

Early Intervention



A module designed to introduce primary health care providers to early intervention services and delivery systems.

*Developed by:
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 - D: Reprint of: American Academy of Pediatrics, Committee on Children with Disabilities (1994). Screening Infants and Young Children for Developmental Disabilities. Pediatrics, 93 (5), 863-865.
 - E: Reprint of: Dworkin, P. H. & Glascoe, F. P. (1996). Early Detection of Developmental Delays: How Do You “Measure Up?” Contemporary Pediatrics, 14 (4), 158-168.
 - F: Sample Letters to Physicians Regarding IFSPs
 - G: Additional Reading Prior to Component Three: NICU Follow-Up Clinic Visit
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INTRODUCTION

Primary care physicians who treat infants and toddlers with disabilities must have a thorough understanding of early intervention services. This module is designed to inform you, the pediatric resident, about Part C of the Individuals with Disabilities Education Act (IDEA), which pertains to services provided for children ages birth to three with special needs. You will learn about the basic components of an Individualized Family Service Plan (IFSP) and the roles physicians and other professionals play in this process. In addition, you will learn about best practices in providing early intervention services and will see first hand how these services are provided in early intervention programs.

ORGANIZATION OF MODULE

The Early Intervention module is divided into four components. The first is a didactic component that covers Part C of IDEA, the IFSP, and integrated care. The second component requires you to visit the home of a child with special needs to observe an early intervention program visit. Component three provides you time to observe a community-based early intervention program. The fourth component requires you to attend the NICU follow-up clinic at Connecticut Children's Medical Center to learn more about the issues families face when their children are born prematurely.

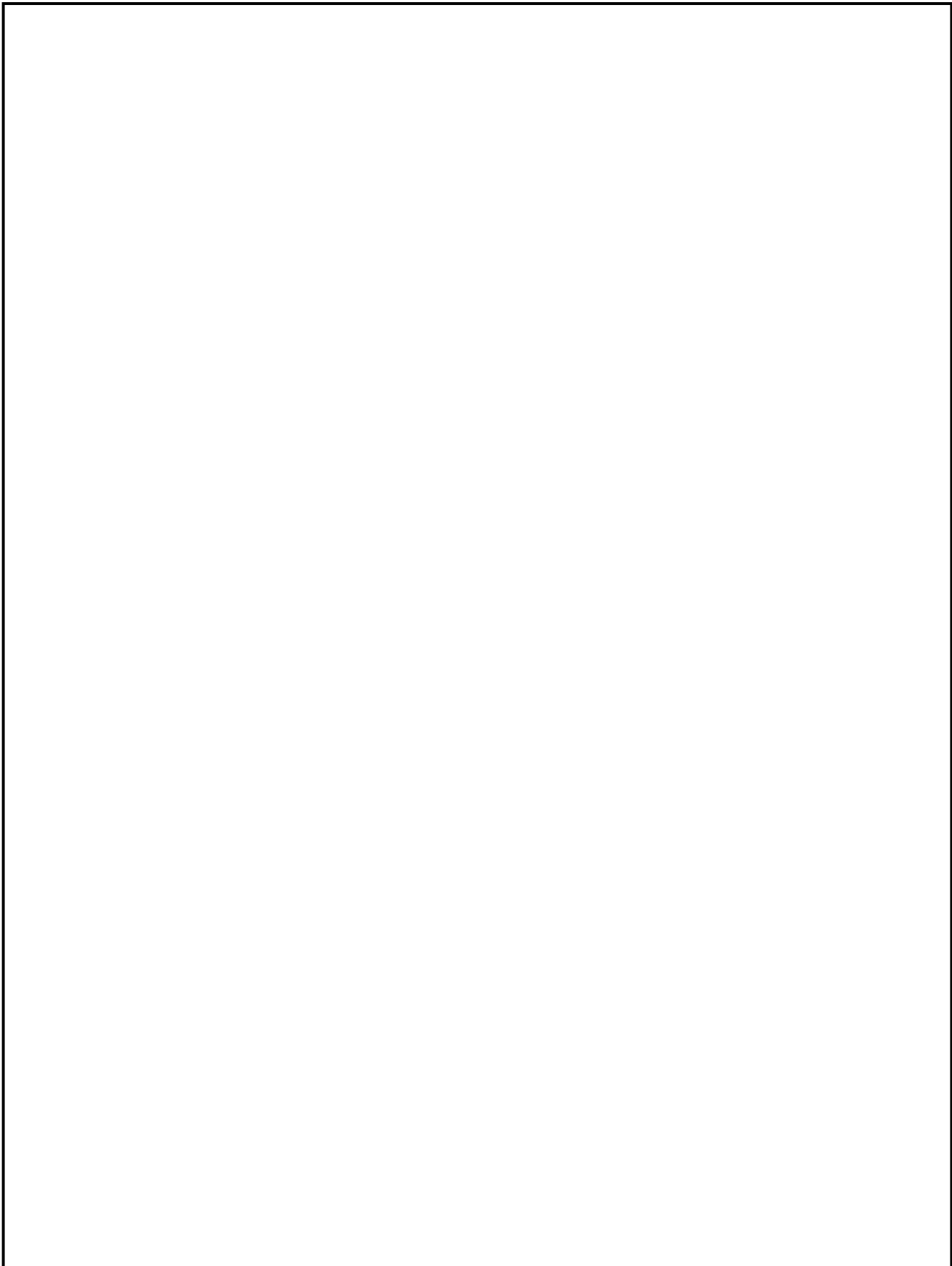
Summary of organization of module:

- ❖ One half day didactic
- ❖ One half day observation of home-based early intervention program
- ❖ One half day observation of community-based early intervention program
- ❖ One half day NICU follow-up visit

OBJECTIVES

At the completion of the Early Intervention module, you will be able to:

1. Describe the historical perspectives that led to early intervention and best practice.
2. Describe the rationale and essential components of Part C of IDEA, including eligibility for children ages birth to three.
3. Explain the importance of assessment and family involvement in the process.
4. Explain the IFSP process, the components of the IFSP, and the role and responsibility of the physician in the process.
5. Explain the integrated care model.
6. Describe the services available for eligible infants and toddlers under Part C of IDEA.
7. Explain the importance of service delivery in the natural environment.
8. Explain the implications of procedural safeguards in reference to parent participation in early intervention services.



COMPONENT ONE: INTRODUCTION TO EARLY INTERVENTION

Location and Times:

These will be established by the project coordinator in conjunction with the chief residents. You will be notified by either the coordinator or a chief resident with as much advanced warning as possible.

Format:

Information will be presented through discussion, reading materials, and case studies. Videos are optional.

Resident's Responsibilities:

Please arrive on time and come prepared to participate in the conversation. It will be a more productive session if you have read the materials beforehand. Be prepared to critique the session afterwards.

REFERENCES

RELATED READINGS

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Thornton, S. (Producer), & Herlinger, M (Director). (1990). CREATING A NEW VISION: The Individualized Family Service Plan [Videotape]. (Available from *Early Childhood Section, Colorado Department of Education, 201 East Colfax, Denver, CO 80203*)

EARLY INTERVENTION HISTORICAL PERSPECTIVES

The history of early intervention spans multiple disciplines and fields of study. Each area has contributed to current thinking and the way early intervention practices are provided under federal and state law. The field has been impacted by theories and practices from several areas including child development, maternal and child health, early childhood education, and special education.

The fields of child development and education define early intervention as the provision of educational or therapeutic services to children under the age of eight. In federal and state legislation, the term early intervention describes services provided to families and children during the years from birth to three. The terms early childhood special education or preschool special education describe the period of preschool years (ages 3 to 5). Special education refers to services provided to children ages 6 to 21.

CHILD DEVELOPMENT

Child development literature provided the field of early intervention a theoretical focus that evolved from the transactional model of development. At one time, child development theory was polarized into two competing schools of thought: a biologically based view of development and one that stressed behavioral and environmental factors. The transactional model of development, a synthesis of these two theories, represents the interactive nature of child development by simultaneously emphasizing biological,

behavioral, and environmental factors. This model suggests that the environment can be modified to minimize a child's biological limitations, and conversely, a deficient environment can lead to delays in a child's development. This viewpoint has greatly influenced both early intervention strategies and service delivery models.

MATERNAL AND CHILD HEALTH

The maternal and child health field underscores the role of government in designing and supporting practices that promote the well-being of children. Several governmental agencies and programs have been established within the maternal and child health field to support and fund early intervention services and programs. The history of this field dates back to 1912, when Congress established The Children's Bureau. Subsequently, a national network of Maternal and Child Health centers and services were established. The Social Security Act (1935) and its amendments increased services for children, including Medicaid coverage and the Early and Periodic Screening Diagnosis and Treatment (EPSDT) program which assists in the early identification and treatment of children's health and developmental needs.

EARLY CHILDHOOD EDUCATION

The field of early childhood education was also an important contributor to current early intervention service models. Initially, early childhood programs were developed to serve low income or disadvantaged children, and to some extent the parents of these children. Kindergartens were the original formal

early childhood programs. The concept of kindergarten was established in the early 1800s by proponents such as Friedrich Froebel in Germany.

Preschools or nursery schools were established in the early 1900s, and as with kindergarten, the concept was developed in Europe. The focus was on the development of self-care, responsibility, and educational readiness skills for disadvantaged children. In Rome, Maria Montessori also established early education programs that emphasized learning through active involvement with the environment.

The Great Depression and World War II prompted the U. S. government to provide assistance for expanding early education opportunities for young children in both daycare and kindergarten programs. This effort was primarily intended as a support for mothers entering the work force. During the Kennedy Administration (1960-1963), President Kennedy expanded the nation's commitment to early care with increased legislation and appropriations. The largest government-funded early childhood program, Head Start, was established in 1965. Head Start provided comprehensive early childhood services that focused on health, education, social services, and parental involvement for four- and five-year-old children in low income families.

Most recently, the Federal Family Support Act (1988) and the Child Care and Development Block Grant (1991) recognized the importance of early care and early education programs. Through these legislative efforts, states are authorized to coordinate early education programs to ensure that families have accessibility to child care, Head Start, and other children's services.

SPECIAL EDUCATION

The field of special education contributed to the development of early intervention through its emphasis on remedial and compensatory services and instructional techniques. Special education history began in the late 1700s in France with the story of Victor, a child who had grown up with wolves. Jean-Marc Itard developed and provided an intensive education program to teach Victor (known as the “Wild Boy of Aveyron”) language and behavior skills. Itard’s success led a student of his, Edouard Sequin, to develop a physiological method for educating children with disabilities. This method emphasized the importance of early education and the use of detailed assessment information to develop a remediation plan. Despite the work of these two men, the preferred treatment for people with disabilities during the 1800s in both Europe and the United States was institutionalization and segregation from society.

In 1946, after World War II, the U. S. Office of Education established a section for exceptional children. Parents of children with disabilities recognized the increase in rehabilitative services being provided to injured service men and organized advocacy groups to increase the availability of similar services for their children. Many of these advocacy organizations became leaders in the development of services and programs for children with special needs.

THE INDIVIDUALS WITH DISABILITIES EDUCATION ACT, PART C (IDEA)

Since the early 1970s, a series of educational and civil rights laws have directly or indirectly opened the doors to community services and programs to people of all ages with disabilities. Please see Appendix A for a chronology of the legislation pertaining to individuals with disabilities.

The IDEA provides special education and related services to children from ages 3 to 21. In 1986, Congress extended IDEA benefits under Part C (formerly known as Part H) to include infants and toddlers from ages birth to three. Part C stresses a family-centered approach in its provision of early intervention services to families and children. The primary goal of Part C is “to develop and implement a statewide, comprehensive, coordinated, multidisciplinary, interagency program of early intervention services for disabled infants and toddlers and their families.”

GOALS

Part C of IDEA establishes numerous comprehensive goals:

- ❖ To enhance the development of infants and toddlers with disabilities and to minimize their potential for developmental delay.
- ❖ To reduce the educational costs to our society, including the nation’s schools, by minimizing the need for special education and related services after infants and toddlers with disabilities reach school age.

- ❖ To minimize the likelihood of institutionalization of individuals with disabilities and maximize the potential for them to live independently in society.
- ❖ To enhance the capacity of families to meet the special needs of their infants and toddlers with disabilities.
- ❖ To enhance the capacity of state and local agencies and service providers to identify, evaluate, and meet the needs of historically underrepresented populations, particularly minority, low-income, inner-city, and rural populations.

A state may (or may not) choose to provide federally-assisted services to infants and toddlers and their families. Part C of IDEA provides incentives for states to develop this entitlement program, but it must be based on a comprehensive, interagency, and multidisciplinary model of service delivery.

Key components

Key components that all states are required to follow under Part C of IDEA include:

- | | |
|---|---|
| ◆ Public awareness program | ◆ Lead agency designation and responsibilities |
| ◆ Child find | ◆ Central directory of information |
| ◆ Evaluation and assessment | ◆ Data collection system |
| ◆ State definition of developmental delay | ◆ Comprehensive system of personnel development |
| ◆ Individualized Family Service Plan | ◆ Personnel standards |

- ◆ Policy for contracting or otherwise arranging for services
- ◆ Procedure for timely reimbursement of funds
- ◆ Procedural safeguards

- ❖ **Public awareness program:** States must establish a public awareness program focusing on early identification of eligible infants and toddlers. The regulations require states to inform the public about the statewide early intervention program and the child find system, including how to make referrals and how to gain access to evaluation and services. The law also requires that states disseminate informational materials to all primary referral sources, for example, hospitals, pediatricians, and family practitioners.
- ❖ **Child find:** A comprehensive child find system is to be established as the single point of entry for making referrals into the early intervention system. Such a system will include procedures and timelines that ensure that all eligible infants and toddlers are identified, located, and evaluated.

Connecticut's single point of entry is through INFOLINE, at an easy access phone number of 2-1-1. The physician may call to make a referral, or a family member may do so. Once a referral has been made, the family will be contacted by an early intervention professional who arranges an evaluation to determine whether the child is eligible to receive services. This person will assist the family in becoming familiar with the early intervention system and will act as a coordinator throughout the process.

If it is determined that a child is not eligible for early intervention services, a family can request INFOLINE to place the child on a monitoring system (Ages and Stages questionnaire) by completing a form that is returned to INFOLINE. At a parent's request, the physician can receive a copy of the completed Questionnaire. After the questionnaire is reviewed by INFOLINE, and if a developmental delay is suspected, the family will be contacted and another evaluation may occur.

- ❖ **Evaluation and assessment:** With parental consent, each child referred must be given a timely, comprehensive, multidisciplinary evaluation to determine the child's status in each of the five developmental areas for eligibility purposes. This evaluation also includes family-directed identification of the needs of each family and child in order to appropriately assist in the child's IFSP.

- ❖ **State definition of developmental delay:** Infants and toddlers qualifying for Part C services must experience developmental delays in one or more areas of physical, cognitive, communicative, social and emotional, and/or adaptive development. Developmental delay refers to a discrepancy between a child's developmental skills and his or her chronological age. Infants and toddlers can also qualify for services if they have an established condition. An established condition refers to a physical or mental condition that carries a high probability of causing developmental delays. Examples of established conditions are Down Syndrome, hearing or visual impairments, major congenital syndromes, or genetic disorders. Each individual state has the option of serving children who are "at risk" of experiencing substantial delays if they do not receive early intervention. Currently, Connecticut does not serve the "at risk" population.

❖ **Individualized Family Service Plan:** An Individualized Family Service Plan (IFSP) is developed by a multidisciplinary team, including the parents. It is the framework for meeting the unique needs of the child and family. The IFSP is the legal document used to develop and deliver appropriate early intervention services to an infant or toddler with disabilities and his or her family. Federal guidelines stress the importance of parents and professionals working together collaboratively in order to plan, implement, and evaluate services designed to address the family's concerns, priorities, and resources. Connecticut's IFSP form may be found in Appendix B. An article explaining IFSPs and how they can be used effectively is in Appendix C.

❖ **Policy for contracting or otherwise arranging for services:** IDEA mandates that 14 services are available depending upon a child's identified needs through assessment and the IFSP process, including:

- ◆ Assistive technology devices and services
- ◆ Early identification, screening, and assessment services
- ◆ Health services and nutrition services
- ◆ Psychological services
- ◆ Social work services
- ◆ Speech and language pathology and audiology services
- ◆ Medical services only for diagnostic or evaluation purposes
- ◆ Nursing services
- ◆ Service coordination
- ◆ Special instruction

- ◆ Occupational therapy
- ◆ Physical therapy
- ◆ Transportation and related costs
- ◆ Vision services

- ❖ **Lead agency designation and responsibilities:** Each state is to designate a lead agency which will be responsible for the administration of funds under Part C. Connecticut's lead agency is the State Department of Mental Retardation (DMR).
- ❖ **Central directory of information:** This directory should include information on public and private early intervention services; resources and experts available in the state; research and demonstration projects being conducted in the state; and professionals and other groups that provide assistance to eligible children and their families. Connecticut's directory can be accessed through INFOLINE.
- ❖ **Data collection system:** States must set up a system for compiling data on the number of infants and toddlers and families in need of early intervention services, the number served, and the types of services provided.
- ❖ **Comprehensive system of personnel development:** Each system must include a comprehensive system of personnel development to provide for preservice and inservice training to be conducted on an interdisciplinary basis, to the extent appropriate. The lead agency further assures that the training provided (which includes primary referral sources) relates

specifically to understanding the basic components of early intervention services; relates to meeting the interrelated social and emotional, health, developmental, and educational needs of eligible children; and relates to assisting families in enhancing the development of their children and in participating fully in the development and implementation of IFSPs.

- ❖ **Personnel standards:** Personnel working in early intervention must hold the highest requirements (i.e., highest entry-level academic degree, certification, licensing, or registration) in the state applicable to the profession or discipline in which he/she is providing services.

- ❖ **Procedure for timely reimbursement of funds:** Most federal Part C funds have been used primarily for planning by the lead agency, rather than for direct services. The law prohibits using Part C funds to replace existing funding or to reduce state medical assistance or other benefits to eligible children and families. Funding for services can come from a variety of places: Medicaid or private insurance, sliding fee scale (payment from parent), annual state appropriation, and/or annual federal awards.

According to federal and state law, families can not be charged for referral to the Birth to Three system, the evaluation and assessment to determine eligibility and needs, the development of the IFSP, and the implementation of procedural safeguards.

GUIDELINES FOR BEST PRACTICE IN EARLY INTERVENTION

Best practice in early intervention has evolved over many years. Particularly unique to Part C compliance are family-centered care principles, models of team-based service delivery, and interagency collaboration. Best practices are incorporated into the assessment and IFSP process, service delivery, natural environment, and program evaluation.

- ❖ **Family role of the family:** The philosophy of family-centered care is based on the premise that the family is the enduring and central force in the life of a child and has a large impact on the child's development and well-being. Most often pediatricians are the first individuals to listen to concerns that families have about their child's development. They need to communicate with the families and have the resources available to assist them in accessing services and interventions. In their unique situation they can work collaboratively with families to monitor the child's development over time.
- ❖ **Team-based service delivery:** While infants and young children with disabilities may require the combined expertise of numerous professionals providing specialized services, the coordination of both people and services is frequently overwhelming. For example, personnel with medical expertise, therapeutic expertise, educational/developmental expertise, or social service expertise traditionally have been involved in the provision of services to infants and young children with disabilities and their families.

Each of these service providers may represent a different professional discipline and a different philosophical model of service delivery. In fact, each discipline has its own training sequence (some require undergraduate, while others require graduate degrees), licensing and/or certification requirements (most of which do not require age specialization for young children), and treatment modality (e.g., occupational therapists may focus on sensory integration techniques).

In order to improve the efficiency of the individuals providing early childhood intervention, it has been suggested that services be delivered through a team approach. The team is composed of professionals from different disciplines that teach, learn, and work together to accomplish a common set of intervention goals for a child and his or her family.

Physicians play a key role on the team for children and families with special health care needs. Their role involves coordinating the child's medical status with the education and service providers that are involved in the child's intervention.

- ❖ **Interagency collaboration:** Collaboration describes efforts to unite organizations and persons for the achievement of common goals. The major reason for collaboration between individual service providers and federal, state, and local agencies is that the needs of infants and toddlers and their families are complex and multifaceted. Early intervention requires many agencies to work together to develop joint activities focusing on collaborative service models.

Linkage and coordination of services are conveyed in Part C through the efforts of service coordination and implementation of the IFSP.

On a higher level, Part C provides for federal, state, and local interagency councils that serve as major mechanisms for bringing together key agencies, service providers, and state groups that have a common interest in young children. While interagency and cross disciplinary collaboration is the first step toward implementing collaborative service models, the ultimate goal is to provide a seamless system of service delivery that addresses the needs of families and children with special health care needs.

ASSESSMENT PRACTICES

FAMILY ASSESSMENT

The assessment process includes a family's identification of their child's strengths and needs as well as the professional's assessment and identification of the child's strengths and needs. Part C states that every family has an opportunity to express their families' resources, priorities, and concerns. The service coordinator's role can be to identify informal and formal resources for families based on needs and priorities and to assist families in developing effective ways to access needed resources on their own. The goal of family assessment by a service coordinator is to have families become stronger, more capable, and more competent. The importance of family empowerment as a meaningful outcome of service delivery cannot be underestimated or overlooked by the early intervention system.

CHILD ASSESSMENT

Assessment is the process of gathering information in order to make a decision. Best practice suggests that parent participation and partnership should be facilitated during the screening and assessment process. Parents and other family members can provide a wealth of knowledge about a child's abilities, including specific skills, motivations, interactions with others, and learning style. Parents should be encouraged to share their observations of what is typical for their child, even though he or she may not demonstrate these skills during the assessment process.

Information gathered during this process should become an integral part of the intervention plan, introducing the parents as equal partners in fostering their child's development. To ensure family involvement, the following points should be addressed:

- ❖ Determine the parents' perceptions of the purpose of the assessment and the outcomes they hope to achieve.
- ❖ Ask family members to share their questions and concerns.
- ❖ Inquire about family preferences for:
 - ◆ Areas to be addressed
 - ◆ Nature of the assessment process
 - ◆ Methods to be used
 - ◆ Desired level of parental participation
 - ◆ Where assessment will take place
- ❖ Inquire about special family traditions, practices, and cultural norms which may impact assessment.

- ❖ Continually check back with parents to see if the child's performance is typical.
- ❖ Speak clearly, explaining the assessment process without the use of professional jargon.

Early intervention should be guided by the individual characteristics of the child. The goal of assessment should be to gain information about the specific strengths and needs of the child. This knowledge can then be used to develop intervention strategies for that child. Best practices indicate that assessment techniques should be valid, reliable, and ecologically sound.

In early childhood intervention, three separate assessment purposes have been identified: screening, eligibility for services, and program planning.

- ❖ **Screening:** Developmental screening is the process through which children are identified as having a possible developmental need or delay and, therefore, will require additional assessment. The major goal of screening is to reduce the time that elapses before intervention begins. For screening to be effective, it must be accurate, comprehensive, and cost effective.

The pediatrician plays a central role in the screening process. The American Academy of Pediatrics emphasizes the need for early detection of developmental delays and encourages pediatricians to include developmental monitoring in their provision of health services to children. The pediatrician is in a unique position to identify young children with developmental delays. First, pediatricians are often the professionals most

likely to be involved with families with young children. Second, pediatricians typically follow families and children over a long period and thus are able to monitor developmental progress over time. Finally, pediatricians are often aware of familial and environmental factors that may put children at risk for developmental delay.

Screening can occur through a variety of methods, including parent interviews, observations of the child, or the use of a specific instrument or checklist. Pediatricians may choose to employ the developmental surveillance.

This involves:

- ◆ Eliciting family member's input (observations, concerns, etc.) about their child.
- ◆ Using clinical observations of the child.
- ◆ Obtaining a comprehensive developmental history.
- ◆ Consulting with other professionals involved in the child's care.
- ◆ Monitoring the child's progress over time.

Because of the wide range and variations in normal development and behavior during the early years, infants and young children can be difficult to screen. Parent involvement in the screening process may alleviate some of these difficulties. One technique that has been used to do this is the parent-completed screening questionnaires. These include the Ages and Stages Questionnaire (ASQ), the Child Development Inventories (CDI), and the Parent's Evaluations of Developmental Status (PEDS). Appendix C contains an article from the

American Academy of Pediatrics on early identification and screening for disabilities in infants and young children, and Appendix D contains an article on early detection of developmental delays.

- ❖ **Eligibility for services:** A second purpose of assessment is for diagnostic or eligibility purposes. Usually this assessment is comprehensive and includes a variety of measures (sometimes using standardized tools) and professionals with discipline-specific expertise. Parents should participate in the assessment because they have the most knowledge about their children's development. It is important that early evaluation provides a foundation for continuous and ongoing assessment to access the most appropriate services for children with disabilities and special health care needs.

- ❖ **Program planning:** A third purpose of assessment is to determine intervention outcomes, goals, objectives, and strategies. Assessments conducted for program planning should use a variety of instruments and discipline-specific professionals, as needed. It is most important that the family participates actively in the assessment to ensure the validity of the outcomes or goals.

To conduct nondiscriminatory assessments, professionals should take into account a child's cultural background, family values, and socioeconomic status when designing a test battery. Tests that do not contain culture-specific items and those which have been validated on an appropriate population should be selected. Assessment procedures and results are biased when a child's performance on a

test is unfairly influenced by race, sex, cultural background, or religious affiliation. Biased assessment can result in a child being labeled as disabled or cognitively deficient when in fact the test itself contributed to the low score received by the child.

Children should be observed and assessed in their natural environments (e.g., home, daycare, play group) and during naturally occurring routines (e.g., eating, playing with peers, dressing, etc.). This allows the assessment team to discover the extent to which the child uses his or her skills and how they are integrated for functional purposes into the child's daily routines.

THE IFSP PROCESS

The Individualized Family Service Plan (IFSP) is a planning document that shapes and guides the day-to-day provision of early childhood intervention services. The IFSP is required for the provision of early intervention services for eligible infants and toddlers (ages birth to 3) and their families. This document relies very much on a family-centered and community-based orientation to service delivery. The IFSP process includes:

- ❖ Identifying the family's concerns, priorities, and resources: beginning a partnership.
- ❖ Identifying the family's activity settings: the value of home and community.

- ❖ Identifying the child's developmental strengths and needs in the context of the family's activity settings: functional assessment strategies.
- ❖ Identifying collaborative outcomes:
 - ◆ To enhance family capacity
 - ◆ To enhance child competence
 - ◆ To expand activity settings
- ❖ Promoting participation in activity settings:
 - ◆ Adaptations
 - ◆ Supports
 - ◆ Intervention strategies
- ❖ Assigning responsibilities across team members:
 - ◆ Collaborative consultation
 - ◆ Building community capacity
- ❖ Evaluating progress:
 - ◆ The child
 - ◆ The family
 - ◆ The community

Part C mandates that every IFSP contains the following written requirements:

- ❖ The present level of the child's development.
- ❖ A statement of the family's concerns, priorities, and resources.
- ❖ A statement of expected major outcomes for the child, which may include social behavior, adjustment to the family, as well as developmental goals.
- ❖ A statement of necessary services for the child.

- ❖ A statement of the natural environments in which early intervention services shall be provided.
- ❖ Projected dates and duration of services.
- ❖ The steps for supporting the child's transition from the early intervention program to the mandated special education program within the local school district at age three.
- ❖ The name of a service coordinator.

RESPONSIBILITY OF THE PHYSICIAN TO THE IFSP

In 1996, the reauthorization of Connecticut's Birth to Three program changed Connecticut law to include the requirement that physicians collaborate with the early intervention team and sign the IFSP document.

As of 1998, Connecticut is the only state that mandates physician involvement and signature on the IFSP. This provides a natural opportunity for the physician to become involved in a child's early intervention program in a meaningful way. The IFSP is a legal document that cannot be enforced until the physician has signed it. A sample of Connecticut's IFSP form may be found in Appendix B. Samples of letters that accompany the IFSP to the physician are included in Appendix F.

To comply with this mandate and be a functioning member of the IFSP team, it is the physician's responsibility to:

- ❖ Review the IFSP in its entirety.

- ❖ Decide whether the contents of the IFSP (e.g., functioning levels, goals, objectives, etc.) are appropriate for the child and his or her family.
- ❖ Assure that any medical concerns that may impact a child's programming are addressed.
- ❖ Assure that any other concerns of the family are addressed.
- ❖ Decide whether the recommended services and supports are appropriate for the child and his or her family.
- ❖ Assure that nothing has been omitted.

The IFSP is a *working document*. Any questions or concerns that the physician has should be directed to the service coordinator or the service delivery team. While this may seem a great responsibility, it is in keeping with best practices for services that are family-centered, coordinated, and collaborative.

INTEGRATED CARE

To meet the needs of infants and toddlers with special needs and their families, services must be provided within an integrated care model. The IFSP must incorporate the child's medical, social, and developmental needs. Instead of providing separate and often fragmented services, which address specific needs or "deficits," a more holistic approach should be used. The approach should take into consideration all aspects of the child's life, with a particular focus on the child within the context of the family. The emphasis should be on helping families identify their own strengths, concerns, priorities, and resources, as well as providing ways to facilitate their child's growth based on his or her strengths.

In order to improve the efficiency of the individuals providing early childhood intervention, it has been suggested that services be delivered through a team approach. A group of people become a team when their purpose and function are delivered from a common philosophy with shared goals. Ongoing communication among all team members (e.g., the primary health care provider, early intervention providers, family members, etc.) is essential for the delivery of effective services to infants and toddlers with special health care needs and their families. Open communication facilitates the process as IFSPs are developed and implemented, as children's developmental or medical needs change, and as the families' experiences effect changes in their concerns, priorities, and resources.

For the primary health care provider to be an effective member of the IFSP team, he or she must be able to access the information needed to make decisions about the child's medical, developmental, and educational needs. Procedures for maintaining ongoing communication must be put into place so that the primary health care provider and the service coordinator can be in contact whenever questions arise. In addition, ongoing communication (via meetings, phone calls, e-mails, faxes, conference calls) among all team members allows the primary health care provider to stay abreast of the services the child is receiving and function as an integral member of that team.

The primary health care provider also serves the vital role of providing important health and medical information to the family and the rest of the team. By having a procedure in place for facilitating ongoing communication, other team members are able to obtain essential medical information from the primary health care provider. This information can then be incorporated into the IFSP when

developing outcomes and service delivery strategies. Having an established procedure for communicating with the primary health care provider is especially useful when there are changes in the child's health status that demand immediate attention.

SERVICE DELIVERY AND NATURAL ENVIRONMENTS

One of the most important aspects of the IFSP document is a statement of the natural environments in which early intervention services shall appropriately be provided. Part C mandates that early intervention services are developmental services that to "the maximum extent appropriate" are provided in natural environments, including the home and community settings in which children without disabilities participate. Services can only occur in settings other than a natural environment when early intervention cannot be achieved satisfactorily for the infant or toddler in a natural environment.

IDEA lists 14 different services that are to be provided to families and children based upon the assessment of family and child needs during the IFSP process.

They include:

- ❖ **Assistive technology devices and services:** any item, piece of equipment, or product system that is used to increase, maintain, or improve the functional capabilities of children with disabilities. Assistive technology service directly assists a child with a disability in the selection, acquisition, or use of an assistive technology device. This service includes:

- ◆ Evaluation of the child's needs.
 - ◆ Purchasing, leasing, or otherwise providing for the acquisition of assistive technology devices.
 - ◆ Training for the child's family, caregivers, teachers, aides, etc., so that they can ensure the proper use of the assistive technology devices.
 - ◆ The coordination of other interventionists utilizing devices associated with existing appropriate services to meet the child's needs.
-
- ❖ **Early identification, screening, and assessment service:** family training, counseling, and home visit services provided by social workers, psychologists, and other qualified personnel to assist the family in understanding the special needs of the child and enhancing the child's development.

 - ❖ **Health services and nutrition services:** services necessary to enable a child to benefit from the other early intervention services, including such services as clean intermittent catheterization, tracheostomy care, tube feeding, the changing of dressings or colostomy collection bags, and other health services; consultation by physicians with other service providers concerning the special health care needs of children that will need to be addressed in the course of providing other early intervention services.

 - ❖ **Nutrition services:** conducting individual assessments; developing and monitoring appropriate plans to address the nutritional needs of children;

making referrals to appropriate community resources to carry out nutrition goals.

- ❖ **Medical services only for diagnostic or evaluation purposes:** services provided by a licensed physician to determine a child's developmental status and need for early intervention services.
- ❖ **Nursing services:** the assessment of health status for the purpose of providing nursing care; provision of nursing care to prevent health problems, restore or improve functioning, and promote optimal health and development; administration of medications, treatments, and regimens prescribed by a licensed physician.
- ❖ **Occupational therapy:** services to address the functional needs of a child related to adaptive development; adaptive behavior and play; and sensory, motor, and postural development. This therapy is designed to improve the child's functional ability to perform tasks in home, school, and community settings.
- ❖ **Physical therapy:** services to address the promotion of sensorimotor function through the enhancement of musculoskeletal status, neurobehavioral organization, perceptual and motor development, cardiopulmonary status, and effective environmental adaptation.

- ❖ **Psychological services:** administering psychological and developmental tests and other assessment procedures; interpreting assessment results; obtaining, integrating, and interpreting information about child behavior and child and family conditions related to learning, mental health, and development; and planning and managing a program of psychological services.

- ❖ **Service coordination:** activities carried out by a service coordinator to assist and enable a child eligible under Part C and the child's family to receive the rights, procedural safeguards, and services that are authorized to be provided under the state's early intervention program.

Service coordination is an active, ongoing process. The service coordinator is responsible for serving as the single point of contact in assisting parents to gain access to early intervention services and other services identified in the IFSP. The service coordinator is responsible for facilitating the timely delivery of available services, continuously seeking the appropriate services, and coordinating them across agency lines. More specifically, the activities include, coordinating evaluations, assessments, facilitating and participating in all aspects of the IFSP, monitoring the delivery of services, facilitating the development of the transition plan to preschool, and informing the families of availability of advocacy services.

- ❖ **Social work services:** evaluating a child's living conditions and patterns of parent-child interaction; preparing a social or emotional developmental assessment of the child within the family context; providing counseling with parents, other family members, and with the child and parents; identifying, mobilizing, and coordinating community resources and services to enable

the child and family to receive maximum benefit from early intervention services.

- ❖ **Special instruction:** the design of learning environments and activities that promote the child's acquisition of skills in a variety of developmental areas, including cognitive processes and social interaction; curriculum planning that leads to achieving the outcomes in the child's IFSP; providing families with information, skills, and support related to enhancing the skill development of the child; and working with the child to enhance the child's development.
- ❖ **Speech and language pathology and audiology services:** identification of children with communicative or oropharyngeal disorders and delays in development of communication skills; referral for medical or other professional services; and provision of services.
- ❖ **Audiology:** identification of children with auditory impairment, referral for medical and other necessary services, provision of auditory training, and determination of the child's need for individual amplification.
- ❖ **Transportation and related costs:** includes the cost of travel (e.g., mileage or travel by taxi, common carrier, or other means) and other costs (e.g., tolls and parking expenses) that are necessary to enable a child eligible for Part C services and the child's family to receive early intervention services.

- ❖ **Vision services:** includes the evaluation and assessment of visual functioning, including diagnosis and appraisal of specific visual disorders, delays, and abilities. This service also includes referral for medical or other professional services necessary for the habilitation and/or rehabilitation of visual functioning disorders, or both. Lastly it includes training in communication skills, mobility in all environments, independent living skills, and additional training necessary to activate visual motor abilities.

The law mandates that the IFSP must include a statement about the natural environments in which early intervention services shall be appropriately provided, including a justification of the extent, if any, to which the services will not be provided in a natural environment.

Natural environments are the places that children live, learn, and play. Some examples of natural environments are:

- ❖ Home
- ❖ Parks
- ❖ Gymnastic programs
- ❖ Neighborhood play groups
- ❖ Book stores and library story hours
- ❖ Church festivals
- ❖ Child care
- ❖ Swimming pool
- ❖ Mommy and me class
- ❖ Fast food restaurants (and play spaces)

Providing services in natural environments has become a goal of the Birth to Three system because it ensures that children with disabilities have the opportunities for the same types of experiences as children without disabilities. Some of the benefits are:

- ❖ Every child has an opportunity to participate in his or her community.
- ❖ A child is more likely to generalize skills learned in natural environments.
- ❖ All children learn to understand and accept differences.
- ❖ A child is more likely to learn appropriate and effective social skills.

Most children's early learning experiences take place in the child's daily routines and activities (e.g., meal time, bath time, play time). Activity settings that are identified by families can be the basis for identifying strengths and outcomes for successful intervention strategies. For example, a child's setting may include playing with pots and pans in the kitchen while family members prepare meals. In this example the initial assessment may identify 1) learning opportunities in this setting (i.e., banging lids together, drumming, and stirring) in this part of the family routine and 2) what family members may do to encourage motor and cognitive development. These learning opportunities build on existing capabilities and interests and are fun for the child and family to participate in.

For many families, some of the naturally occurring routines and activities occur outside the home. Birth to Three providers should work with families to participate in these activities in the community environments to lead to the accomplishment of IFSP outcomes. For example, if a family spends time at the beach in the summer, the provider can work with the family to identify learning opportunities that will help the child reach his or her outcomes in this setting, such as shoveling sand into a bucket and working on eye-hand coordination.

Early intervention should be developmentally appropriate, meaning that both the age and developmental level of the child are taken into account when providing services. Early intervention should be not only age-appropriate but also individually-appropriate; it should be tailored to the child's needs and interests. This can be especially challenging when the child has severe developmental delays. For example, while it may be appropriate for a physical therapist to work on having a two-year-old child with severe motor impairment reach for an object, it would be inappropriate to use an infant toy such as a rattle. Instead, more age-appropriate toys like a car or doll should be used as a way to motivate the child to reach during play time. By providing service in this way, the materials can be concrete, real, and relevant to the lives of young children and assist in generalizing the skills to other environments.

PROCEDURAL SAFEGUARDS

IDEA provides procedural safeguards and mechanisms for parents and the early intervention system or local school district to resolve disputes before going to state or federal court. By law, administrators are obligated to inform parents of their rights under the law. Procedural safeguards include:

- ❖ Parents may examine all records pertaining to their child. All personally identifiable information must be kept confidential.
- ❖ Parents have the right to obtain an independent evaluation of their child, in addition to that provided by the school district and its staff.

- ❖ Parents must be given the opportunity to consent or object to the identification, evaluation, or placement of their child. Parents may accept or decline services without jeopardy, and the state must establish procedures for resolving complaints. They must be informed of the Planning and Placement Team (PPT) conference (for an IEP) and parents must be provided information in their native language or preferred mode of communication (for an IFSP). Meetings must be scheduled at times convenient for parents and appropriate communications must be maintained with them.
- ❖ Parents or guardians must receive written notice if a change is proposed in their child's classification, evaluation, or educational placement; and written consent must be obtained from parents for any actions that will affect their child.
- ❖ Parents have a right to mediation and/or an impartial due process hearing conducted by a hearing officer if they are in disagreement with the agency or school district. Parents have the right to be represented by a lawyer, to give evidence, and to cross-examine. Hearings may be requested by the parent or by the agency or the school district.
- ❖ Surrogate parents must be appointed to provide representation and informed consent for children whose parents or guardians are not known or who are not available.

If a parent and the persons serving a child cannot come to an agreement regarding the IFSP or IEP, both the parent and the agency or district have the right to legal

proceedings to remedy the situation. This right is guaranteed under the procedural safeguards provided by the IDEA and most recently by the amendments to IDEA which further define mediation and due process procedures. Examples of common due process issues include:

- ❖ The need for evaluations or disagreements over the results of an evaluation (often leading to a request for an independent evaluation).
- ❖ Curriculum accommodations and modifications.
- ❖ Accommodations required to meet health care or medical needs.
- ❖ Extended day or extended year programming.
- ❖ Specific goals and objectives on the IFSP or IEP.
- ❖ Related services and frequency of these services.

The request for due process must be submitted in writing by the parent, agency, or school district to:

- ❖ The Department of Mental Retardation (for children ages birth through 2).
- ❖ The State Department of Education (for children ages 3 to 21).

Once the request for due process is filed, the child's program **cannot** be changed until the dispute is resolved.

The 1997 amendments to IDEA include provisions for mediation hearings as an intermediate step between an IFSP or IEP meeting and a more formal due process hearing. Mediation hearings are voluntary and cannot be used to delay a parent's

right to a due process hearing or any other rights under the law. A mediation hearing must be held within 30 days after receipt of the request. In addition, the hearing must be conducted by a qualified, impartial mediator. The Birth to Three lead agency, local education agency (LEA), or state education agency (SEA) may establish procedures to require parents who choose not to use mediation to meet with a “disinterested party” to explain the benefits of the mediation process. The state maintains the cost of the mediation process, including all meetings. The result of the mediation is a written agreement describing how the issue is to be resolved. However, all discussions in mediation are confidential and may not be used as evidence in subsequent due process hearings or civil proceedings.

If the dispute is not resolved during the mediation hearing, both parties automatically go to a due process hearing. A hearing must be held within 45 days of the receipt of request, and an impartial hearing officer is appointed to preside over the case. If the date or location is not suitable for either party, a written request can be submitted for an alternate date. It is important to note that attorney fees are not reimbursed to families of children under the age of three in a due process hearing (under Part C of IDEA). However, fees are reimbursed to families of children ages 3 to 21 (under Part B of IDEA) if they prevail in the case.

Under the new amendments, the law states that at least five days prior to the hearing, each party must disclose all evaluations and recommendations that it intends to use in the case. Failure to disclose this information may result in a refusal of introduction of the materials at the hearing without the other party’s consent.

During the hearing, both parties, the parent or guardian and the lead agency or school district, have the following rights:

- ❖ To be accompanied and advised by counsel and by individuals with special knowledge or training with respect to the problems of children with disabilities. If the information is requested, the lead agency or school district must inform the parent or guardian of any free or low-cost legal and other relevant services available in the area.
- ❖ To present evidence and confront, cross-examine, and compel the attendance of witnesses.
- ❖ To prohibit the introduction of any evidence at the hearing that has not been disclosed at least five days before the hearing.
- ❖ To obtain a written or electronic verbatim record of the hearing.
- ❖ To obtain written findings of fact and decisions.

Parents involved in a hearing also have the right to have the student who is the subject of the hearing present his or her case and the right to open the hearings to the public. The findings and decisions are prepared without any personally identifiable information and are transmitted to the state advisory panel and made available to the general public. The hearing decision is final, unless the parent or guardian, the lead agency, or school district disagrees with the results and appeals the decision to the state or federal court.

FAMILY STUDY

Polly is 18 months old and lives with her family in central Connecticut. She was born prematurely and is the sole survivor of a set of triplets. Polly was hospitalized for 13 months following birth. Her medical and developmental conditions include:

- ❖ Brain damage
- ❖ Heart problems
- ❖ Frequent infections that result in hospitalizations
- ❖ Dependency on oxygen
- ❖ Self-abusive episodes, including severe head banging

Because of her condition, Polly and her family have been receiving a variety of services, including:

- ❖ Health care through her primary pediatrician
- ❖ Occupational therapy once per week
- ❖ Speech therapy once every other week
- ❖ Physical therapy once per week
- ❖ Home educational intervention through a Birth to Three agency twice per week
- ❖ Sixteen hours a day of home nursing care
- ❖ Medical supply vendors delivering special formulas and oxygen
- ❖ Specialty care at the hospital through a variety of clinics

The family regularly has many professionals coming to and going from their home. During the five months that Polly has been home, services have been provided by five therapists, two teachers, ten nurses, and a hospital-based team comprised of a physician, two nurses, a psychologist, a full range of therapists, and a social worker. Also assigned to Polly's care are two social workers, three program supervisors, and three case managers from three separate agencies.

It is not surprising that Polly's parents are often caught in the middle of conflicts among the various professionals, each of whom seems to have a different opinion about Polly's needs, appropriate treatments, payment options, and service schedules. For example, each of the three case managers gave the family different information about their eligibility for various sources of public funding, including the Medicaid waiver. As a result, their application for benefits was delayed, and they had to pay several thousand dollars out-of-pocket for some of Polly's care. In addition, the nursing agency and the different therapists disagree about the amount of therapy Polly needs and, therefore, do not cooperate with one another. Because there is no coordination among the service agencies and providers, the family finds that the services Polly receives often cause confusion in their lives. A week in their house looks like this:

- ❖ Monday: 16 hours nursing/teacher/supervisor/ Department of Income Maintenance case manager
- ❖ Tuesday: 16 hours nursing/occupational therapy/DMR case manager
- ❖ Wednesday: 16 hours nursing/teacher/clinic visit at tertiary care hospital/physical therapy

- ❖ Thursday: 16 hours nursing/physical therapy/vendor delivery/nurse supervisor/teacher
- ❖ Friday: 16 hours nursing/speech therapy/adaptive equipment fitting at tertiary care hospital
- ❖ Saturday: 16 hours nursing
- ❖ Sunday: 16 hours nursing

The family has concluded that caring for Polly is not the primary cause of their stress, rather that the multiple layers of fragmented services are causing much havoc in their family. Polly's parents are now seeking out-of-home placement for her because they feel the need to put some order back into their lives. Neither parent feels "functional" with so many people in and out of the house. In Polly's case, reducing the likelihood of institutionalization, one of the intents of IDEA, has not been realized.

FAMILY STUDY--REVISITED

DISCUSSION QUESTIONS

Polly's parents have come to you because you are Polly's primary pediatrician. They have told you that they are seeking out-of-home placement for Polly. Just six months ago Polly's parents were elated that she was finally coming home. You are very concerned about the sudden change in attitude. Consider what steps you can take to help Polly, her parents, and the service delivery team.

As Polly's primary pediatrician, evaluate the following:

Which medical and developmental services does Polly need at this time?

What concerns, priorities, and resources are identified by Polly's parents?

How can you support Polly's parents in their primary caregiving role?

In what ways can you work with the service delivery team?

DISCUSSION QUESTION ANSWERS

- ❖ Which medical and developmental services does Polly need at this time?
 - ◆ Occupational therapy, once per week
 - ◆ Speech therapy, once every other week
 - ◆ Physical therapy, once per week
 - ◆ Nursing care, sixteen hours per day
 - ◆ Oxygen
 - ◆ The love and support of her family

- ❖ What concerns, priorities, and resources are identified by Polly's parents?
 - ◆ Coordination of services among service agencies and providers
 - ◆ Being caught in the middle of conflicts among professionals
 - ◆ Health care financing
 - ◆ Too many people in and out of their home
 - ◆ Out-of-home placement for Polly

- ❖ How can you support Polly's parents in their primary caregiving role?
 - ◆ Advocate for them at the IFSP meeting
 - ◆ Help parents with decision-making and problem solving regarding their concerns

- ❖ In what ways can you work with the service delivery team?
 - ◆ Meet together, as a team, to collaboratively develop a service structure which accomplishes the IFSP goals according to the family's schedule and priorities.
 - ◆ Remove the stress Polly's family feels from the current lack of cooperation between providers. One way would be to use the consultation model to deliver services which would reduce the number of people in and out of their home.

RESOLUTION

The team that is providing services to Polly requires both interagency and intra-agency collaboration. In order for the professionals to provide transdisciplinary services, members of the service delivery team will have to collaboratively develop a service structure which accomplishes the IFSP goals according to the family's schedule and priorities. One practice the service team must initiate is a regular time for meeting, during which they can identify mutual goals and service strategies. Since the nurses have the most frequent contact with Polly, it seems reasonable to suggest that the nurses (along with Polly's parents) provide her with primary service delivery. In this scenario, the therapists and teachers will monitor Polly but focus most of their effort on the training and support of the nurses and parents through consultation. The key to the success of this model will be the ability of the members to commit the necessary time to build relationships and release their roles for the benefit of Polly and her family.

As Polly's primary pediatrician, you could help Polly and her family by working with the service delivery team to reduce the stress the family is feeling.

COMPONENT TWO: OBSERVATION OF HOME-BASED EARLY INTERVENTION PROGRAM

Location and Times:

You will visit a child's home while they are receiving early intervention services (physical therapy, occupational therapy, speech and language therapy, etc.). The visits will be scheduled based on the block schedule and will be coordinated with the family and service provider.

Format:

You will observe the therapy session or meeting in order to gain an understanding of how early intervention services can be provided in the home. Please refer to *Guidelines for Home-Based Early Intervention Program Visit*.

Special note: You should arrange to visit a child from your continuity clinic for either the observation of home-based early intervention program or the observation of community-based early intervention program (see *Component Three, page 61*). Contact the project coordinator if you are unable to identify a child from your continuity clinic receiving home- or community-based early intervention services.

Resident's Responsibilities:

You will need to provide your own transportation to the family's home. You should observe what goes on and ask questions (using the guidelines) for the visit of the family and service provider.

Complete the *Resident Self-Evaluation* form for the early intervention visit. The family member or preceptor should complete the *Performance Rating by Preceptor: Home-Based Early Intervention Program Visit*. These should be returned to the University of Connecticut A.J. Pappanikou Center for Developmental Disabilities.

GUIDELINES FOR HOME-BASED EARLY INTERVENTION PROGRAM VISIT

Purpose:

- ❖ To gain an increased understanding of the goals and practices of an early intervention program by observing the delivery of services within a home.

Early Intervention Home Visit--Suggested Outline:

- ❖ Observe the interactions between the child and the early intervention service provider during the home visit.
 - ◆ Does the service provider prepare the environment so the child can learn through active exploration and interactions with others?
 - ◆ Is the environment adapted appropriately for the individual needs of the child?
 - ◆ Are the learning activities and materials activity-based, concrete, real, and relevant for the child?
 - ◆ Does the service provider modify his or her style of interaction in order to match the developmental level of the child?
 - ◆ Does the service provider increase the difficulty of the activities as the child becomes involved in them and as he or she develops understanding and skills?
 - ◆ How does the professional respond to child-initiated activities?

- ◆ Does the service provider incorporate the child's interests into the activities, allowing for child choice of activities?
- ◆ Does the service provider incorporate several areas of development (physical, emotional, social, and cognitive) into an integrated activity-based approach?

- ❖ Observe the interactions between the caregiver and service provider during the visit.
 - ◆ How does the service provider involve the caregiver (setting up materials, service delivery, selecting activities, etc.)?
 - ◆ How does the service provider include the caregiver in planning?
 - ◆ How does the service provider include other members of the family in the visit?
 - ◆ What is the nature of the relationship between caregiver and professional?
 - ◆ How does the service provider elicit and respond to the concerns, priorities, and resources of the family?

- ❖ Observe the interactions between the caregiver and the child during the visit.
 - ◆ How does the service provider support the caregiver's interactions with the child?
 - ◆ How does the service provider enhance the capacity of the family to foster the child's development?

COMPONENT THREE: OBSERVATION OF COMMUNITY- BASED EARLY INTERVENTION PROGRAM VISIT

Location and Times:

You will observe a community-based early intervention program visit. The visit will last from one to two hours and will be scheduled based on your block schedule and the availability of the program.

Format:

Observe a child's early intervention program to see what a typical day is like for the child. The child's program may be located in a school, a daycare center, library, recreation department, or community play group. You should talk with the early interventionist, daycare provider, and/or other related support staff implementing the program. Please refer to *Guidelines for Community-Based Early Intervention Program Visit*.

Special note: You should arrange to visit a child from your continuity clinic for either the observation of home-based early intervention program (see *Component Two, page 57*) or the observation of community-based early intervention program. Contact the project coordinator if you are unable to identify a child from your continuity clinic receiving home- or community-based early intervention services.

Resident's Responsibilities:

You are responsible for your own transportation to the school, home, or program. You should observe what goes on (using the *Guidelines* for the visit), and ask questions of the family and service provider.

You should complete the *Resident Self-Evaluation* form for the early intervention program visit. The family member or preceptor should complete the *Performance Rating by Preceptor: Early Intervention Program Visit*. These should be returned to the University of Connecticut A. J. Pappanikou Center for Developmental Disabilities.

GUIDELINES FOR COMMUNITY-BASED EARLY INTERVENTION PROGRAM VISIT

Purpose:

- ❖ To gain firsthand knowledge of how early intervention services may be provided for children with disabilities in community-based programs.
- ❖ To consider how children with disabilities can be included in preschool classrooms and community settings with appropriate supports.
- ❖ To consider what role the physician or other health care providers should play in addressing a child's health concerns within the community-based setting.

Program Observation--Suggested Outline:

- ❖ Identify the components of the program.
 - ◆ In which setting do the children receive early intervention services (e.g., child care center, library, play group)?
 - ◆ How many children are in the classroom?
 - ◆ What is the daily schedule?
 - ◆ How often throughout the day are the children with special needs with their non-disabled peers?

- ❖ Identify the special services being provided to the child.
 - ◆ Are children receiving specialized instruction? Are any other services being provided (e.g., physical or occupational therapy, speech and language therapy, counseling, assistive technology, nursing, or nutrition)?
 - ◆ Do any of the children have an aide or paraprofessional providing assistance? What type of assistance is being provided? Does the paraprofessional also provide assistance to other children?
 - ◆ Do the therapists or special educator consult with the regular education teacher to carry over intervention? How often is consultation/support available?
 - ◆ Are any assistive devices being used (e.g., wheelchair, alternative communication device, computer, modified seating)? Is the staff provided release time for training in the use of these devices?
 - ◆ Are other children involved in the activities with the related service staff?
 - ◆ Are the services provided age-appropriate?

- ❖ Identify how disabilities and/or special health care needs impact the children's ability to participate in community-based activities.
 - ◆ Are the children included in all activities?
 - ◆ What accommodations need to be made to include the children in all activities?

- ◆ How much social interaction is there between the children with special needs and the other children?
- ◆ Do the children with special needs have friends?
- ◆ Do friendships carry over to other settings?

- ❖ Identify the positive elements of the early intervention program as you observe them.
 - ◆ What appears to be going well for the children?

- ❖ Discuss with the teacher/daycare provider any of his or her concerns pertaining to the children with special needs.
 - ◆ Does the teacher/daycare provider identify any need for support regarding health care needs?
 - ◆ Is training in modifications in curriculum, technology, adaptive devices, alternative communication, and fostering peer relationships made available?
 - ◆ What environmental modifications were made for the students?
 - ◆ How frequently is inservice training offered? Are they mandated or optional?
 - ◆ How frequently does the teacher communicate with other team members?
 - ◆ How frequently does communication occur between home and the community-based program?
 - ◆ What are the challenges of inclusion?

- ❖ Discuss the service delivery team.
 - ◆ Who are the members of the service delivery team?
 - ◆ Does the team include a physician? How is he or she involved?
 - ◆ Is there a team leader or appointed case manager? What role does he or she play?
 - ◆ How are therapists included in the team?
 - ◆ How are paraprofessionals included in the team?
 - ◆ Does the team appear to be well coordinated?

COMPONENT FOUR: NICU FOLLOW-UP CLINIC VISIT

Location and Times:

You will be scheduled to attend the NICU follow-up clinic.

Format:

You will attend the NICU follow-up clinic for one half day and observe what takes place. The focus will be on understanding the family members' perspectives on this experience. During this time you will interview at least one family. See attached *Guidelines for NICU Follow-Up Clinic Family Interview*.

Resident's Responsibilities:

Prior to attending the NICU follow-up clinic, you should complete some independent reading about the medical issues associated with the disabilities or conditions treated in this clinic.

During the NICU follow-up clinic visit, please follow these procedures:

- ❖ Inform the preceptor that you are there to observe and learn about that specialty from the family/child point of view as part of the Children with Disabilities curriculum experience.
- ❖ Be introduced (by the preceptor) to one or two families to follow during the half-day experience.
- ❖ Follow at least one family throughout their entire appointment. For example, stay with the family as they wait to be seen by the clinic team, during the evaluation, and as they receive feedback from the team.
- ❖ Observe the provider interacting with the child and family.
- ❖ Interact with the family (see *Guidelines for NICU Follow-Up Clinic: Family Interview*).
- ❖ Observe the debriefing session with the preceptor or NICU follow-up clinic team.
- ❖ Participate in the team meeting.
- ❖ Complete the *Resident's Self-Evaluation of the Specialty Clinic Visit*.
- ❖ Provide the clinic preceptor with the *Performance Rating by Preceptor: NICU Follow-Up Clinic Visit* form.

GUIDELINES FOR NICU FOLLOW-UP CLINIC FAMILY INTERVIEW

Purpose:

- ❖ To gain a better understanding of how to provide care for children with disabilities and/or special health care needs, including recognizing the impact of disabilities and special health care needs on childhood development; obtaining knowledge of the array of services available for children with special needs; and learning how to coordinate comprehensive medical care for children with special health care needs.
- ❖ To learn how issues specific to a child's disability may impact the child and family in terms of their ability to participate in typical routines within the home, school, and community.
- ❖ To gain an in-depth awareness of how clinic visits are viewed through the eyes of the child and family.

Family Interview--Suggested Outline

- ❖ Find out about the family composition, including who lives in the home, where they live, language spoken at home, sources of income, etc.
 - ◆ What is a typical day/week like for this child and family?

- ◆ Identify the family's perceptions of the child's needs with regard to the home environment, school or child care program, and health care system.
- ◆ Does the family feel that these needs are being adequately addressed?
- ◆ What types of changes can be made, if any?
- ◆ If appropriate, ask for the child's input about this clinic visit. What are his or her concerns, questions, priorities, things he likes about coming, dislikes, feelings, etc.?
- ◆ What types of social support does the family have?
- ◆ How did the family get to the clinic? Is transportation an issue?
- ◆ What does the family feel is the purpose of today's appointment?
- ◆ What types of questions do the family members have for the medical team?
- ◆ Have any early intervention services been implemented? If so, what are they? How are they implemented?
- ◆ How comfortable does the child appear to be? The family?

APPENDICES

- A:** Chronology of Legislation Chart
- B:** Sample Copy of an Individualized Family Service Plan
- C:** Reprint of: Bruder, M (2000). The Individual Family Service Plan
- D:** Reprint of: American Academy of Pediatrics, Committee on Children with Disabilities (1994). Screening Infants and Young Children for Developmental Disabilities. Pediatrics, 93 (5), 863-865.
- E:** Reprint of: Dworkin, P. H. & Glascoe, F. P. (1996). Early Detection of Developmental Delays: How Do You "Measure Up?" Contemporary Pediatrics, 14 (4), 158-168.
- F:** Sample Letters to Physicians Regarding IFSPs
- G:** Additional Reading Prior To Component Three: Nicu Follow-Up Clinic Visit
- Reprint of:
- Fazzi, E., Orcesi, S., Telesca, C., Ometto, A., Rondini, G., & Lanzi, G. (1997). Neurodevelopmental outcome in very low birth weight infants at 24 months and 5 to 7 years of age: Changing diagnosis. Pediatric Neurology, 17,(3) 240-247.
- Fletcher, J. M., Landry S. H., Bohan T. P., Davidson, K. C., Brookshire, B. L., Kramer, L. A., & Francis, D. J. (1997). Effects of intraventricular hemorrhage and hydrocephalus on the long-term neurobehavioral development of preterm, very-low-birthweight infants. Developmental Medicine & Child Neurology, 39, 596-606.
- Hussey-Gardner, B. T., Wachtel, R. C., & Viscardi, R. M. (1998). Parent perceptions of an NICU follow-up clinic. Neonatal Network, 17,(1) 33-39.
- Singer, L., Yuamashita, T., Lilien, L., Collin, M., & Baley J. (1997). A longitudinal study of developmental outcome of infants with bronchopulmonary dysplasia and very low birth weight. Pediatrics, 100, 987-993.

APPENDIX A

CHRONOLOGY OF LEGISLATION CHART

Chronology of Legislation

Year	Law and Key Components
1965	<p>Head Start Pilot Project - Head Start Program Key Components: Provided comprehensive services for children from low income families to help eliminate risk factors and improve children’s outcomes.</p>
1967	<p>Early Periodic Screening Diagnosis and Testing (EPSDT) Key Components: Provided funding for early screening for children with possible disabilities. Medicaid must offer EPSDT under P. L. 101-239, the Omnibus Budget Reconciliation Act of 1990.</p>
1968	<p>Handicapped Children Early Education Act (P. L. 90-538, HCEEA) Key Components: Provided funds for model demonstration projects that educate infants and pre-schoolers with disabilities and their families. Provided federal support to university teacher training programs.</p>
1973	<p>Section 504, The Rehabilitation Act (P.L 93-112) Key Components: Mandates that services be provided to persons with a wide array of disabling conditions including training for and placement in full-time, part-time, or supported employment in the competitive labor market.</p>
1975	<p>The Education for All Handicapped Children Act (P. L. 94-142) Key Components: Part B requires states to furnish all children with disabilities (ages 3-21) a free, appropriate public education in the least restrictive environment; provide special education and related services designed to meet the unique needs of these children; and to develop an Individualized Educational Plan for each child.</p>
1986	<p>The Education for All Handicapped Children Act Amendments (P. L. 99-457) Key Components: The addition of Part H provides for the development of “a statewide, comprehensive, coordinated, multidisciplinary, interagency system to provide early intervention services for infants and toddlers (birth to three years of age) with disabilities and their families;” the establishment of a state interagency coordinating council; and the development of an Individualized Family Service Plan for each eligible infant or toddler and his or her family.</p>
1988	<p>Technology-Related Assistance for Individuals with Disabilities Act (P. L. 100-407, Tech Act) Key Components: Allows assistive technology aids and devices to be part of the IEP.</p>
1990	<p>The Americans with Disabilities Act (P.L. 101-336, ADA)</p>

Year	Law and Key Components
	<p>Key Components: A wide-ranging civil rights law that prohibits discrimination against people with disabilities or physical and mental impairments that substantially limit their activities such as working, walking, talking, seeing, hearing, or caring for themselves; the requirement that employers make reasonable accommodations for employees with disabilities; and prohibition of discrimination in commercial facilities and in any activity or service operated or funded by state or local government, including daycare centers and other programs which serve children <u>without</u> disabilities.</p>
1991	<p>Individuals with Disabilities Education Act (P.L. 101-476, IDEA)</p> <p>Key Components: This reflects a name change that shifts the terminology from “<u>handicaps</u>” to “<u>disabilities</u>” and encompasses all of the components from the Education for All Handicapped Children Act and its amendments.</p>
1994	<p>Families of Children with Disabilities Support Act (P. L. 103-230)</p> <p>Key Components: The purpose of this Act is to establish a comprehensive, coordinated system of family support that will avoid duplication of services, use existing resources more efficiently, and prevent gaps in services to families of children with disabilities in all areas of the state. The lead agency in Connecticut is the Department of Mental Retardation. Twenty-six states have enacted family support legislation, and in 1994 the Federal Family Support Act was passed, but was not funded.</p>
1996	<p>Developmental Disabilities Assistance and Bill of Rights Act (DD Act)</p> <p>Key Components: The purpose of this Act is to help people with a disability attain independence, productivity, and integration into the community. The Act provides federal funds to states so that the states, their local agencies, and public or private nonprofit agencies may provide comprehensive services and plan those services; establish module programs; operate university affiliated programs of interdisciplinary training and service provision; and operate statewide systems of protection and advocacy for people with developmental disabilities and those with mental illness.</p>

Year	Law and Key Components
1997	<p>IDEA Amendments of 1997 (P. L. 105-17)</p> <p>Key Components: <u>Amendments to Part B</u> include changes in formula for distributing money; serving children with disabilities in private/parochial schools; flexibility in triennial reevaluations; use of Braille; addition of mediation as an option for resolving disputes; discipline policies and interim alternative placements; including children with disabilities in statewide and districtwide assessments with accommodations; and others.</p> <p><u>Amendments to Part C</u> include strengthening parent/professional partnerships; establishment of a federal interagency coordinating council; delivery of services in “natural environments;” flexibility in addressing needs of “at risk” infants and toddlers; and others.</p>

APPENDIX B

SAMPLE OF:

An Individualized Family Service Plan

APPENDIX C

REPRINT OF:

Reprint of: Bruder, M (2000). The Individual Family Service Plan

APPENDIX D

REPRINT OF:

American Academy of Pediatrics, Committee on Children with Disabilities (1994). Screening infants and young children for developmental disabilities. Pediatrics, 93 (5), 863-865.

APPENDIX E

REPRINT OF:

Dworkin, P.H., & Glascoe, F.P. (1996). Early detection of developmental Delays: How do you “measure up”? *Contemporary Pediatrics*, 14 (4), 158-168.

APPENDIX F

SAMPLE OF:

Letters to Physicians Regarding IFSPs

APPENDIX G

REPRINT OF:

Fazzi, E., Orcesi, S., Telesca, C., Ometto, A., Rondini, G., & Lanzi, G. (1997).

Neurodevelopmental outcome in very low birth weight infants at 24 months and 5 to 7 years of age: Changing diagnosis. Pediatric Neurology, 17, (3) 240-247.

Fletcher, J. M., Landry S. H., Bohan T. P., Davidson, K. C., Brookshire, B. L.,

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longitudinal study of developmental outcome of infants with bronchopulmonary dysplasia and very low birth weight. Pediatrics, 100, 987-993.