

Emotion Dysregulation in Autism Spectrum Disorder: Why it Matters and What We Are Doing About It

Q&A Follow-up

The following questions are adapted from those submitted during the Emotion Dysregulation webinar featuring Carla Mazefsky, Ph.D. Attendee questions were sent to Mazefsky following the webinar.

Understanding Emotion Dysregulation

1. Are there any common triggers for dysregulated emotion in individuals with autism? Are there signs to look out for that may indicate impending distress?
 - We show emotion and distress differently. We also respond uniquely to different situations and stressors, so triggers are also personal. That said, below are some of the common signs and indicators of dysregulation or distress.
 - Some common signs may include (Note: these may not be specific to emotion dysregulation and can be signs of other things such as bodily pain):
 - Whining
 - Rocking (especially if increased, out of the norm, or with other signs)
 - Clenching fists, tense body
 - Pacing
 - “No” – turning head to the side or away
 - Not answering or shutting down
 - Pushing toys or objects away
 - Increased escape or avoidance behaviors, such as silliness, roaming, or hyperactivity
 - Crying
 - Some common triggers include
 - Hunger, thirst, or pain
 - Being tired
 - Environments that are not sensory friendly
 - Transitions and changes, especially unexpected
 - Social rejection or hostility from peers

- Experiencing invalidation from others (someone not believing them, questioning their experiences)
 - Lack of acceptance of self or specific behaviors (repetitive behaviors being blocked)
 - Non-preferred activities or requests
 - Difficulty expressing needs and wants or difficulty communicating
2. Are there suggested dos and don'ts for parents and caregivers when approaching a situation of dysregulated emotion?

General concepts to keep in mind:

- This is not the same as misbehaving, which often has a goal (like avoiding a command).
- Identify triggers—maybe you identify particular times, places, or activities that are likely to precipitate distress. If able, ask the person if they know when they are about to have a meltdown. Can the person offer suggestions on how you can help? Are there signs you can look out for? Can they signal to you?
- Try to minimize known triggers, like overwhelming sensory environments and changes in routine. However, total avoidance is not suggested as that will prevent learning adaptive strategies.
- Prep the person ahead of time, including reminding them of one or two simple strategies to try.

Dos:

- Try to redirect attention early if you notice any warning signs. Try redirecting to calming activities: a preferred activity, fidget toys, listening to calming music, mindful breathing, or other strategies that have been taught for coping or emotion regulation.
- Reduce environmental stimuli: turn off music or the TV, turn off overhead lights, clear out other people.
- Give them space and time.
- Remain calm and monitor your voice volume. If two people are upset, the situation often escalates. So, assuming that it is safe to do so, walk away and take a moment to regain your composure.
- Use the person's name when talking and use simple statements.

- Develop a way to cue the person to use calming strategies (a verbal cue, a “coping card”).
- Acknowledge the feeling and model an accepting mindset about emotion – that having emotions is normal, even when the feelings are not positive.
- Simplify the task (“This seems really hard. Let’s do it one step at a time.”).
- Have a collaborative attitude – let’s solve this problem together.
- Try modeling calming strategies (“Let’s breathe together”). Note that it is helpful and important to model strategies even if the autistic person does not engage in doing it together.
- Maintain warm, neutral acceptance – they are doing the best they can with the tools they currently have.
- Remember that the person may be continuing to process the situation or may remain on “high alert” long after the meltdown has ended, so proceed slowly when re-engaging.

Don’ts:

- Do not ask a lot of questions.
- Do not ask how the person is feeling or why they are feeling this way. But you can help them understand by acknowledging their distress (“I see you are upset.”).
- Do not tell the person to “calm down,” “relax,” or “just breathe.” Even people who do not have autism rarely calm down on command, and such statements can escalate the situation and frustrate all parties involved.
- Do not demand eye contact.
- Do not try to talk the person out of a repetitive behavior or routine, as sometimes familiar rituals can serve a calming purpose or restore a sense of self-control.
- Avoid getting into a debate.
- Avoid placing additional demands or insisting on difficult tasks during clear signs of increasing distress.
- Be careful about letting meltdowns or behavior lead to getting out of non-preferred activities, as the behavior can become a learned response (re-introduce the task at a later time, with supports).

3. Have you found emotional dysregulation to be more common for individuals who have more severe difficulties with communication?

- Research findings on this are inconsistent – some find an association with communication ability, and some do not.
 - Research has not yet fully explored the nuances of communication as related to emotion dysregulation. It may be that the research needs to get more specific. It is likely that communication is more critical than speaking ability. And there are many forms of communication. When stressed, there may be greater difficulty in specifically communicating about emotions and in communicating effectively. It may be that the ability to make basic requests (when in a calm state) is unrelated to emotion dysregulation.
 - Overall, it may be that difficulty communicating poses an additional barrier. For example, it may be harder to express that something is bothering them or to ask for help or request external support for emotion regulation.
4. Do you think social rejection, exclusion, and other negative social experiences common to people on the spectrum may contribute to emotion dysregulation (for example, they know they are being rejected but do not know why)?
- These are situations that might lead to emotion dysregulation for anyone, autistic or not. However, autistic people may be more likely to face these challenges if they are in an unaccepting environment or peer group.
 - Anything that is a challenge requires the ability to manage emotions. Any time someone is hurt, they have to process what happened and regulate. So, yes, any of these examples would make it harder to regulate. The social experiences referenced in this question may be especially pronounced barriers to managing emotions when the individual does not also have supportive social partners. Also, if they experience many challenges, this can be additive and harder, especially if there isn't a lot of time in between to process.
 - It is also important to note that although viewing rejection and exclusion as challenging and upsetting may be most common, there is variability in this, as with almost everything. For example, some autistic adults note that a strength of their autism is that they do not crave external validation as much as their non-autistic peers. So, they are less bothered by some of these examples (like being excluded).

5. How do we encourage our autistic loved ones who have post-traumatic stress disorder (PTSD) from previous therapies to seek help?
 - Trauma experienced from therapy can occur (not always formally diagnosed as PTSD). Most often, autistic adults describe feelings of invalidation or downplaying of their experiences, which may or may not lead to PTSD. Regardless, prior negative experiences may create hesitancy around getting involved in therapy.
 - It is important to know that each doctor is different. It can help if there is someone trusted who can provide a recommendation and describe how the therapy would be different. Also, with the right doctor, the autistic person can learn how to advocate for themselves if trauma happens again.
 - When encouraging someone to try therapy in general, it can be helpful to frame it as finding someone who will better appreciate what they have been through versus seeking help. In other words, it can be helpful to not just frame it as a way to “fix” what is “wrong” with the autistic person. In addition to addressing mental health or vulnerabilities to stress that they may have, therapy can also be about validating their experiences and giving them skills to handle situations that may be challenging or environments that may be unsupportive.
6. How is emotion dysregulation in autism similar or different from emotion dysregulation in borderline personality disorder?
 - This is an under-researched question in terms of actual comparisons between people with borderline personality disorder and autistic people. Separate research on borderline personality disorder and autism seems to indicate some similarities in the presentation of emotion dysregulation. For example, both autistic people and those with borderline personality disorder may be prone to emotional reactions that come on fast, are strong, and are long-lasting. Studies have demonstrated that emotion dysregulation in those with borderline personality seems most pronounced in response to social stress (especially perceived rejection, abandonment, insult, etc.), whereas emotion dysregulation may be related to social situations in ASD, but it is also thought to be more global or general. However, emotion dysregulation in non-social situations has not been well studied in borderline personality disorder, so the idea of this possible

difference is uncertain (those with borderline personality disorder may also be more emotionally reactive in general).

7. How can self-injurious behavior (SIB) and aggression be seen as NOT dysregulated?
 - SIB and aggression are forms of behavioral dysregulation, but the question is how much they are related to emotion dysregulation.
 - Our data show that emotion dysregulation happens together with SIB and aggression for at least some autistic people. But, observable signs of emotion dysregulation are not always there. It could be that emotion is not expressed outwardly in a way that others can tell there is underlying distress.
 - There can also be non-emotional reasons for behavior, such as a pain response (in response to feeling pain or to increase bodily sensations), reactions to sensory stimulation, feeling threatened in some way, or some sort of reinforcement (getting out of a non-preferred task, receiving attention, etc.). Any of these types of reasons could contribute to SIB or aggression on their own, or, potentially, together with emotion dysregulation. Our research did not measure other contributors to SIB and aggression, but it does suggest that emotion dysregulation may be important to consider and address if it precedes or follows behavior.
8. How does attachment to others (or challenges with attachment) affect emotion regulation in children with autism?
 - Based on research, we don't yet know the answer to this in autism. But we do know that all children learn how to regulate emotions in large part through relationships with others, particularly their parents (starting with parent-led emotion regulation and co-regulation). There may be many factors that play a role in the co-regulation of emotion beyond attachment, such as the clarity of the child's emotional signals, which is research our team is beginning to undertake.
9. Do you see more emotion dysregulation across seasons? I'm a self-contained autism teacher and seem to always have more aggression and regulation issues with my students around this time of year (late winter/spring).



- There is not a lot of research on seasons and emotion dysregulation in autism. We do know that moods can change with seasons for all people. It is possible this may be more pronounced among those with greater underlying emotion dysregulation or who are autistic. However, this pattern is not seen just in autism, so it is not autism-specific.
- We know that physical activity can improve mood and the amount of physical activity may change with seasons.
- Sometimes the change of seasons can lead to overstimulation. And again, this is a change like any other change.

Questions about Emotion Dysregulation Research

1. Did you evaluate changes in emotional dysregulation during puberty?
 - Emotion dysregulation often increases during puberty in general. But it is important to remember that puberty is a long process. There may be periods with greater emotion dysregulation followed by maturation and improved emotion regulation ability.
 - There is limited research on puberty in autism, but we are beginning to look at this in our studies.

2. What strategies were helpful to children in your studies?

The ideas below are primarily informed by our work developing and testing the Emotion Awareness and Skills Enhancement (EASE) Program, which is a mindfulness-based intervention to improve emotion regulation. Here are some aspects of EASE that we think are helpful:

 - Help the person understand that emotions are natural and helpful, even “bad” or uncomfortable emotions. For example, anxiety can help us recognize a situation where we need to be careful.
 - Emotions become a problem when we lose control over them. This often happens when the emotions come on too fast or strong, or when they last a long time (difficulty calming down once upset). Sometimes emotions may get in the way of things we want to do. Therefore, the goal is not to feel no negative emotion, or even to relax. The goal is to be able to stay in control in the face of strong negative emotion.
 - Increasing awareness of one’s own emotions is an essential first step to managing them. We work with people to learn to notice the body sensations, thoughts, and situations when heightened emotions occur (and if possible, signs that emotion is getting stronger). For instance, a person may notice that when they are angry, they feel hot in their chest, clench their fists, or even feel their heart pounding faster. Often the people we work with describe not noticing that they were becoming upset until they were very upset.
 - EASE is focused on learning to identify changes in emotional intensity as opposed to being able to label or describe discrete emotions (for example, sad versus mad). The idea is to be able to identify changes in emotional intensity in sufficient time to employ an emotion regulation strategy,

before the individual becomes so dysregulated that this becomes too difficult.

- Mindfulness involves attending to present moment thoughts and emotions without judgment. This may be a useful strategy for promoting emotional awareness and regulation. Mindfulness can be cultivated through repeated meditation practices. Mindfulness is also thought to promote successful regulation through decreased reactivity.
 - Although we emphasize mindfulness as the primary strategy in EASE, we recognize that unhelpful thoughts can sometimes get in the way of emotion management. The role of thoughts is addressed through the introduction of strategies that fit with the person's cognitive profile. Some examples include:
 - Helper thought mantras – a simple phrase to apply to situations commonly experienced as frustrating, such as “That’s your opinion,” “Just a little longer,” or “I’m still learning.”
 - Reappraisal – learning to think about things in a way that may be less emotionally arousing.
 - Defusion – learning to remind yourself that a thought is just a thought, and that we can choose to act on our thoughts or not.
 - EASE was also designed to promote acceptance of self and fostering self-compassion, which can have positive effects on mental health.
3. The EASE treatment seems to help emotion reactivity – did you also see improvement with dysphoria?
- We see similar (large) improvements in both reactivity and dysphoria.
 - In fact, (so far) our data suggests that EASE is better than individualized supportive therapy for dysphoria in particular.
4. What role does alexithymia play? Does EASE therapy focus on emotion language acquisition?
- Alexithymia is the inability to recognize or describe one's own emotions.
 - We have seen a big range of emotional awareness in our EASE participants. Some really struggle with emotional awareness whereas others are very capable of noticing and labeling emotions but have trouble coping with emotions.

- EASE focuses on building skills to promote success in managing emotions. We think that being able to identify emotions is a fundamental part of this process, but this is different from emotion language acquisition. What we focus on is identifying changes in emotional intensity versus developing language for different types of emotions. (See above about EASE teaching emotion intensity instead of labeling).
- In EASE, we rely heavily on mindfulness to increase awareness of emotions through routinely scheduled meditation practices, which are easily tailored to support an individual's cognitive and verbal needs. Sometimes this is built gradually, starting with noticing external stimuli (such as the sound of the air conditioner blowing) and followed by something tangible (such as the sensation of a stuffed animal or other object) before noticing more internal processes (such as change in feelings in one's own body).
- Increased awareness (and emotion communication with others) is also supported in EASE through consistent and repeated use of a co-developed and personalized emotional "language" (may be non-verbal, can include colors, numbers, pictures of a preferred interest). This gives the autistic person and their family members (and anyone else in their lives) a way to express when they notice their emotions becoming more intense.



Online Resources about Emotions and Behavior in ASD:

Mental health: <https://paautism.org/resource/mental-health/>

Meltdowns: <https://autism.org.uk/advice-and-guidance/topics/behaviour/meltdowns>

Suicide: <https://paautism.org/resource/suicide-health-mood/>

Challenging behaviors: <https://www.autismspeaks.org/tool-kit/challenging-behaviors-tool-kit>

Mindfulness resources:

<http://www.mindful.org/>

<https://www.aheadforwork.com/>

<http://www.mindfulnessforteens.com>

Mindfulness practices streaming audio:

<http://marc.ucla.edu/body.cfm?id=22>

<http://mindfulnessforstudents.co.uk/resources/mindfulness-audio-guided-practices/>

Sample of a simple mindful breathing practice from EASE:

<https://www.react.pitt.edu/resources/>

Mindfulness books for children:

The following books and suggestions are made primarily for parents to use, or for parents to read with their child or teen. They are not intended to address severe problems with emotion regulation.

- Snel, E. Sitting still like a frog: Mindfulness exercises for kids (and their parents). Shambhala (2013)



- Willey, K. Breathe like a bear: 30 mindful moments for kids to feel calm and focused anytime, anywhere. Rodale Kids (2017)
- DiOrio, R. What does it mean to be present?. Little Pickle Press (2020)
- Grossman, L. Master of mindfulness: How to be your own superhero in times of stress. Instant Help (2016)
- Shapiro, L.E. The relaxation and stress reduction workbook for kids: Help for children to cope with stress, anxiety, and transitions. Instant Help (2009)
- McDonnell, P. The gift of nothing. Little, Brown Books for Young Readers (2005)