# ANXIETY DISORDERS

WORKBOOK FOR COMMUNITY HEALTH WORKERS

TEAM UP SCALING AND SUSTAINABILITY CENTER

TEAM UP SCALING & SUSTAINABILITY CENTER ™

## Acknowledgements

TEAM UP has been developed with funding from the Richard and Susan Smith Family Foundation and The Klarman Family Foundation in collaboration with participating practices.

# TABLE OF CONTENTS

# How to Use this Workbook

## Goals for this Workbook

- TEAM UP Workbooks are designed to provide a framework for the CHW scope of practice within the TEAM UP Model and emphasize three core areas of work:
  - Engagement
  - Education
  - Care coordination
- Each workbook focuses on a developmental or behavioral concern and aligns with training content available in the TEAM UP CHW Foundational Training and the TEAM UP Virtual Learning Platform.
- CHWs can use this workbook to guide their work with patients and families.
- All tasks and activities outlined in this workbook can be coordinated between the CHW and other members of the integrated care team.
- CHWs should collaborate with others on the integrated care team on work outside of their scope.

## Adapting this Workbook

- This workbook is meant as a guide and is intended to be adapted to suit each practice's needs while maintaining the CHW scope of practice as defined within the TEAM UP Model.
- Please maintain all acknowledgements to the TEAM UP Scaling and Sustainability Center as the originator of this workbook's content.

## A Family Centered Approach to Healthcare

When communicating with and about people with mental health conditions, it is important to understand how they view themselves and to use inclusive language that respects their self-conceptions. Popularized in the 1970s and codified in the Americans with Disabilities Act, people-first language centers on an individual's personhood when describing their health condition. For example, using a people-first approach, a person diagnosed with autism would be referred to as a *person with autism* rather than an *autistic person*.

However, as social values evolve, so does the language surrounding mental health. Some individuals view their mental health condition as an integral part of their identity and prefer an identity-based approach. This perspective emphasizes the sense of belonging that comes from identifying with a community of people who share the same condition. Using this approach, a person diagnosed with autism might prefer to be called an *autistic person* rather than a *person with autism*.

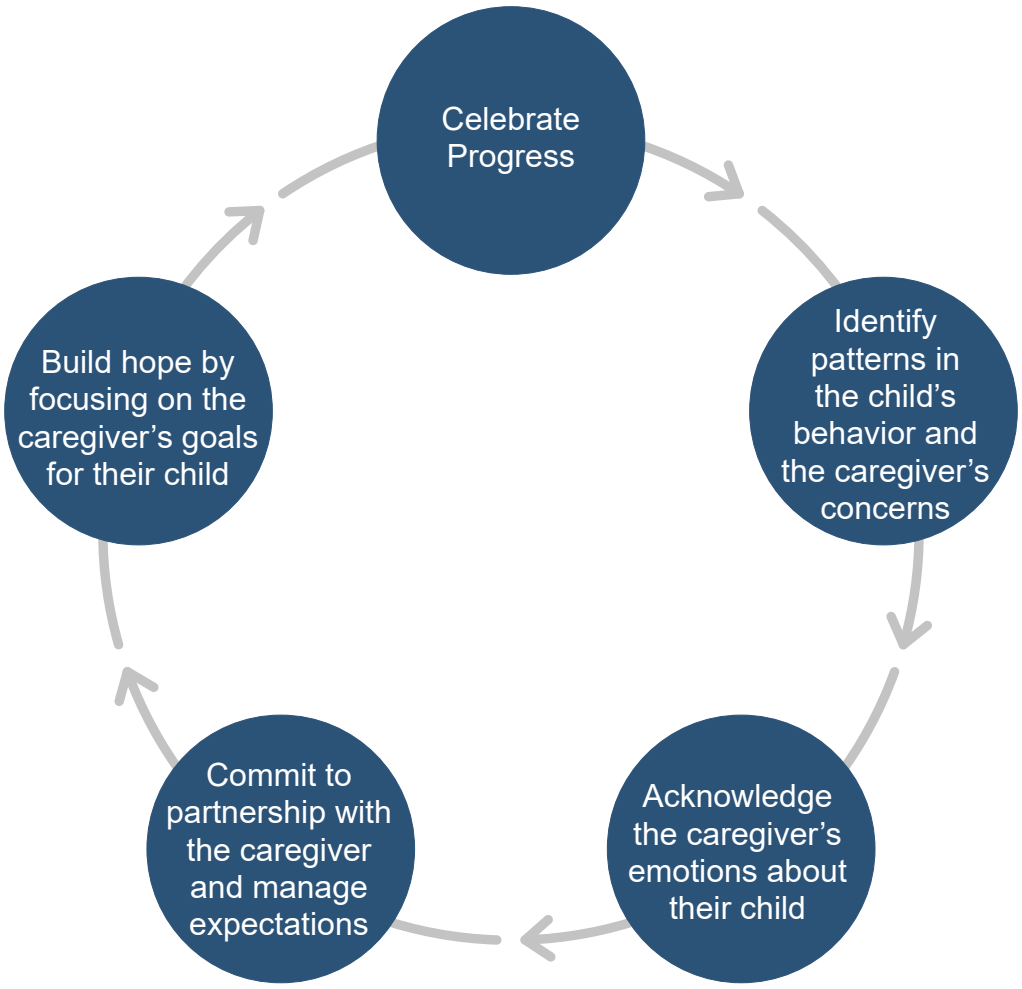
Given the diversity of perspectives on self-identity and language preferences, it is important to be thoughtful and respectful in communication about mental health conditions. While the TEAM UP Center is committed to using inclusive language that honors people's identities, it does not favor using people-first or identity-based language over the other. To be consistent in its content, this workbook uses people-first language to describe conditions impacting children.

Practitioners should equip themselves with knowledge about the range of ways that people identify, but the most direct way to honor preference is to elicit input from individuals themselves. Using a patient- and family-centered approach involves using the terms preferred by the person or people with whom you are working.

## Working with Caregivers

When a child is diagnosed with an anxiety disorder, caregivers may experience a range of emotions, including stress, confusion, or uncertainty about what this diagnosis means. Caregivers may feel overwhelmed by their child's behaviors, and unsure how to best support them. Caregivers may not understand when or why anxiety affects the child's life and may feel frustrated or concerned when their child is having trouble coping with fears and worries.

It is important to frame this diagnosis as an opportunity for caregivers to learn how to best support their child's unique needs and as a means to get access to more services. As CHWs engage with caregivers, it is important to approach these conversations with empathy and encouragement, keeping the following considerations in mind:



## Core Symptoms

It is common for children to experience fear or anxiety at different stages of their development. They may feel distress when separated from their caregivers or experience temporary fears of specific stimuli (like the dark, storms, strangers, or animals). These types of anxieties are short-lived, age-appropriate, and do not interfere with their daily functioning. For most children, once the situation causing anxiety passes, their symptoms naturally begin to ease.

Anxiety may become concerning when a child's fears and worries are persistent and disrupt their functioning at home, at school, or in social settings. Common psychological symptoms of general anxiety include (American Psychiatric Association, 2022):

- Consistent distress in the absence of a stressful situation
- Absence from school or enjoyable activities
- Fear and avoidance of new situations or everyday activities
- Poor concentration and inattention
- Negative relationships at home and/or school
- Repetitive or intrusive thoughts
- Irritability

Additionally, anxiety can manifest as the following physical symptoms. In most situations, these symptoms dissipate after the stressor inducing anxiety resolves. However, when these symptoms persist in the absence of a stressor, this can be indicative of an anxiety disorder. The following are examples of common physical symptoms (American Psychiatric Association, 2022):

- Sweating
- Nausea
- Stomachaches
- Dizziness
- Heart racing
- Shortness of breath
- Restlessness

Every child is unique, and experiences of anxiety are subjective. Manifestation of anxiety symptoms can vary with age and result in different types of anxiety. Recognizing the common sources of worry across developmental stages helps differentiate between typical and problematic anxiety that may need further intervention. Listed below are developmentally appropriate sources of anxiety (Wicks-Nelson & Israel, 2022):

| Developmental Stage | Source of Anxiety |
|---|---|
| **Infancy (0-2 years)** | • Stranger Anxiety (6-9 months): child begins to differentiate between familiar and unfamiliar faces<br>• Separation Anxiety (10-18 months): child becomes distressed when separated from caregiver<br>• Loud noises or sudden movements: child is startled by unexpected stimuli |
| **Toddlerhood (2-3 years)** | • Caregiver separation: child is distressed when separated from primary caregivers<br>• Fear of animals<br>• Fear of the dark<br>• Fear of toilet training |
| **Pre-school age (3-5 years)** | • Imaginary creatures or monsters<br>• Fear of thunderstorms or loud noises<br>• Separation anxiety: though to a lesser degree then earlier, the child is distressed when separated from caregiver, especially in new situations |
| **Early School (6-8 years)** | • Fear of being lost/abandoned<br>• Fear of failure or rejection<br>• Fear of physical harm as children understand the concept of danger better<br>• Health anxiety: children experience fear about getting sick or experience psychosomatic symptoms |
| **Middle Childhood (9-12 years)** | • Performance anxiety: fear of failure in school, activities, or social settings<br>• Social anxiety: stressed about fitting in with peers and being accepted by social groups<br>• Fear of death: as children understand mortality, they can become anxious about their own death or deaths of loved ones |
| **Adolescence (13-18 years)** | • Social judgement: anxiety about social rejection, embarrassment, bullying, or the desire to belong in social groups<br>• Anxiety about the future: adolescents may worry about academic success, career paths, and future success<br>• Body image: adolescents may be concerned about their physical appearance and self-worth |

## Cultural Considerations

Around age 6, anxiety disorders can manifest differently across genders. Research shows that anxiety disorders tend to be more prevalent among children assigned female at birth (AFAB) and those who identify as girls. However, it's important to consider multiple factors that may contribute to these differences, including:

- Reporting bias: Children socialized as girls may feel more comfortable expressing their fears and anxieties.
- Social roles, experiences, and genetic influences: These may increase vulnerability to anxiety in AFAB individuals and those who identify as girls.
- Caregiver perception: Caregivers may be more inclined to interpret certain behaviors as fearful when exhibited by girls or those perceived as such.
- Social stigma: Non-binary and transgender children may experience unique stressors, such as societal discrimination or internal struggles with identity, which could also contribute to anxiety. More research is needed to fully understand the diverse experiences of anxiety across the gender spectrum.

Additionally, demographic characteristics can have an impact on the severity of symptoms and response to treatment among youth. Research shows that socioeconomic status, family psychopathology, and family functioning are correlated with the efficacy of CBT and medication intervention in anxiety symptom reduction (Norris & Kendall, 2020).

Further, caregivers may also exhibit anxiety that reinforces their child's anxiety. It is important to engage in dialogue with the child's caregivers about how stress, worry, and fear are discussed in the family. It is also important to talk to caregivers about how strategies to mitigate stress and fear manifest in their culture. While untreated anxiety can impair the child's functioning, early intervention and consistent support can help meditate anxiety symptoms.

## Screening

Children are often first screened through general developmental screening tools like the Survey of Well-Being for Young Children (SWYC), which asks about child behavior, child development, and family questions, Ages and Stages Questionnaire (ASQ), or the Parents' Evaluation of Developmental Status (PEDS) (American Academy of Pediatrics, n.d.).

Anxiety is often diagnosed with the Screening for Child Anxiety and Related Disorders (SCARED), which combines self-reports from parents and children to evaluate anxiety across the following 5 domains (APTA):

- generalized anxiety
- separation anxiety

- social anxiety
- panic or somatic symptoms
- school avoidance

The SCARED is a valuable tool due to its ease to administer in care settings, and availability in both child and caregiver versions, allowing insights from multiple perspectives. It has strong psychometric properties, making it a reliable and valid tool for screening anxiety. Additionally, its subscale scoring, helps to identify specific anxiety-related concerns, such as social or school avoidance (American Academy of Pediatrics, 2024).

The Generalized Anxiety Disorder Scale-7 (GAD-7) is another tool utilized in the primary care setting for diagnostic purposes. The GAD-7 consists of 7 questions based in part on the DSM criteria for GAD and reflects the frequency of symptoms during the preceding 2-week period. It is a self-report questionnaire validated for use with children aged 11-17 (American Academy of Pediatrics, 2024).

Screening tools are easy to administer in care settings, and require minimal time to complete, allowing for efficient and time-saving data collection. Screeners, such as the SCARED and GAD-7, are reliable and can be re-administered to track symptoms and inform treatment planning and effectiveness.

## Interfering Behaviors

Anxiety disorders can be associated with the following:

- conduct disorders and ADHD
- mood disorders
- difficult peer relationships
- trauma and PTSD
- smoking and substance use

With intervention and consistent support, these associated conditions can also be managed, and symptoms can improve over the child's lifetime.

## Interventions

Interventions for children commonly involve caregiver active participation, psychoeducation, developmental education and emotion regulation skills, behavioral management and coping strategies, and, when appropriate, directly addressing behavioral and mental health concerns in a safe therapeutic setting. For young children, play-based interventions are most typically used to support a child's developmental capacity for expression and interpretation of their experiences. Below are examples of commonly used interventions for children and families.

### Outpatient (OP) Therapy

OP therapy is a common and effective treatment approach for supporting children and families with behavioral health concerns. It is flexible and centered around the patient's and family's needs. Therapists are able to support the development of essential skills, such as coping, caregiving strategies, and behavioral plans, to increase and stabilize the patient's ability to function and succeed in the home and other settings. OP therapy can be delivered in an individual, family, play, or group setting. Therapists provide follow-up and ongoing monitoring.

### Cognitive Behavioral Therapy (CBT)

CBT focuses on adjusting unhelpful thinking patterns to positively impact mood and behavioral responses. A foundational piece of the CBT model is known as the CBT triangle, which is a visual representation of the relationship between a person's thoughts, feelings, and behaviors. For more information, see Appendix.

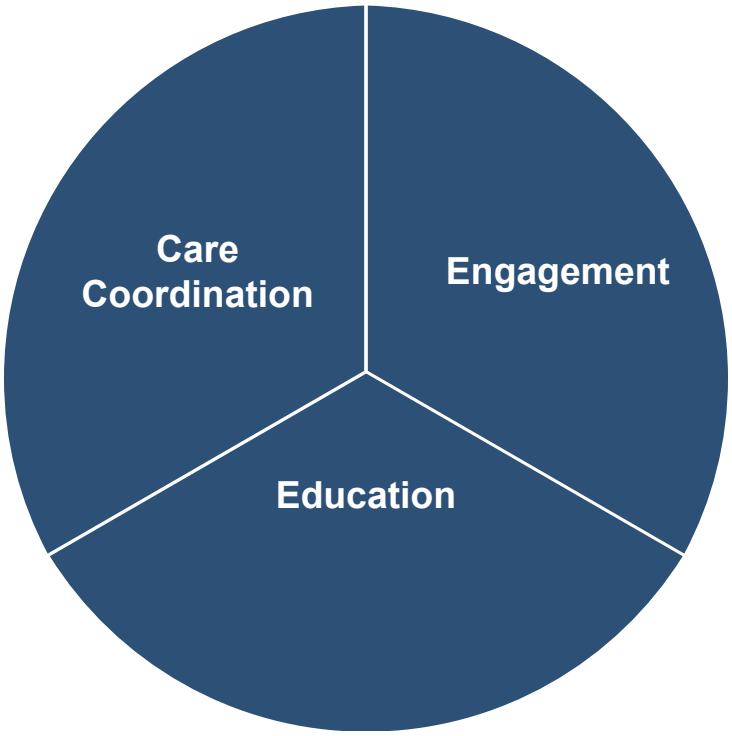
### Children's Behavioral Health Initiative (CBHI)

CBHI provides children and their families with integrated behavioral health services and a comprehensive, community-based system of care. Services under CBHI include, but are not limited to, intensive care coordination (ICC), in-home therapy (IHT), therapeutic mentors (TM), and in-home behavioral services (IHBS) (Children's Behavioral Health Initiative, 2015).

While all the CBHI services provide support for children and their families, IHBS may be particularly helpful for children with anxiety. IHBS is similar to ABA in that a team works with the child and family to create a behavior plan that targets specific behavior challenges to change behaviors that interfere with everyday life (Children's Behavioral Health Initiative, 2015).

## Overview of the CHW Role in Anxiety Disorders

CHWs within the TEAM UP Model specialize within 3 core areas described below to support the developmental and behavioral health needs of pediatric patients at their practice:



## Engagement

**Engage** families in understanding healthy child development, navigating diagnostic processes and pathways, accessing appropriate formal supportive services, and seeking support for parenting stress. This includes outreach to families lost to care or experiencing gaps in care and informal counseling and coaching to promote healthy development, increase access to care and services, reduce stigma, and improve informed decision making for patients, caregivers, and families. Outlined below are some of the ways CHWs can effectively engage with families and caregivers.

Communication Style

- Listening actively
  - Offer encouragement
  - Paraphrase patients' and caregivers' thoughts
  - Observe non-verbal cues and identify emotions
- Asking open-ended questions to allow for more sharing and closed questions to obtain specific details

Motivational Interviewing

- MI is a directive, client-centered approach for eliciting changes in behavior by helping patients and caregivers to explore and resolve ambivalence; this approach focuses on:
  - Collaboration with the patient or caregiver
  - Evoking responses
  - Corroborating the patient or caregiver's autonomy
  - Offering compassion
- MI uses a four-pronged approach to engage with patients and caregivers, called OARS:
  - (O)pen questions: invite others to tell their story without leading in a specific direction
  - (A)ffirmations: recognize patient and caregiver strengths and acknowledge behavior that leads in the direction of positive change
  - (R)eflective listening: is a pathway for engaging others in relationships, building trust, and fostering motivation to change
  - (S)ummaries: apply reflective listening to summarize back what the patient or caregiver shared; can be used throughout conversation

Problem Solving

- Problem solving is an approach to engagement that seeks to:
  - Increase understanding of the link between current problems, stress, and depression risk
  - Define problems and set concrete, realistic goals
  - Teach a systematic problem-solving strategy
  - Promote behavioral activation with concrete tasks including pleasant social and physical activities
- Problem Solving Education (PSE) is a 7-step method for applying problem solving skills to decrease caregivers' stress, improve functioning, and promote wellbeing; PSE steps include:
  - Exploring the problem
  - Setting realistic goals
  - Brainstorming solutions based on set goals
  - Examining pros and cons of the proposed solutions
  - Choosing a solution
  - Making an action plan to execute solution
  - Reviewing tasks, effectiveness of chosen solution for problem, and reinforcing success reinforcing success

Caregiver Coaching and Support

- Recognize the impact of sociocultural differences on mental health awareness and caregivers' subsequent feelings of frustration, grief, shame, and stress
- Help caregivers work on parenting strategies, structure, reinforcement mechanisms, coping skills, and advocacy for appropriate services
- Emphasize that caregivers' emotions affect children's emotions by:
  - Modeling coping strategies
  - Validating children's struggles
  - Maintaining consistency in disciplinary measures
  - Making themselves accessible to their child
- Empower caregivers to communicate effectively:
  - Describe their child's behavior in specific terms
  - Identify triggers for their child's behavior
  - Provide insight into patterns of behavior (stimulus and reaction)

Supports and Services

- Early Intervention for children under the age of three
- School-based assessments beginning at 2.9 years of age
- Developmental screeners and assessments
- Outpatient services, such as outpatient individual or family therapy based on child's symptoms and family's needs
- School-based services, such as ABA, speech, PT, OT, special education instruction, paraprofessional, and other services based on child's symptoms and needs to support functioning and access to school curriculum
- In-home services, such as IHBS and ABA

## Education

**Educate** and offer support to caregivers regarding child growth and development as appropriate including information about symptoms, diagnosis, management, services available for caregivers, family members, and youth, and other resources to promote informed decision-making related to care and to manage parenting stress. This also includes education to support caregiver self-management skills that anticipate and address barriers to accessing services and treatment. CHWs should provide education about:

- Child growth and development
- Common symptoms for developmental delays and appropriate screeners
- EI referral process
- Diagnostic process
- Local options for services

## Care Coordination

**Coordinate care** and assist families in connecting to and maintaining treatment, services, and resources through ongoing collaboration with patients, caregivers, primary care providers (PCP), behavioral health clinicians (BHC), and other care team members.

- Assist with navigation pathways, including pre-diagnosis, diagnostic, and post-diagnosis stages
- Assist with connecting to EI services (see Appendix)
- Assist with initiating CORE evaluation for school-based services (like IEP Checklist in Appendix or 504 Plan)
- Assist with referrals to developmental/behavioral pediatrics (see Appendix)
- Assist with additional outpatient or in-home services, such as outpatient therapy, IHBS, ABA, and ICC

# Resources

## Child Development

- The Basics
- CDC Act Early Resources and Milestone Tracking App

## Anxiety

- Substance Abuse and Mental Health Services Administration (SAMHSA)
- American Academy of Child and Adolescent Psychiatry

## Caregiver Resources

- Center for Disease Control (CDC) Positive Parenting Tips Handouts
- Zero-to-Three Parenting Resources
- Parent/Professional Advocacy League
- Parenting Stress Line (1-800-632-8188)

# Citations


American Academy of Pediatrics. (2024). Developmental screening and surveillance. In Bright Futures Tool and Resource Kit (2nd ed.). https://publications.aap.org/toolkits/resources/15625.

American Academy of Child and Adolescent Psychiatry. (2023.). The Anxious Child. https://www.aacap.org/AACAP/Families_and_Youth/Facts_for_Families/FFF-Guide/The-Anxious-Child-047.aspx#:~:text=Anxious%20children%20are%20often%20appear,and%20fears%20may%20be%20missed.

American Physical Therapy Association. (October, 2023). Screen for Child Anxiety-Related Disorders (SCARED). https://www.apta.org/patient-care/evidence-based-practice-resources/test-measures/screen-child-anxiety-related-disorders-scared#:~:text=SCARED%20is%20a%20quick%20and,fewer%20symptoms%20than%20their%20children.

American Psychiatric Association. (2022). Diagnostic and statistical manual of mental disorders: Fifth edition, text revision: Dsm-5-Tr.

American Psychological Association (2017). What is Exposure Therapy? Clinical Practice Guideline for the Treatment of Posttraumatic Stress Disorder. https://www.apa.org/ptsd-guideline/patients-and-families/exposure-therapy.pdf.

Children's Behavioral Health Initiative (2015). MassHealth Behavioral Health Services for Children and Youth Aged 20 and Younger. https://www.mass.gov/ doc/mass-health-behavioral-health-services-for-children-and-youth-aged-20- and-younger-a-guide-for/download.

Children's Behavioral Health Initiative (2015). In-home Behavioral Services Practice Guidelines. https://www.mass.gov/doc/in-home-behavioral-ser- vices-ihbs-practice-guidelines/download.

Mossman, S. A., Luft, M. J., Schroeder, H. K., Varney, S. T., Fleck, D. E., Barzman, D. H., Gilman, R., DelBello, M. P., & Strawn, J. R. (2017). The Generalized Anxiety Disorder 7-item scale in adolescents with generalized anxiety disorder: Signal detection and validation. Annals of Clinical Psychiatry, 29(4), 227–234A.

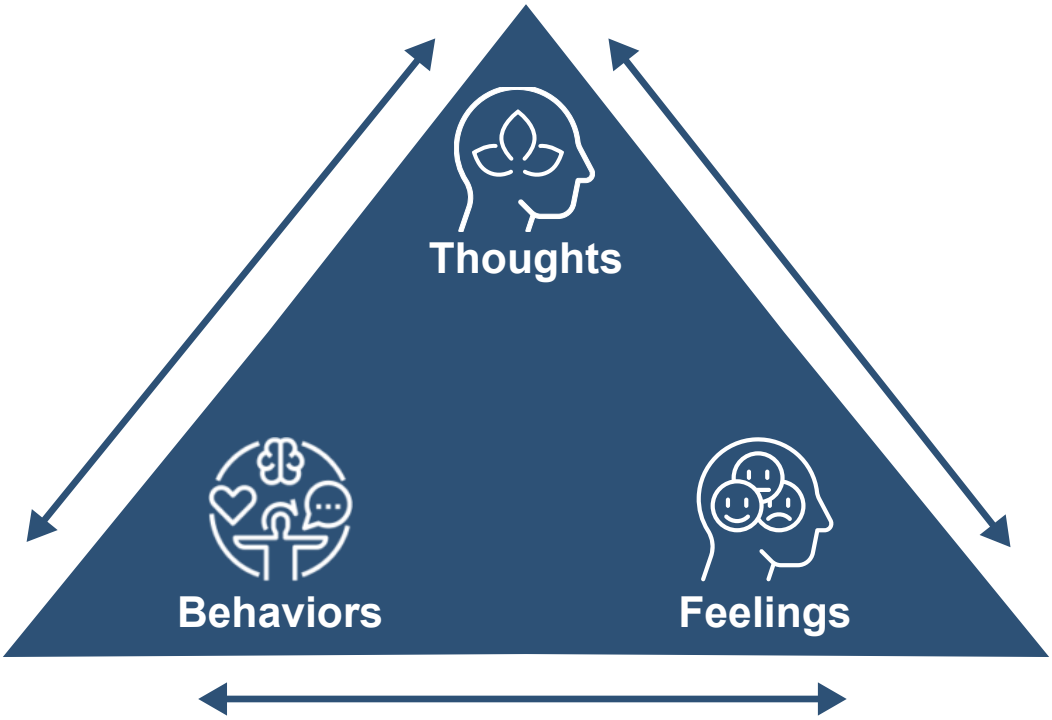
Norris, L. A., & Kendall, P. C. (2020). Moderators of Outcome for Youth Anxiety Treatments: Current Findings and Future Directions. Journal of Clinical Child and Adolescent Psychology, 50(4), 450–463. https://doi.org/10.1080/15374416.2020.1833337.

Wicks-Nelson, R., & Israel, A. C. (2022). Abnormal child and adolescent psychology with DSM-V updates. Psychology Press.

Wooldridge, S. (2023, April 12). Writing respectfully: Person-first and identity-first language. National Institutes of Health. https://www.nih.gov/about-nih/what-we-do/science-health-public-trust/perspectives/writing-respectfully-person-first-identity-first-language.

# Appendix

## Cognitive Behavioral Therapy (CBT)




CBT interventions typically consist of the following 8 steps (American Psychological Association, 2024):

| Intervention Stage | Description |
|---|---|
| **Cognitive Reframing** | • **Identifying and Challenging Negative Thoughts:** CBT helps individuals recognize distorted or unhelpful thought patterns that exacerbate anxiety. These can include catastrophic thinking (assuming the worst will happen) or overgeneralization (thinking one bad outcome means all future outcomes will be bad).<br>• **Reframing Thoughts:** The goal is to challenge these automatic thoughts and replace them with more balanced, realistic, and evidence-based ones. |
| **Exposure Therapy** | • **Facing Fears Gradually:** A key CBT technique for anxiety disorders is exposure therapy, where individuals are gradually and repeatedly exposed to the source of their anxiety in a controlled and safe environment. This process helps desensitize the person to the feared object, situation, or thought.<br>• **In-vivo exposure:** Directly facing feared object/place/situation in real life<br>• Imaginal exposure: Vividly imagining the feared object/place/situation<br>• Systematic Desensitization: This involves gradual exposure paired with relaxation techniques to reduce anxiety responses. |

| Intervention Stage | Description |
|---|---|
| **Behavioral Activation** | • **Encouraging Positive Activities:** For people with anxiety, avoiding situations that cause stress can be common, but this avoidance can reinforce the anxiety. Behavioral Activation helps patients engage in meaningful activities that they may have been avoiding- improving mood and reducing anxiety. |
| **Problem Solving** | • **Developing Effective Coping Skills:** This involves learning to break down overwhelming problems into smaller, manageable parts and finding practical solutions, which can reduce anxiety related to feeling out of control or overwhelmed. |
| **Relaxation Techniques** | • **Breathing Exercises and Progressive Muscle Relaxation:** CBT often incorporates relaxation strategies like deep breathing, mindfulness, and progressive muscle relaxation to help manage the physiological symptoms of anxiety. |
| **Psychoeducation** | • **Teaching About Anxiety and CBT:** CBT includes education about how anxiety works and how thoughts, feelings, and behaviors interact to maintain the anxiety. Recognizing these links helps individuals take an active role in their treatment. |
| **Mindfulness and Acceptance** | • **Focusing on the Present Moment:** Mindfulness is sometimes integrated into CBT, encouraging individuals to observe and accept their thoughts and feelings without judgment, rather than reacting to them emotionally.<br>• Mindfulness techniques help individuals to recognize the connection between mind and body. |
| **Goal Setting** | • **Setting Specific, Measurable Goals:** CBT focuses on concrete goals related to reducing anxiety, and therapy is structured around working toward these goals. Tracking progress helps maintain motivation and gives a clear sense of accomplishment. |

## Developmental Behavioral Pediatrics Checklist

| Developmental Behavioral Pediatrics Referral, Assessment and Services Checklist | | | |
|---|---|---|---|
| | **KEY TASKS** | **DATE COMPLETED/ TEAM MEMBER** | **TIMEFRAME** |
| **REFERRAL STAGE** | | | |
| | Confirm referral placed by PCP and reason for referral is clearly identifiable | | |
| | Check-in with family:<br>• Share information re: referral to DBP and why<br>• Provide education, address family's concerns, and explore benefits and challenges<br>• If family declines or is hesitant – loop PCP in and continue to provide support as needed<br>• If family consents to referral, explain referral process | | |
| | Collect releases for EI, school, and other providers as necessary | | |
| | Work with family to gather IFSP, 504 Plan, IEP, or other documents | | |
| | Complete referral cover letter and send to DBP with IFSP, other documents | | |
| | Support family to schedule evaluation appointment(s) and develop plans for attending appointment<br>• If PT-1 is needed, begin process early to ensure it is scheduled in time | | Referrals take 3-10 business days for CHCs not on Epic |
| | Document details in EMR:<br>• Dates and details of scheduled DBP appointments<br>• All work performed, provider's information<br>• Set reminder to call family 3 days before scheduled appointment(s) | | |
| | Call family 3 days before scheduled evaluation appointment(s):<br>• If using PT-1, confirm requests have been placed<br>• Review intake and evaluation process<br>• Offer/set-up after visit follow-up | | |
| | For missed appointments, help with rescheduling:<br>• Assist with scheduling additional appointment(s) if necessary<br>• Set reminder to call family 3 days before appointment(s)<br>• If using PT-1, confirm requests have been placed | | |

| Developmental Behavioral Pediatrics Referral, Assessment and Services Checklist | | |
|---|---|---|
| | Check-in with DBP and family after the completed evaluation appointment(s):<br>• Answer questions or concerns family may have<br>• Explain feedback appointment and process<br>• Prepare family for potential diagnosis and remind parents that PCP and BHI team will continue to support and assist regardless of outcome | |
| | Support feedback process:<br>• Assist family in scheduling feedback appointment<br>• Schedule check-in visit/call with family within 2 weeks of feedback appointment | Feedback to occur 1-2 weeks after evaluation |
| **SERVICE STAGE** | | |
| | Get a copy of DBP report and ensure it is documented in EMR for PCP review, confer with PCP on needed referrals | |
| | Call/meet with family and review DBP recommendations together | |
| | Explain available services and process for connecting to services | |
| | If child under 3 years:<br>• Ensure family gives DBP report to EI service coordinator, place referral for EI if not already involved | |
| | If child at least 2 years, 9 months:<br>• Assist with request for IEP testing<br>• If EI is involved, request for EI service coordinator to assist with transition to school | |
| | If child is over 3 years:<br>• Follow up with family/school to make sure appropriate services are in place or plan to begin, e.g., ASD specialty classroom, pullout services for speech, OT, PT, ABA supports, etc. | |
| | If child diagnosed with ASD, explore home-based services | |
| | Remind family about DBP follow up visit, if applicable | |
| | Offer additional resources to family, e.g., parent groups | |
| **OPTIONAL** | | |
| | Explore eligibility for Supplementary Security Income (SSI) | |
| | Explore eligibility for Dept. of Developmental Services (DDS) | |
| | Explore eligibility for Medicaid (families with private insurance) or other ASD specific coverage | |

| Developmental Behavioral Pediatrics Referral, Assessment and Services Checklist | |
|---|---|
| | Complete autism waiver application |
| | Explore eligibility and need for placard |
| | Explore need for personal care attendant (PCA) referral |
| | Explore need and support connection to other resources as needed |

## Early Intervention Checklist

| Early Intervention (EI) Referral, Assessment and Services Checklist | | | |
|---|---|---|---|
| | **KEY TASKS** | **DATE COMPLETED/ TEAM MEMBER** | **TIMEFRAME** |
| **REFERRAL STAGE** | | | |
| | Engage family to confirm consent to refer | | |
| | Provide education on EI and referral process | | |
| | Provide referral information and instructions to contact EI provider directly, e.g., have not been contacted by EI provider within 1 week of referral date (provide handout or send letter with this information as needed) | | |
| | Get release signed | | |
| | Coordinate with family and EI provider to schedule intake and assessment (if needed) | | |
| | Document scheduled appointment(s) in EMR | | |
| | Place reminder call to family 3 days before scheduled intake and assessment appointment(s) | | |
| **ASSESSMENT STAGE** | | | |
| | Provide education on process of EI intake and assessment, including eligibility criteria | | |
| | Address anticipated logistical barriers for completing assessment (note that assessments usually occur in the home, a childcare setting, or EI location) | | |
| | Help reschedule appointment if necessary | | |
| | Follow up with family and EI provider within 3 days of completed assessment | | |
| | Obtain copy of eligibility determination and assessment from EI provider for EMR | | |
| | Document eligibility determination and assessment, along with any family-reported information, in EMR | | |
| **SERVICES STAGE** | | | |
| | If eligible, obtain a copy of the Individualized Family Service Plan (IFSP) and document in EMR – may need to resend release to agency and request copy of IFSP | | |
| | Loop in PCP to ensure they review IFSP and continue to support family with ongoing EI services | | |
| | Address potential barriers to service engagement, such as appointment location, times, etc. | | |

| Early Intervention (EI) Referral, Assessment and Services Checklist | |
|---|---|
| | Continue to communicate and collaborate with EI provider and PCP, and support referrals for additional services, such as outpatient (OP) speech, occupational therapy (OT) or physical therapy (PT) |
| **TRANSITION STAGE** | |
| | Engage family at 30-month well child visit, inquire about aging out of EI plans, and/or provide information on what to expect |
| | Loop in PCP to ensure continuity of care – message through EMR or face-to-face consultation for urgent concerns |
| | Encourage and support family to speak with EI provider about the transition process and plan |
| | Outreach to EI provider to inquire about transition/ discharge plan, i.e., referrals to OP services, preschool, or school for IEP testing |
| | Obtain copy of transition plan and document in EMR |
| **DISCHARGE PLAN** | |
| | Collaborate with EI provider and PCP to support discharge plan, and possible referral(s) to OP services (speech, PT, etc.), connecting with preschool, information on school IEP testing |
| | Ensure family understands the discharge plan |
| | If discharged to OP services, ensure family and PCP are aware of the plan to continue services on an outpatient basis and support family in locating and connecting to new providers |
| | If discharged to preschool program, ensure family understands available options, i.e., public preschool, Head Start (may have slots for children with special needs), private preschool, center-based childcare facility (many childcare centers offer financial assistance), etc. |
| | If discharged to school for IEP assessment, ensure family understands IEP process (assessments typically begin at 2.9 years, and if eligible, preschool begins at age 3) |
| | Consider with PCP whether specialty developmental testing, e.g., BMC's DBP Clinic, is beneficial for specialized accommodations, e.g., school supports, ABA, etc. |

## Early Intervention (EI) Referral, Assessment and Services Checklist

### COMMON CHALLENGES IN SUPPORTING FAMILIES WITH EARLY INTERVENTION SERVICES

**Initial Connection:**

- It is crucial to ensure caregivers are aware of and agree to a referral to EI. Many EI providers will not schedule an intake or assessment if caregivers are not agreeable to services as EI is voluntary.
- Also, it may be helpful to walk through the intake and assessment process with families to support their engagement in services, particularly for families with scheduling constraints or concerns about EI services. In many cases, EI providers are able to offer an alternative schedule for on-going sessions; however, caregivers must be present for the initial intake or assessment appointment.
- This is an opportunity to collaborate with EI providers and families to find creative solutions that would best serve the child. For example, caregivers could take one day off from work to be present for the intake appointment, and the EI provider would meet with the child while at daycare moving forward. It may also be helpful to address caregivers' concerns through other lenses, such as cultural factors that may influence their decision-making process.

H**igh-risk Patients:**

- It is helpful to identify the EI staff members working with the patient—developmental specialist, speech therapist, social worker, etc.—and the best method to contact them. Many EI staff are out of the office doing fieldwork and can be difficult to reach through their office number. Having a cell phone number or email will allow for seamless communication and collaboration on an individual patient's needs.

**Transitioning Out of EI:**

- It may be helpful to begin planning for transition out of EI around the 30-month well child visit. Initiate conversation, provide information to caregivers on what to expect, and explore options. Particularly for children that may require a referral for a core evaluation with the school for an Individualized Education Plan (IEP).
- In such cases, it may be helpful to begin the process of referring for a developmental assessment, if one has not already been placed. External assessments, such as through Developmental Behavioral Pediatrics, further support and ensure patients will receive adequate and appropriate accommodations at school.
- For patients who will require on-going intensive OP services, such as speech therapy, it may be helpful to support families in beginning the process before EI ends as there may be a lengthy wait for services.
- If the patient is not being referred for an IEP evaluation, it may be helpful to explore options for preschool or childcare, particularly for families that may need financial assistance.

## Individualized Education Plan Checklist

| Individualized Education Plan (IEP) Checklist | | | |
|---|---|---|---|
| | **KEY TASKS** | **DATE COMPLETED/ TEAM MEMBER** | **TIMEFRAME** |
| **REFERRAL STAGE** | | | |
| | Engage family to confirm consent to refer | | |
| | Provide education on school district and referral process | | |
| | Support caregivers with writing “letter” requesting school assessment | | Within 5 days district notifies caregivers and provides consent form for testing |
| | Get release signed | | |
| | If child in EI, coordinate with EI provider | | |
| | Support caregivers with gathering records, e.g., DBP assessment, IFSP, etc. | | |
| | Place follow up call within a week to confirm caregiver signed and returned consent form | | |
| **ASSESSMENT STAGE** | | | |
| | Provide education on evaluation process and remind caregivers to provide IEP Team with important documents, e.g., DBP assessment, IFSP, etc. | | Must be completed within 30 days of district receiving signed consent |
| | Ensure caregiver understands when and where assessment will take place (note that assessments usually occur in the child’s school or if not already attending school, a school within the district) | | |
| | Address anticipated logistical barriers for completing assessment | | |
| | Help reschedule assessment if necessary (note that waiting periods for next available dates may be long) | | |
| | Ensure that child will be tested in all areas of suspected disability, e.g., speech, physical, cognitive, etc. | | |
| | Follow up with family and EI provider 3 days before scheduled assessment to review questions, concerns, and important documents have been given to the district | | |

| Individualized Education Plan (IEP) Checklist | | |
|---|---|---|
| **ELIGIBILITY DETERMINATION** | | |
| | IEP Team eligibility meeting was or will be scheduled after completion of assessment. A completed evaluation report can be requested 2 days before the scheduled meeting. | Must occur within 45 school days of receiving signed consent |
| | Schedule follow up visit to review evaluation report together. Asist caregivers in understanding assessment results and preparing questions for determination meeting. Determine if it would be beneficial for CHW to accompany caregiver at the meeting. | |
| | At the meeting, the IEP team will discuss findings from assessments and determine disability and how it negatively impacts access to educational programming. | |
| | If eligible, the Team will recommend services, goals, and delivery options for proposed IEP. Caregivers will receive a hard copy in the mail. | IEP must be developed and sent to caregivers within 30 days of determination meeting |
| | If not eligible, caregivers may request a 504 plan or informal support plan | |
| **ACCEPTING PROPOSED IEP** | | |
| | Assist caregivers in reviewing proposed IEP | |
| | Ensure services are clear and goals are defined with measurable outcomes and time components. | |
| | Provide education on caregiver's options (accepting in full, accepting in part, or rejecting in full). It is recommended that caregivers accept at least parts of the IEP they agree with to avoid delays in child receiving services. | |
| | Obtain copy of IEP and document in EMR | |
| **IEP REVIEWS** | | |
| | Provide caregivers with education on review schedules and options | |
| | IEPs are reviewed once every year | |
| | Re-evaluations occur every 3 years, or sooner if there are other concerns, needs, or information | |
| | Caregivers may request the team convene at any time if there are concerns | |

## Individualized Education Plan (IEP) Checklist

### COMMON CHALLENGES IN SUPPORTING FAMILIES WITH SCHOOL SERVICES

**Initial Connection:**

- It is crucial to ensure caregivers are aware of educational rights and the school navigation process.
- It may also be helpful to explain the difference between medical and educational diagnoses, as well as the most commonly identified disabilities in school settings. It's important for caregivers to understand that having a diagnosis does not automatically mean a child will qualify for an IEP. The IEP Team must determine whether the disability impacts the child's academic access and performance.
- If a child is found not eligible, this is an opportunity to collaborate with school and families to find creative solutions that would best serve the child. It may also be helpful to address caregivers' concerns through other lenses, such as cultural factors that may influence their decision-making process.

**Special Circumstances:**

- Manifestation determination – if a child with an IEP or 504 plan**s** has been suspended for more than 10 days, from school, transportation, or other programming, for misbehavior there should be a meeting to determine if it is due to the child's disability.
- At the manifestation determination meeting, the Team must answer 2 questions:
  - Is the conduct a direct result of the district's failure to implement the IEP?
  - Does the conduct have a direct and substantial relationship to the disability?

If the team answers yes to either of these questions, then it is a manifestation of the disability. The Team must answer no to both of these questions for a determination of the behavior not being a manifestation of the disability.