

Introduction

Introduction to Module 1

Many parents wish their children came with instruction booklets. For parents of a child with a special need, this feeling may be magnified. As you learn about your child's disability and interact with medical and educational professionals, remember that you are the expert on your child. Although you may feel overwhelmed by the challenges you face and may have many questions, no one knows your child as well as you do. Use this module as a guide to help find solutions for your problems and answers to your questions. You are not alone.

You Think that Your Child Has a Delay or Disability

Sometimes, you may wonder if your child is developing like other children. If this is your first child, you may think that he or she should be smiling at you or starting to sit up or walk. Maybe your friend's child is already babbling and pointing at things. If you have other children, you may have a concern that *this* child is not developing like an older brother or sister.

Although some parents may suspect their child has a delay, sometimes they hesitate to ask for help, perhaps hoping that their child will 'catch up.' If you have any questions or worries about your infant or toddler's development, it is a good idea to make an appointment to talk with your child's doctor. Be sure to share your observations and concerns. Your child may have a disability or developmental delay, or may be at risk of having a disability or delay.



A developmental delay means that an infant or young child is developing at a slower pace than other children of the same age. For example, he or she may not be walking or talking like most other children. At risk means that a child's development may be delayed if extra help or guidance is not provided. If your infant or toddler is suspected of having a delay or disability, additional evaluations or tests may be needed. Your doctor may refer you to a medical specialist or consultant. When there is a concern about development, it is also possible to find out if your child is eligible for Early Intervention Services (EIS).

"The first few years after the diagnosis, I was struggling with the dire predictions, but I can see now that we are going to be fine."

Louise, mom to son with autism, Quantico, VA

Some Parents Feel ...

Denial

Denial is a natural reaction to any loss. Like other new parents just learning that they have a child with a disability or serious illness, there is an initial sense of loss when you consider that your dream of having a normal, healthy child may be unattainable. When you receive your child's diagnosis, you may feel you need to get a second opinion.

Guilt

It is not unusual for parents to blame themselves for having done or not done something that caused their child's impairment. This can be especially difficult for mothers who may look back on their pregnancy and wonder if something they did caused their child's disability or illness.

Anger

When you find out that the healthy child you had planned for has a disability, you may experience anger as another natural reaction. While you are entitled to feel angry—and may be asking, "Why me? Why my child?"—keep in mind that many parents are able to use their anger to energize themselves to get the best possible services for their child.

Sorrow

Sadness and disappointment are inevitable as you realize that the future you had envisioned for your child might never materialize. Grief is a natural reaction.

Anxiety and Fear

Coping with a child who has a disability or is chronically ill can be exhausting and confusing. Worries about the future and your own ability to be a good parent are common.

Acceptance and Hope

The roller coaster ride starts to level out eventually. Your child still has special needs, but you have a greater understanding of his or her condition and you realize that you can take good and loving care of your child. You realize that while your child may not be typical, he or she is loving and lovable.

What Can I Do?

Learn about Your Child's Condition

- Search your library and the Internet for information on your child's condition.
- Ask your doctor any questions you have about your child's condition.
- Write down questions you have as you go through your day.
- If you do not understand something, do not be embarrassed to say so.
- Visit the Military OneSource online library for disability-specific books at www.militaryonesource.com.

Contact The STOMP Project

The Specialized Training of Military Parents (STOMP) Project is a valuable resource for military families. You will find support and advice regardless of the special challenges your child may face.

Join the discussion boards and correspond with other parents of children with special needs at www.stompproject.org or call (800) 5-PARENT.

Connect with Other Parents

Realize that you are not alone. The installation's Exceptional Family Member Program (EFMP) can help you connect with military families who have faced similar challenges.

To find the closest EFMP, go to www.militaryinstallations.dod.mil.

Seek Out Your State Parent Training and Information Center

Every state has Parent Training and Information (PTI) Centers. PTI Centers serve families with children with all disabilities and can help you obtain appropriate educational services for your child. PTI Centers train parents and professionals and can help resolve problems between schools and families.

To find a PTI Center in your state, go to www.militaryhomefront.dod.mil/tf/efmp/resources. Click on "State Resources" and choose the link for your state.

Overseas, the military departments provide EDIS by geographic area (e.g., the Navy is responsible for providing services to all eligible children in mainland Japan and Okinawa).

Early Intervention

What Are Early Intervention Services?

Early Intervention Services (EIS) are usually described as special services to meet the needs of infants and toddlers, from birth through age two, who have a developmental delay or disability, and their families. These special services and supports help a child grow and develop, and are provided in the ‘natural environment,’ where the child and family lives and learns.

In 1986, Congress recognized the importance of getting help for young children with special needs and their families, and amended the Education for All Handicapped Children Act of 1975. This amendment ensures that children with an eligible disability or developmental delay will not have to wait until they are school-age to receive needed services and family supports. Today, Part C of the Individuals with Disabilities Education Act (IDEA) requires that all fifty states and jurisdictions, as well as the Department of Defense (DoD), have a system of EIS for all children with disabilities from birth until they turn three years of age.

State systems use the term “Part C” when referring to EIS. “Part C” refers to a specific section of the IDEA related to EIS. Each state has one agency, or lead agent, in charge of the early intervention system. The lead agent may be the state department of education, the health department, or another designated agency. For more information about the IDEA, go to <http://idea.ed.gov>. A list of state lead agencies can be found at www.nectac.org/contact/Ptccoord.asp.

Usually, military families receive EIS from state-based agencies. However, at military locations in the United States served by Department of Defense Education Activity (DoDEA) schools, the military medical departments provide EIS through Educational and Developmental Intervention Services (EDIS).

EDIS program locations can be found on the MilitaryINSTALLATIONS website at www.militaryinstallations.dod.mil.

How Do I Get a Referral to Early Intervention Services?

If your doctor has concerns about your child’s development, you may be referred to an EIS point of contact in your community. EIS is responsible for conducting developmental screenings and evaluations to determine if a child is eligible for services. These developmental screenings are part of Child Find activities.

Child Find is a coordinated process of public awareness activities, developmental screenings, and evaluations. These community activities are

designed to locate, identify, and refer babies or young children with a delay or disability, and their families, who are in need of EIS as early as possible. This Child Find screening, or evaluation, to determine if your child may be eligible for EIS is provided at no cost to you. For information about Child Find, visit www.childfindidea.org.

Even if your doctor does not refer you to an EIS program, you can contact EIS yourself and explain that you are concerned about your child's development. State points of contact can be found at www.nectac.org/contact/Ptccoord.asp.

Additional parent resources are available at www.raalliance.org.

If you are located overseas or living at a military installation served by a DoDEA school, you may contact the EDIS program or local Exceptional Family Member Program (EFMP) for assistance.

Service Coordinators and the Evaluation Process

Once you have contacted your EIS program and your child is referred for services, a service coordinator is assigned to assist you. Usually, your child will receive a developmental screening to determine if a comprehensive evaluation is needed. Your service coordinator is your point of contact to discuss results and to begin planning services if your child is found eligible.

A comprehensive multidisciplinary evaluation is completed in order to find out about your child's strengths, delays, or challenges, and whether your child is eligible for EIS. Multidisciplinary means that qualified professionals who have different areas of training and experience are involved in completing your child's evaluation. The evaluation of your child's abilities usually consists of an interview with the parent or caregiver to discuss concerns about your child's development, as well as their likes and dislikes. A review of your child's medical and developmental history, current health status, and developmental assessments are also discussed. In order to determine your child's developmental status, five areas are evaluated:

- adaptive/self-help, such as eating, dressing, and toileting
- social/emotional development, such as playing and relating to others
- communication, such as talking, listening, and understanding
- physical development, such as reaching, rolling, crawling, and walking
- cognitive development, such as thinking, learning, and solving problems

Your family's resources, priorities, and concerns are also identified. This information helps determine which supports and services will meet your child's developmental needs.

To find the early intervention program in your area, you can call The National Dissemination Center for Children with Disabilities at (800) 695-0285.

Your service coordinator will work with your family to ensure that the proper assessments are performed and that the services in the IFSP are carried out. He or she will also assist you with the transition out of EIS when your child reaches the age of three.

Who Is Eligible for Early Intervention Services?

In order to participate in EIS, children must meet IDEA eligibility guidelines for services to infants and toddlers. An infant or toddler, from birth through age two, may be eligible for services if he or she meets the following criteria:

- has a diagnosed condition, which is likely to result in a developmental delay
- has a developmental delay in one or more of the following areas: adaptive/self-help skills, social/emotional development, communication, physical development (including vision and hearing), or cognitive development as measured by appropriate assessments, procedures, and criteria
- is considered to be at high risk of developing a delay if EIS are not provided

Each state sets EIS eligibility guidelines to meet IDEA standards. Eligibility for EIS varies from state to state due to differences in state definitions of developmental delay and lists of conditions that are likely to result in developmental delay. Children who are eligible for services in one state may not be eligible in another state. Additionally, some states provide EIS for infants and toddlers who are at risk of developmental delay and for their families. For information on the definition of disability under the IDEA and eligibility criteria for early intervention in your state, contact your state's Part C coordinator at www.nectac.org/contact/Ptccoord.asp.

The Eligibility Meeting

After assessments are complete and all of the additional information is gathered, an eligibility meeting is held. You and your service coordinator will determine the timing of this meeting. This meeting allows you to discuss the evaluation results with the professionals involved in your child's evaluation. The evaluation results are compared with the eligibility criteria to determine if your child is eligible for EIS. You will have an opportunity to ask questions and voice your concerns.

What if My Child is Not Eligible for Early Intervention Services?

If your child is not eligible to receive EIS and you still have concerns about his or her development, it is important that you make an appointment with your child's doctor to discuss your continuing worries. There may be other resources available for support and assistance.

Individualized Family Service Plan

If your child is found eligible to receive EIS, you, your service coordinator, and other members of your support team will meet to develop an Individualized Family Service Plan (IFSP). This plan will identify your child's current developmental levels, results that you would like to see your child achieve, and services and other supports that will assist you and your child in achieving those outcomes.

It is important for the early intervention service providers and family to understand that the best way to meet a young child's needs is to support and build upon the strengths of the family. EIS supports the family's needs relative to their child's functioning within day-to-day routines and activities (i.e., their natural environment).

The IFSP includes the following:

- information about your family resources, priorities, and concerns
- outcomes, or results, that your child and family are expected to achieve
- what service is needed
- how often the service will be provided
- number of sessions and how long each session will last
- where the sessions will take place
- how the service will be delivered (e.g., individual, consultation)
- a statement about the natural environment where the services will be provided
- the name of the service coordinator who will help coordinate and obtain the services
- a transition plan for moving out of EIS as your child approaches age three

The IFSP is a family plan with the parents as key contributors in its development.

The involvement of other EIS team members depends on what the child and family need to support the child's growth and development.

Families will review this document with their child's service coordinator regularly to be sure that there is progress towards meeting IFSP outcomes and to revise or update the plan as needed.



The Individualized Family Service Plan is intentionally family-focused. Its purpose is not only to address the needs of the child, but to aid the family in their efforts to support and encourage their child.

The eligibility meeting determines your child's eligibility for services.

How Long Does it Take to Get EIS Started?

The IDEA mandates timely access to EIS. Your child's IFSP should be developed within forty-five days of your first contact with the EIS program. This means that the comprehensive evaluation is complete, the eligibility meeting is held, and the IFSP is developed within forty-five calendar days.

Types of Services

The IFSP defines what type of services will best support your child's and family's needs. It may include services and support related to the following:

- service coordination (refers to the on-going activities carried out by a service coordinator to assist and enable the family to receive information regarding their rights, procedural safeguards, and EIS)
- family training, counseling, and home visits
- special instruction
- speech-language pathology services (i.e., speech therapy)
- audiology services (i.e., hearing impairment services)
- occupational therapy
- physical therapy
- psychological services
- medical services (only for diagnostic or evaluation purposes)
- health services (needed to enable your child to benefit from the other EIS)
- social work services
- vision services
- assistive technology devices and services
- transportation
- nutrition services



Child development research shows that the rate of human learning and development is most rapid in the preschool years. If the most teachable moments or stages of greatest readiness are not taken advantage of, a child may have difficulty learning a particular skill at a later time.

How Are Services Provided?

EIS are required by law and are available throughout the fifty states, United States territories, and DoD locations where there is a DoD school. EIS providers may include therapists, child development specialists, social workers, or other professionals from a variety of agencies. The providers work together with families on IFSP outcomes to meet the needs of your child and your family. EIS may be provided by a single provider, supported by a team of specialists, or by varied providers coordinating their services so that you and your child are not overwhelmed. To the maximum extent possible, the services are to be provided where your child lives and learns, meaning with his or her family and caregivers in the home, day care, at the park, or maybe even at the store.

Transition Planning: What Happens When My Child Turns Three?

Usually six months before your child turns three, your service coordinator and EIS providers will begin to talk with you about options for services that may be available for your child after his or her third birthday. For some children, EIS is all that is needed and no further services or supports will be provided.

Before your child began EIS, your child had to be eligible to receive those services. Your child had to meet state/program eligibility criteria consistent with the IDEA. The same holds true once your child turns three and is being considered for school special education services. Your child must meet the state criteria in order to be eligible for services and support.

Some children may need continued services during their preschool years and beyond and will transition to school special education services as regulated by Part B of the IDEA. If your child is eligible for special education services provided by the local education agency, you will be part of the special education team, which determines the services provided based on your child's individual needs and abilities.

When you are involved in planning your child's transition out of EIS, there are often many forms to complete, evaluations to arrange, and meetings to attend. As a result, you may have many questions about your child's eligibility, options, future needs, or possible services. Your service coordinator may be able to answer some of your questions or put you in contact with those who can address your concerns. For additional information, visit www.nichcy.org/babies/transition.



Parents may choose the natural environment in which the child will receive services. This may be at home, in a preschool setting, or at another location.

Parents know their children best and can share vital information about their daily activities, which can assist in the early intervention process.

"I started to feel better when I realized that asking for help didn't mean I wasn't a good enough mom."

Karen, mom to daughter with Down syndrome and sensory integration dysfunction, Ft. Lewis, WA

What if My Child is Not Eligible for School Special Education Services?

If your child does not meet the eligibility criteria for school special education services, it means that your child's growth and development is now more like other children his or her age. If you still have concerns about your child's progress or development, or would like additional information and support, your EIS service coordinator can provide you with information about additional resources in your community.

Your Role as Advocate

The law gives parents the right to participate as part of the IFSP team to determine which early intervention and educational services and supports will allow their child to grow and learn. How can these rights be used to benefit your child? For detailed information about how to become an advocate for your child, see *Module 5, Advocating for Your Child*.

Support

Service members and families have many groups and agencies to turn to for help with their child. Take advantage of available resources. Remember you are not alone and knowledgeable people are ready and waiting to help. *Module 6, Resources and Support*, provides lists of contacts, ways to connect with support groups, and other sources of help and information.

For More Information

For information about infant and toddler development and developmental milestones, visit the following websites:

- www.nncc.org/Child.Dev/mile1.html
- www.MilitaryOneSource.com/birthtotwo
- www.aap.org



Read or download the other modules of this Parent Tool Kit at www.militaryhomefront.dod.mil/tf/efmp:

- *Module 2, Special Education*
- *Module 3, TRICARE® Health Benefits*
- *Module 4, Families in Transition*
- *Module 5, Advocating for Your Child*
- *Module 6, Resources and Support*

For parents of babies and toddlers with a developmental delay or disability, the following resources are especially helpful.

HOMEFRONTConnections

HOMEFRONTConnections, a DoD social networking site, provides a secure place where military family members with special needs can meet and interact online to share experiences, post pictures and videos, write blogs, and create discussion boards. Join an existing group or create your own. Visit HOMEFRONTConnections at <https://apps.mhf.dod.mil/homefrontconnections>.

Parent Training and Information Centers

Each state has a minimum of one PTI Center designed to serve families of children and young adults from birth to age twenty-two with disabilities. Centers may provide information, training, referrals, and advocacy services to assist parents in obtaining needed resources within their communities. To locate the PTI Center in your state, visit www.militaryhomefront.dod.mil/tf/efmp/resources. Click on “State Resources” and choose the link for your state.

National Dissemination Center for Children with Disabilities

The National Dissemination Center for Children with Disabilities (NICHCY) is funded by the Department of Education and offers a wealth of information, in both English and Spanish, on disabilities in children and youth. To learn more about EIS for infants and toddlers and specific disabilities, visit their website at www.nichcy.org.

Specialized Training for Military Parents Project

The STOMP Project is a PTI Center dedicated to educating and training military parents of children who have special education or health care needs. STOMP assists military families by providing information, support, and advice. Visit STOMP at www.stompproject.org.

