

CROSSROADS

of Adverse Childhood
Experiences (ACEs) and
Developmental Disabilities

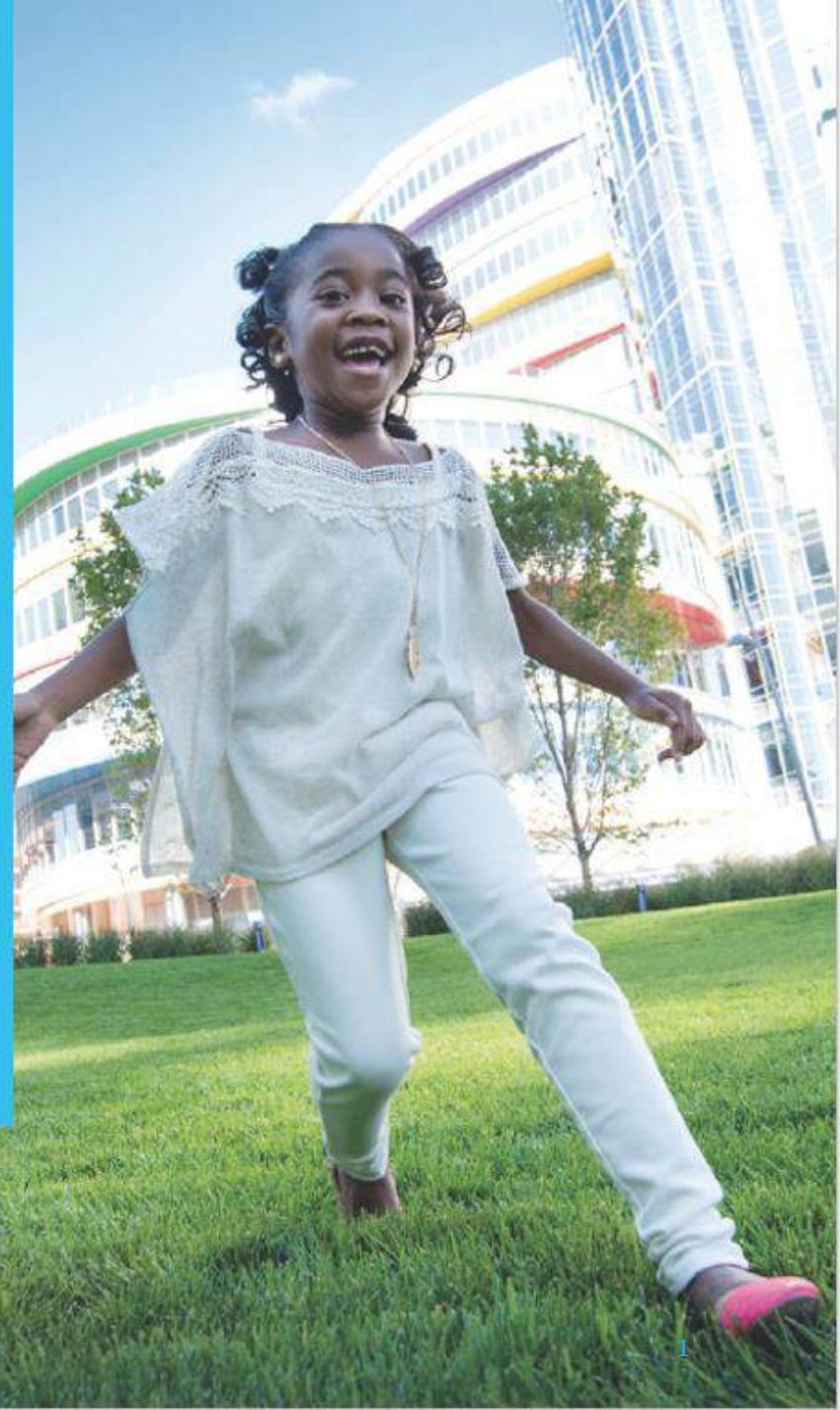
March 5, 2019

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TODAY'S MODERATOR

Patty Huang, MD

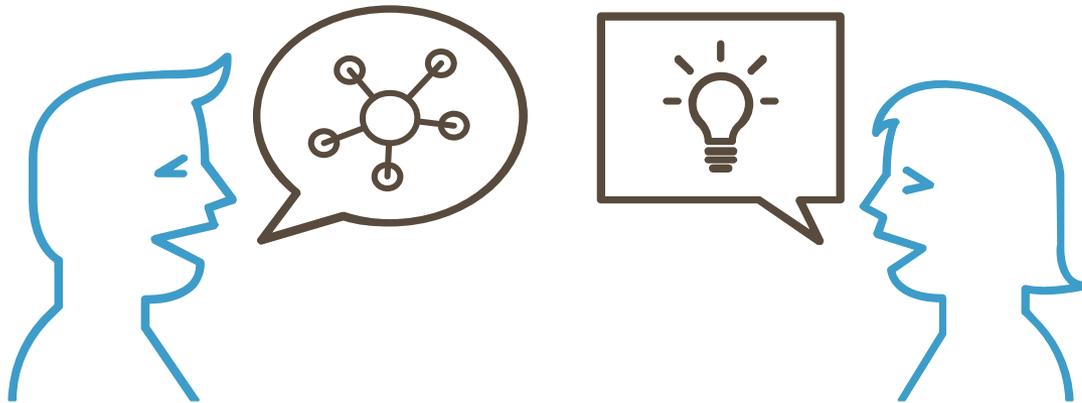
Attending Physician within the
Autism Integrated Care Program
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Philadelphia



GOAL FOR TODAY

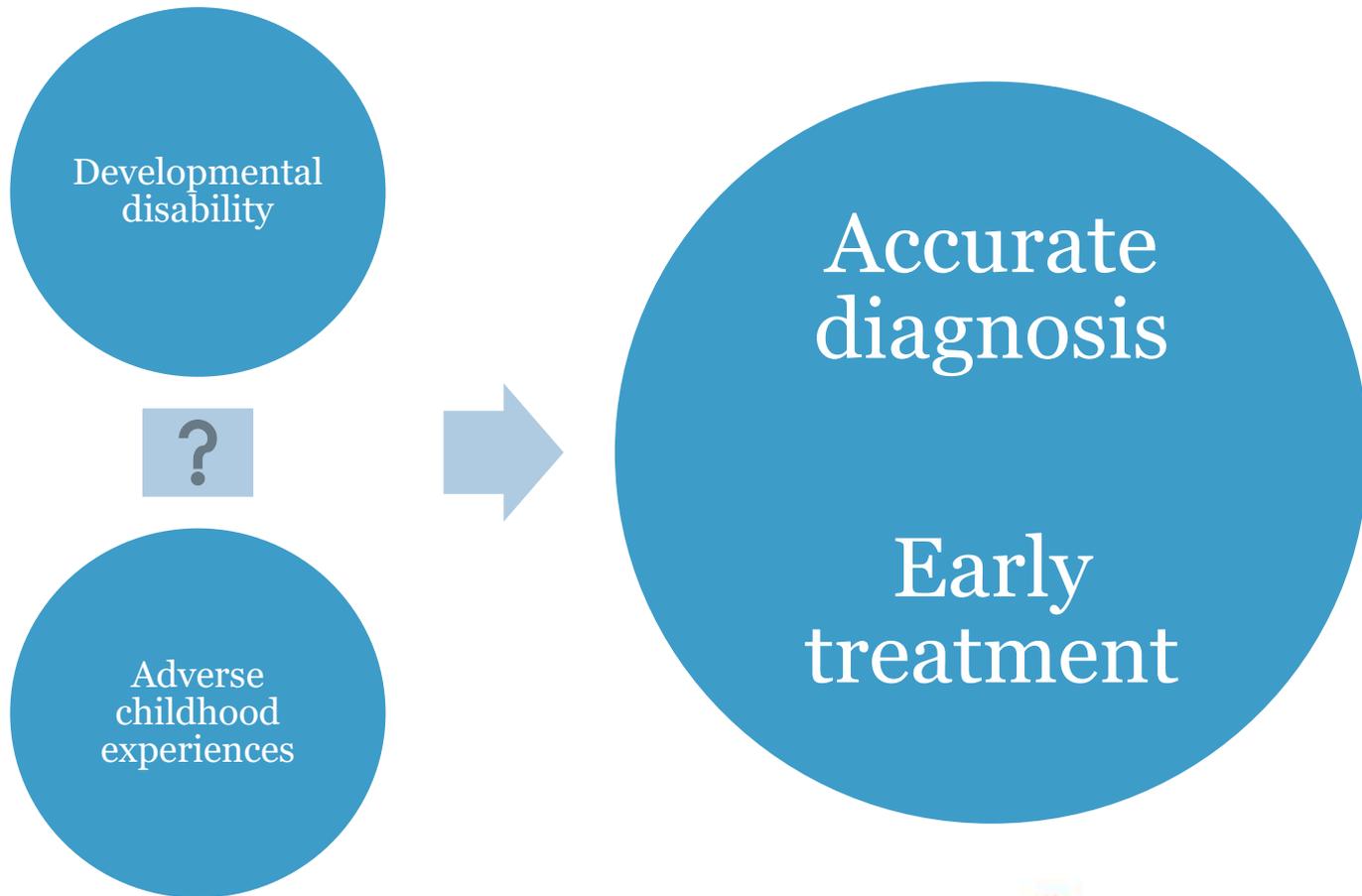
What can you do to address the overlap of ACEs and developmental disabilities in a healthcare setting?



OBJECTIVES

1. Describe adverse childhood experiences (ACEs) and their impact on behavior and development
2. Identify the overlap of signs, symptoms, and risk factors of ACEs and developmental disability
3. Explain how ACEs and developmental disabilities can be addressed in a healthcare setting

ACEs AND VIOLENCE PREVENTION



ACEs AND VIOLENCE PREVENTION

Disabilities and

↑ risk experiencing violence

3.6 times risk physical violence

3 times risk sexual violence

Cognitive impairment a significant risk

ACEs AND VIOLENCE PREVENTION



Childhood

Adulthood

TODAY'S PRESENTERS



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Developmental and Behavioral Pediatrician within the Division of Developmental and Behavioral Pediatrics and a member of the Center for Autism Research team at Children's Hospital of Philadelphia



Sandhya Iyengar, MD, FAAP
Fellow within the Division of Developmental and Behavioral Pediatrics at Children's Hospital of Philadelphia

ADVERSE CHILDHOOD EXPERIENCES



Roy Wade, Jr., MD, PhD, MPH, MSHP

Assistant Professor of Pediatrics at the University of Pennsylvania, general pediatrician at Children's Hospital of Philadelphia, and VPI Fellow

OUTCOMES ASSOCIATED WITH ADVERSE CHILDHOOD EXPERIENCES: A LIFE COURSE PERSPECTIVE

Childhood:

Fetal Death
Developmental Delay
Behavioral Problems
Cognitive Impairment

Adolescence to Young Adulthood:

Mental Health
Academic Achievement
Juvenile Justice

Adulthood:

Mental Health
Physical Health
Disability
Early Mortality

ADVERSE CHILDHOOD EXPERIENCES STUDY

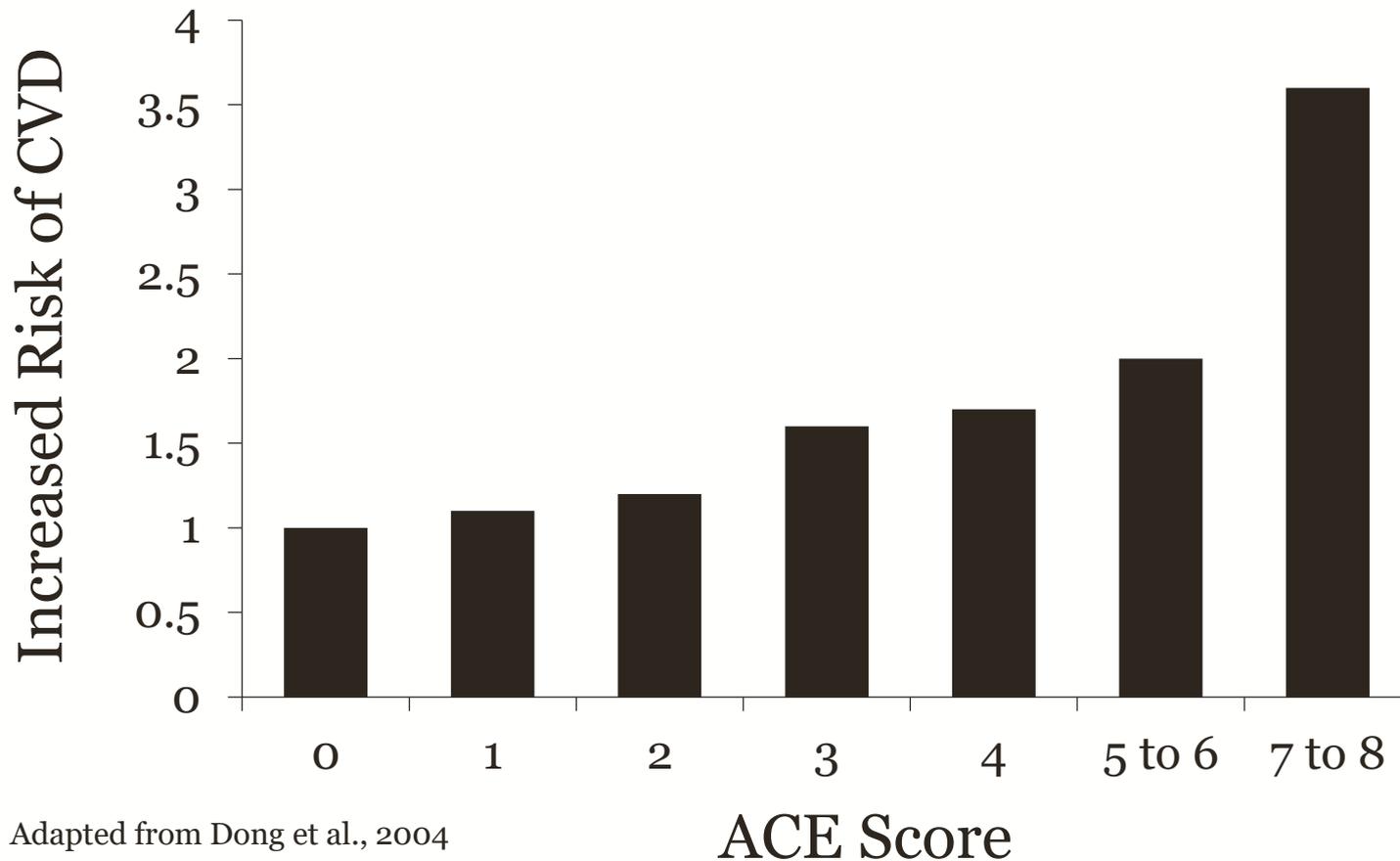
- Published by CDC/Kaiser in 1998
- Surveyed 17,000 policy holders
- Understand relationship between childhood adversity & adult health outcomes

Childhood Exposure	Subcategory
Abuse	Emotional Physical Sexual
Household stressors	Substance abuse Mental illness Intimate partner violence Criminal behavior Divorce
Neglect	Emotional Physical

Adapted from Felitti et al., 1998

GRADED RELATIONSHIP BETWEEN ACE SCORE AND CARDIOVASCULAR DISEASE

Association between ACE Score and Risk for Cardiovascular Disease



Adapted from Dong et al., 2004

GRADED RELATIONSHIP BETWEEN ACE SCORE AND HEALTH OUTCOMES

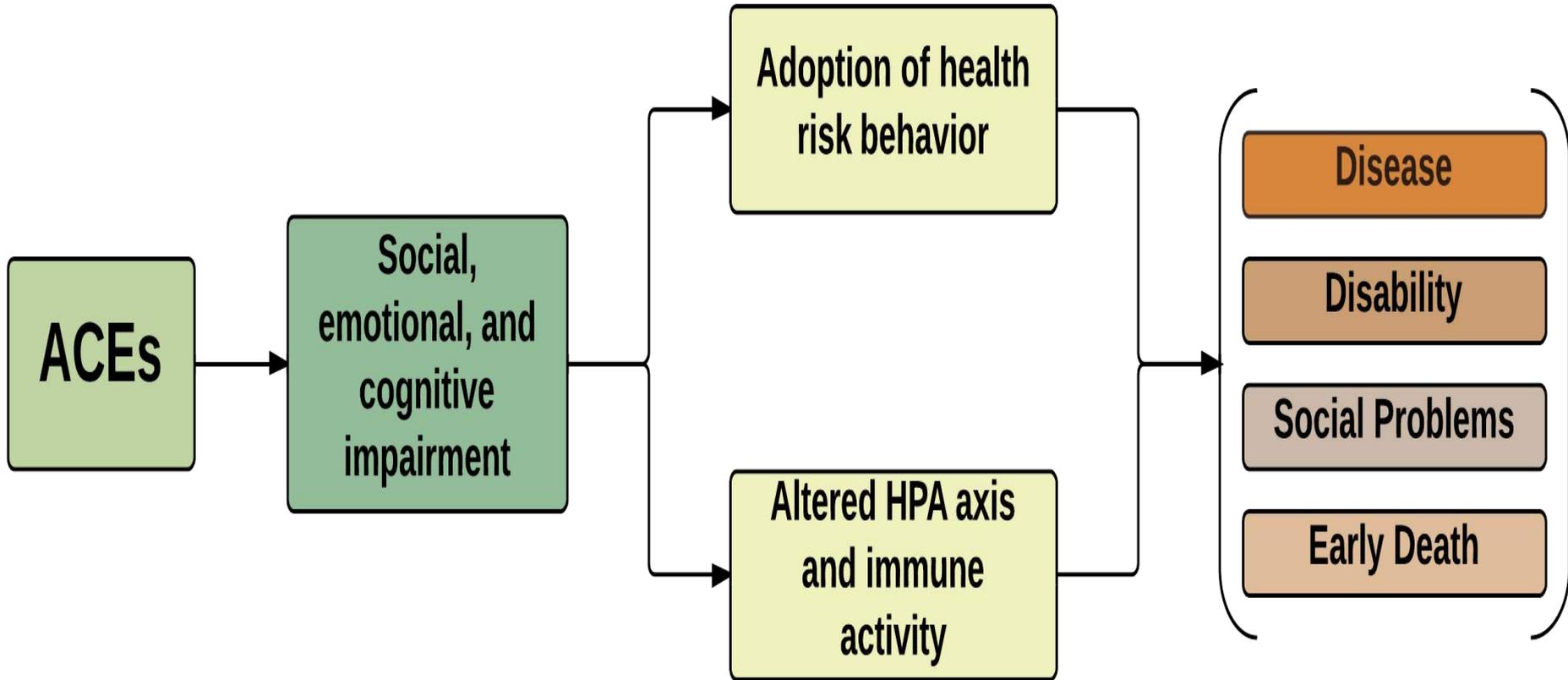
Health Risk Behaviors	Mental Health Conditions	Physical Health Conditions
Smoking	Depression	Cardiovascular Disease
Alcohol Abuse	Anxiety	Diabetes
Drug Abuse/Illicit Drug Use	PTSD	Emphysema
High Risk Sexual Behavior	Hallucinations	Cancer
	Suicide	Obesity
		Liver Disease
		Headaches
		Autoimmune Disease
		Sexually Transmitted Infections
		Self-Reported Health
		Disability
		Fetal Death
		Mortality

Health outcomes highlighted in red are among the top ten leading causes of death in the US

INDIVIDUALS WITH 4 OR MORE ACE ARE AT HIGHEST RISK FOR POOR OUTCOMES

- 4- to 12-fold increased risk for health risk behaviors
- 1.4- to 1.6-fold increased risk for adult diseases

HOW DOES CHILDHOOD STRESS GET UNDER THE SKIN?



THREE LEVELS OF STRESS

Positive Stress:

Brief increases in heart rate, mild elevations in stress hormone levels

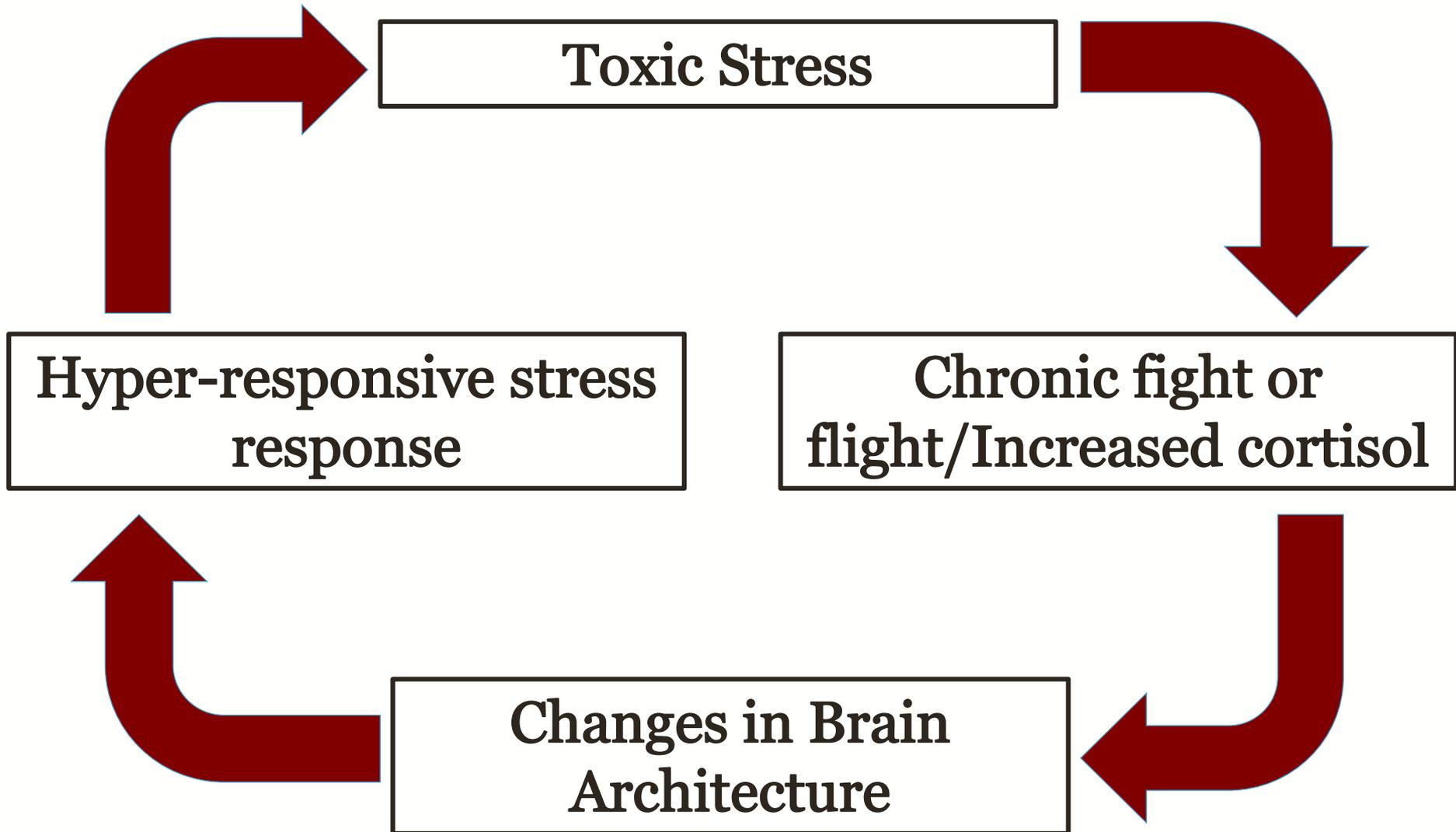
Tolerable Stress:

Serious, temporary stress responses buffered by supportive relationships

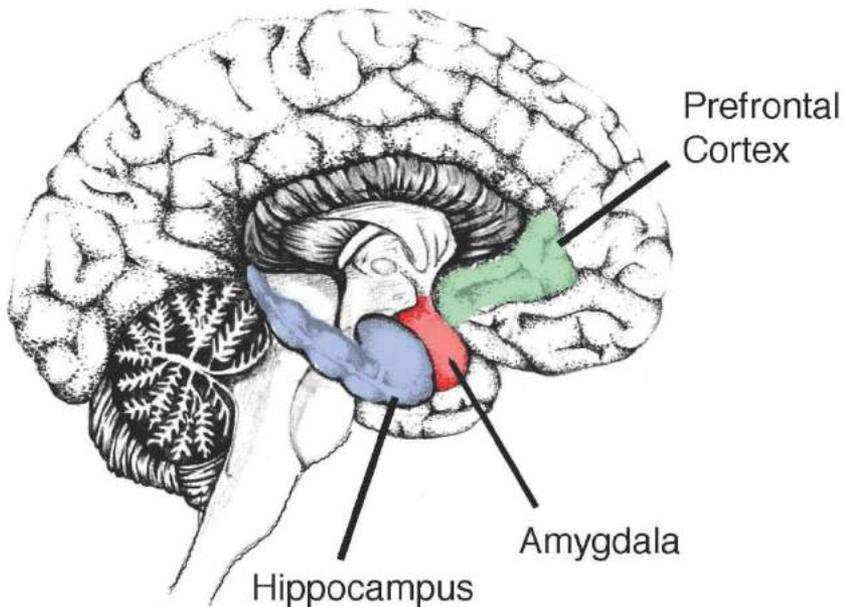
Toxic Stress:

Prolonged activation of stress response systems in the absence of protective relationships

IMPACT OF TOXIC STRESS



KEY AREAS OF BRAIN IMPACTED BY ADVERSE CHILDHOOD EXPERIENCES



- Prefrontal Cortex
 - Center of executive functioning
 - Regulates thoughts, emotions, and actions
- Hippocampus
 - Center of short term memory
 - Connects emotion to fear
- Amygdala
 - Triggers emotional responses

ADVERSE CHILDHOOD EXPERIENCES CAUSE CHANGES IN DEVELOPING BRAIN ARCHITECTURE

Area of the Brain	Volume Change
Hippocampus	↓
Amygdala	↑
Prefrontal Cortex	↓
Cerebral	↓

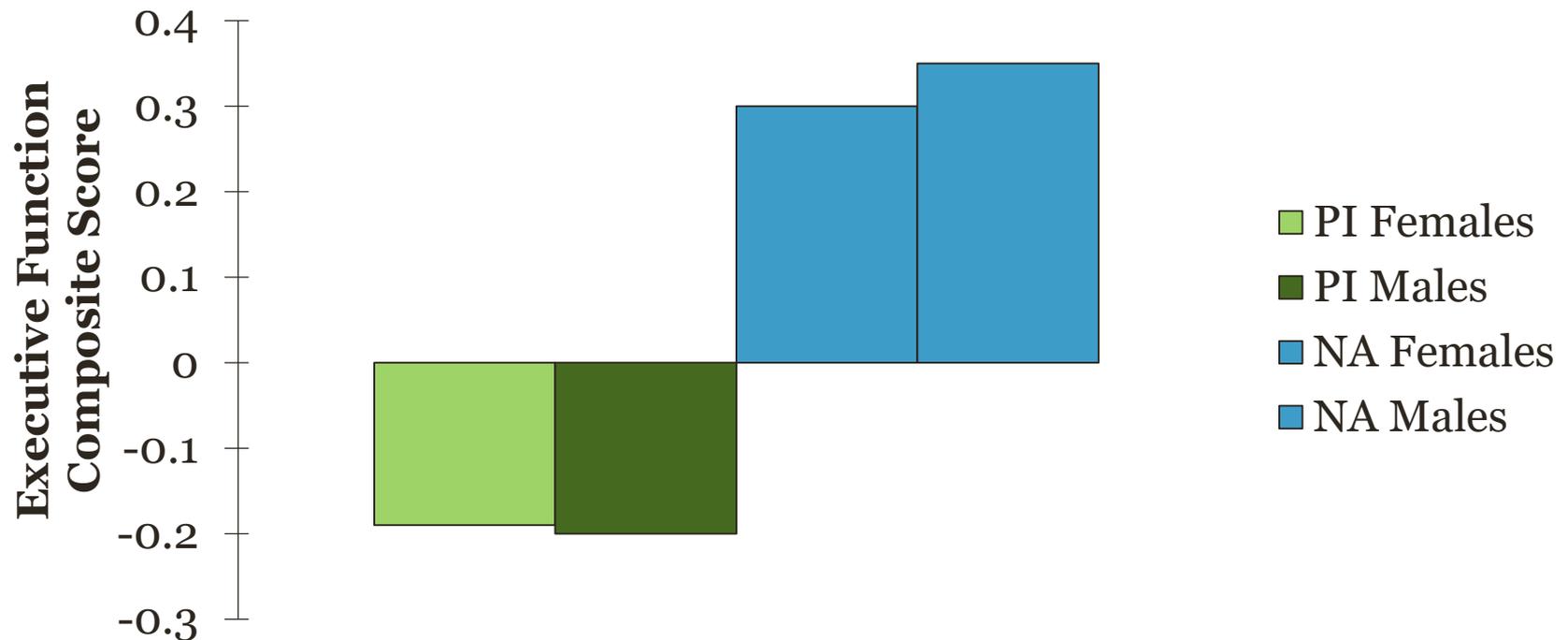
ADVERSE CHILDHOOD EXPERIENCES IMPAIR COGNITIVE SKILLS

IQ	Foster Care	Orphanage	Control
Verbal Comprehension	87.48	81.22	110.18
Perceptual Reasoning	83.81	82.30	106.79
Working Memory	87.80	83.88	108.92
Full Scale IQ	81.46	76.16	107.00

Adapted from the Bucharest Early Intervention Project

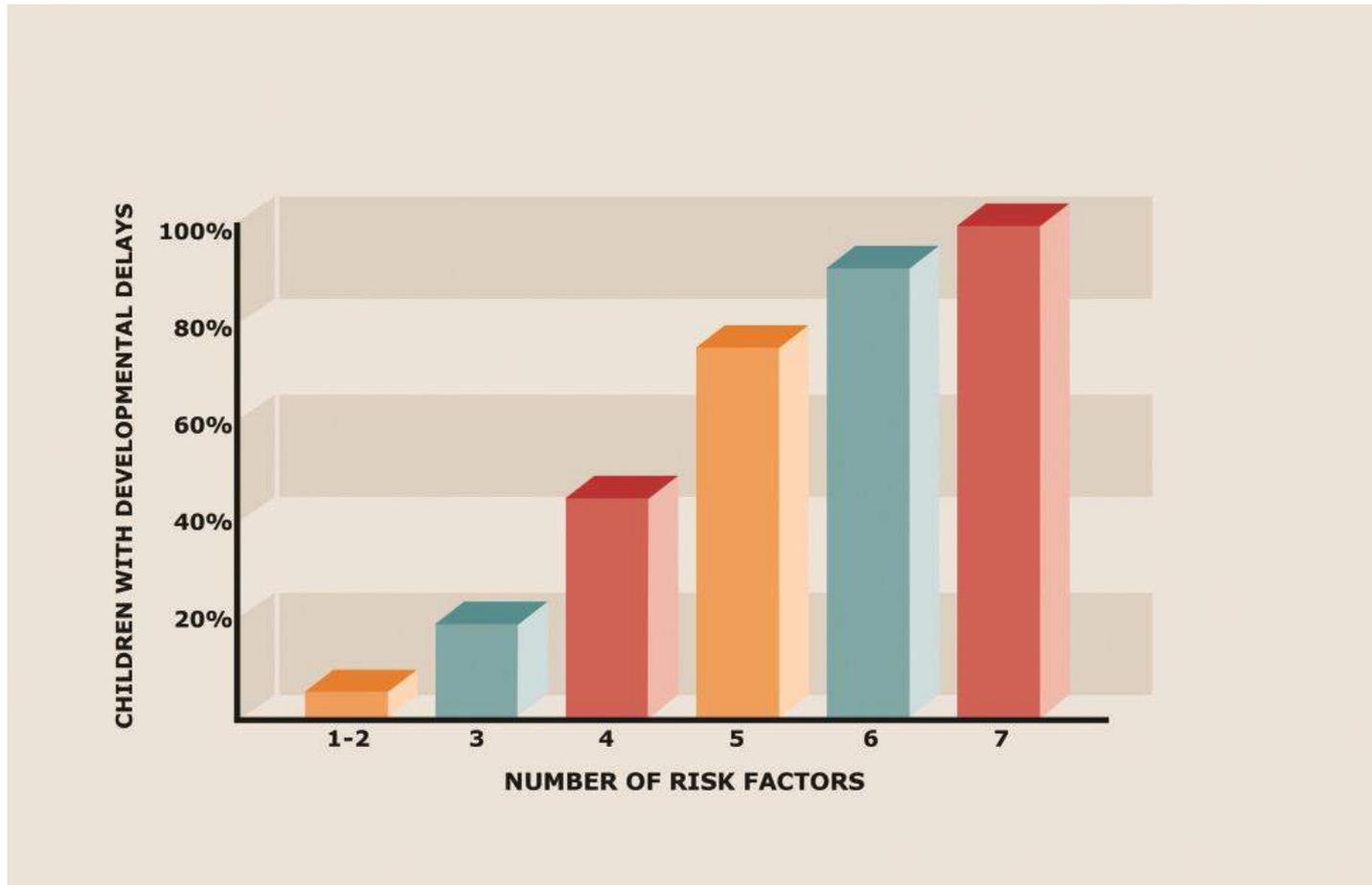
ADVERSE CHILDHOOD EXPERIENCES IMPAIR EXECUTIVE FUNCTIONING SKILLS

Executive function of post-institutionalized (PI) and non-adopted (NA) children



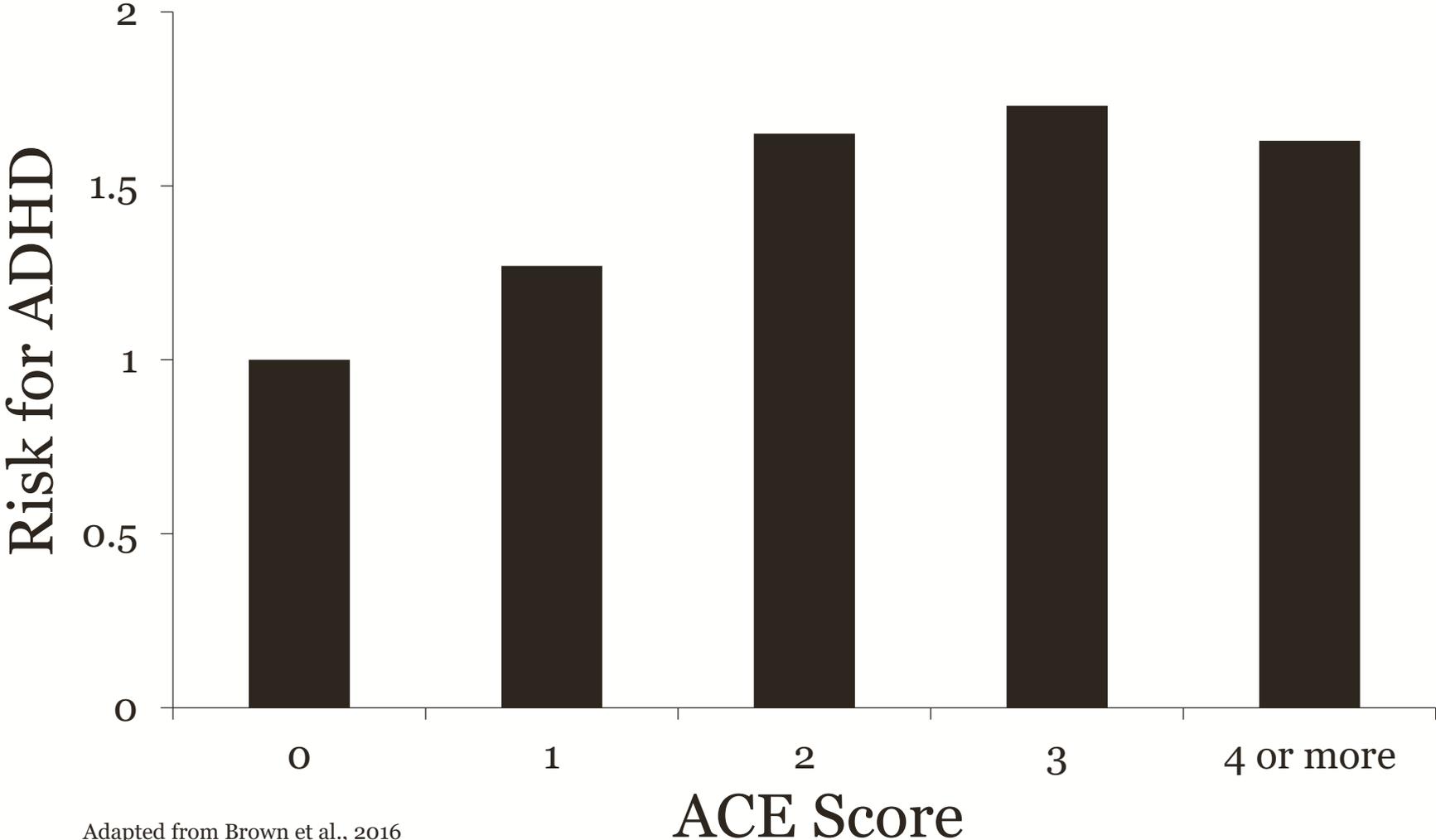
Adapted from Hostinar et al., 2012

ASSOCIATION BETWEEN ADVERSE CHILDHOOD EXPERIENCES AND DEVELOPMENTAL DELAY



Adapted from Barth et. al, 2008

ASSOCIATION BETWEEN CHILD ACE AND ADHD



Adapted from Brown et al., 2016

DEVELOPMENTAL DISABILITIES



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OBJECTIVES

- Most common developmental disabilities in U.S.
- Red flags for developmental disabilities
- Approach to identifying red flags
- Resources and referrals



COMMON DEVELOPMENTAL DISABILITIES

- 15% of children 3-17 years old in the U.S. have a developmental disability
 - Global Developmental Delay/Intellectual Disability
 - Attention-Deficit/Hyperactivity Disorder (ADHD)
 - Autism Spectrum Disorder (ASD)
 - Sensory Impairment (Vision/Hearing)
 - Learning Disability



DEVELOPMENTAL DELAYS AND RED FLAGS



GLOBAL DEVELOPMENTAL DELAY & INTELLECTUAL DISABILITY

- GDD = significant delay in two or more developmental domains
 - Gross and fine motor
 - Speech and language
 - Cognition
 - Personal/social development
 - Activities of daily living
- Intellectual Disability = impairments in intellectual functioning (IQ) and adaptive behavior (daily living skills)
 - “during developmental period” = before 18 years of age
 - Often not identified before 4-6 years old

RED FLAGS FOR INTELLECTUAL DISABILITY

- Persistent delays in development
- Difficulty learning new skills
- Difficulty with solving common problems
- Limited or lack of curiosity
- Failure to understand social/behavioral expectations
- Memory difficulties



ATTENTION-DEFICIT/ HYPERACTIVITY DISORDER

- Diagnostic Criteria
 - Patterns of inattention and/or hyperactivity/impulsivity
 - Interferes with functioning or development
 - Symptoms present in childhood (before 12 years old)
 - Not better explained by another medical or psychiatric condition
- Median age of diagnosis = 6 years
- Male > Female
- Prevalence ~11%



RED FLAGS FOR ADHD



- Not seeming to listen
- Difficulty sustaining attention in tasks (conversations, play), being easily distracted
- Difficulty organizing activities, losing things
- Carelessness, being more forgetful
- Fidgets/squirms
- Interrupts, talks nonstop
- “On the go,” difficulty participating in quiet/calm activities
- Difficulty waiting turns

AUTISM SPECTRUM DISORDER

- Diagnostic criteria:
 - Deficits in development of social communication skills
 - Restricted, repetitive, stereotypical, sensory-based patterns of interest and/or behavior
 - Symptoms interfere with functioning and present in early childhood
 - Not better explained by an intellectual disability
- Median age of diagnosis: 3.5-5 years
- Prevalence: 1 in 59



RED FLAGS FOR ASD



- Not responding to name, poor eye contact
- Speech delays or difficulty with using language for functional/social purposes
- Difficulty with imitation, functional/imaginative play
- Difficulty initiating and/or sustaining interactions with others (particularly peers)
- Repetitive movements and/or speech (echolalia or scripting)
- Strong reliance on rituals/routines
- Overly sensitive to external stimuli, seeking out certain sensory experiences

SENSORY IMPAIRMENTS

- Prevalence:
 - Hearing impairment 2-3/1000 U.S. children
 - Vision impairment ~3% U.S. children
- Presence of sensory impairments can impact many streams of development
 - Speech delays
 - Fine motor/Visual motor delays
 - Limited coordination/motor delays
 - Limitations in adaptive functioning



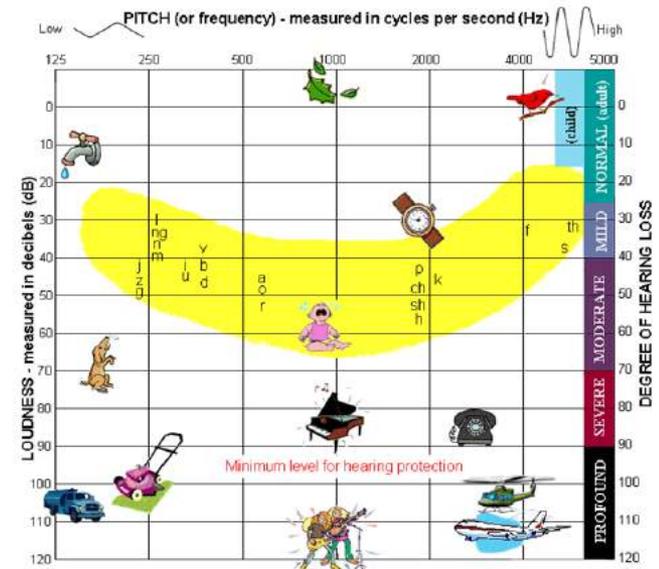
RED FLAGS FOR SENSORY IMPAIRMENTS

- Vision

- Delayed visual tracking milestones
- Limited interest in surrounding environment
- Limited eye contact
- Poor coordination

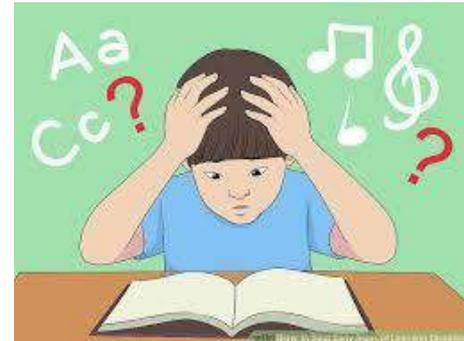
- Hearing

- Limited response to sounds
- Not babbling or progressing in language skills
- Not responding to name
- Unusual vocal quality or speech errors



LEARNING DISABILITY

- Significant difficulties in the acquisition and use of listening, speaking, reading, writing, reasoning, or mathematical abilities
- Central nervous system dysfunction occurring across lifespan
- Can occur with other disabilities or environmental factors but not caused by them:
 - Social difficulties
 - Self regulation problems
 - Sensory impairment
 - Emotional disturbance
 - Intellectual disability
 - Inadequate instruction
 - Cultural differences
- Prevalence 5-6% U.S.



RED FLAGS FOR LEARNING DISABILITIES

- Speech language deficits in early childhood
- Difficulty with early literacy skills
- Difficulty with cause-effect and basic concepts
- Academic problems/avoidance
- New onset/worsening behavior problems
- Anxiety or somatic complaints (stomachache, headache)



HOW DO I IDENTIFY RED FLAGS?



- Surveillance – ask caregivers about concerns
- Screening – use standardized measures at defined age points to best capture potential delays/deviations in development
 - Ages & Stages
 - PEDS
 - SWYC
 - M-CHAT

RESOURCES

- Early Intervention: U.S. Department of Education Office of Special Education Programs (OSEP)
<https://www2.ed.gov/programs/osepeip>
- Bright Futures Resources and Screening Guidelines: American Academy of Pediatrics (AAP) www.aap.org
- Learn the Signs: Autism Speaks
www.autismspeaks.org
- Center for Autism Research RoadMap
www.carautismroadmap.org
- ECHO Autism: twice monthly web-based case discussions disandroc@email.chop.edu

CROSSROADS: ACES AND DEVELOPMENTAL DISABILITIES



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MEET JOEY

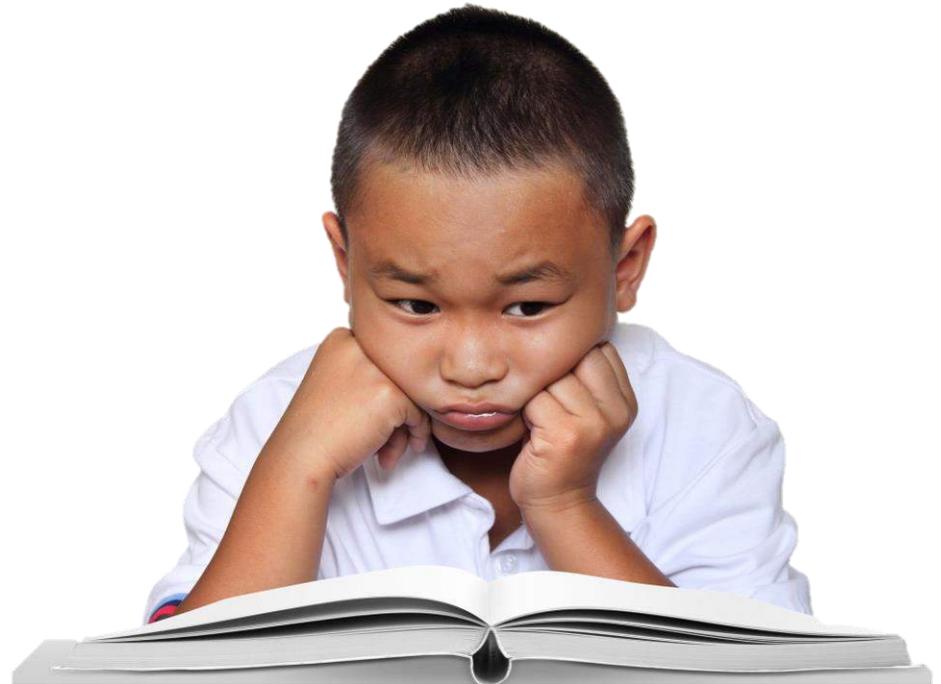
- Joey is a 7 year-old boy presenting to his pediatrician for parental concerns of high energy level and short attention span. He's always on the go and gets easily distracted. Mom says "it's like he doesn't even listen."
- He is frequently irritable and acts out by slamming doors, but hasn't hurt himself or anyone else. Mom thinks he's generally sweet and funny, but he has out-of-the-blue outbursts.
- Joey dislikes school and doesn't always complete the work, but is meeting benchmarks.

MORE ABOUT JOEY

- Medical review of systems: Vague stomachaches and headaches, otherwise healthy. Has a hard time falling asleep.
- Family history: Anxiety and depression in mom. ADHD in older brother.
- Social history: Lives in a crowded apartment in inner city with 2 teenage brothers, parents, and extended family.
- Physical exam: No atypical findings.

WHAT'S GOING ON?

- ADHD?
- Mood disorder?
- Learning issue?
- Sleep problem?
- Toxic stress?



POLL THE AUDIENCE

What would be your next step?

- A. Give parenting tips and follow-up in 6mo
- B. Diagnose ADHD and monitor over time
- C. Diagnose ADHD and prescribe stimulant medication and behavioral therapy
- D. Recommend behavioral therapy
- E. Refer to mental health counseling
- F. Dig deeper

DIGGING DEEPER

- You notice mom is shifting uncomfortably in her seat and she starts to say something, but stops.
- You ask, “Is there anything else?”
- Mom answers “No.”
- You think about your trauma-informed trainings, and choose to offer an open ear.
- “Sometimes families tell me that things can be stressful at home. Is that something you are experiencing?”

DIGGING DEEPER

- Dad has been in **prison** for 3 years and returned home several months ago, unemployed and unhappy. Mom and dad yell at each other constantly.
- Last year, Joey witnessed his cousin being **shot in the neighborhood** and now avoids being outside.
- Though mom and grandparents work full-time, bills are high and there doesn't seem to be **enough money** to cover it all.

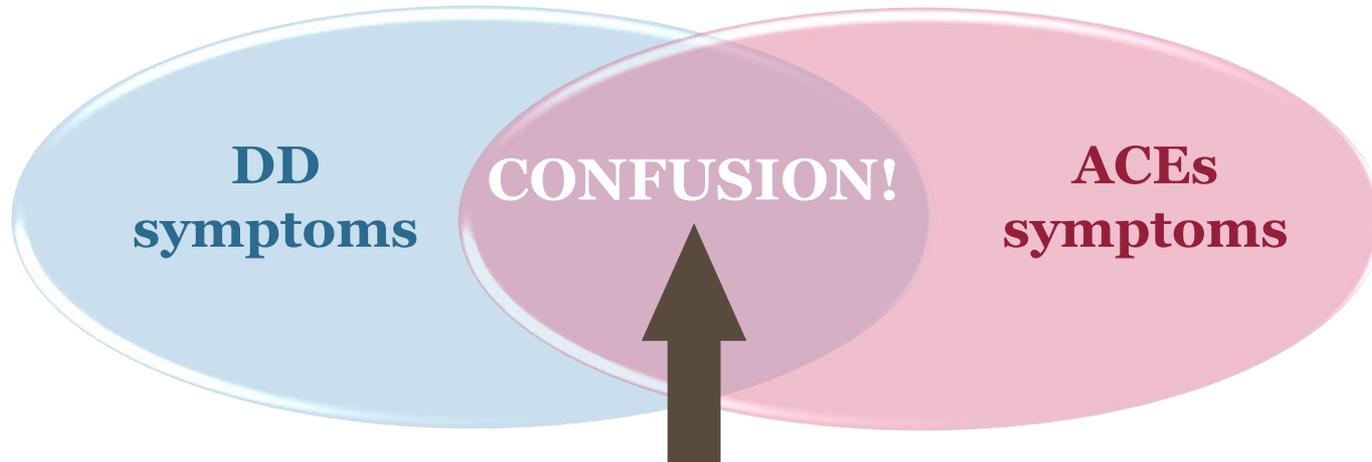
10 MONTHS LATER

- Joey continues to have trouble with paying attention, impulsivity, and hyperactivity.
- Stimulant medication was briefly trialed, but script wasn't refilled.
- Joey is not yet receiving behavioral therapy.
- He has frequent crying episodes when things don't go the way he expected, which can escalate into outbursts.
- Mom worries he's been labeled a "bad kid" at school.

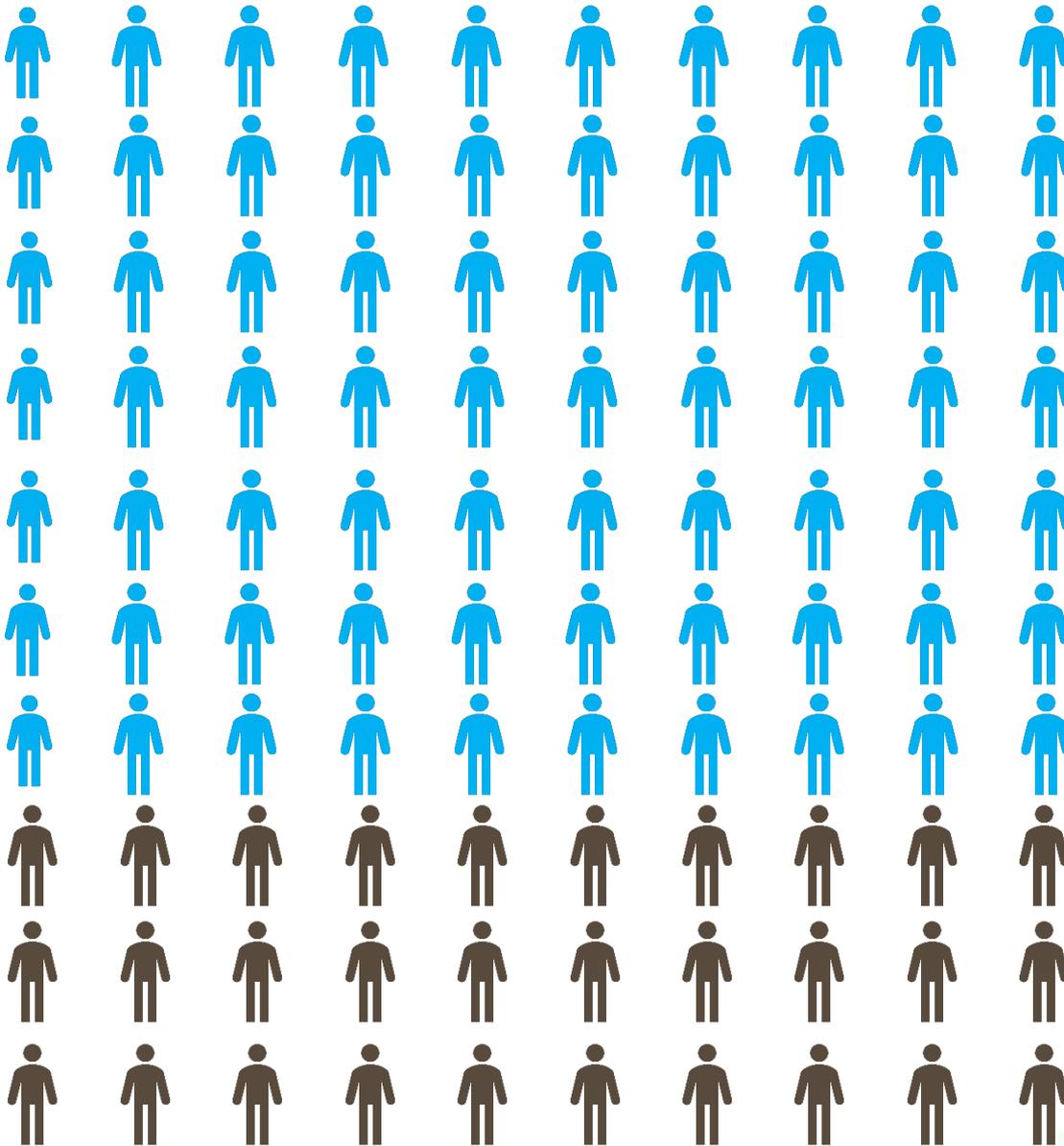
SOME IMPORTANT ISSUES HIGHLIGHTED IN JOEY'S CASE

- Symptom overlap between ACEs & DD
- Possibility of diagnostic overshadowing
- ACEs →
increased risk for ADHD/DD
- ADHD/DD →
increased risk for ACEs
- Disparities in access to diagnosis and interventions for children with ACEs & DD

SYMPTOMS OVERLAP



- attention problems
- temper
- aggression
- social problems
- disruptive behaviors
- impulsivity
- executive dysfunction
- depression
- anxiety
- sleep disturbance
- withdrawal
- academic difficulties



70% of US
children
with ADHD
have been
exposed to
ACEs

ACES & ADHD

- Children with ACEs were more likely to have ADHD diagnosis
- 4 ACEs = 4 times odds of ADHD
- Increased severity of ADHD symptoms
- Children with ADHD, higher prevalence of each ACE and cumulative ACE score



ACES & ASD

- Higher cumulative and specific ACEs
- 1.66 times more likely to have multiple ACEs
- Children with ASD are bullied 3-4 times more than peers
- More co-morbid psychiatric and medical health problems



ACES & OTHER DD

- Children with ACEs are more likely to have an emotional, mental, or behavioral disorder
- 83% of children with ID experienced ACEs
- Children with DD are 3.7 times more likely to have neglect or physical abuse and 3.1 times more likely to have sexual abuse



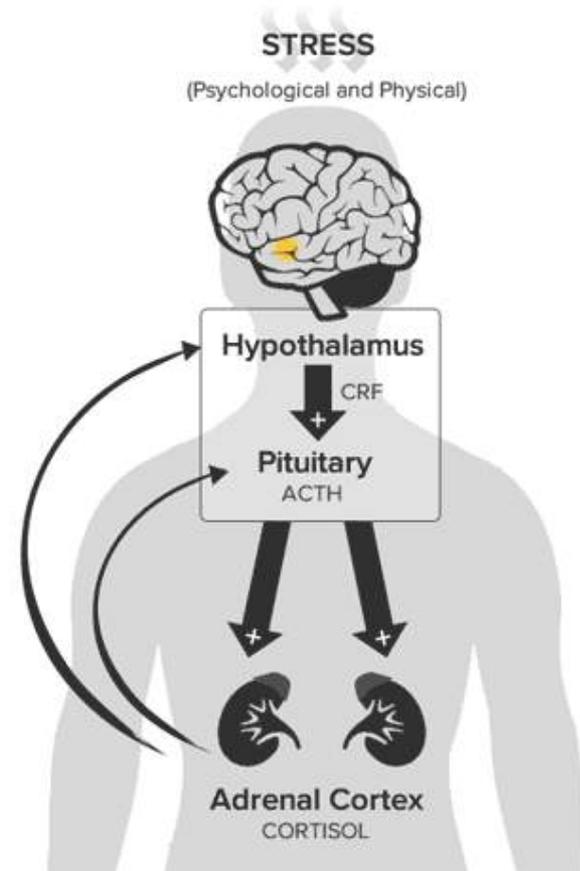
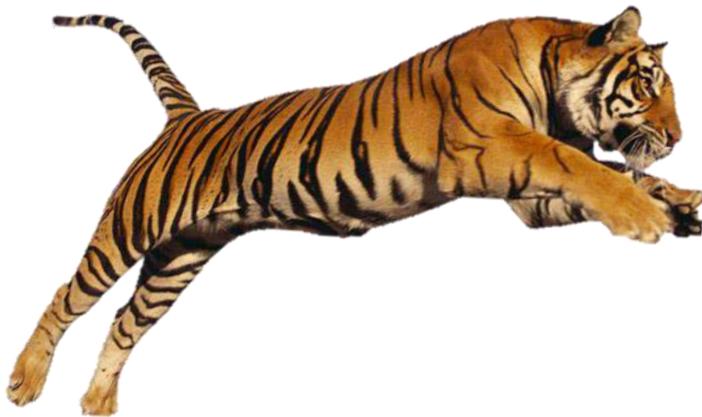
IMPACT OF ACES IN DD: LIMITED UNDERSTANDING



- More severe functional impairment at home
- More sleep disturbance
- Toileting difficulties
- Increased risk for obesity for low-income families

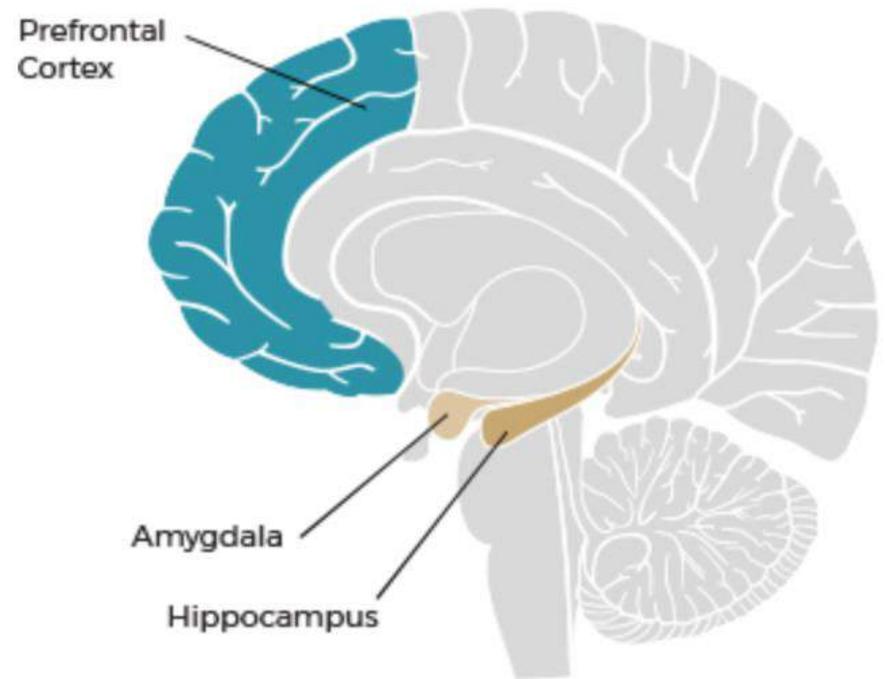
WHY?

- Toxic stress impacts the brain's development



WHY?

- Toxic stress impacts the brain's development



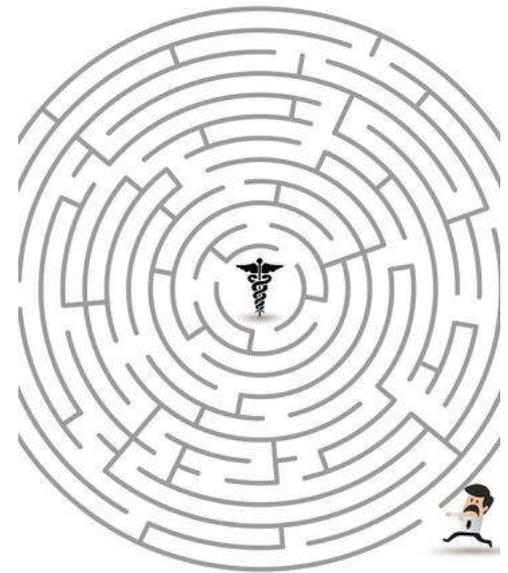
ACES: DISPARITIES IN CARE



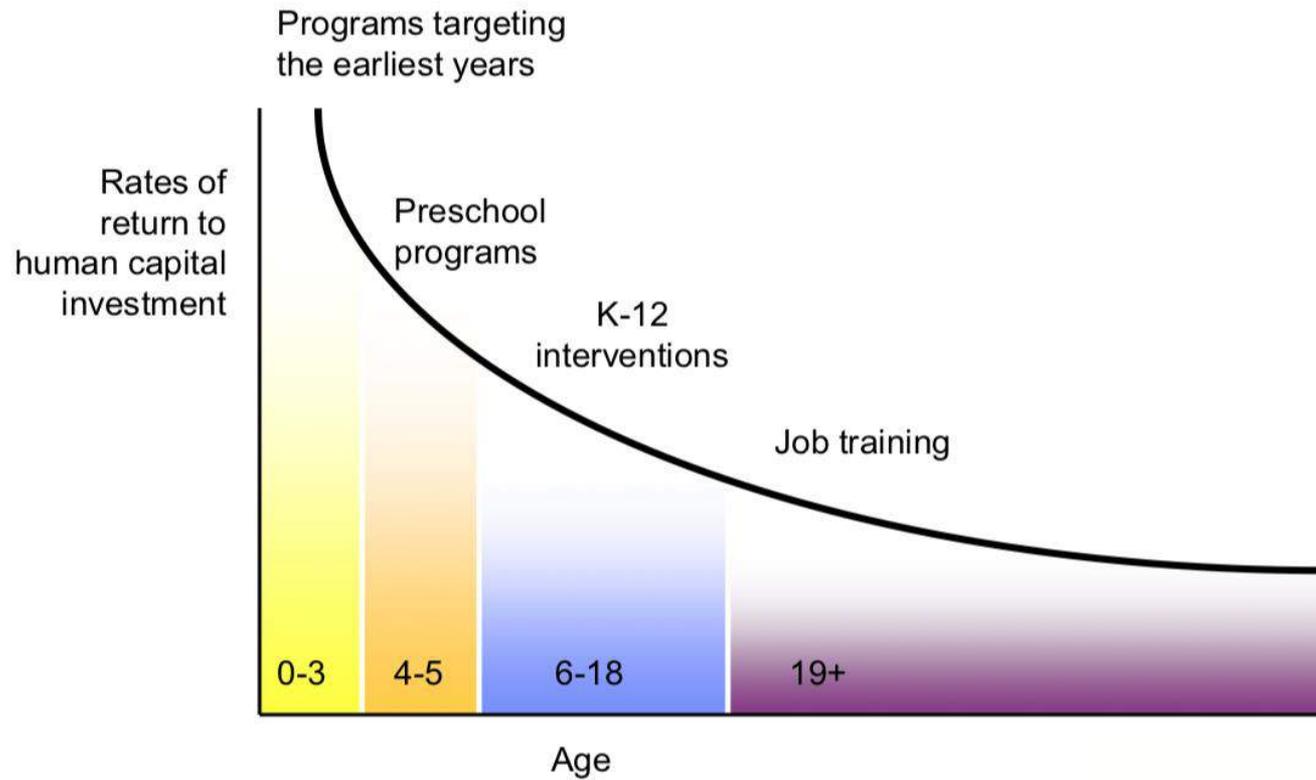
- Unmet health care needs
 - ASD: more than twice as likely to report difficulty getting needed medical, mental, or dental care
- Delayed diagnosis
 - Prolonged time to receipt of ASD diagnosis
- Access to interventions
 - Increase in median age of entry into services for ASD

ACES: DISPARITIES IN CARE

- Families with history of trauma may face barriers to navigate the complex health insurance systems, scheduling, and transportation issues
- Limited resources/information
- Juggling family demands



Preventive Intervention is More Efficient and Produces Higher Returns than Later Remediation



“IT IS EASIER TO BUILD STRONG CHILDREN THAN TO REPAIR BROKEN MEN.” FREDRICK DOUGLASS

CHECKING IN WITH JOEY

- His parents were referred to a Spanish-speaking trauma-informed parenting class.
- Joey meets with a counselor once weekly where he can process his experiences. He has also found an artistic expression for his voice – painting!
- He is taking stimulant medication which helps his energy and focus during the school day.





MOVING INTO ACTION

FIRST STEPS

- Remember no one is immune to ACEs
- Create a safe, welcoming space
- Make no assumptions – ask
 - or thoughtfully screen
 - Whole Child Assessment (<https://lluch.org/health-professionals/whole-child-assessment-wca>)



A WORD ABOUT “MISDIAGNOSIS”

- Not either-or!
- Whole-child approach considering the family and environment
- Consider especially when sub-optimal response to traditional treatment
- Multimodal therapy

WILL KNOWING ACES CHANGE THE MANAGEMENT OF DD?

- Behavioral therapy using principles of applied behavior analysis is often recommended for children with DD
- How does that differ from trauma-informed therapies?
- Need to acknowledge trauma “beneath the surface”



PID.THENADD.ORG

My Book Rec

This is the
Traveling the Lo

I have been through so much
life!

Here are some of the things th
have gone through:

1. _____
2. _____
3. _____
4. _____
5. _____
6. _____
7. _____
8. _____
9. _____
10. _____

It is incredible to think about a
have been through!

I am a survivor!

What makes me happiest right now
is:

What I am most glad is over is:

RESILIENCE

- Understanding and creating protective factors within the DD community



RESOURCES

- The National Child Traumatic Stress Network (www.nctsnet.org)
- Sesame Street (www.sesamestreetincommunities.org)
- ACEs Connection (www.ACEsconnection.com)
- Multiplying Connections (www.multiplyingconnections.org)
- Local to Philadelphia: CAP4Kids (www.cap4kids.org)
- Local to Philadelphia: Children's Crisis Treatment Center (www.CcTCKids.org)

WWW.SESAMESTREETINCOMMUNITIES.ORG



Using These Resources



Comfy-Cozy Nest



What Are Traumatic Experiences?



Printable
Self-Care: During & After a Crisis



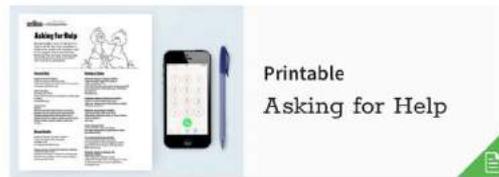
Printable
Let's Help: A Guide for Grown-Ups Helping Children Through the Toughest Times



Printable
Let's Play: A Children's Activity Book



Article
H Is for Hope



Printable
Asking for Help



Workshop
Feeling Safe



Workshop
Connect



Workshop
Breathe



Workshop
Express Yourself

THANKS!

Please take a few minutes to complete the survey after the webinar closes!

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