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

Carla A. Mazefsky, PhD
mazefskyca@upmc.edu

Professor of Psychiatry, University of Pittsburgh School of Medicine
Director, Regulation of Emotion in ASD Adults, Children, and Teens (REAACT) Program; www.reaact.pitt.edu
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The work of many – Thank you!

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Josh Golt
Alexis Brewe
PJ McCarroll
Shannon Porton
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Pittsburgh Autistic Adult Research Collaborative
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

Eastern State Hospital is the oldest psychiatric hospital in the United States. It was established on 12 Oct. 1773, when Virginia was still a British colony, with the mission of treating and discharging the curable mentally ill. In 1641, under the leadership of John Minson Galt, the hospital initiated new reforms characterized as "moral management," a self-directed form of rehabilitation that changed the social perception and treatment of mental illness in America. Beginning in 1955 and ending on 28 Jan. 1970, the entire institution gradually moved to Dunbar Farm.
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
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. Day¹ · Matthew Siegel² · Susan W. White³ · Lan Yu² · Paul A. Pilkonis⁴ · 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

JOURNAL OF CLINICAL CHILD & ADOLESCENT PSYCHOLOGY
https://doi.org/10.1080/15374416.2019.1700710

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

Carla A. Mazefsky*, Lan Yu*, and Paul A. Pilkonis*
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?
**IAN: Interactive Autism Network**

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

Recruited online through national autism research registry

**AIC: Autism Inpatient Collection**

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 = 432
[N = 1,441 now]

**YouGov**

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

N = 1,000
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
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
- Neurooptimal 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

| SPARK | Pitt CTSI | Pediatric PittNet | Loma Linda University |

<table>
<thead>
<tr>
<th>Autism spectrum disorder</th>
<th>Developmental disabilities/delays</th>
<th>Typically Developing</th>
</tr>
</thead>
<tbody>
<tr>
<td>n = 983</td>
<td>n = 133</td>
<td>n = 1008</td>
</tr>
</tbody>
</table>
“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.”
Predictors of Severity and Change in Emotion Dysregulation among Children and Adolescents with ASD

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

Current Behavior:
How much of a problem has this been in the last 7 days?

- Very Severe: Almost always happens and/or causes a serious problem
- Severe: Happens at least half of the time and/or substantially interferes
- Moderate: Happens less than half of the time and/or causes some problems
- Mild: Present occasionally and/or does not cause too much of a problem
- Not at All: Never happens

Past Behavior:
How does the recent behavior compare to the behavior over his/her lifetime?

- Same: Although it may vary from day to day, the person has reacted or behaved this way to a similar degree most of his/her life
- Worse: The behavior or reaction is more severe or more frequent than it used to be
- Better: The behavior or reaction is less severe or less frequent than it used to be
- New: The behavior or reaction never happened before or was very rare and did not cause a problem at all until recently
### Reactivity

<table>
<thead>
<tr>
<th>Severity</th>
<th>Autism Sample</th>
<th>General Population Sample</th>
</tr>
</thead>
<tbody>
<tr>
<td>low</td>
<td>6.7% (N=88)</td>
<td>5.3% (N=49)</td>
</tr>
<tr>
<td>medium</td>
<td>18.8% (N=24)</td>
<td>9% (N=83)</td>
</tr>
<tr>
<td>high</td>
<td>15.3% (N=203)</td>
<td>2.7% (N=25)</td>
</tr>
</tbody>
</table>

### Dysphoria

<table>
<thead>
<tr>
<th>Severity</th>
<th>Autism Sample</th>
<th>General Population Sample</th>
</tr>
</thead>
<tbody>
<tr>
<td>low</td>
<td>4.9% (N=65)</td>
<td>3.1% (N=29)</td>
</tr>
<tr>
<td>medium</td>
<td>14% (N=185)</td>
<td>6.2% (N=57)</td>
</tr>
<tr>
<td>high</td>
<td>8% (N=106)</td>
<td>3.4% (N=31)</td>
</tr>
</tbody>
</table>

### Perceived Change

<table>
<thead>
<tr>
<th>Severity</th>
<th>Same</th>
<th>Better</th>
<th>Worse</th>
</tr>
</thead>
<tbody>
<tr>
<td>low</td>
<td>0.3% (N=4)</td>
<td>1.6% (N=21)</td>
<td>13.8% (N=182)</td>
</tr>
<tr>
<td>medium</td>
<td>0.2% (N=2)</td>
<td>2.8% (N=26)</td>
<td>3.5% (N=32)</td>
</tr>
<tr>
<td>high</td>
<td>45.2% (N=416)</td>
<td>26.2% (N=24)</td>
<td>5.1% (N=47)</td>
</tr>
</tbody>
</table>

### Severity

- Low
- Medium
- High

### Proportion of Sample

- <5%
- 5-10%
- 10-15%
- 15-20%
- 20%-30%
- >30%
## Predictors within ASD

<table>
<thead>
<tr>
<th>Predictor</th>
<th>Reactivity</th>
<th>Dysphoria (controlling for Reactivity)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>↑ age, ↓ severity</td>
<td>↑ age, ↑ severity</td>
</tr>
<tr>
<td>Gender</td>
<td>Males ↓ severity</td>
<td></td>
</tr>
<tr>
<td>Parent Education</td>
<td>↑ education, ↓ severity</td>
<td></td>
</tr>
<tr>
<td>RRB</td>
<td>↑ RRB, ↑ severity</td>
<td>↑ RRB, ↑ severity</td>
</tr>
<tr>
<td>Intellectual Disability</td>
<td></td>
<td>Mild: ↓ severity</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Moderate to Severe: ↓ severity</td>
</tr>
<tr>
<td>Verbal Ability</td>
<td>Fluent ↑ severity</td>
<td></td>
</tr>
</tbody>
</table>
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
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.

Double coding performed on ~20% of observations for each case indicated good inter-rater reliability (mean kappa = .74).
How often do SIB and Aggression occur with vs. without overt Emotion Dysregulation?

Mean Percent of SIB intervals with Overlapping Emotion Dysregulation

- SIB w/o ED: 51%
- SIB w/ED: 49%

Mean Percent of Aggression Intervals with Overlapping Emotion Dysregulation

- Aggression w/o ED: 64%
- Aggression w/ED: 36%
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

N = ~95

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

<table>
<thead>
<tr>
<th>Suggestion</th>
<th>Examples</th>
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| Add training in emotional psychoeducation      | • 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        | • 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          | • 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 | • 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    | • 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                     | • 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.

- **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)
Susan White (Co-PI)

Carla Mazefsky (PI), Caitlin Conner, Kelly Beck

Decreased psychiatric symptoms (depression, anxiety)

Decreased problem behaviors, including aggression

Decreased functional impairment across settings (school/work, home, community)
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.’”
I’ve learned that emotions are part of me.

I can’t avoid them completely.

Emotions ≠ Dysregulation
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


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
• 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.”

---

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

Mundane

Continue

Irritated

STOP
1. Body Scan or Breathing
2. Distraction
3. "That's your opinion."
4. Mindful walking

Crucial

STOP
1. Body Scan or Breathing
2. Distraction
3. "That's your opinion."
4. Mindful movement
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

General lack of research on any psychosocial treatment for adults

Poor adult outcomes & high societal costs

Shattuck et al., 2020

Slide from Kelly Beck, PhD
## EASE Potential Adult Modifications

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

Coming soon through SPARK!
Adult Functioning Scale,
EDI Self-Report, and EXPAND studies!

To find out more about opportunities to participate in our research:
1-866-647-3436
autismrecruiter@upmc.edu