NATIONALLY SPEAKING

Occupational Therapy in Early Intervention: New Perspectives Create Greater Possibilities

Historically, occupational therapists have provided services to infants and toddlers within hospitals and other public agencies (Hanft, 1988). The Education of the Handicapped Act Amendments of 1986 (Public Law 99-457) marks a shift in the focus and priorities for a comprehensive system of services for young children and their families (Gallagher, Trohanis, & Clifford, 1989). The law establishes new policies based on the needs of children and families and on the documented evidence that suggests that early intervention services are beneficial (Trohanis, 1989). Because occupational therapy services are included in the legislation and are part of many community-based service provision agencies, knowledge of this law and its impact on the service environment is imperative.

A useful first step is to obtain a copy of the law and the corresponding regulations. A copy of the law can be obtained from any U.S. senator or congressman; the law is also reprinted in Guidelines for Occupational Therapy Services in Early Intervention and Preschool Services (American Occupational Therapy Association [AOTA], 1989). Recently, the regulations for the implementation of Public Law 99-457 mandates were published in the Federal Register (June 22, 1989). A complete copy of these regulations can be obtained from the Federal Register, from any senator or congressman, or from the U.S. Department of Education, Office of Special Education Programs; the regulations are also included in the Guidelines for Occupational Therapy Services in Early Intervention and Preschool Services (AOTA, 1989).

Several sections of the regulations are of particular interest as the role of the occupational therapist as a professional in early intervention services is redefined. Key sections of the regulations are presented here to introduce some of the concepts that will affect occupational therapy practice. By studying the full law and its regulations, early intervention service providers can gain the necessary background to function effectively in the evolving service provision environment. Knowledge of particular state plans to comply with the federal mandates will also be important, because state parameters will define practice within the agencies of that state.

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Pertinent Regulations

Subpart A, section 303.1, of the regulations contains the following statement of purpose for the early intervention program for infants and toddlers with handicaps:

The purpose of this part is to provide financial assistance to States to—
(a) Develop and implement a statewide, comprehensive, coordinated, multidisciplinary, interagency program of early intervention services for infants and toddlers with handicaps and their families;
(b) Facilitate the coordination of payment for early intervention services from Federal, State, local, and private sources (including public and private insurance coverage); and
(c) Enhance the States' capacity to provide quality early intervention services and expand and improve existing early intervention services being provided to infants and toddlers with handicaps and their families.

States are responsible for providing a comprehensive early intervention program directed at meeting the needs of children and families. Within that broad scope, many forms of early intervention services may be provided. Subpart A, section 303.12, establishes the parameters of an early intervention service with the following definition:

(a) General. As used in this part, "early intervention services" means services that—
(1) Are designed to meet the developmental needs of each child eligible under this part and the needs of the family related to enhancing the child's development;
(2) Are selected in collaboration with the parents;
(3) Are provided—
(iii) In conformity with an individualized family service plan; and

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(iv) At no cost, unless subject to §303.520(b)(3), Federal or State law provides a system of payments by families, including a schedule of sliding fees; and

(4) Meet the standards of the State, including the requirements of this part.

(b) Location of services. To the extent appropriate, early intervention services must be provided in the types of settings in which infants and toddlers without handicaps would participate.

(c) General role of service providers. To the extent appropriate, service providers in each area of early intervention services included in paragraph (d) of this section are responsible for—

(1) Consulting with parents, other service providers, and representatives of appropriate community agencies to ensure the effective provision of services in that area;

(2) Training parents and others regarding the provision of those services; and

(3) Participating in the multidisciplinary team's assessment of a child and child's family, and in the development of integrated goals and outcomes for the individualized family service plan.

Subpart A, section 303.12(d), contains definitions of the types of services that might be provided, including a definition of occupational therapy:

(b) “Occupational therapy” includes services to address the functional needs of a child related to the performance of self-help skills, adaptive behavior and play, and sensory, motor, and postural development. These services are designed to improve the child's functional ability to perform tasks in home, school, and community settings, and include—

(i) Identification, assessment, and intervention;

(ii) Adaptation of the environment, and selection, design and fabrication of assistive and orthotic devices to facilitate development and promote the acquisition of functional skills; and

(iii) Prevention or minimization of the impact of initial or future impairment, delay in development, or loss of functional ability.

As can be seen from these definitions, there is a directed effort to make families the focal point for activities and to provide services in integrated, age-appropriate settings rather than in the segregated settings that have predominated services in the past (Gallagher, 1989). Campbell (1989) commented that professionals must be aware of the changes that need to be made in order to ensure that they occur in the future. The support needs of parents vary over time and from one family to another (Shelton, Jeppson, & Johnson, 1987). The complex nature of this process emphasizes the importance of professionals being well informed about public policy, available community services, and discipline-specific areas of expertise. Occupational therapists have a great deal of expertise that can be used to maximize the success of these more natural settings and situations. For example, the infant's self-care needs may be a concern for the parents. The occupational therapist understands self-care regimens and their demands, and so can either teach the parents effective care strategies or design an adaptation that facilitates both parent–child interactions and successful task completion during caregiving. Case Smith (in press) provided several good examples of creative uses of occupational therapy skills within this new framework.

Subpart A, section 303.16, of the regulations defines the population of infants and toddlers with handicaps:

(a) As used in this part, “infants and toddlers with handicaps” means individuals from birth through age two who need early intervention services because they—

(1) Are experiencing developmental delays, as measured by appropriate diagnostic instruments and procedures in one or more of the following areas:

(i) Cognitive development;

(ii) Physical development, including vision and hearing;

(iii) Language and speech development;

(iv) Psychosocial development, or

(v) Self-help skills; or

(2) Have a diagnosis of an identifiable physical or mental condition that has a high probability of resulting in developmental delay

(b) The term may also include, at a State's discretion, children from birth through age two who are at risk of having substantial developmental delays if early intervention services are not provided.

The states are responsible for defining the exact nature of a developmental delay, including how the parameters will be identified within their state. Additionally, the states may choose to include in their efforts those children who are at risk; however, the designation at risk must be defined. It will be important for occupational therapists who work in early intervention to be very familiar with state criteria for eligibility. There may be children who can be identified by occupational therapists to have difficulties with the performance of daily life tasks but who do not qualify for services within a particular state's criteria. The regulations provide guidance regarding the creation of these definitions in subpart D, section 303.300:

Each statewide system of early intervention services (system) must include the definition of “developmental delay” that will be used by the State in carrying out programs under this part. The State's definition must—

(a) Specify that a child may be determined to be eligible if the child has a delay, in accordance with paragraphs (b) and (c) of this section, in one or more of the following developmental areas: Cognitive development; physical development, including vision and hearing; language and speech development; psychosocial development; or self-help skills.

(b) Designate the levels of functioning, or other criteria, that will be used in determining a child's eligibility as a result of developmental delay; and

(c) Describe the procedures the State will use to determine the existence of a developmental delay in each developmental area included in paragraph (a) of this section.

In addition to the parameters of the child, the regulations also define the parameters of evaluation and assessment. Family assessment is a new component of services within this law; therefore, it is defined specifically in subpart D, section 303.322:

(d) Family assessment. (1) Family assessments under this part must be designed to determine the strengths and needs of the family related to enhancing the development of the child.

(2) Any assessment that is conducted must be voluntary on the part of the family.

(3) If an assessment of the family is carried out, the assessment must—

(i) Be conducted by personnel...
trained to utilize appropriate methods and procedures;
(ii) Be based on information provided by the family through a personal interview; and
(iii) Incorporate the family's description of its strengths and needs related to enhancing the child's development.

As can be seen by this definition, family assessment is an interactive process between the professional and the family members; it will include as much information as the family shares. Occupational therapists will participate in family assessments as they relate to their areas of expertise. For example, occupational therapists will be more likely to interview the family about self-care issues than to discuss marital interaction patterns. Because all of the data collected are related to the goal of enhancing the child's development, and the family frequently has concerns about daily life routines and tasks within the family, occupational therapists can offer their expertise to point out the family's strengths in dealing with these issues as well as to identify areas of additional need. This information is then used to create the individualized family service plan (IFSP), a process that is described in great detail in the law. Many of the components required in the individualized education plans (IEPs) for school-aged children are also included in the IFSP. However, the IFSP has a much stronger emphasis on the process of collaboration between professionals and families to design a service provision process that is well suited to both the family's style and its needs. Subpart D, section 303.344, defines the IFSP as follows:

(a) Each system must include policies and procedures regarding individualized family service plans (IFSPs) that meet the requirements of this section and §§303.341 through 303.346.
(b) As used in this part, "individualized family service plan" and "IFSP" mean a written plan for providing early intervention services to a child eligible under this part and the child's family. The plan must—
(i) Be developed jointly by the family and appropriate qualified personnel involved in the provision of early intervention services;
(ii) Be based on the multi-disciplinary evaluation and assessment of the child, and the assessment of the child's family, as required in §303.322; and
(iii) Include services necessary to enhance the development of the child and the capacity of the family to meet the special needs of the child.

Subpart D, section 303.344, outlines the content of the IFSP very carefully for the states:

(a) Information about the child's status. (1) The IFSP must include a statement of the child's present levels of physical development (including vision, hearing, and health status), cognitive development, language and speech development, psychosocial development, and self-help skills.
(2) The statement in paragraph (a)(1) of this section must be based on professionally acceptable objective criteria.
(b) Family information. With the concurrence of the family, the IFSP must include a statement of the family's strengths and needs related to enhancing the development of the child.
(c) Outcomes. The IFSP must include a statement of the major outcomes expected to be achieved for the child and family, and the criteria, procedures, and timelines used to determine—
(i) The degree to which progress toward achieving the outcomes is being made; and
(ii) Whether modifications or revisions of the outcomes or services are necessary.
(d) Early intervention services.
(1) The IFSP must include a statement of the specific early intervention services necessary to meet the unique needs of the child and the family to achieve the outcomes identified in paragraph (c) of this section, including:
(i) The frequency, intensity, location, and method of delivering the services; and
(ii) The payment arrangements, if any.
(2) As used in paragraph (d)(1) of this section—
(i) "Frequency" and "intensity" mean the number of days or sessions that a service will be provided, the length of time the service is provided during each session, and whether the service is provided on an individual or group basis;
(ii) "Location" means, subject to §303.12(b), where a service is provided (e.g., in the child's home, early intervention centers, hospitals and clinics, or other settings, as appropriate to the age and needs of the individual child); and
(iii) "Method" means how a service is provided.
(e) Other services. (1) To the extent appropriate, the IFSP must include—
(i) Medical and other services that the child needs, but that are not required under this part; and
(ii) If necessary, the steps that will be undertaken to secure those services through public or private resources.
(2) The requirement in paragraph (e)(1) of this section does not apply to routine medical services (e.g., immunizations and "well-baby" care), unless a child needs those services and the services are not otherwise available or being provided.
(f) Dates; duration of services. The IFSP must include the projected dates for initiation of the services in paragraph (d)(1) of this section, and the anticipated duration of those services.
(g) Case manager. (1) The IFSP must include the name of the case manager from the profession most immediately relevant to the child's family's needs, who will be responsible for the implementation of the IFSP and coordination with other agencies and persons.
(2) In meeting the requirements in paragraph (g)(1) of this section, the public agency may—
(i) Assign the same case manager to be responsible for implementing a child's and family's IFSP who was appointed at the time that the child was initially referred for evaluation; or
(ii) Appoint a new case manager.
(3) As used in paragraph (g)(1) of this section, the term "profession" includes "case management."
(h) Transition at age three. (1) The IFSP must include the steps to be taken to support the transition of the child, upon reaching age three, to—
(i) Preschool services under Part B of the IDEA to the extent that those services are considered appropriate; or
(ii) Other services that may be available, if appropriate.
(2) The steps required in paragraph (h)(1) of this section include—
(i) Discussions with, and training of, parents regarding future placements and other matters related to the child's transition;
(ii) Procedures to prepare the child for changes in service delivery, including steps to help the child adjust to and function in, a new setting; and
(iii) With parental consent, the transmission of information about the child to the local educational agency, to ensure continuity of services, including evaluation and assessment information required in...
§303.322, and copies of IFSPs that have been developed and implemented in accordance with §303.340 through 303.346.

Deal, Dunar, and Trivette (1989) advocated a flexible and functional approach to writing the IFSP. Johnson, McConigle, and Kaufmann (1989) agreed and cautioned that the written IFSP document may be the least important aspect of the IFSP process. They commented that the interaction and collaboration between families and professionals may be the most critical feature of the IFSP process. For the IFSP to work, parents and professionals must develop mutual respect and trust. Parents and professionals need to share problem solving and decision making throughout the process and must be willing to evaluate services and adjust them when necessary to improve outcomes.

Another important aspect of the regulations is the inclusion of case management as a key role in the service provision process. The case manager coordinates the activities of both team members and other agencies in the provision of needed services. Subpart A, section 303.6, defines case management:

(a) General. (1) As used in this part, “case management” means the activities carried out by a case manager to assist and enable a child eligible under this part 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.

(2) Each child eligible under this part and the child’s family must be provided with one case manager who is responsible for—

(i) Coordinating all services across agency lines; and

(ii) Serving as the single point of contact in helping parents to obtain services and assistance they need.

(3) Case management is an active, ongoing process that involves—

(i) Assisting parents of eligible children in gaining access to the early intervention services and other services identified in the individualized family service plan;

(ii) Coordinating the provision of early intervention services and other services (such as medical services for other than diagnostic and evaluation purposes) that the child needs or is being provided;

(iii) Facilitating the timely delivery of available services; and

(iv) Continuously seeking the appropriate services and situations necessary to benefit the development of each child served for the duration of the child’s eligibility.

(b) Specific case management activities. Case management activities include—

(1) Coordinating the performance of evaluations and assessments;

(2) Facilitating and participating in the development, review, and evaluation of individualized family service plans;

(3) Assisting families in identifying available service providers;

(4) Coordinating and monitoring the delivery of available services;

(5) Informing families of the availability of advocacy services;

(6) Coordinating with medical and health providers; and

(7) Facilitating the development of a transition plan to pre-school services, if appropriate.

(c) Employment and assignment of case managers. (1) Case managers may be employed or assigned in any way that is permitted under State law, so long as it is consistent with the requirements of this part.

(2) A State’s policies and procedures for implementing the statewide system of early intervention services must be designed and implemented to ensure that case managers are able to effectively carry out an interagency basis the functions and services listed under paragraphs (a) and (b) of this section.

(d) Qualifications of case managers. Case managers must be persons who, consistent with §303.34(g), have demonstrated knowledge and understanding about—

(1) Infants and toddlers who are eligible under this part;

(2) Part H of the Act and the regulations in this part; and

(3) The nature and scope of services available under the State’s early intervention program, the system of payments for services in the State, and other pertinent information.

Occupational therapists may serve as case managers within their service provision agency, because those service providers who are most familiar with a particular family’s needs are most likely to serve as that family’s case manager (Johnson et al., 1989). Effective case managers will need to be able to carry out multiple roles with the family, including acting as a service provider and coordinating several services simultaneously. They will serve as a link between multiple agencies within the community who serve particular family needs (Johnson et al., 1989). Therapists will need to make themselves aware of educational opportunities to develop case management skills for this emerging role in early intervention.

This Issue

This issue of the American Journal of Occupational Therapy is dedicated to the topic of early intervention. As is evident from the regulations discussed above, many changes in service provision will occur as a result of Public Law 99-457, and occupational therapists will have an important role in that process. The materials contained in this issue are designed to provide useful information about the present state of occupational therapy early intervention services and to introduce conceptual information that facilitates the shift toward a more family-centered approach to program planning and intervention. Although it is sometimes difficult to adjust to new perspectives and priorities, family-centered care and family-professional collaboration will become commonplace activities in service provision during the next decade. We will then be ready for the next set of challenges.

Concepts and principles can help us get from one place to another to move closer to a vision of society based on enduring human values like freedom, community, equality, dignity and autonomy. Yet they must be viewed in historical context. The concepts that guide us today can mislead us tomorrow. . . . When one concept is achieved, we must be prepared to find new ideas and principles to guide us through the challenges and dilemmas we will undoubtedly face. (Taylor, 1988, p. 51)

References


