Chapter 2

Positive Adaptation and Coping Strengths of Families Who Have Children with Disabilities

Jean Ann Summers,
Shirley K. Behr, and Ann P. Turnbull

Families who have a member with a disability have long been objects of pity. Society as a whole tends to view the presence of a child with a disability as an unutterable tragedy from which the family may never recover. Researchers and service providers in the field of developmental disabilities have mirrored this societal perception, and tend to view the family as a whole as embroiled in a series of acute crises interspersed with chronic sorrow (Olshansky, 1962). Thus the task of family support is seen as ameliorating the deadly pall of tragedy that hangs over the family.

The day-to-day experiences of many thoughtful service providers, however, cast doubt on the universal validity of that perception about families who have members with disabilities. To be sure, one encounters families who seem to fit the stereotype—who are unable to cope with the emotional implications of the disability and/or the daily demands that are placed on them as a consequence of the disability. But there are other families who do quite well, with or without interventions from service providers. These are the families who roll up their sleeves and get on with the task of finding the best available services for their child: who both accept the reality of the disability and are able to love the child for who she or he is; who manage to have successful marriages and emotionally well-adjusted children, both with and without disabilities. Many of them have enough energy left over from coping with the demands of their own lives to provide support to other families, and even to

give encouragement now and again to weary educators and service providers. These families are said to have made a *positive adaptation* to their child with a disability. We meet these families every day in the course of our educational or health practices.

Yet seldom, if ever, are they presented in the research literature or the textbooks designed to prepare practitioners to work with families who have members with disabilities. The typical portrait is one of families who are in distress, and the goal of the practitioner is to alleviate that stress, to "fix" the problems associated with a child with a disability (Turnbull, Blue-Banning, Behr, & Kerns, 1986; Turnbull & Turnbull, 1986). This perception is, in the authors' opinion, a great loss. Families who successfully meet the challenge of a child with a disability have much to teach us, not only about what works, so that we may provide support to those who are struggling, but also about our own attitudes toward people with disabilities. Furthermore, a focus on distress makes the practitioner's task more difficult since there is less opportunity to build on family strengths as a part of the overall intervention strategy.

The purpose of this chapter is to explore some of these success stories. It begins by considering ways in which the experience of having a child with a disability may strengthen families as well as create some distress. Second, the chapter describes some of the cognitive coping strategies that families may use to meet the challenges of a child with a

disability. Finally, it considers some of the implications of these positive contributions and cognitive coping strategies for practitioners who will be supporting those families.

EVIDENCE OF POSITIVE CONTRIBUTIONS BY PEOPLE WITH DISABILITIES TO THEIR FAMILIES

Family Narratives and Anecdotal Reports

Perhaps because of the focus on distress that has been pervasive in research on families of persons with disabilities (Summers, 1988; Turnbull & Turnbull, 1986), the vast majority of evidence for positive contributions lies not in the empirical literature but in parent narratives and anecdotal literature. One of the earliest voices to be raised in this vein was from Murray (1959), a mother of a child with mental retardation:

> It has been my privilege to have talked with hundreds of parents of retarded children. One of the favorite themes which permeates our conversation is how much our children have meant to us. This thought runs like a bright golden thread through the dark tapestry of our sorrow. We learn so much from our children . . . in patience, in humility, in gratitude for other blessings we had accepted before as a matter of course; so much in tolerance; so much in faith—believing and trusting where we cannot see; so much in compassion for our fellow man; and yes, even so much in wisdom about the eternal values of life. (pp. 1087-1088)

Similar observations have been shared through conversations with family members, newsletters of consumer organizations, and the popular media. For example, the *Down Syndrome News* (Watson, 1986) printed a portion of an essay written for a college entrance application by the sister of a girl with Down syndrome. A portion of that essay reads:

> My sister . . . is truly one of the most wonderful human beings in the world. Melissa has taught me to accept all people and respect their feelings. She enables me to realize, in a moment of panic, that a

homecoming date will not determine my future happiness. She reminds me to slow down, when my schedule gets so frantic I lose time for my family. (Watson, 1986, p.54)

Another sibling described the contribution of her sister with mental retardation as giving her family a sense of strength and identity:

> I always felt there was something very special about our family. . . . Because of [Cathy's] difference there was a degree of specialness or closeness that made us all very, very close. We all pitched in and helped each other out and Cathy was the one thing in difficult times that we could focus on. (Klein, 1972, p. 25)

The themes of narratives written by family members include those mentioned above—tolerance, faith, strength, professional and personal growth and development, and understanding the meaning of life (see, e.g., Featherstone, 1980; Turnbull & Turnbull, 1985).

In a content analysis of 60 books written by parents of children with a wide variety of disabilities, Mullins (1987) identified four major themes: 1) a realistic appraisal of the disability, 2) extraordinary demands on families, 3) extraordinary emotional stress, and 4) resolution and growth. With regard to this last theme, Mullins (1987) found that the majority of authors felt their lives were enriched and made more meaningful, regardless of the type or severity of their child's disability. Mullins cites a comment from one parent that she notes as typical of the prevailing attitude of most of the authors:

> I write now what fifteen years past I would still not have thought possible to write: that if today I were given the choice to accept the experience, with everything that it entails, or to refuse the bitter largess, I would have to stretch out my hands—because out of it has come, for all of us, an unimagined life. And I will not change the last word of the story. It is still love. (Park, 1982, p. 320, cited in Mullins, 1987, p. 33)

Empirical Studies

A few empirical studies have found evidence of positive contributions, in some cases as an incidental finding to the major interest of the investigation. Wikler, Wasow, and Hatfield (1983), in the conduct of a study concerning chronic sorrow experienced by parents, included a question asking whether the respondents felt that raising a child with a developmental disability made them stronger or weaker. A total of 75% of this small sample (*n* = 27) indicated that their experiences had made them stronger, with 46% indicating that they had been made *much* stronger. In contrast, only 9% of the professionals surveyed in this study (*n* = 43), believed that parents would feel that their experience had made them much stronger.

In a study of coping resources of families who have children with mental retardation, Abbott and Meredith (1986) found that 88% of a sample of 36 parents reported positive contributions of their child with a disability. These included a closer and stronger family (55%); personal growth, such as more patience, compassion, and unselfishness (41%); and a greater appreciation for the small and simple things of life (17%).

Turnbull, Guess, and Turnbull (1988) content-analyzed letters sent to the Select Subcommittee on Education in the United States House of Representatives in support of regulations concerning treatment of newborns with disabilities. The 174 letters sent by parents, relatives, and individuals with disabilities were coded as to type of respondent, reasons for supporting the regulations, and the inclusion of recommendations pertaining to providing parent support or adoption options. Thirty-five percent of the respondents identified, as a reason for supporting the regulations, at least one positive contribution (usually to the family) by the person with a disability. Furthermore, approximately two-thirds of persons with disabilities and one-third of family members mentioned positive attributes of people with disabilities. In the 61 letters mentioning positive contributions to the family, six subcategories of contribution emerged: 1) source of joy (39% of 61), 2) source of learning life's lessons (28%), 3) source of love (28%), 4) source of blessing or fulfillment (28%), 5) source of pride (8%), and 6) source of family strength (5%).

(Percentages exceed 100% because many respondents identified more than one contribution).

Turnbull, Behr, and Tollefson (1986) conducted unstructured interviews with 18 parents who have a child with a disability, and 10 parents who have children with no disabilities. These parents were asked to describe the areas of their life (e.g., marriage, other children, extended family) that had been affected by their child, how their life would be different without their child, what pleases and displeases them about their child, an example of a positive and a negative experience with their child, and some of the positive contributions the child may have made to the family, friends, and society. Responses of parents of children with disabilities were coded, initially using the six categories of contribution generated in the Turnbull et al. (1988) study described above. Eight new categories were identified; parents of children with disabilities now identified their children as either sources of or reasons for:

1. Increased happiness
2. Greater love
3. Strengthened family ties
4. Strengthened religious faith
5. Expanded social network
6. Greater pride and accomplishment
7. Greater knowledge about disabilities
8. Learning not to take things for granted
9. Learning tolerance and sensitivity
10. Learning to be patient
11. Expanding career development
12. Increased personal growth
13. Assuming personal control
14. Living life more slowly

The sample of parents whose children had no disabilities contributed similar responses, except that they had no responses related to "living life more slowly" or "strengthening religious faith," but these parents added new categories of "source of energy and enthusiasm," and "source of practical help." (The category "source of knowledge about disability" was reconstituted to a more general category, "source of knowledge about child-rearing and family life.") These findings suggest that parents not only perceive their children with disabilities as making positive

contributions to their lives, but also that those to perceptions about positive contributions of children without disabilities.

Theoretical Rationale
for Positive Contributions
The idea that families might derive some positive effects from an event that is considered stressful and undesirable is plausible from the perspective of stress theory. To understand a rationale for positive growth deriving from stressful events, it is necessary to consider some of the current thinking in social stress theory.

Stress theory has its roots in the work of Hill (1949), who formulated the ABCX model of stress. That theory postulates that a family's reaction (X) to an event (A) is mitigated by the family's resources (B) and its perceptions of the significance of the event (C). Hill's theory has undergone numerous modifications and elaborations since 1949 (McCubbin et al., 1980), but the basic structure remains. McCubbin, Sussman, and Patterson (1983), however, have called attention to the need for stress theory to accommodate the possibility of positive outcomes as a reaction to stress. They note:

> Our review of the field has left us with some discomfort regarding the lack of recognition, on the conceptual and empirical levels, that stress can be productive in some instances. Researchers have tended to use a unidirectional, pathological model which implies that the recipient experiencing stress as a consequence of one or more stressors must adapt, reach a steady state, recover, or if not destroyed will function less than adequately afterwards . . . few workers can visualize stress in a more positive framework. It can be postulated that creativity, effective communication in interpersonal relationships, motivation, and increased competence in brain, verbal and physical skills are outcomes of stress experience. (pp. 1-2)

McCubbin and Patterson (1983) attempt to rectify this problem through their proposed Double ABCX model, in which the family's reactions (X) create multiple events (Aa), and additional resources as well as altered perceived contributions are relatively similar perceptions, in a continuous cycle. Thus, the process of reacting to a stressful event is not seen as a single event but as an ongoing process in the life of a family. Depending on the family's reactions, this could lead to adaptation or accommodation resulting in a progressively upward spiral of growth ("bonadaptation," in McCubbin and Patterson's [1983] terms), or a downward spiral of dysfunction and crisis ("maladaptation"). McCubbin and Patterson (1983) define bonadaptation as follows:

> The positive end of the continuum of family adaptation, called bonadaptation, is characterized by a balance at both levels of functioning which results in (a) the maintenance or strengthening of family integrity; (b) the continued promotion of both member development and family unit development; and (c) the maintenance of family independence and its sense of control over environmental influences. (p. 20)

In short, current thinking in stress theory suggests that a given family's reaction to a challenging event could cause it to marshall its resources and focus its perceptions on positive aspects of its life, and, in the process of solving the initial problem, employ that event as a catalyst to improve other aspects of family life.

Beyond stress theory, it should be acknowledged that a child with a disability encompasses a multitude of characteristics, some related to the disability and some not. Some characteristics or personality traits may lead to stress in the family, while others may yield nonstressful effects that may be either positive or negative. In this regard, a child with a disability may be similar to children without disabilities. For example, an adolescent may have no disabilities but may experience special problems such as drug or alcohol use, sexual exploitation, eating disorders, or a multitude of other possibilities creating stress in the family; and *at the same time* the adolescent may provide assistance with household chores, serve as a source of pride in accomplishments, and become a participant in shared hobbies with parents. Children with disabilities may offer their own mixtures of positive and negative contributions (Turnbull, 1985). The

tendency to define *impact* in terms of a unitary construct such as stress, may obscure the multiplicity of effects of the total human personality (Summers, 1988).

Summary and Conclusion about Positive Adaptation

The consistency of parent narratives reporting positive growth, love, and other benefits invites a more systematic program of investigation. The studies reported above should be considered first steps in that direction. They should be considered hypotheses of types of positive contributions to be validated by more extensive research. Nevertheless, parent narratives and empirical studies consistently suggest that children with disabilities do contribute positively to their families, and that some families may not only survive their experience with disability, but also grow stronger. Theoretically, such positive contributions are possible within the context of stress and coping theory because the family utilizes stress as a catalyst to improve its functioning, and because stress and coping theory recognizes multiple outcomes that allow for a variety of positive and negative effects.

On a substantive level, the contributions of children with disabilities are usually seen as some type of intangible value or resource, such as greater strength, closer family ties, personal or career growth, and love. In short, in the experience of many families who have children with disabilities, those children are not devalued objects, but active and contributing members of their families, whose presence makes a real contribution to an improved quality of life.

All of this is not to deny, however, that all children, including those with disabilities, do present a special challenge to their families. And, those who successfully meet the challenges of a child with a disability may be equipped with particular coping skills and resources that allow them to do so. The next section of this chapter considers coping skills and resources that may contribute to success.

COPING SKILLS AND RESOURCES THAT ARE PREDICTIVE OF FAMILY SUCCESS

In the mid 1980s, a new strand of research on families who have children with disabilities has diverged from the documentation of distress in these families, to an identification of factors that may contribute to successful coping in families (see, e.g., Abbott & Meredith, 1986). This shift has in essence required a reversal of the dependent and independent variables under study. For example, rather than considering the impact of a child with a disability on the quality of the parents' marriage, the question becomes: What is the impact of the quality of the marriage on the ability of the family to cope successfully with the demands of the child with a disability (Friedrich & Friedrich, 1981)? This line of inquiry is fairly recent, but has produced results that point the way toward an understanding of how families may successfully cope.

Investigators concerned with families of people with disabilities have increasingly adopted the ABCX stress and coping model described previously, in order to explain variances in family responses to a child with a disability. The ABCX model has been utilized by several reviews of literature and analyses of impacts of events in families who have children with disabilities (Bristol & Schopler, 1983; Cole, 1986; McDonald-Wikler, 1986; Turnbull, Summers, et al., 1986).

Concerning family resources (B in the ABCX model), a number of potentially effective resources and interpersonal skills that may lead to successful coping have come to the attention of investigators. These include: problem solving and behavior management skills (see Chapters 4 and 5, this volume); negotiation and communication skills in working with professionals (see Chapter 6, this volume); informal social support, including other family members (see Chapter 7); and generic community support (see Chapter 8). Similarly, all of the formal service programs designed to provide family support, such as respite care and family subsidies, might be conceptualized as programs intended to enhance family resources for coping.

Family perceptions (the C factor in the ABCX model) have been much less extensively explored as they relate to families of children with disabilities. McDonald-Wikler (1986) notes that "we are very far . . . from developing instruments or even concepts that can confidently be employed in the study of family perceptions" (p. 190). Yet perceptions

may be powerful predictors of successful family coping. In fact, some theorists have suggested that resources such as social support may enable people to gain access to perceptions that reduce feelings of threat or stress associated with an event; for example, comparisons with others may lead a person to perceive his or her problem as less difficult than those faced by others (Shumaker & Brownell, 1984).

The key to a study of perceptions may lie in the work of cognitive coping theorists. Cognitive coping strategies refer to the ways in which individual family members may change their subjective perceptions of stressful situations (McCubbin et al., 1980). Taylor (1983) proposes a theory of cognitive adaptation in which she hypothesizes that adjustment to threatening events is mediated by three dimensions of cognitive adaptation: 1) attributing a cause for the event, 2) establishing a sense of mastery or control over the event in particular and over one's life more broadly, and 3) enhancing one's self-esteem. This chapter utilizes Taylor's framework to consider how these cognitive coping strategies may improve successful adjustment in families who have children with disabilities.

Casual Attributions

The first construct might be seen as an initial or related step toward either or both of the other dimensions of establishing mastery or enhancing self-esteem. Theory suggests that people who encounter a threat or an aversive experience may initiate a search for the cause of that experience in order to establish or re-establish a sense of control (Taylor, Lichtman, & Wood, 1984) and/or a sense of the orderliness and predictability of the environment (Rothbaum, Weisz, & Snyder, 1982). Similarly, people may tend to interpret the meaning of an event (the "why me" question) in such a way as to preserve or enhance their self-esteem (Taylor, 1983).

Investigators have found that people who have experienced a variety of threatening events tend to assign a cause or find some meaning in those events (Affleck et at., 1985; Bulman & Wortman, 1977; Patterson, 1985; Silver, Boon & Stone, 1983). There is support for the notion that finding meaning, purpose, or cause in a child's disability is correlated with

better psychological and physical health (Affleck, Tennen, & Gershman, 1985). Commentators have remarked that parents may be overly preoccupied (from the perspective of the service provider) with a search for the cause of their child's problems (Blacher, 1984), and may engage in "shopping behavior"; that is, parents may contract with a series of professionals to conduct diagnostic assessments of their child. Rather than a dysfunctional response based on denial, however, attribution theory suggests that identifying a cause may be a part of the adaptive process. For example, Bernheimer, Young, and Winton (1983) found that mothers of children with Down syndrome tended to experience less stress than mothers whose children were diagnosed with a developmental delay of unknown origin.

Whether the specific content of a causal attribution has a relationship to positive adjustment is not clear. One may blame a variety of sources for an event, including oneself, other people, the environment, a spiritual entity (God), or, more nebulously, fate or luck. Some research suggests that self-blame is associated with positive adjustment (e.g., Affleck, Allen, McGrade, & McQueeney, 1982), presumably because it serves as a basis for establishing control of the situation in the future. Consistent with this notion, other research has found that blaming others is associated with poorer adjustment (Bulman & Wortman, 1977; Taylor et al., 1984). Still other research suggests that the content of the cause is not as important as the fact of perceiving a cause in and of itself (Lowery, Jacobsen, & Murphy, 1983; Taylor, 1983), and that finding a cause may not be as important immediately after the onset of the crisis as it is at a later point in time (Bulman & Wortman, 1977; Taylor et al., 1984).

Mastery

The second construct, mastery, involves "gaining a feeling of control over the threatening event so as to manage it or keep it from occurring again" (Taylor, 1983, p. 1163). In the perspective of some commentators, one of the ultimate aims of humanity is to predict and control events (Kelly, 1967); thus, the ability to maintain control of a situation, or to perceive that one has control, may be a

powerful factor in reducing feelings of stress. Affleck et al. (1985) found that mothers of newborns in intensive care who believed they had greater personal control over their child's recovery tended to experience significantly less depression and significantly fewer major stress reactions (e.g., troubled dreams, blunted sensations). Other studies have found that parents with an internal locus of control tended to be better adjusted, to seek services for their children more actively, and to participate more actively in their child's treatment program (Affleck et al., 1982). Individuals may also perceive that others, such as doctors, service providers, or God, have the power to influence positively the outcome of a traumatic event. Taylor et al. (1984) found that belief in one's own control and in the control of others were both significantly associated with positive adjustment in women who have cancer. This line of research leads to the hypothesis that families of children with disabilities who perceive the future course of a situation as controllable may tend to experience better adjustment.

A further issue to be explored is the form of control a person may take. Two types of control suggested by Thompson (1981) are *information control* (learning about the situation) and *behavioral control* (taking direct action to change or improve the situation). An analysis of the relationship to adjustment by cancer patients to information control and various specific types of behavior control (e.g., changing diet, exercising more) yielded ambiguous results (Taylor et al., 1984). Future research might focus on the degree to which particular control strategies, such as partici-pating in a child's educational program or becoming active in advocacy groups, may enhance positive adjustment in families of children with disabilities.

Enhancing Self-Esteem

The third major construct of cognitive adaptation theory, enhancing self-esteem, is generally achieved through selectively attend-ing to the positive aspects or benefits of a situation, and/or comparing oneself positively to others. Selective attention, that is, focusing on positive attributes, has been identified as a coping strategy (Pearlin & Schooler, 1978), and a component of cognitive reframing (McCubbin, Larsen, & Olson, 1982). Taylor

(1983) labels construing positive benefit as establishing cognitive or retrospective control of a situation. For example, deriving a sense of pride in a child's accomplishments can center around the nature of the accomplishments, the perceived innate ability of the child, or the child's level of effort. Since level of effort may be more highly valued in this culture (Lavelle & Keogh, 1980), a perception that a child with a disability is working hard to achieve what might be considered by an outside observer to be a minimal gain might serve as a source of pride for families (see, e.g., Turnbull & Turnbull, 1985, for anecdotal reports that families do feel a sense of pride in the accomplishments of their child with a dis-ability). Focusing on the benefits of a situation involves a "search for a silver lining" (Venters, 1980). Researchers have found that people may construe positive benefits from a number of traumatic experiences, including cancer (Taylor, 1983), incest (Silver et. al., 1983), paralysis (Bulman & Wortman, 1977) and cystic fibrosis (Venters, 1980). Families who have a child with a disability may be no exception, given the number and variety of positive contributions that were described earlier in this chapter. A hypothesis emerging form these findings and self-reports is that families who are able to identify benefits from their experiences may have greater levels of family well-being. Whether the specific content of or the number of benefits identified has a relationship to well-being or positive adjustment is a further question to be pursued.

Self-esteem may also be enhanced by comparing oneself favorably to others. The idea is that people may feel better about their own situation if they perceive others as less fortunate in some way. An example of this phenomenon is the commonly held belief that wealthy people lead neurotic, shallow, and unhappy lives; the concomitant of this belief is that the observer is, by comparison, more fortunate to be poor but happy. Making positive comparisons is a coping strategy identified by Pearlin and Schooler (1978). Taylor (1983) found in her studies of women with breast cancer that women differentially chose their referent for comparison so that they could see themselves advantageously; for example, women with lumpectomies felt better off than women with radical mastectomies, and married women with mastectomies felt they

were better off than single women with mastectomies. Taylor's (1983) findings are paralleled by findings in a qualitative study conducted by Turnbull, Summers, and Brotherson (1984). Parents of children with disabilities in this sample either compared their children favorably to children without disabilities (e.g., believing that their child was easier to raise than the typical teenager), or compared their child's disability favorably to other disabilities (e.g., grateful that their child's disability was less severe or, alternatively, grateful that their child's disability was so severe that he or she could not be aware of and hurt by community stigma and rejection). These findings lead to the hypothesis that families who compare themselves favorably to others may tend to experience greater levels of family well-being.

In summary, people may employ a variety of cognitive coping strategies designed to reduce feelings of stress. First, individuals may search for the meaning or cause of a stressful event, either to render it more controllable in their minds, or to enhance their self-esteems. Second, copers may seek to gain a sense of mastery or control over a situation, to convince them-selves that they may be able to either prevent the recurrence of a situation or relieve or solve the problem. Third, copers may seek to enhance feelings of self-esteem in the face of stressful events by looking for the positive aspects of a situation (i.e., the positive contributions of a child with a disability), and by comparing themselves favorably to others in similar situations. All of these coping strategies have implications for family support services, which are considered in the final section of this chapter.

IMPLICATIONS OF COGNITIVE COPIES STRATEGIES FOR FAMLY SUPPORT SERVICES

Implications for Support Services

All types of family support services have the potential to enhance the use of cognitive coping strategies, to the extent that they may reduce stress enough to allow families to engage in calm reflection. Respite care programs, for example, may give families a chance to relax and view the situation from a more detached perspective. Two types of family support services, however, may have a more direct ability to encourage the use of cognitive coping strategies. These are social support groups and family education or informational services.

Social Support Groups Social support or self-help groups have become increasingly popular forms of family support among families who have children with disabilities (Pearson & Sternberg, 1986; Walsh, 1987). Support groups may be organized by a professional or may arise informally through associations among family members, but their chief characteristic is the provision of support among the peer members of the group (Scott & Doyle, 1984).

Support groups may serve a number of functions that enhance cognitive coping strategies. For example, the validation of one's feelings by other group members (Oster, 1984) might be seen as an enhancement of self-esteem. Also, family members who meet others in similar situations have opportunities to make comparisons with others, to share positive experiences, and to look at situations with a humorous eye, all of which relate to self-esteem. Finally, support groups, especially those whose members participate in advocacy, may help the participants achieve a sense of mastery or control through group accomplishment. The sharing of information that often occurs in support groups may also lead to a greater sense of empowerment (Oster, 1984). In addition, group leaders may directly explain the use of these coping strategies and encourage the members of the group to share their own effective strategies with one another (see Chapters 5 and 6, this volume, for a description of how this intervention may be helpful to some families). It may be useful for professionals or consumer volunteers who facilitate support groups to consider how the group can best enhance feelings of mastery and self-esteem.

Family Education and Informational Services A number of curricula for parent education have been developed that may serve to enhance cognitive coping strategies. Behavior modification training, for example, may enhance parents' sense of control and mastery over their child's behavior. Similarly, training and/or counseling programs designed to teach problem-solving and communication may increase control as well as self-esteem through increased feelings of competence.

Finally, educational programs providing family members with information about participating in decision making for their child's educational or habilitation program may directly enhance a sense of mastery and control through empowering family members.

A further question to be considered is whether these cognitive coping strategies can be taught directly. Stress-management training materials often contain sections on cognitive coping or reframing as a part of the curriculum (see, e.g. Hawkins, Chapter 5; Summers, Turnbull, Shaffer, & Brotherson, 1987); however to the authors' knowledge there has been no attempt to systematically teach families who have members with disabilities to use coping strategies directly related to causal attribution, mastery, and enhancement of self-esteem, or to evaluate whether this or any other type of training results in increased use of cognitive coping strategies.

The question of whether these strategies can be taught or are an integral part of an individual's personality traits is an empirical one requiring further investigation. Such a research agenda would require, first, a study of families who are good copers to identify the types of strategies they use, how they use them, and how they learned those strategies. Second, these results might be used to develop a curriculum to teach coping strategies. A careful evaluation of such a curriculum would also require a well-designed and psychometrically valid measure of the extent to which participants utilize these cognitive coping strategies. The curriculum could then be evaluated in the context of a controlled research design, comparing gains in the use of cognitive coping strategies by participants in the training with those who participate in peer support groups, and with those who receive no interventions.

Implications for Family-Professional Relationships

One of the most important aspects of family support is the relationship between the professionals serving a child with a disability and the family. Unfortunately, family members have often cited interactions with professionals as a source of stress as well as help (see, e.g., Warren, 1985). Kupfer (1984) notes that a certain amount of animosity between parents and professionals may be endemic, since pro-

fessionals are unable to fulfill parents' ultimate wish, that their child be cured. Kupfer (1984) also notes that professionals may choose to work with people with disabilities and find that they gain self-esteem from their work; however, since families do not choose to have a child with a disability, they may not have that foundation of strong confidence and self-esteem.

Also, family members and professionals may have stressful interactions due to negative attitudes about disability that may be held by the professional, by the family, or by both. Those attitudes include beliefs that the family is in part the cause of the child's problem, that the child is a devalued object of no worth to the family, and/or that the family is responsible for everything that happens to the child. All of these assumptions at best lead to poor family-professional relationships (Turnbull & Summers, 1987), and at worse lead to self-fulfilling prophecies in which families experience crisis based on the expectation that they should feel that way (Blackard & Barsh, 1982).

While there are still many unanswered questions about the function and use of cognitive coping strategies in families who have children with disabilities, there are several implications about the information that is known for family-professional relationships. Professionals who understand the function and value of these coping strategies may not only be able to help families enhance their use, but may also gain insights into the family's behavior that may enhance the professional's ability to respect and collaborate with the family. There are implications for family-professional interactions in all three of the major types of cognitive coping strategies.

Causal Attributes The search for the meaning or cause of an event appears to be an important coping strategy. Families who are able to attribute some cause to the problems that their child is experiencing may have a stronger foundation for their later ability to cope, since the attribution of cause may be part of the reassertion of a sense of control or mastery of the problem. Professionals who perceive families as locked into the process of searching for a cause should not immediately infer that the family is unable to accept the child's disability; rather, the family may sim-

ply be attempting to reassert control of the situation.

The family's need to identify a cause of the problem and to attach a comprehensible label or name to the child's condition may come into conflict with the values of some professionals who believe it is important to avoid labeling, especially in the case of young children. In this case it is important for professionals to realize that labels may be unimportant in relation to the type of service to be provided and to the child's potential in society, and in fact a label may become unimportant to the family at a later point in life. However, at an early stage, when the family is newly aware of the child's disability and is struggling to make sense of the problem, it is vital to provide as much information in as clear a fashion as possible. This requires careful and complete explanations of all diagnostic information. When the cause of the disability is unknown, as it often is in the case of cognitive disorders like mental retardation and learning disabilities, it is important to provide families with as much information as possible.

One might ask, however, about the appropriate stance of a professional working with a family member who ascribes a "magical" cause to the disability. A "magical" cause is an illusory or unsubstantial belief about the cause of an event that may range from a spurious association (e.g., taking cold medicine in the first trimester of pregnancy) to a belief in divine intervention. It should be noted that magical causal attributions are distinct from denial or passive appraisal, which is yet another type of coping strategy (McCubbin et al., 1982). Denial is an avoidance of the stressful event or a refusal to believe that a problem exists; denial has not been discussed in this chapter because its prolonged use may too often result in problems (see, e.g., Pollner & McDonald-Wilker, 1985), and thus may not be part of the coping arsenal of successful families. Nevertheless, magical causal attributions may also be dysfunctional if they lead to a lowering of self-esteem or a reduction of a sense of mastery (e.g., believing that the child's disability is a punishment from God). The dilemma for professionals is how to distinguish between constructive and destructive causal attribution. And, in the case of the latter, how might professionals guide families in more constructive directions?

It is at this point that the lack of research information begins to impede practice. There are a number of empirical questions yet to be examined; whether the specific content (i.e., whether the attributed cause is illusory or not) is significant in enhancing coping; and whether the specific identified causal agent (i.e., self or others) is significant. The relationship between causal attributions and self-esteem or mastery is also unknown. Furthermore, there are no empirical studies, to the authors' knowledge, relative to the efficacy of interventions designed to change causal attributions. All of these issues require a long-term research effort before professionals can have definitive guidance in working with families who make dysfunctional causal attributions.

Gaining Mastery   A sense of mastery or control may be a vital coping strategy for families who have children with disabilities. People who believe that they can control what happens to them in life are more likely to persist in spite of the difficulties, and may be less likely to be debilitated by stress (Brickman et al., 1982). Without a sense that interventions or actions on the part of family and professionals will actually be useful, the family may not only fall prey to feelings of anxiety and helplessness, but could fail to participate fully in programs that could be of great value to the child. Thus it is important for professionals to take every possible opportunity to point to progress that the child is making. Even more importantly, professionals should try to link that progress to some action taken by the family. For professionals who regularly employ behavior modification in their service settings, the principle is simple: pair the reward (e.g., improvements by the child, greater happiness or satisfaction on the part of the child) with the behavior of the family.

In the long run, the establishment of a sense of mastery and control may be one of the most important outcomes of parent participation in educational/program decision-making. For this reason, all of those principles related to encouraging meaningful participation in decisionmaking, as well as attending to parent and consumer preferences for educational or habilitative objectives, take on an importance beyond mere legal compliance. The concept that the professional is essen-

tially in charge has the effect of reducing families to clients, or helpless recipients of intervention (Barnard, 1984). A shift in attitude, placing the family at the center of the universe with professionals seen as consultants, can lead to empowered families who truly make a difference in the developmental and medical outcomes of their children (Barnard, 1984; Oster, 1984; Turnbull & Summers, 1987).

Enhancing Self-Esteem As noted in the previous section, the identification of positive aspects of a situation—the "silver lining" effect—may be one of the most powerful cognitive coping strategies of all. As noted in the description of positive contributions made by people with disabilities to their families, it is clear that families do recognize positive contributions, and in fact often do choose to focus on those positive aspects as a part of their coping effort. Service programs that adopt positive and optimistic attitudes can go a long way toward enhancing the family's capacity to focus on the positive (Dyson & Fewell, 1986).

A question that may arise is whether the positive contributions described earlier in this chapter are indeed *real* contributions to families, or whether the families' perceptions of those intangible contributions are, like magical causal attributions, mere rationales designed to relieve feelings of stress. While attributions of positive benefits may indeed be coping strategies, those attributions need not in any way be considered mythical or illusory. To the authors of this chapter, the question is irrelevant, as long as the attribution of positive benefits is not accompanied by prolonged denial (once again, a distinction is drawn between denial and cognitive coping). To the extent that the attribution of positive benefits leads to enhanced self-esteem and reduced distress, then their objective reality is irrelevant. In fact, due to the intangible nature of most of the positive contributions that families identify (e.g., unconditional love, pride, tolerance), the objective reality or unreality of these contributions may be impossible to prove. If they are real to the family, then professionals must accept that they are, in essence, real.

Helping families identify positive contributions of their experiences with a child with a disability, and enhancing self-esteem through appreciation of positive aspects of the situation requires that professionals themselves hold these positive attitudes. Professionals should examine their own feelings about the value of people with disabilities (Dudley, 1983) and should be able to identify ways in which particular children and adults with whom they have worked have enhanced their own life. There is no way to pretend a positive attitude; families and people with disabilities can spot insincere statements as easily as anyone else. Therefore, to the extent that professionals actually enjoy their work and actually believe in the intrinsic worth of the people they serve, they will be able to enhance the family's ability to see positive worth in both themselves and in their child with a disability.

CONCLUSION

An understanding of the coping strengths of families and an appreciation of the positive contributions of people with disabilities and their families also has implications for societal change and generally held attitudes about disability. In many ways, the message of this chapter is that it is the attitude of society, rather than the families and/or the people with disabilities, that needs to be addressed. It is not the nature of the handicap itself, but the way it is interpreted, that determines the impact on individuals (Grossman, 1972), and stress may largely be a product of a community's expectations about how people "should" react to particular events (Reiss & Oliveri, 1983).

An appreciation of successful families who have adapted positively should be achieved without sanctifying these families. Many parents have commented that they resent implications that they are somehow superhuman or saintly as much as they do the implications that their lives must be endless tragedies (Willette, 1987). Such sanctification of families who succeed suggests that adaptation requires heroic efforts beyond the reach of an "ordinary" family, and again leads back to the assumption that the impact of children with disabilities is pervasively negative. It is important to emphasize that these coping strengths are available to most families, and that families who cope successfully are simply ordinary people who are doing the job of raising a child with a handicap much the same as they would approach raising any other child. As one parent put it, "You just do it and

you are not more special than anyone else because of it" (Yudenfriend-Glaser, 1987, p. 7).

Much has been written about disability as a social value judgment, and about handicaps as socially imposed limitations (Meyerson, 1963). Stigma is a result of social attitudes about negative impact of disabilities and about the worthlessness of persons with disabilities (Goffman, 1963). For this reason, it is vital to continue investigations of positive contributions of people with disabilities to their families and to society as a whole. Empirical evidence of positive value will go a long way toward strengthening the value that all persons in this society are worthy and useful human beings. Indeed, "when we look for the good in people, we will find ways to make the world better" (Blatt, 1987, p. 46).

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