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Toward Developing Standards and Measurements for Family-Centered Practice in Family Support Programs

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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.

Maya Angelou

Families, in all their rich and confusing complexity, hold within themselves the greatest possibilities of nourishing each member.

Albert Gore

The term *family-centered* has been used to describe the nature of certain forms of service delivery to families with children since at least the 1950s (Birt, 1956; Scherz, 1953). The term now is used in a 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, 1991a, b), 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).

Despite its broad use, the term *family-centered* still causes confusion because it is used by authors in different ways and 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). Confusion also surrounds the concept of *recommended practice standards* for family-centered service delivery, because these standards have never been developed into a single collection that could be used to guide practice across disciplines and settings.

Because the family-centered service delivery approach exemplifies recommended professional practice for families with dependent children, clarification and elaboration of the basic concept are essential. In short, family-centered practice is considered a hallmark of family support programs, an essential component of family support. With a clear definition of the term, the concept could be interpreted into specific standards for professional behavior. In this way, family support programs could be evaluated in terms of their degree of family centeredness and improvements made as needed. This also would allow researchers to determine if higher levels of family-centered practice lead to more effective outcomes.

This chapter reviews the literature on the development of the concept of family-centered service delivery in several disciplines, notably social work, education, and health care, culminating in a definition of family-centered practice for families with dependent children that captures the thinking in these fields as of 1995. This definition is critiqued, and some clarification of ill-defined aspects of the concept are offered. An alternative model for conceptualizing family-centered service delivery across disciplines is presented, along with examples of its application for practice and research.

REVIEW OF THE LITERATURE

The central, common element of family-centered practice *is the family as, the unit of attention*. This section analyzes broad historical trends in service delivery that have bolstered this family focus and reviews family-centered developments in the fields of education, health care, and social work.

Historical Trends

There are several historical trends, common across disciplines, 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, and an increase in the willingness of politicians to consider the adoption of family-oriented policies.

Parents have served as more of an impetus for change in family-centered practice for families with dependent children than have professionals (Collins & Collins, 1990; Friesen & Koroloff, 1990; Leviton, Mueller, & Kauffman, 1992; Petr & Spano, 1990; Turnbull & Summers, 1987; Turnbull & Turnbull, 1990). Historically, service providers across disciplines have tended to focus solely upon the child, resulting in what has been termed *child-centered service delivery*. If the family was considered at all, it was viewed 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 mentality first exhibited during the Progressive Era of the early 20th century. Then, the out-of-home care of children was supported by the emerging *social science paradigm*, which endorsed the idea that children's problems were largely the result of parenting 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). Under this paradigm, the professional's superiority in decision making regarding the care given to these children was assumed, and choice about the nature of this care was removed from the child, the family, and public scrutiny (Petr & Spano, 1990). The *medical model of care* also gained prominence in this era but, in recent years, 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, & Cornwell, 1988; Larimore, 1993; Turnbull & Turnbull, 1990). Despite these movements, many professionals in the Progressive Era advocated a return to traditional, more family-oriented views, including "parental authority, home education, rural life, and the independence of the family unit" (Petr & Spano, 1990, p. 230).

With the 1972 *Wyatt v. Stickney* decision that established the concept of least restrictive environment, the development of a range of psychotropic medications, and the fiscal concerns of government bodies, the movement toward deinstitutionalization and community-based care of those requiring human services was strengthened (Foley & Sharfstein, 1983; Schulberg & Killilea, 1982). Then, in 1975, the U.S. Congress passed two bills that specifically reinforced the delivery of community-based services to children.

The Community Mental Health Centers Amendments of 1975, PL 94-63, which required all community mental health centers to establish children's services, and PL 94-142, the Education for All Handicapped Children Act of 1975, led to the creation of better services within schools for children requiring special care (Petr & Spano, 1990). In the mid-1970s, the decriminalization of juvenile status offenses added to the movement to maintain children with special needs in or near their own homes (Frankel, 1988).

Since the 1960s, the elaboration of *systems theory* and its increased application to professional practice 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 with consumers (Bryce & Lloyd, 1979; Cunningham & Davis, 1985; Frankel, 1988; Friesen & Koroloff, 1990; Hartman & Laird, 1983; Stehno, 1986). Other applications of systems theory support the creation and maintenance of integrated, comprehensive, community-based service networks, which are characteristic of such work (Langley, 1991).

Langley (1991) suggests that the 1979 White House Conference on Families laid the foundation for political initiatives that focus upon the needs and capacities of families, countering the country's historical focus upon individual rights. By the mid-1980s, the acknowledgment that social problems were emerging that threatened families stimulated a new climate for consensus among conservatives, moderates, and liberals--a climate that encourages the creation of supports for families, including the development of family-centered, community-based, integrated social service delivery systems (Turnbull, Garlow, & Barber, 1991).

Education, Health Care, and Social Work

Since the 1970s, the fields of special education and early childhood education, fueled by several national education initiatives, have done much to explore and explicate the nature of family-centered service delivery. The Head Start program has encouraged parent involvement by providing training to improve parenting skills and by emphasizing parent control of the program. The Education for All Handicapped Children Act of 1975 required parental involvement in educational planning for children with disabilities, while PL 99-457, the Education of the Handicapped Act Amendments of 1986, mandated that states provide early childhood education for children with special education needs from birth to kindergarten. Under the latter law, "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 Council for Exceptional Children's Division for Early Childhood has established standards for practice that recommend 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) have written that exemplary early childhood programs are characterized as being integrated, comprehensive, normalized, adaptable, peer and family referenced, and outcome based.

Outside of special and early childhood education, few efforts have been made to incorporate a family-centered philosophy into the educational process as recommended education practice. However, 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).

The nursing profession and the medical specialties of family practice, obstetrics, and pediatrics all have been leaders in the area of family-centered health care practice for families with young children since the 1960s. An increasing number of service delivery systems have undergone significant restructuring in order to pursue an approach to caregiving that supports the service recipient's self-determination. 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 family members are being addressed (Pomerantz, 1984; Seltzer, Litchfield, Kapust, & Mayer, 1992).

Such service delivery for families with young children is most evident in the specific areas of maternity care and neonatal intensive care. Based upon needs expressed by child-bearing couples, maternity care units of hospitals have examined their policies and procedures to assess their adherence to consumer wishes. In many situations, those policies and procedures not based upon scientific fact or mandated by state code have been discarded or left to the mother's or couple's decision in order to maximize choices available to new parents (Timberlake, 1975). Neonatal intensive care units (NICUs) also have evolved from child centered to family centered (Brown et al., 1991). These units now consider the relationship between the individual and the environment and among all of the interacting units of the service delivery system, including family members (Thurman, 1991).

Family-centered approaches to care are not limited to newborns. Former Surgeon General of the U.S. Public Health Service, C. Everett Koop, called for the establishment of a national agenda for the care of children with special health care needs, including a focus on the families of these children and the development of a family-centered, community-based, coordinated care system (Brewer, McPherson, Magrab, & Hutchins, 1989). The necessity of involving family members in the care of adults with a chronic illness, of viewing the entire family as the client, has become an accepted principle of care for this population, as well (McIntier, 1979; Nelkin, 1987; Panel on Women, Adolescents, and Children with HIV Infection and AIDS, 1991; Taylor-Brown, 1991; Wetle et al., 1989; Woodruff & Sterzin, 1988).

Family centeredness seems to be a perfect focus for social workers, as its core values (i.e., a belief in client self-determination) are directly relevant

to and consistent with principles underlying family-centered practice. Furthermore, this 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). 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). In addition, both COS and settlements utilized, developed, and coordinated the resources of the communities they served.

Social work endured a struggle during the first half of the 20th century between those who affirmed a focus on the family and the growing number, influenced by the mental hygiene movement and psychoanalytic theory, who defined service delivery in terms of individuals. The former position was illustrated by the Home Service, created in 1917 to assist service men and their families with a range of functional problems (Black, 1991). The latter position was supported by the training of social workers to assist psychiatrists in military hospitals. However, interest in the functioning of families and in the provision of more comprehensive services to them has never left social work completely, and the 1950s saw a renewal in the profession's attention to families (Hartman & Laird, 1983).

In the 1950s, the Family-Centered Project of St. Paul, Minnesota, coined the term "family-centered" and established a system of multiple-agency collaboration in the delivery of coordinated, comprehensive social services to multiproblem families (Birt, 1956). Scherz (1953) used the term, before family systems theory was fully developed, to describe a system of individual counseling with multiple family members as a way to address family problems.

In the area of child welfare, PL 96-272, the Adoption Assistance and Child Welfare Act of 1980, has supported the notion of strengthening families so that removing children from their biological homes may be prevented or reduced in duration (Bribitzer & Verdick, 1988; Bryce, 1979; Frankel, 1988; Nelson, 1984; Nelson et al., 1990; Pecora, Delewski, Booth, Haapala, & Kinney, 1985). Several states have adopted or are exploring the possibility of adopting New Zealand's family group conference process for decision making regarding children at risk, which supports the extended family taking responsibility for developing a plan for the care and protection of the child, usually within the family system itself (Allan, 1991; Firman, 1993). This model extends the concept of family centeredness beyond that currently in use by most American child welfare systems.

Family-centered service delivery also has made advances in the mental health care of children and adolescents. Residential treatment and group

care facilities for children have increased the involvement of parents in their children's care and developed interventions to help the child and family learn to live and cope together (Finkelstein, 1980; Martone, Kemp, & Pearson, 1989). The Children and Adolescent Service System Program was initiated in 1984 to further the development of multiagency, coordinated, community-based systems of care for children and adolescents with serious mental health needs, at both state and local levels. It encourages the full participation of parents with children who have emotional disturbances in all areas of service planning and delivery (Allen, 1991; Collins & Collins, 1990). Many communities have begun to experiment with ways to coordinate the multiple service needs of families with children who have emotional disturbances and to increase their capacities to attain goals set by these families, often through the development of *individualized* or *wraparound service delivery systems* (Burchard & Clarke, 1990; Lourie & KatzLeavy, 1991).

Social work's focus on the family also is evident through its presence in settings dominated by other professions. Within host settings, social work has been the discipline most often assigned responsibility for relating to parents and other family members and for allocating and providing access to community-based resources (Constable, 1992; Pennekamp, 1992; Sefansky, 1990). Social work also has enriched the family-centered service delivery of other disciplines by developing and using service coordination models, such as case management (Bennett, Nelson, Lingerfelt, & Davenport-Ersoff, 1992; Marcenko & Smith, 1992).

FAMILY CENTERED PRACTICE: CONSENSUS DEFINITION AND CHARACTERISTICS

In order to fully understand the current usage of the term family centered, the authors reviewed more than 120 professional articles from various disciplines, some of which incorporated the views of family members in their exploration of this concept (Collins & Collins, 1990; Cournoyer & Johnson, 1991; Cunningham & Davis, 1985; Dunst et al., 1988; Lee, 1993; Leviton et al., 1992; Mahoney, O'Sullivan, & Dennebaum, 1990; Nelkin, 1987; Ooms & Owen, 1991; Summers, Turnbull, et al., 1989; Turnbull & Turnbull, 1990). A simple content analysis of the 28 definitions of the term found within this literature was performed and used to derive a definition that reflects thinking across disciplines in 1995.

Ten key concepts were identified in this analysis. They are listed here, with a number to indicate how often each appeared in the definitions:

- Regarding the "family" as the unit of attention or concern (28)
- Involving parents or forming a collaboration/partnership between parents and professionals (10)
- Addressing needs of the consumer (9)
- Providing specific types of services (e.g., home-based, comprehensive, integrated, coordinated, community-based continuum of care) (9)

- Relying upon family choice or decision making (8)
- Emphasizing the strengths or capabilities of families (7)
- Maintaining children in their own homes (5)
- Attending to the uniqueness or culture of families (2)
- Empowering families (2)
- Following principles of normalization (2)

Based upon this content analysis, the following consensus definition of the concept was developed, which 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. This model 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, interrelated components and characteristics is essential to developing an understanding of its implications for service delivery.

Elements of the Consensus Definition

Unit of Attention

Family-centered service delivery, as described above, focuses upon the family as the unit of attention, recognizing that children cannot be served appropriately without consideration of the family or families with whom they have lived. The entire family becomes a focus of assessment, planning, and intervention, even though the presenting concern may relate to only a part of the family.

Family-Professional Collaboration

The definition's next element focuses on organizing assistance collaboratively, pairing family members with professionals in an equal 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). This conceptualization breaks down the barrier between worker and client, making them both workers with expertise, knowledge, skills, and energy to contribute to the helping process. " '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).

Family Choice

The third component of family centeredness addressed in the definition above is the organization of assistance for families in accordance with their wishes or choices. 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 believe 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, & Kaufman, 1991; Leviton et al., 1992; McGonigel, 1991; Summers, Turnbull, et al., 1989). This latter interpretation expands the meaning of collaboration from working *with* families to working *for* them.

Family Strengths

The definition of family centered next includes a consideration of family strengths-acknowledging them, incorporating them into intervention plans, and building upon them. Although, as Saleebey (1992) notes, "most such nods to building on strengths are little more than lip service," 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; Dunst et al., 1988; Saleebey, 1992; Summers, Behr, & Turnbull, 1989). This perspective modifies the view of family members as people who only cause problems and are obstacles to the improvement of clients and it is consistent with the notion of collaboration as a preferred style of family-professional interaction. It may also facilitate the empowerment of families, which often is mentioned as a principle or goal underlying family-centered work (Dunst et al., 1988; Larimore, 1993; McGonigel, 1991; Petr & Pierpont, 1992; Seltzer et al., 1992; Stehno, 1986).

Family Needs

The fifth component of the consensus definition addresses family needs. As noted above, family-centered service is offered and available to all members of a family, not only to the member with the presenting problem, and allows for changes as a family's needs change. This component takes a holistic view of the family's circumstances, concerns, and resources.

Individualized Services

The final element of family-centered service delivery specifically referenced by the consensus definition calls for individualized services to each family. The processes and products of assessment, goal setting, and intervention planning and implementation must be matched to the needs, coping strategies, and formal and informal resources of each particular family, rather than expecting every family to fit into a formulized approach to care (Bazyk, 1989; Dunst 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).

The concept of individualized services also respects the structural and cultural uniqueness of each individual family. It does not assume that families who have certain structures, lifestyles, socioeconomic statuses, and belief

systems are less healthy, functional, or desirable than others (Krehbiel et al., 1991; Thurman, 1991; Woodruff, 1985). It also specifies that 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).

Additional Characteristics of the Consensus Definition

In addition to service characteristics specifically mentioned in the consensus definition are several others that the literature considers essential to the implementation of this model. Several of these are described below.

Family-Sensitive Information-Sharing Processes

Information exchange reflects the collaborative model, and Collins and Collins (1990) suggest that "full parental involvement" in service delivery includes sharing all relevant information with parents, just as it is shared with other team members (p. 523). This information should be shared in a way that is most useful for a particular family member as well as 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, King, & Cadman, 1992; Rushton, 1990; Summers, Turnbull, et al., 1989). Within this model, the family generally maintains control over what information is shared, with whom, and in what manner, and confidentiality of family information is important.

Normalization

Undergirding the concepts of strengths and empowerment is a normalization perspective--the recognition that much of what service recipients are experiencing is typical, 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). A normalization perspective dictates that interventions support the functioning of family members in their natural roles (Murphy & Lee, 1991; Panel, 1991).

User-Friendly Service Delivery

The final characteristic of family centeredness' relates to the structure in which services are delivered. The dominant features of this structure are 1) maximized accessibility (Collins & Collins, 1990; Frankel, 1988; Pecora et al., 1985; Rushton, 1990); 2) flexibility and customizing of services in as many areas as possible (Bryce, 1979; Leviton et al., 1992; Pierce & Frank, 1992; Turnbull & Summers, 1987; Woodruff & Sterzin, 1988); 3) noncategorical service delivery and funding (Friesen & Koroloff, 1990; Hutchinson & Nelson, 1985; McDonnell & Hardman, 1988); 4) comprehensiveness in scope (Brown et al., 1991; Friesen & Koroloff, 1990; Nelkin, 1987; Panel,

1991); 5) coordination of the service delivery system (Donahue-Kilburg, 1992; Murphy & Lee, 1991; Petr & Pierpont, 1992; Thurman, 1991); and 6) the incorporation and expansion of a wide variety of community-based supports and resources, including both informal networks and formal services (Bribitzer & Verdieck, 1988; Brucker & MacMullen, 1985; Dedmon, 1990; Dunst et al., 1991; Wetle et al., 1989).

Critique of the Consensus Definition of Family-Centered Service Delivery

Although this definition of family-centered service delivery answers many questions, several issues and difficulties still arise as one attempts to operationalize it: how to resolve conflicts among various parts of the definition, how to identify the limits to family choice, how to define family, and how to handle disagreements among family members.

The primary difficulty arises from the family choice element of the definition, which may conflict with other elements in practice. For example, a family may wish to identify only a single member as the unit of concern or recipient of care and ask professionals to leave the rest of the family out of the process. Or, they may choose not to be fully involved in information sharing, in planning for services, or in participation within the policymaking mechanisms of the organization. When these conflicts arise, which element of the definition is to take priority?

The consensus definition presents other family choice-related issues. For example, a consumer's wishes cannot and should not be fulfilled all of the time due to ethical, safety, practical, and legal constraints. Additionally, collaborations seldom are conflict free. When there are disagreements between family members and professionals, some process must enable a decision to be made because mutual consensus is not always possible.

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 consider 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 caregiver, who usually is the mother (Larimore, 1993; Mahoney et al., 1990; Marcenko & Smith, 1992; Panel on Women, Adolescents, and Children with HIV Infection and AIDS, 1991; Sparling, Berger, & Biller, 1992; Turnbull & Summers, 1987). In this light, it may be more accurate to refer to many family-centered programs as "parent centered" or "mother centered" (Drotar, 1991; Simeonsson & Bailey, 1991).

To complicate the matter further, although many references have been made to the family (as decision maker, as recipient of services, and as the 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 the unit of attention a concept that is fraught with difficulties.

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 (Firman, 1993; Lee, 1993; Leviton et al., 1992; Tumbull & Summers, 1987), suggest that the concept's current definition requires modification if valid practice standards and measurement tools are to be developed. The family-centered service delivery concept seems to be guided by two indispensable elements: *family choice* and *the adoption of a strengths perspective*. Therefore, a new definition of family centeredness 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 with dependent children are described below.

Family Choice: Areas in Which Choice Is Exercised

The first core element of family-centered practice, as defined in this chapter, is family choice. The family is viewed as the director and consumer of the service delivery process, as the party with ultimate decision-making authority (Bailey et al., 1992; Bazyk, 1989; Donahue-Kilburg, 1992; Dunst, 1991; Kramer et al., 1991; McGonigel, 1991; Nelkin, 1987; Summers, Tumbull, et al., 1989). Thus, a family-centered approach would maximize family choice in each of the following areas.

Choice Regarding the Definition of the Family

Webster's New Collegiate Dictionary defines family as "a group of individuals living under one roof and usually under one head" (Mish, 1991, p. 448), which certainly improves upon the dyadic (parent-child or mother-child) view of the family often encountered in practice. In fact, family-centered service delivery requires the family itself to define its boundaries. Therefore, the definition of family proposed by the National Association of Social Workers' Commission on Families 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).

Many things affect our thinking about family membership and structure, including ethnicity and culture (Ho, 1987). 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). Even nonrelatives, 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 will respect this choice and incorporate it into the design of service delivery.

Choice Regarding Who Makes Decisions

Although ideal, consensus decisions among family members regarding service delivery are not always possible or desirable. 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 that may result (Friesen & Koroloff, 1990); this does not alter the position that the parents or caregivers ultimately must be responsible for making choices regarding care.

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. A family-centered approach needs to guard against *adultcentrism*, the tendency of adults to view children and their problems from a biased, adult perspective (Petr, 1992). Just as professionals should not preempt the roles and choices of parents, parents should not assume responsibilities or make decisions that could be handled by their children. The growth and empowerment of the person with special needs should always be supported.

Group Action Planning provides an example of ways in which families with children with disabilities have exercised their decision-making options.

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 by using this empowering network to share visions of and create action plans for a lifestyle preferred by the individual with disabilities. This approach to care goes beyond various individualized service plans to build a stronger, broader, more intimate base of support for both individuals with disabilities and their families (Turnbull & Turnbull, 1992).¹

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 (pp. 32-33). The "hapu" is a clan or a section of a tribe (Williams, (1957), while an "iwi" is a tribe (Barlow, 1991).

Choice Regarding the Unit of Attention

The family-centered professional respects the family's right to choose who to involve in the service delivery process. The child-caregiver dyad is a reasonable place to start for the initial engagement between the family and the practitioner. However, over time, the professional must respond to the wishes of the family regarding the expansion or reduction of this unit of attention.

Choice Regarding the Nature of the Family-Professional Relationship

In family-centered service delivery, the family also makes choices regarding the nature of the family-professional relationship (Leviton et al., 1992). The professional serves as a source of information about the options available to the family and a negotiator of roles (Bennett, Nelson, Lingerfelt, et al., 1992), but the limits of these negotiations are still determined by the family and might include any style of interaction ranging from professional directed to parent controlled. In professional-directed approaches to care, the professional is in charge of care and may avoid or minimize involvement with the family, according to the professional's goals (Cunningham & Davis, 1985; Donahue-Kilburg, 1992). The dominant family-professional approach advocated by family-centered practitioners is collaborative, pairing professionals and families as equal partners who work 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 an agent for the family (Donahue-Kilburg, 1992; Dunst et al., 1988; Lee, 1993; Tower, 1994). According to professionals at the Kennedy Institute's Department of Family Support Services, parents value professionals' knowledge and clinical expertise in relation to their child but feel that only they have the necessary expertise to determine whether the recommendations of professionals can be successfully incorporated into their own families (Leviton et al., 1992). This model of service delivery conceptualizes the professional role as one of "consultant" (Bazyk, 1989; Donahue-Kilburg, 1992; Roberts & Magrab, 1991), in which the professional works for the family and is at their service.

Choice Regarding the Sharing of Information

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 regarding the child's and family's situation, the activities of the professionals involved, and community resources (Brown et al., 1991; Dunst, 1991; Leviton et al., 1992; Nelkin, 1987; Rushton, 1990). Only relevant information is requested by professionals, and the family chooses the form in which the material is provided (i.e., face-to-face interviews, videotaped

formats, or filling out a form) (Bazyk, 1989; Dunst, 1991; Leviton et al., 1992; Summers, Turnbull, et al., 1989; Turnbull & Summers, 1987). As members of the intervention team, family members have access to the same information as other team members and control over how information is shared among various sources (Collins & Collins, 1990; Leviton et al., 1992; Roberts & Magrab, 1991). Regardless of format, communication between family members and professionals should be as free of jargon and patronizing, blame-laden language as possible (Collins & Collins, 1990; Leviton et al., 1992; Summers, Turnbull, et al., 1989). It also should match the developmental demands and abilities of the recipient (Kutner, 1994). Professionals must also find the most effective way of establishing and maintaining communication between providers and family members whose primary language differs (Woodruff, 1985).

Choice Regarding the Identification of Needs, Goals, and Intervention

Family-centered practice begins by identifying child and family concerns and goals as the family sees them (Bennett, Nelson, & Lingerfelt, et al., 1992; Dunst et al., 1988; Friesen & Koroloff, 1990; Hutchinson & Nelson, 1985; Krehbiel et al., 1991; Thurman, 1991; Turnbull & Summers, 1987; Turnbull & Turnbull, 1990). The professional may present additional potential areas of concern to the family, 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 the consideration of needs and goals is as comprehensive as the family wishes it to be. The family also provides suggestions and makes choices regarding the interventions used to reach these goals (Bazyk, 1989; Cunningham & Davis, 1985; Firman, 1993; Hutchinson & Nelson, 1985; Rushton, 1990). Professionals and family members (including the people with special needs, as they are able) together compile an exhaustive list of formal and informal resources needed to meet family goals and of the intervention options (Leviton et al., 1992; Woodruff, 1985). Family members receive a full explanation of each option's potential costs and benefits to help them develop a plan. In the process, the family and professional negotiate their respective responsibilities for implementing the plan (Dunst, 1991; Pierce & Frank, 1992; Roberts & Magrab, 1991).

The family also 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, not all families want to be decision makers. Furthermore, only some place a priority on implementing home intervention programs; some like support groups, while some benefit from written self-help materials; some wish to be designated as team leaders or as service coordinators, while others do not want the responsibility. Families may choose to use only a few of the available service options or to totally reject involvement with the formal service delivery system. 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 and, within any one family, to change over time (Donahue-Kilburg, 1992; Dunst, 1991; Rushton, 1990).

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. 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 rights, strengths, and capabilities of families to make reasonable, informed decisions, even if they differ from those of professionals (Finkelstein, 1980; Roberts & Magrab, 1991).

Second, the parent or family must be ready to assume responsibility. In terms of family members of infants who are in NICUs, Krehbiel et al. (1991) suggest that "this concept [parental/family readiness] 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'" (p. 30). Briar (1991) reminds professionals to move at a pace suitable to each family, as their timetable and ability to use services may be different from those of the professional. Research with members of families that include children who have disabilities shows that families want to be introduced gradually to their role of decision maker and to be taught the skills they need to be effective in this role (Summers, Turnbull, et al., 1989). 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).

Third, 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 physically, emotionally, or sexually abuse their children (Cunningham & Davis, 1985; McGonigel, 1991).

Fourth, a person cannot 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 are obligated to inform families when they disagree about means or ends, when they are being asked to do something that they are not capable of doing, when family wishes conflict with limits of the professional's expertise or licensure or with those placed by the organization that employs them, or when they cannot perform or condone certain behaviors because they are illegal or unethical.

Fifth, logistical considerations can limit the choices of families. Often, the resources needed to meet a family's goals may not be available (Kramer et al., 1991). The cost of services can be prohibitive, and difficult decisions

sometimes must be made when allocating scarce resources. This fiscal reality also applies to political and nonpolitical entities that could or do fund services.

Strengths and Capabilities

The second core element of family-centered practice is a commitment to family strengths and capabilities. Family-centered practice is virtually impossible without a strong belief in the importance of the family and a strong respect for the inherent strength and capability of family members (Dunst et al., 1988; Simeonsson & Bailey, 1991). Too often, professionals across disciplines have focused upon the deficiencies of children and families, to the extent that families feel under attack rather than supported by the people trained to help them (Briar, 1991; Collins & Collins, 1990; Cournoyer & Johnson, 1991). Family-centered service delivery represents a significant shift in the way professionals and families consider each other and prevents this cycle of family blame.

This approach to service delivery is guided by an awareness of and respect for families' positive attributes, abilities, talents, resources, and aspirations (Saleebey, 1992). Sometimes, the professional needs to encourage family members to adopt this perspective by helping them identify functional, productive aspects of their lives as strengths, aspects of which they lack conscious awareness, take for granted, or have viewed only as problems. Family-centered professionals are committed to using these resources to overcome shortcomings, and to support rather than criticize (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 is sometimes challenged when professionals interact with families of a different race, culture, sexual orientation, or socioeconomic status (McGonigel, 1991; Nelkin, 1987). Then the family-centered professional must guard against judging competency through an ethnocentric lens, which could distort or cloud the strengths and competencies of different cultures and lifestyles.

The functional aspects of a particular family's life must be identified, sanctioned, and expanded to those areas which do not work as well. Dunst et al. (1988) point out 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 their full repertoire of skills.

Evidence shows that many families feel that their lives have been enhanced and strengthened by the presence of a child with special needs. They report that the experience has strengthened them in the following ways:

- 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.
- They have a greater appreciation of the value of different kinds of people
- (Blue-Banning et al., 1992; Kutner, 1994; Pierce & Frank, 1992; Summers, Behr, et al., 1989).

As a 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). Dunst et al. (1988) found that parents receiving services characteristic of the family-centered model, particularly their being allowed to make decisions regarding their families, was associated with their feeling increasingly in control over the care of their children. Thus, the concepts of strength 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.

This focus on strengths extends to the identification, use, and building of strengths among families' support networks and broader communities (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*, which are both 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 FOR PRACTICE AND RESEARCH

Implications for the Development of Standards for Practice

According to this model of family-centered service delivery, family members are in the best position to judge whether services are indeed family centered and to determine if they successfully meet their needs. The realization of the vision of service delivery described below requires, for many professionals and parents, a dramatic shift in their views regarding each other's roles, particularly ideas about who is in charge of the service delivery. Professionals must learn to trust families--to trust that they have strengths, that they genuinely and deeply care for their children, that they are interested in and capable of growth, and that they can make effective decisions on their own behalf. They must also actively reinforce the process of sharing information with family members so that their decisions may be as informed as possible.

The potential for conflict within this framework (among family members, among staff, and between family members and professional staff) is acknowledged; therefore, service organizations need to create structures to address grievances and resolve conflicts. Staff must be trained and supported in their efforts to address disagreements with and within families constructively.

In outlining this vision of family-centered service delivery, the authors acknowledge the inspiration provided by the New Life Center of Family Hospital in Milwaukee, the Kennedy Institute's Department of Family Support Services, and New Zealand's family group conferences (Firman, 1993; Leviton et al., 1992; Timberlake, 1975).

Initial Contact

Within a family-centered service delivery system, family members could initially contact a service provider through a variety of means: by telephone, in person with or without an appointment, by e-mail or FAX, or via a third party. Regardless of the means, the family member(s) can easily reach a staff member who will listen to their concerns and wishes and ascertain that the appropriate service provider has been contacted. Families in the service delivery process always are spoken to in easy-to-understand language.

Paperwork at this point is limited to the minimum required to move on to the intake process and/or referral to another provider. Each service delivery system has staff available who are thoroughly familiar with the full range of community resources and who can facilitate easy access to these other resources. Staff always treat family members as competent people with expertise and the best intentions concerning their child. Staff express an attitude of "we are here to work for you" and "let's see how we can get this done."

Intake and Assessment

The intake and assessment process is both efficient and flexible. Family members are able to direct its pace, location, and timing, so that they are as comfortable as possible with the process. Intake and assessment cover as comprehensive a range of life domains as the family members wish, reinforcing the notion that the service provider is there to assist them with whatever concerns or needs they have, regardless of the presenting issue. Because multiple providers and service systems may be involved with a family, an efficient means of coordinating services throughout the service delivery process is established at this point.

During this and all other phases of the service delivery process, family members are provided with all information they want and need, and which legally can be given to them, regarding the service provider, the child's or family's area of special need, community resources, assessment results and care plans, and so forth. It is available to them in a variety of formats (written, visual, oral) and in the everyday language of the consumers. They

are given copies of all documents they are required to sign and of all materials available to other members of the service team. They are incorporated as much as possible and as they wish as contributors to the writing of documents pertaining to their care.

Early on, the parents are asked to define who constitutes their family and which family members should be included in the assessment. The specific evaluation instruments, procedures, staffing, scheduling, location, and choice of participants remain flexible, so that family members, with the consultation of staff members, are able to design the assessment around their concerns and wants. The assessment includes a thorough exploration and explication of the family's strengths and resources, as well as their concerns. The observations and understandings of family members are incorporated into the process and given weight that is consistent with their roles as experts about their child and family. Assessment results are shared with family members orally and in writing as soon as possible. Family members are able to edit the reports for accuracy and choose who receives copies.

Care Planning

Care planning focuses upon concerns selected by the family, after they have received their staff members' viewpoints and assessments. The professional staff's primary duties are to provide helpful information to the family as they make decisions about care and to provide the support needed by the family to implement its plans, without pushing its members to make decisions they do not feel ready to make. The family is able to select intervention options from a "menu" of alternatives, while contributing their own ideas to this list of options. The parents attend all care planning meetings and decide which professionals and members of their support network will attend. In addition, they are able to call care planning meetings whenever they feel that plans need to be reviewed and/or revised.

Intervention

Parents and their children with special needs determine the breadth and form of intervention. When negotiations about plans or interventions fail to result in decisions acceptable to all parties, the wishes of the family members prevail over those of staff. Intervention is designed primarily to utilize and build upon existing strengths and capacities of family members, rather than to identify and correct deficiencies. Throughout the intervention process, case records are kept simple, confidential, and available to the parents.

Evaluation and Termination

Ongoing review of the family's situation and experience with the service delivery system is built into the intervention process. Family members take part in the design and implementation of the evaluation plan, including determining the conditions under which intervention will be suspended or

ended. If the family and the professional disagree about whether termination should occur, the family makes the final decision. Termination is approached in a planful manner, providing ample time for the family to make adjustments for the approaching end of care, to initiate transitions into other services, and to make decisions regarding such issues as follow-up, evaluation of the service delivery process, and the handling of case records.

Advocacy

Family members are able to participate in the service program's decision making process as members of committees, task forces, and boards. They are hired to train staff and other parents and are encouraged to organize themselves in order to meet their own goals and needs. Family members are also provided information on service gaps and limitations and are supported in their efforts to advocate for improved services within and outside a particular service system. Staff are willing and able to help them develop the skills and confidence they need for these endeavors.

Implications for Research and Measurement

This model of family-centered service delivery, when operationalized, provides an approach to the evaluation of family support programs. Consumers, policy makers, and program funders are interested in the extent to which these programs are family centered, and whether this concept correlates with or affects the outcomes of services. The Beach Center on Families and Disability has developed a scale that measures the degree of family-centered behavior of service providers who work with families with children who require special resources. The process used to develop the scale illustrates the application of family-centered principles to research.

Consumers were involved in all stages of this family-centered research inquiry. A Constituency-Oriented Research and Dissemination (CORD) Committee (Fenton, Batavia, & Roody, 1993) was created in the initial research design process. The CORD consists of parents of children who require special resources, service providers and policy makers, and the research staff. It meets approximately once per quarter to review and critique the progress of the study and to provide suggestions for the next stages of work.

The study's literature review incorporated references that cited and summarized parental views on service delivery. The conceptualization of family-centered service delivery was discussed thoroughly with three groups of parents and professionals. Next, six focus groups were held to discuss potential items for the Family-Centered Behavior Scale. These groups included 22 parents of children requiring special resources and 20 professionals who work with families. Their comments were used to improve the potential items and select the final scale items; they also made invaluable suggestions for maximizing parental response to the survey. The

scale and accompanying materials were field-tested by a group of parents of children who require special assistance. Some focus group participants were paid a small fee for their work, and survey respondents were offered the opportunity to receive the Beach Center's newsletter and a summary of the research findings.

This study made a concerted effort to broaden the range of families receiving the validation study research packets. Strategies were explored to increase the ethnic, gender, and socioeconomic diversity of the respondents, as well as to include parents who receive services from systems with highly confidential consumer lists (i.e., child protection). The research packet was printed in both English and Spanish in an effort to respond to the needs and wishes of the growing population of Spanish-speaking citizens in the United States. Over 450 caregivers of children with physical, developmental, or emotional needs responded to the validation survey.

The scale itself is completed by parents or guardians of children who require special resources (the child could also be asked to complete the questionnaire). Parents are asked to describe the extent to which their service delivery professional performs certain behaviors associated with family-centered practice. The scale items address the *degree of choice*, and the *degree of strengths perspective* exercised by the service provider. Two examples of such items are, "The staff member supports my making as many decisions as I choose to about what is done for my child and family," and "The staff member points out what my child and family do well."

The scale is now available to programs for use in assessing their current level of family centeredness and identifying areas in which they are particularly strong or weak.¹ They may be able to compare their performance against that of other programs or against standards of practice which may be established. These results can then be used to inform the program and its consumers of those aspects of service delivery that may need to be changed or initiated. Repeated use of the instruments will allow programs to track their performance over time.

The scale also will be used by the Beach Center as part of a research protocol to test the assumption that family-centered service delivery contributes to improved consumer and service outcomes. As with the scale-development portion of the study, the project's CORD committee will work with the researchers to design this stage of the project. Consumers of the service delivery systems to be evaluated will be consulted regarding the outcomes to be studied and the research methodology to be used.²

² The Family-Centered Behavior Scale is available 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

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