EXAMING THE COPING STRATEGIES OF PARENTS

WHO HAVE CHILDREN WITH DISABILITIES

by

Amy Pritzlaff

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Sally M. Hoge, Ph.D

Investigation Advisor

**The Graduate College
University of Wisconsin – Stout
August 2001**

The Graduate College
University of Wisconsin-Stout
Menomonie, WI 54751

ABSTRACT

	Pritzlaff	Amy	L
(Writer)	(Last Name)	(First)	(Initial)

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Parenting is one of the most challenging jobs an individual will ever face. Raising children can be stressful at times, but also very rewarding. Becoming the parent of a child who has a disability is a time of great stress and change (Thompson, 2000). Parents who have children with disabilities report higher amounts of physical, emotional, psychological, and financial demands; however the extent of stress depends upon a number of variables that were first introduced in family stress theory and identified in Hill's ABCX family crisis model (Hill, 1949). A family's perception of having a child with a disability, the characteristics of the family, the family's internal and external resources, and the child's characteristics are all examples of factors that influence the amount of stress a family experiences. Coping is the family's attempt to manage or deal with the stressful situation. It is important that families learn how to deal with their stress effectively in order to avoid negative psychological, emotional, and physical consequences.

The purpose of this study was to identify the coping strategies utilized by parents who have children with disabilities. This study surveyed 89 parents who have children currently receiving services from Cerebral Palsy, Inc.'s Birth to Three Program. The F-COPES scale (McCubbin, Olsen, & Larsen, 1981) was used to assess parental coping attitudes and behaviors that are developed in response to problematic situations. An additional open-ended question was added addressing what has been the most helpful strategy for parents adjusting to their child's disability. An analysis of the data was conducted to determine if demographic variables had any significant relationships to coping strategies used by the parents in the study. Descriptive statistics were also used to analyze the data. Results indicated that the most helpful strategies reported by parents were social support (M = 31) and reframing (M = 31). The majority of respondents were female and married; therefore, the researcher was unable to report significance regarding these two variables. Statistical significance was found between passive appraisal and the number of children in the household. There was also a positive relationship between annual income and the strategies of seeking spiritual support and reframing.

Implications were made for professions working with families who have children with disabilities. Recommendations for future research included sampling a more diverse population and gathering a larger sample of participants from other agencies who provide early intervention services to children and their families; the use of interviews and longitudinal studies examining parental stress and coping behaviors throughout the family life cycle were also recommended.

ACKNOWLEDGEMENTS

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"Some of the most cherished relationships are found within the family"
(Stinnett & DeFrain, 1985, p.4).

CHAPTER ONE

Introduction

Families are the foundation for a child's development, socialization, and formation of

his/her values and beliefs. Families can be a source of great happiness, as well as stress.

Parenting is a highly stressful job, and becoming a parent of a child with a disability is one of the

most stressful life events that can occur (Rose, 1987; Thompson, 2000). How parents react to

this stress depends on a variety of individual, family, and environmental factors. Some families

may view the situation as uncontrollably threatening, while others may view the added stress as a

challenge and become stronger in the process (McCubbin & Patterson, 1983a; Reiss & Oliveri,

1983; Schilling, Gilchrist, & Schinke, 1984). In the past, the majority of research has focused on

the negative and potential dysfunction of having a child with a disability, while the beneficial

aspects of parenting a child with a disability have been largely ignored (Bailey, Jr.&

Simeonsson, 1988; Kazak & Marvin, 1984; Longo & Bond, 1984; Wilker, Wasow, & Hatfield,

1983). Research and professional attention has begun to shift from looking at the difficulties and

problems that caregivers face who have children with disabilities, towards focusing on family

strengths and successful, adaptive functioning (Judge, 1998; Kwai-sang Yau & Li-Tsang, 1999).

Defining Disabilities

According to Wellner (1998), one in 10 Americans had a severe disability in 1994-95. In

Kraus, Stoddard, and Gilmartin's (1996) report, almost one out of every five people has a

disability. The discrepancy between reports might be due to the severity of the disability;

however, the two statistics illustrate the increase in the number of individuals reporting a

disability.

Disability is difficult to define, because there is no single definition or classification system that is used (Aron, Loprest, & Steuerle, 1996; Wellner, 1998). For example, American's with Disabilities Act (ADA) defines disability as "any physical or mental impairment that substantially limits one or more major life activity" (Capper, 1996, p.75; Wellner, 1998, p.308). Whereas, LaPlante, Carlson, Kaye, and Bradsher (1996) define a person with a disability as "one who is unable to perform his or her major activity or is limited in the amount of activity" (p. 2).

Definitions are also influenced by societal and cultural attitudes, which creates several discrepancies (Darling, 1983; Fewell, 1986; Fewell & Gelb, 1983). In our society, disability is often used interchangeably with impairment, physically or mentally challenged, handicapped, or developmentally delayed. It is important to note that each type of disability is unique and varies in severity and complications. For purpose of this report, the terms "disability" and "child with special needs" are utilized.

In the past, individuals with disabilities were formally considered liabilities, suffered inhumane treatment, and were often institutionalized away from society (Fewell, 1986). Society's attitude has changed dramatically in the past 30 years with public acknowledgment of the importance of caring for the handicapped and the constitutional rights for the disabled (Newman, 1983; Rubin & Quinn-Curran, 1983). Several trends such as advances in technology, medical care, mandated services, and mainstreaming the individuals with disabilities back into society rather than placing them into institutions have all helped the disabled live better lives and function in the community. As the prevalence of disabilities continues to rise, so will the need for advocacy and family support.

Children With Disabilities

According to the U.S. Census Bureau's (1999) definition of disability, 11,942,000

children in the United States who are less than 3 years old have a disability. Most childhood

disabilities are referred to as developmental disabilities, defined as any physical or mental

condition that may impair or limit a child's ability to develop cognitively, physically, and

emotionally compared to other children (Pueshel, Bernier, & Weidenman, 1988). The origin of a

child's disability may be the result of a variety of conditions that can occur at any time such as

childhood accidents, chronic illnesses, infections, or genetic disorders (Rose, 1987). Even with

the advancement of medical technology, some causes of certain disabilities are still unknown

(Rose, 1987). Unlike obvious physical anomalies, which are usually noticed at birth, many

developmental disabilities are left undiagnosed until a child reaches school age. Identifying a

developmental disability may be difficult for a parent if s/he is unaware of a child's

developmental stages. Professionals often have difficulty diagnosing a specific disability at such

an early age, so the term developmental delay is utilized to qualify a child for services in infant

and pre-school programs (Aron et al., 1996).

Mainstreaming children with disabilities back into society and the entitlement to an equal

education have been the two major movements, which promoted the rights of children (Newman,

1983). The Education for All Handicapped Children Act, Public Law 94-142, passed in 1975,

provided free and appropriate education to children 3 to 21 years of age according to their needs

(Aron et al., 1996; Pueschel et al., 1988). The law also protects the rights of the child and their

parents. In 1990 the law was changed to Public Law 101-476, otherwise known as Individuals

with Disabilities Act (IDEA) (Thompson, 2000).   Part H of IDEA supports early intervention

programs for children ranging from birth to three years of age (Aron et al., 1996).

Children with disabilities need the same kind of love, support, discipline, and direction as

other children; however, caring for a disabled child may require additional equipment, home

modifications, time, and patience. According to Thompson (2000), children with disabilities

need additional items such as special clothing, equipment, communication devices, and bathroom

aids. Although children with disabilities may have additional needs, despite their disabilities

they are children first (Capper, 1996; Pueschel et al., 1988). Those who work with children

should remember to focus on the child's strengths and abilities, not their limitations.

Parents Who Have Children With Disabilities

Parents can never fully prepare themselves for the news that their child is different

(Pueschel et al., 1988). Whether the diagnosis of a disability is shortly after birth or later on in

life, family dreams and expectations suddenly change (Rose, 1987). Parents may have to face

immediate decisions about their child's medical care and treatment (Thompson, 2000). Even

though there are no universal reactions to the added stress of raising a child with disabilities

(Kwai-sang Yau & Li-Tsang, 1999), several researchers have noted that there are similar patterns

or stages that the parents experience emotionally (Blacher, 1984; Miller, 1994). Some parents

will experience a variety of intense emotions including initial shock, numbness, denial, guilt,

fear, and anger (Featherstone, 1981; Rose, 1987; Thompson, 2000). Many researchers studying

the impact a child with special needs has on a family employ an ecological perspective, which

looks at how the environment and the family affect one another (Bristol & Gallagher, 1986;

Bubolz & Whiren, 1984; Crnic, Friedrich, & Greenberg, 1983). The parents' feelings toward

their child will influence their ability to cope and also have an affect on how the child and other

family members react to the child's disability (Callanan, 1990; Kwai-sang Yau & Li-Tsang, 1999; Rose, 1987).

Parents of children with disabilities cope with the same responsibilities and pressures that other parents face; however, one reoccurring theme reported among these parents is the higher amounts of stress they experience and greater demands made by caring for a child with special needs. The everyday tasks of feeding, toileting, traveling, and communicating are much more physically and emotionally demanding for parents who have children with disabilities (Ambert, 1992; Featherstone, 1981). This sense of stress may be associated with a child's characteristics, (Bailey & Simeonsson, 1988; Beckman, 1983), greater financial and care-giving demands (Ambert, 1992; Kazak & Wilcox, 1984: LaPlante et al., 1996; Minnes, 1988), feelings of being unprepared for the tasks of parenting (Scott, Sexton, Thompson, & Wood, 1989), and a sense of loneliness and isolation (Featherstone, 1981; Kazak & Wilcox, 1984).

With the establishment of family-centered care and the Individualized Family Service Plan (IFSP), which are part of the Education of the Handicapped Amendments of 1986, more families are able to collaborate with professionals regarding their child's level of care. Family-centered care focuses on family strengths, resources, and needs for both the child and his/her family (Bennett, Lingerfelt, & Nelson, 1990; Shelton & Stepanek, 1994). Since children with disabilities have more needs compared to a non-disabled child, caring for a child with a disability may involve additional stress. Locating appropriate services for a child with a disability is also noted as a source of stress (Rubin & Quinn-Curran). Therefore, parents who become more involved in their child's care will need support and resources (Fewell, 1986).

Parental Coping

Coping involves psychological resources and coping strategies that help to eliminate, modify, or manage a stressful event or crisis situation (McCubbin & Patterson, 1983a). Having a child with a disability creates a crisis event, for which parents have little to no preparation (Gallagher, Beckman, & Cross, 1983; Rose, 1987). How parents respond to the stresses of raising their child with special needs depends on a wide variety of factors influencing their ability to cope, such as their interpretation of the crisis event (Kwai-sang Yau & Li-Tsang, 1999; Lazarus, 1991), and the family's sources of support, resources, and family structure (Bailey & Smith, 2000). Depending upon which type of strategy is used, one form of coping can be more effective than another (Bailey & Smith, 2000; Judge, 1998). The personality characteristics of the family members, their financial status, educational level, problem-solving skills, and spirituality all influence a family's ability to cope (Abbott & Meredith, 1986; Bailey & Smith, 2000; Minnes, 1988). Strong martial relationship and social support also help determine parental adjustment (Abbott & Meredith, 1986; Kwai-sang Yau & Li-Tsang, 1999).

With the additional demands of parenting a child with a disability and the approval of deinstitutionalization, IFSP, and individual rights movements, more families need assistance in caring for their disabled child at home (Burr, Klein, Burr, Doxey, Harker, Holman, Martin, McClure, Parrish, Stuart, Taylor, & White, 1994). The constant change in medical treatment, adaptive technology and equipment, and the structure of the family, makes it imperative that professionals stay updated on how families are coping. Individuals who work with families who have children with disabilities must understand how to assist the families in coping with their stressors. In order to accomplish this, we must understand how the family is currently coping and what is working for them. Because each family system is unique, each family may have

different coping strategies. Recognizing the diversity of families, while respecting and

understanding their differences is a must. In order to help the families who have children

enrolled in Cerebral Palsy, Inc.'s Birth to Three Program in Green Bay, Wisconsin and the

professionals working with these families, parental coping strategies were assessed using the

Family Crisis Oriented Personal Evaluation Scales (F-COPES) (McCubbin et al., 1981).

Purpose of the Study

The purpose of this descriptive research is to identify existing coping strategies of parents

who have children with disabilities and determine whether there is a relationship between the

coping strategies and the parents' demographic variables. A questionnaire developed by

McCubbin, Olson, and Larsen, (1981), called the Family Crisis Oriented Personal Evaluation

Scales (F-COPES) has been used to identify the problem solving attitudes and behaviors, which

families develop in response to problematic situations or difficulties (McCubbin, Thompson, &

McCubbin, 1996). The F-COPES coping strategies are divided into five subscales; acquiring

social support, reframing, seeking spiritual support, mobilizing family to acquire and accept help,

and passive appraisal. The demographic variables measured include gender, age, marital status,

number of children, income, and the nature of the child's disability.

The goals of this study are:

1) To determine the descriptive statistics for each of the five subscales in order to identify what

   coping strategies were used most frequently and whether the results of this study are similar

   to normative data.

2) To determine if there is a relationship between the demographic variables (parents' gender,

   age, marital status, number of children, income, or type of child's disability) and the five

subscales (acquiring social support, reframing, passive appraisal, seeking spiritual support, or mobilizing family to acquire and accept help).

3) To include an open-ended question, which allowed parents to list what coping strategies were most helpful.

CHAPTER TWO

Review of the Literature

This chapter will review the literature on the ideology of stress, the physical and

emotional consequences of stress, and briefly mention some stress management techniques in

order to acquaint the reader with the components of stress. It also reviews information relating

to earlier models and theories on family stress, as well as research and factors associated with the

amount of stress families who have children with disabilities experience. The final portion of the

chapter addresses various definitions of coping, coping strategies, and resources parents utilize

when they face the everyday stressors and challenges of raising a child with special needs.

Stress

Definition and Causes of Stress. Stress is a normal part of life and everyone will

experience stress in different degrees, depending on a person's tolerance level (Rose, 1987).

Similar to disability, stress is difficult concept to define because it is based on an individual's

perspective (Bailey & Simeonsson, 1988). According to Merriam-Webster's Collegiate

Dictionary (1993), one definition of stress is "a constraining force or influence such as a

physical, chemical, or emotional factor that causes bodily or mental tension and may be a factor

in disease causation" (p.1164). Stress is caused by changes in a person's life style, job pressures,

financial problems, family problems, environmental episodes, personal loss, or negative

emotions (Callanan, 1990; Khalsa, Azok, & Leutenberg, 1994; Rice, 1992). Stress can also be an

outcome resulting from interactions with people, situations, and the environment (Romas &

Sharma, 2000). Stress can be caused by small everyday hassles, as well as pervasive, ongoing

factors, which may arise from specific events, but have long-term ramifications (Bailey &

Simeonsson, 1988; Romas & Sharma, 2000). When we experience tension, this tension creates

stress, which requires some type of change or adaptation (Bobolz & Whiren, 1984; Callanan, 2000).

Eustress and Distress. When we think of stress, a negative connotation often comes to mind. Most people associate stress with pressures, strain, and something that should be avoided. This type of stress is referred to as distress, which drains our energy (Atwater, 1983; Rice, 1992). However, not all stress is bad; stress can also be positive. Eustress, or positive stress heightens our awareness, increases our mental alertness, and leads to superior cognitive and behavioral performances. If we did not have positive stress, we would not be motivated to meet our deadlines (Curran, 1987). The point in which positive stress becomes distress, and starts to interfere in daily functioning will vary depending upon an individual's perception of the stress and his/her resources (Curran, 1987).

Types of Stress. According to Rose (1987), there are three major types of stress: stress by choice, situational stress, and chronic stress. An example of stress by choice would be joining committees, accepting a job promotion, or becoming a parent. Situational stress is more likely to be damaging than stress by choice, because it catches us unexpected, however it most often is short-term and can be reduced once the initial crisis is over (Rose, 1987). Chronic stress is the most harmful type of stress, because the human body is unable to tolerate high levels of stress for an unlimited period of time.

Theories and Models of Stress. There are numerous theories that have been developed to explain what stress is, how it works, and how it relates to health (Rice, 1992). Hans Selye was one of the first researchers to study stress and its physiological effects on the body. In the 1970's, Selye had introduced the General Adaptation Syndrome theory (Rice, 1992). According to Selye's theory, all organisms strive to maintain equilibrium and when stressors upset this

equilibrium the body reacts in order to protect itself (Gallagher et al., 1983). Depending upon

the stressor, the organism will either return to that equilibrium or result in exhaustion. One

major criticism of Selve's theory is that it fails to include cognitive factors, which are crucial in

determining whether an event is stressful or not (Rice, 1992).

According to the cognitive model of stress, the perception of the stressor is the most

important factor in determining a person's response towards that stress (Romas & Sharma,

2000). What is stressful to a certain person may not be stressful for another. Lazarus also

introduced the terms primary appraisal, secondary appraisal, and reappraisal to the cognitive

model of stress (Rice, 1992). Primary appraisal is the individual's first response to the situation

and whether it poses as a threat, harm, or challenge to them. Secondary appraisal focuses on

whether the individual has the coping skills or resources to manage the situation, and reappraisal

looks at the whole situation after primary and secondary appraisals have occurred.

There are also psychological models of stress, which look at personality types, an

individual's self-esteem, and sense of control.   Researchers have linked Type A personalities as

more prone to stress than people with Type B personality traits (Rice, 1992; Romas & Sharma,

2000). Type A personalities are characterized as being more aggressive, impatient, and

competitive compared to Type B personalities, who are more relaxed.

Consequences of Stress. There are increasing amounts of empirical research linking

intense stress to a vulnerability to illness (Atwater, 1983; Pilisuk & Hillier-Parks, 1983). As

stress increases, the heart pumps faster, which increases blood pressure (Rice, 1992). The

negative consequences of stress can be either acute or chronic. Some examples of physical,

emotional, and behavioral symptoms of acute and chronic stress include dry mouth, diarrhea,

heart palpitations, headaches, weight loss or gain, excessive sleeping, constant fatigue, mood

changes, irritability, crying, lack of concentration, feelings of helplessness, use of alcohol, medication, smoking, pacing, and pulling hair (Romas & Sharma, 2000; Toner, 1993). Stress has also been linked with a variety of disorders including, coronary heart disease, angina, hypertension, migraine headaches, ulcers, diabetes, and arrhythmia (Greenberg 1999; Stinnett & DeFrain, 1985).

Stress Management. Stress can be quite debilitating, but can also be an opportunity to strive and overcome hardships. The goal of stress management is to control stress at its optimal level. One guiding principle is to first understand what stress is and the seriousness of its consequences, and develop a variety of ways to reduce that stress. Enhancing our awareness of stress begins by identifying an individual's sources of stress and recognizing the emotional, behavioral, and physiological responses to stress. Muscle relaxation, meditation, time managements, using social supports, seeking information, maintaining a healthy diet, exercising, and strengthening communication skills are all ways in which individuals can diminish or reduce stress (Rice, 1992; Romas & Sharma, 2000). One key point to remember is that stressors only have the potential of eliciting stress; the important thing is how we react (Greenberg, 1999). By reducing stressful behaviors, increasing healthful behaviors, and learning effective ways of coping, individuals can learn better ways of managing stress (Bailey & Smith, 2000; Romas & Sharma, 2000).

Family Stress

Defining Family Stress. Unlike individual stress, family stress involves every family member (Curran, 1987). The family is made up of a variety of subsystems, that all influence one another. A change in an individual or group relationship will cause change throughout the entire family system (Turnbull, Summers, & Brotherson, 1986). Family stress varies depending upon

the nature of the situation, the family's psychological and material resources, and the definition the family makes of the event (McCubbbin & Patterson, 1983a). Family stress is defined as "a state that arises from an actual or perceived imbalance between demand (e.g., challenge, threat) and capability (e.g., resources, coping) in the family's functioning" (McCubbin & Patterson, 1983b, p.10). A stressor event in the family produces a change in any part of the family's system: boundaries, roles, values, structure, or goals (Burr, 1982).

Family stress may come from within the family, such as adding or losing a family member, or from outside the family, such as environmental stressors (Curran, 1987). Marital conflict and parenting are common sources of stress in families (Rice, 1992). The number one stress reported by 450 respondents in Curran's (1987) survey about common stresses in the family is family finances or budgeting. Family stress is also related to the number of parents in the household. Single parents have the added stress of combining the two-parent household responsibilities (Curran, 1987).   A family is thrown into a state of disorganization when a stressful life event occurs. If the family is unable to restore their sense of equilibrium or manage their stress, a crisis will emerge (McCubbin & Patterson, 1983a; Minnes, 1988).

ABCX Model of Family Stress Theory. In the last decade, Hill's (1949) ABCX model has been used as the foundation for studying family stress theory. In this theory, (A) the stressor event interacts with (B) the family's crisis-meeting resources, and (C) the family's definition of the stressor event to produce (X) the crisis (McCubbin & Patterson, 1983a; McCubbin et al., 1980; Minnes, 1988). Some families who experience stress may not even reach a crisis, depending upon the ability to restore stability, and use existing resources. The stressor event (A) is defined as a life event or transition that produces, or has the potential of producing, change in the family social system (McCubbin, & Patterson, 1983a). Hardships are defined as those

demands on the family that are associated with the stressor event. Examples of the demands

would be a change in the family routine to accommodate hospital visits of a sick family member

or need for extra support or cooperation in caring for that individual.

Family resources (B) are the family's ability to cope with the specific stressor or crisis.

Family resources include an individual's personal resources, the family system's internal

resources, social support, and coping (McCubbin, Joy, Cauble, Comeau, Patterson, & Needle,

1980). Personal resources, which include finances, education, health, and psychological

resources, have been researched the most (McCubbin et al., 1980). The family's resources are

the strengths the family has available to them, which help the family adapt to the stressful event.

The family itself can be a major source of social support; however, support can also be found

outside the family (Rice, 1992). Boss (1987) defined family's coping resources as individual and

collective strengths that help the family adapt at the time the stressor event occur (Burr et al.,

1994). Examples of family and individual strengths would be finances, health, intelligences,

communication skills, and social supports.

The (C) factor involves the family's definition of the stressful event. This is a critical

factor in determining the severity of the stressor event and whether or not the family will

experience a crisis (McCubbin et al., 1980). The subjective definition of the stressor event is

influenced by family values, the family's previous experience with stress, the cultural definition

of the stressor, and the community's image of the event (McCubbin & Patterson, 1983a;

McCubbin & Patterson, 1983b).

The original ABCX Model focuses on the stress associated with the single crisis event

and the variables that account for the family's capability to cope with the stressor event

(McCubbin & Patterson, 1983b). The Double ABCX Model, developed by McCubbin &

Patterson (1982, 1983a), expands upon Hill's original ABCX Model by adding other life stressors or changes that may influence the family's ability to achieve adaptation (McCubbin & Patterson, 1983b). The Double ABCX Model is much more dynamic, because rarely do families deal with a single stressor, but a wide variety of stressors resulting from the individual, family, and the community (McCubbin & Patterson, 1983b). In this model, the family reevaluates the meaning of the stressful event after it looks at the initial stressor; developmental or life cycle changes; the wide variety of demands and strains resulting from the individual, family, and community; prior experience with stressors; and the availability of resources and social support (McCubbin & Patterson, 1983b). In this model, the family struggles to maintain a balance between the individual, family, and the community (McCubbin & Patterson, 1983b).

Family Life Cycle Theory. Family stressors and/or crises can be separated into normative and non-normative life events. The major differences between normative and non-normative life events are that normative changes or transitions are expected, predictable, short term, and occur in most families (McCubbin & Patterson, 1983b). Non-normative life events include situations such as a chronic illness, unemployment, death, or natural disaster, which are sudden, unpredictable, and can be overwhelming. The type of family stress discussed in this section is considered normative, whereas having a child with a disability would be non-normative. Research on family stress has used the family life cycle theory to represent the normative and non-normative life changes that alters the family's structure and functioning (McCubbin et al., 1980; Turnbull et al., 1987). The family life cycle theory focuses on growth and transitions of families as they move through time historically, developmentally, emotionally, and socially (Turnbull et al., 1987).

Family Development Theory. The amount of stress families experience will vary

depending on their stage of family development. The family development theory, developed by

Duvall and Hill in 1948 is used to define family changes and transitions. The authors divided

family life into eight stages using the criteria of (a) major change in family size, (b) the

developmental stage of oldest child, and (c) the work status of the breadwinner (Mederer & Hill,

1983). Individuals and the family experience developmental tasks and responsibilities at

different stages in their life cycle. At each stage of development, adults and children experience

numerous changes that are associated with stress (Mederer & Hill, 1983). The developmental

crisis for one family member is often stressful for other family members, therefore, creating a

ripple effect. Some examples of normative changes or transitions that can cause stress in

families, are marriage, parenthood, dual-career families, single-parent families, blended families,

stages in child and adult development, and retirement (McCubbin et al., 1980; Mederer & Hill,

1983).

The Impact of Stress on Family Functioning. Family stress will also have an effect on

family functioning. After examining parental reactions to stress, Koo (1946) developed a roller-

coaster model, representing the changes in the family functioning after a crisis situation (Burr et

al., 1994). Koo's theorized that before the crisis, families function at a normal state, which is

represented by a horizontal line. After the stressful situation, the family experiences a period of

disorganization, which is depicted by a drop in the line. As time passes, families will eventually

adjust to the stressful situation, by using a variety of coping strategies and reach a new normal

level of functioning. Burr and associates (1994) questioned the universality of Koo's roller

coaster pattern and hypothesized that families would respond in different ways. Burr et al.

(1994) identified four additional developmental patterns found in families experiencing six

different types of stressors: bankruptcy, infertility, a child with muscular dystrophy, a child with

a handicap, and a teenage child who requires some sort of psychiatric help. Of the 82 families

studied, 51% percent indicated a roller-coaster pattern, 18% percent experienced an increase in

family functioning, 15% experienced no change in family functioning, 5% of family functioning

decreases, and 11% experienced a mixed pattern (Burr et al., 1994). Although the majority of

families studied exhibited a roller-coaster pattern, the results of this study demonstrate that

families respond to stressful situations differently and not all families will experience a decrease

in family functioning.

Summary. Family systems are continually coping and adapting to changing internal and

external conditions (Bubolz & Whiren, 1984). "Family stress refers to circumstances, events or

experiences with which the family must somehow cope" (Reiss & Oliveri, 1983, p.62). After

reviewing the literature on family stress theory, an individual should be aware that while families

are changing they experience periods of growth and balance, as well as disorganization.

"Family's outcomes following the impact of a stressor and/or a crisis event are the by-products

of multiple factors in interaction with each other" (McCubbin & Patterson, 1983a, p. 7). The

heterogeneity of responses in Burr et al.'s (1994) research emphasizes the need to study each

family's reaction to stressful life events on an individual basis.

Stress in Families Who Have Children With Disabilities

In the two previous sections, definitions of stress and normative family stressors were

given. One of the characteristics of stress was change. Adding a member to an existing family is

a change that alters the family's social system. This change can be particularly stressful if the

child has a disability (Kazak & Marvin, 1984). Families of children with special needs are likely

to experience changes in their daily routines, roles, and expectations of their child in addition to

the normal stresses of parenting (Crnic et al., 1983; Gallagher et al., 1983). Parents of children

who have disabilities are frequently bombarded by questions and concerns regarding their child's

disability, as well as dealing with society's negative attitude towards individuals who are

different. As a group, parents who have children with a disability experience greater levels of

stress than parents of children without a disability (Gallagher et al., 1983). The extent to which

families will experience stress depends on many factors including the child's characteristics,

structure of the family, family resources, and coping strategies (McCubbin & Patterson, 1983a).

Hill's (1949) ABCX Model and McCubbin and Patterson's (1983a) Double ABCX Model are

valuable models for understanding each families reactions to having a child with special needs.

Not all families will experience high amounts of stress and dysfunction, despite the greater risks

for stress (Bailey, Jr. & Simeonsson, 1988). The next section will review the characteristics of

non-normative events, some of the added stresses parents of children with special needs may

experience, factors that influence this stress, parental reactions towards having a child with a

disability, and studies comparing parents of disabled children to parents of non-disabled children.

     Definition of Non-Normative Events. Even though having a child with special needs

affects a large number of people, it is still considered to be a non-normative stressful event.

Figley and McCubbin (1983) define a catastrophe as an event which is sudden, unexpected, and

often life threatening to an individual or someone they care about.

> Catastrophic or non-normative stressors differ from normative stressors in
>
> the amount of time one has to prepare; previous experience with the stress;
>
> sources of guidance available to manage the stress; the extent to which
>
> others have experienced the stress; the amount of time in a "crisis" state;
>
> the degree to which there is a sense of loss of control or helplessness; loss;

disruption and destruction; danger experienced by people exposed to the

stress; the quantity and quality of the emotional impact of the stress; and

medical problems associated with exposure to the stress (Figley, 1983, p.

14).

Stress in Families Who Have Children With Disabilities. Parents of children without a

disability have the potential relief of sharing household responsibilities with their children. One

stressor for parents who have children with special needs is that they may continue to care for

their child for extended periods of time, which can be physically and emotionally draining

(Turnbull et al., 1986; Wikler, 1981). Another stressor that is chronic for parents having a child

with developmental delays is society's negative attitude toward their child. Even though

society's attitude and the treatment of people with disabilities has gradually changed, there are

still going to be some people who feel uncomfortable around their child, and want to avoid

contact with them or their child (Wikler, 1981). Similarly, reflecting on personal experience and

research, Featherstone (1980) reports a sense of isolation and loneliness that many parents

experience. The family's social and recreational patterns may be altered due to the added care

needed by the child (Seligman, 1983).

Parental stress may also be related to attempts to locate appropriate services and

education for their child among the maze of human service agencies that often have confusing

acronyms, and overlapping boundaries (Bailey, Jr. & Simeonsson, 1988; Kazak & Marvin, 1984;

Rubin & Quinn-Curran, 1983). In the beginning, parents may lack information regarding their

child's diagnosis and how to care for their child, therefore, feeling dependent on professionals

for the answers until they become more comfortable in their interactions with their child and

professional, which can also be a source of added stress (Rubin & Quinn-Curran, 1983; Wikler,

1981). Based on data drawn from the 1980 National Medical Care Utilization and Expenditure

Survey, Newacheck and McManus found the children with disabilities require twice as many

health services as non-disabled children, which result in higher medical expenses for families

(Aron et al., 1996).   Besides the daily expenses that come with caring for any child, parents who

have children with special needs have the added burden of finding special clothing, adaptive

equipment, and making home modifications (Peuschel et al., 1988; Thompson, 2000).   The child

with special needs may require extra time for feeding, toileting, and taking the child to and from

appointments (Fewell, 1986). One of the hardest things parents' face is balancing the demands

of the child's and the family's normal life against the demands of the disability (Featherstone,

1980). Considering all this information, it is assumed that parents who have children with

disabilities are at a higher risk for added stress.

Additional Life Events and Strains in Families Who Have a Child With Cerebral

Palsy. In reviewing the research on families who have a child with Cerebral Palsy, the

number of hardships parents have reported include: altered relationship with friends,

major changes in family activities, medical concerns, medical expenses, specialized

child care needs, time commitments, and intra-family strains besides the everyday life

events of typical families (McCubbin, Nevin, Cauble, Larsen, Comeau, & Patterson,

1982). McCubbin et al. (1982) tested the normative and non-normative life stressors

and strains of 217 families who have children with Cerebral Palsy. The majority of

families were White, married, had a high school education, and income ranging from

$5,000 to $40,000 a year. The researchers used the Family Inventory of Life Events

and Changes questionnaire developed by McCubbin, Patterson, and Wilson in 1981,

which records two types of changes families experience events and strains. The

family's most frequently reported events were the child changing to a new school

(36%), child becoming seriously ill (36%), and other family members becoming

seriously ill (34%) (McCubbin et al., 1982). This data suggest that besides taking care

of the child's ongoing needs, the family experiences a pile-up of life events, which can

cause additional stress. The most frequent strain reported by 83% of the parents was

increased expense for basic needs (food, clothing, etc.,), followed by an increase in

medical/dental expenses (50%). This information support the concepts proposed in

McCubbin and Patterson's (1982) Double ABCX Model, that families in general

experience a wide variety of stressors rather than a single, stressful event.

Factors Influencing the Amount of Stress Experienced by Parents Who Have a Child with

a Disability.   According to Wilker (1981), there are five critical periods in which the child is

supposed to achieve developmental milestones, such as beginning to walk or go to school.

"When a discrepancy occurs between what parents expect of a child's development and of

parenting as opposed to what actually takes place, a crisis may occur" (Wikler, 1981, p. 284).

Depending on the severity of the disability, many children with special needs will master fewer

of the normal developmental tasks faced in childhood (Bailey, Jr. & Simeonsson, 1988). The

delayed achievement of these developmental milestones becomes a source of heightened stress

for parents (Trout, 1983; Wikler, 1981). Other sources of stress are specifically related to the

child with a disability, such as the diagnosis of the developmental delay, when a younger sibling

achieves higher levels of functioning compared to the child with special needs, and questions

concerning care or out of home placement (Wikler, 1981).

Each child and his or her disability are unique. Parental reactions and the amount of

stress they experience are influenced by the child's behavior and personality characteristics

(Bailey, Jr. & Simeonsson, 1988). Beckman (1983) examined the relationship between the child's characteristics and stress in families of infants with a disability. She focused on five childhood characteristics: rate of child progress, responsiveness, temperament, repetitive behavior patterns, and the presence of additional or unusual care-giving demands. The majority of the sample population was White, middle class, and ranged in socioeconomic status and severity of disability. Mothers were interviewed using the Questionnaire on Resources and Stress (Holroyd, 1974), which was designed specifically to measure stress in families who had children with a disability. All of the childhood characteristics, except rate of child progress, were specifically related to amount of stress reported by mothers (Beckman, 1983). The only demographic variable associated with additional stress was the number of parents in the home; single mothers reported more stress compared to a two-parent household. This finding can be associated with less help in care-giving activities (Beckman, 1983). Limitations of this study include a small sample size, and the population was primary White, and all women.

Parent and child interactions also influence the degree to which a family who has a child with special needs experiences stress. Depending on the child's ability to interact and communicate with their parents, parents may have to adjust their interaction styles to meet the needs of their child (Peuschel et al., 1988). Children with developmental delays may have difficulty establishing eye contact, interacting with the parents, and communicating their needs and feelings (Beavers, Hampson, Hulgus, & Beavers, 1986; Fewell, 1986). Parents who do not receive cues or feedback from their child may experience added stress (Fewell, 1986; Laborde & Seligman, 1983). Many parents with children with disabilities adapt the way they interact with their child, but some families need help in communicating and interacting positively with their child (Bailey, Jr. & Simeonsson, 1988).

When parents correctly identify the meaning of a child's cues, parent-child interactions

often bring about desired effects and enhance parental feelings of efficacy and competence

(Bailey, Jr. & Simeonsson, 1988). Mothers of children with a disability have reported difficulty

reading some of their child's cues (Bailey, Jr. & Simeonsson, 1988). In a longitudinal study by

Goldman and Johnson-Martin (1987) parental perceptions were assessed regarding the

readability of their infants' expressions of distress, happiness, and interest. Both mothers who

have children with and without disabilities perceived their infants to be equally readable for cues

regarding distress and happiness (Bailey, Jr. & Smeonsson, 1988). On the other hand, mothers

who have children with special needs were less sure of their infants' cues regarding learning and

interest in social interactions (Bailey, Jr. & Simeonsson, 1988).

The number of parents in the home and family size also seems to be related to the amount

of stress experienced by the parents. The presence of older siblings can help take care of the

child with special needs and share household responsibilities appears to reduces stress (Crnic &

Leconte, 1986; Seligman, 1983). Most of the literatures about parents who have children with

disabilities have focused on the mother. Fathers were reported as being most involved with the

financial concerns and the traditional provider role, while the mothers' role was primary

caregiver (Kazak & Marvin, 1984; Kwai-sang Yau & Li-Tsang, 1999). Singe parents face the

added stress of assuming multiple roles of physically, financially, and emotionally caring for the

child with special needs. Single parents lack the emotional support from a spouse, although they

may find support from extended friends and family (Vadasy, 1986). The single mother's ability

to work depends on the availability of child-care with specialized training, and whether she can

afford or find it (Vadasy, 1986). To summarize the above findings, unrealistic expectations of

their child, the child's characteristics, parent-child interaction, and the number of people in the

household all have an affect on the amount of stress perceived by the family who has a child with special needs.   The next section will address the hypothesis that parents who have children with disabilities experience predictable stages of adjustment.

Stage Models of Parental Coping. Several researchers have hypothesized that parents are apt to follow similar patterns or predictable stages that most parents go through, even though the models differ in terminology (Blacher, 1984; Callanan, 1990; Mori, 1983). Some examples of these stages include initial shock, denial, emotional disorganization, and reaching a final stage of adjustment or acceptance (Blacher, 1984).

Wikler, Wasow, and Hatfield (1981) hypothesize that parents of children with special needs experience periodic crises during the child's development rather than a time-bound adjustment. In their study, parents of mentally retarded children were directly asked if they experience chronic sorrow, and to graph their adjustment experiences of either time-bound grief or chronic sorrow on free form and structured developmental graphs. Chronic sorrow means that their feelings of grief would reappear as the child reaches different developmental stages. Questionnaires were also sent to professional social workers to examine their expectations of how parents adjust. A total of 32 families and 32 professional were involved in this study.   On the free form graphs, 75% of the parents drew a series of ups and downs with no ascent, depicting chronic sorrow (Wikler et al., 1981). Social workers' perceptions of parents' feelings on the free form and structured graphs were quite accurate, however they overestimated how upsetting the parents' early experiences were and underestimated how upsetting the later experiences were. The results of this study indicate that the parents experienced periods of stress and sadness over time, however the peaks and valleys of their adjustment indicate that their sorrow was not continuous (Wikler et al., 1981). Some limitations of this study were the small,

nonrandom sample sizes obtained from clinical records, the low number of respondents among

parents who were contacted. Also, the manner in which the parents graphed their experiences

raises questions about validity of the responses. The term chronic sorrow also raises some

opposition. Chronic sorrow has a negative connotation that may have either turned parents off or

offended them in some way. All families experience their ups and downs, and to say parents

experience chronic sorrow might imply that there is no relief. After reviewing the factors

influencing parental stress in families who have children with disabilities and the possible stages

of adjustment, a comparison must be made between families with and without children with

disabilities.

 Comparative Research of Families With and Without Children Who Have Disabilities.

Margalit, Raviv, and Ankonina (1992) examined 78 families of children with disabilities and 83

families who had children without a disability. The authors investigated whether these families

differed in their coping styles, sense of coherence, and personal growth. Active coping refers to

managing the stressful situation and avoidant coping strategies refers to denying or minimizing a

stressful situation (Margalit et al., 1992). A high sense of coherence indicates that an individual

has confidence that life situations will work out (Margalit et al., 1992). All families had similar

demographic variables, besides having a child with a disability. The results of the study found

that parents of disabled children reported significantly higher avoidance coping, less emphasis on

family interrelations, few opportunities in the family for personal growth, and lower coherence

than did parents of non-disabled children (Margalit et al., 1992). The results may reflect a

cultural difference in attitudes and treatment of individuals with a disability. Limitations in this

study include small sample size, and errors in translating the questionnaire from English to

Hebrew. This research emphasizes the fact that professionals need to study families with

different ethnicities and be cognizant of cultural values.

Kazak and Marvin (1984) investigated the differences in 100 families with and without

children with a disability in regard to three types of stress (individual, marital, and parenting) and

three structural characteristics of their social support networks (size, density, and boundary

density). Network size refers to the number of persons offering support to an individual or a

family. In support of larger social networks, researchers (Wilcox, 1981) have found that the

degree of successful adjustment is associated with larger social networks (Kazak & Marvin,

1984). Network density is the extent to which members of the network know and interact with

each other independent of the focal person, signifying a measure of interrelatedness. Boundary

density is the measure of the membership overlap between two or more individuals (e.g.,

divorced women may have shared networks with husband). The parents were given a packet of

stress questionnaires and questions about their social networks. The results of the study reveal

that parents who had children with special needs experience more personal stress than parents

who do not have children with special needs, with mothers subjected to the highest amounts of

stress (Kazak & Marvin, 1984). According to the scores on the Parenting Stress Index,

developed by Abidin and Burke (1978), mothers who had children with special needs reported

more daily care-giving demands, less time for themselves, and felt less competent as mothers

(Kazak & Marvin, 1984).

The results of the study shown that the social support networks of the parents who have

children with disabilities were significantly smaller than those of the comparison group in terms

of friendship networks, but not extended family (Kazak & Marvin, 1984). The families of

children with special needs had significantly more dense networks, with greater boundary

density as well. There were no significant differences between the groups in martial satisfaction.

In fact, parents who have children with special needs indicated higher levels of martial

satisfaction (Kazak & Marvin, 1984). These results are in direct dispute with previous research

that suggested a child with special needs has a negative impact on the marital relationship.

Despite the reports of added stress, and smaller networks, Kazak and Marvin's (1984) study

show that some, but not all subsystems are affected by the stress.

Abbott and Meredith (1986) conducted a study of parents' marital and family strengths,

and personality characteristics. A final sample of 60 parents (30 married couples) who have

children with some type of disability was paired with 60 parents of similar characteristics, except

having a child with a disability. The authors used four scales to measure the parents' responses:

Family Strengths Scale (Olsen, Larsen, & McCubbin, 1982) which measures the amount of

pride, trust, loyalty, and competency in resolving problems; Dyadic Adjustment Scale (Spanier,

1976) which measures marital strength; Edwards Personal Preference Schedule (Edwards, 1959)

measuring psychological needs; and the Family Adjustment Survey (Abbott & Meredith, 1986).

There was no difference between the two groups on marital and family relations or personality

characteristics (Abbott & Meredith, 1986). The researchers found that parents of children with

an intellectual disability were less critical of family members, and they had fewer persistent

family problems. Compared to the parents who did not have a child with a disability, 42% of the

parents who had an intellectually disabled child indicated that they had more difficulty in

parenting, 27% felt a greater financial burden, 25% worried more about their child's future, 25%

felt restricted on their family's activities, and 15% were concerned about their child's number of

friends (Abbott & Meredith, 1986). However, thirty-three of the 36 parents (88%) reported

developing traditional family strengths; 55% said that they had a closer and stronger family; 41%

mentioned personal improvements (patience, compassion); and 17% found they had a greater appreciation for the small and simple things in life (Abbott & Meredith, 1986). The data suggests that even though parents experience a number of stressors, they are able to adjust to the challenges of raising a child with a disability, especially when they have a strong martial relationship (Abbott & Meredith, 1986).

Focusing on Family Strengths Verses Their Limitations. Much research in the past (Margarit et al., 1992; Trout, 1983; Wikler, 1981; Wikler et al., 1983) has focused on problems, stresses, inadequacies, and dysfunction in families who have children with special needs. When parents mentioned their strengths in the Wikler et al. (1981) study, the parents' strengths were interpreted as being defensive or in denial. Seventy-five percent of the 32 parents in the study said that although they had experienced chronic sorrow, they had become stronger because of their experience (Wikler et al., 1983). At the time of the original study (Wikler et al., 1981), the authors discounted the findings that having a child with disabilities made them stronger (Wikler et al., 1983). Although parents of developmentally delayed children experience periodic sadness and stress, many are able to cope successfully (Wikler et al., 1983). As noted by Kwai-sang Yau and Li-Tsang (1999, p. 38), "one should not automatically assume that a family is experiencing debilitating stress when they have a child with a disability."

Past Research. It was said before that past research has focused on the negative effects of raising a child with a disability while ignoring the positive aspects. Childhood characteristics and behavior have an influence on parental stress. Since children with different disabilities exhibit different types of behavior, it is reasonable to suggest that family adaptations will vary according to each child and their disability (Kazak & Wilcox, 1984). Many previous studies have focused on children with mental retardation (Kazak & Wilcox, 1984). Therefore, research

examining the impact multiple disabilities have on parental coping is necessary. Much of the

research examining families who have children with developmental delays was performed before

the implementation of the children's rights to receive free and appropriate education and

mainstream them into society. With the enactment of the Education for All Handicapped Act

(1975), the issues of integrating the child into the community and the types of daily demands that

arise in the home are in need of investigation (Kazak & Wilcox, 1984).

All families are different and all families experience stress. The level and the amount of

stress an individual or family experiences are difficult to measure. There are many variables that

influence a family's vulnerability to stress, including the child's disability, family's structure,

individual and family resources, and coping strategies. It is imperative that professionals stay

updated on the stresses the parents are experiencing. The previous section reviewing the

literature on stress, stress in families, and stress in families who have children with disabilities

was an important foundation for the following discussion of coping strategies. The type of

coping strategies parents' utilize will have a strong impact on the amount of stress mentioned

earlier.

Coping Strategies

Becoming a parent of a child with a disability can be a time of stress and change

(Thompson, 2000). The diagnosis of a disability may disrupt the family system and require a

new level of organization or balance (Burr, 1982; Patterson & McCubbin, 1983;). Examples of

the various stresses experienced by families who have children with disabilities were cited in the

previous section. Some life events can be influenced and shaped by individuals. Having a child

with a disability is an event that leaves many parents feeling they have little control; however,

they do have significant control over how they react and cope with their situation (Rose, 1987).

It was mentioned before that having a child with a disability creates a crisis event. The Chinese symbol for the word crises has two meanings: "danger" and "opportunity" (Stinnett & DeFrain, 1985, p.149). How well a family copes with the disability will depend on multiple factors, including parental support, the parents' evaluation of the situation, their ability to function, and any additional stress they are experiencing (McCubbin & Patterson, 1983a). With all that in mind, a crisis can be seen as a turning point rather than a disastrous event (Stinnett & DeFrain, 1985). Researchers studying family stress have focused their attention towards identifying what families, under what conditions, with what resources, and with what coping behaviors are better able to endure the hardships of life (McCubbin et al., 1980). The focus of this section is on the B and C variables in Hill's ABCX Model: the family's crisis meeting resources and how the family defines the event (McCubbin & Patterson, 1983a). Past research has focused on the stress and difficulties among parents of children with disabilities; this section reviews the strengths and resources of parents who have children with disabilities.

Definitions of Coping Strategies. Resources and coping strategies have often been used interchangeably, because they are mistaken to mean the same thing. Boss (1987) was the first researcher to make a distinction between the two concepts (Burr et al., 1994). The family's coping resources are the individual and collective strengths or assets the family has available to it, whereas coping strategies are what family members actually do, think, and feel with these resources (Burr et al., 1994). Prior literature on family stress theory and coping behavior has found that family members do not merely react to stressful events; rather they actively employ coping strategies (McCubbin, 1979). The coping process involves virtually every level of human functioning: cognitive, affective, behavioral, and physiological (Pargament, 1997, p.87). Family members may use existing coping behaviors that have worked in the past, or develop new

behaviors. The goal of coping strategies is to strengthen or maintain family resources, protect the family from the demands of stressful encounters (Judge, 1998), reduce the sources of stress or negative emotions (McCubbin, 1979), and achieve a balance in family functioning (McCubbin et al., 1980). In Pargament's book on *The Psychology of Religion* (1997), he describes coping as involving possibilities and choices meaning that a potentially stressful situation can be an opportunity for growth or devastation, depending upon a person's attitude and actions.

Coping is difficult to operationalize, because it is a very ambiguous and complex concept. Many factors are involved, varying in function (problem-solving or reducing negative emotions), mode (active versus passive), and outcome (more or less effective) (Crnic et al., 1983). There is a wide collection of coping definitions in family stress research and researchers have all developed their own categories to define coping patterns. Examples of the most common categories have been identified and included in this section: internal, external, adaptive, palliative, and adjustment strategies.

Based on the work of McCubbin and Patterson (1983), the coping styles of families can be classified as internal and external strategies (Turnbull et al., 1986). Internal strategies mainly involve cognitive aspects of passive appraisal (e.g., avoidance response) and reframing (e.g., redefining the situation). External coping strategies involve more behavioral repertoires, including seeking social support and spiritual support (Turnbull et al., 1986).

Judge (1998) and Bailey and Smith (2000) have identified two main types of coping patterns: adaptive coping methods (e.g., information seeking and problem solving) and palliative coping strategies (e.g., efforts to deny, minimize, or escape the stressful situation).   Adaptive coping strategies are directly aimed at coping with the source of stress, whereas palliative strategies indirectly help reduce a person's awareness of the stress (Atwater, 1983; Judge, 1998).

Palliative strategies include a person's unconscious defense mechanisms, which are spontaneous reactions to stressful situations. Individuals often use these defense mechanisms to help protect an individual from excessive threat, painful awareness, or from becoming overwhelmed by psychological stress (Atwater, 1983). Defense mechanisms may be helpful when used for a short amount of time; however, excessive reliance on them prevents personal growth (Atwater, 1983). Adaptive coping strategies are found to be more effective than palliative in reducing stressors (Bailey & Smith, 2000).

McCubbin and Patterson (1983b) have documented that the family may employ either one of the following types of coping strategies when faced with changes in the family: adjustment or adaptive coping strategies. Adjustment strategies are usually short-term and are often unable to meet the demands the family encounters. In the very beginning the family may try to deny that there is a stressful situation, or minimally change or alter the definition of the stressful event. These types of adjustment strategies serve to minimize or protect the family unit from having to make major changes in the family structure (McCubbin & Patterson, 1983a; McCubbin & Patterson, 1983b). If the family is unable to cope with the demands in the family system by utilizing adjustment strategies, a crisis will occur and the family will have to employ adaptive strategies, which include changes in family functioning or the family system (McCubbin & Patterson, 1983b). Examples of adaptive strategies are changes in family rules, roles, or expectations.

Essentially, coping strategies can be defined as cognitions and behaviors used by the individual in evaluating stressors that involve either active or avoidant coping strategies aimed at decreasing the amount of stress (Folkman & Lazarus, 1988; Lazarus & Folkman, 1984; Margalit et al., 1992). Coping is a major determinant in the relationship between stressful events and

adaptation outcomes (Judge, 1998, p.263). Even though some strategies have been found to be

more effective than others, it is difficult to assess the outcomes of coping because some people

strive for different means, and some approaches may be helpful in the short-term, but

problematic in the long run (Pargament, 1997). Efforts aimed at examining coping efficacy and

the criteria for identifying dependent variables to measure the outcomes of coping are in need of

further exploration (McCubbin et al., 1980).

     <u>Personal and Family Resources.</u> A family's response to stress will involve the various

coping mechanisms of individuals and the family as a whole (Crnic et al., 1983). Personal

resources are the broad range of support available to each family member (McCubbin et al.,

1980). Personal resources will influence a person's ability to cope effectively in stressful

situations. When family members have a sufficient amount of personal resources available to

them, they are less likely to view the situation as stressful (McCubbin et al., 1980). There are

four basic components of personal resources: financial, educational, health, and psychological

resource (Kwai-sang Yau & Li-Tsang, 1999). Educational resources help facilitate a person's

ability to problem solve, psychological resources include personality characteristics and self

esteem, financial resources refers to how well-off the family is financially, and family members'

physical health all have an effect on coping. Pearlin and Schooler (1978) found that self-esteem

and sense of mastery over the situation are more efficacious than actual coping behaviors when

facing strains over which an individual has little or no control (McCubbin et al., 1980;

McCubbin & Patterson, 1983b). However, when it comes to interpersonal relationships, specific

coping behaviors are often more efficacious than psychological resources (Pearlin & Schooler,

1982). One can conclude that specific situations require different types of resources or coping

strategies.

The family's resources are the sociological, economical, psychological, emotional, and physical assets that family members can draw upon in response to a stressful event (Burr et al., 1994). A family's structure at the beginning or prior to the crisis event influences the family's ability to cope and the response outcome (McCubbin & Patterson, 1983a). Prior experience with stressful situations may help reduce the strain of having a child with special needs and enhance family stability, or it may retard the development of additional coping behaviors directed at the stressful event (McCubbin, 1979). A family raising a child with a disability may have financial problems due to hospital bills, and adaptive equipment (Seligman 1983). Some families may have an advantage when it comes to stressful situations, due to greater income, resulting in more access to resources and respite or day care (Farran et al., 1986; McCubbin et al., 1982). Those who have more education will be better equipped to use problem-solving skills (McCubbin et al., 1982). A family's resources may place an individual at a greater advantage for coping with having a child with special needs.

Family resources can also include the number of parents in a household. Several studies (Abbott & Meredith, 1986; Friedrich et al., 1985; Schilling et al., 1994) have documented the importance of having a strong parental coalition. These researchers found that marital satisfaction was the single best predictor of parental adjustment and reduced amount of stress associated with caring for a child with a disability. The results of these studies indicate that marital strength is critical in predicting adaptation to a stressful situation (Abbott & Meredith, 1986). Researchers have found that single parents who have children with disabilities are at greater risk of increased stress due to having added role demands of a two-parent household (Beckman, 1983; Vadasy, 1986).

McCubbin et al. (1982) researched coping behaviors and resources in 217 families who have children with Cerebral Palsy and found that keeping the family functioning together as a unit, maintaining stability, and cooperating were important for both mothers and fathers who had children with Cerebral Palsy. McCubbin, McCubbin, Nevin and Cauble (1979) also found that mothers whose coping was directed at maintaining family cohesiveness and fathers who offered their support and concern were able to successfully manage caring for a child with a disability. Burr et al. (1994) found that maintaining family cohesion is one of the most frequently used and helpful strategies of families experiencing stress.

A well-functioning family is seen as having clear, but flexible boundaries between subsystems, flexible role relations, shared power and responsibilities, which promote personal growth and autonomy (Kazak & Marvin, 1984; McCubbin et al., 1980; McCubbin & Patterson, 1983b). Schaefer and Edgerton (1981) found that mothers who reported that their husbands shared in housework and child-care roles indicated greater marital satisfaction (Dunst, Trivette, & Cross, 1986). The family members work together as a team to establish new rules, roles, and responsibilities in order to achieve stability (McCubbin & Patterson, 1983b). One of the major coping strategies depicted by wives who were coping with separation from their significant others was to take on additional role responsibilities and become self- sufficient (McCubbin, 1979). This research indicates that families who maintain a sense of unity, but are able to be flexible have higher levels of functioning compared to other families. It is also important that parents share responsibilities in the home (Pueschel et al., 1988).

Four broad dimensions of coping resources were analyzed by Friedrich et al. (1985) to measure the adequacy of coping strategies in parents who have a mentally retarded child. The coping resources that were assessed were: utilitarian resources (e.g., family income, level of

education); health/energy/morale (e.g., physical and psychological well-being); social networks (e.g., marital, family, and friends' social support); and general and specific beliefs (e.g., self-efficacy, spirituality). The researcher's found that mother's who had fewer individual and family problems and scored low on measures of depression had high self-efficacy, and considered themselves to be capable of making changes (Friedrich et al., 1985).

The family's ability to communicate and express their thoughts and feelings is also an important component in healthy families (Bennett et al., 1990). Open and honest communication involves listening to one another and being sensitive to nonverbal communication (Burr et al., 1994). Fostering healthy communication, as well as sharing thoughts and feelings are vital components in parental adjustment (Pueschel et al., 1988). Even though communication and expressing emotions are most helpful to a family's well being, poor communication and negative emotions are found to be most harmful to families, which emphasizes the importance of promoting effective strategies (Burr et al., 1994).

Trute and Hauch (1988) examined the strengths of families who have positively adjusted to the birth of a child with a developmental delay. A total of 40 families were interviewed on family adjustment, child emotional stability, and the child's developmental process. Even though the characteristics of the child were insignificant to the level of parental adjustment, the results of their study revealed that the physical dynamics of the family influenced the parents' ability to cope (Trute & Hauch, 1988). Two-parent families with few children were at a distinct positive advantage. In a study examining healthy and problematic coping strategies in families who have an intellectually disabled child, Beavers et al. (1986) identified families that were struggling as having only one defined caregiver that focused all attention on the child with a disability.

Although certain families may have additional resources to cope with stress, not all families have to be from two-parent households, financially well off, or well educated to overcome hardships. Strong families have qualities and guidelines that they live by. They also have to work at being strong (Stinnett & DeFrain, 1985). Healthy families recognize stress as a means for accentuating family strengths and resources while becoming stronger in the process (Curran, 1987). Families who handle stress effectively work together to find solutions, to share responsibilities, to communicate, to share their feelings with one another, and to feel good about them in the end (Curran, 1987).

Stress Management Techniques. Some of the stress management techniques previously cited in the stress section above are mentioned again here, because they are also beneficial coping mechanisms. While parenting can be a source of joy and satisfaction, it can also be a source of stress. Parenting a child that requires extra time, care, and attention can drain a person's energy (Miller, 1994). When someone feels like he/she has too many responsibilities and not enough control over his/her life, he/she will experience stress (Miller, 1994). The first step in coping with stress is to understand it and identify the sources (Miller, 1994; Rose, 1987). Healthy families are able to recognize stress and deal with it (Curran, 1987). Once an individual recognizes his/her stress signals, he/she can try to anticipate the sources of stress, and try to eliminate some of the stress in advance.

Time management may be an effective coping strategy to alleviate some of the stressors of caring for a child with special needs (Turnbull et al., 1986). Another major coping strategy frequently mentioned by parents who have children with disabilities is taking one day at a time, rather than worrying about the future (Schilling et al., 1984; Turnbull et al, 1986).

McCubbin et al. (1982) examined the coping behaviors and resources in parents who had children with Cerebral Palsy and found that both mothers and fathers listed taking care of themselves as a helpful coping strategy. Caring for a child with a disability can be overwhelming; therefore, it is important that parents set some time apart to take care of themselves first, otherwise they will be unable to care of other family members (Thompson, 2000). Healthy families adjusted their expectations and values to focus on small gains and what is happening in the present rather than focusing on limitations or worrying about the uncertainties of the future (Beavers et al., 1986). Families have to change their priorities, goals, and expectations once their child is diagnosed with a disability (Pueschel et al., 1988; Rose, 1987). It is also important that parents realize that they are going to make mistakes and to let go of the feelings that they have to be perfect (Rose, 1987). Healthy families recognize stress as a temporary, normal part of life and are able to prioritize time and needs (Curran, 1987).

Cognitive Coping Abilities in Parents Who Have a Child with a Disability. The majority of strategies explained in this section involve cognition, which is the C factor in the ABCX Model (McCubbin & Patterson, 1983a). It is difficult to differentiate whether the amount of stress a family experiences is due to specific factors of the situation, or part of the family's perception of the event (McCubbin et al., 1980). It has been noted that "an individual's perception of a situation is a key factor in determining the severity of the stressor event and whether the family will experience a crisis" (McCubbin et al., 1980, p. 865). A person will view the situation as a crisis if they feel threatened or they do not possess the skills, resources, or energy to cope (Lazarus & Folkman, 1984). Pargament (1997) states that, "negative events are no less constructed than positive ones (p. 95)," which emphasizes that importance of cognition as a mediator in coping.

Judge (1998) investigated the coping strategies that were predictive of family strengths in 69 parents who have children with disabilities. The children had identifiable diagnoses that were considered developmentally at-risk or delayed, and the majority of demographic variables were quite diverse, except for gender and ethnicity, thus reducing applicability of the results. The coping strategies were assessed using the Ways of Coping Questionnaire (Folkman & Lazarus, 1988) and the Family Hardiness Index (FHI: McCubbin, McCubbin, & Thompson, 1991). The Ways of Coping Questionnaire has eight subscales: confrontive coping; distancing; regulating one's feelings; seeking social support; self-blame; wishful thinking; planful problem solving; and positive reappraisal. The Family Hardiness Index measures a family's internal strengths and durability. Fifty-eight percent of the coping strategies used by parents were problem-focused, including, concentrating on the next step, increased efforts to make things work, and creating a positive meaning by coming out of the experience better (Judge, 1998). Wishful thinking and self-blame was used more frequently when mothers have less education and a lower socioeconomic status (Judge, 1998). Passive appraisal (e.g., wishful thinking, self-blame, distancing, and trying to control one's feelings) was negatively related to family strengths (Judge, 1998).

Coping and Emotions. It was previously stated that it is difficult to measure the efficacy of coping strategies. One way researchers can assess the effectiveness of coping strategies is by measuring how well coping resources prevent hardships from resulting in emotional stress (McCubbin et al., 1982). In the past, coping was viewed primarily as a response to certain emotions. However, it was found that the relationship between coping and emotions has a bi-directional effect. The way a person feels in stressful situations will affect their form of coping. Some forms of coping are associated with positive affect, whereas some are associated with

increases in negative affect (Folkman & Lazarus, 1988). Folkman and Lazarus (1988) examined the extent to which eight different types of coping would mediate the emotional responses in a younger (ages 35-45) and older sample (mean age of 68) of White men/women who had recently experienced a stressful encounter. Coping was associated with all four types of emotions: disgust and anger; pleasure and happiness; confidence; and to a lesser extent fear and worry (Folkman & Lazarus, 1988). Planful problem solving was associated with an improved emotional state, suggesting that people often feel better when they directly focus on finding solutions to the problem (Folkman & Lazarus, 1988). Confrontive coping and distancing had a negative effect on emotions, because it failed to diminish the distress (Folkman & Lazarus, 1988). Positive reappraisal had improved emotional states in the younger group, but seemed to contribute to a worsened emotional state in the older group. One explanation for this could be that the older group had difficulty sustaining the positive beliefs, when faced with difficult situations. The results of this study support the hypothesis that certain coping strategies are related to varying emotional states, and one form of coping may be more effective than another in increasing positive emotions. The differences found between the age groups could be due to methodology, different types of stressful situations explained by the different groups, or the developmental changes in coping efficacy (Folkman & Lazarus, 1988).

Gender Differences in Coping. Several studies have also shown gender differences in coping. Women tend to involve themselves more in the emotional roles of caring for the well being of family members, whereas fathers assume the provider role (Hobfoll, Cameron, Chapman, & Gallagher, 1996). According to Burr et al.'s (1994) study on effective coping strategies, women tend to use a wider range of coping strategies, such as reaching out to people, involvement in religious activities, and openly expressing their feelings. Men tend to withdraw,

keep their feelings inside, and use more harmful types of strategies (e.g. alcohol) (Burr et al., 1994). Patterson and McCubbin (1983) found that a father's coping patterns complement a mother's patterns. The parents' ability to effectively adjust to the added demands of taking care of his/her child also has a positive effect on other family members and society.

Functional vs. Dysfunctional Coping. In a study of 40 families, at different stages of the life cycle, Beavers et al. (1986) examined the families healthy and problematic coping strategies through clinical observation and the Beavers Family Assessment Model (Beavers et al., 1986), which assesses family structure, flexibility, and competence. The sample consisted of people of diverse ethnicities and family dynamics. Parents had a high school education or less. Well-functioning families had a positive outlook on life, an acceptance of their responsibilities, an ability to resolve conflicts, and take one day at a time (Beavers et al., 1986). Well-functioning families focus on their child's strengths or abilities, rather than their limitations (Abbott & Meredith, 1986; Schilling et al., 1984). A parent coping with the added stress of raising a child with disabilities found that accepting the situation was the most helpful coping strategy (Burr & Klein et al., 1994). Abbott and Meredith (1986) found that the successful adaptation of having a child with a disability was accomplished when the parents defined their situation in a positive way.

Unhealthy coping behaviors were often related to the way the families defined their situation (e.g., a view of life as unfair, beyond their control, and seeing themselves as victims) (Patterson & McCubbin, 1983). Families that do not handle stress effectively tend to blame other people; focus on family problems rather than the positives; view social support or outside stress as a sign of weakness or inability to handle their problems; and let the stress take over them (Curran, 1987). In Beavers et al. (1986) unhealthy families focused on negative feelings and

denied that their child had a disability or even belonged to the family. The most harmful coping

strategy found in parents who have a child with a chronic illness was expressing less affection

and trying to go on as if nothing had happened (Burr et al., 1994). Finally, the results of a

McCubbin et al.'s study (1982) were that high-conflict families experienced a pile-up of life

changes or stressors with little coping ability.

When examining the efficacy of coping mechanisms, researchers found that having a

wide range of responses is more helpful than any one single mechanism (Pearlin & Schooler,

1982). In addition, Trute and Hauch (1988) found that families who have positively adjusted to

the birth of a child with developmental delays viewed themselves as members of strong families.

Research has shown that families who respond to stressful situations more successfully tend to

define the situation in a more optimistic, proactive manner and are able to accept the situation

(Burr et al., 1994). Defense mechanisms, such as denial, serve a useful purpose in the short term;

however, parents who deny the existence of their child's disability may be delaying the use of

specialized services and support that can help them (Schilling et al., 1984).

Acquiring Social Support. The study of social support is relatively complex. The

vagueness of the term social support has lead to some confusion over what types of interventions

to employ (Coyne & Delongis, 1986). Social support can be defined as individuals, groups, or

institutions that provide assistance to help other individuals overcome stresses that strain a

person's resources (Schilling et al., 1984). Researchers have identified several major areas of

social support: financial, emotional, educational, material, formal, and informal (Shelton &

Stepanek, 1994). Informal sources of support include individuals (e.g., family, friends,

neighbors, relatives, co-workers) and groups (e.g., church organizations, parent-groups).

Informal supports are available without contact through a professional helper or agency (Bennett

et al., 1990). Formal supports include both professional helpers (e.g., physicians, social workers, counselors) and agencies (e.g. hospitals, early intervention programs, day care centers). Research has shown that informal support has more positive effects than formal support (Bennett et al., 1990).

Seeking social support has been positively associated with family strength and greater family confidence in families who have children with disabilities (Judge, 1998). Research indicates that individuals who have access to social support are protected against the emotional and physical effects of stress (Pilisuk & Hillier-Parks, 1983). A study by Peterson (1984) examined the importance of social support and its impact on raising a child with a disability and found that mothers with high stressors and high support had fewer outcome problems compared to mothers with low support and high stressors (Bailey Jr. & Simeonsson, 1988).

Social support is helpful because it fills the basic human need for relatedness and connection (Ryan & Solky, 1996). The ability to obtain levels of social support will vary depending upon individual characteristics, availability of resources, and the culture in which one lives (McCubbin et al., 1980). The capacity to trust others and allow oneself to become dependent upon others is a key variable in establishing social support (Coble, Gantt, & Mallinckrodt, 1996; Rubin & Quinn-Curran, 1983). Individual family members and the families themselves will vary in the type of social support they need (Shelton & Stepanek, 1994).

Social support increases positive parental attitudes toward their child with a disability (Crnic et al., 1983). Participants in Abbott and Meredith's (1986) study found participation in parent support groups and other social services as helpful. Support groups offer parents the opportunity to meet other parents and establish potential childcare for one another (Schilling et al., 1984). Parents' self-help/support groups are places in which parents can share their feelings,

discuss their concerns or problems, exchange information about disabilities or community

services, offer advice to one another, and focus on positive ways of helping their children

(Darling, 1983; Thompson, 2000). Parent groups help parents feel connected to others, which

reduces the feelings of being alienated from the rest of society. Parents express that the common

thread or sense of universality that binds them together is the greatest benefit of belonging to a

parents' group (Meyerson, 1983). "The voices of other parents can bring a measure of comfort"

(Featherstone, 1980 p.11). In addition to being supportive of their members, mutual self-help

groups often focus on changing attitudes and policies, which are beneficial towards problem

situations (McCubbin et al., 1980).

Social support differs according to the cultural context (Dilworth-Anderson & Marshall,

1996). Where European-Americans value independence, African-Americans, Hispanics, Native

Americans, and Asians tend to be more family-centered and have stronger social support

networks. Helping professionals working with families need to be sensitive to the family's

cultural heritage.

There are also gender differences in social support. Several studies (e.g., Barbee,

Cunningham, Winstead, Derlega, Gulley, Yankeelov, & Druen, 1993) have shown that women

rate supportive behaviors as more satisfying than men (Acitelli, 1996). Men and women utilize

social support systems differently; men typically isolate themselves under high stress conditions,

while women may reach out (Hobfoll et al., 1996).

As previously stated, whether one is married and the quality of the marriage are a strong

determinant of coping in stressful situations. A strong parental subsystem and utilizing the

support of family and friendship networks have been shown to be indicative of strong positive

family adaptation following the birth of a child with a developmental delay (Trute & Hauch,

1988). Persons who are unhappily married are likely to be stressed by the strain in their

marriage, and one could assume that the strain of their marriage is exacerbated by stress in other

areas of their life (Coyne & Delongis, 1986).

Past studies (Kazak & Marvin, 1984; Kazak & Wilcox, 1984) have analyzed the

characteristics of families who have children with disabilities and have found that the friendship

networks were smaller for families who have children with special needs compared to families

who do not have children with special needs. However, members of these social networks seem

to know and interact with each other, signifying that they have overlapping friendships. This

implies that members of families of children with disabilities are small and highly

interconnected. It is important that professionals encourage families to join parent support

groups, to extend their social resources and build friendships, as well as offer additional support

(Kazak & Marvin, 1984).

Perceived Social Support. Similar to the subjective appraisal of stress, supportiveness is

in the eye of the beholder (Lakey & Lutz, 1996). Behavior that is not found to be supportive is

not considered to be helpful (Pierce et al., 1996). One component of social support is support

schemata, which is a person's perception that others will provide aid when they need it (Pierce et

al., 1996). Perceived support availability has been demonstrated to buffer the effects of stress on

psychological outcomes (Kessler & McLeod, 1985). Individuals with greater perceived support

may view the situation as less stressful and thus have less of a need to engage in coping

strategies (Ptacek, 1996). A study by Wethington and Kessler (1986) showed that perceived

support was more strongly linked to reduction in stress than the actual effects of supportive

behavior. It is possible that people who perceive themselves as having access to support are

more likely than others to elicit supportive behaviors when a stressful situation occurs (Wethington & Kessler, 1986).

Spiritual Support. One of the best predictors of emotional adjustment is religion (Atwater, 1983). Spirituality is difficult to define because it means different things to different people (Pargament, 1997). Spirituality can be described in various ways: faith in humanity, ethical behavior, concern for others, or interaction in relation to a greater Being (Stinnett & DeFrain, 1985). "Spirituality helps people appreciate what they themselves cannot control" (Pargament, 1997, p. 8). It is a personal way of life in which a person strives to find meaning and significance. Many people find spiritual support in the form of prayer, literature, participation in religious activities, joining organizations, or attending religious services (Pargament, 1997). Faith and religious coping methods are the most frequently reported coping strategies among parents who have children with disabilities (Burr et al., 1994; Pargament, 1997). Others use religious reframing as a way to put things in a new perspective and make the situation more manageable. Religion offers guidelines for living and offers a sense of stability. Families may view the difficult situation as an opportunity for spiritual growth (Pargament, 1997).

The question has been raised as to whether more people use religion as a coping strategy, compared to other types of strategies, and whether more people turn to religion in times of crisis than in other times of their lives. It was found that individuals appear to involve themselves with religion to a greater extent in more stressful situations than in less stressful moments of their life (Pargament, 1997). People will also turn to religion more than other resources when religion is more available to them and if it is already a part of their lifestyle (Pargament, 1997).

Pargament (1997) looked at three different approaches to control in religious coping: self-directing approach, deferring approach, and collaborative approach. The self-directed approach places more coping responsibility on the individual verses God. The deferring approach is described as an individual passively putting responsibility onto God. In the collaborative approach, both the individual and God are active participants in the coping process. The collaborative approach has been associated with a greater sense of self-esteem, personal control, and a lower sense of control by chance (Pargament, 1997).

Pargament (1997) has broken religious coping down into different categories in order to determine which types of religious coping are helpful or harmful. Spiritual support, congregational support, prayer, and benevolent religious reframing were found to be helpful, whereas viewing negative events as a punishment from God, and discontentment with God or the congregation was considered harmful (Pargament, 1997). In *The Healing Power of Faith*, Koenig (1990) presents scientific evidence supporting the therapeutic power of religion and faith, as well as examples of individuals who have benefited from having a spiritual life. Studies conducted at Duke University's Center for the Study of Religion/Spirituality and Health have found that people with stronger faith are: less likely to suffer from depression; live healthier lifestyles; have stronger immune systems; and have a stronger sense of well-being and life satisfaction compared to nonreligious counterparts (Koenig, 1999). Research at Duke University confirms that religious people cope better with major stress events those who lack the comfort of personal faith or the emotional support of a congregation (Koenig, 1999).

Three studies by McCubbin (1979) examined wives' coping responses in the face of family separations and what has been helpful in overcoming their hardships. Some wives experienced prolonged separation of up to 6 years, moderate separation of 8 months, and

minimally severe separation of 1 week due to military and/or business duties. McCubbin (1979) found that spiritual support played an important role in the family's ability to manage stress, particularly in the most severe situations.

Abbott and Meredith's (1986) comparative study investigated the use of specific coping strategies and found that strong religious beliefs were helpful resources in coping with the challenges of rearing a child with disabilities. In a comparative study, Weisner, Beizer, and Stolze (1991) found differences between 102 religious and non-religious parents who had a child with developmental delays. Individuals often turn towards their religion or spirituality in attempts to explain certain situations and give meaning to their struggles. Religious parents differed from non-religious parents in the view that their child with a developmental delay was an opportunity rather than a burden (Weisner et al., 1991). They also differed from non-religious parents in their beliefs in the importance of the family life, and tended to focus somewhat more on family than other strategies. The groups did not differ in measures of peace of mind, emotional adjustment, and social support.

Parents who are coping with the diagnosis of the child and the many stressors of raising the child with a disability may find comfort in spirituality. Certain spiritual strategies such as using religion to explain the event, seeking spiritual support, and collaborating with God were found to be more helpful than other strategies. Helping professionals should be knowledgeable about various religious practices and inquire as to whether spirituality plays a role in the family's lives. It is important to note that much of religious coping is measured through self-reports, which are potentially biased. Information on the prevalence of religious coping is variable due to methodological errors (Pargament, 1997).

Summary. Several researchers (Beckman, 1983; Kazak & Marvin, 1984) have found that parents who have children with disabilities experience higher amounts of stress. Previous research has focused on the decline in family functioning. However, researchers now know that the family's system and level of functioning can remain stable or even improve when a family faces a severely stressful situation (Burr et al., 1994). The results of Burr et al. (1994) demonstrate the complexity of family functioning. The family's adjustment will depend on multiple factors, ranging from the family's resources, coping strategies, and perception of the event. It is important that researchers study families who have a child with a disability within their social environments in order to understand the way in which the environment may provide support to these families (Kazak & Wilcox, 1984). The culture, immediate home environment, the schools, workplace, neighborhoods, interpersonal networks, agencies, and social services are all interrelated and contribute to a family's ability to cope effectively (Crnic et al., 1983).

After asking 78 families who have coped with stressful situations, Burr et al. (1994) found that different coping strategies were helpful in different situations. There is no single best way to cope for all people and in all situations. Every family is different. It is also important to note "not all coping strategies are helpful for everyone in every situation" (Burr et al., 1994, p.202). Good coping is defined as what works well for each individual in a particular situation (Pargament, 1997). However, there are certain strategies that place the family at a disadvantage and may produce more stress rather than alleviate it. Helping professionals should encourage the use of strategies that are beneficial to all family members.

Since medical technology, adaptive equipment, society's attitudes, and families are always changing, it is important that we continue to examine family coping strategies and the resources that help buffer the amount of stress in their lives. In order to help professionals who

work with families who have children with disabilities, it is important to understand what coping

strategies parents utilize and which ones are most helpful for them.

CHAPTER 3

Methodology

This chapter will discuss the process of selecting participants for the study, a description

of the subjects involved, and the services offered at Cerebral Palsy, Inc. An overview of how the

data was collected, the instrumentation used in the study, and how the data was analyzed will

also be discussed.

Participants

After consultation with the Director of Children's Services at Cerebral Palsy, Inc.,

located in Green Bay, Wisconsin, the researcher was given permission to send questionnaires to

all parents who currently have children enrolled in the Birth to Three Program at Cerebral Palsy,

Inc. In order to help the professionals who work with these families, a cluster sample of 89

parents was chosen as the population to be studied. Cerebral Palsy, Inc. offers a wide variety of

services to children and adults who have temporary and permanent disabilities in Northeastern

Wisconsin. The children who receive services have varying types of conditions that include, but

are not limited to: Cerebral Palsy, speech and language problems, cognitive, social, and/or

emotional delays. The Birth to Three Program is a component of Part H in the Individuals with

Disabilities Education Act (IDEA) established in 1986, which supports early intervention

services mandated for infants and toddlers with disabilities (Aron et al., 1996). The Birth to

Three Program offers many services to the child and their family through a coordinated system.

The families who have children with special needs are able to receive services either at Cerebral

Palsy or in their natural environments, which seems to be the most common service site.

Of the 45 participants, 42 were female (93%) and 37 were married (82%). Eighty-two

percent of the parents were married, while the remaining 18% were either single or divorced.

The majority of respondents were between ages thirty to thirty-nine (54%), 22% were between

18-24, 11% were ages 25-29, and 13% were 40 or older. Thirty-six percent of the parents had 1

child, 38% had 2 children, and 27% had 3-4 children. Forty-seven percent of the parents had an

annual income of $39,000 or less and 53% earned $40,000 or more. The majority of children

had a physical disability (44%) or a combination of physical, emotional, and/or cognitive

disabilities (26%).

Procedures

A human subjects review was completed and approved by the University of Wisconsin -

Stout's Graduate School prior to conducting research in order to protect the rights of the parents.

The researcher contacted the Director of Children's Services at Cerebral Palsy, Inc. to gain

permission from Cerebral Palsy to send questionnaires (Appendix A) out to all the families who

have children receiving services in the Birth to Three Program. Letters (Appendix B) were sent

to area businesses to request coupon donations as a token of appreciation for completion of

questionnaire and to increase parental response rates. Cover letters from the researcher

(Appendix C) and the Director of Children's Services (Appendix D) describing the researcher

and the purpose of the study were included with the questionnaire, along with a consent form

(Appendix E), and coupons from McDonald's and Dairy Queen.

A self-report questionnaire was sent to each parent, who were given instructions to

complete and return the survey in the self-addressed, stamped envelope within two weeks. It

was specified that their participation was completely voluntary and that their answers would

remain entirely confidential and anonymous, since the researcher had no access to their names or

other identifying information.

Instrument

   The purpose of the study was to examine parent coping strategies and determine if any

one strategy is used more than another. Parental coping strategies were assessed using the

Family Crisis Oriented Personal Evaluation Scale (F-COPES) developed by McCubbin, Olson,

and Larsen (1981). This 5-point likert, self-report scale was designed to record problem-solving

attitudes and behaviors that parents develop in response to problems or difficulties (McCubbin et

al., 1996). The scale indicates the point at which a person agrees or disagrees with each

statement (1= strongly disagree and 5= strongly agree). The F-COPES contains 30-items that

been divided into five coping pattern subscales: acquiring social support, reframing, seeking

spiritual support, mobilizing family to acquire and accept help, and passive appraisal. Acquiring

social support is the family's ability to actively engage in acquiring support from relatives,

friends, neighbors, and extended family (e.g., sharing our difficulties with relative) (McCubbin et

al., 1996). Reframing assesses the family's capability to redefine stressful events in order to

make them more manageable (e.g., knowing that we have the strength within our family to solve

our problems). Seeking spiritual support is finding comfort in a higher belief system (e.g.,

participating in religious or spiritual activities). Mobilizing family to acquire and accept help is

the family's ability to seek out community resources and accept help from others (e.g., seeking

assistance from community agencies and programs designed to help families in situation).

Passive appraisal is the family's ability to accept problematic issues that minimizes reactivity

(e.g., believing if we wait long enough, the problem will go away) (McCubbin et al., 1996). An

additional open-ended question was added by the researcher that asks the parents to further state

what was most helpful in coping with their child's disability (i.e., seeking spiritual support,

maintaining a positive attitude, family, friends, community resources, etc.).

The F-COPES (1981) was initially tested on a sample population of 2740 husbands, wives, and adolescents who were graduate and undergraduate students. The sample population was split into two halves (Samples 1 and 2), and the researchers used factor analysis to come up with the five subscales. Cronbach's alpha was computed for each subscale, resulting in an overall alpha reliability of .86 for the first half and .87 for the second half (McCubbin et al., 1996). Test-retest reliability coefficients were obtained from students, which showed that more concrete behavioral items, such as mobilizing family supports, had higher scores on test-retest reliability compared to reframing and passive appraisal (McCubbin et al., 1996). Researchers have used the F-COPES in a variety of circumstances, some of which include: parents coping with children who have learning disabilities, mental retardation, or physical disabilities; caregivers of Alzheimer's patients; or families coping with major illnesses, injuries, or diagnoses (McCubbin et al., 1996). With the exception of the last question, F-COPES has been shown to have high construct validity and reliability (McCubbin et al., 1996).

The parents were also asked to record their demographic characteristics that included gender, age, marital status, number of children, family income, and the nature of the child's disability in order to help describe the families.

Data Analysis

The quantitative data was analyzed for the each of the subscales and demographic variables using descriptive statistics, including frequencies, means, modes, and standard deviations. Responses to the open-ended question were calculated and categorized according to similarity. Demographic variables were computed using a multiple-choice format ranging from 1 = strongly disagree to 5 = strongly agree. A comparative analysis was conducted to see if any demographic variables had a significant relationship to coping strategies. T-tests were utilized to

calculate significance between marital status, income, and the five coping subscales. ANOVA

analysis was used to determine the significance between number of children, age and any of the

coping patterns.

CHAPTER FOUR

Results

The purpose of this study was to identify the coping strategies and attitudes most frequently utilized by parents who have children with disabilities. This chapter will discuss the statistical results of the research and data analysis. Frequencies and percentages of the demographic variables will be presented. Descriptive statistics will be reported on each of the five subscales. Means and standard deviations will be compared between the normative data and results of this study. In addition, this section will also discuss any significance found between demographic variables and coping strategies, as well as the results of the open-ended question.   .

Demographics

Of the 89 questionnaires mailed to the parents who have a child currently receiving services from Cerebral Palsy, Inc.'s Birth to Three Program, 45 of the surveys were returned by the due date, thus having a response rate of 51%.   Frequency counts and percentages were calculated for the demographic variables pertaining to the respondent's gender, marital status, age, number of children in the household, annual household income, and type of disability respondent's child has (see Table 1). As shown in Table 1, the majority of respondents were female ($\underline{n} = 42$) and married ($\underline{n} = 37$). Most of the parents reported their child as having a physical disability ($\underline{n} = 20$), or a combination of physical, emotional, and/or cognitive disability ($\underline{n} = 12$).

Table 1

Demographic Variables

	Statistics	
Variables	Frequency	Percentages

Gender of Respondent

Male/Both Parents	3	7%
Female	42	93%

Marital Status

Single/Divorced	8	18%
Married	37	82%

Age

18-24 Years Old	10	22%
25-29 Years Old	5	11%
30-34 Years Old	12	27%
35-39 Years Old	12	27%
40 or Older	6	13%

Number of Children

1 Child	16	36%
2 Children	17	38%
3-4 Children	12	27%

Annual Income

$39,999 or Less	19	42%
$40,000 or More	21	47%

Child's Disability

Physical	20	44%
Emotional	1	2%
Cognitive	8	18%
1 & 2 Combination	1	2%
1 & 3 Combination	9	20%
2 & 3 Combination	1	2%
1-2-3 Combination	1	2%
Not Known	3	7%

Findings

In reviewing the results of this study, the two most frequently utilized coping strategies were seeking social support ($\underline{M}$ = 31) and reframing ($\underline{M}$ = 31). Seeking spiritual support ($\underline{M}$ = 14) was the least utilized. However, if one looks at the frequencies and percentages for each individual item rather than the subscales as a whole, the most strongly agreed with item was Item 30: "Having faith in God or a higher power" ($\underline{n}$ = 25), followed by Item 9: "Seeking information/advice from the family doctor" ($\underline{n}$ = 23). The most disagreed with item was Item 28: "If we wait long enough the problem will go away" ($\underline{n}$ = 32). Means, and standard deviations for each of the coping subscales were computed and compared using the normative data and results from the sample population (Graph 1).

Graph 1

Standard Deviation and Mean Comparisons Between Cerebral Palsy's (C.P.) and Normative Data's Coping Subscales

Descriptive Statistics For Subscales

Legend:
- C.P. Standard Deviation
- C.P. Mean
- Normative Standard Deviation
- Normative Mean

Categories (x-axis): social support, reframing, spiritual support, mobilizing, passive appraisal
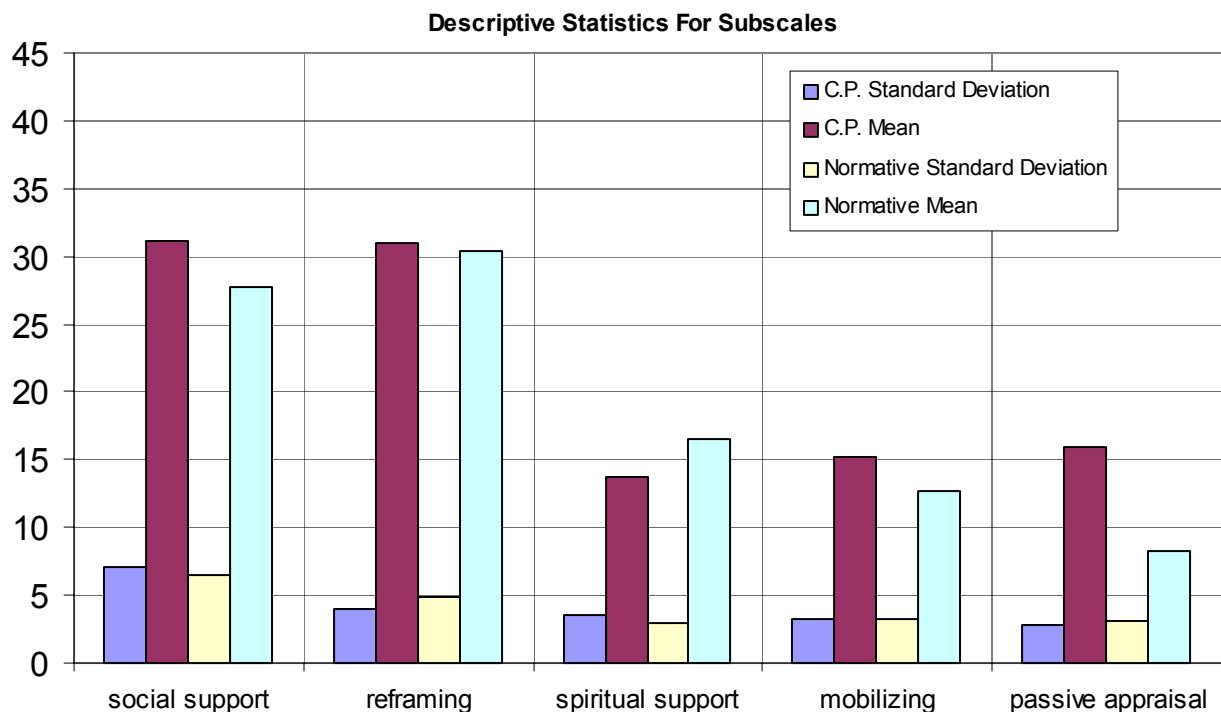
Table 2

Standard Deviation and Mean Comparisons between Cerebral Palsy and Normative Data

	Statistics	
Subscale Groups	Mean	Standard Deviation
Acquiring Social Support		
Cerebral Palsy	31	7
Normative Data	28	7
Reframing		
Cerebral Palsy	31	4
Normative Data	30	5
Seeking Spiritual Support		
Cerebral Palsy	14	4
Normative Data	17	3
Mobilizing Family to Acquire and Accept Help		
Cerebral Palsy	15	3
Normative Data	13	3
Passive Appraisal		
Cerebral Palsy	16	3
Normative Data	8	3

Means and standard deviations of the subscales acquiring social support, reframing, and mobilizing family to acquire and accept help, were comparatively similar to the normative data (see Table 2). However, passive appraisal subscale ($\underline{M}$ = 16) differed the most from the norm group ($\underline{M}$ = 8).

Independent t-tests were conducted in order to examine the significance between the parental coping strategies and the parents' marital status and annual income. No significance

was found regarding parental coping strategies and marital status. However, a significant relationship was found between family income and reframing (p<.05), as well as family income and seeking spiritual support. Parents who had a higher income of $40,000 or more utilized reframing and seeking spiritual support coping strategies to a greater extent than those who earned $39,999 or less. For the significance reported on the reframing subscale, equal variances were assumed. Equal variances were not assumed for seeking spiritual support. Due to the high number of female respondents and low number of male respondents, the researcher was unable to compute any significant relationship between gender and coping subscales.

An ANOVA was conducted to determine the statistical significance between the demographic variables including, age of the respondents and number of children in the home, and the five coping subscales. No differences were found between the age of the respondents and any coping scale. Significant findings were found between number of children and passive appraisal (p<.01). As the number of children increased, the amount of passive appraisal decreased. The researcher was not able to determine statistical significance between the child's disability and subscales due to the three types of disabilities chosen to represent the child's disability. The majority of respondents indicated that their child had a physical disability or a combination of physical, emotional, or cognitive disability. Due to the complexity and overlapping characteristics of a disability, it is difficult for both parents and professionals to label the child as having a distinct disability.

With regard to the narrative question, the most helpful and frequently used coping strategy indicated by participants was family support (n = 20). The second most reported response was maintaining a positive attitude (n = 15) followed by support from friends (n = 11), community resources (n = 10), and seeking information and support from professionals (n = 10).

Summary

The data analysis revealed that acquiring social support ($M = 31$) and reframing ($M = 31$) were the most frequently used coping strategies used by the parents who have children currently receiving Birth to Three services at Cerebral Palsy, Inc. The mean of the passive appraisal subscale ($M = 16$) was slightly higher compared to seeking spiritual support ($M = 14$) and mobilizing family to acquire and accept help ($M = 15$). The majority of respondents utilized acquiring social support and reframing, which are highly successful strategies.

The means and standard deviations on the subscales were comparatively similar with those of the norm group, except for the passive appraisal and acquiring social support subscales. The parents in this study seemed to use passive appraisal and acquiring social support to a greater extent than the normative group.

In regard to the demographic variables, significance was found between family income and the reframing and seeking spiritual support subscales. Parents who had a higher income seemed to utilize reframing and seeking spiritual support more often. Significance was also found between the number of children in the household and passive appraisal; as the number of children increased, passive appraisal seemed to decrease.

The most helpful coping strategy reported by the parents on the open-ended question in descending order was family support ($n = 20$), maintaining a positive attitude ($n = 15$), support from friends ($n = 11$), community resources ($n = 10$), and professional support ($n = 10$), spiritual support ($n = 8$), parents in similar situations ($n = 4$), healthy communication ($n = 3$), and changing expectations ($n = 2$).

CHAPTER FIVE

Discussion, Limitations, and Recommendations

This chapter will discuss the results of the study in relationship to the material described

the literature review. Implications for helping professionals, limitations of the present study, as

well as future recommendations will also be addressed.

Discussion

As a group, parents who have children with special needs report higher amounts of stress

compared to families who do not have children with special needs (Gallagher et al., 1983; Kazak

& Marvin, 1984). A family's ability to adapt to stressful situations depends upon a number of

variables, including an individual's psychological strengths, individual and family resources, and

the type of coping strategies utilized (Abbott & Meredith, 1986; McCubbin & Patterson, 1983a).

The purpose of this study was to examine the coping strategies of parents who have children

receiving Birth to Three services at Cerebral Palsy, Inc. The researcher utilized the F-COPES

scale of measurement to assess the coping behaviors and attitudes. Of the 89 parents who were

mailed questionnaires, 45 parents responded (51% response rate). The data was collected and

analyzed using descriptive statistics. Frequency counts and percentages were calculated for the

demographic variables. Means, medians, and standard deviations were reported on all five

subscales. The means and standard deviations were compared using the normative data of the F-

COPES scale. The demographic variables were analyzed for statistical significance in

relationship to each of the subscales.

It was previously mentioned that it is difficult to assess the outcomes of coping due to the

many variables involved. The literature review suggests that there are certain strategies that are

more adaptive or effective ways of coping than others. The goal of coping strategies is to

strengthen or maintain family resources (Judge, 1998), reduce the source of stress or negative

emotions (McCubbin, 1979), and achieve a balance in family functioning (McCubbin et al.,

1980). Strategies directly aimed at coping with the source of stress, such as problem solving and

seeking information are more adaptive strategies than those efforts to deny or minimize the

situation (Bailey, Jr. & Smith, 2000; Judge, 1998). An individual's perception of the event is a

critical factor in determining whether the event will be stressful or not. Parents who defined

having a child with a disability in a positive way had more successful adaptations and family

strengths (Abbott & Meredith, 1986; Burr et al., 1994). Seeking social support (Judge, 1998;

McCubbin et al., 1982) and spiritual support (Abbott & Meredith, 1986; Koenig, 1999) are also

strategies that are efficacious and frequently utilized. In a study by Judge (1998), passive

appraisal was negatively related to family strengths. With regard to coping strategies and

emotions, positive reappraisal and planful problem solving was associated with an improved

emotional state, whereas, blaming, and distancing had a negative affect on emotion (Folkman &

Lazarus, 1988).

The F-COPES measured parenting strategies in the participants of this study based on

five subscales; social support, reframing, spiritual support, mobilizing family members to acquire

and accept help, and passive appraisal. Of the five subscales, social support, reframing, spiritual

support, and mobilizing family members to acquire and accept help are the most beneficial

according to the literature review. The results of the study indicate that the means were highest

for social support, reframing, supporting the information found in the literature review. Passive

appraisal had the third highest mean, followed by mobilizing family members to acquire and

accept help and spiritual support. The parents in this study used passive appraisal to a larger

extent than the individuals in the normative data.

Significance was found between number of children and passive appraisal subscale. Parents who had 3-4 children used passive appraisal less than parents who had 1 or 2 children. This finding supports the data that other siblings can be a source of support (Crnic & Leconte, 1986; Gallagher et al., 1983; Seligman, 1983). This data seems to suggest that having more children renders it easier to cope with having a child with a disability. The higher use of passive appraisal by parents in this study could be explained by the higher number of households with one or two children. The larger use of passive appraisal was surprising due to parental responses on the individual items for the passive appraisal subscale. For example, Item 30 reads, "If we wait long enough the problem will go away." Thirty-two of the 45 parents strongly disagreed with this sentence, which indicates that parents are utilizing a more adaptive strategy. However, the responses were more divided on Item 26, which is "Feeling that no matter what we do to prepare, we will have difficulty handling problems." This variation may be due to self-report bias, methodological flaws, or other extraneous variables such as cultural attitudes or present perceptions. Even though passive appraisal may be helpful on a short-term basis, professionals should encourage and promote the use of more effective strategies, such as finding supports and developing positive attitudes.

Researchers (Abbott & Meredith, 1986; Friedrich et al., 1985; Schilling et al., 1994) have found that having a strong parental coalition is a high predictor of parental adjustment and reduced amounts of stress associated with caring for a child with a disability. Single parents are at a greater risk for experiencing higher amounts of stress (Beckman, 1983; Vadasy, 1986), signifying that two parent families are at a distinct advantage (Trute & Hauch, 1988). Significance could not be calculated between coping strategies and marital status in this study. Several studies have also shown gender differences in coping, as well as differences according to

a child's disability, however no differences were found in gender, perhaps due to the limited sample size.

Statistical significance was found between coping strategies and annual income. Parents who had an income of $40,000 or more utilized reframing and seeking spiritual support to a greater extent than those who earned $39,999 or less. One possible reason for this may be that parents who have a higher income may also have more resources available to them, which helps make the situation less stressful and they may look at their situation as an opportunity for growth rather than an uncontrollable, devastating event. Five people chose not to respond to this question, which may be because their annual income is not known or the sensitivity of the subject.

The variety of responses listed on the narrative question were highly significant. The advantage of this question is that parents are able to list more than one response and supports the information found in the literature review that "having a wide variety of strategies is more helpful than having only one or two" (Burr et al., 1994, p.147).

As the results indicate, this research contains useful information regarding parental coping strategies. The information is important for other parents who have children with disabilities and the professionals who help theses families at Cerebral Palsy, Inc.

Practical Implications

The open-ended question provided a valuable amount of information regarding this study. As was expected in response to the added question, parents had listed a variety of helpful coping strategies. Since each family is unique, professionals need to know that what coping strategies are helping each family. One should not assume that any one specific strategy works well for all families (Burr et al., 1994). The literature review revealed that a number of strategies are helpful

depending upon various occasions and time frames. The results of this study found that the

majority of respondents (n = 20) listed family support as the most helpful. This does not mean

that support from friends (n = 11) or professional support (n= 10) is any less helpful.

Professionals should identify family sources of support and promote the utilization of both

formal and informal support systems (Bennett et al., 1990). As was mentioned in the literature

review (Abbott & Meredith, 1986; Darling; 1983; Meyerson, 1983; Schilling et al., 1984;

Thompson, 2000) and in this study, knowing other people who are in similar situations and

belonging to a support group is very helpful. Professionals should be advocating the use of

support groups for individuals who might benefit from group interactions. Maintaining a

positive attitude (n = 15), acquiring additional information (n = 10), and spiritual support (n = 8)

were also listed as helpful strategies. Professionals should help the parents foster positive

attitudes, locate needed services or resources, and be willing to discuss spirituality if applicable.

The professional-parent relationship is also very important. While professionals may

suggest ways to help a child with disabilities and offer information regarding the child's

disability, parents are the real experts on their child's like/dislikes and how they communicate

(Peuschel et al., 1988). Parents and professionals need to work together concerning their child's

level of care, as well as individual and family needs. Professionals should also direct their

attention towards what is helping the families cope with the added stressors of raising a child

with special needs.

As delineated in the review of literature, one reoccurring theme reported by parents who

have children with disabilities is the added stress related to raising a child with special needs

(Kazak & Marvin, 1984). Parents often need assistance in understanding and identifying sources

of stress and developing ways to manage that stress (Burr et al., 1994; Kazak & Marvin, 1984).

However, not all families will experience high amounts of stress; therefore, it is necessary to individually assess a family's strengths and needs (Bailey & Simeonsson, 1988). Professionals also need to be sensitive and knowledgeable about diverse cultures in order to be aware of strategies that correspond to a family's belief system.

Limitations

The methodological limitations of the study are as follows:

1)   The clients served by Cerebral Palsy, Inc. may have different demographic variables compared to other individuals served by agencies in Northeastern Wisconsin. Therefore, the results of the study cannot be generalized to parents who have children in other Birth to Three programs.

2)   Since there was no manipulation of independent variables, extraneous variables may have influenced parents' coping strategies.

3)   The majority of respondents were female (93.3%) and married (82.2%). Men and individuals who are not married may use other strategies.

4)   Of the 89 surveys mailed, 44 questionnaires were not returned for reasons unknown to the researcher.

5)   Due to the uniqueness and the overlapping characteristics of a child's disability, it was difficult for parents to complete the question about the child's disability and also for the researcher to analyze the parents' responses. The majority of respondents had a child who had a physical disability, or a combination of a physical, emotional, and/or cognitive disability.

6)   The research sample was composed of parents who have children receiving

        services from Cerebral Palsy's Birth to Three Program, and the normative data

        was obtained from adolescents who were in residential treatment centers.

7)   Parents self-reported the child's disability, rather than a professional who may be

        more knowledgeable about the child's diagnosis.

8)   Data was self-reported, thus may be subject to bias.

Recommendations for Future Research

This study was limited to parents who have children receiving services at Cerebral Palsy,

Inc. Cerebral Palsy is only one of three agencies in Green Bay, Wisconsin that provides Birth to

Three services to the general public.   The experiences of these families may not be applicable to

others. Another shortcoming of the study is that the majority of responses were from mothers

and married individuals. Whether other people would assess similar strategies as helpful is

uncertain. Future research should be done on additional and larger populations for a more

diverse sample. Also, the use of self-reports may have limited the findings concerning

helpfulness of coping strategies and the type of child's disability.

Additional research might address the coping strategies of other family members, such as

siblings and the extended family, and explore how the child's disability affects other family

members. Personal interviews could be conducted to strengthen and support the information

received on the questionnaires. It was mentioned in the literature review that families who have

children with disabilities are likely to experience critical transitions throughout the life cycle

(Wikler, 1981). Examining parental coping strategies at different stages of development would

be an interesting avenue for future research.

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APPENDIX A

QUESTIONNAIRE

<u>Purpose</u>

The purpose of this questionnaire is to identify problem-solving attitudes and behaviors that families who have children with disabilities utilize. The results will be beneficial for families with disabled children, as well as the professionals who work with them.

<u>Directions</u>
First, read the list of "Response Choices" one at a time.
Second, decide how well each statement describes your attitudes and behavior in response to problems or difficulties. If the statement describes your response very well, then circle the number 5 indicating that you strongly agree; if the statement does not describe your response at all, then circle the number 1 indicating that you strongly disagree; if the statement describes your response to some degree, then select a number 2, 3, or 4 to indicate how much you agree or disagree with the statement about your response.

Please circle a number (1, 2, 3, 4, or 5) to match your response to each statement. Thank You.

1 = Strongly Disagree
2 = Moderately Disagree
3 = Neither Agree Nor Disagree
4 = Moderately Agree
5 = Strongly Agree

When we face problems or difficulties in our family, we respond by:

1. Sharing our difficulties with relatives   1   2   3   4   5

2. Seeking encouragement and support from friends   1   2   3   4   5

3. Knowing we have the power to solve major problems   1   2   3   4   5

4. Seeking information and advice from persons in other   1   2   3   4   5
    families who have faced the same or similar problem

5. Seeking advice from relatives (grandparents, etc.)   1   2   3   4   5

6. Seeking assistance from community agencies and   1   2   3   4   5
    programs designed to help families in situation

7. Knowing that we have the strength within our family   1   2   3   4   5
    to solve our problems

8. Receiving gifts and favors from neighbors (e.g., food taking in mail, etc.)   1   2   3   4   5

9. Seeking information and advice from the family doctor   1   2   3   4   5

10. Asking neighbors for favors and assistance   1   2   3   4   5

11. Facing the problems "head-on" and trying to get solution right away   1   2   3   4   5

12. Watching television   1   2   3   4   5

13. Showing that we are strong   1   2   3   4   5

14. Attending religious services   1   2   3   4   5

15. Accepting stressful events as a fact of life   1   2   3   4   5

16. Sharing concerns with close friends   1   2   3   4   5

17. Knowing luck plays a big part in how well we are able to solve family problems   1   2   3   4   5

18. Exercising with friends to stay fit and reduce tension   1   2   3   4   5

19. Accepting that difficulties occur unexpectedly   1   2   3   4   5

20. Doing things with relatives (get-togethers, dinners, etc.)   1   2   3   4   5

21. Seeking professional counseling and help for family   1   2   3   4   5

22. Believing we can handle our own problems   1   2   3   4   5

23. Participating in religious or spiritual activities   1   2   3   4   5

24. Defining the family problem in a more positive way so that we do not become too discouraged   1   2   3   4   5

25. Asking relatives how they feel about problems we face   1   2   3   4   5

26. Feeling that no matter what we do to prepare, we will have difficulty handling problems   1   2   3   4   5

27. Seeking advice from a minister or spiritual leader   1   2   3   4   5

28. Believing if we wait long enough, the problem will   1   2   3   4   5
    go away

29. Sharing problems with neighbors   1   2   3   4   5

30. Having faith in God or a higher power   1   2   3   4   5

Overall, what has been the most helpful for you in coping with your child's disability
(i.e. seeking spiritual support, maintaining a positive attitude, family, friends, community
resources, etc.)?

Demographic Information
(Please circle the appropriate answer)

1) Gender: Male   Female

2) Marital Status: Single   Married   Divorced

3) Age: 20-24   25-29   30-34   35-39   40+

4) Number of   1   2   3   4+
    children:

5) Annual Income:

APPENDIX B

LETTERS TO AREA BUSINESSES

Amy Pritzlaff   10/2/00
5830 Donegal Lane
Oconto Falls, WI 54154
1-(920) 846-2298

Dear Sir or Madame,

My name is Amy and for the past three years, I have been an employee at Cerebral Palsy,
Inc. located in Green Bay, WI. I am also currently working on my Master's degree in Mental
Health Counseling at the University of Wisconsin-Stout. One of the requirements to complete
my degree is to conduct a research project.   My research is going to focus on various coping
strategies of parents who have children with disabilities. It is my hope that the information
received from these parents will help other families in similar situations and also the
professionals who work with these families.

I will be sending questionnaires to 120 families, who receive services from Cerebral
Palsy Inc., to gather information about each family's coping strategies. To increase the response
rate, I wanted to include a token of my appreciation. I was hoping that you would help by
donating enough coupons (ice cream cone, etc.) so that one could be enclosed along with each
questionnaire. I believe that this would greatly improve the accuracy of this research and help
families who have children with disabilities, who need our extra support.

Sincerely,

Amy Pritzlaff

APPENDIX C

COVER LETTER

October 12, 2000

Dear Parents,

My name is Amy Pritzlaff and I have been working at Cerebral Palsy, Inc. for the past three years in the Adult Program, Day Care, and Summer Transition Program. Currently, I am in the process of completing my Graduate Degree in Guidance and Counseling at the University of Wisconsin – Stout in Menomonie, Wisconsin. One of the requirements for obtaining my degree is to do a research project. Since I have been working at Cerebral Palsy, Inc., I wanted to do something related to that field. My research is going to focus on different coping strategies parents have used to adjust to having a child with special needs and what has been the most helpful for them.

Enclosed is a questionnaire that includes statements of various coping behaviors and attitudes in addition to brief demographic information regarding family characteristics. It is my hope that the data obtained will be useful to other families and individuals who will work with families who have children with special needs. The results of the survey will be available at Cerebral Palsy, Inc. after March/2001 for those who are interested.

Your participation is entirely voluntary and your answers will be kept completely confidential and anonymous. There is no place for your name or address on the questionnaire. If you choose to participate, your total time commitment will be approximately five minutes. I would be extremely grateful if you could help me by completing the attached questionnaire and return it in the enclosed addressed, stamped envelope by October 30, 2000. I have also enclosed tokens of my appreciation for free McDonald's French fries and a free ice cream cone at Diary Queen.

If you have any questions, please feel free to call my research advisor, Sally Hage, at (715) 232-3094 or myself at (920) 846-2298.

Thanks for your time!
Amy Pritzlaff

APPENDIX D

CONSENT LETTER
(AS IT WOULD APPEAR ON CEREBRAL PALSY'S LETTERHEAD)

October 12, 2000

Dear Parents,

Enclosed is a questionnaire Amy Pritzlaff, a graduate student, is requesting that you complete to help her fulfill her graduate degree program.

To insure your confidentiality, Cerebral Palsy, Inc. has agreed to do the mailing; your name and address have not been given out to Amy or anyone else. Completion of the questionnaire is voluntary and anonymous. Directions for completing the form are included, as well as a stamped, self-addressed envelope.

If you have any questions, please feel free to give me a call at the Center (337-1122). Thank you for your participation.

Sincerely,

Jessie Raymaker
Director Children's Services

APPENDIX E

CONSENT FORM

I understand that by returning this questionnaire, I am giving my informed consent as a participating volunteer in this study. I understand the basic nature of the study and agree that any potential risks are exceedingly small. I also understand the potential benefits that might be realized from the successful completion of this study. I am aware that the information is being sought in a specific manner so that no identifiers are needed and so that confidentiality is guaranteed. I realize that I have the right to refuse to participate and that my right to withdraw from participation at any time during the study will be respected with no coercion or prejudice.

NOTE: Questions or concerns about participation in the research or subsequent complaints should be addressed to the researcher or research advisor and second to:

Dr. Ted Knous, Chair   (UW-Stout Institutional Review Board for the
11 HH, UW-Stout   Protection of Human Subjects in Research)
Menomonie, WI 54751
phone 1(715)232-1126.

Researcher: Research Advisor:
Amy Pritzlaff   Sally Hage, Ph.D.
5830 Donegal Lane   UW-Stout
Oconto Falls, WI 54154   P.O. Box 790
1(920)846-2298   Menomonie, WI 54751-0790
                                                1(715)232-3094