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THE EFFECTS OF FAMILY-CENTERED SERVICE COORDINATION:
A SOCIAL VALIDITY STUDY

by
Eileen Frances Romer

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A Dissertation Submitted to the Faculty of the
DEPARTMENT OF SPECIAL EDUCATION AND REHABILITATION
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For the Degree of

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THE UNIVERSITY OF ARIZONA
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As members of the Final Examination Committee, we certify that we have
read the dissertation prepared by Eileen Frances Romer

entitled The Effects of Family-Centered Service Coordination:
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Signed

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Finally, to my husband, daughter, parents, siblings, and friends, thank you for your infinite love and support.

DEDICATION

To the families we serve

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ABSTRACT

The purposes of this study were to design, implement, and analyze the effects of family-centered service coordination to families with children, birth to three years of age, who participate in Part H of IDEA. The research questions investigated were: (1) does the family's level of satisfaction improve when family-centered service coordination procedures, acquired through training, are implemented? and, (2) does the training program result in implementation of this family-centered service coordination model?

The participants included three service coordinators and nine families. Three families were served by each of the three service coordinators. Data were collected monthly from each of the nine families using a questionnaire and a procedural reliability checklist. Procedural reliability was calculated across all conditions to determine the degree to which the service coordinators implemented the procedures of family-centered service coordination they learned about in training.

A family-centered paradigm was used to develop the research questionnaire, training program, and service delivery model. The defining characteristics of this paradigm were: (a) incorporation of family support

principles, (b) family-centered intervention practices, and (c) an enabling and empowering philosophy.

A multiple-baseline design across subjects was used to study the effects of implementation on satisfaction reported by the families. The stages of this design included Pre-Training, Post Training, and Implementation. The Implementation Phase was added, again in a multiple-baseline design, because none of the service coordinators adequately implemented the model in the Post Training Phase. The Implementation Phase was initiated in a different sequence than that used to stagger the training. The duration of each experimental phase depended on the responses given each month by the families.

Results indicated that when the family-centered model was implemented, families reported a high degree of satisfaction and a low degree of dissatisfaction. In contrast, when the model was not implemented, families reported very little satisfaction and a high degree of dissatisfaction. Moreover, training alone did not lead to implementation of the family-centered model. With individualized support, service coordinators achieved better implementation.

CHAPTER 1

INTRODUCTION

Experts defining best practice in the field of early intervention advocate the adoption and implementation of a family-centered philosophy into all aspects of service delivery. The adoption of this philosophy, along with the implementation of Public Laws 99-457 and 102-119, passed by Congress in 1986 and 1991, has led to a significant change in the organization and delivery of services to infants, children, and their families. Part H of Public Laws 99-457 and 102-119 is the legislation that affects infants and toddlers birth through two years of age and requires states "to provide quality early intervention services to handicapped infants and toddlers and their families" (U.S. Congress, 1986, 100 STATUTE, 1145-1146). Part H provides financial assistance to states to develop comprehensive, multidisciplinary systems of early intervention services for infants and toddlers from birth to three years of age who evidence developmental delay or, at state discretion, are deemed "at-risk" for developmental delay (U.S. Congress, 1986). According to the Mental Health Law Project (1992), the Part H program recast federal policy by taking a family-centered approach. Although advocates of this philosophy

contend that its adoption will benefit both families and professionals alike (Johnson, Jeppson, & Redburn, 1992; Edelman, 1991; Zipper, Hinton, Weil, & Rounds, 1993), changing priorities and organizational practices is proving to be difficult. In part, this may be due to a lack of evidence that families are actually better off when a family-centered approach has been used.

In recent years, it has been argued that a primary pursuit for early intervention service systems is to provide family support (Zigler & Black, 1989; Bailey, McWilliam, Winton, & Simeonsson, 1992; Dunst, Trivette, & Deal, 1988; Shelton, Jeppson, & Johnson, 1987; Bailey, Simeonsson, Winton, Huntington, Comfort, Isbell, O'Donnell, & Helm, 1986). Service coordination is a critical component of service delivery that can simplify service systems and provide support to the family. Service coordination is an administrative function that makes each state's Part H program accountable to each family served under this law. Service coordinators are responsible for "coordinating all services across agency lines and serving as a single point of contact in helping parents to obtain the services and assistance they need" [Section 303.22] (U.S. Congress, 1991). The service coordinator is the family's link to the complex and uncoordinated service delivery system.

Background of the Problem

Service coordination, previously referred to in the 1986 version of the law as "case management," is the Part H program's strategy for ensuring that the system works for each eligible infant and toddler. The regulations define service coordination as "an active, on-going process" that enables and assists families "to receive the rights, procedural safeguards, and services that are authorized to be provided under the state's early intervention program" (U.S. Congress, 1991). Services that are coordinated by a case manager for the family include: (1) coordinating the performance of evaluations and assessments; (2) facilitating and participating in the development, review, and evaluation of Individualized Family Service Plans (IFSP's); (3) assisting families in identifying available service providers; (4) coordinating and monitoring the delivery of available services; (5) informing families of the availability of advocacy services; (6) coordinating evaluations and assessments with medical and health providers; and (7) facilitating the development of a transition plan to preschool services, if appropriate (U.S. Congress, 1986; U.S. Congress, 1991; Mental Health Law Project, 1992).

Case managers have been accused of withholding required services, using quarterly evaluations to threaten service

reduction (Perkes, 1992), and intimidating parents with referrals to the state Child Protective Services agency (Foster, 1992). In April 1992, The Arizona Republic, a Phoenix, Arizona newspaper, ran a series of three articles that criticized the state's Division of Developmental Disabilities and their case managers. Parents claimed that frequent changes in case managers, management's insensitivity to the needs of parents, and a nonsupportive attitude towards families created a rift between the Division and the families it is supposed to serve (Perkes, 1992). According to one unidentified case manager, inadequate training, broad job requirements, poor salaries, and high caseloads were the circumstances that contributed to the poor service delivery (Perkes, 1992).

For the most part, service delivery in early intervention has been either system-centered or child-centered. The "strengths and needs of the system" or the "strengths and needs of the child" (Edelman, 1991) have driven the delivery of services. To comply with the mandates of Public Laws 99-457 and 102-119, the "priorities and choices of the family "must" drive the delivery of services" (Edelman, 1991). According to the law and regulations, early intervention services can include: service coordination (automatically provided to all eligible children and their families); family training, counseling,

and home visits; special instruction; speech pathology and audiology; medical and health services for diagnostic and evaluation purposes; assistive technology services and devices; vision services; physical therapy; occupational therapy; psychological services; and transportation and related services that enable an infant or toddler and family members to participate in early intervention services (U. S. Congress, 1986; U.S. Congress, 1991).

The fact that IDEA recommends a family-centered approach to the delivery of early intervention services, however, has not necessarily led to the implementation of such an approach. Public Law 102-119 requires service coordinators to coordinate the delivery of Part H services across all agency lines, and commands the recognition of the central role played by the family in the development of the IFSP. Families and case managers alike insist they need training and administrative support in order to change to a family-centered model (Edelman, 1991; Bailey, et al, 1992; Edelman, Greenland, & Mills, 1992; Edelman, Elsayed, & McGonigel, 1992; Zipper, Hinton, Weil, & Rounds, 1993). Even though professionals "aspire to high levels of family-centered services" (Bailey, et al, 1992), there is no evidence to suggest that a shift from a professional-centered to a family-centered service system for case management services in early intervention has occurred.

Statement of the Problem

Public Law 99-457 establishes family support as a primary outcome for early intervention and stresses the interrelationship between children and their families. The service coordinator is the one individual required by law to assist in the development, implementation, review, and evaluation of the IFSP. The IFSP is the plan that drives the delivery of services and is that portion of the legislation that best exemplifies Congress's intent that a family-centered approach be implemented in early intervention. The law and regulations dictate the content for each IFSP. Each IFSP is to include: a statement of the child's developmental status in five specified developmental areas; a statement, if the family consents to its inclusion, of family resources, priorities, and concerns; a statement of the major outcomes expected to be achieved for the child and family, with criteria, timelines, and procedures for measuring progress; a statement of specific early intervention services necessary to meet the identified outcomes; a statement of the natural environments in which the services will be provided; and a statement of the "other" services that the child and family might need but that are not required by Part H including medical and health care. One of the most important improvements made by the

1991 amendment to Part H is the new statutory requirement of informed parental consent. The contents of the IFSP must be explained in detail to parents or guardians and their signature must be obtained before services are provided. The new requirement is meant to ensure that the child and family receive only the services agreed to by the parents.

A family-centered approach describes a particular method of working with families that combines specific beliefs and practices to provide services that are consumer-driven and competency enhancing (Dunst, Johanson, Trivette, & Hamby, 1991). A family's resources, priorities, and concerns are to determine the aspects of service delivery. Intervention practices should be "strength and competency-based" (Dunst, et al, 1991). In a family-centered approach, professionals are to be the facilitators who promote family competence and decision-making ability.

In recent years, several authors have identified the key elements of family-centered care (National Center for Family-Centered Care, 1990; Johnson, Jeppson, & Redburn, 1992; Edelman, 1992), defined a family-centered model and practices (Dunst, et al, 1991; Simeonsson, & Bailey, 1991), and described methods for implementing a family-centered philosophy in early intervention practices (Bailey, McWilliam, & Winton, 1992; Pearl, 1993; Dunst, et al 1991; Barrera, 1991). What is lacking are data verifying that

services and service coordination that is family-centered is somehow better than the type of the service the family has previously received.

The purposes of this study were to design, implement, and analyze the effects of family-centered service coordination to families with children, birth to three years of age, who participate in Part H of IDEA. Categories of family support principles (Dunst, Johanson, Trivette, & Hamby, 1991) were incorporated into the design of a training program completed by three participating service coordinators. The same categories were used in developing a questionnaire that was completed every month by participating families. The categories included: the enhancement of a sense of community, the gathering of resources and supports, shared responsibility and collaboration, the protection of family integrity, the strengthening of family functioning, and the development of proactive human service practices.

The following research questions were investigated:

1. Does the family's level of satisfaction improve when family-centered service coordination procedures, acquired through training, are implemented in the delivery of services to infants and toddlers who, along with their family, are participating in Part H services?

2. Does the training program result in implementation of this family-centered service coordination model?

Definition of Terms

Developmental Delay

Developmental delay refers to a delay or difficulty in obtaining developmental milestones expected of children at certain ages.

Developmental Milestones

Developmental milestones are the skills regarded as having special importance in the development of infants and young children that are associated with a particular age.

Developmental Disability

Developmental disability refers to a severe chronic disability which is attributable to mental retardation (Arizona Revised Statutes, A.R.S., Section 36-551(26)), cerebral palsy (A.R.S., Section 36-551(8)), autism (A.R.S., Section 36-551(5)), or epilepsy (A.R.S., Section 36-551(16)). It manifests before the age of 18, is likely to continue indefinitely, and results in substantial functional limitations (A.R.S., Section 36-551 (13)(D)) in major life activities that include: receptive and expressive language,

mobility, self-care, self-direction, capacity for independent living, learning, and economic self-sufficiency.

At-Risk or Developmental Risk

At-risk or developmental risk refers to those children having difficulty achieving developmental milestones because of biological or other factors. High risk conditions which may qualify a child for services through Arizona's Division of Developmental Disabilities (DDD) include: (1) a birth weight of less than 1,000 grams; (2) Grade 3 or 4 intraventricular hemorrhage; (3) periventricular leukomalacia; (4) hydrocephalus with shunt; (5) congenital infection, such as cytomegalovirus (CMV), (6) rubella or toxoplasmosis; (7) microcephaly; (8) syndromes which are known to have a high probability of resulting in mental retardation; and, (9) meningitis or encephalitis.

Empowerment

Empowerment refers to those activities that enhance an individuals' or families' ability "to function as independently as possible" (Dunst, & Trivette, 1989; Levine, & Fleming, 1984) while recognizing each family's unique characteristics and resources. It is both a process and an outcome that takes different forms in different families (Rappaport, 1984; McGonigel, 1991).

EHA or IDEA

The Education of the Handicapped Act (EHA) Amendments of 1986 (P.L. 99-457) was renamed the Individuals with Disabilities Education Act (IDEA) in 1991. It was broadened to include comprehensive early intervention services for children with disabilities from birth. The law strengthens the role of the family and mandates the development of the Individualized Family Service Plan. Throughout this document, IDEA will also refer to the former Education of the Handicapped Act (P.L. 99-457 and P.L. 102-119).

Individualized Family Service Plan

The Individualized Family Service Plan (IFSP) is a written plan detailing the provision of early intervention services to families with infants and toddlers birth to three years of age. The IFSP documents a process which is comprised of several steps: the establishment and maintenance of a relationship with the family; the clarification of family resources, priorities, and concerns; the evaluation and assessment of the child's strengths and needs; the development of a plan for meeting the unique needs of the child and family; the monitoring and evaluation of the delivery of services; and transition to preschool services (Part B).

Service Coordinator or Case Manager

Public Law 99-457 uses the terms "case manager" and "case management". In the reauthorization, Public Law 102-119 substituted the terms "service coordinator" and "service coordination". Throughout this document, both sets of terms will be used interchangeably.

Case Management

Case management comprises a multiplicity of roles including: identifying clients in need of services, assessing the individual needs of clients, identifying and planning services to meet specified needs, linking clients with services providers and service providers with each other, advocating for the rights of their clients, monitoring and evaluating the effectiveness of services, and problem resolution (Bailey, 1989).

Part H

The Program for Infants and Toddlers, Part H of Public Laws 99-457 and 102-119, is the legislation affecting infants and toddlers birth to thirty-six months of age. Part B is the preschool component for children aged three to five.

Family-Centered

This term describes a philosophy and an approach to working with families in which the diversity and individuality of each family is recognized and respected. Professionals and parents work collaboratively to develop, implement, and evaluate services. Professionals encourage and support family decision-making ability and share information that allows each family to understand the complex service system. When a family-centered approach is implemented, the service delivery system is responsive to family-identified resources, priorities, and concerns.

Professional-Centered

This term describes a philosophy and an approach to working with families that is responsive to the needs of the professional and the service system under which the professional operates. Service delivery is based on the resources, priorities, and concerns of the system and/or the professional. Services are coordinated without input from the family. Service plans are developed, implemented and evaluated by the professional.

Summary

The evolution of federal policy in early childhood education was marked by two decades of federal initiatives that resulted in the passing of Public Laws 99-457 and 102-119. These laws and regulations hold the service coordinator accountable for ensuring that families receive the rights, procedural safeguards, and authorized services under the state's early intervention program. The adoption of a family-centered philosophy of care into service coordination is regarded as "best practice" in the field of early intervention. The need for documenting the effects of family-centered service coordination in this, and other fields, remains.

CHAPTER 2

REVIEW OF THE LITERATURE

This review of the literature will discuss the publications related to the legislative mandates of IDEA, Public Law 99-457, and its reauthorization, Public Law 102-119. Case management in the human services practice will be reviewed historically through its effect on the delivery of services in early intervention. Paradigms or models of service delivery in the field of early intervention will be summarized, and research on case management services related to developmental disabilities will be examined.

Infant and Toddler Legislation

The Education of All Handicapped Children Act (EHA) of 1975, Public Law 94-142, mandated a free appropriate public education (FAPE) for all eligible children ages 3 through 21 by September, 1980. The impact of this early legislation was minimal for children with disabilities, 5 years and younger, because a free appropriate public education was not mandated, by the federal government, below age 6. According to Hebbeler, Smith, and Black (1991), the law was silent with regard to infants and toddlers except for a requirement

that all children with disabilities be identified and evaluated.

Public Law 99-457, IDEA, deemed the most important piece of federal legislation since the passage of Public Law 94-142 (Harkin, 1991; Liaison Bulletin, 1986) was signed into law by President Reagan on October 8, 1986. According to the American Academy of Pediatrics (1986), IDEA is significant for several reasons. First, the law represents the first time the federal government has provided funds to establish a system that affords comprehensive early intervention services to children with disabilities from birth. Second, the law is designed to require better cooperation between health and special education programs. Third, the law strengthens the role of the family, and mandates the development of an individualized family service plan.

IDEA contains four parts. Title I describes the requirements for the new program to serve infants and toddlers, birth through two, and their families. Title II, also referred to as Part B, describes the revised pre-school grant programs for 3-5 year olds. Title III enumerates the revisions in the discretionary grant programs, and Title IV contains several amendments to Public Law 94-142 (Liaison Bulletin, 1986). Title I of IDEA is referred to as Part H, Handicapped Infants and Toddlers. In 1986, the United

States Congress (20 U.S.C. 1471) determined that there is an “urgent and substantial need: (1) to enhance the development of handicapped infants and toddlers and to minimize their potential for developmental delay; (2) to reduce the educational cost to our society by minimizing the need for special education and related services after handicapped infants and toddlers reach school age; (3) to minimize the likelihood of institutionalization of handicapped individuals and maximize the potential for their independent living in society; and, (4) to enhance the capacity of families to meet the special needs of their infants and toddlers with handicaps”. In the 1991 reauthorization, a fifth purpose was recognized: “(5) to enhance the capacity of the State and local agencies and service providers to identify, evaluate, and meet the needs of historically underrepresented populations, particularly minority, low-income, inner-city, and rural populations” (20 U.S.C. 1472(1)(A)).

Infant and Toddler Services

IDEA mandates assistance to each State “to develop a statewide, comprehensive, coordinated, multidisciplinary, interagency system to provide early intervention services for handicapped infants and toddlers and their families” ([Section 673], U.S. Congress, 1986). Part H defines early

intervention services designed to meet the developmental needs of eligible children and the needs of the family related to the enhancement of the child's development. All eligible children and their families are entitled to service coordination, on-going assessment, and the development, implementation, review, and evaluation of an Individualized Family Service Plan (U.S. Congress, 1986; Mental Health Law Project, 1992).

According to the law and its regulations, services are deemed appropriate if they are: (a) designed to meet the unique needs of the child and family; (b) arranged to enhance the development of the child and the family's capacity to meet the child's special needs; (c) selected in collaboration with the family; (d) provided by qualified personnel following an IFSP; and (e) furnished in the natural environments infants and toddlers ordinarily participate in (U.S. Congress, 1991).

Early intervention services are developmental services which include: family training, counseling, and home visits; special instruction; speech pathology and audiology; occupational therapy; physical therapy; psychological services; service coordination; medical services for diagnostic or evaluation purposes; early identification, screening, and assessment services; health services necessary to enable the infant and toddler to benefit from

the other early intervention services; vision services; assistive technology devices and assistive technology services (U.S. Congress, 1986). The services are to be provided by qualified personnel, including: special educators; speech and language pathologists and audiologists; occupational therapists; physical therapists; psychologists; social workers; nurses, and nutritionists (U.S. Congress, 1986).

IFSP Process and Philosophy

By the time Public Law 99-457 was passed, early intervention practitioners and organizations widely recognized the primary importance of the family. This consensus was substantiated in a Congressional Report provided by Gilkerson, Hilliard, Schrag, and Shonkoff (1987). According to McGonigel (1991), the development of an IFSP process that incorporates the caregiving role of the family is a complex task involving many people. It is critically important that individuals working with the family throughout the development, implementation, and review of the IFSP share a family-centered philosophy and conceptual framework.

The principles underlying the IFSP process are entrenched in the belief that early intervention services enhance the strengths present in all families.

Practitioners recognize that infants and toddlers are uniquely dependent on their families for their nurturance and survival. This dependence, states McGonigel (1991), necessitates a family-centered approach in the delivery of early intervention services. Various definitions of what constitutes a family are suggested (Hartman, 1981; Weinstein, 1979; Richardson, 1979). Common to all is the realization that each family has its own structure, values, beliefs, and problem-solving strategies. According to McGonigel (1991), respect for and acceptance of this diversity is the cornerstone of family-centered early intervention.

The IFSP documents the services, identified by the family and other team members, that will lead to progress in achieving the family's desired outcomes. Under the law and its regulations, the service coordinator is the one individual mandated to ensure that all services are coordinated "across agency lines" and to serve "as a single point of contact in helping parents" obtain the "services and assistance they need" [Section 303.22] (U. S. Congress, 1991). Family-centered early intervention addresses all of the urgent needs that the family perceives and expresses (McGonigel, 1991; Bailey, 1988; Dunst, Trivette, & Deal, 1988). Needs are addressed either directly or through referral services and community linkages, with the service

coordinator assisting the family in acquiring the services (McGonigel, 1991). Family and professional collaboration and partnership are the keys to family-centered early intervention and to successful implementation of the IFSP process (McGonigel, 1991; Edelman et al., 1992).

Adherence to specific principles underlying the IFSP process ensures that families receive early intervention services that are enabling and empowering. "Enable" and "empower" are words that have gained support as the terms that best exemplify the spirit and essence of family-centered services (Dunst & Trivette, 1987; Shelton, et al., 1987; McGonigel, 1991). These terms describe ways of interacting with families that maintain their integrity and expand their ability, as necessary, to meet their needs and the needs of their children (Dunst et al., 1988).

The implications of these legislative mandates for service delivery and professional training are far reaching (Krauss, 1990). The need for interdisciplinary training programs for early intervention professionals that incorporate child and family development has been widely recognized (Shonkoff & Meisels, 1990; Bailey, Farel, O'Donnell, Simeonsson, & Miller, 1986; Krauss, 1990). In order to ensure that pertinent and required services are provided to families, early intervention programs and service coordinators, in particular, will have to become

knowledgeable about the range of services available in their communities and will need to develop coordinated referral systems (Krause, 1990).

Service Coordination in Early Intervention

The roots of case management in the United States can be traced back to 1863 when charitable organizations provided services to persons who were sick and poor (Weil, & Karls, 1985; Amado, McAnally, & Linz, 1989). As described by Weil and Karls (1985), two kinds of service coordination can be identified in the early history of human services. The first type, case coordination, was allegedly rudimentary -- but effective. Charitable Organization Societies (COSs) as well as settlement houses engaged in case and service coordination. Case coordination consisted of index card files listing each family's needs and involvement's; the socialization, recreation, and vocational training groups for children and adults; and the neighborhood issues and environmental problems. The COS movement was the first major effort at interagency cooperation and can be viewed as a forerunner of today's United Way and sectarian federations of agencies (Weil & Karls, 1985).

The Social Security Act (SSA) of 1932, had a significant impact on the development of social services. The act established a role for the federal government in meeting

human needs and brought together programs such as public assistance, social insurance, and maternal and child health (Amado et al., 1989). According to Weil & Karls (1985), over the last one hundred years, the concept of case management has operated under a variety of names including case coordination, service integration, service coordination, and social service exchange.

Bailey (1989) traced the roots of current case management to the deinstitutionalization movement of the 1970's. After the release of "mentally disabled" and "mentally ill" clients from hospitals and institutions, case management systems were established to ensure the successful reintroduction of institutionalized individuals into society. According to Bailey, case management, from the historic perspective, has been based on two assumptions. The first assumption is that the client is unable to manage his or her own affairs because they "lack assertiveness," have difficulty "coping with daily living," and are very dependent on others (Berzon, & Lowenstein, 1984). The second assumption is that the client is confronted with a large, complicated, and uncoordinated service system. The goal of case management has been to work within the system instead of changing the system to meet the needs of the client (Bailey, 1989).

Weil & Karls (1985) believe that placing case management in its historical context and analyzing its philosophical structure, goals, and objectives results in an appreciation of the complex roles, tasks, and skills necessary to provide efficient and effective services. A review of this nature clarifies the importance of the dual functions of case management, which have been described as the concern to provide quality service coordination and to deliver services in the most efficient and cost-effective manner (Weil & Karls, 1985).

Service Coordination and IDEA

Service coordination is a highly complex process even though the basic functions sound uncomplicated. In Part H, service development, coordination, and monitoring are critical aspects of service coordination. As described by Zipper et al. (1993), the service coordination process extends from outreach and client identification, through assessment, resource identification, and development of the IFSP, to service implementation, monitoring, and evaluation of service outcomes. This broad definition of service coordination incorporates the multiple functions of case management. Zipper et al. (1993) maintain that it is impossible to implement effective service coordination

without collaboratively involving the family in assessment, planning, and evaluation.

Standards that underlie the process of service coordination include: (1) family-centered versus system-centered service coordination (Bailey, McWilliam et al., 1992; Dunst, Johanson et al., 1991; Edelman, Elsayed et al., 1992; Zipper et al., 1993; Bruder et al., 1993; Cormany, 1993); (2) service coordination roles and functions which support and strengthen family functioning (Bailey et al., 1992; Dunst, Trivette, & Deal, 1988; Dunst, & Trivette, 1988; Zipper et al., 1993; Edelman, Elsayed, & McGonigel, 1992; Johnson et al., 1992; Bailey, 1988); (3) linking parents with community resources (Bailey et al., 1992; Bruder et al., 1993; Zipper et al., 1993); (4) flexibility and ability to perform multiple roles (Dunst et al., 1988; Bailey et al., 1992; Edelman et al., 1992; Bruder & Bologna, 1993); and (5) the ongoing training of service coordinators (Bailey, Buysse, Edmondson, & Smith, 1992; Cormany, 1993; Bailey, Palsha, & Simeonsson, 1991; Shonkoff, & Meisels, 1990; Bailey et al., 1986; Bailey et al., 1992).

Even though service coordination tasks may be assumed by family members, or other service providers, the service coordinator is held responsible for each step in the coordination process. According to Dunst et al. (1988), the role of the service coordinator is determined by the

intensity or degree of assistance a family might request. Thus, it is the family who should be given the opportunity to determine the coordinator's role at any given time. Service coordinators ought to expect that their roles will change over time with the families' ever changing resources, priorities, and concerns (Dunst et al., 1988).

Intervention Paradigms and Practices

Since the passage of IDEA, efforts to establish standards, consistent with the legislative intent, have resulted in descriptions of models of family-oriented early intervention programs (Dunst et al., 1991), elements of family-centered care (National Center for Family-Centered Care, 1990; Edelman et al., 1992), and "forces that drive service delivery" (Edelman et al., 1991).

Dunst and colleagues (1991) describe paradigms as models that provide a way to understand the family-oriented programs, a certain type of family-oriented program (e.g., family-centered), and the relationship between elements that define certain segments of family-oriented programs (e.g., family support principles). These models diagram the conceptual framework or operational philosophy of each type of family-oriented early intervention program. The paradigms identified in the literature include: "family-centered" (Dunst, Johanson, Trivette, & Hamby, 1991;

McBride, Brotherson, & Joanning, 1993); "family-focused" (Dunst et al., 1991; Bailey et al., 1986; Simeonsson, & Bailey, 1991); "family-allied" (Dunst et al., 1991); and "professional-centered" (Dunst et al., 1991; McBride et al., 1993). These terms are also used to characterize early intervention service approaches, interventions, and practices (Bailey, McWilliam, & Winton, 1992; Bailey, Buysse, Edmondson, & Smith, 1992; Thurman, 1991; McBride et al., 1993; Bailey et al., 1992; Pearl, 1993; Edelman et al., 1991).

According to Dunst et al. (1991), in the "professional-centered" model, the professional is presented as the expert who, based on his or her own opinion and perspective, determines the needs of the child and family. The family is seen as incapable of "solving their own problems" or of making appropriate decisions regarding the care and development of the child. Early intervention practices that deny families' participation in decision-making for their child and their family unit would be professional-centered.

The "family-allied" paradigm view families as being somewhat more capable of affecting change in their life, although this is accomplished under the supervision of professionals (Dunst et al., 1991). Families engage in implementing interventions prescribed by professionals. In

a family-allied paradigm, the case manager defines the role the family is expected to play (Dunst et al., 1991).

Families are seen in a more positive light in the "family-focused" paradigm (Dunst et al., 1991). Professionals work collaboratively with families to outline what families need in order to provide a more stable environment for the child. They are encouraged by case managers and others to use professional service networks to meet their needs. IFSP outcomes focus on family needs as they relate to the child's development.

The "family-centered" paradigm is distinct from the family-focused paradigm in intent and structure. The families' resources, priorities, and concerns drive the delivery of services. Accordingly, intervention practices support and strengthen the family's capacity to build both formal and informal support systems (Dunst et al., 1991). The professional provides services in ways that promote family decision-making capabilities and competencies. In the family-centered paradigm, the role of the case manager is determined by a family's needs and desired level of participation (Dunst et al., 1991).

Implementing family support is a critical component to providing a family-centered approach to services in early intervention. Turnbull (1988) contends that family support involves providing assistance to families in order to meet

their identified needs, which maximizes their strengths as a family. She also argues that family support should permeate every contact one has with children and families.

Social intervention efforts that utilize family support principles are said to be family-centered. Dunst et al. (1991) maintain that family support principles are statements of beliefs about the method in which resources and community supports ought to be provided in a family-centered manner. Dunst (1990) organized family support principles into six major sets of principles: (a) enhancing a sense of community, (b) mobilizing resources and supports, (c) sharing responsibility and collaboration, (d) protecting family integrity, (e) strengthening family functioning, and (f) employing proactive human service practices. Dunst and colleagues (1991) believe that these principles provide one set of standards for assessing whether any aspect of a program shows a predisposition toward "family centeredness" in ways that support family functioning.

Family-centered care is the name given to an assemblage of philosophies, attitudes, and approaches to care for children with special educational and health needs (Edelman et al., 1992). Family-centered care supports the family's natural caregiving role and acknowledges and respects diverse family structures, cultural beliefs, and values. Bailey, McWilliam, and Winton (1992) believe that the lack

of a clear definition of family-centered care is a barrier to implementing a family-centered approach. The “key elements” of family-centered care were first identified in 1987 by Surgeon General C. Everett Koop (Edelman, 1991). These key elements were revised and expanded in 1990 (National Center for Family-Centered Care, 1990) and have been widely accepted as the best practice.

The key elements of family-centered care, as defined by the National Center for Family-Centered Care (1990), bring into focus the importance of the family and their strengths and individuality. The importance of and need for facilitating parent and professional collaboration, family-to-family support, and networking are stressed. Understanding and incorporating the developmental needs of infants, children, and adolescents into responsive health care systems while honoring the racial, cultural, ethnic, and socioeconomic status of the family are identified as critical. Another essential element is the sharing of unbiased, complete information with parents on a continual basis. Finally, the implementation of comprehensive policies and programs that provide emotional and financial support to meet the needs of families are pivotal in implementing family-centered care.

Edelman and colleagues (1992) contribute another means for determining the direction of the service delivery

system. "System-centered", "child-centered" and "family-centered" are labels identified by Edelman (1992) as the "driving forces" of service delivery. The priorities and choices of the family are the thrust of service delivery in a family-centered service system. One can distinguish between system-centered and child-centered service systems by determining whether the strengths and needs of the "system" or the strengths and needs of the "child" are the forces "driving" service delivery systems. The priorities and choices of the family determine service delivery in a family-centered system.

Case Management Research on Early Intervention

Researchers and practitioners alike are concentrating on the interactional behaviors of professionals and how their collaboration, or lack thereof, affects the families they serve. According to Compher (1989), the significance of the service coordinators' relationship with the client and others in the service networks cannot be underestimated and requires constant surveillance. Compher also notes (1989) that families are better able to focus on problem resolution when their immediate service network is effectively organized.

Much of the literature on the effectiveness of case management is conceptual rather than based upon empirical

studies. Amado and colleagues (1993) contend that most research on the empirical effectiveness of case management has focused on general social services, rather than on persons with developmental disabilities. Some of this research, they maintain, is beneficial in documenting the advantages of an integrated case management approach and in uncovering problems in case management programs. Various authors have described issues in case management, developed standards for case management programs, and suggested roles for case management as a process of quality assurance and accountability (National Council on Social Welfare, 1981; Morell, Straley, Burris & Covington, 1980; Wray, Basuray, Miller & Seiler, 1985; Ashbaugh, 1981; Amado et al., 1993).

Characteristics of case managers and case management systems have been evaluated. In a comparative study of four public social service systems, Brody (1974) found that case managers spend more time on administrative tasks than in providing services. Berkeley Planning Associates (1977) reported that case manager effectiveness and continuity of services to clients was more likely to occur in small, nonbureaucraticized settings in which the workers had more experience, education, and training.

Examining qualitative data, Dunst, Trivette, Starnes, Hamby, & Gordon (1991) ascertained the relationship between helping styles and the extent to which case managers adopted

family-centered intervention practices. The five defining characteristics of case manager beliefs and practices that these investigators used to identify case manager helping styles were: (a) adherence to family support principles, (b) enabling and empowering philosophy, (c) resource-based approaches to intervention, (d) consumer-driven approaches to intervention, and (e) family-centered intervention practices. Dunst et al. concluded that they could predict a case managers' ability to be family-centered based on the helping style adopted.

In a review of case management in early intervention, Bailey (1989) identified 18 data-based descriptions of certain aspects of case management. The studies were categorized into two groups. First, surveys of case managers were used to determine time allocation, job related attitudes, and issues surrounding service implementation. The second group studied the effects of case management or the relative effects of different approaches to case management. Only two of the 18 studies were conducted in the field of developmental disabilities. The surveys of case managers indicated that, across populations and settings, case managers spend more time in indirect service monitoring than in direct support or service provision. In a study conducted by Middleton (1985), and reported by Bailey (1989), case managers described their work as equivocal,

without a clearly defined purpose and role. In addition to the ambiguity, Middleton (1985) reported a gap between implementation of case management services and accepted best practice. Taken collectively, the studies suggest that clients who receive case management services are generally pleased with them. Rapp & Chamberlain (1985) also found some evidence that case management enhances a range of client outcomes in the vocational/educational domain, income, housing, transportation, personal skills, and family life.

Conclusion

This review of the literature has focused on the requirements of the Individuals with Disabilities Education Act, service coordination in early intervention, service delivery models, and related research. The review revealed that research on service coordination is spotty and insufficient. Existing studies have been criticized for failing to adequately describe the types of services provided by the service coordinator, for using nonrandomized comparison groups, and for providing a narrow view of the outcome measures (Rapp et al., 1985; Bailey, 1989). Although none of the research focused on case management with families of handicapped infants, Bailey (1989) believes that the issues are relevant to case management in early intervention.

Some evidence suggests that "clients" who received case management services were pleased with them. However, it is not clear what services these clients were pleased with nor how these services were provided. In the field of developmental disabilities, case managers reported a lack of clarity as to their purpose and role (Middleton, 1985). These same case managers reported a substantial gap between "best practice" in case management and actual implementation of case management services.

CHAPTER 3

METHOD

This chapter includes descriptions of the participants, the data collection instruments, procedural reliability data, the design, and the training component.

Participants

The participants included three service coordinators and nine families (i.e., three families served by each of the three service coordinators).

Service Coordinators

Each service coordinator was employed in this capacity to work with infants and toddlers with disabilities and their families throughout Pima County, Arizona. Two were employed by the Arizona Department of Economic Security (DES), Division of Developmental Disabilities (DDD). The third was employed by a community service provider who contracts with DDD to provide service coordination and early intervention services.

Service Coordinators were selected based on their amount of experience, caseload, and willingness to commit one year to participating in the study. All three had been employed

as service coordinators for at least one year prior to the beginning of the study. Participation in this study required that the service coordinator have a caseload that included many families with an infant or toddler with disabilities, birth through two years of age.

The service coordination activities these people were to perform included: (a) working with families to identify resources, priorities, and concerns; (b) coordinating initial, six-month, and annual assessments and evaluations; (c) assisting families and their teams in developing and implementing IFSP's; (d) working with families to identify available services, as well as formal and informal support systems; (e) coordinating and monitoring service delivery; (f) providing information about community and advocacy services; and (g) facilitating transitions to preschool services. More detail on each of the service coordinators follows.

Donna. Donna had been employed by DDD for the last six years. She had served as a service coordinator for children, birth through three years of age, for the past four. She served families with children who participated in family and centered-based programs, and those with children in foster care. Donna was bilingual and had a Master's degree in Social Work. Her total caseload remained close to 60 for the duration of the study.

Harriet. Harriet had been employed by DDD for four years. During that time, she had served as a service coordinator for school-aged children and for families with infants and toddlers in early intervention programs. The families Harriet worked with had children in family and centered-based programs, foster care, and temporary residential nursing facilities. She was bilingual and had a Bachelor's degree in Child Development and Family Relations. Although her caseload fluctuated throughout the study, it generally consisted of 70 families.

June. June had been employed by a community service provider for three years. She had served as an early intervention specialist and a service coordinator. She served families with infants and children in family and center-based programs. There were 40 families on her caseload throughout the study.

Families

Nine families (i.e., three that received services from each of the three service coordinators) agreed to participate in this study for one year. Each family had at least one child, birth to two years of age, who required services from DDD. Participation required (a) the likelihood of remaining with the same program for the duration of the study, and (b) accessibility by telephone.

These inclusion criteria were chosen to limit the potential for transitions to other programs and increase the chances that all families would participate for the duration of the study. Typically, when children transition from one program to another, the service coordinator changes.

All families that met these inclusion criteria received a letter of introduction and explanation. Nonrandomized groups of families were selected based on the inclusion criteria and their willingness to participate in the study. Although randomization would have been preferable, it would have created uncertainty and could have prevented completion of the study.

Family composition and the disabilities represented in these families varied. Five children lived in married or two-parent households. Three children lived in single-parent-with-extended-family households (i.e., mother and children with maternal grandmother and children) and one child lived in a single-parent household. The ethnic backgrounds represented included Hispanic American, African American, and Anglo. The disabilities represented include four children who had multiple impairments, two who had Down Syndrome, and three who had speech and language delays.

Data Collection Instruments

Data were collected each month from each of the nine families participating in the study. Each month, every family responded to a set of questions designed to assess two areas: (a) procedural reliability (i.e., the degree to which the service coordinator adhered to the intervention procedures), and (b) satisfaction with the service coordination they had received during the previous month. Data on procedural reliability were derived from two sources: a checklist and a portion of a questionnaire (both described below). Data on satisfaction also came from two sources, i.e., the two remaining portions of the questionnaire, items 1 (b) through 6 (b) and questions 7, 8, and 9.

Checklist

The Implementation Checklist (See Table 1, p. 53) was used to document each family's response to these procedures each month thereafter. This checklist required one of three responses for each item: (a) Yes, (b) No, or, (c) Not Applicable. The checklist items are presented in Table 1.

Table 1

IMPLEMENTATION CHECKLIST			
Month _____			
Family _____			
	YES	NO	N/A
1. Discussed the services the family currently receives.			
2. Discussed with the family, their current needs, concerns, and resources.			
3. Informed the family of the state funded and community services available to address their expressed or generated needs.			
4. Explored with the family their informal support system and community resources to satisfy needs which cannot be covered by State funding.			
5. Responded to requests for services within three (3) working days.			
6. Contacted family to inform them of services provided (when provided) and the expected initiation date.			
7. Assisted in the development of the "Action Plan" and update as needed.			
8. Reviewed progress on identified outcomes as written into the "Action Plan" and update as needed.			
9. Provided information to build on family's knowledge (of community resources, etc).			
10. Linked the family with another source/ resource who is best able to help them.			

(Numbers 1, 2, 8, and 9 are required monthly)

Service coordinators were required to interact with each family on a monthly basis by telephone or home visit. During this interaction, each was to discuss the services the family currently was receiving in order to monitor service delivery (Table 1, Number 1). A discussion of current needs, concerns, and resources was to be held (Table 1, Number 2). The service coordinator was required to review the child and family outcomes as written into the "Action Plan" (IFSP) and to update them, as needed (Table 1, Number 8). Information that would build on the family's knowledge of community resources and services was to be provided (Table 1, Number 9).

When appropriate, the service coordinator was asked to:

- (a) inform the family of state funded and community services available to meet their needs (Table 1, Number 3);
- (b) explore with the family their informal support system and other community resources to satisfy needs which could not be covered by State funding (Table 1, Number 4);
- (c) respond to requests for services within three working days (Table 1, Number 5);
- (d) contact the family to inform them of services provided and the expected initiation date (Table 1, Number 6);
- (e) assist in the development of the "Action Plan" and update as needed (Table 1, Number 7); and
- (f) link the family with another source or resource who was best able to help (Table 1, Number 10).

Procedural reliability was calculated by dividing the number of program components implemented by the number of required components. A minimum of four program components (Numbers 1, 2, 8 and 9) were required on a monthly basis. The number of program components beyond that varied depending on the needs of each family.

Throughout the entire study, procedural reliability data were gathered and documented on the Questionnaire (See Appendix A, p. 89) and Implementation Checklist. Data collection procedures were identical during all phases of the study.

Questionnaire

A family-centered paradigm was used to develop a research questionnaire. The defining characteristics of this paradigm were: (a) incorporation of family support principles (Dunst et al., 1991), (b) family-centered intervention practices (Bailey et al., 1992; Edelman et al., 1991; 1992), and (c) an enabling and empowering philosophy (Dunst et al., 1988).

The questionnaire had three parts. The first part included six "a" questions (i.e., Questions 1(a) through 6(a)), each of which is followed by descriptors (See Appendix A, p. 89). Families responded to each question based on the activity of the service coordinator during the

previous month. Each family was asked to circle the descriptor that best described the service coordinator. For each question, the "A" descriptor reflected little or no behavior that would be required by the family-centered model. The "B" descriptor reflected an increase in behavior but little that would be required by the family-centered model. The "C" descriptor reflected the minimal behavior that would be required by the family-centered model, and the "D" descriptor reflected "best practice". Questionnaire item's 1(a) through 6(a) served as a second measure of procedural reliability.

The second part of the Questionnaire, Questions 1(b) through 6(b), required families to indicate their level of satisfaction with service coordination as it pertained to each question. For these items, a three-point rating scale was used. For each question, participants indicated their level of satisfaction as: Satisfied, Nearly Satisfied, or, Not Satisfied.

The third portion of the questionnaire, Questions 7 through 9, required YES or NO responses. These three items were summative and provided additional information not acquired in other satisfaction measures. Question 7 measured each family's level of satisfaction with services provided by each of the three service coordinators each month throughout the study. This measure was included in

order to determine whether families were pleased with the services provided by the service coordinator, based on the model as described above.

Prior to the study, the initial version of the questionnaire was used, critiqued, and modified in a six-month pilot with families with children birth through two years of age who were receiving services through DDD. Several experts in the field reviewed subsequent versions and suggested additional modifications which were then pilot-tested again for six months with ten families.

Procedural Reliability Data

Procedural reliability was calculated across all conditions to determine the degree to which the service coordinators implemented the procedures of family-centered service coordination they learned about in training. Questionnaire descriptors "A" through "D" describe inadequate to best practice for each item. When procedural reliability on the checklist was 85% or greater, the probability of a "C" or "D" rating (indicating acceptable to exemplary compliance with the model) was 99%. When procedural reliability on the checklist was less than 85%, the probability of an "A" or "B" rating (indicating inadequate implementation) was 97%.

Design

A multiple baseline design across subjects was used to study the effects of implementation on satisfaction reported by the families. This multiple baseline design consisted of three conditions: the Baseline or Pre-Training Phase; the Post Training Phase; and the Implementation Phase. The Implementation Phase was added, again in a multiple-baseline design, because none of the service coordinators adequately implemented the procedures of family-centered service coordination they had learned about in training. The Implementation Phase began during different months for each service coordinator and was in a different sequence than that used to stagger the training. Every month, each participating family responded to the Checklist and Questionnaire. The first month of baseline data were collected by the researcher during a home visit with each family. Subsequent data were collected by telephone or home visit.

The checklist and questionnaire were completed with the participating families at each family's convenience. Home visits were made initially with all families. After several months, families preferred to complete the questionnaire over the telephone. One family completed the questionnaire by mail for several months and then resumed telephone contact.

The duration of each experimental condition depended on the outcome of data reported each month by the families. Target behaviors were monitored concurrently and continuously across each subject throughout all three phrases of the study. For Donna, the Baseline Phase lasted three months, the Post Training Phase started in month four, and the Implementation phase started in month nine. Harriet remained in the Baseline Phase for four months; the Post Training Phase started in month five, and the Implementation Phase started in month eleven. For June, the Baseline Phase lasted five months, the Post Training Phase started in the sixth month, and the Implementation Phase started in month eight.

Pre-Training Phase

Parents who indicated an interest in the study were sent a questionnaire. An appointment was made with them to discuss the purpose of the study and their role as participants. Baseline data were collected during that first visit. Queries regarding questionnaire responses were answered and discrepancies between available responses and actual subject behavior were discussed prior to choosing a response.

Parents also were given the opportunity to decide how they would like to be contacted. Preferences ranged from

telephone contacts to home visits. During each monthly contact, the researcher read the questions and responses to the parent, and then the parent indicated his or her response. Notes of all discussions and queries were written on the questionnaire for reference and clarification.

Training Component

Training was conducted by the author in a multi-purpose room at a local social service agency. Each training session involved at least four professionals (i.e., one of the service coordinators and at least three other professionals who were not otherwise involved in the study). Additional interactions with the participating service coordinators occurred over the telephone, in their offices, and in other community settings. All meetings were scheduled and held at a convenient time and location for the service coordinator.

Project Copernicus, a "Train-the-Trainer Series in Family-Centered Service Delivery" (Edelman et al., 1992) was chosen as a prototype for developing the training component. This training program focuses on three areas: "Building Parent/Professional Collaboration"; "Family-Centered Communication Skills"; and an "Overview of Family-Centered Service Coordination". Project Copernicus activities were re-structured to provide small group training activities.

Topics for the six-hour service coordination training program included: (1) recognizing family-centered care; (2) elements of family-centered service coordination; (3) active listening skills; (4) family-centered communication skills; (5) family and professional collaboration; and (6) service coordination roles and activities (See Appendix B, p. 93).

Early intervention specialists and service coordinators from community service providers and DDD were invited to participate on each of the three service coordinator training days. A minimum of three additional participants was required to implement the small group training activities. The training day for each subject was held during the first week of the month that each service coordinator was to enter the Post Training Phase. Data for the previous month were collected prior to training.

Post Training Phase

Immediately following the six-hour training, an additional two hours was spent with each subject, that same day, delineating the procedures each was to follow throughout the Post Training Phase. At this time, the three participating families were identified to each service coordinator. The Service Coordinator Log (See Appendix C, p. 124) was explained to each service coordinator with instructions that it needed to be completed each month for

each family. The service coordinators were asked to record their monthly contacts with each family during the Post Training and Implementation Phases. Each service coordinator was asked to: (a) record the type of contact (e.g., home visit, evaluation, telephone, written), (b) list the concerns and needs expressed by the family, (c) record the date they responded to the family's request, and (d) describe any barriers each experienced in implementing the model.

Implementation Phase

This phase was established because the data on procedural reliability demonstrated that none of the service coordinators adequately implemented the training they had received. The focus here was on providing individual assistance to each service coordinator so that they would adequately implement the required procedures.

June transitioned into the Implementation Phase first because her procedural reliability was 85% or greater with two of the three families for two consecutive months after training. A two-hour meeting was held with her to determine the barriers to implementing the procedures. Assistance requested by June included clarification of the program components and help with ways to implement them with these particular families. Organizational skills needed to

accomplish service coordination tasks within three days were also reviewed and additional Service Coordinator Logs were given. June stated that "it takes determination and a positive attitude to implement these components on a monthly basis." She admitted that she had forgotten about the third family participating in the study and had misplaced her Service Coordinator Logs. Although she was contacted monthly, June did not require further assistance after the two hour meeting. She achieved 85% or greater reliability with all three families for the duration of the study.

Donna moved into the Implementation Phase second after June had achieved procedural reliability of 85% or greater with all three families. Discussion of barriers to implementing the required procedures revealed Donna's personal dissatisfaction with the lack of support she received in her Division office. A lack of clerical help, case turn-over rate, low pay, and a lack of trust between co-workers were initially described as the barriers to implementation. After further discussion, Donna conceded that she was no longer following the procedures described for the Post Training Phase. Difficulty contacting families during work hours, poor relationships with families, and lack of timely follow-through further hampered implementation of the procedures. The program components were clarified for Donna and alternative ways of contacting

and working with families was discussed (e.g., giving her pager number to families she needed to reach; showing more of an interest in the families). Donna did not achieve reliability with any of the three families after a two-hour meeting. An hour of additional follow-up was provided, after which Donna achieved 85% or greater reliability with all three families. Follow-up included telephone discussions of previously discussed barriers to implementing the procedures and any new barriers experienced.

After Donna achieved procedural reliability of 85% or greater with all three families for one month, Harriet transitioned into the Implementation Phase. Barriers identified by Harriet, during a one and a half hour meeting included her overall caseload size (although only three families were part of the study), her on-going relationship or lack thereof with the families, and, her expectations of the families and their abilities. Harriet held firmly to the belief that if a family needed her help they would contact her, regardless of whether they had ever met her before their need arose. Follow-up telephone conversations continued throughout the final two months of the study. Harriett achieved procedural reliability of 85% or greater with only one family during each of the last two months.

Summary

The effects of a treatment package on levels of satisfaction and the performance ratings of service coordinators were evaluated using a multiple-baseline design across three subjects. The stages of this design included Pre-Training, Post Training, and Implementation phases. These stages have been described in conjunction with data collection procedures. Data were recorded on the Questionnaire, Implementation Checklist, and Service Coordinator Log.

CHAPTER 4

RESULTS

This section reports results of family satisfaction related to implementation of the family-centered model of service coordination, and of the effects of training on implementation. The term "implementation" will be used to refer to those months in which a service coordinator achieved procedural reliability of 85% or greater. The term "non-implementation" will be used to refer to those months in which a service coordinator failed to achieve procedural reliability of at least 85%.

To assess the variability among the six satisfaction ratings given by each family each month, an analysis was made between the rating given to Questionnaire Item 1 and to those given to Items 2-6. The purpose of this analysis was to determine whether families tended to report the same degree of satisfaction across all six Questionnaire Items each month. For example, if the response by Family 1 to Question 1 in the first month was "Not Satisfied", what was the probability that the other questions were given the same rating that month? This analysis revealed a 93% probability that the ratings given to Questions 2-6 were identical to that given to Question 1, regardless of whether the response

was "Not Satisfied", "Nearly Satisfied", or "Satisfied". Therefore, results for Questionnaire Items 1-6 will be presented in summary form across all items (See Table 2, p. 68). Questionnaire items 7, 8, and 9 are summative in nature and will be presented separately.

Satisfaction Related to Implementation

Each family's level of satisfaction with the services provided was assessed every month as it related to each questionnaire item. Throughout the baseline or Pre-Training Phase, implementation was not achieved by any of the service coordinators (See Figures 1-6, pp. 69-74). On these Figures, arrows indicate those months in which the model was implemented. Across all experimental conditions, when service coordinators implemented the model (i.e., obtained procedural reliability of 85% or greater), only 2% of the responses indicated dissatisfaction. In contrast, when the model was not implemented, 85% of the responses indicated dissatisfaction. Ratings of "Nearly Satisfied" were given on 22% of the responses when the model was implemented, compared with 14% when the model was not implemented. As shown in these Figures and in Table 2, when implementation occurred, 76% of the responses indicated satisfaction; in contrast, when the model was not implemented, only 1% of the responses indicated satisfaction.

Table 2

Level of Satisfaction When the Model Was Implemented or Not Implemented.

	With Implementation	Without Implementation	
Satisfied	76%	1%	Satisfied
Nearly Satisfied	22%	14%	Nearly Satisfied
Not Satisfied	2%	85%	Not Satisfied

Satisfaction with Information Provided

Satisfaction with Decision-Making Involvement

Figure 2

Satisfaction with Resources and Support

Figure 3

Satisfaction with Receiving Services Requested

Satisfaction with Approach

Figure 5

Satisfaction with Service Coordinator Interactions

Questionnaire items 7, 8, and 9, (See Questionnaire, Appendix A, p. 89) were summative items that required a "Yes" or "No" response. Data on these items are presented in Table 3 (See Table 3, p. 76). Question 7 addressed whether the service coordinator provided an important service for the family. With implementation, there was 93% agreement. Without implementation, there was only 13% agreement.

Question 8 asked families to determine whether the information they received from their coordinator allowed them to seek assistance from other agencies without the coordinator's assistance. Data indicate 69% agreement with this statement when service coordinators implemented the model. Without implementation, only 1% agreement was indicated.

Item 9 asked whether the service coordinator helped connect the family with those individuals who were best able to help them (e.g., Parent Support Group, State and Federal Assistance, O.T., P.T.). With implementation, data indicate 93% agreement. Without implementation, there was only 8% agreement.

Table 3
Percentage of Agreement

	With Implementation	Without Implementation
Importance of Service Question 7	93%	13%
Mobilizing Resources and Supports Question 8	69%	1%
Enhancing Sense of Community Question 9	93%	8%

The Effects of Training and Implementation

Training by itself did not lead to adequate implementation (See Figures 1-6, pp. 69-74). In the Post Training Phase, Donna implemented the model 6 out of 15 times (40%), Harriet implemented the model only 2 out 18 times (11%), and June implemented the model 4 out of 6 times (67%).

Because no one adequately implemented the model with training alone, a third experimental phase involving individual technical assistance was established to improve implementation. In this phase, Donna achieved 50% implementation, Harriet reached 33% implementation, and June achieved 100% implementation.

Summary

When the family-centered model was implemented, families reported a high degree of satisfaction (76%) and a low degree of dissatisfaction (2%). In contrast, when the family-centered model was not implemented, families reported very little satisfaction (1%) and a high degree of dissatisfaction (85%). In addition, training alone did not lead to implementation of the family-centered model. However, with additional individualized support, each service coordinator achieved much better implementation. From the Pre-Training to the Implementation Phase, the

increases were as follows: 0% to 50% for Donna, 0% to 33% for Harriet, and 0% to 100% for June.

CHAPTER 5

DISCUSSION

The present study is one of only a few investigations of service coordination in the field of developmental disabilities. It is the only study that examines the efficacy of family-centered service coordination in early intervention, the effects of its implementation on family satisfaction, and the effects of training on implementation.

This chapter includes a summary of the research, the significance and relationship of the research to other literature, limitations of the study, implications for future research, and implications for practitioners in the field.

Summary of the Research

The purposes of this study were to design, implement, and analyze the effects of family-centered service coordination to families with children, birth to three years of age, who participate in Part H of IDEA. The research questions investigated were: (1) does the family's level of satisfaction improve when family-centered service coordination procedures, acquired through training, are implemented in the delivery of services to infants and

toddlers? and, (2) does the training program result in implementation of this family-centered service coordination model?

The participants included three service coordinators and nine families. Three families were served by each of the three service coordinators. Data were collected monthly from each of the nine families using a questionnaire and a procedural reliability checklist. Procedural reliability was calculated across all conditions to determine whether the service coordinators implemented the procedures of family-centered service coordination they learned about in training.

A family-centered paradigm was used to develop the research questionnaire. The defining characteristics of this paradigm were: (a) incorporation of family support principles (Dunst et al., 1991), (b) family-centered intervention practices (Bailey et al., 1992; Edelman et al., 1991; 1992), and (c) an enabling and empowering philosophy (Dunst et al., 1988).

A multiple-baseline design across subjects was used to study the effects of implementation on satisfaction reported by the families. The stages of this design included Pre-Training, Post Training, and Implementation. The Implementation Phase was added, again in a multiple-baseline design, because none of the service coordinators adequately

implemented the model in the Post Training Phase. The Implementation Phase began during different months for each service coordinator and was initiated in a different sequence than that used to stagger the training. The duration of each experimental phase depended on the responses given each month by the families.

Results indicated that when the family-centered model was implemented, families reported a high degree of satisfaction and a low degree of dissatisfaction. In contrast, when the model was not implemented, families reported very little satisfaction and a high degree of dissatisfaction. Moreover, training alone did not lead to implementation of the family-centered model. With individualized support, service coordinators achieved much better implementation.

Significance and Relationship to Other Literature

The major findings of this study are significant for several reasons. First, there are only a handful of studies in the literature that address service coordination in the field of developmental disabilities. Furthermore, none of these studies has involved service coordination in early intervention.

Second, this study examined the impact of service delivery on those who received services. In contrast, most

research on case management has focused on the case manager. For example, surveys of case managers have identified attitudes about case management (Rubin & Johnson, 1982; Middleton, 1985), described issues related to implementing services (Middleton, 1985), and explored time allocation (Kurtz, Bagarozzi, & Polane, 1984; MacEachron, Pensky, & Hawes, 1986; Wright, Skelbar, & Heiman, 1987). Although a few studies have attempted to examine the effects of case management on recipients and have suggested that recipients benefit from the services they receive (Baker & Weiss, 1984; Rapp & Chamberlain, 1985; Zimmerman, 1987), these studies have been criticized on methodological grounds. For example, Bailey (1989) argued that it is not possible to draw any conclusions from these studies because they failed to use acceptable research designs.

Third, since the early 1990's, the early intervention literature has been flooded with descriptions of the family-centered philosophy, values, service approaches, intervention policy and practice, training procedures, and models. Millions of dollars have been spent educating, training, and disseminating information on the family-centered approach to early intervention personnel, community service providers, families, pre-school special education personnel, and legislators. Furthermore, the field has collectively agreed that a family-centered approach

constitutes "best practice." Perhaps most interesting is the fact that all of this has occurred in the absence of any data that support the approach. Fortunately, the results of this study support the direction the field has taken.

Finally, this study points out that although training programs are continually being developed and implemented, their impact is questionable. One cannot assume that individuals will implement the training they receive. Despite intensive, individualized training using nationally recognized training materials, service coordinators did not implement the model as designed. Although millions of dollars are being spent annually to train early intervention professionals and para-professionals, there is some reason to question whether training in best practice will be sufficient to result in implementation of best practice.

Limitations of the Study

The findings of the current investigation are limited to the three service coordinators and the nine families that participated in the study. Caseloads for the three service coordinators during the study ranged from 40 to 70 families each. It should not be inferred that these results generalize to these service coordinators' entire caseloads. In addition, the effects of caseload size on the

implementation of the family-centered model cannot be determined from this study.

Participation in this study by the nine families and the three service coordinators was voluntary. Self-selection by the service coordinators did not necessarily result in implementation of the model. The service coordinators' belief systems, organizational skills, and organizational support systems were a few of the factors that influenced their implementation. Furthermore, it is not known whether similar results would occur with a randomized selection of service coordinators and families.

This study looked only at the implementation of this model; it did not consider other demands made on the service coordinators. For example, service coordinators are expected to integrate differing service systems (e.g., health and education), provide for high quality services, maintain cost-effectiveness, and satisfy the demands made by superiors. None of these other factors was considered in this study.

The individualized support given to service coordinators to improve implementation of the model did not provide the researcher with sufficient information on the variety of supports that might be needed by service coordinators to enable them to implement the model consistently over time. Supports provided during the Implementation Phase were based

on the individual identification of the barriers each service coordinator experienced in attempting to implement the model. The specific barriers that other service coordinators might encounter could be quite different.

Implications for Future Research

A number of implications can be derived from this study. First, it is necessary to replicate the study to include the full caseloads of early intervention service coordinators. In conjunction with this replication, it would be important to analyze the supports (e.g., administrative, technical, emotional) required to help service coordinators implement a family-centered model.

A second area for research involves the effects of family-centered service coordination on the service coordinator. Social validity is used to assess the social significance of potentially relevant goals, procedures, or effects. It has provided a critical measure of the social impact and importance of intervention in applied behavior analysis since the mid-1970's (Kennedy, 1992). The current study demonstrated good social validity for families by documenting the high degree of satisfaction that occurred when the family-centered model was implemented. If service coordinators are expected to implement a family-centered model, it is important to consider the social validity of

this model not only for the service recipients, but for the service coordinators as well.

A third area for research involves the impact of training on implementation. The results of this study substantiate that training alone does not lead to implementation. This result is significant for all educators and trainers in all situations in which the expected outcome of training is implementation. Therefore, methods of training and follow-up that result in the implementation of training components need to be researched.

Finally, it is important to conduct more studies that assess the social validity of "best practice" in early intervention. Only through such studies will we be able to determine the importance, value, and impact of early intervention practice on those receiving services and to those providing services.

Implications for Practitioners

Training and Technical Assistance

In this study, follow-up and technical assistance emerged as critical components in training service coordinators to implement a family-centered service coordination model in the provision of Part H services. When service coordinators received additional individualized

support, each achieved better implementation. Levels of support varied, however, and were determined to an extent by the researchers' ability to locate and communicate with each service coordinator. The most effective level of support included weekly contacts with two face-to-face meetings and two telephone conversations each month for an extended period of time (i.e., five months). The least effective level of support included one direct telephone contact each month for a short period (i.e., two months).

Issues surrounding individual service coordinators' belief systems and their perceived lack of organizational support were difficult to resolve during the study. In part, this may have been due to the limited number of successful contacts made during the Implementation Phase. In addition, the researcher was unable to provide the internal support (e.g., reduced case load size, clerical assistance, mentoring) needed to reduce or eliminate identified barriers.

Data Collection Instruments

One of the purposes of this study was to analyze the effects of family-centered service coordination on family satisfaction. The Questionnaire and Implementation Checklist were used to document levels of satisfaction and implementation of a family-centered service coordination

model. Questionnaire items (i.e., items 1(a) - 6(a), and 8 and 9) and corresponding descriptors (i.e., A, B, C, and D) were used to develop the Implementation Checklist. In retrospect, the resulting repetition of information was unnecessary. If these items were eliminated, it would not dilute or alter the data gathered.

To simplify data collection, questionnaire items 2 through 4 and 7 through 9 should be eliminated. Questionnaire items 1, 5, and 6 should be incorporated into the Implementation Checklist. Questionnaire items 5 and 6 should be added to those required monthly (i.e., Numbers 1, 2, 8, and 9).

A revision of the method in which satisfaction data are documented also is recommended. An analysis of the variability among the six satisfaction ratings given by each family each month revealed a 93% probability that the ratings given to Questions 2-6 were identical to that given to Question 1. This was true regardless of whether the response was "Not Satisfied", "Nearly Satisfied", or "Satisfied". Therefore, the documentation of levels of satisfaction can also be incorporated into the Implementation Checklist for data collection on a monthly basis.

APPENDIX A
QUESTIONNAIRE

THE EFFECTS OF FAMILY-CENTERED SERVICE COORDINATION

QUESTIONNAIRE

THE EFFECTS OF FAMILY CENTERED SERVICE COORDINATION

TO ANSWER THE FOLLOWING QUESTIONS, USE THE "QUESTIONNAIRE CRITERIA" PROVIDED. CIRCLE THE LETTER THAT BEST DESCRIBES YOUR RESPONSE FOR EACH MONTH.

1(a) We are informed, by (Name), of the services that are available to us.

- A:** (Name) has not communicated with us this month (via letter, telephone, or home visit) regarding services.
- B:** (Name) has asked questions and/or given information only about those services we are currently receiving.
- C:** (Name) has informed our family of additional services and has explained the services to us.
- D:** (Name) has reviewed all the services available to our family and has answered all of our questions regarding the appropriateness and availability of the services.

**1(b) How satisfied are you with this level of service?
(Does this meet your needs; are you pleased)**

Satisfied Nearly Satisfied Not Satisfied

2(a) (Name) involves us in making decisions about the services we receive.

- A:** (Name) has not communicated with us this month.
- B:** (Name) may share some information on the services we can receive and may or may not tell us about the changes in services when they occur.
- C:** (Name) shares information on services we can receive and may or may not involve us in making decisions regarding the amount, level, and duration of services.
- D:** (Name) ensures that we have all the information we need to make the best, most informed decisions about services for our child and family, and regularly shares information about services and changes in services. We decide the amount, level, and duration of these services, and our level of participation.

**2(b) How satisfied are you with this level of service?
(Does this meet your needs; are you pleased)**

Satisfied Nearly Satisfied Not Satisfied

3(a) We play a major role in deciding which resources and support we need and would like to receive.

- A:** (Name) has not communicated with us this month.
- B:** (Name) decides when we need a particular service, then tells us about it (eg: evaluations, alternative programs).
- C:** (Name) tells us we may be entitled to a service after we have expressed a need in that area. We may or may not receive the service.
- D:** After (Name) informs us of all the services available to us, we determine what we need based on our priorities, resources and concerns. We discuss community and family resources and the ability of state funded programs to pay for services. We work together to obtain the services we need.

**3(b) How satisfied are you with this level of service?
(Does this meet your needs; are you pleased)**

Satisfied Nearly Satisfied Not Satisfied

4(a) We are receiving the services we feel are needed for our family.

- A:** We are unable to discuss our needs with (Name); she has not communicated with us this month.
- B:** We still receive essentially the same services.
- C:** (Name) has talked with us about our priorities and concerns, has told us what services we can receive, and has or has not obtained them for us.
- D:** (Name) has informed us of all services that are available and has helped us identify our resources, priorities and concerns. We are now receiving the services we requested at the time and place that is best for us.

**4(b) How satisfied are you with this level of service?
(Does this meet your needs; are you pleased)?**

Satisfied Nearly Satisfied Not Satisfied

5(a) (Name) understands the decisions we make as a family.

A: (Name) has not contacted us this month and therefore, cannot understand the types of decisions we need to make.

B: (Name) is critical of the decisions we make.

C: For the most part, (Name) does judge us or the decisions we make.

D: (Name) does not judge us or the decisions we make whether or not she understands them. She supports us and advocates for our needs.

5(b) How satisfied are you with this level of service?
(Does it meet your needs; are you pleased)?

Satisfied Nearly Satisfied Not Satisfied

6(a) The service coordination/case management we receive respects our family's personal and cultural beliefs and values.

A: (Name) has not maintained regular contact with us so we do not know whether she respects our families' beliefs and values.

B: (Name) has maintained contact with us but does not consider or respect us and our lifestyle, beliefs, and values.

C: (Name) appears to respect each member of our family and considers our personal and cultural beliefs and values.

D: We know through experience that (Name) respects each member of our family, advocates for us, and protects our rights under the DDD system.

6(b) How satisfied are you with this level of service?
(Does this meet your needs; are you pleased)?

Satisfied Nearly Satisfied Not Satisfied

PLEASE CIRCLE "YES" OR "NO" IN RESPONSE TO EACH QUESTION AS IT PERTAINS TO EACH MONTH.

7. (Name) provided an important service for our family.

YES NO

8. The information we received from (Name) allows us to seek assistance from other agencies with depending on her for help.

YES NO

9. (Name) linked our family with those individuals who are best able to help our family (eg: Lekotec, WIC, Food Stamps, Parent Support Groups).

YES NO

APPENDIX B
SERVICE COORDINATION TRAINING COMPONENT

This Appendix contains the training agenda, the training activities, and the script used throughout the training component.

SERVICE COORDINATION TRAINING

The following materials/activities were restructured for this training component:

- Edelman, L., Elsayed, S.S., McGonigel, M. (1992). Overview of family-centered service coordination. (Project No. MCJ-245028) St. Paul, MN: Pathfinder Resources, Inc.
- Edelman, L. (Ed.) (1991). Getting on board: Training activities to promote the practice of family-centered care. Bethesda, MD: Association for the Care of Children's Health.
- Edelman, L., Greenland, B., & Mills, B. L. (1992). Family-centered communication skills. St. Paul, MN: Pathfinder Resources, Inc.
- Edelman, L., Greenland, B., & Mills, B. L. (1992). Building parent/professional collaboration. St. Paul, MN: Pathfinder Resources, Inc.

Activity 1	Recognizing Family-Centered Care Handout and Discussion -- 40-60 minutes
Activity 2	Key Elements of Family-Centered Service Coordination Activities and Discussion -- 60 minutes What's In It For Me? Applying Key Elements to Practice What Is Family-Centered Communication?
Activity 3	Active Listening Discussion -- 30 minutes
Activity 4	Watch Your Language! Activity -- 30 minutes
Activity 5	Assessing Family-Centered Communication Skills Self-assessment -- 10 minutes

Activity 6 **The Evolution of Family-Centered Service Coordination**
Presentation of Information & Discussion -- 15 minutes

Activity 7 **Family/Professional Collaboration**
30 minutes

Discussion of the question: What is the nature of the relationship between the family and the coordinator?

Activity 8 **Service Coordination Activities and Roles**
Presentation, Discussion, Reading --60 minutes

What actually happens in service coordination?

Who does what?

The IFSP: How services are documented and monitored

Activity 9 **Specific Procedures**
2 hours

Procedures for Implementing the Family-Centered Service Coordination Model

THE EVOLUTION OF FAMILY CENTERED SERVICE COORDINATION

"A family centered approach to service coordination didn't just happen. A transition from traditional case management to family centered service coordination has occurred and is still in process."

"Trends in the evolution of case management for families who have children with special needs represent a move toward a more family centered approach. There is a real difference between traditional case management and family centered service coordination."

"Traditional case management in the disability field grew out of a medical model. People with disabilities or chronic illnesses received a diagnosis and a corresponding treatment plan that was developed by a team of professionals from a variety of disciplines. The case manager's role was to coordinate the activities of the various professionals and to ensure that the care and services in the plan were provided. With the proliferation of human services in the mid 1960's, case managers increasingly became responsible for coordinating care and services from a variety of agencies, organizations, and programs on behalf of the identified 'client'."

"In contrast, family centered service coordination is a newly emerging concept. It represents a marriage of the key elements of family centered services with the service coordination aspects of traditional case management. In this new approach, families in consultation with professionals, determine the services they want and make the final decisions about their service plans. The family centered service coordinator's role is to help families meet their goals for their children and themselves. This is accomplished within the context of strong, trusting, collaborative relationships between the family and the service coordinator."

ACTIVITY: "Let's take a few minutes to look at the differences between traditional approaches to service coordination and new approaches in family centered service coordination."

Use a flip chart to list the participants' responses.

THE EVOLUTION OF FAMILY-CENTERED SERVICE COORDINATION

TRADITIONAL APPROACHES	NEW APPROACHES
Focus on the child	Shift to a focus on the child in the context of the family
Focus on deficits, pathology, illness, weakness	Shift to a view of all children and families as having strengths and resources
Focus on the power and control of the case manager	Shift to a recognition that families are the ultimate decision makers
Focus on working within complex, uncoordinated service systems	Shift to a focus on changing these systems to make them more responsive to children and families

When finished, place the overhead transparency, The Evolution of Family Centered Service Coordination, on the overhead projector & review.

Do you have any questions or comments you would like to make?

"As we've seen, this change from traditional case management to family centered service coordination hasn't happened over-night. It's been a long time in the making and still is in the process of evolving."

"In the next activity, we will review the key elements of family centered service coordination, and discuss the benefits for professionals, parents, and organizations."

ACTIVITY 2

KEY ELEMENTS OF FAMILY CENTERED SERVICE COORDINATION

"Family centered communication involves practicing a set of skills that reflect the key elements of family centered care. A good place to begin a discussion of family centered communication skills is with these elements."

Place the transparency, Key Elements of Family-Centered Services, on the overhead and then say:

"The key elements were identified in 1987 as part of former Surgeon General Koop's initiative on family centered, community-based, coordinated care for families with children with special health needs. They have since been further defined by the National Center for Family-Centered Care at the Association for the Care of Children's Health."

Review all elements.

ACTIVITY: *"What's In It For Me?"*

*Assign one question to each of three small groups of two or more;
Group jots ideas down on paper;
One person from each group shares their ideas.*

KEY ELEMENTS OF FAMILY-CENTERED SERVICES

- Recognizing that the family is the constant in a child's life, while the service systems and personnel within those systems fluctuate.
- Facilitating parent/professional collaboration at all levels of service provision: services for an individual child; program development, implementation, and evaluation; and policy formation.
- Honoring the racial, ethnic, cultural, and socioeconomic diversity of families.
- Recognizing family strengths and individuality and respecting different methods of coping.
- Sharing with parents, on a continuing basis and in a supportive manner, complete and unbiased information.
- Encouraging and facilitating family-to-family support and networking.
- Understanding and incorporating the developmental needs of infants, children, and adolescents and their families into service delivery systems.
- Implementing comprehensive policies and programs that provide emotional and financial support to meet the needs of families.
- Designing accessible service delivery systems that are flexible, culturally competent, and responsive to family-identified needs.

ACTIVITY: 3 "WHAT IS FAMILY- CENTERED COMMUNICATION?"

Although family-centered communication involves all of the *Key Elements*, let's focus in more depth on 3 of those key elements.

--put up overhead and discuss each one individually

"I'd like you to suggest some examples of how each element might influence the way that service providers communicate with families."

Honoring the racial.....

- communicate with a family using their language--no jargon*
- avoid assuming that any one way will work*

Recognizing family strengths....

- respect a family's right to make their own decisions even when different than the professionals*
- recognize that different family members have different ways of handling situations*

Sharing with parents....

- all information and options should be offered*
- don't censor information out of fear that families won't be able to handle it*

"Do you see the relationship between communication and the key elements of family-centered services? Do you need further discussion of this?"

ACTIVE LISTENING

"A common barrier to communication occurs when people are more intent on expressing themselves than on listening to and understanding others."

"Steven Covey (author of *The seven habits of highly effective people*) suggests that we should

first seek to understand, then to be understood."

"By using the skills involved in active listening, we can better understand others' point of view and avoid making assumptions that will impede communication."

"Take a few minutes to read this description of the elements of ACTIVE LISTENING."

----show the overhead and briefly review each

"As we all know, it's really a challenge to do this all the time. Let's try an activity that will allow us to practice the elements of active listening."

"There are three roles in this exercise--- a speaker, a listener, and an observer. Each of you will eventually get to assume each role. Begin by deciding who in your group will play each of these three roles."

Active Listening

First seek to understand, then to be understood.

Stephen Covey

The purpose of active listening is to help you clearly understand *exactly* what the speaker is trying to communicate, and to let the speaker know that you have understood. In active listening, we listen for both the content and the feeling conveyed in the message. Good active listening includes all of the elements described below.

Elements of Active Listening

1. Be Attentive	Pay close attention to what is being said; demonstrate that you are listening through attentive body language.
2. Be Impartial	This is perhaps the most difficult of these elements -- it means not agreeing, disagreeing, or stating <i>any</i> opinion about what is being said. Remember, the purpose of active listening is to understand the other person.
3. Reflect Back	Use the same or similar words to reflect the speaker's idea back to him or her. For example -- Speaker: "I'm really unhappy about the meeting we had today." Listener: "It sounds like you have some concerns about how it went." This technique helps both to convey your interest and to elicit more information.
4. Listen for Feelings	If something is important to the speaker, he or she will have feelings about it. Often, the feelings themselves are the most important part of the message. Acknowledge the feelings the other person is conveying to you. For example -- "It sounds like you have some concerns about how it went," or "From the way you describe the situation, it sounds like you're very frustrated."
5. Summarize	Pick out what you think were the most important parts of the speaker's message. Summarize them back to the speaker, to be sure you understand and to convey your understanding to the speaker.

*"The **speaker's role** is to describe an experience that you have definite feelings about that you have had with a family. It could be an experience with a family you know, a family you have worked with, or your own family. Choose an experience that you can describe in a couple of minutes.*

*"The **listener's role** is to listen to the speaker, pay close attention, and use the elements of active listening that we discussed."*

*"The **observer's role** is to observe the exchange, and, when they are finished, give the listener feedback on how well she used the elements of active listening."*

---Time: 2-3 minute scenarios
offer feedback to each other and discuss what has been learned

*"What kind of feedback did you give each other?"
"What issues did you discuss?"*

In conclusion:

Many barriers to communications can be prevented if active listening skills are practiced.

"Let's shift our attention from listening to speaking. Let's look at the power of language, and how the words we use affect the families we provide services to."

WATCH OUR LANGUAGE

"Family-centered care is built on partnerships between families and service providers. Many words used to describe families with children who have special needs are outdated, inaccurate and stem from misconceptions. These words create attitudes and behaviors that hinder the development of trusting relationships between families and service providers. It's important to know the effect these words have on the families who hear them and on the service providers who use them."

Label the left hand column "Negative Words"

"Let's think about some words used to describe families that reflect negative attitudes. Let's make a short list of the negative words you have commonly heard, read, or even used about families."

Label the middle column "Feelings"

"We've identified some words that are commonly used to describe families. How would you feel if you heard your family described by these words?"

Label the right hand column "Assumptions"

"When we hear or see these words used to describe families, we tend to make assumptions. What assumptions do we make about families when we hear them being described by these words?"

When finished:

"We've identified some words, thought about the effects they have on families, and thought about the assumptions we make as service providers about the families these words are applied to. We can see that these words can hinder a trusting, collaborative relationship between families and service providers."

"Let's take a moment to think about some alternatives to using these words to describe families. The alternatives we come up with can be considered guidelines for speaking about and describing families."

*Label a sheet of paper: **"Guidelines for Speaking About Families"***

Tell the group:

"Let's make a list of guidelines that should influence the language we use when we refer to, or talk with, families."

When finished:

"This list of guidelines will be saved, typed, and distributed to all of you. It can serve as:

- * a basis for discussions at team meetings;
- * a foundation for developing policies;
- * a reference to be placed near your desk or phone as a reminder of the importance of word choice."

In summary:

"As service providers, we help shape the views others have of families. Very often, we use shorthand, jargon, and labels without realizing the effect on families and on the perceptions others develop about them. We need to incorporate the guidelines we generated today for speaking about families into the way we write reports, discuss families in staff meetings, and talk with families themselves."

ASSESSING FAMILY-CENTERED COMMUNICATION SKILLS

(Adapted from Edelman, Greenland, & Mills, (1992). *Family-Centered Communication Skills*)

Tell the group:

"We have reviewed and practiced skills and strategies in active listening, word use, and communicating respectfully. We've also discussed how challenging it can be to apply these best practices all the time. Even though we provide excellent services, there is always room for improvement. In order to continually improve how well we serve families, we each need to examine the extent to which we use these skills. Do we use them as often and as well as we know we can?"

*Hand-out self-assessment: Assessing Family-Centered
Communications Skills Worksheet*

"This self-assessment is a tool that each of us can use to strengthen our family-centered communication skills. Various ways this can be used include:

- * Review it before engaging in a conversation with a family
- * Use it after a home visit or evaluation to check how you did
- * Complete it just after a conversation that you felt went poorly. It can help you assess what happened, and help you do better next time.

Please take a moment to read though it and fill it out if you would like to.

Are there any questions or comments?"

Assessing Family-Centered Communication Skills Worksheet

	Never	Rarely	Occasionally	Frequently	Always
Use active listening					
Avoid using offensive language					
Use non-judgmental language					
Avoid making assumptions					
Avoid jargon, explain terms					
Share complete information					
Offer opinions as options					
Answer questions directly if you can, or say "I don't know"					
Avoid patronizing language and tone					
Consider differing abilities to understand					
Clarify mutual expectations					
Clarify next steps					
Realign the power					
Respect cultural differences					
Recognize time and resource constraints					
Pay attention to nonverbal cues					
Allow for open communication					

ACTIVITY 4

BUILDING MUTUAL TRUST AND RESPECT AND CLARIFYING ROLES AND EXPECTATIONS

(Adapted from Edelman, L., Greenland, B., & Mills, B.L. , 1992, *Building Parent/Professional Collaboration*)

Explain the 4 Rules of Brainstorming (Osborn, 1963):

1. Quantity is desirable.
2. Divergence is encouraged.
3. Combine and build on the ideas of others.
4. No negative comments or "Yes, But! (s)".

On two separate wall charts write:

Developing Relationships:

1)building mutual trust and respect 2)clarifying roles and expectations

"Collaborative relationships don't just happen on their own. Positive relationships develop as parents and professionals demonstrate their mutual trust and respect, and clarify what they can expect of each other. Let's first explore how to build mutual trust and respect."

Lead the group in discussion based on this question:

"What can you do to build mutual trust and respect?"

"What actions can you take to build mutual trust and respect?"

*List the responses. eg: Be honest.
Follow through on what has been planned
Communicate without jargon.....*

When finished with that discussion, say:

"Trust and respect are very powerful factors that can shape the quality and degree of collaboration."

"Another factor that influences collaborative relationships is the extent to which families and professionals share the same vision of the roles and responsibilities each will assume."

"What can you do to assure a mutual understanding of each other's roles and of what each of you can expect of one another?"

List responses on 2).

*eg: Don't leave important questions unspoken.
Write down what was said, what took place, what's to happen next.
Clarify important information early on in the relationship (roles)*

"In the activity following lunch we will focus our attention on the activities and roles of the service coordinator."

ACTIVITY 5

SERVICE COORDINATION ACTIVITIES AND ROLES

(Adapted from Edelman, L., Elsayed, S. S., & McGonigel, M. *Overview of Family-Centered Service Coordination*. 1992)

Put up overhead.

"In this activity we'll look at these questions:

"What actually happens in service coordination?"

and

"Who does what?"

"Let's look at what coordinators and families actually do as part of service coordination." "Give me your ideas and examples and I'll write them down."

When finished, put on Edelman Overhead and show how each example they gave fits into each of the activities.

SERVICE COORDINATION ACTIVITIES

- **Planning**
- **Referring**
- **Coordinating**
- **Monitoring
and Evaluating**
- **Advocating**

Service Coordination Activities

Planning:

Helping families identify and clarify their goals for their children and themselves. Designing, organizing, and reviewing strategies, activities, resources, and services to meet these goals.

Referring:

Directing families and others to the resources, services, and supports necessary to meet family-identified goals.

Coordinating:

Establishing and maintaining links among the resources, services, and supports necessary to meet family-identified goals.

Monitoring and Evaluating:

Documenting and tracking the delivery of services and evaluating the extent to which these services meet the family's goals. The information is often used for subsequent planning.

Advocating:

Influencing systems and decision-makers on behalf of individual children and families; participating in efforts to strengthen and improve services for all children and families.

"Do you have any questions or comments about these kinds of activities?"

"Now that we've looked at the kinds of things that might happen during service coordination, we can examine the next question:

"Who does what?"

Let the group generate some ideas, then.....

"The answer is that families and coordinators work together not only to determine what needs to happen, but also to decide who will do it. If it is decided that the coordinator will be responsible for a particular activity, another decision must then be made. How will the service coordinator provide that service?"

"In family-centered service coordination, the coordinator's role will correspond to the degree of assistance requested by the family. To better understand how these roles work, take a few minutes to read

Service Coordination Roles

After they finish reading,

"The Townsends have a specific problem - - finding a baby-sitter who is capable of watching their son Ricky. They want help from their service coordinator to resolve this particular issue."

"The role that the service coordinator plays in assisting the Townsends depends upon what the Townsends want and what they ask their service coordinator to do."

"In this example, the service coordinator was asked to help the Townsends locate someone capable of watching Ricky by referring the family. We read how this could be done in three different ways----consultation, teaching, or direct assistance."

SERVICE COORDINATION ROLES

A unique thing happens in family-centered service coordination. Families and service coordinators work together, not only to determine what needs to happen, but also to decide who will do it. If they decide that the coordinator will be responsible for a particular activity, another decision must then be made. What role will the coordinator play? Or stated another way, *how* will the service coordinator provide that service? In family-centered service coordination, the coordinator's role will correspond to the degree of assistance that is requested by the family. To better understand how these roles work, consider three possible service coordination roles: consultation, teaching, and direct assistance. To illustrate, we'll explore how these three roles might apply to a common situation encountered by families of children with special needs:

The Townsend family has a little boy, Ricky, with developmental disabilities. He occasionally has very serious behavior problems. The teenage babysitter who lives next door, who took care of their other child before Ricky was born, doesn't really want to take care of Ricky because she never knows how he will act. The Townsends want help finding a babysitter who is capable of taking care of Ricky, so that they will be able to go out more in the future.

The Townsends might ask their service coordinator for *consultation*. They may ask the service coordinator for information: does the coordinator know of other families with children who behave like Ricky does at times? Perhaps one of these other parents can trade babysitting with the Townsends or refer them to a babysitter. When the service coordinator shares this kind of information with the Townsends, she is providing *consultation*.

The Townsends might ask their coordinator for *teaching*. They may decide that they want to see if they can get help from an agency that provides respite services, but they have never made this kind of inquiry. They ask the coordinator to show them where to look for such agencies, and to teach them how to ask questions and evaluate the services. When the service coordinator teaches the Townsends ways to perform service coordination activities, she is offering the family *teaching*.

The Townsends might ask the coordinator for *direct assistance*. They may be under a time crunch and may ask their coordinator to help by researching possible providers and inquiring about services. In this case, the coordinator is providing *direct assistance* by doing an activity for the Townsends at their request. Sometimes family circumstances can be so overwhelming that a family will request a form of immediate direct assistance, crisis intervention. If, for example, Mrs. Townsend is home alone with Ricky one evening when his behavior becomes completely unmanageable, she might call the service coordinator to request emergency respite help.

The three service coordination roles — consultation, teaching, and direct assistance — can be used to carry out any service coordination activity, from planning to advocacy. Because these roles represent the intensity or degree of assistance that a family might request from a service coordinator, it is the family who determines the role the coordinator will use at any given time. Service coordinators should expect that these roles will change over time, with families' changing concerns, priorities, resources, and circumstances.

"To better understand these three roles, let's look at another example. Let's think about what these roles might look like when applied to **advocating**, one of the service coordination activities that we reviewed earlier."

"Let's review each of the three service coordination roles, one at a time. For each, suggest some examples of how a coordinator might **advocate** within that role."

Consultation: provide information, resources, names of organizations

Teaching: teach a parent how to testify at a legislative hearing/rights and responsibilities regarding the public schools

Direct Assistance: service coordinator might accompany a parent to a meeting to speak as an advocate for the family.

In summary:

"Family-centered service coordination can happen in many different ways. But, service coordinators must follow the family's lead---constantly being flexible and responsive to the family's preferences and priorities. This isn't necessarily easy to do, it takes practice.

"So far we have talked about communication skills, how we build trust, respect, and collaboration. As a group, let's discuss how these elements can be applied to our daily work with families."

Pass out "Applying the Key Elements to Practice"

SERVICE COORDINATION ROLES

Consultation:

Teaching:

Direct Assistance:

Applying the Key Elements to Practice

Key Element	Applying it to My Job
Recognizing that the family is the constant in a child's life, while the service systems and personnel within those systems fluctuate.	
Facilitating parent/professional collaboration at all levels of health care.	
Honoring the racial, ethnic, cultural, and socioeconomic diversity of families.	
Recognizing family strengths and individuality and respecting different methods of coping.	
Sharing with parents, on a continuing basis and in a supportive manner, complete and unbiased information.	
Encouraging and facilitating family-to-family support and networking.	
Understanding and incorporating the developmental needs of infants, children, and adolescents and their families into health care systems.	
Implementing comprehensive policies and programs that provide emotional and financial support to meet the needs of families.	
Designing accessible health care systems that are flexible, culturally competent, and responsive to family-identified needs.	

The key elements of family-centered care were developed by the National Center for Family-Centered Care of the Association for the Care of Children's Health.

ACTIVITY 6

RECOGNIZING FAMILY-CENTERED CARE

To paraphrase Tom Peter's description of excellence, family-centered care is not a final destination, but a continual pursuit. The philosophy of family-centered care describes collaborative relationship between parents and professionals in the continual pursuit of being responsive to the concerns, priorities, and resources of families with children who have special needs. This philosophy has received increasing attention and acceptance in recent years. As both families and professionals embrace this notion, one of the challenges that remains is to apply the philosophy of family-centered care to practice. Our challenge is to envision and pursue new ways that we can provide services to families, ways that are more responsive to families' choices.

Family-centered care requires that we look closely at what we do now and envision what we can create. A good place to start is to look closely at our current practices and ask questions such as:

Why do we do things this way?

Is this the only way possible?

Is this the best way?

Do we do it because this is the way it has always been done?

Recognizing Family-centered Care is an activity designed to help professionals recognize and understand the driving forces that shape the services they provide. If we can recognize the forces that drive our programs and services, then it will be easier to visualize new possibilities.

(Adapted from Edelman, et al. 1991, *Getting On Board*)

Driving Forces of Service Delivery

System-centered: the strengths and needs of the system drive the delivery of services

Child-centered: the strengths and needs of the child drive the delivery of services

Family-centered: the priorities and choices of the family drive the delivery of services

"Three different forces can influence the programs and services that we offer, as well as the way that we offer them. Let's take a look at these forces."

Reveal each one at a time and read the definition.

Ask the group to suggest a hypothetical example of how a service could be driven by that force.

"These three driving forces influence the services we provide and the way we provide them. In the following activity you will practice how to recognize these driving forces in programs and services."

Recognizing the Driving Forces of Services _____

Driving Forces:

- S** **System-centered:** the strengths and needs of the system drive the delivery of services
- C** **Child-centered:** the strengths and needs of the child drive the delivery of services
- F** **Family-centered:** the priorities and choices of the family drive the delivery of services

- ___ A family must bring their child to the office for case management services.
- ___ A complete assessment is done on a child and family.
- ___ Occupational therapy sessions are arranged according to a family's schedule.
- ___ Child care is provided for the brother and sister while the child who has special needs receives treatment.
- ___ The office hours of the dentist are Monday through Friday, 9:00 a.m. - 4:00 p.m.
- ___ A physical therapist sends the order for a seating device home with the child.
- ___ Transportation to the clinic is available from 9:00 a.m. - 5:00 p.m.
- ___ Parent support groups may use the facility's conference room in the evenings.
- ___ A local school board's planning committee consists of professionals, parents, and representatives from the community.
- ___ A child's medical records are available 3 - 5 days after a release of information is received.
- ___ A speech therapist comes to the home twice a week for a one hour session with a child.
- ___ A care plan developed by a multidisciplinary team is given to the parent.
- ___ School is closed for a day so that parent/teacher conferences can be held.
- ___ Parents choose to send their child with diabetes to a church camp instead of a special camp for children with diabetes.
- ___ A hospital social worker arranges for all of the medical equipment ordered by a physician for a child.

APPENDIX C
THE SERVICE COORDINATOR LOG

THE SERVICE COORDINATOR LOG

MONTH _____

FAMILY _____

Type of contact with family this month (Please circle):

HOME VISIT	EVALUATION (IFSP)	TELEPHONE	WRITTEN
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List the needs & concerns expressed by the family; the services (this can be hard services, information, phone calls, etc.) the family requested &/or those generated through discussion with the family.

Date

_____	_____
_____	_____
_____	_____
_____	_____
_____	_____

Give the **date** you responded to the family's request, identify which **service** & the **action** you took.

_____	_____
_____	_____
_____	_____
_____	_____
_____	_____

Describe any barriers you had this month in implementing this model.

REFERENCES

- Amado, A. N., McAnally, P. L., & Linz, M. H. (1989). Research review of effectiveness of case management in the United States. In M. H. Linz, P. McAnally, & C. Wieck (Eds.), Case management: Historical, current, and future perspectives(pp. 1-20). Cambridge, MA: Brookline Books.
- American Academy of Pediatrics. (1986). P.L. 99-457: Education of the Handicapped Amendments of 1986. Unpublished Fact Sheet. National Committee on Children with Disabilities.
- Arizona State Legislature, Arizona Revised Statutes, Section 36-551 (5, 8, 13, 16, 26).
- Ashbaugh, J. (1981). Accountability of community providers for services to the mentally retarded and other developmentally disabled persons: An argument for case manager citizen-based accountability mechanisms. In T.C. Muzzio, J.J. Koshel, & V. Bradley (Eds.), Alternative community living arrangements and non-vocational social services for developmentally disabled people. Washington, DC: Urban Institute and Human Services Research Institute.
- Baer, D. M., Wolf, M. M., & Risley, T. R. (1968). Some current dimensions of applied behavior analysis. Journal of Applied Behavior Analysis, 1, 91-97.
- Bailey, D. B. (1987). Collaborative goal-setting with families: Resolving differences in values and priorities for services. Topics in Early Childhood Special Education, 7(2), 59-71.
- Bailey, D. B. (1988). Considerations in developing family goals. In D. B. Bailey & R. J. Simeonsson (Eds.), Family assessment in early intervention (pp. 229-249). Columbus, OH: Charles E. Merrill.
- Bailey, D. B. (1989). Case management in early intervention. Journal of Early Intervention, 13(2), 120-134.
- Bailey, D. B., Buysse, V., Edmondson, R., & Smith, T. M. (1992). Creating family-centered services in early intervention: Perceptions of professionals in four states. Exceptional Children, 58(4), pp. 298-309.

- Bailey, D. B., Farel, A. M., O'Donnell, K. J., Simeonsson, R. J., & Miller, C. A. (1986). Preparing infant interventionists: Interdepartmental training in special education and maternal and child health. Journal of the Division for Early Childhood, 11, 67-77.
- Bailey, D. B., McWilliam, P. J., Winton, P. J., & Simeonsson, R. J. (1992). Implementing family-centered services: A team-based model for change. Cambridge, MA: Brookline Books.
- Bailey, D. B., McWilliam, P. J., Winton, P. J. (1992). Building family-centered practices in early intervention: A team based model for change. Infants and Young Children, 5(1), pp. 73-82.
- Bailey, D. B., Simeonsson, R. J., Winton, P. J., Huntington, G. S., Comfort, M., Isbell, P., O'Donnell, K. J., & Helm, J. M. (1986). Family-focused intervention: A functional model for planning, implementing, and evaluating individualized family services in early intervention. Journal of the Division for Early Childhood, 10, 156-171.
- Baker, F., & Weiss, R. S. (1984). The nature of case management support. Hospital and Community Psychiatry, 35, 925-928.
- Barrera, M. E. (1991). The transactional model of early home intervention: Application with developmentally delayed children and their families. In K. Marfo (Ed.), Early intervention in transition: Current perspectives on programs for handicapped children (pp. 109-146). New York, NY: Praeger Publishers.
- Beckman, P. J., Robinson, C. C., Rosenberg, S., & Filer, J. (in press). Family involvement in early intervention: The evolution of family-centered services. In L. J. Johnson, R. J. Gallagher, M. J. LaMontagne, J. B. Jordan, J. J. Gallagher, P. L. Hutinger, & M. B. Karnes (Eds.) Early intervention for children and their families: Providing services from birth to three. Baltimore, Paul H. Brookes Publishing Company.
- Berkeley Planning Associates (1977). The quality of case management process: Final report, Volume 111. In The Evaluation of Child Abuse and Neglect Projects 1974-1977. U.S. Department of Commerce, National Technical Information Service: Washington, DC.

- Berzon, P., & Lowenstein, B. (1984). A flexible model of case management. In B. Pepper & H. Ryglewicz (Eds.), Advances in treating the young adult chronic patient. New directions for Mental Health Services, no.21 (pp.49-57). San Francisco: Jossey Bass.
- Billingsley, F., White, O. R., & Munson, R. (1980). Procedural reliability: A rationale and an example. Behavioral Assessment, 2, 229-241.
- Brody, R. (1974). A comparative study of four public social service systems. Ann Arbor: University of Michigan: Microfilms Limited.
- Code of Federal Regulations (CFR): Title 34; Education; Parts 1 to 499, July 1986. Federal Register. Washington, DC: U.S. Government Printing Office.
- Compher, J. V. (1989). Case management and the case conference revisited: A systems perspective. In J. V. Compher, Family-centered practice: The interactional dance beyond the family system (pp. 101-108). New York, NY: Plenum Publishing.
- Cormany, E. E. (1993). Family-centered service coordination: A four-tier model. Infants and Young Children, 6(2), 12-19.
- Dunst, C. J. (1990). Family support principles: Checklists for program builders and practitioners. Family Systems Intervention Monograph, 2(5), Morgantown, NC: Family, Infant and Preschool Program, Western Carolina Center.
- Dunst, C. J., Johanson, C., Trivette, C. M., & Hamby, D. (1991). Family-oriented early intervention policies and practices: Family-centered or not? Exceptional Children, 58(2), 115-126.
- Dunst, C. J., & Trivette, C. M. (1987). Enabling and empowering families: Conceptual and intervention issues. School Psychology Review, 16(4), 443-456.
- Dunst, C. J., & Trivette, C. M. (1988). An enablement and empowerment perspective of case management. Topics in Early Childhood Education, 8(4), 87-102.
- Dunst, C. J., Trivette, C. M., & Deal, A. G. (1988). Enabling and empowering families: Principles and guidelines for practice. Cambridge, MA: Brookline Books.

- Dunst, C.J., Trivette, C.M., Starnes, A.L., Hamby, D.W., & Gordon, N.J. (1991). Family support programs for persons with developmental disabilities: Key elements, differential characteristics and program outcomes. Family System Intervention Monograph, 3, Number 1. Morgantown, NC: Center for Family Studies, Western Carolina Center.
- Edelman, L., Elsayed, S. S., McGonigel, M. (1992). Overview of family-centered service coordination. (Project No. MCJ- 245028) St. Paul, MN: Pathfinder Resources, Inc.
- Edelman, L. (Ed.). (1991). Getting on board: Training activities to promote the practice of family-centered care. Bethesda, MD: Association for the Care of Children's Health.
- Edelman, L., Greenland, B., & Mills, B. L. (1992). Family-centered communication skills. St. Paul, MN: Pathfinder Resources, Inc.
- Edelman, L., Greenland, B., & Mills, B. L. (1992). Building parent/professional collaboration. St. Paul, MN: Pathfinder Resources, Inc.
- Foster, E. (1992, April 12). Agency vs. parents: Care givers complain about lack of help with disabled children. The Arizona Republic, (pp. 1, 8).
- Gilkerson, L., Hilliard, A. G., Schrag, E., & Shonkoff, J. (1987). Report accompanying the education of the handicapped amendments (Report #99-860) and components on P.L. 99-457. Washington, DC: National Maternal and Child Health Clearinghouse.
- Harkin, A. (1991, September 16). Individuals With Disabilities Education Act Amendments. Floor Statement published in the Congressional Record - Senate, Washington, D.C.
- Hartman, A. (1981). A family: A central focus for practice. Social Work, 26, 7-13.
- Healy, A., Keesee, P. D., Smith, B. S. (1989). Early services for children with special needs: Transactions for family support (2nd Ed.). Baltimore: Paul H. Brookes Publishing Company.

- Hebbeler, K. M., Smith, B. J., & Black, T. L. (1991). Federal early childhood special education policy: A model for the improvement of services for children with disabilities. Exceptional Children, 58(2), 104-112.
- Johnson, B. H., Jeppson, E. S. & Redburn, L. (1992). Caring for children and families: Guidelines for hospitals. Bethesda, MD: Association for the Care of Children's Health.
- Kennedy, C. H. (1992). Trends in the measurement of social validity. The Behavior Analyst, 15(2), 147-156.
- Krauss, M. W. (1990). New precedent in family policy: Individualized family service plan. Exceptional Children, 56(2), 388-395.
- Kurtz, L. F., Bagarozzi, D. A., & Polane, C. P. (1984). Case management in mental health. Health and Social Work, 9, 201-211.
- Levine, I. S., & Fleming, M. (1984). Human resource development: Issues in case management. Baltimore: Center of Rehabilitation and Manpower Services.
- Lewis, V. S. (1973). Charity organization society. In Encyclopedia of Social Work. (16th ed.) Vol. 1. Washington, DC: National Association of Social Workers.
- MacEachron, A. E., Pensky, D., & Hawes, B. (1986). Case management for families of developmentally disabled clients: An empirical policy analysis of a statewide system. In J. J. Gallagher & P. Vietze (Eds.), Families of handicapped persons (pp. 273-290). Baltimore: Paul H. Brookes.
- McBride, S. L., Brotherson, M. J., Joanning, H., Whiddon, D., & Demmitt, A. (1993). Implementation of family-centered services: Perceptions of families and professionals. Journal of Early Intervention, 17(4), 414-430.
- McGonigel, M. J. (1991). Philosophy and conceptual framework. In M. J. McGonigel, R. K. Kaufmann, & B. H. Johnson (Eds.), Guidelines and recommended practices for the individualized family service plan (2nd ed.) (pp. 7-28). Bethesda, MD: Association for the Care of Children's Health.

- Mental Health Law Project. (1992). Early intervention Advocacy Network Notebook. Washington: D.C.
- Morell, J. E., Straley, C. I., Burris, C. I., & Covington, E. (1980). Design specifications for case management/service coordination and individualized planning. Falls Church, VA: Rehab Group, Inc.
- National Center for Family-Centered Care. (1990). What is family-centered care? (brochure). Bethesda, MD: Association for the Care of Children's Health.
- National Conference on Social Welfare. (April, 1981). Final Report - Case management: State of the art. Grant No. 54-P-7 1542/3-01. Submitted to Administration on Developmental Disabilities, United States Department of Health and Human Services.
- Pearl, L. F. (1993). Providing Family-Centered Early Intervention. In W. Brown, S. K. Thurman, & L. F. Pearl (Eds.), Family-centered early intervention with infants & toddlers: Innovative cross-disciplinary approaches (pp. 81-101). Baltimore, MD: Brookes Publishing.
- Perkes, K., S., L. (1992, April 13). Friend or foe of parents? Critics: Agency foils families of disabled. The Arizona Republic, pp. 1, 2.
- Rapp, C. A., & Chamberlain, R. (1985). Case management services for the chronically mentally ill. Social Work, 30, 417-422.
- Rappaport, J. (1984). Studies in empowerment: Introduction to the issues. In J. Rappaport, C. Swift, & R. Hess (Eds.), Studies in empowerment: Steps toward understanding and action. (pp. 1-37). New York: Haworth Press.
- Richardson, B. B. (1979). Human service delivery for high risk infants. In An ecological model of services to inner city minority handicapped infants. (pp. 12-16). Los Angeles: Charles R. Drew Medical School.
- Rubin, A., & Johnson, P. J. (1982). Practitioner orientations toward serving the chronically disabled: Prospects for policy implementation. Administration in Mental Health, 10, 2-12.

- Schwartz, I. S., & Baer, D. M. (1992). Social validity assessments: Is current practice state of the art? Journal of Applied Behavior Analysis, 24(2), 189-204.
- Shelton, T. L., Jeppson, E. S., & Johnson, B. H. (1987). Family-centered care for children with special health care needs. Washington, D. C.: Association for the Care of Children's Health.
- Shonkoff, J. P., Meisels, S. (1990). Early childhood intervention: The evolution of a concept. In S. Meisels & J. P. Shonkoff (Eds.), Handbook of Early Childhood Intervention. (pp. 3-31). New York: Cambridge University Press.
- Simeonsson, R. J., & Bailey, D. B. (1991). Family-focused intervention: Clinical, training, and research implications. In K. Marfo (Ed.), Early intervention in transition: Current perspectives on programs for handicapped children (pp. 91-108). New York, NY: Praeger Publishers.
- Staff. (1986, October 22). EHA amendments of 1986 becomes law; Established new partnerships for early intervention programs. Liaison Bulletin, pp. 1-3.
- Thurman, S. K. (1991). Parameters for establishing family-centered neonatal intensive care services. Children's Health Care, 20(1), 34-39.
- Turnbull, A.P. (1988). The challenge of providing comprehensive support to families. Education and Training in Mental Retardation, 23, 261-272.
- United States Code (U.S.C.): Title 20; 1471-1472, July 1986. Washington, DC: U.S. Government Printing Office.
- U.S. Congress, Public Law 99-457, Individuals with Disabilities Education Act Amendments of 1986, 100 STAT. 1145-1177.
- U.S. Congress, Public Law 102-119, Individuals with Disabilities Education Act Amendments of 1991, 105 STAT. 587-608.
- U.S. Department of Education, Office of Special Education and Rehabilitative Services. (1993). Fifteenth Annual Report to Congress on the Implementation of the Individuals with Disabilities Education Act. Washington, DC: Author.

- U.S. Department of Education. Early intervention program for infants and toddlers with handicaps; Final Regulations. (1989, June 22). Federal Register (Doc. Publication No. 34 CFR, Part 303). Washington, DC: U.S. Government Printing Office.
- Weinstein, V. (1979). An ecological model for intervention with inner-city poor and/or minority handicapped infants and their families: The community. In An ecological model of services to inner city minority handicapped infants (pp. 27-29). Los Angeles: Charles R. Drew Medical School.
- Weil, M., & Karls, J. M. (1985). Historical origins and recent developments. In M. Weil, J. M. Karls & Assoc., Case management in human service practice: A systematic approach to mobilizing resources for clients (pp. 1-28). San Francisco: Jossey-Bass.
- Weissbourd, B. (1987). A brief history of family support programs. In S. L. Kagan, D. R., Powell, B., Weissbourd, & E. Zigler (Eds.), America's family support programs (pp. 38-56). New Haven: Yale University Press.
- Wolfensberger, W. (1972). The principle of normalization and its implications to psychiatric services. American Journal of Psychiatry, 127, 291-297.
- Wray, L. D., Basuray, M. T., Miller, H., & Seiler, D. V. (1985). Working together to meet the needs of North Dakotans with developmental disabilities: Regional developmental disabilities and service provider roles in service coordination. Falcon Heights, Minnesota.
- Wright, R. G., Sklebar, H. T., & Heiman, J. R. (1987). Patterns of case management activity in an intensive community support program: The first year. Community Mental Health Journal, 23, 53-59.
- Zigler, E., & Black, K. B. (1989). America's family support movement: Strengths and limitations. American Journal of Orthopsychiatry, 59, 6-19.
- Zimmerman, J. H. (1987). Negotiating the system. Public Welfare, 45, 23-27.
- Zipper, I. N., Hinton, C., Weil, M., & Rounds, K. (1993). Service coordination for early intervention: A manual for parents. Cambridge, MA: Brookline Books.

Zipper, I. N., Hinton, C., Weil, M., & Rounds, K. (1993).
Service coordination for early intervention: Parents
and professionals. Cambridge, MA: Brookline Books.