

# Emotion Dysregulation in Autism: Why it Matters and What We are Doing About It

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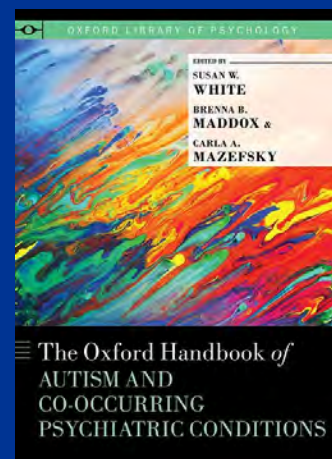


1

## Disclosures

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- KL2 TR001856 (PI Beck)
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2




**Regulation of Emotion in Autistic Adults, Children, & Teens**

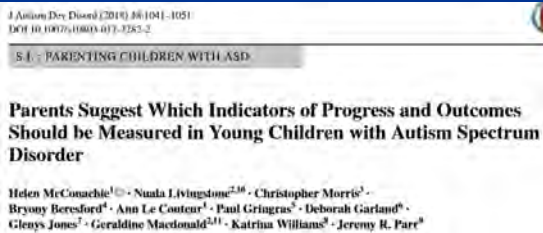
**Mission:** Conduct research that will improve mental health & well-being for autistic people across the lifespan  
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3


# Consensus on mental health



**Top 10 included:**  
 Happiness, Anxiety, Distress,  
 Self-esteem, Aggression, Sleep



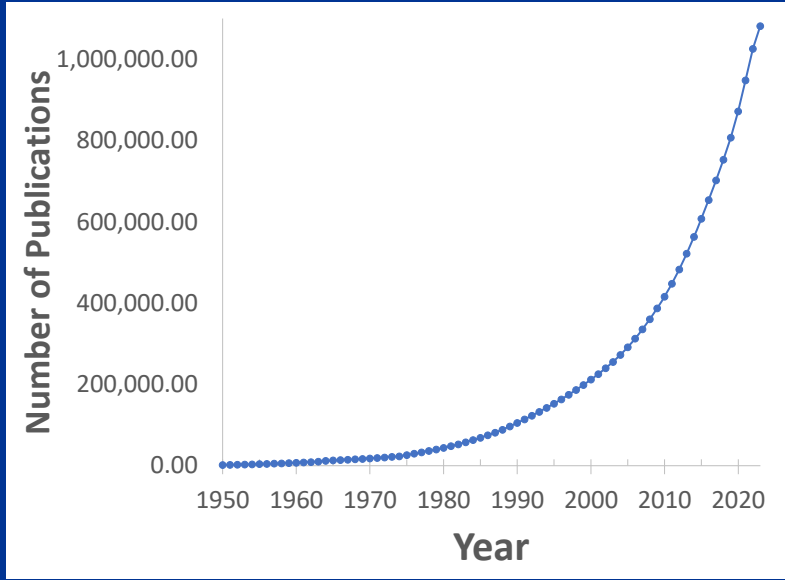
Both self-reporting adults and legally authorized representatives of adults rated mental health as important



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4

# Progress and momentum!



### Search Terms:

Autism +

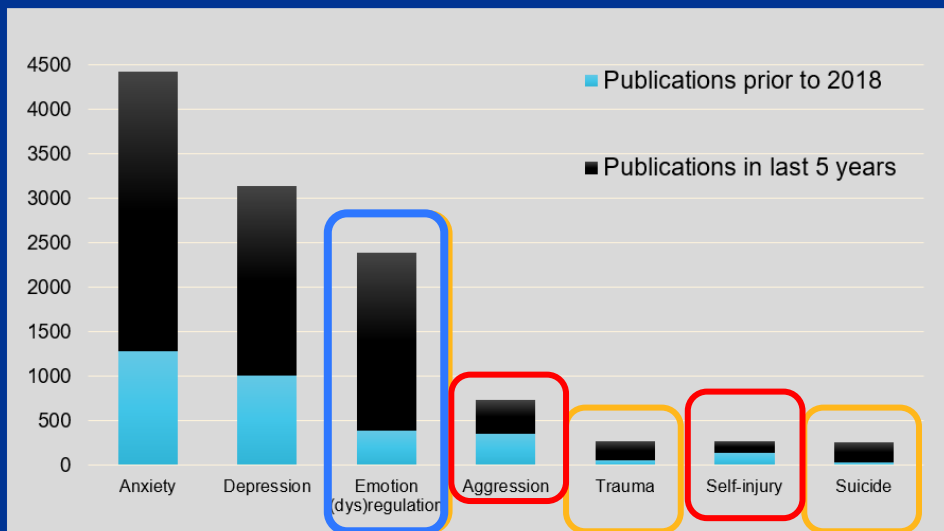
- mental health
- psychiatric disorder
- anxiety
- depression
- emotion (dys)regulation
- self-injury
- aggression
- trauma
- suicide



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# Progress By Topic and Timing



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## Disorder-specific approaches are a challenge

Blurry diagnostic boundaries

41% have 2+ disorders, and  
24% have 3+ disorders  
(Simonoff et al., 2008)

## Instead focus on emotion (dys)regulation



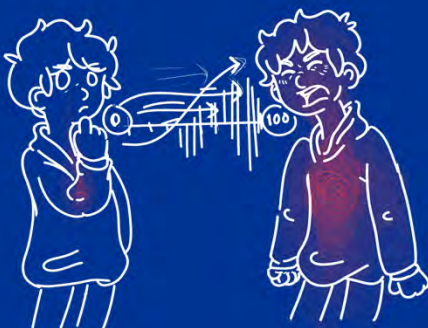
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7

## Emotion dysregulation

- Difficulty changing or controlling strength or length of emotional response
- Interferes with ability to meet goals



“My husband and I describe him as being at once the most capable and most disabled person we know...His dysregulation manifests in severe emotional outbursts, both verbal and physical; however, when regulated, he is more rationale, kind, and mature than his older neurotypical brothers....**emotional dysregulation is absolutely his chief obstacle to living a full life and having the chance to enjoy his many talents (and they are many!).**” -Mom of a 9-year-old son with autism

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This is both...

- May feel intense emotions on inside but not notice or show emotions until so strong they can't control it anymore.

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9

## Sometimes it is not clear, which can make a big difference!

Child is getting agitated or upset	→	Child communicates that emotion clearly	→	Can help comfort, provide help, redirect	→	Child accomplishes tasks, learns to regulate
	→	Communication is ambiguous	→	Child escalates; appears to go 0-100	→	Very hard to calm down or accomplish task; meltdown

ONE YEAR

By Jessie Northrup, PhD  
**CURRENTLY RECRUITING**

- Ages 3-5,
- Autism, delays, typically-developing

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# What does emotion dysregulation “look like” in autism?


- Meltdowns and Shutdowns:
  - Can occur when completely overwhelmed or overstimulated
  - Can become out of control of behavior:
    - Screaming, crying, aggression, destroying objects, etc.
  - May “shut down” – stop interacting or responding, withdraw

***These are typically signs of real distress, not on purpose or trying to manipulate***







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11



## Emotion Dysregulation Inventory

Reactivity	Dysphoria
 	 
<p><b>Has explosive outbursts</b></p> <p><b>Has extreme or intense emotional reactions</b></p> <p><b>Emotions go from 0 to 100 instantly</b></p> <p><b>Has trouble calming themselves down</b></p>	<p><b>Does not seem to enjoy anything</b></p> <p><b>Not responsive to praise or good things happening</b></p> <p><b>Seems sad or unhappy</b></p> <p><b>Appears uneasy through the day</b></p>



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12

Emotion Dysregulation Inventory  
Young Child

EDI

Emotion Dysregulation Inventory  
Self-Report

Proxy report; Ages 2-5

Proxy report; Ages 6+

Self-report; Ages 11+

Validated in autistic and non-autistic populations

Can be used across any verbal or intellectual ability

Sensitive to change

Has norms and clinical cut-offs

Brief, efficient, & precise - 6 or 7 items!

**FREE** – Request here: [www.react.pitt.edu](http://www.react.pitt.edu)

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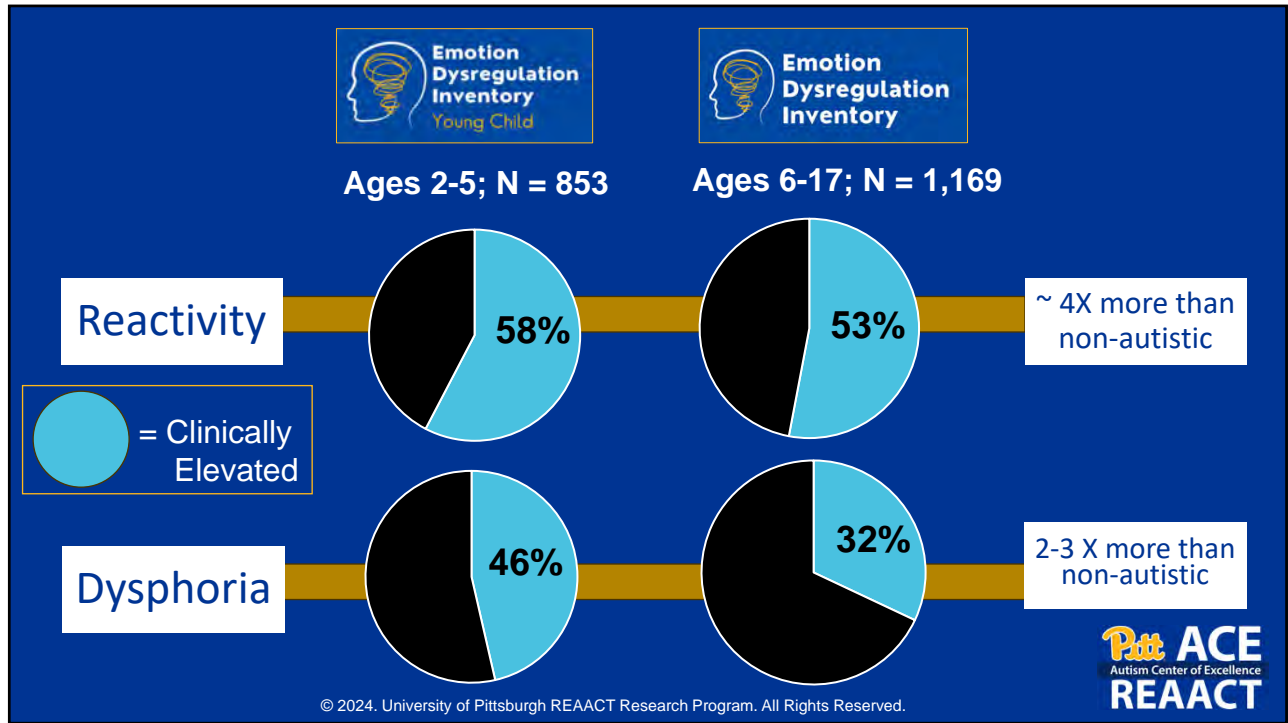
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14



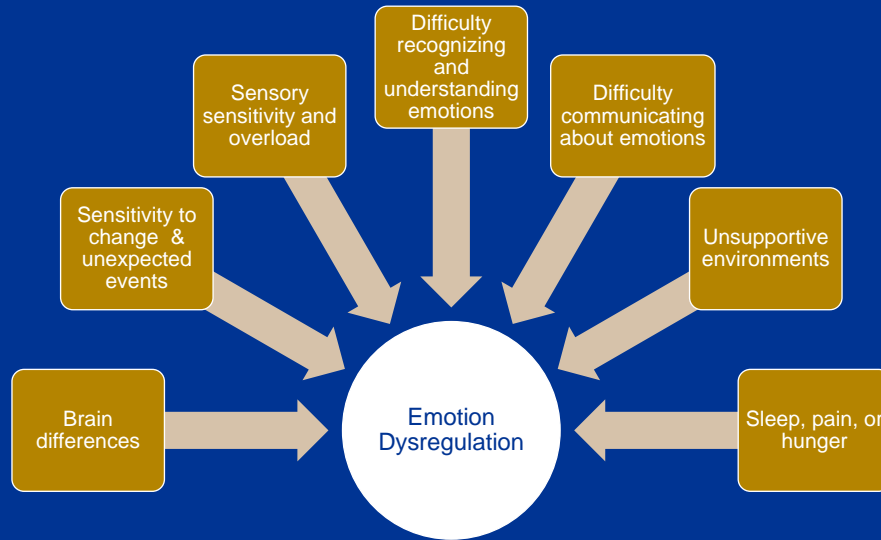
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16



## Why might autistic people have more difficulty managing emotions?



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17

## Recent Advances on Contributors to Poor Mental Health

- Hiding neurodivergent traits to fit in (masking)
- Spending excessive energy trying to adhere to neurotypical social norms
- Unsure how to manage sensory needs
- Bullying, chronic invalidation, discrimination
- Trauma



(Beck et al., 2020; Cassidy et al., 2021; Botha et al., 2020; Cassidy et al., 2023)

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18

**RESEARCH ARTICLE**

**Emotion Dysregulation is Substantially Elevated in Autism Compared to the General Population: Impact on Psychiatric Services**


Caitlin M. Conner, Josh Golt, Rebecca Shaffer, Giulia Righi, Matthew Siegel, and Carla A. Mazefsky

*Journal of Autism and Developmental Disorders*


pp 1-16 | Citations

**A Comparative Study of Suicidality and Its Association with Emotion Regulation Impairment in Large ASD and US Census-Matched Samples**


Authors: Caitlin M. Conner, Josh Golt, Giulia Righi, Rebecca Shaffer, Matthew Siegel, Carla A. Mazefsky




- It is an underlying process *across* disorders and challenges (depression, anxiety, suicidality, etc.)
- And it impacts:




Community Life and Relationships




Family Life




Educational and Work Opportunities



More Medications



Use of crisis services, hospitals, police contact

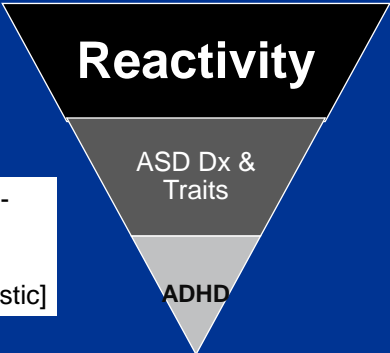


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19

## Strong association with aggression

**1,050 2- to 5-year-olds**  
[513 autistic, 536 non-autistic]



**Reactivity**

ASD Dx & Traits

ADHD

Speaking ability, intellectual disability


**Aggression**


**Early Childhood Aggression in Autistic and Non-Autistic Preschoolers: Prevalence, Topography, and Relationship to Emotional Reactivity**

Shalini Sivathasan, PhD, Safaa Eldoeb, PhD, Jessie B. Northrup, PhD, Ligia Antezana, PhD, Amy Ionadi, PhD, Lauren S. Wakschlag, PhD, Carla A. Mazefsky, PhD

JAACAP Open  
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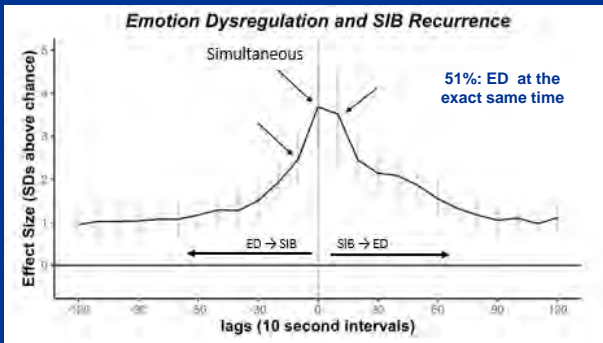




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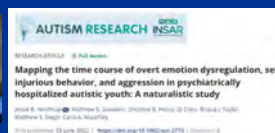
20

# Strong association self-injurious behavior



- Children and adolescents from the Autism Inpatient Collection (AIC) seen during their stay at an inpatient psychiatric hospital.
- 298 sessions with observed behavior
  - M = 5.62 sessions per participant
- 506.55 hours of observation
  - M = 9.55 hours per participant
- Average Session Duration: 68.15 mins

N = 53 participants observed engaging in at least one behavior

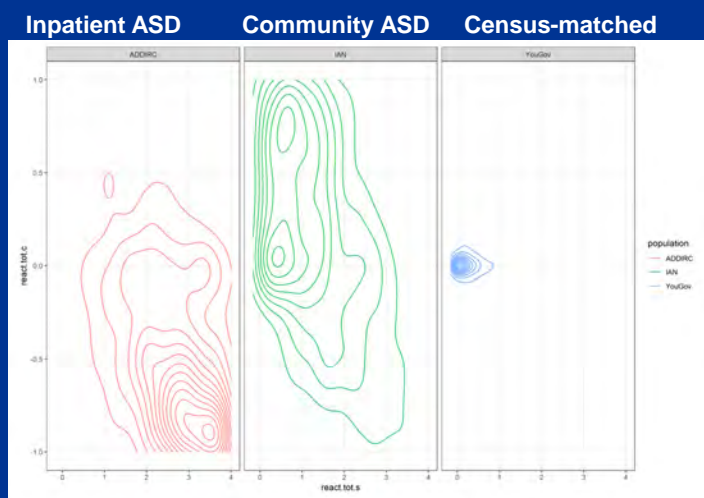


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21

# Emotion dysregulation is highly variable in ASD

More  
.  
.  
Change over time  
.  
Less



low--Severity--high



Published in final edited form as:  
*J Child Abuse Negl* 2021; 50(6): 708-729. doi:10.1080/15374416.2021.1955369.

**Predictors of Severity and Change in Emotion Dysregulation among Children and Adolescents with ASD**

Jessie B. Northrup,  
University of Pittsburgh School of Medicine, Department of Psychiatry, Pittsburgh, PA

Mark T. Patterson,  
Carnegie Mellon University, Department of Social and Decision Sciences, Pittsburgh, PA


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22

So, we should be screening!  
Consider measurement-based care



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Validated in autistic and non-autistic populations

Can be used across any verbal or intellectual ability

Sensitive to change

Has norms and clinical cut-offs

Brief, efficient, & precise  
- 6 or 7 items!







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23

The Emotion Awareness & Skills Enhancement Program


Developed by  
Kelly Beck, Caitlin Conner,  
Carla Mazefsky, & Susan White










**EASE**  
TOOLS FOR CALMING THE CHAOS





24

# Developing the Original Manual

## • Based on:

- Theories of emotion regulation in autism
- Research on emotion regulation and dysregulation in autism
- Evidence-based treatment for emotion dysregulation in other populations



Reactivity	Dysphoria
Has explosive outbursts Has extreme or intense emotional reactions Emotions go from 0 to 100 instantly Has trouble calming themselves down	Does not seem to enjoy anything Not responsive to praise or good things happening Seems sad or unhappy Appears uneasy through the day

## • Input from:

- Autistic adults
- Caregivers of autistic people
- Providers, including autistic providers



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25



Developing and testing EASE for those with greater support needs – it can be done!

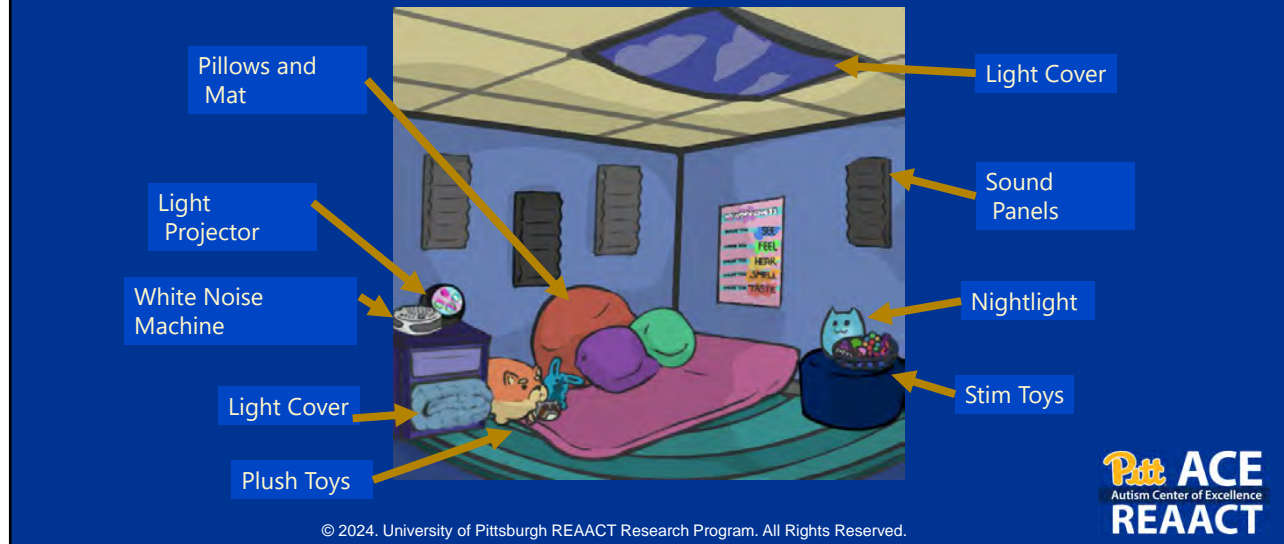
DIMENSIONS OF ACCOMMODATION	
Greater Support Needs	Fewer Support Needs
Support Person Involvement	
More support person involvement .....	Primarily client-only sessions, support person as coach (or no coach involved)
Focus on Cognition Change	
Less focus on reframing, no distancing .....	Considerable focus on reframing, More focus on awareness, environmental change distancing, cognitive techniques
Pace	
Slower pace, more repetition .....	Faster, pace, less repetition
Use of Scripts	
Reliance on repetitive phrases to aid memory .....	More explanation, limited repetitive phrases other than EASE key concepts

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26

## Autism-focused design: Incorporating Sensory considerations



27

## Supporting language processing and learning

### What should I consider?

- Precise, concrete language
- Use of visuals and lists
- Integrating pauses for processing information
- Wait for autistic client to respond
- Do not demand eye contact
- Find ways to reduce verbal discussion
- Reduce amount of explaining, unless it's asked for
- Make sure you use autism-affirming language

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28

## The little things go a long way

- “Of course, there were difficult and distressing topics to discuss and questions to answer, but the way **everyone showed up and showed me compassion and BELIEVED ME** (something that is, unfortunately, quite rare in my experience with medical professionals) **made me feel so safe** when I participated. I truly felt like I could answer all of the questions--even in in-person interviews--completely honestly because I didn't feel judged by the person asking. I am not exaggerating when I say that of the studies I've participated in in the past, this was by far the best experience. I felt so unbelievably safe and supported throughout my entire participation in this study!”
- “I liked that the researchers were well adjusted for handling autistic behaviors. It made it a lot less weird, and I felt more comfortable. To me, it was a relief to not be treated as a strange and misunderstood creature that acts a little bit oddly... but to be treated as a valuable research participant. **I was as genuine as I could be, and I felt happy to not have to pretend to be something that I'm not, which is the case in most interactions...**”

Illustrative anonymous feedback from REACT Study participants on the impact of providing an autism-affirming environment

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29

## EASE Key Elements

### Theoretical Tenets

- Mindful awareness
- Present-focused
- Noticing changing emotional intensity
- “All Emotions are OK”
- Self-compassion

*General goal: Manage your emotions to meet your goals*

### Delivery/Implementation

- Client-focused to promote self-determination
- Modular and flexible to address neurodivergent learning styles
- Promote acceptance and learning through modeling
- Promote generalizability with practice sessions

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30

## Two Steps in EASE

Builds over the treatment

1. Improve non-judgmental awareness of emotions
  - Not avoiding negative emotions
  - Negative and strong emotions will still happen
2. Use EASE Tools to manage emotions and meet goals
  - Can't use tools if we don't notice when we need them
  - Practice, repetition of new tools to manage your emotions
  - Emotions will still happen but want to act in ways consistent with goals



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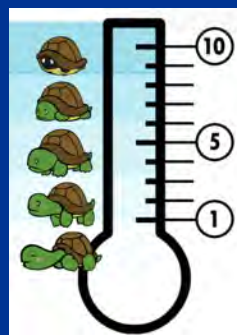
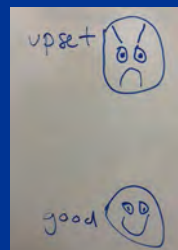
31

## Identifying distress early

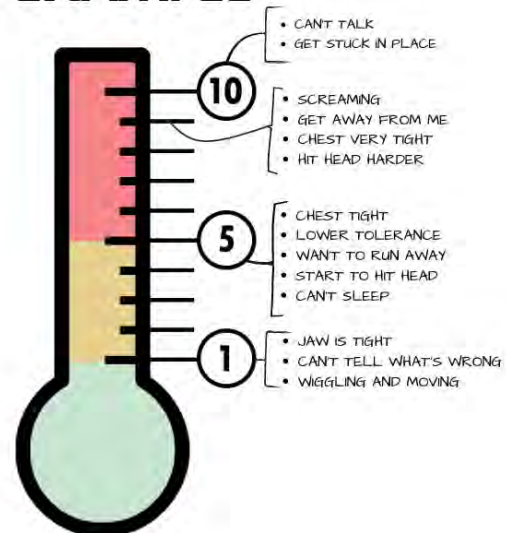
*"The skill I will definitely use again in the future is awareness - I like this one because you have to notice what's happening like your emotions and thoughts before you can change them" – EASE client*

### Noticing my Emotions Scale

– Emphasis on **dimensional** rather than discrete emotions  
 -- Finding a consistent "language"



### EXAMPLE



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32



# Mindfulness May Help

- What it is- Paying attention to present moment sensations, thoughts, and emotions without judgment Kabat-Zinn et al., 1985
- Why we think it makes so much sense:
  - Increase awareness of emotions, sensations, and thoughts to:
    - Promote the ability to slow down before action
    - Decrease tendency to escape/suppress
  - Promote self-compassion
  - Practice-based and easily tailored (Beck breakout)



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33

# Mindfulness

Mindfulness Practice	Routine to support this tool		
Body Scan		STOP & Breathe	
Mindful Walking		STOP & Move	
Mindful Breathing		STOP & Change Focus	
Self-Compassion Statement			

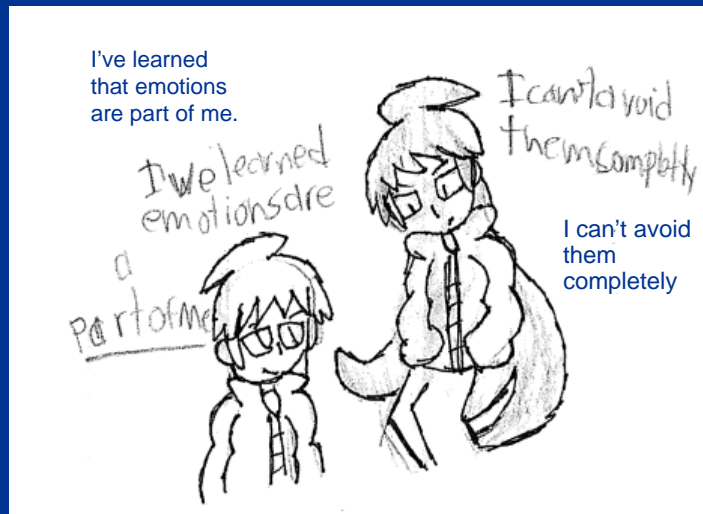


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34

## "All Emotions are OK"

- Trying to just avoid or stop "bad" emotions can backfire
  - Not as helpful: "Calm down", "It's not a big deal"
- You can help cultivate
  - "It's okay to be nervous [angry/sad/upset]"
  - Note: that doesn't mean all behaviors are OK.



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35

## Temporarily Change Focus

- Help to keep in control
- Especially useful when: Surprise, need to stay in place, sudden, change in emotions
- 1. Creating a physical sensation (without tool)
  - Wiggling toes, tapping feet, pressing hands, etc.
- 2. Activities or tools to help create physical sensation
  - Showering, sand, stress ball, fidget, other sensory



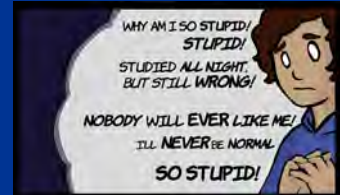
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36

# Thoughts also play a role

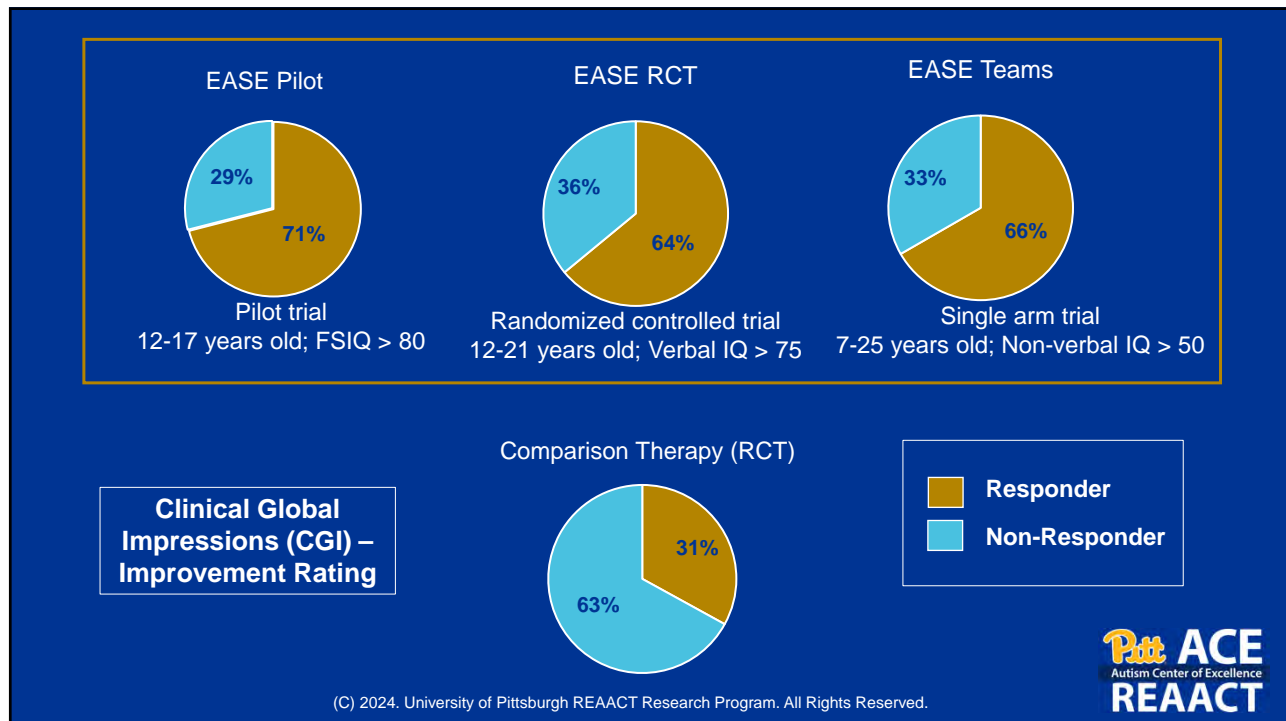
- Create distance – “I am noticing I am having the thought.....”
- Helper thoughts – Identify common thought or learn to reframe specific thoughts

	THOUGHT	FEELINGS	SENSATIONS	ACTIONS	
<b>EXAMPLE</b>	First Thought	I'm so dumb	8/10	Heart Racing	Yell get in trouble!
	Alternative Thought #1	This is hard	7/10	Chest Tight	Ask for help.
	Alternative Thought #2	I am still learning	5/10	Tired	Try Again



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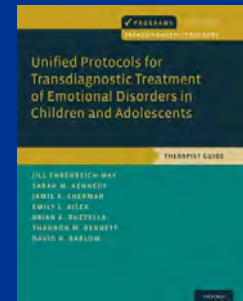


38

## Do therapies not developed for autism work just as well?



- Emotion-focused cognitive-behavioral therapy (CBT)
- Substantial evidence base
  - Sakiris & Berle (2019) • 15 studies and 1244 patients •
    - Large effect size reductions across anxiety and depressive symptoms and disorders • Improved functioning and QOL
  - Carlucci, Saggino, & Balsamo (2021) • 19 RCTs and 13 uncontrolled trials – 2183 patients •
    - Large to moderate combined overall effect size for both anxiety and depression at posttreatment and 3-6 month FU



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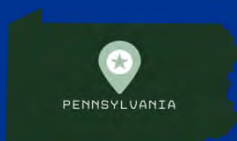
39

## Comparative Effectiveness Clinical Trial (PCORI)



### Recruitment – Goal of 450 participants across 10 clinics

- 12-25 years old
- Professional diagnosis of ASD
- Communicative ability (verbal or nonverbal)
- Clinically elevated score on the EDI Reactivity or EDI Dysphoria scale
- Involvement of a support person who can complete surveys
- Free of concerns that suggest a higher level of care is needed (imminent suicide or homicide threat, acute psychosis, mania)
- Reside in Alabama or Pennsylvania



Merakey - Westmoreland  
 Merakey - State College  
 Merakey - Carlisle  
 FBR - Greensburg  
 FBR - Monroeville  
 FBR - New Kensington



40

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*Advancing research on adult mental health & suicide*

The U.S. Department of Health and Human Services, Interagency Autism Coordinating Committee, and autistic adults have called for research on **adult mental health** to improve safety and quality of life, and to reduce premature mortality.

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41

# Suicide

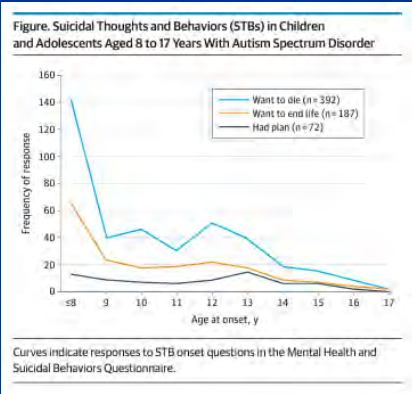
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[www.youtube.com/@PittREACT](http://www.youtube.com/@PittREACT)

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42

# Not just an adult issue



- In an 8-17 yo sample: Lifetime STB incidence was:
  - wanting to die: 392 (40.5%)
  - wanting to end their own life: 187 (19.3%)
  - having a plan: 72 (7.4%)
- Of these, onset of 8 yo or younger reported in:
  - wanting to die: 142 (36.2%),
  - wanting to end their own life: 66 (35.3%),
  - having a plan: 13 (18.1%)

Schindel, B. J., Chen, B. B., Wilcox, H. C., Marvin, A. R., Law, J. K., & Lipkin, P. H. (2024). Suicidal Thoughts and Behaviors Among Children and Adolescents With Autism Spectrum Disorder. *JAMA pediatrics*.

The **youngest age of suicide attempt was 7 years** and the average ages of first and most-lethal suicide attempts in children ( $n=24$ ) was 12.71 and adults ( $n=42$ ) was 19.21 years.

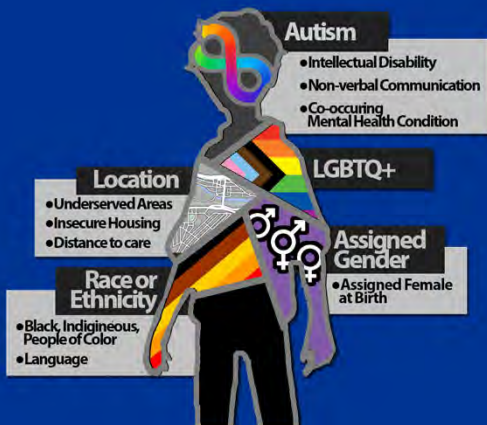
-Schwartzman et al, preprint; "Elevated Suicidal Thoughts and Behaviors and Self-injury in Autism Across the Lifespan: A Multinational Study"



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43

# Why heightened risk?



Cassidy et al., 2014; Cassidy et al., 2018; Kirby et al., 2019; Raymaker et al., 2020; Hedley et al., 2017, 2018; Kölves et al., 2021

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More likely in autism:	Unique factors:
<ul style="list-style-type: none"> <li>• Co-occurring psychiatric conditions</li> <li>• Social isolation</li> <li>• Impulsivity</li> <li>• Difficulty with decision making</li> <li>• Difficulties with executive functioning</li> <li>• Emotion dysregulation</li> <li>• Self-injury</li> </ul>	<ul style="list-style-type: none"> <li>• Autistic burnout</li> <li>• Masking of autistic characteristics</li> <li>• Late autism diagnosis</li> <li>• Difficulty with life transitions</li> <li>• Struggles with employment and housing</li> </ul>

Trauma Type	N (%)
Emotional Abuse	34 (79%)
Physical Abuse	17 (40%)
Sexual Abuse	9 (21%)
Emotional Neglect	19 (44%)
Physical Neglect	19 (44%)



44

The Pitt ACE is designed to:

Rapidly improve understanding by collecting data **across multiple methods** and many areas of **both individual characteristics and life experiences.**

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## Autism Suicidality Inventory

**Develop** and **validate** a self-report questionnaire that captures *a range* of suicide risk in autistic adults

- Prevention and support
- Monitor change in treatment
- Tell us more about suicidality – what items are most tightly linked to propensity for suicide?

- **Team:** Autistic adults with and without suicidality, suicide researchers, autism/mental health researchers.
- **Participants:** ACE core participants, plus an additional 700 adults online and 250 teens (add-on study)

**\*\*NOW RECRUITING**

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46

# What else are we doing? A LOT!







35 brief questionnaires – self-report, proxy report, and frequency and support response options [FREE]









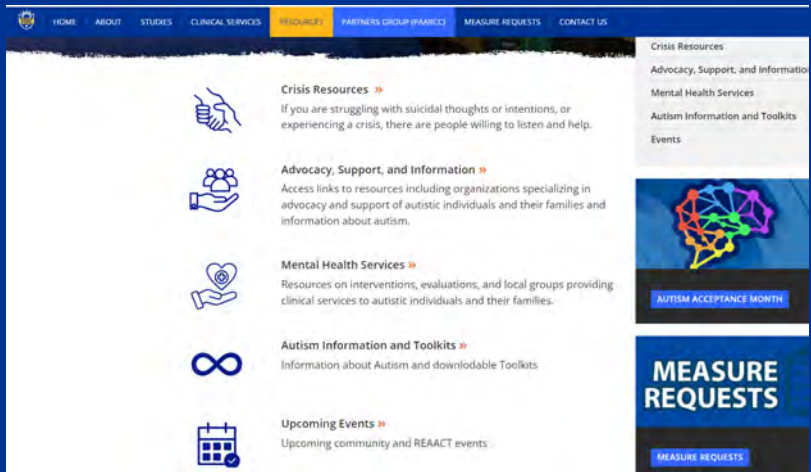







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47




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48



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## The Work of Many!!!



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49