

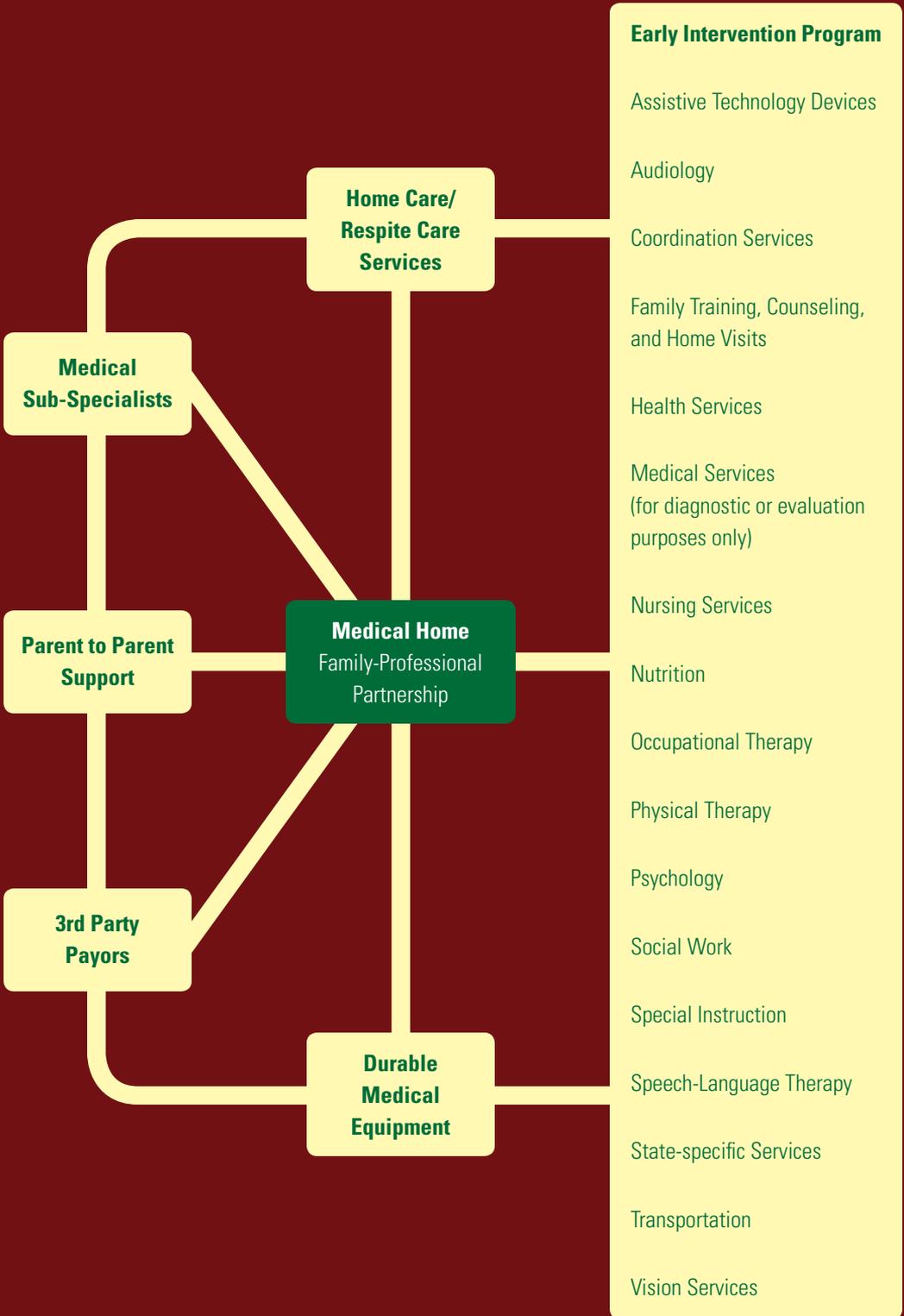
The Medical Home
and
Early Intervention
Programs



American Academy
of Pediatrics
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Figure 1



Note: The full text of the federal regulations for 34 CFR Part 303, Early Intervention Program for Infants and Toddlers with Disabilities including definitions of services can be viewed at <http://nectac.org/idea/303regs.asp>

Background: The Importance of Early Identification and Treatment

Increasingly, the benefits of early identification and treatment on child health outcomes are being proven.¹ **With this knowledge comes the responsibility to identify children with special health care needs (CSHCN) as early as possible so that treatment and intervention can begin promptly. The pediatric clinician that provides the medical home is the ideal person to identify these children through early and continuous screening that is performed in the context of routine, well-child care. The medical home is an approach to providing comprehensive primary care in partnership with a child's family. Care within a medical home is described as accessible, family-centered, compassionate, comprehensive, continuous, coordinated, and culturally effective.**²

One of the primary goals of routine preventive health care is to ensure that a child is developing normally. Although pediatric clinicians choose to monitor development in various ways, studies have shown that the most effective method is through the utilization of formal, validated screening tools.³ Unfortunately, recent evidence indicates that most pediatric clinicians continue to rely on informal measures of development.⁴ This technique has been shown to identify only 30% of children who have developmental delays. The American Academy of Pediatrics (AAP) recommends the use of formal, validated tools to screen for developmental delays.⁵

Once a child is identified through screening; appropriate follow-up, diagnosis, and intervention is needed, as screening is just the first step in the process of ensuring that CSHCN are diagnosed and treated early. The medical home plays a central role in coordinating such care for these children, as many young CSHCN require access to a broad spectrum of services offered by an array of health care providers, programs, and agencies (see Figure 1).

In order for the medical home to be effective, pediatric clinicians need to be aware of the various community-based services that exist. This is especially true for young children from birth to 3 years of age because they are particularly vulnerable and require the expertise of health care, educational, and non-medical professionals to provide effective community-based services. Therefore, the ideal source of a medical home is a pediatric clinician who provides primary care and works in partnership with the family to identify and access all medical and non-medical services needed to help children reach their full developmental potential.²

However, in a recent survey of pediatricians, it was found that many pediatricians were unaware of the types of services provided by their state early intervention program.⁴ In order for the medical home to ensure that the needs of the child and family are met, a comprehensive knowledge of local resources, such as early intervention, is critical.

Early intervention programs funded under Part C of the Individuals with Disabilities Education Act (IDEA) are one place where young children (birth to age 3) with disabilities or at risk for disabilities should be referred. Optimally, there should be a seamless referral system in place, as well as firmly established lines of communication between the early intervention program and the medical home. However, historically, communication has been limited between medical homes and early intervention programs. This brochure has three goals:

One is to educate pediatric clinicians about early intervention programs funded under Part C of IDEA;

Second, to educate early intervention programs about the role of the medical home in providing comprehensive, coordinated, collaborative care in concert with the family and other medical and non-medical service providers; and

Third, to provide strategies for effective collaboration and communication between the pediatric clinician and early intervention programs in the provision of quality, comprehensive care.

According to the federal Maternal and Child Health Bureau (MCHB) definition, which was adopted by the AAP, CSHCN are defined as “those children who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition, and who also require health and related services of a type or amount beyond that required by children generally.”⁶ Although all CSHCN should receive appropriate developmental screening, not all CSHCN will be eligible for early intervention programs under IDEA. Early intervention programs are specifically designed to meet the developmental needs of an infant or toddler with a disability, and in some states children at risk for developing disabilities (see Eligibility Determination).

At each Suburban Pediatrics well-child visit, parents are given the 10 question Parents' Evaluation of Developmental Status (PEDS) Response Form to complete in the waiting room. The PEDS Response Form elicits parents' concerns and observations in each area of development including behavior and social-emotional skills.

Bobby Smith, now 18 months of age, has been a patient at Suburban Pediatrics since birth and recently has had several visits for ear infections. His mother, Mrs. Smith, noted a concern about speech-language development on the PEDS Response Form but otherwise remarked that his fine motor, social, and other skills seemed to be progressing well. Depending on state criteria, at Bobby's age, a single parental concern about speech-language skills could place Bobby in a moderate risk category and indicate the need for additional screening.

Dr. Thomas, Bobby's pediatric clinician, examined Bobby's ears and found them to be free from fluid and infection. Hearing was also assessed and felt to be within normal limits.

What is Part C of IDEA?

The early intervention program for Infants and Toddlers with Disabilities (Part C of IDEA) is a federal grant program that assists states in operating a comprehensive, coordinated, multidisciplinary, interagency system of early intervention services for infants and toddlers with disabilities from birth to age 3, and their families. In order for a state to participate in the program it must ensure that early intervention services will be available to every eligible child and their family. Currently, all states and eligible territories participate in the Part C program.

Part C programs (commonly referred to as early intervention programs) are state-based. This means that although the statute for Part C contains many requirements, including sixteen minimum components of a comprehensive statewide early intervention system,⁷ every state has the flexibility to determine certain aspects of these components. For example, each state determines which state agency will administer the early intervention program. In most states, this is either the Department of Education or the Department of Health and Human Services. Another important example is that although the IDEA statute for Part C specifies the developmental areas that are to be included in states' definitions of developmental delay, states must identify appropriate diagnostic instruments, procedures (including the use of informed clinical opinion), and levels of functioning or other criteria that will be used to determine eligibility. As a result, definitions of eligibility differ significantly from state to state, as well as the types of services that are provided to these children. To learn about your specific state program and what services are available, go to:

<http://www.nectac.org/contact/ptccoord.asp>

How Does the Early Intervention Program Work?

Identification/Screening

The first step in the early intervention system is the identification of a child with a disability. The optimal time for early identification is during a well-child examination in the primary care setting, as pediatric clinicians have regular contact with the majority of children in this age range.

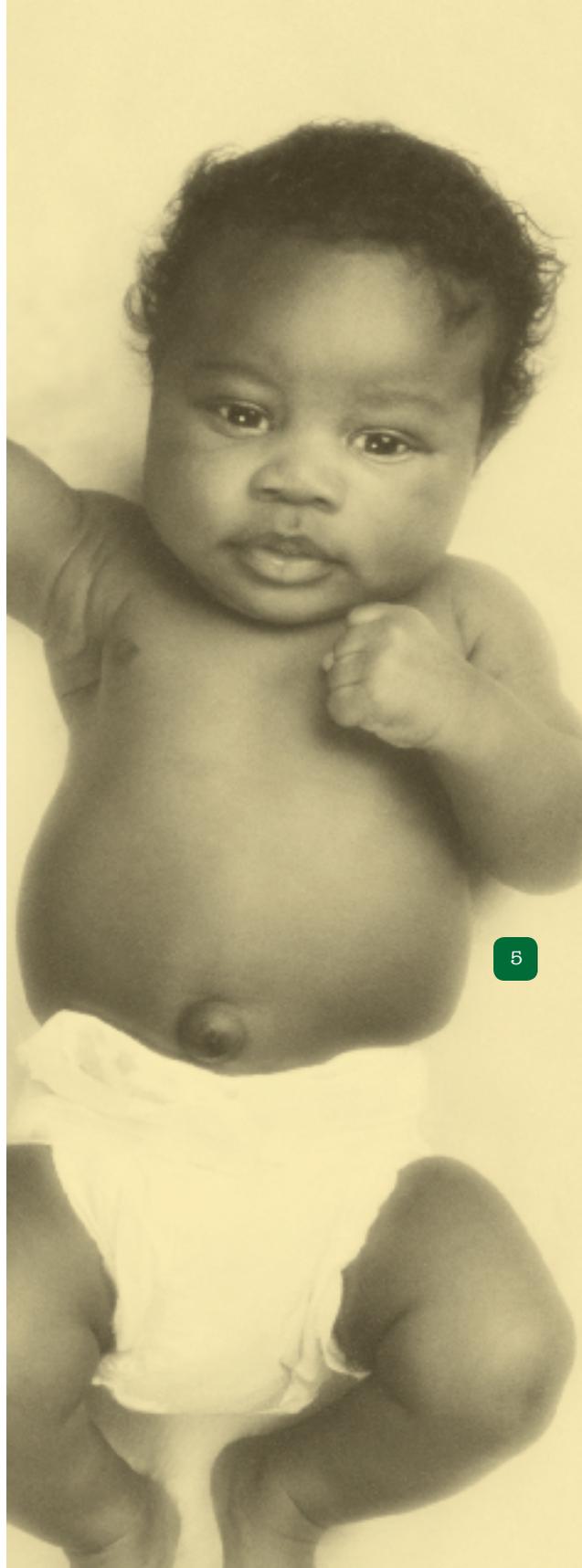
Historically, most children with milder developmental disabilities remained unidentified until school entry, primarily due to the fact that few physicians utilized standardized tools, but relied on clinical judgment alone. Research indicates that clinical judgment detects fewer than 30% of children who have developmental disabilities.³ Although some instruments rely on administration by office staff, while other instruments utilize a parent report, identification of developmental delays are most accurate when using a formal validated screening instrument, and is the approach the AAP recommends.

Referral to the Early Intervention Program/Initial Service Coordination

Once a child is identified as either having or being at risk for a developmental delay, he/she should be referred to the state's early intervention program promptly. Because the lead agency that provides early intervention services differs from state to state, one must first identify the correct agency to contact. Some states use the strategy of a single toll-free number for all referrals, thereby simplifying this process.

A referral to early intervention services can be made by anyone, including social workers, physicians, parents, childcare providers, teachers, other pediatric clinicians, etc. The early intervention program typically acts on referrals quickly, assigning a service coordinator as soon as possible. The service coordinator then contacts the family to set up an evaluation to determine program eligibility.

Part C requires each state to have a "comprehensive child find system" to ensure that all children birth to age 3 who are eligible for services under Part C are identified, located and evaluated.⁸ For Part C, the lead agency with the advice and assistance of the state interagency coordinating council ensures that the system is coordinated with all other major efforts to locate and identify young children by other state health, education, tribes, and social service organizations. This comprehensive system addresses referral procedures and timelines for agencies to act on referrals. It targets primary referral sources including hospitals, physicians, parents, child care programs, local education agencies, public health facilities, other social service agencies and other pediatric clinicians.



Doctor Thomas recommended a referral to the local early intervention program to get a more careful look at Bobby's development. Mrs. Smith agreed and gave permission for Dr. Smith to make the referral and forward significant medical information. Dr. Thomas also suggested that Mrs. Smith call the early intervention program to follow up on the referral and he provided her with the contact information for the agency in charge of the state's early intervention program. She contacted the agency, and the service coordinator set-up an appointment with a speech-language pathologist to conduct an evaluation of Bobby.

Eligibility Determination

Once a child who is suspected of having a disability is referred to the early intervention program, the state is obligated to conduct an evaluation and initial assessment within 45 days of receiving a referral to determine whether the child is eligible for services. Each child who is suspected of having a disability is entitled to receive a comprehensive, multidisciplinary evaluation to determine his/her needs and strengths, and to identify the needs of each child's family to appropriately assist in the development of the child. Multidisciplinary means *the involvement of two or more disciplines or professions in the provision of integrated and coordinated services, including evaluation and assessment activities* in Sec. 303.322⁹ and development of the Individual Family Service Plan (IFSP) in Sec. 303.342.¹⁰ If necessary, medical services to determine a child's developmental status and need for early intervention services may also be provided.

Any child with a developmental delay or disability is at higher risk for additional delays and therefore the pediatric clinician should consider a complete assessment and not just an evaluation for the condition noted, i.e. speech. The early intervention program may be able to provide the needed complete assessment, but if not, then the pediatric clinician may need to seek other resources.

States are obligated to provide early intervention services to eligible children with disabilities from birth to age 3 and their families. States may also choose to provide services to children and families who are considered to be "at risk" of having substantial developmental delays if early intervention services are not provided. Eligible children include those who:

- (1) Are experiencing developmental delays, as measured by appropriate diagnostic instruments and procedures, in one or more of the following areas:
 - a. Cognitive development
 - b. Physical development, including vision and hearing
 - c. Communication development
 - d. Social or emotional development
 - e. Adaptive development; or
- (2) Have a diagnosed physical or mental condition that has a high probability of resulting in developmental delay

Development of the Individualized Family Service Plan

The state agency will work to develop an IFSP for a child that is found to be eligible for services based on the state's eligibility criteria. Simply put, an IFSP is a written plan that identifies the major outcomes expected to be achieved for the child and family, as well as a statement of the specific early intervention services necessary to meet the unique needs of the child and the family to achieve the identified outcomes. Early intervention services include:

- Audiology
- Assistive Technology Devices
- Health Services
- Nursing Services
- Medical Services (for diagnostic or evaluation purposes only)
- Physical Therapy
- Occupational Therapy
- Family Training, Counseling, and Home Visits
- Transportation and Related Costs
- Psychological Services
- Nutrition Services
- Social Work Services
- Special Instruction
- Speech-Language Pathology Services
- Vision Services
- Service Coordination
- Other State-specific Services

Note: The full text of the federal regulations for 34 CFR Part 303, Early Intervention Program for Infants and Toddlers with Disabilities, including definitions of services can be viewed at

<http://nectac.org/idea/303regs.asp>

The use of an IFSP illustrates the family-centered philosophy of early intervention programs. A dual focus, on both the child and family, underscores the importance of the family in enhancing a young child's development. Families play an active role in the development of the IFSP, along with a multidisciplinary team including the pediatric clinician, the service coordinator, and other professionals involved in assessment and service delivery.

The speech-language pathologist administers a more in-depth evaluation, using the 60 item Early Child Development Inventory (ECDI). This test indicated that Bobby had speech-language delays that likely would make him eligible to receive services through the early intervention program. The speech pathologist also gave Mrs. Smith an informational handout on how to stimulate Bobby's language and modeled some of the techniques.

A couple of weeks following Bobby's evaluation, the service coordinator contacted Mrs. Smith to set up an IFSP meeting. Dr. Thomas was also invited to attend as the medical home provider, as was the speech pathologist who evaluated Bobby, and other speech pathologists who would be providing speech pathology services. A copy of the IFSP was given to Mrs. Smith, who then provided her written consent for the early intervention services outlined in the IFSP.

It is very important to involve the child's pediatric clinician in the development of an IFSP because the family and pediatric clinician may have already developed a comprehensive plan of care as a part of the child's medical home.

An initial IFSP meeting must be held within 45 days of the initial referral to the early intervention program. The contents of the IFSP must be fully explained to the parents and informed written consent from the parents must be obtained prior to the initial provision of the early intervention services described in the plan. In the event of exceptional circumstances that make it impossible to complete the evaluation and assessment within 45 days (e.g., if a child is ill), an interim IFSP can be developed and implemented.

Service Provision

The financing of early intervention services provided to eligible children and their families varies among states. Some states provide services at no charge to the parents; whereas other states use a sliding fee scale for some services. The inability of a parent of an eligible child to pay for services does not result in the denial of services to the child or family. At a minimum, the state must provide the following functions without a charge to parents:

- Implementing child find requirements
- Evaluation and assessment
- Service coordination
- Administrative and coordination activities related to the development, review, and evaluation of IFSPs, and implementation of procedural safeguards.

A child typically receives services through various community service providers with coordination of services through the state agency. The state determines the occupational category for who provides services directly to the child and family. For example, this can be a paraprofessional consulting with a certified therapist, or it can be an occupational therapist who is providing multidisciplinary services with the consultation of other therapists as deemed necessary based on the IFSP. Qualified personnel can include:

- Audiologists;
- Family therapists;
- Nurses;
- Nutritionists;
- Occupational therapists;
- Orientation and mobility specialists;
- Pediatric clinicians and other physicians;
- Physical therapists;
- Psychologists;
- Social workers;
- Special educators;
- Speech and language pathologists;
- Vision specialists;
- Paraprofessionals; and
- Parent-to-parent support personnel.

A review of the IFSP for a child and the child's family must be conducted every 6 months, more frequently if conditions warrant, or if the family requests such a review. A meeting must be conducted on at least an annual basis to evaluate the IFSP for a child and the child's family, and as appropriate, to revise its provisions. A plan is also developed to ensure a smooth transition for children receiving early intervention services to preschool or other appropriate services at age 3. For a child who may be eligible for preschool special education services under a separate IDEA provision, part B, the early intervention program, with the approval of the family, must convene a meeting with the family, staff from the early intervention program and the local educational agency to discuss any services the child may receive. This meeting must be held at least 90 days, and at the discretion of the parties, up to 6 months, before the child is eligible for the preschool services.

Communication Between the Medical Home and Early Intervention Programs

Research has indicated that care for CSHCN is often fragmented, and includes a mixture of duplication and gaps.⁶ Although the role of pediatric clinicians in the early intervention system is clear, their involvement has been less than optimal.

Part of the problem may be in the communication between pediatric clinicians and early intervention programs, as well as a lack of knowledge of each other's services and approaches to providing care to children with disabilities and their families. Improvements could be made by both the medical community and the early intervention program to ensure that communication is handled more effectively.

Understanding the role of the medical home in the coordination of care is vital to effective collaboration with the early intervention program and the family. The medical home coordinates needed medical and non medical services by: maintaining a central record/database containing all pertinent medical information (ie, hospitalizations, specialty care), assisting the child and family in communicating clinical issues when a child is referred for a consultation or additional care, and evaluating and interpreting the consultant's recommendations for the child and family. The medical home is also likely to have a better awareness of psychosocial factors in the family as well as medical findings and changes that could impact early intervention success. Through open communication and efforts to collaborate on service delivery and coordination of care, the child and family have a plan that all providers are working on together to support the child and family. Not only will this avoid duplication of services, but it will improve the quality

of life for the child and family, as they will have the support of all of their providers working together to ensure that the child and family are thriving, obtaining the services they need, and setting a course for their future.

What early intervention programs want to know from pediatric clinicians:

- Any concerns the pediatric clinician may have regarding the child's medical condition, limitations, medications, family dynamics, etc.
- Major changes in medical services or health conditions that have direct implications for services provided by early intervention service providers
- Child's progress on health related outcomes included in the IFSP (if applicable)
- Whether or not families frequently miss scheduled appointments

What pediatric clinicians want to know from early intervention programs

- Acknowledgment that the early intervention program received the referral
- Inability or difficulty in contacting the family
- Initiation date/s of services/treatments
- Progress or lack of progress in treatment/s
- Disposition (program eligibility, discharge from services, change in program participation)
- Contact information for the early intervention service coordinator and those providing direct services through the early intervention program
- Bulleted list of services received by the child and/or family (summary statement)
- Findings of the early intervention assessments and evaluations
- Medical concerns noted by early intervention program staff

See sample letters and correspondence attached.



Bailey Thomas, MD
285 Congress Parkway
Crystal Lake, IL 60014

Dear Dr. Thomas:

Thank you for referring your patient, Bobby Smith (DOB: [date]) to the Illinois early intervention program. We had the pleasure of meeting with Bobby and his mother on [date]. For your records, we have enclosed a copy of the signed consent that allows bilateral exchange of information between the early intervention program and your office. We have also enclosed a copy of the evaluation report for your records.

As part of Bobby's evaluation, we administered the Early Child Development Inventory. This test indicated that Bobby has speech-language delays that make him eligible to receive services through the early intervention program. We are scheduling a multidisciplinary meeting to develop the Individualized Family Service Plan (IFSP) with Bobby and his family. We would greatly appreciate your input and participation at the IFSP meeting. Please let us know what dates and times would best fit your schedule and we will try to accommodate you. In the event that you are unable to attend this meeting, we would welcome your feedback by mail or phone.

Once the IFSP has been developed, we will provide you with a summary of services that your patient will receive. If you have any questions, please do not hesitate to contact us.

Sincerely,

Illinois Early Intervention Program Staff

Note: Parental consent is required before this information can be presented by the early intervention program to the pediatric clinician or another third party. Therefore we recommend that consent be obtained at the time of the initial evaluation or meeting by the early intervention staff.

Bailey Thomas, MD
285 Congress Parkway
Crystal Lake, IL 60014

Dear Dr. Thomas:

We saw your patient, Bobby Smith (DOB), on [date]. During this visit, we had the opportunity to develop an Individualized Family Services Plan to address Bobby's speech language delays. Below, please find a summary of the services that Bobby will receive:

Summary of Services (add services as needed):

- Audiology
- Speech-Language Pathology Services

Contact Information:

Service Coordinator:

Phone: _____ Fax: _____ E-mail: _____

Speech Pathologist:

Phone: _____ Fax: _____ E-mail: _____

(List other providers and their contact information)

If you have any questions, do not hesitate to contact us.

Sincerely,

Illinois Early Intervention Program Staff

For Additional Information

- National Early Childhood Technical Assistance Center (NECTAC) www.nectac.org
The NECTAC supports the implementation of the early childhood provisions of the IDEA. Their mission is to strengthen service systems to ensure that children with disabilities (birth through 5) and their families receive and benefit from high quality, culturally appropriate, and family-centered supports and services. The NECTAC is funded by the US Department of Education.
- National Center of Medical Home Initiatives for Children with Special Needs (National Center) www.medicalhomeinfo.org
The National Center provides support and technical assistance to any individual interested in improving the care of children/youth with special health care needs, and helping improve access to medical home. The Web site of the National Center contains a wealth of resources and links about newborn and infant screening, and integration of children with special health care needs into the medical home.
- US Department of Education Web site www.ed.gov/about/offices/list/osep/index.html
This site includes a full-text version of the IDEA legislation, as well as general information about research and programs offered through the Office of Special Education and Rehabilitative Services.

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Although the US Department of Education has reviewed this document for consistency with IDEA, the contents of this document do not necessarily reflect the views or policies of the US Department of Education. The US Department of Education has not reviewed the sources and Web sites cited in this article, so it does not provide any assurances regarding their consistency with IDEA. In addition, the cited sources and Web sites do not necessarily reflect the views or policies of the US Department of Education, nor does mention of other organizations imply endorsement by those organizations or the US Government.

Endnotes

- ¹ American Academy of Pediatrics, Committee on Children with Disabilities. Role of the pediatric clinician in family-centered early intervention services. *Pediatrics*. 2001;107:1155-1157.
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- ⁷ Adapted from 20 U.S.C. § 1435(a) (1997).
- ⁸ 34 C.F.R. § 303.321 (1999).
- ⁹ 34 C.F.R. § 303.322 (2003).
- ¹⁰ 34 C.F.R. § 303.342 (1999).





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