The passage in 1986 of the Education of the Handicapped Act Amendments (PL 99-457) marked a turning point in public policy commitments to meeting the educational and therapeutic needs of children with disabilities and their families. Described as "the most important legislation ever enacted for developmentally vulnerable young children" (Shonkoff & Meisels, 1990, p. 19), the law consists of three major provisions. First, the law establishes a new discretionary program for family-centered, community-based, multidisciplinary, comprehensive services of early intervention for children with handicaps or developmental delays and their families (Part H of the law and the focus of this chapter). Second, the law reverses the contemporary retrenchment in special education services for children between the ages of 3 and 6 (Mallory, 1981), by mandating entitlements to special educational services beginning at age 3 years. Third, it reauthorizes a variety of discretionary programs under the Education of the Handicapped Act for deaf-blind children, personnel preparation, and early childhood research institutes. Thus, the law begins the task of creating an infrastructure for a national system of early intervention and preschool services that reflects the diverse social, health, educational, and therapeutic needs of young children with known or probable developmental disabilities and their families (Hauser-Cram, Upshur, Krauss, & Shonkoff, 1988).

The law's passage is a tribute to the achievements of early intervention and preschool programs during the latter half of the 20th century. During this period, important research was reported that documented the cognitive gains made by infants and toddlers with disabilities participating in a broad array of early intervention programs (Farran, 1990; Shonkoff & Hauser-Cram, 1987). Moreover, several research efforts fueled general public support for early childhood programs, despite retrenchment in federal funding of other social and educational programs. The most widely publicized early childhood research project for disadvantaged children was the Perry Preschool Project (Berreute-Clement, Schweinhart, Barnett, Epstein, & Weikart, 1984), which reported significant developmental and socially important long-term benefits for participating children and families. The Perry Preschool results added to a broad base of findings from other early childhood projects on the longitudinal effects of early education (Lazar, Darlington, Murray, Royce, & Snipper, 1982). As a group, such findings marshalled much support for early childhood programs for vulnerable children.

Despite the legacy of accomplishment and public commitment to early intervention and preschool programs in the latter quarter of the 20th century, the provisions of PL 99-457 raise significant issues for programs as they enter the 21st century. This chapter discusses the challenges faced by the early intervention policy and service community in fulfilling the goals expressed by Congress. These challenges include fuller recognition of the changing demographic characteristics of the target population and their families, the development of flexible service models that will respond to the complex and varying needs of the target population, and the changing role of families within the service system. While these issues are not unique to the early intervention service community, there is a general belief that PL 99-457 will create a coherent, equitable, and responsive system of services that will be emulated by other service systems affecting persons with disabilities and their families.

Definition of Early Intervention Services and Target Populations

The term early intervention services, as defined by Part H of PL 99-457, includes publicly supported services designed to meet a handicapped infant's or toddler's physical, cognitive, language and speech, psychosocial developmental needs, or self-help skills. The services include family training, counseling, and home visits, special instruction, speech pathology and audiology, occupational or physical therapy, psychological services, case management services, medical and health-care services, and early identification, screening, and assessment services. These services must be provided in conformity with an Individualized Family Service Plan (IFSP) that is based on a multidisciplinary assessment of the child's and family's unique strengths and needs and the identification of services appropriate to those needs.

In contrast to the specificity regarding the services to be available within early intervention programs, the law is less definitive about the eligible target population. It states (Sec. 672) that the term handicapped infants and toddlers "means individuals from birth to age 2, inclusive,
who need early intervention services because they are experiencing developmental delays, as measured by appropriate diagnostic instruments and procedures in one or more of the following areas: cognitive development, physical development, language and speech development, psychosocial development, or self-help skills, or (who) have a diagnosed physical or mental condition which has a high probability of resulting in developmental delay." Further, states are given discretionary authority to serve infants and toddlers who are "at risk of having substantial developmental delays if early intervention services are not provided."

The sanctioning of services to the "at-risk" population has generated considerable controversy regarding the reliability and validity of criteria used to identify this group. Because biological factors alone account for only a small proportion of intellectually delayed children (Broman, Nichols, & Kennedy, 1975; Sameroff & Chandler, 1975), clinicians and researchers have focused on identifying parental or environmental markers that are predictive of poor child outcome (Meisels & Wasik, 1990). For example, Trohanis, Meyer, and Prestridge (1982) found that screening procedures for high-risk infants generally focus on maternal characteristics such as age (advanced or adolescent), history of substance abuse, low education or cognitive functioning, or low income. Others point out, however, that "it is the accumulation of risk variables rather than the action of specific factors that produce [sic] morbidity in a variety of domains" (Sameroff, Seifer, Barocas, Zax, & Greenspan, 1987, p. 349). While there is a deeper understanding of the factors associated with at-risk children's resilience and vulnerability to impoverished environments (Rutter, 1987; Werner, 1990), it is clear that targeting services within the at-risk population remains an art rather than a science. States intending to include the at-risk population within their early-intervention programs will continue to face a significant challenge in determining valid outreach and screening criteria. As Werner notes, "Risk factors are not black boxes into which one fits children to be neatly labeled and safely stored away. Like protective factors, they are probability statements, the odds of a gamble whose stakes change with time and place" (1990, p. 112).

Changing Demographics of Target Populations

While we anticipate that knowledge of the effects of various combinations of risk factors will expand during the 1990s, the population of children at risk for atypical development is likely to increase as well. Four general trends in the demographic and social characteristics of families in the United States will have important implications for early intervention services, both in terms of the eligible population and the nature of the services provided. These trends include (a) the increase in the number of children living in poverty, (b) the increase in children afflicted with human immunodeficiency virus (HIV) infection and disabilities caused by maternal substance abuse, (c) the disproportionate increase of minority and non-English-speaking families within the general population, and (d) the increase in the employment rate of women with young children.

First, estimates indicate that about one in every four children lives in poverty at some point during his or her formative years (Newberger, Melnicoe, & Newberger, 1986). The rise in family poverty is attributable to many causes, including increases in births to adolescents (Henshaw, Kenney, Somberg, & Van Vort, 1989), in female-headed households, and in the working poor (Ellwood, 1988). Projections indicate that the number and proportion of children living in poverty and with poorly educated mothers will increase steadily over the next three decades (Halpern, 1987). Although poverty is only one risk factor, it is associated with both prenatal and perinatal effects on the child that make normal development less probable (Parker, Greer, & Zuckerman, 1988). An increase in poverty will result in not only more children with environmental risk factors but also more children with biological or established risk who come from families with multiple critical needs.

Second, several changes in the characteristics of the children served by early intervention programs will have significant impacts on the nature of services. Among the most alarming is the rise in the number of infants born with HIV infection, which is projected to become the largest infectious cause of mental retardation and brain damage in children within the next 5 years. By 1991, the Center for Disease Control estimates that 10,000 to 20,000 infants and children will be infected with HIV (Dokecki, Baumeister, & Kupstas, 1989). Nearly all become developmentally disabled through central nervous system involvement (Diamond, 1989). Their service needs are essentially the same as other children with developmental problems, with the added complications of serious medical considerations and the public concerns about the transmission of infection to others (Crocker, 1989).

Another rising concern is the number of children born to substance-abusing mothers. Although precise figures are difficult to gather, one population-based study in the state of Florida found that 14.8% of pregnant women had positive urine toxicology tests for alcohol, cocaine, opiates, and other similar substances (Chasnoff, Landress, & Barrett, 1990). Cocaine use by pregnant women is associated with a host of structural and neurological defects as well as with preterm labor and low birth weight (Chasnoff, Burns, & Burns, 1987; Hoyne et al., 1990). Because many of these children may begin their lives living in dysfunctional households, the combined risk factors are increased substantially for them. When the basic needs of the family are not being met, the role of other services, such as early intervention, may need to be reshaped.

Third, the population in the United States is increasingly affected by differential fertility rates, which will result in a disproportionate increase in the minority population. Predictions indicate that by the year 2010, one
of every three Americans will be African American, Hispanic, or Asian American (Hodgkinson, 1986). Moreover, the proportion of children who speak a primary language other than English is expected to rise from about 2.5% in 1982 to 7.5% in the year 2020 (Pallas, Natriello, & Mcdill, 1989). Such changes in the population will multiply the need for service providers who represent these various communities.

Finally, estimates indicate that nearly two thirds (63%) of mothers with children under 6 years of age are in the labor force either full-time or part-time (U.S. General Accounting Office, 1990), and projections indicate a continuous rise in this percentage (Bloom & Steen, 1988). The employment of women with young children has had substantial impact on the daily lives of families and created a necessity to restructure the ways that the needs, including service needs, of various family members can be met.

Changing Service Models Within Early Intervention

Changes in the demography of the target population will have a profound effect on the strategies by which programs provide services. The ability of early intervention programs and service personnel to meet the range of complex and multiple needs of families that occur when children live in poverty or when parents are substance abusers will surely be challenged. Meeting these needs will require extensive efforts in interagency coordination. The staff time and expertise required to be effective linkages and brokers of services adds a new dimension to the range of resources needed within early intervention programs.

The ability of early intervention programs and service personnel to meet the multicultural needs of a diverse population is also a major challenge for the future. The absence of qualified minority personnel (Baca & Amato, 1989) and the dearth of instructional materials available in different languages limits the capacity of early intervention programs to serve fully minority infants and toddlers with disabilities or to work productively with their families. What is needed is not simply translations of curriculum and learning materials, but rather individuals who have a similar heritage, a common language, and a respect for the cultural values of those they serve. Tempting such individuals to obtain training necessary to become early intervention service providers is a critical challenge for the field as a whole.

Finally, the traditional model of a center-based program to which children and their parents (usually mothers) come once or twice a week for either individualized or group therapies and services may prove to be inadequate for meeting the varied family contexts and child-care arrangements of the 21st century. The use of home visits, another staple early intervention service-delivery mechanism, will be challenged by the increasing labor force participation of women with very young children.

New methods of service delivery that respond to the work lives of both mothers and fathers will be required and will undoubtedly demand greater flexibility on the part of early intervention service providers and programs. Early intervention and day-care services will need to join together more closely in the future to provide the full range of services needed by the child and family. Early intervention service programs will need to seek ways to ensure that the family’s role in early intervention services is not diminished, even though the child may be spending less time in the family. Indeed, the family’s role in intervention will be a critical challenge to the early intervention system in general.

Changing Context of Family Involvement

The distribution of roles and responsibilities between parents and professionals has been an enduring issue in compensatory or special educational services since the 1960s. In Head Start Programs (PL 89-794) and in demonstration projects authorized by the Handicapped Children’s Early Education Program (PL 90-538), parents were encouraged to participate in the development and operation of preschool programs and, in some cases, were eligible for parent training as a component of these programs. The rationale for the planned involvement of parents was that it was a critical ingredient in increasing program effectiveness, both because parents possessed considerable “instructional” time for their children and because their parenting skills would be enhanced through program participation.

The watershed for parent involvement, however, was the passage in 1975 of the Education for All Handicapped Children Act (PL 94-142), which codified a much deeper and more responsible role for parents in the educational planning for their children. Parents are entitled to notification before formal testing of their child, to explanations of the results of testing or proposed services, to participation in formal planning meetings from which educational plans are established, to access to all school records regarding their child, and to appeals procedures if they disagree with the outcomes or process of educational planning. Thus, parental roles shifted from advisory (as authorized in federal compensatory programs passed in the 1960s) to decision makers. The mandates of PL 94–142 reduced professional dominance and control over the lives of young children with disabilities and articulated a parent–professional partnership that had been the goal of many for decades (Turnbull & Turnbull, 1986; Zeitlin, Williamson, & Rosenblatt, 1987).

While parental roles in early childhood programs have evolved considerably over time, IFSPs now required within early intervention programs set a new precedent in public policies for families (Krauss, 1990). Rather than simply enjoying legal rights to participate in educational planning, parents are now potential recipients of services because of...
their child’s handicaps or delays. Although this mandate enables early
intervention programs to provide more comprehensive services to the
family as a unit, it fundamentally restructures the process and outcomes
of child and family assessment procedures and service provision.

The IFSP codifies the prevailing practice within many existing early
intervention programs to provide multidisciplinary assessments and to
include parental perspectives on the identification of needs and deter-
mination of relevant services. It extends current practices, however, in
requiring that the service plan focus on the family as mass rather than
the child in isolation from his or her environment and in requiring that a
case manager be appointed for each family (McConigal & Garland,
1988). It requires that the plan contain a statement of the child’s present
functioning in a variety of areas and of the family’s strengths and needs
related to enhancing the development of the family handicapped infant
or toddler. Specific goals for the child and family are to be enumerated,
along with the criteria and timing to be used to evaluate goal achievement.

Numerous analyses of the implications of the IFSP have focused on the
radical shift in the orientation of early intervention programs engendered
by this critical provision of the PL 99-457 (Dunst, Trivette, & Deal,
1988; Krauss, 1990; Sheehan & Sites, 1988). For example, the IFSP transforms
programs from being family oriented to family focused. Rather than
simply acknowledging the importance of the family context, programs are
now accountable for “evaluating” or assessing this context with respect to
its contribution to the therapeutic needs of the child and the family. As a
result, the IFSP requires direct programmatic involvement with families
who might not otherwise invite or need professional intervention.

Important issues about the nature and context of family involvement
have been generated by the IFSP mandates that will test the flexibility
and maturity of early intervention programs. Specifically, the form and
process by which family assessment will occur has been subjected to
sharp debate. The IFSP provisions have stimulated deep thinking by
researchers, early intervention program personnel, and parent-advocacy
groups about methods of family assessment that are responsive to the
spirit of the legislation while preserving respect for family privacy and
avoiding a presumption of family pathology (Dunst et al., 1988; Sumners
et al., 1990). The perceived potential for intrusive or insensitive questions
of family life and parental adjustment has led to formulations of “family-
friendly” approaches to family assessment. These strategies are char-
erized by informality, by emphasis on family strengths rather than deficits,
and are driven by family preferences rather than professional
judgment. The approaches are based on the belief that effective col-
aboration between professionals and families involves the development
of personal relationships, in which informal conversations replace formal
processes for client assessment and service planning.

Conversely, the IFSP provisions have also invigorated efforts to
develop standardized assessment procedures that enable program person-
nel to collect information systematically on service recipients. Structured
assessment procedures offer service providers more reliable information
about the functioning of the family in various domains, its formal and
informal resources, and its service needs. They also offer possibilities of
group comparisons and more refined testing of important questions about
the characteristics and needs of families of children with disabilities.
Because most strategies for standardized assessment rely on instruments
developed initially for research, rather than programmatic, purposes,
their utility for accomplishing the goals of the IFSP process needs further
testing (Bailey & Simeonsson, 1986; Fewell, 1986; Krauss & Jacobs,
1990).

Further, the requirement that parents be part of the multidisciplinary
team that guides the delivery of services alters traditional divisions of
roles between parents (as recipients of services for their children) and
professionals (as providers of services). As Healy, Keesee, and Smith
(1985) note:

The concepts of parental empowerment and parental involvement in decision
making have been increasingly a part of early intervention rhetoric. But a con-
crete understanding of what these concepts mean for professionals is still evolving
and may yet lead to revolutionary changes in practices. (pp. 37–38)

While this is the goal of many early intervention professionals (Dunst et
al., 1988) and families served in such programs (Ziegler, 1989), methods
for truly integrating parents with widely varying characteristics and
resources into the business of assessment and service planning have yet to
be fully developed and promulgated. Interestingly, an analysis of the
proposed FY 1987 activities of the 50 states and the District of Columbia
revealed that few states gave a high priority to developing quality and
responsive IFSP procedures (Campbell, Bellamy, & Bishop, 1988).

There is little doubt that Congress’s intent was to protect the interests
of families as critical decision makers about their own unique needs
as well as those of their child with a disability or delay. The benefits
attributed to meaningful parental involvement in programs serving
very young children and their families have been articulated persuas-
ively in the scientific and applied literature (Bricker & Casuso, 1979;
Bronfenbrenner, 1974; Florin & D’Okecki, 1983; Peterson & Cooper,
1989). However, the stylistic and philosophical differences between the
“family-friendly” and systematic, structured family assessment
procedures illustrate one of the basic tensions between professionals and
families that have surfaced since the law was passed. On the one hand,
there is a strong and vocal community within the early intervention
system that advocates for greater family control over the delivery of
services. On the other hand, there is concern that the professional skills
and expertise of early intervention specialists are being unduly dismissed
(Shonkoff & Meisels, 1990). Negotiating the differences between these
two communities constitutes an important and fundamental challenge for
early intervention programs, which are required to implement an IFSP process that meets both legislative and programmatic objectives.

**Summary**

Over the last quarter of the 20th century, early intervention programs for very young children with disabilities demonstrated increasing versatility in providing a complex range of therapeutic services to a population about which scientific knowledge was often grossly inadequate. With the passage of PL 99-457 in 1986, the Congress signaled its intention of equalizing the access to early intervention programs nationally, expanding the target population to include children with probable rather than demonstrated delays and respecting the primary role that families play in the lives of such young and vulnerable children. In an era characterized by retrenchment rather than expansion of service systems, the success of the scientific, clinical, and advocacy communities to secure the future of early intervention services can only be described as a major national achievement.

In previewing the challenges facing the early intervention system in each state during the 21st century, it is clear that the ambitions of Congress will stretch existing resources, knowledge, and practices to a significant degree. For example, strategies for identifying children in need of early intervention services become far more complicated when risk factors rather than demonstrated delays are used as criteria. While much is known about the types of environments and individual characteristics that are associated statistically with developmental problems, the probability of false-positives is still unacceptably high for most clinicians and service providers. Whether states promulgate eligibility policies that cast a wide net (and thus tolerate a high level of false-positives) or seek to limit their responsibility is an issue of considerable importance for the future.

Ambiguity also surrounds the effects on early intervention programs of the projected increases in the number of children whose developmental problems will stem from HIV infection or drug addiction. Meeting the needs of these children and their families will require a much deeper linkage among a variety of community-based service providers and a different range of professional skills than may be typical among existing early intervention programs. This is clearly an area in which college- and university-based professional training programs must assume leadership in attracting and training new students who are equipped with a multidisciplinary perspective on the social and developmental needs of a large group of children with problems that were unheard of when most practicing clinicians were trained.

The problem of identifying the full range of potentially eligible children and preparing for a group of children with extremely complex social, medical, and developmental needs is matched by the problem of developing service models that are sufficiently flexible to respond to the changing demographics of the American family. Congressional interest was focused on enumerating the types, not the method, of services to be provided. Considerable programmatic experimentation (accompanied by well-designed evaluation studies) will be needed to yield model delivery systems. The array of early-intervention programs that will be available by 2025 may look vastly different from those currently used.

Early intervention programs have also been handed an important responsibility to develop methods for truly integrating a family approach into the human services. The traditional distinction between services for children and services for families should be increasingly blurred by the 21st century, at least within the early intervention network. Whether the benefits of this approach can catalyze other service systems affecting children and adults with disabilities to adopt comparable family-based approaches is of substantial policy and programmatic importance.

Public and professional commitment to enhancing the educational, health, and social opportunities of young children—with and without disabilities—has been galvanized by the passage of PL 99-457 in 1986 and the celebration of the 25th anniversary of the Head Start program in 1990. Whether the popularity of such programs will be sustained into the 21st century depends, to be sure, on adequate resources to meet expanded public expectations. It also depends, however, on a partnership between researchers and program personnel to collaborate in systematic investigation on the efficiency of various screening approaches, the effectiveness of new program models, and the methods for forging new roles between parents and the professionals who serve them and their children.

**References**


14

The Changing Face of Residential Services

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This chapter about “residential services” for persons with mental retardation begins with a reminder that what we are really talking about are the homes of over 300,000 people who live neither independently nor with their families. Our use of general terms like residential services must not detract from or change how we think about the basic qualities of the homes provided to persons with mental retardation and how well these qualities reflect the cultural standards for desirable home settings. This issue will be examined more fully later in this chapter because we believe that a growing concern about cultural standards of quality of life will substantially alter our perspectives on residential service programs.

Background

The 21st century in the United States will begin with perspectives governing residential services for persons with mental retardation that differ radically from the perspectives that prevailed throughout much of the 20th century. These new perspectives have generated and continue to generate major changes in the nature, purpose, and location of residential services. In the 1950s, when a small group of parents joined together in Minneapolis, Minnesota, to form what is today the Association for Retarded Citizens, they could scarcely have imagined the changes that have taken place since then, much less the ones yet to come. For them, the mental retardation system provided two choices: placement of their children in large, isolated institutional settings, or maintaining them at home without the benefit of the most basic public support, not even schooling. Today, a wide and growing variety of residential and support options are available to persons with mental retardation and to their families.

In the broadest sense, residential services can be defined as the protection and assistance provided to people with mental retardation in their homes, whether those homes are institutions, studio apartments, or the