The Development of Young Children With Disabilities and Their Families
Implications for Policies and Programs

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Most prospective parents hope and expect to have children who exhibit typical patterns of development, yet about 12% of children in the United States have difficulty performing one or more everyday activities, including learning, communication, mobility, and self-care, such as feeding, dressing, and bathing (America’s Children, 1999). These include children with biologically based developmental disabilities, such as Down syndrome or other distinct syndromes, autism or other communication disorders, and mental retardation or other forms of developmental delay. In this chapter, we examine the empirical evidence about young children with developmental disabilities and their families from the perspective of current policies and with a view toward service provision. We begin with a discussion of service-related policies for children with developmental disabilities and their families. Next, we review the theoretical and empirical literature on the relation between family functioning and the development of children with disabilities. Third, we consider the importance of cultural perspectives in terms of parental goals, the meanings parents ascribe to a disability, family relationships, and patterns of communication. In the final section, we discuss implications for service provision. We are limiting this review to children with biologically based cognitive disabilities; others (e.g., Farran, 2000; Halpern, 2000) provide

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extensive discussion about the service needs of children with developmental delays due to poverty and related adverse circumstances.

The term developmental disabilities is rarely defined but generally refers to individuals who are exhibiting unusual or delayed patterns of cognitive development. Children with mental retardation comprise a large proportion of those with developmental disabilities. Definitions of mental retardation were once based exclusively on cognitive performance but now include limitations in at least two adaptive skill areas (e.g., communication, self-care, social skills, daily living, and other similar domains) along with substantial deficits or delays in cognitive performance (American Association on Mental Retardation, 1992). Some maintain that categories such as developmental delay and mental retardation are socially constructed (Blatt, 1985), because the delineation between typical and atypical patterns of development is arbitrary and is based on ideals of age-appropriate behaviors and skills constructed by the dominant cultural group. Nevertheless, the current need for definitions is driven by requirements to determine which children are eligible for legally mandated services.

SERVICE-RELATED POLICIES FOR YOUNG CHILDREN WITH DISABILITIES

Throughout the 20th century, many policy changes related to children with disabilities occurred in the United States. At the beginning of the century, children with disabilities were often housed in crowded institutions in which they received custodial care, little or no education, and were isolated from the rest of society (Meisels & Shonkoff, 2000). Isolation and forced sterilization were common practices based on beliefs about the link between mental retardation and criminal behavior (Kamin, 1974). More benevolent attitudes toward those with disabilities emerged at the end of World War II, when citizens encountered and knew many disabled veterans. Further stimulated by the Civil Rights movement of the 1950s and 1960s, along with optimism about the malleability of intelligence generated by psychologists such as D.O. Hebb (1949), J. McVicker Hunt (1961), and Benjamin Bloom (1964), a change in public opinion occurred about the potential benefits of public services for the positive development of children with disabilities. In the 1970s, deinstitutionalization became an important movement, and families increasingly reared children with disabilities at home rather than placing them in institutions (Lakin, Bruininks, & Larson, 1992). As a result, service needs for young children changed from being institution based to being family focused.

Educational initiatives also reflected a change in public policies for children with disabilities. Beginning in 1975 with the Education of All Handicapped Children Act, legislation focused on the education of children of traditional school age with disabilities in the "least restrictive environment." Other important legislation followed, including the Education for All Handicapped Children Act Amendments of 1986, which mandated "free and appropriate" education for 3- and 4-year-olds with disabilities and encouraged (but did not mandate) states to provide early intervention services for children with disabilities from birth. This marked the first time that public educational services applied to children of preschool age. The act was reauthorized in 1990, renamed the Individuals with Disabilities Education Act (IDEA). Legislation passed in 1997 reauthorized IDEA and included a component, Part C, which is an optional program for infants and toddlers. Although Part C is voluntary, all states and territories are currently participating and have developed statewide systems of early intervention services for infants...
and toddlers with developmental delays or diagnosed disabilities and their families.

One important aspect of Part C is the requirement that early intervention programs develop an individualized family service plan (IFSP) for each family enrolled. This plan differs from the individualized education plan (IEP), which is developed for preschool and older children served by public schools through its focus on the family, rather than only on the child. For example, an IFSP may contain information about how a family's strengths could be used to enhance a child's language development. The family is considered central to the optimal development of young children, and the requirement to develop an IFSP stems from an ecological and contextual perspective of child development.

THE RELATION BETWEEN THE FAMILY SYSTEM AND CHILDREN'S DEVELOPMENT: THEORETICAL PERSPECTIVES AND EMPIRICAL EVIDENCE

The family is the primary context in which most young children learn and are nurtured (Bronfenbrenner, 1986). Relationships within families are complex and multidirectional; children affect the well-being of their siblings, parents, and other caregivers, and those individuals also influence children's development (Minuchin, 1988). Furthermore, these relationships are dynamic because constantly changing needs and influences affect the family over time (Lerner, 1991). The quality of these relationships is central to children's development (National Research Council and Institute of Medicine, 2000). In this section, we review theoretical and empirical work on the relation between the development of children with disabilities and the family system in which they are nurtured.

The family relationship most investigated in studies of children with developmental disabilities is the one between the primary caregiver, usually the mother, and the child. In contrast, little evidence exists about the father-child relationship, even though fathers are often highly involved caregivers (Lamb & Billings, 1997). Drawing from the large body of research on relationships between mothers and their typically developing children, studies of the mother-child dyad in families in which the child has a disability have been guided by a transactional model (Sameroff & Chandler, 1975). This theoretical framework describes a dynamic interactive process through which reciprocal interaction of the mother-infant dyad continues to exhibit more complex behaviors over time and across contexts (Sameroff & Fiese, 2000).

The mother-child relationship is important in its own right, as well as being predictive of social and cognitive development of children born full term or with low birthweight (Landry, Smith, Miller-Loncar, & Swank, 1997) and of children with developmental disabilities (Hauser-Cram, Warfield, Shonkoff, & Krauss, 2001).

Mothers, of course, have a larger range and repertoire of responses than do their infants. Through the early social signals of infants, mothers begin to understand their children's temperaments and usually become proficient at responding to their children's needs. The contingency of a mother's response to her child regulates the child's future behaviors as the child begins to recognize the relation between his or her actions and the responses of others (Goldberg, 1977). A mother's sensitivity and contingent responsiveness to her child's social signals are essential for the infant's development of security and attachment, which in turn supports the child's exploration of the environment and development of autonomy (Bell & Ainsworth, 1972). In contrast, mothers who exhibit high levels of control or intrusion into children's play diminish children's motivation to explore objects and the environment and
reduce children's opportunities to develop self-efficacy (Heckhausen, 1993).

Thus, the quality of the mother-child transaction is central to children's optimal development (Guralnick, 2001). Referring to the rhythmic interactive pattern between mother and child as a "dance between partners," Barnard (1997) emphasized the importance of contingent responding of both partners. When one partner consistently leads, the mutuality of the relationship is diminished and the tempo is disrupted. Several researchers have reported that such disruption often occurs in dyads in which the child has a disability (Kelly & Barnard, 2000).

Investigators have reported that mothers of children with disabilities tend to adopt directive and controlling styles of interaction with their children (McCullum & Hemmeter, 1997). For example, Eheart (1982) reported that even during free play, mothers of preschool children with Down syndrome tended to instruct their children about the appropriate use of toys more often than did mothers of typically developing preschoolers.

Many researchers have focused on maternal interactive patterns with children with Down syndrome, and they suggest that children’s developmental delays may make their signals difficult for parents to read. For example, Berger (1990) found that children with Down syndrome were beginning to develop eye contact at the chronological age typically developing children are using referential eye contact to engage their caregivers. Harris (1992) reported that the delayed use of referential eye contact by infants with Down syndrome elicited less verbal interactions from mothers, which in turn contributed to fewer verbal learning opportunities for the child. Others have reported that children with Down syndrome demonstrate fewer appropriate social signals (Beeghly, Perry, & Cicchetti, 1989) and have less predictable responses to caregivers (Landry & Chapieski, 1990).

The interactive relationships of children with autism and their caregivers also have been studied fairly extensively. Young children with autism often display minimal interest in people, rarely make eye contact or respond to caregivers’ attempts to engage them in play (Hoppes & Harris, 1990). These behaviors may reduce the opportunities of infants with autism to engage their caregivers in “joint attention” necessary for language development. The diminished responsiveness of children with autism has been reported by parents to violate their expectations and reduce their perceptions of attachment to their children (Hoppes & Harris, 1990).

Some researchers maintain that the high levels of directiveness observed in mothers of children with developmental disabilities reflect an adaptive response by mothers to their children's competence (Marfo, 1990). For example, Crawley and Spiker (1983) found that parents were more directive of children who showed less interest in play and initiated fewer interactions. Tannock (1988) found that maternal directives assisted children with Down syndrome in participating more fully in the interaction. Thus, caregivers tend to provide more directives to children who are less responsive in attempts to engage them more fully in the ongoing activity.

Other investigators suggest that maternal directiveness may indicate diminished sensitivity of mothers to the abilities of their children with developmental disabilities. Mahoney, Fors, and Wood (1990) reported that during observations of free play, mothers of children with Down syndrome directed their children’s attention away from objects they were playing with and toward potentially overly challenging tasks. In contrast, mothers of typically developing children (of similar mental age) were more focused on supporting the activities that engaged their children at the moment. These findings indicate that mothers of children with developmental disabilities may gear their behavior
toward instruction but also may have difficulty judging the appropriate degree of scaffolding required by the children.

Marfo (1990) argues that directiveness is only one dimension of a complex system of interactive behaviors. Caregiver responsiveness and support are other critical dimensions less often investigated. In a study of maternal interactive behaviors with children with Down syndrome, chronologically matched peers, and mental-age-matched peers, Roach, Barratt, Miller, and Leavitt (1998) found that mothers of children with Down syndrome demonstrated both more directiveness and more supportiveness. Directives tended to occur within a supportive context in which mothers facilitated children’s play by moving or steadying objects, for example, and by providing vocal praise. They further reported that maternal supports were associated with more object play and vocalization. Thus, the combination of directives and supports may be central to the development of beneficial interactive patterns between caregivers and young children with developmental disabilities.

The caregiver-child dyadic relationship occurs within the larger system of the family. Children affect their mothers and other members of the family system, including fathers and siblings. Historically, research on the effects of a child with disabilities on the family has been based on an assumption that such children disrupt and distort family life (Gallimore, Bernheimer, & Weisner, 1999). Many researchers have focused on documenting deleterious outcomes of various family members, a trend that can diminish the ability of service providers and families to recognize family strengths and develop productive partnerships (Turnbull, Turbiville, & Turnbull, 2000).

Four theoretical perspectives have guided investigations of families in which children have developmental disabilities: stage theory models, stress and -coping models, family systems models, and social-ecological models. During the 1960s and 1970s, a stage theory model (i.e., a predictable sequence of patterns) was used to explain the patterns of adjustment that parents pass through when coping with the birth or diagnosis of a child with disabilities (Blacher, 1984). This model was influenced by reports of clinically observed stages of grieving after the death of a close family member. An assumption was made that parents of children with disabilities also experience similar grief for their longed-for typical children (e.g., Solnit & Stark, 1961). Generally, three stages were delineated. In the first stage, parents experience disbelief and often “shop” for physicians and treatments. The second stage is characterized by guilt, anger, and disappointment. In the third stage, parents reorient themselves toward adjustment and acceptance and often become advocates for their children and others with disabilities. The empirical evidence for these stages is weak (Blacher, 1984), and scholarship has turned toward understanding parental adaptation and accommodation rather than documenting parental reactions according to characteristics of purported stages.

The ABCX model of family adaptation (Hill, 1949) has stimulated much research over the last two decades. According to this model, the adaptation of the family to an event such as the birth of a child with a disability is postulated to be explained by several factors, including the meaning ascribed to the child’s disability and the internal and external resources of the family. An expanded version of this model, the double ABCX model, includes a developmental component stipulating that families change over time in terms of their stressors, resources, and the meaning ascribed to the children (McCubbin & Patterson, 1982).

Several researchers have compared stress in parents of children with disabilities to that reported by other parents. Studies have been
fairly consistent in finding normative levels of stress reported during the infancy period (Shonkoff, Hanise-Cram, Krauss, & Upshur, 1992), followed by increasing stress levels during early childhood (Innocenti, Huh, & Boyce, 1992), and high stress levels during middle childhood (Warfield, Krauss, Hauser-Cram, Upshur, & Shonkoff, 1999). Middle childhood appears to be a particularly vulnerable time for parents of children with disabilities; stress levels are higher than at any other childhood phase (Orr, Cameron, Dobson, & Day, 1993). Middle childhood may be a particularly vulnerable period for parents because they expect children's behaviors to be better regulated than in earlier years.

Research indicates that parent stress levels are related to children's self-regulatory behaviors and temperament rather than to the tasks of parenting per se (Innocenti et al., 1992; Warfield et al., 1999). The internal (i.e., psychological) and external (i.e., social support) resources of parents also relate to the increase in stress experienced by parents during the middle-childhood period. Mothers with more satisfying social support networks and fathers with higher levels of problem-focused coping strategies experience comparatively fewer increases in stress related to their children with disabilities from early to middle childhood than do other parents (Hauser-Cram et al., 2001).

Although fathers' perspectives are often neglected in research on children with disabilities (Lamb & Billings, 1997), a few researchers have investigated whether parenting stress differs for fathers and mothers. Some have found that maternal and paternal stress levels are similar in families with children with disabilities (e.g., Dyson, 1997; Roach, Orsmond, & Barratt, 1999). In contrast, Scott, Atkinson, Minton, and Bowman (1997) reported that mothers evinced more psychological stress than fathers. Krauss (1993) found that during the early years, fathers reported more stress related to their children's temperaments and self-regulatory behaviors, whereas mothers reported more stress related to the parenting role (i.e., their own emotional resources and adjustments to providing children's caregiving needs). Increases in stress levels of both mothers and fathers, however, appear to be more consistently related to children's behavior problems than to the type of disability or extent of cognitive delay (Hauser-Cram et al., 2001).

Parenting stress is only one aspect of parent well-being, however. Family systems theory posits a broad conceptual model of family processes that relate to the well-being of both parents and children. From this perspective, the family is considered to be an open, interactive system that operates according to a generalized set of principles (Walsh, 1980). Changes in one family member affect changes among other members, producing multiple iterative responses. Thus, rather than focusing on unidirectional effects of a particular child on the family, those operating from the family systems perspective consider simultaneous, multiple, and iterative effects of family members on each other (Minuchin, 1988).

Although many researchers emphasize the value of a family systems perspective, few investigators have rigorously employed this model in empirical studies of families in which a child has a disability. The work of Mink and Nihira (1986) is unique because they have developed a series of family typologies based on the psychosocial environment of the home. They found that children with mild mental retardation had more positive self-esteem and social adjustment when they lived in more cohesive families. Their development of typologies serves as a useful model for researchers who want to move away from unidimensional questions about whether having a child with a disability affects a family to broader questions about the “fit” between the functioning of the child and the family.
From the vantage point of developmental systems theory, the family system itself operates within multilayered interacting systems (Bronfenbrenner, 1986; Lerner, 1991). Multiple systems are involved when families make accommodations to sustain the daily routines for any child (Weisner, 1993). In making arrangements for children's daily lives, parents make decisions that involve many social-ecological systems, including, for example, their employment, children's schooling, and community services. Gallimore and colleagues (Gallimore, Coots, Weisner, Garnier, & Guthrie, 1996) investigated the functional adjustments that families make to sustain their daily routines when raising children with disabilities. For example, parents may need to make adaptations in the home for a child with a motor impairment or may adapt their employment schedules to meet a child's medical needs. Gallimore and colleagues found that although parents made a wide range of accommodations during early childhood, they needed to make an even greater number of accommodations during the middle-childhood period. The manner in which families organize their daily activities and the meaning they attribute to their patterns of organization are essential to achieve a fuller understanding of family functioning (Gallimore et al., 1999).

In all four theoretical perspectives discussed above, the focus of research has been on the child with a disability, the mother, and to a lesser extent, the father. Siblings, however, are also an integral part of the family. Similar to early studies of parents of children with disabilities, investigations of siblings have often focused on potential pathology. Typically developing siblings were considered to be at risk for maladjustment as a consequence of the chronic stress, social stigma, and responsibilities associated with the care of brothers or sisters with disabilities (e.g., Farber, 1959). Most recent reviews of empirical research on sibling relations, however, indicate equivocal support for the hypothesis that siblings of children with disabilities assume greater caregiving or are at greater risk for psychopathology (Damiani, 1999; Stoneman, 1998). In fact, some researchers report that typically developing siblings demonstrate more prosocial behaviors, greater maturity, patience, and a deeper understanding of individual differences than do their peers (Dyson, 1989). Some adolescent and adult siblings have indicated that the experience of living with a brother or sister with mental retardation helped them to develop greater empathy and appreciation of family relationships (Eisenberg, Baker, & Blacher, 1998).

The adjustment of siblings is related to multiple factors, including the severity of the brother's or sister's disability, the temperament of each sibling, as well as behavioral, psychological, and health problems related to the sibling's disability (Stoneman, 1998). In particular, siblings appear to have more difficult adjustments when their brothers or sisters with disabilities exhibit behavior problems (Brody, Stoneman, & Burke, 1987). Children with certain disabilities, such as Fragile X syndrome or autism, are more likely to display maladaptive behaviors and thus make the sibling relationship potentially problematic. When a child exhibits difficult behaviors, parents often expend more resources caring for that child, which results in differential treatment of siblings (Corter, Pepler, Stanhope, & Abramovitch, 1992). Perceived discrepancies in the attention parents give to their children can lead to more conflictual interaction between siblings and less prosocial behavior of typically developing siblings (Brody et al., 1987). Siblings of children with developmental disabilities, however, may adjust to such discrepancies as they come to understand the legitimacy of their siblings' needs and attribute differential attention, rather than parental favoritism, to those needs (McHale & Pawletko, 1992).
Older sisters of children with developmental disabilities often have greater child care responsibilities than other children. When examined longitudinally, these greater responsibilities have been associated with increased sibling conflict and reduced time socializing with friends outside the home (Stoneman, 1998). When the abilities of younger, typically developing siblings surpass those of older siblings with developmental delays, younger siblings often experience role reversal. These younger siblings often assume more teaching and helping roles than is found in other families (Brody, Stoneman, Davis, & Crapps, 1991).

The functioning of the larger family system appears to be especially important for the positive adjustment of typically developing siblings. Lynch, Fay, Funk, and Nagel (1993) found that conflict between parents and disorganized family functioning were associated with poor sibling outcomes. In contrast, parents who perceive their children with disabilities and the functioning of their families more positively tend to have typically developing children with more positive feelings about their families and better psychological adjustment (Weinger, 1999). Thus, sibling relationships may be sensitive to behavior problems and to caregiving responsibilities, but the ways in which the family functions and copes with those behaviors and responsibilities relate to positive outcomes of all family members.

A CULTURAL PERSPECTIVE ON FAMILIES OF CHILDREN WITH DISABILITIES

Most of the research studies on families of children with disabilities (described in the prior section) are based on families of Euro-American descent. Given the changing demographic makeup of this country, in which ethnic, cultural, and linguistic variation has increased substantially (U.S. Bureau of the Census, 2001), a broader understanding of families of children with disabilities is needed.

Individuals usually have been the primary unit of analysis in developmental psychology. Child development research has often relegated the pervasive influence of culture to a marginal entity or conceptualized it as an aspect of context that mediates developmental outcomes (Garcia Coll & Magnuson, 2000). A contrasting and growing view, however, is that culture is an organizing principle of development (Valsiner, 1989). From that perspective, culture is defined as a multifaceted construct that serves to organize multiple dynamic systems of meaning for individuals, such as values, beliefs, and expectations. These systems of meanings are transmitted through social groups but constantly evolve as individuals construct meaning from their experiences in the environment (Super & Harkness, 1997; Valsiner & Litvinovic, 1996). Individuals often belong to more than one social group, and thus, culture involves levels of shared discourse and practices related to one’s religious affiliation, socioeconomic status, and occupation (Harwood, Miller, & Irizarry, 1995). Although many aspects of culturally related dynamics are integral to parenting a child with a disability, in this section, we highlight four areas that have implications for service provision: (a) parents’ goals for their children, (b) the meaning ascribed to a child’s disability, (c) family relationships, and (d) patterns of communication.

Parents’ Goals for Their Children

LeVine and his colleagues suggest that parental goals consist of culturally shared assumptions about skills and values necessary for children to become well-functioning adults (LeVine et al., 1994). Such assumptions are often unconscious or transparent to their users. Historically, there has been
an implicit assumption within the field of developmental psychology that the values and practices of educated white middle-class North Americans constitute the optimal environment for children's development (Patterson & Blum, 1993). This view is reflected by interventions that seek to enlighten parents from minority groups about the behaviors and practices reflected in white middle-class values (Garcia Coll & Magnuson, 2000). Child-rearing practices and parental values that differ from mainstream Euro-American culture have been considered deficient, rather than alternative, pathways to normal development (Patterson & Blum, 1993). For example, cosleeping between parents and infants is common in countries throughout the world, reflecting values of close physical proximity that foster strong emotional bonds between mother and child (Morelli, Rogoff, Oppenheim, & Goldsmith, 1992). Among some Euro-Americans, however, this practice breaches cultural taboos of appropriate physical intimacy and is thought to stifle the development of independence in children, which is a highly valued trait in this culture (Morelli et al., 1992).

The assumption that Western practices and values are optimal for children's development is reflected in many standardized tests that use developmental milestones of Euro-American children as standards for normative behavior (Garcia Coll, Meyer, & Brillon, 1995). Some have argued that the conceptualization of "normative behavior" is a social construction created by members of a dominant culture who transmit the necessary knowledge to members of that culture, providing them with the resources to succeed in society. If this implicit knowledge is not transmitted to members of minority groups, it diminishes their power and resources (Delpit, 1995). Children with disabilities from minority or immigrant groups face double jeopardy because their disabilities as well as their cultural behaviors may not meet narrow mainstream standards of development.

The cultural values of parents and professionals are likely to influence the goals that each perceives to be most crucial for a child and the needs they identify. For example, parents from cultures that value harmony among all members of a family, and especially between different generations, may seek to instill an understanding of respect and social hierarchy in their children. The goals of these parents may reflect a desire for their children to learn behaviors that demonstrate respect and deference to elders. These goals may differ from those of Euro-Americans who foster the development of independent decision making and self-assertion among children (Zuniga, 1998). Similarly, professionals from Euro-American backgrounds may expect parents and children to exhibit behaviors associated with their own values, such as maintaining direct eye contact and asserting one's opinion during conversations. These behaviors, however, may directly oppose the values held by the family. Likewise, parents who value cooperation more than competition between individuals may focus their parenting goals on the development of interpersonal skills in their children more than on the timely achievement of other cognitive milestones (Zuniga, 1998).

The transmission of parenting and socialization practices are guided in part by cultural values and in part by parents' active construction of the demands of the social context (LeVine et al., 1994). Parents must choose strategies that solve the needs of the immediate situation. Their decisions, however, also reflect future goals they have for their children with disabilities in relation to the well-being of the family system. These goals can range from securing the basic safety of their children to ensuring that their children develop the skills necessary to flourish in their future and in accordance with cultural values (LeVine et al., 1994).
Parents of children with disabilities often face uncertain futures for their children, and some seek to foster behaviors that increase the likelihood of their children being accepted and cared for by others in the future. For example, Arcia, Reyes-Blanes, and Vazquez-Montilla (2000) found that Puerto Rican and Mexican mothers of young children with Down syndrome, cerebral palsy, and spina bifida emphasized the value of respectful, compliant behavior and wanted their children to develop a sense of right and wrong, be respectful and responsible, and be close to the family. These highly valued characteristics reflect behaviors that would be adaptive and support their acceptance by others in the classroom and in related settings.

The personal experience of having a child with a disability also may influence the values and goals of parents. For example, in one study, Quirk and colleagues (Quirk, Sexton, Ciottone, Minami, & Wapner, 1984) found that Puerto Rican mothers of children with disabilities valued health and creativity more than did Puerto Rican mothers of nondisabled children; however, they reported few other differences within ethnic groups. Other studies have not found the role of disability to affect cultural values (e.g., Arcia et al., 2000). More often, studies have shown that cultural values influence the meaning parents ascribe to their children's disabilities, which can in turn influence the internal and external resources available to them for the care of their children (Blacher, Lopez, Shapiro, & Fusco, 1997).

The Meaning Parents Ascribe to a Child's Disability

Cultural values influence the meaning that parents ascribe to a child's disability and their role as parents of a child with special needs. Individuals differ in the extent to which they attribute the etiology of disability to fatalistic determination, spiritual intervention, biological chance, or personal responsibility. Cultural beliefs and expectations about children's illnesses or disabilities influence parents' perceptions of their ability to influence the course of their children's development. Mardiros (1989) found that parents of children with disabilities who believed that their children's disabilities were the result of fatalistic or supernatural forces perceived themselves to have less control over their children's outcomes. Alternatively, parents who viewed their children's disabilities as punishment for their own personal actions were more likely to assume greater roles in helping their children develop positively (Mardiros, 1989).

Sometimes, cultural beliefs about etiology and treatment of a disability are distinctly different from those held by personnel in the mainstream service system. Fadiman (1997) describes the misunderstandings and clashes that occurred between a Hmong family whose child had epilepsy and the medical system they encountered in the United States. The parents viewed the cause of their child's disorder, which they described as a “loss of soul,” as the result of a fright from the abrupt sound of a door slamming shut. Furthermore, they considered their daughter's condition to be a possible indication that she might become a shaman, a person of great respect in her community, because of her trancelike state and potential ability to see things others cannot see. They viewed healing as a holistic and spiritual matter not restricted to the taking of medication, especially preventative medications that have potentially deleterious side effects. In contrast, the Western physicians considered the parents' unwillingness to treat their child with medications that might stabilize or prevent seizures as a lack of compliance and eventually, a sign of neglect. Even when interpreters were available to assist communication between the family and Western medical personnel, the distinct belief system of each culture and the lack of knowledge...
of each other’s belief system prevented a collaborative relationship.

The construction of meaning is dynamic, evolving through transactional interactions between individuals across multiple systems (Bronfenbrenner, 1986). For example, a parent’s conception of disability may be influenced by interactions with members of their ethnic group, their religious identity, as well as their exposure to mainstream beliefs about disability. Skinner and colleagues (Skinner, Bailey, Correa, & Rodriguez, 1999) found that Catholic Latino mothers of children with disabilities differed in the extent to which they incorporated religious beliefs into the meaning they ascribed to disability and its relation to their role as parent. Some mothers incorporated the religious image of a “good mother” into their descriptions of themselves, one who sacrifices herself for the sake of caring for her children. These mothers rejected religious conceptions of disabilities as representing punishment for their sins. Many retained positive images of themselves as morally virtuous and viewed their children as symbols of God’s belief in their strength and capability to care for their children’s special needs. Other mothers believed that disability was the consequence of personal transgressions. They also, however, described their personal meaning of disability as providing positive transformations in their identities as advocates and more compassionate persons. In general, religious and cultural beliefs were reported by mothers to increase their internal strength and support their parenting practices.

**Family Relationships**

Consistent with current models of family adaptation (e.g., McCubbin & Patterson, 1982), cultural values can influence the internal (e.g., psychological well-being) and external resources (social support) available for a family. For example, interdependence among individuals is exhibited in the value of familism in Latino culture, which represents loyalty and solidarity among nuclear and extended family members who rely on each other for support (Zuniga, 1998). Some practices associated with familism can serve as sources of strength for families of children with disabilities. For example, extended family members are reported to provide emotional support, which has been found to reduce stress among Mexican American mothers of children with developmental disabilities (Shapiro & Tittle, 1990). Alternatively, lack of solidarity among Latino families with children with mental retardation has been associated with higher rates of depression among mothers (Blacher et al., 1997). Similarly, South Asian mothers of children with developmental delays reported that a lack of extended family members contributed to their feelings of loneliness and dissatisfaction with social support (Raghavan, Weisner, & Patel, 1999).

Cultures that have broad definitions of family may include extended family members, such as grandparents, or non-kin, such as unofficially adopted children or godparents. Joe and Malach (1998) found that the extended family often plays a central role in obtaining and organizing services for children with disabilities among Native American cultures. Collectivist values of interdependence between family members may help to strengthen family relationships through various pathways, such as honoring of family obligations and self-sacrifice of family members for the sake of the family unit. The practices associated with these values can, however, exact a cost from parents in terms of time and effort. Turnbull, Blue-Banning, and Pereira (2000) found that extended family social networks provided the main source of friendship for many children with disabilities. Yet mothers reported that the time required to foster these family relationships reduced opportunities available to help their children develop social
networks outside the family. The manner in which familism and related values influence caregiving practices is important for professionals to understand; it remains a core value for many families in the United States despite different levels of acculturation (Zuniga, 1998).

The role of cultural factors in a family system is dynamic and likely to change across the family life span. Valsiner and Litvinovic (1996) emphasized that humans are “innovating carriers of the collective culture” (p. 61) as they actively reconstruct and reinterpret expectations on the basis of new experiences and unique characteristics of each situation. For example, Magana (1999) found that self-sacrifice among mothers for the sake of their children (marianismo) is strongly valued among some Catholic Latino families. Although this value contributes to positive maternal caregiving practices among mothers of young children with disabilities, it has also been associated with poorer health among Puerto Rican mothers of adults with mental retardation (Magan, 1999). Cultural values of familism and marianismo may contribute to positive functioning and cohesion among families with young children but may also be less adaptive as mothers age and members of the nuclear family assume their own family responsibilities.

**Patterns of Communication**

From a socioecological perspective, culture is embodied in a social context that pervades all aspects of an individual’s life, guiding the ways people interpret and act in varied situations and influencing patterns of behavior and communication (Super & Harkness, 1997). In some cultures, communication patterns require that an individual’s position in a social hierarchy (e.g., elder vs. younger person) be acknowledged (Hecht, Andersen, & Ribeau, 1989), or misunderstandings can result. For example, Fadiman (1997) described how a physician’s decision to communicate to younger rather than elder members of a family violated the social expectations in Hmong culture even though the younger members had greater facility with English. Furthermore, nonverbal aspects of communication, such as body stance, facial expressions, eye contact, and gestures often have different interpretations in different cultural groups (Hecht et al., 1989). If service providers are unaware of their own styles of communication and how they differ from the ones valued by the families whom they serve, miscommunication can result.

Cultural values influence parents’ engagement in collaboration with professionals in planning and implementing services for their children. Individuals’ cultural meanings are influenced by processes occurring between and within individuals in dynamic and constantly unique environments (Valsiner & Litvinovic, 1996). Garcia Coll and Magnuson (2000) suggest that cultural differences can become “risk factors” when they are misunderstood and confused by socioeconomic status. For example, Harry (1992) found that passivity demonstrated by some African American and Puerto Rican parents of children with disabilities reflected their feelings of powerlessness over their children’s programs. Parents who were unhappy with their children’s programs demonstrated their disagreement by refusing to attend meetings or sign forms, rather than engaging in active confrontation with teachers. Many mothers reported that the collaborative process only minimally involved their informed consent and that they did not feel empowered to question the authority of the group of professionals, whom together, mothers viewed as wielding much greater power than an individual mother could independently.

Lack of understanding about cultural patterns of communication can impede collaboration efforts. In a 3-year longitudinal study, Harry, Allen, and McLaughlin (1995)
interviewed African American mothers of preschool children with various disabilities and found that reliance on written communication, the use of unexplained jargon, and differences in the goals of parents and professionals deterred true collaboration. When mothers’ conceptualizations of their children’s programs differed from the ones provided by school personnel, mothers became disillusioned and less willing to engage in collaboration. For example, some mothers believed that the goal of preschool special education was to give children a chance to catch up with their peers. Mothers were upset when they realized that their preschoolers were increasingly stigmatized by the experience of being labeled as mentally retarded and placed in self-contained classrooms with older children who had more serious behavioral problems. A focus on labeling children’s deficits rather than promoting their strengths and the failure of professionals to respect cultural differences in parenting, such as the involvement of extended family, were reported as deterrents to communication.

IMPLICATIONS FOR SERVICE PROVISION

Services provided to young children with disabilities are best conceptualized as systems designed to support families in ways that promote children’s development (Guralnick, 2001). Such services often concern basic care issues such as sleeping, feeding, and health, which reflect the cultural beliefs, values, and practices of a family. Parent-child interactions occur within a family system that functions according to certain daily routines developed to accommodate the needs of many family members, including the child with disabilities. Despite strong evidence of the importance of growth-promoting parent-child (especially mother-child) interaction, focusing on those interaction patterns without paying attention to parents’ goals, values, and beliefs is misguided. Similarly unfounded are attempts to assist parents in diminishing their levels of stress without understanding (a) the relation of parent well-being to internal and external resources and (b) family values related to those resources. Intervention in the form of support to families involves an understanding of the complex developmental system.

In the case of young children with developmental disabilities, collaboration between parents and service providers often occurs at a time when parents are focusing on their children’s daily needs. Differences in communication styles between professionals and parents can create fertile ground for tension and misunderstandings to develop. Cultural collisions may be most likely during periods in which parents must make crucial decisions that evoke anxiety and strong emotions (Hanson, 1998). One factor that underlies these patterns of communication is the difference in the value placed on time between Euro-Americans and members of other cultural groups. An orientation to the future and a preoccupation with managing time and achieving multiple tasks within a given period are predominant in the values of Euro-Americans, but this may clash with families who place greater value on fostering interpersonal understanding and trust between parents and professionals through conversation and casual exchange (Zuniga, 1998). Although professionals often have multiple responsibilities that must be fulfilled within limited time, the burden of adjusting one’s style must not be placed solely on the parent (Harry, 1992). Rather, cultural understanding requires professionals to adapt their agendas to match the styles and tempos of families.

Another example of potential mismatch between service providers and families relates to male and female roles and power structures within families. Equality between sexes
is often valued among Euro-Americans, which influences their expectations that a family structure will be democratic. Euro-Americans who work with culturally diverse families may anticipate shared decision making between spouses but may find that some families, such as those from some Middle Eastern cultures, value differential status between the sexes (Sharifzadeh, 1998). Social hierarchies play important roles in some families and guide interactions among members in ways that Euro-American service providers may misunderstand or overlook.

Cultural understanding involves facilitating meaningful communication and relationships related to the delivery of services in ways that are respectful of the cultural heritage of the family (Roberts, 1989). Although such understanding involves more than sensitivity to the families, little scientific evidence is available about the way this can be accomplished (National Research Council and Institute of Medicine, 2000). Agreement centers on the need for service providers to recognize their own cultural values, assumptions, and beliefs and to understand how those concepts influence their interactions with members of other cultural groups. In this regard, Hanson (1998) suggests that mentoring relationships with members of different cultures can assist professionals in reflecting on their own cultural perspectives.

Training in cultural understanding that involves making generalizations about specific cultural groups can result in the development of stereotypes, however. This is especially detrimental to the understanding of multiculturalism as the structures of families in the United States become progressively more diverse, more often representing bicultural marriages and blended cultural values and practices. The factors that influence individuals are dynamic and vary both within and between cultural groups, such as degree of acculturation, socioeconomic status, occupation, and religious identity (Harwood et al., 1995). Skinner and colleagues (Skinner et al., 1999) suggest that one way to minimize the construction of stereotypes is to learn to listen to family stories as a way of gaining a perspective on parents' values and meaning systems. Researchers are increasingly acknowledging the power of personal narratives as important markers of family relationships (Fiese et al., 1999), and service providers who attempt to understand the meaning-making process in families may be more able to engage in true collaboration.

What are some ways early intervention services could more fully incorporate cultural perspective? First, involving community members in planning the range of services offered by early intervention programs and recruiting professionals and paraprofessionals from targeted cultural groups are critical steps. Positive relationships between early intervention programs, local community groups, and respected community leaders need to be created. The need for productive relationships between early intervention personnel and medical and school personnel is fundamental to most early intervention programs. The need to develop strong relationships with other community groups and leaders, however, is equally important, especially in diverse communities.

Second, service providers would benefit from experiences that make their own assumptions, for example, about how children develop and optimal child-rearing styles, apparent rather than transparent. Although no experience substitutes for that of actually living in a culture quite distinct from one's own, service providers might benefit from learning techniques that allow them to gain knowledge and perspective from personal narratives. Such techniques involve the ability to listen not only to the words of the stories but also to the meaning behind the words (Skinner et al., 1999). Personal stories indicate how parents make meaning of their children's development, but they also suggest
ways in which parents cope and the strengths they bring to parenting experience.

Third, based on a medical anthropological perspective, Kleinman, Eisenberg, and Good (1978) suggest that physicians develop questions to elicit a patient’s explanatory model of a particular illness. The physician then makes explicit his or her model of healing and negotiates a shared model with the patient. A similar approach could be taken by individuals providing services to families of children with disabilities. Early intervention service providers could develop questions aimed at understanding how parents perceive their children’s delayed development, experiences parents consider beneficial to their children’s development, and the way parents see their family supporting their children’s potential trajectory. Because parents’ theories of development are important frameworks within which early intervention services work, understanding those theories is a central part of the collaboration between families and service providers.

Finally, service providers might benefit from a collection of examples in which potential collisions between families and service providers were averted. For example, Fadiman (1997) describes several examples in which medical personnel worked within families’ belief systems to assist the individual who was ill, sometimes necessitating changes in the processes by which the physicians usually worked. A collection of positive examples in which early intervention personnel have also revised their standard practices in ways that support family beliefs and benefit children would be advantageous to the field.

In conclusion, research clearly points to the importance of the family system in promoting the positive development of children with developmental disabilities, their siblings, and their mothers and fathers. The cultural beliefs, values, and practices of the family are an integral part of that system. Recognition and knowledge of the multiple and changing facets of the family system are essential for the promotion of positive development among all children, including those with developmental disabilities.

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