9

Creating Family–Professional Alliances

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"Professionals are people, too. They have good days and bad days. They work long hours that are emotionally draining. They've chosen their profession because they care deeply about children, and nurse the same hopes for your child that you do. You each have your own–partial–expertise. Together you form a complete team."

—Robin Simons (1987, p. 51)

"I cannot describe the assessment in any great detail. Like the first conversation with our pediatrician, of which I could only remember certain features against a hazy background, this assessment remains in my memory like an impressionist painting upon which a student of realism has superimposed six or seven contrasting strokes."

—Beth Harry (2010, p. 70)

"As a staff, the professionals should strive to make the parents an integral part of the intervention team. Parents should be welcomed, needed members of any therapeutic team providing services to their child [with a disability]."

—Gay S. McDonald (1978, pp. 126–127)

This is a book of encouragement; it is about the resilience of families and about the ways in which families and professionals can work together to improve their lives and the lives of children. The importance of these alliances has been recognized in the literature for many years, but partnerships of all kinds are easier to describe than to create and maintain. Tension between families and professionals is not unusual; in fact, some tension is a healthy result of the different roles that family members and professionals play in the lives of children. Parents and family members know their children better than anyone else. They understand the needs of their family system and the beliefs and behaviors that they value and by which they live. On the one hand, family members are typically the child's best advocate because they are trying to meet the child's needs rather than balance the child's needs against larger social, political, and economic needs that professionals confront within their organizations, communities, and states. Professionals, on the other hand, bring advanced knowledge and skill training, extensive experience, and a range of tools and techniques that have been honed over

time. They know more children and families than a family by itself will probably meet in a lifetime. Although family service professionals are often strong advocates for the children and families that they serve, most work within a bigger picture of priorities and needs than those of a family or child alone. Sometimes, admittedly, for family service professionals the bigger picture takes precedence.

This chapter discusses family–professional tensions and alliances in the context of a family-centered approach to intervention from the perspectives of research and practice. It defines the goals and principles of family-centered service, dispels the myth that professionals have little to contribute in this approach, and discusses family–professional roles and relationships. It describes evaluation as an important tool in determining whether family-centered practices are being implemented and discusses ethical practice and professional codes of conduct as the underpinnings of service delivery. The chapter concludes with suggestions for putting effective partnerships into practice.

A SHORT HISTORY OF CHANGE IN FAMILY–PROFESSIONAL RELATIONSHIPS

Family-centered services have become the gold standard of early intervention systems, programs, and services since the mid-1980s. In a review of early education programs and outcomes, Bronfenbrenner (1975) concluded that active parent involvement was a major contributor to the success of these programs. In his book *The Future of Children* (1975), Nicholas Hobbs, eminent child psychologist, asserted that the true role of intervention programs was to marshal socializing agents within the family, neighborhood, and community as a way of strengthening families and their functioning. That assertion was more fully described in a later book by Hobbs et al., *Strengthening Families* (1984). The notion of using informal supports rather than formal supports was viewed as a more natural, normalized way of assisting families. The emphasis on the importance of families and of determining family needs from the family's point of view emerged as central to child health care (Baird, 1997).

Fields such as child health care adopted this new model, and research and ideology in areas such as early intervention began to shift. Building on their research with families, philosophy, and evolving notions of best practice, Dunst (1985) and others (Bailey et al., 1986; Dunst, Trivette, & Deal, 1988) challenged the traditional view of child-directed services as the optimal model for early intervention. Turnbull, Summers, and Brotherson's (1984) contributions to the application of family systems theory to families of children with disabilities or children at risk for disabilities moved the field forward in both philosophy and practice. (See Chapters 3 and 4 for details of the family systems framework.) The Education of the Handicapped Act Amendments of 1986 (PL 99-457) (retitled as the IDEA Amendments of 1997 [PL 105-17]) gave planning grants to states to develop early intervention services for families with children from birth to 3 who have, or who are at risk for, disabilities. It also mandated free and appropriate public education for preschoolers with disabilities. The new legislation and its subsequent amendments (IDEA, 2004) created a vehicle for putting new ideology into practice through the IFSPs for children birth through age 3. The IFSP gives families a central role in determining services and the ways in which they are delivered (Hauser-Cram, Upshur, Krauss, & Shonkoff, 1988). It also underscores the need for systems, programs, and individual service providers to rethink their approach to serving children and families.

This rethinking changed the locus of services from children alone to children in the context of their families. Determining family priorities and needed supports became as

important as child-centered activities, approaches, and interventions. Family-centered approaches incorporate family support in service delivery, and family support emphasizes family strengths (Dunst, Trivette, Starnes, Hamby, & Gordon, 1993; Singer & Powers, 1993). Professional contributions to family support typically enhance families' well-being and competence, as well as model and teach relationship skills. Professionals must reflect ethical behavior in all interactions, employ strategies for training specific skills and behaviors, and demonstrate knowledge and ability to teach strategies that enhance supports. Optimally, they must display a commitment to collaborative partnerships and place value on the power of self-help groups (Singer & Powers). These skills are foundational to family-centered practices, and wisdom from the family support movement provided evidence that families were quite capable of identifying their own needs.

This view has been reinforced by research in subsequent years in which families of children with disabilities were asked about their own needs and preferences related to information gathering and services. In a qualitative study that examined parents' and professionals' expectations of family outcomes in early intervention and the preferences of each group for gathering information about family strengths and needs, Summers et al. (1990) found that family members looked to early intervention professionals to provide emotional support and friendship. Contrary to professional training curricula that emphasize professional distance and boundaries, these findings underscore the value of personal, informal relationships between professionals and family members when parents are first learning that their son or daughter has a disability. The study also found that early interventionists and early intervention programs were expected to provide information, assist in linking families with other families in similar situations, and help parents and other family members develop skills that would facilitate later relationships with service systems. Professionals were also expected to help parents develop the skills necessary to work more effectively with their son or daughter with disabilities. This last point is critical, for it has been so frequently omitted as programs have attempted to become family centered. Although the role of professionals in family-centered practice has changed, its importance and value have not.

In a similar qualitative study, parents' primary expectation for early intervention was accurate information, positive reactions, and uncensored information about what is available so that parents can decide (Able-Boone, Sandall, & Frederick, 1990). Family members expressed their desire to have the knowledge that would empower them to make informed decisions. This study, too, supported families' desire for professionals who are knowledgeable and who bring their knowledge and skills to the partnership.

In addition to participating in research conducted by professionals, parents and other family members have developed models and approaches to services that underscore the many tenets of family-centered practice (Santelli, Poyadue, & Young, 2001). Parents throughout the country have developed parent-to-parent networks. In parent-to-parent networks, a trained, supportive parent of a child with a disability or risk condition provides information and emotional support as needed to a matched parent who requests assistance (Singer et al., 1999). The veteran parent is often available around the clock for questions, conversations, and emotional support (Santelli, Turnbull, Sergeant, Lerner, & Marquis, 1996). The veteran and referral parents are often matched by children's disability or risk condition, the children's ages, or the even geographic proximity of the families. Parent-to-parent programs have been cited as particularly valuable in providing information and emotional support for families of children with disabilities

(e.g., Meyer, 1993; Santelli, Turnbull, Lerner, & Marquis, 1993; Santelli et al., 1996; Turnbull & Turnbull, 2001). The opportunity to talk with someone who has "been there" is often an invaluable resource for families who are encountering new feelings, new demands, and new systems. Parent-to-parent programs do not include professionals and do not represent models of family–professional collaboration. Instead, they underscore the importance of personal contact and knowledge of daily life with a child with disabilities or serious risks–something that most professionals have not experienced.

As additional research on family-centered approaches to service delivery has been conducted, its validity as an approach has been confirmed. In a meta-analysis consisting of eight studies representing 910 toddlers and their families, data suggested that a family systems model of intervention positively affected parent–child interactions and child development (Trivette, Dunst, & Hamby, 2010). Effectiveness of the approach is, in part, dependent not only on the training and skills of professionals but also on their ability to connect emotionally with family needs (Brotherson et al., 2010) and a supportive administrative structure (Epley et al., 2010).

Cognitive Coping

Cognitive coping, according to Turnbull and Turnbull (1993, p. 1), entails "thinking about a particular situation in ways that enhance a sense of well-being." The ability to reframe a situation that is negative or is perceived to be negative in a more positive light is another way to define cognitive coping. Parent-professionals–recognized researchers who are also parents of children with disabilities–have driven research on cognitive coping in the area of developmental disabilities. Contrary to societal views and much of the literature in the field of developmental disabilities, many families feel enriched by their son, daughter, brother, or sister with a disability (Harry, 2010; Turnbull, 2009; Turnbull, Patterson, Behr, Murphy, Marquis, & Blue-Banning, 1993). Expressing these feelings of being enriched by living with, learning from, and loving a child with a disability is an example of cognitive coping. The research on cognitive coping underscores the family-centered principles of empowerment and respect for family perspectives.

A Realignment of Priorities and Ways of Working Together

The professional literature in early childhood special education is replete with guidelines and recommendations for implementing family-centered approaches, but the shift from child-focused to family-centered services has not been easy (Murray & Mandell, 2006; Sandall, Hemmeter, Smith, & McLean, 2005). It was akin to a shift in planetary alignment–all elements within the model now relate differently to one another. This new family-centered approach required that professionals and parents alike develop new ways to work together. As stated by Vacca and Feinberg:

> The new paradigm requires that early interventionists learn to adapt to the culture and aspirations of the families with whom they work. A unidirectional strategy in which parents are expected to become acculturated to the world of the early interventionist is replaced by a bidirectional system in which both the clinician and family learn from and adapt to each other. (2000, p. 41)

Although a family-centered approach remains the gold standard, it continues to be challenging to implement, plagued by misunderstanding, and in need of further research, especially in relation to family outcomes (Dempsey & Keen, 2008).

WHAT DOES FAMILY CENTERED REALLY MEAN?

Several tenets characterize family-centered practice (e.g., Bailey, Raspa, & Fox, 2012; Baird, 1997; Dunst et al., 1988; Hanson, 1996; Hanson & Lynch, 1995; Lynch & Hanson, 2011):

1. It recognizes parents or primary caregivers as experts on their child.
2. It acknowledges the family as the ultimate decision maker for their child and family.
3. It views the family as the constant in the child's life and the service providers and systems in their life as transitory.
4. It respects and works to support family priorities, their goals for service, and the extent to which they choose to be involved.
5. It values trusting, collaborative relationships between parents and professionals.
6. It works to ensure culturally competent services.
7. It includes a focus on capacity building within the family.

To help implement family-centered programs and services, administrative structures need to be based upon a clear vision, possess an organizational climate that nurtures collaborative teamwork, balance professional autonomy with accountability, and have adequate, flexible resources (Epley et al., 2010). The goals of family-centered practices are to strengthen the relationship between the child and family; respect the family's wisdom, priorities, and culture; and deliver services within the routines and activities that are a part of the family's daily life resulting in meaningful outcomes for both the child and family (Bernheimer & Weisner, 2007; Cambray-Engstrom & Salisbury, 2010; Dempsey & Keen, 2008). Although many professionals and program administrators believe that these characteristics describe their practice and their programs, closer examination suggests that this is generally not the case. Consider the story of Marta that describes service delivery in an approach that is not family centered.

Marta

Marta is 28 months old. Her parents are very concerned because she seems to be regressing instead of progressing in the areas of socialization and communication. Until recently, Marta had seemed to be developing typically. She had said her first words at 12 months in both English and Spanish and had developed a vocabulary that allowed her to name her favorite objects and put two words together. Although she was never as cuddly as her older sister had been, she enjoyed being held and was socially engaging.

The family physician and a university clinic staff member assess Marta and tell her parents that they think that her increasing problems in social interactions and communication place her on the continuum of autism spectrum disorders. They suggest an early intervention program. Marta's mother contacts the program to express her concern and interest. Although the person who answers the telephone is friendly and sounds

supportive, she makes it clear that they only accept referrals from other professionals. Marta's mother must ask the family physician or someone at the clinic to make the referral and send any reports that have been written so that program personnel can determine the appropriateness of the referral before they meet Marta or her parents.

Marta's mother agrees, requests the referral, and has the reports sent to the program. Program staff members decide that it is an appropriate referral but want to conduct their own assessment. In their assessment, various staff members administer various tests, play with Marta, and observe Marta's behavior. The only questions they ask Marta's parents have to do with birth history and developmental milestones. None of the staff members ask them any questions about their immediate concerns, what they have been told up to this point, their observations as parents, or what they need as a family to make this challenging time easier for them.

The program staff members meet and determine that Marta is eligible for services. They develop goals, objectives, and outcomes that they present in a finished-looking draft to Marta's parents at the IFSP meeting. Marta's mother and father were hoping that she could continue to attend the community toddler/preschool program that her sister attends, but the program administrator states that serving Marta in that setting would spread his staff too thin. They need to see Marta at their center 3 days a week. They also emphasize the importance of weekly home visits—something that is difficult for her parents to arrange because of their work schedules. The meeting ends with the staff's suggestions and draft accepted as is, and Marta begins to attend the program. During the subsequent home visits, a staff member demonstrates how to work with Marta. The staff member then leaves activities for Marta and her parents to do together and data collection forms for Marta's parents to complete before the next home visit.

Let us examine this vignette in relation to the principles of family-centered services. In this example, staff members did not recognize the parents or primary caregivers as experts on their child. They required a professional referral and professional reports before talking with the family about their concerns. In the assessment, program staff relied on the administration of various tests, observations, and play activities without soliciting or listening to the parents' concerns and asking about their observations. IFSPs and IEPs are to be jointly developed by parents and staff members. In this IFSP, no opportunity was given for the family's expertise to be incorporated. In fact, when they expressed their desire to keep their daughters together at the program Marta's older sister attends, they were simply told that it could not be done. Finally, the home visits were used only for instruction on the goals and objectives developed by the program. They were not related to any concerns expressed by the parents or integrated into the family's normal routines.

The professionals in this vignette did not acknowledge the family as the ultimate decision maker for their child and family. If families are the decision makers, their referral and concerns should be adequate for program staff to begin assessment for eligibility. Referral from another professional would not be required. Parental requests at the IFSP would have been heeded rather than ignored, and the need for, time, or place for home visits would have been discussed and negotiated.

When families are viewed as the constant in the child's life and the service providers and systems viewed as transitory, every effort is made to incorporate intervention into the daily life and routines of the family. Interventions that create additional burdens are less likely to be continued and less likely to be effective over the long term.

Viewing families and family members as the constant also leads to efforts to build capacity within the family and empower parents for a lifetime of negotiations and decision making related to their son or daughter.

In this vignette, Marta's parents' priorities, goals, and level of involvement were neither respected nor supported. Her parents were never really asked about their priorities and goals. The program staff developed the IFSP outcomes without consultation. The community toddler/preschool program that Marta's parents preferred was ruled out without investigation, and the home visits were conducted as a program requirement while ignoring the parents' concerns.

When programs value trusting, collaborative relationships between parents and professionals, the family-centered principles are not ignored. An ongoing attempt is made to examine practice, consider alternatives, and seek family input to determine ways to improve. Although these staff members may be competent in the technical skills of their professional disciplines, they have not shown that they value family–professional relationships.

To be family centered is to acknowledge, respect, and tailor programs and services to meet the cultural and sociocultural needs of families (i.e., to be culturally competent). In the case of Marta and her family, culture or preferred language was not considered. The service providers made the assumption that there was nothing salient about the family's cultural beliefs, values, or language that would affect intervention. When culture is not broached, it is never addressed, and services cannot be assumed to be culturally competent.

In this example, the program and professionals associated with it were not malevolent people. They did not deliberately bypass a family-centered approach. They were simply operating on a set of principles that are no longer acceptable in intervention, whether it takes place in health care, early intervention for children with disabilities, child care, or Head Start. Failing to provide family-centered services is a serious shortcoming of any program.

Myths and Misunderstandings in Family-Centered Practice

Although family-centered practice is the goal, all too often, programs and professionals have embraced the words without understanding the content. The subsequent sections illustrate some of the myths, misunderstandings, and mistakes that occur when service providers, programs, and policy makers do not fully understand family-centered practice.

Myth: The Role of Professionals Is Diminishing Standards of practice in all fields change over time. They are influenced by research, philosophy, politics, economics, and policy decisions. It is not uncommon for the pendulum of practice to swing wildly from one approach to another in an attempt to align with the current trend. This often occurs before all of the data are in and is often based on a cursory reading and understanding of the underlying principles and goals of the trend. This certainly was and continues to be the case with family-centered practice. In a rush to become family centered, professionals and their skills were initially devalued and their roles disregarded. The children who had been the reason behind the families and professionals getting together in the first place were barely registering on the radar screen. Child-focused interventions were minimized in favor of a family focus. Professionals often misinterpreted critical research (e.g., Able-Boone et al., Summers et al., 1990) on family preferences and needs and asked new or recently referred parents what they wanted or needed without

providing information to assist in decision making. In the absence of accurate information, it is impossible to make an informed decision.

Put yourself in the following situation. Imagine learning that you have a significant health problem. You find the specialists in this field, ask about their experiences with various treatment regimens, and request their recommendations for your particular situation. In this scenario, you would expect the specialists to listen to you, but you would also expect the professionals to share information freely and provide recommendations based on their knowledge of the possibilities, their experience with others with the same diagnosis, and your own unique circumstances. You would also assume that the professionals would use their skills in determining and carrying out your treatment. Few people would stay with a professional who assured them that they could treat themselves effectively but never taught them how.

The same can be said of working with families. By the time families seek professionals for assistance and support because of concerns about their children, they want more than a friendly face. They want knowledge and assistance in putting that knowledge into the family's context–their values, beliefs, strengths, and needs. Any interpretation of family-centered practice that excludes professional knowledge, experience, and expertise is faulty, as is any interpretation that leaves the child out of the picture. Trivette et al. clarified the perspectives on working with families consistent with family-centered practice:

> The model is implemented by practitioners by using capacity-building help-giving practices to have family members identify their needs, the supports and resources to meet those needs, the use of family members' existing capabilities (strengths), and the development of new abilities to obtain resources and supports to meet their needs. (2010, p. 3)

Professionals are vital to effective intervention. Their training, knowledge, skills, and experience complement the family's knowledge of their own child, their preferences and priorities as a family, and their commitment to care over a lifetime. Without equal respect for what each person brings to the relationship, there can be no partnership; this is one of the guiding principles of family-centered practice.

Myth: Only Family Concerns Are Important An extension of the myth that professionals are devalued in a family-centered model of practice is the myth that service providers should address only those issues that the family identifies as important. Thus, if the family is only concerned that the child's behavior is a serious problem, the professional should not mention her concerns that the child may also have a hearing loss. This perspective, in fact, runs counter to family-centered practice. If families are to be the ultimate decision makers, they must be provided with the necessary information to make informed decisions (Able-Boone et al., 1990). If families and professionals are to develop real partnerships, professionals cannot withhold information that they consider to be important. They may consider the family's concerns first and work on one issue at a time, making the family's concerns the first priority; but they should also voice their own concerns and request the family's permission to proceed. Most important, information given to families should be given in capacity-building ways that support their self-confidence and ability to parent and facilitate their learning without threatening their knowledge and ability (Bruder, 2000; Trivette et al., 2010).

Myth: Formal Supports Are Bad Another misunderstanding is that formal supports such as counseling, classes, or workshops on behavior support or agency-organized

inclusive playgroups are inherently bad and should be avoided. Some people prefer formal supports to informal opportunities to learn, receive help, or socialize. One of the guiding principles of family-centered practice is the individualization of services to meet the preferences of diverse families. The definition of early intervention proposed by Dunst, Trivette, and Jodry (1997) included formal supports as part of the mix of supports that families may need.

Consider, again, the earlier example in which you learn that you have a significant health problem. In addition to seeking out the experts in the field, you may talk to friends and family members, attend a support group of individuals who have had the same problem, read articles about the problem (on the Internet, in medical journals, or in popular magazines), and investigate alternative treatments. Each person performing this exercise might do it differently. For example, one person might do one of these things, whereas another person might do them all. It is also likely that the value that each person places on each activity would vary, but all are strategies for learning about the problem and facing it emotionally.

This range of responses is no different for families with a child with disabilities, behavioral challenges, or health concerns. Considerable attention has been paid in recent years to informal support–the marshaling of resources that are part of a family's daily life, such as other family members, friends, neighbors, colleagues at work, and faith communities. These personal networks have been shown to be important resources for families and research has suggested that informal support through personal networks showed the strongest relationship to child and family outcomes (Dunst, 1999). Effective supports, however, may also be direct. They may include structured opportunities for families to participate in learning about resources, their child's disability, and strategies for working more effectively with the child, professionals, and agencies. Although informal supports are important and often make us feel good, they are seldom sufficient to address all of the issues surrounding a child with a disability or serious behavioral problems.

Myth: Only Professionals Must Change A third myth is that for family-centered practice to be effective, only professionals have to change. Rather, for family-centered practice to be achieved, professionals, families, agencies, and policy makers may all have to change. Family-centered practice is not easy to develop or maintain (Bruder, 2000). At a time when an increasing number of families have more complex problems and children have more complicated needs, early interventionists are trying to provide comprehensive, coordinated, family-centered services (Krahn, Thom, Hale, & Williams, 1995). Professionals have had to engage in additional training, obtain new certifications in some instances, and spend increasing amounts of time collaborating with adults at other agencies when they entered the field to work with children. Sometimes all of the effort that professionals have put into retraining themselves has been negated by policy decisions at the state or agency level. The belief that well-trained professionals could singlehandedly make family-centered practice a reality *is* a myth.

Hence, other changes must occur for family-centered practice to be effective. Family members must have the resources and desire to participate in new ways. Participation may vary widely across families and within families over time, but each family must decide on what they want for their child and how they want to be involved in intervention. In family-centered practices, services vary. Service providers do not assume that a service that is helpful for one family is equally helpful for another. Customizing services

requires that families put forth additional effort to make selections that they consider best for their child and family and that professionals work to ensure that customized services are integrated. Just as implementing a specific teaching strategy or behavior change technique takes learning and time, so do making decisions about priorities, formulating long- and short-term objectives, and monitoring outcomes.

Agencies and policy makers must also change if family-centered support is to become the norm. The current emphasis that some intervention programs place on offering a menu of services as opposed to integrated programs in early intervention has some serious, negative consequences. As McCollum articulated so well when discussing the fee-for-service approach to early intervention,

> The consequences have been a return to fragmented services at the level of the child and family and less opportunity for collaboration among professionals working with each child and family. It has become much more difficult for service providers of all disciplines to be "family-centered," to embed their interventions within the contexts of families' daily lives, and to integrate their interventions with those of other professionals in recognition of the integrated nature of early development. (2000, pp. 85–86)

Until the entire system can be designed to facilitate family-centered services, the burden will continue to fall on those closest to the issues–families and direct-service professionals.

Avoiding Myths and Misunderstandings Each of these myths, misunderstandings, and mistakes can be overcome. At its simplest level, family-centered practice is providing supports and services that the family desires and values to enhance child and family outcomes within a respectful partnership between families and professionals. If practice is guided by this definition, myths and misunderstandings are likely to decrease.

FAMILY AND PROFESSIONAL ROLES AND RELATIONSHIPS

This section focuses on power, becoming empowered as a parent, and the variables that families and professionals identify as important to effective collaboration.

Power and Becoming Empowered

In most situations in which families and professionals interact, power is a factor–and professionals hold considerable power over information, possibilities, and outcomes of the interaction (Jenkins & Sullivan, 2011). Their power comes from real and attributed knowledge, the power of "the system," and long-held assumptions that the system cannot be critically questioned (Seligman & Darling, 2007). This has certainly been true in systems of care and education for children with disabilities and their families. Interventions in the not-so-distant past tended to focus on direct, hands-on, professional intervention with children. Parents were considered secondary in the treatment or intervention and were generally expected to follow directions dictated by professionals. Parents were provided with parent education opportunities typically designed and taught by professionals. Very often these opportunities focused on what professionals wanted parents to do rather than on what parents wanted to learn. As discussed in earlier sections of this chapter, this approach would not be considered to be family-centered.

From its inception, one of the guiding principles of a family-centered approach is empowerment (Dempsey & Keen, 2008; Dunst et al., 1988)–in other words, the skills

needed to recognize family needs, find ways to get those needs met, and effectively plan and negotiate their implementation. Proactive empowerment through partnerships, described by Dunst (1985), included three tenets that emphasized 1) family strengths rather than deficits in early intervention practice; 2) family control over services rather than dependency-producing, disempowering practices; and 3) collaborative rather than professional-centered practice. These principles not only spawned considerable research but also became guiding principles in family-centered practice.

Empowerment in its most basic form is providing the tools that individuals need to gain access to services and make decisions about them. Empowerment enhances capability. To be empowered is to have the information and sense of personal competence necessary to advocate for oneself or someone else. Thus, for family–professional partnerships to flourish, balancing the power between families and professionals is critical to success. Being passionate about an issue does not necessarily empower individuals to do something about it. Empowerment often requires some coaching. Many families may need information and support to become empowered when it comes to issues involving their children. Part of the role of the professional in family-centered services is to help family members become empowered–to engage in capacity building–to ensure that families and professionals recognize that each comes to the relationship with different but equally valued knowledge and skills (Trivette et al., 2010).

Although providing the tools and support to assist family members to become empowered is a cornerstone of family-centered services, it is a concept that does not resonate equally with families across cultures. In a pilot study comparing African American and Latino mothers in Southern California with white, non-Latino parents of children with disabilities in Australia, issues of disempowerment and empowerment were clearest to the African American mothers (Hall, Lynch, Macvean, & Valverde, 2000). Many had had experience with the Civil Rights movement and were very aware of the parallels between the need to feel empowered as black women as well as mothers of children with disabilities. The Latino mothers interviewed had not had similar experiences, and empowerment and disempowerment were not terms that were familiar to them. Even when these terms were translated conceptually rather than literally, Latino mothers were less able to describe situations related to their child in which they felt a sense of competence and control rather than a sense that they had no control.

Because of the importance of issues of empowerment within a family-centered framework, cross-cultural work on empowerment needs to be pursued. Approaches to empowerment that conflict with cultural and sociocultural beliefs and approaches to interaction are, by definition, disempowering (Lynch, 2011).

Variables that Support or Interfere with Collaborative Partnerships

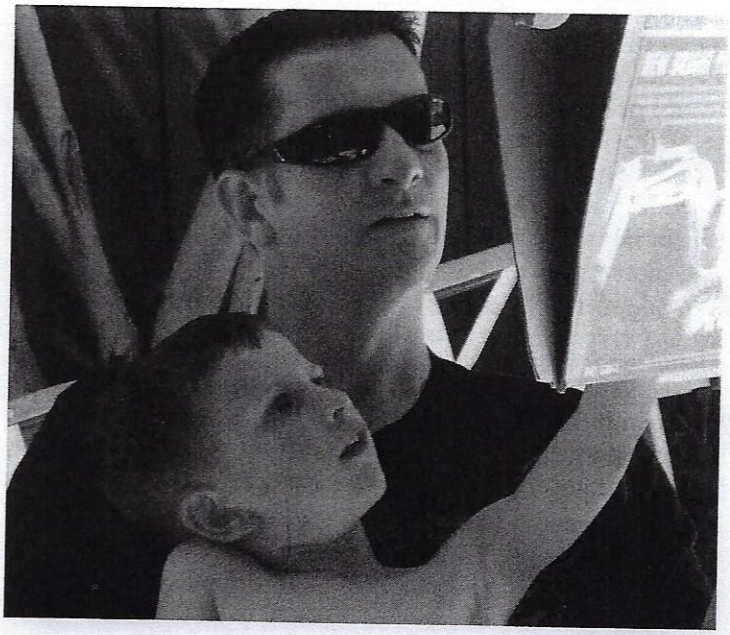
Professional and Family Variables In a large, national study of families and professionals, the variables that families and professionals bring to interactions were examined to determine which variables support and which hinder collaboration. Five categories and one subcategory of variables important to collaboration for both families and professionals emerged (Dinnebeil, Hale, & Rule, 1996). The categories included the following:

- Dispositions/personal and family characteristics
- Philosophical beliefs and attitudes

- Ways of working together
- Knowledge base
- Outside influences

The subcategory of putting beliefs into practice was an amalgamation of philosophical beliefs and values and ways of working together. Dispositions and characteristics were important to both family members and professionals. Being optimistic, friendly, open-minded, and caring were considered to be important traits. When the sociocultural and lifestyle match between professionals and families was missing, it was more difficult to collaborate. Philosophical beliefs and values contributed to or interfered with collaboration. Family-centered practices such as trusting, being nonjudgmental, respecting, and accepting differences contributed to effective collaboration, as did positive beliefs about disabilities. Some families thought that the professional's willingness to be involved as a friend was helpful; however, not all service coordinators felt that friendship enhanced the collaboration (in this study, the professionals were service coordinators). Ways of working together that supported collaboration included open communication, honesty, tact, establishing a positive atmosphere, and using expertise to share information and model ways of working more effectively with the child. Although the importance of the professional's knowledge base was mentioned fewer times than dispositions and philosophical beliefs, it was nonetheless considered important by family members.

Knowledge of disability, strategies, and resource information contributed to collaboration, as did cultural knowledge and the ability to communicate in the family's language. Outside influences, such as scheduling constraints, size of caseloads, limited options for service, and so forth were also identified as barriers or facilitators, when the constraints had been overcome, of collaboration. These influences were considered to



be very important to effective collaboration, but they were not considered to be under the control of families or professionals. Additional influences such as bad weather, distance from services, lack of resources, lack of transportation, and lack of opportunity for staff to be trained in collaboration were also identified. It is interesting to note that issues such as scheduling and availability of services were considered to be outside the control of professionals and parents alike. Given a model that supports empowerment, it would seem that professionals would begin by working to change the system to more satisfactorily accommodate family needs. The subcategory, putting beliefs into practice, showed that professionals "practiced what they preached." They scheduled appointments that were convenient for families, kept appointments, respected families as decision makers, and supported approaches to service that allowed families to live more normal lives.

A qualitative study by Brotherson et al. (2010) examined the extent to which parents' and professionals' emotional needs were met in an early intervention program using a home visiting model. They found that the emotional needs of both parents and professionals mutually influence the effectiveness of partnerships between parents and professionals. As in any relationship, when the emotional needs of both parties are congruent, there is greater satisfaction with the relationship. When they are not congruent, there is less satisfaction. This mismatch of emotional needs can play out in many ways when professionals and family members try to work together. In the study, researchers found that parents of children with disabilities often felt a sense of urgency and a sense of hope related to their child's disability. They urgently wanted to find answers and solutions to their child's problems, and they felt hopeful that this would occur. In most cases, these emotional needs were congruent with those of early intervention professionals. They, too, were eager to find the answers that parents wanted and felt that together they would succeed in finding answers and solutions. However, when professionals had a sense of urgency that parents did not share, professionals became frustrated because of what they perceived as parents' lack of follow-through (Brotherson et al.). As this study suggests, both professionals and parents are emotionally involved in providing services. Although professionals typically maintain some distance from the families that they serve and have boundaries that are part of their profession's code of conduct, there is always some degree of emotional involvement with each family and each family member.

A case study approach was used to determine the characteristics of professionals that lead to effective collaboration; five themes related to interpersonal interactions as well as two themes related to knowledge of children emerged (McWilliam, Tocci, & Harbin, 1998):

- Having a family orientation
- Being positive and viewing the family in a favorable light
- Sensitivity to the family
- Responsiveness or willingness to do what needs to be done
- Treating parents as friends
- Child and community skills, which included knowledge about disabilities and methods for interacting with and teaching children and integrating their work into the larger community

Although many would seek the majority of these characteristics in their search for a competent and understanding professional, the one area in which these descriptors and professional preferences may depart is in the area of friendship. Throughout a professional's career, many parents become friends, but a professional is neither trained nor encouraged in training to develop friendships with the families they serve. McWilliam et al. (1998, p. 215) acknowledged this difference in expectations and suggested that many professionals would "be more comfortable with the *friendly professional* stance than with a *professional friend.*"

In a study of parents' and professionals' perspectives on services needed and services provided, professionals were enthusiastic about their family-centered practices but families reported that they were receiving less than a quarter of the services that they needed (Filer & Mahoney, 1996). Worth noting is that families rated child-level activities provided by early intervention programs as more important than family-level activities. Professionals reported substantially greater needs for service in four out of five categories than parents reported. Professionals felt that families needed 1) more information about their children and how to interpret test results, 2) additional support in preparing for the child's future and advocating for their son or daughter, 3) ways of coping with their child and getting support, and 4) assistance in finding resources or services. The findings of this study are particularly interesting because of families' emphasis on more direct assistance to the child. This certainly does not suggest that family support services are not critical to families. What it does indicate is that a truly family-centered model determines what families believe is most important and builds services on that basis. For these families, the most important support would have been more services for their children such as child care, therapies, and medical treatments.

In a small, qualitative study of the practices within home visits, Cambray-Engstrom and Salisbury (2010) found that joint interaction between the home visitor and mother led to greater participation among Latina mothers. In joint interaction, both the home visitor and mother worked with the child as partners, and the home visitor gave no explicit feedback. The researchers hypothesized that joint interaction may have provided a sense of equality in the interaction because the professional does not try to direct or influence the parent. As a result, parents may have felt comfortable participating more freely. Because the study included only 10 mothers and was limited to Latinas, the findings cannot be generalized. It may, however, provide a springboard for further research on specific practices that encourage family-centered interactions and perhaps an affirmation that the sense of parent–professional friendship is valued by some parents and families.

Program Variables A study by Dinnebeil, Hale, and Rule (1999) that examined family and professional variables influencing collaboration also investigated program variables that support or interfere with collaboration. More collaborative programs had a philosophy and climate that supported collaboration, operated within a community context, used a team-based approach, implemented policies and procedures conducive to collaboration, and delivered services in ways that demonstrated that collaboration was valued. A subcategory was qualified personnel. Respondents frequently addressed the importance of having well-trained personnel with good communication skills. These findings suggest that program-level decisions, procedures, and processes influence the collaborative process and set the tone for developing partnerships.

The study of Latina mothers' participation during home visits suggested that joint interaction increased participation (Cambray-Engstrom & Salisbury, 2010). The

researchers also suggest that the following program components were also critical to the collaboration between parents and professionals: administrative support, ongoing staff development and training, reflective practice, and an intraagency community of learning.

Synthesis These studies provide an extensive list of professional, program, and family characteristics that support family–professional alliances. They also describe characteristics and behaviors that are not conducive to cooperation, collaboration, and partnership. It is clear that the ability to establish and participate in trusting relationships, communicate effectively, and respect families' roles and responsibilities as the ultimate decision makers for their child and family is critical. It is equally clear that possessing knowledge and skills related to children with disabilities, working within the context of the family and community, being positive and open-minded, and following through on promises contribute to effective collaboration with families. Professionals who are perceived to be dishonest with families, do not share information fully, do not respect family roles and responsibilities, display negative attitudes toward families or their job, and are not well trained for their jobs are not able to form collaborative partnerships. Though based on research, these findings are almost intuitive. In any relationship, respect, positive attitudes, and honesty are critical elements. In programs and services for families, they are essential.

Program variables also help or hinder collaboration. Even the most highly trained and experienced service provider can appear noncollaborative when working within agency policies and procedures that do not support collaboration. Putting all interactions "on the clock" in fee-for-service systems, working only during traditional hours, following required assessment protocols that minimize family input, or refusing needed services in order to underspend the budget in an effort to look good to superiors can make the most family-centered professional look bad. A family-centered professional would also use his or her skills and creativity to help change the system to make it more responsive to families and children rather than simply view the complaints as unsolvable problems, however.

In most of the literature about family–professional collaboration, the emphasis is on the characteristics of professionals and systems and how they can change to enhance family–professional collaboration. This is appropriate in that it is the job of the professional to be the collaborator, to meet families "where they are," and to support family goals and priorities—often not easy tasks. Parents and families sometimes have characteristics that interfere with collaboration and partnering. Dinnebeil et al. (1996) identified certain lifestyles, personality traits, attitudes, and a lack of communication skills as family characteristics that make collaboration extremely difficult. In a study of more than 350 families, Mahoney and Filer (1996) found that families with the most positive characteristics, such as enough time and resources, positive family functioning (cohesion, control, expressiveness), and the interpersonal skills to negotiate the system, received the most services. These findings, if they can be generalized, are not surprising, but they are troubling. They suggest that families with the greatest needs may be the least well served. Families that do not function well, those that lack the skills to navigate the system, and those that do not have the time to be involved may be in double jeopardy. They have more problems at the outset and are receiving less help in resolving them. Considering the numbers and range of families that this might include—teenage parents, families whose primary language is not English, those who are living in poverty, families

with mental health problems, and families who have problems with substance abuse, addiction, and violence–the findings suggest that family–professional collaboration is far from reality in many situations.

Some data are promising, however. Unger, Jones, Park, and Tressell (2001) studied the involvement of low-income, single caregivers in an urban environment. Most of the 104 caregivers who participated were African American, lived alone, and were the biological mothers of the children being studied who were attending an early intervention program. In this study, caregivers who were stressed, had difficulties with family functioning, and were less knowledgeable about child development were more likely to become involved with the program. Their involvement was predicated on a welcoming climate and teachers' efforts to reach out to them.

No family will like every professional equally, nor will professionals resonate with each family in the same way. People respond to different characteristics in different ways. Individuals are inexplicably drawn to some people and not to others. It is the professional's responsibility to provide the same level of information, support, and energy to all families, however. For those who have worked with challenging families, the concern is usually that as professionals they have done everything they can do, but the family "continues to miss home visits," "doesn't follow through," "is so involved in their own issues that they have no time for the child," "doesn't have the skills/ability to parent effectively," "is unrealistic," or "wants everyone else to do the impossible but doesn't want to do anything themselves." All of these may be true, but it is the role of the professional to continue to meet the family "where they are" and to work to support the family and the child. When should a professional give up? The answer is never, where the child is concerned. When a professional feels that she or he may be endangered by continued interaction with the family, however, it is time for a change. Concerns about safety for the child, another family member, or oneself should be immediately reported to supervisors and any other authority or agency determined by state law and program policies.

In addition to families with limited resources, difficult circumstances, and inadequate interpersonal skills, there are families whose resources to challenge the system seem unlimited. They are often knowledgeable, articulate, and well defended (personally and with advocates and attorneys). They typically get what they ask for. For many of these families, the concerns are centered on the needs of the child and the families' willingness to go to any length to obtain what is necessary to improve functioning, opportunity, and daily life. For others, challenging systems has become a way of life. Being litigious in every interaction is one way of gaining power in a situation that one is powerless to change, such as having a child with a disability. As difficult as it is to work effectively with these families, it is essential to try and try again. If the energy that they spent fighting for their son's or daughter's needs could be used to effectively change the shortcomings of service delivery systems, they could be professionals' most important allies.

Research guides the thinking and practice of professionals. It provides data that define best and promising practices and evidence of approaches, models, and services that are effective and those that are not. It, along with professional ethics and codes of conduct, is foundational to working effectively with children and families. But there is something more. Every interaction with every family adds a little more knowledge to a professional's skills and understanding. When a professional is truly listening, families will tell you what they need and how they would like to join the partnership.

BUILDING FAMILY–PROFESSIONAL ALLIANCES

Considerable work remains in evaluating parent/caregiver involvement and family support in programs for young children who are at risk or who have special needs (Bailey, 2001). Although research continues to provide data that enables professionals to refine family-centered practices, until more comprehensive evaluation has been undertaken, professionals must rely on what is known about models and practices that support family-centered practices. Several of the studies discussed in this chapter suggest that family–professional collaboration requires more than a positive attitude or philosophy about the role of families in service delivery. Collaboration requires that these attitudes and philosophies be put into practice. This section describes promising and proven models and strategies for putting collaboration into practice.

Every interaction between a family member and a professional supports or interferes with collaboration. Whether the interaction is face to face, on the phone, in an e-mail or text, or through a form that has been mailed, it influences the likelihood of collaboration and alliance building. Therefore, interactions, procedures, and policies must be examined to determine the extent to which they facilitate collaboration or act as barriers. The systems-level issues are in some ways the easiest because they often do not require a change in personal behavior or a retooling of interpersonal skills.

Making Policies and Procedures More Family Centered

Almost all organizations have policies and procedures that are not customer friendly. Whether it is the registration process at a university, duplicate questions on health information forms, or the policies and procedures in an agency serving children and families, there is always room for improvement. One method of examining policies and procedures within programs and agencies is to invite a task force of parents to examine the policies and procedures to determine how they affect collaborative partnerships. The charge to the task force should be clear with timelines attached and should indicate that the program is committed to making its approach to services more family centered. It should also indicate that every concern identified will be considered and task force members will assist in sorting and prioritizing the concerns that they identify. In creating such a task force, it is important to remember that because it will take time and energy—time and energy that some parents may not have—there should be no pressure to accept the invitation. Developing multiple levels of involvement such as participating online, responding to a short survey, or reviewing the group's work during the process may make it easier for some parents to participate.

Staffing the task force with a professional who can act as an administrative assistant may be helpful, but it is important not to overload the group with professionals and administrators at the beginning. Those who have been involved in such groups know the temptation of administrators and program professionals to defend policies and procedures whenever they come under scrutiny. Although resolving issues jointly is a critical part of collaborating and developing alliances, identifying policies and procedures that inhibit collaboration may be something that should begin with families working together, apart from professionals, so that families will not have to work through their concerns *and* professional defensiveness.

In the second phase of the process, several professionals (including a program administrator) can join the task force. Family members should be in the majority, however. At this point, the initial charge should be restated and elaborated. The task of this

expanded group is to sort and prioritize the concerns. Sorting may be done along a variety of dimensions. One approach is to sort by categories such as "can make changes internally," "requires external approval," and "cannot be changed because of regulation or law." The last category should have few, if any, items. Policies and procedures are often designed to enact law, but there are many ways to conform to law more creatively. Another approach to sorting is by the strength of families' concern. These categories might include "serious deterrent to collaboration, needs immediate attention," "needs to be changed but is not an immediate priority," and "room for improvement." Another approach to sorting and prioritizing concerns is to put issues into the component of the program that they involve. For example, problems might occur at intake, initial assessment, program planning (IFSP or IEP), intervention, progress monitoring, and transition. Although this categorization can be helpful, issues may overlap and it may place greater emphasis on child-level rather than family-level services. These approaches are simply illustrations. The group may have other ways of organizing and prioritizing concerns. The important piece is that the group develops priorities, action plans, and timelines.

In the third phase, those responsible for the action plan report periodically to the task force on their progress. Although it may ultimately be the administrator's responsibility to make changes, family members on the task force and others should be part of the process. For example, if the intake paperwork is determined to be unfriendly to families, task force members and other families should be involved in the revisions, assist in field tests of new forms, and give approval for the new and improved version.

Processes like the one described take time and energy. To be effective, the process must be authentic and result in change. Any process that is, or is perceived to be, a sham only makes matters worse. Nothing leads to the perception of deception more than filling a task force with the program's most supportive parents. Always include parents that the team would rather not include and listen carefully to what they say. Regardless of the time and energy involved, processes like this result in improved policies, procedures, and collaborative relationships. As family members gain ownership over program policies and procedures, the possibilities for partnerships and alliances increase.

Creating Parent-to-Parent Programs

Although this book focuses on professionals who work with children and families, professionals are not the only (or sometimes the best) people to work with a family. There are times when another parent with special training can provide the most support, assistance, and understanding: strategies for sharing information about your child's disabilities with neighbors, techniques for soothing a child in pain because of chronic health problems, how to have a successful trip to visit grandparents with a child with autism, or the best place to find reasonably priced clothes for a premature infant–many families face all of these issues and many more in daily life. Working on specific goals and objectives, teaching and learning from professionals, and having programs and services that provide help and support are important in the lives of most families of children with disabilities. There are, however, countless times when a conversation with another parent who has faced the same issues is more valuable than anything that professionals can offer. Other parents can often help bridge language and cultural differences in programs in which staff members are not as diverse as the communities being served. A Somalian parent, in some instances, may help another Somali family access and use services more effectively than any of the professionals on staff.

There are ways to create opportunities for parents to have access to other parents who have experienced similar joys and problems. One strategy that programs can use is to partner with community or state parent-to-parent organizations. These groups can link trained parents to novice parents face to face, on the phone, or online. Another way is to have one or more paid parents on staff. They can serve as the program's link to program and community resources. In some instances, they may even be the first point of contact with new families. In other instances, they would be available as requested or needed. Whatever strategy a program uses, having trained parents available to work with families and help professionals understand family concerns is one of the hallmarks of family-centered practice.

Encouraging Family-Centered Interactions

Changing the system is sometimes easier than changing individuals within it. Family-centered practice relies on the knowledge, interpersonal style, and commitment of the professionals who see families every day. Policies and procedures that are models of family-centered practice do not make up for the actions and interactions of a single individual who believes that families really do not know what is best for their children. Therefore, it is critical for new professionals to be well trained in family-centered principles and for veteran professionals to have opportunities to reevaluate their practices.

Focusing on What Services Families Want and Need

In 2006, a summit on the next steps in creating family-centered services was held at the Beach Center at the University of Kansas, Lawrence. The purpose of the summit was to create a vision for the future. Attendees agreed that the focus of family-centered practice had been on *how* to deliver family-centered services and not on *what* services should be available to children and families. In other words, there has been considerable attention given to the way in which professionals honor parent preferences, interact with families, establish partnerships, and so on. The emphasis has been on helping professionals develop interpersonal skills as opposed to developing the range and types of services that meet families' needs. The overriding theme of the summit was the need for the field to develop a conceptual framework of the types of services and supports that early childhood professionals should have the competence to provide and early childhood programs should have the resources to deliver (Turnbull et al., 2007). Although developing interpersonal skills should continue, the recommendation to attend to the development of needed services and the competence and resources to provide them is a critical next step in improving family-centered services.

Providing Preservice Training

Perhaps the greatest shortcoming in training programs for professionals entering family/child service fields is the lack of interaction with parents of children with disabilities. Although students typically take courses on working with families, are able to faultlessly recite the literature on family-centered practice, and have typically heard presentations by parents and other family members in their classes, few have been trained by parents or alongside parents in their classes. When such training opportunities do occur, they produce some remarkable benefits for students and parents alike (McBride, Sharp, Hains, & Whitehead, 1995; Murray & Mandell, 2006). The authors of this book have

had multiple experiences that confirm the value of this model–having a parent as a facilitator in a class on working with families, having students in class who were also parents of children with disabilities, and requiring assignments that pair students with families in a nonprofessional, helping capacity. In each situation, the parent perspective increased dialogue and reflection and enhanced professional understanding. One of the most important and needed changes in preservice training is creating structures that enable faculty to align their instruction with the family-centered, interdisciplinary demands of early intervention (Stayton & Bruder, 1999).

Providing Ongoing Professional Development

Since the early 1990s, intervention programs across disciplines and throughout the country have put considerable emphasis on training staff members to be more family-centered and collaborative. Because of these efforts, changes have been made. In any profession, however, ongoing opportunities to learn, reflect on practice, develop new skills, and hone old ones are necessary. Knowledge about collaboration and alliance building is not new, and it is unlikely that anyone currently in a field that focuses on children and families has not been exposed to it. Each professional's skills in developing family–professional collaboration varies, however. Much of what is required is based on interpersonal skills, and the characteristics and behaviors that support collaborative partnerships are well documented in the research reported earlier in the chapter. Based on what is known, the following are important to effective collaborative partnerships: friendliness, optimism, patience, sincerity, open-mindedness, caring, trust, respect, commitment to the relationship, effective communication, responsiveness, willingness to share and disclose information, honesty, tact, a positive climate, flexibility, and knowledge (Dinnebeil, Hale, & Rule, 1996). Others also include empathy and an attitude of humility (Jones, Garlow, Turnbull, & Barber, 1996). The question is, can these skills and behaviors be taught? The answer is yes; these are behaviors that can be taught and learned, but what is equally important is that the underlying attitudes and beliefs exist within professionals who work with families. If that is not the case, the Japanese proverb will be affirmed: "Sooner or later you will act out what you really believe."

These characteristics and behaviors can be put into practice in every component of service delivery. They are part of getting acquainted with families and their children (intake), learning about the child as well as the family's values, strengths, and needs (assessment/diagnosis), jointly deciding on and planning services (IFSP/IEP/treatment), jointly reviewing progress and evaluating outcomes (monitoring progress), and assisting the family as they make plans for the future (transition). At every step in the intervention process, professionals have the opportunity to collaborate, form partnerships, and develop alliances with families.

PROGRAM EVALUATION AS A KEY TO FORMING FAMILY–PROFESSIONAL ALLIANCES[1]

The most thorough approach to determining the effectiveness of any program is to conduct a program evaluation. Comprehensive program evaluation involves periodic assessment preferably conducted by independent, external evaluators as well as ongoing

[1]The section on "Program Evaluation as a Key to Forming Family–Professional Alliances" is based on a chapter by Patrick Harrison (1995) and is used with the author's permission.

assessment by stakeholders (e.g., those who receive services, those who deliver services, agencies that work with the program, and the agency or organization that sponsors the program or services). In many settings, resources are not available for external evaluators, and the program administrator is tasked with evaluation. Perhaps the majority of evaluations conducted in settings that serve children and families focus on satisfaction: Are recipients satisfied with the services that they received? Although this is an extremely important component of evaluation, it is far from comprehensive evaluation. Comprehensive evaluation also asks questions related to implementation, resources, outcomes, philosophy and validity of practice, cost, and unplanned outcomes.

Implementation Questions

Implementation questions focus on how the program is being carried out. All programs begin with stated or unstated goals, objectives, and management plans. There is typically a target for the number of assessments that will occur, the number of children and families to be served, and the type and number of contacts such as home visits, consultations, or clinic visits. Implementation questions examine what is occurring compared to what was planned. If there are differences between the plan and reality, the evaluation seeks to determine what those differences are and why they have occurred. For example, a fully integrated, private preschool program opened 3 months ago in the community. Based on the projected need, classes should be full, but they are not. Surprised by this, the administrator decides to focus on implementation questions in her interim evaluation. In this she learns that far more families than expected have applied to send their children to the preschool. As a result, the entry assessments are behind schedule, creating a bottleneck in accepting and assigning children to classes. What appeared to be a situation in which the program was running seriously under capacity was in fact a miscalculation of the time and personnel that would be needed to make the program fully operational.

Resource Questions

Resource questions, as the name suggests, focus on the elements needed for the program or service to function effectively. Resources for programs and services for children and families typically include personnel, materials, space, equipment, supplies, transportation, insurance, and so forth. Having the necessary resources does not ensure that programs and services will be of high quality, but lacking significant resources can cause a program to be inadequate or fail. Consider a program in a remote, rural area developed to serve children with disabilities and their families. Many families live 60–80 miles from the program's center. Although home visits are the primary way in which services are delivered, the program also includes periodic center-based activities so that families can come together. The program provides a mileage stipend for families as well as breakfast and lunch. In the past, these events have been very well attended, but recently the attendance has dropped sharply. Concerned about this, the program administrator decides to conduct an evaluation of program resources to try to determine if their resource issues are part of the problem. The findings of the evaluation are clear. The attendance dropped off as the price of gas increased and the mileage stipends did not change. Many families felt that they could no longer afford the gas for the long drive. The administrator immediately increased the mileage stipend and at the next (well-attended) event asked participants if they would be interested in other ways of meeting with other families (e.g., video chats, creating a group on a social networking site). The families

were not only happy about the increased stipend but several were very excited about the online opportunities.

Outcome Questions

Providing programs and services is, in itself, not enough. They must be effective, and outcome questions provide data on their effectiveness. In programs and services that are family centered, it is important to ask questions that focus on family outcomes as well as the outcomes of children being served. Are families given the opportunity to be full participants in the programs and services being offered? Are families meeting the goals that they set for themselves? In what ways are parents and families collaborative partners? These and similar questions would provide data on outcomes.

Imagine that a therapy service in the community believes that it has organized its services to be family centered, but they would like to learn how families experience their services. They conduct an evaluation of their outcomes. In addition to examining clients' progress on their speech and language, physical, and occupational therapy goals, they ask families to participate in a short interview or complete a written or online questionnaire about their perspectives on their involvement as partners in their child's therapy programs. The findings of the assessment are mixed. The majority of children seem to be making progress, but families report that they are involved in only limited ways. They are given handouts with directions for doing exercises at home and they can request therapy on a specific day of the week, although few report that their choice was honored. None reported that they had been asked what their therapy priority was. Finally, 97% of the families were satisfied with the services, but none reported that they felt an integral part of those services. The therapy program learned that their definition of family centered was far from that of the families that they served. They now have enough information to take the next step and learn what they might do to become more family centered. This is a good example of a common situation in intervention programs. Recipients of services, especially in programs for young children with disabilities, often report satisfaction with services they receive even when those services are not congruent with best practice.

Philosophy and Validity of Practice

Programs and services may satisfy families and the professionals who offer them, but they may not always reflect current knowledge, research, and best practice in the field. In ongoing programs that operate under numerous rules and regulations and many demands for service, there is seldom time to reflect on practice, review new research, and ensure that the program is doing a good job at the right thing. For programs and services to be good, they must be based on evidence that supports their validity. This is one of the most challenging forms of evaluation because it asks each person, team, and administrator to examine long-held beliefs and established practices. In essence, everything about the program or service must be open to minor or major revision.

Consider a program that has been in the community for many years. They have an excellent reputation and are very well schooled in their approach to serving children with reading problems. As part of their 25-year celebration of offering assessment and tutoring services in reading, they decide to conduct a comprehensive evaluation that includes all of the types of evaluation questions described in this section of the chapter. With one exception, the data that they collected were very positive. They learned from a review of literature on teaching reading to struggling readers that the method that

they use does not result in the best outcomes. New studies of learning, the brain, and methods suggest that at least two other approaches have better results. Program staff and administrators are shocked; however, after careful scrutiny, it is clear that the evidence for the effectiveness of their approach is not there. It will be challenging in every respect, but they decide that they must retrain themselves and reorient their approach to one that is educationally valid.

Cost

Few programs and services are funded to the extent that they would like, but cost is a major consideration for administrators, legislators, and taxpayers. Evaluations of cost-effectiveness range from those that tally the expenditures for the program or various components of the program and divide by the number of individuals receiving services or the number of services provided. Cost-effectiveness and cost-benefit analyses are much more complex and have to be conducted by professionals with special expertise in that area of evaluation. At the most simplistic level, a program might want to determine the costs of providing bus transportation to its clients versus providing taxi vouchers. In determining the costs, the evaluator would need to determine the costs of purchasing or leasing buses, hiring drivers, maintaining buses, insurance, and so forth. The same kinds of calculations would be made for taxi vouchers. In addition to projected costs, the evaluation might also include other issues related to accessibility, client preference, safety, availability of taxis, and so forth. This combination of monetary and quality of service issues would help to make the decision about the kind of transportation that the program should use.

Unplanned Outcomes

One of the major questions that a program administrator, legislator, or community members may want to have answered is: What is happening as a result of this program? Although this question is less precise than those described earlier, it is an important question that may yield data about unplanned outcomes. Imagine a community that has successfully implemented a family-centered program for infants and toddlers with and without disabilities. The program has operated for over 10 years and has been so well received that the state would like to have it replicated in other communities. As part of a comprehensive evaluation that the state commissions, program description questions are included. The findings indicate that many unplanned outcomes have resulted from the integrated infant/toddler program. As a result of their experience in this program, parents have advocated for parks and recreation programs to be inclusive and serve children with and without disabilities together. A charter school has been developed that is also based on inclusive principles. Families of children with disabilities who attend the infant/toddler program and the charter school have not filed any complaints about their son or daughter's special education services whereas complaints from families in other programs have risen. Finally, in the charter school, general and special education teachers work as teams with each sharing loads and responsibilities. In other elementary schools, general and special education seem to be separate, unintegrated entities. This data suggests that the approach has resulted in many positive but unplanned outcomes.

Satisfaction

As mentioned initially, many programs and services assess the satisfaction of those that they serve. These data are valuable to both administrators and staff members and

provide guidelines for improving services. As can be seen from the previous paragraphs, however, satisfaction data do not provide adequate information. In life, people often are satisfied with things that could and should be much better.

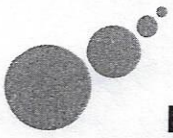
Evaluation is critical to all programs and services to ensure that they meet the standards that parents and children deserve and professionals want to provide. Evaluation data can also yield information about how family centered a program or service is. From this data, programs and services can be refined to optimize their effectiveness.

ETHICAL CONSIDERATIONS

Ethics are the principles that underpin our beliefs and behaviors. At the macro level, they help frame law and policy decisions. At the micro level, they guide daily interactions. Often referred to as moral principles, they may be grounded in religious, spiritual, legal, or utilitarian beliefs. One's personal beliefs are always consciously or unconsciously part of decision making; however, for professionals working with families, professional codes of conduct and legal requirements must supersede personal beliefs. For professionals, ethics may be thought of less as moral principles and more as core values, beliefs, and related legislation. Each professional discipline has its own ethical standards and code of conduct, but at the root of each is the phrase attributed to the Hippocratic Oath: First, do no harm. In all interactions with families, this phrase should be the starting point for assistance and intervention.

In professions that focus on working with children and families, codes of ethics often include principles such as respect for individuals, family units, and their diversity; evidence-based practice; acceptance of responsibility; advocacy; professional collaboration; family empowerment; confidentiality; and personal integrity. These, along with compliance with the law, legal mandates, and appropriate research protocols if research is being conducted, comprise the bulk of most codes for early childhood (National Association for the Education of Young Children, 2005, April), early childhood special education (Division of Early Childhood, 2009), social work (National Association of Social Workers, 2008), psychology (American Psychological Association, 2010), health and related health care professions (e.g., American Medical Association, n.d.; American Nurses Association, 2001; American Physical Therapy Association, 2011; American Speech-Language-Hearing Association, 2010; American Occupational Therapy Associations, 2010) . When professionals receive their certification, credential, or license, they agree to abide by the profession's code of ethics.

Although codes of ethics and conduct provide a framework and general guidelines, they do not always provide answers to questions that professionals may have about specific situations. The scenarios that follow illustrate some of the situations that may pose dilemmas for professionals in their work with children and families.

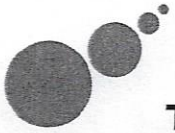


Bart's Family

Bart is 4 years old. He is able to read kindergarten books. He is also obsessed with spinning toys and has very limited interaction with other children and adults. Bart's parents believe that he is gifted. Bart's teacher has acknowledged his strength in reading but

expressed concern about his difficulties with social interactions and his focus on spinning objects. On several occasions, she has talked with them about autism spectrum disorders and suggested that Bart be assessed to determine his needs. Bart's parents believe that his inattention at preschool, obsession with spinning toys, and limited social interactions are further evidence that he is highly gifted and bored by preschool children and class activities. Bart's preschool teacher is very fond of both Bart and his parents but feels that they are denying his problems and failing to get the kinds of services that Bart needs to make progress.

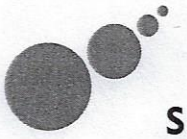
In the scenario presented in this section, Bart's teacher's ethical dilemma concerns balancing what she believes is best for Bart and her respect for the parents' perspective and opinions. She does not want to push Bart's parents, but she also wants to ensure that Bart is not being deprived of services that would be helpful to him. If you were Bart's teacher, what do you think you would do? Why?



Tyler's Colleague

Tyler's colleague, Josh, has been very late to several recent meetings at the clinic; over the past 6 weeks, he has said very little and seemed detached from clinic activities and his responsibilities. Much of the time, Josh just does not seem to be paying attention. Typically very neat and tailored, Josh has frequently appeared disheveled in recent weeks. Yesterday, Tyler had some private time with Josh. Over coffee, Tyler mentioned that lately Josh had seemed preoccupied and wondered whether there was anything that he could do. Josh became defensive and claimed to be fine.

Tyler's ethical dilemma is whether or not he should share his concerns about Josh with their supervisor. Although he does not want to cause any problems for Josh, he also does not want to ignore something that could be serious for Josh and the clinic. If you were Tyler, what would you do? Why?



Shanoor's Family

Shanoor Akwal is 6 months old, a premature infant who is slowly beginning to grow and thrive. She and her family participate in an early intervention program for children who are at risk or have disabilities. During home visits, Shanoor's father confers with his wife in Arabic about Shanoor's care and then relates her responses to the home visitor. Shanoor's mother understands and can speak English, but she does not comment during the visits. The home visitor can see Shanoor's mother's interest in everything that they discuss, and she feels that the program's parenting program would be a wonderful experience for both Shanoor and her mother. On the last home visit, she mentioned the program and suggested that they attend. Without conferring with his wife, Mr. Akwal said that she could not attend. The home visitor let it pass but came back to the program

later in the visit. Again, Mr. Akwal said no. The home visitor thought that Mrs. Akwal seemed very interested in the idea but, as usual, she did not comment.

The home visitor's dilemma is related to cultural issues. The home visitor is aware that the Akwals are traditional Muslims and that Mr. Akwal's refusal to allow Mrs. Akwal and Shanoor to attend the parenting program is probably related to their beliefs. As an early interventionist and feminist, she really wants Mrs. Akwal to attend. On the other hand, she recognizes that it is not her place to interfere with the family's practices. What would you do if you were the home visitor? Why?

There are multiple approaches to resolving ethical dilemmas (Berkeley & Ludlow, 2008; Brophy-Herb, Kostelnik, & Stein, 2001; Sileo & Prater, 2012). Regardless of the approach selected, one must identify the ethical issue or concern, determine how the professional code of conduct relates to the issue, consider the perspectives of all of those involved, select a course of action, take action, and assume responsibility for actions taken. One of the most challenging aspects of ethical practice is separating one's own moral code from the code of ethics that applies to the workplace. As in the last scenario, a professional may take a very strong stand for women's rights in her or his personal and political life. That stand, however, may not be ethical when working with a family whose perspective on male and female roles differs from the interventionists.

In addition to ethics, there are laws that govern professional practice. States differ in their legislation and its interpretation, but it is critical for professionals to understand their professional obligations under the law. Reporting of child abuse is probably the most common law that affects many professionals. When child abuse or neglect is suspected, professionals are typically subject to mandatory reporting requirements. It is incumbent upon all professionals and the programs and agencies that employ them to have clear procedures for responding to legislated requirements.

Ethical practice is the right of every child, family, and individual that receives services and the obligation of those who provide those programs and services. Although resolving ethical dilemmas is not always as clear cut as other aspects of practice or problem solving, it can be and is done on a daily basis. Being aware of the parameters of ethical practice is the first step in achieving it.

SUMMARY

Family-centered services and creating family–professional alliances is one of the goals of programs that serve families and their children who are at risk for or have disabilities. Increasingly, it is also a goal of programs serving children and families in which disability is not an issue. Collaborative partnerships between families and professionals require mutual respect, trust, and the ability to agree on and pursue mutual goals. Family-centered services, a hallmark of quality services for children and their families, provide a first step toward family–professional collaboration and partnership. Its principles include the following:

1. Recognizing the parents or primary caregivers as experts on their child
2. Acknowledging the family as the ultimate decision maker for their child and themselves
3. Viewing the family as the constant in the child's life and the service providers and systems as transitory

4. Respecting and working toward supporting family priorities, goals for service, and their choice in involvement
5. Valuing trusting, collaborative relationships between parents and professionals
6. Working toward ensuring culturally competent services

Although considerable work has been done to realize the goal of family-centered practice, the goal has not been universally achieved. Making policies, procedures, and interactions more family friendly all contribute to more family-centered services. So, too, does a greater emphasis on family-centered approaches in preservice training and staff development. Program evaluation is a key tool in determining program effectiveness. In addition to assessing how family-centered a program or service is, comprehensive evaluations can provide data on all aspects of the program's functioning and performance. The information can then be used to highlight areas of strength and strengthen weaker components. A comprehensive program evaluation can provide information about services that need to be developed as well as about the unexpected outcomes of existing services. To be of high quality, programs and services must be grounded in ethical practice with guidelines provided by each discipline's code of conduct. Applying ethical principles as well as laws governing practice is the responsibility of every professional and every program and service.

ACTIVITIES TO EXTEND THE DISCUSSION

1. **Think about the last time that you visited a physician, registered for class, or applied for some service for yourself or a family member.** Write down a few words that describe the experience. Were there any aspects of the process that made it family centered (or perhaps consumer or client friendly)? What were they? What could have been done differently to make it easier for you as a client to use the service? Make a list of those things and share it with others in your group.
2. **Imagine that you were asked to give a presentation on family-centered practice.** How would you define it? What are some of its characteristics? Why would you say that it is important? Provide at least three illustrations of family-centered practices in an educational, social service, or medical/allied health setting.
3. **Think of a program or service that you are familiar with.** Develop an evaluation question for each of the components of a comprehensive evaluation.
4. **Find the code of ethics and/or the code of professional conduct for your profession or discipline or the one that you are studying for.** Review the code(s) and discuss them in relation to the code(s) of another professional discipline. What are the major differences? What are the major similarities?

TO LEARN MORE: SUGGESTED WEB SITES

The Beach Center on Families and Disability
http://www.beachcenter.org

Family Voices
http://www.familyvoices.org

The National Early Childhood Technical Assistance Center
http://www.nectac.org

National Parent Technical Assistance Center
http://www.parentcenternetwork.org

REFERENCES

Able-Boone, H., Sandall, S.R., & Frederick, L.L. (1990). An informed, family-centered approach to public law 99-457: Parental views. *Topics in Early Childhood Special Education, 10(1),* 100–111.

American Medical Association. (n.d.). *AMA's code of medical ethics.* Retrieved July 20, 2012, from http://www.ama-assn.org/ama/pub/physician-resources/medical-ethics/code-medical-ethics.page

American Nurses Association. (2001). *Code of ethics for nurses.* Retrieved July 20, 2012, from http://nursingworld.org/MainMenuCategories/ThePracticeofProfessionalNursing/EthicsStandards/CodeofEthics.aspx

American Physical Therapy Association. (2011). *Core ethics documents.* Retrieved July 20, 2012, from http://www.apta.org/Ethics/Core/

American Psychological Association. (2010). Ethical principles of psychologists and code of conduct: 2010 amendments. Retrieved July 20, 2012, from http://www.apa.org/ethics/code/index.aspx

American Speech-Language-Hearing Association. (2010). *Code of ethics.* Retrieved August 6, 2012, from http://www.asha.org/docs/html/ET2010-00309.html

Bailey, D.B. (2001). Evaluating parent involvement and family support in early intervention and preschool programs. *Journal of Early Intervention, 24,* 1–14.

Bailey, D.B., Raspa, M., & Fox, L.C. (2012). What is the future of family outcomes and family-centered services? *Topics in Early Childhood Special Education, 31*(4), 216-223.

Bailey, D.B., Simeonsson, R.J., Winton, P.J., Huntington, G.S., Comfort, M., Isbell, P., et al. (1986). Family focused early intervention: A functional model for planning, implementing, and evaluating individualized services in early intervention. *Journal of the Division for Early Childhood, 10*(2), 156–171.

Baird, S. (1997). Seeking a comfortable fit between family-centered philosophy and infant-parent interaction in early intervention: Time for a paradigm shift? *Topics in Early Childhood Special Education, 17,* 139–164.

Berkeley, T.R., & Ludlow, B.L. (2008). Ethical dilemmas in rural special education: A call for a conversation about the ethics of practice. *Rural Special Education Quarterly, 27*(1/2), 3–9.

Bernheimer, L., & Weisner, T. (2007). "Let me tell you what I do all day . . . : The family story at the center of intervention research and practice. *Infants & Young Children, 20,* 192–201.

Bronfenbrenner, U. (1975). Is early intervention effective? In B.Z. Friedlander, G.M. Sterritt, & G.E. Kirk (Eds.), *Exceptional infant: Vol. 3. Assessment and intervention* (pp. 449–475). New York, NY: Brunner/Mazel.

Brophy-Herb, H.E., Kostelnik, M.J., & Stein, L.C. (2001). A developmental approach to teaching about ethics. *Young Children, 56*(1), 80–84.

Brotherson, M.J., Summers, J.A., Naig, L.A., Kyzar, K., Friend, A., Epley, P., et al. (2010). Partnership patterns: Addressing emotional needs in early intervention. *Topics in Early Childhood Special Education, 30*(10) 32–45.

Bruder, M.B. (2000). Family-centered early intervention: Clarifying our values for the new millennium. *Topics in Early Childhood Special Education, 20,* 105–115.

Cambray-Engstrom, E., & Salisbury, C. (2010). An exploratory case study of providers' collaborative consultation practices with Latina mothers during home visits. *Infants & Young Children, 23,* 262–274.

Dempsey, I., & Keen, D. (2008). A review of processes and outcomes in family-centered services for children with a disability. *Topics in Early Childhood Special Education, 28*(1), 42–52.

Dinnebeil, L.A., Hale, L.M., & Rule, S. (1996). A qualitative analysis of parents' and service coordinators' descriptions of variables that influence collaborative relationships. *Topics in Early Childhood Special Education, 16,* 322–347.

Dinnebeil, L.A., Hale, L.M., & Rule, S. (1999). Early intervention program practices that support collaboration. *Topics in Early Childhood Special Education, 19,* 225–235.