The Pediatric Professionals’ Role in Early Intervention

TA for Pediatric Professionals

Division of Developmental Disabilities Services / Children’s Services
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Early identification of developmental disorders is critical to the well-being of children and their families. It is an integral function of the primary care medical home and an appropriate responsibility of all pediatric health care professionals.

AAP recommends that developmental surveillance be incorporated at every well-child preventive care visit. Any concerns raised during surveillance should be promptly addressed with standardized developmental screening tests. In addition, screening tests should be administered regularly at the 9-, 18-, and 30-month visits.

The early identification of developmental problems should lead to further developmental and medical evaluation, diagnosis, and treatment, including early developmental intervention. Children diagnosed with developmental disorders should be identified as children with special health care needs, and chronic-condition management should be initiated. Identification of a developmental disorder and its underlying etiology may also drive a range of treatment planning, from medical treatment of the child to family planning for his or her parents.

Updated policy:

Identification Is Essential for Intervention

Birth to three is a critical time in a child’s development.

A delay in diagnosis can cause “setbacks” that may compromise a child’s chances for success.

Developmental screenings should be a part of every well-baby visit. Screenings provide a quick and simple way to monitor a child’s healthy development. The earlier a developmental delay or disorder is detected, the better the prognosis for the child.

During the early years, children make regular visits to their PCP. First Connections recognizes and promotes public awareness of the importance of EPSDT but encourages physicians to use the “well baby checkups” to monitor more than physical development. Well visits provide crucial opportunities to monitor and chart a child’s social, emotional, and cognitive development and screen for developmental disorders.

Basic screenings using major developmental milestones is effective and simple, taking only a few minutes. There are many ways physicians can partner with parents to seamlessly weave developmental screenings into well visits. A parent might fill out a paper or Web-based screening form in the physician’s waiting room, at home before a well visit, or with the assistance of a nurse or other professional in the examination room.

“With developmental, behavioral, and learning disabilities on the rise, there is much that remains poorly understood, from cause to cure. However, there is one widely-accepted fact: early and intensive intervention can have a profound impact on the quality of life for children at risk and their families. The key is early detection. But recognizing the early signs can be a challenge for parents and healthcare professionals alike.”

Guiding Principles in Providing Effective Early Intervention

1. All children are unique with individual strengths and talents. Disability is natural, and the presence of a disability or special need is not a defining characteristic of any child. Children with and without special needs learn important things from one another. All children have the right to belong, to be welcomed, and to participate fully in the typical places and activities of their communities.

2. The primary goal of EI is to support families in promoting their child’s optimal development and to facilitate the infant’s/toddler’s participation in family and community activities.

3. EI requires a collaborative relationship between families and providers, with equal participation by all those involved in the process. An ongoing parent-professional dialogue is needed to develop implement, monitor, and modify therapeutic activities.

4. The goal of EI is to encourage active participation of families in the therapeutic process by imbedding intervention strategies into family routines and by providing parent/caregiver education and training.

5. Parents are a child’s first teacher, and children develop in the context of relationships with their families and other caregivers. Providers working with caregivers equip them to creatively adapt their child care methods to facilitate the development of their child, while balancing the needs of the rest of their family.

6. Intervention must be linked to family-centered, specific goals that are functional and measurable. Intervention strategies should focus on facilitating social interaction, exploration, and autonomy.

7. Intervention shall be integrated into a comprehensive plan that encourages transdisciplinary activities and avoids unnecessary duplication of services. The plan shall be built around family routines, with written home activity programs to encourage family participation in therapeutic activities on a daily basis.

8. Intervention is provided only after an Individualized Family Service Plan (IFSP) has been developed and (written) parental consent has been obtained for services. The IFSP (or plan of care) is monitored/assessed periodically (quarterly) to assure that the strategies implemented are successful in achieving outcomes.

9. Children and their families receiving early intervention deserve to have services of the highest possible quality. Intervention shall be based on appropriate peer-reviewed, evidence-based practices, to the extent practical and related to functional outcomes and developmentally appropriate practices. Services are provided by qualified providers who meet the state personnel guidelines for each early intervention service. Services will be provided in a culturally relevant manner, including use of an interpreter, if needed.
Highlights of IDEA Guidelines Governing EI:

**Referral/Intake**
34 CFR §303.303(a)(2)(i) – Once a primary referral source identifies an infant or toddler who needs evaluation or early intervention services, a referral for evaluation/assessment must be made within seven (7) days. [NOTE: Referrals can be faxed to the Central Intake Unit along with pertinent medical records / screening results and a prescription for evaluation.]

34 CFR §303.31 – Each infant/toddler referred will receive a timely, comprehensive, multidisciplinary evaluation to determine eligibility (unless child is referred with a diagnosed condition qualifying eligibility) and a family assessment of the needs of the family to appropriately assist in the development of the infant/toddler. [NOTE: “no single procedure is used as the sole criterion for determining eligibility” – child’s level of functioning is assessed in each of the five developmental areas. The process involves: two testing instruments used by qualified personnel, interpretation of test results using informed clinical opinion, and a narrative report.]

**IFSP**
34 CFR §303.310 – For an infant/toddler referred for early intervention services and determined eligible, the meeting to develop the initial IFSP must be conducted within 45-days from the date of referral. [NOTE: sending all pertinent records and a prescription for evaluation helps the family receive services in a timely manner and enables First Connections to comply with federal timelines.]

34 CFR §303.344(d)(1) – The IFSP must include a statement of the specific early intervention services, based on peer-reviewed research (to the extent practicable), that are necessary to meet the unique needs of the infant/toddler and family to achieve the results or outcomes identified in paragraph (c – “measurable outcomes expected to be achieved for the child including: pre-literacy and language skills, as developmentally appropriate for the child”). The IFSP must include the criteria, procedures, and timelines used to determine degree to which progress is being made and whether revisions of the expected outcomes and/or EI services are necessary. The IFSP also include information about the length, duration, frequency, intensity, and method of delivering early intervention services and the location/s – including justification for services provided outside of the natural environment with a transition timeline/plan for re-integration into the natural environment.

34 CFR §303.342(e) and §303.420(a)(3) – The projected date for the initiation of each early intervention services is provided on the IFSP; services should begin as soon as possible after the parent consents to the services.

**Natural Environments**
34 CFR §303.26 – “Natural environments means settings that are natural or typical for a same-aged infant or toddler without a disability, may include the home or community settings . . .” [NOTE: The family assessment gathers information about the family’s daily routines and resources to, whenever possible, to embed coaching into the family’s typical activities.]

34 CFR §303.126(a) services are provided “to the maximum extent possible” in natural environments and (b) in other settings only when early intervention services cannot be achieved satisfactorily in a natural environment (as determined by the multidisciplinary IFSP team).
Finance
34 CFR §303.510 -- State’s “Part C” programs are the payor of last resort.

34 CFR §303.521 – Families will not be charged any more than the actual cost of service and families with public or private insurance/benefits will not be charged disproportionately more than families who do not have coverage.

34 CFR §303.520(a)(2)(ii) – Providers may not require parents to sign up for or enroll in a public benefits or insurance program as a condition for their infant/toddler to receive early intervention services.

34 CFR §303.520(a)(3) – A provider may not use public or private insurance or benefits of an infant/toddler or parent to pay for early intervention services unless prior written notification to the parent/caregiver is provided.

“No Cost Protection Provision”
34 CFR §303.520(a)(2)(ii) and §303.520 (b)(1) – An EIS provider must obtain consent to use an infant’s/toddler’s or parent’s public or private insurance or benefits if that use would --

(a) Decrease available lifetime coverage or any other insured benefit for the infant/toddler
(b) Result in the infant’s/toddler’s parents paying for services that would otherwise be covered by the public benefits or insurance program
(c) Result in an increase of premiums or discontinuation of benefits or insurance for the infant/toddler or for the parent
(d) Risk loss of eligibility for the infant/toddler or the parent for home and community-based waivers based on aggregate health-related expenditures.

34 CFR §303.520(a)(3)(iii) – Parents have the right to withdraw consent to disclosure of personally identifiable information to the agency responsible for administration of the state’s public benefits/insurance program at any time.
Frequently Asked Questions:

Q. How do I refer?
A. Referrals are made by faxing a referral along with pertinent records and a prescription for evaluation to the Central Intake Unit.

1-800-643-8258 (toll free information line) 501-682-8890 (fax)

Q. Do I have to wait until there is a confirmed diagnosis to refer?
A. No. Federal IDEA guidelines indicate that a referral “for evaluation” MUST be made as soon as possible (but not more than seven days) after a suspected disability/developmental delay. When faxing the referral form, please be sure to also fax a copy of any developmental screening information and/or copies of pertinent medical or developmental evaluations that will inform the evaluation process.

Q. Will I receive feedback on my referral?
A. Yes. First Connections follows up with the referral source.

Q. What services does First Connections provide as part of “Part C” early intervention?
A. The sixteen early intervention services outlined under Part C are:

- Speech Therapy
- Physical Therapy
- Health/Nursing Services
- Medical Diagnostic Services
- Multi-Disciplinary Evaluation
- Vision Services
- Nutritional Services
- Social Work Services
- Assistive Technology
- Occupational Therapy
- Service Coordination
- Special Instruction
- Transportation
- Audiological Services
- Psychological Services
- Family Training/Home Visits/Counseling

*(coming soon – Sign language/cued language)

Once eligibility has been established, in most cases, a prescription is required for therapy. Other services identified by the IFSP team but not outlined under Part C as necessary to reach specified developmental goals and objectives are provided as well.

Q. How common are developmental disorders?
A. “Developmental disabilities are common and were reported in ~1 in 6 children in the United States in 2006–2008. The number of children with select developmental disabilities (autism, attention deficit hyperactivity disorder, and other developmental delays) has increased, requiring more health and education services. Additional study of the influence of risk-factor shifts, changes in acceptance, and benefits of early services is needed.”
The U.S. Department of Education reports that less than 3% of children under three are being served through the federally-funded (“Part C”) early intervention program even though approximately 17% of children under the age of 18 are affected by a developmental, behavioral, or learning disability.

**Q. Who makes up a child’s IFSP team?**

**A.** The IFSP team is a multidisciplinary team that must include: the family and anyone the family chooses to invite, the EI service coordinator, an EI professional qualified to interpret evaluation results. Other professionals that participate on the team are the EIS providers directly involved with service provision to the child/family. The child’s PCP may choose to be a part of the IFSP team and is encouraged to do so. As a child approaches his/her third birthday, a representative from Early Childhood Special Education under Part B (3-5) or a representative of an appropriate agency to which the child may transition may join the team to prepare the toddler for what lies ahead.

**Q. Who is eligible for early intervention through First Connections?**

**A.**

1. Infants/toddlers (0-3) with a diagnosed physical or mental condition with high probability of developmental delay.
2. Infants/toddlers whose multidisciplinary evaluations identify a significant delay (25% or more of chronological age) in one or more areas of development: adaptive, cognitive, communicative, physical, social and emotional

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The Pediatrician's Role in Development and Implementation of an Individual Education Plan (IEP) and/or an Individual Family Service Plan (IFSP)

Abstract

The Individual Education Plan and Individual Family Service Plan are legally mandated documents developed by a multidisciplinary team assessment that specifies goals and services for each child eligible for special educational services or early intervention services. Pediatricians need to be knowledgeable of federal, state, and local requirements; establish linkages with early intervention, educational professionals, and parent support groups; and collaborate with the team working with individual children.

Special education in each local school district is protected and regulated by strong legislative and judicial safeguards created by the federal Education for All Handicapped Children Act (PL 94–142). This act was reauthorized in the 1991 legislation PL 101–476 under the new title, Individuals With Disabilities Education Act (IDEA), which has four key components: 1) identification of children with learning-related problems; 2) evaluation of the health and developmental status of the child with special needs, determining current and future intervention requirements, and developing a plan to match services to needs; 3) provision of services that include educational and related services; and 4) guaranteed due process. These federally legislated safeguards establish that children with disabilities and their parents share the same legal right to a free and appropriate education as children without disabilities.

Federal legislation requires that each child recognized as having a disability that interferes with learning has a written plan of service: an Individual Education Plan (IEP) for children aged 3 through 21 years, an Individual Family Service Plan (IFSP) for infants and toddlers birth through 3 years, and a Transitional Services Outcome Plan for young adults at 16 years of age. Federal legislation defines transition from school as a coordinated set of activities for a student designed to promote movement from school to post-school activities, including postsecondary education, vocational training, integrated employment, continuing and adult education, adult services, independent living, and community participation. This transition plan highlights and validates the lifelong needs of individuals with disabilities and is the beginning of an integrated program that enables adults with disabilities to live, work, and play in our towns and cities. The pediatrician is in a key position to participate in planning services and to provide care for these children and young adults.
The Individual Education Plan (IEP)

In 1975 Congress enacted PL 94–142, the Education for All Handicapped Children Act, as an educational bill of rights to assure children with disabilities a free and appropriate education in the least restrictive environment. In 1977 implementation of services was extended to children 3 to 21 years old, although services for children aged 3 to 5 years remained optional. States were also requested to identify children who had not previously received services.

PL 94–142 (currently Part B) allowed children with mental retardation, hearing deficiencies, speech and language impairments, specific learning disabilities, visual impairments, emotional disturbances, orthopedic impairments, and a variety of medical conditions that may interfere with education (categorized as Other Health Impaired [OHI]) to receive special education services. To meet the eligibility criteria, a child's disability must interfere with the educational process and normal school performance to the extent that special education assistance is needed.

Other portions of the law provide the following:

1. Every child must have a multidisciplinary evaluation by a team. This team, working in collaboration with the family, is responsible for designing an IEP that has specific education and therapeutic strategies and objectives. Each plan must be reviewed annually.

2. Every child must be educated in the least restrictive environment. This criterion supports the concept of integrating children with and without disabilities as much as possible and with extra supports and services when necessary to facilitate inclusion.

3. The evaluation team may recommend the following related services: transportation; developmental, corrective, and other supportive services (including speech pathology, audiology, psychological services, and physical and occupational therapy); recreation (including therapeutic recreation); and social work services (including rehabilitative counseling) and medical services (for diagnostic and evaluative purposes only). These services may be required to assist a child to benefit from special education and include early identification and assessment of disabling conditions. If the parents approve the IEP, they sign a document and the school is committed to providing these outlined services.

4. The rights of the parents and child to “due process” shall be protected. This ensures the parents' rights to be involved in developing the educational plan and for the meeting to be conducted in their native language or other mode of communication if it is not a written language understandable to the general public. The IEP/IFSP team leader is responsible for arranging and paying for an interpreter if English is not the native language of the home or if the parent has a hearing impairment. Furthermore, parents have the right to appeal when they view the team's decision as inappropriate or harmful.

The Individual Family Service Plan (IFSP)

In 1986 Congress enacted the Education of the Handicapped Act Amendments, PL 99–457. It was reauthorized in PL 105–17 in 1997. Part C of this reauthorization legislation, formerly known as Part H, called for the creation of statewide, coordinated, multidisciplinary, interagency programs for the provision of early intervention services for all infants and toddlers with disabilities. Although the law did not mandate these services, partial reimbursement of costs was made readily available to states that wished to participate. All states have established programs for children birth to 3 years. These developmental services are designed to meet needs in the areas of physical, cognitive, communicative,
and psychological development, and in self-help skills. The purpose of these services is to enhance the development of the infant and toddlers with disabilities; to minimize their potential for developmental delay; and to optimize the abilities of the families to meet the special needs of their children. It was also hoped that this would minimize the cost over time of special education services when youngsters attained school age, decrease the need for institutionalization, and enhance the potential for independent living.

The law requires each state to create its own definition of developmental delay as a basis for determining eligibility for services. Pediatricians played a significant role in determining this eligibility by advocating for a broad definition of developmental delay. Services are provided for children with developmental delay, as well as for those whose biological conditions have a high probability of having a delay. In addition, states have the option to provide services to those children who are at risk of manifesting developmental delays attributable to environmental factors.

A major difference between Part C of PL105–17 and Part B of PL94–142 is that Part C focuses on the involvement of the family and supports for the family. Under this law, the evaluation, assessment, and planning take place with family participation and approval. Early intervention services are all optional, subject to family approval, and are provided in natural settings such as the parents' home and child care settings as well as more formal child development programs. The current discussions about early brain development center around children from birth to 3 years. It is during this period that the growth and organization of the brain is most influenced by environmental factors that Part C strives to make optimal.

Children referred as potentially eligible receive a comprehensive multidisciplinary assessment. The assessment describes the abilities and needs of the child and family. Following assessment, an IFSP is created, to include the following:

- the child's present attainments,
- family strengths,
- how to enhance development of the child,
- major outcomes expected, including the outcome measures and criteria, and time lines to achieve specific goals,
- specific early intervention services that the child and family will receive,
- projected dates for initiating services and their duration,
- name of the service coordinator responsible for coordinating and helping the family implement the plan,
- steps to help the child and family with the transition to school services at an appropriate time.

The statute specifies a wide array of other services, but the only health services included are those that are “necessary for the infant or toddler to benefit from other early intervention services.” Diagnostic and consultative medical services are also included, but the extent to which these services are funded by the early intervention program varies.
MEDICAL ROLE AND RECOMMENDATIONS

Several roles for the pediatrician exist under IDEA. All pediatricians should ensure that in their practices, every child with a disability has access to the following services:

1. **A medical home.**
   - A medical home provides care that is accessible, continuous, comprehensive, family-centered, coordinated, and compassionate. For children with special health care needs, many of whom have an IEP or an IFSP, the pediatrician's central role as the provider of primary care means that he or she would participate in the plan development. In addition, the pediatrician should collaborate with community resources in treatment planning and in promoting early intervention programs that work.

2. **Screening, surveillance, and diagnosis.**
   - The pediatrician should screen all children from the first encounter, checking for risk or existence of a disability or developmental delay. Pediatricians are in key positions to identify at the earliest possible age those children who may benefit from services under IDEA. Pediatricians should provide screening and surveillance using a combination of methods best designed to take advantage of multiple sources of information.

3. **Referral.**
   - The pediatrician should be knowledgeable about the referral process to early intervention programs in his or her community and knowledgeable about the parents' right for multidisciplinary team evaluation by the school- or state-designated agency if a disabling condition may be present. In addition, some of the best support of parents comes from other parents who are able to offer emotional and social support and practical advice. Many communities have programs in which parents support each other and help parents new to the system better navigate the system. Family Voices, a nationwide grassroots network of families and friends speaking on behalf of children with special health care needs, is a creditable organization that can assist parents and pediatricians and is accessible by telephone and the Internet (1–888-835–5669; [www.familyvoices.org](http://www.familyvoices.org)).

4. **Diagnosis and eligibility.**
   - For early intervention, the pediatrician has an important role in the identification of children with established delays and in the diagnosis of conditions with a high probability of developmental delay, which will qualify a child for this program. Each state has developed a definition of these conditions, which should be obtained from the state's lead agency for this infant and toddler program. In addition, some states include “at risk” conditions as defined by the state as eligible for services. Further information about these issues can be obtained from the single point of entry into Part C locally or the state's lead agency. A list of lead agencies for state early intervention services can be obtained from the National Childhood Technical Assistance System (919/962-2001; [www.nectas.unc.edu](http://www.nectas.unc.edu)).

5. **Participation in assessment.**
   - A child identified through screening or observation as meeting the definition for developmental delay should receive a comprehensive multidisciplinary assessment. The pediatrician has an important role as a referral source or, if more extensive participation is elected, as a member of the multidisciplinary team. Few pediatricians have the flexibility in their schedules to participate in person in lengthy team meetings. Usually, these meetings are scheduled with a short lead time and at the convenience of the educators arranging them. However, all pediatricians should offer to be available by written communication or participate...
by conference call or other means to offer input to and receive feedback from the assessment team. Ideally, the pediatrician should be a member of the team and attend the IEP/IFSP meeting.

6. **Counsel and advice.** During the assessment process, families will need a knowledgeable person for medical advice and counsel. Pediatricians can alert parents to the benefits of a pre-IFSP or pre-IEP conference; of their right to sign the IFSP or IEP only when they are comfortable with the recommendations; and their right to have a friend or other advocate at the IFSP and IEP conference. Although a parent may bring their personal attorney to the conference, most parents do not. If an attorney is going to attend on behalf of the family, the family should notify the school agency of that fact before the meeting to give the school an opportunity to have their legal counsel or top administrator scheduled for the conference. The appeal process begins at the district school board where the child resides. The president of the school board and superintendent of schools should receive the written appeal document. If appeal at the district level fails to satisfy the family’s concerns, their next appeal is to the State Board of Education. Rarely does an appeal by either the school district or family go to state or federal supreme courts. Each district school board has a published document that advises parents of procedural safeguards, which can be obtained at no cost to the family. Most assessment teams nominate a member as service coordinator to work with the families. A strong link should be developed between the assessment team and the primary care pediatrician, as well as an open sharing of concerns between parents, the pediatrician, and the assessment team.

7. **Creation of the IEP and IFSP.** Pediatricians who participate in the assessment process should be consulted by the assessment team when these documents are created. Such consultation is vital to preparing an appropriate and effective plan. The pediatrician should review the plan developed, counsel the family, and comment on health-related issues as needed. The pediatrician should determine if the health-related services proposed are appropriate and sufficiently comprehensive and assist parents in performing their advocacy tasks when there is evidence of inappropriate planning. Ideally, when schools or educational agencies are developing the IEP or IFSP, a pediatrician should serve as a member of the assessment team.

8. **Coordinated medical services.** When medical services are part of the IEP or IFSP, they should be conducted by the primary care pediatrician or an appropriate pediatric subspecialist. Medical services and communication should be coordinated by the primary care pediatrician or his or her designee in those cases in which the children have complex medical needs involving several physicians or centers. Special education personnel should be made aware of the restrictions of health care insurance including limited referral options and the role of the primary physician as “the gatekeeper” in some programs.

9. **Advocacy.** Pediatricians have many local and state opportunities to serve as knowledgeable, thoughtful advocates for improved community and educational services for children with disabilities. Pediatricians who select this role need to be aware of the structure of services in the community and the key persons who implement them. Examples of advocacy roles for pediatricians include participation in the local or state early intervention interagency council, consulting with the local school system or state department of education, or becoming a school board member.
CONCLUSION

Participation in interdisciplinary efforts for children with disabilities can help the pediatrician focus on the needs of the child with disabilities or developmental delay and improve the coordination of all forms of service and care for the child and the child's family. The pediatrician's role in IEP and IFSP development and implementation includes knowledge of federal statutes and state and local mandates and regulations; establishing linkages with local early intervention and education professionals and parental support groups; and collaborating with the team serving the individual child. Collaboration among parents, pediatricians, and educators can lead to better quality of care and paves the way for a better quality of life for the child and young adult with a disability.

3. Individuals With Disabilities Education Act (PL 102–119)


