

DELIVERY OF SERVICES

MEETING THE MANDATE OF PUBLIC LAW 99-457: Early Childhood Intervention in the Nineties

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The Education of the Handicapped Act Amendments of 1986 (PL 99-457) represents the most far-reaching public legislation ever enacted for disabled and developmentally vulnerable young children. This paper presents the basic requirements of the law and discusses the elements of a comprehensive system of early childhood intervention. The challenges and problems created by the law are delineated, and recommendations presented.

Early childhood intervention services are poised at a historic moment. After years of public policy that neglected young, disabled children, and after several well-publicized claims that questioned the efficacy of such services (*Casto & Mastropieri, 1986; Ferry, 1981*), recent federal legislation has brought unprecedented attention to this field. *Public Law 99-457*, which in 1986 amended the *Education for All Handicapped Children's Act (PL 94-142)*, establishes a national policy for young, disabled children and their families. Representing the most far-reaching national agenda ever implemented for young children, *PL 99-457* affirms the will of Congress:

... to provide financial assistance to states to: develop and implement a statewide, comprehensive, coordinated, multi-disciplinary, interagency program of early intervention services for all handicapped infants and their families; facilitate coordination of payments for

early intervention services from various public and private sources; and enhance its capacity to provide quality early intervention services and improve existing services . . . (*Education of the Handicapped Amendments of 1986, para. 671*).

The bill stops short of mandating universal services to children younger than age six (the lower limit of entitlement under *PL 94-142*), but it strengthens incentives for states to serve 3-6 year-olds, and it establishes a new discretionary program (Part H of the statute) that provides services to children from birth to three years old.

DEFINING EARLY INTERVENTION

In most general terms, early childhood intervention consists of any sustained and systematic effort to assist young, disabled, and developmentally vulnerable children from birth to age three, and their families. Early intervention incorporates a host of services and service providers that bridge sev-

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eral disciplines and orientations. Indeed, in order to achieve a thorough understanding of early intervention as it has been articulated in the new law, one must adopt a set of assumptions that emphasizes this plurality.

The first such assumption concerns interdisciplinary activity. Effective early intervention services require the contribution of professionals from many different orientations (Dunst, Snyder, & Maniken, 1987; Shonkoff & Meisels, *in press*). This follows from the variety of the problems posed by young, disabled, and developmentally at-risk children, and by the range of services required to meet their needs. Some infants and toddlers are best served by physical therapists and other health professionals, while other children's needs may only be addressed adequately by professionals or lay professionals who are skilled in parent consultation, family dynamics, and "curricula" for disabled infants. There is no single formula or prescription that can be universally applied to this diverse population.

The second key assumption focuses on the family. According to *PL 99-457*, infants served in intervention programs should not be viewed as isolated service recipients. Rather, their needs can only be fully appreciated and understood within a family context. In turn, families must be seen as embedded within a larger social context (Dunst, Trivette, & Cross, 1986; Garbarino, *in press*; Turnbull, Summers, & Brotherson, 1983). This focus on the child within the family and the family in the larger social context represents one of the most far-reaching provisions of Part H of *PL 99-457*. As will be seen, the family focus suffuses all aspects of the early intervention service system—from prevention, to identification, to assessment, to service delivery. No longer is it meaningful to separate the child's needs from those of the child's family. With the advent of Part H, early intervention services imply services that are sensitive to family concerns, that build on family strengths, and that seek to enhance and create within families new capabilities

to support and facilitate infant and toddler development and to prevent developmental problems.

These two fundamental assumptions can be combined into a general definition. Early childhood intervention services consist of multidisciplinary programs for children from birth to three years old who are disabled and developmentally vulnerable, and for their families. These programs are intended to enhance development, minimize potential developmental delays, remediate existing problems, prevent deterioration or acquisition of additional or more severe handicapping conditions, and improve family functioning. These goals are to be accomplished by providing developmental and therapeutic services to children, and support and instruction to families.

The comprehensive nature of this definition reflects three key elements: the fundamental assumptions already cited, the underlying rationale for early intervention services, and the diversity of the children and families who can profit from these services.

RATIONALE FOR INTERVENTION

The most enduring rationale for early intervention is the view that behavior and developmental potential are neither fixed in early life by genetic factors nor impossible to change after a supposed sensitive period (Lerner, 1987; MacDonald, 1985). Scholars have shown that infants' capacities are open to change, that they can be influenced by external events, that IQ and developmental potential are not immutable, and that interventions can be designed to facilitate developmental advance (Gallagher & Ramey, 1987; Hunt, 1979; Lazar & Darlington, 1982; Meisels, 1985a). In other words, infants and toddlers are changing, evolving individuals. Their developmental potential—whether they begin life at genetic and physiological disadvantage or amidst environmental adversity—cannot be fully appreciated or defined at birth.

Still another rationale for intervention has

been formulated during the past two decades. This views the influences on child growth and development as extending beyond the infant's genetic capacities to include environmental effects as well. Several researchers have suggested that early intervention is justified in part by the potential of the child's family for major impact on the child's development (*Campos, Barrett, Lamb, Goldsmith, & Stenberg, 1985; Cramer, 1987; Sameroff & Chandler, 1975; Sameroff & Fiese, in press*). They suggest that the child and the child's caretaking environment tend mutually to alter one another, thereby creating a miniature social system in which the nurturance provided by the environment can result in positive developmental outcomes. However, to the extent that the child elicits or is the target of negative environmental responses, the child may be at high risk for later difficulties. In brief, this view suggests that development is a transactional process between organism and environment. Since dysfunctions resulting in disabilities can be precipitated by either the child or the family environment, interventions must take into account contributions from both members of the dyad.

This focus on the transactional model places in sharp relief the idea of plasticity in development. Research and practice have brought us to accept a fundamental malleability in children. No longer, as Lerner (1987) noted, can we assume that early experience is:

... a virtually immutable shaper of the entire life course; that development is essentially a within-the-person phenomenon, largely unaffected in quality or quantity by the context of life; and that, by and large, all people develop in fairly standard, normative manners. (p. 3)

These assumptions have been challenged, and early intervention has been one of the chief sources of evidence concerning children's potential for change in developmental outcomes (*Anastasiow, 1986*).

In a reanalysis of data from more than 30 studies of early intervention programs, Shonkoff and Hauser-Cram (1987) reviewed the

effectiveness of early intervention in advancing the developmental progress of infants and toddlers with established handicapping conditions. Their study demonstrated that programs that adopted a joint focus on the child and the family were the most effective in achieving their goals. Moreover, research on the economic costs and benefits of early intervention, which includes an analysis of the economic impact on the family, shows that intervention for environmentally at-risk children and their families can be a sound fiscal investment (*Seitz, Rosenbaum, & Apfel, 1985*). While less is known about the economic benefit of intervention with disabled children, evidence exists that would justify such an expenditure (*Barnett, 1986, 1988; Barnett & Escobar, in press*). Early intervention is effective, but programs that overlook the importance of the family's role in fostering optimal development will probably not realize their full potential or that of the children they serve (*Seitz & Provence, in press*).

RECIPIENTS OF SERVICES

One of the most complex issues to be faced in implementing Part H of *PL 99-457* concerns the question of who should be served by early intervention programs. Many of the labels and categories that can be applied to older disabled children, such as mild mental retardation, learning disability, speech and language impairment, or emotional disturbance are simply inappropriate for use with infants and toddlers. They cannot be used because some handicapping conditions do not manifest themselves until early or middle childhood, or because the methodology for identifying these problems in very young children has not yet been devised.

For these reasons, among others (*Meisels & Wasik, in press*), infants and toddlers who are at risk for developmental problems or disorders have been targeted for early intervention services. Such infants are assumed to have a high probability of acquiring or manifesting developmental disorder

in early childhood. The best known classification of such risk conditions was devised by Tjossem (1976). In addition to infants and children with established developmental delays or disabilities (e.g., Down's syndrome, inborn errors of metabolism, or cerebral palsy) he proposed two specific risk groups: 1) infants and children at increased *environmental risk* (e.g., poverty, low socioeconomic status, single parent, adolescent mother), and 2) infants and children at increased *biological risk* (e.g., premature/low birth weight graduates of neonatal intensive care units [NICU], asphyxiated full-term infants). These two risk categories—environmental and biological—constitute the populations that are the most difficult to identify and serve, and for whom epidemiologic data are unavailable, and possibly unattainable.

The three most common approaches to identifying at-risk children consist of single-factor methods, psychometric approaches, and multifactorial risk indexes. Each will be briefly described and their major problems identified.

Single-factor methods. Children are frequently considered to be at developmental risk if they have been exposed to a recognized high-risk condition (e.g., preterm birth, NICU admission, anoxia, poor prenatal care). Those who come from very poor families, or who have very young or relatively old mothers of limited education, are also considered to be at risk. While many children who have been exposed to these conditions display developmental problems, the majority do not (Bell, 1986; Ramey & MacPhee, 1986; Werner, 1986). Thus, the focus on single-risk factors usually results in extensive overidentification. This has the potential to overwhelm diagnostic and treatment resources and cause parents needless anxiety.

Psychometric approaches. Another method of identification involves the use of screening tests. However, very few such tests exist, and most of those that do are known to underidentify large numbers of at-risk chil-

dren (Meisels, 1988, 1989), in contrast to single-factor methods. Even when combined with single-factor categories (e.g., "only screen preterm infants"), the error rates remain high, and many children who should be classified as high-risk are missed, while others are tested unnecessarily.

Multifactorial indexes. To solve some of the problems of over- and underidentification, several researchers have constructed a "risk index" (Field, Hallock, Ting, Dempsey, Dabiri, & Shuman, 1978; Kochanek, Kabacoff, & Lipsitt, 1987; Littman & Parmelee, 1978; Minde, Whitelaw, Brown, & Fitzhardinge, 1983; Sameroff, Seifer, Barocas, Zax, & Greenspan, 1987). Such indexes combine data concerning the mother's reproductive history (e.g., prenatal care, number of pregnancies and live births), the child's neonatal and postnatal course (e.g., birth weight, gestational age, illnesses, hospitalizations), and other maternal, familial, and cultural variables (e.g., maternal mental health, parent-child interactions, parental education and occupation, social support, family size, and life events). Some approaches favor a "two-tier" identification in which the risk index is used to select at-risk children and families, and then a screening test or assessment is administered to the children identified in this manner.

There are, however, two major problems with the multiple-factor approach. First, the risk indexes described in the literature were developed for specific groups of high-risk children. There are virtually no studies that apply a risk index developed for one sample to a group of children drawn from a general population. Hence, we do not know how effective these indexes might be when used as general methods of identification.

Second, the most sensitive of the indexes rely on measures of the home and family environment that are extremely sophisticated, and that require highly trained personnel for implementation. For example, assessments of maternal anxiety, parent-child interaction, or maternal-infant attachment are actually research tasks that are

potentially inappropriate or impractical in a service setting. More research in this area is needed so that the right children are given access to services, and for the improvement of administrative, fiscal, and manpower planning.

ELEMENTS OF EARLY INTERVENTION

Early intervention comprises a complex collection of services and activities. To satisfy the requirements of PL 99-457, an early intervention system should include the following major functions: public awareness, screening and identification, diagnosis and assessment, intervention programs (child-, caregiver-, and family-focused), case management and interagency coordination, personnel training, and a system of program evaluation.

Very few states currently provide all these services and activities. A 1986 survey of the 50 states and the District of Columbia showed that no single function was being implemented by even half of the states for birth to three-year-olds (Meisels, Harbin, Modigliani, & Olson, 1988). The most commonly mandated services were public awareness, and diagnosis and assessment. The two elements least frequently mandated were case management and training—especially parent training. It was particularly striking that intervention programs were mandated much less frequently than diagnosis and assessment.

Although they are only one element of an early intervention system, intervention programs are the most complex of all the functions. They may be delivered by nurses, pediatricians, social workers, psychologists, audiologists, ophthalmologists, child care workers, neonatologists, special educators, paraprofessionals, physical therapists, occupational therapists, speech and language pathologists, or nutritionists. All these individuals may provide somewhat different though complementary services.

In addition to therapeutic treatments that may be discipline-specific, there are three generic types of early intervention programs:

child-focused, caregiver-focused, and family-focused.

Child-focused approaches consist of "a systematic and planned effort to promote development through a series of manipulations of environmental or experiential factors initiated during the first five years of life" (Guralnick & Bennett, 1987, p. 19). In a child-focused approach these efforts are primarily directed toward disabled children and may include a major emphasis on instructional content (Bricker & Veltman, *in press*). Although most approaches of this type require children to attempt to master specific fine and gross motor, language, and cognitive goals and objectives (Bailey, Jens, & Johnson, 1983), the overall trend in recent years has been to select instructional strategies that are ecologically-based. Thus, the focus is on child-initiated activities, generalization of learned responses, and training based on daily activities and familiar contexts (Bagnato & Neisworth, 1987).

Caregiver-focused models of early intervention focus on the "central importance of parents for the health, well-being, and development of the infant and young child" (Seitz & Provence, *in press*). Several different types of caregiver-focused models exist, including 1) a general pediatrics model in which the parent is the recipient of developmental guidance; 2) parent/child models, in which the treatment of the parent's problems is seen as the most effective means for helping the child (Fraiberg, Adelson, & Shapiro, 1980); 3) the parent as therapist, in which parents carry out all or part of the therapeutic program for their children (Minde, Marton, Manning, & Hines, 1980; Nurcombe, Howell, Rauth, Teti, Ruoff, & Brennan, 1984); and 4) the parent as teacher, in which the parent provides supplementary stimulation and instruction to the child in conjunction with a professional or lay professional (Bromwich, 1981; Olds, Henderson, Tatelbaum, & Chamberlain, 1986; Provence, Naylor, & Patterson, 1977). All these approaches assume that the child's family is sufficiently intact to

provide a nurturant and responsive therapeutic environment.

Family-focused intervention represents the third major approach to structuring early intervention programs. Going beyond the family as cotherapist or as an extension of the instructional program, this approach views the family as an important target of intervention in its own right (*Simeonsson & Bailey, in press*). Several models of this type have been implemented and evaluated (*Bailey et al., 1986; Barrera, Rosenbaum, & Cunningham, 1986*). Of particular relevance to this approach is the requirement in Part H to prepare an Individual Family Service Plan for each child who is receiving services. This plan is to be developed on the basis of a multidisciplinary evaluation of infant, toddler, and family needs. Hence, to a certain extent, *all* early intervention is family-focused intervention.

FORMULATING STATE POLICIES

Compliance with the requirements of Part H will result in state policies eventually reflecting some national uniformity. Indeed, by 1991, the end of the five-year planning and implementation phase established by the law, all states are required to implement a comprehensive service system that includes 14 specific components: definition of developmental delay; timeline for implementation; multidisciplinary evaluation of infant, toddler, and family needs; Individualized Family Service Plan; system for child find; public awareness; central directory of services; comprehensive system of personnel development; administrative procedures for establishing the lead agency; appointment of an Interagency Coordinating Council; contract procedures; reimbursement of funds; procedural safeguards; and data collection and reporting (*Campbell, Bellamy, & Bishop, 1988*). These components are closely related to the early intervention system functions described earlier.

However, in addition to these requirements for continued federal funding, optimal state policies should devote particular

attention to the "infrastructure" of early intervention (*Meisels et al., 1988*). This infrastructure constitutes such areas of policy as state funding, program administration, evaluation and monitoring, interagency cooperation, and professional training. It is relatively easy for policy makers to establish a mandate and to propose that certain services be provided. It is significantly more complicated to finance, properly staff, provide daily leadership, and establish productive interagency linkages for these proposed services so that they may begin to realize their potential for helping children and their families (*Meisels, 1985b*). Thus, an optimal state policy system will require going beyond establishing a mandate and providing comprehensive services. Also critical will be plans for funding, interagency cooperation, program regulation, personnel preparation, and program administration (*Hauser-Cram, Upshur, Krauss, & Shonkoff, 1988*).

UNRESOLVED ISSUES

Despite the substantial research that has taken place and the practices that have been developed, many problems remain to be solved in the coming years. The following are some of the key unresolved issues.

Identifying Service Recipients

Effective program planning requires relatively accurate estimates of the number of potential service recipients. However, no such estimates are currently available for the population of disabled and developmentally at-risk infants and toddlers (*Meisels & Wasik, in press*). Not only is there a paucity of appropriate instruments available for use with this age group, many children move in and out of risk status as a function of age, genetic background, environmental resources, and other factors. Furthermore, many children are considered to be at high developmental risk because of the familial and economic situations in which they were born. Hence, methodologies for identification must account for multiple risk factors;

traditional psychometric strategies of screening and identification can only offer part of the essential information. Future resources should be devoted to developing sensitive and specific multifactorial indicators of risk and disability in the first three years of life.

Labeling

The early and inaccurate designation of a child as disabled or at risk represents a major concern for everyone working with special needs children. Given the absence of clear and unequivocal risk factors in infancy and the toddler years, the potential is high for inaccurate labeling and for tracking children into a "career" of special education and special services. The sense of stigma and disillusionment that can be associated with labeling may be particularly salient for parents of infants and toddlers. Typically, they will not have had opportunities to adjust to their baby's disabilities, and in many cases they may not even recognize that any risk or disability is present. Safeguards, including the establishment of a schedule of periodic reassessments, should be devised to minimize the danger of inaccurate and insensitive labeling.

Program Flexibility

The population of children from birth to three years old who should receive early intervention services is extremely diverse in several different dimensions. First, the types of disabling conditions are varied, and the extent of their severity and intensity may also differ greatly. Second, children vary in terms of the family resources with which they are endowed. Some have two parents, some only one; some families have two wage earners, some have none; some are extended and some isolated. Third, the racial and ethnic mix of the families making use of these services varies. These cultural differences may involve language barriers, lack of familiarity with professionals, or resistance to allowing outsiders into the home. Early intervention services should be structured so that a wide range of child,

family, and cultural differences can be accommodated within a diverse mix of programs and services.

Program Intrusiveness

Early intervention services have been characterized as family-focused. This represents a unique feature of these services, especially when compared with many other services in the medical and educational arenas. Consequently, the need of families for privacy, confidentiality, and freedom from blame for their child's risk status must be carefully guarded. Also important is the need to respect each family's need to just "be a family." Constant rounds of appointments with members of interdisciplinary teams, complex schedules of therapeutic appointments and home visits, and intense involvement in family assessments may create additional burdens for some families. Early intervention services should reflect the individualized needs and concerns of specific families. The elaboration of the case manager position is crucial to the sensitive implementation of responsive, family-based services.

Costs

Highly differentiated and specialized services for infants and toddlers and their families are potentially very expensive. Until better estimates of the size of the target population are devised, and until a plan for a continuum of diversified, family-oriented services is created, accurate fiscal projections may be unattainable.

Since the potential cost of these services is so great, it is essential that all potential public and private sources of funds and in-kind services be utilized. This includes such programs as Early Periodic Screening, Diagnosis, and Treatment (EPSDT), Title V-Crippled Children, *PL 89-313*, and such third-party payers as Medicaid and private insurance. The risk in taking advantage of these categorical programs is that services will be fragmented to meet the specific unit allocations of the various fiscal agents. Other

resources to be considered include those generally available to families, such as informal community supports, and generic child care services. A comprehensive fiscal analysis of early intervention services still awaits completion. Particular attention should be devoted to modifying the requirements of existing funds and in-kind programs so that they do not curtail some critical services in making others possible.

Interdisciplinary Cooperation

Interdisciplinary coordination constitutes, in conjunction with the family focus, the second basic assumption upon which *PL 99-457* is built. Although interagency coordination has been made part of the states' planning function through the formation of the interagency council, actual cooperation and coordination must eventually be implemented at the level of local service providers and on the scale of individual family concerns.

Central to this goal is the recognition that no single discipline or professional group has priority in delivering early intervention services. Although *PL 99-457* is an amendment to the Education of the Handicapped Act, it does not exclude any discipline. Indeed, for Part H to be fully implemented, multidisciplinary efforts that combine the contributions of educators, mental health professionals, and other health care and early childhood workers are essential. Without such cooperation, early intervention services will be ineffective, inefficient, and ultimately unsuccessful. A systematic plan for altering perceptions and expectations of service boundaries and mandates should be devised by the case manager so that interagency cooperation becomes a functional component of the early intervention system.

Personnel

Early intervention policy has grown more rapidly than has the training potential of institutions that prepare individuals to work with disabled and at-risk infants and toddlers. Currently, we are in the midst of a

major national crisis in personnel preparation. Not only are there severe, documented shortages of personnel who are trained to deliver the various types of early intervention services noted earlier, also lacking are sufficient personnel to train the service providers who are needed in the field. In short, we face a multigenerational problem in which both trainees and trainers must be prepared. Furthermore, the focus of such preparation should reflect the multidisciplinary and the family-focused concerns of Part H of *PL 99-457*—concerns that are represented in very few discipline-specific training programs.

The shortage of trained early interventionists must be addressed rapidly and comprehensively. In addition to traditional programs of professional preservice education, other approaches, including systematic inservice education and training of lay professionals, should be explored carefully.

DISCUSSION

Early childhood intervention, as mandated by *PL 99-457*, represents an exceedingly progressive approach to public policy for young children and their families. Included within the purview of early intervention are such elements as prevention, family focus, interdisciplinary cooperation, case management, and use of multiple sources of funding. Never before has federal legislation been implemented that has such remarkable potential for so many young children and their families. Currently, each of the states is engaged in a five-year planning process in anticipation of full implementation by 1991. As with most new federal initiatives, regulations have been delayed, funding is inadequate for achieving all of the goals implicit in the law, and inter- and intrastate coordination is still quite limited.

Nevertheless, *PL 99-457* opens a new chapter for young, disabled, and developmentally vulnerable children and their families, representing a further expansion of public access to public programs of treat-

ment, remediation, and prevention. While the tasks that lie before us are formidable, if we are successful in overcoming the initial barriers described earlier, more and more children and families will have the opportunity to lead fulfilling and productive lives.

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