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#### ABSTRACT

A case study approach was used to examine how six service providers constructed the meaning of family-centered services in programs providing early intervention services to the families of young children with disabilities. Six professionals from a pool of over 40 service providers were identified as providing highly family-centered services. Family orientation was defined as a willingness to orient services to the whole family, rather than just to the child. Service providers and some families they served were interviewed. Five underlying components of family-centered services were identified: (1) positiveness (a philosophy of thinking the best about the parents); (2) sensitivity (an ability to put oneself in the parents' shoes); (3) responsiveness (paying attention to parents and taking action when parents expressed a need or a complaint); (4) friendliness (the development of rapport between family and service provider); and (5) child and community skills (child-level skills and competence in integrating their work with the broader community). Implications for policy and preservice/inservice training are drawn. An appendix provides profiles of each of the six case service providers. (Contains 35 references.) (DB)

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An Institute for the Study of Education, Health Care, & Social Service Utilization of Infants, Preschool Children, and Their Families

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## **Executive Summary**

The purpose of this study was to examine how six service providers constructed the meaning of family-centered services. How they felt about serving families and what actions with families they reported taking are part of the construction of the shared meaning of family-centeredness. Six professionals from a pool of over 40 service providers were identified as providing highly family-centered services. They and some families they served were interviewed. Five underlying components of family-centered services were found: positiveness, responsiveness, orientation to the whole family, friendliness, and sensitivity. In addition, these service providers displayed skills with children and communities. Understanding these features of high quality service provision provides a basis for policy, training, and service recommendations.



# Family-Centered Services: Early Intervention Service Providers' Constructed Meanings

The concept of family-centered services has come a long way from the notion of parent involvement, which says that parents should participate in the activities professionals deem important. A change occurred in the 1980s, when Dunst (1985) and Foster, Berger, and McLean, (1981) denounced this notion as simplistic and one-sided; they argued that, in early intervention, professionals should build partnerships with families to empower them. Empowerment then became a shibboleth for this new way of thinking about working with families (Dunst, Trivette, & Deal, 1988). An important component of family-"focused" early intervention was to give them previously denied decision-making power, especially in the development of the intervention plan (Bailey et al., 1986). These approaches became variously known as family-focused, family-friendly, familydirected, family-driven, and family-centered. The last term was adopted from the health care field, where the Association for Children's Care and Health (Shelton, Jeppson, & Johnson, 1987) defined principles of meeting the whole family's needs, not simply those of the patient. Dunst later used some of these various terms in a continuum consisting of professional-centered, professional-focused, family-focused, and family-centered (Dunst, Dunst, Johanson, Trivette, & Hamby, 1991). The nuances of these different terms, and the debate swirling around which one is most appropriate for describing the ultimate set of practices, symbolize the complexity of the concept of providing services to families.



# **Family-Centeredness Categories**

Defining <u>family-centered practice</u> has become increasingly important in the evolution of early intervention. One way of ascertaining the meaning of this complex construct is to examine how it has been measured. Murphy, Lee, Turnbull, and Turbiville (1995) have provided a useful overview of family-oriented program evaluation instruments. This shows that quantitative measures consist of items organized either contextually or conceptually. A <u>contextual</u> organization of items identifies the times and places where practices can be, to a greater or lesser extent, family-centered (e.g., Bailey, 1991; Bailey & McWilliam, 1993; Jesien & Tuchman, 1992; Mahoney, O'Sullivan, & Dennebaum, 1990; McWilliam & Winton, 1990). These contexts generally consist of first contacts, assessment, intervention planning, and providing services.

A conceptual organization of items identifies theoretical philosophies and types of practice that transcend contexts. Taken together, the extant literature suggests that the construct of family-centered practice can be defined as a friendly, respectful partnership with families that includes (a) the provision of emotional and educational supports (Burton, 1992; Dunst, 1990, Kovach & Kjerland, 1989), (b) the provision of opportunities to participate in service delivery and to make decisions (Bailey, 1989; Burton, 1992; Dunst, 1990; Murphy & Lee, 1991), and (c) activities to enhance family members' capacities to carry out their self-determined roles (Dunst, 1990; Epstein et al., 1989; Kovach & Kjerland, 1989; Murphy & Lee, 1991; The Arc, 1993). The implicit message is that a



family-centered approach is more effective than just a child-centered approach (Dunst, 1985).

We thought it important to explore the <u>meaning</u> of family-centered practice from service providers' perspectives. What should occur has been described in the literature. Recent studies also document what does occur (Bailey & Henderson, 1993; Bennett, Algozzine, Fleming, & Hellrung, 1994; Dunst, Trivette, & Deal, 1994). This study sought to examine *why* practices related to families occur the way they do.

## The Service Provider's Voice

One investigation of family-centered practice (McWilliam, Harbin, et al., 1995) demonstrated the type of information gained by asking service providers for their perspectives. Parents (<u>n</u> = 118) and service providers (<u>n</u> = 198) completed parallel instruments (Bailey, 1991; Bailey & McWilliam, 1993; McWilliam & McWilliam, 1993). Results showed that both professionals and families rated current services as quite highly family centered and ideal services even higher. Having no more than a bachelor's degree, working for an early intervention program (as opposed to an evaluation center or a health department), and providing home-based (as opposed to center-based) services were the best predictors of highly family-centered ratings by professionals. Experience (years working in early intervention) had a positive effect for home visitors but a negative effect for clinic-based professionals whose jobs were to conduct evaluations.



As part of this study (McWilliam, Harbin, et al., 1995), telephone interviews were conducted with 20 professionals (10 with high family-centeredness self-ratings and 10 with low ratings). Professionals believed in a family-centered approach, they especially valued families that liked them, and they felt interagency collaboration had enhanced their abilities to provide family-centered services. They reported that paperwork, lack of specialized services, the IFSP process, and families who appeared not to want services were all barriers to effective family-centered service provision.

In a study designed specifically to determine service providers' views of early intervention services, a survey of 198 professionals revealed problems in the amount of inclusion opportunities for preschoolers, undesignated service coordination for preschoolers and their families, meeting families' needs comprehensively, families' paying for services that possibly should be free of charge, and administrative/systems barriers to providing best possible services (McWilliam & Lang, 1995). Strengths were reported in the improvement of services, responsiveness to families' priorities, and knowledge of child intervention areas. These studies show that professionals have important information for reform of early intervention services.

# Individual Service Providers as a Strength of Early Intervention Services

Although families receiving early intervention services have been found to have lingering needs (see Able-Boone, Goodwin, Sandall, Gordon, & Martin, 1992; McWilliam, Lang, et al., 1995; Sontag & Schacht, 1993), by and large they



have found their individual service providers to be a source of strength and support. McWilliam, Lang, et al. found that the two themes of families' "good experiences" (p. 55) were the characteristics of individual professionals and professional-family partnerships. Parents reported that professionals were responsive, a major source of support, caring, competent, and encouraging of parents' participation as team members. In another study in which parents were interviewed, professionals' interpersonal characteristics were supremely important (McWilliam, Harbin, et al., 1995). Specifically, nontherapist professionals (e.g., educators, child development specialists) were friendly to families, oriented to the whole family, encouraging, and flexible. Families' experiences with physical, occupational, and speech-language therapists, however, were more mixed. They had some positive and some negative experiences with therapists' interpersonal styles, whereas experiences with nontherapist early interventionists were almost universally positive.

Family centeredness, like other constructs, has evolved historically; it is continually defined and redefined in professionals' practices. A discourse on family centeredness has emerged in the early intervention profession. The purpose of this study was to examine how six service providers constructed the meaning of this discourse for themselves. The ways they enacted the concept are part of the construction of the larger shared meaning. We do not expect all professionals to share this meaning, so we were careful to select professionals who demonstrated some investment in the world of family centeredness as we understood before data analysis.



#### Method

# **Case Study Procedures**

An instrumental case study approach (Stake, 1995) was used to investigate patterns of service use in early intervention. Case study families were selected from a larger sample of families participating in an early childhood research institute (Harbin & Kochanek, 1992). The full sample of families was recruited through nomination from early intervention professionals in three states, Colorado, North Carolina, and Pennsylvania. From the full sample, within each of the nine communities (three per state), six infants or toddlers and two preschoolers were purposively selected to represent different levels of service need complexity, different races, different socioeconomic status levels, and different ages within the infant-toddler and the preschool groups. The communities within each state were nominated by state-level administrators as having high quality early intervention services. Three levels of population density were selected: high (i.e., large cities), moderate (i.e., medium-sized towns), and low (i.e., predominantly rural).

After the first family interview, we interviewed the professional each family told us was their primary service provider. Service provider interviews were semistructured, focusing on descriptions of working with families and children, administrative support, and barriers and enhancers to effective service provision.



#### **Selection Procedure**

This exemplary case design (as described in Yin, 1993) required us to screen the service provider cases and select those cases that best demonstrate "the occurrence of exemplary outcomes" (p. 11). The outcomes we identified were characteristics of recommended practices with families: a holistic view of families, shared decision-making with families, and introspection about their work. Although some of these criteria for selection could be confused with the results of the study, this is the challenge of exemplary case studies. If you want to study what makes a good basketball player good, you don't pick bad basketball players. We wanted to hear the voice of family-centered professionals to capture an in-depth view of their own construction of family-centered theory.

#### **Service Providers**

Descriptive information was gleaned from the interviews with the service providers and the families they serve as well as from sociodemographic information the former provided. Names have been changed to preserve anonymity. Profiles of each of the six case professionals are provided in the appendix.

All six of these service providers were white females; in the larger study, all the professionals ( $\underline{N}$  = 43) were female and almost all ( $\underline{n}$  = 41) were White. The service providers in this study all had bachelor's degrees except for one who had a master's degree, whereas almost half the larger sample had master's degrees. Compared to the larger sample, these service providers were of



average age. Their range of experience in early intervention was considerable; the large-sample average was 7 years. These demographic data are not presented to suggest any patterns relative to family-centeredness (e.g., that having a bachelors' degree is more closely associated with family centeredness). The are simply presented as a sketch of the participants and as an indication of their demographic representativeness.

## Analysis

The transcripts were analyzed using constant comparative coding (Miles & Huberman, 1994), in which codes were developed as themes emerged. Transcripts were read and reread to ensure that all portions of every transcript were coded similarly. Initially, each transcript was coded with an independent set of codes. The six sets of codes were then compared to look for themes and to group overlapping codes. Finally, one set of codes was used for all six transcripts.

Page numbers from each service provider's transcript were listed beside each code. Pages were used for our reference during constant comparison and as a way of assessing the frequency of the codes without maximizing frequency (i.e., restricting the frequency of multiple statements within a conversational chunk). If separate issues within the same code appeared on one page, the code was listed more than once for that page, with explanatory notes. Statements could be coded with multiple codes (i.e., statements were not mutually exclusive).



#### Verification

Cross-investigator reading and member checks maximized the consistency of representation and interpretation. The first two authors read the transcripts independently. Tocci supervised and participated in initial coding of all the transcripts in the larger study, and McWilliam performed the coding specific to this study. McWilliam analyzed the information as described above and wrote draft reports, which Tocci examined in light of her knowledge of the transcripts of the six individuals and all the other service providers in the large study. The two investigators then exchanged drafts of the report until they were both satisfied that it was a fair representation and interpretation of the service providers' perspectives. Harbin interpreted the findings in light of results from the larger study.

Member checks were accomplished by sending a draft report to the six service providers, who were asked to make changes on the draft and to write down whether the report (a) included their perceptions, (b) fairly represented them, (c) obscured their identity, and (d) was useful for the field. If they answered in the negative, they were asked to elaborate. Based on member checks, only minor changes were needed and made.

## Results and Discussion

Case studies of six family-centered service providers produced the meaning these people shared of the somewhat nebulous concept of family-



centered practice. An overall orientation to services as well as two philosophical approaches and two behavior classes were identified.

Because the six service providers studied were chosen for their sensitivity to families, we were not surprised to find that respect for families cropped up time and time again in the interviews. Our aim was to discover how six family-sensitive people constructed their meaning of "family-centeredness." Five themes emerged. Each of these is discussed in the order of the frequency with which the themes were mentioned.

## Family Orientation: Opening the Door

[If mom's needs aren't met,] Robbie's in jeopardy again. He's at risk. And I think that's what we're kind of seeing at this point. You know, we've got to keep this family healthy, in all respects, mental as well as physical.

What does a family orientation consist of? Willingness to orient services to the whole family, rather than just to the child, was an enduring theme of family-centered service providers. This orientation went beyond helping the family to become "involved" in the child's programming; it consisted of, first, using sensitivity and good rapport to establish enough trust with parents to be able to ask them about their own concerns, whether or not related to the child. This trust does not necessarily take a long time to establish. In interviews with parents served by other professionals, we found families telling us highly personal things that they said they had not told their service providers. When we asked why, they



said that either they had not been asked or they did not think that was what the early interventionists were there for.

Another dimension of family orientation was creating little distance between "professionals" and "clients." What distinguished the six service providers in this study was their clear view that the well-being of the parents was as important as the developmental progress of the child. Their statements and the interviews of the families they served revealed that the service providers adopted the role of naturally curious and concerned <u>family</u> friends (see friendliness theme later in this paper), not just <u>teachers</u> or <u>therapists</u> for the child. For the most part, they showed no interest in distancing themselves from families by maintaining traditional professional-client relationships that tend to ignore parents' well-being.

Another dimension of family orientation was that service providers did not draw boundaries around the child. Nancy showed that her work was not bounded by the classroom walls. She talked about giving parents information about job and schooling opportunities, but showed a realistic view of her power to change families: "You can encourage and promote and do all that, but the desire in the person has to be there." Nancy valued services, such as a home-based medical program, that helped to "relieve the stress" of a family with whom she worked. The outcome in which she was interested was not just the child's health, but the family's psychological well-being. Norma understood the importance of asking questions. During intervention planning, "this is one of my main questions and I almost always pose it to the parent: When you're at home



with your child and you're going through your day, what is the most difficult time of your day?... What do we need to do to get to that point to make that a more pleasant time?" Her questions show that she's concerned about the family outcome of a pleasant time; the child's ability to perform specific skills are seen as intermediaries to the family outcome, rather than as ends themselves.

Having a family orientation was not necessarily consistent, although three of the service providers talked only in family-oriented ways (i.e., none of the statements made by these three was coded as <u>child oriented</u>). One service provider had no statements coded for family orientation, but she had none coded for child orientation either. Two service providers had some child orientation codes. The preponderance of orientation codes, however, were for family orientation (140) rather than child orientation (19). The service provider with the most family orientation codes, Anita, was also the one with the most child orientation codes. This case suggests that a family orientation might not be dichotomous from a child orientation.

At this point, we should stress that we defined child orientation as statements reflecting an interest in the child to the exclusion of interest in the parents. The definition is important because, clearly, interest in the child, within the context of interest in the family as a whole, is quite appropriate for a family orientation. When a service provider's statement reflects concern for the well-being of the child only, she might assume that those are the parents' priorities. Indeed, research supports the rather predictable importance families place on their children as opposed to themselves (McWilliam, Harbin, et al., 1995;



McWilliam, Lang, et al., 1995; McWilliam, Tocci, & Harbin, 1995). Nevertheless, when the needs, aspirations, hopes, and feelings of the parents, regardless of whether child priorities are intertwined, are not considered, the service provider is displaying a child orientation.

Returning to the apparent paradox of a service provider with both types of orientation, we saw that Anita doubted that one mother was willing to "expand" into talking about nonchild needs. (Our discourse analysis approach suggests that Anita's use of "expand" reveals that Anita thought the mother's first priority in her relationship with Anita was the child.) Anita went on to say, "but the option [to talk about nonchild needs] just really isn't available for her." Because Anita was the service provider, presumably she meant that she did not provide the mother with that opportunity. We possibly caught Anita at a time in her life when she was just starting to shift her orientation away from children only towards families as a whole. She talked about starting a program of activities for a mother to do with her child some time before the interview, when she came to a sudden realization: "It was like someone hitting me in the face, saying, 'How important do you think it's going to be that [the mother] sits down with [the child] for 15 minutes a day and works on language. Please!"

A family orientation requires that the door to parents' concerns, needs, and priorities be opened. In talking about the possibility of assessing and addressing a parent's concerns, Anita said, "I don't think the door is completely closed." When Anita did not open the door, it was unclear whether she did so out of sensitivity to the parents' privacy or out of fear of crossing the threshold and



losing rapport: "There are... people who are very private and it really impinges on them and it doesn't do your relationship any good and it makes them incredibly uncomfortable". Although some service providers might not open the door because of their own discomfort with asking personal questions, Anita denied that this was the case with her: "I don't think so much that it would be uncomfortable for me because I can go through that kind of stuff." An issue for service providers will perhaps be to assess their reluctance to make families uncomfortable if they have not even turned the handle, let alone cracked the door. Anita revealed some of her barriers to opening the door: parents' inability to speak English, the amount of time home visits took (up to 3½ hours), and her working part-time. Other powerful barriers the service providers told us they face are families' privacy boundaries, professionals' concepts of maintaining a "professional" distance, and professionals' lack of training in family-centered practices.

From the interviews, it appears that a family orientation is comprised of both a mindset about early intervention and a set of assessment and intervention behaviors. Linda summed up this combination in describing what she does on the second visit to a family:

I let them know that my role is not only to work with their child, but to help their family be a family that feels better about itself—be a family that feels like it's more knowledgeable about how to care for this child and to work on whatever goals or whatever challenges it's



facing at this point, or things that they've always wanted to do and just couldn't figure out how to make it all work together.

Linda thus revealed a family-oriented mindset in describing her role and she talked about family-oriented behaviors in describing how she would help a family.

Analysis of the transcripts of the service provider interviews revealed four remaining components of family-centeredness. The first two, positiveness and sensitivity, have to do with a philosophy and the last two, responsiveness and friendliness, have to do with behaviors supporting those philosophies. Although we found all these components to be associated with a family orientation to service provision, one philosophy and one behavior could also exist within a child-centered although family-friendly approach (see Table 1). In a family-friendly approach, the service provider can be positive about the child and family and can develop a close rapport with the parents, but, according to our findings, this would not be a family-centered approach unless the service provider were also highly sensitive to the intra-individual needs of the parents and highly responsive to those needs.

As the following descriptions will show, the kind of sensitivity and responsiveness demonstrated through conversations with our six service providers and their families exceeds the sensitivity and responsiveness one might find in strictly child-oriented, family-friendly service providers. We do not claim that these characteristics, as normally understood, cannot coexist with a



Table 1
Philosophies and Behaviors Consistent With Family and Child Orientations

Component	Consistent with	Consistent with
	Family Orientation	Child Orientation
Philosophical	-	
Positiveness	x	X
Sensitivity	x	
Behavioral		
Responsiveness	×	
Friendliness	X	X

child orientation. The way they were described in these case studies, however, shows that they would be unlikely in child-oriented service providers. (Although this study did not have a contrast group of child-oriented service providers, our familiarity with this traditional approach to service delivery allows us to make comparative statements. Nancy aptly showed how a child orientation and a family orientation are not inconsistent but how the latter can be overlooked: "You sometimes look at the needs of the kids and forget that there's people behind them that are constantly taking care of them and they have needs too."

# Positiveness: Thinking the Best of Families

Positiveness consists of a philosophy of thinking the best about the parents, without passing judgment. This component is similar to what Dunst



(1985) called a proactive approach. All six of our service providers showed this philosophy. Peg, for example, talked about families' having "their ducks in line for as much as they can handle." The philosophy is not easy to keep at all times; Linda said, "Probably one of the hardest skills and one that I consistently push towards is being nonjudgmental." Recognizing the effort parents make is another characteristic of positiveness. After acknowledging that "vision and hearing kinds of things are areas that are kind of difficult for parents to figure out how to stimulate," Donna reported that a mother with whom she worked "took my ideas and then really built on them." This statement shows how service providers can be positive about parents in relation to their child intervention activities. These professionals also tended to be positive about children; Nancy described a little boy with chronic illness as a "fighter.... He's going to keep coming back."

We have called this general characteristic positiveness because it encompasses an enthusiasm for activities for which others have reported lack of enthusiasm. For example, Carla said she liked IEP meetings because it was an opportunity to get together with families (cf. McWilliam, Harbin, et al., 1995). The philosophy of positiveness therefore seems to include a belief in parents' abilities, a nonjudgmental mindset, optimism about children's development, and enthusiasm for working with families.

# Sensitivity: Walking in Parents' Shoes

Sensitivity consists of service providers' putting themselves in the parents' shoes. Our professionals' statements suggested that they understood families'



concerns, needs, and priorities. For example, Nancy reported that her agency was having difficulty with attendance at a parent support group: "I think it might be because so many of our parents live so remote that it's just something that, once they get home, get their kids home, they don't care about coming back." The service providers were especially sensitive to parents' lack of time for themselves, individually or as couples. The professionals' self-reported behaviors suggested an underlying philosophy of sensitivity. Anita worked with a mother who did not follow through with her advice to sign up for Medicaid, but Anita paused to "find out if she wants that and if there's some reason for her not wanting that." Donna showed that sensitivity to the parents could result in ostensibly child-focused intervention. When she went to a particular family, the mother would sometimes "be [in] a frazzle," so Donna would work with the child. The mother could then "just get a break time because her day had been so intense." (Note that working directly with the child was done for the purpose of changing parent outcomes.)

Linda most clearly articulated the concept that sensitivity means putting oneself in the parents' shoes: "You [the interviewer] and I are no different. How would we be if we had a special needs child come into our life?" According to the frequency with which sensitivity was coded, Peg was the most obviously sensitive of the service providers. This was remarkable because she had had to report one of the mothers about whom we interviewed her to social services for using emotionally abusive disciplinary measures, even after Peg had warned her. Peg's sensitivity in the face of this difficult situation included telling the social



worker from the beginning that this was a "culturally different family and they have much stricter rules." The social worker, in collaboration with Peg, did not investigate further. Instead, she had Peg talk to the father, who was not from overseas and who spoke English, about persuading his wife not to discipline the child in that manner any more. Peg explained to the father that she had to put the child's needs first, by law and by the employment contract she signed. Even though a language barrier existed, Peg asked the father to put the mother on the telephone and said, "Do you understand what I had to do and why I had to talk to [your husband]?"

Despite this awful interruption of Peg's attempts to establish rapport with the family, at the time of the interview she seemed to have a friendly relationship with them. She felt the mother was "really tired" because she worked until 2 a.m. and was up at 6 a.m. with her child. She wished she "could find a grant or something" for the father because he was multilingual, musical, and stuck in a "really horrible job." To handle the language and cultural barriers Peg experienced in working with this family, she got in touch with a minister of the same cultural background of the mother. The minister helped Peg understand the values of the society in which the mother had grown up. The most common theme running throughout Peg's descriptions of the families she worked with was the stress the mothers were under. Her sensitivity was evident in her attempts to understand this stress.

Based on the statements of these service providers, it appears that a sensitive philosophy towards families includes understanding why families do not



partake of intervention opportunities, understanding that parents have little time to themselves, gaining knowledge (by asking families and experts) about families so they can expand upon their own sensitivity, understanding possible cultural differences from the service provider's mores, working through interpersonal challenges with parents, understanding how much parents have to do in a day, and recognizing parents' aspirations for themselves. This list is doubtless incomplete yet still might seem, to child-oriented professionals, a tall order. The sensitive philosophy might be encapsulated, however, in the idea of putting oneself in the parent's position in order to anticipate how families might feel. This is different from prejudging families or thinking for them. As our service providers demonstrated, an important behavior associated with this philosophy is checking out families' feelings and reasons before jumping to conclusions.

# Responsiveness: Doing Whatever Needs to Be Done

Responsiveness consists of attending to parents' concerns. Two forms of responsiveness were evident: paying attention and taking action when parents expressed a need (e.g., for information, for support) and paying attention and taking action when parents had a complaint. We found that a number of statements initially coded as empowerment (see Dunst, Trivette, & Deal, 1988) came under the larger category of responsiveness. Initially, empowerment was coded when the service provider described a parent's expressing his or her needs. The majority of these incidents were discussed in the context of the



service provider's responding to the expressed needs so they were subsumed under the responsiveness category.

Peg was responsive when the mother described above asked her, at the beginning of their relationship, to change appointments almost every week. Another mother with whom Peg worked called the early intervention program to complain that her child was not getting what he needed. One of Peg's colleagues "kept saying, 'Well, our focus is supposed to be what the family wants, and you [the complaining mother] just bring it to our attention that we failed and that we'll have to do a better job" (emphasis added). Responsiveness was probably either a requirement of the agency or understood to be recommended practice.

One characteristic of responsiveness is that it shows an individualized and flexible approach to service provision.. By responding to needs or complaints, service providers adapt their activities to the particular parent's concerns, sometimes with little regard for the standard way of operating. In describing how she introduces a "family focus" when working with families, Linda said, "It's different for different families." She also defined empowerment: For one mother who had dropped out of school but was thinking of resuming her education, "empowering her was making her believe she could go to school.... But, for some families,... that's not the level of empowerment they need. They need the level of empowerment to know they can make their doctor's appointment on time."

Responsiveness sometimes means the service provider's holding back and not pushing an agenda. As Donna said, "Let moms take the lead." When



Donna was asked whether she thought it was helpful for the parent and the service provider to have similar educational and cultural backgrounds, she said,

Not necessarily, because I think sometimes, when there aren't those similarities, the parents are still as vested. I think it's part of just them feeling that we really care, and them really caring and us acknowledging that they know what they're doing and know what they want and us just supporting that."

Anita worked with a child who was receiving poor nutrition. The child's diet consisted largely of leftovers the mother brought home from her work in a restaurant. Anita talked to the mother about all aspects of child development, including diet, and said to her, "Listen, I can do whatever needs to be done here." This gave her the opportunity to offer to develop easy menus, budgeting, gaining access to the Women, Infants, and Children nutrition program, and so on. I can do whatever needs to be done shows Anita's flexibility, support, family orientation, responsiveness, and willingness to provide options.

Some readers might interpret Anita's responsiveness as paternalistic. This might be true, although the evidence in the transcripts suggests otherwise. She did not force the family into anything. Rather, she made sure they had access to information and services and she paid attention to needs the family expressed.

Attention to parents' concerns—responsiveness—was clearly an important philosophy of family-centered service providers. Nancy, who was a classroom teacher, expressed the essence of this philosophy: "My basic function is the needs of the children and in order to do that I need to cooperate with their



parents." We note the difference between this approach and the traditional teacher-parent approach, encapsulated in the all-too-common salutation in teachers' letters to parents—thank you for your cooperation. In family-centered early intervention, it was clear who should be cooperating with whom.

## Friendliness: Treating Parents as Friends

Rapport, which has been used in human services to describe a valued professional-client relationship, perhaps understates the behavior our six service providers displayed. They treated parents as friends. The mother with whom Anita worked described Anita as one of the most supportive people in her life. Anita said this made her sad because "you need somebody closer, like family or a really good friend." She attributed the friendship she had with this mother to the fact that they "share things back and forth." Anita did not feel all that close, however, to another family, although they have "gotten more comfortable as time goes by." In this situation, the family did not speak English very well, and Anita did not speak Spanish. Despite the language barrier, rapport was building slowly. The development of rapport over time has been suggested as one reason for families' reporting that they have experienced more family-centered practices the longer they have been in early intervention (McWilliam, Harbin, et al., 1995). Peg reiterated this theme when she acknowledged that she "didn't have the greatest relationship [with one of her parents] because we didn't have much time to develop it."



Although it appears that Donna saw her official role on home visits as providing therapy to the child, she found herself engaging in what Powell and Eisenstadt (1988) have called kitchen talk:

We'd spend a good time just talking about frustrations that the kids weren't helping out, or they wrecked the house, or her husband wasn't helping out..., which, you know, I think too is more like being a friend than just a therapist coming in.

Carla thought that one of the benefits of becoming involved with the family was that families gained access to services other than those she provided. Interestingly, she, like families, saw the home visitor as part of the informal support system as well as the formal support system: "They need that person that's not being paid or, you know, part of this system, like a home visitor or like me as a teacher.... They needed me as a friend and a personal acquaintance... even though I was her teacher."

Peg's relationship with the parents, which involved their talking to her about sensitive matters not directly related to the "client" child, raises an important issue for service providers who might question whether they are trained to provide counseling or psychotherapy to families. Our six professionals worked at getting close to parents, thus opening the door for listening to the parents' own concerns (i.e., beyond those directly related to the child), and providing whatever support they could. That support was the sort that <u>friends</u>, not necessarily psychotherapists, provide: listening, encouraging, and offering



practical help such as babysitting or running errands. These behaviors conveyed that they cared.

One of the benefits to service providers who develop friendships with parents is that they can afford to be straightforward, without the parents' becoming offended. In fact, parents who had friendships with their service providers identified the professionals' honesty as a positive characteristic, whereas parents in the larger study who had less friendly relationships with their service providers (not the six in this report) perceived similar behavior as bluntness or intrusiveness.

Friendliness is a set of behaviors that undergirds many other aspects of family-centered practices. According to these interviews, it entails developing a reciprocal relationship, building trust, taking time to talk to parents about their concerns, listening to parents, encouraging them, offering practical help, and conveying caring for both the parents and the child. Friendliness was, therefore, a corollary of responsiveness.

# **Child and Community Skills**

Family-centered practices, as revealed through interviews with these six service providers and the families with whom they work, therefore, are comprised of a family orientation, positiveness, sensitivity, responsiveness, and friendliness. We noted, though, that these professionals—as well as the parents with whom they worked—also acknowledged the importance of their child-level skills and their competence in integrating their work with broader community activities.



Assuming that child-level skills are familiar to most readers, we will briefly describe what the service providers did with the community. First, some of them recognized the effects of the community economic situation on families. Anita, for example, felt that the reason nearly half of her families were "involved with social services and there were abuse and neglect issues going on" was because of the recent closing of a major employer. At the other end of the spectrum, Peg, who lived in a booming community, noted the challenge of growth; caseloads are always at a maximum. Second, some of the service providers appraised their communities critically. Carla described how people in her town in the 1970s thought of "the retards up on the hill outside of town.... That is their model to go by." Linda bemoaned the lack of "good day care settings." Third, the professionals knew their communities well and were obviously well-known in their communities, especially for advocating for children and their families. Carla said.

I am just fascinated by the educational and the sociological problems going on in this rural community and love everything that I get my foot in, and it's usually in my mouth. But people in this community know me, so that's OK.

Peg felt she needed to improve her knowledge of preschools (critical self-appraisal was a consistent theme of these professionals): "I really need to take maybe a week just to go visit all the preschools again to see what they're doing and what kind of programs they have." Fourth, all the service providers were eager to establish collaborative relationships with other community agencies.



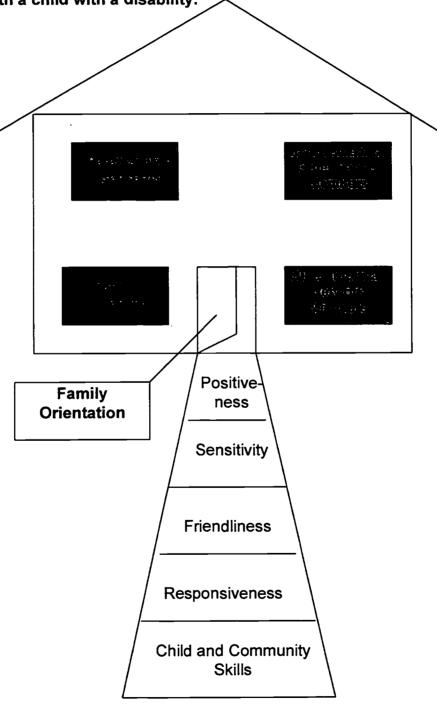
The community skill and involvement these service providers displayed consists, therefore, of (a) awareness of economic impacts and the cultural comate, (b) familiarity with agencies, and (c) a desire for collaboration. In general, these professionals themselves appeared to be well-integrated into community life and they tried to carry that integration over to their services to families. Competence in child development and intervention, as well as community-level involvement, seemed to be integral to their family-centered practices.

In conclusion, service providers' positiveness, sensitivity, friendliness, responsiveness, and child and community skills provide the path to the family orientation door, as shown in Figure 1. Opening the door gives service providers access, to the extent the family desires, to the many dimensions of a family's experiences with a child with special needs. The family still has the choice of which doors within their house to open to the service provider. Some of the rooms to which family-centered service providers may have access are parents' own concerns (e.g., finances, the relationship between the mother and father), involvement of other family members (e.g., grandparents' babysitting), family marital, parent-child, sibling), and other informal-network dynamics(e.g., members (e.g., friends, neighbors, church). The house and room metaphor is simplistic and only used for heuristic purposes. For an individual family, the complexity of the issues within one room might be immense, whereas the issues in another might be relatively uncomplicated. The job of the family-centered service provider is to use the strategies we have identified to understand and



respond to all the forces having an impact on the family. Failure to enter any of the rooms should happen only because the family chooses to keep that door

Figure 1
The path to the family orientation door, giving access to a family's experiences with a child with a disability.





closed, not because the service provider has failed to adopt family-centered philosophies and perform family-centered behaviors.

The main purpose of this analysis was to discover the philosophies and behaviors of family-centered practice, but we also remained open to any other themes that emerged through the constant comparative coding process. For example, we discovered that these family-centered service providers' self-concept included both confidence and self-criticism, that the service providers were flexible, and that time constraints interfered with service coordination, getting paperwork done, and collaborating with other professionals. These themes will be explored by analysis of the transcripts of the larger study.

The major themes in the present study answered our questions about family-centeredness. Family-centered practices were found to consist of five interrelated components. The most powerful of these was that the service providers had a family orientation rather than simply a child orientation to their jobs. This is a critical finding, because interviews with families had shown that parents were fond of their service providers, but that they thought of most of them as focusing primarily on the needs of the child (as discussed in McWilliam, Tocci, & Harbin, 1995). These service providers, by contrast, showed equal concern for the parents' well-being (and other family members') as well as for the child. What was striking about their practices was that this orientation did not result in the abdication of their responsibilities for helping with the child's health and development. Because the child was obviously a part of that family and the one with the most obvious needs, the support the professionals provided was



most often directly or indirectly related to the child in question. The difference between child and family orientations is encapsulated by what professionals and parents talked about and what professionals did during home visits. Discussions with families made it clear, from first contacts, through assessments, and into direct services, that the parents' perceptions, concerns, and needs were of great importance to these six service providers. Interview transcripts suggest that, during home visits, the service providers talked to families and did not just focus on teaching the child. In contrast, interviews with other service providers and families in our case study sample revealed that their home visits were centered around the toy bag. Child-oriented professionals went to the home to work with the child. They might talk to the parents at the same time or afterwards, but discussions most often were centered on the child's progress or the parents' concerns about carrying out home programs. Not surprisingly, parents served by child-oriented professionals did not think that their own concerns were any business of the early interventionists. In contrast, parents served by our six family-oriented professionals recognized that the professionals were there to help them as well as their child.

The perceptions of families served by "child-oriented professionals" can be dangerously misleading. These families are likely to say that the parents' concerns are none of the early interventionist's business (McWilliam, Tocci, et al., 1995). This perception could lead some early interventionists to endorse a child-oriented approach. After all, we would not want to be intrusive. The logic, however, is flawed because families served by child-oriented professionals have



been conditioned, albeit unintentionally, to think that the child's development and health are the sole focus. The current study shows that, when professionals present themselves as nonjudgmental, amicably curious friends of the parents, the family will extend their boundaries and perceive early interventionists' interest as appropriate and supportive, not inappropriate and intrusive. Families' perceptions of intrusiveness are based on violation of expectations. If a hitherto child-oriented professional attempts to cross already-established boundaries, the family's expectations are violated and they are likely to consider the professional intrusive. Most families do not know what to expect on their first contacts with early interventionists. (We did find that, sometimes, the referral source had already made the mistake of describing early intervention solely in terms of therapy and education for the child.) If, therefore, the family's first contact conveys a family orientation, the family creates an expectation of this orientation and establishes a relationship with the service provider (as long as other familyfriendly behaviors are also practiced) with boundaries wider than the child.

# **Building a Taxonomy of Family-Centered Practices**

The five dimensions of family-centered practice we found are consistent but not synonymous with other classifications of family-centeredness.

Positiveness has much in common with respecting the family's expertise and strengths as well as building positive expectations (Murphy et al., 1995).

Responsiveness has been identified in previous work (Kovach & Kjerland, 1989; Murphy & Lee, 1991) and shares features with three of Murphy et al.'s factors:



flexibility and innovation in programming, providing and coordinating responsive services, and individual services and ways of handling complaints. Friendliness is similar to building proactive relationships (Dunst, 1990; Murphy & Lee, 1991) as well as communication timing and style, developing and maintaining comfortable relationships (Murphy et al., 1995). Two dimensions we found in this study, a family orientation to services and sensitivity, appear to be different from other measures of family-centeredness, but they are not discrepant from the principles underlying those measures (e.g., Turnbull & Turnbull, 1985). Our finding that child and community skills were elemental to the quality of familycentered professionals' services is consistent with the family-centeredness classifications of providing information (Kovach & Kjerland, 1989; Murphy & Lee, 1991), using community resources (Dunst, 1990; Epstein et al., 1989; Kovach & Kierland, 1989), and mobilizing supports (Burton, 1992; Dunst, 1990; Kovach & Kjerland, 1989). The literature suggests that our case studies were not exhaustive in explaining family-centered practice. Other practices, such as parent-professional collaboration and respecting the family as decision-maker also have been identified as critical to family-centeredness (Bailey, 1989; Burton, 1992; Dunst, 1990; Murphy & Lee, 1991; Murphy et al., 1995). The contribution of this study appears to be, therefore, the identification of family orientation and sensitivity as crucial themes of family-centered service provision.

The findings should be considered in light of at least two limitations. First, the interpretation of the service providers' voices (in the research sense of the noun) was restricted by having only one researcher conducting the primary



analysis. Although a second researcher verified the interpretation and a third provided a wider context, all researchers worked on the same project and could be considered similar in many of their ecocultural viewpoints. Second, we may have been insufficiently familiar with the data sources (the service providers) because the primary data consisted of a single interview. This limitation was somewhat mitigated by the fact that, at the time of analysis, we had twice interviewed families with whom they worked.

Four possible strengths of the study should help readers assess the relevance of our data. First, the data sources were selected from over 40 service providers working in communities nominated as providing high-quality services. Our sampling was therefore purposive but from a large pool of potentially viable cases. Second, the qualifications of the investigators allowed for informed interpretation of events and opinions. Third, family interviews accompanying the service provider interviews permitted triangulation across data sources. Fourth, member checks (i.e., soliciting interviewees' input into our summaries and report) ensured both accurate description and feasible interpretation. These study characteristics may compensate for some limitations.

Quantitative studies to assess the extent to which the five components of family-centeredness are distinct factors would be a value accompaniment to this study. Measurement of both family-centered behaviors (opening the door to parents' concerns, responsiveness, and friendliness) and family-centered mindsets (family orientation, responsiveness, and sensitivity) are, however, all difficult to measure. Researchers must rely on parents' and professionals'



reports, even though some are in the form of rating scales. Difficulty of measurement mitigates the extent to which factor analysis might confirm the existence of five separate components. Further qualitative research such as the current study would also be beneficial.

# **Implications**

The implications from these findings for <u>policy</u> are, first, that state and local policies governing early intervention practices should require professionals to "open the door" to family-level needs assessment and intervention. Second, policies should address the expectation that professionals will be responsive to families in the ways described in this report.

Early intervention policies, especially Part H, address the importance of working with families. Some of the evidence, such as the statement of the professional who was reported to have said, "We're supposed to do it that way," suggests that policies do make a difference. Data from the larger study show that some activities that the State emphasizes are also emphasized at the local level. Not only should policy require "opening the door" but it should suggest how this should be done.

These policies will only make a difference if they are accompanied by vigorous <u>preservice and inservice training</u>. Many nuances in determining and designing family-centered practices cannot be captured in policy. Because we found that family-centeredness encompasses both philosophy (i.e., attitudes, beliefs) and behavior (i.e., practices), innovative approaches to staff



development will be needed. It is unlikely that the traditional approaches to training, such as conference presentations and lecture-style workshops, will adequately lead to change in practitioners' philosophies and behaviors. A second reason to use innovative training is that family-centered practices require sensitivity to read individual parents' preferences and reactions. Simulations of different scenarios, such as the case method of instruction (see McWilliam, 1993), hold promise for training professionals in the development of both the philosophy and practice of family-centered early intervention.

Finally, the findings have implications for practice itself. Program directors should emphasize a family orientation, friendliness, sensitivity, responsiveness, and a positive approach in job requirements. Practitioners, many of whom have well-honed child and community skills, should use these to undergird family-centeredness, rather than treat family-centeredness as an addendum to direct treatment.



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# **Appendix**

#### **Profiles of the Six Case Service Providers**

#### **Anita**

Anita was a 39-year-old speech-language pathologist with 4 years of experience in early intervention. She worked in a small town that used to be a thriving mining center but the populace of which now largely provides services to nearby resorts. She had three children of her own. Anita worked part-time, making home visits to 10 children on average. The hardest thing for her, about her job, was "preserving and protecting the office time" for planning because if a family needed something she'd find herself attending to those needs instead of the paperwork. About two thirds of her time was consumed with direct service, and one third with service coordination (i.e., calling and meeting with personnel from other agencies). One of the challenges of part-time work was coordinating schedules with other part-time personnel. Her supervisor was supportive and "flexible." She was studying for her master's degree, sporadically ("doing the slow boat to China"); taking classes was "a Godsend" for her. Although Anita saw herself as family-centered in the midst of other professionals who "looked at me like I had three eyes," she revealed conflicting values when stating that a challenge was working with families who "aren't as invested in getting services as you are." This theme was found in another study of family-centered practices (McWilliam, Harbin, et al., 1995). She served five of our case study families, who said she was outgoing, friendly, good with the child, encouraging, helpful, and



willing to listen. One mother said she went beyond the call of duty, "because I'll call her at home."

# **Nancy**

Nancy was 35 years old, trained in regular and special early childhood education, and with 8 years experience in early intervention. She had 2 children of her own. She worked as a classroom teacher in a large reverse-mainstreamed center (i.e., typically developing children were enrolled in a center primarily established for children with special needs) in a small town. Her job included sharing service coordination with the person at the center who has primary responsibility for service coordination. Although she found paperwork "overwhelming," it could wait, whereas "the kids aren't going to wait. They're here a certain number of hours a day and that's the part of the job I like. I like to play." We interviewed the mother of a child in Nancy's classroom. She talked about Nancy's willingness to do more than expected of classroom interventionists, such as calling every day when the child was in the hospital, taking papers to the home "instead of making me go out of my way to do it," taking children and their families to the regional hospital 80 miles away, and keeping the children so the parents can go out together. Nancy's proactive (Dunst, 1985) approach to families was reflected when she was told about the positive things a mother had said about her: "[This mother and her husband] have tried so hard and I just can't give them enough credit for what they've done and what they continue to do."



#### Donna

Donna was a 43-year-old occupational therapist, with 10 years experience in early intervention, and with two children of her own. She worked as an infanttoddler coordinator and provided direct services to 20 children and their families. The community was classified by the research institute as one of medium population density. Her typical workday began at 7 o'clock and ended at 5:30. The biggest challenge her agency faced was insufficient personnel for the number of children served, which left little time for "communication" and paperwork. She saw the importance of individualized plans, however, and recognized that she had less paperwork than if she worked in a hospital. Another challenge was collaboration with other community professionals with different philosophies; speaking of therapists working in hospitals, she said, "I don't know that they really support that the parents are the ones that are the bosses." She also felt that, because therapy cost so much, therapists were "pushing the kid to the nth degree." The mother we interviewed said Donna was her "pillar" and "like a bolt of sunshine that walks through your door every week."

# Peg

Peg was 37 years old, had five children, had worked in early intervention for 12 years, and was trained first in early childhood education and then in early childhood special education. She had worked with children of many ages, but she said she particularly liked this age group: "I like the contact with the parents." She worked for an agency providing both home- and center-based services, where she had a caseload of 17 children and their families. The community was



a fair-sized university town with many well-educated residents as well as some families with more modest backgrounds. Like Anita, she worked part-time (24 hours a week), which she felt curtailed the time needed to let families know about community opportunities. She was considering pursuing a master's degree in occupational therapy, but thought she wanted to do something that was more family-centered: "Most of the stuff I do.... I'm a mixture between a social worker, a family support person." Her agency had a consulting psychologist, whom Peg found helpful because her own view of families was confined by being "just so in the trenches." Peg viewed her role vis à vis families as that of a friend who listens. The family we interviewed appreciated her skills with their child, her sensitivity to the mother's Asian "ways," and her helping with practical activities such as going to the doctor, obtaining babysitting, and "clearing up some insurance referral problems."

#### Linda

Linda was a 34-year-old social worker who also had a master's degree in child development, had worked in early intervention for only 1 year, and had three step children. She worked in a largely urban area. She viewed her job as developing families' skills in dealing with service systems, such as how to call a doctor for the first time. Her job with the agency was part social worker and part developmental therapist, and she had 12 or 13 children on her caseload. She provided services in child care centers and in homes. On home visits, she carried the symbol of child-centered services, the toy bag, but she also "helps



parents to make home-made toys." Paperwork consumed some time, as it did for all the professionals, but she found some relief in dictating her notes. Service coordination is what suffered because of lack of time: She regretted having to put off taking a mother to the farmer's market, where nutrition certificates could be used, for 3 weeks. As with the other service providers, Linda appreciated opportunities for training: "It's important because when you stop growing you start dying." The mother with whom she worked considered Linda a friend. Linda, for example, had her church "adopt" the family, she offered to babysit for whole weekends, and she provided the mother with encouragement after the mother was rejected from a job training program.

#### Carla

Carla was 44 years old and the adoptive mother of two children with disabilities. She was trained in special education, and had worked in early intervention for 10 years. It appeared that, earlier in her career, she had been fired from a public school job for advocating for families too enthusiastically. At the time of our study, she had recently retired after working in the community for a total of 20 years. Her approach to families was to help them as soon as they expressed a need. She felt responsible for families she felt did not have enough support, but she had referred families, successfully, to mental health services. Her agency had to conduct child evaluations for the whole community, which she found "a big pain and a burr in our butts." She expressed frustration that therapists in her community treated her as "just a preschool teacher... a horrible



stigma" and acted as though she knew nothing about physical and occupational therapy. The mother to whom we spoke was impressed with Carla's honesty and availability.





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