

Emotion Dysregulation in ASD: What Have We Learned and Where Do We Need to Go

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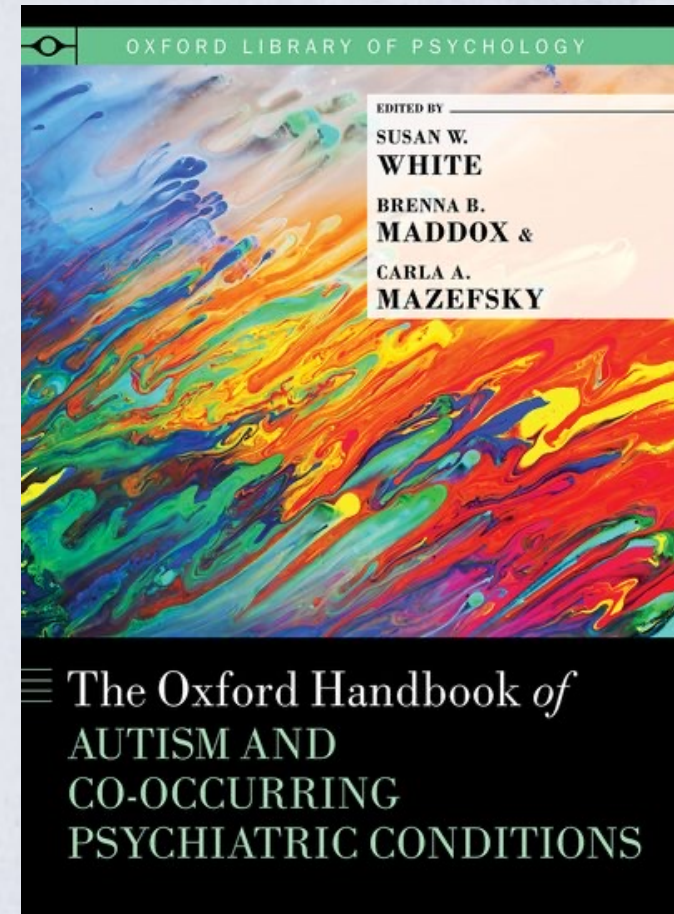
Professor of Psychiatry, University of Pittsburgh School of Medicine
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(REACT) Program; www.react.pitt.edu



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The work of many – Thank you!

Susan White

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Lan Yu

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Caitlin Conner

Kelly Beck

Martine Lamy

PJ McCarroll

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Jessie Northrup Taylor Day

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Murat Akcakaya

Isaac Smith

Kexin Luo

Rebecca Elias

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Paul Kim

Josh Montrenes

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Tina Gupta

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Busra Susam

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**And especially the families
who participate!**



Agenda for Today

Emotion dysregulation:

- Emotions are stronger than regulatory capacity
- Cannot adequately modify the intensity or duration of emotional responses
- Interferes with goals

Our work on:

- Assessment
- Outcomes
- Risk factors
- Intervention



Where it all began



Do you want to
help make a
miracle?



*“once he starts to
have a meltdown,
it continues to
escalate and
there is no talking
him down”*

“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

“After 9 months of intensive sessions twice a week- results nothing short of miraculous. This, after trying every other type of therapy and medication out there. **Without addressing her emotion regulation issues, nothing else was possible.**”

– Mom of a young adult female with ASD

One major barrier –

Hard to study (or treat) what you can't (properly) measure

- Measures not developed or evaluated in ASD
- Measures not appropriate for use across the autism spectrum



Paul
Pilkonis, PhD




Lan Yu, PhD

Development of the Emotion Dysregulation Inventory: A PROMIS[®]ing Method for Creating Sensitive and Unbiased Questionnaires for Autism Spectrum Disorder

Carla A. Mazefsky¹ · Taylor N. Day^{1,4} · Matthew Siegel² · Susan W. White³ · Lan Yu¹ · Paul A. Pilkonis¹ · For The Autism and Developmental Disabilities Inpatient Research Collaborative (ADDIRC)

RESEARCH ARTICLE

The Emotion Dysregulation Inventory: Psychometric Properties and Item Response Theory Calibration in an Autism Spectrum Disorder Sample

Carla A. Mazefsky , Lan Yu, Susan W. White, Matthew Siegel, and Paul A. Pilkonis

928

Autism Research 11: 928–941, 2018

INSAR

JOURNAL OF CLINICAL CHILD & ADOLESCENT PSYCHOLOGY
<https://doi.org/10.1080/15374416.2019.1703710>



Psychometric Properties of the Emotion Dysregulation Inventory in a Nationally Representative Sample of Youth

Carla A. Mazefsky^a, Lan Yu^b, and Paul A. Pilkonis^a



Parent Input From the Beginning

- Item generation
 - “My child goes from 0 to 100”
- Item refining – Cognitive Interviews
 - In your own words, can you describe what this means?





Recruited online through national autism research registry

N = 1,323

Clinical ASD diagnosis + SCQ > 12
Mean age = 12; Range 6-17.9
13% IQ < 70
42% minimally verbal
20.9% female



N = 432
[N = 1,441 now]

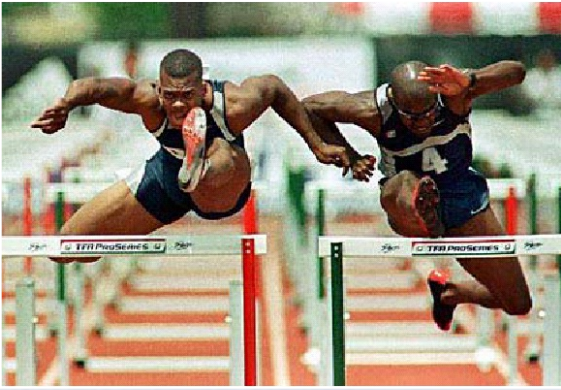
6 site study (now 3) of 4- 20-year-olds (mean of 12) with ASD admitted to specialized psychiatry units
ADOS-confirmed ASD
48% minimally verbal, 42% Intellectual Disability



N = 1,000

US census-matched youth recruited through a polling company

Mean age = 12; Range 6-17.9
78.9% White, 17.6% African-American
17.5% Hispanic



IRT Advantages



**Rare tool that can be used
across any verbal or
intellectual ability**

**Sensitive to change
Has norms and cut-offs**

Brief, efficient, and precise

The Emotion Dysregulation Inventory

Reactivity



- Has explosive outbursts**
- Has extreme or intense emotional reactions**
- Emotions go from 0 to 100 instantly**
- Has trouble calming him/herself down**

Dysphoria

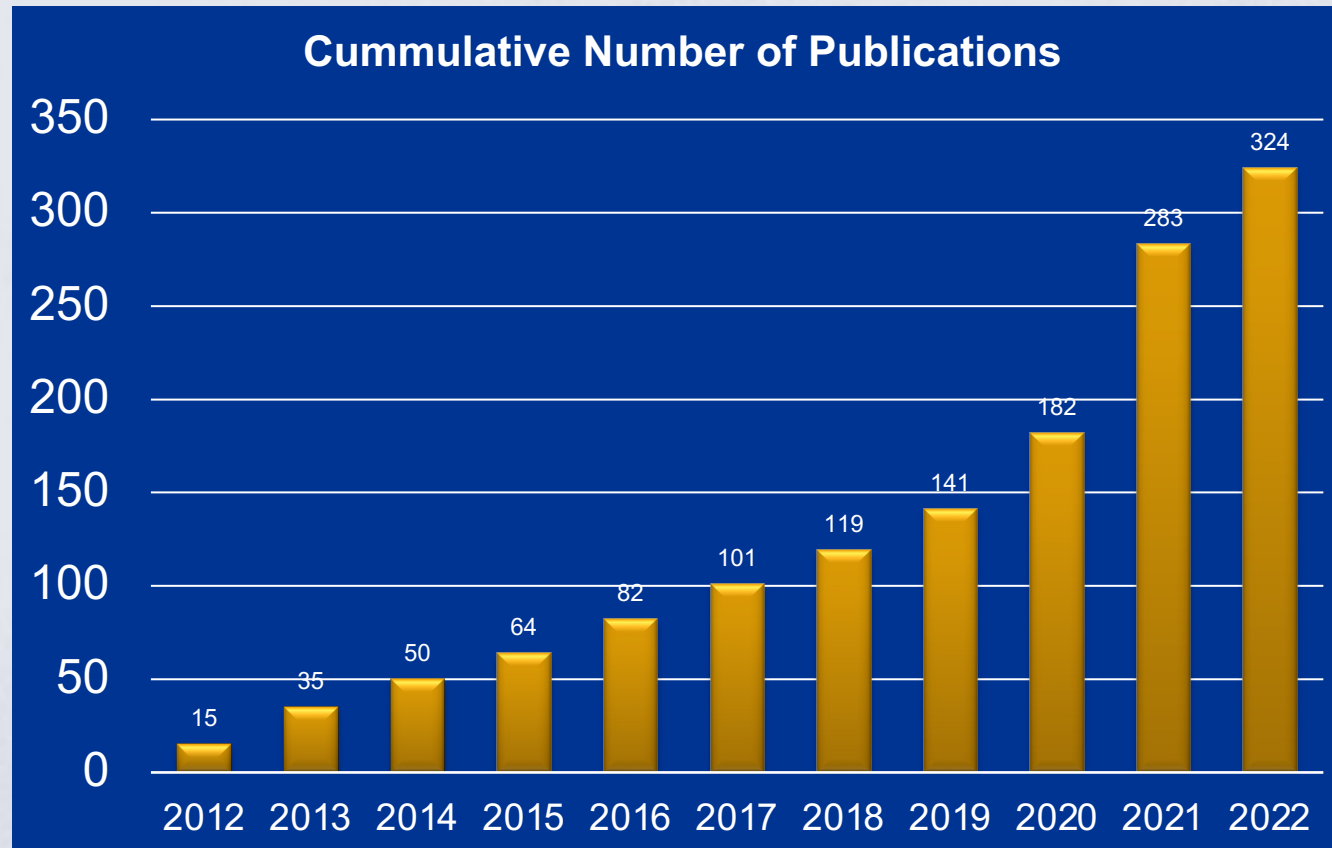


- Does not seem to enjoy anything**
- Not responsive to praise or good things happening**
- Seems sad or unhappy**
- Appears uneasy through the day**

JOURNAL OF THE AMERICAN ACADEMY OF CHILD & ADOLESCENT PSYCHIATRY
VOLUME 52 NUMBER 7 JULY 2013

The Role of Emotion Regulation in Autism Spectrum Disorder

Carla A. Mazefsky, Ph.D., John Herrington, Ph.D., Matthew Siegel, M.D.,
Angela Scarpa, Ph.D., Brenna B. Maddox, M.S., Lawrence Scahill, M.S.N., Ph.D.,
Susan W. White, Ph.D.



Abstracts
with:
“Emotion
Regulation”
and
“Autism”

That doesn't even capture ongoing work

EDI Use Across the Globe



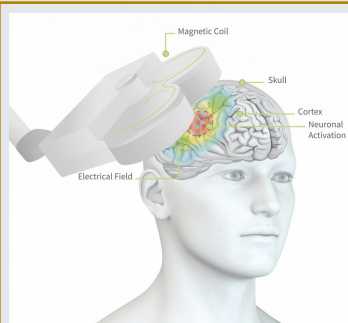
Interesting ways the EDI is being put to good use!

Universal Screening

- UPMC
- UCSF
- Karakter child and adolescent psychiatry University Center, Netherlands
- Children in custody of a welfare program in New Zealand
- Schools, private practices

Progress monitoring and clinical trials –

- Forensic setting in Australia - Joseph Allan Sakdalan, PhD
- OT programs in Canada, Chile,...
- Mindfulness treatment studies –Regulating Together, AZ, France
- Neuroptimal Neurofeedback –Thor Thor Hoberg Peterson in Denmark and across the world
- RCT of two diets in ADHD – EU consortium Eat2benice



Repetitive Transcranial Magnetic Stimulation (rTMS); Hsiang-Yuan Lin, M.D. Dr. Hsing-Chang Ni

Neural Synchrony;
Susan Perelman, PhD
(Pitt now WashU)



Therapeutic Horseback Riding RCT; Robin Gabriels, PsyD, Colorado Children's



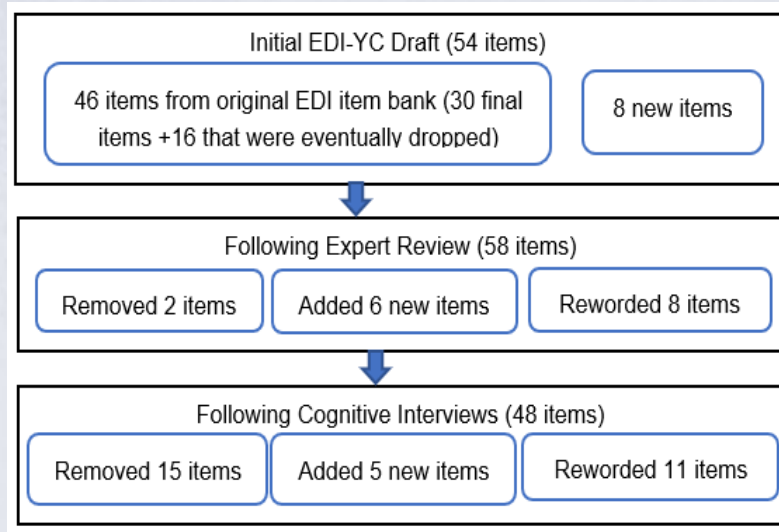
Ongoing Measure Development



- EDI Self-Report (11 through adulthood); adult norms for informant report
 - Almost done with cognitive interviews
- Adult Functioning Scale (AFS) – social, employment, autonomy, satisfaction
 - Launching psychometrics
- Positive and Negative Inventory (Foss-Feig, PI)
 - Collecting psychometric and validity data

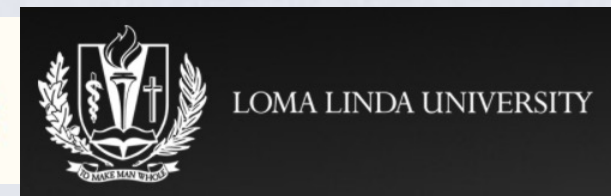


EDI- Young Child (ages 2-5)



Item development paper just accepted into the Journal of Autism and Developmental Disorders

Taylor Day, PhD



Autism spectrum disorder	Developmental disabilities/delays	Typically Developing
n = 983	n = 133	n = 1008

Predicting Uncertain Multi-Dimensional Adulthood Outcomes From Childhood and Adolescent Data in People Referred to Autism Services

Gordon Forbes^{1*}, Catherine Lord², Rebecca Elias² and Andrew Pickles¹

¹ Department of Biostatistics and Health Informatics, Institute of Psychiatry, Psychology and Neuroscience, King's College London, London, United Kingdom, ² Department of Psychiatry, University of California, Los Angeles, Los Angeles, CA, United States

“The aspects of the outcome related to symptoms of depression, contentedness with life and positive emotion, where we had the greatest challenges in making predictions, were amongst the areas given highest priority on average by parents.”

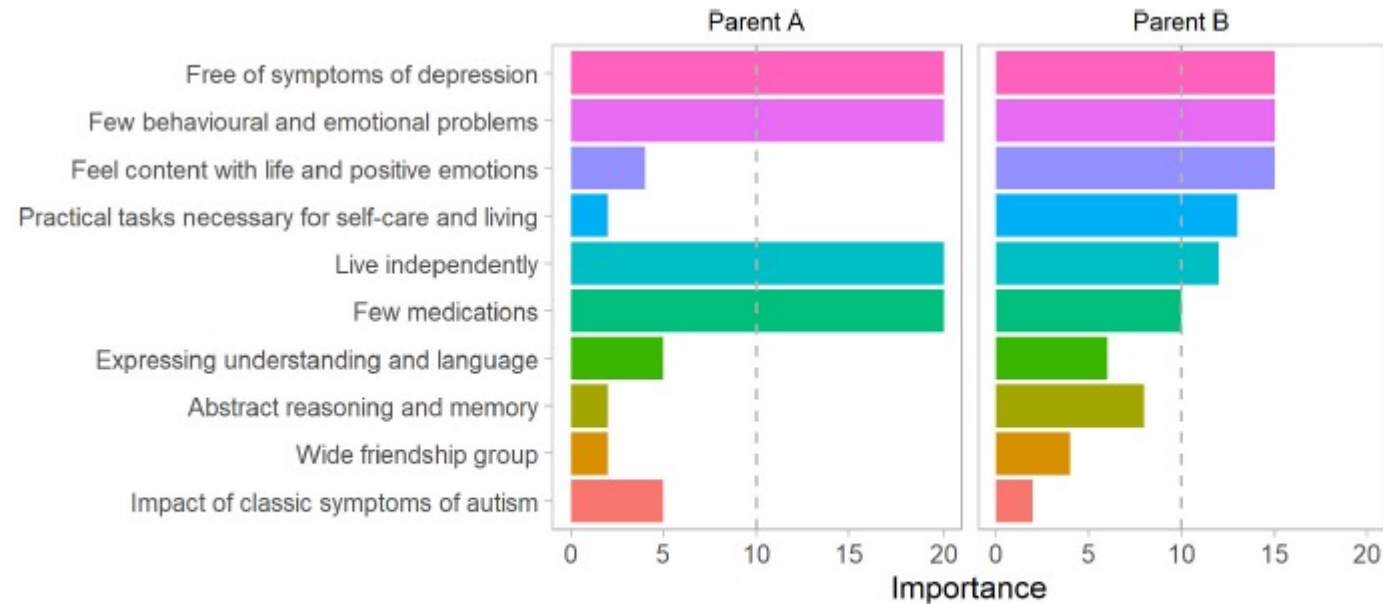
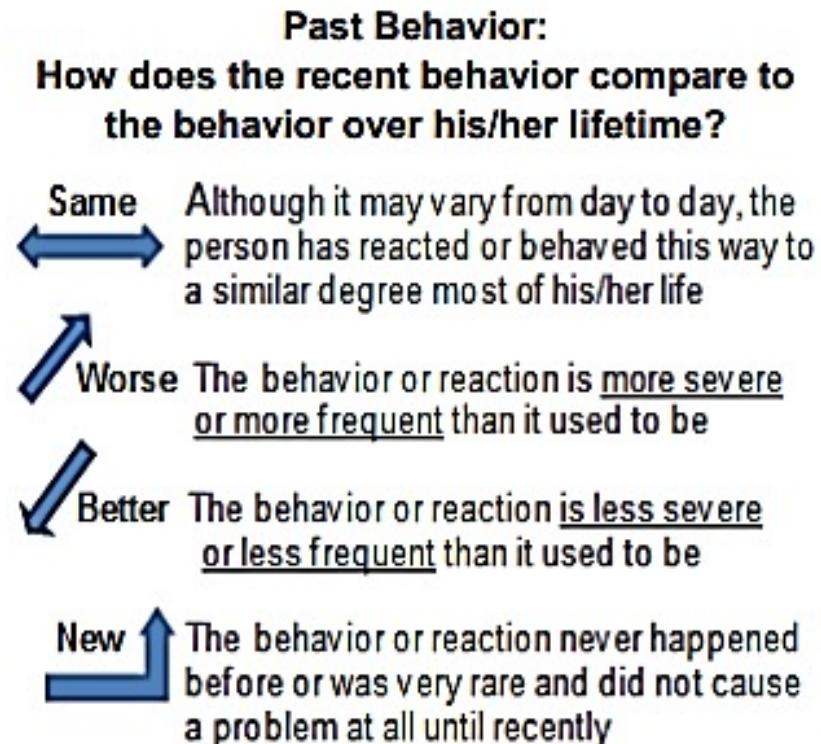
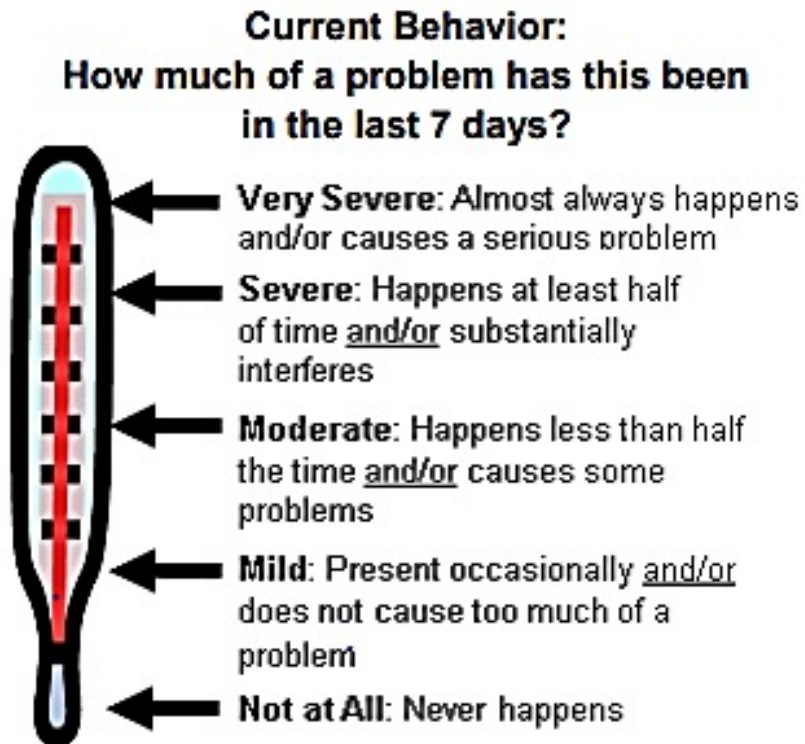


FIGURE 4 | Individual parent priority profiles for two parents. This figure shows outcome priorities elicited from two parents of autistic children, labeled parent (A) and (B). The dashed vertical line shows the priority that would be given if all outcomes were considered equal.



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

Jessie B. Northrup^a, Mark T. Patterson^b, and Carla A. Mazefsky^a

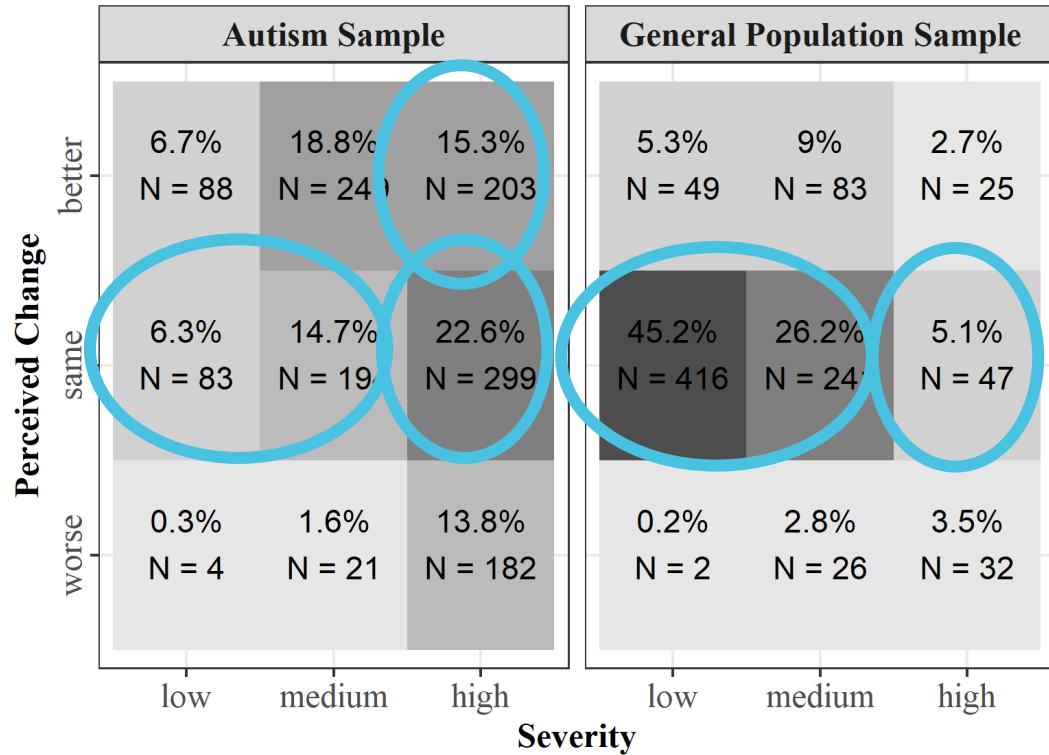


Jessie Northrup, PhD

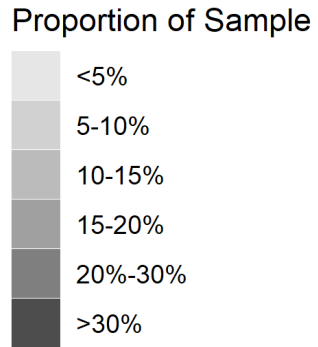
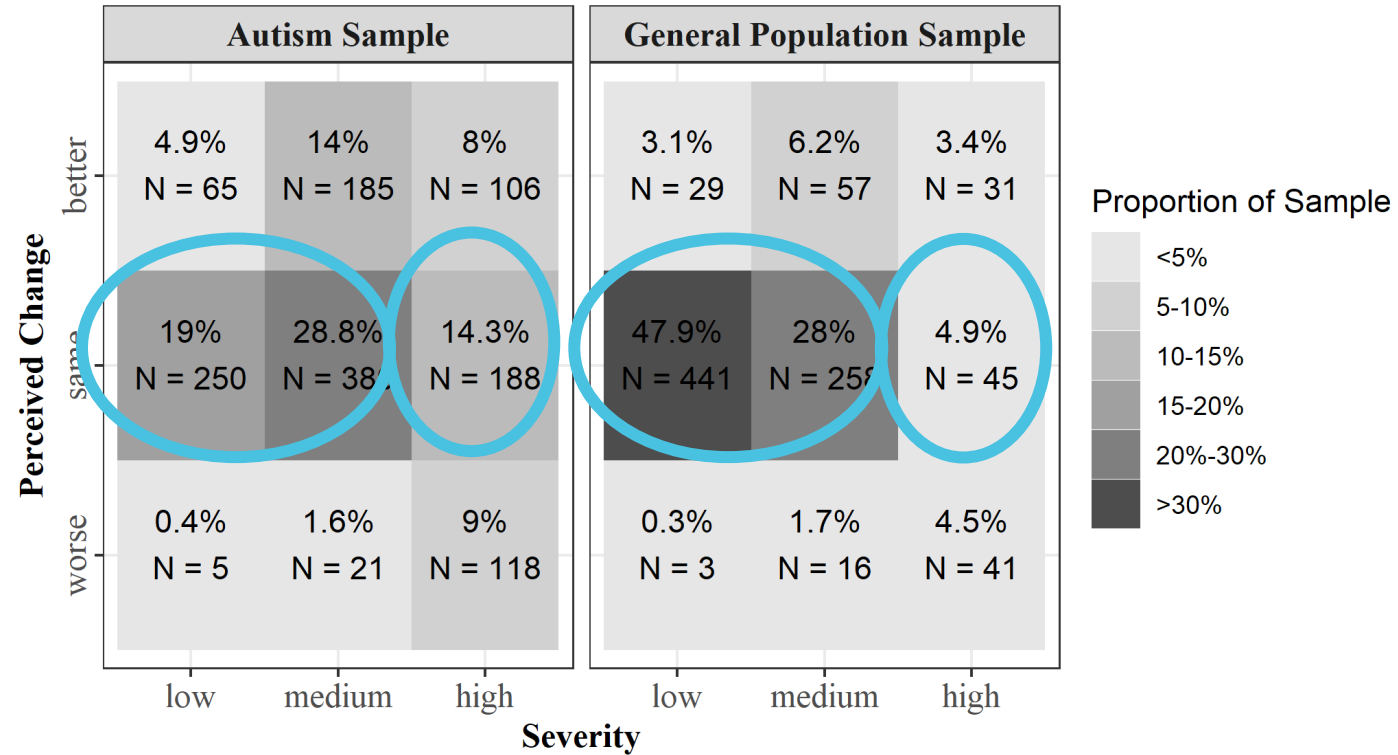
Predictors of Severity and Change in Emotion Dysregulation among Children and Adolescents with ASD

Jessie B. Northrup^a, Mark T. Patterson^b, and Carla A. Mazefsky^c

Reactivity



Dysphoria



Predictors within ASD

	Reactivity	Dysphoria (controlling for Reactivity)
Predictor	Severity	Severity
Age	↑ age, ↓ severity	↑ age, ↑ severity
Gender	Males ↓ severity	
Parent Education	↑ education, ↓ severity	
RRB	↑ RRB, ↑ severity	↑ RRB, ↑ severity
Intellectual Disability		Mild: ↓ severity Moderate to Severe: ↓ severity
Verbal Ability	Fluent ↑ severity	

Higher emotion dysregulation (on the EDI), then more likely to:

- Have depression symptoms, anxiety, and aggression
- More suicidal thoughts and behaviors

- Be on psychiatric medications
- Have had a crisis evaluation in the last two months (police contact, ER visit, in-home evaluation)
- Been admitted to a psychiatric hospital inpatient unit

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 

INSAR

Autism Research 14: 169-181, 2021

169



[Journal of Autism and Developmental Disorders](#)

pp 1-16 | [Cite as](#)

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

Authors

[Authors and affiliations](#)

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



Caitlin Conner, PhD

How do behaviors relate to one another in real time?

- Children and adolescents from the Autism Inpatient Collection (AIC) seen during their stay at an inpatient psychiatric hospital.

N = 53 participants
observed engaging in at
least one behavior

- 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



Jessie Northrup,
PhD

Live Coding

Emotion Dysregulation

Perseverative agitation
OR

Rapidly escalating, intense,
or labile negative affect and
difficulty calming down

Examples: Appearing angry or
irritable, crying, angry threats,
yelling/screaming,
throwing self to floor.

SIB

Behavior that may cause
injury to self
OR

Repetitive motor
movements that result in
injury to the person
themselves or have the
potential to inflict injury

Examples: Hitting self, biting
self, scratching self, banging
head.

Aggression

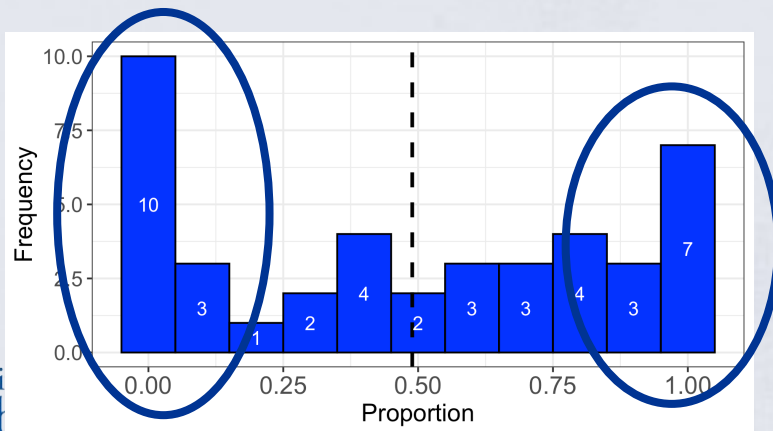
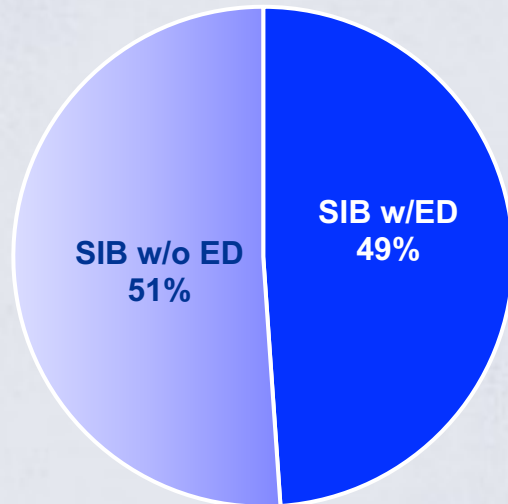
Behavior that may cause
injury or harm to others
OR

Forceful physical contact
with another person

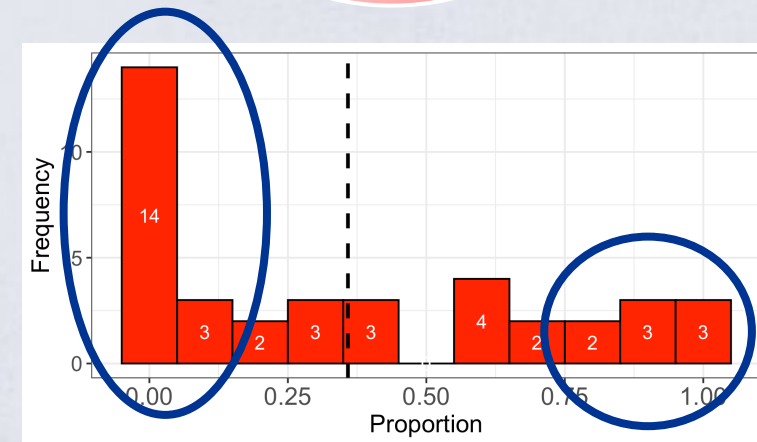
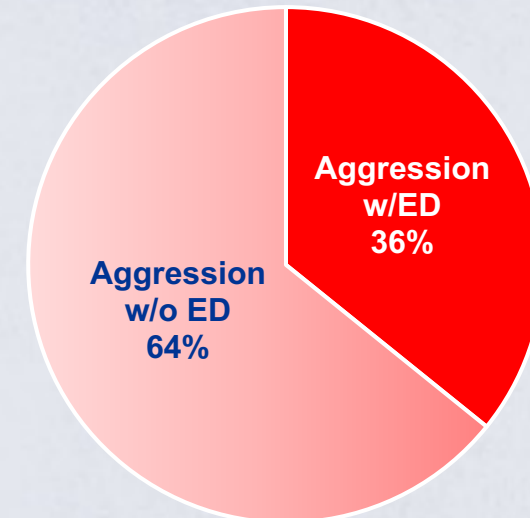
Examples: hitting, kicking, biting,
scratching, grabbing, pushing,
hair pulling.

How often do SIB and Aggression occur with vs. without overt Emotion Dysregulation?

Mean Percent of SIB intervals with Overlapping Emotion Dysregulation





Mean Percent of Aggression Intervals with Overlapping Emotion Dysregulation



Could we be missing something?

RESEARCH ARTICLE

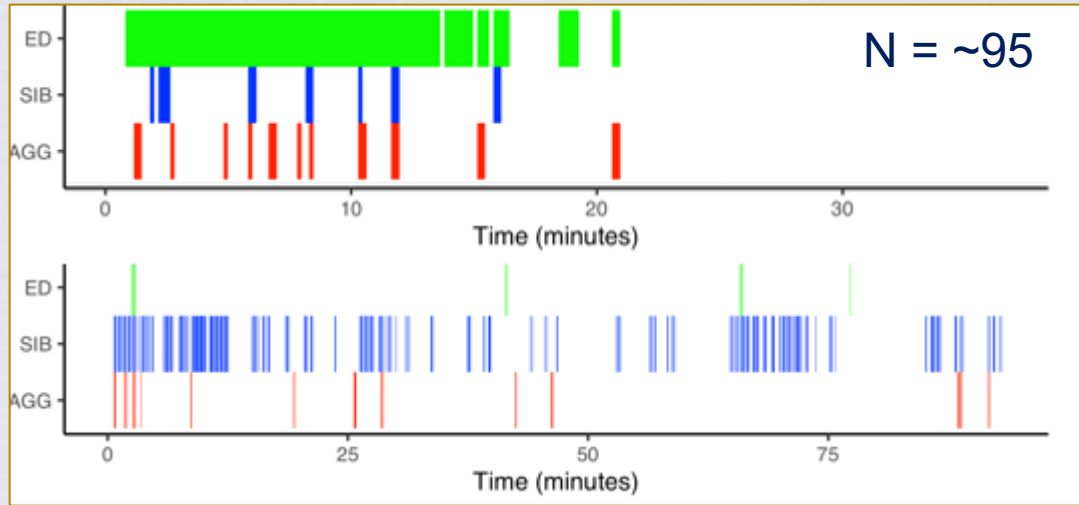
Predicting Aggression to Others in Youth With Autism Using a Wearable Biosensor

Matthew S. Goodwin , Carla A. Mazefsky , Stratis Ioannidis, Deniz Erdogmus, and Matthew Siegel

Unpredictable and potentially dangerous aggressive behavior by youth with Autism Spectrum Disorder (ASD) can isolate them from foundational educational, social, and familial activities, thereby markedly exacerbating morbidity and costs associated with ASD. This study investigates whether preceding physiological and motion data measured by a wrist-worn biosensor can predict aggression to others by youth with ASD. We recorded peripheral physiological (cardiovascular and electrodermal activity) and motion (accelerometry) signals from a biosensor worn by 20 youth with ASD (ages 6–17 years, 75% male, 85% minimally verbal) during 69 independent naturalistic observation sessions with concurrent behavioral coding in a specialized inpatient psychiatry unit. We developed prediction models based on ridge-regularized logistic regression. Our results suggest that aggression to others can be predicted 1 min before it occurs using 3 min of prior biosensor data with an average area under the curve of 0.71 for a global model and 0.84 for person-dependent models. The biosensor was well tolerated, we obtained useable data in all cases, and no users withdrew from the study. Relatively high predictive accuracy was achieved using antecedent physiological and motion data. Larger trials are needed to further establish an ideal ratio of measurement density to predictive accuracy and reliability. These findings lay the groundwork for the future development of precursor behavior analysis and just-in-time adaptive intervention systems to prevent or mitigate the emergence, occurrence, and impact of aggression in ASD. *Autism Res* 2019, 12: 1286–1296. © 2019 International Society for Autism Research, Wiley Periodicals, Inc.



Current Steps and Goal



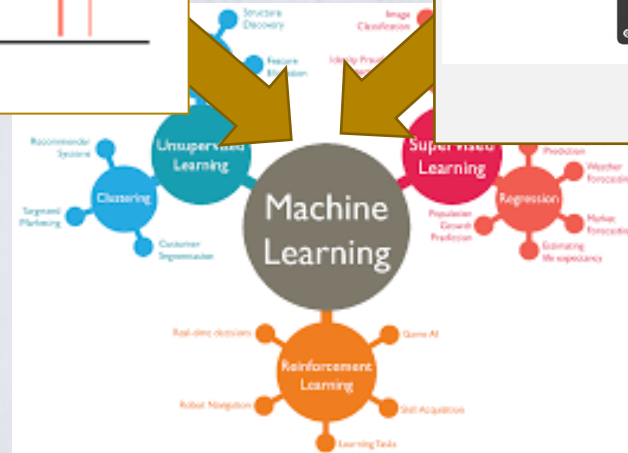
Battery life
Streaming Mode: 20+hrs
Memory mode: 36+ hrs

Data Management
Flash memory
Bluetooth LE (Smart)

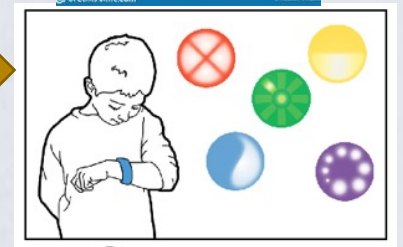
Form Factor
Small and comfortable
Case: 44 mm x 40 mm, height 16 mm
Weight: 25 gr

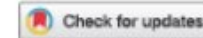
Certification
CE certification
FCC certification

Sensors
Photoplethysmography (PPG)
Continuous Heart Rate (HRV, Stress, Relaxation)
3-axis Accelerometer
Movement, Activity
Temperature + Heat flux
Activity, Context info
Electrodermal Activity (EDA)
Skin Conductance (Arousal, Excitement)



Matt Siegel (MMC), Lauren Bylsma,
Helmet Karim, Safaa Eldeeb





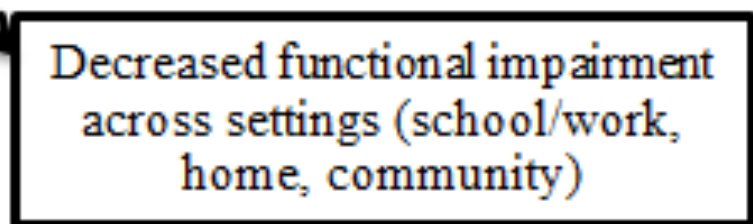
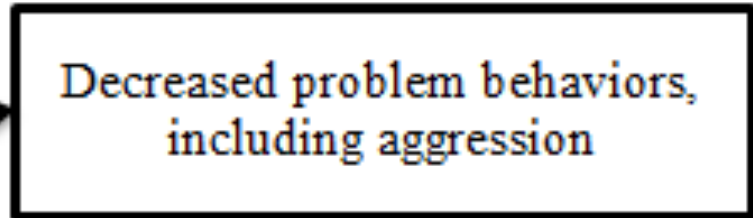
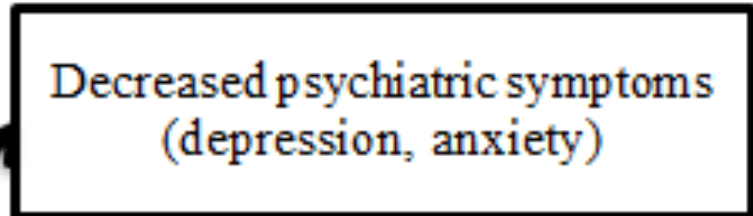
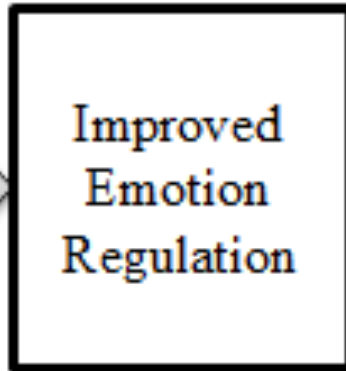
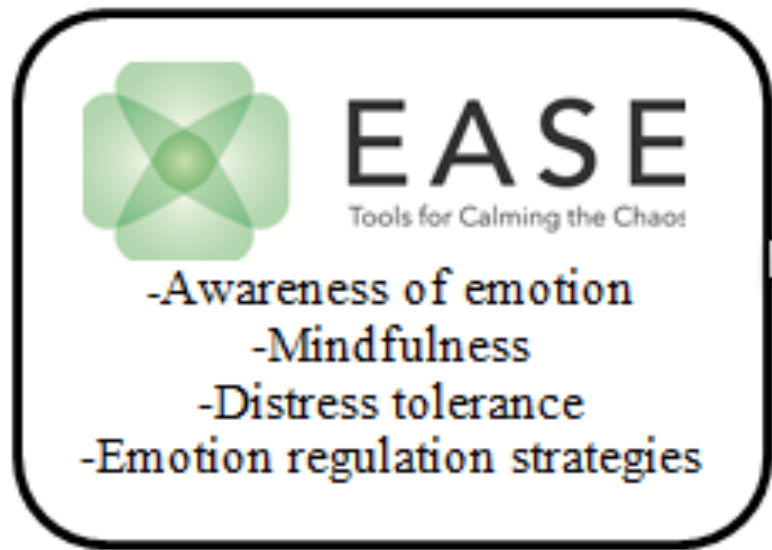
Clinical Update: The Implementation of Evidence-Based Emotion Regulation Treatment for Clients with Autism

Susan W. White, Caitlin M. Conner, Kelly B. Beck, and Carla A. Mazefsky

Suggestion	Examples
Add training in emotional psychoeducation	<ul style="list-style-type: none">● Help client understand that emotions are natural, even when they feel “bad”● Ensure understanding that negative emotions are unavoidable and that regulation is never perfect (setbacks do not mean starting over)
Train recognition of emotional intensity	<ul style="list-style-type: none">● Teach that awareness of emotional states is different from emotion identification and labeling● Emphasize noticing intensity (and change) in emotion strength and valence rather than identifying and labeling discrete emotions● Use media (e.g., favorite TV show) to identify emotion expressions and regulatory strategies
Evoke emotional content experientially	<ul style="list-style-type: none">● Work where event happened or bring in props (triggers) to try to reenact● Recordings (e.g., parent using their phone) from the situation can be useful to help client recall
Use visuals and other concrete means to scale intensity of emotions	<ul style="list-style-type: none">● Use emotion thermometers with client’s examples of situations, feelings to anchor written or visual session schedule● Use worksheets and props (e.g., ER strategies attached to “tools”)● Maintain session structure (and allow client to track progress, cross off agenda)
Adjust session duration, frequency, location	<ul style="list-style-type: none">● Longer sessions to allow slower pace, repetition of content, and more breaks during sessions● Longer treatment duration with more sessions (explained in beginning, at consent)● Consider having sessions in the “community” (e.g., mall, school, home) so that practice can occur in naturalistic environment and involve real triggers
Accommodate cognitive style	<ul style="list-style-type: none">● Consider addressing misconceptions or incorrect expectations of therapy, owing to “black-and-white” thinking (e.g., therapy won’t “fix” the problem)● Use straightforward statements and feedback● Avoid overquestioning; allow ample time for responses

Emerging Treatment Evidence

- **Stress and Anger Management Plan (STAMP)**, 5-7 year olds, CBT-based group intervention. 67% considered treatment responders (n=18).
 - Swain D, Murphy HG, Hassenfeldt TA, et al, 2019
- **Secret Agent Society: Operation Regulation.** ER activities (emotion awareness, mindfulness, acceptance) focus on generalization of new ER skills to school and home environment through exposure activities and practice. RCT with waitlist control (n=68). Moderate to large effect sizes on ER skills, lability/negativity and problem behaviors.
 - Weiss JA, Thomson K, Burnham Riosa P, et al, 2018
- **Regulating Together.** 8-12 year olds, group trial with children and parents, teaches and practices key regulation skills and parent management strategies (n=40) 53% judged responders.
 - Shaffer RC, Wink LK, Ruberg J, et al., 2019
- **Emotional Awareness and Skills Enhancement (EASE).** Open pilot trial with 12– to 17-year-olds with IQ greater than 80, ER impairment, anxiety, and depression symptoms decreased with medium-to large effect sizes (n = 20); RCT ongoing
 - Conner CM, White SW, Beck KB, et al., 2019
- **Dialectical Behavior Therapy (DBT).** Small case studies (Bemmouna et al., 2021, Hartmann et al., 2021, Sakdalan 2022)
- **RE-STAR.** Ongoing project to develop a school-based emotion regulation intervention for ASD and ADHD (King's College London)



Carla Mazefsky (PI),
Caitlin Conner, Kelly Beck



Susan White (Co-PI)

EASE development

- Manual draft – clinical experience, EDI development, emotion regulation research in ASD
- Stakeholder review
- Pilot study (n=20; 2 sites)
- Current RCT (n=80, 2 sites)
- EASE-Teams adaptation - Stakeholder-partnered manual adaptation study (micro trial n = 6 pilot trial n = 10)
- Qualitative interviews
- Manuals merged

Hopefully...Comparative Effectiveness Trial

Not a behavioral approach: Self-compassion & distress tolerance

“In a lot of places, the focus is on changing the behavior, not finding the cause or soothing methods, or not accepting. A lot of times autism spaces come across as ‘how can we make your kid not autistic,’ instead of ‘how can we make your child’s existence better.’”

Emotions ≠ Dysregulation

I've learned
that emotions
are part of me.

I've learned
emotions are
a
part of me

I can't avoid
them completely

I can't avoid
them
completely



Mindfulness May Help

- What it is- Paying attention to present moment sensations, thoughts, and emotions without judgment
- 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

Kabat-Zinn et al., 1985

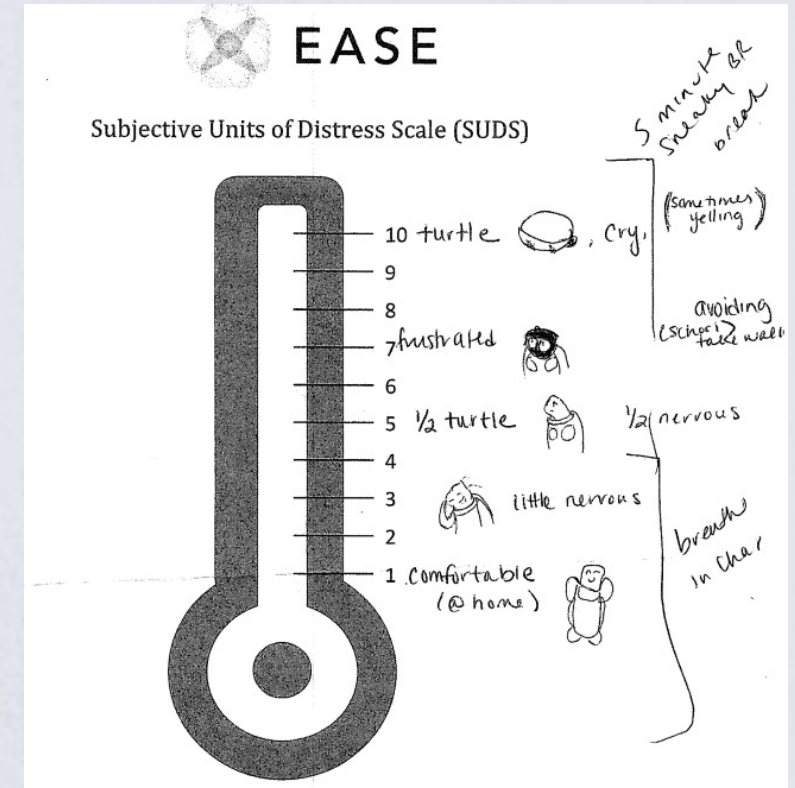
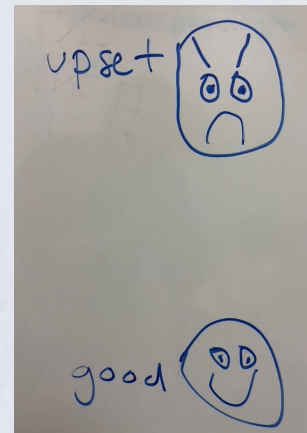
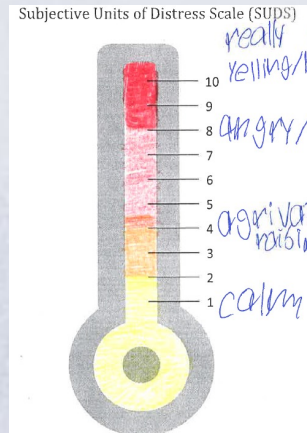
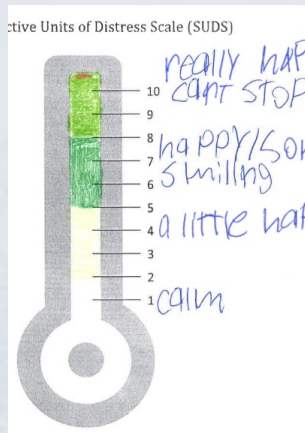


Awareness as the Foundation

“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”

Noticing my Emotions Scale

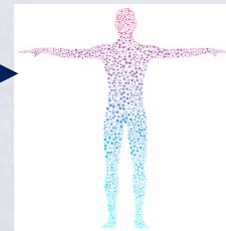
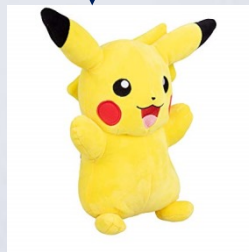
- Emphasis on **dimensional** rather than discrete emotions
- Finding a consistent “language”



Awareness Cultivated Through Mindfulness

“What did you notice in that meditation?” Response: “I don’t know”. “Did you notice anything in your body?” Response: “Calm.” “Great, where did you notice calm in your body?” Response: “I don’t know”. “Did you notice your breathing?” No response. “Emotions?” No response.

Client unable to identify body sensations, feelings, and thoughts






Mindfulness in the moment

- Examples:
 - External distraction options:
 - Pressing legs/thighs together while sitting
 - Holding a warm cup of water
 - Sensations petting stuffed animal
 - Squeezing stress ball/brain
 - Internal distraction
 - Focus on the feet (wiggling toes, walking)
 - Identify neutral body sensation (breathing if client takes to this)
 - Grasping hands tightly



Mindfulness “Here and Now”: Strategies for Helping Adolescents With Autism

Kelly B. Beck, PhD   • Caitlin M. Conner, PhD • Susan W. White, PhD • Carla A. Mazefsky, PhD

DOI: <https://doi.org/10.1016/j.jaac.2020.07.004> •  Check for updates

- Limit metaphors & imagery
- Longer meditations; more space
- Permissive language
- Review ‘rules’ each session
- Encourage routine practice
- Impromptu repetition
- Consider physical aide if needed



Practice – Mindfulness in Daily Life

- A lot of repetition – daily (or multiple times a day) practice
- Supported practice in natural situations
- Decrease overall reactivity – better able to try other strategies and control actions

Having helpful thoughts

“Just a little longer”

“Emotions are okay”

“I can try”



Thought = “No one likes me”

Distancing (Defusion)

“I’m having the thought that
no one likes me”

Reframing (Reappraisal)

“These kids aren’t into the
same things as me”

Team Approach

- What it is:
 - Be a **good model**: “I notice that I am getting _____, I am going STOP & Breathe.”
 - Be a **team**: Suggest doing it together: “I see you are _____” Let’s do_(strategy)___ together”
- What it is not:
 - Saying “just calm down” or “you need to breathe”
 - Asking “how are you feeling” or other processing of emotion

So far, so good...

- “My wife has never done any mindfulness stuff, and so, the meltdowns were the hardest for her. And she is able to handle half of them now. And she is able to calm her down, and she has never been able to do that before. [...] And so, that has been a huge help because I have someone else that I can go and say, ‘I need to tag you in because I am empty.’”
- “I learned that from [CLINICIAN] -- giving him that space to be able to make his own decision and come to it himself once he exposed enough to it. [...] He started meditating very regularly at bedtime now.”

**OUTSIDE
LOOKING IN**

High-functioning autism from one mother's perspective

by
Vivian M. Lumbard

April: I did two things today.

Me: Two things!?! What were they?

April: I asked for help in math class and my teacher helped me.

Me: That's great! I'm glad you're getting what you need by speaking up for yourself. What was the other thing?

April: I raised my hand to answer a question in science and I got it wrong.

Me: (confused) Okay, you got the answer wrong. What happened then?

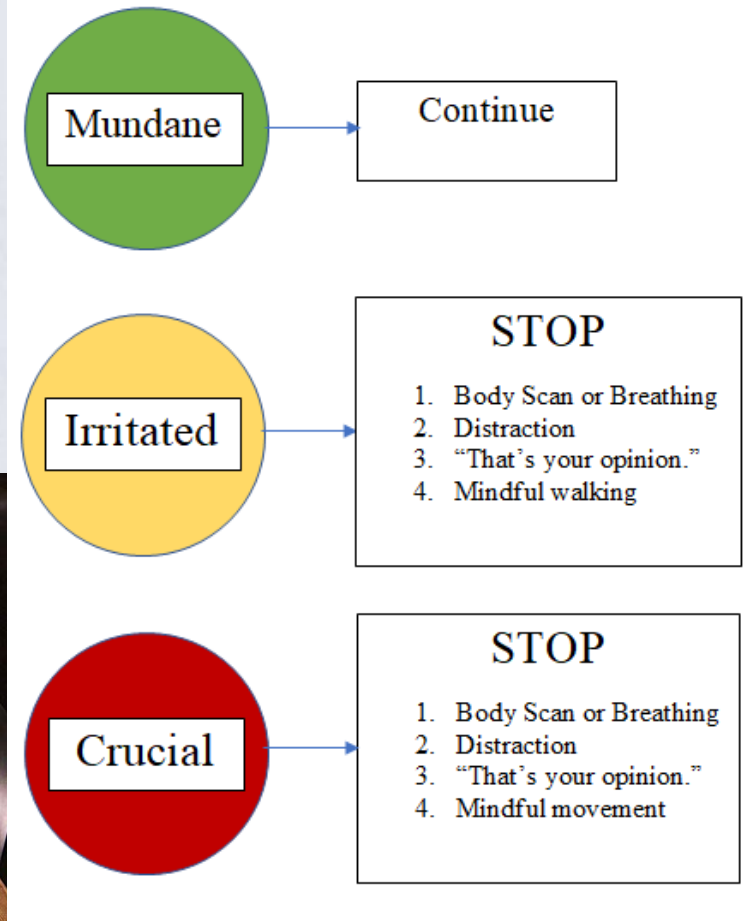
April: Mom, you don't get it. I got the answer wrong and I didn't think to myself, “I'm so stupid.” I didn't get upset for not having the right answer.

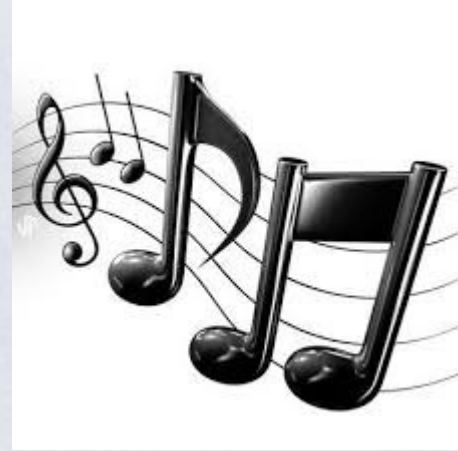
Me: (light dawning) Baby girl, that's fantastic! I'm so proud of you.

18-year-old young man

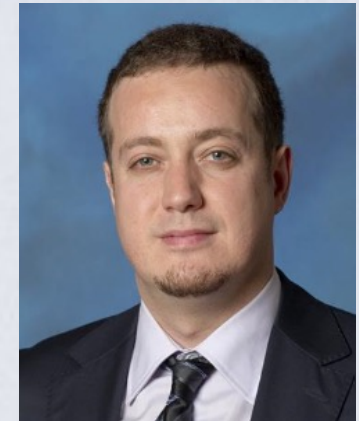
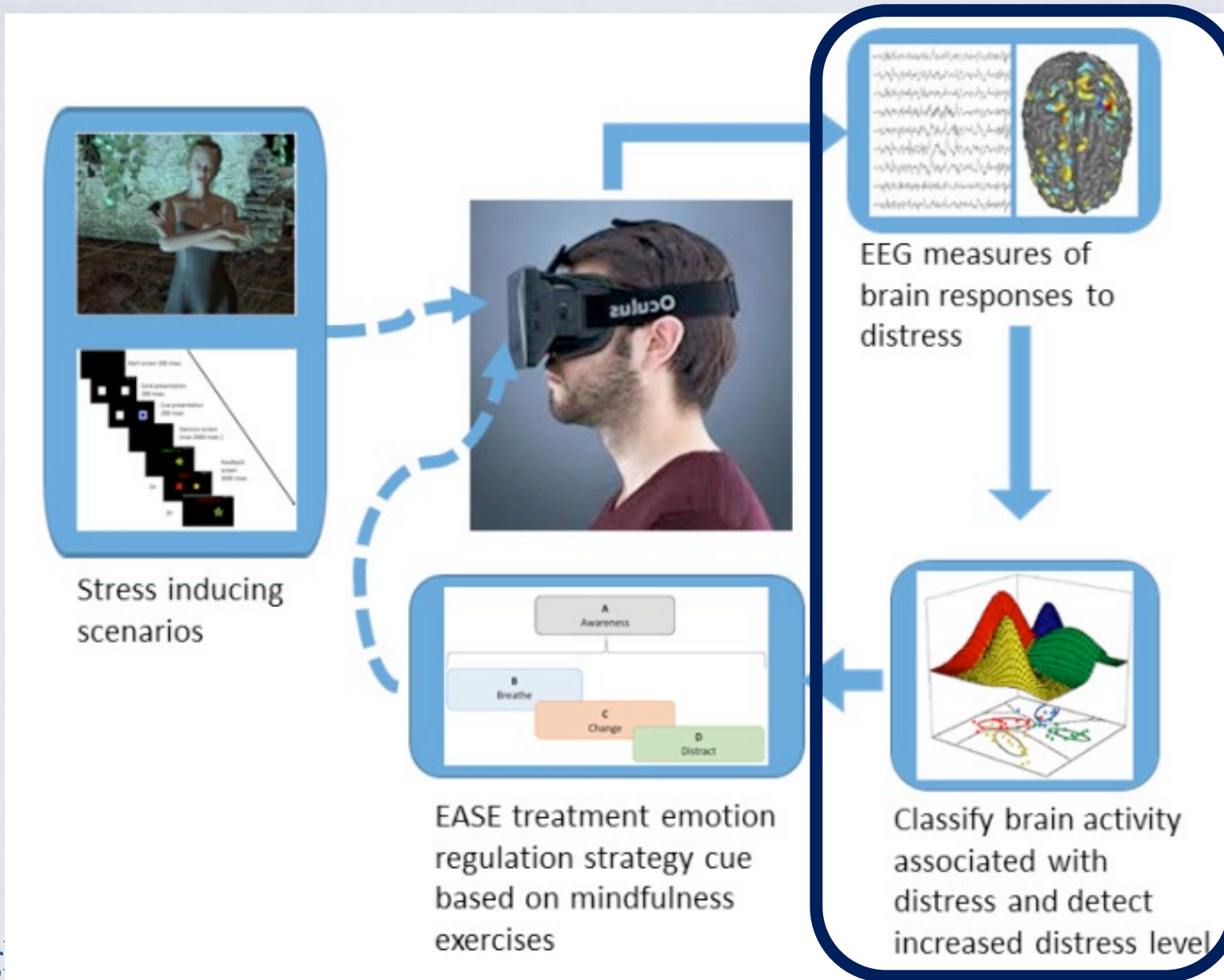


Final Community Session





Towards a Biologically Informed Intervention for Emotionally Dysregulated Adolescents and Adults with ASD



Murat Akcakaya

National Science Foundation Award - CAREER:

EASE for All

Goal: Identify facilitators and barriers influencing optimal implementation of EASE in community settings

- **Focus groups with 5 community mental health clinics**
- **Semi-structured interviews:**
 - **Caregivers of adolescents and adults with ASD**
 - **Adolescents with ASD**
 - **Adults with ASD**
 - **Community-based clinicians**

Kelly Beck's KL2 Scholar Aim & Edith L. Trees Trust Foundation Award



Kelly Beck, PhD

Autism 'Service Cliff'

97% of the funded ASD research in the United States has focused on youth

Projected 1,116,000 adults with ASD by 2030

Shattuck et al., 2020

General lack of research on any psychosocial treatment for adults

Poor adult outcomes & high societal costs



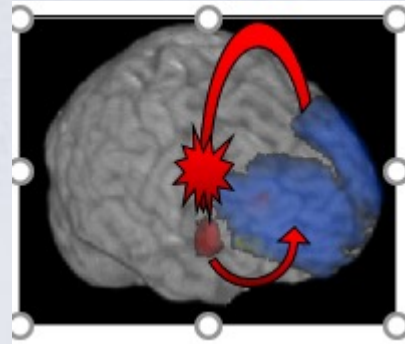
EASE Potential Adult Modifications

Theme	Selected quote	Ideas for Intervention
Less reactivity; burnout	“I need to ride the meltdown wave, but I have to push it down. It’s exhausting.”	Reasonable accommodations; ‘meltdown’ plans.
Utility of CBT	“Many situations cannot be reduced to faulty thinking patterns”	Focus on autism acceptance / self-compassion, validation
Sensory Component	“Sometimes I cannot tell if I am feeling emotions or sensory sensitivities.”	Mindful awareness of physical sensory needs
Lack of autism acceptance	“People need to understand autism. I’m not the only one that needs to change”	Participatory approach



Other Needs & Future Directions

- Developing sensitive suicidality measures and improving understanding of suicide risk
- Underlying mechanisms for emotion dysregulation



- More attention on adults with high support needs and SIB/aggression
- Longitudinal studies



It's not always easy, but
any mountain can be
climbed.



Thank you! Questions?

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Coming soon through SPARK!
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