CHAPTER 6  Counseling Families and Children With Disabilities

Timothy R. Elliott, University of Alabama at Birmingham, and Larry L. Mullins, Oklahoma State University

The occurrence of a physical disability has practically always had repercussions within the family system. A physical disability may be congenital or acquired; in both scenarios the occurrence may be best construed as an off-time life event in terms of the normative developmental expectations for the family and the child with the condition (Neugarten, 1979). Although a physical disability is not a welcomed occurrence, the ramifications of the condition vary considerably among families, and there is no set pattern that typifies family reactions and subsequent adjustment. Many children with severe physical disability may have considerable difficulty living independently, and a parent may be compelled to assume assistive duties at the expense of their personal career goals, social activities, and interpersonal relationships. Due to tremendous advances in medical technology, individuals who incur severe physical disability often have considerable life expectancy, and thus the need for assistance from family members may exist throughout a lifetime.

Counselors need at their disposal a working knowledge of the family and a useful model that can guide assessment and intervention strategies. In this chapter, we focus on the epidemiology of physical disability and the specific issues and task demands experienced by these families, and we provide a working model to organize relevant information about factors that facilitate the adjustment of family members.

WHAT COUNSELORS NEED TO KNOW ABOUT CHILDREN WITH DISABILITIES AND THEIR FAMILIES

Children with disabilities constitute a large, heterogeneous group of individuals, with varying degrees of physical limitations and cognitive development. Collectively, it is estimated that approximately 4 million children in the United States have a significant disability (Wenger, Kaye, & LaPlante, 1996). Prevalence rates vary, but somewhere between 10% and 20% of children in the United States appear to evidence some form of disability at any given point in time (Gortmaker &
Sappenfield, 1984). Children from lower socioeconomic backgrounds are at higher risk to have a severe condition that limits their daily functioning (Perrin & McLean, 1988).

Children with disabilities often contend with various sensory and mobility impairments, endure recurrent hospitalizations and medical procedures, and adhere to complex therapy regimens. The nature of their disabilities also affects interpersonal relationships by reducing social contacts and the number of individuals in their social network (Lyons, Sullivan, Rito, & Coyne, 1995). Children with developmental disabilities are at high risk for manifesting significant behavior problems at a rate 5 times greater than that of children without health problems (Wallander, Varni, Bahani, Banis, & Wilcox, 1989). Research also indicates that having a disability places a child at significantly greater risk for abuse and neglect by a parent compared with a child without a disability (National Center on Child Abuse and Neglect, 1993). Indeed, up to one third of all children with disabilities have experienced some form of maltreatment (Sullivan & Knutson, 2000). Thus, substantial evidence indicates that children with disabilities constitute a population at risk for various medical, psychological, and social problems.

The task demands of caring for and parenting a child with a disability can be substantial. Parents are confronted with complicated medical regimens and health crises, and financial resources are often strained, especially when only one parent can work, or only one parent is present. Many researchers have commented on the considerable stress placed on parents of these children (e.g., Kazak & Simms, 1996), and although many appear to cope well, some clearly do not. Overall, the extent research indicates that parents of children with disabilities are at risk for adjustment problems, which in turn may place their children at even greater risk for behavioral problems and possibly maltreatment.

To understand the wealth of information concerning family and child adjustment following disability, it is imperative that we recognize that disability does not occur in a vacuum. Disability is always defined by the immediate environment, and by the historical and temporal context in which it occurs. At its intellectual core, rehabilitation psychology embraces a Lewinian field-theory perspective to understand observed behavior associated with a disability, as expressed in the classic equation, $B = f(F, E)$. As succinctly conveyed in this statement, any observed behavior associated with a disability is a product of the interaction between the person and the environment. For our purposes, it is essential that we recognize the many facets of the environment and the behavioral processes of the different family members that contribute to the family experience of disability.

Second, it is critical that we recognize that adjustment can be defined in positive and negative terms. Historically, the study of adjustment following physical disability was restricted to negative indicators of adjustment. Much of this work was conducted in clinical settings in which the attention was directed to serviceable activity to facilitate the detection and treatment of problems presented by children and families. This context resulted in a pathological model of adjustment, so that there was little—if any—recognition of the ways in which families might benefit or experience positive growth following the occurrence of a physical disability.
Client With a Disability

backgrounds are at risk for abuse and neglect (Perrin & Perrin, 1995). Children with significant behavior problems also indicate that they have more physical health problems than children with disabilities. A disability can be a term that encompasses relevant elements in several broad-based domains, each of which has considerable impact on areas of adjustment that subsume positive and negative outcomes. This model, as first described in a model of positive growth following disability (Elliott, Kurylo, & Rivera, 2002), owes much to the "disability-stress-coping" models that were designed to explain why some children fare better following chronic illness than others (Thompson & Gustafson, 1996; Wallander et al., 1989). Essentially, these models argue that chronic illness or disability serves as a stressor to which the individual and the family attempt to adapt.

The present model differs from these previous conceptualizations in a number of important ways. As depicted in Figure 6.1, the model is designed in such a way to understand issues that may affect adjustment over the life span, taking into account development, ecological, and temporal factors that occur as people age, as relationships change, and as significant technological advancements occur. This model is not specific to the understanding of child adjustment per se but is meant to be useful in appreciating adjustment of people with chronic disease and disability across the life span.

**FIGURE 6.1** Model for understanding positive growth following disability.
Additionally, the concept of stress is not a centerpiece of this model; rather, it emphasizes the pivotal role of phenomenological appraisals and personal experience of events, and the dynamic processes that occur as people respond to the ambiguity, banality, and occasional urgency of everyday life. The model recognizes that certain aspects of living with a disability will impose specific activities as a part of health maintenance and self-care regimens for optimal adjustment. However, the degree to which these will be experienced as stressful or incorporated into everyday routines will depend on the phenomenological ways in which people process information, accommodate change, and develop new behaviors. The model also recognizes that problems are associated with disability and disease outside the realm of personal volition. These can include a variety of social, institutional and service-related issues (e.g., school placement, support from public health services). These problems vary in valence and impact at any point in time, and each individual should be consulted to determine the degree to which these are problematic.

Thus, the model recognizes that individuals (and a family) operate as active stakeholders in their health and well-being, and many factors can promote or undermine the degree to which individuals can operate as active and informed consumers in their health care. Families who have a member living with a chronic disease or disability are best viewed as competent yet dynamic entities that are influenced by an array of societal systems (Aashehsel, Pearlin, Mullan, Zarit, & Whitchurch, 1995).

In the present model, the phenomenological experience of children living with a condition is influenced by not only the enduring characteristics of the condition but also the individual differences that pertain to their developing personality characteristics and learned patterns of behavior. Their experience, perceptions, and appraisals are also influenced by factors in their social environment, which can serve to ameliorate, buffer, or exacerbate their day-to-day life. This aspect—the phenomenological perspective—stands as a separate component in the model. The components and the major outcomes that encompass the major aspects of adjustment in both positive and negative terms are described in the following sections.

ENDURING CHARACTERISTICS AND INDIVIDUAL DIFFERENCES

This component of the model includes the specific demographic characteristics of the family and its members, disability-related characteristics (e.g., the type of disability), and various behavioral patterns and personality characteristics of the family members.

Demographic Characteristics

The extant literature is inundated with descriptive differences between children with disabilities (of any kind) and those without disabilities; similarly, there is considerable work documenting differences between families living with a child's
disability and families that do not. To a great extent, this work was not grounded in any a priori theory, and the focus of the work was decidedly negative, largely disinterested in any positive outcomes or comparisons. Research essentially assumed that the presence of a disability in a family is sufficient to cause disruptions in the person and the family and development of subsequent "psychopathology" (Harper, 1991). For example, some early research guided by this premise reported that siblings of a child with a disability were at risk for behavioral and emotional problems (Breslau & Prabucki, 1987).

However, many demographic characteristics may exert considerable influence on family adjustment, including the socioeconomic status of the family. A disproportionate percentage of families with children with disabilities live below the poverty line throughout the United States. This situation translates into restricted access to health care, fewer resources for therapy and other adjunctive services (e.g., respite care, vocational rehabilitation), and fewer opportunities for acquiring assistive devices. There is a greater likelihood that these families will live in neighborhoods that have physical barriers that impede mobility and schools districts that are inadequately funded and thus unprepared to educate children with complex needs. Under such circumstances, families living in poverty face incredible obstacles that conspire against the best interests and well-being of the child.

Concepts of gender and ethnicity share considerable overlap with the social and environmental component of this model because these are often socially defined constructs; thus, gender and ethnicity are discussed in a later section that addresses social and environmental influences on adjustment.

Disability-Related Characteristics

Among children with disability it is essential that counselors understand the complex nature of a disability and its concomitant characteristics, and the ensuing ramifications on the other components within the model. To understand family and child adjustment following disability, counselors should explore the following issues in a thorough assessment:

- Does the child experience alterations in the typical brain-behavior relationships as a feature or consequence of the disability?
- What are the prerequisite requirements (i.e., task demands) for maintaining and promoting the optimal health and well-being of the child?
- To what extent does the disability pose particular physical limitations?
- To what extent does illness intrusiveness exist (Devins, Cameron, & Edworthy, 2000)? In other words, to what degree does the disability limit the child's ability to engage in desired activities?

Disabilities associated with impairments in higher cortical functions (e.g., cerebral palsy, epilepsy, traumatic brain injury) may result in permanent brain-behavior alterations that adversely affect learning ability and social behavior. In some cases a child may have limited or restricted intellectual capacities; among children with brain injuries, behavioral disruptions such as agitation, impulsivity, or emotional
lability may be present independent of intellectual impairments. Some chronic conditions (e.g., narcolepsy, idiopathic hyposomnia) may have fluctuating and unpredictable effects on alertness and awareness.

For many children with disability, optimal health may be contingent upon successful completion of a daily array of medical and behavioral activities. Some medications may be necessary to maintain alertness or facilitate appropriate social behavior. Many disabilities that impair central nervous system function require adults to assist the child in movement (turning, stretching, transferring, etc.), toileting, and other activities of daily living (eating, clothing, grooming). In these situations, the concomitants of the disability (e.g., motor paralysis) interact with the qualities of the social and interpersonal environment to directly affect the health and well-being of the child. Parents vary considerably in their propensity to adhere to behavioral regimens for care and in having access to appropriate services from medical, educational, and public institutions.

Certain disabilities also result in significant physical limitations, which in turn may or may not impinge on the ability to engage in valued life activity. Numerous studies now point out that disease severity in and of itself is not as predictive of adjustment as is the extent to which the condition intrudes on one's ability to engage in pleasurable life activities (Devins et al., 2000).

**Personality Characteristics of Family Members**

Personality characteristics or traits are often related in predictable ways to family adjustment following disability. Although many different constructs have been studied in this area, variables that are grounded in cognitive-behavioral models appear particularly promising. These models often feature a logical framework with testable hypotheses, a supportive literature base, psychometrically sound measures, and clear directions for interventions. Exemplary research has been guided by a model of social-problem-solving abilities (D'Zurilla & Nezu, 1999). Mothers of children with disabilities who report a greater sense of confidence in their problem-solving ability report higher levels of adjustment than mothers who lack this confidence (Noojin & Wallander, 1997). These beneficial effects appear independent of stress levels reported by the mothers. Effective social-problem-solving abilities are predictive of family caregiver depression, anxiety, and ill health over the first year of the caregiver role (Elliott, Shewchuk, & Richards, 2001).

Parents who have more effective written and verbal problem-solving skills adhere more to complex self-care regimens for their children than parents of children noted for poor compliance (Fehrenbach & Peterson, 1989). Families that exhibit effective problem-solving strategies in interpersonal interactions report less distress, and these benefits can be observed up to 3 years later (Rivara et al., 1996). These skills may be a major determinant of child behavioral outcomes over the first year of traumatic brain injury (Kinsella, Ong, Murtagh, Prior, & Sawyer, 1999).

Children also vary in the degree to which they possess adaptive personality characteristics, some of which reflect specific cognitive patterns or styles. Children may have hopeful beliefs about themselves, their goals, and ways to achieve...
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these goals, and these beliefs have been inversely related to distress reported by children with sickle-cell disease (Lewis & Khewer, 1996) and burns (Barnum, Snyder, Rapoff, Mani, & Thompson, 1998). Higher levels of hope are uniquely associated with improved maternal adjustment, and this effect seems to be most pronounced under conditions of high stress specific to the condition (Horton & Wallander, 2001). Children with Type 1 diabetes who exhibit a negative attributional style (i.e., learned helplessness) are at risk for adjustment problems and difficulty in adherence to their medical regimen (Kuttner, Delameter, & Santiago, 1990). Similarly, perceived control has been linked to adjustment in children with Type 1 diabetes (Band & Wiesz, 1990). Collectively, these studies underscore the importance of attending to the cognitive-behavioral characteristics of children with disability and of their parents.

SOCIAL AND ENVIRONMENTAL FACTORS

This component of the model encompasses the social and environmental factors that can have a tremendous impact on a child’s behavior, including stigma, social relations, family interactional patterns, social support, gender-related issues, parental modeling, and issues of ethnicity.

Stigma, Competence, and Social Relations

The special education literature is replete with evidence demonstrating the deleterious effects of social stigma on children with disabilities, as it is encountered in educational institutions from peers and adults. Stigma may occur in reaction to the physical features of the disability or its treatment, but it may also be in reaction to a diagnostic label for an “invisible” disability (e.g., attention-deficit disorder). Stigma is associated with decreased expectations for performance, lowered accountability, and increased expectations for failure.

Less obvious has been the experience of stigma perpetrated by helping professionals toward the family and child. Many health-related professionals anticipate negative outcomes, and positive behaviors will often be construed in a negative light. For example, an adolescent with an outstanding history of scholastic achievement and personal adjustment was criticized by rehabilitation staff for stating her optimistic goal to return to school as soon as possible following her discharge from an inpatient program for traumatic brain injury (Elliott & Kurylo, 2000). Her goals were interpreted by staff as “pathological denial,” and the neuropsychologist recommended the girl should miss a year of school. The team did not recommend any assistive devices to support her pursuits. The parents were forced to choose between their daughter’s stated goals and the team’s recommendations. The family supported their daughter over the objections of the team; the daughter successfully met her goal to graduate on time with her high school class (and has since earned her bachelor’s degree from a major state university).

This case may not be representative of many outcomes following brain injury. Nevertheless, it illustrates the difficulties families must navigate in their interactions with health care professionals—who may pressure families to discount
their personal experience and the opinions of the child—in order to pursue an agenda that may be more suitable to professional bias than the family.

Social Relations

Children with disabilities that affect the central nervous system (e.g., cerebral palsy, epilepsy, spina bifida) may experience significant difficulties with social competence and peer relations. In part, the cognitive impairments associated with these conditions may blunt the learning, understanding, and recognition of social cues and interpersonal relationships (Nassau & Drotar, 1997). Low cognitive ability is associated with diminished social skills (Bellanti & Bierman, 2000). Children with cancerous brain tumors may also demonstrate difficulties with social competence. Such problems may be related to treatment procedures, to the time spent away from school in lengthy and time-consuming treatments, and to parental overprotectiveness (Fuemmenler, Elkin, & Mullins, 2001). Thus, children with disabilities may experience considerable disruption in their social relationships.

Family Interactional Patterns

For many years, clinical lore concerning family dynamics in the wake of a chronic health condition was driven by Minuchin’s conceptualization of rigid, overprotective, and enmeshed family interaction patterns that contribute to the development and exacerbation of physical symptoms in children (Minuchin et al., 1975). Subsequent research has not supported the basic tenets of this model (Coyne & Anderson, 1989), and alternative models have been suggested that involve biobehavioral formulations (Wood, 1993) or transactional stress and coping approaches (Thompson & Gustafson, 1996). Such contemporary approaches have empirical support and lend themselves to continued research on family interaction. For example, recent evidence indicates that some of these interactive patterns in which a child’s input is recruited into dyadic discussions may be related to marital quality and may be useful in long-term coping, monitoring, and management of a chronic condition (Northey, Griffin, & Krainz, 1998). Increased family cohesion and high quality of mother-child interactions are predictive of positive growth in socialization, daily living skills, and communication among young children with Down’s syndrome (Hauser Cram et al., 1999).

Social Support

Despite the usually unquestioned premiums associated with social support, the extant literature does not provide clear implications for counselors in search of therapeutic direction for clinical practice. For many mothers who provide care to a child with a disability or chronic disease, social support once at hand erodes with the passage of time (Quittner, Glueckauf, & Jackson, 1990). Social support also seems to depend on personal characteristics: Mothers who have more personal resources (e.g., self-esteem, mastery), more intimate personal resources, and lower discomfort in seeking support report more support over a year of caregiving for a child with chronic illness (Hobfoll & Lerman, 1989).
Other research indicates that mothers of children with physical disability may experience a lack of positive reinforcement (or opportunities for such) in pleasant interactions with the world outside the family. Quittner and colleagues have found that mothers of children with chronic disease have fewer leisure activities, as they are preoccupied with caregiving tasks (Quittner, Opipari, Regoli, Jacobsen, & Eigen, 1992). Time spent in recreation might mediate the relation between role strain of parents and their distress (Quittner et al., 1998). This dearth of meaningful, rewarding leisure time may deny family members the opportunity to experience positive reinforcement and positive moods associated with these activities.

**Issues of Gender**

Research to date indicates distinct parent gender differences in the context of children's disability. Women are more likely to assume the role of primary caregiver for a child with a disability (Moen, Robison, & Dempster-McClain, 1995). Women in caregiving roles report more distress than men in similar roles, but these differences may be attributable to the willingness of women to report distress and the different appraisal processes between men and women (Buurman & Margolin, 1992).

Children's adjustment is often associated with the mother's adjustment, but maternal caregiver adjustment is influenced more by stress, family support, and personal resources than the severity of the condition or functional abilities of the child (Wallander, Pitt, & Mellins, 1990; Wallander et al., 1989). Although mothers often encounter social isolation as they care for a child with a chronic disease or disability, fathers report more strains associated with financial obligations and work-related activities that affect the care and well-being of the child (Frank, Brown, Blount, & Bunke, 2001).

The emotional needs of men and women may also vary considerably while parenting a child with a disability. As an example, although fathers and mothers of children with spina bifida reported less parental satisfaction than those in a comparison group, the mothers—and not the fathers—of these children reported higher levels of social isolation and lower levels of perceived parental competence (Holmbeck et al., 1997). These mothers were also more likely to rely on avoidant coping behaviors, implying a possible association between palliative coping behaviors, lower competence, and distress. Other longitudinal research indicates that spouses' use of avoidance coping is predictive of poorer parental adjustment 1 year later among parents of children with juvenile rheumatoid disease (Timko, Stovel, & Moos, 1992).

Although the impact of fathers on child adjustment has been largely overlooked in past research, accumulating evidence now demonstrates that fathers have a considerable impact on adjustment of a child with a chronic health condition, even when the father does not assume the role of family caregiver per se. For example, fathers' drinking problems and parental strain were predictive of child adjustment over a 4-year period (Timko, Baumgartner, Moos, & Miller, 1993). Chaney, Mullins, Frank, and Peterson (1997) found child adjustment over a year was directly related to increases in fathers' distress, and not the mothers' distress.
A decline in fathers’ adjustment was inversely related to mothers’ adjustment. Such research clearly demonstrates the need to attend differentially to fathers and mothers as it concerns their specific response to child disability.

**Modeling Influences From Parent to Child**

Parents can model effective coping skills for their children, who in turn may use similar strategies (Kliwer & Lewis, 1995). Parental support and coping behavior are positively associated with a child’s compliance with self-care regimens (Chaney & Peterson, 1989). In contrast, behavioral problems and health complaints of adolescents with chronic disease are more likely in families lower in family competence (Kell, Kliwer, Erickson, & Ohene-Frempong, 1998) and in marriages characterized by poor adjustment and interactional strain between husbands and wives (Clay, Wood, Frank, Hagglund, & Johnson, 1995; Frank et al., 1998). Numerous studies now document a clear pattern; one of the single best predictors of child adjustment to illness is parent adjustment (Mullins & Chaney, 2001). What remains to be determined are the specific processes by which this modeling occurs.

**Issues of Ethnicity**

Research to date has yet to systematically address issues associated with minority status and ethnic backgrounds in this area (Drotar, 1997). The very constitution of family in minority ethnic groups can differ from the majority in American society. For many European American families, the close family consists of mother, father, and children; in many minority families this can include grandparents, aunts, and uncles (Basic Behavioral Science Task Force, 1996). Pickett, Vranjak, Cook, and Bertram (1993) observed that African American parents of children with disabilities had higher feelings of self-worth and lower levels of depression than European American parents with children who had disabilities. Importantly, the extended family structure and the collectivist spirit characteristic of many minority families suggests that these families might be able to cope better with a disabling condition of a family member than European American families.

However, such conclusions should be made cautiously. Errors in judgment about cultural groups are frequently based on such stereotypes. Because families of color are often depicted as being close-knit and supportive of their kin, for example, social service agencies may not take the time to assess the actual needs of this population. Such assumptions may lead to less allocation of resources, personnel, and finances for outreach to these communities (Valle, 1981), which in turn, may help perpetuate the misconception that they underutilize social services because they are taken care of by their own families (Henderson & Gutierrez-Mayka, 1992).

**PHENOMENOLOGICAL PROCESSES IN ADJUSTMENT**

Cognitive appraisals reflect personal experience and interpretations of events, and because they are influenced by personal and social factors, they are dynamic and complex. Generally, clinicians encounter phenomenological appraisals as they are
expressed in times of duress as individuals search for meaning and avenues for coping. Clinicians are then vigilant for manifestations of denial, assuming family members are unconsciously unable to accept the fact that a loved one may be permanently affected by a diagnosis. However, clinicians often fail to appreciate that many people are generally unaware or uninformed about specific health problems and their concomitants and thus may have legitimate difficulty in understanding the meaning and ramifications of a specific condition. Denial is not a single, simplistic entity: Families may not deny the factual existence of a particular disabling condition, but in turn they also may not accept the implications of the condition as promulgated by clinical staff. Families that maintain positive goals and expectations and that express optimism in the wake of an acquired disability are often labeled by staff and treated with disregard and condescension when in fact a family may express nothing more than a difference of opinion with staff.

Phenomenological perspectives are also expressed in terms of personal values and goals. Goals of personal importance are more likely to be attained in rehabilitation programs than goals imposed by a treatment team (Webb & Glueckauf, 1994). Family members may experience positive shifts in their values and reconsider goals that were altered in the face of disability, and these shifts are indicative of stress-related growth and subjective well-being (King & Patterson, 2006; King, Scollon, Ramsey, & Williams, 2000).

Furthermore, families are quite capable of identifying the specific problems they experience in facing their child’s disability and in recommending ways to address these problems and meet their needs. Families are not usually seen as active stakeholders in their health care, so decisions about problems to be addressed and services to be provided are often made by institutional staff with no input from these consumers (Elliott & Shewchuk, in press). We have learned in focus groups, for example, that mothers of adolescents with cerebral palsy report specific problems with finances, patience, worries about outliving their child (and the child’s subsequent welfare), and difficulties with public resources, sources of assistance and support, and other relationships. These are problems that can be actively addressed in intervention programs for the family. Such problems also have implications for public and social policy that affects these families. Other researchers have developed instruments that are oriented toward identifying specific areas of concern for intervention, which can be more useful than a global index of stress for diagnostic or research purposes (e.g., Noonin & Wallander, 1996).

In this model, we recognize the need to understand and appreciate the individual experience as it is expressed in the report of problems, concerns, and stress, and in terms of personal meaning, values, goals, and attributions. In this fashion we avoid a top-down approach in which we assume the nature of stress or the types of problems “typically” experienced. This permits a more strategic tailoring of interventions to meet the unique needs of the family and the child and incorporates these individuals as active participants in their health and well-being. It also allows us to respect the development and dynamic process of adjustment and accompanying changes that may occur for the individuals over time, without being confined to condescending and demeaning language that emphasizes pathology (conveyed, e.g., in the term relapse).
DEFINING ADJUSTMENT AND QUALITY OF LIFE

Optimal adjustment, as depicted in Figure 6.1, entails physical health and personal well-being, and these broad concepts are often related. Difficulties and personal setbacks in health, which often result in secondary complications specific to a condition (e.g., pressure sores associated with a spinal cord injury), usually occur at great expense to the child, the family, and service institutions and health care programs. These are often understandably associated with distress and discouragement. However, maintenance of health and optimal adjustment is also associated with a greater sense of well-being and satisfaction.

Although researchers and clinicians usually focus on the adjustment problems experienced by families following disability and disease, some families experience positive changes (Perlesz, Kinsella, & Crowe, 1999). Acquired disability can force family members to directly confront issues of trust, mortality, and values, which in turn compel members to develop deeper commitments and restructure the meaning of marriage or kinship (Olkin, 1999). Some family members report a greater sense of closeness, a greater emphasis on family and personal relationships, and positive changes in shared family values (Crewe, 1993). Many studies appear to overreport or misrepresent distress experienced by siblings of children with disability, and these issues seem to be adversely slanted by methodological and theoretical approaches that perpetrate negative views and ignore positive aspects of this experience (Perlesz et al., 1999; Summers, White, & Summers, 1994). Indeed, some studies actually indicate that siblings of children with developmental disabilities report a number of positive consequences of growing up in such a family (McHale, Sloan, & Simeonsson, 1986).

INTERVENTIONS

Working with families and children with disability requires a more expanded role than is typical in many settings. Because by definition intervention therapeutic efforts are often interdisciplinary and multisystemic (Mullins & Chaney, 2001) counselors will often serve as individual therapist, family counselor, case manager, advocate, and systems consultant in almost simultaneous fashion. Clearly, the family remains the centerpiece of the intervention effort. The role of family members is routinely acknowledged as a major focus of psychological intervention for a child with a disability or chronic disease (Kazak, Segal-Andrews, & Johnson, 1995). Counselors should first and foremost develop interventions that best meet the needs of the child and family, as they are experienced and reported by these individuals. Interventions that address the specific needs of families and their members—as they perceive them—may be more likely to succeed (Burnam & Margolin, 1992). Parents will need education about the nature of a particular disabling condition, its course, and the likely effects it may have on their child's development. Moreover, they will need continued support at strategic times in the developmental course of a given condition. Shifting role responsibilities within the family system may also be a concern, not to mention financial stress. Counselors should also develop adjacencies ability and should half of the families knowledgeable about Disability Education they are working at and culture, as for the many intervent

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Counselors should also be mindful of the impact different social, educational, and medical agencies have on the well-being of parents and children living with a disability and should advocate for the need to intervene with these systems on behalf of the family (Kazak et al., 1995). In this regard, the counselor must be knowledgeable of both local public education law as well as the Individuals with Disability Education Act (IDEA) and the implications for the child with whom they are working. Finally, the counselor must be cognizant of medical systems and culture, as frequent contact with health care professionals is an essential part of many intervention efforts.

There are times when counselors will intervene to provide specific skill-building activities so that a child may be better equipped to negotiate the realities of his or her social and interpersonal world; social skills training is an effective intervention for these children (Varni, Katz, Colegrove, & Dolgin, 1993). Children can be taught to recognize social cues, develop social competency, and engage in assertive responding through the use of role plays and modeling. In recent years, empirically supported treatments have also been developed for promoting treatment adherence (e.g., Lemanek, Kamps, & Chung, 2001) and for managing acute and chronic pain (e.g., Wilco, Sterling, Conte, & Engel, 1999). Each of these problems is particularly common in children with disabilities. And, because many children with disabilities are often targets for teasing and bullying, efforts can also be extended to teaching specific adaptive responses to teasing and threats. Finally, cognitive behavioral interventions developed for nondisabled children can be readily adapted and utilized for helping children cope with anxiety and depression.

In other situations, it may be more strategic to directly address the needs of the parents, and this may at times involve some nontraditional accommodations to circumvent barriers in transportation and mobility. This is particularly true for parents who live in geographically remote areas. One multisite, randomized trial of face-to-face problem-solving training sessions for mothers of children with cancer offered some telephone sessions for participants if they were unable to make the designated site and if they had attended at least one session with the trainer (Sahler et al., 2002). After an 8-week intervention, mothers assigned to the treatment group had significantly lower distress and higher problem-solving skills in comparison with control group participants.

Computer-based technologies can be used to conduct family counseling sessions, and these modalities have been used successfully with families that have a teenage child with seizure disorders (Hufford, Glueckauf, & Webb, 1999). Home-based video counseling and speaker phone counseling, and face-to-face office-based counseling appear to be equally effective in reducing problem severity experienced by families and preadolescents with epilepsy; moreover, these respondents preferred the two home-based modalities over the traditional office visit (Glueckauf et al., 2002). Virtual-reality technologies have also been developed to help children and adolescents learn specific skills (e.g., cope with intense pain; Hoffman, Doctor, Patterson, Carrougher, & Furness, 2000) and attain greater mobility and independence (learn activities of daily living, driving skills; Schultheis & Rizzo, 2001). Counselors should be aware of alternative
interventions and assistive technologies that can promote behavioral change and enhance quality of life.

Other less traditional forms of intervention may also be initiated by the counselor for families of children with disability. In recent years, respite care has become an increasingly popular form of care offered as a means of alleviating caregiver burden or stress. Respite care can be offered on an outpatient, inpatient, or in-home basis according to the desires of the family and available resources. Recent evidence suggests that short-term inpatient respite stays (3–7 days) can result in significant decreases in psychological distress experienced by parents of children with severe disability (Mullins, Aniol, Boyd, Page, & Chaney, 2002). Importantly, these benefits were maintained over a 6-month period.

Counselors will invariably be in a position to consult with educational and other service institutions on appropriate interventions for children. Well-intentioned but misguided efforts have often assumed that increased contact between children with and without disability will dispel stigma and foster peer acceptance, but research presents a very different picture. The quality of the contact and the experience of achievement and the emphasis on ability (rather than the disability) will have ameliorating effects on stigma. In other cases, counselors may need to advocate on behalf of the family for certain and specific services to increase the likelihood of achievement or may need to suggest appropriate accommodations that promote access and independence in an environment.

Cases and Questions

1. You are a university counselor at a major university and you also direct the Employees Assistance Program. A staff member calls and seeks your help in dealing with his 7-year-old son's adjustment to Type 1 diabetes. Diagnosed approximately 3 years ago, he is refusing to take his insulin shots, test his blood sugar, or adhere to his diet. He displays a defiant attitude, and in his father's words, now "runs the family." The parents apparently disagree over ways to discipline the child, and the father sounds bitter and angry in describing their arguments. The school is threatening to recommend a home school program if he cannot get his blood sugar under control in the school environment.
   (a) What family systems factors might be operating to perpetuate these behavior problems?
   (b) How might you go about assessing the parents' phenomenological perspective on their son's difficulties?
   (c) How might you empower these parents to enhance their role as stakeholders in their child's health?
2. A local school counselor calls you expressing his concerns about a 13-year-old African American boy who was diagnosed at birth with cerebral palsy. Although he uses a wheelchair, he is quite mobile and has little difficulty negoti-
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at the school environment. He has no known cognitive impairments and typically has performed well in his classes. The school counselor, who has known this adolescent and his mother for the past 4 years, has noticed distinct changes in his behavior in recent months. He has appeared withdrawn, his grades have dropped, and he seems to be hanging out with a "roug"er" crowd.

A teacher also reported that he was no longer taking care of his personal hygiene, and that his mother uncharacteristically did not attend a parent-teacher meeting earlier this year, as she has apparently taken a second job.

(a) What approach might you take in consulting with this school counselor?

What issues would you want the counselor to further assess?

(b) What issues might emerge as it concerns the adolescent’s African American background? Would this influence how you might conceptualize the change in his behavior, or not?

(c) How might you go about differentiating between how this client’s problems are influenced by his disability versus other factors at home and at school?

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