Supporting the Mental Health of School-Aged Youth with ASD: The Positive Potential of School Partnerships

9th Annual JFK Autism Spectrum Disorder Conference – October 2021

Judy Reaven, Ph.D.
Professor of Psychiatry and Pediatrics
JFK Partners, University of Colorado Anschutz Medical Campus
Judy.reaven@cuanschutz.edu
Conflict of Interest:

Royalties:
Facing Your Fears: Group Therapy for Managing Anxiety in Children with High-Functioning Autism Spectrum Disorders
Paul Brookes Publishing Company

www.brookespublishing.com
http://facingfears.org
Significance: Mental Health and Youth with ASD

- **Prevalence**
  - MH symptoms are common in people with ASD/NDD (Middleton et al. in press; Simonoff et al. 2008)

- **Impact**
  - MH symptoms increase risk for academic, social, and emotional problem (Rotheram-Fuller & MacMullen, 2011)

- **Without Intervention Symptoms Can Worsen Over Time**

- **Potential to Treat**
  - Best practice approaches (CBT) are effective in non-autistic youth (Olatunji et al. 2010)
  - CBT extended to youth with ASD encouraging (McConachie et al. 2014; Storch et al. 2013; Wood et al. 2009; 2020)
Colorado Stakeholder Input: Mental Health Survey (October 2020)

PARTICIPANTS (N=88)

- Professionals: 62.5%
- Parents/Other family members: 47.8%
- Support person: 11.4%
- Autistic Adults: 6.8%
# Common Mental Health/Behavioral Concerns

<table>
<thead>
<tr>
<th>Common Mental Health or Behavioral Concerns (Choose top 3)</th>
<th>Percent Response</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anxiety, Fears, Worries</td>
<td>72.7%</td>
</tr>
<tr>
<td>Attention, Concentration, Impulsivity</td>
<td>64.8%</td>
</tr>
<tr>
<td>Outburst, meltdown, tantrums</td>
<td>55.7%</td>
</tr>
<tr>
<td>Noncompliance, refusals, defiance</td>
<td>25%</td>
</tr>
<tr>
<td>Aggression (people or property)</td>
<td>17%</td>
</tr>
<tr>
<td>Sadness, irritability, depression</td>
<td>14.8%</td>
</tr>
<tr>
<td>Video Game or other online addiction</td>
<td>14.8%</td>
</tr>
<tr>
<td>Increase in behaviors (e.g., sensory-seeking, repetitive behaviors)</td>
<td>13.6%</td>
</tr>
<tr>
<td>Self-harm or suicidal behaviors</td>
<td>11.4%</td>
</tr>
</tbody>
</table>
### Common Mental Health/Behavioral Concerns: Family Members and Professionals

<table>
<thead>
<tr>
<th>Common Mental Health or Behavioral Concerns (Choose top 3)</th>
<th>Percent Response</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Anxiety, Fears, Worries</td>
<td>84%</td>
<td>71%</td>
</tr>
<tr>
<td>Attention, Concentration, Impulsivity</td>
<td>56%</td>
<td>73%</td>
</tr>
<tr>
<td>Outburst, meltdown, tantrums</td>
<td>36%</td>
<td>62%</td>
</tr>
<tr>
<td>Noncompliance, refusals, defiance</td>
<td>32%</td>
<td>27%</td>
</tr>
<tr>
<td>Aggression (people or property)</td>
<td>12%</td>
<td>18%</td>
</tr>
<tr>
<td>Sadness, irritability, depression</td>
<td>20%</td>
<td>9%</td>
</tr>
<tr>
<td>Video Game or other online addiction</td>
<td>20%</td>
<td>13%</td>
</tr>
<tr>
<td>Increase in behaviors (e.g., sensory-seeking, repetitive behaviors)</td>
<td>8%</td>
<td>16%</td>
</tr>
<tr>
<td>Self-harm or suicidal behaviors</td>
<td>12%</td>
<td>4%</td>
</tr>
</tbody>
</table>
## Contributing Factors – COVID-19

<table>
<thead>
<tr>
<th>COVID-19 FACTORS</th>
<th>DEFINITE IMPACT</th>
<th>VERY MUCH OF AN IMPACT</th>
<th>PERCENT TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Impact on School (Virtual learning, hybrid models, technology challenges, helping children with homework)</td>
<td>39.1</td>
<td>51.7</td>
<td>90.8</td>
</tr>
<tr>
<td>Family Stress (multiple roles, financial challenges, job loss/change, relationship conflict)</td>
<td>39.1</td>
<td>33.3</td>
<td>72.4</td>
</tr>
<tr>
<td>Restrictions</td>
<td>37.5</td>
<td>31.8</td>
<td>69.3</td>
</tr>
<tr>
<td>Worry About Illness</td>
<td>31.8</td>
<td>5.7</td>
<td>37.5</td>
</tr>
</tbody>
</table>
COVID and ASD/NDD: Lost opportunities (Bellomo et al. 2020)

- Disproportionately impacted youth with ASD/NDD (and different communities)
- Disruption in usual medical care/educational experiences
- Missed diagnoses – both NDD and MH
- Unknown impact of social isolation – missed opportunities to have challenges addressed
- Impact of Covid-19; fear of illness/disease; financial burden
- Even with telehealth delivery, burden on parents/caregivers
- Home school and multiple roles of parents
Identifying MH Concerns in ASD

<table>
<thead>
<tr>
<th>Age of Identification</th>
<th>Fam</th>
<th>Prof</th>
</tr>
</thead>
<tbody>
<tr>
<td>6-9</td>
<td>44%</td>
<td>33%</td>
</tr>
<tr>
<td>10-12</td>
<td>32%</td>
<td>38%</td>
</tr>
<tr>
<td>13-15</td>
<td>12%</td>
<td>18%</td>
</tr>
</tbody>
</table>

First to Notice MH concerns

- Parents/Caregivers (90.8%)
- Teachers/School Professionals (66.7%)

Age of Identification

- 6-9 (37.9%)
- 10-12 (33.3%)
- 13-15 (18.4%)
Where Do Youth with ASD Receive MH Services?

Ages 6-9: Schools (60%)

Ages 10-12: Day Treatment Programs (38.5%); Private MH (35.4%)

Ages 13-15: Private MH (47.9%); CMHC (34.7%); Outpatient MH through Hospitals (34%)

“Most families I see get the majority of services from schools - at least until high school. They rely heavily on school services due to cost, wait lists, availability, schedules, etc. “
Why Form School Partnerships?
Importance of Working in Schools

- Students with ASD/NDD display marked anxiety/problem behavior in school (Rotheram-Fuller & MacMullen, 2011).
- Evidence-based interventions frequently unavailable in school settings
- Effective way to reach historically underserved students
- Training non-mental health providers expands capacity to serve students
- **Schools are the location of choice** (Mychailyszyn et al., 2011; Van Acker & Mayer, 2009).
Substantial Disparities in Access to Mental Health Services

Racial Disparities in CBT Research for Anxiety in ASD (Pickard, Reyes, & Reaven, 2018)

- Reviewed 14 studies, 473 participants with ASD and anxiety in the US
- Compared demographics of the participants with US Census
- Significantly more White participants/significantly fewer Black/Latino youth than what US Census would suggest
- Highly educated sample – most caregivers with college degree or above

Implications
Real World Impact of Anxiety

Common Fears:

- Using the school bathroom (e.g., toilets flushing, other kids, or germs)
- Fear of being late
- Talking to new people or in class/asking for help
- Separating from parents to attend school
- Making mistakes/accepting criticism
Real World Impact (in a virtual world)

Common Fears:
- Trouble logging on; internet connectivity
- Keeping the video on
- Talking/answering questions/asking for help
- Making mistakes/accepting criticism
The Obstacle of Anxiety
Cognitive Behavior Therapy

- Connection between thoughts, feelings and behavior
- Changing thinking patterns; calm your mind; relax your body
- Use problem-solving skills to manage difficult situations
- Structured approaches to teaching new skills (e.g., role play, modeling)
- Homework/practice
- Emphasis on coping strategies
FYF Treatment Program – Youth with ASD and Anxiety (ages 8-14) (Reaven et al. 2011)

- **Duration of treatment:** 14 weeks – 1 ½ hour per session
- **Modality:** varied; children alone, parents alone, dyads and large group work
- **First seven weeks:** Define anxiety symptoms, identify anxiety provoking situations, develop a set of “tools” (somatic management, helpful thoughts, emotion regulation, graded exposure)
- **Second seven weeks:** Identify goals and create stimulus hierarchy, apply “tools” across settings, in-vivo graded exposure, video activity to reinforce core concepts
- **Parent involvement:** ongoing; integrated parent curriculum
- **Booster session:** 4-6 weeks post-treatment
Cognitive-Behavioral Group Treatment for Anxiety Symptoms in Children With High-Functioning Autism Spectrum Disorders

A Pilot Study

Judith A. Reaven
Audrey Blakeley-Smith
University of Colorado Denver, School of Medicine
Shana Nichols
Fay J. Lindner Center for Autism
New York University School of Medicine
Karyn Flanagan
University of Colorado Denver
Susan Hepburn
University of Colorado Denver, School of Medicine

Individuals with autism spectrum disorders (ASD) are at increased risk for developing anxiety disorders relative to children without ASD and those with other developmental disabilities. Thirty-three children with high-functioning ASD and their parents participated in an original, manualized cognitive-behavioral group treatment aimed at reducing severity of anxiety symptoms. Parent-child dyads entered into either an Active Treatment Condition or Wait List Control Condition. Results indicated significant reductions in parent report of anxiety symptoms after the delivery of the group treatment, compared with the Wait List Control Condition. The findings of this study are promising, particularly in light of the high rates of anxiety disorders in children with ASD.

Improving transportability of a cognitive-behavioral treatment intervention for anxiety in youth with autism spectrum disorders: Results from a US-Canada collaboration

Judy Reaven, Audrey Blakeley-Smith, Erica L. Bostian, April Sullivan, Eric J. Mooney, Jessica A. Stern, Susan L. Hepburn, and Isabel M. Smith

Abstract

Anxiety disorders frequently co-occur in youth with autism spectrum disorders. In addition to developing efficacious treatments for anxiety in children with autism spectrum disorders, it is important to examine the transportability of these interventions to real-world settings. The current study evaluated the effects of the group treatment for managing anxiety in children with high-functioning autism spectrum disorders to feasibility and to examine transportability of the intervention for real-world settings.

Keywords: Anxiety, autism spectrum disorders, group treatment.
Implementing CBT in Colorado Schools

Low income
Racially/ethnically diverse communities

Denver Public Schools
Littleton Public Schools
Cherry Creek School District

HRSA# : R41MC31075-01-00
Aims of the FYF-School Based Study

Year 1:
- Focus Groups & Program Development (Qualitative Phase)

Year 2:
- Pilot Groups & Training Interdisciplinary Providers

Year 3:
- Randomized Trial; Delivering FYF through a Train-The-Trainer Approach
FYF-School Based
12, 40-minute sessions (during school day)

Session 1 & 2
Welcome & Introduction
- Getting to know you/ice breaker
- Learning about emotions
- Everybody worries and gets upset sometimes
- How I react/feel when I worry

Session 3 -4
Understanding My Worry/Upset and Calming My Body
- Time Spent Worrying/Upset
- Externalizing worries: Worry bugs
- False Alarms; Stress-o-meters
- Measuring worry/upset; Deep Breathing

Sessions 5-6
Managing the Mind; Calming the Body
- Identifying relaxing activities
- Active Minds and Helpful Thoughts
- Putting it Altogether
- Plan to Get to Green

Sessions 8-12
Practice Facing Fears
- Introduction to Exposure: Facing Fears
- Creating exposure hierarchies/steps to success
- Optional: Movie Making
- Review & Graduation

Two Parent Sessions

Session 1:
Overview of FYF-SB; introduce tools/strategies

Session 2:
Introduction to Graded Exposure; Wrap-up and review student progress

FYF -School Based
12, 40-minute sessions (during school day)
Core Components of FYF-SB

- Psychoeducation
- Cognitive strategies/somatic management
  - Increase emotion vocabulary
  - Identify anxiety symptoms (enhance self-awareness)
  - Identify physiological symptoms of worry/anxiety/upset
  - Compare “anxiety” vs “fun” time
- Emotion Regulation:
  Calming the body/managing the mind
- Plan to Get to Green
Core Components of FYF-SB

Graded Exposure

- Identify anxiety/fears that interfere with school functioning
- Develop a fear hierarchy or “to do” list
- Practice facing fears a little at a time to manage/conquer the fear
- Emphasize fear tolerance!
Using Videos to Teach Exposure: Facing Your Fear of Toilet Flushing

1. Student stands outside the bathroom entrance and toilet flushes.
2. Student stands closer to a stall and toilet flushes.
3. Student flushes the toilet himself.
4. Student stands close to a stall and several toilets flush and a peer washes hands.
FYF-SB SWAG
Training and Implementation Phase
(Similar for Pilot(Randomized Trial)

School Provider Inclusion Criteria

- Interdisciplinary school providers working with students with ASD
- At least one mental health provider on the team
- Included all disciplines, but not paraeducators (yet!)
- Attended 12 hour didactic/interactive workshop
- Received 20-30 minutes, bi-monthly consultation calls
Student Participants

- **Inclusion Criteria**
  - Students with ASD or suspected ASD
  - Elevations on the Social Responsiveness Scale (SRS-2) (Constantino & Gruber, 2005) (Above T-Score – 60)
  - 2nd – 8th grade students
  - Estimated IQ above 70
  - Interfering anxiety symptoms

**Treatment Outcomes:**
- SCARED (Birmaher et al. 1999)
- PRAS-ASD (Scahill et al. 2019)
- School Anxiety Scale (Lyneham et al. 2008)
- ADIS-ASA (Kerns et al. 2017)
Expanding FYF-SB across Colorado: Train-the-Trainer Approach

27 school teams (13 Treatment; 14 Control) at 25 schools
N=99 Student/caregiver names provided

N=5 excluded in screening [N=4 not interested in enrolling; N=1 No response]

N=76 caregivers sent measures online
N=18 caregivers completed measures in-person
Total of N=94

N=13 did not enter study [N=3 were siblings randomized; N=2 moved; N=1 withdrew interest; N=7 late or no paperwork]

N=81 students/caregivers entered study (N=39 Fall; N=42 Spring)
School Providers
14 trainers (2018-2019)
77 school providers (2019-2020)

- Speech and Language Pathologists (23.4%)
- Other Mental Health/Social Workers (10.3%)
- Psychology (29.9%)
- Special Education Teachers (32.5%)
- OT (3.9%)
IEP Eligibility Designation (n=58)

- ASD: 39.5% (n=32)
- Learning Disability: 9.9% (n=8)
- Language Disorder: 8.6% (n=7)
- Serious Emotional Disability: 8.6% (n=7)
- Other Health Impairment: 3.7% (n=3)
- Developmental Delay: 1.2% (n=1)
Preliminary Outcomes (RCT)

- Treatment Completion and Fidelity (Adherence)
  - Thirteen fall schools delivered FYF-SB
  - # of sessions completed: 6-12 ($M=10$)
  - 60% of sessions were coded for fidelity
  - Adherence (absence/presence of core components): Range: 76-98% ($M=86.15\%$)

Most school teams were able to deliver the program as intended!
Acceptability Data

Providers
- “FYF-SB was easy to understand and put into practice” (90% agree/strongly agree)
- “FYF-SB enhanced my ability to manage my students’ anxiety (88% agree/strongly agree)

Students
- “How much did you enjoy participating in FYF-SB?” (71% very much/the most)
- “Do you feel better after participating in FYF-SB?” (68% very much/the most)
Preliminary Treatment Outcomes - SCARED

- Parent Report (SCARED)
  - *Significant reductions*: Total Score: Panic, separation, social anxiety symptoms
  - *Non-significant*: school anxiety; generalized anxiety

- Student Report (SCARED)
  - *Significant reductions*: Separation and social anxiety improved
  - *Non-significant*: Panic, school and generalized anxiety
Real World Success

► Using bathrooms at school
► Walking into the classroom, even when late.
► Talking to new people; asking for help
► Going to school and/or after school activities
► Turning in homework, making mistakes on tests
► Keeping your video on
► Using the chat function on zoom
What I Hope You Will Remember

- MH conditions are common in youth with ASD/NDD, and anxiety is one of the most common
- There are effective interventions to manage anxiety and emotion regulation in youth with ASD
- Non-mental health providers can deliver interventions
- School partnerships may hold the key to access and success
Acknowledgements

- Organization for Autism Research (FYF: FYF-IDD)
- Doug Flutie Foundation
- Cure Autism Now (CAN)
- Autism Speaks
- Centers for Disease Control (CDC) – CADDRE network
- JFK Partners – UCEDD – Grant #90DD0561;
  Administration on Developmental Disabilities
- NIMH: #1R21MH089291-01; 4R33MH089291-03
- HRSA: #1R40MC15593A; #1R41MC31075-01-00
- Children/Adolescents with ASD and their families
- Community Stakeholders
Thank You!!

Our Panelists:

Rachel S. Kerstiens, School Psychologist, Denver Public Schools
Sue Loeffler, MA, CCC-SLP, Speech/Language Pathologist, Denver Public Schools
Michelle Butler, CCC-SLP, Speech/Language Pathologist, Littleton Public Schools
Jessica Kendall, LCSW, School Social Workers, Cherry Creek School District
Alison Garvey, School Psychologist, Cherry Creek School District