# Treating depression in autistic youth: Partnering with autistic people in clinical research and service

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- **Funding**: NIMH, The Saban Research Institute, and Las Madrinas Foundation
- **Practice**: One-day clinic and teaching at CHLA

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**Neurodiversity-affirming language in alignment with community preferences will be used throughout this presentation* (Kapp et al., 2016)

# Surgeon General Warns of Youth Mental Health Crisis

While Dr. Murthy noted the pandemic's effect on youth mental health, he also acknowledged that mental health issues among young people were already prevalent prior to 2020. Along with referencing the increasing number of **teen emergency room visits for mental health**, the advisory on youth and mental health cites CDC statistics showing a **40 percent increase** over the last decade in the number of high school students reporting persistent feelings of sadness and hopelessness. Moreover, suicide rates among teens and young adults have gone up by **57 percent** since 2007.

The Surgeon General advisory also explores the factors contributing to the youth mental health crisis. Some experts suggest that the statistics may reflect the growing willingness among young people to report and discuss mental health challenges. However, the advisory includes research pointing to a variety of other factors that are detrimental to youth mental health:

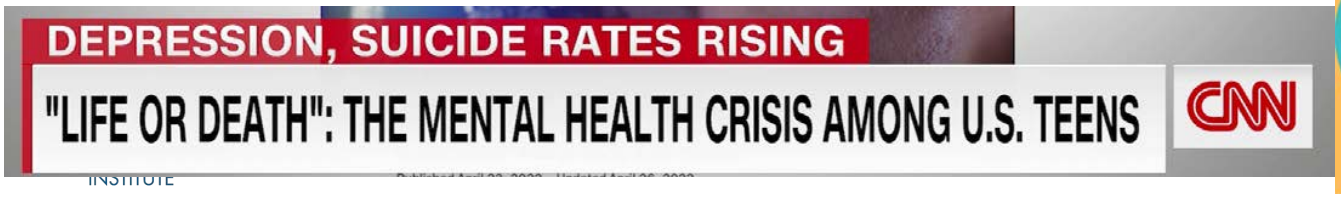




The New Yor

***'It's Life or Death': The Mental Health Crisis Among U.S. Teens***

Depression, self-harm and suicide are rising among American adolescents. For one 13-year-old, the despair was almost too much to take.





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# What do we know about mental health outcomes among autistic youth?

# Mental Health Outcomes in Autistic Youth

- 3-4x more likely to experience depression
- 6-8x more likely to experience anxiety
- 8-9x more likely to experience victimization
- 6-7x more likely to attempt suicide
- Far more likely to utilize emergency departments and psychiatric inpatient units – this is extremely costly
- Caregivers also at risk for mental health distress

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# Mental Health Outcomes in Autistic Youth

Historically, autistic people have been **systematically excluded** from mainstream mental health research & clinical trials…what are the **cascading effects**?

- Significant provider uncertainty in treating autistic people – reject referrals or refer out to nonexistent specialty providers
- Lack of provider training, education, and experience with autistic people
- Few evidence-based treatments, with most research in anxiety treatments
- Autistic people remain in perpetual states of crisis and cannot access care

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# Treating Depression in Autistic Youth:

## Where do we begin?

**We begin with lived-experience experts and community advocates**

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# Community-Based Participatory Research

- Recognizing the strength of each partner to collaborate on **all aspects** of a research (or clinical) project
- Needs assessment, planning, intervention design, implementation, evaluation, and dissemination
- Community members involved in the CBPR program as **equal partners**
- Shared power and decision-making increases project's **alignment** with community values and needs

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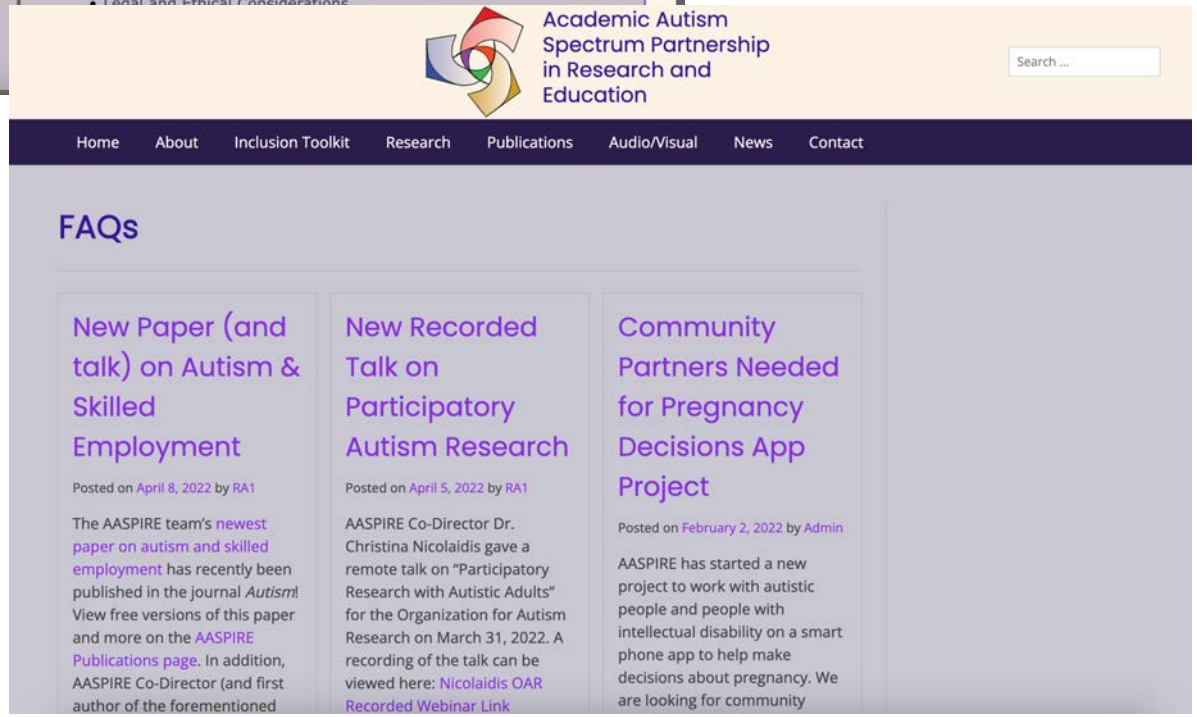
# Community-Based Participatory Research


https://autismandhealth.org/

# TREND Neurodivergent Advisory Team

- **Team**: Neurodivergent adults, caregivers, researchers, clinicians, and community members
- **Shared Goal**: Improve mental healthcare for neurodivergent youth and adults
- **Diverse Expertise**: Suicide assessment and prevention, Parent-child relationships, Clinical measurement and trials, Gender identity development, Latinx mental health

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# TREND Neurodivergent Advisory Team

- **Roles**: Co-Investigators, Co-Principal Investigators, Consultants, Group Facilitators, etc.
  - Formal designations – grants, institutions, etc.
  - Compensation – financial, authorship, presentations, etc.
  - Types and level of involvement discussed through meetings, written documents, and group discussions

- **Meetings:** Flexible format (e.g., group, individual) and method (e.g., phone call, texting, Zoom, in-person)

- **Decision Making**: Clearly defined at the outstart, shared and evenly distributed, and reviewed quarterly

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# TREND Neurodivergent Advisory Team

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**Dr. Ann Patterson** *(she/her)*
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*Interests: Parent-child relationships*

**Zack Williams** *(he/him)*
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*Interests: Sexual and gender diversity in autistic people*

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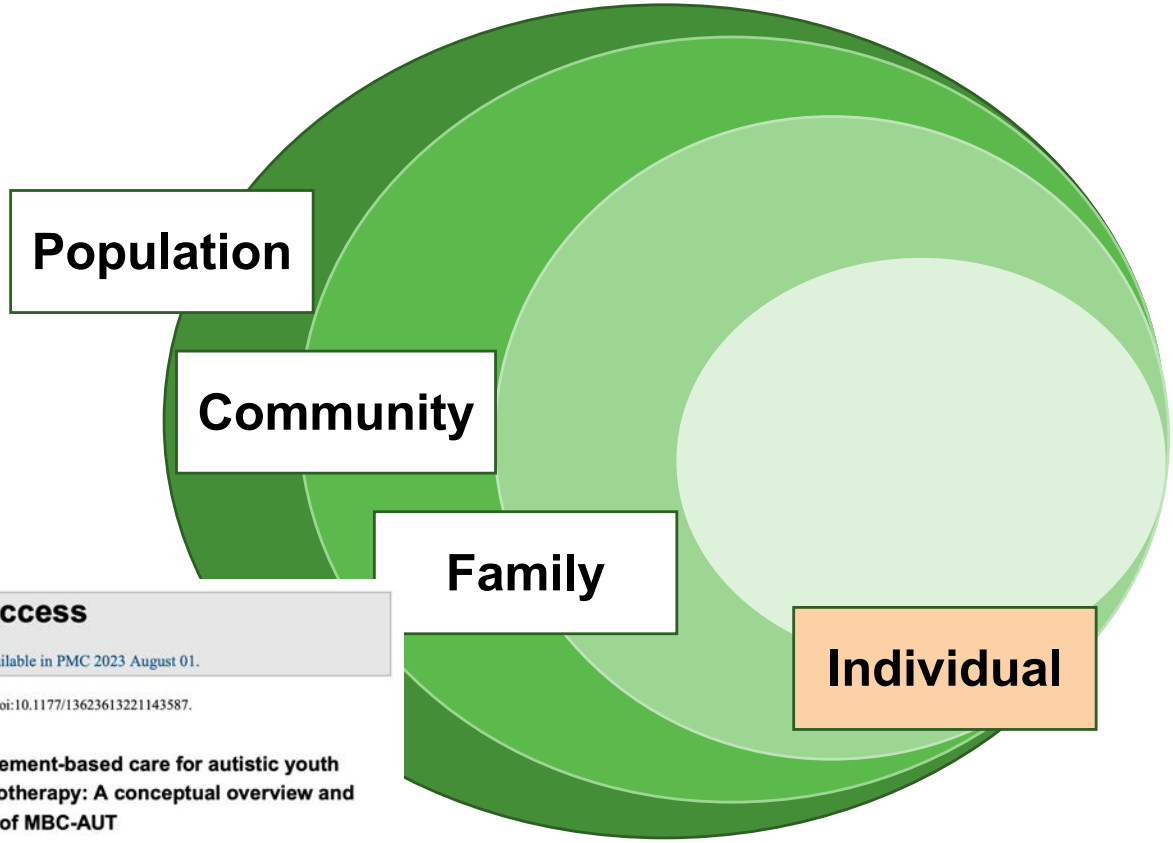




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## Community-guided measurement-based care for autistic youth and adults receiving psychotherapy: A conceptual overview and pilot implementation study of MBC-AUT

**Jessica M Schwartzman**[1], **Zachary J Williams**[1,2], **Ann V Paterson**[3], **Alexandra X Jacobs**[4], **Blythe A Corbett**[1,2]

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## Safety Planning for Suicidality in Autism: Obstacles, Potential Solutions, and Future Directions

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## Community-guided, autism-adapted group cognitive behavioral therapy for depression in autistic youth (CBT-DAY): Preliminary feasibility, acceptability, and efficacy

**Jessica M Schwartzman**[1,2], **Marissa C Roth**[2], **Ann V Paterson**[3], **Alexandra X Jacobs**[4] and **Zachary J Williams**[1,2]

# Cognitive Behavioral Therapy for Depression in Autistic Youth (CBT-DAY)

National Center for Advancing Translational Sciences

U.S. National Library of Medicine

ClinicalTrials.gov

Pre-registered Clinical Trial
NCT05430022

## Mood Group for Teens with Autism

Clinicians at Vanderbilt University Medical Center are offering autism-adapted ***Cognitive Behavioral Therapy (CBT) groups*** for teens with autism experiencing depression.

**Eligible Youth:**

- Have Autism Spectrum Disorder (ASD)
- Currently in middle school or high school

**Intervention**

- Youth: 12 group sessions *(Wednesdays 4:00-5:30pm)* at the VUMC Psychiatry Outpatient Clinic *(1500 21st Avenue South, Nashville)*
- Caregivers: 8 group sessions (*Wednesdays 4:00-5:30pm*) at the VUMC Psychiatry Outpatient Clinic
- Content: Autism-adapted Cognitive Behavioral Therapy (CBT)
  - Emotion Regulation
  - Relaxation Practices
  - Friendship Skills
  - Optimistic Thinking
  - Coping Skills
  - Boosting Self-Esteem
- Compensation: $30 per family per visit, for up to $90 total.

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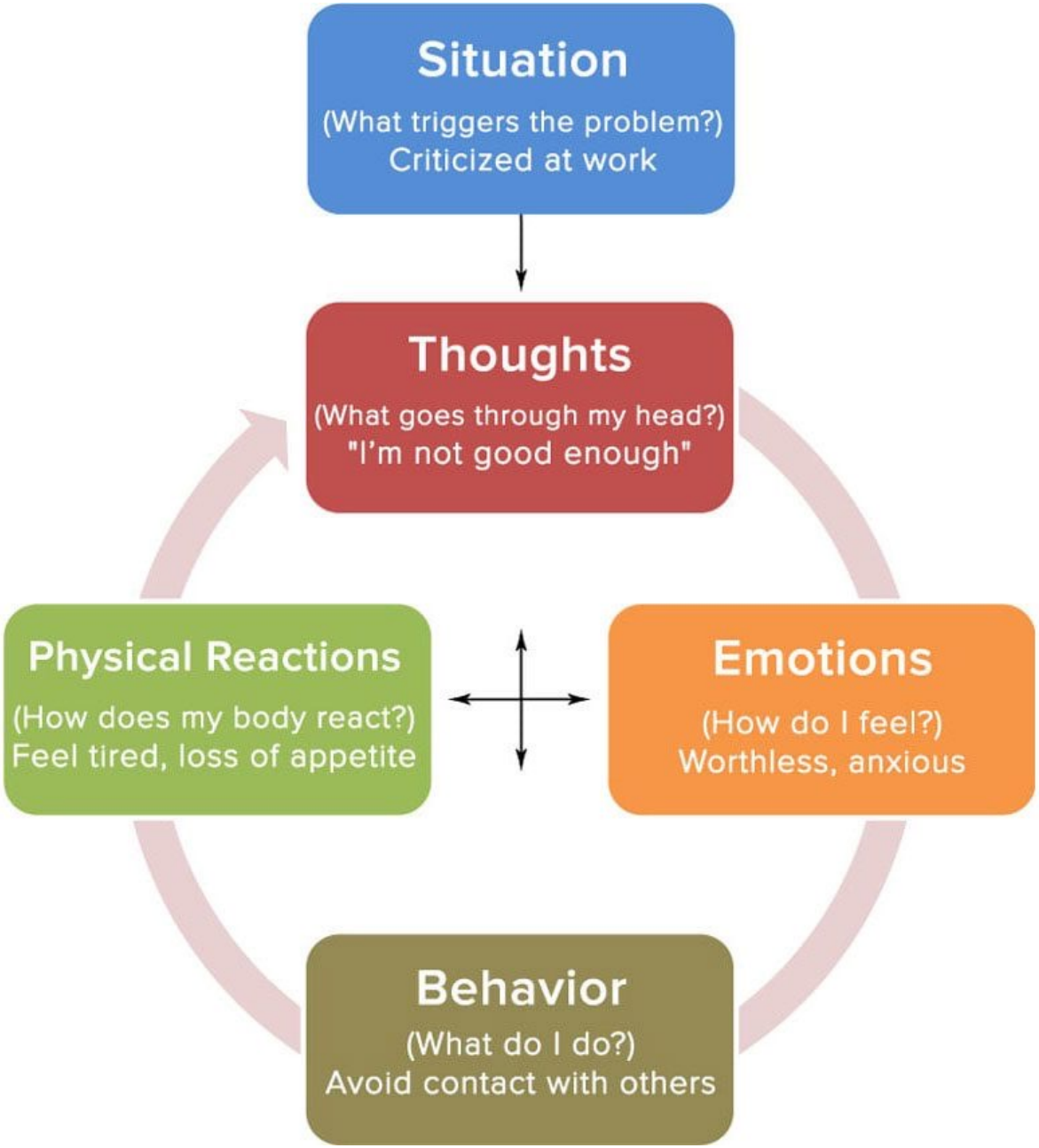
**For more information, contact:**
**Jessica Schwartzman, Ph.D.**
**Phone: (615) 343-9683**
**Email: jstrendlab@gmail.com**

# CBT Overview



# **CBT Adaptations:** What did we consider?

**Cognitive Styles**
Insistence on sameness, Concrete / formulaic approaches, perspective taking

**Affective Systems**
Alexithymia, distress intolerance, emotion regulation differences, autistic burnout

**Linguistic Features**
Minimally verbal, verbally fluent, nonverbal; Diversity in linguistic communication preferences

**Social Communication**
Diversity in social engagement, initiation, fulfillment, and context-dependent experiences

**Behaviors**
Stimming, routines or rituals, predictability and stability, isolation for regulation, etc.

**Sensory Experiences**
Hypo- or hyper-sensitivities to light, sound, texture, taste, smell, and interoceptive signals

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# CBT-DAY

- **Design**: Pilot nonrandomized trial with outcomes measured before, during, immediately after, and 3-months following treatment
- **Population**: Autistic youth (11-17 y.o.) with current depression presenting to clinic for care
- **Primary Outcome**: Reduction in depressive symptom severity
- **Target Mechanisms**: Negative self-esteem, Emotion dysregulation
- **Format**: 12-week outpatient group CBT (8-9 youth per group, 3 facilitators)

# **CBT-DAY:** Treatment Content

**Emotion Recognition and Regulation**

**Goal:** Identify emotions and intensity; Explore links between emotions and behaviors; Apply emotion regulation skills.

**Session 1:** Group Introductions and Expectations
**Session 2:** Psychoeducation and Emotion Equations
**Session 3:** Emotion Regulation Skills Part 1
**Session 4:** Emotion Regulation Skills Part 2

**Self-Esteem**

**Goal:** Identify thoughts of self and associations with emotions and behaviors; Identify and challenge negative thoughts of self.

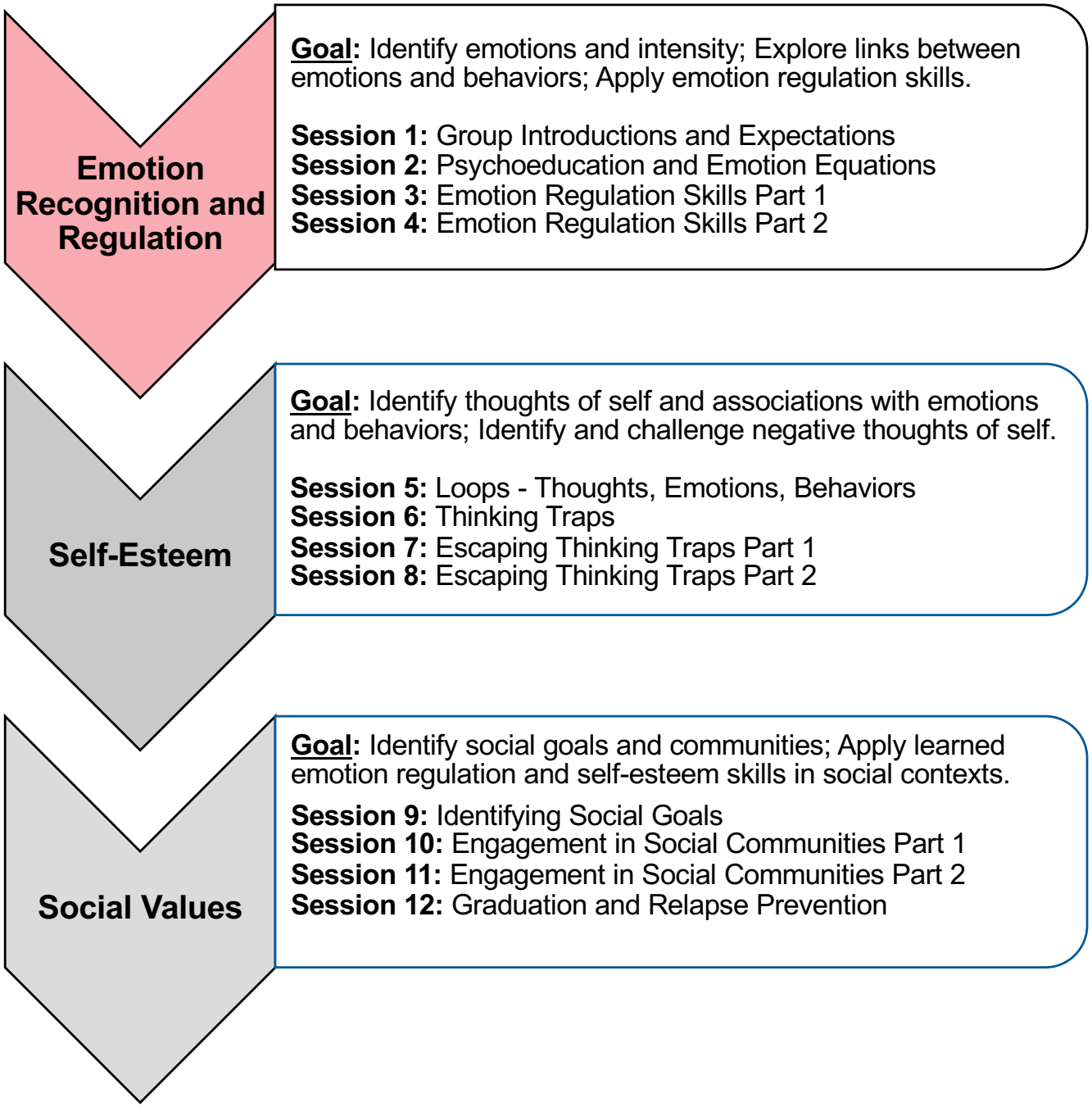
**Session 5:** Loops - Thoughts, Emotions, Behaviors
**Session 6:** Thinking Traps
**Session 7:** Escaping Thinking Traps Part 1
**Session 8:** Escaping Thinking Traps Part 2

**Social Values**

**Goal:** Identify social goals and communities; Apply learned emotion regulation and self-esteem skills in social contexts.

**Session 9:** Identifying Social Goals
**Session 10:** Engagement in Social Communities Part 1
**Session 11:** Engagement in Social Communities Part 2
**Session 12:** Graduation and Relapse Prevention

# **CBT-DAY:** Treatment Content



# **CBT-DAY:** Week 2 Emotion Equations

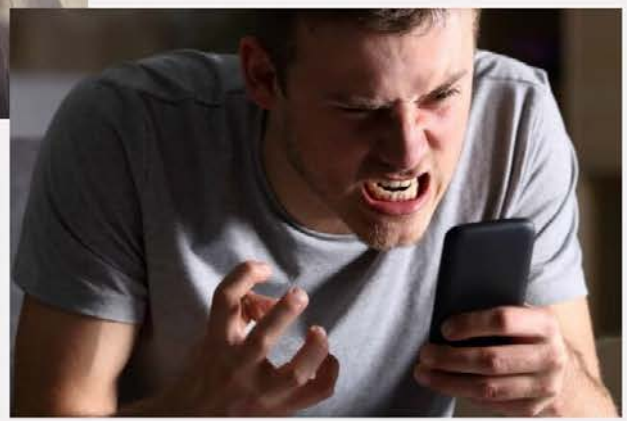
- **Premise**: Emotions can be complex, abstract experiences that are difficult to identify and explain to others

- **Adaptation**: Can we begin to improve emotion recognition by developing a more concrete method? Can the emotional experiences of others be useful in identifying our own emotions?

**Emotions = Body Signals + Behaviors**

# **CBT-DAY:** Body Signals

**What external body signals do you see?**
**How are they feeling?**



**External Body Signals of Mad**

1. Scrunched eyebrows
2. Open mouth (+ teeth)
3. Big face
4. Clenched hands
5. Red tint to skin

**Other External Body Signals of Mad**

1. Waving arms
2. Pacing back and forth
3. Loud voice

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# **CBT-DAY:** Body Signals

**Common mad body signals are...**

1. _____

2. _____

3. _____


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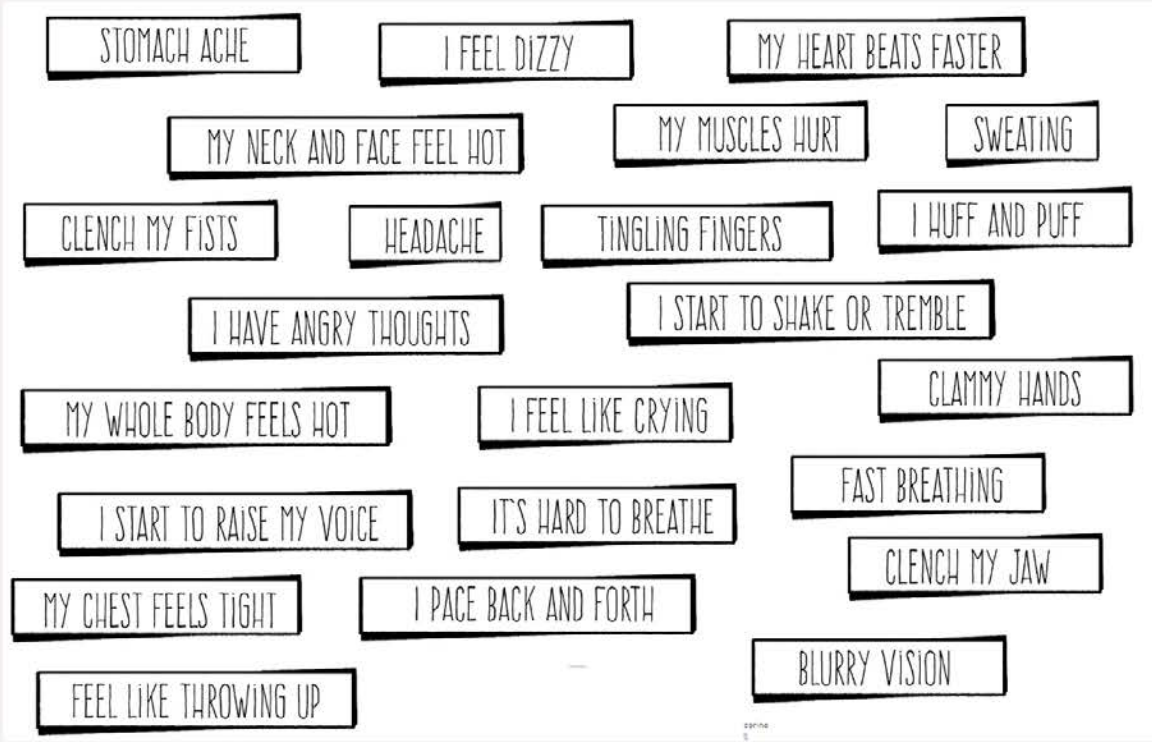
# **CBT-DAY:** Body Signals

**My mad body signals are...**

1. _____

2. _____

3. _____

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# **CBT-DAY:** Behaviors

**My mad behaviors are...**

1. _____

2. _____

3. _____



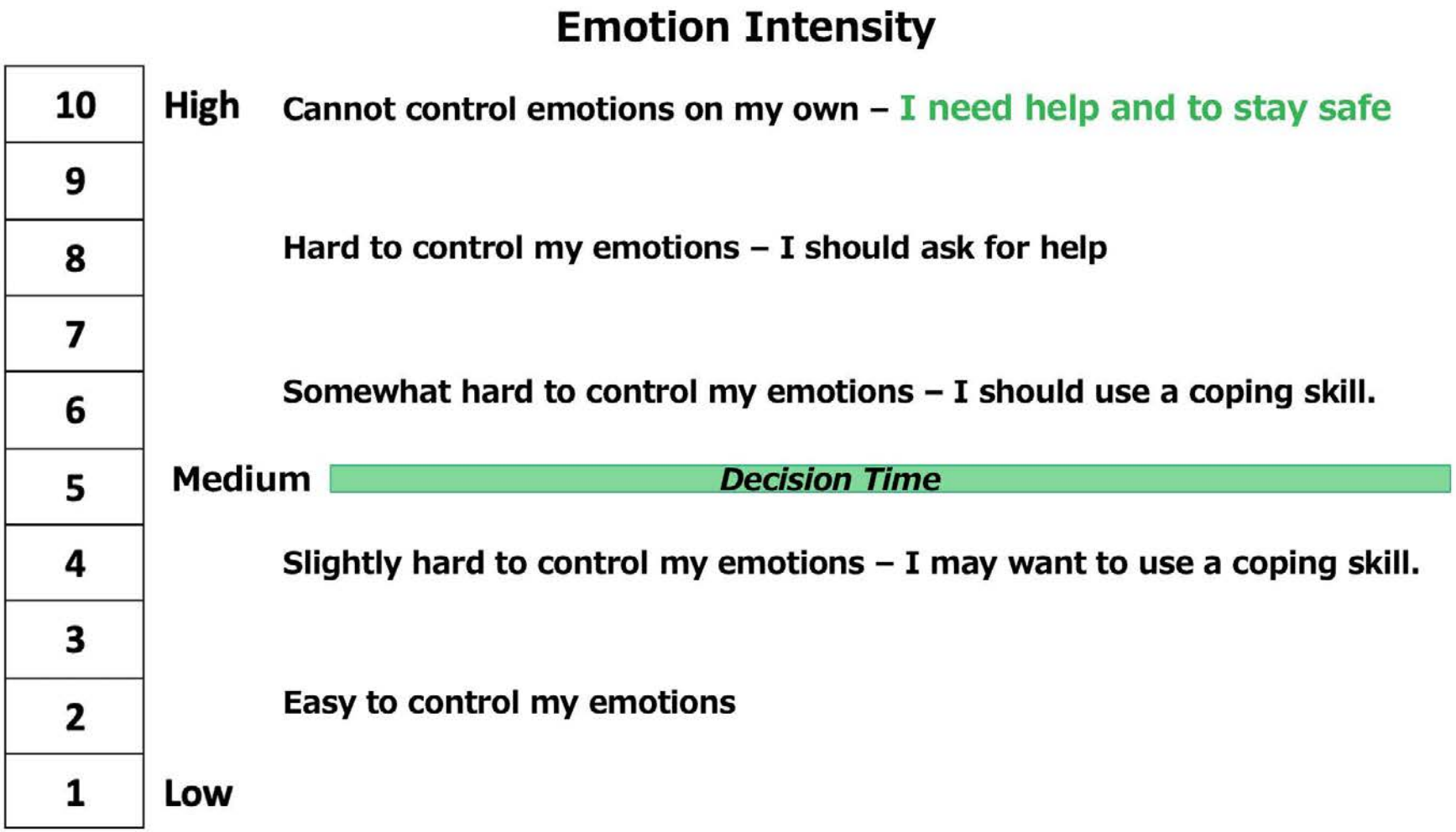
*J. Schwartzman 2021*

# **CBT-DAY:** Weekly Exercise

**CBT Groups – Exercise Week 2**
***Noticing my Emotion Equations***

| **Day** | **Body Signals**<br>*Write 2 body signals you experienced.* | **Emotion**<br>*Based on your body signals, circle the emotion you were feeling.* |
|---|---|---|
| *Example* | *1. Heaviness in my chest*<br>*2. Felt like crying* | *(Sadness,) Anger, Anxious, Chill* |
| Day 1 | 1. _____<br>2. _____ | Sadness, Anger, Anxious, Chill |
| Day 2 | 1. _____<br>2. _____ | Sadness, Anger, Anxious, Chill |
| Day 3 | 1. _____<br>2. _____ | Sadness, Anger, Anxious, Chill |
| Day 4 | 1. _____<br>2. _____ | Sadness, Anger, Anxious, Chill |

# **CBT-DAY:** Emotion Score



# **CBT-DAY:** Participants

| Demographic | Frequencies |
|---|---|
| Age | *M* = 13.79, *SD* = 1.96 |
| Sex | 15 male / 9 female |
| Gender | 14 cisgender male / 5 cisgender female / 5 gender non-binary |
| Ethnicity | 20 Not Hispanic/Latinx / 4 Hispanic/Latinx |
| Race | 20 White / 4 Black |
| Annual Household Income | 2 participants $25,000-$50,000<br>8 participants $50,000-$75,000<br>2 participant $75,000-$100,000<br>2 participant $100,000-$125,000<br>9 participants $125,000+<br>1 participant Prefer Not to Say |

| | |
|---|---|
| Psychotropic Medication Status | 10 participants not taking medications<br>14 participants taking medications<br><br>11 Selective serotonin reuptake inhibitors (sertraline x6, citalopram x3, paroxetine, fluoxetine)<br>7 Psychostimulants (methylphenidate x4, mixed amphetamine salts x3)<br>3 Second-generation antipsychotics (aripiprazole x2, quetiapine)<br>2 Bupropion<br>2 Alpha-2 agonists (clonidine, guanfacine)<br>2 Anticonvulsant mood stabilizers (oxcarbazepine, lamotrigine)<br>1 Tricyclic antidepressants (amitriptyline)<br>1 Other (memantine) |

| Demographic | Frequencies |
|---|---|
| Psychiatric Diagnoses | 3 PDD, mild; ADHD inattentive presentation<br>3 PDD, mild; SAD; ADHD inattentive presentation<br>1 PDD, mild; Tourette syndrome; ADHD combined presentation<br>1 PDD, mild; Gender Dysphoria<br>1 PDD, mild; GAD; Gender Dysphoria; ADHD inattentive presentation<br>2 PDD, moderate; GAD; Gender Dysphoria<br>3 PPD, moderate; GAD; ADHD inattentive presentation<br>1 PDD, moderate; OCD; Gender Dysphoria; ADHD inattentive presentation<br>2 MDD, single episode, mild*; ADHD combined presentation<br>2 MDD, single episode, mild*; OCD<br>2 MDD, single episode, mild*; GAD; ADHD combined presentation<br>1 MDD, single episode, mild*; SAD; ADHD inattentive presentation<br>1 MDD, single episode, moderate*; ADHD inattentive type; Specific phobia<br>1 MDD, single episode, moderate*; GAD |
| Psychiatric Hospitalization | 9 participants hospitalized for suicidal thoughts and behaviors<br>15 participants never hospitalized |
| C-SSRS | Suicidal Ideation: 9 past month, 14 lifetime<br>Suicidal Attempt: 0 past three months, 9 lifetime<br>NSSI: 3 past three months, 10 lifetime |
| Previous Psychotherapy | 4 no previous psychotherapy<br>20 previous psychotherapy |
| RCADS-C T-scores | |
| Depression | 62.58 (11.1); Range: 39-80 T-score |
| Total Internalizing Symptoms | 56.71 (11.9); Range: 37-80 T-score |
| RCADS-P T-scores | |
| Depression | 63.25 (12.1); Range: 38-80 T-score |
| Total Internalizing Symptoms | 63.83 (13.9); Range: 38-80 T-score |

# **CBT-DAY:** Feasibility in Outpatient Setting

- **Attrition:** 20/24 youth completed the CBT-DAY program (83.33% graduation rate)
  - Transportation difficulties (*n*=1)
  - Intensive outpatient care (*n*=1)
  - Lack of interest in continued participation (*n*=2)

- **Attendance**: 85% of youth attended at least 10 of 12 sessions (i.e., full treatment dosage)
  - Remaining youth attended 9 of 12 sessions

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# **CBT-DAY:** Feasibility in Outpatient Setting

- **Outcome data collection**
  - Before treatment: 100% of families (24/24)
  - Mid treatment: 95% of families still enrolled (19/20)
  - Post treatment: 95% of families enrolled (19/20)
  - 3-month follow-up: 75% of graduates (15/20).

- **Recruitment**: Groups filled 2-3 months early.

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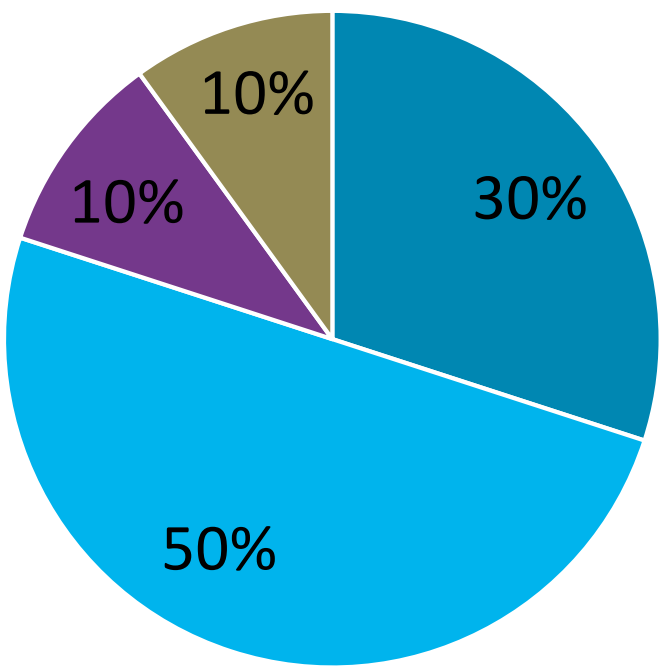
# **CBT-DAY:** Teen Acceptability

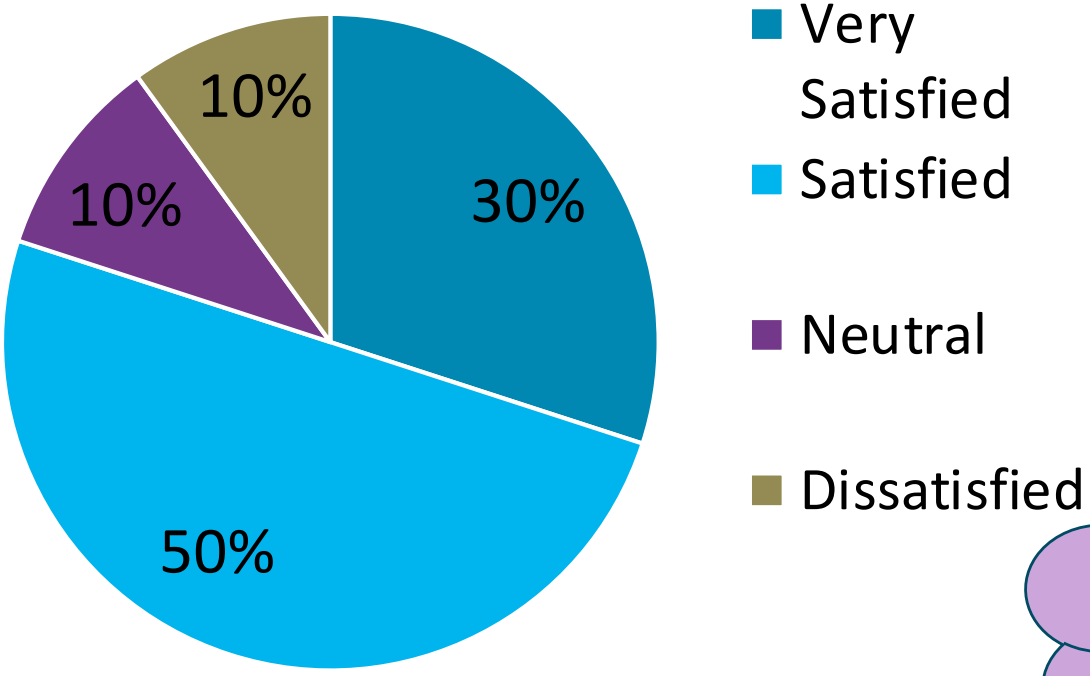



- Very Satisfied
- Satisfied
- Neutral
- Dissatisfied

**Top-Rated Skills**

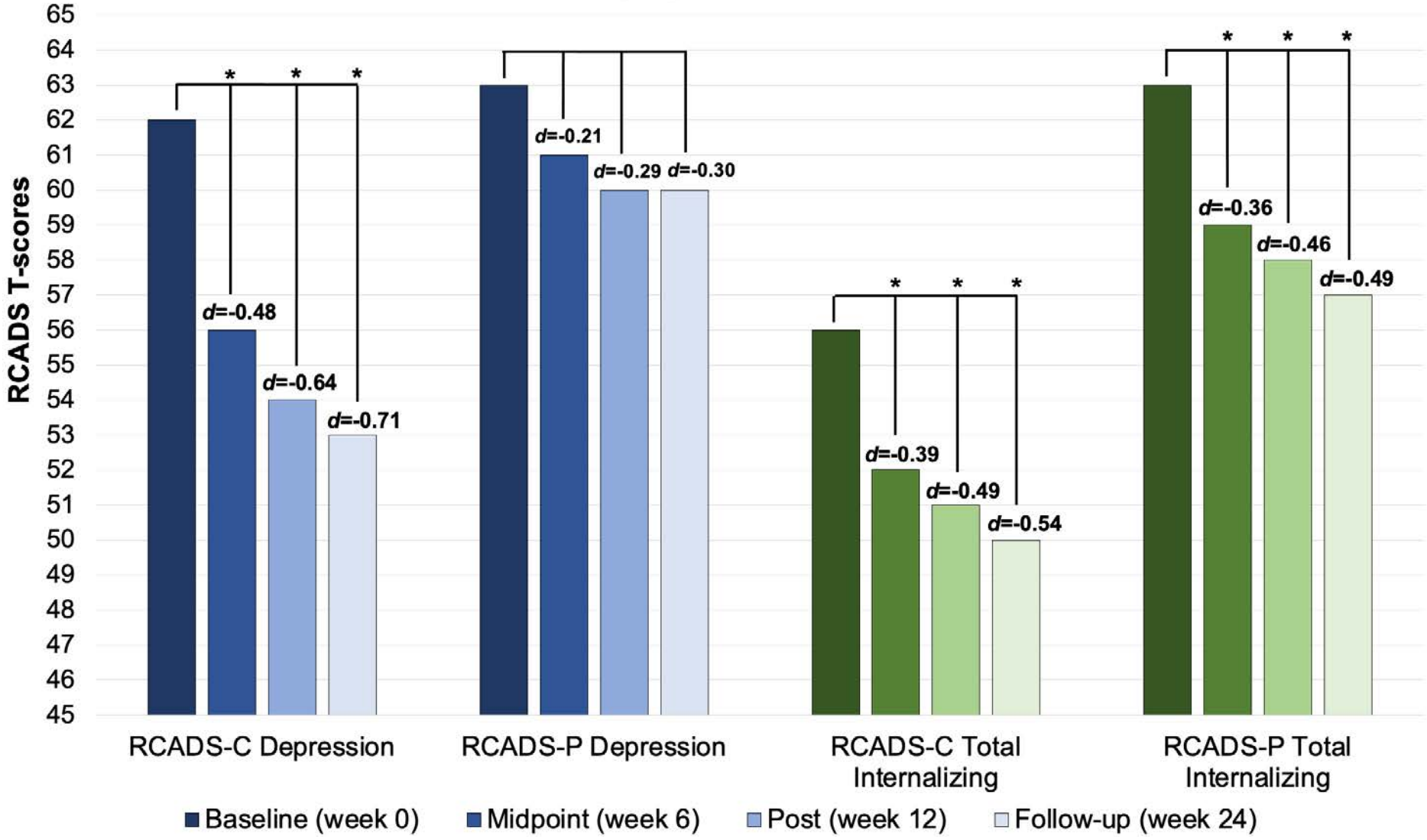
- Emotion Regulation
- Social Values & Goals
- Thinking Traps

# **CBT-DAY:** Teen Acceptability

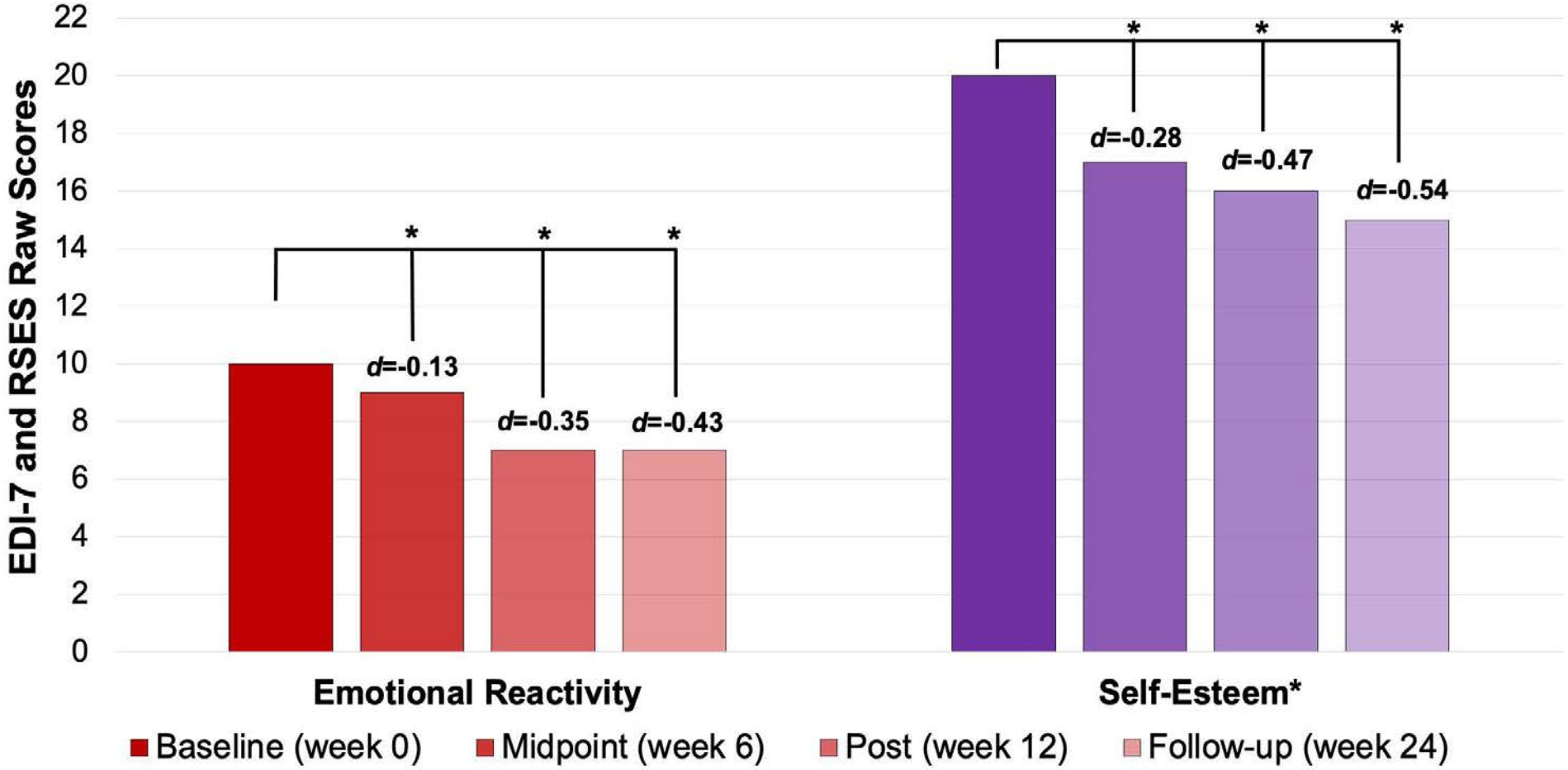



**Current work:**
Who does not benefit from treatment and why?

# Clinical Outcomes: Changes in Adolescent Depressive and Internalizing Symptoms over CBT-DAY



## Mechanisms: Changes in Adolescent Emotional Reactivity and Self-Esteem over CBT-DAY



## CBT-DAY Protocol for Assessing, Addressing, Recording, and Reporting Harms

**Overview:** In intervention studies (including psychotherapy), it is *critical* to routinely monitor for, and immediately address, any potential harmful effects experienced by participants. This practice not only prioritizes participants' safety, but also highlights areas for intervention improvement. Although the definitions of harm vary across psychotherapy studies (Klatte et al., 2023), harms in the present intervention are defined as, "Adverse events (AEs) experienced by participants that include any undesirable experience associated with research procedures." Additional details on characterizing and classifying AEs are provided in the next section.

**Goal**: The characterization and classification of AEs enables researchers, institutions, and families alike to assess and prioritize participant safety and well-being, and adjust intervention approaches accordingly.

**Design of CBT-DAY Protocol:** The foundation of the CBT-DAY Harms Protocol is built on leading work by Klatte and colleagues (2023; citation below). Before starting in CBT-DAY groups, review established guidelines from Klatte and colleagues (2023).

- Klatte, R., Strauss, B., Flückiger, C., Färber, F., & Rosendahl, J. (2023). Defining and assessing adverse events and harmful effects in psychotherapy study protocols: a systematic review. *Psychotherapy*, *60*(1), 130-142.

**Updates:** The CBT-DAY Protocol will be updated with new information on psychotherapy harms reporting research and/or insights from the CBT-DAY intervention. Below is a summary of important aspects of what harms/AEs are and our steps for assessing, addressing, recording, and reporting them.

# **CBT-DAY:** Takeaways

- Engaging autistic people in the design, testing, and interpretation of interventions demonstrates promise for treating depression in youth

- Negative self-esteem and emotion dysregulation may be salient intervention mechanisms

- CBT-DAY may be feasible, acceptable to teens and caregivers, and efficacious in improving depressive symptom severity in youth

# **CBT-DAY:**
# Next Steps

- How can we increase **measurement rigor** for treatment outcome and response?

- **Who benefits** from which treatment?

# **CBT-DAY:** Next Steps – CIAPM

- Goal: First large-scale RCT of depression treatments for autistic youth, leveraging CBPR and EEG methodologies

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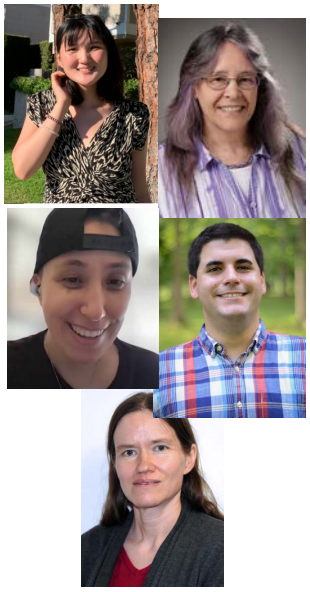

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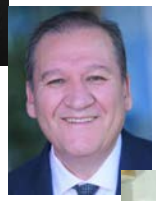

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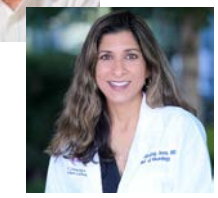

**Co-I: Shafali Jeste, M.D.**
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# **Next Steps:** CIHR

CIHR IRSC Canadian Institutes of Health Research / Instituts de recherche en santé du Canada

Partnering for Prevention: Strategies to Support Autistic Youth Following a Suicide Attempt

Goal 1: What are the needs of autistic youth and their families following discharge from the hospital for a suicide attempt?

Goal 2: How can we partner with autistic youth, adults, and families to translate this information into interventions?

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THE ENHANCE LAB

PI: Carly McMorris, Ph.D.

We must connect with, empower, and collaborate with our communities at all stages to progress towards **meaningful change**

TREND LAB
TRAINING AND RESEARCH TO EMPOWER NEURODIVERSITY

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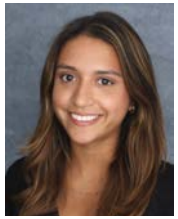

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