Maximizing Your Role in Early Intervention

Early intervention’s special characteristics and focus not only aid children and their families but also make the practice dynamic and rewarding for PTs.

By Michelle Vanderhoff

Early intervention--the provision of physical therapy and other services to children ages 0-3 under the Individuals with Disabilities Education Act (IDEA)--is a dynamic and rewarding area for physical therapists (PTs), according to PTs involved in such programs. They cite early intervention's distinguishing characteristics, including a family-centered orientation, a team approach, and the provision of services in a "natural environment."

As defined by Part C of IDEA, early intervention applies to children who are experiencing developmental delays or have a condition with a high probability of resulting in developmental delays. Part C is an optional program; states are not required to provide Part C services. However, if they opt in, then they are required to provide services to those categories of children. A child's early intervention service is specified in an Individualized Family Service Plan (IFSP). (See "Early Intervention in Brief.")

Natural Environment

Although many PTs are familiar with providing interventions in clinical settings, IDEA Part C requires--and PTs involved in early intervention endorse--a different perspective. The law specifies that, to the maximum extent appropriate to the needs of the child, early intervention services be provided in natural environments, including the home and community settings in which children without disabilities participate.

Children learn better in the environment in which they will be practicing their skills or exercises, says Beth McKitrick-Bandy, PT, MA, PCS. She explains, "[Physical therapy] does them no good if, while doing well in my gym by themselves, they can't generalize those skills in other situations like Sunday school or with friends." Also, she says, a PT can more accurately evaluate a child's progress by observing him or her at home or on the playground. Although she now is based in an acute care facility in Arkansas, McKitrick-Bandy formerly worked in early intervention for 11 years, both in a private clinic which contracted out to school districts and agencies and in a preschool early intervention program.

Toby Long, PT, PhD, says, "Our goal is to embed therapeutic strategies into routines irrespective of where they're occurring. For example, you can teach transfer skills from wheelchair to toilet in a variety of locations--home, work, restaurant, or library." Long is associate director for training at the Georgetown University Center for Child and Human Development and is Section Delegate for APTA's Section on Pediatrics. Lynn Jeffries, PT, PhD, PCS, points out that one step in the "natural learning process includes assisting families to identify other community locations where learning occurs." Jeffries is on the staff in the Department of Rehabilitation Sciences, College of Allied Health, University of Oklahoma Health Sciences Center.

The definition of "natural environment" is not even limited by physical location. Long says, " 'Natural environment' is defined by activities and routines within a context. It really depends on what you want for an outcome. You could provide your services in a variety of places--for example, a grocery store--if one of the family's goals is for the child to sit up in the grocery cart while the parent shops."

That said, there may be occasions in which a PT may be unable to provide physical therapy in a particular environment due to safety or other reasons, notes Barbara Connolly, PT, EdD, FAPTA. Connolly is president of APTA's Section on Pediatrics. In those cases, services might be provided in a child care facility or in another family member's home, Connolly says. If this occurs, the reason for the change in therapy environment should be clearly noted in the IFSP. PTs must be flexible in their approach: Frequent communication with the parent will make it easier to identify new places to work with the child and observe his or her progress. "Flexibility is key, in order to meet the individualized needs of the child and his or her family," McKitrick-Bandy points out.

Family-Centered

Early intervention is explicitly family-centered. In fact the document that is developed to guide the services is the Individualized Family Service Plan, as specified in Part C of IDEA. Long notes that this stands in contrast to Part B of
IDEA, which defines a parallel document, the Individualized Education Plan (IEP), for children over the age of 3. "Unlike Part C, which is family-centered, Part B services are child-centered. The child's needs are addressed in the IEP."

A recent presentation during a program on providing services in natural environments identifies the gathering of information from families as a key practice in the IFSP process. A family's interests, assets, and priorities should be identified by asking such questions as:

- Where do you and your child spend time?
- What activities do you and your child like to do?
- What activities do you and your child have to do?
- What activities would you and your child like to do?

McKitrick-Bandy points out the importance of incorporating family dynamics when appropriate. For example, involving siblings in the therapy session may help them feel included.

**The Team Approach**

IDEA defines the role of the service provider as consulting with parents, other service providers, and representatives to ensure the effective provision of services; training parents and others to provide those services; and participating in a multidisciplinary team assessment of a child and the child's family, and in the development of integrated goals and outcomes for the IFSP.

The early intervention team consists of the parent(s) and health care and other professionals. These may include social workers, psychologists, occupational therapists, speech-language pathologists, and, of course, physical therapists. The composition of the team varies from child to child, reflecting the individual needs of the child and family.

Long explains why early intervention teams may not be limited to health care professionals. "Early intervention consists of a range of services, not professionals. Transportation can be an early intervention service. Assistive technology can be an early intervention service."

Collaboration is a critical component of teaming in early intervention. A variety of service delivery models are available (see below). The recommended and generally accepted models of practice are interdisciplinary and transdisciplinary. "[PTs] have a responsibility to discuss [a child's intervention] with the team, but all team members do. That can be an education process, too. Sometimes people don't know what PTs can or can't do," says Irene McEwen, PT, PhD. McEwen, an educator at the University of Oklahoma Department of Rehabilitation Sciences, has worked in early intervention in school systems in Washington and Arizona. She adds, "It's important to have good communication within a team."

That's a sentiment echoed by many PTs in early intervention settings. In her doctoral dissertation, The Culture of a Transdisciplinary Early Intervention Team, Jeffries defines the basic elements of teamwork as "communication, collaboration, conflict prevention and resolution, and personal and professional development."

However, when team members are working under busy schedules, communication easily can break down and coordinating services can become a challenge. Connelly offers a remedy: Plan contact times with team members in advance, either by phone or email. Don't leave it at an informal "when-I-have-time" schedule. If team members don't discuss cases frequently, they miss out on opportunities to share—and listen.

**Early Intervention: Physical Therapy Under IDEA**

The Individuals with Disabilities Education Act (IDEA, PL 105-17) is a federal law that supports the provision of public education for all children regardless of the nature or severity of their disability. Part C of IDEA is an optional federal program that supports early intervention for infants and toddlers (birth up to 3 years). All states currently participate in Part C.

Under IDEA, states are mandated to provide identification, evaluation, treatment, and follow-up services to such children and their families to promote development and lessen the effects of the condition. Early intervention services must be provided at no cost to the family.

Implementation of IDEA Part C is the responsibility of each state through a lead agency appointed from education, health, human services, public health, or another related state agency. Part C requires that multiple agencies work together and collaborate on meeting the needs of infants and toddlers and their families in their states and communities. Eligible children are those who have a developmental delay or a medical diagnosis that has a high probability of a developmental delay. States define the eligibility criteria for developmental delay by addressing the child's development in cognition, physical, communication, social or emotional, and adaptive (self-help) domains or areas.

Screening, evaluation, and assessment are distinct processes with different purposes under the provisions of Parts C and B. Screening (including developmental and health screening) includes activities to identify children who may need further evaluation in order to determine the existence of a delay in development or a particular disability. "Evaluation" is defined as the procedures used by appropriate qualified personnel to determine a child's initial and continuing eligibility," consistent with the state definition of infants and toddlers with disabilities. It includes determining the status of the child in each of the developmental areas.
to--problems they are encountering or progress the child is making. Either of these can affect decisions regarding frequency and nature of physical therapy and other services.

Open and frequent communication is essential among all team members--and this includes the parents. By asking questions about the child's progress and listening to parents' concerns (and joys!), a PT can provide interventions more effectively and positively reinforce or gently correct the way a parent is working with their child. "If you don't listen, you won't know how much is learned between visits," says Kathryn David, PT, MS, PCS. David has been a pediatric clinical specialist for over 25 years, most recently working with the 0-3 population at an Iowa educational agency. She cautions that when therapists consider a parent "noncompliant," sometimes the real issue is that the PT hasn't fully listened to the parent.

Service Delivery Models

The role of the physical therapist in all models includes coordination, communication and documentation, and patient/client-related instruction. The specific role of the physical therapist and of other team members will vary depending in part on the service delivery model being used. A number of different models exist. In all service delivery models, the parents are full participants in the team and have the final say in the nature of interventions, including, but not limited to, frequency and duration of interventions and which outcomes are the highest priority. Long says, "The choice of model should be based on the needs of the child and family." The models include--

Multidisciplinary--In the multidisciplinary approach, professionals provide separate evaluations and assessments, set their own discipline-specific goals for the child, and implement individual intervention plans. The team members may communicate with each other on a less frequent and less formal basis than with other models.

Interdisciplinary--An interdisciplinary team requires interaction among the team members for the assessment and development of the intervention plan (IFSP). The team determines the best method for service delivery that may include one or more providers. Susan Effgen, PT, PhD, at the University of Kentucky, has worked in early intervention since the 1970s. She says the interdisciplinary model "helps in coordination [of services], because there are less folks involved in child's care in the home." She says that this model, when properly implemented, can lead to more people with relevant expertise providing hands-on services than in other models.

Transdisciplinary--Today, the most prevalent model is the transdisciplinary one, according to a 2002 survey reported by Jeffries.¹ This model calls for one team member to provide all the interventions. To accomplish this other members must teach the service provider aspects of their discipline. This is called role-release. Taken literally, therapists would have legal and ethical concerns "releasing" aspects of their discipline. Taken in a broader perspective, therapists may teach others activities or intervention strategies that do not require the expertise of the therapist. The Guide to Physical Therapist Practice² provides for this practice in coordination, communication and documentation, and patient-client-related instruction. It is important that the family and other team members understand that when performing the activities the therapist taught them, they are only doing activities, not providing physical therapy.

Primary Service Provider--This is an example of the transdisciplinary model. In this model, a single, long-term service coordinator is assigned to a family from the point they enter into the program. The selection of service provider should be determined by the area of greatest need. The provider establishes a relationship and works with the child and family throughout the duration of the child's care. Long notes, "One reason the primary service provider evolves is that young children should not have to tolerate the interaction with four or five different professionals every week. With a primary service provider, a child can develop a significant relationship with one provider who is collaborating with the other team members."

Physical therapists, Connolly says, collaborate on a regular basis when teaching others on how to physically manage a child on a day-to-day basis. For example, a physical therapist may not always be available when it is necessary to
position or reposition a child during speech therapy, so the PT must demonstrate to the speech pathologist the appropriate ways to position the child during therapy.

Alternatively, a physical therapist might need to teach the child sucking/swallowing in order to give the child fluids or food during a session. Sucking/swallowing is not something exclusive to speech pathologists, as it also qualifies as an oral-motor skill and is part of the APTA Section on Pediatrics' "Competencies for Physical Therapists in Early Intervention." and is included in functional training in self-care and home management in the Guide to Physical Therapist Practice.

Empowering Parents

Empowering the parents is critical to the early intervention process because parents ultimately are the ones who will facilitate their child's progress. Connolly advises PTs: "Remember, this is the parents' child, not your own. We are not with the child 24 hours a day; the parents are. It's our job to empower the parent. It's not your hands that make the difference, it's your brain that makes the difference." When a PT is successful in teaching the parent how to work with their child, the child is more likely to develop the necessary skills, Connolly says.

One responsibility of a PT in early intervention is to educate parents by providing them with accurate and current information about their child's condition. At the time of initial evaluation, most parents are not knowledgeable about their child's particular medical condition and may not understand how their child's prognosis will translate into everyday life activities, according to McKitrick-Bandy. This is true of both parents whose children were born with disabilities and those whose disabilities are acquired, such as in a car accident. "We have to educate and prepare parents in how to use home programs to help their child," McKitrick-Bandy says. She warns, "PTs often feel a strong need to help parents [with daily routines], but it is the job of the PT to teach them to advocate for their child and to make sure parents know what their child's needs are."

Even though at times it may be difficult, the team must respect the parent as the final authority on the goals for their child. IDEA gives parents the final say unless their decision endangers the child. This may result in differences of opinion between the PT and the parent about the child's needs. To effectively advocate for the child without overstepping one's bounds, Effgen suggests providing books, brochures, and Web sites to educate the parents about their child's condition. "Parent groups are also helpful to meet other parents who have children with similar problems, see how they've dealt with it, and learn why a therapist suggests certain things," she says.

By communicating openly, educating each other, and listening to the parents and other professionals on the team, PTs can empower parents and instill confidence in a child. Effgen says, "Parents really want to participate. It's critical getting them involved in daily activities."

Parent education also should take into account most parents' relative lack of knowledge about their rights under IDEA. A PT might need to explain how an IFSP works and how important the parents' role is in the IFSP process. For instance, parents may not know that IDEA requires reviews at least every 6 months—more frequently if the parents request—and should be evaluated annually. Nor may parents know that they themselves hold the final decision-making power. Of course, in order to make sure parents know the law, PTs must be well-versed in it. McKitrick-Bandy offers, "PTs should be encouraged to keep up with changes in the law so that they can pass this knowledge on to families."

And that's true for all PTs with pediatric patients, Long says. "Even if they're not involved in early intervention, PTs should know the system intimately because the children they see might be eligible for services if sought by the family. Services are provided not only for remediation, but also for support to the family to manage their child. Therefore, support could be from individual providers, or by helping the family get to a support group, transportation for the child, respite care, connecting the family to others in the community with the same disability, assisting with Medicaid, or completing paperwork for Social Security benefits. Although the physical therapist would not necessarily be providing that assistance, the entire early intervention system would be involved."
A Different Perspective

Long says, "The early intervention system has prompted in many practitioners a different way of thinking about providing intervention. It starts with 'What do you want the child to accomplish?' and works backward to figure out what services they need to accomplish that outcome. Always start from the endpoint, then develop your strategies."

One researcher in the area of early intervention describes a new paradigm for developing and implementing such programs. Characteristics of this approach include:

- Family-centered vs professionally-centered models
- Strength-based vs deficit-based models
- Empowerment vs expertise models
- Resource-based vs service-based models
- Enhancement and optimization of competence and positive functioning vs remediation of a disorder, problem, disease, or its consequence
- Professionals as agents of families and responsive to family desires and concerns vs professionals as experts who determine the needs of people from their own perspectives

Long also says that early intervention has prompted PTs to reevaluate their own role. She says, "Health care providers have assumed, 'If the person is in the room, they must need me' instead of asking 'What does this person need?' Even if he or she has a disability, what they need may have very little to do with your skills and abilities. The therapist needs to think about her role within a system of care. A system of care for children with disabilities is large and varied. It could include the family, the medical community, the education or early intervention system, the social service system, community-based resources such as libraries, parks, and activities. The providers of all these systems and activities could have skills to help the family reach their goals for their children and realize their dreams."

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References
1 Jeffries LM. The Culture of a Transdisciplinary Early Intervention Team [dissertation]. Oklahoma City, OK: The University Of Oklahoma Health Sciences Center Graduate College; 2003.