ABSTRACT

Title of Document:	Spiritual Community Experiences of Families of Children with Disabilities
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This mixed methods investigation examined experiences of families of children with disabilities in their spiritual communities. Using the Spiritual Community Experiences Inventory, fifty-eight parents rated importance of and satisfaction with clergy, various religious activities, and support received from clergy and spiritual community members. Families reported that participation in religious activities and support from clergy and members were important. Moreover, families were highly satisfied with these activities and support. As predicted, a significant relationship was found between frequency of attendance, amount of support, and satisfaction with activities and support. Only in the case of formal ceremonies was frequency/satisfaction relationship not significant.

Parents described a variety of factors that influenced their level of satisfaction with spiritual community experiences. Families reported that participation was influenced by: (1) amount and quality of social interactions with other children and adults, (2) level of knowledge, training and understanding of staff and volunteers, (3) level and appropriateness of accommodations provided, and (4) degree to which their child's disability interfered with participation. Additionally, parents reported that their experiences were affected by availability of emotional and practical support targeted to their unique needs, existence of social support networks, level of acceptance and knowledge of community members and clergy about disability, and the value the religious community places on parental knowledge of disability. Parents did elaborate on negative experiences and lack of support, which led to their non-participation and in some instances to switching communities.

Further testing and refining of the instrument is required to strengthen its reliability and validity, clarify ambiguities, and identify factors families believe are important to participation. Additionally, leaders of spiritual communities must identify needs of families of children with disabilities. By tapping families as "experts" and networking with other religious communities, disability groups, and agencies, they can better meet these families' needs.

SPIRITUAL COMMUNITY EXPERIENCES OF FAMILIES OF CHILDREN
WITH DISABILITIES

By

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Dissertation submitted to the Faculty of the Graduate School of the
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Dedication

I wish to dedicate this dissertation to my son, Devin. Without his inspiration, I would not have embarked on this journey nor have reached this point. His remarkable perseverance, always with a sense of humor, encouraged me to continue when I thought I could go no further. I want to thank him and ask that he share the accolades.

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I would also like to thank all my friends and family who encouraged and supported me in this effort.   I would especially like to thank my support network, most importantly, my husband, Charlie, for loving and supporting me throughout this journey. I would like express my heartfelt gratitude to my mentor, Dr. Bob Politzer, and my sister, Cathy Barney, whose assistance, guidance and encouragement were instrumental in my final transformation. I am deeply grateful to Karen and Jeff, who led me to a better understanding of myself. I am indebted to my friends Laura and Randi for their emotional support, constant encouragement, and belief in me. Lastly, I reserve special thanks to Devin and Rocco, for reminding me to laugh.

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CHAPTER I

Introduction

Families of children with disabilities have found many positive ways of coping with the

challenges of raising a child with special needs (Bennett & Deluca, 1996; Dunst, Leet &

Trivette, 1988; Judge, 1998; Lin, 2000; White & Hastings, 2004). In fact, many families

believe that having a child with a disability has transformed their lives in a positive and

meaningful way. Religion is one way families cope with the challenges that accompany

the raising of a child with a disability and provides a source of meaning concerning

disability (Choe, Singer & Brenner, 2000; Payne & Stoneman, 1997; Scorgie & Sobsey,

2000; Tarakeshwar & Pargament, 2001; Weisner, Beizer & Stolze, 1991). However, not

until the 1990s, did researchers begin to study religion as a coping mechanism for

families dealing with disability. An interest in viewing families more holistically has

prompted researchers to more closely examine families' spirituality and participation in

religious organizations.

The rationale for studying religiosity as an important source of support for

families of children with special needs emanates from a variety of sources. First, family-

centered practice is at the heart of current early childhood special education practice and

policy and religiosity is often at the center of many families' lives (Beckman, 1996, 2002;

Dunst, 2002). Second, a variety of theoretical and conceptual frameworks concerned

with family functioning emphasize the importance of examining the needs of the family

and the family's quality of life to better support a child with a disability (Broderick &

Smith, 1979; Bronfenbrenner, 1979; Hill, 1949; McCubbin & Patterson, 1983; Turnbull,

Summers & Brotherson, 1984). Finally, empirical literature, focused on the needs of

families of children with disabilities, stresses the importance of successful family coping to better support the child with a disability, the role of social support as a means of successful coping, and in particular, religion, as a positive means of support for families raising a child with a disability (Dunst, Trivette & Deal, 1994; Fewell, 1986; Judge, 1998; Poston & Turnbull, 2004).

<div align="center">Rationale</div>

Disability and Faith Communities

Great potential exists to improve the lives of individuals with disabilities, estimated by the United States Census Bureau (2005) at approximately 54 million (18.7%), simply by educating religious communities about inclusion. While literature concerning the relationship between faith and disability is limited, with little evidence linking religion with attitudes towards those with disability, Selway and Ashman (1998) indicate "inconsistent cultural attitudes—many based on religious sentiment—that have existed over time…show the potential of religion to influence community attitudes, and the well-being of families and caregivers of persons with disabilities." (p. 429)

The National Organization on Disability [NOD] (2004) reports that 65% of individuals with disabilities consider faith to be very important. However, these individuals (47%) attend religious services less often than those without disabilities (65%). NOD (2004) suggests " … a barrier of architecture or attitude — [holds] people with disabilities back from attending services at a church/parish, synagogue/temple or other place of worship." (p. 38) Teaching the inclusion concept within American faith communities could change attitudes in general and more fully open them to those with disabilities, who could substantially benefit from participating.

Family Centered Policy and Practice

Early childhood special education has not always been rooted in family-centered policies and practice. Although Public Law 94-142, the Education for All Handicapped Children Act enacted in 1975, established educational protection for children with disabilities and provided parents with some rights, the shift from organizational-centered to family-centered policy and practice did not begin until 1986 with the passage of Part H of the Education for All Handicapped Children Act. This Act was the first law to recognize the family as an integral part of child development and provide rights and supports to families of young children with disabilities. For example, this law required a service coordinator assigned to each family to facilitate partnerships between parents and practitioners in determining the educational needs of the child. Since then, the effects of these laws have driven the field to develop more family-centered practices (Wehman, 1998).

Family centeredness "refers to a particular set of beliefs, principles, values and practices for supporting and strengthening family capacity to enhance and promote child development and learning…" (Dunst, 2002, p. 139). Current early childhood educational practices emphasize the concept that a child is part of a larger family unit (Dunst, 2002). Further, these educational practices take into account not only the needs of the child but also how these needs fit into the needs of the family (Beckman, 1996). To be family centered, intervention needs to include "relational and participatory" practices (Dunst, 2000).

Theoretical and Conceptual Models

Family centered practice is grounded in several theoretical and conceptual frameworks that focus on the impact of environmental influences on children and their families and how families adapt to stress. These theories describe the complex relationships within families and the effects of these relationships on other family members. They have been extensively used to develop techniques to support families of children with disabilities. Although these theoretical approaches will be described more extensively in Chapter 2, they are briefly described here because they provide an important basis for understanding the role of religion in the lives of parents.

Urie Bronfenbrenner (1979) was one of the first researchers to describe child development in terms of ecological theory. He argued that influences on development should be viewed as a series of nested systems, each of which has a reciprocal influence on one another. Many researchers view this framework as a useful tool for studying the range and complexity of influences on families of children with disabilities (Beckman et al., 1998). It explains the impact of multiple contextual influences such as the multiple influences religion may have on family and child development.

Researchers in the field of family and disability have also focused on how families deal with stress. Hill's (1949) ABCX Model of wartime stress continues to explain, in different and updated forms, how families deal with the impact of a stressful event (McCubbin & Patterson, 1983; Patterson, 1988). The ABCX and the Double ABCX models explain how a family reacts to stressful events throughout the family life cycle. Researchers have suggested these models are useful in explaining the reactions of

families of children with disabilities to stress and the within-family variability of these reactions (Hastings, 2002).

In addition to these theories, researchers have found Broderick and Smith's (1979) Family Systems theory useful when examining the specific dynamics of families. Turnbull, Summers, and Brotherson (1984) have specifically applied this theory to families of children with disabilities. This model examines the four elements of the family interactional process: inputs, family interactions and processes, outputs, and stages of the family life cycle. The family is viewed as an interactional unit with unique needs and experiences. What affects one member of the family influences all members of the family (Gargiulo & Kilgo, 2005). Notably, spirituality is considered one of eight important factors that influence how families function and deal with stress. Researchers have found this theory to be useful in explaining the varying reactions families have to disability.

All these approaches are a source for further understanding of family functioning. Specifically, they provide: (a) contextually based models to identify the systems that influence all aspects of development, (b) examine how individual families react to various life events, and (c) identify how these families function at different points in time. Further, each of these theories can be directly applied to how families function and adapt to having a child with a disability. Finally, they each provide a framework for examining how spirituality and organized religion can influence families' development and functioning.

Empirical Literature.

    Researchers and practitioners in the field of disability have long recognized the

need to study the impact of having a child with a disability on the family (Gallagher,

Beckman & Cross, 1983; Innocenti & Kwisun, 1992). Researchers have investigated the

effects of stress inherent in having a child with a disability on family functioning and

child development (Beckman, 1983, 1986; Fewell, 1986; Dyson, 1996; Troster, 2001),

and ways in which these families cope with such stress (Judge, 1998; Margalit, Raviv &

Ankonina, 1992; McCubbin et al., 1983). Further, researchers have investigated social

supports as an important coping mechanism families use to mediate stress (Singer, 2002;

Stainton & Besser, 1998). In particular, Judge (1998) suggests that many families use

"emotional and informational social support[s]" (p. 266) to cope with stress. Turnbull,

Turnbull, Erwin and Soodak (2005) argue the need for practitioners to provide families

with both social and emotional supports.

    The study of both emotional and social supports for families was prompted, at

least in part, by Bronfenbrenner's (1979) model concerning the impact of ecological

influences on family and child development. Since then, researchers who study families

of children with disabilities have studied the impact of social supports on these families

and have found that social support can decrease parental stress, enhance parental well-

being, promote child development and increase parent's commitment to intervention

(Crnic, Greenberg, Ragozin, Robinson & Basham, 1983; Dunst et al., 1988; Wehman,

1998). However, Dunst (1985, 1994), based upon his extensive work in the field of

social support systems and early intervention, advocates that social support must match

the needs of the family and allow the family to meet its own needs to achieve desired

family outcomes. Informal supports, such as family, friends and spiritual support, were found, more often than formal supports such as social service or disability agencies, to mediate stress for families of children with disabilities (Crnic et al., 1983; Dunst et al., 1988; Kramer & Houston, 1999; Lin, 2000; Payne & Stoneman, 1997; White & Hastings, 2004). An extensive body of literature on informal supports of families of children with disabilities exists (Crnic et al., 1983; Dunst et al., 1988; Kramer & Houston, 1999; Lin, 2000; Payne & Stoneman, 1997; White & Hastings, 2004). However, there is limited empirical information regarding religion and spirituality within the field (Scorgie & Sobsey, 2000).

Few studies have focused on the importance of religion as a social support in the lives of families of children with disabilities (Selway & Ashman, 1998). Further, most studies regarding religion have either only included religion as one source of social support (Choe et al., 2000; Mailick, Holden, & Walther, 1994; Payne & Stoneman, 1997; Scorgie & Sobsey, 2000) or studied religion in a general way with a focus on beliefs (Chang, Noonan, & Tennstedt, 1998; Tarakeshwar & Pargament, 2001; Weisner et al., 1991). Only a handful of studies have focused on how a religious community supports families of children with disabilities (Coulthard & Fitzgerald, 1999; Dollahite, Marks & Olson, 1998; Haworth et al., 1996; Rogers-Dulan, 1998; Skinner, Correa, Skinner, & Bailey Jr., 2001). Of the studies that have included evaluations of organized religion and its support for families of individuals with disabilities, most report mixed results. Moreover, the authors report decreasing church attendance of families due to lack of support and lack of willingness on the behalf of churches to include their child (Haworth et al., 1996; Rogers-Dulan, 1998; Skinner et al., 2001). Finally, many of these studies are

only exploratory in nature and of poor empirical quality. Hence, further quality research is needed in this area (Skinner et al., 2001).

<p style="text-align:center">Definitions of Terms</p>

Because religion is a largely untapped and important source of help for families with disabilities, it is important to outline its meaning as well as what research suggests it can offer. Canda (1998) defines religion as "an institutionalized and organized pattern of beliefs, morals, rituals, and social support system." (p. 4). This description encompasses beliefs systems as well as the organized-community aspect of religion, extending to spirituality, an important distinction that applies to some families of children with disabilities. One of the purposes of this study was to broaden the concept of "religious community" to include non-Christian spiritual groups, opening the door to those cooperatively practicing a non-traditional faith (e g., groups that are a part of the American Ethical Union) that meets Canda's criteria.

Within that religious/spiritual framework, social support is a multi-dimensional concept, defined differently by various researchers (Dunst, 1985, Turnbull, Turnbull, Erwin, et al., 2005.) Dunst (1985) describes it as "emotional, physical, informational, instrumental and material assistance … to maintain well being, promote adaptations to different life events and foster development in an adaptive manner." (p. 171). He further distinguishes types of support as formal or informal. Formal support encompasses professionals, agencies and organizations that help those with disabilities survive the larger world. Informal support refers to individuals and social groups that aid daily living (Dunst, 1985).

Fewell (1986) purports that religious organizations offer parents of children with disabilities several kinds of assistance, including emotional and instrumental/practical support. Turnbull, Turnbull, Erwin and Soodak (2005) define emotional support as providing encouragement and understanding in coping with life events. Additionally, they describe instrumental/practical support as tangible, such as childcare or other tools for daily living (Dunst, 1985; Turnbull, Turnbull, Erwin et al., 2005). The following section presents research questions and the study hypothesis.

<div align="center">Research Questions</div>

Both the theoretical and empirical literature suggest that social support may help families adapt to the issues of raising a child with a disability. Religion seems to be a potentially important source of such support. Therefore, the purpose of the present study is to examine the type of experiences families of children with disabilities have within their religious community. The following questions and hypothesis about organized religion's role in the lives of families of children with disabilities will be addressed.

Question 1. Where do families of children with disabilities rate their experiences in the spiritual community on a continuum of positive to negative?

Question 2. What experiences in their spiritual communities do families report as important to their child's participation?

Question 3. What experiences in the spiritual community do families report as important to their own participation?

Question 4. What about these experiences do families describe as positive or negative?

Hypothesis: It is hypothesized that family ratings of experiences and support will be significantly and positively correlated with the amounts of activity participation and support received. That is, families who report positive experiences will also report participating more in activities and receiving more support from their spiritual community. In contrast, families who report fewer positive experiences will also report that they participated less in activities and received less support.

CHAPTER II

Review of the Literature

For nearly three decades, professionals who work with children who have

disabilities have recognized the importance of social support in mediating stress for

families of children with disabilities (Dunst et al., 1988; Fallon & Russo, 2003; White &

Hastings, 2004). Although religion has been identified as a source of support for families

(Dollahite et al., 1998; Fewell, 1986; Haworth et al., 1996; Skinner et al., 2001; Treloar,

2002; Turnbull et al., 2005) research has been limited (Tarakeshwar & Pargament,

2001). The purpose of this literature review is to focus on both the theoretical and

empirical findings that have contributed to an understanding of the role that participation

in spiritual communities plays in the lives of families of children with disabilities. The

review begins with an overview of the search procedures used in this research to gather

information about religion and families, followed by a discussion of the theoretical

concepts that apply to this study. This overview is followed by a review of current

literature concerning family support and coping techniques and community inclusion.

Finally, this section includes studies that focus on the role of religion for families of

children with disabilities.

Search Methods

To gather information relating to religion and families with disabilities, computer

and ancestral searches were conducted between the years of 1961 and 2008. This time

span was chosen because none of the studies referenced any study prior to 1961. In

addition, there is no evidence that any literature review is available on this particular

topic. The computer search included multiple electronic databases such as Academic

Elite, ATLA Religion Index, ERIC, Education Abstracts, Family & Society Studies

Worldwide, Psych Info, Social Sciences Abstracts, Social Sciences Citations Index, and

the University of Maryland System library catalog. The following keywords were used

to generate the search for references: "family," "disability," "religion," and "supports."

Also, an ancestral search was conducted of references from several articles related to the

topic. In addition, 12 articles already collected from a previous search were included.

The search was then further limited by examining the abstracts to determine whether each

article was representative of the topic at hand. Of the approximately 200 articles found,

138 were deemed appropriate for review.

<div align="center">Theoretical Foundations</div>

The concept of family centered practices is grounded in theoretical and

conceptual models related to environmental influences on child development and

family's adaptation to stress. These theories attempt to explain the complex relationships

within families and the influence of internal and external factors on these relationships.

They have been extensively studied to develop techniques to support families of children

with disabilities. This section includes the theoretical models that are important to this

study.

Bio-Ecological Model

Much of the literature concerned with families views the family as a system. One

particular model that researchers (Beckman, 1996, 2002; Dunst, 1988) have found useful

when studying families is Bronfenbrenner's (1979) ecological model of human

development. In this model, an individual is conceptualized as part of a series of nested

systems each of which exerts mutual influence on all levels of the system. This process

is bi-directional with both the individual and the environment changing over time based on influences at multiple levels of the system. The environment in which children develop is not considered just the immediate setting in which an individual resides but a series of settings, one larger than the next, "nested" within each other, which are influenced by each other and the individual.

Specifically, Bronfenbrenner (1979) identifies these nested systems as the microsystem, mesosystem, exosystem and the macrosystem. The "microsystem" includes the most immediate contexts in which the individual directly participates. The microsystem includes "activities, roles and interpersonal relationships" that individual's experience on a regular basis (p.22). These experiences can occur for a child or adult, at home, school, daycare, neighborhood or work but they must be meaningful to this individual. The "mesosystem" is considered a "system of microsystems" (p. 25) and refers to the relationship between two microsystems; both the individual and the settings within the mesosystem exert influence over each other. An important example can be drawn from two common microsystems in which children participate: the school and the home. For example, the relationship between parents and a teacher may directly influence the kind of educational support parents will provide at home which, in turn, may directly influence the child's level of educational performance.

The "exosystem" includes larger systems in which the individual is not a direct participant but can have an impact on the microsystem or macrosystem. For example, for a child and his or her family the exosystem might be the policies and practices of the school system. If the school system does not provide adequate support for a child with a learning disability, the child's motivation to learn can be affected, which in turn, can

affect how the family interacts with the school system. The largest and least direct of these systems is the "macrosystem."

The macrosystem is the larger political, cultural, and legal systems that influence all of the other systems within a particular society. This system has indirect effects upon the individual. For example, cultural beliefs of a family may influence how they might view authority and discipline which will have an effect on all other levels of the system. In Bronfenbrenner's theory, all systems exert mutual influence over each other to influence outcomes for the child and family.

In 1995, Bronfenbrenner expanded his original model to include another system, the chronosystem. This extension of the ecological model was renamed the bioecological model. The chronosystem incorporates the dimension of time and change throughout a person's life. These changes occur as a result of "proximal processes" "which are enduring interactions in immediate environments" (Eamon, 2002, p.232). These processes occur over time which "generate the ability, motivation, knowledge and skill to engage in such activities both with others and one's own self" (Bronfenbrenner, 2004, p.6) and are considered the "primary engines of development" (p.6). Examples of these processes may include a mother feeding a baby or playing with her child or a child playing alone or in a group (Bronfenbrenner, 2004).

This model emphasizes that the setting in which a child interacts and the interactions the child has are directly influenced by the family and the larger social system. Bronfenbrenner (1995) also states that when families experience stress these interactions may be disrupted which can subsequently influence the individual's development. When the family and child successfully interact in different community

social settings with different individuals, child development may be enhanced

(Bronfenbrenner, 1995). For example, when a family provides a variety of opportunities

for the child to interact at places such as pre-school, day care, religious community

involvement, and play groups, the child's development can be positively influenced

(Bronfenbrenner, 1995). The bioecological model suggests that, although stress can

affect the family, appropriate social supports can positively influence family and child

development.

ABCX Models

Another theoretical model that may help explain the role of religion in the lives of

families of children with disabilities is the ABCX model. Over the years, several

researchers have been interested in stress and its impact on families. One of the earliest

models developed to study family stress is Hill's (1949) ABCX model, which is an effort

to explain the variability in reaction among families when faced with stress. Hill (1949)

developed this model while studying families' reactions to stress during wartime

separation, but it has been applied to family reactions to other potentially stressful events

such as the birth of a child with a disability (see Figure 1). The "A" in Hill's (1949)

model represents the stressor event such as having a child with a disability, the "B"

represents the family's available resources to react to the event (e.g., time, financial

resources, supportive extended family), and the "C" represents the family's perception of

the stressor event (e g. the family believes that a child with a disability is a gift from

God). Acting together A, B and C determine "X," the family's response to the event and

whether the stressful event becomes a crisis (e.g., whether each family member helps

with the care of a child) (Hill, 1949; Beckman, 1996; 2002).

Figure 1

ABCX Model
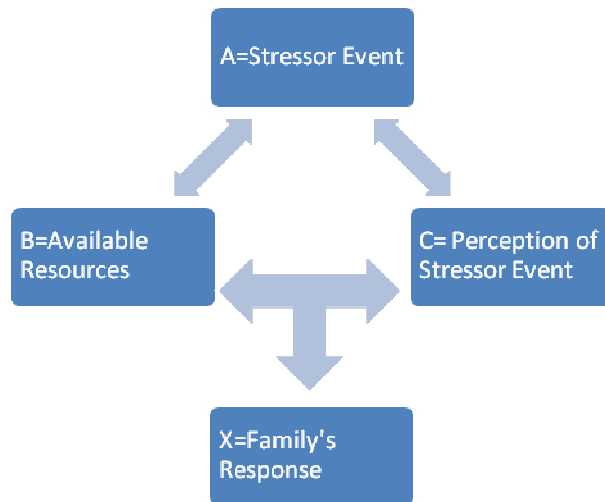
Because Hill's (1949) model only focuses on "pre-crisis" factors that families use to cope with stressful situations, McCubbin and Patterson (1983) expanded upon Hill's (1949) model to take into account the variables that families use over time when dealing with a crisis. Like Hill's (1949) model, McCubbin and Patterson's (1983) Double ABCX model identifies the A, B and C factors prior to X, the crisis. However, McCubbin and Patterson (1983) add factors post-crisis, aA, bB, cC, and xX.

The aA factor in McCubbin and Patterson's model represents multiple stressors occurring at different times in the family-life cycle that have the potential to "pile-up" on the family over time. For example, a family at one point may have small children and financial issues; at another point in time, a family may be dealing with children in college and taking care of elderly parents. As the demands on the family change, some of the stressors may diminish while other stressors can "pile-up" over time. For example,

having a child with a significant disability may entail multiple appointments with medical and educational professions, increased financial obligations and a change in caregiver demands. However, depending directly upon a particular family's ability to cope with these stressors, pile-up may or may not affect the family.

The bB factor represents the resources families and individual family members have available to cope with stressors and include individual, familial, and social resources. Individual resources are those that any one individual brings to the family and include both material resources such as money, housing, knowledge-based resources such as problem-solving skills or organizational skills, and emotional resources such as positive family outlook. These resources are unique to the family member but provide support to the family as a unit in adapting to a crisis event. Family resources are those that define how a family adapts as a unit to a crisis and include coping skills and social resources. Family balance during a crisis can only occur when there is a "demand-capability" balance (McCubbin & Patterson, 1983, pg. 18). Examples of this balance may include a family's positive outlook about a crisis or the support that family members provide each other during a crisis. Social resources are those that provide families with a barrier against stress and promote recovery from the stressors experienced by a family. Social resources include support from extended family members or social organizations such as a church (Williams & Williams, 2005).

The cC represents the family's ability to assign meaning to the crisis. How the family does this assigning can influence how well the family copes with stress. For example, if a family uses their religious beliefs in a positive manner and define an event

as a way to grow, they may have a better outcome than if they view a crisis as an insurmountable problem.

The xX factor determines how the family will adapt over time. McCubbin and Patterson (1983) refer to this adaptation on a continuum with bond-adaptation at the positive side and maladaptation on the negative side of the scale. Family's positions on this scale are based upon their ability to attain balance post-crisis with balance achieved when the amount of family demands is equal to their adaptive resources (McCubbin & Patterson, 1983).

FARR model. McCubbin and Patterson (1983) and Patterson (1988) renamed the Double ABCX model the Family Adjustment and Adaptation Response (FARR) model. The purpose for renaming the model was to explain the two-phase process in which families adjust and adapt to stressful events. Phase 1 is characterized by a period of family adjustment to a stressor. This active process requires families "to balance family demands with family capabilities as these interact with family meanings to arrive at a level of family adjustment or adaptation" (Patterson, 2002, p.350). *Family demands* include both normative and non-normative stressors, enduring family tensions and daily family issues. *Normative stressors* are those that occur regularly in most families *and non-normative stressors* are specific events of family change that are unanticipated and not typically experienced. *Enduring family tensions* include long-term unresolved family issues such as a child with a permanent disability. *Family capabilities* include family resources (e.g., what the family has to do to adjust to the stressor and coping behaviors). Both demands and capabilities can arise from the individual family members, the family

unit or from outside community circumstances. Families attempt to balance their

demands with their capabilities to try to adapt to a stressor and find meaning in the event.

The second phase of the FARR model explains how families adapt to stressors.

Families must employ different coping strategies to maintain balance such as making

changes to the family structure, rules, and roles. More supports and levels of family

maintenance are required. Families must "restructure" internally, interact, and change in

response to the outside community (McCubbin & Patterson, 1983; Patterson, 2002). If

the family is successful, it adapts and improves its function. However, if the family is not

successful in adapting then poor family function might result. For example, working

parents of a child with a disability are not immune to economic downturns. In some

cases, the caregiver must enter the workforce to subsidize a full or partial job loss of the

working parent. Whether the family is able to find another source of care giving will

determine the success or failure of this adaptation to the stressor.

All versions of the ABCX model emphasize the importance of resources to help

families successfully adapt to stress (Hill, 1949; McCubbin & Patterson, 1983; Patterson,

1988). Spiritual communities may play a significant role in providing the family with

successful means to deal with a crisis event and provide long-term support to help

families cope across the life cycle.

Family Systems Model

Seeking out support from others is an effective form of coping for families when

dealing with stress (McCubbin & Patterson, 1983; Patterson, 1988). Social supports are

considered by many researchers to be one of the most important coping techniques

families use when dealing with a crisis. Of particular interest to educational researchers

are supports that promote successful adaptation of families of children of disabilities. Other theoretical models that emphasize the importance of social supports have been introduced that evaluate how resources support families (Broderick & Smith, 1979; Dunst, 2000; Turnbull, Turnbull, Erwin & Soodak, 2005).

Broderick and Smith (1979) developed family systems theory to explain family coping and adaptation. This model's premise is that each family functions in a unique way to meet the family's needs for affection, self-esteem, spirituality, economics, recreation, socialization, and education. The model is comprised of four components: (a) family structure, which includes relationships of members as well as individual family member characteristics, (b) family interactional styles, (c) family functioning when faced with a crisis, and (d) family stages. Based upon general systems theory, Broderick and Smith (1979) applied this concept to family functioning and later Turnbull et al. (1984) applied this framework to families of children with disabilities. Turnbull et al. (2005) expanded theory encompasses four broad components: inputs, family interactions and process, outputs, and stages of the family life cycle.

Inputs. In the Turnbull et al. (2005) framework inputs include the family's unique characteristics as a unit, characteristics of individual family members, family cultural beliefs, and ideological philosophies (Turnbull et al, 2005). Families can differ as a unit. For example, only one parent may head a family or extended family members may live within the household. In addition, member characteristics (e.g., a family member with a disability) may change the dynamics of the family. Family cultural beliefs can also influence their interactions and philosophies. For example, a family's culture may influence the way they view disability and in turn affect how they interact with the child

with a disability and provide support for that child. Finally, the ideological structure of a

family includes its beliefs, values, and coping abilities. For example, a family with a

strong faith may perceive disability differently than a family who does not. This

perception can affect how the family deals with disability and what supports are available

to this family (Broderick & Smith, 1979; Turnbull et al., 2005).

     Family interactions and process. The interactions within this framework are

directly based on Broderick and Smith's (1979) theory and include four types of

relationships that exist and the interactions between family members. Extended family,

marital, parental and sibling interactions all influence family relationships. Families of

children with disabilities are no different from those that do not have a child with a

disability; what effects one family member will affect all family members (Turnbull,

Turnbull et al., 2005). Further, the concepts of family adaptability and cohesion are also

introduced. Cohesion refers to the level of emotional bonding and independence within

the family unit. This concept is viewed on a continuum from more to less cohesive.

Most families fall somewhere in the middle of the continuum and, in general, need to find

a cohesive balance. Typically, families that are more cohesive have more positive

outcomes than less cohesive families. For example, some reports suggest that some

families of children with disabilities value the increased cohesiveness that comes from

dealing with disability (as cited in Turnbull et al., 2005). Adaptability refers to a family's

ability to cope with change or stress. Like cohesion, adaptability is viewed on a

continuum; at one end are families who are unable to change in response to stress, and at

the other end are families that are changing so much it affects their ability to function.

The most successful families are those that are able to balance between high and low

adaptability (Turnbull et al., 2005).

Outputs. How a family functions based upon the inputs and family interactions is

called output. Turnbull et al. (1984) identified eight categories of family functioning:

affection, self-esteem, spiritual, economics, daily care, socialization, recreation and,

educational. Although each of these categories is discrete, family's strengths or

weaknesses can influence other functions. For example, negative spiritual beliefs about

disability (e.g., viewing the birth of a child with a disability is a punishment from God)

can effect family's affection and self-esteem. Every member of the family greatly

influences the family's degree of success in carrying out these functions (Turnbull,

Turnbull et al., 2005). In the case of spiritual communities, each of the family

functioning categories can be affected either positively or negatively depending upon a

family's experiences.

Family life cycle. Finally, all of these inputs, processes, and outputs change

throughout the family life cycle. Families endure both stable and unstable periods. For

example, the birth of a child with a disability can initially create a period of instability,

but as the family adapts to these changes it can move to a period of stability. The

unstable periods are called transitions. These transitions may be part of the normal

family life cycle, referred to as "on cycle," or may occur at an unusual time, referred to as

"off cycle." Whether these changes are "on" or "off cycle" they can create stress within

the family. As the family changes throughout the life cycle so does its characteristics,

interactions and functions (Turnbull et al., 2005).

Summary. The bio-ecological, family stress and family systems models all provide a basis for the current research conducted on families of children with disabilities. Each model includes social supports as an important mechanism that helps families maintain balance, especially in times of stress. Helping families find and develop social support networks in programs for families of children with disabilities is essential for family adaptability and cohesion. Further, each of these models, either indirectly or directly, recognizes religion as an important support for some families. The bio-ecological model suggests that religion is one system in which the family and child may choose to participate. The family systems model explicitly identifies spirituality as one of the eight family functions that can have a direct and significant impact upon the other seven functions. Because of the importance of spirituality in the lives of many families of children with disabilities, it is critical for researchers to understand how it affects the family and what kinds of support it provides. The empirical literature on social supports and families with disabilities provides some insight into the ways that families participate in a spiritual community as a system of support. The following review of the empirical literature focuses on studies of families of children with disabilities and their social, community, and religious supports.

<div align="center">Empirical Literature</div>

The models described above provide a theoretical foundation for studying families of children with disabilities and have been applied to the study of social supports for families who have a member with a disability. In this section, the literature on stress and support is reviewed as well as the research on coping techniques of families of children with disabilities.

Stress in Families of Children with Disabilities

Research about the stress experienced by families of children with disabilities is mixed (Friedrich & Friedrich, 1981; Dyson, 1991, 1997; Singer & Irvin, 1991; Stainton & Besser, 1998; Walker, Van Slyke & Newbrough, 1992; Singer, 2002). Some researchers have found that families experience stress when having a child with disabilities (Podolski & Nigg, 2001; Saloviita, Italinna & Leinonen, 2003; Troster, 2001; Wang et al., 2004), and others have found that families of children with disabilities have the same amount of stress as families of children without disabilities (Podolski & Nigg, 2001; Saloviita et al., 2003).

Researchers do know that amounts of stress can vary over time and are associated with a variety of factors including type of disability, child temperament, SES, family and individuals traits, limited resources, and care giving demands (Beckman, 1983; Beckman, 2002; Beckman & Pokorni, 1988; Floyd & Gallagher, 1997; Gallagher et al., 1983). Stressors may vary and may include the need for medical care, specialized educational needs and emotional distress of family members (Dyson, 1991). The following section describes several studies that examine factors that influence stress families of children with disabilities experience.

Beckman's (1983) landmark study focused on factors related to stress in families of infants with disabilities and the influence of certain child characteristics on family stress. Beckman (1983) interviewed 31 mothers of infants with disabilities to determine what behaviors and characteristics of their children were linked to increased stress in mothers. Participants were interviewed using a variety of instruments including the Questionnaire on Resources and Stress, an adapted version of the Holmes and Rahe

Schedule of Recent Experience, the Carolina Record of Infant Behavior and a care giving

checklist developed by the author (as cited in Beckman, 1983). In addition, child's rate

of progress was determined based on data from the Infant Behavior Record of the Bayley

Scales of Infant Development (as cited in Beckman, 1983). Instruments had established

reliability and validity. The behaviors evaluated included rate of child progress,

responsiveness, temperament, repetitive behavior patterns and amount and type of care

giving demands.

Authors conducted correlational and multiple regression data analysis. Results

indicated certain characteristics and behaviors were associated with higher levels of

stress. Of the five characteristics examined, all but rate of child's progress were

significantly associated with the amount of stress reported by mothers. Unlike other

studies, age and sex of the child were not related to stress. The author cautioned that this

result could be a function of the limited age range of children in the study: 6.6 months to

36.6 months of age. Additionally, the ability to generalize the findings to other

populations is restricted because of the limited sample size and demographics of the

sample, (i.e., 96.7% of participants were Caucasian and middle class).

More recent research produced similar findings. Troster (2001) studied 47

mothers of children ages 8 months to 7 years of age with visual impairments and, in some

cases, other disabilities, to identify types of stress, factors contributing to stress and stress

reducing resources. Participants completed a parent questionnaire. The questionnaire

was divided into two sections with demographics, family information, and disability

information comprising the first part. The second section included questions about study

factors such as identifying daily stressors and perceived social supports as well as an adaptation of the Parenting Stress Index (PSI) (as cited in Troster, 2001).

The adapted PSI was shown to be internally consistent. Mothers of children with visual impairments experienced more stress than mothers of children without disabilities. Authors indicated this result was a function of the child's behavior and the presence of multiple disabilities. In addition, mothers of children with low vision experienced more stress than mothers of blind children. Authors suggested this finding might be a function of inattentiveness of children with low vision. However, authors noted that these results may be difficult to generalize because of sample selection effects and the limited number of stress variables examined.

Building on this theme, Podolski and Nigg (2001) looked at fathers and mother's distress related to their child's disability in 66 children from 7 to 11 years of age with ADHD. Authors examined parent stress in relation to the severity of the level of ADHD and parent coping strategies. Families completed the Revised Duncan Socioeconomic Index, the Satisfaction with Parenting Performance Subscale of the Parenting Satisfaction Scale, the Parent Stress Index-Short Form, and the Family Crisis Oriented Personal Evaluation Scales (as cited in Podolski & Nigg, 2001). In addition, children completed a shortened validated version of Wechsler Intelligence Scale for Children (as cited in Podolski & Nigg, 2001). A variety of statistical techniques including analysis of variance (ANOVA), correlations, and regression models were used to analyze the data.

Both mothers and fathers reported increased stress related to the child's behavior problems. However, only mothers reported increased stress due to inattentiveness. In addition, positive reframing, which authors defined as "the parent's ability to redefine

stressful events to make them more manageable" (p.507), and spiritual support, defined as seeking support from religious organizations or religious faith, were associated with lower levels of parental stress. However, mothers reported more distress when seeking other types of community supports. This particular result differed from other research studies that found seeking community supports are beneficial to families (Bennett & Deluca, 1996; Fallon & Russo, 2003; Onaga, McAdoo & Villarruel, 2000; White & Hastings, 2004). However, authors suggested that this discrepancy might have occurred because mothers were already at a high level of distress when seeking community supports or because community supports may have been ineffective. Additionally, the study did not provide specific information on how authors operationalized community supports; therefore, it was difficult to understand the nature of the results and may have influenced participants' interpretation of the meaning of community supports. Interestingly, only positive reframing for both mothers and fathers was associated with reduced stress levels. The study further determined that the relationship between spiritual support and parental distress was nonsignificant. However, the authors did not discuss these particular results in detail nor did they intercorrelate spiritual, community, or social support with reframing to determine whether any supports assisted in the reframing. The authors suggested further study of results is required because of the limited sample size. In addition, because of the unusual results about community support, further study of when and how these supports are effective is necessary.

Saloviita et al. (2003) of Finland, using the Double ABCX Model of adaptation, examined parenting stress in 236 mothers and fathers of children from 1 to 10 years of age with intellectual disabilities. Authors analyzed family demands, family adaptive

resources, and family definition of the situation to see how well families adapted to care giving duties. Participants completed the Finish version of the Questionnaire on Resources and Stress, Friedrich Edition, Inventory for Client and Agency Planning, the Marital Adjustment Test of Locke and Wallace, Assessment of Intimacy in Relationships, the Family Support Inventory, the Ways of Coping Checklist-Revised, the Social Readjustment Rating Scale and the Definition Scale (as cited in Saloviita et al., 2003). Stress of participants was assessed using stepwise regression analysis.

Like the previous study, the way parents defined their circumstances was strongly associated with stress levels in parents. Both mothers and fathers who defined their child's situation as a "catastrophe," reported higher stress levels. For mothers, this definition was influenced by the child's behaviors and for fathers it was determined by the lack of social acceptance. Authors cautioned that the correlational nature of the study does not provide firm evidence for causality. In addition, because the study occurred in Finland, a country that is demographically homogeneous, it is difficult to generalize to different populations.

More recent literature about families of children with disabilities emphasizes evaluating family quality of life. Although there is no consensus about the definition of Family Quality of Life (FQOL), Poston and Turnbull (2004) define FQOL as "conditions where the family's needs are met, family members enjoy their life together as a family, and family members have the chance to do things that are important to them" (Poston & Turnbull, 2004, p. 96).

Wang et al. (2004) examined the concept of quality of life in 234 mothers and 130 fathers of children with disabilities in an early intervention program. Authors examined

the influence of income and severity of disability on mother and father's satisfaction with family quality of life. Mothers and fathers were asked to complete separate versions of the Beach Center Family Quality of Life Scale (as cited in Wang et al., 2004) and provide demographic information. Data were analyzed using structural equation modeling.

Results indicated that severity of disability was negatively correlated to both mother and father's satisfaction with family quality of life. Income was positively correlated with mother's satisfaction of family quality of life, but not father's. However, authors suggested this finding might not be an accurate portrayal of the father's perception of income and family quality of life, because the latter result was not consistent with previous research that indicated income is associated with father's satisfaction with family quality of life.

Summary. The stress and family quality of life literature suggests that disability is frequently associated with higher levels of family stress (Podolski & Nigg, 2001; Saloviita et al., 2003, Troster, 2001; Wang et al., 2004). Certain factors were associated with higher levels of stress, such as severity of the disability and specific behaviors associated with the child's disability (Beckman, 1983; Podolski & Nigg, 2001; Troster, 2001). Similarly, although a much more limited sample of respondents, fathers reported that the severity of the disability and behaviors were also associated with higher perceived stress levels as well as lack of social acceptance (Podolski & Nigg, 2001; Saloviita et al., 2003; Wang et al., 2004). In a more limited fashion, increased stress in mothers was positively associated with seeking community supports and having a negative outlook when having a child with a disability (Podolski & Nigg, 2001; Saloviita et al., 2003). Finally, a few studies indicated that positive reframing was associated with

lower levels of parental stress and, in one particular case, spiritual support was associated with decreased stress levels (Podolski & Nigg, 2001, Saloviita et al., 2003).

Some families experience stress when dealing with their child's disability. The literature, however suggests that families do cope with this stress and, in some cases, positively manage this stress (Singer, 2002; Stainton & Besser, 1998). The following section will review studies that specifically address how families cope with disability.

Coping with Disability

There is a significant body of literature that focuses on the importance of effective coping strategies to mitigate stressors that families face when having a child with a disability (Bailey & Smith, 2000). Coping strategies can be defined as the "way [s] in which individual family members alter their subjective perceptions of stressful situations" (McCubbin et al., 1980, p. 865). Much of the current family coping literature is grounded in the work done by Pearlin and Schooler (1978) and Lazarus and Folkman (1984). These early works suggested that the coping process is a major link between a stressful event and adaptation (Judge, 1998). Researchers in the study of families of children with disabilities have found similar results; those families with positive coping strategies are more successful (Lin, 2000). This section reviews coping techniques of parents of children with disabilities.

In a seminal study by McCubbin et al. (1983), 100 parents of children with Cystic Fibrosis where surveyed to examine parental coping patterns when having a child with a chronic illness. Families were sent the Coping Health Inventory for Parents (as cited in McCubbin et al., 1983) and asked to provide information about coping mechanisms and

family psychosocial environment. Factor and correlation analysis were used to analyze data.

Results indicated three important parental coping patterns: (1) maintenance of family integration, cooperation, and positive definition of situation; (2) maintenance of family social supports, self-esteem and psychosocial stability and; (3) understanding of child's medical situation. However, because of the small sample size and the specific nature of the disability, caution is required when generalizing study results.

Margalit et al. (1992) quantitatively investigated coping, family coherence and climate in families with and without children with disabilities. Authors defined coherence as "a generalized world view that expresses the extent to which a person has enduring, dynamic confidence that his or her internal and external environments are predictable and that there is a high probability that life situations will work out as well as can be expected"(p.202). Seventy-eight Israeli parents of children with disabilities and 83 Israeli parents of children without disabilities were surveyed about coping, environment, and coherence. Instruments included a Hebrew adaptation of the Coping Scale, The Family Environment Scale, and the Sense of Coherence Scale (as cited in Margalit et al., 1992) which was written in Hebrew. Multivariate analysis of variance (MANOVA), multivariate analysis of covariate (MANCOVA), univariate analysis, and Pearson correlations were used to analyze data.

Results indicated that parents of children with disabilities employed more avoidant coping strategies than parents of children without disabilities. For example, families of children with disabilities who exhibited disruptive behaviors tended to use more avoidant coping strategies such as denying or avoiding the situation. However,

authors cautioned that these results can only be generalized to other Israeli families and cannot be compared to families within the United States.

Judge (1998) examined the relationship between coping and strengths in families of children with disabilities. Sixty-nine parents, primarily white, middle-class mothers (88%) of young children, ages birth to 5 years of age, with a variety of disabilities, were recruited and asked to complete the Ways of Coping Questionnaire and the Family Hardiness Index (as cited in Judge, 1998). Descriptive data were provided and hierarchical multiple regression was used to analyze results.

Researchers identified specific problem-focused coping strategies positively associated with family strengths including seeking out social support, actively using problem-solving techniques and maintaining a positive outlook. On the other hand, emotion-focused coping techniques such as self-blame, wishful thinking and distancing were associated negatively with family strengths. Authors indicated that the lack of diversity and limited geographic region of the sample limits the generalizability of the sample to other families and locations.

Lin (2000) examined coping and adaptation of 274 family members of individuals with cerebral palsy (CP). Combining descriptive and ex-post facto design, researchers surveyed the individuals using three instruments, a modified and validated version of the Family Crisis Oriented Personal Evaluation Scale, the Family Demographic Form, the General Functioning Scale of the McMaster Family Assessment Device (as cited in Lin, 2000). A variety of quantitative statistical techniques including multiple regression, analysis of covariance (ANCOVA), and analysis of variance (ANOVA) were used to analyze data.

Descriptive results indicated that five factors were associated with family coping: positive family appraisal, support from others, spiritual support, personal growth, and advocacy. Other results, associated with positive coping strategies such as seeking information and outside support, were employed by families of young children with cerebral palsy versus families of young adults with cerebral palsy. The study was limited by the nature of the sample, which included primarily Caucasian women in the Midwest. In addition, because the severity of cerebral palsy was not indicated it is difficult to generalize this sample to other populations.

Summary. Parents of children with disabilities employed a variety of strategies that helped them cope with disability. Problem focused strategies that provided families with both internal and external support appeared to help families successfully deal with disability (Judge, 1998). The value of social supports including support from others and spirituality appeared to provide strong coping techniques to families of children with disabilities (Judge, 1998; Lin, 2000; McCubbin et al., 1983). So what are the social supports that families of children with disabilities need? The next section will specifically address social supports for families of children with disabilities.

Social Supports

Prior to discussing the literature on social supports for families of children with disabilities, it is important to review what is meant by social supports. As stated previously, Dunst (1985) defines social support as "emotional, physical, informational, instrumental, and material assistance…to maintain well being, promote adaptations to different life events, and foster development in an adaptive manner." (p.171). The purpose of social networks is to "nurture and sustain linkages among persons that are

supportive of one another on both a day-to-day basis and in times of need and crisis."

(Dunst, 1985, p. 172).

Dunst (1985) differentiates between types of support: formal and informal.

Formal supports include professionals, agencies, and organized entities required to

support individuals seeking assistance. Informal supports include individual and social

groups that provide support for daily living. Much of the literature discusses how both

formal and informal supports can mitigate stress in families of children with disabilities

(Bennett & Deluca, 1996; Dunst et al., 1988; Fallon & Russo, 2003; White & Hastings,

2004).

Dunst et al. (1988) surveyed 45 mothers of developmentally delayed infants and

toddlers about their family resources (e.g., food, shelter, transportation, social time,

health care, financial status, child care), well-being and commitment to programs

suggested by professionals. Participants completed three scales that included the Family

Resource Scale, the Health, and Well-Being Index and the Personal Allocation Scale (as

cited in Dunst, Leet & Trivette, 1988). Data were analyzed using multiple regression

analysis.

Results indicated that having adequate resources was related to both the mother's

well-being and commitment to prescribed interventions even when mothers and child's

age, SES, and developmental quotient were statistically removed. In addition, mothers

who reported inadequate levels of family resources, primarily financial and interfamily

support, were less likely to see the value in prescribed interventions and less likely to

carry out such treatments. However, like many other studies, this inquiry only included

mothers. In addition, this study looked at a broad range of resources rather than just family supports.

More specifically, Bennett and Deluca (1996) studied the use of informal resources that families' access across the life cycle to adapt. Using qualitative techniques, authors interviewed 12 families of children with a variety of disabilities. The children ranged in ages from 15 months to 30 years of age so authors could gather life cycle data. A nonscheduled standardized format (as cited in Bennett & Deluca, 1996) was used to interview families. Triangulation, group debriefings, and member checks were used to analyze data and ensure rigor.

Results indicated that informal social supports such as family, friends, parent groups, and religious beliefs could be extremely helpful to families. In addition, more formal supports from professionals can also be of value. However, this study only represented Caucasian families and primarily mothers.

More recently, Fallon and Russo (2003) looked at how military families living with a child with a disability adapt to stress when adjusting to military life and military medical services. Two hundred and fifty three active duty military families of children with disabilities, birth to 6 years of age, were surveyed. Part of a larger study by Levine & Dougherty (as cited in Fallon & Russo, 2003) families were asked seven questions about family stress levels. Also, a family cohesion subscale was administered adapted from the Sense of Family Coherence Scale (as cited in Fallon & Russo, 2003). Data were analyzed using descriptive statistics, Pearson Product Moment correlations, and analysis of variance (ANOVA).

Results suggested a positive correlation between reduced levels of stress over time and satisfaction with military medical services. This particular study was included because it demonstrates that formal, well-coordinated social supports are critical to reducing family's stress levels. Further, the study also suggested that military families might have a more difficult time adapting to stressors associated with rearing a child with a disability. Yet, these results cannot necessarily be generalized to the rest of the population because of the differences between military and civilian lifestyles.

White and Hastings (2004) performed a more in depth study on social supports. The authors' purpose for this study was to include multiple measures of social support and sample a more heterogeneous group of children. Researchers' recruited thirty-three parents of children 13 to 18 years of age with moderate to severe disabilities were recruited. Authors administered nine scales in the areas of child behavior, parental well being, informal social support (e.g., family and friends), support functions (e.g., individuals available to help families), and formal support scales targeted towards families of individuals with intellectual disabilities. Data were analyzed using correlational analysis techniques including Pearson's Product Moment and Kolmogorov-Smirnov tests.

Results indicated that the helpfulness of informal support and practical sources of support were associated with parental well being. Emotional supports were not associated with parental well being. Finally, families that accessed more professional supports reported higher levels of stress. This study emphasized the importance of supports that are directly helpful to families. However, authors cautioned that with such a small sample size, the limited number of fathers surveyed, and the high proportion of

respondents who were parents of children with autism limit the generalizability of the results. In addition, specifics about questionnaires were not provided.

Summary. Clearly, social supports can mitigate stress for families of children with disabilities. The studies reviewed above included children of varying ages, types, and levels of disability and families of varying income and life styles. All reported the positive effect of social support in both reducing stress and improving parental well-being. Results also indicated both informal and formal supports were important to families. Informal sources of support that included family, friends, and parent groups were specifically identified at positive supports for families. Formal sources of support such as medical services were are also identified as helpful to families. (Bennett & Deluca, 1996; Dunst et al., 1988; Fallon & Russo, 2003; White & Hastings, 2004). The following section will discuss community inclusion of children with disabilities

Community Inclusion

An increased emphasis on the inclusion of children with disabilities in settings that include children without disabilities has occurred in the last twenty years (Beckman et al., 1998; Bricker, 1995; Bruder, 1993; Guralnick, 1990; McLean & Hanline, 1990; Salisbury, 1991). The focus, however, has been primarily upon inclusion within the classroom. Recently, families and practitioners have extended this notion beyond the classroom into the community (Amado, 1993; Turnbull, Turnbull & Blue-Banning, 1994). The following studies examine the importance of community inclusion for families of children with disabilities.

Ehrmann, Aeschleman, and Svanum (1995) compared participation of pre-school children with disabilities in community activities with those of non-disabled peers.

Eighty-two parents of children with disabilities and 132 parents of children without disabilities completed three questionnaires including a demographic questionnaire, the Community Activities Questionnaire and Parent Experience Survey, both developed for this study. The Community Activities Questionnaire is a measure in which parents provide information about the types of activities in which their children participate. The Parent Experience Survey is a self-report measure assessing parent's experiences when involving their children in a typical community activity. Appropriate internal consistency data was found for both scales. Data were analyzed using a variety of statistical techniques including analysis of variance (ANOVA), Cohen and Cohen's hierarchical regression analysis (as cited in Ehrmann et al., 1995) and factor analysis.

Results indicated that children with disabilities participated less in community activities than children without disabilities. However, on other measures both groups were similar. For example, both groups reported that community activities frequently provided educational opportunities yet community outings were sometimes difficult because mothers were fatigued, their children misbehaved or they had to bring their other children. Authors cautioned the generalizability of results because they only asked in which activities children participated and not about the quality of and support received when participating in activities. In addition, there were little data to establish reliability or validity of the measures. Further, because this research was an initial study in the field, authors suggested future research should identify the quality of children's participation and support needed for children with disabilities to participate in community activities.

Beckman et al. (1998) studied preschool aged children with and without disabilities and their families to identify factors about children's inclusion in community activities and settings. Researchers used ethnographic techniques to collect and analyze data. Open-ended interviews were conducted with families and service providers. Field notes and observations were used to attain triangulation and ensure rigor.

Facilitators of community inclusion included a sense of community, having extensive social contacts, interconnections between children, appealing characteristics of the child, purposeful family strategies to involve the child in community settings and environmental adaptations that facilitate child participation. Barriers to community inclusion included neighborhood decline and or instability, neighborhood safety issues, negative peer interactions, limited resources for community involvement, unavailable peers, family schedules, geographical distances from programs, negativity in the community about individuals with disabilities and limits based on the child's individual characteristics. Authors cautioned that results did not include information from other community members and identified themes were based on general questions.

Onaga et al. (2000) examined the role of parents in promoting school and community inclusion for their children with disabilities. Using both focus groups and interviews, families of children with disabilities were surveyed to identify the roles parents played when facilitating school and community inclusion. Seven focus groups consisting of 164 participants including parents, students, teachers, administrators, and adult service providers were asked questions about transition as well as a question about roles and expectations of families, educators, and adult services providers. In addition, a

case study method was used for six volunteer families and students over a 5-year period to track roles of families across time.

Focus group sessions lasted 1.5 hours and were tape-recorded and a note taker and facilitator recorded information provided by participants. Content analysis was used to identify themes. However, there was no mention of how this analysis was preformed and if triangulation occurred. Individual interviews were conducted annually during the 5-year period and content analysis was used to identify themes. Like the focus groups, no information was provided about data analysis and what types of questions were asked in the interviews.

Focus group and interview results indicated that family members felt that they played these types of roles: learner, educator, advocate, transporter, employer, caretaker, network builder, and linker when including their child in both community and school. Results suggested that families played a significant role in community and school inclusion of their child with a disability. Often, professionals did not recognize this role and the importance some families placed on including the child in all activities. However, it is difficult to determine the credibility of findings without a full description of data analysis techniques.

Summary. Unfortunately, there are limited studies about families of children with disabilities and community inclusion. However, from the information available, community inclusion as a social support for children with disabilities was extremely important to these families. Onaga et al. (2000) suggested that families would go to great lengths to support their child in community activities because they believed in developing the whole child. However, these families encountered more barriers, physical as well as

attitudinal, facing them than families of children without disabilities. (Beckman et al.,

1998; Ehrmann et al., 1995; Onaga et al., 2000).

      As can be seen, families need and want community social supports to help cope

with raising a child with a disability. Even though social supports are an essential part of

successful coping for families of children with disabilities (McCubbin et al., 1983; Judge,

1998; Lin, 2000), and religious faith appears to be an important form of social support for

many families (Bennett & Deluca, 1996; Saloviita et al., 2003), little research has

addressed how religious organizations can support families of children with disabilities

(Speraw, 2006). The following section examines the studies available about religious

supports and families of children with disabilities to gain a better of understanding of

where the field currently stands.

Religious Supports and Families of Children with Disabilities

      Because so many families access and rely upon their religious beliefs and

supports to cope with disability, it is important to define religion and understand why it is

important to study when supporting families of children with disabilities (Bennett,

Deluca, & Allen, 1995). Canda (1998) provides a general definition of religion as "an

institutionalized and organized pattern of beliefs, morals, rituals, and social supports

systems" (p. 4). Further, Bronfenbrenner, Moen, and Garbarion (1984) have suggested

that any study of the family concerning its social structure and ethnicity needs to include

the function of religion. Additionally, Fewell (1986) suggests that organized religion,

which includes attending church and religious practices, and religious beliefs, which

includes faith and spirituality, should be considered as a separate form of support for

families of children with disabilities and needs to be studied as such. Until recently,

research in this area has been limited. Most studies have focused on the positive aspects

of religion and lack specificity regarding beliefs and experiences derived from spiritual

communities and how they affect families of children with disabilities (Marshall, et al.,

2003; Rutledge, Levin, Larson & Lyons, 1995; Tarakeshwar & Pargament, 2001). To

clarify the need for such a study, this section reviews research that examined the role

religion plays in the lives of families of children with disabilities and the impact of

disability on families' religious beliefs and practices. The studies are divided into the

following categories: studies that focus on a particular religion, studies that focus on

certain ethnic or cultural populations and studies that focus on a particular disability or

group of disabilities.

Religions. Dollahite et al. (1998) examined religious beliefs of 16 married fathers

of children with disabilities. All were members of the Church of Latter Day Saints.

Interview questions focused on when fathers felt either closest or more distant from their

children, times when they either did or did not meet their children's needs, and ways in

which fathers attempted to develop a relationship with their child. In-depth narrative data

were collected from fathers. Authors used Atheorectical coding to analyze interview data

to enable authors to understand the fathers' explanations of the role of their religious

perspectives played in parenting a child with a disability.

Religious beliefs appeared to be a significant factor in fostering hope and

supplying peace and strength for fathers. Organized religious experiences were

considered positive and church members and clergy provided positive support. For

example, individual congregation members provided help and financial assistance for

some families. In other instances, clergy provided prayer and guidance. However, there

were limited comments about these assertions, which makes it difficult to know if these types of supports are helpful to other fathers and families. Authors suggested that these positive community and spiritual experiences occurred because the Mormon religion encouraged active participation of fathers and considered fathers the spiritual leaders of their family. In addition, researchers suggested that leaders of organized religious communities needed to understand the importance of their role in positively supporting families of children with disabilities. However, authors provided little information about specific analysis techniques and assurance of rigor.

Treloar (2002) interviewed 13 parents of children with disabilities and nine adults with disabilities about the use of spiritual beliefs to establish meaning for disability. All participants were of an Evangelical Christian background, predominately white and lived in a southwestern metropolitan area of the United States. Using an interpretive framework, families were sent interview questions to review prior to the interview. Qualitative data were analyzed using memos, constant comparative and line-by-line analysis. As part of the member check process, written portraits that included interview data with thematic analysis were provided to participants for review of accuracy.

Participants indicated that their personal religious beliefs were more important to them than the support they received from a religious community. Faith for both parents and those with disabilities provided effective coping support when facing difficulties. Some participants commented that some religious communities were not ready to welcome them and minister to them, although no specific examples of what was meant by "not ready" were provided. Additionally, study results did not necessarily reflect the

experiences of families that have younger children because participants were primarily families of older children or adults with disabilities.

In 2003, Marshall et al. published a descriptive study of Latter-Day Saints (LDS) parents' ability to adapt to living with a child with a disability. Participants were interviewed about religious practices and beliefs and the impact they have on adapting to having a child with a disability. Thirty-two parents of children with a variety of disabilities, such as Down syndrome, cerebral palsy, and communication disorders, were interviewed using open-ended questions. All parents considered themselves Mormon and resided in the state of Utah. The children ranged in ages from 18 months to 18 years of age with over 80% of the children under the age of 12. Data were collected and analyzed using a variety of specific qualitative methods including content analysis methods as described by Lincoln and Guba (as cited in Marshall et al., 2003), persistent observation, peer debriefing, and member checking. Lincoln and Guba and Sandelowski (as cited in Marshall et al., 2003) based rigor and credibility on persistent observation, peer debriefing, and member checking.

Parents reported, "the system, specific religious practices, and social support of the church community offered a resource for coping with daily life" (p. 70). Parents felt that their faith and its particular structure provided them with a "unique and transcendent perspective" (p. 63) concerning disability. Authors suggested that this perspective might be attributed to Latter Day Saints families' belief in tenants of the church and the ability of these families to develop a unique meaning about their situation. However, further clarification of these unique perspectives and what is meant by transcendence needs to be examined. Authors suggested that this particular study results can only be applied to the

Mormon community. However, this study provides insight into the impact that a supportive religious community can have on families of children with disabilities.

Dollahite (2003) followed-up on his 1998 study of fathers of children with disabilities. Thirty Latter Day Saint (LSD) fathers, ages 25 to 29 years old, were interviewed using twenty open-ended questions. This time he examined how father's religious practices and beliefs provided meaning to their experiences when parenting a child with a disability. Children ranged from birth to 16 years of age and disabilities of the children included health disabilities, autism, Down syndrome, blindness, deafness and various other disabilities. Interviewed by two-person teams, fathers were asked open-ended questions examining their relationship with the child with special needs, challenges posed by raising a child with special needs, and the helpfulness of religion. Using a grounded theory approach, which seeks to develop thematic concepts found in the data, the author identified how Latter Day Saints theology influenced father's perceptions of their child. No other specific qualitative analyses techniques were discussed.

Results indicated that religion provided these fathers with a framework that guided their behaviors as fathers. The author suggested that their "belief in a divine plan" (p. 247) provided this framework and gave these fathers a sense of meaning to attach to disability. In addition, because these fathers believed in life after death, they felt it necessary to establish an "eternal" (p. 247) relationship with their child despite the disability. Finally, religion inspired these fathers to be a more responsible parent by "loving, serving and caring" (p. 249) for the child with a disability. Researchers cautioned that these results have a variety of limitations. All participants were Mormon, had high SES, and all of the fathers were young and did not have the perspective of an

older parent. In addition, the study assertions do not provide any information about how organized religion is important to these fathers. Uniquely, the author recently had a child with a disability and felt that this unique perspective permitted him to be viewed as an "insider" which may have helped him obtain more data that are personal from participants.

Summary. Studies that focus on a single religion can help determine how a specific religion supports families when dealing with disability and identify factors that help guide future research on different populations. In this case, three of the four studies focused on families and in particular fathers who belong to the Church of Latter Day Saints. It is clear that this religious community provided a belief framework and a strong social support network that helps fathers cope successfully when having a child with a disability. However, this information is limited and cannot necessarily be applied to other faiths. The only study outside of the Mormon faith provided other viewpoints and suggested that personal faith was better at helping families cope with having a child with a disability than religious communities. The following section will review studies on the religious perspectives of different cultural and ethnic groups.

Ethnicity and culture. Rogers-Dulan (1998) examined the impact of religious experiences on the well-being of African American families who have a child with an intellectual disability. Fifty-two Christian families in an urban area of Southern California were interviewed using both structured and semi-structured questionnaires: a family data questionnaire and the Religious Connectedness Questionnaire developed for this study. Authors defined religious connectedness as "indicative of the impact of religion within the culture and various aspects of personal, family and community life"

(p. 92). Adjustment was measured using the Center Depression Scale, The Questionnaire on Resources and Stress—Friedrich short form, The Family Problems Scale and the Family Impact Questionnaire (as cited in Rogers-Dulan, 1998). The narrative data were coded for themes using a system developed by the author and inter-rater reliability was established using the point-by-point method of agreement (as cited in Rogers-Dulan, 1998). No reliability data for the Religious Connectedness Questionnaire were reported.

Results revealed several issues about religion and how it supports families who have children with disabilities. In general, organized religion functioned positively for families by providing experiences associated with participation in the community and socialization with others of faith. Personal religious beliefs and support by clergy appeared to be the most important to this group. In addition, data suggested, "church membership and greater religiousness were negatively related to stress and depression in the family's adjustment" (p. 96). However, families comments were mixed about help and assistance they received from religious communities. One family reported, "the church members are especially good in helping my daughter's self-confidence." (p.98). While other families felt they were not always provided the needed assistance and some members of their religious organization were not helpful.

Authors indicated that study results were specific to particular African American cultural beliefs. They suggested that because African Americans have experiences inherent in a racially inequitable society, these individuals may have a need for "meaning, hope and a sense of self worth" and to believe that reality is both "material and spiritual"(p. 100). In addition, because a copy of the questionnaire was not provided and no explanation was given about what was meant by participation and support, it is

difficult to interpret results. Using a qualitative approach, Rehm (1999) interviewed 25 Mexican-American parents of children with chronic conditions about religious and secular responses to illness. Participant families all resided in a western city in the United States and were primarily married couples with a high school education and Roman Catholic. Children's ages were not specified but children's disabilities included cancer, genetic syndromes, prematurity, and heart conditions. Data were analyzed using a constant comparative approach.

Results focused on beliefs of the participants. In general, families believed the child's fate rested in the hands of God, which determined the outcome of the child's illness and provided a link between health care and religion. Because families felt an obligation to God, "they themselves, their families, and the medical team played crucial roles in the final outcome [of their child's health]" (p.37). Finally, families often sought God through others and felt that their faith provided optimism in light of their child's issues. Results are limited in the sense that this information is only applicable to Mexican-American families of Roman Catholic affiliation and only addressed religious beliefs. However, results were similar to other studies in that religious beliefs played a key role in supporting families who deal with disability.

Skinner et al. (2001), using a mixed-methods approach, examined the degree of perceived support from religion of Mexican and Puerto Rican families of children with disabilities. Personal religious beliefs and supports provided by organized religion were used to measure perceived levels of support. Two hundred and fifty families throughout the United States were interviewed and asked to complete a modified version of the Fewell Scale of Religiosity (Fewell, 1986) which was used to determine parental views of

organized religion and personal beliefs and the impact their child's disability had on these views. Quantitative data were analyzed using analysis of variance (ANOVA) procedures. Narrative data were analyzed using thematic analyses to determine recurrent themes, and content analyses and cultural model analysis (as cited in Skinner et al., 2001) were utilized and yielded a count of responses to the question: How and to what degree did parents interpret the child's disability within a religious worldview? In addition, the processes of analytic induction and negative case analysis (as cited in Skinner et al., 2001) were used to compare emergent themes to responses.

Results focused on personal beliefs and organized religion as sources of support. Respondent's definition of organized religion included a place to worship, a place that provided community and support for the needs of the child and the family, and a place that provided religious education to their child. Personal faith appeared to be a stronger source of support than organized religion for both mothers and fathers. For example, respondents reported that personal faith allowed them to feel the presence of God, which helped them feel less depressed and helped parents do what was necessary for their families. However, mothers reported significantly higher levels of faith than fathers did. Results were mixed about supports from organized religion. Half of the families reported decreasing church attendance for reasons that included time constraints inherent in having a child with a disability, the churches inability to deal with their child's needs, ill-equipped facilities, and lack of training of church personnel. This particular result is significant because very few studies have provided specific information regarding reasons for lack of attendance (Haworth et al., 1996; Tarakeshwar & Pargament, 2001). Families also reported churches' willingness and ability to include children with

disabilities. Families indicated that the members and clergy provided both emotional and practical support to their families such as transportation to medical appointments or visiting the child in the hospital. Families mentioned that they wanted their child to participate in worship, religious education activities, and formal religious ceremonies such as religious rites and communion and viewed the church as a place to provide these opportunities for participation. However, authors indicated that the results were specific to this population and not applicable to other cultures or ethnic groups.

Summary. The previous studies provide an interesting perspective about culture and religion by demonstrating how these factors influence the family's perception of disability. However, many of the results are similar to other religious study results: faith provides more support than organized religious communities do. In addition, the studies by Rogers-Dulan (1998) and Skinner et al. (2001) provide some insight into what experiences are important to families including religious socialization, church participation, and religious media. However, like previous studies, these results are limited to a particular population and difficult to generalize. The final section focuses on studies that look at religion from a disability-centered perspective.

Disability. Zuk et al. (1961) provided one of the earliest studies of religion, disability, and family. Zuk et al. (1961) surveyed 125 mothers of children with intellectual disabilities and the relationship between religious affiliation and maternal acceptance of a child with a disability. Authors examined mothers of Catholic, Protestant, and Jewish religious affiliations. The authors that measured religious practices and attitudes devised a questionnaire about feelings and beliefs participants had about their child with an intellectual disability. Data were analyzed using factor analysis.

Results indicated that mothers that considered themselves more religious (e.g., faithful church attendance, loyal to religious training, more consistent in prayer), appeared to be more accepting of their child with intellectual disabilities. In addition, results suggested that Catholic mothers were more accepting of their children than non-Catholics because Catholic doctrine absolves parents of the guilt of having a child with a disability. However, these results may only apply to other Christian-based faiths because of the limited response from other religions. This study set the stage for future research in the area of religion and disability.

Fewell's 1986 seminal study of religion, disability, and families was the first to identify the differences between support from religious beliefs and support from religious organizations. Eighty mothers of children with Down syndrome were asked questions about supports from organized religion and personal religious beliefs. A scale specifically examining religiosity was developed and administered. The original Fewell Scale of Religiosity was part of a larger questionnaire looking at supports for families of children with disabilities. Using a 5-point Likert scale, the Fewell Scale of Religiosity included 12 questions with six on religious beliefs and 6 on supportiveness of the organized church. Scale data were analyzed using means, standard deviations and t values.

Results indicated that mothers received significantly more support from their personal beliefs (e.g., belief in a spiritual being, prayer) than from their religious organizations. In addition, the authors indicated that personal beliefs and religious organizational supports are two separate forms of assistance for families with beliefs buffering stress and providing a more positive form of coping. However, it is difficult to

generalize the results from a small sample. In addition, authors provided very limited demographic information about respondents other than age and child's disability. Despite the study's limitations, it was the first to distinguish between support from religious beliefs and support from religious organizations.

Weisner et al., (1991) examined how families cope with having a child with disabilities and what role religion plays in the coping process. Subjects included 102 families of children 3 to 5 years of age with unknown developmental delays in the Los Angeles metropolitan area. Families were interviewed and asked to fill out a questionnaire about basic family information as well as religious affiliation and supports information. Participants were divided into groups based upon a religiosity score (highly religious, moderately religious, and nonreligious) which researchers determined from information acquired from participant interviews and questionnaires. The majority of participants who identified themselves as religious were Christian with a small percentage identifying themselves as Jewish (13%). Interviews and field notes were reviewed by five coders and scored based on The Accommodation Interview Summary (as cited in Weisner et al., 1991). These data were analyzed using chi-square analysis to identify associations on the religiosity portion of the questionnaire.

Like the Fewell (1986) study, results were divided into two areas: personal religious beliefs and organized religion. For families that were religious, beliefs played a "more powerful" role in explaining their child's disability. As expected, highly religious families reported seeking and receiving more support from their religious community than did the nonreligious families. In addition, these families reported receiving more support from friends and neighbors and participating in more social activities than non-

religious families. Yet, results should be viewed cautiously because the sample shared common cultural and Christian beliefs; therefore, results may not reflect viewpoints of other religions or cultures.

Also in 1991, Erin, Rudin, and Njoroge surveyed 161 parents of children with visual disabilities about their religious perceptions concerning their child's disability. Researchers were interested in changes that occurred in their beliefs after their child's diagnosis, how religion was used to interpret disability, and perceived support from religious organizations. Respondents were primarily female, white, protestant, married mothers. The children had a variety of vision related issues including blindness (20%), with a large percentage of children having both a vision disability and an additional disability. Frequency data were provided.

Results revealed some differences between family's religious beliefs and religious community support, however not as strongly as other studies. Families reported that their religious beliefs provided an important source of support when understanding and dealing with their child's disability. Most respondents reported that their religious communities were positive and supportive. Approximately 30% of the families said that their children had minimal contact with their faith community; however, no explanation was provided as to why these families had minimal contact. In addition, 29% of the participants were somewhat dissatisfied with the religious instruction available to their children with disabilities. Authors suggested that results should be viewed cautiously because of an overrepresentation of highly religious respondents and Texans. In addition, there were no data about the instrument reliability. Therefore, is it difficult to generalize these findings to other populations.

Haworth et al. (1996) studied how parents view religion in the context of coping with the rearing of children with disabilities. Two hundred and four families were interviewed using a semi-structured format and asked to complete the Fewell Scale of Religiosity (Fewell, 1986) about religious views. Participants were heterogeneous with respect to age, income, and education levels, with slightly more mothers (203) interviewed than fathers (165). Children had a variety of disabilities with a mean age of 78 months. Two raters independently coded, rated, and categorized comments as positive or negative on a 5-point Likert scale. Inter-rater reliability was established for comments pertaining to religion. Also, one-way analysis of variance (ANOVA) was used to identify associations between the two subscales and total scale of the Fewell Scale of Religiosity.

Frequency of maternal statements about religion and the Fewell Religiosity Scale (1986) were positively correlated. Additionally, all one-way analyses of variance for the subscales and total scale were significant. Mothers that expressed positive comments about religion had a higher score on the Fewell Religiosity Scale and mothers who expressed negative or no comment about religion had lower scores on the Fewell Religiosity Scale. Participant's comments about religion, as in other studies, focused on the themes of organized religion and religious beliefs. Mothers expressed mostly positive comments about the support they received from their religious organizations (e g. Sunday school and social networks that provided, "friendship and comfort" (p. 275).) Although most suggested that religious organizations provided support, some families reported that members and leaders did not accept their child nor did they provide support for the families and discouraged families from being active in the church. Mothers who

discussed religious beliefs did derive strength from their personal beliefs. However, only 29% of the sample commented on religion, so it is difficult to generalize this information to the rest of the sample or other populations.

Using a mixed-methods approach, Coulthard and Fitzgerald (1999) investigated the relationship between perceived support from organized religion, personal faith beliefs, and health status. Part of a larger study looking at the impact of having a child with autism, 56 Irish mothers, and 4 fathers of children with autism were studied. Interviews and several scales were used including the Childhood Autism Rating Scale, General Health Questionnaire Scaled 28, and Support From Religious Organizations and Personal Beliefs Scale based on the Fewell Scale of Religiosity (as cited in Coulthard & Fitzgerald, 1999). Quantitative data were statically analyzed using simple linear regression, correlation, paired and two-sample Student's t.

Families reported significantly more support from personal beliefs than organized religion. Many times clergy and community members were not helpful: possibly because the child had a disability in the Autism spectrum and clergy did not know about the diagnosis, and others withdrew from the family. In addition, families only sought help 5% of the time from organized religion. Families were specifically asked about their satisfaction with availability of religious education and almost half of the families (46%) were happy with the religious education that their child received. Many parents mentioned that their children participated in formal ceremonies including first communion and confirmation. However, authors mentioned that often these rites are administered in the child's special education facility, not the church, and are more socially isolating. Regarding personal beliefs, families reported that their personal beliefs

about disability were a stronger source of support than the organized church. However, because the study was specific to families with children who had autism, this information is not applicable to families of children with other types of disabilities. In addition, this study omitted details about the sample, sampling procedures, and instrumentation reliability and validity, which make it difficult to generalize the results to other populations.

Tarakeshwar and Pargament (2001) completed a mixed-methods study that assessed families of children with autism coping skills in relation to religion. Forty-five parents were initially surveyed, with 21 being interviewed, and assessed about religious coping. The Brief Religious Scale (RCOPE) (as cited in Tarakeshwar & Pargament, 2001) identified both positive and negative aspects of religious coping such as seeking spiritual support or questioning the power of God. In the interview portion, religious outcome was measured using three items that concentrated on perceived religious changes. Quantitative data were analyzed using correlational analysis techniques and hierarchical regression analyses. Additionally, participant's responses were coded into 21 categories identified in Pargament, Koeing, and Perez (as cited in Tarakeshwar & Pargament, 2001).

Overall, results indicated that religion could be a resource for families dealing with issues when raising a child with autism. Results from the RCOPE indicated that the use of positive religious coping indicated a more positive religious outcome and vice versa negative religious coping indicated a more negative religious outcome. Authors suggested that this outcome is significant for families who seek religion as a source of support when rearing a child with a disability because these families can be encouraged

to use religious coping to manage parenting a child with a disability. Notably, frequency of church attendance was related to overall religious involvement. Qualitative data indicated that families looked to the church as a possible place for emotional support about questions related to having a child with autism. Interestingly, several parents reported that the ritualistic nature of church provided a calming effect for their child with autism. On the other hand, many parents reported that churches were insensitive to their child's needs and many families were unable to attend church because of their child's behavior during the service. However, results must be interpreted cautiously because of the small sample size and characteristics of the sample.

Finally, Poston and Turnbull (2004) interviewed 187 individuals about how religious beliefs and practice affect family quality of life. Family quality of life is a relatively new area in the field of disability. Poston and Turnbull (2004) define family quality of life as a "condition where the family's needs are met, family members enjoy their life together as a family and have the chance to do things that are important to them" (p. 96). Much of the literature discusses individual quality of life, but few have studied overall family quality of life and the role religion plays in determining family quality of life. Poston and Turnbull (2004) interviewed participants in a focus group format about religion and family quality of life. Participants included family members, siblings of children with disabilities (78), individuals with disabilities (8), family members of children without disabilities (33), service providers (33) and administrators (17). Focus groups were held in two urban areas and one rural area throughout the United States. For participants with English as their second language, individual interviews were conducted with interpreters. A variety of sampling techniques were used to acquire participants and

multiple procedures were incorporated to address credibility, transferability, and dependability of the data.

Results, like many of the other studies, fell into two categories: support from religious beliefs and support from religious communities. Participants reported that spiritual beliefs played an important role in the emotional and family quality of life. However, an equal amount of participants had positive and negative experiences with religious communities. Comments about religious community experiences included information about participation and acceptance. Families reported that participation in their spiritual community afforded opportunities for them and their child to be involved in activities and meetings and to establish connections with other members of the community. Families also indicated that their religious community was a source of unconditional acceptance and spiritual and emotional support. Conversely, a similar number of participants commented on the lack of acceptance and support their child received when at their spiritual community which led to a decrease in participation for both the child and family, often because families had to provide direct support to their child. Interestingly, the authors suggested that a partnership between schools and religious personnel could help religious communities' better support families of children with disabilities. However, authors cautioned against broad generalizations because of the exploratory nature of the study. In addition, almost all participants expressed a Christian point of view, which is not representative of other religious views.

Summary. Religion can support families of children with disabilities in a variety of ways. However, until recently, the empirical literature has been limited and unclear about the role religion plays in the lives of families of children with disabilities (Rogers-

Dulan & Blacher, 1995; Selway & Ashman, 1998). For the most part, study results can be divided into support families derive from their personal religious beliefs and support families receive from organized religious communities. Support from beliefs appeared to provide families with: (1) a sense of meaning concerning disability, (2) strength and hope, (3) a tool for coping with disability and stress related to parenting a child with a disability, and (4) improved family quality of life (Dollahite et al., 1998; Haworth et al., 1996; Rehm, 1999; Poston & Turnbull, 2004; Treloar, 2002; Weisner et al, 1991).

On the other hand, religious communities received mixed reviews about support. On the positive side, families felt that religious organizations played a more important role for those who were highly religious and provided an important form of support, especially for Latter Day Saints (Weisner et al., 1991; Haworth et al., 1996; Rogers-Dulan, 1998; Dollahite et al., 1998; Treloar, 2002; Marshall et al., 2003; Dollahite, 2003). Alternatively, many families were unable to find the supports they need from organized religion. Families voiced concerns that religious education did not meet their child's needs and churches did not welcome families nor provide for their needs and in some cases even discouraged attendance (Erin et al., 1991; Haworth et al., 1996; Rogers-Dulan, 1998; Coulthard & Fitzgerald, 1999; Skinner et al., 2001; Treloar, 2002).

Conclusions

Researchers concerned with families of children with disabilities have long recognized that many families experience stress (Podolski & Nigg, 2001; Saloviita, Italinna & Leinonen, 2003; Troster, 2001; Wang et al., 2004). The literature also suggests that social support can mediate this stress (Bennett & Deluca, 1996; Dunst et al., 1988; White & Hastings, 2004). The limited research conducted on religion and support

purports that religious beliefs appear to provide the most support where as organized religious communities are not always as supportive. Because of the recent interest in this topic, the study of religion and children with disabilities is primarily exploratory in nature and lacks specificity (Tarakeshwar & Pargament, 2001; Rogers-Dulan & Blacher, 1995; Selway & Ashman, 1998). Further, much of the emphasis has been on spiritual beliefs and "global organizational practices" (Tarakeshwar & Pargament, 2001, p.249) of spiritual communities. Hence, little research has addressed the specific experiences parents have encountered in their spiritual communities, factors that influence involvement in their spiritual communities, or what characteristics of these communities they find supportive or not supportive.

Little information is available to identify specific experiences of families of children with disabilities when attending spiritual communities. Recently, Poston and Turnbull (2004) identified three general attributes that families would like from their religious communities: acceptance, support of their child, and emotional and spiritual support for themselves. However, the specific meaning of these attributes is not yet understood. Further, Marshall et al. (2003) suggested that research "…need[s] to distinguish among personal spiritual belief, religious belief derived from church affiliation, and cultural belief that emerges from association in a church cultural community" (p.70). However, research has provided little insight in identifying support experiences that families want and need.

Further, researchers have not identified the factors that encourage further involvement in a religious community for families of children with disabilities and what specific types of religious communities families seek out and why. Knowing how and

why families of children with disabilities become more involved in a religious community after the birth of a child with a disability may provide evidence to substantiate the claim that religious families' experiences may provide them with a greater sense of support and acceptance.

With the realization that religion can play a significant role in the lives of families of children with disabilities and, for some families, it may provide a more meaningful type of support than other traditional forms, it is important for researchers to identify specifically what activities and behaviors families of children with disabilities consider supportive when attending a religious community. Therefore, the purpose of the present study is to examine religious community support experiences of families of children with disabilities. The following questions and hypothesis about organized religion's role in the lives of families of children with disabilities will be addressed.

Question 1. Where do families of children with disabilities rate their experiences in the spiritual community on a continuum of positive to negative?

Question 2. What experiences in their spiritual communities do families report as important to their child's participation?

Question 3. What experiences in the spiritual community do families report as important to their own participation?

Question 4. What about these experiences do families describe as positive or negative?

Hypothesis: The literature does establish some positive relationships between spiritual community attendance, spiritual community participation, and levels of religiosity (Haworth et al., 1996; Rogers-Dulan, 1998; Tarakeshwar & Pargament, 2001;

Weisner et al., 1991). However, there is little statistical evidence concerning the

relationship between parental satisfaction with their participation in their spiritual

community and amount of their participation. Therefore, it is hypothesized that family

ratings of experiences and support will be significantly and positively correlated with the

amounts of activity participation and support received. That is, families who report

positive experiences will also report participating more in activities and receiving more

support from their spiritual community. In contrast, families who report fewer positive

experiences will also report that they participated less in activities and received less

support.

CHAPTER III

Methodology

The primary purpose of this study is to examine religious community support experiences of families of children with disabilities. Using a mixed methods approach the author developed a web based survey instrument to address the following research questions and to test the following hypothesis:

Question 1. Where do families of children with disabilities rate their experiences in the spiritual community on a continuum of positive to negative?

Question 2. What experiences in their spiritual communities do families report as important to their child's participation?

Question 3. What experiences in the spiritual community do families report as important to their own participation?

Question 4. What about these experiences do families describe as positive or negative?

Hypothesis: It was hypothesized that family ratings of experiences and support will be significantly and positively correlated with the amounts of activity participation and support received. That is, families who report positive experiences will also report participating more in activities and receiving more support from their spiritual community. In contrast, families who report fewer positive experiences will also report that they participated less in activities and received less support.

The following sections discuss recruitment and characteristics of participants, development of the instrument and measures, the pilot study and data collection and analysis of the primary study.

Recruitment

The following agencies agreed to recruit participants for the study: Learning Disabilities Association of Montgomery, Howard and St. Mary's County, Arc of Maryland and Prince George's County, Family Networks, Parents Place of Maryland, State and Howard County chapters of Partners in Policy Making, Maryland Association of Nonpublic Special Education Facilities, Community Connections, MCNeeds, Catholic Disability Outreach Ministry, the Howard County Special Education discussion group and the Autism Society of Howard County. Although all of these agencies agreed to participate, three of the larger agencies did not contact members about participation in the study.

The agencies were contacted by phone or e-mail to request permission to speak to their membership about participation in the study. On agency approval, the researcher provided the organizational contact with a pre-written request to circulate to their membership. Agencies contacted their membership in variety of ways using list serves or newsletters. Members who were interested contacted the researcher directly through e-mail and the researcher responded with information about the survey, a copy of the consent form, and a link to the survey.

There were several problems with recruiting participants that affected the sample size. Only 43 responded to the survey after four months of recruitment and four were ineligible for the study (one child too old, two children's ages could not be determined, two surveys incomplete). Many agencies, local and national that were contacted either did not respond to requests or agreed to recruit participants but did not do so, even after repeated attempts by the researcher to solicit their assistance. Although a sample size of

85 was desired to obtain sufficient power to detect differences, the difficulty gaining participants for the study, and the depletion of the available sample for the study to assure instrument reliability reduced the study sample size. It was determined that this reduced sample size might not generate minimally sufficient power for the statistical tests performed in the main investigation. To help improve power in the small sample, it was decided to include participants from the pilot study after comparing the pilot participants with the survey participants on known factors. The 19 pilot participants (one pilot participant was excluded because child's age was misstated) were comparable to the 39 main survey participants on age, gender, income, religious affiliation, amount of attendance, ages of children, disability type, and gender of child. Therefore, these 19 participants from the pilot study were included in the study sample which increased the sample size to 58.

Participants

Participants in this investigation included a sample (n=58) of parents of children with disabilities. For this particular study an adapted version of a definition of family, from Poston and Turnbull (2004), was used to define parents: people who consider themselves caretakers of a child with a disability, "whether related by blood or marriage or not, and who support and care for [this child]" (p.96). All participants met the following eligibility criteria:

> 1. Individual had to be the parent (see previous definition) of a child with a disability.

2. Both mothers and fathers were eligible to participate. However, participation was limited to only one parent/caregiver of a particular child.

3. The child must be between 6 months and 21 years of age.

4. The parent was able to read, write, and speak English, as determined by answers to open-ended questions.

5. The child had to be living with the family.

Parental relationship to the child, parental age, family income, spiritual community characteristics. Parents in this sample consisted of 51 females (89.5%), 6 males (10.5%), and one response missing. Parents' average age was 46.2 years old. The median family income level was $100,000 and above (62.0%), with eight participants declining to respond. Participants' religious affiliations included Muslim, Jewish, Catholic, Protestant and other, with Protestants the largest group represented (62.1%). The majority of respondents (67.2%) attended spiritual community activities every week (see Table 1).

Table 1

Characteristics of Study Participants (Parents)

Variable	n	%[a]
Relationship to Child (n=57)		
Mother	51	89.5
Father	6	10.5
Age (n=57)		
30-39	8	14.0
40-49	32	56.1
50-60	17	29.8
Income (n=50)		
Less than $15,000	0	0
$15,001-$45,000	5	10.0
$45,001-$75,000	9	18.0
$75,001-$100,00	5	10.0
$100,000 and above	31	62.0
Religious Affiliation		
Buddhist	0	0
Catholic	10	17.2
Hindu	0	0
Jewish	3	5.2
Muslim	1	1.7
Protestant	36	62.1
(Methodist, Baptist, Orthodox Christian)		
None	0	0
Other	8	13.8
Spiritual Community Attendance		
Never	2	3.4
Once a Year	3	5.2
About once a month	10	17.2
Every week	39	67.2
Several times a week	4	6.9

[a] Percentages may not add to 100, due to independent rounding

Child's age, gender and disability. Children in this sample consisted of 18 females (31.0%) and 40 males (69.0 %). Their mean age was 13.1, with the youngest 10 months and the oldest 21 years of age. Children with autism (41.4 %), learning disabilities (29.3%), mental retardation (29.3%), speech or language impairment (27.6%), and other disabilities (36.2%) were represented the most frequently. Other disabilities represented included orthopedic impairment, emotional disturbance, visual impairment, traumatic brain injury, hearing impairment, and deaf/ blindness with many of the children possessing co-morbid disabilities (e. g., autism and mental retardation) (see Table 2).

Table 2

Characteristics of Study Participants (Children)

Variable	*n*	*%*
Gender		
Male	40	69.0
Female	18	31.0
Age		
10 months of age	1	1.7
3-10	16	27.6
11-15	24	41.4
16-21	17	29.3
Disability		
Autism	24	41.4
Deaf Blindness	2	3.4
Emotional Disturbance	5	8.6
Hearing Impairment	2	3.4
Learning Disability	17	29.3
Mental Retardation	17	29.3
Orthopedic Impairment	7	12.1
Speech or Language Impairment	16	27.6
Traumatic Brain Injury	2	3.4
Visual Impairment (including blindness)	4	6.9
Other	21	36.2

Measures and Instrument Development

A web-based survey instrument was developed for the study. The on-line survey format was selected for several reasons. Specifically, the on-line format provided a means to reach families of children with disabilities with multiple commitments and who may have lacked respite care to permit attendance at meetings. It was also anticipated that this format would elicit more honest responses due to the sensitive nature of the subject. Finally, this method provided a vehicle to reach a larger group of participants and to reduce the amount of time and activity involved for families participating in the project.

The Spiritual Community Experiences Inventory (SCEI) (see Appendix A for complete inventory) was designed by this author based on the religious support literature (Coulthard & Fitzgerald, 1999; Dollahite et al., 1998; Dollahite, 2003; Poston & Turnbull, 2004; Rogers-Dulan, 1998; Skinner et al., 2001; and Tarakeshwar & Pargament, 2001), the researcher's personal experiences, and several previous instruments developed to identify general religious attitudes of families of children with disabilities (Fewell, 1986; General Social Survey, 2006; Skinner et al., 2001). Questions were developed with guidance from a survey expert, several reviewers, doctoral committee feedback, survey literature (DeVellis, 2003; Orcher, 2007), and question scales that appeared on the General Social Survey (2006). Participants completing the SCEI were asked to read statements about their and their child's experiences in their spiritual community. They were then asked to rate the importance of those experiences, their satisfaction with their experiences, and the rationale behind their rating of those experiences in an open-ended format.

There were two groups of scaled questions: questions about importance of participation and support and questions about level of satisfaction with participation and support (e.g., questions 10 and 12 on SCEI). Questions that included scaled items were developed with guidance from the survey expert, the General Social Survey (2006), and doctoral committee input. Other question response categories included yes/no or frequency of participation (e.g., questions 9 and 11 on SCEI). In addition, demographic data were collected. Moreover, a survey professional, experts in the field, and parents of children with disabilities extensively reviewed instrument content. All reviewers indicated the survey instrument was well worded and of the proper length. The final version of the instrument included 36 questions.

Privacy and Distribution

The survey was housed at Survey Monkey, an internet-based survey development company. The privacy policy of Survey Monkey states that they will not use any data collected in any way for their purposes. All equipment used for the Survey Monkey websites are kept in a secure facility with 24-hour surveillance. When the researcher deletes the information, it is purged from the website servers within 30 days.

 Because this instrument was developed specifically for this study, a pilot study was conducted prior to the main investigation to test the instrument and determine initial reliability. Prior to the pilot study, Institutional Review Board (IRB) approval was obtained from the University of Maryland at College Park. After receiving IRB approval, survey questions were entered into Survey Monkey and tested prior to the pilot study. The researcher recruited two individuals to test the instrument using Survey Monkey for

accuracy and technical considerations. Any problems identified by these individuals were corrected prior to initiation of the pilot study.

For both the pilot study and primary study invitations and consent forms were e-mailed to participants inviting them to complete the survey. The invitation included information about the study, researcher contact information, and a link to the survey. At the beginning of the survey, participants were presented with a consent form. Once participants provided their consent, they were permitted to begin the survey. The survey also included a description of the study, criteria for participation, and instructions on how to complete the survey.

<div align="center">Pilot Study</div>

As stated previously, a pilot study was conducted prior to the main investigation. The pilot study was designed to use a multi-step process to test reliability of the survey instrument. To evaluate test-retest reliability, ten participants completed the questionnaire at two different times. To determine inter-rater reliability ten husband and wife couples completed the survey independently. However, after careful consideration it was determined that mothers and fathers were not comparable judges because of the variability in their experiences with the same child. Therefore reliability assessment was confined to test-retest reliability. Nevertheless, acceptable completed couples' surveys were randomly selected without duplication of child and were included in the main survey. Pearson correlation was used to determine test-retest reliability.

Participants

The pilot study was conducted in a suburban Maryland county located between Washington D.C and Baltimore. Participants in the pilot were acquaintances of the

researcher who had children with disabilities and met eligibility criteria. Ten individuals

(see Table 3) were recruited for test-retest analysis.

Table 3

Pilot Study Family and Child
Characteristics (Test-retest Participants)

Variable	n
Parent's Relationship to Child	
Mother	10
Father	0
Other	0
Parent's Age	
30-39	1
40-49	6
50-60	3
Parent's Income	
Less than $15,000	0
$15,001-$45,000	0
$45,000-$100,000	0
$45,001-$60,000	3
$100,000 and above	6
No Response	1
Child's Gender	
Male	8
Female	2
Child's Age	
3-10	1
11-15	5
16-21	4
Child's Disability	
Autism	2
Deaf/ Blindness	1
Emotional Disturbance	2
Hearing Impairment	1
Learning Disability	3
Mental Retardation	4
Orthopedic Impairment	0
Speech or Language Impairment	3
Traumatic Brain Injury	0
Visual Impairment (including blindness)	1
Other	2

Pilot Study Procedures

Potential participants in the pilot study were sent an e-mail asking for their participation. Once those contacted agreed to complete the survey, they were provided a link to the survey. For tracking purposes, pilot participants were prompted to provide an e-mail address at the end of the survey. Participants who completed the survey twice for purposes of test-retest reliability were sent a second e-mail three weeks after completing the first survey. Participant survey completion progress was tracked and up to four follow-up e-mails were sent to individuals who had not completed the survey.

Analyses of Pilot Data

The primary focus of the statistical analyses for the pilot study was to establish test-retest reliability for questions. Test-retest data were analyzed between the first and second instrument administrations using the Pearson Product Moment Coefficient. Ten participants completed the survey twice with about three weeks between administrations. Test-retest was established by examining questions about religious attendance, opportunities for participation, importance of participation, amount of participation and satisfaction with participation experiences. Twenty of the 26 questions indicated a significant relationship. Of these, ten questions indicated a significant positive correlation at the .01 level, and ten questions indicated significant positive correlations at the .05 level (see Table 4).

As stated previously, 20 of the 26 (77%), or nearly four out of five, questions were significantly correlated using the Pearson Product Moment Correlation. Of the remaining 6 questions, three (24, 27, 30) were not significant because some of the respondents did not answer the question on either one or both test administrations. These

non-responses dropped the sample size too low to accurately reach significance. Of the remaining three questions (20, 23, 26), although complete, some responses varied by such a great degree that correlation was reduced to non-significance. Of the responses for question 20, seven (70%) responses agreed but three responses varied by two. Eight (80%) responses agreed for question 23, one response varied by one, but another response varied by three. For question 26, four (40%) responses agreed and five (50%) responses varied by one. Given these results, it was decided that questions would be retained as worded.

Table 4

Pilot Study Test-Retest Pearson Product Moment Correlations Question 6 and Question 9 through Question 19

	Q6	Q9	Q10	Q11	Q12	Q13	Q14	Q15	Q16	Q17	Q18	Q19
Q6	1.00**											
Q9		1.00**										
Q10			.82**									
Q11				.67*								
Q12					.94**							
Q13						.88**						
Q14							.66*					
Q15								1.00** [a]				
Q16									.82**	.		
Q17										84*		
Q18											.91**	
Q19												.67* [b]

*p<.05. **p.01.

a. Since all responses on both test and retest were identical, a correlation coefficient could not be directly calculated. However, 100% of respondents matched in test and retest. Therefore, a coefficient of 1 was inferred.

b. Since all responses for this yes/no question on the first administration were identical, a correlation coefficient could not be calculated. However, 80% of respondents matched in test and retest. Therefore, a coefficient of .67 was inferred from question 11, which was also a yes/no question with 80% test retest match.

Table 4

Pilot Study Test-Retest Pearson Product Moment Correlations 20 through Question 33

	Q20	Q21	Q22	Q23	Q24	Q25	Q26	Q27	Q28	Q29	Q30	Q31	Q32	Q33
Q20	.59													
Q21		.71*												
Q22			.64*											
Q23				.53										
Q24					.63									
Q25						.90**								
Q26							.44							
Q27								.28						
Q28									.65*					
Q29										.74*				
Q30											.36			
Q31												.76*		
Q32													1.00**	
Q33														.75*

*p<.05. **p.01.

Summary. Test-retest reliability indicated that the survey instrument appeared consistent overtime and multiple administrations. Twenty of the 26 (77%) questions indicated a significant relationship and either sample size or one or more large test-retest response deviations affected the remaining six. Therefore, the instrument appeared to demonstrate consistency across time.

The main purpose of the pilot study was to assess the reliability of the instrument using quantitative measures. However, responses to open-ended questions were reviewed to ensure participant responses generally matched the question construct. Some variations in interpretation and repetition of answers were detected, however, only in a few instances. Therefore, question wording and survey length were not changed.

Changes to Instrument Based on Pilot Data

Although the questions were not changed based upon the quantitative and qualitative data from the pilot study, other concerns arose that required other changes. First, there were several instances of unexplainable missing data. On further inspection, questions were identified that appeared to have been unintentionally skipped, possibly because of the online completion process. To assure a maximum of complete surveys, an addendum to the original Institutional Review Board (IRB) application was requested to allow participants to return to previous answers. Also included in the addendum was a request that participants directly contact the researcher about survey participation. In preliminary participant recruiting activities, participating agencies had been unwilling to collect participant e-mails and provide them to the investigator. Agencies cited difficulty in coordinating personnel to implement this procedure and general lack of staff to support

such an effort. In addition, it was assumed that involving more individuals in the process might increase risk to participants. Therefore, it was also requested that participants would directly contact the researcher regarding participation. The IRB approved these changes on April 1, 2008.

Further inspection of data determined that some of the missing data were related to the nature of the questions. The questions that had the most missing data were questions about whether families and their child had the opportunity to participate in a particular activity. If participants responded that their child did not have the opportunity to participate in a particular activity, they were directed to the next set of questions. Therefore, it appeared that most of these data, although missing, were missing for a reason. Additionally, when participants contacted the researcher directly, there appeared to be an increase in responses because the researcher was able to send the survey link to the participant as soon their request was received and was able to make multiple requests for completion of the survey.

Limitations

The purpose of the pilot study was to test instrument reliability before study implementation. Although reliability of the instrument appeared sufficient in the pilot study, it should be noted there were several limitations of the pilot study. The sample size for the test was small so it may not accurately depict true relationships. Also, since this pilot study was the first administration of this instrument, there was no previous information with which to compare results. Even with issues of sample size, the initial administration of the survey appeared to be reliable. Based on the favorable results

regarding instrument reliability, it was decided the study could advance once IRB approval was obtained regarding administrative changes.

<div align="center">Study Data Collection</div>

As proposed, data were collected using the SCEI questionnaire. Test-retest comparisons were used to determine instrument reliability. Descriptive statistics and correlation analyses were calculated to address the following research questions and study hypothesis:

Question 1. Where do families of children with disabilities rate their experiences in the spiritual community on a continuum of positive to negative?

Question 2. What experiences in their spiritual communities do families report as important to their child's participation?

Question 3. What experiences in the spiritual community do families report as important to their own participation?

Question 4. What about these experiences do families describe as positive or negative?

Hypothesis: It is hypothesized that family ratings of experiences and support will be significantly and positively correlated with the amounts of activity participation and support received. That is, families who report positive experiences will also report participating more in activities and receiving more support from their spiritual community. In contrast, families who report fewer positive experiences will also report that they participated less in activities and received less support.

The following sections provide a description of the data collection methods for the study.

Quantitative Data Collection and Analyses

To collect quantitative data, participants completing the SCEI were asked to read statements related to various spiritual community experiences of their child and family and indicate if their child had the opportunity to participate in various activities. They were asked to rate the importance of those experiences and their satisfaction with their experiences. Additionally, families were asked to provide demographic data. Data were collected over a 4-month period.

Prior to analyses, data were downloaded to Excel and then to SPSS. Variables were coded using standard codes for categorical data (e g. female =1 and male = 2). Continuous variables were coded using both positive and negative numbers (e. g. somewhat negative= -1 and somewhat positive =1). Missing data were coded as 9.

Once survey data were coded, descriptive statistics including frequencies, minimum and maximum values, means, and standard deviations were calculated to screen data for errors or missing values. Several instances of missing data occurred. Some missing values had a systematic pattern, which included instances when respondents did not answer the question. In some cases, missing answers may have occurred because certain questions did not pertain to the respondent, such as when the child did not have the opportunity to participate and respondents were directed to skip the remaining questions in this category. In the demographic portion of the survey, several respondents did not report their income, possibly due to the sensitive nature of the question. In other cases, missing data occurred because of data transfer errors from the survey internet website to Excel. In those instances, individual participant surveys were

reviewed to identify the missing data. These missing data were manually inserted into SPSS.

Descriptive analyses were performed on each question included in the correlation analysis (questions 12, 13, 16, 17, 20, 21, 23, 24, 26, 27, 29, 30) to determine if the data were normally distributed and to identify outliers that might affect analyses (see Appendix A for SCEI). Analysis revealed that the scores for both sets of data were not normally distributed, and in both cases, were skewed to the right, meaning most scores fell in the positive range (Skewness for frequency of participation questions = -.699, Skewness for satisfaction of experience questions = -.929). Based upon this information, and because the two scales were correlated included both categorical and continuous data, it was determined that non-parametric statistics were the most appropriate for the analysis for this study, in this case Spearman's rho.

In addition, outliers were identified during this process. Only four questions produced an outlier response in terms of affecting the mean. Therefore, each outlier was inspected to determine if it was a true outlier or an error. Two of the four questions, outliers were in error (e.g. incorrect data) and data were corrected. For the other outliers, it was determined that they were accurate responses and were not eliminated from analysis (e g., frequency of religious education attendance averaged once per week and one respondent indicated that their child did not attend at all).

For the final quantitative analyses, varieties of analyses were performed using SPSS statistical software. Descriptive data were calculated for both categorical (e.g., type of disability) and continuous variables (e.g., level of satisfaction). For categorical and continuous data frequencies and percentages were calculated. Finally, correlation

analyses regarding the study hypothesis were conducted using the Spearman rho

correlation coefficient. Twelve questions were included in this analysis: six pertaining to

level of participation and six pertaining to satisfaction. Based upon the distribution

analyses and the determination that one of the scales being correlated was categorical in

nature, it was decided to use a non-parametric test. The outcome of these analyses is

reported in the results section of this paper.

Qualitative Data Collection and Analysis

Qualitative data analyses for this study were based on procedures by Bogdan &

Biklen, 2003; Glaser, 1998; and Ryan & Bernard, 2003. The qualitative data collected as

part of this study was used to answer the research question: What about these experiences

do families describe as positive or negative? The main source of qualitative data were

responses to open-ended questions on the SCEI about families' activity and support

experiences in their spiritual communities (see appendix A for SCEI). Therefore, each

series of questions regarding level of satisfaction (questions 13, 17, 21, 24, 27, 30) and

the availability of opportunities for participation (questions 11, 15, 19) included an open-

ended question to identify why parents rated their spiritual community experience in that

way or why parents did not have the opportunity to participate. Additionally, questions

31 and 32 asked about negative experiences and question 33 asked about switching

spiritual communities. The procedures for data analysis will be discussed in the

following section.

Prior to qualitative analysis, responses for each open-ended question were

downloaded into individual text documents. To analyze the qualitative data, several

methods were used to identify themes among the data. Initially, "pawing" or

"eyeballing" was the technique used to identify codes. This technique requires the analyst to review the data multiple times to develop patterns and themes (Ryan & Bernard, 2003). Initially the text was scanned for phrases relevant to the question asked. Relevant phrases and keywords were highlighted. Next, all keywords and phrases were reviewed again and identified codes were written in the left margin. Codes for each question were typed and key quotes were listed beneath. Many codes were repetitious and often overlapped; therefore the codes were combined. Once codes were combined, they were written on note cards and related quotes were then pasted on note cards. During this process, the researcher noticed that codes were clearly linked to the larger categories of participation or support. Therefore, the cards were sorted into two piles, codes associated with participation and codes associated with support. Cards were resorted for each of these categories, organized by code, and combined into thematic groups. For example, there were several codes related to successful participation of their child: teacher support, staff support, knowledge of teacher, trained staff, special needs ministries. These codes were combined and called knowledge and understanding.

Throughout the coding process, the researcher used memoing to define, keep track of, and compare ideas. Memos are the write-up of codes and their relationships as they emerge during coding (Glaser, 1998).

Peer debriefing was used to establish credibility. Another parent of a child with a disability reviewed participant comments and developed her own set of codes. These codes were compared to codes developed by the researcher for irregularities and or missing themes. Interestingly, although the themes were similar, the parent reviewer independently identified specifically what themes were positive and what themes were

negative. This result provided insight into how themes were divided among positive and negative remarks and helped to arrange the themes for the final analysis. The themes were divided between these two broad categories: positive and negative participation experiences and positive and negative support experiences.

To further support the data generated from the analysis, emergent themes from the study were compared to a list of themes generated prior to the project proposal and grounded in the religious and family support literature (Beckman et al., 1998; Coulthard & Fitzgerald, 1999; Dollahite et al., 1998; Dollahite, 2003; Poston & Turnbull, 2004; Rogers-Dulan, 1998; Skinner et al., 2001 and Tarakeshwar & Pargament, 2001), (see Appendix B for list of themes). Although themes were arranged somewhat differently, all appeared similar to generated themes except for a theme found in the literature about financial support. Study data did not provide any codes linked to this topic.

Chapter IV

Results

The following table links the results presented in this chapter with the appropriate

research question and hypothesis:

Table 5

Research Questions, Hypothesis and Associated Results

Research Questions	Results
Question 1	Negative Experiences, Exclusion Experiences and Reasons for Switching Spiritual Communities
Question 2	Level of Satisfaction with Participation/Support Importance of Participation
	Children's Opportunities to Participate
Question 3	Importance of Participation and Support
Question 4	Negative Experiences, Exclusion Experiences and Reasons for Switching Spiritual Communities
	Level of Satisfaction with Participation/Support
	Qualitative Results Participation Experiences Acceptance and Support
Hypothesis	Frequency of Participation in Activities or Experiences and Amount of Support
	Level of Satisfaction with Participation/Support
	Correlation Analysis

Quantitative Results

In this study, quantitative and qualitative data from the Spiritual Community Experiences Inventory (SCEI) were collected to identify the types of activities and support that parents of children with disabilities found important in their spiritual community. This section presents the quantitative findings of the research questions and hypothesis posed in the study.

Descriptive statistics and correlational data were calculated to address the research questions and the study hypothesis. Descriptive data were tabulated and analyzed for the following information: frequency of participation, availability of opportunities for the child to participate in spiritual community activities, parent's perceptions of importance of spiritual community participation for their child in each activity, parent's perceptions of importance of spiritual community support for the family, parent's ratings of satisfaction with child's participation in each activity, parent's ratings of satisfaction with support provided to the family, extent to which experiences were negative or exclusive, and their consideration of switching spiritual communities. Additionally the relationship between parents' satisfaction ratings with a particular activity or support experience and the frequency of participation in the activity or support experience was analyzed using Spearman rank correlation. Descriptive data will be presented first.

Descriptive Data

Descriptive statistics for importance of participation and support. Research questions two and three of this study asked families to indicate what activities were important to their children's participation in their spiritual community and what types of

support were important to their own participation. Descriptive statistics were used to

summarize participant responses. Percentages are reported for each question. Items were

rated on a three-point scale: not important (-1), important (0), and very important (1).

The data were coded using both positive and negative numbers to preserve the

relationship that negative numbers represent items that have negative attributes and

positive numbers represent items that have positive attributes. It was expected that about

half of the respondents would rate their experiences as important with the other half

evenly divided between not important and very important. In all cases, the results were

highly skewed in the direction of very important. Participants rated all activities

(religious education, youth activities, formal religious ceremonies, and worship services)

as important to their child's participation (see Table 6). In all cases, more than 90% of

respondents rated these activities as either important or very important. In fact, for

religious education and formal ceremonies more than half rated these activities as very

important. In addition, more than 90% of respondents rated support from both religious

leaders and members as either important or very important, with more than 50% rating

religious leader support as very important.

Table 6

Importance of Participation/Support
Descriptive Statistics

Variable	n	%a
Religious Education		
Not Important	4	6.9
Important	24	41.4
Very Important	30	51.7
Youth Activities		
Not Important	4	6.9
Important	28	48.3
Very Important	26	44.8
Formal Ceremonies		
Not Important	5	8.6
Important	21	36.2
Very Important	32	55.2
Worship Services		
Not Important	5	8.6
Important	25	43.1
Very Important	28	48.3
Religious Leader Support		
Not Important	4	6.9
Important	24	41.4
Very Important	30	51.7
Member Support		
Not Important	4	6.9
Important	27	46.6
Very Important	27	46.6

a. Percentages may not add to 100, due to
independent rounding

Descriptive statistics for questions about opportunity for participation, negative or exclusive experiences, and switching spiritual communities. Families were asked if their child had the opportunity to participate in religious education, youth activities, and formal ceremonies. Three quarters of the children (77.6%) had the opportunity to participate in religious education activities with only 13 (22.4%) that did not. More than two thirds of the children, (70.7%) had the opportunity to participate in youth activities with only 17 (29.3%) that did not. About three quarters of the children, (75.9%) had the opportunity to participate in formal religious ceremonies while only 14 (24.1%) did not (see Table7).

More than two-thirds of participants (68.4%) reported their child had a negative experience in their community, while 18 (31.6%) participants did not. More than half (53.3%) reported the child with a disability was excluded from activities within their spiritual community; while more than a two-fifths (46.7%) did not. On the other hand, more than one-third of participants (37.7%) considered switching spiritual communities because of experiences related to their child, while 33(62.3%) nearly two-thirds of participants did not (see Table 8).

Table 7

Children's Opportunity to Participate
Descriptive Statistics

Variable	*n*	*%*
Religious Education		
Yes	45	77.6
No	13	22.4
Youth Activities		
Yes	41	70.7
No	17	29.3
Formal Ceremonies		
Yes	44	75.9
No	14	24.1

Table 8

Negative Experiences, Exclusion Experiences and Reasons for Switching Spiritual Communities Descriptive Statistics

Variable	*n*	*%*
Negative Experiences (n=57)[a]		
Yes	39	68.4
No	18	31.6
Exclusion Experiences (n=45) [a]		
Yes	24	53.3
No	21	46.7
Switching Communities (n=53) [a]		
Yes	20	37.7
No	33	62.3

a. Respondents less than 58 due to nonresponse

Frequency of participation in activities or experiences and amount of support.
Amount of participation and support were generally high but varied by activity and type
of support. Parents reported that their children participated most often in religious
education and youth activities and slightly less often in worship services. In addition,
more than 90% of children participated at least once in formal ceremonies. More than
80% participated in religious education at least once a month and more than two thirds
participated in youth activities at least once a month. Similarly, about 80% participated
in worship services at least once a month.

Participants reported receiving support (emotional or practical) on a more regular
basis from members than from spiritual leaders. A third never received support from
spiritual leaders while a quarter never received support from members (see Table 9).

Table 9

Frequency of Participation and Amount of Support
Descriptive Statistics

Variable	n	%
Religious Education (n=45)[a]		
Never	3	6.7
Once a Year	5	11.1
About Once a Month	7	15.6
Every Week	25	55.6
Several Times a Week	5	11.1
Youth Activities (n= 41) [a]		
Never	3	7.3
Once a Year	10	24.4
About Once a Month	14	34.1
Every Week	10	24.4
Several Times a Week	4	9.8
Formal Ceremonies (n = 45) [a]		
Never	4	8.9
Once	10	22.2
Once a Year	14	31.1
About Once a Month	12	26.7
Every Week	4	8.9
Several Times a Week	1	2.2
Worship Services (n=58)		
Never	8	13.8
Once a Year	3	5.2
About Once a Month	17	29.3
Every Week	29	50.0
Several Times a Week	1	1.7
Religious Leader Support (n=58)		
Never	19	32.8
Once a Year	14	24.1
About Once a Month	16	27.6
Every Week	8	13.8
Several Times a Week	1	1.7
Member Support (n=58)		
Never	15	25.9
Once a Year	14	24.1
About Once a Month	12	20.7
Every Week	12	20.7
Several Times a Week	5	8.6

a. Sample size varies because some respondents
indicated their child did not have the opportunity
to participate

Level of satisfaction with participation and support. The first research question asked how families of children with disabilities rate their experiences in their spiritual community on a continuum of negative to positive. To address their preferences, participant responses to questions 13, 17, 21, 24, 27, and 30 on the SCEI were analyzed. To measure satisfaction, parents rated their experiences on a five point Likert scale as negative (-2), somewhat negative (-1), neutral (0), somewhat positive (1), or positive (2). Like the scale developed for the questions about importance of participation, the data were coded using both positive and negative numbers to preserve the relationship that negative numbers represent items having negative attributes and vice versa.

Families indicated that their experiences were mostly positive. More than 75% of respondents rated the activities as either somewhat positive or positive, with more than 80% rating youth activities and formal ceremonies as somewhat positive or positive. About 15% were neutral and a far smaller percentage were somewhat negative or negative about any of the activities. Participants also rated their satisfaction with support the family received from spiritual leaders and members as either somewhat positive or positive. Almost 90% of respondents rated both leader and member support as positive or somewhat positive. The sample size varied among questions because not all children participated in all activities or participants did not respond to the question (see Table 10).

Table 10

Level of Satisfaction Descriptive Statistics

Variable	n	%
Religious Education (n=42)[ab]		
Positive	24	57.1
Somewhat Positive	9	21.4
Neutral	6	14.3
Somewhat Negative	1	2.4
Negative	2	4.8
Youth Activities (n=41) [a]		
Positive	20	48.8
Somewhat Positive	14	34.1
Neutral	5	12.2
Somewhat Negative	0	0
Negative	2	4.9
Formal Ceremonies (n=39) [ab]		
Positive	22	56.4
Somewhat Positive	10	25.6
Neutral	6	15.4
Somewhat Negative	0	0
Negative	1	2.6
Worship Services (n=50) [b]		
Positive	24	48.0
Somewhat Positive	15	30.0
Neutral	8	16.0
Somewhat Negative	2	4.0
Negative	1	2.0
Religious Leader Support (n=39) [b]		
Positive	25	64.1
Somewhat Positive	10	25.6
Neutral	4	10.3
Somewhat Negative	0	0
Negative	0	0
Member Support (n=43)[b]		
Positive	29	67.4
Somewhat Positive	10	23.3
Neutral	4	9.3
Somewhat Negative	0	0
Negative	0	0

a. Sample size varies because some respondents indicated their child did not have the opportunity to participate.
b. No response to the question or missing data

Correlation Analysis

The following analysis tests the study's hypothesis of a relationship between frequency of participation and nature of experience. Since the two scales in the correlation included both categorical and continuous data and data were not normally distributed, Spearman's rho correlation statistic was used. It was hypothesized that family ratings of experiences and amount of activity participation will be significantly and positively correlated. That is, families who report experiences that are more positive will also participate more in activities within the spiritual community. In contrast, families who report fewer positive experiences will participate less in these activities.

Frequency of participation of children in religious education classes, youth activities, formal spiritual ceremonies and worship services and amount of support families received from religious leaders and members were correlated with satisfaction with each of these activities or experiences (see Table 11). It was expected that two (religious education and worship service participation) of the six correlations would be significant because descriptive data indicated high satisfaction and high frequency among these activities. Surprisingly, despite less frequency of participation in youth activities and less support from religious leaders and members, all were significantly correlated. Satisfaction with religious education experiences was significantly and positively correlated with frequency of participation (r = .44, p < .01). Similarly, frequency of participation was significantly correlated with family's satisfaction with youth activities (r = .33, p < .05), worship services (r = .38, p < .05), spiritual leader support (r = .40, p< .05), and member support (r = .45, p < .01). That is, families who reported positive experiences with religious education, youth activities, worship service, religious leader

support and member support reported more participation in these activities. Similarly,

families who reported negative experiences in these areas reported less participation. The

relationship between satisfaction with formal ceremonies and the amount the child

participated in these activities was not significant.

Table 11

Spearman Rho Correlations between Frequency of
Participation/Support and Ratings of Participation/Support

Activities/Support	Correlation Coefficient
Religious Education ($n = 42$)[a]	.44**
Youth Activities ($n = 46$)[a]	.33*
Formal Ceremonies ($n = 46$)[a]	-.05
Worship Services ($n = 50$)[a]	.38*
Religious Leader Support ($n = 39$)[a]	.40*
Member Support ($n = 43$)[a]	.45**

*p< .05. **p<.01.

a. Sample size varies because some respondents did not participate in all activities.

Summary of Quantitative Findings.

These findings indicated that families, for the most part, rated their children's participation and family support in their spiritual communities as positive and important. In addition, families who reported positive experiences with religious education, youth activities, religious leader support and member support reported a high frequency of activity participation. Only for formal ceremonies was frequency not correlated with satisfaction. The following section discusses results of the qualitative data analysis.

Qualitative Results

Qualitative data in this study were collected to address question four: What about spiritual community experiences do families describe as positive or negative? Qualitative data included written responses to open-ended questions asking those surveyed to explain what factors influenced their ratings of their children's experiences when participating in religious education activities, youth activities, formal religious ceremonies, and worship as well as when they received support from spiritual leaders and spiritual community members. Most responded to these questions and with considerable candor. Data were analyzed using procedures by Bogdan and Biklen (2003), Glaser (1998) and Ryan and Bernard (2003) and included participant comments, creating codes, and developing themes. Participants provided comments about two vital areas: participation and support, and, within each key area, several themes were identified. The following sections review the results of this analysis.

Participation Experiences

Families provided comments about their child's participation in religious education, youth activities, formal religious ceremonies and worship services. Key

themes emerged from these data, including opportunities for socialization; social isolation; levels of staff knowledge, experience and training; degrees of accommodation provided for their child; the child's ability to participate; and opportunities for participation. The following sections provide detailed results about these themes.

Social opportunities. For many participants, activities in their spiritual communities included social experiences that provided children with disabilities a context for social interaction with others, helped improve the child's social skills, enhanced enjoyment of participation, and improved their self-esteem. For example, one mother of a young adult reported, "[He] belongs to our high school youth group as well as a small Bible group of peers every week. He has built very strong ties to his small group [of] guys which helps him enjoy his large group activities." For this young man opportunities for social interaction flowed into other activities and increased his enjoyment. His mother suggested that opportunities to interact with peers strengthened her son's ability to deepen his faith and connections with others: "I see youth activities and Christian education activities as both giving him opportunities to develop his strong faith and connections to fellow believers. He wants to attend every youth group activity and really enjoys talking about faith." Another mother of a child with multiple disabilities commented about social connections others have made with her child and how these connections provided him with a sense of belonging, "My son is a part of the group and people have connected with him at his level."

Interestingly, for many children, worship services also provided opportunities for social interaction. One parent viewed worship as a "great opportunity for him to interact and spend time with our friends, hear music, get used to crowds." Parents identified a

variety of social opportunities within worship that benefited both the child and adults in the community. For example, participants noted that their child enjoyed worship services because it provided an opportunity to be with friends. A mother of a young woman with mental retardation said…, "She now enjoys attending worship service with us as a family and enjoys inviting her disabled best friend when possible." There were also benefits when her child had a role in the worship services and formal ceremonies. A parent reported, "He enjoys worship, has several good friends among the children and the adults there, and really enjoys serving as acolyte. He seems to have a very strong spiritual sense." This parent identified specific benefits that included social opportunities, which allowed her son to actively participate in worship. Whereas most participants reported positive connections between worship participation and social opportunities, one parent stated, that her son is, "… proud that he can participate, but very nervous about his performance." Although her son was anxious, his involvement provided a sense of pride and accomplishment, and a growth opportunity that he would, otherwise, have missed outside this worship context.

For families in this study, participation in their religious community provided the children with social opportunities that helped develop those skills and deeper connections with community children and adults. Moreover, these experiences provided a variety of avenues for participation that enhanced their child's satisfaction and provided a sense of pride. These benefits are important factors that determine perceptions about positive participatory experiences and contribute to the overall worship experience.

Social isolation. Despite these positive encounters, at least six families also reported that their child was socially isolated. Parents credited this isolation to attitudes

(from children and adults) toward their child and their child's inability to connect with peers. Parents frequently mentioned that sometimes other children did not readily accept their child. Most often, the lack of acceptance occurred in either religious education programs or youth activities, where children would typically have the most opportunities for peer contact. Parents reported that other children did not include their child. For example, a parent said, "…She is basically shunned by the other kids who find her odd or different." Another parent provided this account:

> When she was younger, up to 17 years old, her experiences had been positive, but as her peers grew older and [acquired] more typical teen group thinking, it changed into a nice but not as inclusive [experience] as it could have been.

Parents also described situations in which they felt their child had difficulty connecting with other children. A participant explained: "He likes doing activities, but it is hard for him to make friends with the other children." Similarly, a parent stated, "My daughter is very outgoing and makes her experiences the best she can, yet she does have some difficulty with age-level peer interactions and this is apparent during these activities." These instances suggest that participants believe that their child's inability to connect – whether because of other children or their child – somehow makes the social experience less fulfilling and leads to social isolation.

Staff knowledge, experience, and understanding of disabilities. Families felt staff and volunteers who were knowledgeable and understanding of disability created more positive participatory experiences for their children. Qualities of staff that seemed to encourage children's participation included prior experience and knowledge about working with children with disabilities, sensitivity to the needs of the child, and a positive

attitude towards the child. One mother of a child with ADHD commented that her child's positive experiences happened with trained, experienced staff: "…To me, the bottom line is the religious education leader's skills and knowledge of disabilities." Staff who had previously worked with children with special needs or were sensitive to their needs also contributed to a more positive encounter. Another parent noted that her daughter had "…success [with] Sunday school teachers who did have experience or sensitivity to teach special needs children and teens." Similarly, teachers who encouraged their child and were happy to work with them also provided a positive experience. One mother reported that her son, "looks forward to going and the teachers were enthused about him despite needing a high degree of attention." Another parent stated, "He is in a class of two, and the teacher encourages him." Families view these "qualities" of staff and volunteers as important factors contributing to their overall satisfaction with their child's participation in a religious community.

At least four families participated in religious communities with special-needs ministries expecting that this knowledge and understanding was necessary for their child's meaningful participation. Although these ministries did not always include those without disabilities, parents reported that they provided their child with positive opportunities for involvement. Moreover, parents of children with disabilities often sought out spiritual settings with special-needs ministries. For example, one mother offered these thoughts about their spiritual community's special needs ministry:

> My child is encouraged to participate to the maximum of her abilities. We have [a] ministry dedicated to special needs, which is why we started attending and eventually joined this congregation. The staff understands that everyone had

different needs and tries to accommodate those as best they can. We recently

built a new building that is completely accessible and is used by outside agencies

who serve the disabled community for meetings and seminars.

Interestingly, this congregation not only provided accommodations for its members but also to nonmembers with disabilities within the local community. Religious communities often provided different types and levels of ministries, ranging from separate religious-education classes to full ministries that strive to meet all of the needs of the child and family. For example, one parent described a community that created a class for children with learning difficulties: "[These are] kids who were unable to benefit from the regular Sunday school classroom." This parent provided a detailed account of all of the benefits of a comprehensive special-needs ministry and the lengths parents undertake to participate in such an organization.

I have only recently found a completely positive religious education opportunity

for my child. It is necessary that I drive to worship one hour from my home.

However, [my church] is the only church I have found, and I've spent some effort

looking, that has a staffed ministry [for] the special-needs community from birth

through adult. They are planning to break ground for a respite care facility for

children through 16 years old. There are several hundred participants every

Saturday and Sunday. There are ministry and social activities (drama and choir,

etc) support services, trips and outings. The only reason we do not attend more

than Sundays on a regular basis is the awful traffic conditions to attend weekday

evening activities. However, several times a year I take off earlier or we just

spend the weekend in a…hotel so we can participate in an activity or event.

There are families that come from as far away as West Virginia so a family member can participate. I know of at least three families from [our area]…that attend because of the ministry. However, [the church] is for the whole family---there is a productive, Christ-centered, enjoyable ministry there for everyone from Saturday evening through Sunday evening.

This holistic approach is representative of what many parents of children with disabilities consider when seeking a religious community, including social opportunities for their child, staff with knowledge and understanding of disability and appropriate accommodations for their child. Many families do what is necessary to find a ministry that meets all of their members' needs.

Accommodations. Parents felt it was important to have accommodations available to their child and designed in such a way to encourage participation and inclusion: "He is included with typical peers and has a support person to help make that activity appropriate for him," according to one parent. Accommodations were defined here to include physical or educational support, specific to the child's and family's needs, which facilitate participation. Accommodations included extra time for a child to participate, making room for equipment for the child, and providing appropriate individuals to assist the child with sign language or one-to-one support. For example, a mother of a child with deaf blindness and a physical disability observed "… They provide sign language interpreters. They make room for his wheelchair and any other equipment we might bring." Another parent described her child's baptism: "…She was accommodated with extra help backstage and we were allowed extra time to navigate the baptismal pool. She was well received by the congregation and treated well." These small physical

accommodations meant a lot to the parents and made a big difference in terms of the

child's ability to more fully participate. Another parent described similar

accommodations made for her child during Sunday school:

> My church has a special needs Sunday school class. My son learns about the
>
> Bible and Jesus, while I am in [the] church service. I am a single parent and this
>
> allows me to get a break and knowing my son is in a safe environment. My son's
>
> Sunday school class teachers use Picture Communication Symbols during their
>
> classroom time. My son is excited to be around peers with similar disabilities.

Not only did the child have a successful experience, but also the parent was able to

participate and enjoy worship herself, feeling assured that her son was happy and safe.

When spiritual communities provide appropriate accommodations, children and families

can have a positive experience.

   Although not necessarily a deterrent to their child's participation, parents often

had to provide accommodations themselves. For example, one mother said, "I have to

attend with him and act as his aide…" A mother whose daughter had a physical

disability noted, "For the most part she is included in most aspects. Special

accommodations are sometimes forgotten if I am not involved with the planning of the

activity…" Another mother indicated her child's participation was contingent on her

attendance: "Occasionally he can attend some singing or story telling if I am there as

well." Not all of these situations reduced participation or prompted parents to report

experiences as negative; however, these experiences provide examples of the difficulties

families encounter in getting spiritual communities to help their child participate more

fully.

Lack of training and accommodations. In contrast, many participants reported a lack of staff/volunteer training that prevented their child from participating. Often accommodations were not provided because of a staff's lack of education, training, or willingness. For example, a parent of a child with a learning disability said, "No accommodations are provided for his learning disability and he can't keep up with a regular class without assistance." Most often families reported that a lack of one- to-one support was the reason their child could not participate. One mother stated, "We have a problem including him as there isn't anyone to assist him. He is currently the only child with autism and the teacher stated she doesn't know how to help him." In addition to not having the necessary staff to assist the child, participants stated staff did not know how or did not want to provide the appropriate accommodations to ensure their child's successful participation. One parent reported that a leader working with her child was unable and unwilling to offer support, "… the leader does not know how to handle him and the child can sense that the leader does not like him." These experiences indicate spiritual communities are often not providing accommodations and/or appropriate staff training that allows successful, enjoyable, and meaningful participation of children with disabilities.

Child's ability to participate. At times, participation in worship and activities by both parent(s) and child were specifically influenced by factors associated with their child – the disability or willingness. Characteristics related to the child's disability, such as sensory problems, physical impairments or behavior, were mentioned as obstacles to participation. Families often stated their child's sensory problems (e.g. intolerance for loud noises) interfered with activities. For example, one parent commented that her

child's participation depended upon the, "noise level, length of program and participation level." Similarly, another parent said that their child did not participate in formal ceremonies because "My son has a difficult time dealing with large crowds and loud noises for an extended time period. He can only deal with this situation for a short period of time and one-on-one support." A mother responded that her son's speech impairment kept him from praying or reading aloud and prevented him from participating in any formal religious ceremonies: "[His] speech impairment prevents him from being independent in these areas. He wants to pray or read [but his] inability to read due to [his] disability prevents him from doing so."

Several families reported the effects their child's participation had on their family's involvement. For example, a mother described the impact of her adult child's behavior on the family: "I spend most of the time trying to keep her quiet (even though she is non-verbal) and entertained. She is bored by most of the service. She likes to go…I find it difficult." At least four families did not have the time or energy to participate in many activities within their religious community because of constraints related to their child. For example, a family stated, "[This is] not a priority in a very busy life. There is a lot that we have on our plates with regard to appointments, etc., and we don't have the time to fit it in." These accounts suggest that certain characteristics associated with the child's disability impact both the child and family's involvement.

Often participants mentioned their child did not take part in activities for other, related reasons, such as lack of interest, wanting to do other things, or age. Several participants mentioned their child did not enjoy the service because they were bored or not interested, "He likes parts of the service and being with his father, but he often gets

bored and wants to leave or read a book." Another parent attributed her son's lack of enjoyment to adolescence, "He goes but wishes he did not have to…I think it is an age thing." Further, a participant said his enjoyment depended upon the child's mood, "Sometimes he's eager for the worship service to end so he can do other things, and sometimes he's not in the mood for church. Other times he is very attentive and benefits from all aspects of the services …" These responses are not necessarily linked to the child's disability, but are typical responses that any child might have to worship.

Lack of opportunities. Several participants mentioned that there were not always opportunities available for their child's participation in the spiritual community. Participants frequently reported that their child was too young: "[He is] not old enough for some of these [activities], he will be soon." or "[He] is not in that age group yet." Interestingly, as children grew older, age became a significant factor in availability of programs. A few families mentioned that there were not enough programs for their older children. One participant commented that, as her child got older, activities diminished

> There are not enough activities available in this church for her i.e. dance
> programs, choirs, plays and youth groups. Consequently, as she continued to
> grow there were fewer opportunities for her to participate. She feels welcome but
> there needs to be more done for young adults in this church. This not only applies
> to non-disabled young people but to her ...

The age of the any child, with or without disabilities, can influence the availability of programs

In some cases, an overall lack of programs explained lack of participation. One parent said that their spiritual community offers family activities, but not youth activities:

"[Our] child participates in family activities; [the] synagogue does not have many youth-specific activities." Additionally, a mother reported a gap in the number of children,

> We have very few youth at our church. Four Lutheran churches in our area just combined efforts and are providing youth group activities, but they begin with seventh graders. I helped start this effort and am looking forward to his participation in two years." Another participant reported, "[We] don't know of any programs open to families who have children with disabilities.

These accounts suggest that lack of available programs prevents children from participating.

Interestingly, several families reported that one spouse's religious convictions inhibited their child's participation. For example, a mother said, "The people are much more accepting of my child at the Methodist church. If it weren't for my husband's strong Catholic upbringing, I would change in a heartbeat." Another mother mentioned that her husband's opposition to her faith prohibited her daughter from participating, "[The child's] father is opposed to my religion. [Their] father was raised Catholic but does not currently practice any religion. He opposes any formal affiliation with Jehovah's Witnesses for his children."

Summary. Specific themes emerged which shed light on factors that influenced families' perceptions of as well as actual participation in their religious community. Families believed that participation afforded their child social opportunities that allowed them to interact and grow in a social context; the child obtained a better participatory experience if staff was knowledgeable, experienced and understanding; and appropriate accommodations permitted the child to more actively and successfully participate in

programs. Families also felt unsuccessful participatory experiences eroded their child's

social opportunities and often left their child socially isolated and disconnected from

others in their spiritual community; that staff without training or understanding often

interfered with their child's participation and sense of acceptance; and their child's

disability often interfered with his or her and the family's participatory experience.

Additionally, families believed other factors, not related to their child's disability, limited

participation, such as deficiency of appropriate programs due to the child's age or limited

availability; the child's lack of interest in participating; or the family's religious beliefs.

This qualitative information identified specific characteristics of experiences families

encountered within their spiritual communities. In the following section, families also

describe types of support they received from both spiritual leaders and members of their

spiritual community.

Acceptance and Support for Families

Parents were asked about support they received from spiritual community leaders

and members. Mostly, this support was emotional – such as having a place to talk,

people to listen – or practical – such as small groups accommodating families' schedules.

Families offered a variety of reasons that influenced their perception of this support.

Families felt that the availability of different sources of social support (e.g. community

members, small groups, clergy) and disability-specific support provided them with

general acceptance and contributed to a feeling of connectedness to their religious home.

Additionally, families felt valued when their knowledge of disability was used to inform

spiritual communities. However, families experienced social isolation when they

encountered a lack of community support because of ignorance or intolerance. The

following sections provide detailed results about these themes.

Community acceptance. Families frequently associated positive experiences with

feelings of acceptance and support within their spiritual community. Participants

reported, "Our church welcomes everyone" and "[we are] greeted with enthusiasm and

acceptance." One mother felt that their priest set the tone for the community: "We are

blessed to have a priest that listens and really cares about his church community." This

sense of inclusion provided an overall feeling of welcoming and acceptance. Nurturing

spiritual leaders made one family "…feel very safe, secure and supported ..." This

participant explained those benefits, "The support from members of our church is one of

the things that keeps our family functioning well. Our church family provides

understanding, support, acceptance, and love to each of us." A general sense of

community support and acceptance provides families with a welcoming environment and

a safe haven.

Support from social networks. Participants also felt connected when they had a

network of people to provide emotional and practical support. Families mentioned small

groups as a source of that:

> I have a group of 5 women I meet with every week as a result of a church-wide
>
> book study we did…When the study was over…we kept meeting because we had
>
> all become so close. We continue to meet weekly to support each other, three
>
> years later.

Participants provided examples of ways in which these groups connected and shared. For

example, "We e-mail, phone and chat … We sometimes meet for lunch and are members

of the same small group for Bible study. We share information about seminars and opportunities for education and recreation." Close friends from the church served as a source of emotional support for some families. One parent commented about when clergy were unsupportive: "The friends I established at church have been my family. Where the leadership in my church was lacking the members made up for their ignorance or insensitivity." Moreover, parents described specific ways in which support was beneficial: "We are good friends with many members of our church and they are people I can turn to with thoughts, questions, and troubles…general feedback on life." Participants found that creating networks of individuals for general support was helpful and these connections provided opportunities for parents to share general experiences as well as build mutual support.

Participants who received support addressing their child's disability felt valued and accepted at their spiritual community. Often, networks of people provided emotional and practical support to help the family contend with their child's disability. As before, participants identified small groups of supportive people. A mother reported, "We hold a small group from our church in our home once a week. Our wonderful small group agreed to this so both parents would be able to participate since our son had therapy every Sunday night…" Families also addressed how these groups of individuals provided assistance. For example, one mother reported that when others did not accept their child, they received acceptance and encouragement from those in their small group.

> Please understand we still get those looks when our son is stimming down the
>
> church hallway. I know that well-meaning members are looking and thinking
>
> 'thank God for our healthy son'. Fortunately, we have a smaller group that

connects regularly. Our small group family encourages us every week and

celebrates with each new accomplishment our son makes.

Similar to community support, families believe when specific individuals or groups in

their spiritual community accommodate the family's needs and provide encouragement;

they experience a sense of acceptance and support.

In contrast, families often reported that people within their community did not

know how to support their child with a disability and, in some cases, were intolerant. For

example, one participant reported, "They wanted to help me but didn't know how," while

another said, "They try to be nice but are pretty clueless." In both cases, it appeared that

members did want to help, but did not know how. Often, participants commented about a

lack of understanding regarding disability. One father reported, "Most people at our

church are very supportive but sometimes they don't understand the disability as well as

adolescent behavior." Other participants also reported that some individuals were simply

intolerant of their child's disability and did not understand their child's specific

behaviors, "Many people felt we were a nuisance. Older women especially got up and

moved away from us." A family reported, "At the point where his disability became

apparent, many families avoided us, especially those with "normal" children. It was

expected that we wouldn't bring him to community events." Children with autism

seemed especially vulnerable to intolerance: "People in the congregation do not

understand autistic behaviors---and do not feel the need to take steps necessary to make

families with children with special needs feel included." Often it was the lack of

understanding regarding the behavior that caused the lack of acceptance: "…I was

actually told that it might upset some of the other students if my child reacted

"improperly" to sexual purity talks and was therefore told she would not be welcome at the retreat." Participants' negative experiences indicate that the perceived behaviors associated with the child's disability, misunderstanding and intolerance are major contributors to lack of acceptance within their religious communities.

Insufficient support and acceptance prompted several families to switch spiritual communities, often seeking out congregations that could meet the needs of families of children with disabilities. For example, one mother of a child with Down syndrome reported "I switched several times: however, at [our current church] my child's spiritual needs can be met through adulthood." Another family switched churches: "…once I felt that she was not welcomed."

When considering changing spiritual communities, at least three families visited a variety of communities: "Now it is great, but we switched quite a bit before joining our current church." Other families encountered similar obstacles: "We have visited other communities. We have found in the past that [they have] similar issues. We have heard recently of other communities trying for inclusion; however we are now shy of trying …," This participant reported visiting many churches and finding that "…The thing that was missing from the other locations was the pastoral staff not having an understanding of the varying degrees of disabilities." Although participants' search for a new spiritual home was not always successful, it sometimes led them to identify what they need/desire from a religious community.

Sadly, several participants stopped participating in a spiritual community, temporarily or completely, usually because the community did not accept or support their child. A few participants stated they stopped attending for a period of time, but,

eventually, found a new religious home. A mother reported, "Rude stares; snarls from membership; ushers being inconsiderate; just bad vibes. I was so turned off that I stopped attending my former church and stopped worshiping formally for over 2 years…" One participant stated, "I'd love to attend a church if they included my child. My whole family would return to church." Similarly, a participant reported, "…My views are as follows: if my daughter doesn't belong, then we all (my family) don't belong. Because of this belief, we unfortunately have not been to church since my children have been very small." Only one participant reported they don't attend any longer because they are "not particularly religious as a family…however, at difficult times, we might feel the need for support and regret that it isn't available." Most often, participants report that either they left their spiritual community for long periods of time or completely because they did not receive the support, they needed for their family or child.

Families felt that often this lack of acceptance was part of a bigger issue: non-acceptance for all with disabilities.

There is a large-scale ignorance concerning disabilities, particularly mental disabilities and emotional problems in young children. Views expressed concerning disabled/mentally-retarded children were negative; some religious scholars have suggested abortion is not disapproved of if the child is known to have a disability. Children with disabilities are seen as "trials" from God or burdens rather than equal participants in the community, therefore marginalized or isolated.

This comment suggests that, in some cases, there is an overarching lack of acceptance for those with disabilities, which sometimes contributed to intolerance. Another parent provided her observation:

> I have never seen a child with a disability participate in any activities, kid's choirs, and plays. In a church of ten thousand, I felt like we were the only ones there. You never saw people with disabilities. I'm thinking that most don't worship regularly at a church and you are not welcomed.

Clearly, families feel that lack of acceptance for their child specifically and a general intolerance toward those with disabilities contributes to the limited support they receive in their spiritual communities.

Clergy support. Families reported receiving assistance from clergy in their spiritual community. Clergy frequently served as a listening post for their concerns. One participant stated, "Our bishop has been supportive. We could turn to him whenever we need to, but he has only pulled us aside once to talk with us. But we can talk to him whenever we need to." Similarly, another parent stated, "[it is] very helpful to have someone to talk to during a difficult time." Other types of help were also provided by their spiritual leaders. For example, a family member stated, "[our] Rabbi was supportive in planning [the] bat mitzvah and after our daughter had surgery…" Another mother provided positive examples practical support from her leader: "[He] links us with other members that can relate to our situation. Provides other resources [such as] support groups, classes, mentors etc." Knowing that support is available from clergy is helpful to families, making them feel connected to those leaders.

Support for the child. Families perceived emotional and practical support for their child from their spiritual community as an indication that their child was accepted. A Jewish mother of a child with multiple disabilities stated, "Congregants are routinely asking about our daughter and asking if there is anything they can do to help us." Another parent reported, "There are people who will have my son sit with them when he wanders around in our pew." Similarly, a mother reported, "People in our ward have been very supportive! They have volunteered to take turns walking her around during Sunday school and they have come to love her. She loves having all her friends and greets them with a smile every time she sees any of them!" These comments suggest that providing support directly to the child, as well as to the family, makes the family and child feel accepted. Further, the other congregants learn about disability and come to better understand the needs of the family.

Parents as contributors. Participants felt valued when their parental input was used to enhance the spiritual community's knowledge about disabilities. For example, a mother reported,

> I have been asked to prepare and present a presentation to the church about my struggle as a parent of a child with special needs. We have a ministry for special needs, and I am in contact with that leader in a small group regularly. Our pastors are open to communication and receptive to suggestions for improvement.

Another parent discussed her experience helping her spiritual community, "Initially, they really didn't understand, but the more input I had, the more individuals who did have experience working with differently abled people came forward to help my daughter…It took time, but have thus far been successful." Over time, parents' input

encouraged others to come forward to support her daughter and, possibly, others with disabilities in the community. Corroborating this sentiment, another participant stated that the leaders of the spiritual community were "willing to learn about my child's disability and support my efforts to help him in every way." When a spiritual community is open to parental input and education, it creates an environment that provides support for the family, makes the family feel valued and increases acceptance of the child with disabilities.

Summary. Successful support for families made them feel connected, valued and accepted: "It is delightful to be associated with such a caring group of people. If I need help, they give it. It is the moral support and the ability to talk things through with someone else that I need the most. I view the other members of the congregation as family and I believe that they view me and my child the same way." On the other hand, families felt that ignorance and intolerance contributed to non-acceptance of their child and that ultimately led to families experiencing a lack of support and social isolation within their spiritual community.

Summary of Qualitative Findings

Families provided evidence for a deeper understanding of factors that influenced perceptions of participation and support in spiritual communities. Families reported that the participation experiences of their child in spiritual community activities were influenced by the amount of social opportunities and quality of social interactions with children and adults in the religious community; the level of knowledge, training and understanding of staff and volunteers working with their children; the scope and appropriateness of accommodations for their child; and the degree to which the child's

disability and willingness impacted participation outside of the child's disability.

Additionally, parents reported that their experiences were influenced by the availability

of emotional and practical support specific to the needs of their family; the existence of

social support networks within the community; the level of acceptance and knowledge of

community members and clergy regarding disability; and the community's value of and

openness to parental knowledge of disability. In some instances, low levels of

availability led families to switch spiritual communities as a way to acquire needed

support or leave altogether.

CHAPTER V

Discussion

The research questions were addressed and the hypothesis was tested by administering the Spiritual Community Experiences Inventory to a sample of 58 families. Overall, families rated their spiritual community experiences positively. They rated all activities as important, with participation of their child in religious education and youth activities slightly more important, while rating spiritual leader and member support as comparably important. Parents also provided descriptions of a variety of other factors that influenced their perceived level of satisfaction with their experiences. As predicted, results indicate that a relationship does exist between satisfaction with experiences and the level of participation. This chapter discusses the results in the context of existing literature and theoretical models, and presents the study limitations, directions for future research, and implications for practice.

The theoretical and empirical literature on coping and adaptation for families of children with disabilities has frequently acknowledged the importance of social support (Bennett & Deluca, 1996; Dunst et al., 1988; Fallon & Russo, 2003; & White & Hastings, 2004), and often states that religion can play an important role, although these relationships have not been frequently studied (Tarakeshwar & Pargament, 2001; Rogers-Dulan & Blacher, 1995; Selway & Ashman, 1998). When religious activities have been studied, families report positive experiences. However, religion may play a more significant role. This study focused on the amount of participation in religious activities, member and clergy support and factors that influenced family satisfaction.

As stated earlier, parents in this study viewed their child's participation and the support they received from their spiritual community positively. Families had the most positive experiences when their child participated in religious education and formal ceremonies and when families received support from both clergy and members of their spiritual community. These findings are consistent with those of Erin et al. (1991) and Haworth et al. (1996), who found that participants provided primarily positive comments about their religious communities. The current study elaborated on these positive experiences noting they were most successful when meaningfully tailored to the individual child.

Additionally, families reported that receiving support from religious leaders was most important for their overall family participation. This result is consistent with Rogers-Dulan (1998) who found that support from clergy appeared important to families. Specifically, in this study, families appreciated their counseling and empathy, yet descriptive data suggest they were more satisfied with and received support more often from members. Qualitative data revealed that such activities as small group bible studies were most rewarding and supportive.

As predicted, the correlation analysis found that positively rated experiences were significantly and positively associated with higher rates of participation, as were negatively rated experiences with lower rates of participation. These findings are similar to the literature concerning the relationships between frequency of church attendance and level of religiosity and church involvement and between participation and socialization (Haworth et al., 1996; Rogers-Dulan, 1998; Tarakeshwar & Pargament, 2001; Weisner et al., 1991). Only one relationship was not significant in the current study: the rating of

experiences with formal religious ceremonies and rate of participation in those activities. As stated earlier, this inconsistency may be explained by the fact that formal ceremonies in general occur less often than other activities in the study, which removes the variability in the frequency and consequently blocks any association between frequency of attendance and satisfaction. The literature (Coulthard & Fitzgerald, 1999; Skinner et al., 2001) does mention that children often participated in formal ceremonies; however nothing was stated about the family's satisfaction with or importance they placed in their child's participation in these ceremonies.

Further qualitative analysis of open-ended questions revealed both positive and negative factors that influenced parental satisfaction with their child's participation in activities and with the support they received from their spiritual community. Most often, parents attributed positive experiences to the provision of necessary accommodations. When accommodations were made, like preparing staff and group members about the needs of children with disabilities, their child's social success was achieved which then influenced their child's willingness to participate in activities. Families used terms such as "opportunities," "part of the group," "enjoys" and "looks forward to" as measures of social success. Results were similar to Beckman et al. (1998) and Skinner et al. (2001) where children who experienced more opportunities for social participation developed deeper connections with other children. Moreover, children who were provided appropriate accommodations were able to more fully participate in spiritual community activities.

The current study also expands the religious support literature (Coulthard & Fitzgerald, 1999; Haworth et al., 1996; Poston & Turnbull, 2004; Tarakeshwar &

Pargament, 2001) by identifying additional activities and characteristics of activities that contribute to positive experiences. Parents believed that worship services, and to a lesser extent formal ceremonies, created many opportunities for their child to spend time with their friends and members of the community. Additionally, children participating in worship services and formal ceremonies, such as serving as an acolyte, often led to opportunities for growth and accomplishment. Finally, parents added that knowledgeable and understanding staff, especially when assisting children who participated in a special needs ministry, helped to solidify their child's participation.

The findings from this study suggest that positive participation has benefits for children with disabilities, which extend beyond what has been reported previously in the literature. These safer social opportunities teach appropriate social skills that have general application in school and other less protective environments. Families view their positive participation as a consequence of spiritual communities addressing a variety of the needs of their child and offering different opportunities for the child to actively and successfully participate.

Families also identified negative experiences their child had when participating in spiritual community activities. Most frequently mentioned by parents were characteristics of their child's disability that detracted from their child's experience. Families mentioned that socially inappropriate behaviors diminished their child's participation, which sometimes led to social isolation of their child and family, lack of acceptance by peers and the community, and reduced participation for the family. For example, families reported that during worship children often could not tolerate "large crowds or loud noises" or "keep quiet." Families feeling rejected by negative member

responses, when other resources were not available, either left the services or elected not to attend. These findings indirectly support Hill's ABCX model, which explains that a stressor event (A), coupled with availability of resources (B) and family perceptions (C), influences consequent actions (X). Furthermore, these findings corroborate results of the family stress and coping literature in that families often experienced more stress when their child with a disability had increased behavior problems (Beckman, 1983; Margalit et al., 1992; Podolski & Nigg, 2001; Troster, 2001). More specifically, these findings are in agreement with Tarakeshwar and Pargament's (2001) study that showed families did not participate because their children could not remain quiet.

Additionally, families indicated that untrained staff who did not provide accommodations for their child, because they did not "know how to help the child," reduced or often prohibited a child's participation and created barriers between staff and children. These findings are similar to those of Skinner et al. (2001) who found that children's general church attendance was also affected by untrained staff.

Families in the current study frequently did not participate because "we have [a lot] on our plates with regards to appointments…and we don't have time to fit it in," or "we simply don't have the energy or the belief that we would have any support." Skinner et al. (2001) also found, in the case of spiritual communities, that families often did not participate because of the time constraints inherent in caring for their child's disability. The family stress and coping literature suggest that families who have a child with multiple disabilities and view their situation negatively experience increased stress levels (Saloviita et al., 2003; Troster, 2001), which may explain why these particular families did not have the ability or willingness to participate in a spiritual community.

Although not described in the literature, it can be inferred from the qualitative results of this study that some children who were not interested in participation or did not have access to programs had lower rates of participation. While not specific to children with a disability, these distractions and access issues nonetheless reduced participation and prompted parents to list these factors as contributing to their child's ability to participate. These examples illustrate that influences from both within the family and the spiritual community affect participation and demonstrate the challenges that families and religious communities face when including children with disabilities in spiritual community activities.

The influences found in this study are consistent with the literature's theoretical models. However, Bronfenbrenner's Bioecological model of human development (1979) which focuses on the interaction between varying environmental systems and the child is most relevant. The data from this study suggest that families believe their children's participation is influenced by factors within their spiritual community, and the program in turn is affected by the quality of that experience. For example, at the microsystem level, families reported that when spiritual communities addressed their child's specific needs and offered many opportunities for their child to successfully interact within the spiritual community, their child's experiences were more positive and their child's participation increased. At the mesosystem level, parents expressed that when the spiritual community provided a welcoming environment and safe haven, their family functioned better. As a result of this family enrichment, their participation in the spiritual community increased. Also at this level, spiritual communities in this study that did not provide adequate support for the child influenced the child's desire to participate in a spiritual community

program, which resulted in negative interactions between the family and the spiritual

community. Finally, at the exosystem level, families' overall religious convictions

influenced their participation. For example, families with one parent bound to their faith

would remain in that congregation despite the lack of opportunities for their child.

It is important to emphasize that the qualitative data about children's

participatory experiences is consistent with the results of the correlation analysis and lend

insight into the nature of the relationship between amount of participation and parents'

satisfaction with their child's experiences. Parents believed that positive experiences

created an environment for their children to be successful, which enhanced their

enjoyment and encouraged more participation. For example, one mother believed her

child's ability to connect with peers in a small group encouraged her son to participate in

a larger group activity. On the other hand, the reverse can be said about negative

experiences. Families believed that staff and volunteer lack of understanding about their

child's disability, especially their behavioral patterns, led to isolation of the child and

discouraged the child and the family from participating. Families identified others

factors that sometimes reduced their child's participation, such as the absence of

programs, age limitations of programs, family time constraints, and within-family

parental disagreements over religious beliefs.

As with participation, families identified factors that were characteristic of

meaningful leadership and member support. Some of the results were supported by the

literature but others were contrary. Similar to other studies (Beckman et al., 1998;

Bennett & Deluca, 1996; Lin, 2000; Podolski & Nigg, 2001), families in this study

reported they felt a sense of acceptance of their family and child when they received

emotional support from both religious leaders and members. These experiences consisted of regular and extensive social interactions within the community that families perceived as positive. In addition, families expressed a sense of support when their child felt connected to their peers.

Consistent with the findings of Dollahite et al. (1998), families in this study received a variety of types of support from their clergy. However, the types of support from clergy in the current study were different from the prayer and guidance found by Dollahite et al. (1998). In this study, participants reported that they had a vehicle to address their concerns, a source of general help, and a link to available resources.

Parents also emphasized the benefits of having different social networks in their spiritual community. This support is also similar to findings by Rogers-Dulan (1998) and Poston and Turnbull (2004). In these studies, families reported that spiritual communities provided opportunities to obtain unconditional acceptance by others of faith through participation in activities and meetings. In the current study, parents also provided information about specific sources of support such as bible study groups, women's groups, and other small groups that family members joined for encouragement, a place to share information, ask questions and receive advice.

Similar to findings of Dollahite et al. (1998), families in the current study received help and encouragement that were tailored to their needs when dealing with a child with a disability. Families believed that when advice and assistance were adapted to their unique needs, they felt positive towards the religious community, while the community members developed a better understanding of disability. In the current investigation, families emphasized the importance of instances in which members of the

community directly asked about or interacted with their child. From the family's point of view, such gestures increased their and the child's comfort levels and reflected the willingness of community members to accept the child. Families further described their connection to the community when they were regarded as the "expert" and were asked to contribute their knowledge of disabilities to enhance the community's understanding and support for those with disabilities. Conversely, parents reported instances in which negative experiences reduced participation. Parents said that "people [with disabilities] don't regularly attend' or "would not be welcomed" or "...expected that we would not bring him…" when reflecting on a lack of support from clergy and members. This information demonstrates that satisfaction with support and participation levels are interrelated.

Findings suggest that support, like participation, needs to be available from both clergy and members and directed at both the general and specific needs of the families. Families felt that specific support from both the community and spiritual leaders were most valuable. These results should be communicated to spiritual leaders to foster spiritual community relationships with families of children with a disability.

In contrast, families described occasions in which they did not receive support and attributed this absence to a lack of understanding about disabilities. In some cases, clergy and/or members of the religious community did not understand their child's behaviors and did not know what to do; in others, members demonstrated intolerance of the behavior by their impersonal and rejecting actions. These findings are consistent with previous research findings by Haworth et al. (1996), where families affirmed a lack of acceptance by members and leaders of their spiritual communities. These results are also

similar to findings by Coulthard and Fitzgerald (1999) in that spiritual communities and clergy were often not helpful, perhaps because the child had autism, and the behaviors of the child caused others to withdraw from the family.

Some families also believed that a general discrimination against those with disabilities was an underlying cause for intolerance. For example, one parent stated, "… In a church of ten thousand, I felt like we were the only ones there. You never saw people with disabilities. I'm thinking that most don't worship regularly at a church and you are not welcomed." Similar to findings of Beckman et al. (1998) and the NOD (2004), families often reported that negative perceptions of those with disabilities were a barrier to inclusion and that individuals with disabilities attend spiritual communities less often, not because spirituality is not important to them, but because of the lack of acceptance by the community. In the current study, families indicated that lack of acceptance prompted them to consider leaving their spiritual community and, in some cases, stop participating completely.

Families suggested that attitudinal barriers that create a lack of acceptance of their child, usually stemming from a lack of understanding or intolerance of individuals with disabilities, are often the hardest to overcome. They stated further that they are often not in the position to educate communities. Sharing the results of the current investigation with spiritual community leaders may foster a dialogue between groups.

It is important to emphasize that despite the reporting of highly positive experiences and support, participants in this study had relatively high percentages of negative experiences. In fact, a large percentage had exclusionary experiences. These

negative experiences did reduce participation, but not enough to routinely result in families leaving their spiritual communities.

The Family Systems Model applied to families of children with disabilities (Turnbull et al., 2005) focuses on family functioning and the unique way families meet their needs for affection, self-esteem, spirituality, economics, recreation, socialization, and education. The data from the current study suggest that family's attempt to meet their own spiritual needs in a pattern that is consistent with this model. Families provided examples of different supports that met the unique needs of that family such as providing a place for families to address concerns and ask questions that helped families function. Each family used different types of support in different ways to help them adapt and remain cohesive.

Limitations

A number of important study limitations need to be considered when interpreting results. First, several characteristics of this study sample hampered generalizability. The project relied on volunteers from local disability organizations who self-selected to participate. Hence, the perspective of families who consider themselves religious yet do not attend spiritual community activities is not adequately represented as well as those families who do not consider themselves religious. Also, some agencies did not track all participation requests so a non-response rate could not be calculated.

Additionally, the main study sample size was uncomfortably small because of the difficulty in obtaining participants within a reasonable period. This small sample size necessitated incorporating participants from the pilot study. Also, inferences from the sample were constrained by the homogenous nature of the participants. Respondents

were primarily the mothers of children with disabilities, thus diminishing the perspective of fathers or other caregivers. The income level of the participants was considerably above average at over $100,000, implying that these findings may not pertain to families in other income brackets. Also, the majority of families were Christian, sharing similar religious beliefs and perspectives, which underrepresented the viewpoints of families from other faiths. Finally, the severity of the disability and the associated behaviors were not identified. This knowledge might have further clarified the relationships between level of participation and support and level of satisfaction. Therefore, the findings of this study are not necessarily generalizable to families that do not reflect the characteristics of these participants.

Second, attributes of the study methodology and design, including its exploratory nature, may have restricted the author's ability to draw conclusions. With the absence of similar studies, it was difficult to develop the instrument, design the analysis, and predict the outcomes of the research questions and hypothesis. Since the study information was collected as part of an online survey, it was not possible to establish follow-up questions to confirm the accuracy of data and expand upon parental responses. The questionnaire was administered without definitions, leaving participants to interpret what is meant by several concepts including formal ceremonies, youth activities, and support. In addition, the inclusion of both activities and support in the same instrument might have blurred the distinction between them and limited the depth and breadth of qualitative responses. Moreover, a future instrument should assure that response categories conform across all questions to limit respondent confusion and simplify analyses. Finally, incorporating pilot with main study participants does not conform to sampling convention and may bias

inferences made from the results. It was decided, given the comparability of pilot and

main study participants on a number of characteristics that increased power would offset

the liability of combining both groups.

Future Research

Despite these limitations, the study results may provide some new directions for

future exploration on this topic. To overcome the homogeneity of the characteristics of

participants and small sample size, future studies need to increase the number of

participants by obtaining a broader array to include a variety of caregivers, religions, and

income brackets. It might be necessary to physically administer the survey to meet this

objective. To address self-selection, future research should include questions that ask

parents why they chose to participate and target families who are religious but are not

currently participating. Also, agencies should be required to count non-responses to

requests for participation so a non-response rate can be calculated to determine the

generalizability of the results. To confirm parental response accuracy, future research

should include follow up interviews via online or paper surveys to clarify participant

responses. Finally, to clarify instrument ambiguities, a revised instrument should include

specific definitions of activities and support and should independently inquire about each.

By separating the instrument into activities and support, participants will likely provide

greater qualitative detail.

Further research might explore other areas. It is important to refine and test the

survey instrument to further establish its reliability and validity. The results here were

satisfactory but could be improved with larger sample size and a separation of activities

from support. In addition, future studies might follow up on some of the issues raised by

families in this study. For example, further identification of factors that families believe are important to successful participation in spiritual communities is warranted to help spiritual communities better understand the need for programs and direct the development of effective training programs. Future studies need to evaluate educational training programs currently available to religious organizations to support families of children with disabilities to identify their strengths and weaknesses and provide guidance for successful implementation.

Conclusion

The findings of this study suggest several courses of action for spiritual communities. Spiritual organizations of all religions and cultures need to be proactive and obtain the necessary knowledge to appropriately welcome and include children and adults with disabilities and their families within their community. First, spiritual organizations should identify the needs of children and adults with disabilities and their families and provide effective and meaningful participation and support that meet those needs. Second, spiritual communities need to identify experts within their community, such as parents of children with disabilities, individuals with disabilities, and other professionals who have worked with individuals with disabilities, to help develop programs that effectively support the needs of these families and individuals. Third, spiritual communities need to establish networks within and between local religious communities and disability agencies to share resources and learn about programs and training available to spiritual communities and families.

Organizations that work with families of children with disabilities need to take a holistic approach in supporting these families and recognize that many need support of

their spiritual communities to better cope with the stresses of raising a child with a disability. Regardless of whether providers or organizations are religious in nature, it is important to recognize the role that religion plays in many families. Therefore, support agencies, academic programs and other disability-related organizations need to partner with religious organizations to develop training programs that combine their unique sets of knowledge to educate religious organizations. These partnerships, which have the potential to integrate knowledge, can produce best practices training modules for participants to use when working with families and children with disabilities.

It is clear from this and prior studies that spiritual communities can help families deal with their child's disability as well as help the child feel included. Therefore, it is vital to disseminate this information to spiritual communities. Improving religious supports available to families can decrease the stress experienced in the family and will improve their quality of life.

Appendices

Appendix A

Spiritual Community Experience Scale

Section 1: The following questions are about your child with a disability. Please respond to these questions by selecting the most appropriate answer:

1. **Child's Age_____**

2. **Child's Gender_____**

3. **What type of disability does your child have?**

(Mark all that apply)

□ Autism

□ Deaf blindness

□ Emotional disturbance

□ Hearing impairment

□ Learning disability

□ Mental retardation

□ Orthopedic impairment

□ Speech or language impairment

□ Traumatic brain injury

□ Visual impairment (including blindness)

□ Other health/medical disability

Please describe_____

□ Other_____

Section 2: The following questions are about your family's spiritual community participation. Please respond to these questions by selecting the most appropriate answer:

4. **Which best describes your spiritual community membership?**

___Buddhist

___Catholic

___Hindu

___Jewish

___Muslim

___Protestant (e.g., Methodist, Baptist, Orthodox Christian)

___Other. Please define _____

___None

5. **Do you have a regular place of worship?**

___Yes

___No

(If no, skip to question 6; If yes skip to question 8)

6. **Have you attended or been a member of a spiritual community in the past?**

___Yes

___No

(If yes, skip to question 7; If no, skip to thank you page)

7. **Are you interested in completing the survey in regards to your previous spiritual community experiences?**

   ___Yes

   ___No

(If yes, skip to question 8; if no skip to thank you page)

8. **How often do you attend religious services at your place of worship?**

   ___Never

   ___Once a year

   ___About once a month

   ___Every week

   ___Several times a week

Section 3: The following questions are about participation experiences of your child with a disability you reported on in Questions 1, 2, and 3. Please respond to these questions by selecting the most appropriate answer:

9. **Does your child have the opportunity to participate in religious education activities such as Sunday School, Catechism Class, or Hebrew School within your spiritual community?**

    ___Yes

    ___No

    If _no_, why has your child not had the opportunity to participate?

10. **How important is it to have your child participate in religious education activities at your spiritual community?**

    ___Not important

    ___Important

    ___Extremely Important

    (If no to question 9, Skip to question 13)

11. How often does your child participate in religious education activities within your spiritual community?

___ Never

___Once a year

___About once a month

___Every week

___Several times a week

12. How would you rate your child's experience while participating in religious education activities at your spiritual community?

____Positive

____Somewhat positive

____Neutral

____Somewhat negative

____Negative

Why did you rate this experience this way?

13. Does your child have the opportunity to participate in religious youth activities such as a music or dance program, youth groups, plays or mission trips within your spiritual community?

___Yes

___No

If _no_, why has your child not had the opportunity to participate?

14. How important is it to have your child participate in religious youth activities at your spiritual community?

___Not important

___Important

___Extremely Important

(If no to question 13, skip to question 17)

15. How often does your child participate in religious youth activities at your spiritual community?

___ Never

___Once a year

___About once a month

___Every week

___Several times a week

16. How would you rate your child's experience while participating in religious youth activities at your spiritual community?

_____Positive

_____Somewhat positive

_____Neutral

_____Somewhat negative

_____Negative

Why did you rate this experience this way?

17. Does your child have the opportunity to participate in formal spiritual/religious ceremonies such as a Bar Mitzvah or Bat Mitzvah, First Communion, Confirmation, or a Seder within your spiritual community?

___Yes

___No

If _no_, why has your child not had the opportunity to participate?

18. How important is it to have your child participate in formal

spiritual/religious ceremonies or rituals at your spiritual community?

___Not important

___Important

___Extremely Important

(If no to question 17, skip to question 21)

19. How often does your child participate in formal spiritual/religious

ceremonies within your spiritual community?

___ Never

___Once

___Once a year

___About once a month

___Every week

___Several times a week

20. How would you rate your child's experience while participating in formal spiritual/religious ceremonies or rituals at your spiritual community?

____Positive

____Somewhat positive

____Neutral

____Somewhat negative

____Negative

Why did you rate this experience this way?

21. Does your child have the opportunity to participate in a regular worship service with your family within your spiritual community?

___Yes

___No

If _no_, why has your child not had the opportunity to participate?

22. How important is it to have your child attend a regular worship service at your spiritual community?

___Not important

___Important

___Extremely Important

(**If no to question 21, skip to question 25**)

23. How often does your child attend a regular worship service with your family at your spiritual community?

___Never

___Once a year

___About once a month

___Every week

___Several times a week

24. How would you rate your child's experience when attending a regular worship service with your family at your spiritual community

____Positive

____Somewhat positive

____Neutral

____Somewhat negative

____Negative

Why did you rate this experience this way?

Section 4: The following questions are about your family's participation in regards to your child with a disability you reported on in Questions 1, 2, and 6. Please respond to these questions by selecting the most appropriate answer:

25. How often have you received support from a religious leader within your spiritual community?

___ Never

___Once a year

___About once a month

___Every week

___Several times a week

26. How important is it to have a religious leader to turn to for support within your spiritual community?

___Not important

___Important

___Extremely Important

(If answered never in question 25, skip to question 28)

27. How would you rate the support you received from a religious leader within your spiritual community?

____Positive

____Somewhat positive

____Neutral

____Somewhat negative

____Negative

Why did you rate this support this way?

28. How often have you received support from one or more members of your spiritual community such as paid or non-paid staff or general members?

___ Never

___Once a year

___About once a month

___Every week

___Several times a week

29. How important is it to have support from one or more members of your

    spiritual community?

___Not important

___Important

___Extremely Important

(If answered never in question 28, skip to question 31)

30. How would you rate the support you have received from one or more

    members of your spiritual community?

_____Positive

_____Somewhat positive

_____Neutral

_____Somewhat negative

_____Negative

Why did you rate this support this way?

31. Have you had any negative experiences regarding your child with a disability

    within your spiritual community?

____Yes

____No

(If no, skip to question 32)

If yes, what are these negative experiences?

32. **Have you experienced exclusion regarding your child with a disability within your spiritual community?**

____Yes

____No

(If no, skip to question 33)

If yes, how have you experienced exclusion?

33. Have you ever considered switching your spiritual community because of supports or issues regarding your child with a disability?

____Yes

____No

(If no, skip to question 34)

If yes, please explain?

Section 4: The following questions are <u>basic demographic information regarding your family.</u> Please respond to these questions by selecting the most appropriate answer:

34. Relationship to child with disability

___Mother

___Father

___Other: _____

35. Your Age_____

36. Combined Household Yearly Income:

(Check one box)

□ Less than $15,000

□ Between $15,001 and 30,000

□ Between $30,001 and $45,000

□ Between $45,001 and $60,000

□ Between $60,001and $75,000

□ Between $75,001 and $100,000

□ More than $100,000

Thank You!!

Appendix B

Religious and Family Support Themes

Positive Experiences	Negative Experiences
1) Family	*1) Family*
a) Participation	a) Participation
i) Activities	i) Activities
• Social	• Social
• Service attendance	• Service attendance
• Meetings	• Meetings
• Other	• Other
b) Acceptance	b) Acceptance
• Of entire family	• Lack of acceptance
	• Abandonment by spiritual organization.
c) Support	c) Support
• Resources	• Lack of resources
• Social	• Lack of social support
• Spiritual community leaders	• Spiritual community leaders
• Spiritual community members	• Spiritual community members
2) Children	*2) Children*
a) Participation	a) Participation
• Religious education	• Accessibility limitations
• Service Participation	• Not able to participate in services
b) Support	b) Support
• Receive full support	• Lack of support in religious education
• Financial	• Untrained personnel
c) Acceptance	c) Acceptance
• Other kids	• Child not accepted
	• Negative attitudes towards child

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