# Fostering Brave Behavior in Adolescents with ASD and Intellectual Disabilities:

### Important CBT Adaptations

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- Organization for Autism Research—funded our pilot study
- Department of Defense—funding a 3-year study starting now!

### Agenda

- Provide overview of anxiety in adolescents with autism and intellectual disability (ID)
- Review the adapted Facing Your Fears program for adolescents with ASD and ID
- Discuss with the Philpott family their experience with anxiety
- Invite families to participate in our research study

# Teens with ASD/ID: An Underserved Population

- Adolescents with ASD/ID are a complex and underserved population who are at particular risk for mental health disorders.
- Anxiety occurs at higher rates in individuals with ASD/ID (53%) than in ID alone (17%; Bakken et al., 2010):
  - Specific phobias
  - Social and transition-to-adulthood fears
- Anxiety is extremely impactful:
  - High rates of problem behavior (Moskowitz et al., 2013)
  - ← High use of psychotropic medications (Spencer et al., 2013)
  - ← Caregivers may be in the position of needing to "take over" tasks for teens with ID which can limit independence (Sandjojo et al., 2018) and contribute to parental burnout

# Barriers to Mental Health Care: Teens and Young Adults

- Communication, insight and behavioral difficulties can make the assessment of mental health challenging (Plesa Skwerer et al., 2019)
- There is a drop off in services during late high school for adolescents with ASD/ID (Wei et al., 2015)
- ← Lack of manualized, evidence-based interventions (Whittle et al. 2018)

# The Importance of Anxiety Treatment in Adolescence/Young Adulthood

- Heightened anxiety in the workplace affecting job retention (Hurlbutt and Chalmers, 2004),
- Yet, we know that anxiety treatment, particularly if provided early (age 14), enhances transition outcomes and employment rates are significantly better (Cimera et al., 2013). Why?
  - Can reduce anxious avoidance,
  - Support active coping across settings,
  - Pre-empt job failure.
- CBT has an emerging body of literature to indicate its effectiveness in youth with ASD but it's use has not been explored in adolescents with ASD/ID
  - (Reaven et al. 2012; Sofronoff et al. 2005; Storch et al. 2013; Sung et al. 2011; White et al. 2013; Wood et al. 2009; 2014

Aim of Pilot Study (Blakeley-Smith et al., 2021)
Adapt Facing Your Fears for Teens with ASD and ID

14 week CBT group treatment



Adaptations to treatment modality, session duration, and content.

# Translate FYF for ASD/ID: Treatment Adaptations

Intervention Feature	FYF (Original)	FYF:ASD/ID
# Sessions	14 + booster	14 sessions
Session length	90 minutes	45 – 60 minutes
Group size	4-6 families	2-4 families
Treatment Modality	Large group Dyads Youth only Parents only	3 Parent only sessions 11 Parent-teen dyads

### Who is Appropriate for FYF:ASD/ID?

- Screening criteria:
  - 12-18 year olds with ASD, intellectual disability, and interfering anxiety
- Single Words; Phrase speech
- Teens with problem behavior (e.g., SIB, aggression, disruption) included; behaviors had to be manageable within group

### **Assessment**

- Differentiate behavior driven by anxiety from other forms of problem behavior via functional assessment interview (O'Neill et al. 1990)
- Anxiety Depression and Mood Scale (ADAMS; Esbensen et al. 2003)
- The Screen for Child Anxiety Related Disorders (SCARED; Birmaher et al., 1999) Parent version
- Fear Survey Schedule for Children-Revised (FSSC-R, Ollendick, 2006)

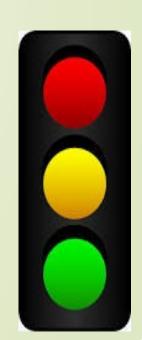
Pilot Study:

Participants N=23

Autism Spectrum Diagnosis Genetic Condition	73.9% (n= 17) 26.1% (n=6)
Age	15.92
Full Scale IQ	M= 58.3, (40-79, SD= 12.16)
Adaptive Behavior Composite	M= 57.4, (40-79, SD= 13.24)
Gender	73% Male
Race/Ethnicity	Caucasian: 56% (n= 13) Hispanic / Latino: 13% (n= 3) More than 1 race: 26% (n=6) Other: 4.3% (n= 1)
Medication to Target Anxiety	69%

### Teaching Emotion Regulation: Supporting Understanding and Practice

- Parents use video or pictures to support teens' understanding of red, yellow and green zones
- Parents identify teens' physical symptoms, teens sort pictures of physical symptoms into zones
- Parents develop a crisis plan for serious red zone behavior and model somatic management for teens
- Over the course of the intervention, parents begin to add FYF strategies for use in yellow zone



### Somatic Management: Importance of Self Calming Strategies

- Many teens become reliant on caregivers to soothe them or are told to "take a break" when anxious. This does not reinforce self competence!
- Provide a range of somatic management techniques through a visual menu, emphasizing deep breathing, and daily practice
- Embed within daily routines



### Cognitive Component: Importance of Replacing Negative Self-Talk

Pay attention to negative self talk, perseverative questions, and reassurance seeking

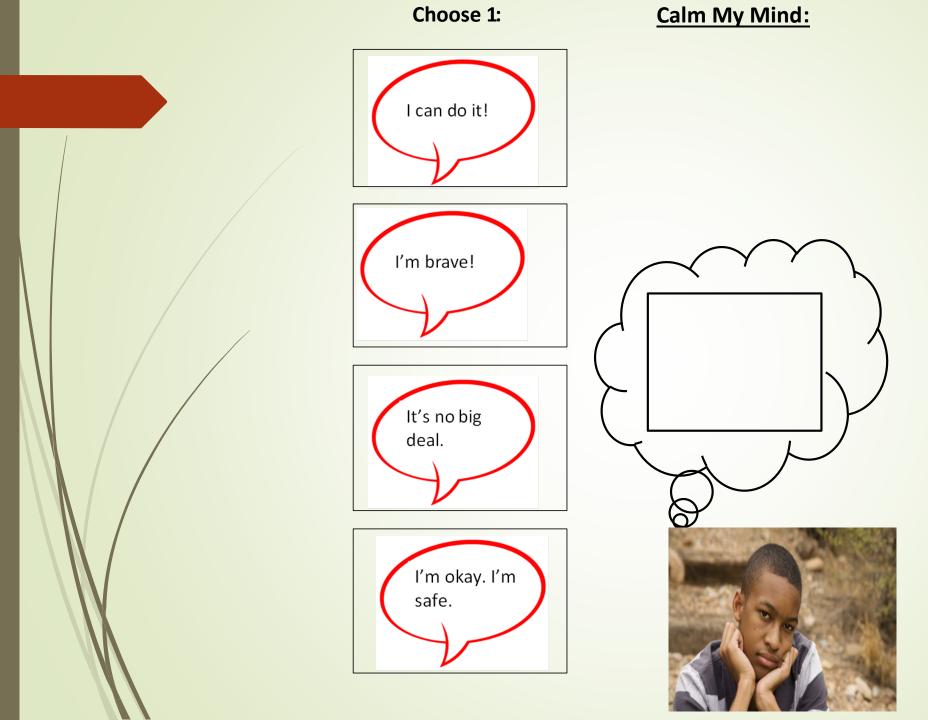
Focus on replacement not identification and challenge of negative cognitions

Use repetitive helpful thoughts designed to reinforce self competence:

I can do it

I can handle it

I'm brave



### Facing Your Fears

Fear and Exposure Hierarchies	Examples	
Social	Social faux pas, requesting help, requesting clarification, peer interaction	
Specific Phobia	dogs, wind, public restrooms, dental and medical procedures	
Generalized Anxiety	parents dying, access to preferred items/technology, future functioning, people who look different/disability status	
Separation	being away from family members	
Obsessive Compulsive Disorder	tolerating cabinets/doors being closed and not removing contents	

# Exposure: Importance of Daily Routines

- Carefully make decisions about fears to face; should be based on degree of interference
- Teen "buy in" may be reduced, so routine and rewards are critical
- Visual schedules are instrumental in supporting engagement
- Practice "being brave" on a daily basis
- Share accounts of bravery



# Results of Pilot Study:

### Feasibility and Acceptability:

Of the 23 adolescent participants, 19 completed treatment and attended 94% of treatment sessions.

Parent acceptability ratings: M = 4.56 (likert scale 0-5, with 5 indicating extremely satisfied)

#### Efficacy:

Results from a linear mixed model analysis model indicated a main effect of time for:

ADAMS:  $F(1, 22.55) = 20.89, p < .0001, \omega_p^2 = .45.$ 

SCARED:  $F(1, 21.09) = 4.92, p = .038, \omega_p^2 = .14$ 

Fear Survey Schedule for Children-Revised (subsample n = 16): F(1,17.60)=6.01, p=.025,  $\omega_p^2=.20$ .

### Summary – Final Thoughts

- It is critical to expand FYF and other similar interventions to meet the needs of individuals across the ASD spectrum (and it is possible to do so!)
- Teens with ASD and ID can make use of both somatic management strategies and brief helpful thoughts
- Exposure, ultimately, may be what is most beneificial
- Additional research, including a randomized controlled trial, is required to determine the effectiveness of this adapted CBT program



### Group Cognitive Behavioral Treatment for Anxiety in Adolescents with Autism and Intellectual Disability: A Randomized Controlled Trial

COMIRB#20-3142 PI: Audrey Blakeley-Smith, PhD

#### What is the study about?



- This research study will investigate a
   <u>Cognitive Behavior Therapy (CBT)</u> group
   treatment to determine if it is more effective
   than therapy services that adolescents with
   ASD and intellectual Disability (ID) are already
   receiving at school, in the community, or
   from their doctor
- This CBT intervention has been adapted for the learning and language needs of teens with <u>Autism and ID</u>

#### What would I have to do?

- 1. Participants may enter the 14-week group within 6 months of consent
- 2. Current therapies will be tracked
- 3. Teens and a caregiver will participate in a 14-week therapy program
- 4. Families will complete assessments before the 14-week therapy program and up to 6 months after completing the program

#### Is this study right for me and my child?

#### Is your child between 12-18 years of age and does your child have:

- 1. Autism spectrum disorder,
- 2. Intellectual disability, and
- 3. Anxiety (fears or worries) and/or Emotion regulation difficulties?

If you answered YES, then you and your child may qualify for this study. Please note that participation is voluntary and you will be compensated for your participation.

For more information, please contact:

#### FYFstudy@ucdenver.edu

### Thank You!!



## Philpott family