# Research Progress and Promise
# The Role of Perceptions in Cognitive Adaptation to Disability

## *Shirley K. Behr and Douglas L. Murphy*

> If science is to tell us anything about the world, if it is to be of any use in our dealings with the world, it must somewhere contain empirical elements . it is in the empirical component that science is differentiated from fantasy.... it is precisely the accumulation of empirical evidence which shapes a welter of opinions into scientific knowledge common to many minds.
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> <div align="right">-Abraham Kaplan (1963, pp. 34-36)</div>

In 1987, our research team began a 3-year study on family perceptions-a topic that, until recently, was explored by few researchers in the disability field. The majority of family. studies have examined family dysfunction, negative impacts, and disability-related stressors. Indeed, parents' affirmations of benefits derived from the presence of their child with a disability all too frequently have been discounted as fantasy or denial, or subjected to unscientific post-hoc interpretations.

The purpose of our research was to develop empirically based instruments for investigating variables associated with successful coping among parents of children and adults with disabilities. The inspiration for the study came from our work as professionals with and on behalf of children and adults with disabilities and their families, as well as from personal experiences coping with disability and chronic illness in some of our own families.

We were further inspired by a paper entitled "Who Are These Researchers and Why Are They Saying These Horrible Things About Me?" by Patty Gerdel (1985), the mother of a child with cerebral palsy in Topeka, Kansas. Gerdel called attention to the unwarranted nature of the conclusions reached by many studies

which suggested that families of children with disabilities tend to be dysfunctional and at risk for failure. She observed that these families are, in most respects, like other families, with their share of difficulties as well as their share of joys.

The vehicle for our exploration was the Family Perceptions Research Project (Summers, Behr, & Murphy, 1991), designed to develop and validate questionnaires that would enable the further study of four perceptions associated with cognitive adaption to threatening events. We anticipated that information collected with these instruments would contribute to the understanding of these perceptions and their roles as cognitive coping strategies. The study was completed in September 1990; this chapter provides a welcome opportunity to share some highlights of where we have been, how we got here, what we have learned, and what we believe are the major milestones of our empirical work. Finally, we reflect on some intriguing questions that emerged from our study.

### WHERE WE HAVE BEEN

Among the reasons for the limited number of studies on cognitive coping are the absence of a clear conceptual framework for understanding perceptions as a phenomenon and a lack of valid and reliable instruments to measure them. The challenges inherent in a study of this nature were aptly described by Jan Spiegle-Mariska (1990), who is the parent of a child with a disability:

> Each parent faces a supreme and very personal challenge to reach acceptance; how each parent finally comes to acceptance is very much a matter of personal coping style. The contributions that a child with handicaps brings to a family are substantial, yet they defy quantification by their very nature. For the most part they are intangible, and they are easily overlooked or hard to focus on when you live nearly every day in a crisis mode.

Families differ in their responses to stressful events, such as having a child with a disability. The ABCX family crisis model (Hill, 1949, 1958; McCubbin & McCubbin, 1987; McCubbin & Patterson, 1983) is an attempt to explain these differential responses. In the model, Factor A refers to events that have been an impact or have the potential to have an impact on the family system. Factor B refers to the family's resources to meet the challenges of these events. Factor C, the family's perception or definition of the events, indirectly influences the degree of crisis (Factor X) that might occur in the family. Crisis is defined as a change in the family system for which the family's previous patterns of response are not adequate.

We have been interested particularly in the role played by Factor C, perceptions, in the process of adaption. Besides the definition of stressful events, Factor C might also include a cognitive reappraisal of the situation to make it more manageable or to maintain an optimistic outlook or acceptance. Examples of

of cognitive reappraisal are present in many parent-written manuscripts that describe how their lives have been enriched and made more meaningful because of having parented their child with special needs (Mullins, 1987).
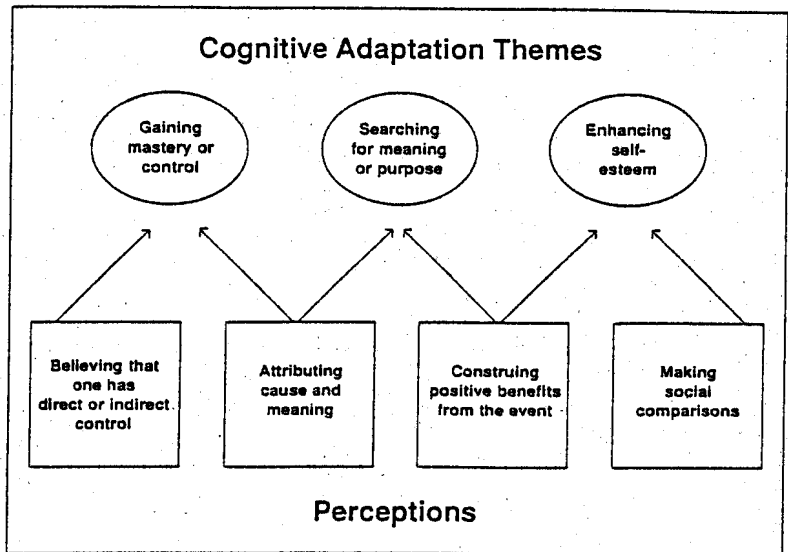
## HOW WE GOT HERE

We based our work on the cognitive adaptive theory (Taylor, 1983; Taylor, Lichtman, & Wood, 1984), which proposes that individuals respond to personally threatening events in their lives through a process of adjustment involving the resolution of three cognitive themes and their respective cognitions or perceptions. *A search for meaning is* associated with finding positive meaning from a negative experience, with the negative experience serving as a catalyst to restructure one's life along more meaningful lines. An *attempt to gain mastery or control is* associated with the belief that one can take active steps to control directly the course of the event or to prevent it from recurring, or that the event can be directly controlled by others. A combination of direct and indirect control is considered to be strongly associated with positive adjustment. *Enhancing self-esteem,* or selectively evaluating oneself in ways that are self-enhancing, is a means of minimizing feelings of victimization, perceiving instead that the impact of the event has been small or that one has profited from it. Through this process, individuals focus on the beneficial qualities of the situation and engage in active coping efforts that foster positive changes related to adjustment or adaption.

We developed four questionnaires related to these cognitive themes:

1. Construing positive contributions for the parent and family from the experience of having and raising a child with a disability, theoretically associated with the search for meaning and the enhancment of self-esteem
2. Attributing a cause for the child's disability, theoretically associated with the search for meaning and the attempt to gain mastery or control
3. Believing that one has direct or indirect control over short- and long-term outcomes for the child with a disability, theoretically associated with an attempt to gain mastery or control
4. Comparing oneself favorably, unfavorably, or similarly with others, theoretically associated with enhancing self-esteem

Figure 1 illustrates theoretical relationships between perceptions and cognitive adaptation themes.

Empirical evidence of positive contributions was initially reported by Turnbull, Guess and Turnbull (1988), who analyzed letters submitted by individuals with disabilities, their parents, and other family members to the U.S. Department of Health and Human Services (HHS; 1983). The letters were written in response to the departments' Proposed Rule, July 5, 1983, which sought to invoke the authority of HHS

## Cognitive Adaptation Themes

Gaining mastery or control

Searching for meaning or purpose

Enhancing self-esteem

Believing that one has direct or indirect control

Attributing cause and meaning

Construing positive benefits from the event

Making social comparisons

## Perceptions

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Figure 1. Theoretical relationships of four perceptions to cognitive adaptation themes.

to regulate the medical treatment of newborns with severe disabilities. A consistent theme for supporting the regulations was that persons with disabilities enrich and enhance the quality of life for family members and friends. The findings of this study laid the groundwork for developing the Positive Contributions Survey (Behr, 1990) to measure the positive benefits associated with having in the family a child or an adult with a disability. Measures of the other three perceptions were developed along dimensions indentified by attribution, control, and social comparison theories.

After developing initial versions of the questionnaires and testing them with a regional sample of almost 400 parents, Summers et al. (1991) revised the questionnaires and used them in a national mail survey study. The primary purpose of the study was to validate the instruments, but we also hoped to collect some data that would enable us to explore further the relationship between our measures of perceptions and outcome measures of family well-being (The Family APGAR, Smilkstein, 1978) and stress (Comprehensive Computerized Stress Inventory, Press & Osterkamp, 1986).

Over 1,200 birth parents, foster and adoptive parents, and legal guardians of children with disabilities participated in the national study. Ages and types of disabilities of these respondents' children varied widely, although a sizable proportion reported that their children had mental retardation. As is common in many mail survey studies, respondents in our study were overwhelmingly white and represented middle to upper socioeconomic levels.

**WHAT WE LEARNED**

**Evidence of Validity**

We believed that each of the four perceptions associated with cognitive adaption could actually be thought of as a cluster of related perceptions. For example, we believed that a parent might construe several distinct types of positive contributions from having and raising a child with a disability and that several categories of causes for the child's disability could be detected. Therefore, the main focus of the construct validity study was to identify the underlying dimensions of the perceptions.

The factor analysis of the data supported our hypotheses. We identified. nine different dimensions of positive contributions, five dimensions of causal attributions, four dimensions of mastery or control over outcomes, and four dimensions of social. comparisons (Summers et al., 1991). The dimensions are listed in Table 1.

**Relationships Between Perceptions and Well-Being and Stress**

A secondary purpose of the study was to explore relationships between parental perceptions and measures of stress and family well-being. It is. outside the realm of this chapter to report in detail findings related to this purpose. Some of those results have been reported elsewhere (Murphy, Behr, & Summers, 1990a,

Table 1. Underlying dimensions of the four  perceptions

| Positive contributions | Social comparison | Attributing a cause | Mastery of control |
|---|---|---|---|
| Learning through experience with special problems in life | Similar comparison Downward comparison Upward/favorable comparison Upward/unfavorable comparison | Fate or chance Special purpose Physiological cause Professional blame Self-blame | Personal control Professional control |
| Happiness and fulfillment | | | |
| Personal strength and family closeness | | | |
| Understanding life's purposes | | | |
| Personal growth and maturity | | | |
| Awareness of future issues | | | |
| Expanded social network | | | |
| Career or job growth | | | |
| Pride and cooperation | | | |

1990b; Murphy, Behr, & Tollefson,1990). Instead, we wish to report themes in our findings that have relevance to further research into cognitive coping among families of children with disabilities.

One of the assumptions of the study was that parents of children with disabilities are not necessarily more at risk for dysfunction than are other parents. Therefore, we selected two outcome measures nonmed on ordinary, wellfunctioning adults: 1) the Comprehensive Computerized Stress Inventory (Press & Osterkamp,1986), designed as a stress and coping check-up for "normal," healthy adults or people dealing with typical lifestyle problems, high levels of stress, or similar difficulties; and 2) the Family APGAR (Smilkstein, 1978), a measure of general satisfaction with one's family as a nurturing and supporting unit.

Data revealed a great deal of variability in perceptions, stress and well-, being among the parents we sampled. In general, they reported stress and well-being levels similar to those of adults in the general population. In other words, we found little evidence that the parents in our study were operating in the "crisis mode" (Summers et al., 1991).

As a group, our respondents said that their children with disabilities made contributions to their families as sources of learning through experiences with disabilities, happiness and fulfillment, and strength and family closeness. They were less likely to say that their children were sources of career or job growth or that they took pride in their children's accomplishments.

These parents did not attribute their children's disabilities to any of the five categories of causes we had identified. It is noteworthy that a substudy group of about 100 parents of children without disabilities believed that parents of children with disabilities would have significantly higher scores on causal attributions measures than was actually observed.

In general, parents compared themselves favorably with other parents who had children with disabilities. This assessment was reached by comparing themselves, their families, and their children with others who were similar to themselves, and with others who were worse off or better off.

There were, however, marked differences in perceptions within the sample. Some individuals reported high levels of positive contributions from their children while others reported low levels. Some attributed the cause of their children's disabilities to specific causes (e.g., physiological factors) and others did not. Some compared themselves favorably with others and some compared themselves unfavorably. Clearly, we believe it is not possible to characterize perceptions of "the family of a child with a disability" as a unitary phenomenon.

We did find that one factor-the age of the child-appeared to be related to some of the differences noted above. For example, parents of younger children reported significantly higher levels of stress and lower perceptions of some kinds of positive contributions (e.g. source of pride and cooperation). These differences were robust, even when the severity of the disability was taken into account.  It was

enlightening to find similarly high levels of stress for parents of young children with

disabilities and those who had young children *without* disabilities, suggesting that raising young children is accompanied by stressors, regardless of the child's disability or nondisability status.

A second theme in the findings is that patterns in relationships between the measures of perceptions and the outcomes varied, depending on the particular outcome studied. To illustrate, several perceptions were significantly related to the measure of overall stress. Parents who had lower levels of stress reported that they compared themselves favorably with others who were better off or worse off than they. They also reported that their child contributed to strength and family closeness.

Different perceptions were significantly related to the measure of satisfaction with family relations. Parents who reported high levels of satisfaction with family relations compared themselves with others who were similar and compared themselves favorably with others who were worse off. They also reported that their children contributed to the expansion of their social network, happiness and fulfillment, strength and family closeness, and pride and cooperation.

A third theme in the findings has implications for theory, research, and practice. At best, the set of perceptions we measured and explored had only a modest relationship with stress and family well-being. This suggests that we must look further to identify factors critically related to these outcomes. However, our analyses showed that the perceptions consistently had a stronger relationship with the outcomes than family variables traditionally studied in this connection. These variables included the age of the child, the severity of the child's disability, the marital status of the parents, family income, and education.

In summary, we applied a theory developed to explain cognitive adaption among individuals who are themselves victims of such threatening events such as chronic illness or accidents, to individuals who experience the long-term challenges associated with parenting children with disabilities. The results of our study (Summers et al., 1991) provide moderate support for the theory, but the weak to moderate relationships found between perceptions and outcomes suggested that more research is needed to explore further the process of cognitive adaption in families of children and adults with disabilities.

## MAJOR MILESTONES OF OUR EMPIRICAL WORK

Dewey (1933) suggested that reflective thinking is best accomplished by "climbing a tree" to get a more commanding view of the situation, looking at additional facts, and deciding how the facts stand related to one another. Metaphorically speaking, we sat in the treetops to gain a view of the milestones and to ascertain the direction in which our work seems to be heading.

We believe one major milestone of our empirical work has been the development of psychometrically sound instruments for measuring some perceptions related to cognitive adaption. Several researchers have already used or adapted these

instruments in studies of mothers and siblings of children with severe and profound disabilities in Costa Rica, caregivers of persons with Alzheimer's

disease, persons with heart disease, parents of children with emotional disabilities, and parents of preschool age children with and without disabilities. As a knowledge base builds with the increased use of these instruments, we anticipate a better understanding of the dynamic relationship of perceptions and various adjustment-related outcomes, refinement of theory on cognitive coping, and direction for the training of service providers who work directly with the families of children with disabilities.

A second milestone stems from the exploratory nature of our study and the findings about the relationships among perceptions, various individual and family variables, stress, and family well-being. However, the contribution of this milestone lies not so much in solid conclusions, but in questions that arise from the tentative conclusions, taken together with findings of other researchers. We discuss two of the most provocative questions next.

## FUTURE DIRECTIONS FOR RESEARCH
## ON COGNITIVE COPING

Our work in cognitive coping among parents of children and adults with disabilities has concentrated on developing measures of perceptions associated with cognitive adaptation. We believe that these tools will contribute to empirical research in this field as they are used to deepen understanding of coping processes in families. Further, we have explored relationships between perceptions and various outcomes, and found moderate relationships among them. While these findings support some predictions from theory, as in all research, their value lies in the questions they stimulate for research. Two major questions for our future work relate to the application research findings and the refinement of theory.

### Application: How Are Cognitive Coping Strategies
### Learned and Can Their Learning Be Enabled or Enhanced?

To introduce this question, let us review the logic of the study we have discussed in this chapter. The rationale was straightforward: Cognitive coping strategies lead to the attainment of certain adaptation goals. Like most cognitive strategies, these are probably learned and applied by individuals when these goals become salient. If the strategies can be understood and described, then it might be possible to help people learn them and use them to enhance their own adjustment or adaptation.

Therefore, it seemed reasonable to develop a means of teaching these strategies to parents of children with disabilities. We chose a workshop-type format in which parents would be introduced to the strategies we had identified, have opportunities to discuss their own use of the strategies, and practice in a secure setting strategies not necessarily in their "coping repertoire." At the outset, we had determined that the target population should be parents of very young children as these parents, according to our findings, are most at risk for experiencing stress and frustration.

We pilot-tested the workshops with members of parent-to-parent groups who served in the role of "veteran" parents with newly referred parents. With few exceptions, these pilot-test participants expressed concern and caution about the potentially negative impact that attending a workshop of this nature might have on parents of very young or newly diagnosed children who might not be sufficiently far enough along in the adjustment process or ready to learn about using cognitive coping strategies.

They suggested, instead, that the workshop would be most useful for veteran parents, by helping them retrospectively affirm the coping process they had already been through and by helping them recognize how they learned to use cognitive coping strategies naturally and incidentally over time. These observations and suggestions were consistent with many comments from parents who took part in the validation study (Summers et al., 1991). These parents told us that their answers to our survey would have been very different had they completed it several years earlier; acceptance of their child's disability had been the result of growth and experience. Work by Affleck and Tennen (chap. 10, this volume) and Singer (chap 16, this volume) has shown that some individuals are very resistant to well-intentioned attempts by others to have them look at their distressing circumstances in a more positive light or to reframe them to be more acceptable or meaningful.

Given these reactions and findings, the question is: If it is not possible to teach these strategies directly to parents of children with disabilities, how *are* they learned, or are they learned at all? Taylor (1989) made the eloquent argument that the tendency for interpreting negative life events in an overly optimistic manner is "inherent in the way that the mind processes and ascribes meaning to information" (p. 245), but her argument does not necessarily extend to specific strategies. We suspect that strategies are learned in the same ways as values, attitudes, beliefs, and other cognitive processes. It is probable that some strategies are acquired through social learning processes, and others are acquired through formal means. For example, there is anecdotal evidence that parents of children with disabilities learn to view their families' lives more positively by participating in mutual support groups with other parents. Does this learning occur incidentally or by more intentional means?

Because we believe these questions are so important, we have directed our current research efforts toward addressing some of them. Our revised workshop, Coping with Change, will be presented to a sample of parents of young children

with disabilities who are members of a support group. We will follow these parents for

several months, using repeated measures, to explore their cognitive coping strategies and the perceived antecedents and consequences of the strategies. A control group of parents who belong to a support group but do not attend the workshop will be included in the study for comparison purposes. Such longitudinal work is essential to developing an understanding of how individuals learn to use cognitive strategies in the constantly changing processes of adaptation. Knowing how this learning can be enhanced might be a great advance in designing services for families of children with disabilities.

**Theory: Is Cognitive Coping a Strategy or a Goal?**
When cognitive coping is defined as a strategy or as a process used to attain a goal, as in the validation study, researchable questions focus on the nature of the process and the nature of the goals. Much of the research in cognitive coping has described the various strategies. We find it intriguing that many of us who have taken the strategy perspective tend to be less than explicit on the topic of strategic goals. For instance, according to the cognitive adaptation theory (Taylor, 1983), the goal of cognitive coping strategies is adjustment or adaptation. However, the theory is not definitive about these goals. For parents who are coping with the challenges of their child's disability, a goal of adjustment might be to exercise instrumental control by finding a competent speech-language therapist. Other goals might be to reduce feelings of distress by finding humor in difficult circumstances or to reappraise the situation by realizing the benefits of the child's presence in the family.

We believe that creative research is needed to clarify the nature of goals of cognitive coping strategies. Are these goals in the realms of instrumental control, emotional adjustment, or cognitive adaptation, or combinations of these, in tandem? Promising theoretical work in this direction has been started by Ortony, Clore, and Collins (1988).

Reflecting on our work from the "treetops" makes it possible to view elements from various perspectives and to reverse assumptions mentally. It occurred to us midway through our work that what we had been regarding as strategies might, indeed, more properly be considered goals. If, as Taylor and her colleagues argued (Taylor, 1989, Taylor & Brown, 1988), people have an inborn tendency to interpret events in wildly optimistic terms, then perhaps perceiving positive contributions, comparing oneself favorably with others, or developing objectively unrealistic illusions about one's mastery over events are the end product, the goal, of a yet-to-be-understood process.

This alternative view raises intriguing research questions. For example, Hill (1949, 1958) distinguished among three types of definitions of the stressor event: those developed by impartial observers, those developed by the community, and those developed by the family. Recalling Hill's ABCX Model, Factor C refers only to the family's subjective definition of the event. If the goal, or outcome, for the individual is positive perceptions that mark successful coping, the other definitions proposed by Hill could be considered independent variables. In that case,

one might ask: How does the community's definition of disability influence the parent's ability to attain an optimum level of positive perceptions? How is the community's definition manifest in the support and services it provides to families? In

institutional resources or barriers that either enable or inhibit the development of positive perceptions within the family? What is the relationship between these manifestations of the community's definition of disability and the family's attainment of the goal?

There is a clear difference between the strategy and the goal points of view. When perceptions are viewed as strategies, the tendency is to focus on the individual's and family's learning and use of strategies and how to intervene with the family. This assumption is not without merit. In contrast, regarding the perceptions as goals focuses attention on factors, both inside and outside the family, that influence the development of the perceptions. These factors might include communication within the family, family cohesion, or problem-solving capabilities. They might also include availability of services, societal attitudes, supports for the family, economic constraints and opportunities, and other community factors.

## CONCLUSION

Our research on cognitive coping among parents of children and adults with developmental disabilities began as a result of our personal observations and interest in evidence that many families not only cope successfully with the challenges associated with disabilities, but seem to make a transition to higher levels of well-being (Mederer & Hill, 1983). With family stress and coping theory and cognitive adaption theory as the framework for research design and instrument construction, we embarked on a course of empirical study to measure perceptions and investigate their relationship to successful coping outcomes.

We recognize the need to study the development of perceptions over time. We recognize, as well, the need to study perceptions among family members of individuals who have a variety of physical and mental impairments, across the life cycle. We anticipate that the adaptation and use of the *Kansas Inventory of Parental Perceptions* (KIPP) (Behr, Murphy, & Summers, 1992) will assist other researchers in such efforts.

We are also engaged in research that addresses the current need in the disability field for empirically based interventions that can support families and enhance their efforts to cope successfully. Toward that end, we are conducting a study to investigate the immediate and longer-term effects of a workshop, Coping With Change, among parents of young children (birth to age 5) with disabilities of a lifelong nature (e.g., mental retardation, spina bifida, cerebral palsy). The context for this workshop emerges from the research described in this chapter, and it is designed to provide parents with an enhanced awareness of perceptions and naturally occurring cognitive coping strategies.

Finally, we have highlighted the need for further research to refine cognitive

coping theory and to address questions related to the application of knowledge about

cognitive coping to helping families cope sucessfully with disability-related challenges.

We believe that research on cognitive adaptation has the potential for helping us understand better how individuals and families cope with challenges associated with disabilities. If greater understanding can be incorporated into the training of those who work with these individuals and families, it is possible that services can be planned and provided that are more sensitive to natural coping processes and that encourage positive adaptation.

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## ABOUT THE AUTHORS

**Shirley K. Behr, Ph.D., O.T.R., and Douglas L. Murphy, Ph.D.** Our research has been inspired and strengthened by personal experiences coping with disability and chronic illness in our own families and by our work with families of children with disabilities. At the Beach Center on Families and Disability, we focused on the cognitive resources parents use to cope successfully with disability-related challenges. We now look forward to expanding this work to investigate cognitive coping processes in other populations and to examine helping professionals' perceptions of positive adaptation among parents who use cognitive coping strategies.

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