AUTISM SPECTRUM DISORDER

WORKBOOK FOR COMMUNITY HEALTH WORKERS

TEAM UP SCALING AND SUSTAINABILITY CENTER

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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.

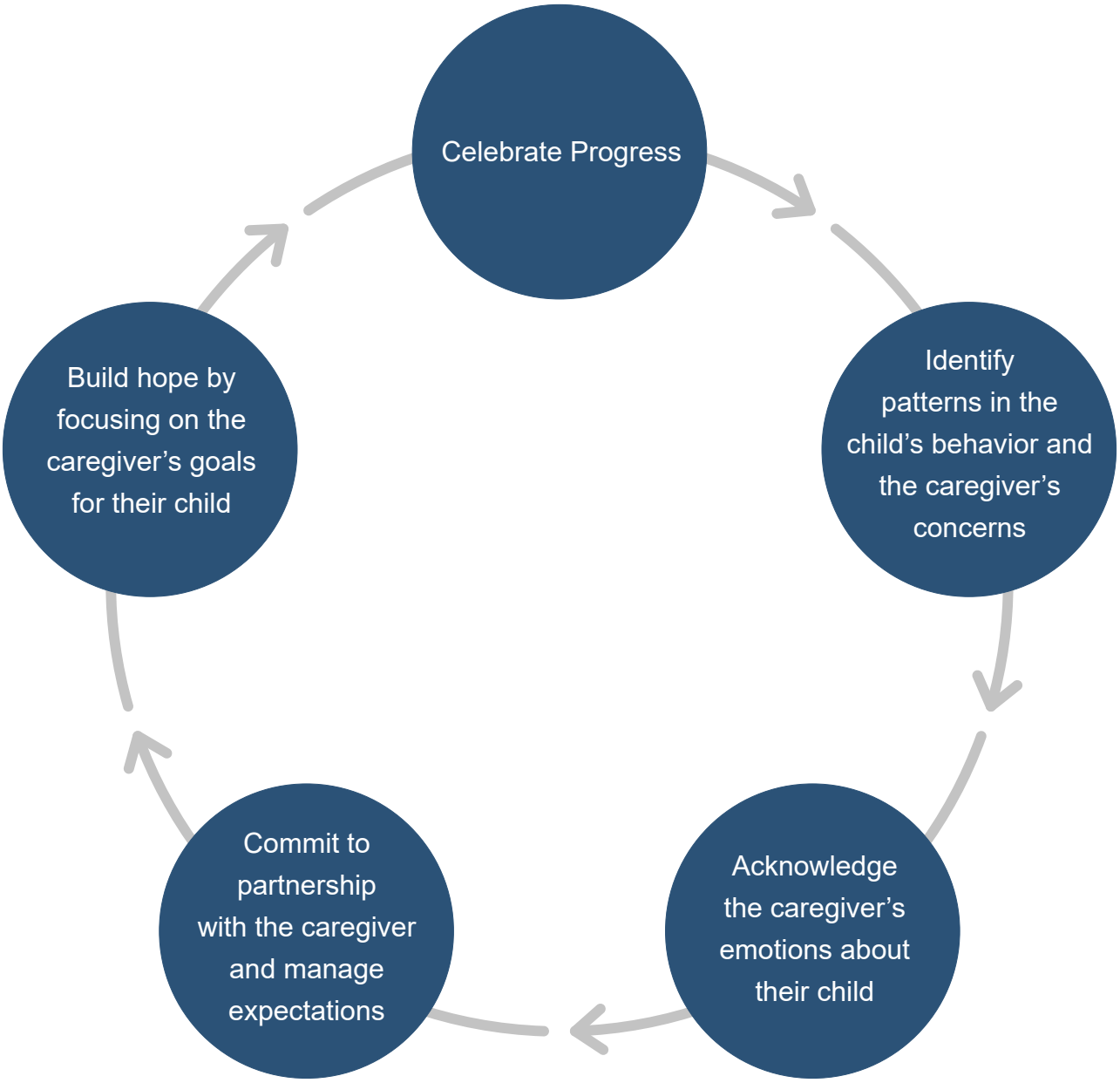
However, as social values evolve, so does the language surrounding mental health. Some individuals view their mental health condition as an integral part of their identity and prefer an identity-based approach. This perspective emphasizes the sense of belonging that comes from identifying with a community 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

Caregivers may experience a mix of emotions with varying degrees of stress and uncertainty when their child is diagnosed with ASD. While it is natural and common to experience stress and uncertainty, it is also an opportunity for caregivers to learn more about their child's neurodiversity and how to best support their child. A formal diagnosis of ASD often opens doors to more specialized 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

Autism Spectrum Disorder (ASD) is a neurodevelopmental condition that can impact a child's functioning across various domains. ASD symptoms generally include the following characteristics (American Psychiatric Association, 2022):

- Challenges with social communication and social interaction across multiple contexts and restricted and repetitive behavior (RRB) and patterns
- Symptoms can generally be detectable in early childhood, and with early intervention and consistent support can improve throughout a child's lifespan
- Symptoms typically exist across a spectrum, and can cause impairment in a child's social, occupational, or other important areas of current functioning
- These symptoms are not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay

Diagnostic Criteria

The DSM-5 TR further categorizes primary symptoms of ASD into two domains (American Psychiatric Association, 2022):

Social Communication (SC) and Social Interaction (SI) impairment – must meet all 3 areas:

Social Reciprocity	Non-verbal Communication	Socialization
Children may display low shared enjoyment, challenges with initiating interactions with others, poor or lack of response to social bids and response to name, and difficulty sharing	Children may display poor eye contact, pointing, gestures use, and range of facial expressions	Children may have low interest in peers, participation in interactive games, and pretend play

Restricted, Repetitive patterns of Behaviors (RRB) – must meet at least 2 of the 4 types:

Repetition	Routine	Sensory Behaviors	Fixation
Repetitive speech or movements; repetitive use of objects Children may repeat words or phrases over and over, hand flapping, lining up objects, interest in parts of objects	Children may demonstrate a strong preference to complete activities identically, may show distress with change in routine, and find comfort in sameness	Children may engage in visual inspection of objects/people, show sensitivity or aversion to noise, and demonstrate sensory seeking behaviors	A child with ASD may have very specific interests or focus on a specific topic for a prolonged period

Specifiers

Specifiers, such as severity level, may also be used to describe current level of symptoms and impairments to functioning. Levels of severity are rated separately for deficits in social communication and for restricted, repetitive behavior, the chart below provides an example for rating (American Psychiatric Association, 2022):

Severity Level	Social Communication (SC) and Social Interaction (SI)	Restrictive, Repetitive Behavior (RRB)
Level 3: "Requiring very substantial support"	• Severe deficits in verbal and nonverbal SC cause severe impairments in functioning • Very limited initiation of SI and minimal response to social overtures from others *Example*: A person with: • Limited intelligible speech • Rarely initiates interaction • Unusual approaches to meet needs only if initiating interaction • Responds only to direct social approaches	• Inflexibility in behavior • Extreme difficulty coping with change • RRBs markedly interfere with functioning in all spheres • Great distress when changing focus or action
Level 2: "Requiring substantial support"	• Marked deficits in verbal and nonverbal SC skills • Social impairments evident even with supports in place • Limited initiation of social interactions and reduced/abnormal responses to social overtures from others *Example*: A person who: • Speaks simple sentences • Whose interactions are limited to narrow special interests • With markedly odd nonverbal communication	• Inflexibility of behavior • Difficulty coping with change • RRBs appear frequently enough to be obvious to the casual observer • Interfere with functioning in a variety of contexts • Distress and/or difficulty changing focus or attention
Level 1: "Requiring support"	• Without supports in place, deficits cause noticeable impairments • Difficulty initiating social interactions • Demonstrates clear examples of atypical or unsuccessful responses to social overtures of others • Decreased social interest E*xample:* A person who: • Can speak in full sentences • Engages in communication but conversation with others fails • Whose attempts to make friends are odd and typically unsuccessful	• Inflexibility causes significant interference in one or more contexts • Problems of planning and organization hamper independence • Difficulty switching between activities

Screening

The American Academy of Pediatrics (AAP) recommends autism-specific screening at the 18 and 24-month well-child visits (American Academy of Pediatrics, 2023. ASD screening tools such as the Modified Checklist for Autism in Toddlers-R/F (MCHAT-R/F) and the Parent's Observations of Social Interactions (POSI) are administered in addition to general developmental screening tools. General developmental screeners include the Survey of Well-Being for Young Children (SWYC) which includes the POSI as one component of the screener, the Ages and Stages Questionnaire (ASQ), or the Parents' Evaluation of Developmental Status (PEDS) (AAP, 2023).

The following is an example of how the use of screening tools may aid providers in effectively identifying children in need of further ASD evaluation (Hyman et al., 2020).

- When using the SWYC, a positive POSI requires follow-up with the MCHAT R/F.
- MCHAT R/F with scores 3-7 require administration of the Follow-Up interview.
- These steps more accurately identify children and high risk for ASD and allow specialty clinics to better prioritize children at highest risk.

Level two screeners, such as the Screening Tool for Autism in Toddlers and Young Children (STAT), include observation that can better identify children at highest risk who should be prioritized for specialty evaluation.

The STAT is a 20-minute interactive screening tool for children ages 24-36 months that consists of 12 different play activities. It assesses play, requesting, communication, and imitation skills. A range of primary care staff including nurses, pediatricians, and mental health clinicians can be trained to administer it (STAT, n.d.).

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.

Early Intervention (EI)

- EI is a program for infants and toddlers (birth to 3 years old) who have developmental delays or are at risk of a developmental delay. EI serves families with children who are not reaching age-appropriate milestones, are diagnosed with certain conditions, or have medical or social histories that may put them at risk for a developmental delay. EI services are meant to help support families and caregivers and to enhance the development and learning of infants and toddlers (Mass.gov, 2024).

Developmental and Behavioral Pediatrics (DBP)

- DBPs provides services to children from birth to 22 years of age with a variety of supports which include assessments of medical, psychological, behavioral, and other specialty areas pertaining to developmental issues. Formal assessments from DBP clinics may help with obtaining specialty services such as Applied Behavioral Analysis, occupational therapy, and speech and language support, and additional special educational support through an Individualized Education Plan (IEP) (Boston Medical Center, 2024).

Applied Behavioral Analysis (ABA)

- ABA is an intervention based on theories of learning styles and behavioral approaches. It is built on the ABCs of understanding behaviors. The antecedent refers to what occurred right before the target behavior. The consequence refers to what happens directly after the target behavior. This information is used to develop a detailed treatment plan, to either eliminate or encourage target behavior by breaking down complex tasks into smaller steps. ABA can be performed in any setting with a board-certified behavior analyst (BCBA). ABA also helps by supporting caregivers and the child build skills that can be used every day. This approach may be used to target areas such as, but not limited to, communication and language, social skills, self-care, motor skills, and learning and academic skills (Autism Speaks, n.d.).

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 the most relevant for children with ASD. 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 improve behaviors that interfere with everyday life. (Children's Behavioral Health Initiative, 2015).

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 centers 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.

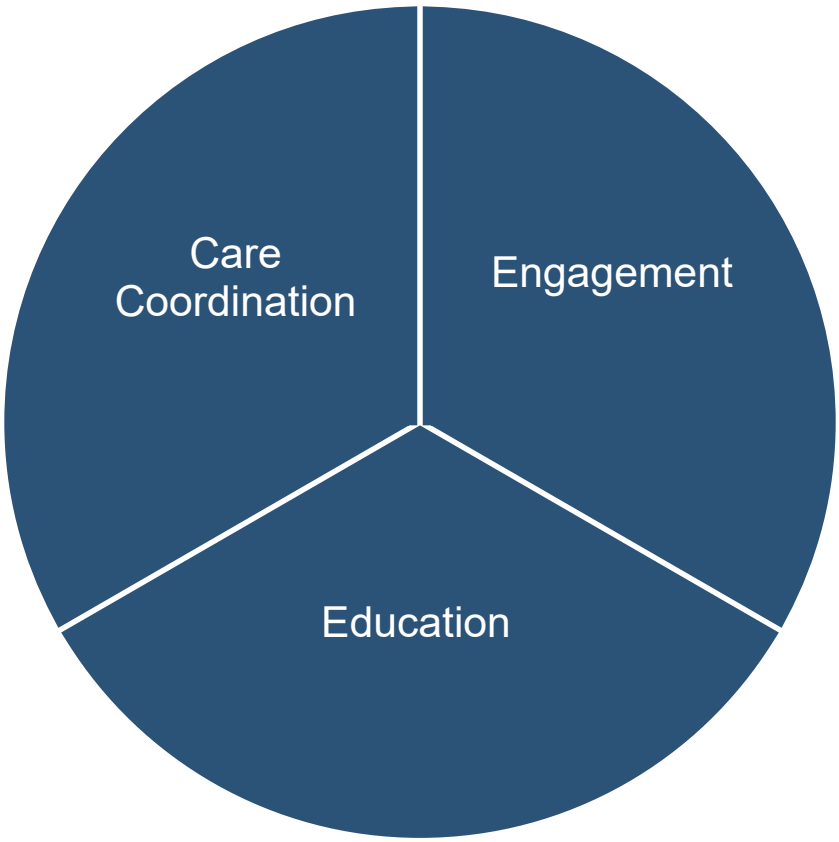
Comorbidities and Interfering Behavior

While autism may be managed as a chronic condition, there is no evidence-based treatment for the core symptoms yet. Interventions focus on improving targeted "interfering" behavior and social skill deficits to increase functioning.

- Common comorbidities and interfering behaviors include, but are not limited to:
  - Hyperactivity/Attention-deficit/hyperactivity disorder (ADHD)
  - Aggression/Self-injurious behaviors
  - Anxiety
  - Depression and other mood disorders
  - Obsessive-compulsive disorder (OCD; repetitive behaviors/stereotypes)
  - Psychosis
- Common medical concerns:
  - Sleep disturbances
  - Gastrointestinal (GI) concerns

Overview of the CHW Role in ASD

- 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, and accessing appropriate formal supportive services. 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)
  - MI is a directive, patient-centered approach for eliciting changes in behavior by helping patients and caregivers 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 Skills
  - 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

- 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
  - Autism spectrum disorder assessments and neuropsychological testing typically will include the following elements:
    - A medical and neurological examination
    - Assessment of the child's cognitive abilities
    - Speech and language abilities
    - Observation of the child's behavior
    - Interview with caregiver(s) to gather information on the child's behavior and developmental history
    - Child's family history, including mental and physical health
  - Outpatient services, such as speech therapy, physical therapy (PT), occupational therapy (OT), and other therapies based on child's symptoms and 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. This also includes education to support caregiver self-management skills that anticipate and address barriers to accessing services and treatment. Related to ASD, CHWs should provide education about:

- Child growth and development
- ASD symptoms and screeners (MCHAT-R)
- 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 (see Appendix)
- Assist with connecting to EI services and/or school-based services
- Assist with additional outpatient or in-home services, such as outpatient therapy, IHBS, ABA, and ICC

Diagnosis Navigation Pathways

Diagnostic Stage	Key Tasks	Timeline
Referral	• Obtain family permission to refer • Provide information and education on referral process • Schedule assessment appointment with family • Obtain signed medical releases	As needed
Pre-diagnosis	• Provide screening and education on referral processes (MCHAT-R/F) • Support referrals to ◦ EI assessment ◦ School-based assessment ◦ Diagnostic assessment • Obtain signed releases for coordination of care across systems ◦ EI services ◦ Any other medical releases	Within 2 weeks of positive screen in primary care
Diagnostic Stage	• Support diagnostic assessment process ◦ Forms, scheduling appointments ◦ EI documents: Individualized Family Service Plan (IFSP) • Address logistical barriers ◦ Transportation, appointment times, childcare • Consider cultural and psychosocial factors ◦ Perceived need for and importance of assessment ◦ No cultural reference for “autism” or “developmental problems”	Within 6 weeks of positive screen
Post-Diagnosis	• Obtain and review diagnostic report ◦ Recommendation for services ◦ Diagnosis ◦ Patient and Family Rights ◦ Document report in EMR • Support access to school-based services/ EI services ◦ EI referral process ◦ Aging out of EI ◦ IEP process • Support access to in-home or outpatient services: ◦ ABA, speech, OT, PT, social skills groups, counseling ◦ Behavioral health services ◦ Parenting management support	Within 6 weeks of diagnostic assessment

Resources

Child Development

- The Basics
- CDC Act Early Resources and Milestone Tracking App
- Thom's Developmental Checklist

ASD Overview

- TEAM UP e-course modules
- Autism Speaks
- BUSM Training Curriculum on Transition Age Youth with ASD
- Massachusetts Child Psychiatry Access Program

ASD Screeners

- Modified Checklist for Autism in Toddlers, Revised, with Follow-Up (M-CHAT-R/F) (PDF)
- Screening Tool for Autism in Toddlers & Young Children (STAT)
- Rapid Interactive Screening Test for Autism in Toddlers (RITA-T)

Caregiver Support Resources

- Zero-to-Three Parenting Resources
- Autism Support Centers
- Arc of Massachusetts
- Federation for Special Needs
- Autism Insurance Resource Center

Citations

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Appendix

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: • Share information re: referral to DBP and why • Provide education, address family's concerns, and explore benefits and challenges • If family declines or is hesitant – loop PCP in and continue to provide support as needed • 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 • 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: • Dates and details of scheduled DBP appointments • All work performed, provider's information • Set reminder to call family 3 days before scheduled appointment(s)		
	Call family 3 days before scheduled evaluation appointment(s): • If using PT-1, confirm requests have been placed • Review intake and evaluation process • Offer/set-up after visit follow-up		

Developmental Behavioral Pediatrics Referral, Assessment and Services Checklist			
	KEY TASKS	**DATE COMPLETED/ TEAM MEMBER**	**TIMEFRAME**
	For missed appointments, help with rescheduling: • Assist with scheduling additional appointment(s) if necessary • Set reminder to call family 3 days before appointment(s) • If using PT-1, confirm requests have been placed		
	Check-in with DBP and family after the completed evaluation appointment(s): • Answer questions or concerns family may have • Explain feedback appointment and process • 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: • Assist family in scheduling feedback appointment • Schedule check-in visit/call with family within 2 weeks of feedback appointment		Feedback to occur 1-2 weeks after evaluation
SERVICES 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: • 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: • Assist with request for IEP testing • If EI is involved, request for EI service coordinator to assist with transition to school		

Developmental Behavioral Pediatrics Referral, Assessment and Services Checklist			
	KEY TASKS	**DATE COMPLETED/ TEAM MEMBER**	**TIMEFRAME**
	If child is over 3 years: • 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		
	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		

Early Intervention (EI) Referral, Assessment and Services Checklist			
	KEY TASKS	**DATE COMPLETED/ TEAM MEMBER**	**TIMEFRAME**
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.		
	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		

Early Intervention (EI) Referral, Assessment and Services Checklist			
	KEY TASKS	**DATE COMPLETED/ TEAM MEMBER**	**TIMEFRAME**
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 with 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.

High-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		

Individualized Education Plan (IEP) Checklist			
	KEY TASKS	**DATE COMPLETED/ TEAM MEMBER**	**TIMEFRAME**
	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		
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 a 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.		

Individualized Education Plan (IEP) Checklist			
	KEY TASKS	**DATE COMPLETED/ TEAM MEMBER**	**TIMEFRAME**
	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		

Early Intervention (EI) Referral, Assessment and Services 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 plans 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?
  - 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.

Contact

Contact our team for any assistance, inquiries, or information you need.

TEAM UP Scaling and Sustainability Center
teamup.learningcommunity@bmc.org
www.TEAMUPCenter.org