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Early childhood special needs 0-5 programming

Donna Elizabeth Faubion

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EARLY CHILDHOOD SPECIAL NEEDS

0-5 PROGRAMING

A Project
Presented to the
Faculty of
California State University,
San Bernardino

In Partial Fulfillment
of the Requirements for the Degree
Master of Arts
in
Education: Special Education

by
Donna Elizabeth Faubion
June 1997
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Approved by:

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ABSTRACT

This review of the literature on early childhood special needs (early intervention) provides a perspective on theory, models, program development and current laws and policies. After an introductory chapter, the second chapter identifies theoretical influences on early childhood intervention, including the work of Piaget, Bronfenbrenner, Vygostsky, Erikson, Montessori and Sameroff. The next chapter looks at various models and approaches including the developmental, functional, biological, and convergent models. The fourth chapter addresses the design and delivery of Early Intervention and Preschool Special Education Programs. The fifth chapter summarizes results of studies showing effects of early intervention on children. Issues for families are identified in the sixth chapter. Chapter seven goes into detail concerning current policy, IDEA and parents' rights under IDEA.
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INTRODUCTION AND BACKGROUND

The field of early intervention although young is growing rapidly. Its roots can be traced to the diverse influences of philosophy, psychology, medicine, special education and early childhood education which have converged in recent years (Summers & Innocenti, 1991, Meisels & Shonkoff, 1993). Early intervention has been described as having four objectives: (1) to maximize the child’s development; (2) to prevent later secondary disabilities; (3) to enable and support families; and (4) to provide cost-effective services (Bricker, 1989).

Currently, early intervention is based on two basic assumptions. The first of these is the recognition that no one discipline can provide the variety of services to address the diversity of problems young vulnerable children may experience, hence the need for interdisciplinary activity, creating the transdisciplinary, multidisciplinary team approach. The second is the acknowledgment that because children need to be seen within their family unit, and the family within the larger social system, there is a need for early intervention services which support and enhance the family’s strength and capacity to facilitate their child’s development (Meisels, Shonkoff, 1993).

Prior to the late 1960’s or early 1970’s very few intervention programs existed for infants and preschool-aged
children who had an intellectual disability or who had multiple disabilities. While there were residential options where care was primarily custodial (Baily & Bricker, 1984), it has only been during the last twenty-five years that early intervention programs have been established to serve infants or preschoolers with moderate to severe disabilities. The development and implementation of early intervention programs coincides with changes in perceptions about people with disabilities as well as the emergence of a strong parent advocacy group.

The rationale for early intervention for children with disabilities was rooted in the same conceptual framework that inspired programs for disadvantaged children, namely, the importance of early experience for later development (Marfo & Cook, 1991). Two scholarly works published in the 1960’s by Hunt, (1961) and Bloom, (1965) were influential in drawing attention to the early years, the importance of environmental enrichment and the plasticity of intellectual functioning.

These stimulated questions which challenged prevailing assumptions about the genetic determination of intelligence and which disputed the myth that people with an intellectual disability were of “fixed intelligence.” Also, parents of children with disabilities were reaching out to other parents, claiming their children should be entitled to live in
their own communities. The growth of parent organizations during this time was fueled by the desire on the part of parents for educational opportunities for their children. In the 1960's, in response to the pressing need for early diagnosis, home support and early education, services were developed which were meant to be comprehensive, community centered, and which would provide a continuum of care.

In the 1970's substantial changes began in policy and program (service) delivery. The purpose of the local, state and federal levels of the service delivery system is to distribute resources to communities. These resources may be in the form of direct services or funding to support needed programs and services. The service delivery system is guided by legislation. Federal and state laws define how the service delivery system operates and regulate the amount of resources that can be distributed. The laws in turn, are created by individuals who are the elected representatives of community citizens. There now is an on-going relationship between families, the community, the Service Delivery System, and legislation. Research played a significant role in the development and implementation of early intervention programs. California has an Early Start Program for infants and toddlers with disabilities and their families. The mission being, to establish a statewide coordinated, interagency system for infants and toddlers
with disabilities, and infants at high risk, and their families. California Early Intervention Services Act (SB1085) states: "Children are our most valuable resource. The investments we make in them today benefits all of California tomorrow. The implementation of Part H through California's Early Start Program ensures that infants and toddlers with disabilities and their families receive coordinated services early enough to make a difference."

Part H (a discretionary program) for infants and toddlers with disabilities ages BIRTH TO THE 3RD BIRTHDAY began October 1, 1986. Full implementation took place October 1, 1994 and the act was reauthorized as P.L.102-119. This was an Amendment to the Federal Education for the Handicapped Act (EHA) now known as Individuals with Disabilities Act (IDEA). This is best known by its predecessor P.L.94-142, PART B for students with disabilities ages 5-21.

Programs serving children from 0-5 in the California schools are no longer optional but mandatory. All laws pertaining to the governing of these programs are now contained in the California Special Education Programs - A Composite of Laws; which in California, Special Education laws are contained in part 30 of the Education Code (California Special Education Programs 18th edition, 1996).
THEORETICAL INFLUENCES ON EARLY CHILDHOOD INTERVENTION.

For many years the basic rationale for early intervention was based on a belief in the importance of the early years for future development (Hunt, 1961; Bloom, 1964). But there was no comprehensive theoretical rationale that went beyond this belief. Theoretical discussion appeared to take a back seat as activity flourished with the establishment of new programs. In the late 1960's the theoretical underpinnings of early intervention began to be questioned (Marfo & Cook, 1991). Challenges were directed to the central rationale of the primacy of early experience. Questions were raised as to whether the timing of intervention was the only issue or whether developmental changes might interact with timing to influence outcome. With little other theory in place, concern was growing with regard to the theoretical nature of much of the work in early intervention (Marfo, Cook, 1991). Zigler (1993) identified a "new theoretical paradigm" that propelled the field of early intervention with children with disabilities forward in the 1970's. This along with the work of Piaget, contributed to a better understanding of developmental theory.

Bronfenbrenner is frequently cited in the literature as having had a major influence with his ecology of human development theory. This theory proposed that neither a child's biological make-up nor their environment influenced
development independently, but that both occurred jointly and interactively (Bronfenbrenner, 1975; 1979). He suggested that for early intervention services to be effective, all aspects of a child’s environment needed to work together. He borrowed from Piaget’s Theory of Cognitive Development and argued that ongoing accommodations between the child and his/her environment, in which the child was an active participant, were necessary (Barrera, 1991). He claimed that involving parents directly in child development activities at a young age provided greater benefits for the child.

Bronfenbrenner’s theory influenced Sameroff’s transitional model, which provided a framework for conceptualizing the intervention process of the relationship between the care taking environment and the child (Sameroff, 1975). The importance of family involvement was reinforced by intervention activities designed to reflect the constant and dynamic interplay within the relationship. Equal emphasis was placed on the child's development and the experience provided by the family and the social context (Sameroff, & Fiesse, 1991).

Minuchin’s Family Systems Theory also contributed to the theoretical base of early intervention (Minuchin, 1974). Family systems theory identified the family as an inter-
action system accommodating to internal and external stresses and operating within a larger ecological system operating within a larger ecological system (community organizations, services, friends) as well as in various layers of the family unit (parents, siblings, extended family). The family as a social system operates as an interactive unit; members being interdependent; events and changes in one unit reverberating and producing changes in other social units; what affects one member affects all members (Glazer, 1991). Later, Synthesized Family Systems Theory emphasized the impact of stress placed on families living with children with disabilities and examined behaviors and needs of individual children in intervention programs, including the relationships and interactions among all family members (Turnbull, 1986).

As a result of these theoretical developments the approach to early intervention began to change. Where as former solutions might have involved removing the child to save her or perceiving a disability as a deficit to be corrected, the new solution argued that the problems of children were no longer seen as being restricted to children (Sameroff, Fiese, 1993).

Recognizing the full magnitude of the problems when highlighted by the ecological framework, Zigler cautioned that early intervention could only have limited success
given the scale of problems families were confronted with, including finding affordable housing, safe neighborhoods and integrated opportunities for their child to learn from peers (Zigler, 1993).
MODELS AND APPROACHES

For many years early intervention programming has been based on distinct models of practice. The early model projects focused on content and method of instruction for children (Vincent, Salisbury, Strain, McCormick, Tessier, 1993).

Developmental Model

The developmental model emphasizes the importance of the child acquiring age-appropriate and sequenced skills in various developmental categories (Marto, & Cook, 1991). The primary goal of the developmental model (Mallory, 1992) is to move children into higher levels of cognition and development, enabling them to become increasingly independent in their thinking, social skills and physical abilities. Characteristics of this model include a set curriculum, adult-child interactions, a relationship between the child’s home and program and a commitment to milestones within a normative framework (Mallory, 1992). Independence is believed to be fostered through play, discovery, problem solving and practice (Bredekamp, 1987). Critiques of the traditional developmental model focus on the didactic teaching of normative skills, the dependence on parents as instructors, and the indiscriminate utilization of whatever packaged assessment and curriculum materials that might be
available (Berkeley, & Ludlow, 1989; Marfo, & Cook, 1991). The emphasis on the acquisition of cognitive skills over other developmental gains was a further area of concern (Zigler, 1993; Marfo, & Cook, 1991).

**Functional Model**

The functional model emphasizes systematic instruction, a curriculum based on specific functional contexts, and the acquisition of adaptive behaviors. These contexts or domains, referred to as external cues and contingencies that shape a child's repertoire of behavior, are viewed as external forces that affect a child's competence. This model advocates that the more severe the disability, the more powerful these external cues have to be (Mallory, 1992). Curricula is designed to foster acquisition of generic and specialized social skills and the ability to perform tasks independently. In the functional model, independence is viewed as a means to social acceptance and social value, the clearest sign of independence being personal self-sufficiency in adulthood (Mallory, 1992).

**The Biological Model**

The biological model starts with the biological/genetic status of infants as they adapt and respond to environmental stimuli (Mallory, 1992). The adaptive responses are assumed to be manifested initially in the ability of young children to acquire stable and regular states of
sleep, arousal and wakefulness. As they grow, innate characteristics such as activity levels, temperature, and drives for arousal, satisfaction, and social interaction supersede the early sensorimotor responses. From the perspective of this model, primitive involuntary responses are replaced by voluntary and increasingly differentiated movements that parallel cognitive and linguistic maturation.

This model proposes that individual differences in rates and quality of development are primarily due to the child's constitutional/biological make-up rather than environmental factors. In the biological model, independence is thought to be achieved when children become sufficiently stabilized and mature and can deal with complex stimuli on their own without adult mediators (Berkeley and Ludlow, 1992).

**Convergent Approaches**

Generally, models and approaches to early childhood intervention are characterized by their distinctiveness from one another. However, the onset of the "new theoretical paradigm" (Zigler, 1993) inspired new thinking about how to adapt practice to fit this family centered paradigm.

The convergence of theoretical perspectives results in a significant move towards transdisciplinary assessment and convergent intervention models. The new convergent approach reinforces the idea that the goal of intervention is to facilitate conventionalized interactive competencies by
fostering collaboration and continuity among specialists and
to a shift in the balance of power toward the child.
Mallory (1992) and Dunst (1988) recommended early inter­
vention programs not be based on one model, but, on an over­
lap in theoretical models as adherence to a rigid approach
based on distinct developmental domains obscures the more
integrated "whole child approach" (Zigler, 1993) to human
development.

Recognizing potential difficulties with the use of
multiple theoretical perspectives in program designs,
(Berkeley and Ludlow, 1992) have argued that the time is
ripe for the adoption of a theory of child development that
represents integration of arbitrarily established separate
domains of development. They analyze to a stage or set to
convey an integrated view of development where development
represents a set, and the domains of development individual
elements in the set.

In an integrated view, these elements are united, with
the domains superimposed on one another so no separate
boundaries or other defining limits exist, except those
resulting from the child's lack of experience (Berkeley and
Ludlow, 1992).

Theorists involved in program design have emphasized
the importance of the relationship between theories, par­
ticularly the relationship between ecological and develop­
mental approaches and have suggested that as these approaches complement each other. Perhaps they can be used together to develop effective early intervention programs (Thurman, Widerstrom, 1990).

Family Support

Key to the shifting models of practice are a number of concepts which view family support as the primary goal of early intervention. Parent empowerment (Dunst, 1985) and enablement (Dunst, Trivette and Deal, 1988; Dunst and Trivette, 1987) are two concepts which are widely used. Enablement has been defined as creating opportunities for all family members to display and acquire competencies that strengthen family functioning. Empowerment has been defined as a family’s ability to meet needs and achieve aspirations in a way that promotes a clear sense of interfamily mastery and control over important aspects of family functioning.

Other concepts include family focused (Bailey, Simeonsson, Winton, Huntington, Confort, Isbell, O’Donnell, & Helm, 1986) and family centered (Shelton, Jeppson, Johnson, 1987) approaches. Although they differ in some respects, each approach incorporates certain common assumptions: (i) because children and families are so intertwined, intervention with one necessarily influences the other; (ii) involving and supporting families is likely to be a more powerful intervention than one focusing exclusively on the
on the child; (iii) family members should be able to choose their level of involvement; (iv) professionals should be able to attend to family priorities for goals and services even when they contradict what professionals might prefer (Baily, Bugsse, Edmondson, & Smith, 1992).

These proactive approaches are based on the recognition of family competence; failure to display competence represents not the failure of individual families but the failure of social systems to create opportunities for competency to be displayed so that individuals could attribute behavior change to their own actions (Dunst et al., 1988). Unless a family’s needs can be met in a way that makes the family more competent to negotiate its course of development, the opportunity to strengthen family functioning is lost.

The concepts of enablement and empowerment are rooted in the belief that parents have the rightful role in deciding what is important for themselves and their family and that they have responsibility for deciding which course to follow to ensure their family’s well-being and rights are protected.

Proponents of these views understand the role of a professional to be one which supports and strengthens the family’s ability to nurture and promote the development of its members in a way that is enabling and empowering (Dunst, 1988). Glazer (1991) argues for a shift from a deficit
oriented and reactive model of intervention to a strength
oriented, proactive model to identify family strengths and
functioning style so families become less dependent on the
service system for help.
DESIGN AND DELIVERY OF EARLY INTERVENTION PROGRAMS  
(Early Childhood Special Education)

Early intervention programs range in intensity from the rocking of low birth weight infants to long-term comprehensive medical, educational and psychological intervention for children with multiple health problems and developmental disabilities. Delivery mechanisms for such programs may include some or all of the following: center based and home based programs, separately or in combination; clinical, rehabilitation services, hospitals, in-home visits, segregated, transitional or integrated day care programs, consultation and referral services.

Traditionally, early childhood intervention has been viewed as a child orientated endeavor with the major purpose of enhancing developmental outcomes for young children with disabilities. As mentioned earlier, in recent years, it has been argued that supporting families should be the principal focus, with efforts being directed at the reform of existing policies and practices to empower families and strengthen their capabilities.

The design and delivery of early intervention programs reflect both approaches. Programs can be categorized according to whether they are child oriented or family oriented. Those assuming a family orientation may be further subdivided as to whether they take a family focused approach or a family centered approach. A review of programs sub-
scribing to these approaches indicates variation in focus, program design and activities, and in the role of parents and professionals. The chart illustrates five aspects of child oriented and family oriented approaches:

<table>
<thead>
<tr>
<th>Focus Of Program</th>
<th>Child Centered</th>
<th>Family Focused</th>
<th>Family Centered</th>
</tr>
</thead>
<tbody>
<tr>
<td>Program Design</td>
<td>Program adapted to child through assessments.</td>
<td>Individualized Family Service Plans. (IFSP)</td>
<td>Developing IFSP involves cooperation with parent and Professional.</td>
</tr>
<tr>
<td>Program Activities/Services</td>
<td>Activities focus on the developmental needs of child.</td>
<td>Skill teaching for parents. Activities fit families routines. Give support to Parents. Funds or emotional</td>
<td>Enablement and empowerment: Respecting autonomy of family. Fostering the skills and competencies necessary for gaining control over resources.</td>
</tr>
<tr>
<td>Involvement of Parents</td>
<td>Role not prescribed for parents. Limited involvement.</td>
<td>Involvement ranges from voluntary non-involvement to participation.</td>
<td>Parents are actively involved in design and implementation of program.</td>
</tr>
<tr>
<td>Role of Professionals</td>
<td>Expert who works in isolation with child.</td>
<td>Advise, teach parents, assist them with their needs.</td>
<td>Cooperate as equal partners with parents. Parents determine role for case manager regarding the kind of support and resources they need.</td>
</tr>
</tbody>
</table>

(Permission to reproduce was given by coordinator of special programs, NAEYC 1 834 Connecticut Avenue, NW. Washington, DC. 20009-5786. 1-800-424-2460.)
Child Centered Services

Focus

The first child centered intervention programs focused on the amelioration of developmental deficits through sensory stimulation or therapy. One of the most common forms of intervention involves the administration of prescribed programs to an infant as the primary target, by trained intervention workers assuming the role of teacher or therapist (Simeonsson, & Bailey, 1973). The rationale for this approach is that extra environmental stimulus is necessary because children with developmental problems require more and/or different early experiences (Bricker, & Veltman, 1993). Programs in the 1960's and the 1970's focused almost exclusively on the developmental needs of children and on addressing their problems with remedial activity (Barrera, 1991; National Information Center for Children and Youth with Handicaps, 1988).

Program Design and Activities

The child centered approach is based on behavioral and developmental theory. In child focused programs, goals directly relate to children. Their behaviors become priorities, although differences exist across programs as to the focus on child-initiated activity or teacher initiated instruction (Bricker, & Veltman, 1993). Bricker and Cripe (1992) described "activity based intervention," a child directed, transactional approach involving intervention in a
child’s individual goals and objectives by particular strategies such as routine, planned, or child initiated activities and the use of logically occurring antecedents and consequences to develop functional skills that could be generalized to different circumstances.

**Role of Parents and Professionals**

Parents are not designated an active role within child centered programs. While parents might accompany their child to therapy, trained personnel are expected to take over. Mittler and Mittler (1983) identified a framework articulating the traditional and evolving relationship between parents and professionals in a series of stages. The first stage involved professional perceptions of disability through the lens of a deficit model. In this stage the child is viewed separately from his/her family unit and the parents are considered a hindrance to their child’s development, a useful justification for excluding parents from the program. The second stage consists of limited parent involvement, generally determined by a professional following a curricula which prescribes a specific set of activities. The parent or other care giver becomes the target of intervention as the professional (expert) transforms skills to her. The third stage represents a growing recognition of the importance of parents and professionals developing and sharing a cooperative working relationship. This approach assumes that there is
no best way for parents to help a child, but that each family ought to be offered assistance to solve its own problems by working in partnerships with professionals (Brynelson, 1990). The parent/professional relationship in child centered intervention can be characterized by the first (or in some cases the second) stage of Mittler and Mittler's framework.

The Movement Towards Family Oriented Approaches

The movement toward family oriented intervention is partly a response to criticisms of the child centered approach. Child centered programs are criticized for their failure to recognize both the ability of the child and the role that parents can play in the intervention process. It overlooks the dynamic relationship between the child's development and his/her environment and dynamic relationships in an ecological context within the family and between the family and the community (Barrera, 1991).

In the late 1970's and early 1980's intervention programs began to shift their focus away from the child alone towards the parent-child interaction (Affleck, McGraw, McQueen, and Allen, 1982; Allen, 1987, Barrera and Rosenbaum, 1986; Bromwich, 1981; and Parmlee, 1979). Since there were problems with child centered programs, two fundamental changes were suggested to improve intervention services. The first of these is the development of
systematic approaches to early intervention that links assessment, intervention and evaluation as a process. The second suggested change is the creation of intervention approaches to develop functional skills that capitalized on the daily interactions of children and their social physical environment.

The conceptual contributions of Sameroff's Transactional Model of Child Development (1975), Bronfenbrenner's Ecological Framework (1979) and Family Systems Theory (Minuchin, 1974) enabled early intervention to become more diverse. "Prevention-Intervention" for example, recognized that not all problems could be fixed, but impairments and secondary disabilities could be minimized through concentrating on strengths and helping the child gain alternative or compensatory learning strategies (National Information Center for Children and Youth with Handicaps, 1988). In addition to becoming more diverse, there is growing interest in the field to focus attention on greater family involvement. Families have come to be seen as recipients of intervention services in their own right (Simeonsson, Bailey, 1993). They have their own needs for supports which early intervention programs can offer, such as information, training, child care community service, case management, or financial assistance (Bailey, & Simeonsson, 1991).

Gradually the importance of involving families of children with disabilities was recognized although the role
was not always clearly defined. Dunst identified four broad classes of family oriented early intervention programs, all of which adhere to a social systems framework and view the family as the unit of intervention. In professional centered programs the family is considered deficient, unable to solve their own problems and in need of an expert to determine what they needed. In family allied programs families become the agents of the professionals. One form of early intervention involved training parents to extend the teaching role of the interventionist. In family focused programs families and professionals collaborate to determine what the family needs: while families were viewed more positively, they were still regarded as needing professional advice and guidance to identify professional networks of service. In family centered programs, families determine all aspects of services and resources. The professional role is one of promoting family competence, decision making and strengthening the family’s own ability to meet their own needs (Dunst, Johanson, Trivette, & Humby, 1991).

Family Focused Programs

Focus

The family focused intervention model described by Bailey et al., (1986) is based on a functional approach consisting of six steps: A comprehensive child and family assessment; generating a hypothesis about intervention
goals; an interview to discuss family needs and negotiate intervention goals; operationalizing of goals; implementing of intervention services; evaluation. Family focused intervention promotes an active role for families, recognizing their unique needs and characteristics and importance of individualized services (Bailey and Simeonsson, 1991).

**Program Design and Activities**

The underlying assumption of this model is that the web in which the child developed included the home environment, family members and relationships, and therefore it was important that early intervention activities similarly occur within that web (Bronfenbrenner, 1979). A program developed by Jepsen (1988) represented one family focused approach to program design and activities. The four fundamental elements involved advocating for the rights of parents and working to identify necessary resources to meet family needs; relying on the home as natural learning environment (classroom programs needed to be concerned with carry-over into home); recognizing each child and parent as unique with their own needs and strengths; and relying on a practical, observable, changeable, behavioral approach. The integration that would naturally occur as a result of learning about culture, values and lifestyle in a familiar environment with one's own family, enhanced the likelihood that the behavior would be maintained. Recommended assessment practices were those that were largely restricted to family
needs as they related to child development; goals and outcomes were mutually selected by families and professionals; case management practices promoted the family's use of professional services (Dunst et al., 1991).

Role of Parents and Professionals

Parents have been designated a significant role in family focused approaches to early intervention. They are recognized as natural reinforcing agents who, with training, can be expected to acquire skills to deal with new behaviors. The family, particularly the mother, becomes a principal agent of change. This approach is seen as heightening the family's awareness regarding their important role in facilitating, guiding and supporting their child's development and enabling them to cope with the day-to-day realities of living with a child with a disability (National Information Center for Children and Youths with Handicaps, 1988). In-home instruction provides realistic opportunities for full family participation in the teaching process, including father, sibling and extended family involvement (Shonkoff, & Meisels, 1993).

Parents recognize the drawback in being taught to teach their children and to integrate therapeutic activities into their child's daily routine because of tendency towards more directive, less natural and enjoyable mother and child interactions (Odom and Karnes, 1988). The challenge for professionals then, becomes one of developing strategies for
teaching parents to incorporate developmental activities without interfering with their capacity to be sensitive and responsive (Odom and Karnes, 1988).

One of the main roles early intervention professionals assume is that of advising parents. The professional acts as a consultant who focuses on family needs as well as the child’s growth and development, rather than on the more narrow correction of a child’s perceived problem. Parents are taught therapeutic and educational tasks but professionals move away from the role of experts. Instead they become partners with parents who are seen as prime contributors in the decision making process (National Information Center for Children and Youths with Handicaps, 1988).

Family Centered Programs

Focus

Family centered services emerged during the mid 1980’s and 1990’s inspired by family systems theory. The family systems approach can be defined in terms of resources, life cycles, functions, and interactions of the family (Turnbull, & Turnbull, 1986). Family systems services focus on the child and family in the context of society and the family’s needs, strengths, and uniqueness.

In family centered services the family is the unit of intervention, rather than the child. The family is the focus of service and the home is the center around which programming is built. The child is viewed in the context of
their family and larger social network (Glazer, 1991; Thurman, & Winderstrom, 1990; Healy, Kusca, & Smith, 1989). The focus continues to move away from the narrow concentration on treating problems and preventing negative outcomes, and towards promoting growth-producing behaviors (Glazer, 1991). Minuchin's family systems theory views the family as an interaction system in which the systematic behavior of children is embedded. The family systems approach recognizes that children need to be an integral part of the wide range of concerns-economic, domestic, health care, recreation, socialization, affection, self-identity, and educational/vocational-addressed by their family and community (Callwood, 1989).

Program Design and Activities

Family support is a core service and a primary goal for family centered services (Heely, Keesca, & Smith, 1989). Social support can be defined as the emotional, physical, informational, instrumental, and material assistance provided to others on day-to-day basis or in times of crisis (Glazer, 1991). The focus on family needs involves several aspects. First, this approach aims to assist the family with those needs that are directly related to parenting and caring for a child with developmental delay (Bailey and Simeonsson, 1988). Second, it helps families recognize and build on their competencies enabling them to acquire a sense of control over how their family functions (Glazer, 1991).
Concepts of enablement and empowerment are fundamental to this approach (Dunst, Trivette, & Deal, 1988). Finally, family centered services are based on a broad definition of needs and supports; programs do not focus merely on material well-being but on emotional well-being of the family. Fostering a stable family environment as well as the child’s development, are goals (Healy, Keesca, and Smith, 1989).

With a focus on enabling and empowering families, broad-based family concerns drive the assessment process. Respect for family autonomy, independence, and decision making are achieved through parent and professional collaboration in the development of individualized program plans or family service plans. Nothing is written on those plans without the family’s clear permission. Whatever the case manager will have on the IFSP, will be determined by the family’s particular needs and life-style (Dunst, et al., 1991; Dunst, Trivette, 1987). It is important that program design communicates a respect for differences in family structure, roles, values, beliefs and coping styles as well as racial, ethnic, and cultural diversity (Glazer, 1991).

Family centered programs focus on helping parents make optimum use of available services, enlarging their knowledge of factors pertinent to growth and development of their child, and learning skills that will enable them to encourage development (Thurman, Widerstrom, 1990). Family centered services are flexible, accessible, and responsive to
family needs (Glazer, 1991).

Role of Parents and Professionals

The literature refers to a new role for the professional which requires increased knowledge about how to support and empower families; an ability to cooperate with parents as equal partners; valuing interdisciplinary skills; listening to the family and supporting their decisions; understanding the means by which parents can become empowered to gain competence and control of their own and their child’s lives (Healy, Keesa, and Smith, 1989; Thurman, & Widestrom, 1990, Newspatch, 1992; Callwood, 1989; Dunst, 1988; Glazer, 1991).

A family centered approach involves an open process of assessing, listening, and negotiating with families to achieve a mutually acceptable and meaningful plan for services (Glazer, 1991). When a child with a disability is involved, professional sensitivity to family emotions such as anger, guilt, grief, stress, or shock; it is important (Thurman, & Widerstrom, 1990). Professionals can support family functioning through assisting in developing and strengthening informal support systems, helping rank priority needs based on the family’s viewpoint, and providing access to formal services (Odom & Karnes, 1988). It is noted that insufficient time and discontinuity of personnel are powerful barriers to effective parent-professional collaboration (Healy, Keesea, Smith, 1989). Since all aspects
of early development are interrelated, an interdisciplinary coordinated approach is most appropriate although this requires changes in professional and agency concepts of territory (Healy, Keesea, Smith, 1989).
EFFECTS ON CHILDREN

In a decade review of published studies focusing on the effects of early intervention on disadvantaged and disabled children between 1977 and 1986, Farran (1993) concluded there were very few studies scientifically valid enough to summarize. Marfo and Cook (1991) identified a growing trend over the past ten years toward an attempt to understand factors related to the effectiveness of early intervention with children with disabilities based on research and analysis with that particular population, a significant departure from earlier attempts to extrapolate from the literature on environmentally at risk or culturally disadvantaged children. This knowledge, they claim, provides sufficient basis for enhancing the quality of early intervention services for children with disabilities (Marfo, Cook, 1991).

From earlier studies (1983) and an analysis of over 400 research studies, White and Casto (1989) found that successful programs were likely to have: (1) more attention spent determining the suitability of a program; (2) thorough documentation; (3) long-term, comprehensive and highly structured programming; (4) a greater focus on motor functions, cognitive stimulation and language development.

Other research suggests successful intervention is related to the child’s age (the earlier the better), the type and severity of the child’s disability (children whose
disability is less severe being more responsive to the intervention), and the quality and degree to which families are involved (Guralnick, 1991).

There is a growing body of evidence which concurs that early childhood special needs programs are generally effective and can be measured in short and long term gains; however, there is less agreement over what types of intervention work best and which are most effective (White and Casto, 1989). Benefits for children who are disabled, at-risk, and disadvantaged are indicated in the areas of cognitive, language, motor, and social emotional growth, as well as improved functioning of family members (Casto and Mastropieri, 1986). Guralnick (1991) reports the result of research studies in which consistent, if modest, benefits are translated into improved IQ scores. Evidence suggests interventions designed for disadvantaged children result in higher educational attainment and employment rates and reduced crime.

Less data exists with regard to children with disabilities for two reasons: (1) many studies have lacked credibility due to the absence of rigid research criteria and (2) the presence of other variables such as the role of families and support systems which complicate measurements. A major problem exists with regards to evaluating programs for infants and preschoolers with disabilities whether or
not they are in child or family oriented programs because of difficulty of obtaining control groups. An ethical question arises with regards to withholding educational services if resources are available in order to determine whether improvements might be a result of intervention or would have occurred naturally (Seitz, & Provence, 1993).

Grant’s study was based on homeless children aged 2-4 years, (Grant, 1990). These children exhibited signs of emotional disturbance and/or speech and language delay and appeared restless, distractible, and over-active with short attention spans. They improved to within normal limits in most areas after 2-3 months in an early intervention program which provided a safe space within a harsh and restrictive environment, a predictable routine, age appropriate material and experiences, supervision and protection that allowed for controlled exploration. The findings suggest that many functional delays of these children are environmentally induced.

Children who are medically at-risk also benefit from early intervention according to data from White’s (1985) study of 326 cases involving children with disabilities (mental retardation), disadvantaged children, and medically at-risk children. Results showed a gain of approximately eight IQ points. Data also indicated an improvement from the 10th to the 22nd or 30th to 50th percentile in motor
functioning. In addition, a reading level equivalent to second grade was achieved after approximately 10 months of reading. These results were similar for every domain and program regardless of philosophical approach.

Although the study produced sound data at which was able to be replicated, it did not produce data on long term effect (White, 1985-86). Sharav and Schlomo (1986) found that children with early infant stimulation function at higher levels than did children who were also cared for at home but who did not participate in an early intervention program. Motor and mental development scores compared until about 18 months, but at that point the children who were cared for at home but were not participating in early intervention dropped in development while the children in the early intervention program sustained improvement until three years of age. The decline of IQ with age was more gradual in the stimulated group. The Sharav and Schlomo-study also found that living at home had positive effects on children with Down's Syndrome. Significant amongst their studies findings was the importance of continuity of training; children with and without intellectual disabilities lost the benefit of early stimulation when it was stopped; and working with parents proved to be particularly beneficial in the area of language. A recent study also revealed the positive effects of early intervention for preventing or
minimizing developmental problems associated with disadvantage and disability (Bloom, 1964).

The Abecedarian Project generated two important findings: a) certain children and families benefit much more than others from early intervention activities, and b) new evidence of long term positive effects of early intervention on IQ and academic achievement (Ramey and Ramey, 1992). The Abecedarian Project was an experiment confirming that intellectual disability, allegedly caused by inadequate environments, could be prevented by providing intensive high quality preschool programs, medical and nutritional supports from birth to kindergarten. The majority of children with mild to moderate intellectual disability came from families with extremely limited economic and educational resources. Early intervention appears to have had a particularly powerful preventative effect on children whose mothers had low IQ’s or who come from economically, socially, or educationally disadvantaged backgrounds. The follow-up study conducted when the children were twelve years old revealed that intensive early intervention can produce long lasting benefits in intellectual performance and academic achievement, dependent on the quality of school programs received after early intervention.

Project CARE yielded similar results (Ramey and Ramey, 1992). This Project involved families with low socio-
economic status. It compared early intervention located in
the home where mothers learned more about how to provide
good developmental stimulation for infants and toddlers, to
center based instruction. The intellectual benefits
associated with receiving home based and center based
interventions are almost identical to the Abecedarian Pro-
ject. The study revealed that the home visit approach did
improve the intellectual performance of these children. The
Infant Health and Development Project focused on premature
infants and infants with a low birth weight (Ramey and
Ramey, 1992). The Project compared home and center based
intervention for families within a wide socio-economic
range, but the majority of data was collected from families
with low socio-economic status and low educational re-
sources. The children included in the study ranged from 12
months to 5 years old. Infants from the low birth weight
category benefited from early intervention, with the close
to normal birthweight children benefiting twice as much as
the lighter ones. The degree to which families and children
participated had a significant effect; the most active
participants had an almost nine-fold reduction in the
incidence of intellectual disability compared to the con-
trol group.

There is evidence that positive outcomes occur for
children with and without disabilities when they participate
in inclusive programs (Guaralnick, 1990). Research has shown that with early intervention, children make significant developmental gains and that the need for future services, such as special education, is reduced by at least 20 percent (Winget, 1997).
ISSUES FOR FAMILIES

The maximal intervention for a child has been identified as that which is provided naturally through being a part of "a good secure family" (Zigler, 1993). The increased emphasis on families in the field of early intervention has arisen from a number of factors. There has been a growth in parental involvement in services and programs concerning their children (Turnbull, & Turnbull, 1986). The growing recognition that children affect and are affected by their families in a reciprocal relationship has focused greater attention on effectiveness, now that the target for intervention has gone beyond the child alone (Simeonssen, & Bailey, 1992). Families have specific needs related to caring for a child with a disability and have come to be seen as recipients of intervention services in their own right. Many families confront difficulties which arise from society's values and assumptions pertaining to the family, their responsibility for providing care and their need for additional resources (Jones, 1986). Accounts by parents themselves describe the need for support and assistance and elevated levels of stress (Turnbull, & Turnbull, 1995).

The ongoing responsibility of caring for a child can affect parental health and stamina especially in communities where resources are scarce and when this responsibility is long-term, stressful, labor intensive, and demanding of a
wide range of support. During the last ten years the survival rate of babies with exceptional health care needs has increased dramatically due to advances in medical science and technology, subsequently lengthening the care families are required to provide. There is an increasing number of children who require continuing technological support for survival and quality of life (Norton, & Schom-Moffat, 1991; Norton, 1993). Parents, administrators and staff identify lack of resources as their greatest concern (Norton, & Schom-Moffat, 1990; Norton, 1993). Suggested additional supports to families include tax incentives, readily available respite at home and in alternate community settings, technical devices, and regular supervision by on-call staff. If funding requirements and family supports are not met, then the resultant physical and emotional stress may lead to re-hospitalization of child and adverse effects of family, sibling care, parental lifestyle/functioning and family finances (Norton, & Schom-Moffat, 1990; Norton, 1993).

Many people with disabilities or chronic illness can, with appropriate support services, participate in community living (Seitz, 1993). Barriers exist, however, which prevent participation in community living in relation to existing levels of support, the level of care required, extra costs and lack of awareness (Seitz, & Provence 1993).
Lack of information is a significant barrier. Without a comprehensive system which enables single access to all supports and services, families and professionals do not know about resources and possible options. Lowered self-esteem and depression, feelings of inadequacy, guilt and helplessness are common amongst primary caregivers of children with disabilities when the limited support available hinders their ability to meet societal expectations. Additional pressures on parents to assume a multiplicity of roles as therapists, teacher, trainer and transporter, in addition to those required in parenting, can place family integration at risk. Overbearing professionals erode parental confidence and cultivate feelings of insecurity and over dependence of staff; parents may resent the teacher role placed on them, feeling forced into an unnatural relationship with their children (Brynelsen, & Ferguson 1991).

Economic stressors include the high costs of equipment, a prolonged period of care and the consequent difficulty with entering the work field (Baily, & Smith, 1992). Families generally lack access to services they need; community based services that are delivered through the family tend to have a low profile and are consequently less visible than these delivered through institutional settings; in families the effects of reduced services are felt
immediately (Baily, 1992). Additional stress is contributed by professionals who may be more interested in a clinical diagnosis of the child than in supporting the family by identifying resources and strengthening social and educational networks (Trute, Hauch, 1987).

In the movement away from child centered programs, there has been a growing interest in the wider environment of the child that extends beyond the family to formal and informal support networks. The literature suggests a strong relationship between the presence of informal supports and family adaptation. Maintaining a healthy social network has been found to be tied to successful family functioning in situations where the demand for caring for a child with a disability is high (Trute, & Hauch, 1987). This challenges professionals to provide support to families by strengthening their informal support systems (extended family, friends, neighbors) and by helping them access the formal support systems (health care, social services, education) so the families can make informed decisions and take control over their own lives (Dunst, 1985). Pizzo (1993) identified the value of mutual support groups and described parent advocates as a resource for early intervention. She identified their power in terms of mobilizing, organizing to promote the establishment of early intervention programs in every community so that all children can receive the ser-
vices they need without having to travel, and reforming established institutions to validate and empower parents and families as the center of young children's lives (Pizzo, 1993).

Today, 35,000 infants and toddlers with disabilities and their families receive early intervention services in California alone (Weinstein, 1997). California was the last state to choose in the early intervention program authorized under Part H of the Individuals with Disabilities Education Act (IDEA). Although planning had occurred since the federal law was passed in 1986, it took "a good deal of advocate energy to make sure California became a participant" (Weinstein, 1997).

Effective intervention starts early with families and professionals working together. Research has shown that growth and development are most rapid in the early years of life. Learning begins at birth and involves a constant interaction between the child and the environment (Dinnebelle, 1996).

A child with a disability or developmental delay could possibly be limited in the ability to interact with the environment and might not acquire many basic skills. The earlier in a child's life that problems or potential risks are identified, the greater the chance of eliminating or minimizing existing problems. Preventing future problems is the goal of early intervention (Markoff, A, 1992).
CURRENT POLICY

California's Early Start Program for infants and toddlers with disabilities and their families and preschool special education programs are designed to meet the unique needs of children from birth through five years old and their families. These programs are unique in that families are critical partners in the intervention and education process and children are served in the context of their family, often in their own home. These specially designed services are developed in an Individualized Family Service Plan and, later, an Individualized Education Plan (program) to enhance the capacity of families to meet the special needs of their children with disabilities (National Information Center for Children with Disabilities, 1994, IDEA Public Law 101-476).

The current federal law that supports special education and related service programming for children and youth with disabilities is called the Individuals with Disabilities Act (IDEA, Public Law 101-476). The original law was enacted in 1975 to establish grants to states for the education of children with disabilities. This law has been amended several times creating what is currently referred to as IDEA (Odom, 1994).

In 1986, the law was amended to provide special funding incentives for states that would make a free appropriate public education available for all eligible pre-school aged
children with disabilities ages three through five. Provisions were also included to help states develop early intervention programs for infants and toddlers with disabilities. This part of the legislation has become known as Part H (Odom, 1994).

**IDEA**

The Individuals with Disabilities Education Act (IDEA, Public Law 101-476) guarantees the rights of parents of a child with a disability to participate in the education decision-making process. This legal right extends only to parents of a child with a disability and should be exercised in cooperative partnership with the professionals who support and educate the child in question (Special Edge, 1997). The parent or guardian also has the right to:

- Receive a written notice of their rights that is understandable and in their primary language.
- Refer child for evaluation and assessment, provide information throughout the process and make decisions about child’s early intervention or special education services.
- Understand and provide written permission or refusal before initial evaluation and assessments are made.
- Participate in the initial evaluation and assessment process.
- Be fully informed of the results of evaluations and assessments.
- Obtain an independent educational assessment, if desired
Receive a completed evaluation/assessment and an IFSP meeting within 45 days after child if referred to a regional center or local education agency to determine eligibility and develop an IFSP (Part H, birth-3 years).

Participate in the development of an IEP and be informed of availability of free appropriate public education (Part B, 3-21 years).

Have access to records, including the right to examine and obtain copies of records regarding child and request an amendment or omission of records.

Have an advocate assist in dealing with the early intervention or special education system.

Have personally identifiable information maintained in a confidential manner.

Request a due process hearing to challenge the findings of any evaluation, assessment, placement or service.

File a complaint alleging the violation of any law governing early intervention or special education services.

(Special Edge, 1997, Permission for reproduction has been given to readers of Special Edge by the California Early Start Program).

**Early Start**

In California, coordinated interagency services for infants and toddlers with disabilities, from birth through 36 months, and their families are provided through the Early
Start Program (Special Edge, 1997). Early Start is administered by the Department of Developmental Services (DDS), Prevention and Children Services Branch. The California Department of Education and DDS share responsibility for providing the leadership and support functions necessary for the program (Special Edge, 1997).

Local education agencies provide individualized services for infants and toddlers with all handicapping conditions. Regional Centers serve infants and toddlers with developmental delays (cerebral palsy, autism, mental retardation, neurological impairments and epilepsy), established the risk and high risk of developmental delay (Special Edge, 1997).

**Preschool Special Education (3-5)**

Special education preschool programs for children ages three to five years old are operated by local education agencies. These programs serve children with exceptional needs. The program is administered by the California Department of Education, Special Education Division, Early Education Unit (Special Edge, 1997). These research and model development projects, along with programs such as Head Start, have proven that early intervention is effective. We now know that if we provide support and services to children "and" families as early as the need is apparent, then: 1) the child’s development will not be as delayed as it would be if left unattended until age 6 or older; 2) the stress
for the family of having a child with disabilities is lessened and they are able to function more productively; and 3) because of these results, children and families are more able to contribute to their community. Early intervention can:

1. ameliorate, and in some cases, prevent developmental problems;
2. result in fewer children being retained in later grades.
3. reduce educational costs to school programs; and
4. improve the quality of parent, child, and family relationships.

Much of what we know about early intervention effectiveness is drawn from this diverse historical base of information.

More recently, researchers have begun asking a more rigorous and differentiated question: For whom and under what conditions is early childhood intervention most effective? This more sophisticated question focuses on the effects of various interventions for specific groups of children relative to the type of program they received. Data from well-controlled research studies indicate that young children with disabilities (e.g., Down syndrome, autism, cerebral palsy, sensory impairments), and those who evidence biological (e.g., low birth weight, premature) and environmental risk factors makes significant gains on both qualitative and quantitative measures of development when provided appropriate services. The involvement of their
parents in reinforcing critical skills in natural context is an important factor associated with the magnitude of the child's progress (Guralnick, 1989). In addition to encouraging parent involvement it has been found that the most effective interventions are those that also:

1. occur early in the child's life,
2. operate from a more structured and systematic instructional base,
3. prescriptively address each child's assessed needs, and
4. include normally developing children as models.

Programs with these characteristics produce the most reliable, significant, and stable results in child and family functioning (DeStefano, Howe, Horn, & Smith, 1991; Hanson & Lynch, 1989; McDonnell & Hardman, 1988).

Conceptually, the fields of early childhood and early childhood special education promote the incorporation of instructional goals, and curriculum content into normally occurring routines in the home, preschool, daycare center, and kindergarten settings (Bredekamp, 1987; Rainforth & Salisbury, 1988). Recognizing that children with special needs require efficient, effective, and functional instruction directed at achieving socially and educationally valid outcomes (Carta, Schwartz, Atwater, & McConnell, 1991), it is important that practitioners identify the nature of each child's needs and the extent to which accommodations and supports will be necessary for each child.
to be successful. Instructional arrangements, curriculum content, and instructional procedures can and should be varied to coincide with the intensity of each child's learning needs. Such accommodations increase the likelihood that children with special needs can be included in a vast array of typical Early Childhood Settings.

While many state and local agencies are still grappling with the issue of what kind of service delivery models they will endorse, it is clear that the special education and related services needs of young children with identified or at-risk conditions can be appropriately met in settings that include normally developing children (e.g., daycare, typical preschools, Head Start, regular classrooms) (Guralnick, 1990; Hanson & Hanline, 1989; Templeman, Fredericks, & Udell, 1989). Integrated settings have, in fact, been found to produce higher proportions, rates, and levels of social, cognitive, and linguistic skills in children with disabilities than segregated settings (Brinker, 1985; Guralnick, 1990).
GENERAL PRINCIPLES TO HELP GUIDE THE SELECTION OF PRACTICES

Five general principles can be used to guide the selection of effective practices: least restrictive environment, family-centered services, transdisciplinary service delivery, inclusion of both empirical and value-driven practices, and inclusion of both developmentally and individually appropriate practices.

Least Restrictive And Most Natural Environment

Individuals with Disabilities Education Act (PL 99-457) states that children should be placed in the least restrictive environment or the most natural setting. This is not simply a placement issue, however; the method of providing services, regardless of setting, should allow for maximum participation in the “mainstream.” Despite the limitations that a disability might place on a child’s and family’s ability to lead an ordinary existence, good services should promote the potential for “normal” rather than “disabled” routines by providing fun environments that stimulate children’s initiations, choices, and engagement with the social and material ecology. Programs should focus on preparing children for the next, less restrictive, environment.

Family-Centered Services

A second principle is that service delivery models should (a) recognize that the child is part of a family
unit; (b) be responsive to the family’s priorities, concerns, and needs; and (c) allow the family to participate in early intervention with their child as much as they desire (Bailey, McWilliam, & Winton, 1992). Services that previously might have been geared almost exclusively toward children must have the flexibility, expertise, and resources to meet the needs of other members of the family as those needs relate to the child’s development (Public Law 99-457). It is strongly recommended that service providers give families choices in the nature of services; match the level of intensity of services desired by the family; and provide center-based services close to where families live.

**Transdisciplinary Service Delivery**

One model for increasing the opportunity for family members to make meaningful decisions and participate in early intervention is transdisciplinary service delivery (Raver, 1991). This model involves team members sharing roles: each specialist helps other members to acquire skills related to the specialist’s area of expertise. This requires both role release (accepting that one’s job can include more than what one was specifically trained to do). Transdisciplinary service delivery encourages a whole-child and whole-family approach, allows for the efficient use of the primary interventionist (i.e., the child and family do not always need to see many different specialists), and fosters skill development in everyone.
Inclusion of Both Empirically and Value-Driven Practices

Empirical research has shown that practices should include such features as adult: children ratios that maximize safety, health, and promotion of identified goals; barrier-free environments; and environments that promote high levels of engagement. Practices guided by values include having someone available to speak the family’s preferred language; basing communication with family members upon principles of mutual respect, caring, and sensitivity; making environments safe and clean; employing clinic-based services only when they are identified as the least restrictive option; and giving opportunities for the family to have access to medical decision-makers.

Inclusion of Both Developmentally and Individually Appropriate Practice

"Developmentally appropriate practice" (DAP) refers to educational methods that promote children’s self-initiated learning (Bredekamp, 1987) with emphasis on individualization of services in response to children’s characteristics, preferences, interests, abilities, and health status and curricula that are unbiased and nondiscriminatory around issues of disability, sex, race, religion, and ethnic/cultural origin.

Final Comments

For over 20 years, the federal government has been
supporting research into the effectiveness of early intervention with handicapped and at-risk young children and their families. In addition to research studies, projects have been funded to develop model practices for effective early intervention. The reality of today’s society is that any child, on a given day, maybe a child with special needs. Recognizing this fact, it is important that local preschool and early education programs tailor curriculum and instructional practices to fit the diversity represented in their classrooms. Adapting the “standard” to fit those who may not fall within expected margins is a strategy necessary for effective teaching and learning and one that enhances the likelihood that children will feel and be successful.

This paper has a follow-up video presentation depicting Early Childhood Special Education in action.
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