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FAMILY-CENTERED EARLY INTERVENTION:

PRINCIPLES AND PROCESS

An Abstract of a Paper

Submitted

in Partial Fulfillment

of the Requirements of the Degree

Master's in Education

Jody Albertson

University of Northern Iowa

August 2003

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TABLE OF CONTENTS

CHAPTER 1

INTRODUCTION

Family-centered early intervention is an evolving idea. This literature review will discuss the principles and the process of family-centered intervention with the families of infants and toddlers with special needs. Providing family-centered intervention requires a commitment to both the principles of family-centered practice and knowledge of the process of family-centered intervention.

Background & History

In order to gain an understanding of family-centered early intervention, two histories must be examined. The history of the concept of family-centered services and the history of early intervention in the United States must be discussed.

History of Family-centered Intervention

Family-centered intervention is not a new term. Bruder (2000a) cited Wiedenback (1967) as first using the term as a descriptor of service delivery. She also cited Lilly (1979) and Tjossem (1976) as writing about families who were integrally involved in early intervention. The term initially meant that families should be involved in the activities that professionals deemed important (McWilliam, Tocci & Harbin 1998). In the 1960s and 1970s, services tended to be child-focused and deficit-oriented (Dunst, Johanson, Trivette, & Hamby 1991). In the 1980s, the term family-centered care was formalized, as was family empowerment, into a set of principles to guide service delivery for children with special health care needs (Dunst, Trivette, & Deal 1988). During the 1990s family-centered early intervention emphasized three values which included a focus

on family's strengths, the promotion of family choice and control, and the development of a collaborative relationship between professionals and parents (Dunst, Trivette, & Deal 1994). Dunst, Johanson et al. (1991) described a continuum of service delivery from professional-centered to professional-focused to family-focused to family-centered. They also stated that the heritage of family-centered early intervention policies and practices can be a mixed blessing. Although this history can provide information regarding how to effectively influence parenting capabilities, it can also hinder advances due to its paternalistic orientation.

History of Early Intervention

The Education of the Handicapped Act of 1970 mandated services to children three and older, but did not include services to infants and toddlers (Saunders 1995). Services for infants and toddlers were finally mandated in 1986 when Congress passed P.L. 99-457, The Education of the Handicapped Act Amendments of 1986, which mandated services for children with disabilities from birth on (Gallagher 2000). This Act was amended again in 1988, 1990, and 1991. In 1990, the original title of the act (EHA) was changed to the Individuals with Disabilities Education Act (IDEA). Part H of this act outlined the requirements for the Infants and Toddlers with Disabilities Program (Saunders 1995). This act was considered revolutionary at the time of its passage, and it mandated a statewide, comprehensive, multidisciplinary service system to address the needs of infants and toddlers who were experiencing developmental delays or a diagnosed physical or mental condition with a high probability of an associated developmental disability in one or more of the following areas: cognitive development, physical development, language and speech development, psychosocial development, and

self-help skills. States also had the discretion to define and serve at-risk children (Saunders 1995). This act was reauthorized in 1997 and these services for infants and toddlers are currently mandated under IDEA, Part C [20 U.S.C. sec. 1431-1445] and (Garrett, Thorp, Behrmann, & Denham 1998). Thompson et al. (1997) stated that several required elements of Part H were designed to enhance family empowerment. The most important of these are the IFSP and the service coordinator required by the mandate. The requirement that the IFSP is a plan relying on the family's assessment of their own strengths and needs is intended to provide families with some control in a setting where they are typically outnumbered by professionals. The authors also state that the service coordinator is intended to be a way for families to communicate preferences to other service providers and arrange services.

History of Family-centered Early Intervention

Part H of IDEA which eventually became Part C brought the ideas of family-centered intervention and intervention with infants and toddlers together. The Office of Special Education Programs (OSEP) at the federal level is responsible for monitoring the states' compliance with IDEA. State monitoring reports are available online (OSEP: Monitoring Reports). The introduction to the family-centered section of these state monitoring reports states:

> In 1986, Part C of the IDEA was recognized as the first piece of Federal legislation to specifically focus attention on the needs of the family related to enhancing the development of children with disabilities. In enacting Part C, Congress acknowledged the need to support families and enhance their capacity to meet the needs of their infants and toddlers with disabilities. On the cutting

edge of education legislation, Part C challenged systems of care to focus on the family as the unit of services, rather than the child. Viewing the child in the context of her/his family and the family in the context of their community, Congress created certain challenges for States as they designed and implemented a family-centered system of services (OSEP: Monitoring Reports).

Part C has five goals:

1. to enhance the development of infants and toddlers with disabilities and to minimize their potential for developmental delay;
2. to reduce the educational costs to our society, including our Nation's schools, by minimizing the need for special education and related services after infants and toddlers with disabilities reach school age;
3. to minimize the likelihood of institutionalization of individuals with disabilities and maximize the potential for their independently living in society;
4. to enhance the capacity of families to meet the special needs of their infants and toddlers with disabilities; and
5. to enhance the capacity of 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. Section 1431(a)(1-5)]

Each state is required to maintain and implement a statewide, comprehensive, coordinated, multidisciplinary, interagency system to provide early intervention services for infants and toddlers with disabilities and their families. [20 U.S.C. sec. 1433] A lead

agency is designated by the Governor for carrying out these services [20 U.S.C. sec. 1435(a)(10)].

At the individual level, Part C requires early intervention team members to develop an Individualized Family Service Plan (IFSP) [20 U.S.C. sec. 1436]. This is the document that drives services to infants and toddlers. It is comparable to the Individualized Education Plan (IEP) which is the document guiding Part B services. The IFSP differs from the IEP in several ways: it revolves around the family, it includes outcomes targeted for the family, it includes the notion of natural environments, it includes activities undertaken with multiple agencies, and it names a service coordinator to help the family during the development, implementation, and evaluation of the IFSP (Bruder 2000b). The requirement regarding natural environments means that services "to the maximum extent appropriate, are provided in natural environments, including the home, and community settings in which children without disabilities participate" [20 U.S.C. 1432 (4)(G)].

IDEA mandates family involvement and consideration of the family's resources, concerns, and needs in the development of the IFSP. In addition to information regarding the infant's or toddler's present levels of development, the IFSP must contain a statement of the family's resources, priorities, and concerns relating to enhancing the development of the family's infant or toddler with a disability. It must contain a statement of the major outcomes expected to be achieved for the infant or toddler and the family and a statement of specific early intervention services necessary to meet the unique needs of the infant or toddler and the family. The IFSP includes a statement of the natural environments in which early intervention services shall be provided, the projected dates for initiation of

services and anticipated duration of services, and the identification of a service coordinator from the profession most immediately relevant to the infant's or toddler's or family's needs who will be responsible for the implementation of the plan and coordination with other agencies and persons. Finally, the IFSP must include steps to support transition of the toddler with a disability to preschool or other appropriate services [20 U.S.C. sec. 1436(d)(1-8)].

In determining whether these requirements are being met in practice, it is useful to look at the state monitoring reports online at OSEP. OSEP gathered data from parents, service providers, state agency staff, local program providers and administrators. They then analyzed this data to identify areas of strength and areas of noncompliance. The reports from Florida, Louisiana, the District of Columbia, Colorado, Arkansas, Arizona, Maryland, Montana, Massachusetts, Nebraska, Wisconsin, Texas, New Jersey, New Mexico, New York, Ohio, and Iowa were examined for this review. Of the seventeen state monitoring reports mentioned above which were chosen because they were the most recent reports available, seven states were cited as failing to adequately identify family supports and services in the IFSPs. One state was cited as having a lack of strategies to ensure opportunity for family assessment. In reading the reports further, the states that were cited as failing to adequately identify family supports and services in the IFSPs said that they did so because they did not have the time nor the tools to complete a family-directed assessment as indicated by IDEA, Part C. Therefore, because they did not do family assessments, they could not identify family resources, concerns, and needs. Because they could not identify family resources, concerns, and needs, they could not

provide appropriate supports and services to the families. These states failed to do even the first step of the process leading to family-centered service delivery.

Search Methods

Research was conducted through databases available online at Rod Library at the University of Northern Iowa. Databases searched include the ERIC database, PsycINFO, Education Full Text, and Social Work Abstracts. Search terms included *early intervention, family-centered early intervention, Part C,* and *family-centered services.* Specific authors' names, such as *Carl Dunst* or *Donald Bailey* were also used as search terms. An internet search was also completed using the terms noted above. Finally, internet sources suggested by University of Northern Iowa faculty members with knowledge or experience in this area were examined. Sources were chosen which were related to the topics of defining the principles of family-centered early intervention and examining the process of family-centered early intervention.

CHAPTER 2

LITERATURE REVIEW

Definition and Principles of Family-Centered Services

Family-centered is a term that has been defined in various ways in the literature. As noted above, the requirement that early intervention services be family-centered was a change for the field in 1986. Dunst, Trivette, and Deal (1994) described four paradigm changes that professionals who intended to provide family-centered services needed to make.

> The first paradigm shift concerns a move away from intervention practices based solely on professionally-identified needs to interventions that are responsive to family concerns and desires, both for the family as a whole and for individual family members. These kinds of intervention practices assume that family members are truly listened to, are provided the necessary information and assistance to make informed, intelligent choices, and that intervention practices are responsive and tailored to individual family needs. This shift requires that professionals impart knowledge that can be used to promote decision making capabilities (p. 224).

Second, services should focus on building and strengthening child and family capabilities rather than on correcting child and family deficits or weaknesses. Third, professionals need to include both informal and formal community resources and supports as ways of meeting needs rather than considering professional services as the only solutions.

> The fourth paradigm shift concerns a change in the help-giving practices employed by professionals away from those that are paternalistic and

> dependency-forming towards practices that create opportunities for both children and families to learn skills and acquire competencies that have empowering consequences. This shift requires changes in the roles and responsibilities of help-giving practitioners predicated upon changes in the objectives and goals of interventions. These *new* roles and responsibilities are ones that help people become better able to meet their needs. The *new* goals are to promote help-seeker competencies in ways that truly result in people becoming competent (p. 225).

A group of leaders and educators in Iowa participates with the Frank Porter Graham Child Development Center at the University of North Carolina in project SCRIPT (Supporting Changes and Reform in Interprofessional Preservice Training). One of the goals of the Iowa SCRIPT group is to assist faculty in increasing the emphasis on family-centered practices in their teaching and practica (University of Northern Iowa). Early ACCESS is the partnership in Iowa between families of young children, birth to age three, and providers from the Departments of Education, Public Health, Human Services, and the Child Health Specialty Clinics (Iowa Department of Education). The Iowa SCRIPT group in cooperation with Iowa's Early ACCESS, put out information regarding guiding principles and practices for delivery of family centered services (Pletcher & McBride 2000). The seven principles that these groups identified were: (1) The overriding purpose of providing family-centered help is family "empowerment," which in turn benefits the well-being and development of the child; (2) Mutual trust, respect, honesty, and open communication characterize the family-provider relationship; (3) Families are active participants in all aspects of services. They are the ultimate decision-makers in the amount, type of assistance, and the support they seek to use; (4)

The ongoing "work" between families and providers is about identifying family concerns (priorities, hopes, needs, goals or wishes), finding family strengths, and the services and supports that will provide necessary resources to meet those needs; (5) Efforts are made to build upon and use families' informal community support systems before relying solely on professional, formal services; (6) Providers across all disciplines, collaborate with families to provide resources that best match what the family needs; (7) Support and resources need to be flexible, individualized and responsive to the changing needs of families.

Pletcher and McBride (2000) continued by identifying assumptions behind family centered principles of practice. These were: all people are basically good; all people have strengths; all people need support and encouragement; all people have different but equally important skills, abilities and knowledge; all families have hopes, dreams and wishes for their children; families are resourceful, but all families do not have equal access to resources; families should be assisted in ways that help them maintain their dignity and hope; families should be equal partners in the relationship with service providers; and, providers work for families.

Dunst (2002) defined family-centeredness in an article regarding the importance of family-centered practices from birth through high school. He said:

> Family-centeredness characterizes beliefs and practices that treat families with dignity and respect; individualized, flexible, and responsive practices; information sharing so that families can make informed decisions; family choice regarding any number of aspect of program practices and intervention options; parent-professional collaboration and partnerships as a context for family-program

relations; and the provision and mobilization of resources and supports necessary for families to care for and rear their children in ways that produce optimal child, parent, and family outcomes (Dunst 2002).

Bruder (2000a) had suggestions for practitioners attempting to provide family-centered services:

> Renew our commitment to helping families (however they define themselves) help their children become competent within a reciprocal learning relationship built on respect. We must always remember that the children we serve belong to their families, and we are privileged to be in their lives for a short time. Except in instances of abuse and neglect, our responsibility is to support the family in their caregiving role so that they can facilitate their child's learning and development. This allows us to focus on, and contribute to, the difference that can be made in the lives of families as they become more able to facilitate the changes they want for themselves and their child.

Baird and Peterson (1997) cited several researchers and authors in stating the tenets of family-centered practice that have become hallmarks of best practice in the early intervention process. These were: (1) the family as the expert on the child; (2) the family as the ultimate decision maker for the child and family; (3) the family as the constant in the child's life and professional service providers as temporary; (4) the family's priorities for goals and services; (5) the family's choices regarding their level of participation; (6) the need for a collaborative, trusting relationship between parents and professionals; and (7) the need to respect differences in cultural identity, beliefs, values, and coping styles.

In the state monitoring reports available at OSEP online, the federal government defined family-centered practices as:

> Those in which families are involved in all aspects of the decision-making, families' culture and values are respected, and families are provided with accurate and sufficient information to be able to make informed decisions. A family-centered approach keeps the focus on the developmental needs of the child, while including family concerns and needs in the decision-making process. Family-centered practices include establishing trust and rapport with families, and helping families develop skills to best meet their child's needs" (OSEP: Monitoring Reports).

Powell, Batsche, and Ferro (1997) discussed a strength-based approach in support of multi-risk families. The six principles they associated with this approach were: (1) a philosophy based on family strengths; (2) a partnerships approach to service provision; (3) a family-centered, family-driven agenda; (4) an individualized response to family needs and capacities; (5) a broad-based comprehensive view of family development; and (6), an assessment of outcomes based on family functioning and the quality of life of family members. These authors assert that a family-focused approach is based on the assumptions that children and families represent an interdependent family system, that intervention is more powerful when families are involved and supported, and that family members should have a voice in all aspects of services that are provided to them.

McWilliam, Tocci, et al. (1998) completed a study examining the practice of six special education providers to determine a definition of family centeredness. They identified six themes that were common in providers providing family-centered services.

These six themes were: family orientation, positiveness, sensitivity, responsiveness, friendliness, and child and community skills. Family orientation meant that the provider was willing to orient services to the whole family. Positiveness is a philosophy of thinking the best about parents without passing judgment. The authors stated that it includes a belief in parents' abilities, a nonjudgmental mind-set, an optimistic view of children's development, and an enthusiasm for working with families. The authors defined sensitivity as the idea of putting oneself in the parent's position in order to anticipate how families might feel. Responsiveness meant an individualized and flexible approach to providing services and responding to the needs and concerns of families and children. The authors were aware that the theme of friendliness goes against the concepts of professional objectivity and boundaries between professionals and clients. However, they felt that the term *rapport* understated this theme. They differentiated between a friendly professional stance and a professional friend and wrote that the providers in their study were probably the latter to the families they served. Child and community skills were also found to be important. Community skills included realizing the impact of the community economic situation on families, appraising community attitudes, knowing their communities and advocating for children and families within their communities, and establishing collaborative relationships with other community agencies. They discussed that family centeredness involves the combination of these characteristics.

Although there are obviously some common themes in the ideas of these researchers regarding family-centered services, there are also some interesting differences. Themes that are mentioned repeatedly include family empowerment; service flexibility, responsiveness, and individualization; the realization that the family is the

expert on their children and a constant in their lives and service providers are temporary; a focus on strengths; formal and informal resources and supports; relationships between family and providers characterized by respect of the family, their culture, values, and beliefs; honesty, trust, collaboration, and open communication in order to share information.

The information on family-centered services from OSEP appeared to be a bit more conservative than many of the researchers cited above. The statement from OSEP that family-centered practices are "those in which families are involved in all aspects of decision-making" appears to contrast with the statements by various researchers (Baird & Peterson 1997, Pletcher & McBride 2000) that families are the "ultimate decision-makers."

Even with the more conservative definition espoused by OSEP, many states were not in compliance with the requirement that early intervention services be family-centered. Since family-centered early intervention was mandated, there has been significant progress in developing tools and general methods for delivery of family-centered services. There has also been progress regarding the evaluation of family-centered services.

Family-Centered Assessment

The logical first step in the process of providing family-centered services is completing a family-centered assessment. Dunst and Deal (1994) clearly described what family-centered assessment is and is not:

> It is important to note what is and is not a family-centered assessment practice. It does not mean assessing marital relationships, family dynamics, family stress or dysfunctional patterns, or any other aspects of the family system that generally falls within the purview of family therapy. It does mean assessing child and family needs and family strengths and capabilities related to meeting those needs. It also means assessing needs and strengths from a family's perspective with assistance and guidance from professionals (p. 73).

Deal, Dunst, and Trivette (1994) proposed that family-centered assessment and intervention is based on four principles:

> Principle 1. Base intervention efforts on family identified needs and aspirations in order to have the greatest positive influences on child, parent, and family functioning.
>
> Principle 2. Build upon existing family strengths and capabilities (family functioning style) as a basis for promoting the family's ability to mobilize resources in order to enhance successful efforts toward meeting needs.
>
> Principle 3. Strengthen the family's personal social network as well as promote utilization of untapped sources of aid and assistance in order to insure the availability and adequacy of resources for meeting needs.
>
> Principle 4. Employ help-giving behaviors that promote the family's acquisition and use of competencies and skills necessary

> to mobilize and secure resources in order to enhance the family's ability to become more self-sustaining with respect to meeting its needs (p. 64).

According to Bailey (1996) there were at least five reasons for making an effort to conduct a comprehensive family assessment:

1. Legislative requirements.
2. The need to individualize services.
3. The need to establish a trusting, open, and collaborative relationship between parents and professionals.
4. Theoretical bases.
5. The need to expand program evaluation activities.

In 1988, Bailey (1988b) discussed barriers to effective family assessment. He noted the lack of a functional model of conceptualizing families and their needs that "identifies important domains of family functioning and provides guidance for assessing each domain and generating relevant family goals and services" (p. 7). He secondly noted in 1988 that although there are many assessment tools to identify the strengths and needs of children in order to plan for services, there is no comparable battery of functional assessment tools for family assessment. A third barrier to effective family assessment he discussed was the limited training of early childhood professionals in working with families. Institutions serving children can also create a barrier to effective family assessment by emphasizing child services. Families can also receive fragmented services when many agencies are involved. Family characteristics can also be a barrier. They may view family assessment as intrusive or irrelevant to their child's needs.

With those barriers noted in 1988 in mind, Bailey (1988b, p. 9) proposed an approach to family assessment that incorporated the following functions:

1. Cover important domains.
2. Incorporate multiple sources and measures.
3. Recognize the importance of family values and traditions.
4. Determine family priorities for goals and services.
5. Vary according to program type and demands.
6. Evaluate family outcomes on a regular basis.

In 1988, Bailey (1988b) emphasized making individual decisions for family assessment but suggested that the domains that appear to commonly be important are child needs and characteristics likely to affect family functioning, parent-child interaction, family needs, critical events, and family strengths. There are many potential areas to assess, including stress, coping styles, teaching skills, parent-child interaction, the home environment, locus of control, support systems, and stages of grief. However, Bailey (1996) reported the appropriate domains of family assessment according to federal legislation are family resources, priorities, and concerns related to the care of the child with a disability. He suggested three key questions to help professionals provide services in a family-centered fashion:

1. What role does the family want to play in the process of making decisions about their child and in providing education or therapeutic interventions?
2. What does this family want from the service system?
3. How do family members perceive the service system and what constitutes an acceptable relationship between parents and service providers?

Bailey (1996) also outlined various methods and tools for family-centered assessment: informal communication, semistructured interviews, surveys and rating scales, and direct observation procedures. In contrast to the concern in 1988 that there was no battery of tools for family-centered assessment, Bailey lists four such tools in 1996. These were the Family Needs Survey (Bailey & Simeonsson, 1990, cited in Bailey 1996), the Family Needs Scale (Dunst et al., 1988, cited in Bailey 1996), the Parent Needs Survey (Seligman & Darling, 1989, cited in Bailey 1996), and How Can We Help? (Child Development Resources, 1989, cited in Bailey 1996).

Finally, Bailey (1988b) suggested a model for family assessment based on the above ideas. The first step is the initial family assessment which includes gathering information regarding family strengths, needs, characteristics, and critical events. The second step is a focused interview which includes verifying needs and identifying domains for further assessment. The third step is to complete follow-up assessments which may include assessment of parent-child interaction, home environment, child characteristics, family support, and transition. The IFSP meeting is the fourth step. The multidisciplinary team generates child and family goals and identifies services. Services are implemented and then evaluated (pp. 20).

Family-centered assessment must certainly be one of the most important, if not the single most important, aspect of family-centered services. If an effective assessment of the family is not completed, and strengths, needs, and goals of the family are not identified, then it would seem impossible to plan for or provide effective family-centered services. Although Bailey's work was written in 1988 and the text edited by Dunst, Trivette and Deal was written in 1994, both appear to continue to be relevant today as

indicated by the state monitoring reports (OSEP: Monitoring Reports) which found that professionals often are not completing comprehensive family assessments and are therefore unable to include family goals or plans for family support and services on the IFSP.

Tools for Family-Centered Assessment

A few useful tools for family-centered assessment have been identified by McLean and McCormick (1993); Dunst and Leet (1994); Dunst, Trivette, and Mott (1994); Trivette, Dunst, Deal, Hamby, and Sexton (1994), and Bailey (1988). These tools can measure a family's strengths, needs, resources, or social supports.

The Family Functioning Style Scale (FFSS) (Trivette et al.1994) is a strengths-based, self-report scale which yields information about the family's perceptions of their strengths and capabilities. The authors contended that "all families have strengths; that these strengths are unique depending upon the beliefs, cultural backgrounds, ethnicity, and socioeconomic backgrounds of the family; and that work with families should build upon the positive aspects of family functioning" (p132-133).

The FFSS consists of twenty-six items designed to assess various family strengths and capabilities. Items are rated on a five-point Likert scale ranging from Not-At-All-Like-My-Family to Almost-Always-Like-My-Family. The authors determined reliability and validity of their scale by asking 241 parents of preschool-aged children to complete this self-report measure as well as three others: the Family Hardiness Index (McCubbin, McCubbin, & Thompson 1987 cited in Trivette et al 1994), the Psychological Well-Being Index (Bradburn, 1969; Bradburn & Caplovitz 1965 cited in Trivette et al 1994), and the

Mastery and Health subscale of the Family Inventory of Resources and Management (McCubbin, Comeau, & Harkins 1981 cited in Trivette et al 1994).

Trivette et al. (1994) found that the instrument is sensitive to differences among families and internally consistent. They also found that the types of family strengths and capabilities measured by the FFSS are multidimensional. Interactional patterns of the family, family values, coping strategies, family commitment, and resource mobilization were five factors measured by the instrument. The researchers found that these five factors were somewhat interrelated but each also represented a unique set of family strengths.

Trivette et al. (1994) assessed the criterion validity of the FFSS by using the Family Hardiness Index (McCubbin, McCubbin, & Thompson 1987 cited in Trivette et al. 1994). They found a statistically significant relationship between these scales, suggesting that they measure similar qualities of family functioning.

Trivette et al. (1994) assessed the predictive validity of the FFSS by comparing results to the results of the Psychological Well-Being Index (Bradburn, 1969; Bradburn & Caplovitz 1965 cited in Trivette et al. 1994) to determine personal well-being. They compared results to the Mastery and Health subscale of the Family Inventory of Resources and Management (McCubbin, Comeau, & Harkins 1981 cited in Trivette et al.1994) to determine family well-being. They found that elevated FFSS scores were related to fewer family-related health problems, fewer indications of negative affect, and a better overall sense of personal well-being.

The authors suggested that this tool could be used as both an assessment tool and an intervention tool. In assessment, the results can help identify a family's strengths from

the family's perspective and provide a starting point for discussion. In intervention, the tool can identify strengths the family is already using to meet their needs and allow intervention to build upon those strengths and capabilities.

Dunst and Leet (1994) described another assessment tool useful with families, the Family Resource Scale developed by the authors. They state that the FRS is "an objective measure for assessing the adequacy of both resources and needs in households with young children" (pp. 105). It contains thirty items that are rated on a five-point scale ranging from Not-At-All-Adequate to Almost-Always-Adequate.

Dunst and Leet (1994) conducted two studies regarding this instrument. First they asked twenty-eight professionals with extensive experience working with preschoolers with disabilities and their families to rank-order the items from most to least basic. They found that the FRS items are roughly ordered from most-to-least basic in a hierarchy ranging from nutritional needs to generativity.

The second study was completed in order to establish reliability and validity of the FRS. They provided forty-five mothers of preschool children participating in an early intervention program with three self-report measures: the FRS, the Health and Well-Being Index (Dunst, 1986 cited in Dunst & Leet 1994), and the Personal Allocation Scale (Dunst 1986 cited in Dunst and Leet 1994).

Dunst and Leet (1994) found that the instrument had reliability of moderate to substantial magnitude. They found that the FRS does measure independent dimensions of personal and family needs and resources. The factors measured include growth and support, health and necessities, physical necessities, physical shelter, intrafamily support, communication and employment, childcare, and personal resources. Subscale categories

of the instrument were: food and shelter, financial resources, time for family, extrafamily support, childcare, specialized child resources, and luxuries. In comparing the results with the HWI and PAS, they found that the well-being and commitment measures were significantly related to the total FRS scores. All seven subscale scores predicted parental commitment to child-level interventions.

> Mothers who reported inadequacies in family resources were less likely to see child-level educational and therapeutic needs as *immediately* important, and consequently were not likely to invest the time and energy to work on professionally prescribed treatments. Presumably, the mothers were more concerned about getting other more basic family needs met, and were investing time and energy towards this end" (Dunst & Leet 1994, p. 112).

Dunst and Leet (1994) suggested this tool as useful in both assessment and intervention. In assessment it can help determine the adequacy of a family's resources and decide the probability of parents having the time and energy to participate in child-level interventions. It can also provide a basis for understanding whether professional demands placed upon a family may have negative effects. In intervention, it can identify parent and family needs and the appropriate targets for intervention. The tool can identify supports or resources needed by the family.

Dunst, Trivette, and Hamby (1994) discussed the Family Support Scale (FSS). This is an eighteen-item self-report measure intended to assess the degree to which potential sources of support have been helpful to families with young children. Items are rated on a five-point Likert scale ranging from Not-At-All-Helpful to Extremely-Helpful. The authors completed analyses to determine reliability and validity of the scale.

Dunst, Trivette, and Hamby (1994) administered the FSS to two hundred twenty-four parents of children with developmental disabilities or children at-risk for poor developmental outcomes. Some of the parents took the test twice, a month apart, and others took the test twice, one to two years apart to establish short-term and long-term test-retest reliability. The authors determined criterion validity by administering a number of subscales of the Questionnaire on Resources and Stress (Holroyd 1987 cited in Dunst, Trivette, & Hamby 1994): poor health/mood, excess time demands, and family integrity measures. They examined whether the FSS predicted these aspects of personal and familial well-being.

Dunst, Trivette, and Hamby (1994) found that the results of their study established both the reliability and validity of the FSS. Their scale has substantial internal consistency in measuring the construct they labeled social support. They also found that social support is a relatively stable construct over both short and long periods of time. In determining construct validity, they found that the FSS is measuring different, independently available sources of social support. In examining content validity, they found that their results measured five factor solutions that paralleled the conceptual model they were building on: informal kinship, spouse/partner support, social organization, formal kinship, and professional services. In determining criterion validity, they found that results on the QRS personal and familial well-being scales correlated with the FSS total helpfulness scores. Higher levels of support were associated with lower levels of personal and family problems.

The authors suggested that this instrument has been useful as a research tool and would also be useful in both assessment and intervention. In assessment, it could be used

to assess the number and quality of social supports available to families. In intervention, it could be used to gauge the success of interventions designed to provide support.

Taylor, Crowley, and White (1993) conducted a psychometric investigation of the FSS and FRS. They gathered data from longitudinal efficacy studies conducted by the Early Intervention Research Institute in order to further establish reliability and validity for these two family assessment instruments. Their sample included nearly 1,000 families with children involved in early intervention who were administered a number of family assessment instruments. They addressed the following questions:

1. What are the internal consistency and test-retest reliabilities?
2. What is the correlation between scores derived from this instrument and other family measures?
3. What is the underlying factor structure of the items?
4. What is the stability (invariance) of this factor structure?
5. How does the factor structure identified in these analyses compare to the factor structure reported in the literature?
6. What is the relationship between child functioning and demographic information and the score on the measure?

Taylor et al. (1993) found that both the FSS and FRS can be described by simple subscale structures that meet both statistical and logical scrutiny. They reported that both instruments are stable, internally consistent measures that appear to adequately measure familial perceptions of support and resources.

The Family Strengths Inventory (FSI) discussed by Stinnett and DeFrain (1985) is a scale that asks families to circle on a five-point scale the degree to which their family

possesses certain qualities of a strong family. A score is obtained determining whether the family is below average, average, or above average. The authors suggest looking at specific items in order to determine what support or services may be beneficial for the family. This inventory was developed as part of the Family Strengths Research Project. The authors report that their statistical analysis of the scale has found it to be highly discriminating between those families with a high degree of family strength and those families with lower degrees of family strength.

The Family Needs Survey (FNS) was developed by Bailey and Simeonsson (Bailey 1988a). It consists of thirty-five items organized into six categories. The categories are: needs for information, needs for support, explaining to others, community services, financial needs, and family functioning. For each item the respondent may choose one of the following responses: "I definitely do not need help with this," "Not sure," or "I definitely need help with this."

The authors suggested using this tool during assessment and providing each parent with separate surveys as they have found differing results from mothers and fathers. They suggested using responses and differences in responses as a starting point for further discussion with the family.

The IFSP, Intervention Planning, & Service Delivery

Development of the IFSP and family-centered intervention follow family-centered assessment. Reviewing the literature on specific interventions is beyond the scope of this review; therefore general information regarding family-centered service delivery will be presented rather than information regarding specific interventions.

Communication and Collaboration

Information from parents and families is essential in determining how to provide effective services that truly are family-centered. Pruitt, Wandry, and Hollums (1998) conducted interviews with parents and family members to determine how special educators can be more sensitive to the needs of families and facilitate a family-centered orientation to educational processes. Although these interviews were conducted with parents of children aged 3-29, their responses are relevant to a discussion of family-centered early intervention. The question on the interview for which responses were examined was "How can educators be more sensitive to the needs of your family?" Some common categories of responses emerged. The most common response (27% of respondents) was "listen to us." Parents recommended that educators should realize that parents know and understand their children and that their contributions and suggestions are valuable and should be heard and respected. Parents also responded that educators should work to develop effective communication between parents and professionals. They suggested that educators should be more sensitive to the needs of their family. They suggested that teachers need to have more knowledge about individual disabilities. They indicated that it was very important for educators to treat their children with respect and accommodate their individual academic and social or emotional needs. Finally, they indicated that the IEP process needs to be improved to develop and implement a quality IEP.

From the parent responses, Pruitt et al. (1998) developed a specific course of action that special educators can take to facilitate more sensitive and productive communication and decision-making partnerships. These are summarized below:

1. Special educators must listen to parents' contributions concerning their child's needs, as well as family issues and concerns.
2. Special educators must determine concrete strategies to improve the quality and quantity of communication with families.
3. Special educators must be sensitive to the needs of the families, not just those of the students they serve.
4. Special educators must continue to increase their knowledge about disabilities.
5. Special educators must respectfully accommodate individual needs of students.
6. Special educators must improve the Individualized Education Plan process to be more receptive to family issues.

This course of action developed based on parent and family interviews could be useful through the entire process of early intervention, from assessment to intervention to evaluation of services.

Muscott (2002) wrote about the importance of partnerships with families in service delivery. He described five general guidelines for creating exceptional partnerships between special educators and families. His guidelines were family-centered and were intended for educators in all levels of education, not only in early intervention.

1. Exceptional partnerships are based on family-centered principles.
2. Exceptional partnerships respect the uniqueness of families.
3. Exceptional partnerships understand that families go through common stages of coping after discovering they have a child with a disability.

4. Exceptional partnerships understand the ways in which families cope and match strategies and resources accordingly.
5. Exceptional partnerships are based on family-friendly schools that provide opportunities for maximum parental involvement.

Another study also looked at information from parents to determine their perception of early intervention. One of the most important components of family-centered intervention is collaboration between service providers and parents. Dinnebeil, Hale, and Rule (1999) examined collaboration and service coordination in early intervention programs by completing a qualitative analysis of responses to two questions posed to parents and service coordinators:

1. Is there anything about the way your early intervention program works that helps collaboration between you and the service coordinator (or parent) with whom you work?
2. Is there anything about the way your early intervention program works that interferes with the collaboration between you and the parent (or service coordinator) with whom you work?

These questions were part of a more comprehensive survey. Collaboration was defined as "the way people work together as partners."

Dinnebeil et al. (1999) found that collaboration was enhanced when the program climate and philosophy was truly family-centered, from the administrators to the personnel providing services. Administrative policies and practices need to support collaboration by rewarding collaborative practice and enabling professionals to work in a collaborative manner. Respondents emphasized the importance of employing program

personnel who were good communicators and whose behaviors and actions reflected a family-centered approach to working with families. Service delivery was found to be important also. Scheduling, including flexibility of scheduling and service location, staffing, and the manner in which services were provided to children and families were important. Families appreciated options, such as group or individual services, in service delivery. They believed home visits were critical, and they appreciated provision of transportation. Communication among team members was found to be important to both parents and professionals. Including parents as part of the team was important. Community context was another important finding. This category included funding, relationships with other agencies, and outside bureaucratic demands.

Development of the IFSP

Development of the IFSP is another area where services can be family-centered. The IFSP should be a document reflecting the family-centeredness of services. McWilliam, Ferguson, Harbin, Porter, Munn and Vandiviere (1998) stated four reasons that this document should be family centered. First, a family-centered IFSP allows families to understand the document that pertains to their child's services and sense that they have some control over decision making. Second, because the IFSP guides services, it needs to reflect family priorities. Third, the IFSP should suggest that recommended practices are being implemented. Fourth, the IFSP should document and communicate actual practice to all service providers. The interventions planned should be systematic rather than haphazard, erratic, or arbitrary.

Dunst and Deal (1994) proposed a model of assessment they described as simple and straightforward that helps to focus assessment specifically on identification of family needs, supports and strengths that can be use to meet those needs. They described their model as responsive, flexible, fluid, highly individualized, and they stated that their approach values and accepts a family's personal and cultural beliefs. Their model included eight elements that should lead to the development of an IFSP that is family-strengthening and empowering. The eight elements were: family concerns, family needs, outcome statement, resources and supports, courses of action, family strengths, partnership, and evaluation (p. 74).

Deal, Dunst, and Trivette (1994) also suggested four guidelines for family-centered IFSP development. They stress the importance of being flexible and functional in service provision and of working to enable and empower families. First, the development of the IFSP is done within the context of collaboration and partnerships between the family and human services practitioners. Second, any and all information included in the IFSP is done so with the explicit permission and authorization of the family. Third, the development and revision of the IFSP should be responsive to the broad-based needs of families, although no human services practitioner or program should be expected to offer support to meet all family needs. Finally, both the development and implementation of the IFSP should emphasize promotion of the competence of the family and interdependence with members of the family's community (p. 66-67).

Evaluating Family-Centered Services

The final step in providing family-centered early intervention is evaluating the services provided. It is important to evaluate services at two levels. First, it is necessary to determine whether or not truly family-centered services have been provided. Secondly, it is important to evaluate whether the services provided achieved the desired outcomes.

Evaluating the Family-Centeredness of Services

One way of evaluating the family-centeredness of services is to examine the IFSP. McWilliam, Ferguson, et al. (1998) assessed the validity of an unpublished rating scale developed by the senior researcher to determine the family-centeredness of IFSPs. The IFSP Family-Centeredness Rating Scale was developed based on previous studies of families' reactions to intervention plans, on reflection writings about family-centered intervention plans, and on curricula for developing family-centered rating plans. Twelve characteristics were identified as important in the development of a family-centered IFSP:

1. The writing should be clear and simple. All families should be able to understand the whole document. (Writing)
2. The active voice should be used to specify who will do what. (Active voice)
3. IFSPs should be positive and emphasize strengths. (Positiveness)
4. Nonjudgmental statements are essential. (Judgment)
5. Long-term outcomes and short-term goals should be functional and should include those that are likely to be necessary for success in everyday functioning or for enhancing development. (Necessity)

6. Outcomes need to be specific and specify endpoints. (Specificity)
7. Goal and strategies should be likely to be incorporated into everyday routines. (Context-appropriateness)
8. Methods should directly address outcomes. (Match outcome)
9. Services should be provided in natural environments. (Inclusion)
10. Short-term goals are considered more family-centered than longer term goals. (Target date)
11. Professionals should work together. (Integration)
12. Goals should state how the family is included. (Family's role)

McWilliam, Ferguson, et al. (1998) studied one hundred IFSPs from children involved in various programs in North Carolina. They then rated them using this scale. They found that items on the scale were not internally consistent. They also completed factor analysis which revealed three factors of clarity, cohesion, and functionality. These accounted for 18%, 15%, and 12% of the variance respectively.

McWilliam, Ferguson, et al. (1998) found that this instrument does provide a useful measure of the quality of IFSPs. The authors suggested that training in family-centered practices should include skills in IFSP development and that this training in the development of IFSPs should address the twelve characteristics summarized above.

Another method of evaluating the family-centeredness of services is the use of evaluation instruments designed to measure family-centeredness. Murphy, Lee, Turnbull, and Turbiville (1995) listed twelve family-oriented program evaluation instruments. Of these, the three that had published psychometric information at that time

were: the Parent Satisfaction Survey (Kovach, & Kjerland 1989 cited in Murphy et al. 1995), the Family-Focused Intervention Survey (FFIS) (Mahoney, O'Sullivan, & Dennebaum 1990 cited in Murphy et al. 1995), and the Family-Centered Program Rating Scale (FamPRS) (Murphy & Lee 1991 cited in Murphy et al. 1995).

Of these three, only the FamPRS included items that assess parents' decision-making roles at policy and systems levels (Murphy et al. 1995). This program evaluation instrument was developed by the Beach Center on Families and Disabilities in order to provide information regarding practice indicators and facilitate the implementation of family-centered practices. It yields information regarding both the quality of services and the perception of importance of various aspects of services. It can be used to monitor a program's progress in providing family-centered services and to promote a greater understanding of what family-centered practices actually are (Murphy et al. 1995).

Murphy et al. (1995) described the process of developing the FamPRS instrument. They began with a preliminary study of the expectations of outcomes from early intervention programs and the preferred methods for assessing families' strengths and needs. They included both parents and practitioners in this study. With the information they gathered, they generated items for a rating scale. They then completed a pilot test and scale revision. Finally, they completed a large-scale field test to investigate the factor structure of the scale and to eliminate items that were redundant or not related to the factors. This article did not indicate which factors were major and minor.

The eleven factors they discovered follow:

1. Flexibility and Innovation in Programming
2. Providing and Coordinating Responsive Services

3. Individualizing Services and Ways of Handling Complaints
4. Providing Appropriate and Practical Information
5. Communication Timing and Style
6. Developing and Maintaining Comfortable Relationships
7. Building Family-Staff Collaboration
8. Respecting the Family as Decision-Maker
9. Respecting the Family's Expertise and Strengths
10. Recognizing the Family's Need for Autonomy
11. Building Positive Expectations

The revised version of the instrument contains 59 items organized into eleven subscales based on these factors (Murphy et al. 1995). They report that content validity of the instrument was ensured through careful and deliberate consultation with experts during every stage of development of the scale. They reported construct validity is evidenced by the analyses of the subscales finding that each of the subscales reliably measures a statistically independent construct. They reported moderate to high reliability for the parents and staff members sampled in the field test (Murphy et al. 1995). These researchers suggested that the FamPRS should be used as a component of a comprehensive program evaluation, program planning, staff development, and research.

Evaluating Outcomes

Bailey, McWilliam, Darkes, Hebbeler, Simeonsson, Spiker, and Wagner (1998) discussed a framework to determine the extent to which early intervention has accomplished the goals inherent in a family-centered approach. They pointed out that the identification of family outcomes, unlike individual child outcomes, has been elusive.

These authors suggested two questions as a starting point in answering whether a family-centered approach results in identifiable benefits: (1) What are expected family outcomes? and (2) How should those outcomes be assessed? In answer to the first question, Bailey et al. (1998) cited various authors and researchers who identify expected outcomes in many different ways, including parent knowledge of developmental milestones, parent attitudes toward child-rearing, parent-child interaction, family's capacity to meet their child's special needs, empowerment of families, family's social support network, motivation outcomes, or knowledge/skill outcomes. In answer to the second question, these authors began by acknowledging the complexity of families. A decision must first be made as to who constitutes the family. An objective assessment is not possible because outcomes for families are personal and can only be reported by the family members themselves. Surveys are simple and economical, but limited in scope. Interviews and direct observations can lead to better understanding, but can be time-consuming. Measurement instruments rate performance in comparison with a normative group or a standard for success, but this can also be problematic.

Bailey et al. (1998) offered the following questions for discussion. They pointed out the limitations of this as this framework has not been validated. They "hope these questions serve as a stimulus for discussion, debate, research, and reflection among researchers, parents, university faculty, practitioners, and policymakers engaged in fundamental inquiry into the purposes and anticipated benefits of early intervention" (Bailey et al. 1988). Following is the set of eight questions that they feel are key in this assessment.

The first set of questions focused on the family's satisfaction with services. They addressed perceptions of appropriateness, efficacy, responsiveness, and individualization of services for the family and the child.

- Does the family see early intervention as appropriate in making a difference in their child's life?
- Does the family see early intervention as appropriate in making a difference in their family's life?
- Does the family have a positive view of professional and the special service system?

The second set of questions focused on the impact early intervention has on family life. They addressed the extent to which early intervention fosters parents' perceived competence as caregivers, ability to work with professionals, informal support systems, optimism about the future, and quality of life.

- Did early intervention enable the family to help their child grow, learn, and develop?
- Did early intervention enhance the family's perceived ability to work with professionals and advocate for services?
- Did early intervention assist the family in building a strong support system?
- Did early intervention help enhance an optimistic view of the future?
- Did early intervention enhance the family's perceived quality of life?

These tools and questions could all prove useful in evaluating services, planning programs, and conducting research regarding family-centered early intervention.

CHAPTER 3

SUMMARY/CONCLUSION

Summary

In summary, there is a great deal of information regarding family-centered early intervention in the literature. Providing effective family-centered services requires knowledge and understanding of both principles and the process. Since family-centered practice in early intervention was first mandated in 1986, much work has been done to define and clarify the principles and to develop practices that would be supportive of these principles. The most common principles appear to be that family-centered services are individual, flexible, responsive, honest, educational, friendly, empathetic, collaborative, empowering, strength-based, respectful, and comprehensive.

Because logically high-quality family-centered early intervention begins with family-centered assessment, many tools were described that would aid practitioners in providing these services. Some family-centered assessment tools that were discussed are the FFSS (Trivette et al. 1994), the FRS (Dunst & Leet 1994), the FSS (Dunst, Trivette & Hamby 1994), the FSI (Stinnett & DeFrain 1985), and the FNS (Bailey 1988a). The FSS (Dunst, Trivette & Hamby 1994) and FRS (Dunst & Leet 1994) have had further research conducted supporting their usefulness (Taylor, Crowley, and White 1993). These appear to be especially useful, reliable and valid tools.

Information was also presented regarding family-centered service delivery. There was information regarding family-centered development of the IFSP and the provision of interventions in a family-centered manner. The inclusion of the family in the IFSP process was stressed. Communication, collaboration, flexibility, responsiveness, and

respect and sensitivity in service delivery were all found to be important points in family-centered service delivery.

Finally, there is information on evaluating both the family-centeredness of services and the effectiveness of early intervention services. McWilliam, Ferguson, et al. (1998) used a rating scale to determine the family-centeredness of IFSPs. The FamPRS (Murphy et al. 1995) appears to be another especially useful tool in evaluating the family-centeredness of services. This is a comprehensive tool that provides information on both the quality of services and the perception of the importance of various aspects of services. As the authors suggested this tool could be very useful in research and program planning, as well as in evaluating services to determine training needs. In evaluating the outcome of early intervention, Bailey et al. (1998) suggested two sets of questions which examined the family's satisfaction with services and the impact of early intervention on the family's quality of life.

Future Research

Unfortunately, research on effectiveness and outcomes of family-centered services does not appear to have kept pace with the information on the philosophy of family-centered services. The idea of family-centered services is intuitively extremely important, but we are practicing in an era when intuition is not enough. Evidence that this practice has a positive effect on outcomes is required. This is an area where the research literature on family-centered services is lacking.

Additional research could take many different directions. Bruder (2000a) suggested that research in family-centered early intervention should be participatory. She pointed out that due to the complexities of family-centered early intervention, families

must be involved in all facets of research. Bruder (2000a) also emphasized the importance of research on effective training models in order to train professionals for family-centered practice. The Iowa SCRIPT group has also identified professional development as an important area of research in family-centered practices. The various tools examined in this literature review could potentially be very helpful in conducting research, evaluating programs, and determining strengths and needs in professional development.

Conclusion

One of the most powerful voices in the family-centered early intervention literature is that of Carl Dunst. Dunst (2002) discussed the importance of family-centered intervention at all levels of services, birth through high school. He reported a call for the adoption of family-centered practices in the elementary grades as well as in secondary schools. He eloquently described the need for future research:

> Although much is known about the characteristics of different approaches to working with families, there is a tremendous need for additional information to inform policy and practice. There is a significant need to use similar conceptual frameworks, constructs, and measurement procedures in studies at all school levels (early intervention through high school) to more accurately establish the similarities and differences suggested by the evidence present in this review. Second it would be of some value to conduct studies that relate family-oriented process measures to

variations in child, parent, and family functioning, broadly conceived. For example, it would be of both theoretical and practical importance to discern whether family-centered practices in fact do a better job of engaging the very families whose children are of primary concern to professionals, those who are delayed in their development and who are doing poorly in school...We need better research to substantiate or refute claims about family-centeredness, with an eye toward increased specificity regarding the characteristics and consequences of family-centered and other family-oriented approaches to working with families...The journey, however, has just begun (Dunst 2002).

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