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Highlights...

The two cover stories in this issue look at the need for equitable care for pediatric anxiety disorders, and at Applied Behavior Analysis treatment for autism spectrum disorders in children and adolescents.

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Monthly reports on the problems of children and adolescents growing up

Anxiety

A team-based service model for increasing equitable access to care

By Mitchell Jackson, B.S., Josh Kemp, Ph.D., and Jennifer Freeman, Ph.D.

Numerous health agencies, including the American Academy of Pediatrics, the U.S. Surgeon General, and the World Health Organization, have declared a state of emergency for child and adolescent mental health fueled by escalating prevalence rates and a troubling shortage of available mental health providers.

Currently, mental health conditions impact 30% of youth and young adults (Kessler et al., 2005). Anxiety disorders in particular have nearly doubled in youth since the start of the COVID-19 pandemic in 2020 (Slomski, 2021).

Pediatric anxiety and obsessive compulsive disorder (OCD) cuts across many aspects of life and can disrupt social, family, and academic functioning. Anxiety and OCD can make it difficult for youth to complete everyday tasks such as attending school, participating in sports, or engaging in social gatherings. Left untreated, these conditions get worse over time and can have detrimental impacts on critical developmental milestones.

Pediatric anxiety/OCD is also associated with increased risk of depression,

*See **Anxiety,** page 3...*

Autism spectrum disorders

Applied behavior analysis interventions for autism spectrum disorders

By Erika Murillo-Candelas and Casey Cragin, Psy.D.

Applied behavior analysis (ABA) has been considered the gold standard intervention for individuals diagnosed with autism spectrum disorder (ASD) for over 60 years. ABA, as a therapeutic intervention, dates to the 1960s and first appeared in studies conducted by Ole Ivar Lovaas. ABA gained the attention of many practitioners in 1987 when Lovaas reported children who received 40 hours or more of ABA treatment per week had significantly better outcomes than children who received 10 hours or less of ABA treatment per week after 2 or more years of intervention (Lovaas, 1987). Lovaas and his team of trained student therapists used interventions informed by behaviorism to target self-stimulatory behaviors, play skills, and expressive language skills among other targeted goals and found that 47% of children in the experimental group achieved a normal score for intellectual and educational functions compared to 2% of children in the control group (Lovaas, 1987).

While Lovaas' results are impressive, Lovaas' methods and the continued practice of ABA by extension have come under some scrutiny within the autistic community from a social justice perspective. Lovaas (1987) describes using physical aversives like delivering a loud "no" or a slap on the thigh to modify undesirable behaviors when social aversives like ignoring, time-outs, or shaping were ineffective and, in his prior work, Lovaas was described as utilizing more violent aversives, such as electric shock (Kirkham, 2017). Lovass (1987) also describes encouraging families to hide their children's history of ASD

*See **Autism spectrum disorders,** page 4...*

Anxiety

From page 1

substance abuse, and suicide attempts later in life. As a result of the dramatic rise in anxiety during the pandemic, the U.S. Preventive Services Task force now recommends that primary care doctors screen all youth ages 8+ for anxiety.

While the pandemic increased the prevalence of mental health concerns and demand for services, it did not increase the number of individuals trained in providing these services. Providers are currently experiencing increased caseload and longer waitlists which makes it difficult for individuals to access the care they need.

Surveys indicate just 20% of youth with anxiety/OCD receive minimally acceptable care (Cartwright-Hatton et al., 2006).

Cognitive behavioral therapy (CBT) is the frontline treatment for anxiety/OCD across the lifespan, with clinical trials showing consistent symptom improvement in youth. CBT typically includes multiple components, and when treating anxiety/OCD, exposure therapy has proven to be both a primary and necessary component.

Exposure involves gradually approaching situations or objects that evoke distress to learn that the situation is less dangerous and/or more tolerable than predicted. Each exposure trial provides new safety learning that gradually overrides individuals' anxious beliefs. Access to high-quality exposure-based CBT in the community is limited, but this is especially so for historically marginalized and underserved populations (based on race, ethnicity, or income).

There are a host of additional barriers for historically marginalized and underserved populations, including lack of access to trained exposure therapists, transportation difficulties, being less aware of the illness and/or treatment options, and experiences of stigmatization and discrimination.

Negative perceptions of treatment and poor fit with providers may also impede treatment quality by reducing engagement and retention. Families may feel misunderstood or not believe in the treatment, and clinicians might fail to adapt for cultural context (e.g., by involving community members such as faith leaders or extended family). There are promising models of care that may better address many of the noted barriers above, a leading candidate is the use of care teams that consist of licensed providers delivering services in tandem with non-licensed staff.

Team-based treatment models (often referred to as "task sharing") pair licensed providers with highly trained non-licensed health providers (e.g., community health workers or promotoras) to increase workforce capacity and access to care. In this team-based model, licensed providers hold each clinical case, but by sharing service delivery responsibilities with a non-licensed provider, they can increase the number of patients on their caseload.

Training and supervision of team

The success of a team-based model is reliant on rigorous training, supervision, and quality monitoring processes to ensure consistency of care. There is strong evidence from numerous systematic reviews that task-sharing improves treatment access while maintaining quality across low- and high-resource settings. Non-licensed health providers are typically members of the communities they serve, thus making them uniquely qualified to build trust and address community-specific barriers to access, implement culturally inclusive conceptualizations of mental health, improve mental health literacy, and address perceptions of mental health care.

Traditional therapy sessions tend to be provider-centered (i.e., take place in a therapist office) which, while effective, can present a number of barriers like limited office space, no-shows, transportation issues, and scheduling conflicts.

Team-based models optimize patient-centeredness by allowing for meetings to occur outside of the clinic (i.e., in the home or community). It is often infeasible for licensed providers to provide services in the home/community due to travel, capacity, and/or billing constraints; however, it is feasible to deploy non-licensed staff outside of the clinic in spaces that are more accessible and familiar to patients.

Providing treatment in the home/community setting offers a number of additional treatment advantages, including enhanced ability to:

1) access naturalistic situations that are difficult to recreate in the office ("treating anxiety where it lives"),

2) discern contextually appropriate fear (e.g., a legitimately unsafe situation) from an excessive anxiety response,

3) facilitate trusting relationships (critically important for families in minoritized groups with historically justified reservations about health organizations), and

4) engage extended family and community members in treatment (a key predictor of better CBT outcomes for anxious youth, particularly those from minoritized ethnoracial backgrounds). Simply put, pairing licensed clinicians with non-licensed staff makes treatment more accessible to those who need it and is likely to create a form of treatment that is better tailored to individual needs.

The Pediatric Anxiety Research Center (PARC) at Bradley Hospital is currently conducting a randomized clinical trial funded by the Patient Centered Outcomes Research Institute (PCORI), titled Improving Access to Childhood Anxiety Treatment (IMPACT), to test a team-based service model versus standard in-office treatment.

Both groups receive exposure-based CBT, the only difference is where the treatment takes place. In the team-based condition, patients meet with a licensed clinical psychologist in the office once a month and all other weekly sessions are conducted by a mobile exposure coach (i.e., highly trained non-licensed provider) in the patient's home or relevant community locations. Mobile exposure coaches undergo extensive training before teaming up with a licensed provider. They also complete quality monitoring measures after each session and engage in weekly supervision with the licensed provider to maintain treatment quality and consistency. Those in the office-based condition receive usual outpatient services consisting of weekly in-office sessions with a licensed psychologist.

IMPACT study

The IMPACT study began in 2018 with a goal of treating 333 youth (ages 5–18 years) with anxiety disorders and/or OCD. Enrollment is over 80% complete and will be finished by the end of 2023. Preliminary results indicate high rates of attendance, exposure use, and retention for the team-based model, meaning patients are regularly presenting for treatment and consistently engaging with exposure tasks both during and between sessions.

Billing codes: A significant barrier to the implementation of a team-based model of outpatient exposure therapy at the outset of the study was a lack of billing codes for the non-licensed provider sessions. However,

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the research team has worked in close partnership with Blue Cross Blue Shield of Rhode Island (BCBSRI) throughout the project and based on positive initial signals from the team-based condition a new set of billing codes have been established to bill for non-licensed provider sessions occurring as part of the team-based service. This agreement with BCBSRI marks an important step forward for making the team-based model of exposure therapy widely available to families throughout Rhode Island.

The IMPACT project serves as an exemplar for developing and disseminating an innovative service model to address the access and workforce crisis in childhood mental health. Efforts to expand the team-based model through additional payer contracts and training initiatives in regional community mental health centers are underway. To learn more, please visit the PARC website at www.parcanxiety.org.

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Mitchell Jackson started working at the PARC in June 2022 after receiving his B.S. in Psychology with a minor in Spanish from Xavier University Of Louisiana. His research interests include improving access, awareness, and overall interventions for evidence-based treatment of anxiety and related disorders, especially for children and adolescents of racial minority groups. Mitchell plans to pursue a PhD in Clinical or School Psychology after his time at the Pediatric Anxiety Research Center.

Joshua Kemp, Ph.D. is a staff psychologist at the Pediatric Anxiety Research Center at Bradley Hospital. His graduate training focused on the study of methods for optimally delivering and disseminating exposure therapy across a variety of service settings, including outpatient, partial hospital, and residential levels of care with both children and adults.

Jennifer Freeman, PhD is the Director of the Pediatric Anxiety Research Center (PARC) at Bradley Hospital. Dr. Freeman is also Professor (Research) of Psychiatry and Human Behavior at The Warren Alpert Medical School of Brown University, Associate Director of the Postdoctoral Research Fellowship Program in the Clinical Psychology Training Program at Brown Medical School, and Associate Director of Research at Bradley Hospital. Dr. Freeman received her BA from Wesleyan University. Along with a talented, collaborative, and ever-growing team, she has led PARC to become a national model for the true integration of active research and training within a busy clinical service line.

Autism spectrum disorders

From page 1

diagnosis and treatment from educators upon enrolling in school and to change schools in cases where educators raised concerns about a child's development or need for special education services. While such methods are unlikely to be used by ABA programs today, ABA's historical roots have nonetheless caused some to criticize ABA as a kind of conversion therapy aimed at making autistic individuals more neurotypical (Pyne, 2020). Concerns have also been raised regarding the methodological limitations of research supporting ABA. For example, a study conducted by the U.S. Department of Defense (2020) concluded that ABA does not meet the criteria for reliable evidence due the lack of studies analyzing longitudinal outcomes, limited sample sizes, and high risk for bias. Contemporary testimonials of autistic adults highlight the use of ABA interventions to reduce self-stimulatory behaviors serving self-regulatory functions but not accepted by society in particular as potentially traumatic. Preliminary research, though also methodologically limited and controversial, supports such testimonials, showing an association between ABA treatment and posttraumatic stress symptoms based on reports from autistic adults and caregivers of autistic children (Kupferstein, 2018).

With many practitioners guiding families to ABA services after a child is diagnosed with ASD, it is important to understand how to protect vulnerable individuals from potential harms. The Ontario Health Professions Regulatory Advisory Council (HPRAC) defines ABA services as "a broad range of activities [...] used to address a client's concerns and needs, such as reducing problem behaviour and increasing desirable behaviour" (Ontario HPRAC, 2018, p. 11). This report describes how there is risk of harm in all phases of ABA, including when conducting an initial behavior assessment and when designing, implementing, monitoring, and evaluating the resulting intervention plan. The Ontario HPRAC also identifies a range of setting, client vulnerability, condition severity, and age-related factors associated with increased risk of harm to individuals receiving ABA. For example, individuals receiving ABA in rural or remote settings, individuals with poor health, mobility, verbal communication skills, or social supports or without access to high quality ABA, individuals with co-occuring mental health conditions or more severe, intense, or frequent behavior problems, and younger or older individuals may be at increased risk for harm. This report to the minister of health and long-term care recommends increased governmental oversight and assurance of ABA provider training and skill as keys to reducing risk of harm.

Another way to reduce risk of harm is to ensure ABA programs and providers are adhering to evidence-based practices (EBPs) and that services are a good fit for individual children and their families. The National Professional Development Center Clearinghouse on Autism Evidence and Practice (NCAEP) has identified 28 EBPs for ASD, many of which are compatible with ABA (Steinbrenner et al., 2020). One such intervention is Discrete Trial Training (DTT), which aims to teach skills that are best learned through repetition and uses meticulously planned rewards and punishments, today often giving or restricting access to preferred objects or activities, to support mastery of those skills. The NCAEP reports that this intensive intervention, both a mainstay of ABA programs today and akin to interventions used by Lovaas and his contemporaries, has been shown to strengthen language, communication, and academic skills in early childhood and to be adaptable to all ability levels (Bogin, 2008). DTT, however, is by no means the only behavioral intervention available to children with a diagnosis of ASD and their families. Research Units in Behavioral Intervention (RUBI), for example, is a behavioral parent training intervention that focuses on providing parent psychoeducation on topics like advocacy, treatment options, behavior principles, reinforcement, and functional communication training. RUBI has been