

The Role of the Physician in Early Intervention for Children with Developmental Disabilities

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MY daughter Cammie is two and a half years old. Cammie has severe developmental delays in all areas and is cortically visually impaired. She has been involved with early intervention since the time of her discharge from the neonatal intensive care unit (NICU). Cammie entered the NICU after I had an ultrasound that identified intrauterine growth retardation, and I had labor induced. Cammie and I lived in the NICU for two months as she struggled with breathing and feeding issues. She grew slowly and eventually was considered stable enough to transfer to the special care nursery. During this time, I was told that Cammie probably had an unidentified genetic syndrome.

Cammie needed a gastric tube (g-tube) to eat and was diagnosed by an early intervention team as having significant developmental delays in all areas. Because of her multiple needs, five different providers from three different agencies visited us at home. Their visits rarely overlapped, though all provided similar things for her. I was totally overwhelmed and discouraged because the providers kept telling me about everything that Cammie should be able to do. Some of the professionals' goals were difficult to live with, such as head control. Cammie was and is very floppy, and the things that the providers did with her have not seemed to help—even though the providers kept the same goals on my Family Service Plan for 18 months.

ABBREVIATIONS TO BE USED IN TEXT:

Individuals with disabilities education act = IDEA

Individualized family service plan = IFSP

Neonatal intensive care unit = NICU

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When the providers talked to me about my future with Cammie, they said that they believed Cammie always would receive home services because she became exhausted easily and would not benefit from being with other children. They even told me that Cammie should be home-schooled when she was older. I was devastated because I wanted her to be a child who participated in life and enjoyed the company of other children.

At Cammie's annual individualized family service plan (IFSP) meeting this year, my husband and I asked for some different plans. We participated in a project that helped us identify what was important to us as a family. I started to feel more confident about Cammie's care and wanted to get back to doing the things we loved to do before Cammie was born. My husband and I wanted and did place different outcomes on the IFSP. Rather than pieces of behavior, we asked for things that included having Cammie canoe, swim, and shop with us. We also asked if fewer people could visit us, because we believed that Cammie became confused by listening and working with so many people. Most importantly, I needed to return to my nursing job; because of that, Cammie needed to have child care. The group of service providers agreed to this, and we began a different model of early intervention than what we had originally. Rather than focusing on what Cammie cannot do, we are building upon what she likes and what she can do.

We now have two early interventionists coming to our house every two weeks. They have been helpful and supportive to me and have developed a different vision for Cammie and for my role in Cammie's plan. Most of the time they help me to figure out how to have Cammie participate in the activities that we value. As a result, Cammie has exceeded my expectations and that of the early interventionists. She is able to go canoeing in a special seat in

our canoe. She loves swimming and now can hold up her head when the water touches her chin. She now also shops with me; she sits in a special seat in the grocery cart. I have noticed so many more vocalizations and attempts to move on Cammie's part when we participate in community activities. Now we have an IFSP that is truly our own.

Cammie entered a child-care center when she was 20 months old and was the only child in the center who had a disability. Including her in the center's everyday activities was a challenge for the providers. We were able to have one of our early intervention providers visit the center twice a week to consult with the caregivers at the childcare center. The caregivers had me come in to train them, and they enrolled in a course on inclusion. Interestingly, including Cammie was simple for the other children to do. They quickly figured out how to engage Cammie, particularly with music. The children would bring toys to Cammie and help her to play games. During snack time, one little girl always helped Cammie to hold onto the pieces of crackers. If Cammie dropped the cracker, the little girl would pick it up and place it back in Cammie's hand.

The children in Cammie's life have such a positive impact on her development and quality of life. These interactions have benefited our family because they remind us daily that Cammie is more "typical" than not and that, in turn, we learn about typical development. This helps us to promote her development appropriately. I cannot imagine where we would be if Cammie had not had these experiences with her peers in the community. Cammie grows exponentially when she is with her peers. She is more engaged, her attention span increases, and she is more likely to participate in activities. This is what early intervention is all about for us."

Introduction

Infancy and early childhood are important times in any child's life. For children with disabilities, the early years are critical for a number of reasons. First, the earlier a child is identified as having a developmental delay or disability, the greater the likelihood the child will benefit from interventions designed to compensate for the child's deficits. Second, families benefit from the support given to them through the intervention process. Third, schools and communities benefit from a decrease in costs because more children arrive ready for school. Legislatively, *early intervention* is used to describe the years from birth to three, while the term *early childhood special education* or *preschool special education* describes the preschool years (ages three to five). This article provides an overview of early intervention as described by the Individuals with Disabilities Education Act (IDEA). In particular, the

article will highlight the philosophical foundation of early intervention and four service delivery components that contribute to effective outcomes for children and families. Lastly, the role and contribution of physicians in early intervention will be discussed.

What is Early Intervention?

More than 50 years of research support the effectiveness of intervention for infants and young children with disabilities.¹⁻³ Though some studies have been criticized because of methodological limitations (eg, heterogeneity of the population, lack of control groups, narrowly defined outcome measures, inappropriateness of standardized measures of intelligence for the population), the data collected thus far demonstrate that early learning and development can be affected by intervention.^{4,5} As society, and families in particular, have become more aware of the importance of the years from birth to three, early intervention models, programs, and services have become increasingly available. Federal law now guides the implementation of early intervention. Certain services and professional disciplines are included in early intervention programs (Tables 1 and 2).

The Philosophical Foundation of Early Intervention

As stated, the provision of services and supports to infants and toddlers with or at risk for disabilities and their families is an accepted practice guided by federal law and state regulations. However, there are many challenges inherent in the delivery of early intervention, most stemming from differences between infants and toddlers in contrast to the older pediatric population. For example, infants and toddlers are developing and learning in the context of their families, and this requires that services and supports be targeted at families as well as the infants and toddlers.⁶ Families have ultimate responsibility for caregiving, supporting the child's development, and enhancing the quality of the child's life. Thus, the caregiving family must be seen as the constant in the child's life and the primary unit for service delivery.⁷ A family-centered approach to early intervention is based on at least three assumptions: a) families and children are interdependent; b) intervention is more powerful when families are involved and supported; and c) family members should have a voice in all aspects of service provision.⁸

Just as the population of children considered to have special needs is not homogeneous, neither are the children's families. Each family will bring unique resources to the task of parenting its child, and each family will identify unique needs that must be addressed through early intervention.^{6,9} In fact, it has been suggested that the primary goal of early intervention is to facilitate parents' awareness of, and adaptation to, their role in parenting a child with a disability.¹⁰

Evidence suggests that families have a powerful effect on children. For example, parents' education level, socioeconomic status, and home environment are related to children's development;^{11,12} in early intervention, these characteristics have been related to service-delivery patterns.¹³⁻¹⁵ Cultural influences embraced by families also may affect components of service delivery.

A second difference in this young age group is the emergence and convergence of various developmental milestones across separate behavioral domains (eg, communication and mobility). This necessitates the delivery of services in a manner that addresses the integration of developmental and behavioral domains, primarily through a team approach with discipline-specific professionals who have the knowledge and expertise to cross traditional domains of behavior. For example, various personnel having medical, therapeutic, educational or developmental, and social-service expertise traditionally are involved in

providing 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 requirements (eg, undergraduate or graduate degrees); licensing or certification requirements (most of which do not require age specialization for young children); and treatment modality (eg, occupational therapists may focus on sensory integration techniques).¹⁶ In addition, many disciplines have their own professional organizations that encompass the needs of persons across the entire life span unlike organizations focused on a single age group. Lastly, research has suggested that most university training programs for those providing early intervention provide little coursework and practice on the unique needs of infants, toddlers, and their families.^{17,18} Nonetheless, as services for young children with disabilities continue to grow, so does the need for well-trained professionals.

To improve the efficiency of the individuals providing early intervention, it has been suggested that services be delivered through a transdisciplinary team approach.^{19,20} This approach was originally conceived as a framework for professionals to share important information and skills with primary caregivers.²¹ The approach integrates a child's developmental needs across the major developmental domains and requires team members from different disciplines to cross domains during intervention. Rather than have a different person from each discipline address a separate developmental domain with a child, the model calls for a consolidation of interventions that cross developmental areas.²² The primary purpose of the approach is to pool and integrate the expertise of team members so that more efficient and comprehensive assessment and intervention services may be provided.

A last difference in early intervention is a result of the attention spans of most infants and toddlers. For example, infants and toddlers have a lower tolerance for time-intensive interventions. As a result, effective interventions should be integrated into their everyday routines and activities (referred to as natural environments), as opposed to structured, episodic, and isolated sessions. For example, rather than have a therapist visit to perform feeding exercises in the afternoon, feeding interventions should be taught to the parents who can then provide intervention to help their child(ren) eat during mealtime. This incorporates the therapy for issues pertaining to swallowing and eating around mealtimes.

Natural environments have been defined as those places where the child would be had he/she not had a disability, for example the home or other environments with their same age peers. Research has demonstrated that children with disabilities do benefit from participating in groups

Table 1.—Program Services

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- Family training, counseling, and home visits
 - Special instruction
 - Speech pathology and audiology
 - Occupational therapy
 - Physical therapy
 - Psychological services
 - Case management services
 - Medical services only for diagnostic or evaluation purposes
 - Early intervention, screening, and assessment services
 - Health services necessary to enable the infant or toddler to benefit from the other early intervention services
 - Social work services
 - Vision services
 - Assistive technology devices and assistive technology services
 - Transportation and related costs that are necessary to enable an infant or toddler and the infant's or toddler's family to receive early intervention services
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34 Code of Federal Register (CFR) §303.12(d)

Table 2.—Professional Disciplines in Early Intervention

Audiologist
 Family therapist
 Nurse
 Nutritionist
 Occupational therapist
 Orientation and mobility specialist
 Pediatrician and other physicians
 Psychologist
 Physical therapist
 Social worker
 Special educator
 Speech and language pathologist

with children without disabilities.^{23,24} In fact, this practice has been cited as a quality indicator of early intervention and adopted by professional organizations.²⁵ Most people agree, as a concept, with the benefits of inclusive early intervention,²⁶ and the term *natural environments* is an expanded application of inclusion for infants, toddlers, and their families.⁶

Many different learning opportunities occur in natural environments, whether (a) preplanned with specific goals and purposes or (b) as the result of opportunities and experiences not having predetermined goals and purposes. Library story times, baby exercise classes, and swimming lessons are examples of planned learning activities. Serendipitous learning activities occur by being in the "right place at the right time." These include such activities as "going along" to a ball game with an older sibling, going food shopping with a parent, visiting a neighbor, etc., all of which are likely to include experiences that enhance development. Both kinds of learning opportunities are important for promoting and enhancing child competence and development and, as such, should be seen as integral to early intervention within natural environments.⁹ The challenge is to remember that intervention should happen throughout the day in all the places that a child and family are. Episodic, time-limited interventions do not necessarily provide enough learning opportunities for both children and families.⁶

Service Delivery Components

Early intervention service delivery should reflect this philosophical foundation and it should be embedded within the following service delivery components.

Early Identification and Entry into Intervention

While children with established conditions leading to disability or developmental delay are usually recognized in the first weeks of life,²⁷ infants and toddlers at risk for delay may not be identified as eligible for services. Children under the age of three are eligible for services if they are experiencing developmental delays in cognitive, physical, communication, social or emotional, or adaptive behavior as measured by appropriate diagnostic instruments and procedures. In addition, children who have a condition (diagnosed physical or mental condition) that has a high probability of resulting in developmental delay are also eligible. Children whose development is at risk may also be included at the state's discretion. Thus, efforts to identify eligible children and their families are somewhat idiosyncratic to each state and locality.

Most child-find activities in state systems rely on receiving referrals from sources closest to a child. These include parents, child-care providers, and most importantly, health-care providers. The sources must be kept informed about early intervention supports, service mod-

els, and data on effectiveness. In addition, outreach efforts to families in particular must be culturally compatible and in a family's primary language.

One method used extensively in many states is a developmental screening questionnaire completed by a parent or health-care provider,⁶¹⁻⁶³ such as a physician. This questionnaire serves a number of functions, ranging from identifying children who may not be meeting developmental milestones (and therefore need additional evaluation) to providing child-development information and education to parents. Similarly, child-development information may be provided at hospital discharge and pediatric well-child visits through anticipatory guidance.⁶⁴

After a child is determined to be eligible for early intervention, further assessment may be done in conjunction with the development of the individualized family service plan (IFSP). This assessment may focus on the child's abilities in the context of family-identified home and community activities and routines that are family priorities. Additionally, information from other contexts in which the child participates (eg, child care, Sunday school, neighborhood park) can be gathered in an effort to present a valid picture of the child's development and competencies in the natural environment.

Service Coordination

An additional requirement of the services under Part C process is the designation of a service coordinator. Part C of IDEA does not designate any one professional to assume this role, and the recent authorization acknowledges the right of family members to fill this role (for themselves or others) if they obtain "appropriate training." The service coordinator is ultimately responsible for the coordination, maintenance, and evaluation of services and supports delivered to a family and child. However, the complexities of tasks across the multiple levels of early intervention (family, service providers, and system administrators) are growing every day. Underlying each of these levels are fiscal challenges facing both families of children with multiple needs and state and local systems of care that are trying to coordinate multiple (shrinking), confusing, and diverse funding streams for service delivery.²⁸⁻³⁰ This is occurring simultaneously with expanding system reforms across systems such as welfare,³¹⁻³³ child care,^{34,35} health care,^{36,37} and mental health.^{38,39}

Recent work in early intervention service delivery has focused on the identification of factors that facilitate service coordination for families. Categories of practice such as the management and delivery of services, the approach for teaming, the program philosophy and climate, and the personal characteristics of providers (including months of experience and attendance in training) have been iden-

tified by both parents and service coordinators as facilitating collaboration.^{40,41} While it is no surprise that service delivery and management (caseload, funding) has been consistently identified as a critical facilitator to coordinated service delivery,⁴²⁻⁴⁴ the personal characteristics of those involved (eg, willingness to work together, leadership, common vision, and trust) have also been increasingly acknowledged as keys to successful service integration.⁴⁵⁻⁴⁹ In fact, it has been concluded that effective service coordination is built upon the foundation of partnerships among the people that comprise agencies, services, and families.⁵⁰

The IFSP

The Individualized Family Service Plan (IFSP) is intended to be a planning document, which shapes and guides the day-to-day provision of early intervention services. The IFSP is required for the provision of early intervention services for eligible infants and toddlers (aged birth to three) and their families. Table 3 contains the requirements that must be included in an IFSP. Of special note is the requirement within the IFSP for a statement of the natural environments in which early intervention will be delivered. The IFSP relies on a family-centered and community-based orientation to service delivery.

It has been suggested that the IFSP contain individualized outcomes, objectives, and intervention strategies that are functional and embedded within daily activity settings and delivered in accordance with the families' wishes.^{51,52} One way to articulate this is to use family-identified activity settings.⁵³ This type of planning utilizes the many naturally occurring events and activities that exist in a young child's life as "learning opportunities."⁵⁴ When this method is used, the IFSP can be developed according to the family's (or other caregiving) routines and priorities. The IFSP should incorporate specific intervention strategies within the activities while utilizing adaptations as necessary. These adaptations should be focused on enabling the child to participate in all of the identified activities and routines in the environment.⁵⁵

The IFSP meeting should culminate with the articulation of the family's priorities for their child's growth and development and the family's needs and priorities related to their child. During the meeting, the intervention team can demonstrate its expertise at devising interventions to support the child's growth and development in the context of the family's identified activities and routines.⁵⁶ The actual IFSP document should be a record of these priorities in a format that allows for ongoing measurement of child and family outcomes. The IFSP must be an accurate portrayal of the child's and family's outcomes in the context in which they will happen. As previously stated, these contexts should be within natural environments.

Table 3.—Requirements of the IFSP

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- a. A statement of the child's present level of functioning in cognitive development, communication development, social or emotional development, physical development, and adaptive development.
 - b. A statement of the family's resources, priorities, and concerns.
 - c. A statement of expected intervention outcomes, including criteria, procedures, and timelines.
 - d. A description of the services that the child and family need including method, frequency, and intensity.
 - e. A statement of the natural environments in which early intervention services shall be provided.
 - f. Projected dates for initiation of services and expected duration.
 - g. The name of the service coordinator who will be responsible for implementation of the plan and coordination with other agencies and persons.
 - h. The procedures to ensure successful transition from infant services to preschool programs.
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Transition

The importance of transition has been addressed in state and federal legislation, federal funding initiatives, and professional literature.⁵⁷ A successful transition is a series of well-planned steps that facilitate the movement of the child and family into another setting. Successful transitions are a primary goal of early intervention.^{2,58} Needless to say, the type of planning and practices that are employed can influence the success of transition and satisfaction with the transition process.¹⁹ Within the field of early intervention, transition is defined as "the process of moving from one program to another, or from one service delivery mode to another."^{59(p246)} Others have emphasized the dynamic process of transition, as children with disabilities and their families will have repeated moves among different service providers, programs, and agencies as the child ages.⁶⁰ While formal transition for young children with disabilities typically occurs at age three (into preschool) and age five (into kindergarten), transition between services, providers, and programs also can occur throughout these early years. Transition procedures should assist families and their children and promote collaboration between the service providers, service coordinators, and families who comprise the transition team.⁵⁷

The Role of the Physician in Early Intervention

Physicians can play a critical role in the provision of early intervention services to infants and toddlers and their families.

In all of the service components previously mentioned, there are specific things physicians can do because of their background, training, and role with the child and family.

Table 4.—Service Delivery Components and Potential Roles for Physicians

Service Delivery Component	Role of Physicians
Early Identification and Entry into Early Intervention	<ul style="list-style-type: none"> • Conduct developmental screening and/or medical evaluation • Education of parents during evaluation process • Referral of children into the early intervention system
Service Coordination	<ul style="list-style-type: none"> • Serve as service coordinator • Liaison with other care coordinators including Title V
The Individualized Family Service Plan	<ul style="list-style-type: none"> • Informant of child's medical needs and assessments • Participant in development of collaborative goals and objectives • Consultant to early intervention team or others providing intervention
Transitions	<ul style="list-style-type: none"> • Identification of potential placements for child and family • Informant of child's future medical and developmental needs

These are listed in Table 4. Additionally, a physician can provide two important functions in the early intervention process. The first is to provide health services necessary to enable the infant or toddler to benefit from other early intervention services. This would include procedures and care conducted in accordance to medical guidelines, such as administration of medications, wound care, and medical procedures. These types of procedures can only be performed by a licensed physician and are critical if a child with medical needs is to benefit from other early intervention services.⁶⁵

Secondly, a physician can be the prime liaison between a child's medical home and the early intervention team.⁶⁶ Both the American Academy of Pediatrics (2002) and the Bureau of Maternal and Child Health of the U.S. Department of Health and Human Services⁶⁷ have endorsed the concept of a "medical home"⁶⁸ for every child with special health-care needs. This "medical home" should be comprehensive, coordinated, family-centered, and community-based. The medical home should provide coordination for all health services delivered to children to insure optimal child health and development.

Concluding Thoughts

Coordination of care for young children with developmental disabilities requires interdisciplinary, real-life, individualized approaches. All concerned parties—including parents and physicians—must work together to achieve the desired goals. Physicians must assume a more active role in this process. This can best be accomplished with improvements in the current systems of care and enhanced reimbursement processes for these services.

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