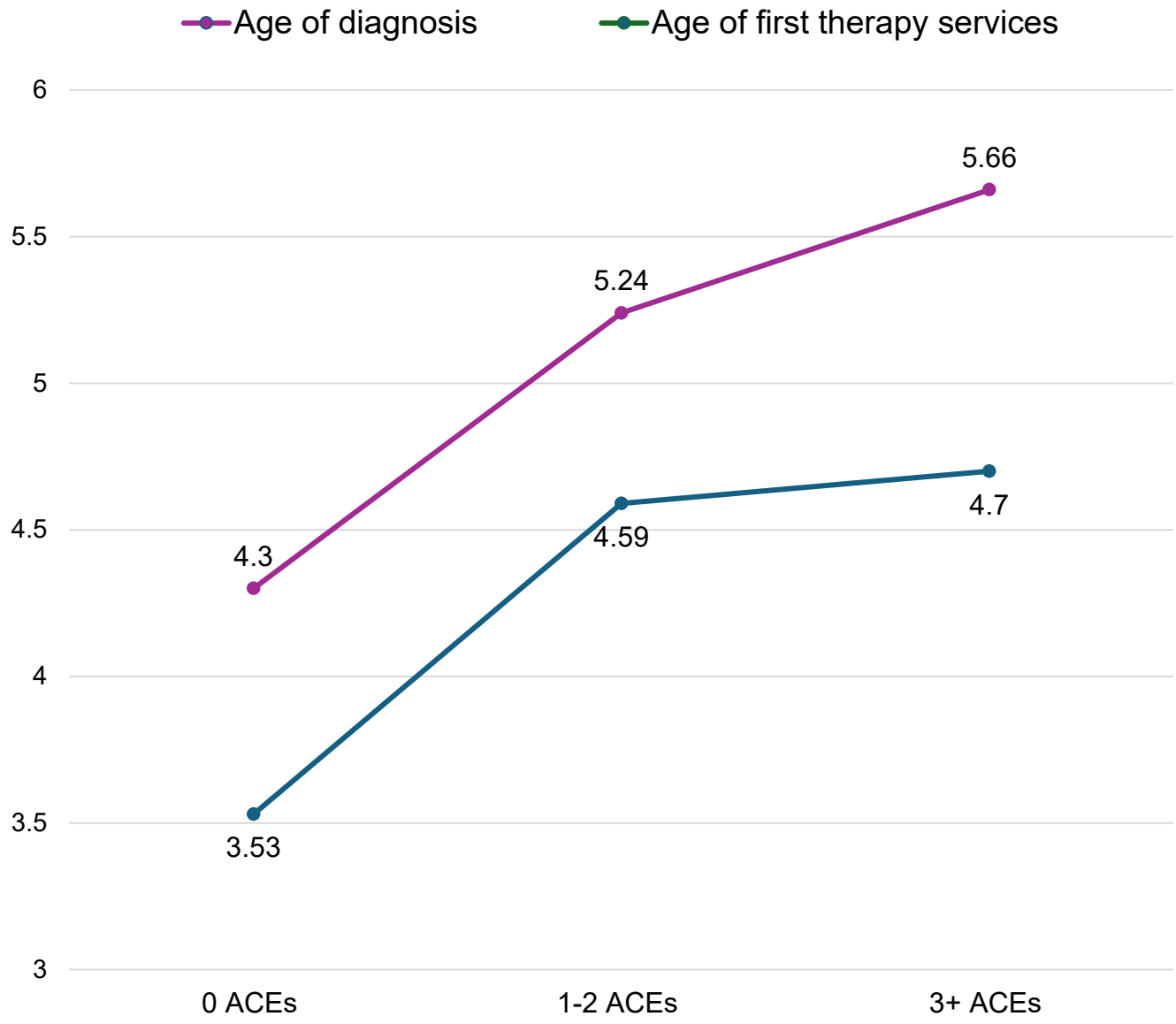
- Parental stress
- Psychological distress and mental illness
- Lack of social support
- Financial strain

Diagnostic Overshadowing

When providers falsely attribute symptoms to an existing diagnosis or condition instead of considering a co-occurring diagnosis.

Impact on services

- Delayed **age of diagnosis** and **entrance into services** (Berg, 2018)
- Higher cumulative ACEs are linked to moderate or severe **ASD symptoms** (Berg, 2016)
- Relationship between **co-occurring mental health conditions** and ACEs (Kerns, 2017)
- Significantly lower predicted levels of **resiliency** compared to peers (Rigles 2017)



Trauma Spectrum

Mild Trauma or with support	Severe trauma With support	Early interpersonal trauma No support
Functional difficulties	Functional difficulties	Functional difficulties
Sleep, eating, toileting, and behavior changes	Sleep, eating, toileting, and behavior changes	Sleeping, eating, toileting, and behavior changes
	Posttraumatic Stress Symptoms: Arousal, Avoidance, Re-experiencing	Posttraumatic Stress Symptoms: Arousal, Avoidance, Re-experiencing
		Affect dysregulation: attention issues, dissociation, violent, or self-destructive behavior
		Negative Self-Concept: worthlessness, shame, guilt, defeat
		Interpersonal disturbances: Difficulty with relationships

2019 Study

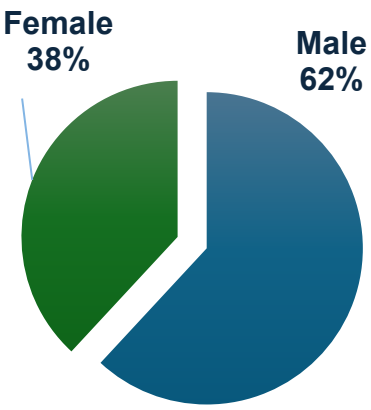
215 families
Parents of children ages 5-12

ASD, No ACEs – 45
ASD, ACEs – 86
Neurotypical, ACEs – 84

CYW ACEs Screener
TSCYC
SRS-2

DEMOGRAPHICS

Gender

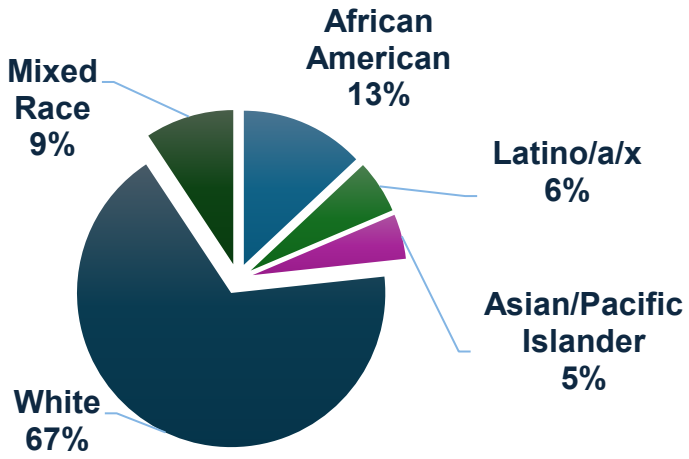


% Male
ASD, ACEs 64.0%

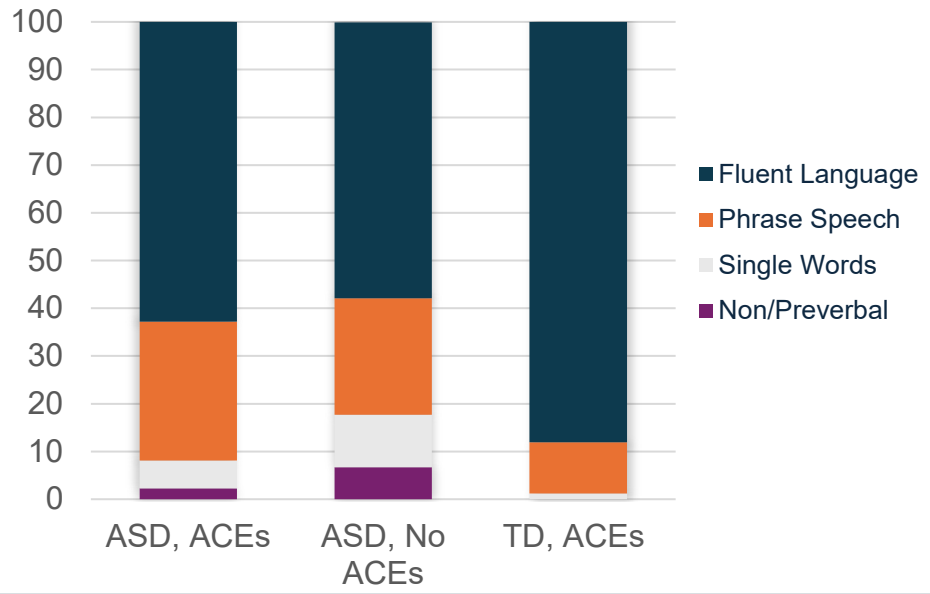
TD, ACEs 59.5%

ASD, No ACEs 62.2%

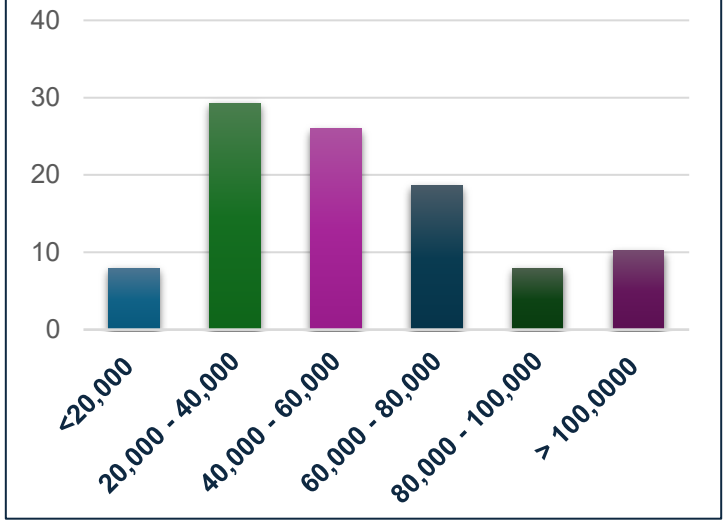
Child Race/Ethnicity



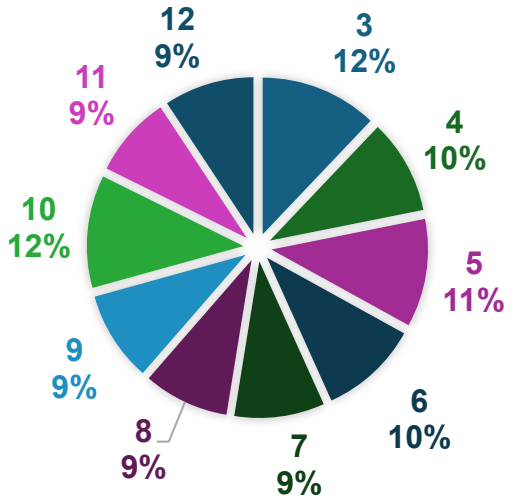
Language Level



Family Income



Child Age (M=7.32 years, SD=2.91)



Psychiatric Comorbidities

Diagnosis	ASD, No ACEs		ASD, ACEs		TD, ACEs		
	M=1.44		M=2.68		M=1.11		*p*<.001
	n	%	n	%	n	%	
ADHD	4	8.9	33	38.4	32	38.1	*p*=.001
Anxiety Disorder	2	4.4	18	20.9	19	22.6	*p*=.03
Autism Spectrum Disorder (ASD)	45	100	86	100	0	0	*p*<.001
Conduct Disorder	0	0	4	4.7	3	3.6	*p*=.36
Depressive Disorder	0	0	14	16.3	8	9.5	*p*=.01
Eating Disorder	1	2.2	5	5.8	2	2.4	*p*=.42
Intellectual Disability	2	4.4	5	5.8	2	2.4	*p*=.54
Learning Disorder	4	8.9	12	14.0	8	9.5	*p*=.57
Mood Disorder/Bipolar Disorder	0	0	4	4.7	4	4.8	*p*=.34
Obsessive Compulsive Disorder (OCD)	2	4.4	6	7.0	7	8.3	*p*=.71
Oppositional Defiance Disorder (ODD)	2	4.4	4	4.7	3	3.6	*p*=.94
Panic Disorder	1	2.2	2	2.3	4	4.8	*p*=.61
Posttraumatic Stress Disorder	2	4.4	2	2.3	1	1.2	*p*=.51

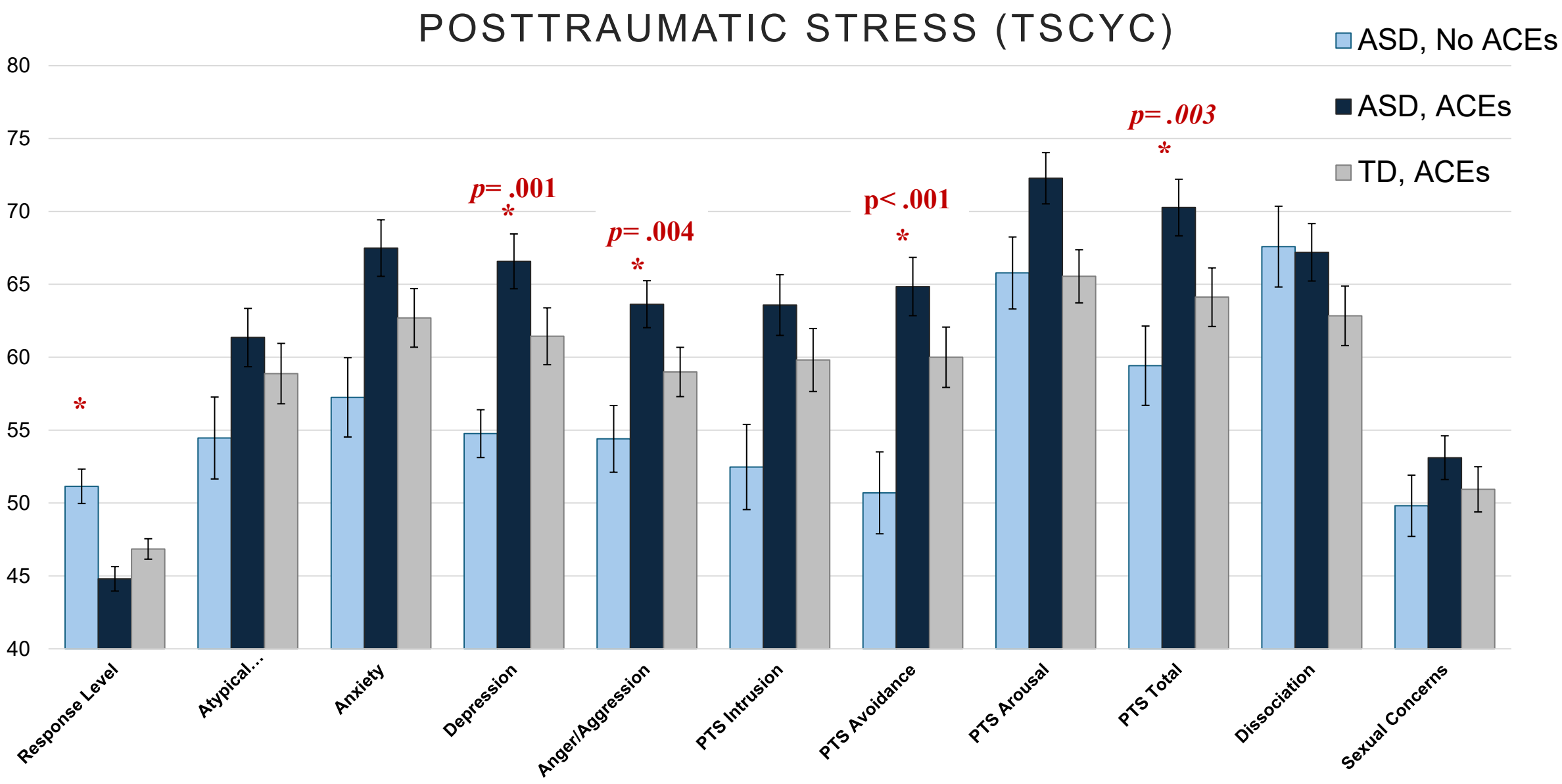
Psychiatric Comorbidities

Diagnosis	ASD, No ACEs		ASD, ACEs		TD, ACEs		
	M=1.44		M=2.68		M=1.11		*p*<.001
	n	%	n	%	n	%	
ADHD	**4**	**8.9**	**33**	**38.4**	**32**	**38.1**	***p*=.001**
Anxiety Disorder	**2**	**4.4**	**18**	**20.9**	**19**	**22.6**	***p*=.03**
Autism Spectrum Disorder (ASD)	45	100	86	100	0	0	*p*<.001
Conduct Disorder	0	0	4	4.7	3	3.6	*p*=.36
Depressive Disorder	**0**	**0**	**14**	**16.3**	**8**	**9.5**	***p*=.01**
Eating Disorder	1	2.2	5	5.8	2	2.4	*p*=.42
Intellectual Disability	2	4.4	5	5.8	2	2.4	*p*=.54
Learning Disorder	4	8.9	12	14.0	8	9.5	*p*=.57
Mood Disorder/Bipolar Disorder	0	0	4	4.7	4	4.8	*p*=.34
Obsessive Compulsive Disorder (OCD)	2	4.4	6	7.0	7	8.3	*p*=.71
Oppositional Defiance Disorder (ODD)	2	4.4	4	4.7	3	3.6	*p*=.94
Panic Disorder	1	2.2	2	2.3	4	4.8	*p*=.61
Posttraumatic Stress Disorder	2	4.4	2	2.3	1	1.2	*p*=.51

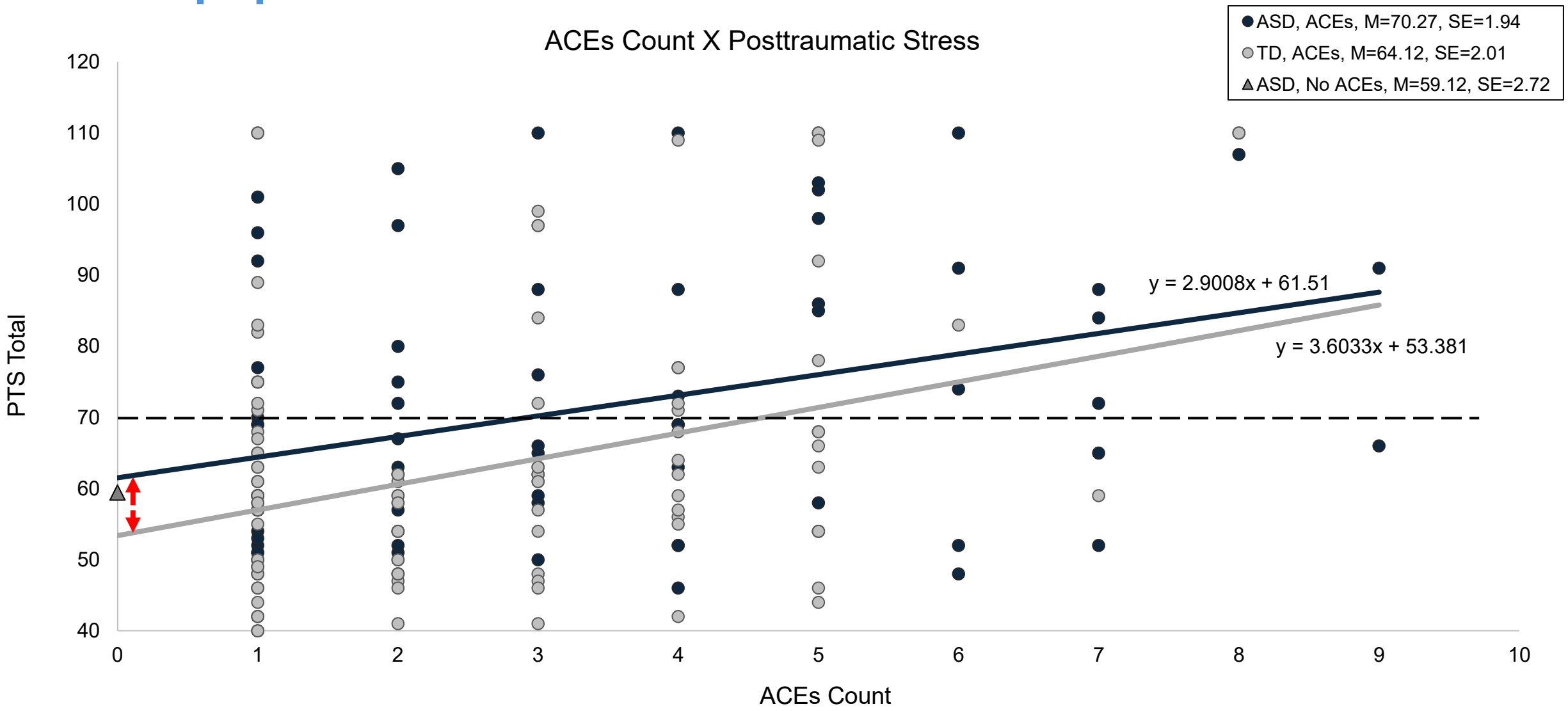
Psychiatric Comorbidities

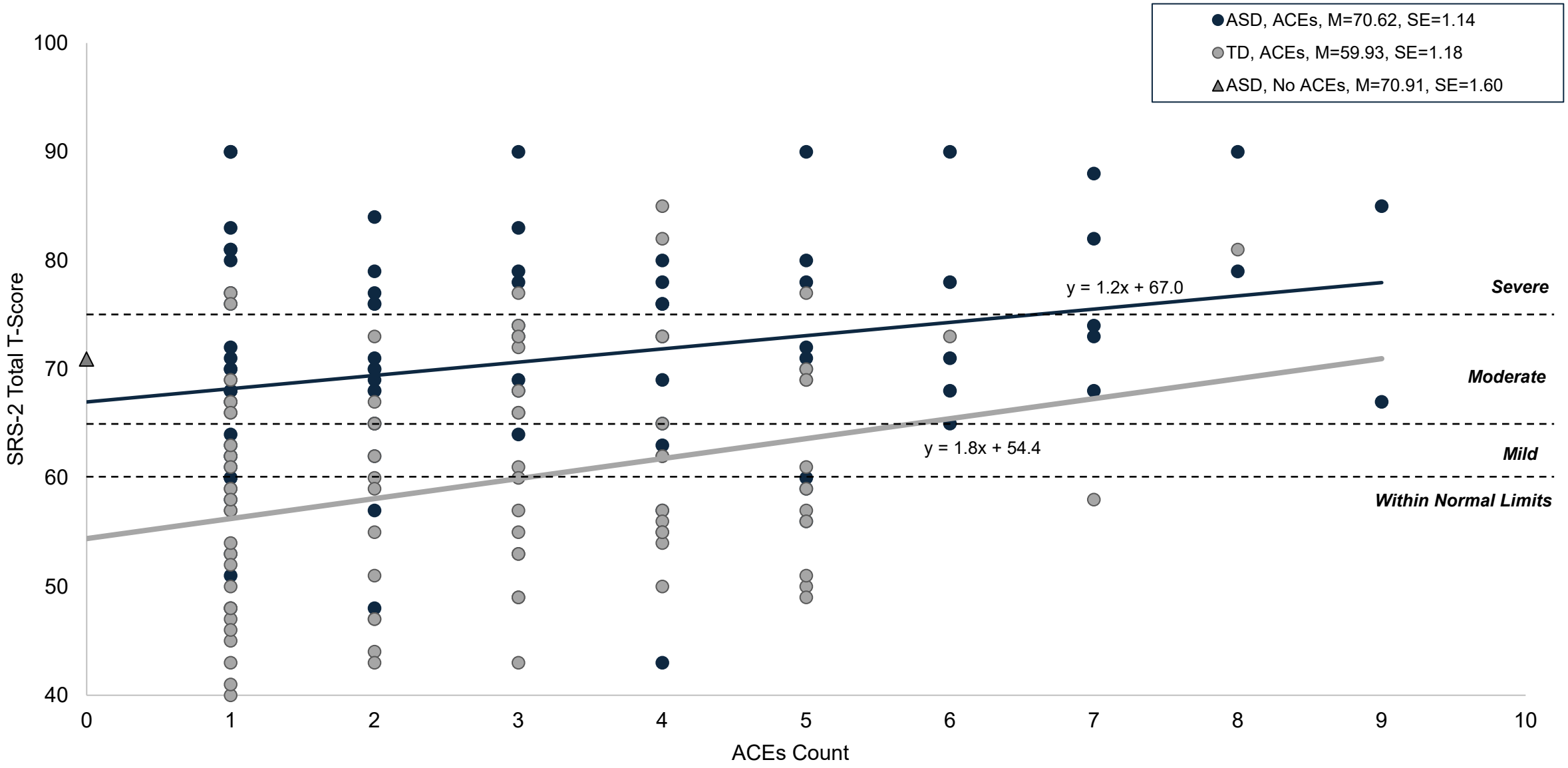
Diagnosis	ASD, No ACEs		ASD, ACEs		TD, ACEs		
	M=1.44		M=2.68		M=1.11		*p*<.001
	n	%	n	%	n	%	
ADHD	**4**	**8.9**	**33**	**38.4**	**32**	**38.1**	***p*=.001**
Anxiety Disorder	**2**	**4.4**	**18**	**20.9**	**19**	**22.6**	***p*=.03**
Autism Spectrum Disorder (ASD)	45	100	86	100	0	0	*p*<.001
Conduct Disorder	0	0	4	4.7	3	3.6	*p*=.36
Depressive Disorder	**0**	**0**	**14**	**16.3**	**8**	**9.5**	***p*=.01**
Eating Disorder	1	2.2	5	5.8	2	2.4	*p*=.42
Intellectual Disability	2	4.4	5	5.8	2	2.4	*p*=.54
Learning Disorder	4	8.9	12	14.0	8	9.5	*p*=.57
Mood Disorder/Bipolar Disorder	0	0	4	4.7	4	4.8	*p*=.34
Obsessive Compulsive Disorder (OCD)	2	4.4	6	7.0	7	8.3	*p*=.71
Oppositional Defiance Disorder (ODD)	2	4.4	4	4.7	3	3.6	*p*=.94
Panic Disorder	1	2.2	2	2.3	4	4.8	*p*=.61
Posttraumatic Stress Disorder	2	4.4	2	2.3	1	1.2	*p*=.51

ACEs led to increased posttraumatic stress for children with Autism



As ACEs increases, posttraumatic stress continues to increase in ASD populations.

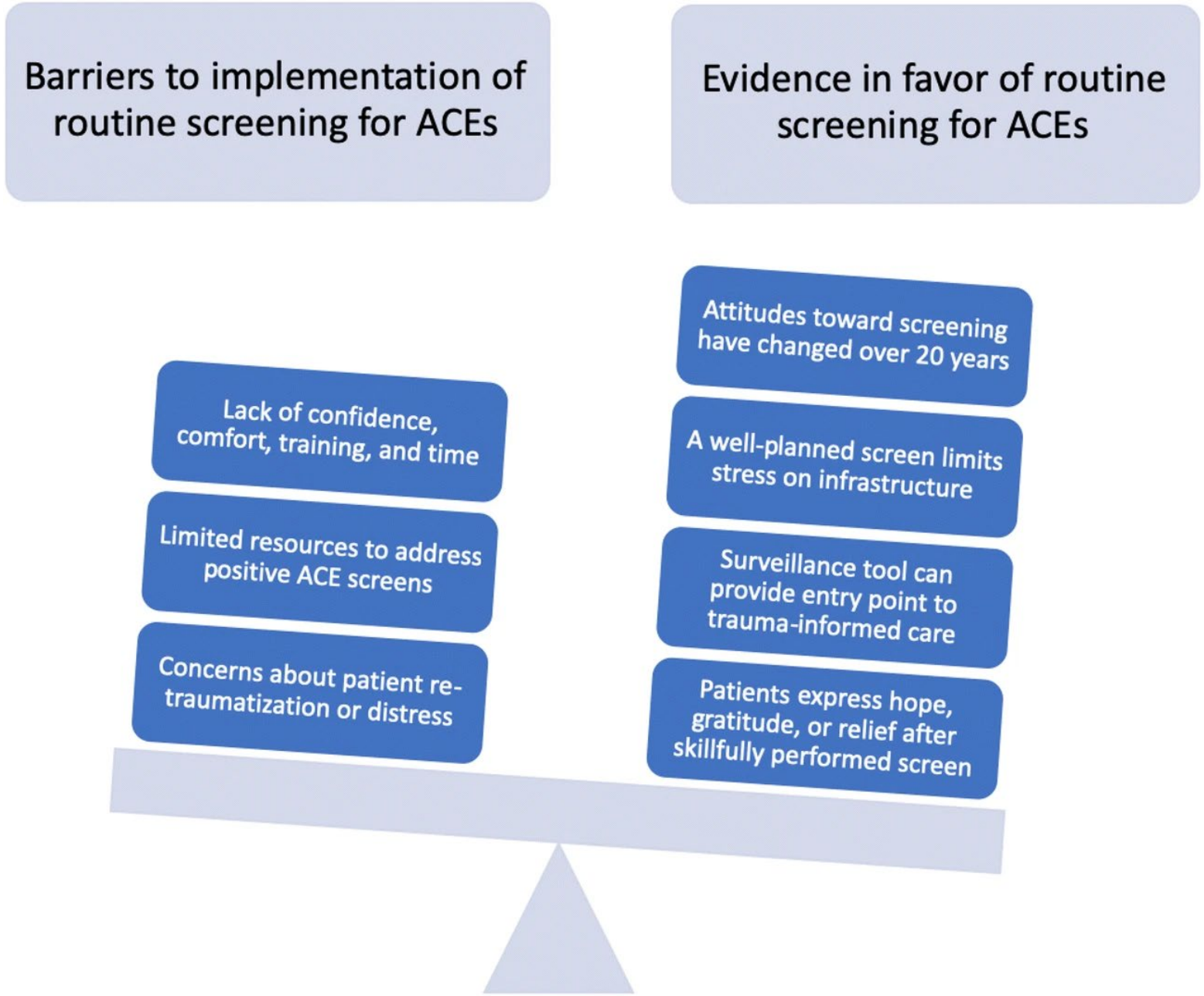




Increased ACEs leads to worsening social impairment symptoms.

What can we do as clinic administrators, directors, supervisors, providers, and direct support staff?

1. Universal Screening for ACEs and Trauma



(Mishra, Atkins, et al., 2021)

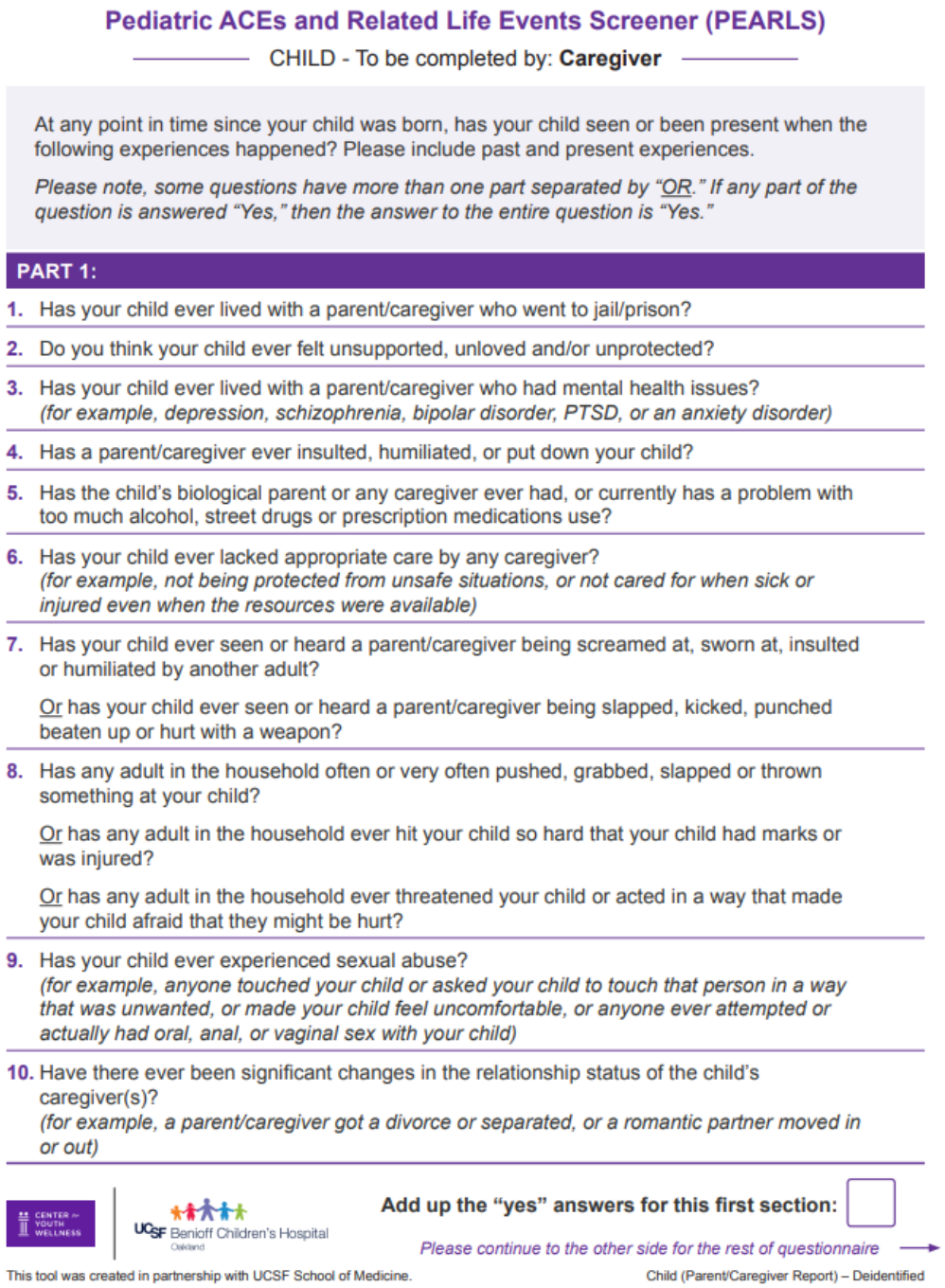
PEARLS

Pediatric ACEs and Related Life Events Screener

PEARLS Child: Ages 0-11 caregiver report
PEARLS Adolescent: Ages 12-19 caregiver report
PEARS Adolescent SR: Ages 12-19 self-report
Adult ACE Questionnaire

Identified: “Check yes where apply”
De-identified: “Add up the yes items”

Available in 17 languages.



Pediatric ACEs and Related Life Events Screener (PEARLS)

CHILD - To be completed by: **Caregiver**

At any point in time since your child was born, has your child seen or been present when the following experiences happened? Please include past and present experiences.

Please note, some questions have more than one part separated by “OR.” If any part of the question is answered “Yes,” then the answer to the entire question is “Yes.”

PART 1:

1. Has your child ever lived with a parent/caregiver who went to jail/prison?
2. Do you think your child ever felt unsupported, unloved and/or unprotected?
3. Has your child ever lived with a parent/caregiver who had mental health issues?
   (for example, depression, schizophrenia, bipolar disorder, PTSD, or an anxiety disorder)
4. Has a parent/caregiver ever insulted, humiliated, or put down your child?
5. Has the child’s biological parent or any caregiver ever had, or currently has a problem with too much alcohol, street drugs or prescription medications use?
6. Has your child ever lacked appropriate care by any caregiver?
   (for example, not being protected from unsafe situations, or not cared for when sick or injured even when the resources were available)
7. Has your child ever seen or heard a parent/caregiver being screamed at, sworn at, insulted or humiliated by another adult?

   Or has your child ever seen or heard a parent/caregiver being slapped, kicked, punched beaten up or hurt with a weapon?
8. Has any adult in the household often or very often pushed, grabbed, slapped or thrown something at your child?

   Or has any adult in the household ever hit your child so hard that your child had marks or was injured?

   Or has any adult in the household ever threatened your child or acted in a way that made your child afraid that they might be hurt?
9. Has your child ever experienced sexual abuse?
   (for example, anyone touched your child or asked your child to touch that person in a way that was unwanted, or made your child feel uncomfortable, or anyone ever attempted or actually had oral, anal, or vaginal sex with your child)
10. Have there ever been significant changes in the relationship status of the child’s caregiver(s)?
    (for example, a parent/caregiver got a divorce or separated, or a romantic partner moved in or out)

CENTER for YOUTH WELLNESS | UCSF Benioff Children’s Hospital Oakland

Add up the “yes” answers for this first section: ☐

Please continue to the other side for the rest of questionnaire →

This tool was created in partnership with UCSF School of Medicine.

Child (Parent/Caregiver Report) – Deidentified

2. Educate clinicians on what posttraumatic stress may look like in children and adolescents

- Fight (aggression, charging)
- Flight (dropping, hiding, eloping)
- Freeze (body tense)
- Irritable, detached
- Easily startled
- Visual scanning the environment (hypervigilance)
- Cowering from touch
- Staring off
- Avoiding triggers or reminders
- Regression of skills (enuresis, encopresis, loss of skills)
- New difficulties focusing or learning in school
- Imitate abuse or traumatic events they've witnessed
- Sleep disruption
- Emergence of psychosis*

Rating Scales for Posttraumatic Stress

- Child and Adolescent Trauma Screen (CATS)
  - CATS Caregiver report – Children 3-6 years old
  - CATS Caregiver report – Children 7-17 years old
  - CATS Self-report – Children 7-17 years old
  - Use clinical cut-offs to indicate need for trauma-focused treatment

- Child PTSD Symptom Scale (CPSS)
  - CPSS Self-report – children 8-18 years old

There are limitations for using these measures with children with disabilities, cognitive impairments, and language impairments.

How to respond when children endorse traumatic experience(s)

Validate their experience	• “I’m so sorry you went through that”, “Thank you for telling me about your experiences.”
Normalize	• “You’re not alone; lots of kids have had experiences like these.” • “I’ve worked with lots of kids who have been through similar things.”
Follow their lead	• Avoid asking the victim to go into detail about their experience. • Get detailed information from a caregiver, CPS worker, etc.

3. Adapt Services

Assess	Learn your patients triggers and know how to prevent them.
Acknowledge	Acknowledge which symptoms are related to their disability vs trauma. What is the root cause of the symptom or behavior?
Adapt	Adapt behavioral strategies to be trauma-informed and meet the individual needs of the client.
Recognize	Recognize that not all behaviors driven by trauma can be treated with a behavioral approach

*

Sarah is a 12-year-old female with diagnoses of Autism and Intellectual Disability (IQ=65) living with her mother and 3 younger siblings.

Sarah was previously in foster care due to her mother's struggles with substance abuse, which led to the family to be without housing and living in motels. Mom is now clean and doing well and CPS has helped them find an apartment.

Sarah has been referred to you for in-home services due to disruptive behavior and aggression at home and school. Sarah has chronically struggled with aggression at school, but previous strategies that worked before are not effective now.

Sarah has difficulties separating from mom when being dropped at school. When given directions, Sarah is sometimes compliant and able to follow them with no difficulties. Other times, she either charges at the adult or hides under a table or behind furniture. She also has accidents intermittently at school and in public settings, a new behavior that was not present 1 year ago.

What else would you want to know about Sarah ?

Upon further assessment and observation, you learn that the following situations are driving factors behind Sarah's behaviors:

- Mom dropping her off at school.
  - Mom used to leave Sarah and her siblings at motels for hours at a time and didn't know when she would come back.
- Being prompted to go to the bathroom.
  - Unknown to mom or CPS, Sarah was touched inappropriately by an adult male in the bathroom of their motel. The male was a friend of Sarah's mom.
- Getting directions from someone who is loud and yelling.
  - Sarah overheard significant community violence while living in hotels. Mom also had other adults around Sarah who yelled and were violent.

3. Adapt Services

Assess	Learn your patients triggers and know how to prevent them.
Acknowledge	Acknowledge which symptoms are related to their disability vs trauma. What is the root cause of the symptom or behavior?
Adapt	Adapt behavioral strategies to be trauma-informed and meet the individual needs of the client.
Recognize	Recognize that not all behaviors driven by trauma can be treated with a behavioral approach

Behavior chart for positive reinforcement

Following Directions

Separating from mom to attend school

Toileting accidents

Remind Sarah that the adults at school are safe and there to take care of her.

Provide education to teachers and staff to minimize triggers:

1. Males should avoid physical touch and adults should use a calm voice.

2. Provide de-escalation when Sarah is triggered and goes into fight or flight.

Identify a staff member to help transition Sarah into school.

Establish a routine of quick goodbyes.

Allow Sarah to bring a comfort item or transitional object to school.

Following Directions

Separating from mom to attend school

Toileting accidents

Identify a staff member to help transition Sarah into school.

Establish a routine of quick goodbyes.

Allow Sarah to bring a comfort item or transitional object to school.

Validate Sarah's feelings and remind her that her mom will come back.

Have a visual schedule so Sarah knows mom is coming back and when. *Predictability*

Following Directions

Separating from mom to attend school

Toileting accidents

Establish a toileting schedule so Sarah doesn't forget to go to the bathroom.

Allow Sarah to have a safe adult accompany her to the bathroom or use an individually locking bathroom at school.

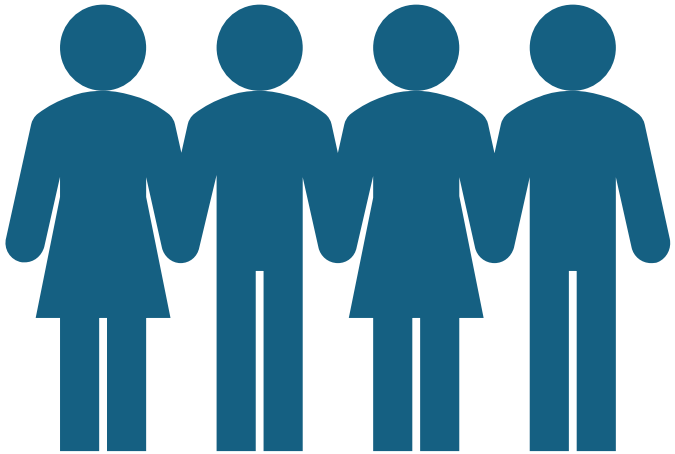
Ask Sarah when might feel like safe times or places to go to the bathroom and structure them in her schedule.

3. Adapt Services

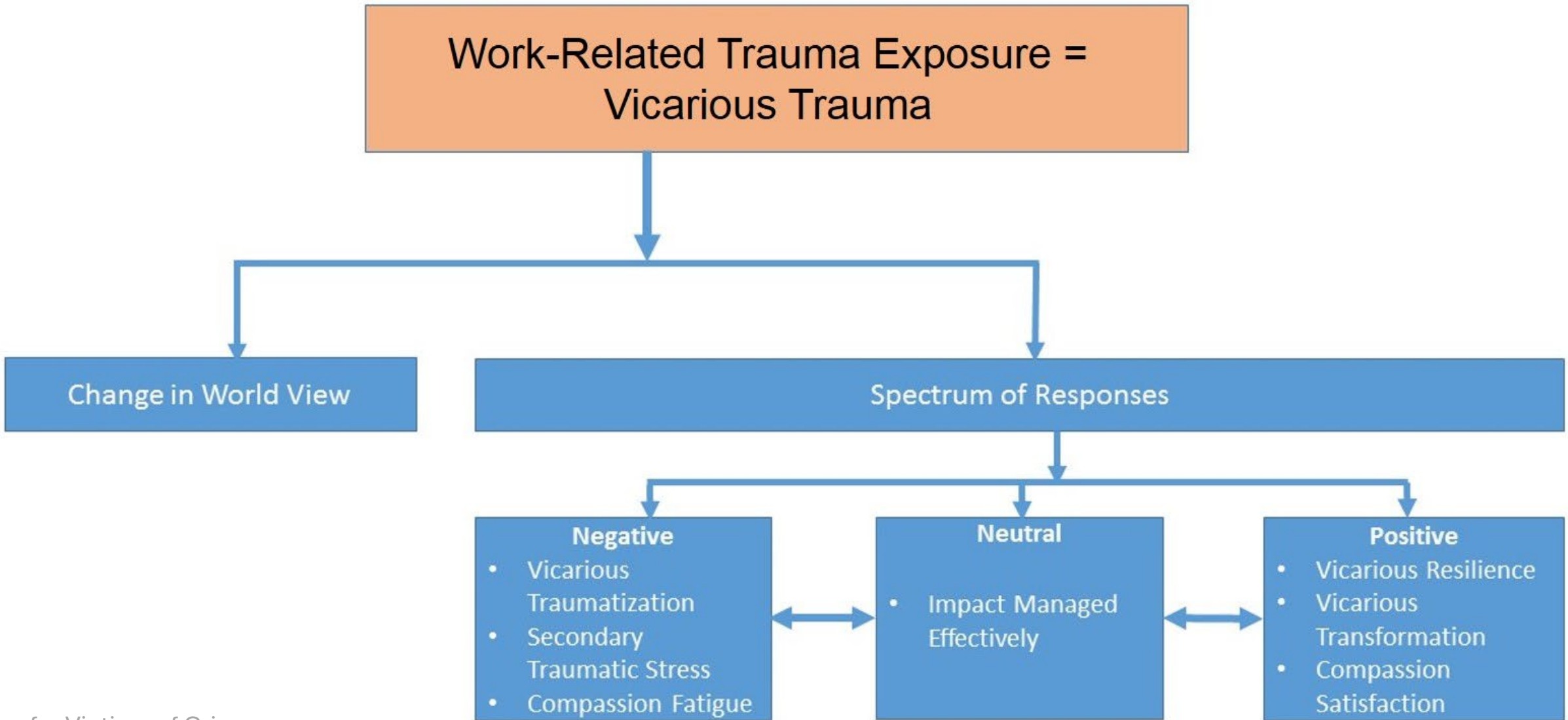
Power of the parents	Parent-focused interventions increase self-efficacy, decrease parental stress, and reduce risk of maltreatment.
Consult/ Refer out	Acknowledge when trauma is significant and requires consultation with trauma-focused providers or additional trauma-focused treatment.
Protect	Most youth are resilient. Most severe trauma presentations occur in the absence of protective relationships. You have an important role in promoting resilience in a child and family's life!
Be Flexible	Be willing to be learn, be flexible, ask for help, and do things outside of the box!

Supporting Staff to be trauma-informed

- Create a policy for universal screening
- Have a protocol for mandated reporting when necessary
- Reduce system causes of vicarious trauma, secondary traumatic stress, and burnout such as workload and exposure to challenging cases*
- Provide adequate supervision
- Provide opportunities for training



Vicarious Trauma Toolkit Model



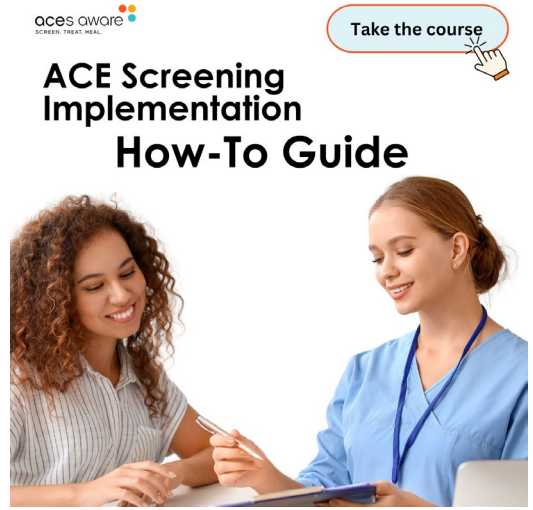
Who is at increased risk of being affected by vicarious trauma?

- **prior traumatic experiences**
- **social isolation, both on and off the job**
- **a tendency to avoid feelings, withdraw, or assign blame to others in stressful situations**
- **difficulty expressing feelings**
- **lack of preparation, orientation, training, and supervision in their jobs**
- **being newer employees and less experienced at their jobs**
- **constant and intense exposure to trauma with little or no variation in work tasks**
- **lack of an effective and supportive process for discussing traumatic content of the work**

aces aware

SCREEN. TREAT. HEAL.

- ACES Screening Implementation Guide
- Getting your practice ready for screening
- Determining who and how you will screen
- How to create safe spaces for clients and patients
- Screenings in bilingual community health programs
- Prevention of burnout for healthcare teams



Thank you! Questions?

Trauma & Developmental Disabilities:
Identifying victims, advocating for families, and supporting staff.

Amy Bernardoni, Ph.D.

University of Rochester Medical Center

Developmental and Behavioral Pediatrics

Amy_Bernardoni@urmc.Rochester.edu

October 22nd, 2024

UNIVERSITY of ROCHESTER MEDICAL CENTER