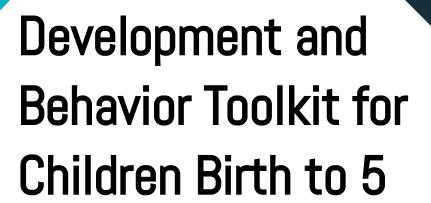
### **Advocacy Handouts**



Activities to Support Healthy Early Child Development

For more information, please contact the Cincinnati LEND program at LENDTraining@cchmc.org







# Advocacy Handouts





# Concerned about development? How to get help for your child.

Talking to the child's primary care provider (doctor/nurse practitioner/physician assistant) is the first step to get a child help if anyone in the child's life is concerned about development. This can include how the child plays, learns, speaks, acts, or moves.

Don't wait. Acting early can make a difference!

- ☐ Make an appointment with the child's primary care provider to report
  - concerns about the child's development.
- Write down any areas of concern you
   (or others) have about the child's development.
- ☐ **Take the list** of concerns to the appointment.
- □ Use an app to keep track of developmental milestones like CDC's Milestone Tracker-It's FREE to download and use!



### **CDC's Milestone Tracker Mobile App**

Use CDC's free Milestone Tracker app to complete a milestone checklist for your child. Click to learn more!

Centers for Disease Control and Prevent...

- □ Discuss specific concerns with the provider and ask if any screening or developmental testing and/or therapy needs to be done.
- □ Make any appointments right away. **There will be a wait.**

For more information on milestones, go to: <a href="https://bit.ly/3lzn4cT">https://bit.ly/3lzn4cT</a>
For a written handout in English and Spanish (Español):
<a href="https://bit.ly/3K4zbYW">https://bit.ly/3K4zbYW</a>



## Concerned about development? How to get help for your child.

buring healthcare appointments, you may hear aniamiliar medical terminology.
Make sure all providers explain them clearly. If you do not understand or have
additional questions, ask before you leave the appointment.
☐ Check your notes to make sure that all your questions are <b>answered.</b>
☐ Make sure you discuss the next steps with the provider.
□ When you get home, follow the steps from the appointment.
Contact your child's primary care provider if you have additional questions or
concerns after visits.
If the child's primary care provider has told you to "wait and see," but you feel
uneasy about that advice, what can you do?
You do not need a doctor's referral for some services to help your child. You can
call to schedule an evaluation to see if the child qualifies for the services below.
□ Before child's 3rd birthday: Call your state's early intervention program.
Find the phone number or website at <a href="https://www.cdc.gov/FindEl">www.cdc.gov/FindEl</a> .

After child's 3rd birthday: Call your local public school district and request



an evaluation for special education.





### What Is An IEP?

An IEP (Individualized Education Program) is a legal document provided by the school district of your child. This document maps out a plan for special education services, supports and accommodations that a child might need to ensure "a free and appropriate education." Programs and services outlined in the IEP may include therapies, instructional accommodations & modifications, assistive technology, or other agreed upon supports.

### Who Can Have an IEP?

Any child that has been evaluated and deemed eligible for special education services. The evaluations include testing, observation, and teachers' and caregivers' reports. If a child is eligible for special education services based on the results of the testing and evaluations, there will be a meeting to develop the initial IEP that will say what services a child will receive.



### Some Legal Background

There is a law called the "Individuals with Disabilities Education Act (IDEA)." According to this law, all children are entitled to Free Appropriate Public Education (FAPE) in an environment that is the least restrictive (which means there should be opportunities to try learning in spaces with peers and to make sure children are not isolated).

### IEP Timeline

- Request Evaluation to Determine Eligibility- Make sure to put the request in writing.
   (The school district can request it too) The caregiver's written consent is required to begin the evaluation.
- □ 30 days from the written request, the school district must get caregiver consent to start the evaluation or provide the parent with a Prior Written Notice explaining why the evaluation will not start at this time.
- ☐ The school must share the evaluation plan before the evaluation happens, so you know what is going to happen in advance.
- ☐ From the date of caregiver consent, the district has 60 calendar days to complete the evaluation.



- □ Development of the written Individual Education Plan has to happen within 30 days after the team meeting. Parents and caregivers are part of the child's team and can and should share ideas and feedback on the IEP.
- □ The IEP should be monitored and reviewed periodically. An annual IEP Meeting should be held at the end of each IEP cycle (Expiration date in IEP)



### What Should The Evaluation Include?

### Objective tests:

Tests designed to evaluate: general intelligence, understanding of reading (reading comprehension), psychological states, social development and physical abilities. You can request an explanation of such tests as well as your child's test results.

### 2. Comprehensive information:

For example, the teacher and parent/caregiver reports, evaluations by experts on your child's disability, letters from your child's primary care provider or counselor and documentation of school performance.

### 3. Conclusion:

Regarding if your child is eligible to receive services.

### What If I Disagree?

If the district concludes your child does not need an IEP and you disagree, you have the right to request an Independent Education Evaluation (IEE) "at public expense."



### Prepare For The Meeting

To be organized and prepared for the meeting:

Get a lot of information about your child's strengths and challenges at school and in other settings.

Do some research about the programs or supports that could help with your child's needs.

Talk to other parents of children with IEPs at your school and ask them what has been helpful to them.

Come up with your own goals for your child's school year. This will help to bring some ideas to the meeting.

You know your child best! Be very clear about your child's needs while being respectful about the opinions of the school professionals.

### The Initial IEP Meeting

- The team will go over your child's performance from the evaluation and/or in school
  and the educational goals and services and supports the school has already started to
  meet these goals.
- A child's IEP must be put in writing and signed by the caregiver and the school district.

  Signing the IEP can be at the end of the meeting (if caregiver agrees and is comfortable) or after the meeting.



### Who should be on the IEP Team?

- Parents/Caregivers
- Special education teacher
- General education teacher
- Special Education Administrator
- Speech/Occupational/Physical therapists
- School psychologist
- Case manager/ team leader
- Social worker (optional)
- Behavioral therapist (if part of the IEP team)
- · Your child, when appropriate

If there are other members that caregivers think would be helpful (like a doctor or a close friend), caregivers can invite them as well. Some parents bring an advocate or mediator, especially if there is a disagreement.



### What should my child's IEP include?

- Current performance
- Child's strengths
- Tests results
- Grades
- Behavioral challenges
- Learning styles (defining your child's strengths and challenges will help build a good educational plan)
- Sensory development
- Motor skill development
- Measurable Goals (Goals will be both academic and functional)
- Services (Speech Therapy, Physical Therapy, etc.) including frequency, duration, location and dates.
- Transportation
- Accommodations (Special seating or interpreters)



### Example of an IEP goal

SUBJECT Communication GOAL

Student will request needed item to complete a work activity when given the visual directions using his communication device "talker" starting DATE, with SLP support, with a baseline of 50%, and with a target of 80% completed by DATE.



### Changing an IEP

- IDEA requires that a meeting is held once per year for the IEP team to formally assess a student's IEP and update it if needed.
- The caregiver or another IEP team member is entitled to call an IEP meeting at any time if they feel there is an issue that needs to be addressed. It can be helpful to request a meeting in writing with a detailed explanation of the issue(s) to address.
- Some examples of why your child's IEP might need updating include:
  - Your child has accomplished a goal earlier than expected
  - · Your child is struggling in a new area
  - There are new services to include (assistive technology or new kinds of intervention) to further support your child's growth
  - Any mental or physical health changes that might require different supports or accommodations

Assessments, grades, homework scores and other test results are clear and easy ways to measure a child's progress. Regularly check in with each member of the team, or any other professionals who are providing services to the child, like SLP, OT, PT etc.



### Disputing An IEP

Though an IEP cannot go into effect without parental/caregiver approval/signature, parents may find an issue with the IEP that they would like to see changed. For example, they may want to see more time for tests, additional hours of a related service or to have an updated goal before signing.

### Resolving a dispute

- Call an informal meeting with the IEP team to share concerns. If concerns are not resolved, then...
- 2. Request a formal IEP meeting. If concerns are not resolved, then...
- 3. Request a Formal Mediation
  - A mediator is someone who is a neutral third party with expertise in special education and IEP.
  - The mediator does not make the decision, but rather facilitates conversations to get to a decision or resolution.



### Things To Remember

### Be Informed

- Monitor progress as often as possible.
- Talk to other parents and research what services and supports others in your school or community have received to make sure you know what is available.
- Know your rights! Learn all there is to know about IDEA.
   An important resource for this is <a href="https://www.wrightslaw.com">https://www.wrightslaw.com</a>

### Be organized - Keep and organize the following information:

- · All school records report cards, evaluations, IEPs
- Health records and any information from the child's health professionals
- Any other private evaluations
- Contact information for all individuals with whom you interact during the
   IEP process



### Things To Remember

### Be Positive

- For an IEP to be effective, it is important that all team members including parents/caregivers have positive and realistic visions for the future.
- Maintaining a positive relationship with all members of the IEP team will lead to greater success throughout the IEP process.
- Remember that the process is about collaboration, not competition.

### Ohio Education Resources



Evaluation Roadmap for Families with Children Ages 3-21 (ohio.gov)

https://bit.ly/iep-English



Evaluation Roadmap for Families with Children Ages 3-21 (ohio.gov)

http://bit.ly/IEP-Spanish



IEP - Basics Acknowledgment: Developed in collaboration with Gretchen Carroll, MEd, Special Educator

# How can a social worker help you?

Social workers can help you to better understand the school and healthcare systems. They serve many roles based on their setting.

You may contact a social worker to see how your child can get help in the following areas:

- Community resources.
- Problem solving and making decisions about your child's services.
- Coordination and referrals for services.
- · Advocacy resources.
- Access tp school and healthcare supports and services.
- Social and emotional supports for caregivers.

After talking to the social worker, if you or your child can benefit from additional supports or resources, the social worker can help connect you to the right places.



### Intervention, Therapy, Treatment

- Services recommended to improve skills in certain areas or to decrease challenges or concerns in other areas.
  - Examples- speech and language therapy to build communication skills; behavior therapy to decrease tantrums
- Can be provided in school or outpatient settings. Therapy in both settings may be needed to make progress toward goals.
- Goals addressed in school will focus on skills or behaviors that impact the school setting, like handwriting.
- Goals addressed in outpatient settings are based on child and family priorities.



Occupational Therapist (OT): Provides evaluation and treatment to children to help increase independence in the following areas (in either a school or outpatient setting):

- Activities of daily living (ADLs): Activities that are performed each day including dressing, bathing, feeding, and/or play.
- Play skills/Social skills: Help a child learn language, imitation skills or taking turns. Play changes as children get older.
  - Functional play: Play with the toy as it is intended, like roll a car on the ground or a track.
  - Pretend play: Play with a toy in a different way than it is intended. An example is putting a banana up to the ear and talking on it like it is a telephone.
  - Parallel play: Playing next to a child, with each child playing on their own. This is common with 2-3-year-olds.



### OT continued

- Associative play: Playing next to a child with the same or similar toy. An example is each child using blocks to build buildings. They may start to talk about what they are doing or ask each other questions. This is common with 4-year-olds.
- Cooperative play: Children playing together. This usually starts around age 4-5 years.
- Fine motor skills: Activities that involve the small muscles of the hands and wrists such as stacking blocks, stringing beads or holding a crayon.
- Visual motor skills: Using the eyes and hands together such as doing a puzzle, cutting out a shape, and/or catching a ball.
- Sensory processing: The way a child takes in, organizes, and responds to sensory information around them. Children who have difficulty with sensory skills can either be over or under responsive to sensory information.



Physical Therapist (PT): Provides evaluation and therapy to children to improve their range of motion, strength, flexibility, and movement patterns. They often help children learn to roll, walk, and skip. They can be in school or in an outpatient setting.

### PTs work on the following:

- Gross motor skills: Activities that involve the large muscles of arms and legs like climbing, running, and jumping.
- Range of Motion (ROM): How well one can move body parts
- **Assistive devices:** Equipment used to help to move around the environment. Examples are crutches, braces, walkers.



Speech-Language Pathologist (SLP): Provide evaluation and treatment to children related to language (expressive language) and articulation and intelligibility (speaking clearly). They also work with children to understand others (receptive language) and for pragmatic communication (social use of language). They can be in school or in an outpatient setting.

- Expressive communication: The use of words, sentences, gestures and writing to show meaning. Examples are being able to label objects, describe actions and events, put words together in sentences, use grammar correctly.
- Articulation: Using sounds that are understandable to others (clear pronunciation) while talking. A child's ability to move the tongue, lips, teeth, and jaw to produce the speech sounds that make up words. If a child has difficulty with articulation, they will be harder to understand.
  - Intelligibility: How well a child's speech can be understood. By age 3, 75% of a child's speech should be understood by adults. By age 5, at least 90% of their speech should be understood by adults.



### SLP continued

- Receptive communication: A child's ability to listen and understand what is communicated to them. For example, how well does a child follow directions. This includes understanding the tone and emotions of others as well as their gestures, like pointing.
- Pragmatic Language: Using communication in social situations (knowing what to say, how to say it, and when to say it). Involves greetings, like "hello" and sharing information ("I like pizza"). It can also include requesting ("Can I play with you?") and taking turns in conversations.
- Oral motor skills: Oral motor skills involve the movements of the mouth, jaw, tongue, lips, and cheeks. Having good strength, coordination, and control of structures is needed for feeding activities such as sucking, biting, and chewing and speech articulation.

Child psychologist: Works with you and your child to improve the child's functioning/outcomes in the following areas: child development, like milestones, social skills, and emotional and behavioral concerns, like decreasing tantrums. Provides evaluation and treatment in school or outpatient settings.

- Behavior plan: A specific plan used to increase positive behaviors (such as eating vegetables, keeping hands to self) or to decrease concerning behaviors such as hitting or tantrums. A behavior plan is unique to each child and is most effective when used consistently across caregivers or settings.
- Reinforcement: A reinforcer is anything that increases the likelihood the behavior will happen more in the future. Used to increase positive behaviors like sharing toys and decrease negative behaviors like tantrums. Often, rewards such as snacks, praise, or access to a favorite toy may be used as reinforcement. For example, if a child has a tantrum and is given their favorite toy, they may have another tantrum to try to get that same toy in the future. If a child shares their toy and is given praise, like "Thank you for sharing your toy" and a favorite snack, they may be more likely to share the toy again.



### Psychologist continued

- Cognitive skills: Skills your child's brain uses to think, read, problem-solve, learn, remember, reason, and pay attention. Together, these skills help children learn at school and at home. Children who have difficulties in one or more of these areas may need additional help in school and at home to reach their full potential.
- Functions of Behavior: Behaviors happened for a reason, typically to communicate a need or want. Working with a psychologist can help figure out the function of a child's behavior and connect strategies to improve quality of life.
- Repetitive behaviors: Repetitive movements of the body (rocking back and forth), play (lining or stacking toys over and over), and speech, (repeating words others say). Repetitive behaviors can also include routines. Examples are needing to walk the same path every time or drinking only out of one specific cup. Repetitive behaviors are common in young children (ages 0-3) and typically decrease as children age.



- Social Worker/Licensed Social Worker (LSW): An LSW or social worker works with doctors, nurses, other medical specialties/disciplines, schools, and government/community agencies to coordinate care and supports. Social workers connect families to various resources within healthcare and their community. Examples are behavioral supports, funding options including Medicaid Waivers, assistance with school questions, or information on support groups and trainings.
- Medical Team: There are several professionals who can assess, diagnose and prescribe medication for your child. These professionals include:
  - **Primary Care Provider (PCP):** A healthcare provider who sees patients that have common medical problems.
  - **Medical Doctor (MD/DO):** A healthcare provider who completed medical school and trained to treat common or specialized medical problems.
  - Developmental and Behavioral Pediatrician (DBP): A medical doctor (MD/DO)
    with extra training to provide healthcare for children and adolescents with
    developmental and behavioral disorders.
  - Nurse Practitioner (NP): A healthcare provider who completed a graduate program in nursing and trained in treating common or specialized health problems.
  - Physician Assistant (PA): A healthcare provider who completed a graduate program in physician assistant school and trained in treating common or specialized medical problems.

- Medical home: Primary care provider and their team in combination with the family/patient to meet medical needs.
  - PPC (Pediatric Primary Care): Center to get medical care from MD/DO, PA, NP, or other medical professionals.
- Developmental milestones: Skills that children develop in how they play, learn, speak, act, and move, such as pointing, talking, or walking.
- Adverse Childhood Experiences (ACEs): Potentially traumatic experiences that occur in childhood and can affect children later in life. Examples are abuse, neglect, financial difficulties/poverty, experiencing or witnessing violence.
- Trauma/Toxic Stress: When children experience stress for long periods of time, such as experiences of physical or emotional abuse, neglect, caregiver substance use disorder or mental health problems. Toxic stress changes the brain and other organs like the heart. It can increase a child's risk of social, emotional, and behavioral health problems.

Toxic stress affects how a child develops.

A loving relationship with a caregiver can protect against the effects of toxic stress.



### Common Education Terms

- Early Intervention (EI): supports and services that assist young children (birth to 3rd birthday in most states) who have developmental delays/disabilities.
- Individualized Family Service Plan (IFSP): a plan put into place for young children (0-3 years) that focuses on the child and family and the services needed to support a child's development needs.
- Academic Services: a variety of educational and instructional supports given to students to help them succeed in school.
- Evaluation Team Report (ETR): an evaluation report created to qualify a student (age 3 and older) for special education services.
- Individualized Education Program (IEP): a specially designed legal instruction program created to support the individual needs of a student (age 3 and older). An IEP gives support services for students in need of additional resources. Resources may include academic or behavior support.
- 504 Plan: a legal plan for a child with an identified disability that requires the school to give accommodations that will make sure they are successful.
- Functional Behavior Assessment (FBA): an assessment that identifies a behavior and the reasons and situations related to the behavior that interferes with a child's success at school.
- Behavioral Intervention Plan (BIP): a plan based on the Functional Behavior Assessment (FBA) which spells out the actions to take to improve or replace the behavior. There should always be a BIP with an FBA.

