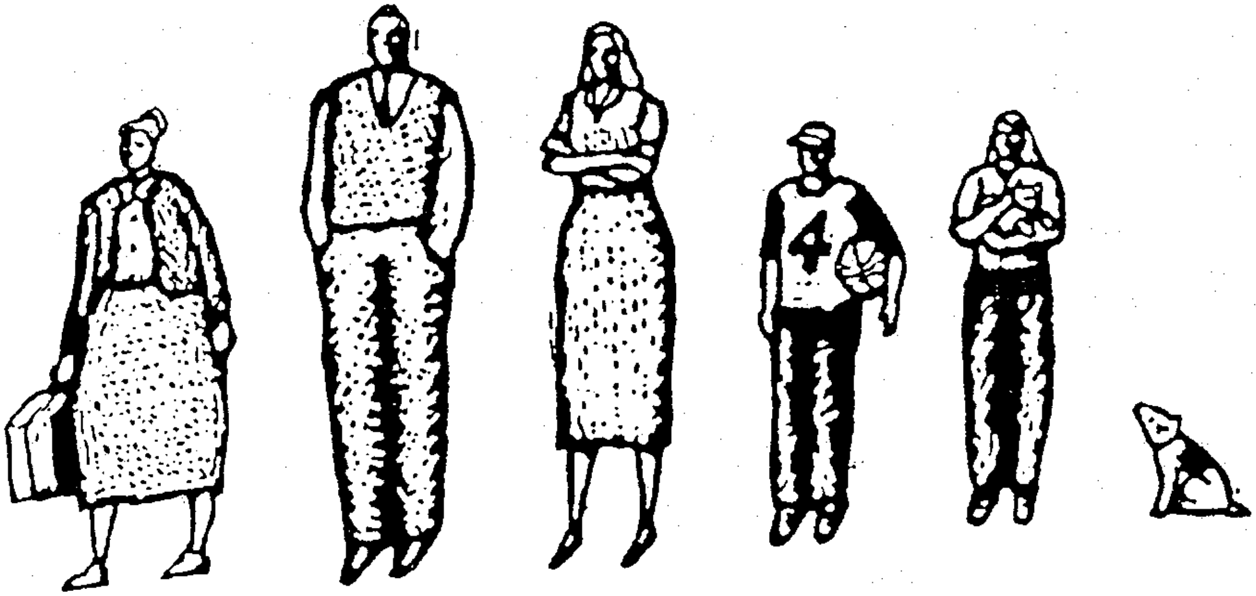
Literature Review

Family-Centered Service Delivery

A Cross-Disciplinary Literature Review and Conceptualization



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The term "family-centered" has been used to describe certain forms of service delivery to families with children at least since the 1950s (Birt, 1956; Scherz, 1953). Both of these authors described models of social work practice, the former referring to the delivery of coordinated, comprehensive social services to multiproblem families, and the latter to a family-oriented perspective on individual mental health treatment with multiple members of a family. The term now is used in a broad range of disciplines, including social work (Bribitzer & Verdieck, 1988; Dedmon, 1990; Frankel, 1988; Hartman & Laird, 1983; Marcenko & Smith, 1992), education (Bailey, Buysse, Smith, & Elam, 1992; Burton, Hains, Hanline, McLean, & McCormick, 1992; Dunst, Johanson, Trivette, & Hamby, 1991; Murphy & Lee, 1991; Roush, Harrison, & Palsha, 1991), health care (Brown, Pearl, & Carrasco, 1991; Brucker & MacMullen, 1985; Fagin, 1970; Krehbiel, Munsick-Bruno, & Lowe, 1991; Larimore, 1993; Weiner & Starfield, 1983), psychology (Roberts & Magrab, 1991), sociology (Sung, 1991), occupational therapy (Bazyk, 1989; Pierce & Frank, 1992), and communication disorders (Donahue-Kilburg, 1992).

Judging by the absence of a precise definition of the term in numerous publications (Bennett, Nelson, & Lingerfelt, 1992; Burton et al., 1992; Dedmon, 1990; Hartman, 1991; Henderson, English, & MacKenzie, 1988; Krehbiel et al., 1991), many professionals seem to assume that a general consensus exists regarding the meaning of family-centered services. However, others acknowledge that for some time, confusion has existed about the term, both because various authors use it in different ways and also because a variety of terms are used to refer to similar service delivery characteristics (Dunst et al., 1991; Lee, 1993; Nelson, Landsman, & Deutelbaum, 1990; Rushton, 1990).

A review of the professional literature supports the latter conclusion. Some examples of ways in which writers describe family-centered services illustrate lack of clarity about the term's meaning (see Appendix A for further detail). Several mental health professionals use the phrase to describe various approaches to family therapy (Blumenstein, 1986; Fagin, 1970; Hartman & Laird, 1983). It also has been used to refer to the processes of serving individuals within the context of their families (Hartman, 1991; Hartman & Laird, 1983; Roberts & Magrab, 1991), providing individual services to more than one member of the same family (Scherz, 1953; Weiner & Starfield, 1983), and involving parents in the delivery of services to their child (Bennett, Nelson, & Lingerfelt, 1992; Cohen & Ooms, 1993; Friesen & Koroloff, 1990). Some authors stress the creation of a partnership between families and service providers (Panel on Women, Adolescents, and Children with HIV Infection and AIDS, 1991; Taylor-Brown, 1991), while others equate family-centeredness, at least in part, with certain characteristics of a service- delivery system, such as its being comprehensive, coordinated, accessible, and community-based (Families of Children with Disabilities Support Act of 1994; Panel, 1991).

Viewing the family as a whole as the client, rather than just the member(s) of the family who initially presented a problem, is considered the essence of family-centered practice by numerous authors (Bazyk, 1989; Finkelstein, 1980; Friesen & Koroloff, 1990; Martone, Kemp, & Pearson, 1989; Scherz, 1953; Sefansky, 1990). Some add the element of family choice regarding care to this description (Donahue-Kilburg, 1992; Lee, 1993; Thurman, 1991). Leviton, Mueller, and Kaufman (1992) blend family choice with the nature of the family-professional relationship (collaborative) to define the concept. Several authors combine a family focus, consumer choice, and enhancement of family strengths, supports, or capabilities to describe a family-centered approach to service delivery (Dunst et al, 1991; McBride, Brotherson, Joanning, Whiddon, & Demmitt, 1993; Roush et al., 1991). This range of conceptualizations of family-centeredness, from serving the individual child within a family context to serving the family as a unit, holistically, within a collaborative relationship in which the family has ultimate decision-making authority, demonstrates one aspect of confusion regarding this approach to service delivery.

Adding to this lack of clarity is the use of terms such as "family-focused," "family-oriented," "family-referenced," "family empowerment," "parent involvement," "wraparound," "individualized care," and "home-based" to refer to a similar range of service delivery patterns that seem interchangeable. Blumenstein (1986), a clinical social worker, refers to family-focused treatment as that which includes the entire family in therapy, while family-oriented treatment reduces the family to subsystems or involves individual therapy that deals with family issues. Dunst et al. (1991) list four broad classes of family-oriented early intervention programs: professional-centered, family-allied, family-focused, and family-centered. Lee (1993) suggests that "there are five major types of family orientations: (a) parent involvement, (b) family focused, (c) family support, (d) family empowerment, and (e) family centered," while recognizing that their definitions are similar (p. 6). Bennett, Nelson, and Lingerfelt (1992) use Lee's latter two categories to refer to the same model of intervention, which is referenced most often in their work as meaning family involvement. Friesen and Koroloff (1990) point out that "family-centered care" and "family support" are used interchangeably. Recent child welfare literature reflects the use of the term "home-based, family-centered services" to describe family preservation or reunification programs, without fully clarifying which program elements are family-centered (Bribitzer & Verdieck, 1988; Frankel, 1988; Nelson, 1984; Pecora, Delewski, Booth, Haapala, & Kinney, 1985). To further cloud the issue, Nelson et al. (1990) seem to suggest that "home-based services," "family-centered services," "family-based services," and "family preservation" represent changes in terminology over time for basically the same model of service delivery.

Another area of confusion within the literature relates to "best practice" standards for family-centered service delivery (Burton et al., 1992; Friesen & Koroloff, 1990). This is not surprising, considering the wide range of use of this and related terms and their adoption across multiple professional disciplines. Many articles and books list characteristics of family-centered service delivery that could be - and in a few cases have been - developed into practice standards (Bryce, 1979; Collins & Collins, 1990; Dunst etal., 1991; Farrow, 1991; Friesen & Koroloff, 1990; Krehbiel et al., 1991; McDonnell & Hardman, 1988; McGonigel, 1991; Nelkin, 1987; Roberts & Magrab, 1991; Rushton, 1990; Thurman, 1991). However, each of these lists differs from the others in its general components and/or in the interpretation of specific applications of these components. Few lists are written in such a way that they could be used across disciplines and settings without some interpretation.

Clarification and elaboration of the concept of family-centered service delivery is important because this approach exemplifies best professional practice with families that include dependent children. The poet Maya Angelou suggests this in her statement, "At our best level of existence, we are parts of a family, and at our highest level of achievement, we work to keep the family alive."

Similarly, Allen (1991) states regarding our public policy toward children, "for most children in this country, the best investment in their future is an investment in a strong family" (p. 64). This assumption is based both upon its means - how services are delivered - and also upon its ends - desired outcomes for children and their families.

Family-centered service delivery operationalizes a philosophical belief in the notions of democracy, self-determination, and the centrality of the family unit in people's lives (Bennett, Nelson, & Lingerfelt, 1992; Briar, 1991; Brown et al, 1991; Firman, 1993), values that the culture as a whole espouses, as do a variety of human service professions. It also is responsive to parents' stated preferences regarding service delivery (Allan, 1991; Cunningham & Davis, 1985; Pierce & Frank, 1992; Rosenbaum, King, & Cadman, 1992; Summers et al., 1989).

Some studies indicate that the incorporation of one or more family-centered practices into the service delivery system improves outcomes. Outcomes that have been positively affected include the child's functioning (Cone, Delawyer, & Wolfe, 1985; Dunst, 1991; Farrow, 1991; Friesen & Koroloff, 1990), increased parent skills and emotional well-being (Cone et al., 1985; Dunst, Trivette, Davis, & Cornwell, 1988; Friesen & Koroloff, 1990; Marcenko & Smith, 1992), parents' perceptions of the effectiveness of services and of their sense of control over their child's care (Farrow, 1991; Dunst, Trivette, Davis et al., 1988), problem resolution in general (Pomerantz, 1984), fewer days in and less usage of out-of-home placements (Firman, 1993; Martone et al., 1989; Nelson, 1984), more positive attitudes of parents toward the use of community resources (Birt, 1956), cost containment (Farrow, 1991; Tower, 1994), and improved functioning of service delivery itself(Coneetal., 1985).

A service delivery model that is consistent with the value base of helping professions, is responsive to consumer demands, and also shows promise for improved intervention outcomes warrants further exploration and explication of practice standards. This paper reviews the literature on the development of the concept of family-centered service delivery in several disciplines, notably social work, education, and health care. This review culminates in a definition of family-centered practice for families with dependent children that captures the current thinking in these fields. This definition is critiqued, and some clarification of ill-defined aspects of the concept is offered. An alternative model for conceptualizing family-centered service delivery across disciplines will be presented, along with examples of its application.

REVIEW OF THE LITERATURE

Historical Trends

Common across disciplines are several historical trends that have supported the development of family-centered service delivery philosophies: parental advocacy for change, criticisms of the medical model, the deinstitutionalization movement, the elaboration of social systems theory, societal changes that questioned the place of professionals and encouraged community empowerment, and an increase in the willingness of politicians to consider the adoption of family-oriented policies. Each of these trends is described briefly.

Professionals in several fields have noted that the impetus for changes toward family-centered practice with families that include dependent children has come more from parents than it has from professionals (Collins & Collins, 1990; Friesen & Koroloff, 1990; Leviton et al., 1992; Petr & Spano, 1990; Turnbull & Summers, 1987). Historically, service providers in various disciplines have tended to focus solely upon the person before them - the person with problems or needs. When the person is a child, this focus can be characterized as "child-centered" service delivery. If service providers considered the family at all, they viewed the family as the source of the problems, as an obstacle to the person's growth, or as irrelevant to the intervention process. Families have resented and disputed this approach and have pushed for changes in service delivery systems (Collins & Collins, 1990; Cournoyer & Johnson, 1991; Cunningham & Davis, 1985; Turnbull & Summers, 1987).

Ambivalence by today's professionals about whether to focus on the children in need of services or on their families is rooted in a similar ambivalence exhibited during the Progressive Era of the early 20th century. During the latter half of the 19th century, which was characterized by a child-centered or "child-saving" approach, many problems related to children were resolved by segregating them from adults in institutions. This practice was supported by the emergence of the social science paradigm, which guided the development of the child guidance movement and which endorsed the idea that children's problems largely resulted from their being parented by people who had character and/or genetic flaws and, therefore, caused their children's difficulties and had no moral right to rear them (Collins & Collins, 1990; Petr & Spano, 1990; Turnbull & Summers, 1987). Even in the delivery of community-based services, treatment of the individual child exhibiting problem behavior became the norm, and parents were either intentionally excluded from the treatment process or else involved only as informants or clients (Collins & Collins, 1990). As Martone et al. (1989) described the role of parents in a children's group home prior to its changing to a family-centered care model, parents were "endured" (p. 13). In addition, the social sciences paradigm assumed the professional's preeminence in decision making regarding these children's care, and choice about the nature of this care was removed from the child, the family, and public scrutiny (Petr&Spano, 1990).

The development of the social sciences paradigm coincided with the emergence of the medical model of care, which is a "professional-centered" model that places the professional in the roles of leader, expert, and rescuer and those seeking assistance in the role of passive recipient. A New Zealand attorney satirically illustrates this approach to families:

> Family lawyers have at least one thing in common with Social Workers - we both know what is best for our clients and we both know that if we were just given the resources we need, well, we could "fix" just about any family.... It would help a lot, too, if the families were not so dysfunctional! Oh and what about a little more cooperation from the clients' families. If only the kids weren't so difficult. What about the clients who sabotage our clear plans for their betterment? Ungrateful sods. (Allan, 1991, Section 6, p. 1)

In recent years, this model has been criticized for its focus on the professional or the facility rather than on the consumer, its limitation of consumer choice and responsibility, its concentration on pathology or deficits, and its too-narrow focus on the individual client as the recipient of care and the resource for change (Bazyk, 1989; Donahue-Kilburg, 1992; Dunst, Trivette, Davis, et al., 1988; Larimore, 1993; Tumbull & Turnbull, 1990).

Despite these movements, many professionals in the Progressive Era advocated a return to traditional (more family-oriented) views in order "to combat the perceived corrupting influences of industrialized city life.... These views included parental authority, home education, rural life, and the independence of the family unit" (Petr & Spano, 1990, p. 230). Although these concepts led to the initiation of policies and programs which were more supportive of families, children continued to be separated from their families in institutions; in fact, there was growth both in the size of the institutions and also in the length of children's stays in them (Petr & Spano, 1990). As noted by Turnbull and Summers (1987), even as late as the 1960s, family intervention with families that included children with developmental disabilities focused primarily on the encouragement of institutionalization and on counselling to help calm the resulting anguish of parents.

Dunst, Trivette, Davis et al. (1988) address the current resistance to family-centered care that sometimes is encountered and which reflects these historical views:

> The *dilemma of helping* that must be acknowledged and addressed by proponents of family-centered health care is the disparity between the helping models typically employed by health care practitioners and the beliefs, attitudes, and behaviors necessary to promote greater participatory involvement on the part of the family. . . . Most professionals have been socialized to believe that they and only they are capable of improving their clients' lot, and to suggest that others might be capable of managing events that professionals have been trained to deal with as experts becomes a direct threat to their sense of competence. (p. 71)

The legal establishment of the concept of least restrictive environment in the 1972 *Wyatt* v. *Stickney* decision, accompanied by the development of a wide range of psychotropic medications and the fiscal concerns of government bodies, strengthened the movement toward deinstitutionalization and community-based care of those in need of human services (Schulberg & Killilea, 1982; Foley & Sharfstein, 1983). The passage of two bills by the U. S. Congress in 1975 specifically reinforced the delivery of community-based services to children. The Community Mental Health Centers Amendments of 1975 (P.L. 94-63) required that all community mental health centers provide children's services, and the Education for All Handicapped Children Act (P.L. 94-142) led to the creation of better services within schools for children with special needs (Petr & Spano, 1990). The decriminalization of juvenile status offenses in the mid-1970s added to the movement to maintain children with special needs within or near their own homes (Frankel, 1988). As a range of services became more community-based, helping professionals were encouraged to focus increased attention on the home lives - the families - of their consumers.

The elaboration of systems theory and its increased application to professional practice over the past three decades has provided a conceptual framework for this increased focus on families. In particular, family systems theory has provided understandings and technologies that are indispensable for family-centered work (Bryce & Lloyd, 1979; Frankel, 1988; Friesen & Koroloff, 1990; Hartman & Laird, 1983; Stehno, 1986). Hartman & Laird (1983) suggest that efforts to strengthen a family focus within mental health care in the 1950s were hampered by the lack of a technology for diagnosing and treating difficulties in family functioning; conceptual tools required to integrate individual and family variables just were not available. During the 1960s, however, the work of professionals who had begun to develop family therapy methodologies in the late 1940s and early 1950s was maturing and spreading throughout the mental health community. More recently, professionals in other fields, particularly special education, have begun to incorporate family systems theory into their interactions with families (Cunningham & Davis, 1985; Dunst, 1991; Roush et al., 1991; Simeonsson & Bailey, 1991; Turnbull & Turnbull, 1990).

Other applications of systems theory support the creation and maintenance of integrated, comprehensive, community-based service networks, which are characteristic of family-centered care. For example, Langley (1991a) suggests that systems theory is at the heart of a new way of thinking by policy makers of all political ideologies, in that it assumes that solutions to problems can be found only when the problem is properly defined in its larger environmental context, which in this case is the entire support system for families and communities. "This is a major breakthrough that enables leaders in social policy to come together around comprehensive strategies for solving problems that now threaten to overwhelm our society" (p. 119).

Stehno (1986) identifies several movements of the past three decades that have contributed to shifts in service delivery systems that are consistent with family-centered practice. The first of these was the antiprofessional ideology of the 1960s, which called attention to certain imperfections in the practice of the helping professions, such as their intrusiveness and judgmentalness, the ethnic and socioeconomic distances between clients and professionals, and the shortage of empirical evidence that professionals were more effective than paraprofessionals or lay helpers. The "backyard revolution" of the 1970s renewed a focus on decentralized community-based service delivery models and the use of community residents in service provision. The growth of self-help movements in the 1970s and 1980s emphasized mutual aid and community control. Some professionals also contributed to changes by supporting people's rights to receive the least intrusive treatment methods available and to refuse treatment, cutting through jargon and red tape, documenting cost-effectiveness - or lack thereof - of services, supporting the use of self-help groups and natural helping networks, and increasing a focus on client strengths and empowerment.

Related to these developments is the consumer rights movement, begun in the 1960s and committed to dispersing power and information to individuals, rather than consolidating it within a bureaucracy. The rights of consumers enumerated to the U. S. Congress by President Kennedy in 1962 are relevant to human services delivery systems today: the rights to safety, to be informed, to choose, and to be heard (Tower, 1994). This movement is challenging the primary dominance of professionals and stressing the principle of consumer self-determination. It assumes that consumers

- in this case, children with needs and their families - possess knowledge, adequate decision-making capacities, and other strengths, and it values their empowerment (Cunningham & Davis, 1985; Koren, DeChillo, & Friesen, 1992); these characteristics are consistent with family-centered service delivery. The consumer movement is demonstrating success in influencing public policy, such as the Americans with Disabilities Act of 1990 (P.L. 101-336), as well as the design of service delivery systems, such as independent living models for services in mental health and developmental disabilities and labor and delivery units in hospitals (Timberlake, 1975; Tower, 1994).

Langley notes that "unlike most Western nations, in which families have routinely been a focal point of social policy, the United States has concentrated on the protection and enforcement of individual rights" (1991a, p. 116). She suggests, however, that the 1979 White House Conference on Families convened by President Carter laid the foundation for political initiatives that focus upon the needs and capacities of families. Although the "pro-family" agenda of President Reagan and ultraconservatives in the U. S. Senate seemed to be directed toward protecting families from federal intrusion, by the mid-1980s federal and state legislators began to acknowledge that social problems were emerging that threatened families and for which no known solutions existed. A new climate for consensus among conservatives, moderates, and liberals began to develop - a climate that encouraged the creation of supports for families, including the development of family-centered, community-based, integrated social service delivery systems (Edelman, 1987; National Commission on Children, 1991; Turnbull, Garlow, & Barber, 1991). This new sense of cooperation resulted in the passage of several pieces of federal legislation (child welfare reform, child care, family leave) as well as a multitude of state-level initiatives. Langley goes on to suggest that there now is a "political ripeness" for the creation of service systems that are more comprehensive and family-centered (1991b, p. 260). It remains to be seen whether the changes brought about by the November 1994 elections will reverse this trend.

Koren et al. (1992) make a point regarding the concept of family empowerment that also applies to family-centeredness: the concept has "benefited from the synergistic effects that comes from many different disciplines focusing on one idea at the same time" (p. 305). As noted above, the movement toward the creation of more family-centered service delivery systems has been supported not just by various professional disciplines but also by the actions of consumers and policy makers. The next three sections of this literature review will describe developments within three professional areas - education, health care, and social work - which have encouraged the evolution of family-centeredness within human services.

Education

Over the past two decades, special education, early childhood education, and developmental disabilities have made significant strides in the development of family-centered services. Much of the impetus for this progress was provided by the creation of the Head Start program and two later legislative actions: the Education for All Handicapped Children Act of 1975 (P. L. 94-142) and the Education of the Handicapped Act Amendments of 1986 (P. L. 99-457).

Since the creation of Head Start in the 1960s, it has encouraged parent involvement by providing training to improve parenting skills and by emphasizing parent control of the program. Although this involvement was based upon a cultural deprivation model (Turnbull & Summers, 1987), it did help to pave the way for increased parental inclusion in educational and disabilities programs and for later educational reform. Evaluations of Head Start's effectiveness have identified a need for more extensive family support services that go beyond the deficit model (National Head Start Association, 1990, cited in Burton et al., 1992, p. 58).

Both P.L. 94-142 and also P.L. 99-457 focused on the needs of children with disabilities. They have had limited impact at this time upon the education of children outside of special education services. The first of these public policy initiatives, the Education for All Handicapped Children Act of 1975, required parent involvement in educational planning for handicapped children. Such involvement most often has been operationalized in the form of the parents' approval of the child's Individualized Education Plan (IEP). The act also resulted in an increased use of parents as teachers or trainers for their children, therapeutic aides of sorts who were to implement at-home intervention plans developed through the IEP process (Turnbull & Summers, 1987).

The Education of the Handicapped Act Amendments of 1986 required states to provide early childhood education for children with special education needs, from birth to kindergarten. Such a task has required that educators increase their emphasis upon the family's importance to a child's development - "a formal recognition of the 'human infrastructure' that is critical to young children's development, and through which intervention must proceed" (Burton et al., 1992, p. 55). Under P.L. 99-457, "early intervention services are designed to meet the strengths and needs of the infant [and young child] as well as the strengths and needs of the family related to enhancing their child's development" (Krehbiel et al, 1991, p. 28). The act specifically calls for several things that directly support family involvement, including the development of Individualized Family Service Plans (IFSPs) for children aged birth-three years and of written plans for family involvement, such as regular home-program communication, training opportunities for parents, interactional opportunities for staff and parents, and outreach plans to encourage greater parent participation. Parents are encouraged to participate actively in screening and assessment, part of which is a determination of the family's strengths and needs that relate to enhancing the child's development. Additional elements of the law encourage service delivery mechanisms that indirectly facilitate a family focus, such as articulation agreements with community resources outside of the educational system, multidisciplinary staffing, the provision of some services in settings outside of the school building, and less dependence on rigid categories of eligibility for services (Bailey et al., 1992; Burton et al., 1992).

As the field of early childhood special education has developed, guidelines for practice also have evolved. Four recommendations for early childhood special education services were made by the Division for Early Childhood of the Council for Exceptional Children. The last of these was that "parent services and support of parent decision making should be included in all programs that receive federal, state, or local government funds" (Burton et al., 1992, p. 59). McDonnell and Hardman (1988) wrote that exemplary early childhood programs are characterized as being integrated, comprehensive, normalized, adaptable, peer- and family-referenced, and outcome-based. As this paper shows below, most of these characteristics coincide with those of family-centered service delivery.

One educational program that exemplifies family-centeredness in action is the Department for Family Support Services of the Kennedy Institute in Baltimore, Maryland. The parents and staff together developed a family-centered consultation model to guide the department's work with families of children with special needs. Families are recognized as the real experts on their children and as the decision makers regarding service delivery. Professionals serve as consultants to them, providing them with information that supports their making informed decisions that they feel are right for them and that use their natural networks more effectively (Leviton et al., 1992).

Within the family-centered consultation model, parents choose the role and the degree of involvement of professionals. Both parties jointly provide information that assists the parents in making informed decisions about which services and resources they would like to receive. Upon request, professionals provide parents with all possible intervention options, both inside and also outside of the Department's program. The parents then formulate strategies to achieve the goals that they have identified as most helpful for their families. As services are delivered, the roles of professionals may vary with changes in the needs and interests of children and their families. The range of services provided may include, among others, training, therapy, advocacy, support, information, and coordination.

Leviton et al. (1992) suggest various examples of ways that service providers can incorporate family-centered practices into their work. Some of these are:

- provide parents with a simple referral process and require only the amount of information from them that is necessary for services to be initiated;
- include parents as members of their service delivery teams;

  allow parents to choose assessment areas and formats, location of the assessments, and their roles in the assessment process;
- frequently check back with parents about whether the service delivery is progressing as they wish, or if they wish to make changes;
- incorporate parents' observations of their children and comments upon the assessment process into its findings and conclusions;
- provide parents with assessment results as quickly as possible, both verbally and in writing, and include practical suggestions in the assessment;
- identify the entire family as the consumer and address concerns regarding whichever members the family chooses;
- avoid jargon in all paperwork and involve parents in the composition and forwarding of correspondence to other involved service providers; and
- allow parents to determine the logistics of meetings between themselves and professionals, focus them upon the families' goals for the meetings, and treat parents the same as other team members.

The shift to more family-centered service delivery within education has highlighted some obstacles that are typical for other disciplines as well. The attitudes of staff towards parents and other family members - and vice versa - are not always conducive to the development of positive, trusting, collaborative relationships. Education professionals often identify gaps in their training and experience that challenge their ability to implement its tenets; for example, they cite a lack of training in counseling skills and of knowledge about family systems (Dunst, 1991; Roush et al., 1991; Simeonsson & Bailey, 1991). There is debate about which professionals are to play particular roles, such as case manager or service coordinator (Bennett, Nelson, Lingerfelt, & Davenport-Ersoff, 1992), and about which services are to be provided within the educational setting and which are to be provided by other organizations in the community. Funding of family-centered services often is difficult, and services needed by families sometimes are not available (Woodruff, 1985; Woodruff & Sterzin, 1988). Such challenges are not unusual when systems are undergoing significant changes in the way they think about themselves and function.

Within the last 15 years or so, the fields of early childhood education and special education have done more to explore and explicate the nature of family-centered service delivery than have other professions. This increase in attention can be credited to the passage of federal legislation that specifically required parental involvement and family-centered services, and the direction in which their activities have gone has been greatly influenced by these policy changes. Outside of special and early childhood education, however, few efforts seem to have been made to incorporate a family-centered philosophy into the educational process, to normalize it as best educational practice. There is some indication that this approach is making inroads in controversial areas such as parental management of schools (Bailey et al., 1992) and the development of school-linked community services such as health clinics (Balassone, Bell, & Peterfreund, 1991; Harold & Harold, 1991; Wagner, 1993). All of these endeavors have served to bring educators into more meaningful interactions with parents and with other helping professionals in the community.

Health Care

Dunst, Trivette, Davis et al. (1988) describe family-centered health care as "based upon principles that are designed to promote self-determination, decision-making capabilities, control (self-efficacy), and other intrapersonal and interpersonal characteristics" (p. 72). The nursing profession and the medical specialities of family practice, obstetrics, and pediatrics have performed leadership roles with regard to family-centered health care practice for over two-and-a-half decades, and the groundwork they laid has contributed to the adoption of this approach to care by other health care providers (Garbarino, 1980; Larimore, 1993; Spreading family-centered care, 1975; Timberlake, 1975). Such service delivery is most evident in the specific areas of maternity care and neonatal intensive care.

Timberlake's 1975 description of the New Life Center (NLC) at Family Hospital in Milwaukee, Wisconsin, now reverberates in numerous labor and delivery units around the United States. Three needs expressed by child-bearing couples led to the development of the NLC: "(1) to labor, deliver, and emerge as a family in an atmosphere of warmth and relaxation ...; (2) to have control over their bodies and some choice and participation in what is done to or for them; and (3) to remain in close touch with loved ones throughout the birth and hospitalization" (p. 1457). Maternity care staff took these expressed needs quite seriously, reexamining every hospital and maternity policy and procedure to assess their fit with consumer wishes. Those policies and procedures that were not based upon scientific fact or mandated by state code were discarded or left to the mother's or couple's decision, for the principle of maximizing choices available to the new parents was at the core of this analysis.

This shift of focus from childbirth as a hospital- or physician-centered experience to a family-oriented experience resulted in the redesign of service delivery in multiple areas: the physical environment (the placement of rocking chairs in postpartum areas, the creation of lounges with various activities available and a well-stocked snack room, the creation of combined labor/delivery/postpartum rooms, the placement of telephones in all labor/delivery rooms); scheduling (the direction of the mother's and baby's postpartum schedules by the mother, choice by the family regarding who will be present at various stages of the process, the arrangement of the staffs work around the needs and preferences of each mother/baby couple); medical care (planning by couples or mothers of as many aspects of the delivery process as possible, such as birth positions and the type of anesthetic); staff roles (nurses are encouraged to develop a warm and nurturing relationship with couples, and some of them carry caseloads that allow them to follow families throughout the pregnancy and to maintain contact for several weeks after the birth); and the designation of the consumer to be served (fathers are considered a part of the health care team, and the needs of siblings can be addressed). It should be noted that the staff of the NLC was instrumental in spreading their philosophy of family-centered care to other units of their hospital and its long-term care facility.

The New Life Center is one example of labor and delivery units that have expanded their role to include follow-up of new families after they leave the hospital. There is a recognition that the birth of a child impacts a family dramatically in a variety of ways and that staff who participate in the childbirth experience are in an excellent position to identify needs that may arise and resources available to meet these needs (Brucker & MacMullen, 1985).

Brown et al. (1991) describe the evolution of Neonatal Intensive Care Units (NICUs) from child-centered to family-centered. These authors embrace the definition of family-centered care presented by The Association for the Care of Children's Health: "a philosophy of care that recognizes and respects the pivotal role which the family takes in the lives of children with special health needs" and which supports families in their "natural caregiving roles" (p. 51). This model attends to the fit between the individual and the environment and among all of the interacting units of the service delivery system, which includes family members (Thurman, 1991).

This development in NICUs has been influenced, as has the field of education, by the passage of the Education of the Handicapped Act Amendments of 1986. Some NICUs initiate the establishment of Individualized Family Service Plans while the infant with a disability still is hospitalized (Krehbiel et al., 1991). Families attend meetings of the multidisciplinary treatment team, and their transition into community-based services is facilitated by hospital staff members.

Family-centered approaches to care for children with special health care needs are not limited to newborns. As surgeon general of the U. S. Public Health Service, Dr. C. Everett Koop (1987) called for the establishment of a national agenda for the care of children with special health care needs; the agenda included a focus on the families of these children and the development of a system of family-centered, community-based, coordinated care. Since that time, work has proceeded to identify methods for implementing this vision (Brewer, McPherson, Magrab, & Hutchins, 1989; Dunst, Trivette, Davis et al., 1988; Rushton, 1990).

Advances in medical technology, along with increases in the numbers of people who have Alzheimer's disease or who are infected with HIV, has strengthened a multidisciplinary emphasis upon the care of adults who are chronically ill. The necessity of involving family members in the care of the chronically ill person, and perhaps of viewing the entire family of the person as the client, has come to be an accepted principle of care for this population (Nelkin, 1987; Panel, 1991; Taylor-Brown, 1991; Wetle et al., 1989; Woodruff & Sterzin, 1988). Literature in this area emphasizes the following concepts as essential to family-centered care: addressing the needs of the family unit, maximizing family self-determination and autonomy, building on family strengths, involving family members in the development of policies and procedures, attending to the basic developmental needs of individuals and families as well as to their medical needs, and designing services that are community-based, comprehensive, coordinated, accessible, and responsive to the needs of individual families.

Despite a long-time emphasis in health care upon the medical model, there are an increasing number of examples of service delivery systems that have undertaken significant restructuring in order to pursue an approach to care that supports the self-determination of the recipient of services. A major impetus for these changes initially was the consumer movement. More recently, legislative initiatives such as P. L. 99-457, an increasing demand for services for people with complex chronic illnesses, and the rising cost of health care have pushed this field toward family-centered delivery systems. In many cases, families are being expected to take more active roles in the health care of their members, consumers are more actively exercising their right of choice, and the needs of multiple members of the family unit are being addressed (Pomerantz, 1984; Seltzer, Litchfield, Kapust, & Mayer, 1992).

Social Work

Family-centeredness could be considered a perfect match for the profession of social work. Its core values, such as a belief in client self-determination, are directly relevant for and consistent with principles underlying family-centered practice. Furthermore, a focus on the family dates back to the beginnings of the profession in the late 19th century. As Hartman and Laird (1983) write, "Our profession began in the company of the family and has returned to it once again" (p. vii).

The Settlement Movement and Charity Organization Societies (COS) both acknowledged the sanctity of the family and supported efforts to maintain family units (Pumphrey & Pumphrey, 1961). The early social work pioneers "cautioned against only interviewing individuals and prescribed interventions with the whole family," using what now is known as a systems or ecological perspective (Cohen & Ooms, 1993, p.8). As Mary Richmond wrote in 1917, "As society is now organized, we can neither doctor people nor educate them, launch them into industry nor rescue them from long dependence, and do these things in a truly social way without taking their families into account" (p. 134). She considered the unit of study, diagnosis, and treatment within social work practice to be the family.

In addition, both COS and settlements considered themselves, in different ways, to be a part of the neighborhoods and communities that they served. They utilized, developed, and coordinated the resources that those communities offered. Stehno (1986) summarized some of the notions of service delivery developed by turn-of-the century friendly visitors, and described in Sophonisba Breckinridge's 1924 publication Family Welfare Work: Selected Case Readings, which seem to have informed current family-centered social work practice:

> Like many providers of these new family-centered child welfare services . . . , Breckinridge's social workers did most of their work in the clients' homes and neighborhoods. Like the "new" family workers, these early workers gave serious attention to the needs - especially the concrete ones such as food and housing - defined by clients, spent enormous amounts of time getting and keeping natural helping networks (relatives, landlords, neighbors) involved, timed visits to meet family needs and respond to crises, and used helping teams (homemakers, visiting nurses) freely. But, most significantly, within the limits of Progressive Era morality and paternalism, these workers held, as we do, the goal of keeping the family together. And so long as the client shared that goal. . . , the family was in charge of the help it got. (p. 233)

Social workers gained new venues for practice during World War I, when the Home Service and the specialty area of psychiatric social work were developed. The Home Service was created in 1917 by the American Red Cross, temporarily operating under the auspices of the War Council as an "efficient arm of the government," to assist service men and their families with a wide range of functional problems. The Home Service was designed by social workers and was to focus on casework, as did Charity Organization Societies. Its workers were trained in "the needs and resources of normal family life and community organization, including health problems, child welfare, and family economics" (Black, 1991, p. 389). This emphasis on normal family life and the recognition that social services may benefit all families at particular times in their lives are reflected in family-centered practice today.

At about the same time, psychiatrists developed a plan to place specially trained psychiatric social workers in military hospitals to assist them in securing personal and family histories from patients who were experiencing war-related mental and nervous disorders. Although the family was considered as these social workers developed social histories and discharge plans, the focus of care was on the individual patient. This movement away from a holistic view of people's lives and of service delivery continued in the post-war period and has been described by Bardill and Saunders (1989): "Psychiatric social workers practiced on mental health teams and as a result, individuals, families, and treatment became fragmented with each professional on the team (psychiatrist, psychologist, and social worker) responsible for certain pieces of the patients, their families, and their treatments" (p. 320).

The profession endured a struggle during the first half of the century between those who affirmed the centrality of the family as a focus of concern and the growing number, influenced by the mental hygiene movement and psychoanalytic theory, who defined service delivery in terms of individuals. However, interest in the functioning of families and in the provision of more comprehensive services to them never has left social work completely, and the 1950s saw a renewal in the profession's attention to families (Hartman & Laird, 1983).

The term "family-centered" apparently was coined originally by the Family-Centered Project of St. Paul and by some family service agencies in the 1950s (Birt, 1956; Scherz, 1953), as noted at the beginning of this paper. The Family-Centered Project formed the basis for much of our current thought regarding working with multiproblem families. It established a system of multiple-agency collaboration in the delivery of coordinated, comprehensive social services to multiproblem families. Diagnosis and treatment were viewed in the context of the entire family rather than in terms of specific problems of individual members of the family. Scherz (1953) used the term somewhat differently as she, in a time prior to the full development of family systems theory, described the use of individual counseling with multiple members of a family as a way to address family problems. Although family members were interviewed separately, their workers communicated with each other and coordinated their work so that certain issues were being discussed with various family members simultaneously.

Additional evidence of social work's family focus is illustrated by its presence in the settings managed by the other professions described above. Within education and health care systems, social work has been the discipline that most often has been assigned responsibility for relating to parents and other family members regarding family needs and with community-based resources that can meet these needs (Constable, 1992; Pennekamp, 1992; Sefansky, 1990). Another way in which social work has enriched the family-centered service delivery of other disciplines is its development and use of case management models, which have served as illustrations of ways in which comprehensive community-based services can be coordinated (Bennett, Nelson, Lingerfelt et al., 1992; Marcenko & Smith, 1992).

As is true in the field of education, legislative initiatives have influenced social work intervention with families. P.L. 96-272, the Adoption Assistance and Child Welfare Act of 1980, has affected practice with families in the area of child welfare. The objective of strengthening families so that the removal of children from their biological homes may be prevented or reduced in duration is in keeping with a focus on the family, rather than on the child in isolation. The act has resulted in changes in practice that include an increase in concrete and counseling services available to families at risk of placement of their children, more involvement of parents in decisions about intervention, and the provision of more thorough information to parents about the child welfare process in general and about the care of their children within this system in particular (Bribitzer & Verdieck, 1988; Stehno, 1986). The law's passage has stimulated the establishment of family preservation programs, which are more family-centered in their approach to child welfare services than have been many earlier alternatives (Bryce, 1979; Frankel, 1988; Nelson, 1984; Nelson et al., 1990; Pecora et al., 1985).

Although P. L. 96-272 has moved the child welfare system in this country toward more family-centered practices, it does not go nearly as far as New Zealand's Children, Young Persons and their Families Act of 1989 (Allan, 1991; Firman, 1993). This law mandates that when the state becomes involved with children who have been abused or neglected or otherwise are "at risk," the power of decision making regarding protection of the child must be given to the family. This is accomplished through the use of Family Group Conferences. The convener of such a conference invites all members of the child's nuclear and extended family (including tribal members) who can be located to attend the conference; if necessary, the state subsidizes the cost of their travel to the meeting. During the first portion of the conference, professionals and family members share with each other the information they have regarding issues concerning the child's safety and potential resources available to assist the family. During the second portion, family members generally are left alone to develop a plan for the care and protection of the child, usually within the family system itself. Except under extraordinary circumstances, the role of the state then is to sanction the plan and negotiate resources that will be required to implement it.

Many social workers would be hesitant to adopt such an approach to child welfare services. However, the outcomes noted after four years of implementation of this law suggest that it does not pose an increased risk to children's safety. Among these outcomes are a 90% reduction in the use of foster care in some areas of New Zealand, more accurate family assessments, the generation of a greater variety of care alternatives, and a strengthening of families' efforts to implement the care plans successfully (Firman, 1993). An attorney who has been involved with this system of service delivery writes: "In my experience, when a plan decided by the child's family does not work, the results are no more damaging to the welfare of that child than the results when the plans under the state-directed system failed. Families then do no worse than state agencies and, in most cases, they do a lot better" (Allan, 1991, Section 6, p. 2).

In addition to the area of child welfare, family-centered service delivery has made advances in the mental health care of children and adolescents, a field of professional practice that includes social workers as well as members of other disciplines. CASSP, the Children and Adolescent Service System Program, was initiated in 1984 by the National Institute of Mental Health to further the development at state and local levels of multiagency, coordinated, community-based systems of care for children and adolescents with serious mental health needs. A guiding principle of CASSP is that parents of emotionally disturbed children should participate fully in all areas of service planning and delivery (Allen, 1991; Collins & Collins, 1990). All 50 states, the District of Columbia, and the Virgin Islands have received CASSP grants; they have developed a range of strategies for accomplishing the program's goals: convening interagency groups, developing regional and local interagency or case-management structures, sponsoring technical assistance and training activities, and creating a variety of ways to encourage family participation in planning, service delivery, and mutual support (Lourie & Katz-Leavy, 1991).

Individual programs also have adopted family-centered practices. Martone et al. (1989) describe the changes initiated by a residential treatment facility for children in order to increase the involvement of parents in their children's care and to integrate family members into as many aspects of the treatment process as possible. Over a four-year period, the average length of stay by children in the program declined significantly (from 65 months to 24 months), an increased percentage of children returned to their own homes at discharge, and families came to be seen as partners in the care of their children and themselves. Similarly, Finkelstein (1980) describes a group care facility for children and adolescents that has shifted its goal of placement from encouraging the adaptation of the child within the institution to that of helping the child and family learn to live and cope together. Parents are involved in the residential center at least twice a week, and they maintain a relatively high degree of decision-making authority while the child is in care, including the determination of the point at which the child will be discharged from care. Many communities have begun to experiment with ways to coordinate the multiple service needs of families with severely emotionally disturbed children and to increase their capacities to attain goals set by these families, often through the development of "individualized" or "wraparound" service delivery systems (Burchard & Clark, 1990; Lourie & Katz-Leavy, 1991). Despite this increased activity, references in the professional literature to "family-centered" mental health care still are relatively rare.

Although the profession of social work has demonstrated more of a family focus over the past century than other human service professions, it has not been at the forefront of the evolution of the concept of "family-centeredness" during the past twenty years. There may be multiple reasons for this: the prevalence of a clinical emphasis among social work practitioners; a relatively weak presence of social workers in juvenile justice, educational, and developmental disabilities settings; and the lack of professionally trained social workers in many policy-level positions in child welfare and mental health departments. Even though references to family-centered services are less prevalent than one might expect in the social work literature, there have been an increasing number of articles in related areas such as collaborative and strengths-oriented approaches to practice; it appears that many elements of family-centered practice are being incorporated into the profession under other terminology. It is clear that the profession of social work brings a wealth of history and experience and a relevant value base to the exploration of family-centered service delivery and that social workers function in a wide variety of settings in which such an approach is desirable.

Family-Centered Practice: Consensus Definition and Characteristics

As stated at the beginning of this paper, many diverse ideas exist in the professional literature and in practice about the meaning and nature of family-centered practice. Some common themes appear in much of the literature, however, and they make a basic level of communication about this concept possible. Consistent with the philosophy of family-centeredness, several authors have involved parents directly in their exploration of these themes (Collins & Collins, 1990; Cournoyer & Johnson, 1991; Cunningham & Davis, 1985; Dunst, Triverte, Davis et al., 1988; Lee, 1993; Leviton et al., 1992; Mahoney, O'Sullivan, & Dennebaum, 1990a, 1990b; Nelkin, 1987; Ooms & Owen, 1991; Summers et al., 1989). This section of the paper suggests a current, consensus definition of family-centered service delivery, describes its basic characteristics, and critiques this conceptualization.

Before describing the current thinking about what family-centered service delivery is, it may be instructive to review what it is not, what some of the alternative models of care are. One of the service delivery options available is to focus on the needs, problems, strengths, and resources of an individual, largely ignoring the social systems of which she or he is a part. The modality of individual treatment in mental health - as well as group treatment of individuals - illustrates this perspective (Finkelstein, 1980; Friesen & Koroloff, 1990; Martone et al., 1989). Roberts and Magrab (1991) point out that such a focus has been the predominant trend in the practice of psychology for the past fifty years. This trend is present in education and health care, as well. Programs in both of these areas sometimes have been described as "child-focused" or "child-centered," indicating their attentiveness to the child who is the recipient of services (Bailey et al., 1992; Bazyk, 1989; Brown et al., 1991; Roush et al., 1991).

Particularly in the case in which the individual who is the focus of attention is a child, the professional often takes on the roles of decision maker and director of the caregiving process (Bazyk, 1989; Donahue-Kilburg, 1992). This has led some writers to describe services as being "professional-centered," "doctor-oriented," "therapist-centered," etc. (Dunstetal., 1991; Larimore, 1993). A variation of the professional-driven approach is one which is led by the structure, needs, and services of the agency or institution providing the care (Hutchinson & Nelson, 1985; Taylor-Brown, 1991). Larimore (1993) refers to "facility-centered maternity care" and Friesen and Koroloff (1990) to "service-centered planning," for example.

To derive a definition of family-centered service delivery that reflects recent thinking across disciplines, a simple content analysis of definitions in the literature was completed (see Appendix A for a listing of definitions). Ten key concepts were identified within the 28 definitions reviewed. They are listed here with an indication of the number of definitions in which each concept appeared:

- the "family" as the unit of attention or concern (28)
- parent involvement or their collaboration/partnership with professionals (10)
- addressing needs of the consumer (9)
- the provision of specific types of services (9)
- family choice or decision making (8)
- strengths or capabilities of families (7)
- maintaining children in their own homes (5)
- attending to the uniqueness or culture of families (2)
- empowerment (2)
- normalization principles (2).

Based upon this content analysis, the following consensus definition of the concept was developed that captures the essence of its meaning for a significant portion of professionals who use the term:

> Family-centered service delivery, across disciplines and settings, views the family as the unit of attention, and organizes assistance in a collaborative fashion and in accordance with each individual family's wishes, strengths, and needs.

Although this may appear to be a simple and straightforward definition, clarification of its key components and characteristics, which are highly interrelated, is essential to the tasks of operationalizing it so it can be used in program development, policy formation, and research. These key characteristics are: a focus on the family as the unit of attention, family-professional collaboration, family choice, an emphasis on family strengths, family-identified needs, individualized services, family-sensitive information-sharing processes, a focus on normalization principles, and the creation of a user-friendly service delivery system. (NOTE: The authors suggest a different definition of family-centered service delivery, which appears later in this document.)

Elements of the consensus definition

The first characteristic of family-centered service delivery as described here is its focus upon **the family as the unit of attention.** This focus does not ignore or deny the fact that the initial contact with a helping professional usually is made as a result of the actions, conditions, or needs of only a part of the family, often just one member of it. These presenting problems or concerns are incorporated into the work of the family-centered professional (Bazyk, 1989), but they do not necessarily limit the focus of care. It is often the case that ripples of concerns flow across the family, that the problems or needs of one or two members affect the other members, or that such problems or needs actually reflect difficulties elsewhere in the family system. At times, various members of a family must be involved in care in order for the presenting concern to be addressed effectively. Family members may be able to provide needed resources, and they may wish to remain the primary caregivers for family members, to not have their roles diminished by professional actions. On the other hand, they may be potential obstacles - intentional or unintentional - to progress; assistance that includes them increases the opportunities for removing whatever obstacles may be present. For these reasons, the family-centered professional maintains concern about the presenting concern(s) while also broadening her/his perspective to explore the possibility that the family as a whole needs attention and involvement (Brown et al., 1991).

The next element of the definition is **the organization of assistance in a collaborative fashion.** Across disciplines, the vast majority of authors of works regarding family-centeredness describe the family-professional relationship as a collaboration or a partnership. The concepts of equality, mutuality, and teamwork are used to describe the nature of this partnership (Bailey et al., 1992; Donahue-Kilburg, 1992; Lee, 1993; Marcenko & Smith, 1992; Timberlake, 1975). DeChillo (1993) defines collaboration as "working together or joining in the pursuit of a common goal" (p. 104). This definition breaks down the barrier between worker and client - both are "workers." Both have expertise, knowledge, skills, and energy to contribute to the helping process. Although these contributions are different, they all are valued and can be useful. "'Equal partners' does not mean that parents and professionals assume each other's roles, but rather that they respect each other's roles and contributions. While professionals bring technical knowledge and expertise to this relationship, parents offer the most intimate knowledge of their children, and often special skills" (Nelkin, 1987, p. 9).

Many authors have described the tendency by professionals to consider themselves to be the primary repositories of knowledge about what consumers of their services need and skills to meet these needs (Allan, 1991; Cunningham & Davis, 1985; Donahue-Kilburg, 1992; Dunst, Trivette, Davis et al., 1988); after all, is that not why people seek their assistance? From a family-centered model, such a perspective demonstrates a lack of regard for and trust in the capabilities of families. It also devalues the element of client choice that is crucial to this model. Many professionals defend their actions - described by some as paternalistic (Stehno, 1986) - with assurances that they want what is best for their clients, that they want them to have the best possible care and to protect them from harm, and that they are invested in their clients' progress. And yet, the people most invested in what happens to these clients usually are located within their own families (Finkelstein, 1980). Cunningham and Davis (1985) quote a parent who addressed this issue:

> Parents are experts too. Help should begin with an understanding of what we believe, expect, and need. This is the foundation of all efforts to help their child. If they [professionals] listened to parents, trusting them to be competent and capable, instead of giving instructions all the time, they would be more useful. It is easier to receive, when you are giving. (p. 1)

In everyday practice, many steps have been taken to facilitate the development of a true partnership between professionals and family members. Particularly in labor and delivery, neonatal, and pediatric units of hospitals, much attention has been paid to the physical surroundings in which care is delivered (Thurman, 1991; Timberlake, 1975). Physical space has been redesigned so that family members are able to be present and to interact with each other and with care providers easily. The delivery of services in the family's own home or in some other location of their choosing carries this principle even further (Bribitzer & Verdieck, 1988; Burton et al., 1992; Frankel, 1988; Nelson et al., 1990). Programs have undertaken comprehensive reviews of their policies, procedures, and routines and modified them so that family members can maximize their involvement in the delivery of care (Martone, et al., 1989; Timberlake, 1975).

Staff in all help-giving professions are receiving more training and retraining in approaches to relating with care recipients in ways that reflect their trust in the ability of family members to engage fully in discussion and make decisions about their care (Larimore, 1993; Rushton, 1990; Spreading family-centered care, 1975). Parents, child clients, and/or other family members are being included as full-fledged members of the service delivery team, not just included in meetings as passive recipients of information and decisions generated by professionals (Cone et al., 1985; McDonnell & Hardman, 1988; Roberts & Magrab, 1991; Timberlake, 1975; Woodruff & Sterzin, 1988). In some cases, parents have been trained as case managers and, thus, share with professionals responsibilities formerly relegated to the latter alone (Seltzer et al., 1992). Family members also are being encouraged and sometimes mandated to participate actively in policy development and review processes within agencies, schools, and legislative bodies (Cone et al., 1985; Friesen & Koroloff, 1990; Panel, 1991). Parents have been included in training delivered to professionals (Bailey et al., 1991) and in some cases have served as the trainers (Roberts & Magrab, 1991). Researchers have begun to develop instruments to measure family participation in service delivery, resulting in improved methods for assessing this element of care (Cone et al., 1985; DeChillo, 1993; Koren et al., 1992).

The third component of family-centeredness addressed in the definition above is the **organization of assistance in accordance with each individual family's wishes or choice.** Although some authors refer to family "involvement" in decision making (Brown et al., 1991; Woodruff, 1985) or to joint parent-professional decision making (Collins & Collins, 1990; Roberts & Magrab, 1991; Rushton, 1990), a growing number express the view that for service delivery to be considered family-centered, the family must, whenever possible, be the primary and ultimate directors of and decision makers in the caregiving process (Bailey et al., 1992; Bazyk, 1989;

Donahue-Kilburg, 1992; Kramer, McGonigel, & Kaufmann, 1991; Leviton et al., 1992; McGonigel, 1991; Summers et al., 1989). This latter interpretation of family choice expands the meaning of "collaboration," from working with families to working for them. The only limitations on this criterion of family choice involve emergency situations in which the family is unavailable for decision making or in which the state supersedes the family as decision maker, such as in cases of child abuse or neglect.

The family-centered definition next includes a consideration of **family strengths.** Trivette, Dunst, Deal, Hamer, and Propst (1990) define family strengths as "the competencies and capabilities of both various individual members and the family unit that are used in response to crises and stress, to meet needs, and to promote, enhance, and strengthen the functioning of the family system" (p. 18). This focus helps to address the very valid complaints of families that they have been blamed, criticized, and labeled as incompetent by service providers, rather than recognized for their capabilities and supported in their parenting role.

Saleebey (1992) noted that although "the idea of building on clients' strengths has achieved the status of adage in the lore of professional social work," in reality "most such nods to building on strengths are little more than lip service; the idea of centering practice on eliciting and articulating clients' internal and external resources has not been reasonably explicated as either an idea or a practice" (p. 3). Such a statement may be adapted as a reference to other disciplines, as well.

However, a genuine professional focus on client strengths and their importance to service delivery has been growing during the past decade (Blue-Banning, Lee, Jones, & Turbiville, 1992; Saleebey, 1992; Summers, Behr, & Turnbull, 1988). The findings of Dunst, Trivette, Davis et al. (1988) support this emphasis. They suggest that help-giving is more effective if help-givers, among other things:

- "employ helping models that emphasize help seekers' acquisition of competencies necessary to solve problems or meet needs,...
- assume that help seekers have the capacity to understand, learn about, and manage *all* events in their lives,...
- build upon help-seeker strengths rather than correct deficits as the primary way of strengthening family functioning,... [and]
- promote acquisition of effective behavior that makes the help seeker more capable and competent.. ." (pp. 73, 74).

Such a perspective modifies the view of family members as people who only cause problems and are obstacles to the improvement of clients and is consistent with the notion of collaboration as a preferred style of family-professional interaction.

A strengths perspective facilitates the empowerment of families, which often is mentioned as a principle or a goal underlying family-centered work (Dunst, Trivette, Davis et al., 1988; Larimore, 1993; McGonigel, 1991; Stehno, 1986; Petr & Pierpont, 1992; Seltzer et al., 1992). As Thurman writes, "All families have power but must be enabled to use that power" (1991, p. 36). Koren et al. (1992) listed the major themes of definitions of empowerment: a reduction of powerlessness; the gaining, developing, seizing, enabling, or giving of power; the ability to influence people, organizations, and environments that affect one's life; the attainment of control over one's life; and democratic participation in the life of one's community. They have developed an instrument to assess empowerment in parents and other family caretakers whose children have emotional disabilities.

Referring specifically to family empowerment, Dunst, Trivette, and Deal (1988) wrote that "by 'empowerment,' we mean a family's ability to meet needs and achieve aspirations in a way that promotes **a** clear sense of intrafamily mastery and control over important aspects of family functioning" (p. x). Researchers at the Beach Center on Families and Disability (1993) have conceptualized empowerment as a developmental process that consists of the motivation to act, the resources and skills needed for effective action, and contexts or environments that respond to families and people with disabilities. All three of these parts interact in ways that can foster or inhibit a family's empowerment. Thurman (1991) suggests that professionals are to provide opportunities for families to acquire or display their competencies and that the sense of empowerment that results is characterized by families taking more control over decision making, which is **a** desired outcome of family-centered practice.

The fifth component of the family-centered definition above addresses **family needs.** As noted above, family-centered service is offered and available to all members of a family, not only to the members with the "presenting problem." In addition, the needs which are considered within this approach are not limited to those initially presented. A holistic view of the family's circumstances, needs, and resources is taken. Dunst, Trivette, and Deal (1988) illustrate this point in the field of early childhood intervention, noting that early intervention must address all the pressing needs that families identify, not just those relating to children's education. They suggest that "early intervention," therefore, needs to be defined in a new, broader way: "the provision of support (i.e., resources provided by others) by members of a family's informal and formal support network that either directly or indirectly influences child, parent, and family functioning" (p. 5).

The final element of family-centered service delivery that is referenced specifically by the consensus definition is that of **individualizing services to each family.** The processes and products of assessment, goal-setting, and intervention planning and implementation must be matched to the needs and resources of each particular family, rather than expecting every family to fit into a formulized approach to care (Bazyk, 1989; Dunst, Trivette, Davis, et al., 1988; Friesen & Koroloff, 1990; Lourie & Katz-Leavy, 1991; Simeonsson & Bailey, 1991; Turnbull & Summers, 1987). As McGonigel (1991) phrases it, services should be "tailor-made" to each individual family (p. 11).

Another aspect of this element of the definition is a respect for the structural and cultural uniqueness of each individual family. Assumptions must not be made that families that have certain structures (such as single-parent families), lifestyles (such as families with homosexual parents), socioeconomic statuses (such as poor families), and belief systems (such as a belief in indigenous healers) are less healthy, functional, or desirable than others (Krehbiel et al., 1991; Thurman, 1991; Woodruff, 1985). Racial and ethnic differences among families must be recognized and accepted, and their implications for service delivery must be taken into consideration as care is provided (Allan, 1991; Brown et al., 1991; Ho, 1987; Krehbiel et al., 1991; Mokuau, 1990; Taylor-Brown, 1991). Culturally competent and family-centered professionals vigilantly conduct self-assessments of their potential biases and of their sensitivity to how culture influences the definition of the family and its help-seeking and coping patterns (Rounds, Weil, & Bishop, 1994).

The family-centered professional also respects each family's current coping strategies and uses them as a starting point for the planning of service delivery, while working with the family to strengthen their repertoire of coping skills (Nelkin, 1987; Rushton, 1990). The formal and informal support networks of each family are acknowledged and, as much as the family wishes, involved in assessment, planning, intervention, and evaluation (Panel, 1991; Taylor-Brown, 1991; Woodruff & Sterzin, 1988).

Additional characteristics of the consensus definition

In addition to those service characteristics that are specifically mentioned in the consensus definition are several others which the literature supports as being essential to the implementation of this model. Several of these are described below: the sharing of information among the parties involved in a fashion that enhances mutuality, confidentiality, timeliness, and completeness; a focus on normalization principles; and the creation of a service delivery system that is flexible, accessible, comprehensive, coordinated, noncategorical, and community-based.

Crucial to the notion of the family as the director of care and the ultimate decision maker is their intimate **involvement in the information-sharing process.** The process of information exchange reflects the collaborative model described above. Many authors note that parents must receive complete, unbiased information in a supportive manner if they are to be involved in decision making (Brown et al., 1991; Friesen & Koroloff, 1990; Nelkin, 1987; Rushton, 1990). Collins and Collins (1990) suggested that "full parental involvement" in service delivery includes the sharing with parents of all relevant information, just as it is shared with other team members. Also addressed is the need for this information to be shared in a such a way that it can be most useful for a particular family member: in a timely fashion, in manageable doses, in the family's primary language, without the use of jargon, on a continuous basis, and in a variety of formats (Pecora et al., 1985; Rosenbaum et al, 1992; Rushton, 1990; Summers et al., 1989).

Protection of the confidentiality of information about families also is important. Within this model, the family generally maintains control over what information is shared, to whom, and in what manner. Family members need to be informed about the manner in which information about them is recorded, shared, and stored and about legal and ethical limits to the right of confidentiality. Their involvement in decisions about these areas is consistent with family-centered practice and supports the development of their sense of empowerment and self-determination (Donahue-Kilburg, 1992; Dunst, Trivette, Davis et al., 1988; Leviton et al., 1992; Nelkin, 1987).

Undergirding the concepts of strengths and empowerment is a **normalization perspective** - a recognition that much of what those who receive services are experiencing is normal, that they can benefit from and have a right to interactions in the community that are typical of others with similar interests, and that services need to be structured and delivered in such a way that the normality of a family's life is disrupted as little as possible (McGonigel, 1991). It is not difficult to lose sight of the fact that a family is more than just the problem it presents to us. Cunningham and Davis (1985) addressed this point:

> Families of children with special needs were just ordinary families before the child became a member. They remain ordinary families, more alike than unlike other families, and their reactions should be seen as normal and typical. They are often subject to greater stress,

> because of increased caring needs and because of the greater variability of such children. (p. 68)

Professionals must maintain a focus on aspects of family life that demonstrate commonalities with others, as well as on those parts that are unique.

This principle is reflected in the way in which language is used to refer to the populations of concern in this paper. As can be observed throughout this paper, an attempt has been made to use "people first" terminology to reflect that the individuals and families are not equated with their needs or difficulties (i.e., "children with disabilities" rather than "disabled children").

A normalization perspective demands that interventions should support the functioning of family members in their natural roles (Murphy & Lee, 1991; Panel, 1991). Family-centered practitioners affirm that the main role of parents is caretakers of their children, rather than therapists or tutors, and that professionals are to support parents in this role (Bazyk, 1989; Blumenstein, 1986; Brown et al., 1991; McDonnell & Hardman, 1988; Pierce & Frank, 1992). Lending support to children in their multiple roles other than patient or client (son/daughter, brother/sister, student, friend) also is characteristic of family-centered practice (Bazyk, 1989). Also facilitating the view of the family as normal is an emphasis upon the family's current situation, rather than upon past assessments or diagnoses (Pecora et al., 1985).

The final characteristic of family-centeredness relates to the **structure in which services are delivered,** which is guided logically by the principles described above. Families must be able to access the services they need. As much as possible, their preferences as to the location and timing of service delivery need to be respected (Frankel, 1988; Hutchinson & Nelson, 1985; Nelkin, 1987; Pecora et al., 1985; Marcenko & Smith, 1992). Rushton (1990) suggested that opportunities for parental involvement in services related to their children need to be designed in such a way that there is minimal disruption of the family's integrity and routines; such consideration certainly may be extended to other members of the family, as well. Accessibility also includes elements of care such as the language used to communicate with families, the professional's emotional and physical availability, continuity of care, affordability, and handicap accessibility of buildings (Collins & Collins, 1990; Dunst, Trivette, Davis et al., 1988; Finkelstein, 1980; Ooms & Owen, 1991; Pecora et al, 1985; Rushton, 1990).

Clearly, if care is to be responsive to the needs, capabilities, lifestyles, and wishes of each individual family, family-centered practice requires that service delivery be flexible and customized in many areas. The literature reflects several areas in which such flexibility is needed:

- functional areas included in the service plan (Bryce, 1979; Cunningham & Davis, 1985; Nelkin, 1987; McCollum, 1991);
- modalities of intervention (Bazyk, 1989; Leviton et al., 1992; Lourie & Katz-Leavy, 1991; McGonigel, 1991);
- selection of which professionals and family members are involved (Kramer, McGonigel, & Kaufmann, 1991; Pierce & Frank, 1992; Summers et al., 1989);
- degree and nature of family involvement (Dunst, 1991; Friesen & Koroloff, 1990; Turnbull & Summers, 1987);
- nature of the role of the professional (Cunningham & Davis, 1985; Friesen & Koroloff, 1990; Leviton et al., 1992);
- resources accessed (Firman, 1993; Leviton et al., 1992; Turnbull & Summers, 1987);
- time schedules (Leviton et al., 1992; Pecora et al., 1985);
- location of service delivery (Bryce, 1979; Summers et al., 1989; Woodruff & Sterzin, 1988); and
- intensity and duration of services (Bryce, 1979; Finkelstein, 1980).

In order for such flexibility to be possible, services need to be noncategorical (Frankel, 1988; Friesen & Koroloff, 1990; McDonnell & Hardman, 1988). Hutchinson and Nelson (1985) list three difficulties with categorical divisions of services: (1) the client must meet the agency's definition of service needs rather than vice versa; (2) the significance of a particular service category is directly proportional to the size of its fiscal appropriation and the political salience of its constituent or advocacy group; and (3) service units tend toward isolation, and workers tend toward specialization, which can contribute to overlapping case assignments or gaps in service. Any rigidity on the part of providers as to the nature of service needs or intervention methods that may be included in the care-giving process diminishes the extent to which the concerns of varied families can be addressed. Some providers correct for this inhibition by referring families to other providers. However, this approach to care risks increasing the difficulty that families have accessing care.

Family-centered services also are comprehensive in their scope (Brown el al., 1991; Hutchinson & Nelson, 1985; Nelkin, 1987; Nelson et al., 1990; Panel, 1991; Pecora et al., 1985;

Rushton, 1990). The provider and family are encouraged to look beyond the presenting problem and to explore as full a range as possible of areas in which family functioning can be strengthened (Friesen & Koroloff, 1990). This approach to care is new to many organizations and professionals whose focus of assistance has been narrowly defined. For example, many teachers and education administrators are reluctant to delve into the needs of families outside of those directly related to a child's classroom experience.

This model does not require that all professionals become experts in the full array of human needs and the services needed to meet them, or that every human services organization provide all services (Briar, 1991; Dunst, 1991; Friesen & Koroloff, 1990). However, it does support the designing of services in such a way that this array may be easily accessed by or for a family. For example, schools may employ or contract with social workers who can explore families' psychosocial situations and with nurses who can more thoroughly meet families' medical needs.

Because an ecological approach to service delivery frequently requires the involvement in care of multiple individual and organizational providers, family-centered practice requires coordination of the care system (Friesen & Koroloff, 1990; Murphy & Lee, 1991; Nelkin, 1987; Petr & Pierpont, 1992). Some practitioners have approached this task through the use of case managers who have the responsibility of maintaining contact with all individuals involved in service delivery with a particular family (Bailey et al., 1992; Panel, 1991; Roush et al., 1991; Seltzer et al., 1992; Woodruff & Sterzin, 1988). Many make use of multidisciplinary, interagency intervention teams that meet on a regular basis and that include the families as members (Donahue-Kilburg, 1992; Finkelstein, 1980; Krehbiel el al., 1991; Marcenko & Smith, 1992; Pomerantz, 1984; Rosenbaum et al., 1992; Stehno, 1986; Thurman, 1991; Woodruff, 1985). Some systems of care combine these two approaches (Roberts & Magrab, 1991). Regardless of the particular method of coordination used, everyone involved must commit themselves to a partnership with the others in order for service delivery to meet the needs of families most efficiently and effectively (Panel, 1991).

The final characteristic of family-centered service is that it incorporates a wide variety of community-based supports and resources. As indicated above, services are to be comprehensive and accessible. This usually necessitates the involvement of more than one service provider. Professionals are encouraged to explore with families the full range of supports within the community that might be useful to them and to work with families to expand this array of resources as necessary (Bribitzer & Verdieck, 1988; Dedmon, 1990; Dunst et al., 1991; Roberts & Magrab, 1991; Wetle et al., 1989; Woodruff, 1985). They also are able to assist families in their efforts to access these other resources (Brucker & MacMullen, 1985).

In exploring potential resources that can be used to assist families with their various responsibilities, it is important that attention be given to building families' informal, naturally occurring support networks, as well as their connections with the formal helping system (Bribitzer & Verdieck, 1988; Friesen & Koroloff, 1990; Pecora et al., 1985; Roberts & Magrab, 1991; Stehno, 1986). The informal structure of people's lives - their family, friends, neighborhood groups, churches, clubs - predated their contacts with professional caregivers and will persist after these contacts end. It provides a continuity, accessibility, and relevance that cannot and should not be replaced by the formal structure of society. Professionals and families also may explore the possibility of adding new elements to their informal support network, such **as** self-help groups, or of including indigenous healers in the care-giving process (Mokuau, 1990).

Discussions of community resources usually assume that the family fulfills only the role of recipient of services. Caregiving institutions - schools, hospitals, mental health treatment centers - often view themselves and are viewed by others as solely the givers of services. Most organizations are structured in such a way that they minimize or limit their dependence upon recipients of services. However, if family-centered practice is to incorporate a view of professionals and families as equal partners, then professionals and the consumers of their services must work together to find ways to establish themselves as interdependent systems. Caregivers must pursue opportunities to involve recipients of care in their neighborhoods and communities in ways that strengthen their identities as productive members rather than only as people in need of assistance. The inclusion of consumers **as** staff trainers and as members of committees, task forces, advisory groups, and boards of directors is a starting point for such an endeavor (Friesen & Koroloff, 1990; Leviton et al., 1992; Petr & Pierpont, 1992).

Critique of the consensus definition of family-centered service delivery

This rather thorough description of family-centered service delivery answers many questions about its nature. However, several issues and difficulties arise as one attempts to operationalize the consensus definition. How does one define "family"? What are the limits to family choice? What happens when various members of a family do not agree about certain choices? How does one resolve conflicts between different parts of the definition, such as when a "family" as a unit chooses not to be the focus of attention? How are various elements of the definition prioritized? Is family-centered service delivery an all-or-nothing proposition, or are there levels or degrees of it? Each of these questions is addressed in the following paragraphs.

Few authors in the family-centered literature synthesized here address the task of defining the family (Firman, 1993; McGonigel, 1991; Spreading family-centered care, 1975; Taylor-Brown, 1991). Although professionals may think about the "entire family" as the unit of attention, in actual practice, involvement and collaboration may be limited to the parents, to a parent-child dyad, or even solely to the primary caretaker, who usually is the mother (Larimore, 1993; Mahoney et al., 1990b; Marcenko & Smith, 1992; Panel, 1991; Sparling, Berger, & Biller, 1992; Turnbull & Summers, 1987). In this light, it may be more accurate to refer to many so-called family-centered programs as "parent-centered" or "mother-centered" (Drotar, 1991; Simeonsson & Bailey, 1991). If we are to retain the name and the spirit of family-centered service delivery, it is imperative that professionals and programs conceptualize "family" more broadly and inclusively.

There are several difficulties that pertain to the issue of family choice, and the literature reflects some divergence of opinion in this area. Although the statement in the consensus definition that the family-centered professional "organizes assistance ... in accordance with each individual family's wishes" may sound simple and clear on first reading, it actually is quite complex and difficult to fulfill in practice. One difficulty is that few professionals in their day-to-day work would grant that a consumer's wishes should be fulfilled 100% of the time. They would raise objections to this practice based upon ethical, safety, practical, and legal grounds, among others. When there are disagreements between family members and professionals, some process must enable a decision to be made. If the family-professional relationship is a collaboration, as the definition states, are the views of each party to be given equal weight when a decision is to be made? If so, which entity breaks ties? If in professional-centered service delivery, the professional directs services, one must ask whether this means that in the family-centered service model, the family directs services.

The second difficulty related to family choice is that this component of the definition may conflict in practice with other elements of it. For example, one must also ask whether a family may choose not to engage in a collaborative relationship, but rather to either assign control of the process to the professional or else take control itself. Similarly, a family may choose not to identify the family as a whole as the unit of attention. They may wish to identify a single member as the unit of concern or recipient of care and to ask professionals to leave everyone else in the family out of the process. They may wish not to be fully involved in information sharing, in planning for services, and in participation within the policy-making mechanisms of the organization. Which element of the definition is to take priority? And if all elements of the definition are not actualized, can service delivery still be thought of as "family-centered"?

To complicate the matter further, although many references have been made to the family - as decision maker, as recipient of services, as unit of attention - it is clear that the family as a whole does not always act in unison. Family members often disagree with each other, and some may be too young or too incapacitated to participate in all aspects of the service delivery process. This makes the-family-as-client a concept that is fraught with difficulties. It is interesting that most of the literature regarding family-centered services does not mention this dilemma, even though it clearly presents itself in practice on a regular basis. Apparently, the resolution of conflicts among family members is an area of practice that many professionals understandably feel ill-equipped to tackle.

The current consensus definition of family-centered service delivery and its elaboration, while providing a helpful beginning for understanding family-centeredness, do pose some questions that are poorly answered in the literature. The predominant difficulty is that various elements of the definition may be incompatible with each other in practice, and the definition itself provides no guidance for prioritizing them.

FAMILY-CENTERED PRACTICE: A NEW CONCEPTUALIZATION

These difficulties, combined with the work of various parents and professionals who are exploring ways to expand the potential of family-centered practice (Bradley, 1992; Firman, 1993; Lee, 1993; Leviton et al., 1992; Turnbull & Summers, 1987), suggest that the current definition of that concept requires modification. Such modification is essential to the development of valid practice standards and measurement tools. Two elements of the concept of family-centered service delivery appear to be indispensable to it and to guide its operationalization: family choice and the adoption of a strengths perspective. Therefore, the definition of family-centeredness proposed by this paper is as follows:

> Family-centered service delivery, across disciplines and settings, recognizes the centrality of the family in the lives of individuals. It is guided by fully-informed choices made by the family and focuses upon the strengths and capabilities of these families.

The implications of this definition for families that include dependent children are described below. Suggestions for its use with other types of families are explicated in the final section of this paper.

Family Choice: Areas in which Choice is Exercised

One of the two core elements of family-centered practice as defined by this paper is family choice. The family is viewed as the consumer and director of the service delivery process, as the party that has ultimate decision-making authority (Bailey et al., 1992; Bazyk, 1989; Donahue-Kilburg, 1992; Dunst, 1991; Kramer et al., 1991; McGonigel, 1991; Nelkin, 1987; Summers et al., 1989). Some of the most crucial areas in which this choice is exercised are the definition of the family; who shall make decisions for the family; the unit of attention of the service delivery process; the nature of the family-professional relationship; the sharing of information; and the identification of needs, goals, and interventions.

Choice in defining the family. Webster's 9th New Collegiate Dictionary defines "family" as "a group of individuals living under one roof and usually under one head" (1991, p. 448). This definition is an adequate starting point for an understanding of family-centered practice and certainly improves upon the dyadic (parent-child or mother-child) view of the family often encountered in practice. However, family-centered service delivery allows - in fact, requires - the family itself to define its boundaries, to decide who is a part of it and who is not. The definition of family proposed by the Commission on Families of the National Association of Social Workers better suits family-centered practice: A family is "two or more people who consider themselves family and who assume obligations, functions, and responsibilities generally essential to healthy family life" (Barker, 1991, p. 80).

Ho (1987) and others remind us that ethnicity and culture, among other things, affect our thinking about family membership and structure. Extended family ties tend to be strong among ethnic minority families and may play a vital part in the functioning of the family. Tribal units may also be considered components of families, as is illustrated by the use of the phrase "family, whanau, hapu, iwi, and family group" to refer to the "family" in New Zealand's Children, Young Persons, and the Families Act (Wilcox et al., 1991).[1] Even non-relatives, such as pastors and close friends, may be considered and function as members of the family (Taylor-Brown, 1991; Woodruff & Sterzin, 1988). The family-centered practitioner respects the choice of the family as to who is a part of it and incorporates their definition into the design of service delivery.

Choice of who makes decisions. Although many theorize that the ultimate incarnation of family-centered practice would involve all family members in reaching consensus decisions about service delivery, such consensus is not always possible. Consistent with family systems theory, caregivers of families - usually the parents - are recognized as the heads of the household and, therefore, the primary decision makers for the unit. Family-centered practitioners encourage each family member to be as involved as possible in the service delivery process and acknowledge the normality of conflict within systems (Friesen & Koroloff, 1990). Because of this, it is important for professionals to be capable of facilitating conflict resolution. This does not alter the position that the ultimately must be responsible for making choices regarding care. Ironically, one of the choices that parents may make is to assign this decision-making responsibility to some other party - the child or other relative, the professional, a minister, or a judge, for example (Rushton, 1990).

Recognizing parents as the primary decision makers in families with children with disabilities does not negate the perspective that family members and professionals need to maximize the self-determination options for those children, especially as they grow into adolescence and adulthood. Just as it is not suggested that professionals preempt the roles of parents, it is not suggested that parents assume responsibilities that could be accepted by their children. The growth and empowerment of the person with special needs is not to be ignored as the family unit is supported.

An example of ways in which families that include children with disabilities have exercised their options as to how decisions are made is Group Action Planning.

> Group Action Planning (GAP) occurs when a group of family, friends, and professionals create a "reliable alliance" for the purpose of creatively, energetically, and joyfully translating great expectations into realities and promoting the preferences of the individual and family. (Turnbull & Turnbull, 1993, p. 1)

GAPs create a context for social connectedness and interdependent caring. They use this empowering network to share visions of a lifestyle that is consistent with the preferences of the individual with disabilities and to create action plans to implement these visions. This approach to care goes beyond individualized service plans of various sorts to build a stronger, broader, more intimate base of support for both individuals with disabilities and also their families (Turnbull & Turnbull, 1992).

Choice of the unit of attention. Another closely related choice regarding care that must be made and reviewed at intervals is that regarding the unit of attention of the service delivery process. As noted above, the predominant concept of family-centered care is defined largely by its focus on the family as the unit of attention. The conceptualization being proposed here, however, emphasizes the role of the family in specifying who will be involved in this process. The practitioner must initiate contact with the family unit in some form, and the dyad of the child and primary caregiver is a reasonable starting point. However, over time, the professional must respond to the family's wishes regarding the expansion or reduction of this unit of attention. Thus, in response to the family's wishes, the practitioner may limit professional intervention to the child only, as long as this reduction did not violate legal or ethical standards. On the other hand, the practitioner may be required to intervene with a large extended family and several close friends of the family. The professional might prefer to work with the whole nuclear family, or with the mother and child, or with some other unit. S/he has the responsibility to express that opinion or preference, but the ultimate decision-maker is not the professional - it is the family. As the unit of attention changes over time, so do the decision-makers. Therefore, the professional must be comfortable working with a variety and range of family configurations and decision-making bodies (Leviton et al., 1992).

The family maintains the right to choose the level and nature of its involvement in the service delivery process (Bazyk, 1989; Dunst, 1991; Firman, 1993; Leviton et al., 1992; McGonigel, 1991; Pierce & Frank, 1992; Woodruff, 1985). As Turnbull and Summers (1987) note, some families want to be decision makers and some do not; some place a priority on implementing home intervention programs and others do not; some like support groups, some benefit from written self-help materials, some wish to be designated as team leaders or as case managers - and others do not. Families may choose to avail themselves of some service options and not others; and in fact, some families may choose not be involve themselves with the formal service delivery system at all. Family-centered professionals must maintain a flexible perspective on how family members may be involved in the helping process and expect the nature of this involvement to differ from family to family. They must seek the family's preferences for participation and recognize that how any particular family wishes to participate may change over time (Donahue-Kilburg, 1992; Dunst, 1991; Rushton, 1990).

Some authors describe a concept which is relevant to the issue of varying levels of family involvement - that of parental or family readiness to assume responsibility. In terms of family members of infants that are in neonatal intensive care units, Krehbiel et al. (1991) suggest that "this concept takes into consideration each family member's ability to take in new information, to become involved in care and decision-making, and to receive 'bad news.'" Briar (1991) reminds professionals that a family's ability to use services and their own timetable may be different from those of the professional; the latter needs to be careful not to move more quickly or more slowly than the family wishes. Research with members of families that include children who have disabilities led Summers et al. (1989) to conclude that families want to be introduced to their role of decision-maker gradually and to be taught the skills they need to be effective in this role. Professionals must be able to determine the readiness of family members to participate in the service delivery process and to offer opportunities for involvement based upon these levels of readiness (Rushton, 1990).

Choice about the nature of the family-professional relationship. The family also makes choices regarding the nature of the family-professional relationship (Leviton et al., 1992). The style of this relationship may vary considerably. In professional-centered approaches to care, the professional is in charge of care and the family as a unit may be either avoided entirely or else involved in service delivery in ways that are determined by the professional and which serve that person's goals (Cunningham & Davis, 1985; Donahue-Kilburg, 1992). The dominant family-professional style advocated by current family-centered practitioners is a collaborative one, in which professionals and families are equal partners and work together as a team toward mutually defined goals (Collins & Collins, 1990; Friesen & Koroloff, 1990; McGonigel, 1991; Roberts & Magrab, 1991; Thurman, 1991).

A recent emphasis of family-centered models places the family firmly in control of the service delivery process, with the professional serving as the agent of the family (Donahue-Kilburg, 1992; Dunst, Trivette, Davis et al., 1988; Lee, 1993; Tower, 1994). As professionals at the Kennedy Institute's Department for Family Support Services found in their work with parents of children with special needs, parents value professionals' knowledge and clinical expertise in relation to their child. However, they state that only they have the necessary expertise to determine whether or not the recommendations of professionals can be successfully incorporated into their own families' lifestyles (Leviton et al., 1992).

The Kennedy Institute's model of service delivery (Leviton et al., 1992), as well as several others, conceptualizes the professional role as one of "consultant" (Donahue-Kilburg, 1992; Roberts & Magrab, 1991; Bazyk, 1989). This relationship is somewhat analogous to the employer-employee relationship, in which the professional works for the family and is "at their service." The mother of a child with multiple chronic medical problems explained this type of a relationship to a nurse in this manner: "We don't follow in your footsteps, you follow in our footsteps" (Pierce & Frank, 1992, p. 975).

This model does not imply that professionals have no power or influence or that they must do whatever the family commands. Professionals are obligated to inform families when they disagree about means or ends, when they are being asked to do something of which they are not capable, when what the family wishes conflicts with limits placed by the organization which employs them, or when they are cannot perform or condone certain behaviors because they are illegal or unethical. However, this model does identify the family as the ultimate authority or decision maker under most circumstances.

Most professionals have a preference for a particular style of consumer- or family-professional relationship, and this preference is based, largely, upon their theoretical stance, their practice experience, and certain aspects of their own personality. The model of family-centered practice described here places the family in the position of making decisions regarding the nature of the family-professional relationship. The professional is engaged in this decision-making process as a source of information about the options available to the family and as a negotiator of roles (Bennett, Nelson, Lingerfelt et al., 1992). The beginning and ending points of these negotiations are determined by the family's desires and might include any style of interaction ranging from professional-directed to parent-controlled.

In professional-centered practice, the predominant flow of information is from the client to the professional. In family-centered practice, information flows in both directions, and the family is in control of the information it discloses as well as the information it receives (Brown et al., 1991; Dunst, 1991; Leviton et al., 1992; Nelkin, 1987; Rushton, 1990). Family-centered practitioners recognize the potential intrusiveness of asking for information and do so in a context of respect for confidentiality and for the family's right to decline to provide the information (Dunst, 1991; Leviton et al., 1992). Only relevant information is requested, and the family is given choices about the form in which the material is provided, i.e., during face-to-face interviews vs. filling out a form (Dunst, 1991; Leviton et al., 1992; Summers et al., 1989). As members of the intervention team, family members have access to the same information as other team members and control over how information from various sources is shared (Collins & Collins, 1990; Leviton et al., 1992; Roberts & Magrab, 1991). Families differ regarding the amount of information they want from professionals, and the family-centered practitioner offers them choices about how much information they are given regarding their child's and their situation, the activities of the professionals involved, and community resources (Rushton, 1990).

The family also has some choice as to the form in which the information is provided, for example, whether the information is shared verbally or in written or videotaped formats (Bazyk, 1989; Summers et al., 1989; Turnbull & Summers, 1987). Regardless of format, communication between family members and professionals should be as free of jargon and of patronizing and blame-laden language as possible (Collins & Collins, 1990; Leviton et al., 1992; Summers et al., 1989). It also should match the developmental needs and abilities of the recipient (Kutner, 1994). Consideration also must be given to the best means of establishing and maintaining communication between providers and family members whose primary language differs (Woodruff, 1985).

Choice about needs, goals, and interventions. Family-centered practice begins by identifying child and family needs and goals as the family sees them (Bennett, Nelson, Lingerfelt et al., 1992; Dunst, Trivette, Davis et al., 1988; Friesen & Koroloff, 1990; Hutchinson & Nelson, 1985; Krehbiel et al., 1991; Thurman, 1991; Turnbull & Summers, 1987). The professional may present additional potential areas of concern to the family for their consideration, acknowledging their right to accept or refuse these ideas. The child's and parents' situations are viewed holistically within the context of the broader family, so that potential needs and goals are not limited to those directly pertaining to these members, to the specific area of the child's difficulty, to the professional's particular area of expertise, or to the specific function of the organization in which the professional is employed (Donahue-Kilburg, 1992; Dunst, 1991; Friesen & Koroloff, 1990; Leviton et al., 1992; Marcenko & Smith, 1992). The consideration of needs and goals is as comprehensive as the family wishes it to be, regardless of the presenting concern.

Just as the family makes choices regarding the identification of needs and goals, so also does it provide suggestions and make choices regarding the interventions that are utilized to reach these goals (Bazyk, 1989; Cunningham & Davis, 1985; Firman, 1993; Hutchinson & Nelson, 1985; Rushton, 1990). Professionals and family members (as well as the people with special needs, as they are able) together compile as extensive an array as possible of intervention options and of formal and informal resources needed to meet the goals of the family (Leviton et al., 1992; Woodruff, 1985). Family members are given a full explanation of the potential costs and benefits of each option and whatever other assistance is needed to help them develop a plan from among their options. In the process, the family and professional negotiate their respective responsibilities for implementing the plan (Dunst, 1991; Pierce & Frank, 1992; Roberts & Magrab, 1992). Ideally, service delivery emphasizes the provision of support to families as they carry out their responsibility of caring for family members and includes informal supports as well as formal services (Bribitzer & Verdieck, 1988; Cunningham & Davis, 1985; Pecora et al., 1985; Roberts & Magrab, 1991).

Professionals are challenged to fulfill the obligation of family choice, even though families may choose to do things that circumscribe their options and their opportunities for growth. Professionals also may feel an obligation to support or nurture families in such a way that they choose increased involvement in the future. Such support is not precluded by this model, and in fact, it may be consistent with the strengths and empowerment focus of this approach. However, professionals must take great care to maintain the primacy of family choice and not to allow their own investment in the caregiving process to determine its direction.

Family Choice: Limits to Choice

Although family choice is central to the concept of family-centeredness, there are limits to any person's self-determination, in any sphere of activity. First, the person must have the capacity to make the choice. Some family members may be too young or have too severe a mental disability to make fully informed choices. However, family-centered practice takes a broad view of capacity, believing in the strengths and capabilities of families to make reasonable, informed decisions and in their right to make decisions that may differ from those of professionals (Finkelstein, 1980; Roberts & Magrab, 1991) and that may, in fact, turn out to be mistakes. Firman (1993) acknowledges this right: "We had to accept that families, like professionals, make mistakes. The luxury we had, of making subsequent decisions following a mistake, had to be extended to them" (p. 11). For family-centered practitioners, the family knows best and professionals do their best to support them.

Second, self-determination cannot infringe upon the rights of others. Choices must be made within a legal framework that respects the rights of all parties. For example, professionals do not sanction parents' choices to abuse their children physically, emotionally or sexually (Cunningham & Davis, 1985; McGonigel, 1991). Third, a person cannot "self-determine" how another should behave. Even though the family-centered practitioner is the "employee" of the family, employees cannot and should not always do what the employer asks. Professionals cannot do what they have not been trained and licensed to do (i.e., social workers cannot conduct speech therapy or prescribe medications), and they should not act illegally or unethically (Kramer et al., 1991).

Logistical considerations also can limit the choices of families. Often, needed resources may not be available to meet a family's goals (Kramer et al., 1991). The cost of services can be prohibitive, and difficult decisions sometimes must be made regarding the allocation of scarce resources. This fiscal reality applies not only to the family itself, but also to political and non-political units - such as governmental bodies, United Ways, and foundations - which could or do fund services that families need. Goodman (1993) suggests that taking parental choice to the limit and overruling the judgment of professionals may result in the sizable expenditure of money, staff, and facilities for very limited benefits, illustrating the practical, legal, and ethical dilemmas confronted as one attempts to implement family-centered service delivery.

Strengths and Capabilities

The second core element of family-centered practice is a commitment to family strengths and capabilities. One cannot engage in family-centered practice without having a strong belief in the importance of the family and a strong respect for the inherent strength and capability of family members (Dunst, Trivette, Davis et al., 1988; Simeonsson & Bailey, 1991). Too often, across disciplines, professionals have focused upon the deficiencies of children and families, to the extent that families feel under attack rather than supported by the very people who have been trained to be helpful (Briar, 1991; Collins & Collins, 1990; Cournoyer & Johnson, 1991).

In this approach to service delivery, an awareness of and respect for families' positive attributes, abilities, talents, resources, and aspirations guides the help-giving process (Saleebey, 1992). The professional sometimes may need to encourage family members themselves to adopt this perspective by helping them to identify as strengths relevant aspects of their life of which they lack conscious awareness, which they take for granted, or which they have viewed only as problems but which have functional, productive qualities.

Family-centered professionals are committed to finding the strengths and capabilities of children and families, to using those strengths to overcome deficiencies, and to supporting rather than criticizing (Bennett, Nelson, & Lingerfelt, 1992; Collins & Collins, 1990; Dunst et al., 1991; McGonigel, 1991; Nelkin, 1987). Strengths come in a variety of forms, and practitioners must be creative and open-minded in their perspectives of what makes a certain characteristic or behavior a positive contribution to a family's life. This attitude can be challenged when professionals interact with families who are different from themselves in race, culture, sexual orientation, or socioeconomic status (McGonigel, 1991; Nelkin, 1987). The professional must guard against judging competency through an ethnocentric lens that distorts or clouds the strengths and competencies of other, different cultures and lifestyles.

The functional aspects of a particular family's life must be identified, sanctioned, and expanded to those areas that do not work as well. Dunst, Trivette, Davis et al. (1988) make the point that professionals may not learn about a family's capabilities because social systems fail to create opportunities for them to be displayed. One of the functions of the professional, then, is to create such opportunities, thereby enabling the family to apply the full repertoire of skills they possess.

There is evidence that many members of families with children with special needs feel that their lives have been enhanced and strengthened by the presence of those children. They report, among other things, that the experience has made them and their families stronger; they have become more patient and compassionate; they have a greater appreciation for the simple things in life; their religious faith has been strengthened; their social networks and career opportunities have expanded; they feel a greater sense of love and joy in their lives; and they have a greater appreciation of the value of different kinds of people (Blue-Banning et al., 1992; Kutner, 1994; Pierce & Frank, 1992; Summers et al., 1988). Clearly, family members bring to the help-giving process attributes that are to be valued and respected and that can drive the service delivery process in positive, affirming directions.

As the family's capabilities are recognized and utilized, the potential for increasing their range of abilities is strengthened (Bennett, Nelson, Lingerfelt et al., 1992; McGonigel, 1991). Brown et al. (1991) suggest that a family's sense of competence can be built by helping them become the best possible decision makers. Dunst, Trivette, Davis et al. (1988) found that an increased sense of parental control over the care of their children - a strength - was associated with their receiving services from helpers that fit the family-centered model, particularly their being allowed to make decisions regarding their family. Thus, the concepts of strengths and choice are intertwined and enhance each other: a belief that families possess the strength and capacity to make decisions for themselves leads to the utilization of a service delivery model that maximizes family choice, which itself contributes to an increase in families' sense of competence.

As noted above, families are dynamic and their capabilities change over time (Nelkin, 1987). This alteration may be toward either greater or lesser abilities and motivation. The help-giving process must be modified on occasion to reflect these changes in family strengths.

This focus on strengths extends to the identification, use, and building of strengths within the support networks and broader communities with which families interact (Roberts & Magrab, 1991). Briar describes one of the benefits of this approach: "The more capacity built through multigenerational families, work groups, and support networks, the less of a capacity crisis the helping systems will experience" (1991, p. 76).

Standards for family-centered practice must be based on the dual, interrelated cornerstones of **choice** and **strengths.** These concepts are at the core of family-centered practice and establish the context for a variety of other decisions and interactions to take place.

IMPLICATIONS OF FAMILY-CENTERED SERVICE DELIVERY

Friesen and Koroloff (1990) describe the state of the art in family-centered practice with families whose children have emotional disabilities:

> Despite increasing attention in the literature, family support concepts are just beginning to be translated into practice for families whose children have serious emotional disabilities. In most communities, "family-centered care" and "family support" are at best goals and not standards of practice. (p. 14)

This statement holds true for most other areas or fields of help-giving, as well. Although many professionals embrace the philosophical and ethical principles of this approach to care, they also recognize the very real difficulties of implementing it in real life. Few received professional training that was embedded in these principles (Cohen & Ooms, 1993), and relatively few have been employed by organizations whose policies and procedures fulfill its vision.

Practice Implications

In the section of this paper that reviewed the family-centered literature in three areas of service delivery, three exemplary programs were described: The New Life Center of Family Hospital in Milwaukee, the Kennedy Institute's Department for Family Support Services, and New Zealand's family group conferences (Firman, 1993; Leviton et al., 1992; Timberlake, 1975). These models, from three different service arenas, exemplify state-of-the-art approaches to family-centered service delivery.

Operationalizing this definition of family-centered practice requires a radical shift in the way in which many helping professionals think about and participate in consumer-worker relationships. The enactment **of** this vision mandates the centrality and maximum exercise of the concept of consumer self-determination. It requires that professionals trust families - trust that families have strengths, that they know what is best for themselves (Weick, 1983), that they genuinely and deeply care for each other, that they are interested in and able to promote growth, and that they can and do make effective decisions on their own behalf.

Organizations that wish to adopt a family-centered approach to service delivery must undertake thorough reviews of their policies, procedures, and practices and modify them as necessary to comply with the principles of this model (Leviton et al., 1992; Timberlake, 1975). Friesen and Koroloff (1990) suggest that this process must result in programs and policies that do not explicitly or implicitly blame families, that are flexible and responsive to family needs, and that ensure full participation of family members at every decision point. The substantive involvement of consumers - children with special needs and their families - in this process helps to ensure that program evaluation and development truly reflects the preferences of families, while also providing a means of strengthening their sense of control and of self-efficacy.

As policies and practices are reviewed and modified, the range of opportunities for consumers to exercise their choices regarding service delivery needs to be as broad as possible. As suggested by Timberlake (1975), unless there is good evidence that a particular intervention is essential to care (or, on the other hand, harmful to the recipient), the ability of the consumer to choose approaches to and characteristics of service delivery from among all available options is indicated. Leviton et al. (1992) emphasize the importance of professionals being diligent in reviewing these options with family members at frequent intervals to be sure that the choices they have made still are working for them.

Assessments, service delivery plans, and interventions must relate to the needs, strengths, and circumstances of as broad a range of family members as the consumer wishes (Firman, 1993). For example, the impact of having a child with special needs upon the parents' marriage and work lives, upon siblings, and upon members of the extended family - and vice versa - needs to be addressed more thoroughly in many cases (Marcenko & Smith, 1992).

Such an approach to service requires that professionals take seriously what children with special needs and their family members have to say - that they recognize, value, and utilize the things that consumers teach them (Pierce & Frank, 1992; Weick, 1983). People with special needs and members of their families possess expertise about their experiences and the meaning of them that professionals can obtain only by listening to their voices. In many cases, professionals can help consumers to strengthen these voices and to incorporate them more thoroughly into their work together.

Service providers and the organizations that employ them must strive to be as fluid and flexible as possible in order to deliver individualized intervention. The hours and locales in which services are available should be determined based upon the needs and wishes of each family (Leviton et al., 1992; Timberlake, 1975). Obviously, professionals and organizations must be willing and able to adapt themselves to such schedules in order to fulfill the demands of family-centered service delivery.

For most helping professionals, this model requires a reconceptualization of the potential and desired roles of both service recipients and also professionals. Professionals must be willing and able to perform in multiple roles, from resource link to direct service provider and advocate for legislative changes (Donahue-Kilburg, 1992; Dunst, 1991; Leviton et al., 1992; Tower, 1994). The selection of these roles is based upon the needs, capabilities, and wishes of individual families and the availability of other resources within the service delivery system. Service providers must be able to assess these consumer and community characteristics accurately and to customize their approaches to particular families accordingly (Roberts & Magrab, 1991).

Some studies of family-centered services have concluded that professionals need to be providing more concrete assistance to families, including basic information and practical advice, help in locating needed resources such as housing and financial assistance, and greater initiative in creating less-fragmented services in the community (Bribitzer & Verdieck, 1988; Collins & Collins, 1990; Frankel, 1988; Mahoney et al., 1990a; Nelson, 1984). The function of the child welfare professional as the person who helps family members connect with resources they need to fulfill their self-identified goals and plans is an example of this task in action (Firman, 1993). Bennett, Nelson, Lingerfelt et al. (1992) have noted that the role of service coordinator or case manager, that role frequently associated with the provision of concrete services, has been an unwelcome and devalued one for many professionals. They suggest that the performance of this role needs to be supported, that professionals filling it need appropriate training, and that steps need to be taken to heighten and maintain the morale and enthusiasm of service coordinators.

Providers also must be prepared to support the performance of multiple roles by consumers and to facilitate their gaining skills that would enable them to broaden their range of roles if they wish to do so. Supporting the efforts of parents and other family members to develop supportive networks, educational initiatives, and advocacy groups is one approach to this task (Friesen & Koroloff, 1990). Helping consumers to get to know and to make their way through the policies and procedures of the various systems relevant to them is another (Tower, 1994).

One of the roles that often is occupied by both professionals and family members in family-centered service delivery is that of member of a multidisciplinary team. Because multiple service delivery systems and professionals may be needed in order to approach the family situation holistically, the use of coordinated and collaborative teams frequently is indicated; some programs always use teams to deliver services. A variety of styles of cross-disciplinary teams is being explored as to their utility within this approach to care, such as multidisciplinary, interdisciplinary, and transdisciplinary models (Donahue-Kilburg, 1992). Regardless of the particular teamwork style used, the substantive involvement of children with special needs, when possible, and their family members within the teams is crucial to the actualization of family-centered service delivery.

Family-centered service delivery demands that deliberate attention be given to the information that is shared among consumers, including family members, and professionals and the ways in which this information is shared. This approach to service delivery maximizes the openness of communication among all parties and maintains with families the control over the information-sharing process (Firman, 1993; Leviton et al., 1992; Timberlake, 1975). Providers must expect to spend a good deal of time with families planning this aspect of service delivery and involving them in it so that consumers can make informed decisions and maintain their sense of privacy.

Organizational policies regarding consumer access to records and the sharing of family-related information need to be designed to meet these demands.

Fully informed consumers are provided with the rationale for proposed professional actions, including the potential benefits and risks of these actions (Leviton et al., 1992; Timberlake, 1975). Accomplishing this goal can be challenging for several reasons, one of which is a lack of definitive information about the effects of certain interventions with particular recipients. Professionals need to be forthcoming with families about the limits of their knowledge and to be wary of promoting interventions that lack a substantive practice basis.

This change in the way in which many professionals work can be difficult to think about and to implement. It may require "attitude adjustments" that can strengthen one's faith in the capabilities of families and commitment to principles of interdependence (Pecora et al., 1985; Roberts & Magrab, 1991). Even when all parties believe in the approach and fully intend to follow its principles, the process can be complicated and difficult at times. For example, as the playwright Simon Gray observed, "Collaboration can be like a civil war" (Robinson, 1994).

Because disagreements will occur in the process of service delivery, organizations need to create structures to address grievances and resolve conflicts. Roush et al. (1991) suggest that areas of conflict need to be resolved in a manner that affirms parental viewpoints, for this supports the principle of family choice and encourages continued parental participation in service delivery. Options for conflict resolution structures include the use of ombudsmen and mediators (Friesen & Koroloff, 1990; Rushton, 1990; Tower, 1994). In addition, individual professionals may need training and supervision to strengthen their abilities to address disagreements with families more constructively.

The demands of family-centered practice upon professionals are broad and varied, and few professionals have the background to fulfill them without additional training and experience. Individual professionals and programs, as well as institutions that train helping professionals, must determine the areas in which such training is needed and develop strategies for meeting these needs (Cohen & Ooms, 1993; Friesen & Koroloff, 1990; Roberts & Magrab, 1991; Roush et al., 1991). The use of children with special needs and their family members, as well as members of multiple disciplines, as trainers will help to ensure that such educational initiatives are relevant and useful, while modeling family-centered service delivery characteristics. The inclusion of parents with staff members as recipients of training initiatives has been attempted with positive results (Bailey et al., 1992). This model can be replicated elsewhere and may include other family members in addition to parents.

Mechanisms must be included in human service organizations' personnel evaluations and program monitoring systems to assess the extent to which programs are moving toward family-centered services (Friesen & Koroloff, 1990; Leviton et al., 1992). Such evaluations need to incorporate direct feedback from family members about their perceptions of services in addition to professional-generated data such as case records.

Although family-centered practitioners agree that services need to be comprehensive in their scope, the lack of needed services in a particular community limits the extent to which the principle can be fulfilled. Parents and professionals must approach the task of locating needed resources creatively, rather than limiting themselves to obvious or traditional choices. They also must work together to develop and implement strategies for expanding the available options. The role of resource developer is one with which family-centered professionals need to become proficient.

The limits of applicability of family-centered principles need to be explored and explicated. For example, the use of this approach with violent individuals and families and with involuntary recipients pose challenging ethical, legal, and practical questions. The development of guidelines and criteria that would help practitioners and family members to identify situations in which digressions from the model are legitimate is needed.

This paper focuses on the application of family-centered concepts to practice with families that include a child with some form of disability or special need. This is not the only group of people who can benefit from this approach. The literature reflects the application of family-centered principles to work with elderly and Alzheimer's disease patients in hospitals (Seltzer et al., 1992; Wetle et al., 1989), with native Hawaiian families (Mokuau, 1990), with mental health clients (Hartman & Laird, 1983), with sex education programs (Kirby, Peterson, & Brown, 1982), and, to a lesser extent, with nuclear families in medical practice (Weiner & Starfield, 1983).

The vast majority of work in the area of family-centered practice has been done with families that have one or more members who need special caretaking (children or elders with illnesses or disabilities). Perhaps it would be useful for providers to explore the potential applications of family-centered practice models to work with other types of families: those with children that do not have disabilities; those with single, childless adults who have extended families; and those whose parents, rather than their children, are the "identified patients." For example, would a family-centered approach to non-special-education students in schools be helpful? Should one or more family members be included, at least at times, in the therapeutic process of some people who are receiving individual psychotherapy services? Should children more often be included in that process for people who are receiving marital counseling? Should family therapy more often include members of the extended family? Applications to prevention and public health services also need to be investigated. Professionals must examine their rationale for limiting the amount of family involvement and assure that such limitations have a sound theoretical ground (Blumenstein, 1986).

Even when the care-giving process focuses upon an individual, family-centered principles are useful guides to good practice. The characteristics of family-centered practice described above - the nature of the consumer-professional relationship, the way information is shared, a respect for the care recipient's uniqueness, the adoption of a strengths or empowerment perspective, accessibility and comprehensiveness of service delivery - all can be applied to individuals as well as to collectives.

It seems clear that the development and evaluation of model family-centered programs continues to be a need at this time. Such models would provide a stage upon which cross-disciplinary standards for family-centered service delivery could be tested and new solutions to emerging difficulties with implementation found.

Policy Implications

Most of this paper has addressed the development of family-centered practice for direct work with families. It should be clear that there are policy implications, as well. An increasing number of researchers are exploring the family-centeredness of programs as a whole (Bailey et al., 1992; Lee, 1993; Murphy & Lee, 1991) and of public policies (Dunst et al., 1991; Langley, 1991a, 1991b; Ooms & Owen, 1991; Petr & Pierpont, 1992; Turnbull et al., 1991).

Clearly, family-centered practice dictates that consumers be included in as many levels and stages of the service delivery process as possible (Allen, 1991; Bailey et al., 1992; Friesen & Koroloff, 1990). They must be a part of reviews, evaluations, and analyses of policies, procedures, and practices at the local, state, and national levels (Dunst, 1991; Friesen & Koroloff, 1990; Nelkin, 1987; Turnbull et al., 1991). They must serve as appropriate on treatment review teams, as well as on boards, committees, and task forces that have real authority to shape programs and allocate resources (Friesen & Koroloff, 1990; Tower, 1994). In short, organizations and providers must seek creative strategies to maximize ways in which consumers can increase their control over their own services and in which they can be acknowledged as valuable resources for these providers.

Friesen and Koroloff (1990) suggest three ways in which administrators of human service organizations can provide support for family participation. First, they can create a climate and opportunities for family participation. Next, they can provide information and training that will enable family members to participate more fully, including knowledge about how to most effectively make an impact on particular systems (Tower, 1994). Third, they can provide concrete support, such as assistance with child care or transportation, and reimbursement for expenses such as meals or time taken from work.

Administrators of programs, organizations, and departments can increase the credibility of their family-centered initiatives by modeling partnerships with family members (Friesen & Koroloff, 1990). They can include family members as part of bodies that make policy or provide advice directly to the administrator, place programmatic responsibility for family participation in a highly-visible and highly-placed position in the organization, and routinely seek consultation from individual family members and from representatives of parent organizations. They also can incorporate people with illnesses and disabilities and their family members into on-going staff development efforts, including them as planners, curriculum developers, and trainers (Bailey et al., 1992; Nelkin, 1987; Roberts & Magrab, 1991).

As such changes are made in organizations, some turmoil is inevitable. When family members are encouraged to speak, they sometimes demand things that are difficult or impossible to provide or offer criticisms of existing policies, procedures, and practices (Friesen & Koroloff, 1990; Tower, 1994). Such conflict is normal and may even be seen as a sign of success, an indicator that the program's intention of strengthening and empowering families is working (Tower, 1994). Administrators, as well as providers of direct services, must be able to respond to these areas of conflict constructively and to use them to improve service delivery and to document the need for additional programming.

Forging bridges between organizational and bureaucratic leadership and self-advocacy groups can facilitate such improvement and expansion of service delivery. Although these groups often are antagonistic toward each other, they also can collaborate to reach common objectives. These parties possess personal and concrete resources that can be used to build upon each other's strengths. Administrators can support the efforts of consumers, including family members, to establish and maintain self-help initiatives and to advocate for themselves and their families (Friesen & Koroloff, 1990; Panel, 1991; Petr & Spano, 1990; Tower, 1994). The latter can provide consultation about the perspectives of people with special needs and their families and work with administrators to advocate for improvements in the service delivery system (Friesen & Koroloff, 1990; Tower, 1994).

Analysts such as Turnbull, Garlow, and Barber (1991) have examined at the state level the extent to which policies are supportive of families. They also have proposed model guidelines for the creation of statutes that incorporate family-centered approaches to service delivery. Similar initiatives have been undertaken at the national level with some success: the Families of Children with Disabilities Support Act was passed as part of the Improving America's Schools Act in October of 1994. This act incorporates family support values, principles, and policies into federal policy for families that have children with disabilities. These policy change efforts are important steps toward the development of service systems that are more responsive to the needs and wishes of American families. They must continue in order to maintain the ground that has been gained and make further headway.

There seems to be a consensus among family-centered professionals that one of the needed improvements in service systems is a shift from categorical programming and financing to a noncategorical structure (Briar, 1991; Farrow, 1991; Friesen & Koroloff, 1990). Such a modification would facilitate the development and implementation of plans to meet families' holistic needs by allowing a focus upon their individual situations rather than around the narrow parameters of a series of specific programs.

The implementation of decategorized programming requires a parallel shift in funding streams. Several states have been experimenting with ways to pool the funds of multiple departments and programs within departments in order to increase the flexibility, relevance, and effectiveness of service delivery (Farrow, 1991). Some also have altered the priorities of funding by increasing the proportion of budgets that are committed to more community-based and family-oriented service delivery systems. The elimination of administrative boundaries among health, education, and social services at state and national levels also would facilitate comprehensive program planning and implementation for children and their families (Allen, 1991; Farrow, 1991; Langley, 1991a).

In order to effect such politically charged alterations in bureaucracies, family-centered programs need to be able to measure and communicate their benefits in terms of policy outcomes and outcomes for children and families (Briar, 1991; Farrow, 1991). These benefits must include the areas of programmatic efficiency and cost-effectiveness, as well as changes in individual and family functioning that are considered important by policymakers.

The principles of family-centeredness may be applied to relationships among organizational participants in the service delivery system, particularly as they interact with each other around concerns of families that they "share." Briar (1991) suggests that "family-focused technologies are best used to promote healthy, non-violent relationships in systems that should share common goals and visions" (p. 70). Family-centeredness, then, becomes a culture in which individuals and organizations can interact with each other at all levels.

Research Implications

As noted above, there also are research implications for family-centered practice. To be consistent with its principles, it must be the family, not the professional, which is the principal evaluator of whether the standards of family-centeredness have or have not been met. This guideline does not forbid the triangulation of research designs through the inclusion of the perspectives of staff members and/or independent evaluators, but it does require that consumer opinion be valued. Serious efforts must be made to include a variety of family members in the research process. For example, a researcher studying parental satisfaction with services must include fathers, as well as mothers, as respondents. The inclusion of families that vary in characteristics such as ethnicity, socioeconomic status, urban-rural residency, and family structure also is desirable.

Consumers also need to be involved in all stages of the research itself, from formulation of research questions to dissemination and utilization of its results. The development and use of research approaches such as Participatory Action Research (PAR) and Constituency-Oriented Research and Dissemination (CORD) illustrate the usefulness and potential of this principle (Fenton, Batavia, & Roody, 1993; Turnbull & Turnbull, 1991).

It follows from the re-conceptualization of family-centered practice described in this paper that the <u>degree of choice</u> and <u>degree of strengths perspective</u> of a policy, provider, or program are the key concepts which must be assessed in family-centered research. The greater the extent to which each of these qualities is present, the greater the level of family-centeredness. For other measures, the most important indicator of family-centeredness is not the degree to which something is present but, rather, the match between that measure as it exists as compared to the measure as the family wishes it existed. For example, regarding the unit of attention of service delivery: it does no good to measure only whether the unit of attention was the child, parent, nuclear, or extended family; one is not more family-centered than another, in and of itself. Family-centeredness exists when there is a close match between the existing unit of attention and the choice of the parent/family for the unit of attention.

Families who are being considered as possible research subjects must be adequately informed of the study's purpose and nature and given ample opportunity to accept or refuse inclusion in the sample. Written and verbal communications with families should be clear, free of jargon, and in a language they understand. The demands made of participants need to fit in with the structure of their everyday lives as much as possible, and the preferences of families for the form of data collection (questionnaire, telephone contact, in-person interview, observation, etc.) need to be considered in the research design's development.

Research that identifies the issues that arise as programs attempt to modify themselves along family-centered guidelines and the solutions to these issues that were developed would provide helpful information to other programs and to policymakers. In this relatively early stage of the development of family-centered practice, the helping professions can benefit greatly from the willingness of programs to share their trials, their failures, and their successes.

During the past decade, several instruments have been developed to assess various aspects of family-centered service delivery (Bailey et al., 1992; Cone et al., 1985; Cournoyer & Johnson, 1991; Dunst et al., 1991; Koren et al., 1992; Kovach & Jacks, 1989; Mahoney et al., 1990a, 1990b; McWilliam & Winton, 1990; Murphy & Lee, 1991; Pecora et al., 1985; Simeonsson & Bailey, 1991). A scale that will measure the degree to which professional behavior is family-centered according to the conceptualization presented here is being developed at this time and will be published in 1995.[2] Programs can use these scales to assess their current level of family-centeredness and to identify areas in which they are particularly strong or weak. Programs may even be able to compare their performance against that of other programs or against standards of practice that may be established. These results then can be used to inform the program and its consumers of aspects of service delivery that may need to be changed and of needs such as staff training. Repeated use of the instruments will allow programs to track their performance over time.

The assumption that family-centered service delivery contributes to improved consumer and service outcomes must be tested further. It is important to explore the relationship between levels of family-centeredness and outcomes that are relevant for consumers (Friesen & Koroloff, 1990; Roberts & Magrab, 1991). Such outcomes might include the following: extent of goal achievement; levels of consumer and family satisfaction with services and with progress toward goal achievement; school or work performance for the child and for other family members; out-of-home placement of the child; stress levels and coping strategies of family members; sense of empowerment of children with special needs and of family members; and the service system's responsiveness to family wishes. It also is necessary to evaluate the relationships between this approach to service delivery and additional outcomes that are of concern to policymakers and funders, such as the cost per unit of service; the impact of care costs and of various funding methods on families; the degree of support of organizational goals, purposes, and values; and compliance with contractural agreements (Friesen & Koroloff, 1990).

Certain aspects of the nature of family-centered service delivery complicate the research effort. Powell (1987) addresses some of the difficulties inherent in attempting to apply conventional research practices to the study of community-based family support programs:

> The stark realities of providing services to families conflict with the ideals of experimental methodology. Research designs and procedures for controlled laboratory settings will not work in the fluid world of a family support program. The lack of control over important family variables, differences between the delivery and receipt of services, and insensitive outcome measures weaken the power and precision of the data. (p. 311)

In addition, within any one program there are a variety of processes and components that may have an impact upon a child and family. Further efforts must be made to link specific program characteristics with consumer outcomes (Friesen & Koroloff, 1990; Koren et al., 1992; Nelson, 1984; Simeonsson, 1988).

Because services are comprehensive, multiple individual and organizational providers often are involved in the help-giving process. It becomes difficult, then, to decide whether to evaluate the performance of a person, a program, or a service system; once this decision is made, it is necessary to identify exactly which person, program, or system is to be the focus of study. Although the choice of research questions sometimes will resolve this dilemma, it will continue to pose a challenge to research efforts for some time to come.

Regardless of these difficulties, a variety of methodologies, both qualitative and quantitative, may be used to study family-centered service delivery (Simeonsson, 1988). A range of single-subject designs may be appropriate as intervention effects are evaluated. The use of qualitative strategies such as focus groups, peer conversations, and in-depth interviews, may be particularly relevant and effective as one explores families' experiences and the meanings of these experiences to them. The reactions of children with special needs and of family members to different methodologies must be considered as the research design is formulated.

There continues to be a need to study the theoretical and practical relationships among concepts such as family-centeredness, empowerment, family involvement, and collaboration (Koren et al., 1992). This need underscores the importance of longitudinal investigations that can explore these service components' interactions over time. The creation of statistical packages such as LISREL and EQS makes it possible to study these interactions in more depth.

CONCLUSION

For the past couple of decades, a variety of human services professions have been exploring models for care delivery that increase the respect accorded to and the control exercised by care recipients. Family-centered practice, in its most highly developed form, exemplifies these qualities. This approach to service delivery, though theoretically simple, is a challenging one for professionals to implement, for it demands that we redefine many aspects of practice and shift the locus of control to the consumers of our services. It is important that we rise to this challenge if we are to fulfill the professional values that we espouse.

ENDNOTES

[1] According to Williams (1957), "whanau" refers to a family group, although "it is questionable whether the Maori had any real conception of the family as a unit" (p. 487). Barlow (1991) translates the term to mean the extended family (p. 32-33). The "hapu" is a clan or a section of a tribe (Williams, 1957), while an "iwi" is a tribe (Barlow, 1991).

[2] The Family-Centered Behavior Scale will be available in 1995 from the Beach Center on Families and Disability, c/o Institute for Life Span Studies, 3111 Haworth Hall, The University of Kansas, Lawrence, KS 66045.

Appendix A

FAMILY-CENTERED DEFINITIONS CHART

Discipline/Field	Author	Definition
Occupational Therapy	Bazyk (1989), p. 724	"The critical difference with family-centered care is that we are guided by the needs of the entire family – the parents, the siblings, and the child with special needs."
Social Work	Birt (1956), p. 42	Family-centered treatment involves the concepts of "diagnosis and treatment in terms of an entire family rather than in terms of specific problems of individual members of the family."
Health Care	Brewer, McPherson, Magrab, & Hutchins (1989), p. 1055	"Family-centered care is the focus of philosophy of care in which the pivotal role of the family is recognized and respected in the lives of children with special health needs. Within this philosophy is the idea that families should be supported in their natural care-giving and decision-making roles by building on their unique strengths as people and families. In this philosophy, patterns of living at home and in the community are promoted; parents and professionals are seen as equals in a partnership committed to the development of optimal quality in the delivery of all levels of health care."
Nursing	Brown, Pearl, & Carrasco (1991), p. 51	"Family-centered care has been defined by The Association for Children's Health Care as a philosophy of care that recognizes and respects the pivotal role which the family takes in the lives of children with special health needs. The major goal of this philosophy is to support families in their natural caregiving roles by building on unique individual and/or family strengths. This approach promotes the family as a partner in the health care of their child."

* parents were involved in the process of defining "family-centered"

* Mental Health	Cohen & Ooms (1993), p. 3	"Family-centered programs. This term is used rather loosely in current reform discussions. Some family-centered reform initiatives are primarily interested in improving outcomes for individual children and adolescents. In these initiatives, family-centeredness, usually meaning involving the parent(s) or other family members, is seen as a more effective way to helping the child. Other family-centered initiatives are focused on providing services for members of at least two-generations in the family, and increasingly for all members of the family. An explicit service goal in these programs is to strengthen the functioning of the family unit as a whole."
Speech Therapy	Donahue-Kilburg (1992), p. 83	The family-centered model of intervention "focuses on the client in the family context, considers the entire family's strengths and needs, and involves family members in assessment, planning of treatment, and in treatment itself at whatever level family members wish to and are capable of being involved."
Early Childhood Education	Dunst, Johanson, Trivette, & Hamby (1991), p. 115	"The term *family centered* refers to a combination of beliefs and practices that define particular ways of working with families that are consumer driven and competency enhancing."
Mental Health	Fagin (1970), p. 1	Family-centered nursing is a method in family therapy which involves "observation and intervention in the family's milieu."
* Disabilities (physical, medical, emotional, developmental)	Families of Children with Disabilities Support Act of 1994 (1994), p. 3940	"The term 'family centered and family-driven' means, with respect to a service or program, that the service or program – (A) facilitates the full participation, choice, and control by families of children with disabilities in – (i) decisions relating to the supports that will meet the priorities of the family; and (ii) the planning, development, implementation, and evaluation of the statewide system of family support for families of children with disabilities; (B) responds to the needs of the

		entire family of a child with a disability in a timely and appropriate manner; and (C) is easily accessible to and usable by families of children with disabilities."
Social Work	Finkelstein (1980), p. 35	Family-centered group care programs are committed equally to the involvement and change of every family member, regardless of which one is occupying the residential bed.
Social Work/ Child Welfare	Frankel (1988), pp. 138-139	"The term 'family-centered, home based services' refers to a diverse collection of programs that are bound together by a common mission and philosophical stance. They may be viewed as a subgroup of a wider array of programs aimed at placement prevention and family reunification in a variety of fields. Although these criteria are not entirely exclusive, family-centered, home-based services are distinguished from programs with similar goals by an ecological view that emphasizes the family, its members, and their social context as the target for change. Services are provided according to need rather than categorically, and are delivered primarily in the family's home."
Social Work/ Mental Health	Friesen & Koroloff (1990), p. 14	The terms "family-centered care and "family support are used interchangeably. "The term 'family-centered care' involves designing services in response to the needs of the total family, including the child with special needs. 'Family support' involves helping families acquire the support they need to cope with the extra stresses that accompany caring for a child with emotional disabilities. This support often helps keep families together and assists them in balancing their lives, giving attention to the needs of all family members."
Social Work/ Mental Health	Hartman & Laird (1983), p. 4	"Family-centered practice is a model of social work practice which locates the family in the center of the unit of attention or the field of action."

Social Work/ Child Welfare	Hutchinson & Nelson (1985), p. 367	"Family-centered services are intended to strengthen and maintain client families and to prevent family dissolution and out-of-home placement of children by providing an optimal level of services over a limited period of time."
* Developmental Disabilities	Lee (1993), p. 6	"Family-centered practices as defined in this study: (a) include families in decision-making, planning, assessment, and service delivery at family, agency and systems levels; (b) develop services for the whole family and not just the child; (c) are guided by families' priorities for goals and services; and (d) offer and respect families' choices regarding the level of their participation."
* Early Childhood Education/ Special Education	Leviton, Mueller, & Kauffman (1992), p. 1	"Kennedy Institute's Department for Family Support Services defines family-centered care as a collaborative relationship between families and professionals in the continual pursuit of being responsive to the priorities and choices of families."
Early Childhood Education/Special Education	McBride, Brotherson, Joanning, Whiddon, & Demmitt (1993), p. 415	"A review of the literature reveals three major principles of family-centered practice that we believe most encompass current values and practice: (a) establishing the family as the focus of services . . ., (b) supporting and respecting family decision-making . . ., and (c) providing intervention services designed to strengthen family functioning."
Early Childhood Education/Special Education	McGonigel (1991), pp. 7-8	"'Enable' and 'empower' are words that have gained increasing acceptance as terms embodying both the spirit and the heart of family-centered services. . . . Enabling families means creating opportunities and means for families to apply their present abilities and competencies and to acquire new ones as necessary to meet their needs and the needs of their children. . . . Empowerment is both a process and an outcome. . . . It means interacting with families in such a way that they

		maintain or acquire a sense of control over their family life and attribute positive changes that result from early intervention to their own strengths, abilities, and actions."
* Developmental Disabilities	Murphy & Lee (1991), p. 1	"Instead of working only with the child, they [some programs that provide services for young children with special needs] plan ways to support the child's family as well, in order to maximize the benefit of services for the family *and* the child."
Social Work/ Child Welfare	Nelson (1984), pp. 10, 35	"The home-based family-centered concept is currently developed primarily as a theoretical formulation, which prescribes a framework for structuring practice activities, rather than a concrete intervention model which requires specific intervention responses (techniques)." The core characteristic of all home-based family-centered programs is a "focus upon the family in its natural setting as the (not necessarily exclusive) client."
Social Work/ Child Welfare	Nelson, Landsman, & Deutelbaum (1990), p. 4	Terminology has changed over time (home-based services, family-centered services, family-based services, family preservation), but all of these programs "are committed to maintaining children in their own homes whenever possible, to focusing on entire families rather than individuals, and to providing comprehensive services that meet the range of families' therapeutic, supportive, and concrete needs. Family-centered services bring this same ecological perspective to the provision of services by emphasizing the importance of training and support for workers and their supervisors, and by identifying the key role the community plays in the resolution of family problems."

* Health Care	Panel on Women, Adolescents, and Children with HIV Infection and AIDS (1991), p. 17	The Ryan White Comprehensive AIDS Resource Emergency Act of 1990 defines family-centered care as a "partnership among parents, professionals, and the community designed to ensure an integrated, coordinated, culturally-sensitive, and community-based continuum of care."
Social Work/ Child Welfare	Pecora, Delewski, Hanes, Booth, Haapala, & Kinney (1985), p. 530	"Home-based family-centered service refers to a method of service delivery to children and families in their own homes. The service is extensive and intensive as required to maintain and strengthen families."
* Health Care	Rosenbaum, King, & Cadman (1992), p. 112	A family-centered approach to care recognizes "the potential social and emotional impact of the disability on all family members and demonstrate[s] willingness to anticipate and respond to each members' problems and needs."
Early Childhood Education	Roush, Harrison, & Palsha (1991), p. 360	In a child-centered model, "the child is often treated as a separate and distinct entity with minimal emphasis on the family or other groups affecting the child." In a family-centered model, there is an emphasis on "the importance of viewing the child in the context of his or her unique family system, involving parents in decision-making, and enhancing formal and informal family support systems."
Social Work	Scherz (1953), p. 343	"Family-centered casework might be defined as casework based on an understanding of the social, physical, and emotional needs of the family as a unit for the purpose of helping the family members attain the best personal and social satisfactions of which they are capable. In family-centered casework, the improvement of the social functioning of the family unit is achieved by direct or indirect treatment of individual family members, so planned, balanced, and controlled that benefits accrue to the total group."

Social Work/ Child Welfare	Taylor-Brown (1991), p. 198	"Family-centered care is a philosophy of practice in which families and health care providers form a partnership to care for children with handicapping conditions."
Health Care/ NICU	Thurman (1991), p. 34	"... to be family-centered, services must make provisions for family involvement in decision making and must be responsive to the needs of families as well as to the individual children being served. A family-centered approach puts dual emphasis on the child and the family and develops interventions which facilitate treatment and development of the child as a member of the family unit. The approach also recognizes that it is the family which is the constant in the child's life."

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