



August 22, 2023

## Partnering with Families to Support Inclusion: Part 2

### Viewer's Guide

This viewer's guide will help you find more information and capture your ideas as you engage with our webinar. During this webinar we will focus on the importance of partnering with families as they navigate the process of referral to an Individuals with Disabilities Education Act (IDEA) agency for a developmental evaluation. We will share resources and strategies that program staff can use to support families as they navigate the IDEA system and become advocates for their child. Helpful resources can be found in the Resources section of this guide.

### Discussing Developmental Concerns with Families



In Part 1 of this webinar series, we discussed relationship-based strategies for sharing and having ongoing conversations about developmental concerns.

We also introduced the concept of family “readiness” to act on developmental concern. We discussed what “readiness” might mean – perhaps asking questions or learning more about concerns or moving forward with the referral process. We also discussed family characteristics and other factors that might impact how ready a family is to act on a concern about their child’s development.

The concept of family readiness resonated with our webinar viewers. We received lots of feedback, including from program staff and families of children with disabilities, about how important it is to recognize family readiness, meet parents where they're at, and have ongoing conversations with families to move forward in the process. Here's what your colleagues had to say:

- “It has happened to my family, and we were afraid.”
- “Sometimes families don't see the same things at home.”
- “It can feel disheartening, but I have learned to trust their journey

and acknowledge that I cannot rush when they are ready.”



National Center on  
Early Childhood Development, Teaching, and Learning

This training was supported by the Administration for Children and Families (ACF) of the United States (U.S.) Department of Health and Human Services (HHS) as part of a financial assistance award totaling \$10,200,000 with 100% funded by ACF. The contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement, by ACF/HHS, or the U.S. Government. This resource may be duplicated for noncommercial uses without permission.

- “I have experienced this when sharing ASQ results that showed ongoing concerns over several rescreens. We kept discussing things the family could try at home, and what we were doing in the classroom. Eventually, the family did decide to make a referral with us.”
- “My oldest daughter needed quite a bit of services and it was difficult. What made it easier at the time was the teachers helping walk us through the steps and using layman's terms during that time for me, since I was unfamiliar with it at the time.”
- “Going through the process of evaluation and IFSP [Individualized Family Service Plan] for my own child helped me understand what families experience when I bring up developmental concerns and gave me the knowledge to describe what they may experience through the process for their own child.”
- “I have always found it helpful to make a personal connection with families first, then the harder conversations come easier.”
- “Keeping good communication with families, ongoing, helps when the need for tough conversations arises.”
- “I love the ASQ [Ages and Stages Questionnaire] or screening tools because they help start and guide the conversation, letting them know that there is nothing wrong with their child and "Billy is still Billy"- we just want to give him some extra help so that as he moves on, he gets the help he deserves and has something in place to back him up.”
- “I’ve had some families that say they don’t know what the next step is or where to start.”
- “Parents also get used to hearing the negative news instead of a balance of what is going on.”
- “I had a father who had a negative experience with special education he received when he was younger. He didn't want the same experience for his son. It took building a positive relationship with him and the 2nd year he was ready.”
- “We have had concerns for years with our son. His old doctor took the "wait and see" approach for over two years. His new doctor referred him immediately after one visit based on her observations alone. Very differing reactions to parent concerns for sure.”

## IDEA: Learning the Language








When a referral is made to an IDEA agency, a family is quickly introduced – often for the very first time – to the law and the system of services. Learning about IDEA – the language, services, professionals, processes, and more – can feel confusing and overwhelming to families. Program staff can support families in many ways as they learn to navigate the IDEA system and advocate for their child.

But IDEA is so important and there’s so much information to share – where do you even start? An important first step is to help families become familiar with the language of IDEA. Special education and early intervention are full of terms that people constantly use in writing and in conversation and it’s important to know what those terms mean.

Here is some key language to get started:



**Individuals with Disabilities Education Act (IDEA):** The special education federal law that ensures the educational needs of students with disabilities are met throughout the nation.

-  **IDEA Part B and Part C:** IDEA Part B regulations relate to the education of children aged 3 and above with disabilities. IDEA Part C regulations relate to early intervention services for infants and toddlers with disabilities.
-  **Developmental Delay:** A delay in an area of development. There are five developmental areas considered: Cognitive, communication, social or emotional, adaptive, or physical development, including vision and hearing. Note: Each state creates its own definition of developmental delay.
-  **Referral:** A referral is a written request to an IDEA agency for a child to be evaluated for IDEA services. A referral can be made by parents, guardians, teachers, or others who know the child. A doctor's referral is not needed for a referral.
-  **Eligibility:** Eligibility means that a child has a disability or delay and needs specialized services from an IDEA provider to make progress.
-  **Evaluation:** An evaluation is the process used to determine whether a child has a disability or developmental delay and is eligible for IDEA services. During an evaluation, professionals will gather information to assess a child's areas of strength, their functioning, and development across areas.
-  **Individualized Education Program (IEP):** An IEP is a written legal document that describes individual special education and related services a child qualifies for. It includes annual goals and objectives and specific accommodations and modifications for a child ages three through high school graduation (or maximum age of 22 years).
-  **Individualized Family Service Plan (IFSP):** An IFSP is a written legal document that describes individualized early intervention services for infants, toddlers, and their families. The plan includes specific outcomes and services for children (birth to age three) and families.

Our partners at the [Center for Parent Information & Resources](#) – also known as the Parent Hub or Parent Training & Information Centers – have wonderful resources that can be used to help families learn about IDEA, including a [glossary of key terms](#) and descriptions of [Part C early intervention](#) and [Part B early childhood special education](#).

**What other terms are important for families to understand as they learn to navigate the IDEA system?**

## Initial Evaluations: What Do Families Need to Know?



The evaluation process is an important step in helping a child and their family access IDEA services. This process – often called the initial evaluation – is used to determine if a child is eligible for IDEA and to answer these questions:

- Does the child have a disability or developmental delay that requires specialized services?
- What are the child’s unique learning characteristics, strengths, and areas of need?
- What specialized services are needed to support the child’s learning and development?

**IDEA outlines specific requirements** related to the initial evaluation process. These requirements are important for families to understand to ensure the child receives the best evaluation possible.

**Before any evaluation, the IDEA agency must:**

- **Provide Prior Written Notice (PWN):**
  - PWN is a document that the IDEA agency must give to the family before any action is taken (or not taken) by the agency, including conducting an evaluation, making a placement decision, beginning services, or changing services.
  - PWN applies to both **Part C** and **Part B** of IDEA.
  - There is specific information that must be included in PWN, such as: A description of the action proposed or refused by the agency, an explanation of why the agency proposes or refuses to take action, and description of each evaluation procedure, assessment, or report used to make their decision.
- **Share Procedural Safeguards:**
  - The procedural safeguards are section of IDEA. The safeguards are designed to protect the rights of children who are eligible for IDEA and their families. The safeguards also describe processes that can be used to resolve disputes between families and an IDEA agency.
  - The **procedural safeguards notice** must include an explanation of all the safeguards available under IDEA and must be written in clear, understandable language.
- **Obtain Informed Consent:**
  - Before the IDEA agency begins the evaluation process, the parent must **provide written consent** to carry out the evaluations.

**During the evaluation process, the IDEA agency must ensure that evaluations are:**

- **Conducted by trained and knowledgeable professionals**

- **Comprehensive:**
  - The evaluation process should assess the child’s areas of strength and need, as well as assessing the child’s functioning and development across domains – cognitive, communication, adaptive, social, and emotional, and physical, including vision and hearing.
- **Consider multiple sources of information:**
  - The evaluation team must use a variety of assessment tools and strategies to gather functional and developmental information about the child, including information provided by the parent.
- **Not discriminatory on a racial or cultural basis:**
  - The assessments used should be culturally appropriate and assessment materials should be provided and administered in the child and/or family’s home language unless it’s clearly not feasible to do so.

**What other questions or concerns do families have about the referral and evaluation process? What resources can you share?**

## Referral & Eligibility Timelines

IDEA states that once a referral is received, the agency that receives the referral must complete a comprehensive evaluation to determine whether the child is eligible for IDEA services.

Here are some common questions and answers related to this process:

### What does “timely” mean?

- For Part C, an agency has 45 days from the time a referral is received to determine whether the child is eligible and complete the development of an IFSP.
- For Part B, an agency has 15 school days from the time a referral is received to set up an IEP meeting to discuss the referral and what evaluations need to take place. Once the consent to evaluate form is signed, the agency has 45 school days to complete the eligibility evaluations and hold an eligibility meeting.

## Can the IDEA agency delay or deny an eligibility evaluation because Response to Intervention (RTI) has not been used?

- No! In a [2011 memorandum](#), the Office of Special Education Programs (OSEP) stated that it's "critical that this identification occurs in a timely manner and that no procedures or practices result in delaying or denying this identification" and that "States and LEAs have an obligation to ensure that evaluations of children suspected of having a disability are not delayed or denied because of implementation of an RTI strategy". Once the referral has been received, the IDEA agency must begin the evaluation process.

## What is RTI?

- RTI, or response to intervention, is a multi-tiered approach to instruction that's used to ensure that all children receive the right type and amount of instruction and support to help them learn and make progress. When using RTI, or Multi-Tiered Systems of Support (MTSS) as it's sometimes called, a school or program uses the following practices in an intentional, ongoing process:
  - **Ongoing progress monitoring** to determine how children are progressing and identify children who may be at risk for poor learning outcomes
  - **Differentiated goals and outcomes** to make sure that learning targets are appropriately matched to each child's learning needs and characteristics
  - **Tiered instruction** using evidence-based practices that are individualized based on the child's learning goals, learning characteristics, and needs for support
  - **Ongoing assessment** to determine whether the instruction being used is effective in helping the child learn

## IDEA and Family Rights



IDEA is designed to uphold and protect the rights of young children with disabilities and their families. The HSPPS state that program staff must support families to understand and participate in the different processes and steps associated with determining eligibility for and receiving IDEA services. An important outcome for families of children with disabilities is to help them understand their rights and support families to develop as advocates for their child and family. **But what are family rights under IDEA and how can you support families to learn about them?**

Here are some important rights for families of children who are eligible for IDEA services:

- Confidentiality
- Receive an explanation of procedural safeguards
- Receive 'prior written notice' before meetings or events
- Use of parent's preferred language or mode of communication
- Review of their child's records

- Participate in meetings
- Obtain an independent evaluation
- Disagree with decisions, including placement decisions
- Give or deny consent for services
- Use resources and processes to resolve disputes

The [Center for Parent Information & Resources](#) has wonderful resources that can be used to help families learn about their rights and support family advocacy. Each state has a Parent Center – **have you looked at the website or contacted yours?** If not, [find your state’s Parent Center](#) today!

## Families as Team Members



Families have the right to participate as a full member of their child’s team, including during the initial evaluation process. Parents play an important role throughout the process by providing information about a child’s strengths, abilities, interests, and challenges. Families may need to be supported to learn about their role on the team, how the team functions, and how they can effectively communicate and participate.

Our partners at the Early Childhood Technical Assistance Center (ECTA) have outlined some steps families can take to help feel prepared to participate in the evaluation process:

- Before your child’s assessment, **ask questions to learn about the assessment process**. For example: What will team members be doing? How long will it take? What kinds of information will be gathered and how? Why is this information needed? What types of assessment tools will be used? How can I be involved in my child’s assessment?
- **Share information with other team members** about the different kinds of activities your child and your family do throughout your day at home and in the community. **Describe how your child participates** in different activities, including things your child does easily and things your child has difficulty doing.
- If other professionals such as doctors or therapists have assessed your child, **provide the evaluation team with copies of the reports** or permission to obtain the reports.

Check out the [Partnering with Your Child’s Assessment Team Members Practice Guide](#) for more tips to share with parents. Share the [Participating on Your Child’s Team Practice Guide](#) to help families learn about becoming active members of their child’s team.

## Benefits of Family Advocacy

All parents are advocates and leaders in the lives of their children. They advocate for their children’s well-being, and as their children grow, they develop as leaders and as parents. Many parents enter Head Start and Early Head Start programs with strong advocacy and leadership skills. Other parents have great potential to develop these skills.

Here's what the research says about the benefits of family advocacy:

- **Benefits to Children**
  - Families act as advocates and leaders when they are choosing an early childhood program. Parents can use the advocacy skills they develop in Head Start and Early Head Start to positively influence their children's learning experiences throughout their education (Trainor, 2010).
  - Families who are involved in advocacy and leadership activities serve as important role models for their children (Cunningham et al., 2012).
- **Benefits to Families**
  - Family members involved in advocacy and leadership activities can experience personal growth. For example, they may develop or reinforce their ability to express their concerns constructively, create and implement plans, and further refine other skills. Many become more confident and are then able to give back to programs that supported them.
  - Opportunities for families to develop their leadership and advocacy skills can contribute to career advancement. For instance, many Head Start and Early Head Start parent leaders continue their education, become staff at Head Start and Early Head Start or other community programs, and improve the financial stability of their families over time.
- **Benefits to Programs, Schools, and Communities**
  - Schools that provide opportunities for shared leadership with families are better able to meet the needs of the school and community (Auerbach, 2010).
  - Family advocates and leaders have knowledge about their communities and may help organizations become aware of a range of issues (Parent Leadership on the Great Start Collaborative, n.d.).

For more information about strategies to support family advocacy, check out the National Center on Parent, Family, and Community Engagement's [Families as Advocates and Leaders](#) research to practice brief.

## Understand Family Priorities

Families will experience the referral and evaluation process in different ways. Depending on a variety of family characteristics and circumstances, the questions, concerns, and needs for information and support a family has will vary.

Program staff can ask families questions that can help identify family priorities and opportunities to support:

- How are you feeling right now?
- What feels stressful? How do you feel like you're managing that stress?
- What feels hopeful?
- How have things changed since the referral/evaluation process started?
- What is something we can help you with?
- What would make life feel more manageable right now?
- Who in your life is available to provide support?



What other questions might you ask families as you engage to understand experiences, collaboratively determine goals, and identify priorities?

## Helpful Resources

### Online Resources

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#### ECLKC

- Engaging Families of Children with Disabilities: Family Advocacy
  - <https://eclkc.ohs.acf.hhs.gov/family-engagement/article/family-advocacy>
- Advocacy and Leadership - Tips for Families: Every Day Leadership Skills
  - <https://eclkc.ohs.acf.hhs.gov/sites/default/files/pdf/everyday-lead-skills.pdf>
- IDEA 101
  - <https://eclkc.ohs.acf.hhs.gov/video/idea-101-partnering-service-providers-support-effective-inclusion>
- Disability Services Coordinator Orientation Guide: Referring and Evaluating Children
  - <https://eclkc.ohs.acf.hhs.gov/children-disabilities/disability-services-coordinator-orientation-guide/referring-evaluating-children>
- Disabilities Services Coordinator Foundations iPD course
  - <https://eclkc.ohs.acf.hhs.gov/professional-development/individualized-professional-development-ipd-portfolio/course-catalog>

## Early Childhood Technical Assistance Center

- Professional Roles in Early Childhood Intervention
  - [https://ectacenter.org/~pdfs/decrp/PGF\\_FAM1\\_professionalroles\\_2018.pdf](https://ectacenter.org/~pdfs/decrp/PGF_FAM1_professionalroles_2018.pdf)
- Family Members Working with Other Team Members
  - [https://ectacenter.org/~pdfs/decrp/PGF\\_TC2\\_familyteam\\_2018.pdf](https://ectacenter.org/~pdfs/decrp/PGF_TC2_familyteam_2018.pdf)
- Sharing What You Know with Professionals
  - [https://ectacenter.org/~pdfs/decrp/PGF\\_TC3\\_sharing\\_2018.pdf](https://ectacenter.org/~pdfs/decrp/PGF_TC3_sharing_2018.pdf)
- Procedural Safeguards: Family Rights, Confidentiality, and Dispute Resolution
  - <https://ectacenter.org/topics/procsafe/procsafe.asp>

## Parent Training & Information Centers

- Advocacy Tips for Parents
  - <https://wapave.org/advocacy-tips-for-parents/>
- Parental Rights Under IDEA
  - <https://www.parentcenterhub.org/parental-rights/>
- Key Terms to Know in Early Intervention
  - <https://www.parentcenterhub.org/keyterms-ei/>
- Overview of Early Intervention
  - <https://www.parentcenterhub.org/ei-overview/>
- Key Terms to Know in Special Education
  - <https://www.parentcenterhub.org/keyterms-special-ed/>
- Special Education Services for Preschoolers with Disabilities
  - <https://www.parentcenterhub.org/preschoolers/>

## Online Communities

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Head Start Disabilities-Inclusion Network MyPeers Community

<https://eclkc.ohs.acf.hhs.gov/about-us/article/mypeers-collaborative-platform-early-care-education-community>