DEVELOPMENTAL CONCERNS

WORKBOOK FOR COMMUNITY HEALTH WORKERS

TEAM UP SCALING AND SUSTAINABILITY CENTER

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Acknowledgements

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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.

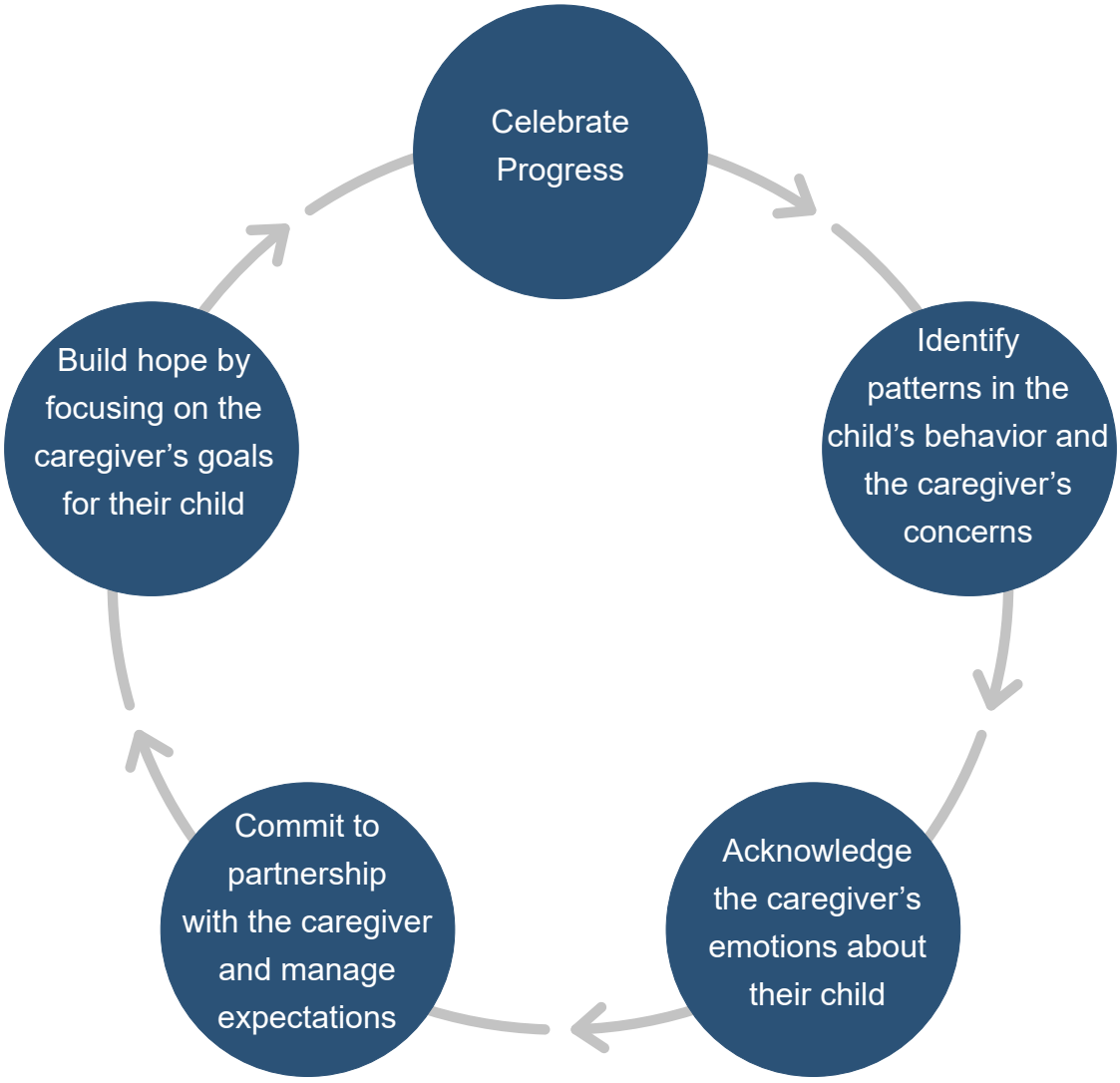
Given the diversity of perspectives on self-identity and language preferences, it is important to be thoughtful and respectful in communication about mental health conditions. While the TEAM UP Center is committed to using inclusive language that honors people's identities, it does not favor using people-first 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 stress understanding developmental guidelines or accepting their child's developmental journey. It is common for caregivers to feel overwhelmed, uncertain about the impact on their child, and at times, distant or disconnected from their child.

It is important to frame any developmental concern as an opportunity for caregivers to learn how to best support their child's unique needs and a developmental diagnosis as a means to get access to more services and support for their child. As CHWs engage with caregivers, keep in mind the following considerations:



Core Symptoms

Developmental delays refer to instances when a child does not reach developmental milestones within the expected times. Delays can occur in one or more key areas of development, including social-emotional, cognitive, speech and language, motor, or adaptive skills. Thom Child & Family Services provides a nice checklist for monitoring typical development for children birth to three which may help identify potential delays (see Resources). Developmental concerns are often identified in early childhood, though in some cases, they may not become apparent until a child is much older. Delays in older children may be noticed when they experience difficulties in school, patterns of social challenges, or exhibit emotional and behavioral issues.

Children with developmental delays may learn and grow more slowly than their peers, however, early identification and intervention can greatly improve overall development and outcomes.

Screening

Children with developmental concerns 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 dynamics, Ages and Stages Questionnaire (ASQ), or the Parents' Evaluation of Developmental Status (PEDS) (American Academy of Pediatrics, 2024).

Interventions

Early Intervention (EI)

- EI is a program for infants and toddlers (birth to 3 years old) who have developmental concerns 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).

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, or group setting. Therapists provide follow-up and ongoing monitoring.

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.).

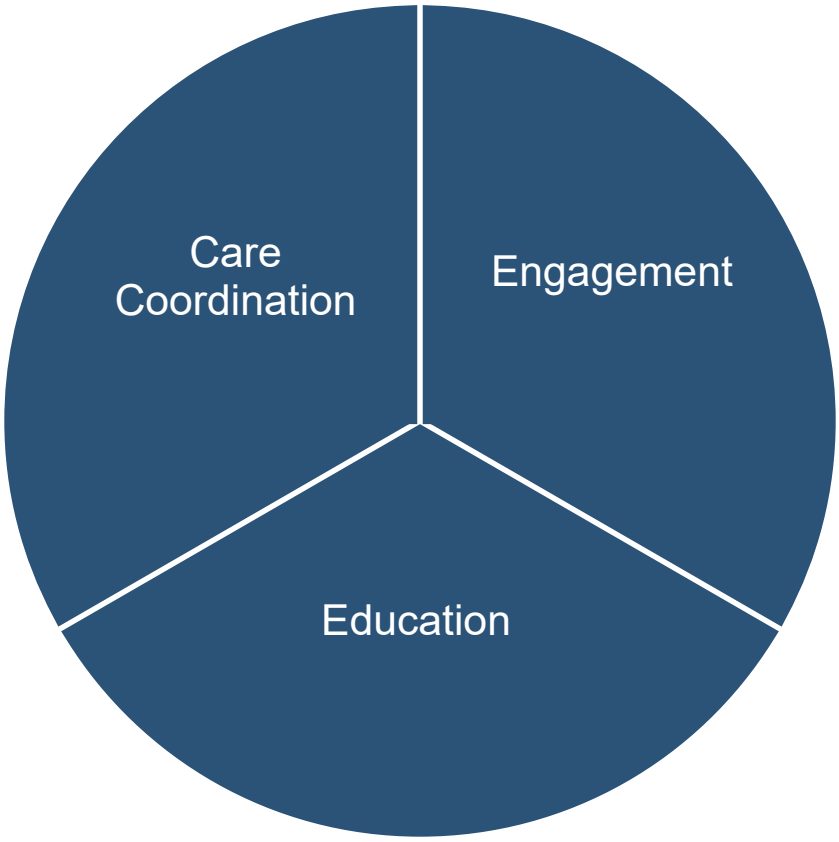
Children's Behavioral Health Initiative (CBHI)

- 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 particularly helpful for young children. In IHBS, 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).

CHW Role in Developmental Concern

Overview of the CHW Role in Developmental Concern

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

- Active listening
  - 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 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 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

Diagnosis Navigation Pathways

Diagnostic Stage	Key Tasks
Pre-Evaluation	• Screening and Education • Referral to EI or school-based assessment • Referral to DBP • Referral to BHC
Evaluation	• Evaluation process: ◦ Forms, scheduling appointments ◦ Coordination with EI, school, DBP • Logistical barriers: ◦ Transportation, appointment times, interpreters, childcare • Cultural and psychological barriers: ◦ Perceived need for and importance of assessment ◦ Perception of externalizing behaviors
Post-Evaluation	• Services ◦ Recommendation for services: EI, School-based, home-based ◦ Specialized programs ◦ Parent services for support if needed ◦ Patient and family rights

Resources

Child Development

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

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)

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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		
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		

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

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

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
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