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MOTHERS OF ADULT CHILDREN WHO HAVE DOWN SYNDROME: UNDERSTANDING THE MEANING OF RELIGION AND SPIRITUALITY IN PERCEPTION, HOPE, AND COPING

by

Stephanie G. Gotay

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I dedicate this dissertation to my loving father, Jim Carr,

who encouraged me to do my best in whatever I endeavored to accomplish

and who always believed that I could.

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Abstract

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Since the 1970s, the number of individuals living with Down syndrome has continued to increase. Many of these individuals live with their families, and mothers are the primary caretakers for most of these children. As the life expectancy of individuals who have Down syndrome continues to rise, theses caregiving roles are expected to last longer. Unfortunately, the supports offered to families, and specifically mothers, have been inconsistent and often inadequate. Spirituality and religion offer some mothers additional supports and can enhance their resilience and endurance.

This qualitative study employed a phenomenological approach to explore the experience of spirituality and religion in the parenting process of six mothers of adult children who have Down syndrome. The six participants resided in the Mid-South region of the United States and reported that spirituality or religion was important in their lives. Four sub-questions guided this exploration to understand how spirituality and religion influenced these mothers': (1) perceptions of meaning or purpose in their child's diagnosis; (2) positive or negative perceptions of Down syndrome within the context of the church; (3) coping resources and strategies; and (4) perceptions of hope for the child's future.

The data collected from a series of three face-to-face interviews with the six participants was processed using Colaizzi's method of data analysis. The findings indicated spirituality and religion were supportive coping resources for the mothers in this study, but they were also sources of stress, particularly religion. Mothers found comfort in the belief that their child had purpose, and several mothers believed they were divinely chosen to be the mother of their child. Although biblical scriptures and stories offered reassurances, the supports received from parishioners and religious leaders were inconsistent and sometimes rejecting. Mothers frequently described the institution of the church as insensitive to the needs of individuals who had Down syndrome. When considering the future, mothers’ reliance on spiritual and religious faith wavered and proactive planning increased. The most frequently reported source of spiritual support among these mothers was their relationship with God.

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Chapter 1

Introduction and Background

In 2013, over 3.93 million babies were born to families in the United States (Martin, Hamilton, Osterman, Curtin, & Mathews, 2015). For many of these families, childbirth is a moment of transformation, creating new purpose and meaning in life and an interconnectedness with others (Crowther, 2014). It is a joyous time that has been described by some as a spiritual experience (Schwartz, 2014). It is a time of renewed hope for the future and a recollection of historical links to ancestral heritage (Crowther, 2014). For religious parents, the birth of a baby has been described as a miracle and a reminder of the wonder of life (Schwartz, 2014). Unfortunately, the negative narratives surrounding disability often rob some parents of this joyous experience as stereotypes and misinformation predict hardship and heartache (Goddard, Lehr, & Lapadat, 2000). Following this socially constructed forecast of despair, it is no surprise the birth of a child with a disability creates distress for some families as they grieve the loss of their dreams for a healthy baby (Green, 2003; Lawrence, 2008b; Pillay, Girdler, Collins, & Leonard, 2012).

Each year, approximately 6,000 babies who have Down syndrome are born to families in the United States, making this the most common birth defect (Presson et al., 2013) and the primary genetic cause of cognitive impairment in the U.S. (Kover et al., 2012). Prevalence estimates of persons living with Down syndrome in the U.S. have not been well-documented and vary from 250,700 (Presson et al., 2013) to 400,000 (NDSS, n.d.b). Despite these variations, there is agreement that the number of persons living in the U.S. with Down syndrome has continued to increase since the 1970s and is anticipated to continue to grow due to improved medical care, better quality of living conditions, and increased life expectancy (NDSS, n.d.b; Presson et al., 2013). For these families, loss, grief, and adjustment become part of the childbearing and child-rearing experience.

Institutionalized support for families is at its peak in the child's early developmental years due, in part, to early diagnosis, specialized pediatric medical care, early childhood intervention programs, and school-based services (United States GAO, 2010; Poehlmann, Clements, Abbeduto, & Farsad, 2005). These supports diminish as children with Down syndrome move into adulthood (Cuskelly, 2006; Heaman, 1995), but this change is not reflective of the needs of persons with disabilities and their families, which often do not diminish. However, families do experience changing needs over the developmental lifespan of a person who has Down syndrome (Abery, 2006; Bailey & Smith 2000; Heller, Hsieh, & Rowitz, 1997; Seltzer, Abbeduto, Krauss, Greenberg, & Swe, 2004). These changing dynamics can affect the entire family and result in potentially stress-inducing adjustments that must be negotiated (Hodapp, Ricci, Ly, & Fidler, 2003; Knox & Bigby, 2007). Unfortunately, the needs of families are often overlooked, since services are designed to target the identified needs of the person who has Down syndrome (Cuskelly, 2006; Llewellyn, Gething, Kenndig, & Cant, 2004). This individually-focused approach fails to consider the holistic needs of the person and neglects the needs of important family supports, particularly mothers, who are crucial in maintaining the well-being and quality of life of the person who has Down syndrome.

Research Literature

Many studies have been conducted with parents of children who have disabilities (Dabrowska & Pisula, 2010; Hall et al., 2012; Heaman, 1995; Hodapp et al., 2003; Poehlmann et al., 2005; Poston & Turnbull, 2004), but there have been no published studies that focus specifically on the role of religiosity and spirituality in the childrearing experiences of mothers of adult children who have Down syndrome. Most studies include multiple disabilities and include parents of minor children rather than adult children. Although coping, stress, and adjustment have been investigated, few of these studies consider religion and spirituality as coping strategies.

Comparative studies between disability groups are common and many include evaluations of the stress, coping, and adjustment patterns of parents of children who have Down syndrome. Dabrowska and Pisula (2010) conducted a study comparing the stress factors of parents of children who have autism, Down syndrome, or were non-disabled. The results indicated that parental stress was higher among parents of children with disabilities than among parents whose children were non-disabled. Hall et al. (2012) researched stress and resiliency factors among families of children who had cerebral palsy, autism, sickle cell disease, and Down syndrome and found that non-stressed parents were more likely to have greater social supports and to identify positive life factors associated with their children who had a disability than were stressed parents. Even though the study included parents of children who have Down syndrome, participants were not differentiated by their child’s disability, so it is unclear if parents of children who have Down syndrome were more frequently identified as stressed or non-stressed or which coping strategies were considered most effective. Another study of mothers of children who have Down syndrome and fragile X syndrome, another chromosomal cause of intellectual disability (Kover et al., 2012), indicated there were many similarities among these mothers, but differences in patterns of adaptation were noted between the two groups (Poehlmann et al., 2005). Hodapp et al. (2003) found that mothers of children with Down syndrome experienced less stress associated with behavior issues or sociability limitations than did mothers of children who had other disabilities. These studies suggest that stress, coping, and adjustment behaviors among parents of children with disabilities differ based on the etiology of the child’s disability.

Some studies have focused on parents of children who have Down syndrome exclusive of other disability groups. Povee et al. (Povee, Roberts, Bourke, & Leonard, 2012) conducted a large study of 224 parents and caregivers of children and adults with Down syndrome that indicated two important points: Religious supports were beneficial, and the needs of families and children changed across time. Though much smaller in scope, Pillay et al. (2012) found that mothers of children with Down syndrome experienced a variety of challenges over the developmental life of their child. They also found that although religious support and spiritual faith can be beneficial, their usefulness was dependent on contextual factors. These studies provide information about the changing needs of families over the course of a child’s life and suggest that spirituality and religion may contribute to adjustment. While valuable, these studies reflect the experiences of mothers and caregivers who live in Australia, which may be different from the experiences of mothers in the United States.

Stress, coping, and adjustment differ among parents of children who have different disabilities, but the parent’s gender is also important in this analysis (Hartley, Seltzer, Head, & Abbeduto, 2012; Ricci & Hodapp, 2003; Roach, Orsmond, & Barratt, 1999). Heaman's (1995) research indicated that stress associated with raising a child with a disability had different effects on mothers and fathers. Although this study included children with Down syndrome, it also included children with other disabilities. Dabrowska and Pisula's (2010) study, which focused specifically on parents of children who have Down syndrome, confirmed that differences in stress, coping, and adjustment do exist between mothers and fathers, which is consistent with the previous report by Spangenberg and Theron (2001) who noted that gender-based differences influence parental stress and coping behaviors.

Parents utilize many coping strategies in the process of adjustment to stress associated with the care of a child with a disability, and evidence suggests spirituality and religion are important factors in resilience among these families. Having a spiritual belief and participating in religious communities provide strength to face daily challenges, develop patience, make sense of the disability, and may provide a sense of acceptance and support for parents and children with disabilities (Poston & Turnbull, 2004). However, this is dependent on the context and the acceptance of the child within the church community (Gaventa, 2012; Speraw, 2006). Nevertheless, for some, having faith in God provides strength and resilience in times of emotional challenge and positively shapes the meaning of a child's disability (Treloar, 2002).

Among parents of children and adults who have Down syndrome, religious supports have been identified as important along with other social, professional, and medical supports (Poehlmann et al., 2005). Mothers have reported that having spiritual faith increased their strength and resilience and made them better caregivers (Zhang &

Rusch, 2005). During times of high stress, mothers have reported that religious and spiritual supports, such as instrumental support in the form of cooked meals or housecleaning and emotional support in the form of encouragement and prayer, are especially helpful (Pillay et al., 2012). For some mothers, optimism and religion are the most frequently accessed sources of coping supports (Norizan & Shamsuddin, 2010).

Several mixed methods and qualitative studies have been conducted on this topic. Povee et al. (2012) conducted a mixed methods study on stress, coping, and religion and spirituality with parents of children and adults who have Down syndrome. However, this study was based in Australia, and the qualitative component was minimal in relation to the overall quantitative data collection. Another mixed method study of parents consisted of mostly mothers of children with various disabilities (Hall et al., 2012), and several qualitative studies have focused on stress and coping among parents of children with varied disabilities (Poston & Turnbull, 2004; Speraw, 2006; and Treloar, 2002). Additionally, one qualitative study explored the experiences of mothers of children age 12 and under who had Down syndrome (Pillay et al., 2012). Yet, none of these qualitative studies investigated the role of spirituality and religion in the experience of mothers caring for adult children who have Down syndrome and who are living in the U.S, and the majority of research has been conducted with mothers whose children are age 18 and younger.

Rationale and Potential Benefits

Rationale. The rationale for this study centered on five collective factors. Though each of these factors have been included in previous research, no study had explored these five factors collectively. These five factors include the study of: (a) the spiritual and religious experiences, (b) of mothers, (c) of adult children who have Down syndrome, (d) who live in the U.S., and (e) through the qualitative theoretical lens of phenomenology. The current study focused on mothers of adult children. These mothers have encountered parenting challenges that are different from mothers who have young children (Abery, 2006; Seltzer et al., 2004). Although occasionally included as a peripheral outcome element in research, spirituality and religion are seldom the central focus of research despite indications that these factors can influence the creation of meaning, self-worth, and positive outlooks for the future (Gaventa, 2012; Swinton, Mowat, & Baines, 2011). The current study focused on understanding and describing how spirituality and religion influenced the parenting experiences of mothers. The use of qualitative methods to address issues related to disability is not uncommon, but this approach has typically been employed in studies that include mothers and fathers who have children with various disabilities, and some intriguing work has been conducted with parents who live in countries other than the U.S. The current study focused on mothers who lived in the U.S. and whose adult children had a diagnosis of Down syndrome.

Potential benefits of research. Mothers, who are a crucial source of ongoing support for their children who have disabilities, often do not receive the supports they need. Describing the experiences of mothers of adult children who have Down syndrome can help others who interact with these families provide supports that are more effective. Parents, particularly mothers, can benefit from the experiences the mothers in this study shared about caring for an adult child who has Down syndrome. Through these stories, professional service providers and mental health clinicians may better understand the experiences of mothers, who are often the primary caregivers of the clients they serve.

Even though it is understood that spiritual and religious issues can positively affect coping and adjustment (Steen, Engels, & Thweatt III, 2006; Morrison, Clutter, Pritchett, & Demmitt, 2009), mental health providers continue to be reluctant to integrate this into practice (Frazier & Hansen, 2009; Gaventa, 2008; Hathaway, Scott, & Garver, 2004; Shafranske & Malony, 1990). Through increased understanding, professionals can be better prepared to address and meet the needs of mothers. With greater insight, clergy and religious leaders may develop supports that meet the needs identified by the mothers in this study. Many religious leaders have attempted to do this, but, at times, have been ineffective in their efforts to provide meaningful religious and spiritual supports (Gaventa, 2012; Hall et al., 2012; Pillay et al., 2012; Speraw, 2006). Neither generalizability nor change is a goal of phenomenological research (Creswell, 2007). However, change can occur, and transferability of information garnered from the descriptions of personal experiences may benefit others (Lareau, 2012). Thus, it is my hope and the hope of the mothers in this study that the findings from this research will benefit other mothers, as well as the professionals who serve these families, the religious leaders who strive to offer them spiritual support, and a society that continues to struggle to accept fully persons who have disabilities and their families.

Personal Relationship with the Research

My previous work with persons who have disabilities and their families positioned me as an insider, which was beneficial in developing collaborative and trusting relationships with the participants in this study. This was an asset because it validated me as a researcher who would approach the work with care and compassion and reassured the participants that my intentions were aimed to benefit them rather than insensitively probe into private aspects of their lives (Rubin & Rubin, 2005). Through my work within the disability community, I developed a network of resources and professional connections that I accessed to recruit potential participants. This was tremendously helpful because potential participants typically knew someone who was directly or indirectly familiar with me and who could vouch for my professionalism and legitimatize my research intentions.

My inspiration for this research study were the many mothers who I worked with for over two decades. These mothers' enduring commitment and care of their children who had disabilities were exemplar models of motherly love that I found heartwarming and admirable. Two factors influenced my decision to work with mothers of adult children who have Down syndrome. First, most of the mothers I previously worked with had adult children, and I understood that the challenges and the rewards they experienced were different from mothers whose children were still attending school. Though I worked with some children, the majority of my work was with adults who had disabilities, so I was most familiar with this group of individuals and their families. Second, throughout my work with mothers whose children had Down syndrome, I recalled the many times mothers told me they were *blessed* to have their child and that their child divinely influenced their life. I appreciated these mothers' faith, and their optimistic attitudes encouraged me. I often wondered if these mothers' experiences were somehow different from other mothers' experiences.

Post-reflexively, as I considered my shifting subjective relationship with the data (Vagle, 2016), I think that the absent presence of Down syndrome in my family positioned me to explore this specific research issue from a unique perspective. Before I was born, my aunt had a child who had Down syndrome. The only thing I knew about this child came from an old picture and my grandmother's brief explanation that he was very sick, he had been placed in an institution when he was two years-old, and he had died. Believing this little boy had died when he was a toddler, I had never questioned my aunt's decisions. Only after her death, when I learned this now adult child was still alive and had spent most of his life in an institution, did I begin to question this old family secret. Interestingly, when I began this research, I did not think my aunt and her little boy had influenced my interest in this topic. Now, I believe it certainly did.

Methodology

The constructionist epistemological foundation of this research relied on a phenomenological theoretical framework. Therefore, I conceptualized and conducted this study from a phenomenological perspective that focused on describing mothers' perceptions of meaning and hope concerning their adult child who has Down syndrome and the influence spirituality and religiosity had on their mothering experiences. Phenomenologists explore personal meaning of lived experiences in an effort to unveil the true essence of the experience (Denzin & Lincoln, 2005: Smith, Flowers, & Larkin, 2009; Vagle, 2014; van Manen, 2014). This goal is often achieved by examining and describing the experiences of several people who have been engaged in similar events or phenomena (Angrosino, 2003; Lareau, 2012), and interviews are a common method of inquiry (DeWalt & DeWalt, 2002; Groenewald, 2004; Vagle, 2014). However, interviews rely extensively on words to construct meaning, and it was important that, during my analysis of the data, I considered not only spoken communications but also the underlying, and sometimes unspoken, unintentional meanings of the participants' lived experiences (McCormack, 2000, Van Manen, 2014). A phenomenological approach was appropriate for this topic because mothers were asked to narrate their own stories of spirituality, religion, meaning-making, hope, and coping throughout their journeys of parenting adult children who have Down syndrome which was often intangible.

Methods and Analysis

The methods for this research employed the common practice of in-depth phenomenological interviews (DeWalt & DeWalt, 2002; Groenewald, 2004; Vagle, 2014) with six mothers of adult children who have Down syndrome. Their narrated experiences were analyzed to identify meaning units using a whole-part-whole analysis approach combined with Colaizzi's seven-step analytical strategy (Abalos, Rivera, Locsin, & Schoenhofer, 2016; Colaizzi, 1978, Edward & Welch, 2011; Morrow, Rodriguez, & King, 2015; Shosha, 2012; Vagle, 2014). I practiced intentional bracketing to identify and extract the personal influences I, as the researcher, brought to this research experience (Smith et al., 2009; van Manen, 2014). I used journaling and memoing to record and track these bracketed experiences so I could reintegrate these biases back into the final data analysis to expose how my perceptions influenced the final interpretations and representations of these mothers' experiences (Birks, Chapman, & Francis, 2008).

Purpose Statement and Research Questions

The purpose of this phenomenological study was to describe and understand the spiritual and religious experiences of six mothers of adult children who have Down syndrome and who resided in the Mid-South region of the U.S. I used a series of three individual, face-to-face interviews with the six participants to explore how spirituality and religion contributed to their perceptions of their child, sense of meaning and hope for their child’s future, and coping behaviors in response to the daily stress of raising a child who has special needs.

I had one central research question, which was the foundation for four sub-questions (Creswell, 2007). The central research question was, “What is the experience of spirituality and religion in the parenting process of mothers of adult children who have Down syndrome?” The following four sub-questions directed the exploration of the central question of this phenomenological research study and provided the frame for presenting the research findings (Creswell, 2007):

1. How do spirituality or religion create or reduce meaning with regard to the child’s diagnosis of Down syndrome?
2. How do the systemic patterns within organized religion influence positive or negative perceptions of Down syndrome?
3. How do spirituality or religion alleviate or aggravate the stress associated with raising a child who has Down syndrome?
4. How does spirituality or religion create or thwart hope for the future of a child who has Down syndrome?

Definition of Terms

The following definitions present concise descriptions of frequently used terms in this manuscript. Detailed descriptions of some of these concepts are addressed in the following chapters. These terms are offered as a point of reference but are not intended to fully address the complexity of these concepts.

Adult child. For the purposes of this study, adult child will refer to sons and daughters who are age 18 or older. By age 18, these sons and daughters have attained most legal rights ascribed to adult status in the United States (Arnett, 2015).

Down syndrome. This is a congenital genetic disorder resulting from an extra chromosome 21 that is typically characterized by impaired cognitive functioning, observable physical traits (e.g. almond-shaped eyes, short stature), and health concerns (e.g. heart defects, vision impairment, hearing loss, leukemia) (Roizen, 2013).

Lived experience. The term *lived experience* is conceptually distinct from the word *experience*. Lived experience identifies a specific moment in which one is actively engaged in a phenomenon and precedes consequential moments of reflecting upon or remembering the event (van Manen, 2014).

Phenomenology. This is a philosophical, theoretical, and methodical approach to research that attempts to understand the lived experience of phenomena as perceived by those involved in the activity/event as it occurs and from an emic or personal perspective (Vagle, 2014; van Manen, 2014).

Post-reflexivity/post-reflexive. These terms refer to the researcher's practice of critically recognizing and assessing one's shifting knowledge and relationship with the research across time (Vagle, 2016).

Reflexivity/reflexive. These terms refer to the researcher's practice of critically assessing one's values, biases, assumptions, and relationship with the research (Schwandt, 2007; Vagle, 2014).

Religion. This refers to a set of beliefs, doctrine, practices, and traditions associated with a divine theology (Eller, 2013).

Spirituality. This refers to a process of transformation by which individuals create meaning, purpose, and value in life as they strive to connect with something greater than themselves (Frame, 2003; Walsh, 2009).

Overview

Chapter 1 introduced this study, explained my rationale for the project, my interest in this subject, and described my subjective relationship with this research topic. This chapter included a summary of the relevant research and highlighted gaps in the literature related to this study. In addition, the chapter included brief summaries of the theoretical foundations of the research, the research methodology, methods, and analytic process. Lastly, Chapter 1 delineated the research purpose and questions, and included some brief definitions of pertinent terminology. The following chapters will expand on this information.

Chapter 2 includes a review of the literature, which explains and supports my decision to conduct this study with mothers of adult child who have Down syndrome. Chapter 3 provides detailed information about my methodology, research methods, trustworthiness and ethical considerations, subjectivity, participant recruitment and selection, and the analytical process. Chapter 4 provides an exhaustive report of the research findings. Finally, Chapter 5 includes a discussion of the findings in relation to the literature, implications for professionals, limitations of the study, recommendations for future research, advice from these mothers, and my final thoughts on this research journey.

Chapter 2

Review of the Literature

There are approximately 6,000 babies born with Down syndrome in the United States each year adding to the estimated 250,700 (Presson et al., 2013) to 400,000 (NDSS, n.d.b) families already facing the challenge of raising a child who has Down syndrome. This means that approximately 1 in every 733 children born in the United States will have Down syndrome (United States GAO, 2010) making this the leading genetic cause of intellectual disability. Although complex, and described in more detail later in this chapter, Down syndrome is caused by a full or partial duplication of an additional chromosome 21. The additional genetic material from this extra chromosome causes varying degrees of developmental delays and physical changes, including short stature, almond-shaped eyes, flat nose bridge, and a small head, mouth, and ears (Batshaw, Gropman, & Lanpher, 2014; Bull et al., 2011; Finesilver, 2002). Due to many changing medical and social dynamics, it is anticipated the number of persons living with Down syndrome will continue to increase in the coming decades (Kover et al., 2012). Consequently, understanding the needs of these individuals and their families will become increasingly important (Presson et al., 2013), particularly in regard to attaining and maintaining an optimal quality of life. For some families, spirituality and religiosity are important coping resources that contribute to a meaningful quality of life.

This chapter begins with a purpose statement, a brief historical review of the research on Down syndrome, an overview of current research trends, and a description of key terms. Next, the review focuses on research that supports the theory that the etiology of a child’s disability affects parental stress and coping patterns. Following this, a review of research is presented which supports the idea that parents' gender affects stress, coping behaviors, and the experience of parenting. Next, the literature review will examine research that focused on the influence of spirituality and religion as part of the parenting experiences of mothers and fathers of children who have Down syndrome. Finally, this literature review concludes with an evaluation of the qualitative research conducted on spirituality and religion as a coping resource among parents of children who have Down syndrome. Attention to cultural considerations in the research are addressed throughout this review.

Purpose

The purpose of this phenomenological qualitative study was to understand and describe how the spiritual and religious beliefs of mothers of adult children who have Down syndrome affect the reported experiences of their (a) perceptions of their child, (b) sense of meaning and hope for their child's future, and (c) coping behaviors in response to the daily stress of raising a child who has special needs. The following literature review highlights the need for the current study and supports the use of a qualitative approach.

Brief History of Down Syndrome Research

Down syndrome has been the focus of research since it was first described by Dr. John Langdon Down in 1866. However, the origin of this disorder was not discovered until the late 1950s. Until that time, much of the research was oriented toward discovering the cause of Down syndrome and addressing related physical health concerns (Smith & Warren, 1985). Around the same time, research expanded to include concerns related to cognitive development, learning, and motor skill development. It was not until the 1970s that researchers began to embrace social concerns regarding persons with Down syndrome and their families. In fact, prior to the 1970s, and lingering long beyond this date, families were often encouraged to consider institutionalization when a baby was born with Down syndrome. The need for family-oriented research did not evolve until the concept of Down syndrome within the family unit became a social reality. Since the 1970s, research has expanded to include social issues and family dynamics (e.g. self-esteem, parent-child relationships, family stress) (Wishart, 1998).

Current Research Trends on Down Syndrome

Much of the current research on Down syndrome is still rooted in understanding the genetics and physical health risks associated with this disorder but the questioning landscape has continued to expand and includes personal and family concerns. A review of current research listed by the National Down Syndrome Society (n.d.a) includes research interests on biomedical (e.g. comorbidity with other emotional and physical disorders, such as heart disease, leukemia, and Alzheimer’s disease), personal (e.g. body image, daily living skills development, employment, learning and language development, and social communications), family issues (e.g. access to supportive care/respite, family resilience, fathers’ internet use as a resource, and parents’ dreams and goals for their children), and cultural factors (e.g. diagnoses experiences of parents who are Hispanic). None of these studies aimed to explore spiritual or religious issues related to parenting a child who has Down syndrome. A review of the currently active research studies listed by the National Institutes of Health (n.d.) replicates this pattern of interest in the areas of biomedical (e.g. genetics, dietary and vitamin therapy, comorbid emotional and physical disorders including respiratory disorders, sleep disorders, hypothyroidism, oral health, and Alzheimer’s disease,), personal (e.g. behavior interventions, learning and communication development, physical fitness, prenatal screening rights, and weight management,), and family issues (e.g. parental stress) but includes no research on spiritual or religious issues.

A review of studies completed over the past two years (i.e. 2017 until 2019) as reported by the ProQuest Dissertation and Theses Global database offered a slightly different perspective of academic research on Down syndrome. Most of the studies reported in this database focused on biomedical issues (e.g. aging, Alzheimer’s disease, brain and memory functions, cancer, genetics, heart health, motor system functions, obesity, oral health, respiratory functioning). A sizable portion of the studies explored treatment interventions (e.g. art therapy, behavior modification, daily living skills instruction, education and learning, hippotherapy, language development, and physical education/activity). A few studies considered personal (e.g. social relationships and inclusion) and family issues (e.g. parent-child interactions and social media supports). However, for the past two years (2017-2019), this database included no studies that focused on the spiritual or religious experiences of persons who have Down syndrome or their families.

Clearly, Down syndrome is not ignored by researchers, but the spiritual and religious experiences of persons who have Down syndrome and their families has received little attention when compared with areas of research such as health, genetics, and treatment interventions. Even so, there are several studies that have been conducted on spirituality and religion as a component of coping and adjustment, which provide important insight into the experiences of parents. However, before going further, it is important to expound on three key terms that are fundamental to this study: Down syndrome, religion, and spirituality.

Terminology

Down syndrome. Down syndrome is a chromosomal abnormality resulting in an extra copy of chromosome 21. Although chromosomal abnormalities occur in many variations and frequently end in miscarriage, the presence of an extra copy of chromosome 21 results in the disorder Down syndrome. This condition is sometimes referred to as trisomy 21 to indicate the presence of a third copy of chromosome 21 (Batshaw et al., 2014; Finesilver, 2002; Roizen, 2013).

Typically, babies are born with 23 sets of chromosomes totaling 46 chromosomes. These chromosomes provide the genetic foundation for development of the embryo. The father’s sperm contributes 23 chromosomes when it is joined through fertilization with the mother’s egg which also contains 23 chromosomes. However, in 95% of instances of Down syndrome, when fertilization occurs there is an extra chromosome 21 present, and this pattern is repeated as the cells begin to divide and replicate (Roizen, 2013). In these instances, every cell of the developing baby will contain 22 paired sets of chromosomes plus one trisomy, or three copies, of chromosome 21 for a total of 47 chromosomes (Batshaw et al., 2014).

In approximately 3% of Down syndrome cases, the extra copy of chromosome 21 is located somewhere other than with the typically occurring set of chromosomes. In these instances, the extra chromosome 21 has broken free from the original set and reattached to another pair of chromosomes. So, although a third copy of chromosome 21 is present in the genetic structure of the cell, it has become rooted in some other location.

This type of Down syndrome is called translocation trisomy 21 (Batshaw et al., 2014; Finesilver, 2002). Although similar in physical presentation to trisomy 21, persons who have translocation Down syndrome have a greater risk of obesity, depression, and dementia. In addition, learning difficulties are likely to be less severe but adaptive skills are likely to be lower among this group when compared with persons who have trisomy 21 (Prasher, 1993).

In approximately 2% of the cases of Down syndrome not all cells have an extra copy of chromosome 21. In these instances, the extra chromosome 21 is present in only some cells whereas other cells contain the typically paired sets of 46 chromosomes. This variation, known as mosaic trisomy 21, may present with fewer physical characteristics normally associated with Down syndrome (Batshaw et al., 2014).

Regardless of the specific type of Down syndrome present, the diagnosis has some characteristic traits and commonalities. Children born with Down syndrome exhibit a range of intellectual abilities most commonly varying between mild to moderate cognitive functioning. In the past, the assessment of cognitive functioning has relied, in part, on intelligence assessments that yielded IQ scores ranging from 50 or 55 to 70 designating mild cognitive impairment and 35 to 50 or 55 designating moderate cognitive impairment (AAP/COG, 2001; APA, 2000). Recently, the emphasis on intelligence assessment scores has diminished and been superseded by adaptive assessments in three areas: conceptual, social, and practical (i.e. daily living skills). Based on this conceptualization, mild levels of functioning reflect lower than typical skill performance in these three areas requiring some additional training or supports. Moderate levels of functioning reflect notably lower levels of skill performance in these three areas with ongoing training and support necessary to function effectively (APA, 2013).

Physical traits may include upwardly slanted almond-shaped eyes, flatness across the bridge of the nose, low or loose muscle tone, short stature, irregularly shaped mouth, enlarged tongue, and wide hands with short fingers (Finesilver, 2002). Common health problems include congenital heart defects, hearing and vision impairments, sleep apnea, thyroid dysfunction, gastrointestinal problems, dermatological disorders, and respiratory and oral infections (Finesilver, 2002; Roizen, 2013). In this study, the term Down syndrome was used to represent all of the above variations of trisomy 21.

Religion. The central research questions of this study include two significant concepts: religion and spirituality. It important to distinguish the similarities and differences between these terms as they are frequently presented together. This conjoined presentation may mislead readers to assume these terms are interchangeable. Although they do share similarities, religion and spirituality are not synonymous and represent distinct constructs.

Upon initial consideration, religion might appear to be a relatively simple term. In fact, it is a complex concept. Frame (2003, p. 3) defined religion as “a set of beliefs and practices of an organized religious institution.” This definition has been expanded by others to include religious ceremonies, rules, principles, moral values, emotions, philosophy, and community (Fukuyama & Sevig, 1999, as cited in Thomas & Schwarzbaum, 2011). Pargament (2007) further developed this definition to include one’s pursuit for meaning and purpose through what is perceived to be sacred. From a sociological perspective, religion is understood to be an organized system of controls that promote social relationships and behaviors. Religion is differentiated from other cultural domains that attempt to promote social order in that religion is said to include a social entity of the nonliving (e.g. the deceased, the saints, and the gods) and the nonhuman (e.g. animals, plants, and natural forces such as the moon, sun, and wind) (Eller, 2013). The Association for Spiritual, Ethical, and Religious Values in Counseling (ASERVIC) defines religion as “an organization of beliefs which is common to a culture or subculture” (ASERVIC, n.d., p. 2) “by which individuals give meaning to (or find meaning in) their lives by orienting them to what is taken to be sacred, holy, or the highest value” (Corbett, 1990, as cited in ASERVIC, n.d., p. 2). At its core, religion evolves from external stimuli that establish a prescribed set of thoughts, behaviors and rituals that are shared in a public forum (Cashwell & Young, 2005).

In the collection of these expressions of religion, we might understand religion to be an organized set of beliefs and rituals that are founded on sacred doctrine and elicit emotions, knowledge, and ethical guidelines from which a community of people can find meaning and purpose in life. However, the degree to which a religion includes any of these elements varies greatly depending on the cultural and social context within which the religion functions. For example, not all religions have formally written doctrines (Eller, 2013). Therefore, it is important to consider one’s personal report of religious experience from the cultural context in which it occurs.

For the purpose of this study, religion was presumptively understood to mean a set of organized beliefs, rituals, and customs based on what is thought to be divinely inspired doctrine and that a community of people share through practice, association, or identity (ASERVIC, n.d.; Cashwell & Young, 2005). However, this definition did not supersede the definitions participants utilized in the creation of their own narratives. Although this definition of religion was a preconstructed conceptualization, it remained fluid and changeable based on the participants' explanations and use of this term.

Spirituality. Although similar, spirituality holds a unique position that is neither inclusive nor exclusive of religion. Spirituality can exist within the domain of religiosity or it can exist without any religious affiliations. According to Hartz (2005), spirituality is comprised of three dimensions: meaning (finding purpose in life), transcendence (connection to the sacred or ultimate reality outside oneself), and love (the ability to act in the best interest of others). The word *spirituality* is derived from the root word *spirit*, or *spiritus* in Latin, and has multiple overlapping meanings including life, breath, wind, energy, and mental or moral strength (Frame, 2003). Most definitions of spirituality generally retain at least some of these concepts. One of the most comprehensive definitions of spirituality has been developed by ASERVIC (n.d., p. 1) and describes spirituality

> as the animating life force, represented by such images as breath, wind, vigor, and courage. Spirituality is the drawing out and infusion of spirit in one's life. It is experienced as an active and passive process…that is innate and unique to all persons. This spiritual tendency moves the individual toward knowledge, love, meaning, peace, hope, transcendence, connectedness, compassion, wellness, and wholeness. Spirituality includes one's capacity for creativity, growth, and the development of a value system. Spirituality encompasses a variety of phenomena, including experiences, beliefs, and practices.

Although commonalities exist between religion and spiritualty such as connectedness, meaning, and the development of values, spirituality is an internal or innate need to be connected to something greater than one's self. It is the desire for global and even universal connections; a unity with all (Walsh, 2009).

For the purpose of this study, spirituality was presumptively understood to mean a personal desire to create meaning and purpose in life thorough a connection with something perceived to be greater than oneself that has altruistic benefits (Hartz, 2005). Like the aforementioned definition of religion, the definition of spirituality remained fluid and open to change. Ultimately, the definition of spirituality that was used in the analysis of the data was individually created by each participant.

Introduction to the Literature Review

Much of the research that has been conducted on spirituality and religion as a coping strategy for parents of children who have Down syndrome has been conducted as part of larger studies of parents of children with various disabilities (e.g. Bennett, DeLuca, & Allen, 1995; Friedrich, Cohen, & Wilturner, 1988; Treloar, 2002). The subsuming of parents of children who have Down syndrome into larger disability groups produced results that reflected a diverse group of parenting experiences. The experiences of parents of children who have Down syndrome have been diluted and possibly even lost through this generalized representation. In addition, the role of spirituality and religion as a coping strategy was often embedded in a broader evaluation of family stress and coping. Consequently, the results of such studies, although valuable, typically reflected outcomes not specific to the etiology of the child's disability, and the role of spirituality and religion often received minimal attention.

Some researchers have attempted to refine the focus of their work through comparative studies that present outcomes between parents of children who have specific disabilities (e.g. Dabrowska & Pisula, 2010; Noh, Dumas, Wolf, & Fisman, 1989; Poehlmann et al., 2005; Stores, Stores, Fellows, & Buckley, 1998). The literature review will begin with an analysis of comparative studies that support the notion that children's disabilities influence parents' level of stress and preferred coping supports. As previously stated, this review will then address studies that support the idea that the gender of the parent influences mothers' and fathers' perceived stress and preferred coping behaviors. Following this, the review will collectively explore quantitative and qualitative research on the role of spirituality and religion as a coping strategy for parents. The literature review will conclude with a closer examination of the qualitative research on spiritual and religious experiences of parents of children who have Down syndrome with particular attention to research conducted with mothers. The existent research has not focused on the spiritual and religious experiences of mothers of adult children who have Down syndrome and who live in the U.S.

Parent stress and coping and the etiology of the child's disability. The stressors parents experience and their consequent coping behaviors appear to be associated with physical, behavioral, and diagnostic characteristics typical of their children's disabilities (Baker, Blancer, & Olsson 2005; Bower & Hayes, 1998; Dabrowska & Pisula, 2010; Eisenhower, Baker, & Blacher, 2005; Hanson & Hanline, 1990; Hodapp, Ly, Fidler, & Ricci, 2001; Hodapp et al., 2003). The most consistent patterns found in the research suggest that parents of children who have Down syndrome experience less stress than parents of children with other disabilities (Griffith, Hastings, Nash, & Hill, 2010; Hodapp et al., 2003; Pisula, 2007; Sanders & Morgan, 1997; Smith, Romski, Sevcik, Adamson, & Barker, 2014) but more stress than parents of children without disabilities (Dabrowska & Pisula, 2010; Noh et al., 1989; Stores et al., 1998; Weiss, 2002). In addition, parents of children who have Down syndrome often report fewer depressive symptoms than parents of children with other disabilities (Abbeduto et al., 2004; Eisenhower et al., 2005; Poehlmann et al., 2005) and frequently report greater life satisfaction and satisfaction in the parenting experience (Griffith et al., 2010; Hodapp et al., 2001).

These positive outcomes may be related to the increased parental warmth exhibited toward children who have Down syndrome (Blacher, Baker, & Kaladjian, 2013; Stoneman, 2007). This emotional response has been associated to decreased problem behaviors among children who have Down syndrome and is linked to increased parent well-being (Dabrowska & Pisula, 2010; Esbensen & Seltzer, 2011; Greenberg, Seltzer, Krauss, Chou, & Hong, 2004; Hanson & Hanline, 1990; Hodapp et al., 2003; Mitchell, Hauser-Cram, & Crossman, 2014). This circular pattern of wellness is sometimes referred to as the Down syndrome advantage, a concept that has not gone unchallenged (Cahill & Glidden, 1996; Griffith et al., 2010; Lopez, Clifford, Minnes, & Ouellette-Kuntz, 2008; Smith et al., 2014; Stoneman, 2007).

Countering the notion of the Down syndrome advantage, some researchers have found no relationship between parental well-being and children’s social skills or behaviors (Griffith et al., 2010; Lopez et al., 2008). Stoneman (2007) further disputed the Down syndrome advantage reporting that the etiology of children’s disabilities was not a predictor of the quality of the parent-child relation or parents’ well-being. According to

Stoneman, the only consistent predictor of depression and parental warmth was family income. Churchill et al. (Churchill, Villareale, Monaghan, Sharp, & Kieckhefer, 2010) found no differences in reported depression among parents regardless of their child's disability or the level of severity. Similar to Stoneman, Churchill et al. found depression to be more closely associated with single parenting and unemployment.

However, many daily concerns of parents do appear to be associated to disability etiology. Parents of children who have Down syndrome have reported fewer daily challenges in the care of their children than have mothers of children with mental illness or autism (Holroyd & McArthur, 1976), and they have expressed less stress regarding limited communication skills than have parents of children with other developmental disabilities (Smith et al., 2014). Parents of children who have Down syndrome have expressed greater concerns regarding their children's education, sibling relationships, and difficulties with extended families more than parents of children who have physical disabilities (Bower & Hayes, 1998). Parents of children with Down syndrome have also expressed fewer concerns about the dependency of their children and were more optimistic about their children's future than were mothers of children who had autism, fragile X syndrome, Williams syndrome, or Smith-Magenis syndrome (Abbeduto et al., 2004; Fidler, Hodapp, & Dykens, 2000; Pisula, 2007). Yet, inconsistencies exist, and previous findings by Sanders and Morgan (1997) reported that parents of children who had Down syndrome and autism were equally pessimistic about the futures of their children.

The etiology of a child's disability impacts family functioning in several ways. Parents of children who have Down syndrome have reported more family cohesion

(King, Baxter, Rosenbaum, Zwaigenbaum, & Bates, 2009), better family harmony, and improved overall family functioning than have parents of children with other developmental disabilities (Cahill & Glidden, 1996). Researchers have also reported that parents of children who have Down syndrome have better relationships with their children than do parents of children with autism or schizophrenia (Greenberg et al., 2004).

Parents' general views of their children have also been associated with disability. Parents of children who have Down syndrome have reported more positive perceptions of their children than have mothers of children who have autism (Griffith et al., 2010; King et al., 2009). These mothers were more likely to describe their children as happy and cheerful, characteristics that were reinforcing to the parents optimistic outlook (Hodapp et al., 2003). Yet concerns regarding the physical health and acceptability of children who have Down syndrome (Hanson & Hanline, 1990; Pisula, 2007) have remained greater concerns among this group of parents.

The etiology of a child's disability can impact not only parental stress but also coping strategies and resources. Greenberg et al. (2004) found that increased optimism and positive parent-child relationships positively impacted well-being among parents of children who had schizophrenia or autism. However, optimism and positive parent-child relationships did not mediate well-being among parents of children who had Down syndrome. Similarly, mothers of children who have mental illness have demonstrated a greater reliance on emotion-focused coping strategies which are generally considered less effective. Mothers of children with developmental disabilities were more likely to use problem-focused coping and planning strategies which deterred depression. Interestingly, when mothers of children with mental illness attempted to utilize the same more positively viewed problem-focused coping strategies, they did not deter depression. Coping strategies have not been equally effective for all parents and effectiveness appears to be related to the etiology of the child’s disability (Seltzer, Greenberg, & Krauss, 1995). Coping resources seem to vary among parent groups as well. Parents of children who have Down syndrome have reported more emotional support from family members, professionals, and their religious communities than have mothers of children with other disabilities (Poehlmann et al., 2005).

***Chronological shifts in parental stress*.** Parental stress and coping are not static and change across the developmental life of a child. Parents have reported increased stress in the early years of a child’s development (Most, Fidler, Laforce-Booth, & Kelly, 2006) but reported decreased stress once children reached middle childhood through early adolescence (Fidler et al., 2000; Woodman, 2014). The rewards of parenting a child prior to adolescence appear to buffer stress in the early years of caregiving. However, as children get older, parenting rewards lose their mediating effect offering diminished support for older parents (Hodapp et al., 2003) who are less likely to report personal growth, purposefulness in life, or feelings of self-acceptance than are younger parents (Greenberg et al., 2004). It appears the trajectory of stress across the lifespan of a child with a disability is not consistent. Rather parental stress has peaks and valleys as new life challenges are faced. The best predictors of the trajectory of parental stress levels include family income and the child’s IQ, temperament, and disability diagnosis (Most et al., 2006).

Though the variations in parents' stress and coping continue to be studied, research provides support for the assertion that parents of children who have Down syndrome have a distinctive parenting experience that is largely favorable. Although research has included both parents, much of the research involving children with Down syndrome has centered on mothers as primary caretakers (Blacher & McIntyre, 2006; Bower & Hayes, 1998; Greenberg et al., 2004; Griffith et al., 2010; Hanson and Hanline, 1990; Hodapp et al., 2003; Most et al., 2006; Pisula, 2007; Poehlmann et al., 2005; Seltzer et al., 1995). Regardless of whether the research focus is on mothers, fathers, or both parents, the association of the etiology of children's disabilities with parental stress and coping has been well documented.

***Cultural considerations regarding parental stress and coping*.** The experience of parenting a child with Down syndrome presents mothers and fathers with challenges regardless of their cultural backgrounds. However, it is important to consider cultural influences as it has been suggested they frame the experience of parenting a child with a disability (Blacher & McIntyre, 2006; Seltzer et al., 2004) and that these disability-specific differences are sometimes the product of cultural values (Cho, Singer, & Brenner, 2005; Norizan & Shamsuddin, 2010; Upadhyaya & Havalappanavar, 2008). A few comparative studies have highlighted cultural differences in parental stress, coping, and attitudes toward children who have Down syndrome.

Latina mothers have reported higher rates of depression and been more likely to perceive their children as having lower adaptive skills than have Anglo mothers of children with Down syndrome. Yet, Latina mothers reported a more positive parenting experience than have their Anglo counterparts (Blacher & McIntyre, 2006). Similarly, African American mothers have reported greater satisfaction in the caregiving experience than have Anglo mothers (Miltiades, 2002). Korean mothers have more frequently attributed the cause of their child's disability to their own misdeeds than have Korean American mothers. Korean American mothers have reported a greater support network, been more likely to access services outside of the home, and have reported a more positive view of their children and the parenting experience than have Korean mothers (Cho et al., 2005).

This research is a reminder that culture influences the parenting experience. Even within the United States, culture impacts the experience of parenting in unique ways. However, most of the research on parents of children with Down syndrome living within the U.S. has focused on collective studies, and comparative results based on culture or ethnicity have been sparse. Nevertheless, when designing my research, I was mindful of not only the etiology of the child's disability but also the influences culture contributed to the parenting experience.

Gender-based differences in parental coping and stress. Research investigating the differences in stress levels and coping behaviors between mothers and fathers of children with disabilities have yielded mixed results. Some studies have suggested parents are similar in their experiences of stress and coping (Churchill et al., 2010; Dyson, 1997; van der Veek, Kraaij, & Garnefski, 2009). Similar rates and severity of depression have been reported by mothers and fathers of children with disabilities (Churchill et al., 2010). Cognitive coping strategies have been reported as equally effective in reducing stress among mothers and fathers of children with Down syndrome, but the type of cognitive coping strategies utilized was indicative of parental stress levels.

The use of positive reappraisal has been strongly associated to decreased levels of parental stress, whereas higher levels of stress were associated with catastrophizing, rumination, positive refocusing, refocusing on planning, and acceptance of having a child with a disability (van der Veek, et al., 2009). Mothers and fathers have reported similar perceptions in areas such as personal growth, comprehensibility, meaningfulness of the children’s disability, and family harmony all of which contribute to well-being (Keller & Honig, 2004; Manor-Binyamini, 2012). In addition, reciprocal spousal supports have positively impacted mothers and fathers (Bristol, Gallagher, & Schopler, 1988). However, these reciprocal patterns have also cultivated negative outcomes as the stress of one parent has been reported to increase the stress of the other parent (Roach et al., 1999; Woodman, 2014). In Dyson’s (1997) study of parental stress and coping resources among mothers and fathers of children with disabilities, no differences in stress levels were found to be associated with the parents’ gender and there were no reported difference in their perception of family functioning. A reciprocal pattern of influence on parental stress was noted as fathers’ stress was negatively associated with their spouses’ perception of personal growth; mothers’ stress was negatively associated with fathers’ perception of personal growth, family organization, social support, and family cohesion. The Dyson study concluded gender differences in overall stress and coping were not significant, but variations were noted. Stress was negatively associated with perceived personal growth for mothers and fathers, but fathers’ stress was also negatively associated with their perceptions of family organization whereas mothers’ stress was also negatively associated with their perceptions of family cohesion and social support.

Nevertheless, the majority of research has suggested that, despite some similarities, differences in stress and coping have been associated with the parent’s gender with mothers reporting higher rates of child-related stress and depression than fathers (Bristol et al., 1988; Glidden & Floyd, 1997; Heller et al., 1997; Lawrence, 2008a; Morris, 2014; Noh et al., 1989; Oelofsen & Richardson, 2006; Olsson & Hwang, 2001, 2008; Scott, Atkinson, & Minton, 1997). For example, in Bristol et al.’s (1988) comparative study of parents of children who had disabilities and typically developing children, mothers of children with disabilities reported more depressive symptoms and more challenges in daily life than fathers or mothers of typically developing children. Mothers of children with disabilities provided most of the childcare with some help from fathers, but fathers of children with disabilities were less engaged in childcare than were fathers of children with no disabilities. In fact, as the severity of the children’s disabilities increased, fathers’ childcare engagement decreased. Fathers of children with disabilities were also much less participatory in household tasks than mothers and were even less engaged in these activities then fathers of non-disabled children. Mothers of children with disabilities reported less emotional and recreational support from their spouses than did fathers. Overall, mothers of children with disabilities encountered more challenges, carried more of the responsibilities of childcare and housekeeping, and received less emotional support than fathers or mothers of non-disabled children.

Glidden and Floyd (1997) examined the relationships between depression and stress in parents of children with developmental disabilities in the development of a depression subscale for the Friedrich Questionnaire on Resources and Stress. They reported that birth mothers exhibited more symptoms of depression than fathers and adoptive mothers. The researchers suggested that adoptive mothers exhibited less depression since they had some control in the decision to become the mother of a child with Down syndrome. Nevertheless, overall, marital satisfaction was the best predictor of mothers' levels of depression. On the other hand, marital satisfaction was more indicative of fathers' adjustment, whereas mothers' adjustment was more strongly associated with family cohesion.

Noh et al. (1989) examined stress in parents who have children with autism, conduct disorder, Down syndrome, and no disability. When compared to these groups, fathers of children who had Down syndrome reported less stress than their spouses and even less stress than fathers of children who did not have disabilities. Mothers of children who had Down syndrome reported higher rates of depression and lower levels of competence in their parenting role than did fathers. Although both parents reported positive personal attributes in their child, fathers rated their children as happier and in a good mood more than mothers. Although the research did not speculate on this pattern of reporting, it is possible mothers more frequent presence as caregivers diminished their child-character ratings since they are more likely to experience both positive and negative child behaviors. Perhaps mothers have a more complete understanding of their child's overall character than do fathers.

Sanders and Morgan (1997) examined family stress and adjustment in parents who had a child with autism, Down syndrome, or no disability. Mothers of children who had Down syndrome were less critical of their children's personal characteristics (e.g. behavior, social skills) than fathers, but they perceived more family problems than fathers. Mothers also reported greater concerns regarding the physical limitations of their child than did fathers. It was speculated this latter finding was related to the increased caregiving time mothers spent with their child which increased the burden of the child's physical incapacitation. Mothers also reported greater limitations in their access to recreational and social activities outside the home than fathers. This limited access to activities generally considered stress reducing may contribute to mothers' increased levels of reported stress.

Lawrence's (2008a) qualitative study of parents of children with disabilities offered a forthright presentation of parents' perception of their gender-based differences in communication and coping behaviors. In this study, parents repeatedly addressed the challenges they faced in a marriage that was strained by the additional concerns of caring for a child with a disability. Mothers and fathers reported a persistent awareness of their different communication and coping styles and spoke of the importance of adapting their interactions to meet the needs of their spouses. Learning how to understand, respect, value, and be responsive to their spouses differing coping needs helped improve their marriage and effectively manage family life.

Olsson and Hwang have conducted two comparative studies of parents of children with intellectual disabilities, autism, or no disability. One study explored parent well-being (2008) and the other examined depression in parents (2001). Although there was no significant difference in depression among the fathers in these groups, differences were notable between the groups of mothers. Mothers of children who had intellectual disabilities reported fewer depressive symptoms than mothers of children with autism, but they were almost double that of mothers of children with no disabilities. In regard to well-being, mothers of children with disabilities reported more health problems, greater financial hardship, and lower rates of overall well-being. For mothers, the best predictors of wellness were sense of coherence and perceptions of their children's positive impact on the family with higher ratings predicting improved wellness. For fathers, only personal health ratings predicted their well-being with better health indicative or better well-being. These variations in parent wellness are important as they inform effective parent intervention strategies.

Influence of behavior problems on parental stress**.** Many factors contribute to parental stress. For some mothers, the greatest predictor of increased stress has been their children's behavior problems, whereas fathers' stress was better predicted by their children's level of social acceptability. In other words, mothers were more concerned with child behaviors that were hurtful, destructive, or socially inappropriate, and fathers were more concerned that their child be accepted by other family members, peers, and the community (Keller & Honig, 2004; Roach et al., 1999; Saloviita, Italinna, & Leinonen, 2003). The severity of the child's disability has been reported to have a stronger positive relationship to mothers' stress than to fathers' stress (Sanders & Morgan, 1997). However, this may be due to the increased childcare demands that result from increased severity of disability. Overall, fathers have reported greater concerns that their children be viewed as normal, but mothers have reported greater concerns that their children be recognized as unique individuals (Pelchat, Lefebvre, & Perreault, 2003). Nevertheless, parents' concerns regarding how their child is accepted by society has remained a significant source of stress for both mothers and fathers (Noh et al., 1989).

Influence of family roles on parental stress. It has also been suggested that mothers experience greater stress from parenting than do fathers regardless of the disability status of the child (Scott et al., 1997). These differences stem, at least in part, from the different expectations mothers and fathers have in the roles they hold as caregivers and the outcomes they set for their children and for societies’ response to and with their children (Pelchat et al., 2003). In general, mothers have reported a more positive perception of their children’s role in the family than have fathers (Trute, Hiebert-Murphy, & Levine, 2007). Mothers have reported their children to be a source of happiness, fulfillment, strength, and family unity, and that their children have helped them to mature, learn from the parenting experience, and expand their social connections (Hastings, Beck, & Hill, 2005). Yet the mothering experience has not been entirely favorable, and mothers have reported having more intrusive negative thoughts, more tension, and more anger than fathers (Scott et al., 1997). On a more positive note for fathers, they have been more likely to perceive their children’s disabilities as more manageable than have mothers (Manor-Binyamini, 2012), and fathers were more likely to perceive their children as a source of pride (Hastings et al., 2005).

The negative emotional experiences of mothers may be attributed, at least in part, to their reported perceptions of higher levels of hardship in the parenting experience (Manor-Binyamini, 2012). It is not a surprising that mothers feel more burdened when considering fathers’ tendencies to minimize their own stress by turning over the caregiving responsibilities to mothers thereby distancing themselves from the childcare experience (Grant & Whittell, 2000). This increased caregiving responsibility is associated with increased levels of depression among mothers but not among fathers even when they do take on caregiving responsibilities. Researchers speculated that the benefits fathers received through increased child-caregiving (i.e. parenting competence and child attachment) contributed to their overall well-being rather than to depression. However, mothers, who typically provided the majority of child-caregiving, did not experience the same difficulties with perceived parent competence and child attachment that fathers frequently encountered. Consequently, the increased child-caregiving did not buffer maternal depression, rather it contributed to depression (Roach et al., 1999).

Increased childcare may contribute to mothers' sense of burden more than it does for fathers, but the opposite has been reported on general housekeeping activities offering yet another point of difference in how mothers and fathers perceive and experience stress. Fathers have reported increased perceptions of burden due to time spent on household tasks, whereas mothers' did not perceive housekeeping activities to be burdensome. Interestingly, mothers' sense of burden increased when fathers spent more time in childcare. Since mothers reported a greater sense of burden with increased childcare, it is easy to assume that having the assistance of fathers would decrease their sense of burden rather than increase it, but that was not the case. In practice, mothers did not decrease their caregiving activities when fathers provided care. Rather, mothers' caregiving time increased as the couple engaged in shared caregiving (Heller et al., 1997). Unfortunately, fathers have paid a price for coping strategies that distanced them from caregiving activities as they have reported decreased confidence in their parenting skills and increased stress due to difficulties developing close emotional relationships with their children (Bristol et al., 1988; Keller & Honig, 2004). Fathers who engaged in more caregiving activities had an increased sense of competence and child attachment (Roach et al., 1999).

Differences in the perception of family quality of life have been noted. Fathers have been more likely to associate well-being with marital satisfaction, and mothers were more likely to associate well-being to family cohesion (Glidden & Floyd, 1997). Mothers have been more likely to report a more positive perception of the family environment than have fathers (Woodman, 2014). Other parental differences identified have included family income and the severity of the child's disability as predictors of mothers' stress but only severity of disability predicting fathers' stress (Wang et al., 2004). Perhaps mothers' decreased ability to consistently influence family income linked this factor to their overall stress levels.

Typically, mothers are considered the primary caretaker of a child with Down syndrome (Pelchat et al., 2003), and they have spent less time working outside the home (Hedov, Wikblad, & Anneren, 2006; Morris, 2014). Mothers have reported feeling fatigued (Hedov, Anneren, & Wikblad, 2002; Scott et al., 1997), and, even though they work outside the home less, they taken 40% more sick days than fathers (Hedov et al., 2006). This increase in mothers' work absences may result from their increased stress due to childcare, an issue that has been reported to be more stressful for mothers than fathers (Dabrowska & Pisula, 2010). Although socioeconomic status has not been directly linked to fathers' stress as it is for mothers, there is an indirect link in that fathers' levels of depression have been associated to the size of their home with smaller homes predicting higher levels of depression (Olsson & Hwang, 2001).

Morris' (2014) study examined the difference of reported stress, work patterns, and mental health among parents of children with and without disabilities. Although mothers and fathers of children with disabilities both reported higher rates of mental health problems than other parents, non-working mothers of children with disabilities were twice as likely to experience mental health problems when compared to the general population. Even working mothers of children with disabilities did not fare as well as fathers or mothers of children without disabilities. Fathers were more likely to be employed and work more hours than mothers which is important since wellness is associated with employment. However, unemployed fathers of children with disabilities were at greatest risk of poor mental health than any other group. For fathers, the lack of employment was more influential in their overall wellness than was the presence of a child with a disability.

Overall, fathers have reported having more vigor, higher self-esteem, and better physical and mental health than mothers (Morris, 2014; Oelofsen & Richardson, 2006; Olsson & Hwang, 2001, 2008; Scott et al., 1997; Trute et al., 2007). Interestingly, for fathers, health concerns have been associated with stress more so than it has for mothers (VanSolkema, 1997). Perhaps this is why fathers have expressed greater concern about their own health as well as the health of their spouse. Mothers have not expressed these same concerns regarding health (Hedov et al., 2006).

Oelofsen and Richardson (2006) examined several measures of health in parents of children with and without disabilities and found that parents of children with disabilities had poorer outcomes in all areas but one when compared with parents of children who did not have disabilities. Parents of children who had disabilities reported receiving more support than parents of children without disabilities. In relation to stress, sense of coherence, and overall health, mothers of children with disabilities fared less well than fathers and parents of children without disabilities. Interestingly, although mothers report poorer overall health, they also were less concerned with this issue (Hedove et al., 2006).

The differences in mothers and fathers reported experiences of stress is prevalent in the research and is influenced by a variety of factors. Nevertheless, it is understood that stress is fluid and changes over time. Variables that influence stress at one point in life, may be less significant at other times. For example, differences in mothers and fathers perceptions of their children's disability on family well-being may be more notable in the early years but become more similar as children get older (Trute et al., 2007).

Coping behaviors. In regard to coping behaviors, mothers were more likely to utilize emotion-oriented strategies which are typically associated with higher rates of reported stress, whereas fathers were more likely to use task-oriented problem solving strategies (Dabrowska & Pisula, 2010; Upadyaya & Havalappanavar, 2008; Zechella, 2014). Other researchers have reported that mothers are more likely to use problem-focused coping strategies than are fathers, and problem-focused coping was a more effective buffer for overall well-being among mothers than it was for fathers (Essex, Seltzer, & Krauss, 1999; Grant & Whittell, 2000). Mothers reported more diversity in their coping resources than did fathers (VanSolkema, 1997) and were more likely to access coping strategies that involved planning, instrumental social support, emotional support, venting emotions, avoiding competing demands, and positive reappraisal (Heaman, 1995; Spangenberg and Theron, 2001; Sullivan, 2002; Upadhyaya & Havalappanavar, 2008). Other research has suggested mothers believed controlling their emotions was more beneficial to their overall stress (Grant & Whittell, 2000).

Mothers were more likely to utilize informal supports and seek outside assistance, an option many fathers considered undesirable. The threat of negative judgment by non-family members seemed to be a barrier for fathers who were more likely to rely on their spouses (Saloviita et al., 2003) and extended families (Pelchat et al., 2003) as primary sources of support. Although fathers may prefer to rely on family support, research has shown that fathers are more focused on issues external to the family, and mothers are more reflective and critical of their ability to provide quality childcare. Fathers have reported less tolerance of the biases and lack of skills displayed by extended family and professionals than have mothers. Further, mothers and fathers have demonstrated polarizing views of their circumstances with fathers perceiving more shared problem solving activities than mothers (Pelchat et al., 2003). However, culture may play a role in coping patterns as Latin American mothers have been found to rely more on formal supports and less on social supports than have Latin American fathers (Bailey, Skinner, & Correa, 1999).

Spiritual and religious coping behaviors. Mothers and fathers also differ with respect to their perception and utilization of spiritual and religious coping practices. Multiple studies have indicated that mothers are more likely to benefit from the ameliorative effects of spiritual and religious supports than are fathers. In a study of Asian Indian parents of children with disabilities, mothers reported greater reliance and benefit from their religious faith than other coping strategies. Fathers were more likely to engage in problem-solving strategies (Upadhyaya & Havalappanavar, 2008).

In a study of parents of children with disabilities, Blair (2003) examined the differences in mothers’ and fathers’ use of religious coping and found that mothers used religions coping strategies more frequently than fathers. Mothers were more likely to seek out support from religious leaders, use religion to create more positive meanings of their child’s disability, and use religion to find new directions in their own lives. However, mothers were also more likely to be discontented with their clergy, church, and fellow parishioners than were fathers.

Mothers have reported more diverse use of coping resources than fathers, including the use of religion to reappraise and create positive meaning of disability. In fact, the majority of mothers in Heaman’s (1995) study of parents of children with disabilities reported using prayer in the process of reappraisal. Fathers, on the other hand, were less likely to use diverse coping strategies and primarily relied on problem-solving strategies when faced with stressful challenges.

In Sullivan’s (2002) study of parents of children who had Down syndrome, gender differences were examined across 15 coping strategies. Sullivan conducted two comparisons of these parents; the first as a collective group, and the second comparing parents of children age 5 and under with parents of children who were over age 5. In the collective group comparisons, differences in mothers’ and fathers’ use of religious coping were evident. Mothers reported relying on this source of support more frequently than fathers. In fact, mothers’ reported use exceeded that of fathers on five additional coping strategies (i.e. planning, seeking instrumental social support, seeking emotional social support, suppression of competing activities, and focusing on and venting emotions). However, when Sullivan compared parents of young children with parents of children who were over age 5, he found gender differences in the use of planning and religious support was not evident among parents of children under age 5. It appeared that time and experience changed how parents utilized coping strategies. Over time, fathers engaged in less planning activities, whereas mothers increased their use of this coping behavior. Although both mothers and fathers increased their use of religious coping as children got older, mothers' use of this resource outpaced fathers' reliance on this source of support.

Religious beliefs have been reported to be a source of strength and a positive influence on perceived well-being among mothers more frequently than fathers (Grant and Whittell, 2000). Further, mothers have more frequently described their child as a "blessing from God" (Marshall et al, 2003, p. 68). Certainly, the experience of parenting a child who has a disability is different for mothers and fathers. Among these differences are the need for and use of spiritual and religious coping supports.

Spirituality and religion in the parenting experience. Research on the spiritual and religious experiences of parents of children who have Down syndrome are seldom conducted with the singular intent of understanding how faith impacts their parenting experience. In fact, even when spirituality or religion are key components of the research design, results are often comingled in studies that include parents of children with other disabilities. Of the following cited studies, less than one third focused primarily on exploring the impact of spirituality and religion in parenthood. The remaining studies focused on a variety of research issues concerning families and caregivers of children who have Down syndrome and other disabilities including parent/caregiver stress, depression, hardiness, strengths, coping behaviors, problem-solving strategies, life management techniques, adjustment, and the use of resources, accommodations, and social supports. Researchers have explored the maternal and paternal experiences of parenthood, aging parents, transformative experiences, diagnostic experiences, communications with professionals, and the positive impact of raising a child with Down syndrome. Additional research questions have focused on maternal perceptions of the child’s disability and the processes by which parents define Down syndrome, make meaning of the disability, and create hope for the future of their children.

Studies with mothers of children who have various disabilities. Only four of the studies that were designed to explore religious or spiritual parenting issues were conducted with mothers of children who had disabilities (Friedrich et al., 1988; Miltiades, 2002; Zuk, 1959; Zuk, Miller, Bartram, & Kling, 1961). In the first of these quantitative studies conducted by Zuk (1959), the primary research question focused on the association between mothers’ religious affiliation and their reported acceptance of their child with a cognitive impairment. In the 1961 quantitative study, Zuk partnered with colleagues to expand on his previous research. In this second study, social workers observed and evaluated mothers’ accepting behaviors toward their children, and these ratings were analyzed with demographic variables including religious affiliation. Friedrich et al. (1988) wanted to expand on this knowledge and understand how religious affiliation might influence coping behaviors. In their study with mothers of children who had various disabilities, they sought to explore the associations between the mothers’ religious beliefs and locus of control with their preferred coping behaviors. In a more recent quantitative study by Miltiades (2002), the researcher focused on mothers of adult children who had cognitive impairments and questioned how African American and White mothers differed in their use of religious coping. Although all of these studies included children who had cognitive impairments, the etiology of the condition was seldom addressed, and none of these studies included mothers of children with Down syndrome exclusively. Nevertheless, many studies have provided insight on the impact of spirituality and religion in the lives of parents of children who have disabilities. This section of the literature review will consider these studies collectively as they reflect the spiritual and religious experiences of mothers, fathers, and caregivers of children with disabilities including Down syndrome.

Studies with parents of children who have various disabilities. Numerous studies of parents of children who have disabilities have produced findings that indicate spirituality and religion are important positive resources that influence the process of coping in unique ways (Abbott & Meredith, 1986; Baker et al., 2005; Bennett et al., 1995; Dollahite, Marks, & Olson, 1998; King, 2001; Poehlmann et al., 2005). The significance of spirituality and religion as a coping strategy is based primarily on one's worldviews and beliefs (Bennett et al., 1995). For some parents, spiritual support or placing their faith in God has been reported to be their most frequently utilized coping resource (Moawad, 2012; Norizan & Shamsuddin, 2010; Pritzlaff, 2001; Van Riper, 2007). Prayer has been reported to be a primary source of spiritual and emotional support and provided a complimentary alternative to traditional medical approaches to improve well-being (Fox, Vaughn, Wyatte, & Dunlap, 2002; Prussing, Sobo, Walker, Dennis, & Kurtin, 2004; VanSolkema, 1997). This has been found to be particularly true for mothers who are more likely to access religious and spiritual supports in response to stress (Haworth, Hill, & Glidden, 1996; Upadhyaya & Havalappanavar, 2008). Faith in God has provided many parents with a source of support and "purpose behind their circumstances and affirmed the potential of suffering to produce positive results in their lives" (Scorgie, Wilgosh, & McDonald, 1996, p. 82). For others, spiritual support is just one of many resources utilized to cope with the stress of caring for a child with a disability (Poehlmann et al., 2005; Scorgie et al., 1996).

Religious affiliation and parents' age. Like stress, one's spiritual and religious experiences are fluid and are influenced by many changing variables over the course of one's life. Prior to the birth of a child, parents' spiritual and religious orientations can influence their morals, values, and responses to the stress associated with the birth and care of a child with a disability. In fact, stronger religious orientations have been associated with increased family-oriented behaviors that tend to strengthen family solidarity and support (Mahoney, O'Sullivan, & Robinson, 1992). Even religious affiliation has been found to impact parents' degree of acceptance of the birth of a child with Down syndrome. Religious affiliation can influence parents' perception of their child as a *cross to bear* or a *mission in life* (Zuk et al., 1961). Mothers who self-identified as Jewish, Protestant, or Atheist have reported higher rates of anxiety than have mothers who identify as Catholic or other unspecified Christian religions (Skotko, 2005). Mothers who affiliate with the Catholic religion have demonstrated higher rates of acceptance of their child with a cognitive disability than have mothers who were Protestant or Jewish (Zuk, 1959). The age of the caregiving parent may also impact how religious and spiritual coping practices are utilized. Several researchers have reported that older parents are more likely to engage in religious activities and more frequently utilize spiritual supports as coping resources (Grant & Whittell, 2000; Hayden & Heller, 1997; King et al., 2006; Sullivan, 2002; Willis, 2007).

Personal and spiritual transformations. The experience of having a child with a disability can be transformative. Parents have reported that it has renewed or strengthened their sense of spiritual connection, increased their religious faith, and brought them closer to God (Bennett et al., 1995; Hughes, 1999; Pillay et al., 2012; Scorgie & Sobsey, 2000; Scorgie et al., 1999; Stainton & Besser, 1998; Taunt & Hastings, 2002). Parents, particularly mothers, have reported that having a child with a disability makes them more compassionate, accepting, stronger, a better parent, and that their lives have been improved through the experience (Pillay et al., 2012). Faith has provided parents with guidance, patience, a sense of peace, personal fortitude and resilience in times of emotional challenge, and positively shaped the meaning of their child's disability (Blair, 2003; Haworth et al., 1996; Heaman, 1995; Lalvani, 2008; Poston & Turnbull, 2004; Rogers-Dulan, 1998; Treloar, 2002; VanSolkema, 1997; Zechella, 2014). Having a child with a disability has also encouraged family participation in social support groups such as church (Reichman, Corman, & Noonan, 2008). Even so, not all parents attribute their positive outlook to a belief in God. Rather, one's personal spirituality has frequently been referenced as an important component in transforming a child's disability from an experience of grief to one of gratitude (Scorgie et al., 1999) or from shameful punishment to thankful blessing (Marshall et al., 2003).

Bennett et al.'s (1995) qualitative study of parents of children who have disabilities including Down syndrome questioned how parents use religion as a support. In this study, religious practice included attendance at religious services and prayer. Religious beliefs that supported these parents included a faith that God had chosen them to parent their child, God had given them the strength and skills to properly parent a child with special needs, and that God would help them on their parenting journey. Although the majority of parents proclaimed that religion and faith were important sources of support in their parenting experience, this was not true for some parents who indicted religion was not important to them. For those parents who found strength in their religious engagement, it seemed this was only attainable if the church community was accepting and supportive of their child's disability.

In a qualitative study of parents of children with disabilities, Stainton and Besser (1998) explored the positive impacts having a child with a disability can have on families. Similar to most families, parents reported their children brought joy to their lives, increased their sense of purpose, increased family unity, and expanded their social network. Having a child with a disability also produced personal growth, strength, tolerance, and understanding. Overall, parents believed their child had a positive impact on their family and on the community. Religion was not identified as a positive impact by all families. For some families, religion simply was not a part of their daily lives. However, when families identified religion as a positive outcome of having a child with a disability, it was generally in reference to their enhanced sense of spirituality rather than a newly developed religious faith. Having a child with a disability seemed to improve parents' perception of their spiritual wellness.

Taunt and Hastings (2002) replicated the previous study by Stainton and Besser (1998) but expanded it to include questions about the benefits a child with a disability might contribute to siblings and extended family members. In this qualitative study, parents reported several benefits a child with a disability contributed to siblings and extended family including increased sensitivity, opportunities to learn, developed optimistic perspectives on life, increased maturity and pride, and improved family relations. Parents indicated they received these same benefits from having a child with a disability but added the additional positive benefits of having a happy child, increased social support, increased confidence, and strengthened religious faith.

A mixed method study conducted by Scorgie (1996) questioned the effective life management strategies of families who had children with disabilities and developed a scale to assess parent traits that were associated with effective management. The study also explored the life transformations these families experienced. Although transformation was found to occur in several areas of life including relational and life perspective, spirituality and religion were most closely associated with personal transformation. Parents frequently reported they would not have made it through the parenting challenges they encountered without their faith, they were stronger for the experience, and their spiritual beliefs were fortified. This transformation was not a philosophical shift, rather it was a renewal and strengthening of a belief system that had been established prior to the birth of their child. The effective parent traits identified in this study and subsequent similar studies by Scorgie included optimism, hopefulness, flexibility, patience, fortitude, effective problem-solving skills, strength, and confidence (Scorgie, et al., 1999; Scorgie & Sobsey, 2000). Interestingly, parents in other studies have mentioned many of the parent characteristics that were identified as important for effective parenting including supportive benefits received through religious and spiritual faith and practice.

Chronological shifts in spirituality. Hughes (1999) conducted a study that questioned families' use of religion to create meaning and enduring hope for the future of their children following the diagnosis of a disability. The results of this ethnographic study indicated the role of religious support changed over the course of the child's life. At the time of the children’s diagnoses, about half of the families reported a strong religious faith. By the time the study was conducted, religious conviction had increased to include the majority of these parents. Most of the children in this study were age 6 to 10, yet it is unclear how long it took for this transition to evolve for parents as some of the children were quite young. Nevertheless, over two-thirds of these parents said their relationship with God was better than it had been at the time of their child’s birth, and 94% reported a hopeful outlook for the future of their children. For these parents, having a child with a disability enhanced their religious engagement which, in turn, increased the support they obtained from this resource.

Spiritual and religious coping and resilience. Increased use of spiritual and religious coping behaviors has been associated with decreased levels of family stress, but how these factors help to reduce stress is uncertain (Abery, 2006). For some parents, religiosity has been found to buffer the stress and potential depression associated with caring for a child with a disability especially regarding child-related issues such as behavior problems and physical limitations. Increased use of religious coping strategies has also been associated with decreased levels of pessimism which is associated with depression. In other words, increased use of religious coping fosters optimism which is associated with greater overall well-being (Friedrich et al., 1988). Those who consider themselves to be more religious have also been found to be more organized in their family structure which, in turn, was a strong predictor of positive family environment, increased external support, and decreased levels of stress (Gousmett, 2006). Higher rates of religiosity have been linked to higher levels of acceptance of children with the disabilities (Zuk et al., 1961). Church attendance, and the support of a religious community and spiritual leaders have provided parents with emotional support, serenity, and a sense of belonging and hope (Bennett et al., 1995; Brasfield, 2008; Kausar, Jevne, & Sobsey, 2003; Marshall et al., 2003; Rogers-Dulan, 1998; Scorgie et al., 1999). In addition, prayer has frequently been identified as a useful approach to positively reframe the child's disability (Heaman, 1995). The most frequently reported benefits of spirituality or religion include providing strength and optimism. This is significant since optimism has been found to be a moderator for parental well-being (Baker et al., 2005; Greenberg et al., 2004).

A willingness to seek spiritual support has been positively associated with a family's ability to reframe challenges mobilizing them to reach outside the family unit to obtain additional coping resources (Lustig, 2002). A process of reciprocal enhancement is created when the parents' increased participation in religious activities results in greater supports from the religious community thereby improving the family's coping skills and resources and enabling them to continue to access additional support (Hughes, 1999). Religious supports can also be a source of instrumental (e.g. cooking, cleaning), emotional (O'Hanlon, 2009), and financial support, but this is often dependent on the families' making these needs known to others (Pillay et al., 2012). However, the benefits of spirituality and religion are derived not only through receiving but also the act of giving. When parents have been able to contribute to their religious community by sharing their expertise on disability to educate others, they gained a sense of appreciation, belonging, and personal value (O'Hanlon, 2009).

Engagement in a religious community is not an inevitable occurrence even among those who report strong spiritual or religious connections, and the benefits of participation are influenced by many factors. For some parents, seeking support from spiritual leaders has not been helpful (Churchill et al., 2010; Friedrich, 1979; Hall et al., 2012; Hastings, Allen, McDermott, & Still, 2002; Hastings & Brown, 2002; Oh & Lee, 2009; Pritzlaff, 2001; Speraw, 2006). In Churchill et al.'s study of coping and depression in parents of children with chronic health conditions, seeking advice from a minister was utilized by only 16% of the participants placing this source of support in the bottom 20% of reported utilized resources along with sharing problems with neighbors, relying on luck to resolve problems, watching TV, or simply waiting for problems to disappear. However, having faith in spirituality was reported as an important coping support by 67% of these parents placing it in the top 20% of utilized resources along with acceptance, facing problems to find solutions, positive reframing, seeking advice from physicians, and sharing problems with close friends.

Religious leaders as a coping resource. Speraw's (2006) qualitative study of parents' experiences seeking religious education for their children who have disabilities unveiled disheartening outcomes when parents approached religious leaders for guidance. Overwhelmingly, the parents in this study were told the church was not prepared to meet the educational needs of their child, and they would have to teach their child on their own. Only in a few instances did parents report support from religious leaders when pursuing spiritual education for their child.

In a study of Korean mothers, Oh and Lee (2009) found that although the majority of mothers reported religious affiliations, they were unlikely to seek out supports from ministers or from church parishioners. Unfortunately, these parents were just as unlikely to seek support from their paternal extended family members, friends, co-workers, other parents of children with disabilities, social groups, or other medical and service professionals. The researchers surmised the culturally-specific negative attitudes toward disabilities prevented mothers from seeking support outside the immediate family unit.

In Pritzlaff's (2001) examination of coping behaviors in parents of children who have disabilities, seeking spiritual support was the least utilized coping strategy and was greatly exceeded by accessing social support and positive reframing. However, despite the overall perception that spiritual support was infrequently utilized, the survey item that was most strongly agreed upon by these parents was the importance of their belief and faith in a Higher Power or God. The decision to not utilize spiritual leaders or formal spiritual supports does not mean spirituality was unimportant to these parents.

Some parents have actively sought advice and support from religious leaders (Bennett et al., 1995; Blair, 2003; Leyser & Dekel, 1991; Rogers-Dulan, 1998). In fact, some parents have reported that spiritual faith is their most frequently accessed coping resource but religious engagement was utilized less often (Churchill et al., 2010). In some cases, parents have reported that spiritual support is more readily available from other parishioners than from religious leaders (O'Hanlon, 2009). Other parents reported that religious involvement was an important coping resource (Gupta, Mehrotra, & Mehrotra, 2012), but this was strongly associated with their child's acceptance and integration into the church community (Merrill, 2010; Pillay et al., 2012; Treloar, 2002).

Religious accommodations. Families have identified specific accommodations churches can implement to help them manage life with a child with a disability. These accommodations have included Sunday school classes that met the needs of their child and offered an opportunity for them to interact with developmentally similar peers (Maul

& Singer, 2009). For parents, the acceptance of their child by the church community was critical to their own inclusion. If their child was not well-integrated into the church community, parents often felt misunderstood, unsupported, and even rejected (Gaventa, 2012; O'Hanlon, 2009). This unfortunate outcome diminished some parents' ability to be renewed through prayer and religious participation (Speraw, 2006).

Religious narratives and beliefs. Religious narratives of disability have encountered mixed responses from parents as they struggle to define the experience of parenting a child with a disability. Sometimes this narrative has included moments of anger with God, and at other times children have been viewed as enriching life lessons (Landsman, 1998). When mothers and fathers are ascribed the status of *special*, *saint*, or *chosen*, and the child is labeled a *blessing* or *gift*, society is attempting to define these families' experiences. Sometimes parents have perceived these ascribed narratives as a source of comfort, support, and inspired meaning (Brasfield, 2008; Lawrence, 2008b; Nugent, 2011). However, sometimes these unrequested characterizations have become unappreciated, unwanted, or even rejected notions as they placed unrealistic expectations on parents to heroically overcome the challenges of caring for a child with special needs (Lalvani, 2011). For some parents, reframing the idea of the child as a spiritually-given gift to one in which the child is the spiritual gift-giver resonated more meaningfully (Landsman, 1999). Whichever narrative parents have chosen to adopt, research suggests that the story that is most meaningful to parents has been the one most likely to result in improved well-being. Further, self-narrated stories that include elements of trials, tribulations, and overcoming obstacles have been associated with personal growth (King, Scollon, Ramsey, & Williams, 2000).

Although spiritual and religious coping experiences are generally reported positively, negative outcomes are also possible and have been identified in numerous studies. Parents experienced negative outcomes when religious communities failed to offer help or alienated families. Negative experiences have developed when spiritual or religious beliefs promoted parents’ perceptions of disability as a cause for personal guilt, self-blame, divine punishment, bad karma, or a curse (Haworth et al., 1996; Poston & Turnbull, 2004; Rogers-Dulan, 1998; Zechella, 2014). Religious beliefs can inform parents of what treatments and interventions are acceptable or appropriate for their child, in some cases, limiting access to services (Blanks & Smith, 2009). Some parents have been discouraged by their church’s lack of instrumental support and disappointed by the church’s failure to adequately address disability issues (King, 2001). Specific areas of concern voiced by parents have included unwanted advice from church members and fears of how their child might fail to fit in or meet religions expectations (Marshall et al., 2003). In some instances, families have been unable to access religious resources as their communities did not offer adequate or effective supports to their children (Turnbull & Ruef, 1996). This negative assessment is important because the perception of available supports is sometimes more important to overall well-being than the actual support (Weiss, 2002). Further, the negative perception of the church community as a failed source of support has been associated with higher rates of stress among parents (Hall et al., 2012).

Cultural influences. At this point, I want to return to the issue of culture. As components of culture, spirituality and religion are intertwined and woven into life experiences in unique ways based, in part, on cultural background (Bennett et al., 1995).

Parents create meaning of their child’s disability within the context of their cultural experiences (Lalvani, 2008). In some instances, religious beliefs are ingrained in societal attitudes and beliefs about disability and provide the foundation for not only understanding disability but also in the acceptance, response to, and treatment of disability (Bryant, Ahmed, Ahmed, Jafi, & Raashid, 2011).

In a recent quantitative study of Israeli parents of children with disabilities, Manor-Binyamini (2012) examined the influence of religion, resources, and sense of coherence on family coping behaviors. Manor-Binyamini examined the differences between religious and non-religious parents and found that ultraorthodox Jewish parents reported a higher sense of coherence and greater personal growth from their parenting experiences than did secular Jewish parents. In fact, as the child’s disability severity increased, ultraorthodox Jewish parents reported greater rates of personal growth. This was not the case for secular parents. The researcher speculated that ultraorthodox parents believed that parenting a child with a disability was a God-given trial, one that was accompanied by God-given abilities to face the challenges before them.

In a mixed methods study of Pakistani parents of children with Down syndrome and the professionals who worked with these children, Bryant et al. (2011) reported that although religious beliefs did not overtly direct perceptions of prenatal testing and Down syndrome for everyone, it was significantly influential for many. Approximately 30% of the respondents believed Down syndrome was the product of Allah’s/God’s will and was a blessing to parents chosen to care for the child. Another 30% of respondents believed Down syndrome was the will of God/Allah, but the child was perceived to be a burden, challenge, or trial in life. Seldom was Down syndrome considered an error as this questioned fundamental beliefs that Allah/God was infallible and that one's destiny is preordained. Among this group, there was consensus that people with Down syndrome had rights and that knowing a person who had Down syndrome was enriching.

Leyser and Dekel (1991) conducted a mixed method study with Israeli parents of children who had disabilities and the professionals who worked with these children. Over three-fourths of the orthodox Jewish parents in this study asked their rabbi for advice, a pattern that is not as frequently reported in Western cultures. These parents also expressed little concern regarding the future of their child as they trusted this outcome to God, having faith He would support them through their parenting journey.

Skinner et al. (Skinner, Bailey, Correa, & Rodriguez, 1999) reported that over half of Latina mothers of children with Down syndrome who lived in the U.S. considered their child a sign from God, and two thirds believed their child strengthened their relationship with God and made them better people. Cho et al. (2005) reported that Korean parents were more likely to hold a punitive view of their child's disability as the result of their own poor moral behavior. However, Korean American parents were more likely to see the disability as part of a transformative divine plan that ultimately benefited the family.

Zechella's (2014) reported similar findings from her investigation of parenting experiences among Asian Indian mothers and fathers who had immigrated to the United States. In this qualitative study, parents of children with disabilities including Down syndrome frequently reported beliefs that their child's disability was the result of a curse, bad karma, or an intentionally negative endowment from God. However, these parents also believed their child had a predetermined purpose in life consistent with Hindu religious beliefs. Although these parents did not consistently report religion as important in their everyday lives, it was evident their worldviews were grounded in the Hindu faith which influenced perceptions of their children's disabilities.

In a qualitative study by Taylor et al. (Taylor, Wall, & Liebow, 2005), spirituality was a prevalent theme in the narratives of minority mothers of children with disabilities but not in the narratives of White mothers of children with disabilities. An earlier study by Miltiades (2002) produced similar results indicating African American mothers of children with disabilities are more likely to draw on religious coping to positively frame the caregiving experience than were White mothers. A similar result was found in King's (2001) qualitative study of African American parents who reported faith as their number one coping resource. However, cultural influences are associated with more than race and ethnicity as demonstrated by Brasfield's (2008) qualitative study with rural mothers. In Brasfield's study, all of the mothers, without exception, identified spirituality and religion as the most significant coping resources available to them along with church and prayer. The lack of extensive supports available in rural areas positioned the church as a center of community support. From these studies, it is evident cultural influences can evolve from nationality, race, ethnicity, and geographical differences. Studies conducted by Zuk (1959), Skotko (2005), and Willis (2007) identify religious affiliation as a culturally influential variable as well.

Studies with parents of children who have Down syndrome. The information provided in this section of the literature review was derived from studies that included parents of children who had Down syndrome. However, children with Down syndrome are sometimes subsumed into larger disability groups such as intellectual disability, cognitive impairment, or mental retardation. Some of the above studies did not identify the etiology of the child's disability as Down syndrome. Nevertheless, if the disability group was one that might contain children who had Down syndrome, the study was included in this review. With that said, only twelve of these cited studies focused exclusively on parents of children who had Down syndrome, and only seven of these were conducted within the United States (Lalvani, 2011; Mussett, 2012; Nugent, 2011; Prussing et al., 2004; Skotko, 2005; Van Riper, 2007; Willis, 2007). Of these seven studies based in the U.S., only two (Mussett, 2012; Willis, 2007) were designed to explore the spiritual or religious experiences of these parents.

The first of these two studies was a quantitative study conducted with parents of children age 1 to 10 who have Down syndrome (Willis, 2007). In this study, Willis examined the relationships between parental prayer practices, religion, spirituality, and well-being. Findings from this study identified a positive relationship between increased prayer engagement and religious well-being and overall spiritual well-being. Parents who self-identified as Catholic reported lower rates of daily prayer activity than did parents who affiliated with the Evangelical or Protestant faiths. However, regardless of one's religious affiliation, prayer activity was positively associated with existential well-being suggesting prayer was related to positive meaning making in life.

The second study conducted in the U.S. included parents of minor and adult children with Down syndrome (Mussett, 2012). The participants in this study responded to an online survey and represented a diverse parent group spanning 33 states. This quantitative study examined the impact of positive and negative religious coping on spiritual and posttraumatic growth. The diagnosis of a child's Down syndrome was the point of trauma from which growth was measured. Mussett found that parents who engaged in positive religious coping (i.e. practices that produced a sense of connection with God and community and added meaning to life) at the time of their child’s diagnosis tended to retain this coping strategy throughout life. In fact, most parents that participated in this study reported moderate to high levels of positive religious coping. Negative religions coping (i.e. practices that created doubt in one’s relationship with God and the world and failed to create positive meaning in life) was reported less frequently at the time of the child’s diagnosis and tended to diminish even further with time. However, spiritual growth and posttraumatic growth were most evident among those parents who had experienced a spiritual struggle following the birth of their child and had resolved this crisis through positive religious coping. If the spiritual struggle remained unresolved, the most likely outcome would be a spiritual decline. A resolved spiritual struggle appeared to be necessary for spiritual growth to develop and was a strong predictor for posttraumatic growth as well.

Both of these studies provide information specific to the experiences of mothers and fathers of children with Down syndrome. However, aside from these two studies, there has been no other research specifically designed to explore the religious and spiritual experiences of parents of children who have Down syndrome within the United States. In addition, there has been no research conducted on spiritual and religious coping solely with mothers of adult children who have Down syndrome. The literature available on this topic has been derived, in part, from studies of parents of children with various disabilities. Additional information has been obtained from smaller components of studies on parental coping. The majority of research data on religiosity and spirituality in parents of children with Down syndrome has arisen from the qualitative design or design components of research studies.

Qualitative Research on the Spiritual and Religious Experiences of Parents

The above cited studies on spirituality and religion include a combination of qualitative, quantitative, and mixed-method studies. Approximately 36% were quantitative studies, almost 19% were mixed-method studies, and approximately 45% of the studies were qualitative. The practice of utilizing qualitative methods to study spiritual and religious issues in parenthood is evident in this body of research. Even so, the use of qualitative methods to understand the experiences of these parents has just begun to explore the complexity of these abstract phenomena, and the use of phenomenological methods to describe these experiences has rarely been employed.

Considering the cited qualitative studies that were designed to explore spiritual and religions issues in parenthood, none were conducted solely with mothers, and none were conducted exclusively with parents of children who have Down syndrome. Nevertheless, they all provide insight into parents' spiritual and religious experiences and some are closely related to the current research study.

Bennett et al. (1995) explored family adaptation and the use of religion as a coping resource across the lifespan. This study was conducted with parents of minor and adult children who had various disabilities including Down syndrome. Church attendance was a source of support for some parents as it created connections with church members and clergy who expressed acceptance of the child's disability and who provided emotional support to the family. For some parents, religious beliefs supported by church doctrine and religious scripture created a sense of hope for the future as it explained the purpose and meaning of their child’s disability. This optimistic perspective helped parents reframed their child’s disability transforming the situation from one of despair to one in which they could overcome and thrive. Religious narratives that proclaimed the child as a blessing, parents were chosen, God would provide the strength needed to face challenges, and that God would aid them along their parenting journey helped bolster parents’ perspectives of life with a child who has a disability.

Marshall et al. (2003) also examined family adaptation as well, yet they explored the influence of religious and spiritual beliefs among Latter-Day Saint families who had a child with a disability. Religious beliefs were present in the narratives of these families in times of despair as well as in times of achievement. Parents consistently identified three assets they obtained from religious participation, including a greater sense of strength, a sense of belonging, and support through inclusion in religious activities and prayer. Families also expressed concerns regarding religious issues. These concerns sprang from unwanted advice offered by church parishioners, fear of not being accepted by the church community, and fear that their child would not be able to meet church expectations and participate fully in the church. Overall, families viewed raising a child with a disability as a spiritual experience that was divinely offered to them by God.

Hughes (1999) explored families’ use of religious practice and faith in the process of making meaning of their children’s disabilities and hope for the future. This ethnographic study focused on parents of young children age 6 to 10 as it questioned their adjustment following the diagnosis of their child’s disability. The majority of parents in this study reported that religious faith was a significant source of strength and support in their lives. This is significant since less than half of these parents reported strong religious faiths prior to their child’s birth. Parents frequently attributed their spiritual growth to the experience of raising a child with a disability. The usefulness of support offered through spiritual leaders was polarized with parents reporting either little to no support or a great deal of support.

The King (2001) qualitative study examined the use of spirituality among older African American caregivers of children with a variety of disabilities. King found that African American caregivers generally reported greater support from their spiritual and personal religious beliefs than they did from the church. Church offered some instrumental and social support, but this was less frequent than expected. Generally, prayer, faith, and a belief in God as a divine companion provided them with support, guidance, and comfort. Similar to other religious families, African American caregivers were not overly concerned about the child’s future as they had faith that God would provide what was needed.

Poston and Turnbull’s (2004) study explored family perceptions of quality of life with a child with a disability. The analysis of this qualitative study identified 10 themes about family quality of life. Religion and spirituality were included in these themes and identified as a significant component of families’ emotional well-being. For these families, faith gave them strength and helped them make sense of their lives. Prayer was reported to be a source of comfort and a means to communicate with God. Religious faith helped some parents make meaning of their child’s disability. Finally, the issue of church attendance and participation yielded conflicting reports as some parents considered this to be a source of support and place of acceptance, and others found church to be a challenging, unaccommodating, and even rejecting environment.

Treloar’s (2002) interpretive study posed research questions that more closely resembled this study as she explored families’ and caregivers’ use of spiritual beliefs to create new meanings and respond to changes due to disability. The children in these families included both minors and adults who had various developmental disabilities or physical disabilities. Participant responses were obtained from persons with disabilities and parents. All the participants in this study were evangelical Christians. Most of the participants in this study believed church was an important source of support which was particularly important to the parents in this study. Several participants expressed a need for the church to establish clearer theology about disability since some biblical narratives are conflicting and unclear. Overall, participants indicated a belief that God helped them find meaning in their disability and a purpose in life.

Among the cited studies that were designed to explore parents’ spiritual and religious issues is a phenomenological study based in Tennessee. In this study, Speraw (2006) interviewed 26 parents and caregivers of children with various disabilities who ranged in age from 4 to 28 years old. The focus of the research was to explore these caregivers’ experiences as they sought to locate formal religious education for children with special needs. Speraw reported that parents believed their child had an enhanced spiritual connection with God and that this was often unrecognized and unacknowledged by others. Although some parents felt supported in their church communities, many parents felt the needs of their child were not adequately addressed by the church. Consequently, these parents felt unsupported and rejected when church communities failed to recognize and support their children. From a theoretical standpoint, this study was more closely aligned with this research than any of the other cited works. However, the research participants and the research questions under study were different from those included in this phenomenological study.

Considering the cited qualitative studies that were not designed to explore spiritual and religious parenting issues but which produced some related data, nine were conducted solely with mothers (Brasfield, 2008; Lalvani, 2011; Landsman, 1999; Lawrence, 2008b; Merrill, 2010; Nugent, 2011; Pillay et al., 2012; Poehlmann et al., 2005; Skinner et al., 1999; Taylor et al., 2005). Of these nine, only three were conducted solely with mothers of children who had Down syndrome (Lalvani, 2011; Nugent, 2011; Pillay et al., 2012). Of these three, one was conducted in Australia (Pillay et al., 2012), leaving only two studies reporting the experience of American mothers (Lalvani, 2011; Nugent, 2011).

The Lalvini (2011) study was a sociocultural psychology study of 19 mothers of young children, under age 7, who had Down syndrome. The study was designed to explore these mothers' experience of motherhood with particular attention to the process of diagnosis, interactions with professional and social peers, family dynamics, and expectations regarding education and the child's future. The participants in this study were similar to the participants in the current study, but they represent a group of mothers of minor children rather than adult children. Further, the qualitative approach and the research questions were aimed at understanding a different construct (i.e. experience of diagnosis) and focused on experiences situated early in the parenting experience.

The Nugent (2011) study implemented a qualitative narrative approach with four young mothers who had pre-school children with Down syndrome. The focus of the study aimed to explore how these women's lives had been altered following the birth of their child. The researcher also explored the effectiveness of the adaptations these women had implemented in their lives. This study differed from the current study on several points. The participants in this study represented mothers of minor children rather than adult children, and the theoretical framework and research questions were designed to address different concerns.

Based on this literature review, it is apparent a qualitative study can offer new insight into how spirituality and religion are experienced. This study considered the role of spirituality and religion as a coping strategy in the creation of meaning, perception, and hope in the lives of mothers of adult children who have Down syndrome. The following chapter describes the theoretical, methodological, analytical, and ethical practices utilized during this research project.

Chapter 3

Methodology

The influence of spirituality and religion among mothers of adult children who have Down syndrome has received limited attention in the professional literature. The use of qualitative research is evident in the literature, but the methodological approach of phenomenology is less prevalent. Most of the qualitative research aimed at exploring parents' use of spirituality and religion as a coping resource has been conducted with mothers and fathers of children with various disabilities, and some research reflects the religious experiences of parents who live in other countries. None of the research studies in this literature review were aimed primarily at understanding the spiritual and religious experiences of mothers of adult children with Down syndrome who live in the United States.

The purpose of this research was to understand and describe how the spiritual and religious experiences of mothers influence the way they define Down syndrome and thereby their perceptions of the personal worth of their children, the stress associated with parenting, and the development of hope for their children's future. The central research question was, "What is the experience of spirituality and religion in the parenting process of mothers of adult children who have Down syndrome?" The four sub-questions that guided the exploration of this central question included:

1. How do spirituality or religion create or reduce meaning with regard to the child's diagnosis of Down syndrome?
2. How do the systemic patterns within organized religion influence positive or negative perceptions of Down syndrome?

3. How do spirituality or religion alleviate or aggravate the stress associated with raising a child who has Down syndrome?
4. How does spirituality or religion create or thwart hope for the future of a child who has Down syndrome?

This chapter identifies the theoretical and methodological foundations of the research, describes the use of specific methods of inquiry, and reviews the trustworthiness and ethical considerations of the research protocol. This chapter also includes an explanation of my subjective position and relationship with this research project, delineates the procedures for participant selection, and outlines the methods of data analysis and presentation.

Methodological Framework: Phenomenology

A qualitative research approach is well suited for existential issues such as spirituality, religion (Magrini, 2012; van Manen 2014), and the process of meaning-making surrounding a child's disability. Qualitative research has the potential to yield more personally-meaningful data from these types of subjective experiences than does a quantitative approach. Further, a qualitative approach does not bind the data to a set of predetermined hypotheses, which can limit researchers' ability to understand social and abstract phenomena (Boston, Mount, Orenstein, & Freedman, 2001). Rather, research outcomes can be meaningfully enriched through qualitative methods that explore the spiritual and religious experiences of mothers of children who have Down syndrome with new and distinct perspectives facilitating deeper understanding of mothers' intimate experiences of this cultural phenomenon (Cuskelly, Hauser-Cram, & Van Riper, 2009; Devenny, 2006; Heaman, 1995).

A phenomenological approach was used in this qualitative research study. From this constructivist epistemological foundation, the research goal was to understand and describe (Gannon & Davies, 2012) these mothers' perceptions of the spiritual and religious messages conveyed about parenting an adult child who has Down syndrome. Phenomenology is a "philosophical approach to the study of experience" (Smith et al., 2009, p. 11) with the aim of understanding how experiences are perceived and how they shape our lives (Groenewald, 2004). Phenomenologists understand that reality and truth are relative constructs and dependent on one's conscious perspective, a point of view that changes across time and context (Vagle, 2014; van Manen, 2014). Consequently, phenomenology helps researchers attempt to understand experiences within the context in which they occur and from the perspective of the individual without presuming any predetermined meaning (Smith et al., 2009). According to van Manen (as cited in deMarrais, 2004), phenomenology attempts to understand the internal meaning structures of a lived experience. These ideas suggest that the essence of spirituality and religion as a coping resource for mothers of children who have Down syndrome can be understood best by studying instances in which mothers have encountered and lived the experience.

Ideally, phenomenology seeks to understand a phenomenon the moment it is experienced before it is reflexively internalized, thematized, and named (van Manen, 2014). This is consistent with some of the earlier phenomenologists such as Heidegger who viewed phenomenology as an attempt to understand experiences primordially before they were situated within a social context. Yet, Heidegger's concept of Dasein, the quality of being human, acknowledged the complexity of human existence as a state of being prior to the shape-shifting influences of social and cultural scripts, which mold the human experience (Crotty, 1998). Van Manen (2014) pragmatically suggests phenomenologists should aim to capture experiences of a phenomenon by bracketing out presumptions and preconceived notions about an experience as well as acknowledging the contextual and temporal influences that shape one's experience of a phenomenon. Consequently, van Manen proposes that some phenomena can be studied in the moment of the lived experience and reflexively.

For this study, the aim of this phenomenological research was to see past the socially-scripted interpretation of these mothers' experiences in order to unveil the essence or true nature of their personal understanding of religion and spirituality in the parenting process (Creswell, 2007) as well as recognize the socially contextual influences of their spiritual and religious mothering experiences. This required mothers to consider and describe their spiritual and religious experiences as lived experiences in the present and reflectively as they recollected how these experiences had been present throughout their mothering journey.

Methods

Interviews. Phenomenology is a theoretical framework and methodological approach (van Manen, 2014) that "enables researchers to examine everyday human experience in close, detailed ways. Through face-to-face interviews, this form of inquiry encourages the discovery of the meaning people place on their lived experiences" (deMarrais, 2004, p. 56). According to Coyle (2008), phenomenological methods allow participants to construct and describe their spiritual and religious experiences in their own terms, creating their own meanings. Similarly, Vagle (2014) suggests that a phenomenological approach is appropriate for researchers who are seeking to describe subjective phenomena that are complex and ambiguous, such as spirituality and religiosity. These points contributed to my decision to use phenomenology as a theoretical framework for this study because my research questions included concerns regarding the experience of spirituality and religion in the meaning-making of a child's disability, all nebulous and complex constructs. Face-to-face, semi-structured or unstructured interviews are commonly used methods in phenomenological research for acquiring insight about participants' thoughts, perceptions, and feelings about experiences (deMarrais, 2004; Vagle, 2014). Semi-structured interviews were the primary means of data collection utilized in this research. Journaling, memoing, field notes, and member checking contributed to the data as a method of bracketing out and questioning presumptive influences and documenting this practice, which added credibility to the data collection process and analysis (Birks et al., 2008; Carlson, 2010; Lincoln & Guba, 1985; Preissle & Grant, 2004; Rodham, Fox, & Doran, 2015).

After receiving approval through my university's Institutional Review Board (IRB), I used a recruitment flyer to invite individuals who were interested in participating in this study to contact me by telephone, email, or through other personal outreach. (See Appendix A for a copy of the recruitment flyer.) Once individuals expressed an interest in becoming a research participant, I contacted them by phone or email to briefly explain the research process and time commitment, ensure they met the eligibility criteria, and schedule an initial meeting. This initial meeting was used to establish rapport and address the participant's questions and concerns regarding the interview process. During the initial meeting, I verbally reviewed and explained the informed consent form and obtained the participant's signature. (See Appendix B for a copy of the consent form.)

The initial meetings lasted between 30 minutes and one hour. Although I did not record these initial meetings, I documented the process in my field notes and reflexive journal. During these meetings, I provided participants with a copy of the consent form and a sample of potential interview questions to allow adequate time to read the material and identify any additional questions or concerns they might have prior to the first recorded interview. (See Appendix C for the abbreviated interview sample questions.)

Following the initial meetings, I met with and interviewed each participant on three separate occasions lasting between 45 minutes to two hours each time. The participants and I mutually selected the day, time, and location of each meeting. I asked the participants to select an interview location that was private and had minimal interruptions and distractions. I hoped that allowing the participants to select the location of the interview would ensure they were comfortable in the interview space and would feel less inhibited in sharing their stories. I interviewed four of the participants in their homes, one participant in her private work office, and one participant in a private room at a public library.

I used a semi-structure interview guide to maintain some consistency across interviews. (See Appendix D for the semi-structured interview guide.) The interview guide included primary interview questions linked to my central research question and each of the sub-questions as well as additional probes to explore further if needed. Although I addressed all of the primary interview questions, I used the secondary probes inconsistently depending on the participants' responses. The primary interview questions included the following:

- As a mother with a child who has Down syndrome, what is it like to have religion and/or spirituality in your life?
- What does your religion/spirituality tell you about your child’s diagnosis of Down syndrome?
- How does your experience of religion and/or spirituality contribute to your view of your child’s disability?
- How do you experience or feel about the messages religion and/or spirituality convey to you about your child’s future?
- What is it like to have religion and spirituality in your life as you cope with the daily challenges of raising a child who has special needs?

In order to maintain continuity and connection with the data, I followed an orderly system throughout the interview process. Within two weeks of the first recorded interview, I returned the verbatim interview transcript to the participant for review, and we scheduled the second interview within the next two-week period. Similarly, within two weeks following the second interview, I returned the second verbatim interview transcript to the participant, and we scheduled the final interview within the next two-week period. When returning the second interview transcripts, I included the first transcript so participants could review their story in full if they wished to, and some did.

This protocol was disrupted only twice: once when a participant was unavailable due to a preplanned holiday and once when a participant had an unexpected illness. The second and third interviews offered participants an opportunity to engage in member checking as they verified the accuracy, or inaccuracies, of the transcribed interviews. Through this process of member checking, participants had the opportunity to consider their transcribed stories and make any changes they believed would improve the representation of their experiences (Carlson, 2010; Groenewald, 2004; Lincoln & Guba, 1985; Preissle & Grant, 2004; Rodham et al., 2015).

When I began this research journey, I expected the initial interviews would be the primary data collection point, the second interviews would focus on clarifying information previously presented, and the final interviews would be optional and used for debriefing. That was not the case. During the second and final interviews, participants provided feedback and clarification on the interview transcripts as anticipated, but they also continued to amend their story offering additional input to represent their experiences fully. As several participants indicated during the second and third interviews, they considered their initial interviews to be incomplete or unbalanced, and additional information was necessary to understand their experiences. Consequently, when offered the option of a third interview, all six participants elected to meet with me. I had not initially planned to record the third interviews, but after the first two participants completed their final interviews, I realized that new information was arising; therefore, I offered the last four participants the option to record their final interviews, which they all elected to do. I transcribed the third interviews but did not share the transcripts with the participants for further critique. Even though new information arose during the final interviews, debriefing was integrated into these meeting and each mother reported she had described her experiences thoroughly. By the conclusion of the final interviews, I had interviewed each of these mothers between four to six hours. Although these mothers had told stories about their children to friends and family, this was the first time they had shared their spiritual and religious mothering stories with such depth and it was cathartic.

Each mother described the experience as rewarding because of the opportunity to reminisce, to reflect on a life of overcoming challenges and achieving successes, to evaluate their own spiritual journey, or simply to share the day-to-day joys of living with their child. For me, as the researcher, it was an emotional and rewarding process, which produced rich, thick descriptions of these mothers' experiences.

Journaling, memoing and field notes. Journaling and memoing served different but sometimes overlapping purposes. Both were written as a personal dialogue similar to a diary, except the content of my reflexive journal and memos were related to the research topic in some way. Unlike my journaling, which was maintained in one document, my memos were dispersed throughout my journal, in the track change notations embedded in the interview transcripts, and sometimes included in the transcripts so the participants had an opportunity to review and comment on my thoughts. Memoing served a variety of functions including the creation of a chronological tracking map of my research plans, reflexive questioning, and analytical considerations as they developed throughout the data collection and analytical process. Memoing provided the instructional foundation for how my research was ultimately carried out and analyzed (Schwandt, 2007). Memos facilitated thought processes that encouraged meaning extraction from raw data (i.e. interviews), and they encouraged communications or mental dialogue between the data and me. One of the key functions of memoing was to promote my writing and thoughtful engagement in the data from the onset of the study and to maintain this momentum throughout the research process (Birks et al., 2008). Although memoing is sometimes used as a reflexive tool to bracket out researcher biases, I used journaling for this function.

Whereas memoing is more concerned with the theoretical cognitive aspects of the research process, journaling refers to a written dialogue where researchers report their psychological and emotional journey through the research process (Birks et al., 2008). Journaling is a reflexive process that allows the researcher to track cognitive shifts in thinking as they react to the collection and analysis of the data. Journaling is an exploration of the researcher's emotional responses to the research process or participants. It is a space for curious questioning and addressing uncertainties and a method of confronting biases and assumptions based on personal beliefs and values that may interfere with data analysis (Carlson, 2010; Rodham et al., 2015; Vagle, 2014). I used journaling to document and explore my cognitive and emotional reactions to the research process, the interviews, the transcriptions, the analysis, the writing, and the overall experience of completing a dissertation. Although all of my journal entries are connected to my research experience in some way, I was surprised to see the personal relationship between the research and myself. Cognitively, I understood that journaling was a valuable tool to bracket out my life experiences, preconceived sense of knowing, and personal values from the research data, but to witness the intensity of these intimate pieces of myself accumulate throughout the pages of my journal was startling. (See Appendix E for excerpts from my journal, which includes memos and reflexive journal entries.)

Field notes are similar to journaling and memoing as they provide another form of researcher notes to self. In the case of field notes, the focus centered not on the process of analysis or researcher reflexivity but rather on what was observed in the process of data collection in the field, or, in the case of this study, observations made during the interview process (Denzin & Lincoln, 2005). Only parts of the interviews were captured in the recorded and transcribed narratives of the participants' stories. Much of the communication that occurred during the interviews was not audibly detectible and included non-verbal communications as well as elements that were left unsaid but were known to me. Additionally, the context of the interview setting and the context of the interview in time was nonverbal but relevant information (DeWalt & DeWalt, 2002). All of these elements influenced the interview and contributed to the overall meaning of the participant's spoken words. These elements were not captured in the interview transcripts, but they were captured in field notes taken during the interview and expanded upon immediately following the interview before these details faded from my memory (Schwandt, 2007). (See Appendix F for excerpts from field notes.)

Trustworthiness

According to Lincoln and Guba (1985), trustworthiness, or the degree to which research has been conducted with rigor and academic soundness, should be evaluated by four criteria: credibility, transferability, dependability, and confirmability. There are a variety of methods a researcher can implement to meet each of these criterion (Shenton, 2004), and I have incorporated a number of these into this study. Although each of the four criterion is important, my most intensive efforts aimed to ensure my research was credible and confirmable.

Credibility. Ensuring credibility is a fundamental component of establishing the trustworthiness of a research study (Lincoln & Guba, 1985). Credibility aims to ensure the research methods truly evaluate and represent what is intended (Shenton, 2004). For this study, credibility means I used research practices that would safeguard my efforts to accurately capture and represent my participants' experiences of spirituality and religion in their mothering journeys with an adult child who has Down syndrome. There were seven factors that contributed to the credibility of this research study: (a) my background and familiarity with mothers who have children with Down syndrome; (b) use of strategies that fostered participants' honest openness; (c) iterative questioning; (d) reflexive journaling; (e) member checking; (f) triangulation; and (g) thick descriptions (Shenton, 2004).

My background and familiarity. Obtaining credibility with research participants and possessing some level of familiarity with the participants is preferred in order to facilitate an open exchange of significant information (DeWalt & DeWalt, 2002). Prior to this dissertation study, I worked for many years as a rehabilitation counselor providing services to individuals who had disabilities, including Down syndrome, and their families. In most instances, mothers were the primary caregivers. My work with persons who have Down syndrome increased the perception of me as an insider among these mothers and encouraged them to view me as an empathic listener who was familiar with their experiences. It was evident these mothers presumed I understood at least some of their experiences and cared about their child by the comments they made to me suggesting my position among people who had disabilities was uniquely different from others who did not have my history of affiliation. This was an advantageous position since it helped develop rapport and helped the participants feel protected from outsider judgment (Rubin & Rubin, 2005).

Fostering participants' honest openness. Because of my previous work, these mothers granted me some level of insider knowing which contributed to their level of comfort during the interview process, and, consequently, to their sense of security in sharing information openly with me (Rubin & Rubin, 2005). However, I did not presume these mothers would see me as an insider, therefore my research strategy was formulated with the understanding that I had to create a safe space for these mothers to share their stories. During the recruitment process, I asked potential participants to contact me if they were interested in contributing to the study. My intention was to avoid any direct or indirect pressure potential participants might perceive and to ensure their engagement was voluntary. After the participants initiated contact with me, we reviewed the purpose of the research, their potential roles in the study, and the time commitments that would be required of them. I assured participants they could choose to terminate their contributions to the study at any point. My previous experience with interviews and my ability to convey empathy helped me create a safe and non-judgmental environment for participants to share information. Additionally, at the onset of the interview process, I explained that participants had the right to control the content of their stories by what they chose to share, what they chose to amend during subsequent interviews, and what they decided was no longer sharable information even after it was told; and we reviewed these rights frequently. I believe this was helpful in fostering an open and honest exchange of information because on multiple occasions participants amended their stories, emailed me additional details after an interview, or discussed how they wanted sensitive information presented, concealed, or left out of the data.

Iterative questioning. Throughout the interview process, I used a repetitive process of questioning to understand more deeply the participants' discourses. These inquires included descriptive questions about what the participants experienced and evaluative questions about how they felt about the experiences (deMarrais, 2004). During and after each interview, I created a list of questions to probe further in the next interview. These probes were designed to encourage a more in-depth description of an experience and to clarify terms and concepts. For example, on one occasion when I wanted to know more about a term a mother had introduced, I asked, “You said she’s a spiritual gift and I hadn’t heard you use those words together. So, let me ask you, how is she a spiritual gift?” On another occasion, I used questioning to explore what a participant had left unsaid when I asked, “You say it wasn’t a dead period, but I wonder what a dead period would be?” At other times, I used questions to explore how a participant’s descriptions of two distinct experiences changed when the circumstances intersected; for example, “How do these two things, Diane’s personhood and the Higher Power work together in this situation?” I also used questions to expose and correct presumptions that I noticed I had made. For example, when speaking with one mother about faith beliefs I presumed I understood, I asked, “I don’t want make an assumption; can you tell me about asking the saints to intercede? What does that mean to you?” Lastly, using a concluding invitation for the participant to answer what I had left unasked encouraged them to fill in the blanks; “Is there something else that I should have asked you along the way that would have helped me understand how spirituality and religion work in your life as a mom?”

Reflexive journaling. In phenomenological research, it is understood that the researcher unavoidably influences the research process, including the collection and interpretation of data. Acknowledging the presence of self in the research must be maintained throughout the data collection process in order to discover the essence of the phenomenon being researched. This is best achieved through a process of eidetic reduction, a technique that strives to remove subjective perceptions from the interpretation of narrative analysis (Angrosino, 2003; Follesdal, 2006; Smith et al., 2009; van Manen, 2014). Data collected through my reflexive journal facilitated eidetic reduction by identifying my personal biases through a process called bracketing. Through this bracketing practice, I consciously attempted to identify my preconceived notions, emotions, and personal perceptions of participants' reported experiences in order to understand these experiences with minimal bias (Smith et al., 2009; van Manen, 2014). Acknowledging and segregating my presumptive attitudes increased my ability to interpret and code participants' narratives more authentically and with greater accuracy (Birks et al., 2008; Charmaz, 2003; Groenewald, 2004; Smith et al., 2009; Wall, Glenn, Mitchinson, & Poole, 2004). The personal biases that I identified and extracted through this bracketing practice were not simply removed from the research process. Instead, I acknowledged this information throughout the data collection and analytic process, and then integrated it back into the final discussion of the research findings to describe the evaluative and interpretive process accurately and transparently.

Member checking. In addition to journaling, participant feedback contributed to the credibility of the data. I obtained participant feedback through a process called member checking in which participants had multiple opportunities to review the transcribed information obtained during the interviews and evaluate its accuracy. Participants determined if the transcribed interviews conveyed what they intended, if additional information was needed to fill-in gaps, or if other changes were needed to more accurately represent their experiences (Preissle & Grant, 2004; Schwandt, 2007).

Allowing participants to review transcribed interviews for accuracy, to provide feedback on analytic memos, and to amend their stories as they determined most appropriate contributed credence to the data. Involving participants in the decision-making process about how sensitive data would be included and how it would ultimately be presented ensured the results accurately represented their stories. For example, during the interviews, some participants shared personal information they considered too private for public report, or they included details they thought might diminish their anonymity. When these instances arose, the participant and I discussed the most appropriate way to manage the data so that it contributed to the overall story but did not expose unnecessary details. There were a couple of instances when participants asked me to delete sensitive information from the final analysis, and I respected their requests. Although these particular details of their stories were important to the participants, removing this information did not alter the data analysis in any meaningful way.

Member checking also offered an opportunity to test my assumptions and analytical conclusions. Incorporating my bracketed assumptions into the interview transcripts helped avoid corrupting the interpretive process by acknowledging the presence of these personal perspectives, and it allowed the participants to make corrections. For example, when one participant discussed her ideas about failing to thrive spiritually, I included the following parenthetical question in the transcription so the participant could reflect on my interpretation of her words: “(Have I gone too far with this paraphrase? Does one die spiritually when they fail to develop their own potential?).” On another occasion, when considering my thoughts about the unspoken meaning embedded within a participant’s spoken words, I included this analytical memo in the transcript: “(I make a speculation that church has been a source of pain for you although you have never said this. Now that you have read your interview transcript and had time to reflect, how would you respond to my speculation?).” Including my assumptions and conclusions in the transcriptions gave the participants opportunities to correct or verify my thoughts, which they did.

Triangulation. A process of triangulation or comparative support through multiple-source data collection served as a measure of credibility checking (Groenewald, 2004; Lareau, 2012; Preissle & Grant, 2004). The goal of multiple-point data collection is to evaluate conclusions from multiple perspectives and across multiple points in time. Including six participants in this study and interviewing each of them on three separate occasions resulted in multiple-point perspectives. Member checking transcribed interviews added another layer to participants’ contributions as they told their story during the interview, then evaluated their stories with my inserted reflexive and analytical memos, and then offered feedback on the transcripts. My reflexive journal, which I used for reflexive bracketing and analytical memoing, served as another data source. Field notes enhanced the contextual representation of each interview adding another dimension to the data.

Thick descriptions. At the onset of my research study, I understood the collection and analysis of qualitative data would be a circular process that I repeated until meaning units were sufficiently identified and few or no new meanings were derived from the data. This practice would ensure that the final interpretation of the data was an accurate representation of the phenomenon (Groenewald, 2004). Consistent with recommended phenomenological research practice, I planned to terminate the data collection when the narratives of participants yielded a repetitive pattern of meaning units with rich, thick descriptions. These thick descriptions would elucidate these mothers' experiences by conveying a sense of the emotional, sensory, social, and historical experience of the phenomenon that would situate the reader within the lived experience, rather than simply reporting facts through which a reader understands the story as an observer (Burley, 2018; Ponterotto, 2006). Thick descriptions yield more than knowledge; they create a visceral connectedness to the data.

The reality of this process was murkier than I anticipated. Because I was recruiting participants faster than I could complete the three-stage interview series, I was interviewing multiple participants at various stages during the same period. I was not inclined to slow my pace because it took at least six weeks to complete a series of interviews once I made my initial contact with the participant, and most interview series extended over a longer period. Consequently, I realized during my fifth interview that I likely had adequate data, which included thick descriptions of the participants' experiences. Nevertheless, a sixth participant had already contacted me, so I initiated and completed the interview series with this final participant, and I am glad I did. The data I acquired from the sixth participant often overlapped with other participants, but there were unique nuances as well. Collectively, the immense thickness of the narratives resonated with me, and I have incorporated parts of these interviews throughout Chapter 4, which added to the credibility of my findings.

Transferability. Since the goal of phenomenological research is to understand the unique truth or essence of the phenomenon from the perspective of the participants, generalizability is not an appropriate anticipated use of research data (Esterberg, 2002).

However, transferability of the knowledge garnered through research can be beneficial to others as the data represents an example of a broader group who experience similar situations (Lincoln & Guba, 1985; Shenton, 2004). The ability to use research results in this manner is best achieved when the population of the research sample is well-defined, narrow, and homogenous (Lareau, 2012) resulting in more clearly-defined results (Boswell, Hamer, Knight, Glacoff, & McChesney, 2007; Specht, King, Willoughby, Brown, & Smith, 2005). This was an important point in developing my research protocol because previous research literature supported the notions that differences in coping and stress are associated with the etiology of the child's disability and the parent's gender. In order to obtain results that were more readily transferable, conducting my research with participants of the same gender and who have children with the same disability diagnosis was a significant consideration. Additionally, culture can influence the transferability of research outcomes, and this context was considered in the design of the study and the selection of the participants in regard to their position within the Bible Belt region of the United States (Brunn, Webster, & Archer, 2011).

Dependability. The concept of dependability is qualitative researchers' counterpart to the use of reliability in quantitative research as a measure of research soundness (Shenton, 2004). According to van Manen (2014), reliability is an unlikely construct for measuring the soundness of phenomenological research because reliability suggests replication of a study would and should produce similar results. This is not the case in a phenomenological study of phenomena because it is understood that time and context influence one's experiences. The assumption that the same study repeated with the same participants should produce the same results is problematic because phenomenologists acknowledge that the experience of phenomena can shift dramatically across time and within different contexts (Shenton, 2004). In fact, when researchers operating from a phenomenological framework replicate a study, they may be looking for new insights rather than confirmation of previous research outcomes (van Manen, 2014). Nevertheless, a measure of dependability is important in reporting the procedural process of a study so that future researchers can replicate the study. I have attempted to meet this criterion by providing detailed reports of the participant recruitment and selection process, the interview questions and timelines, my reflexive process including excerpts from my reflexive journal, and the process of data analysis including excerpts from my analytical memos.

Confirmability. The criterion of confirmability aims to ensure the analysis and results of a study reflect the experiences of the participants and not the bias, values, or imaginations of the researcher (Shenton, 2004; Schwandt, 2007). My use of iterative questions and member checking (e.g. of the transcribed interviews, parenthetical assumptions, and analytical memos) contributed to the confirmability of my research findings. My use of journaling to bracket out my presumptive knowledge, biases, and values allowed me to more clearly hear and understand the participants' experiences. The triangulation of multiple sources and points of data collection (i.e. interviews, member check feedback, field notes, memos, and reflexive journal) all contributed to the confirmability of my research outcomes. Finally, my use of codebooks and the analysis boards provided an additional audit trail for my research analysis, further enhancing the confirmability of my research conclusions. (See Appendix G for a sample of an analysis board.)

Ethics

Because this study involved research activities with human subjects, I obtained approval from the university's research review board prior to initiating participant recruitment. This committee is responsible for reviewing proposed research with human subjects to protect the welfare of research participants and to ensure the study's design is ethically sound. The University of Memphis Institutional Review Board granted approval for this research study in two phases and has reviewed subsequent updates on three additional occasions. The first phase of this study was an exploratory case study that served as a pilot study for the larger project (Ezzy, 2002). The second phase of the study was the completion of the larger project, which is the current study. The University of Memphis IRB granted approval to conduct both of these projects. (See Appendix H and I for a copy the IRB approvals for each of these projects.)

Respect for the participants' rights to make choices about their participation and to control their own data (e.g. their story) was included in my research protocol from the onset of the study. During the recruitment process, I asked individuals to contact me if they were interested in participating to minimize any sense of obligation or pressure they might experience from their position as mothers of children with Down syndrome. During the initial contacts, I shared relevant information with the potential participants about my professional background and the purpose of my study to inform them of my motivation for initiating this study. This allowed participants to develop a sense of who I was as a researcher and how I might be invested and respectful of their stories (Walker, 2007).

Prior to the interviews, I reviewed the consent form with the participants and provided them with an enlarged-type copy for easy reading. The consent form included information about the participants' rights and responsibilities, described the purpose of the study, explained the reasons the participant was asked to join the study, and identified the commitments that were expected of the participant during the interview process. Additionally, the consent form included contact information for the primary researcher, the dissertation chair, and the University of Memphis Institutional Review Board. Possible benefits of the study (i.e. contribution to the literature on parenting a child with Down syndrome may benefit other mothers and professionals) and potential risks were identified. Although minimal risks were associated with this study, reflecting on one's spiritual and religious history and parenting experiences could generate unexpected emotions and this was included in the consent form and discussed during the initial meeting. I informed participants there was no financial compensation for participating in the study, their agreement to contribute to the study was voluntary, and they could choose to terminate their involvement in the study at any time without fear of negative consequences. I assured participants I would protect their anonymity by using self-selected pseudonyms to conceal their identity and that identifying information would be maintained in a secure location and unassociated with transcribed interviews and research notes. Finally, I reviewed the situations in which confidentiality would not be maintained (i.e. threat of harm to self or others, reports of abuse to a person with a disability).

Throughout the interview process, I encouraged participants to direct the process by selecting a location and time for each interview that met their needs and enhanced their sense of safety and privacy. Spacing the interviews out across several weeks gave each participant time to reflect on the emotional experience of recalling challenging events (Walker, 2007). Additionally, I asked participants to offer feedback on my initial assumptions and analytical considerations, and I assured participants they could remove any data from the interview they believed was too personal or threatened their anonymity. Regarding anonymity, each participant selected a pseudonym for herself and her child. I created additional pseudonyms (e.g. names of cities, business, churches, and organizations) to conceal the participants' locations, and I intentionally obscured the demographic information. Protecting the locations of the interviews and participants' geographical locations was important in maintaining their privacy and anonymity (Pearson, Albon, & Hubball, 2015). The initial consent forms were the only identifying information created during this study, and these forms were maintained in a secure location separate from the transcript interviews, codebooks, and analysis boards. These documents were destroyed when the study concluded. The participants' pseudonyms were used to identify all other data and analytic documents.

Concluding the interview series, I engaged in a debriefing session with the participants to review the data a final time, discuss which aspects of their stories were most important in the accurate representation of their experiences, identified sections they wanted to conceal or leave out, and discussed how they thought the information should be presented. This process prompted the inclusion of the final section of this dissertation in Chapter 5: Advice from a Mother.

Subjectivity

Qualitative researchers accept their position as the primary conductor of data collection, interpretation, and presentation, and they recognize that this unavoidable role in the research process can be an opportunity if managed carefully (Finlay, 2002). Qualitative researchers also recognize that to use this position responsibly they must clearly identify the multiple positions they hold in relation to the research. The term *subjectivity* refers to the emotional and cognitive position researchers hold acknowledging they can never enter into this activity free of preconceived notions, values, and biases (van Manen, 2014). Reflexive subjectivity is the process through which researchers persistently practice self-critiques of their relationships with the data in order to understand it more clearly from the participant's perspective while still using prereflexive knowledge about the data to understand it within a larger social and political context. The subjectivity statement identifies how the researcher relates to the research from the onset. Reflexive-subjectivity requires the researcher to consider continuously the influences one's position has on the data throughout the research process. Vagle (2014) calls this the "post-reflexion statement" (p. 133), which is a declaration of one's relationship to and with the object of study.

I began this research project with a prereflexive understanding about my relationship with this subject. My engagement in the process of research has repeatedly transformed my subjective position because my experiences with the data have continued to influence what I think I know. In other words, my subjective position is not static; it has and will continue to transform as my perspective changes across time. The subjectivity or post-reflexive statement that follows is far from where I began, but it is where I find myself today.

One of my initial interests in this research project was my own sense of gratitude for what I believe has been my divinely inspired life journey. Long before I selected my research topic, I knew I wanted to integrate spirituality into my work as a sign of thanksgiving to God for my own life experiences, personally and professionally. My religious affiliations have been fluid throughout my life, and I have a genuine appreciation and curiosity for learning about different faith beliefs. I intermittently define myself as a religious person and consistently consider myself to be a spiritual person. My curiosity about religion allowed me to openly explore the participants' beliefs and practices. During this project, I sometimes became disappointed with religious institutions' responses to persons with disabilities; at the same time, I recognized the importance of the church in creating a bridge for people to connect spiritually with God or their Higher Power. Consequently, promoting inclusion in the church for people who have disabilities and their families has become increasingly important to me.

Prior to this research project, I worked as a rehabilitation counselor with people who had a variety of disabilities, including Down syndrome. During my twenty-five-year career, I provided a variety of services to people who had disabilities and their families, including coordinating environmental modifications and accommodations, ancillary supports, and job placement services. The work that was most relevant to the participants in this research study was my direct and administrative roles in a waiver program, which provided support services to individuals with developmental disabilities. The goal of this program was to increase the opportunities for individuals who had severe disabilities to live in their own homes and participate in their own communities. During this time, I worked with many parents, most of whom were mothers because these women were most frequently the primary caregivers to their children. My role in this work intersected with my research on multiple occasions when mothers described their experiences with similar programs. My familiarity with individuals who had Down syndrome and their families contributed to my presumptions that I had some knowledge and understanding about the experiences of the mothers in this study. By the end of the study, I realized this was minimally accurate, and there was much more I did not know about these mothers than what I had originally assumed.

My personal history with disability also informed by thoughts about caregiving mothers. When I was about 8- or 9-years-old, my neighbor had a son with a disability. I have only a few memories of this mother and her son, but the unquestionable mental notes attached to these old recollections led me to believe she was a loving mother who wanted her son to have a good life.

This memory is striking to me because, at that time, during the 1960s, this mother's son was the only person with a disability I had ever seen, and he intrigued me. My only other exposure to disability was a picture on my grandmother's sewing room wall that held the image of a round-faced little boy dressed in a sailor's suit. According to my grandmother, this little boy was my cousin, Rex, who had Down syndrome and was very sick. Before I was born, Rex was placed in an institution and had died. I heard nothing more about this little boy until approximately four decades later when my aunt died, and I learned Rex was still alive. Rex's sister, who was a little girl when he was institutionalized, was the only surviving family member who knew he was alive. Were it not for her decision to list Rex as a surviving family member in my aunt's obituary, I would never have known this part of his life story. For about 40 years, Rex had lived in an institution. In the late 1990s, he moved out of the institution and was supported by a waiver program similar to the one I had worked with for most of my career. Within five years of learning that Rex was alive, I had begun my work on this research project. I had completed the interviews for this study by the time Rex died in 2017. He was 58 years-old. The photograph included in his obituary was only the second picture I had ever seen of him. These two images, one when Rex was an infant and one before his death, framed the vast in-between space of his life that I knew nothing about.

I chose to conduct this research project because the mothers I worked with inspired me through the dedicated and loving care they gave to their children who had disabilities. I specifically decided to work with mothers of children who had Down syndrome because several of the mothers I worked with told me their child was a spiritual influence in their lives, and I wanted to know more. I had not initially believed that Rex played a role in the selection of my dissertation topic. However, the mystery of his story and the absence of him in my life story weaved into and around the stories these mothers shared during their interviews. Post-reflexively, I believe perhaps that little boy in the sailor's suit influenced several of my life choices, including this research study.

Participant Selection

Although no consistent guidelines have been established for the number of participants included in a phenomenological study, Vagle (2014) has recommended the number be sufficient to adequately describe the phenomenon, suggesting that this number will change based on the complexity of the research issue. In phenomenological research, as few as two to ten participants for in-depth interviews are typical and often all that are needed to identify meaning units when conversational themes are repeated and new meanings cease to emerge (Groenewald, 2004). Others have recommended six to ten (McWilliam, 2010; Morse, 2000), six to twelve (Guest, Bunce, & Johnson, 2006) or up to

10 (Creswell, 1998, as cited in Onwuegbuzie & Leech, 2007; Starks & Trinidad, 2007) participants for phenomenological studies. My decision to interview six mothers fell within these recommended ranges and the data obtained through these interviews was more than sufficient.

Participant recruitment and sampling procedures. Participants were recruited through local support groups, service organizations, churches, and individuals who interacted with or offered services to persons who had Down syndrome. A recruitment flyer was emailed, mailed, or hand delivered for distribution. The flyer identified the purpose of the study, the criteria for inclusion, the risks and benefits of participation, and my contact information. To avoid an unintentional perception of persuasion, I asked potential participants to contact me via email or phone if interested. Specific resources included the International Down Syndrome Coalition, state and local Down syndrome associations, and sports leagues for individuals with disabilities. These organizations disseminated the recruitment flyer through websites and Facebook posts. Other resources, such as service organizations, churches, and individuals, distributed the recruitment flyer by hand or email. The recruitment flyer was designed to attract a homogenous group of individuals based on pre-established criteria to ensure each participant had sufficient exposure and experience with the phenomenon under study (Palinkas et al., 2015). This purposive sampling approach, also known at theoretical sampling, is appropriate for qualitative work as generalizations of research outcomes to a larger population is not a goal of qualitative research. Therefore, the need to obtain a representative sample from a larger population is not relevant (Schwandt, 2007). What is relevant in phenomenological research is that participants have adequate exposure to the phenomenon under study and that they are able to provide rich, thick descriptions of their experiences (van Manen, 2014).

I also attempted to use snowball sampling by sharing the recruitment flyer with participants. Snowball sampling is a process in which new participants are acquired through the referral of other participants who are familiar with the researcher (Groenewald, 2004). This sampling approach had the advantage of accessing additional homogenous participants and provided new participants with a source of reference regarding my trustworthiness as a researcher (Browne, 2005). Although I cannot be certain because I did not ask participants to report how they learned about my research study, I believe purposeful recruitment through organizations, churches, and professionals who were familiar with me, either directly or indirectly, was the most effective recruitment method. (See Appendix A for a copy of the research recruitment flyer.)

Eligibility criteria. The eligibility criteria for participation in this study, required each participant to affirm: (a) she had a child who had Down syndrome and who was age 18 or older and no longer attended high school; (b) religion or spirituality was important in her life (but participation in a religious institution was not required); (c) the child lived with her for at least six months of the year; and (d) she and her child resided in the Mid-South region of the United States (i.e. Arkansas, Mississippi, Missouri, or Tennessee).

Outcomes of phenomenological research are most useful when the population of the research sample is well-defined, narrow, and homogenous in regard to their experience of the phenomenon under study (Lareau, 2012; Vagle, 2014). For this study, that meant participants needed to experience spiritual or religious influences in the process of mothering an adult child who had Down syndrome. Other demographic variables outside the primary parameters of the phenomenon under study become less important in regard to defining the sample of participants (van Manen, 2014). Although race and ethnicity contributed to the context of the participants' experiences, this criterion was deemed less relevant since neither race nor ethnicity were included in the research goals of this phenomenological study. The same was true for the age of the participants. The focus of this study targeted the experiences of mothers of adult children rather than mothers of any particular age group. In addition, religious affiliation was not a criterion for participant selection, and although information about religious affiliation was collected through the demographic questionnaire, participants could affiliate with any religion or none at all. However, since both religious and spiritual experiences were explored in this study, one eligibility criterion required that participants indicate spirituality or religion was important in their lives. Similarly, gender was relevant since this study sought to understand the experiences of mothers, not fathers.

Participant screening. Because I asked potential participants to initiate contact with me, I had the opportunity to review the eligibility criteria and share additional information about the study regarding the time investment and the interview process before meeting with them for the first time. Most potential participants contacted me directly by phone or email; however, two potential participants asked a third party to share their contact information with me so I could contact them. Nine individuals indicated an interest in participating in the study. Following my initial contact and discussion with one mother, she concluded religion and spirituality were not adequately relevant to her mothering experience to warrant participation in the study. Another interested mother had a child who had a disability other than Down syndrome; therefore, she did not meet the eligibility criteria. A third mother met all the research criteria; however, after consideration, she concluded that she did not feel comfortable sharing information for research purposes. The six remaining individuals who contacted me were eligible to participate and maintained their interest after the initial discussion and prescreening.

Participant descriptions. The six mothers who participated in this phenomenological study represented diverse Christian denominations, socioeconomic statuses, educational and employment backgrounds, ethnicities, and ages. In an ideal situation, I would provide rich, thick descriptions of each mother; however, after thoughtful deliberation, I decided to obfuscate these details to protect their identities. To further safeguard anonymity, each mother selected a pseudonym for herself and her child, and additional pseudonyms were created to conceal other identifying elements (e.g. names of churches, schools, organizations, associations, cities, and states). The six participating mothers included Sabrina (whose daughter was Bea), Felicia (whose daughter was Rose), Isabella (whose daughter was Chloe), Helen (whose daughter was Diane), Denise (whose son was Jermaine), and Mary (whose daughter was Angel). Three of these mothers reported their religious affiliations were Baptist, one was Roman Catholic, one was Methodist, and one was non-denominational. Five of the mothers were White and one was African American. Four mothers were partnered or married and two were not. Four mothers were employed full-time, one worked part-time, and one mother was retired. These mothers’ educational achievements ranged from high school diplomas to graduate degrees. Their household incomes ranged from between $20,000 and $40,000 to over $100,000 per year. At the time of the interviews, the mothers' ages ranged from early 40s to mid-70s. At the time of the interviews, their children's ages ranged from early 20s to mid-50s. All of these mothers were young or relatively young when they gave birth to their child who had Down syndrome (e.g. mid-30s or younger). In fact, for five of these mothers, their child who had Down syndrome was their first-born child. Of these six mothers, all but one had multiple children. Table 1 provides a pseudonym guide and additional information about these mothers' approximate ages and their child's gender.

Table 1

Pseudonym Guide

Mother's Pseudonym	Mother's Approximate Age	Child's Pseudonym	Child's Gender
Isabella	40s	Chloe	female
Denise	50s	Jermaine	male
Helen	50s	Diane	female
Sabrina	50s	Bea	female
Felicia	60s	Rose	female
Mary	70s	Angel	female

Data Analysis

Analytical decision-making. The analysis of qualitative data is a complex and ongoing procedure that occurs throughout the data collection process (Guest, Macqueen, & Namey, 2012; van Manen, 2014; Vagle, 2014). Several analytical methods are appropriate for phenomenology. At the onset of this project, I intended to follow Giorgi's four-step process of data analysis: (1) reading the data as a collective unit; (2) rereading and coding the datasets of individual interviews for meaning units, paying special attention to the phenomenon under investigation; (3) reflecting upon and reexpressing the identified meaning units into phrases that capture the psychological intent; and (4) reconstituting the meaning units to develop a composite summary, image, or personality that represents the combined meanings derived through the analysis (Broome, 2011; Giorgi, 2009; Moustakas, 1994; Wertz, 2005).

However, after consideration, I concluded that Giorgi's analytical position that all data collected must be analyzed did not work for me because of stylistic and ethical considerations. Giorgi suggests interviewers direct and limit the interviews so that the transcribed content is relevant to the study. My approach during the interview process was less directive because I was not sure what content was connected to one's spirituality or religiosity until I allowed the story to unfold during the interview. This approach yielded personal data that some participants did not want included in the final analysis, and I honored these requests. Additionally, Giorgi's method of data representation focuses on invariant content (Vagle, 2014). After initiating my interviews, I quickly developed a sense of obligation to represent these mothers' stories collectively and individually, which meant that I would attend to variant content as well as invariant content. All meaning units that represent the whole or the parts are important in the accurate representation of the data (Groenewald, 2004). Including only those meaning units that are common across the majority of participants fails to represent fully the participants' experiences. To ignore the unique qualities of a participant's experience is equivalent to intentionally choosing not to fully understand, an act that is counter to the foundation of phenomenology work (Vagle, 2014; van Manen, 2014). Finally, Giorgi's method of data representation of invariant themes through a composite image would have been an incomplete representation of my research data, and most of the mothers in this study indicated they wanted the uniqueness of their stories to be evident in the final representation of my work.

Vagle's (2014) whole-part-whole analysis retains some of the initial analytical steps of Giorgi's methods (read the whole collection of interviews, then reread the individual interviews, then consider as a collective whole) but acknowledges the importance of balancing individual experiences with collective representation, which is consistent with van Manen's work (2014). I appreciated elements of each of these methods, but I found that my analytical process began with my first interview, and the negotiation of understanding included important feedback from each participant as we moved through the interview series. Ultimately, my presentation of the data aligned most closely with Vagle's whole-part-whole approach as I balanced collective representations of the phenomenon with individuals' experiences. Pragmatically, Colaizzi's (1978) analytical strategy provided a road map for my analytic journey through the data.

Colaizzi's seven-step method of data analysis. Colaizzi's developed his analytical strategy from Giorgi's methods (Edward & Welch, 2011). The Colaizzi (1978) approach was designed specifically for phenomenological research and includes seven steps: (1) read and reread individual interviews; (2) identify content relevant to the research phenomenon; (3) formulate cohesive meaning; (4) categorizes the meaning units into themes noting discrepancies; (5) compile an exhaustive description of the data; (6)

condense the data into a fundamental statement that describes the essence of the experience; and (7) validate the analytical conclusions with the participants (Abalos et al., 2016; Colaizzi, 1978; Morrow et al., 2015; Shosha, 2012; Vagle, 2014). Edward and Welch (2011) added an additional initial step to Colaizzi's original seven-step process: transcribe the interviews and allow the participants the opportunity to review and validate the verbatim content. Because Colaizzi did not assume all content would be relevant to the phenomenon under study, verbatim transcriptions were not included in his seven-step approach. I included Edward and Welch's additional step in my work because this is common practice in phenomenological research (Ezzy, 2002; van Manen, 2014, Vagle, 2014), and this was an important initial step in my analytic process.

Following this recommended process, I completed the verbatim interview transcriptions within two weeks of each interview and returned the document to the participant for review. I embedded some of my field notes and initial analytical memos into the transcripts so the participant could evaluate my observations and interpretations. This practice encouraged me to engage in analysis early in the process, helped me construct follow-up questions to clarify points, improved my targeted questioning and listening, and facilitated thematic linking between and across participants' interviews (Ezzy, 2002). Participants had the opportunity to amend transcribed interviews and add to or delete content during the second and third interviews.

Step one. Because I completed my own transcriptions, I was immediately engaged in Colaizzi's (1978) first step: read and reread the transcripts. When transcribing, I listened to the recorded interviews while typing and then again when proofreading the transcripts. I reread the transcripts before returning the document to the participant to develop my initial analytic thoughts and questions and included some of these ideas in the transcript for the participant to review. I reread the transcript again before meeting with the participant a second and third time to construct my follow-up questions.

Step two. I conducted steps two and three simultaneously as I identified and converted relevant content into cohesive meaning statements, which then underwent a process of categorical maneuvering as I attempted to find an appropriate thematic fit for the data. Colaizzi’s (1978) second step guided me to identify content relevant to the research phenomenon. This process of identifying relevant content occurred during the transcription process and with each rereading of the interviews as the connections between pieces of relevant content across interviews began to intersect and illuminate deeper understand of the participants’ experiences. As I reviewed each participant’s interviews, I considered not words or lines but instead chunks of information that provided meaningful insight about the participant’s experience (van Manen, 2014). Following Giorgi’s suggestion that researchers analyze all the data, I evaluated and coded all of the meaningful interview content, other than those sections participants instructed me to remove, even when it appeared to be unrelated to spirituality or religiosity. The meaning units from each participants’ interviews were copied and pasted into an excel document that I called a *codebook*. I created one codebook for each participant, and I used the codebook to collect relevant content under tentative thematic constructs. By the time I completed the third interview series, these tentative themes had been revised a number of times but represented unified chunks of the data, which fit within the identified thematic constructs. When content from the last three interviews challenged a thematic formation, adjustments were made or a new category was created to accommodate variant data.

Step three. Colaizzi's (1978) third step guided me to formulate cohesive meaning statements about the relevant content. Researchers have developed various names for this *relevant content*. Giorgi (2009) referred to this content as *meaning units* and later *invariant structures,* van Manen (2014) called this content *themes,* and Vagle (2014) referred to this as content as *tentative manifestations*. I use two terms to describe this content; meaning units refers to individual pieces of content specific to an individual's transcribed interviews, and themes refers to collective meaning units within and across the participants' interviews.

Meaning statements reduced a participant's intended meanings into phrases that were succinct and could be integrated with other participants' similar meaning units (Ezzy, 2002; van Manen, 2014; Vagle, 2014). When my participants shared their stories, they sometimes buffered their dialogue with minimizers that distracted or obfuscated their intended meaning. These initial chunks of relevant content were inserted into the first column of a participant's codebook under a thematic page title that I thought best fit the data. The relevant content was then reduced to a brief meaning unit or statement that clearly conveyed the intended content, and this reduced meaning unit was inserted into a second column just to the right of the first column. To track the data as it moved from the interview, to the codebook and then across the columns of the codebook, I coded each piece of data using a letter-number coding system that included the first initial of the participant's pseudonym (e.g. F), the number of the interview (e.g. 2), and the line of transcription within the interview (e.g. 592). For example, using this system, information coded as F.2.592 originated from the participant called Felicia, during her second interview, in line 592 of the transcription. In a third column, I reduced these meaning units one final time. This final reduction merged similar meaning units into a succinct meaning statement, which could then be compared and integrated with other participants' data. Even with this three-step process of meaning reduction, the information included in the third column under each page of each participant's codebook was extensive.

Step four. Colaizzi's fourth step requires the researcher to develop thematic categories under which the individual meaning units unify to convey a cohesive essence of the experience. I had initiated this process with the first transcribed interview and continued to renegotiate these thematic categories as participants offered feedback on the transcribed interviews and my embedded analytic comments. Additional interviews added new information that created and amended previous thematic categories. The process of creating thematic categories was intentionally murky, because I avoided committing to any particular set of themes until the data consistently fit into these constructs. By the conclusion of the interviews with the third participant, I had sufficient meaning units from multiple participants to determine what static themes were emerging from the invariant data.

Although the use of codebooks was helpful in managing the data from each participant's interview series, it was cumbersome to draw collective conclusions from data that was dispersed across six codebooks. Therefore, I visually and physically constructed the final themes using analysis boards. The data from each mother's codebook was printed on colored strips of paper, which were then thematically organized on the analysis boards. This allowed me to visually track where a participant's data fit into the thematic constructs. (See Appendix G for a sample of one of the analysis boards.)

Step five and six. I completed Colaizzi's steps five and six simultaneously. Step five challenged me to compile an exhaustive description of the data, while step six required me to make a condensed statement that fundamentally described the essence of the experience. These two steps involve representation of the data, which is the primary reason I stepped away from Giorgi's analytical methods and toward Vagle's (2014) whole-part-whole analysis and Colaizzi's methods, which are both more amenable to variant data and balanced representation of the collective whole and individual experiences (Vagle, 2014). My goal was to represent these mothers' stories as a collective whole but also retain some aspects of their individual experiences. After thoughtful deliberation and because the data was quite extensive, I concluded that presenting the data around my four sub-questions would be the most coherent approach to report the findings. Based on this structure, I presented an explanation of the findings at the beginning of each sub-question that described the essence of these mothers' experiences as it related to that particular question. Following this brief introduction, I provided an extensive description of the participants' experiences, which I have organized into themes. I have inserted mothers' individual experiences to give credence to the thematic conclusions (Wertz, 2005) and to retain individuals' experiences within the collective presentation. To ensure further the individual was not lost in the collective representation of the whole, I began Chapter 4 by an introduction of the participants through their individual birth stories.

Step seven. Colaizzi's seventh step suggests the researcher validate the analytical conclusions with the participants, which is intended to ensure the data accurately represents the participants' experiences. This is the qualitative counterpart to quantitative validity and can be attained through many methods (Morrow et al., 2015). I implemented Colaizzi's practice by attaining participant feedback of my initial analytical constructions through the memos I included in the transcripts and the feedback the participants provided in subsequent interviews. Additionally, during the third interview, the participants and I engaged in a debriefing process that addressed their thoughts about the accuracy of their stories in representing their spiritual and religious mothering experiences and how they thought I should present their stories in the research results.

Following the introduction of the mothers' birth stories in Chapter 4, I described the research findings in response to each of the four sub-questions. As I have previously indicated, I did not limit or redirect these mothers when they shared information that was unrelated to spirituality or religion because I was not sure what would or would not be relevant and I respected their right to direct their own stories. Consequently, some of the data is unrelated to spirituality or religion. Nevertheless, I have included this information at the end of Chapter 4, which describes additional coping strategies, changes that evolve over time, and mothers' pride in and admiration of their children.

Chapter 4

Research Findings

The purpose of this phenomenological study was to understand and describe how the spiritual and religious experiences of mothers of adult children who have Down syndrome affect the reported development of their (a) perceptions of their child, (b) coping behaviors in response to the daily stress of raising a child who has special needs, and (c) sense of meaning and hope for their child’s future. The central research question was, “What is the experience of spirituality and religion in the parenting process of mothers of adult children who have Down syndrome?” To address this central question, four sub-questions were explored through semi-structured interviews with six mothers who had adult children with Down syndrome. The semi-structured interview method provided a guide to keep the interview focused on the central and sub-questions, it allowed the researcher to follow leads presented during the interview not anticipated prior to the development of the research questions, and it allowed mothers to share information they deemed relevant. As the researcher, I was responsible for regaining focus of the interview when it strayed too far from the phenomenon of study (Vagle, 2014). The four sub-questions used to construct the semi-structured interview guide were:

1. How do spirituality or religion create or reduce meaning with regard to the child's diagnosis of Down syndrome?
2. How do the systemic patterns within organized religion influence positive or negative perceptions of Down syndrome?
3. How do spirituality or religion alleviate or aggravate the stress associated with raising a child who has Down syndrome?

4. How does spirituality or religion create or thwart hope for the future of a child who has Down syndrome?

Because these were semi-structured interviews, mothers had leeway in determining how they presented their stories, and some data is not overtly related to spirituality or religiosity. In this chapter, the findings presented begin with a description of the participants, then an account of each mother's birth story, followed by the spiritual and religious data as it relates to each of the four sub-questions. The chapter will conclude with a description of additional findings not directly related to the research questions, spirituality, or religiosity.

Participant Descriptions

This phenomenological research study was conducted with six mothers who participated in a series of individual interviews. Each participant self-identified as a mother of a child who was 18 years of age or older, who lived in the home with them for at least six months of the year, and who had a diagnosis of Down syndrome. In addition, each mother reported that spirituality or religion was important in her life. In actuality, all of these children lived with their mothers or parents and had done so since birth. Only one child was in the beginning stages of moving into her own independent apartment separate from her parents. To conceal the participants' identities, each mother selected a pseudonym for herself and her child. These pseudonyms included: Isabella whose daughter is Chloe; Helen whose daughter is Diane; Denise whose son is Jermaine; Felicia whose daughter is Rose; Sabrina whose daughter is Bea; and Mary whose daughter is Angel. Detailed demographic data is not included in the description of the participants in order to protect the mothers' anonymity. However, some information related to the child's date of birth and the mother's age at the time of the birth is relevant for understanding the context of these mothers' experiences. Table 2 includes obscure information that situates each mother's experience in historical context. Additional demographic data is included in Chapter 3.

Table 2

Mother Approximate Age at Birth and Decade of Child's Birth

Mother	*Mother's age at birth	Child	Child's gender	Child's decade of birth
Isabella	20s	Chloe	female	1990s
Helen	30s	Diane	female	1990s
Denise	20s	Jermaine	male	1980s
Felicia	30s	Rose	female	1980s
Sabrina	under 20	Bea	female	1970s
Mary	20s	Angel	female	1960s

*Approximations of mothers' ages

Birth Stories

Though I did not ask these mothers to share their child's birth story, they all did. Many of these mothers were spiritual and religious women before their child's birth, therefore, identifying as a spiritual or religious mother was not entirely new for them, at least not the spiritual or religious aspect. However, the motherhood position was new for most of these women and being the mother of a child with Down syndrome was new for all of them. Consequently, to describe the role of spirituality and religion in their mothering journey, for these mothers, it was important to include the genesis of their mothering experience, which was the birth of their child.

Mothers received an abbreviated summary of the interview questions prior to the first recorded interview, so they had time to consider what they would share. One of the first probes introduced during the interview was, "Tell me about a time when religion or spirituality impacted your life as a mother." Most mothers responded to this prompt with their child's birth story, and if not then, the story was soon to follow as the foundation of their mothering experience was painfully and lovingly described. Consistent with Vagle's (2014) whole-part-whole data analysis method, the parts of each mother's story must be understood in context of the original storyteller's experience before pieces are then extracted and integrated with other mothers' stories. This approach retains the authentic uniqueness of each lived experience while integrating parts of each story to create a new collective whole from which to understand the phenomenon. In addition, and more importantly, attempting to remain true to these mothers' accounts of their mothering experiences, introductions are presented from the first person perspective and situated upon the cornerstone of their motherhood - their child's birth story. The introductions have been constructed with intentional effort to retain each mother's vocabulary, use of colloquialisms, tone, and overall linguistic style in order to convey an accurate representation of their stories.

Isabella. I was in my 20s when Chloe was born. It was in the 1990s and my husband and I had been married for a couple of years. I was thankful that God had picked a good husband for me. I had some hard times when I was younger, but finally, things were good and my husband and I had a happy life. When Chloe was born, the whole family was at the hospital with us. When I saw her, I just fell in love with her instantly. We're all looking at this beautiful child, and we don't have a clue that anything is wrong with her. We just thought we were celebrating the birth of a healthy baby girl. So the family goes home, and about 12 hours later, after they looked her over real good in the nursery, things start to change.

The pediatrician comes back in and starts telling me what's wrong with her, and all I hear are the words Down syndrome; I don't know what he said after that. Now, my family has gone home and my husband's in the bathroom and the doctor is saying all this stuff and I'm just looking at him like he's in a tunnel or something. It was like everything was closing in on me, and I said "Stop. I think my husband needs to hear this." Of course, he apologized and said he just lost his bedside manner for a moment, and I think he did. He must have been tired or something because I really liked him. Anyway, when my husband came back, the doctor repeated everything he had told me, and the wheels in my head were just spinning. The first thing I said to him was, "Down syndrome? Is that like Corky on Life Goes On?" He said, "Yea, it is," and I said, "I love that kid!"

So, 12 hours later, I still loved her, but it was a little bit different for me. When I found out she had Down syndrome, I didn't really know what it meant for her, but I knew there were automatically gonna be some limits on her life. I was disappointed for her and, a little bit selfishly, disappointed for myself because maybe, for a minute, I had bigger dreams for her. So I was a little depressed and in shock. I just didn't see it, none of my family saw it. She was just lovely and precious.

So, for about the first two weeks I was confused and bitter. It didn't seem fair and I was questioning God. Why did You do this to me? What did I do to deserve this? How can drug users have healthy kids, and I didn't even drink Cokes or caffeine? I think that was the immature Christian in me; I didn't realize God had a reason. I just had some confused emotions, and I didn't see her as a complete gift yet; I saw her as a "why me?" I feel guilty saying this now, but it was true, and I have never felt that way since. But at the time, I didn't realize what she was gonna teach me. Spiritually, later on, I realized, that God doesn't make mistakes; I think God makes everybody the way they are for a reason. Honestly, I think she's an angel who has already been up to heaven, and God just sent her back down here to teach the world a few things.

Helen. My first child, Diane, was born in the 1990s when I was in my 30s. I was a career mom and my work was an important factor that contributed to my personal identity. I'm also very practical, goal-oriented, and I don't spend much time focusing on historical barriers and challenges because I'm too busy trying to resolve the problems we face today. So, I may not have much to share about Diane's birth, but I sure have a lot to say about the first two years of her life. And rest assured, aside from her diagnosis of Down syndrome, she's had lots of chronic health issues we've dealt with over time. If you know anything about Down syndrome kids, then you know they have a greater risk of congenital heart defects and intestinal issues, and they have higher risks of developing leukemia than the typical population. So, Diane was born with a minor heart defect, which we monitored, but fortunately it did not require surgery. We didn't have to deal with intestinal issues, but the leukemia - strike three. For her first two years, we basically watched her get sicker and sicker as she developed repeated bouts of pneumonia, preleukemia and then eventually received an actual clinical diagnosis of AML, which is acute myelogenous leukemia. Now we had to go through bone marrow transplants, aspiration treatments, blood transfusions, and chemotherapy. At the time, we had a lot on our plate and we struggled.

My biggest worry, at least the worry I had any control over, was what to do about my work. I just saw myself as a working mom, not a stay-at-home mom. I mean, the doctors and medical community were doing everything they could to help. I was responsible for coordinating and accessing resources to get things done, and physically, I had done all that I could. After that, I had to turn it over to God, which basically meant that I sat in my car or in the quiet of the morning hours trying to trust that God would provide what was needed at the appropriate time. If I did my part, God would do His part. So my husband and I were trying to plan our schedules so he could work and occasionally relieve me at the hospital. Once Diane was able to leave the hospital, we were homebound because she couldn't be exposed to all the germs at daycare. Fortunately, we were able to get resources to help pay for in-home daycare, and I didn't have to quit my job.

During that time, we tried to establish a church home, but we had too many demands on our time to make space for church involvement. There may have been people from the church who came by to visit, but I don't remember; it was a hard time. In the same way, I'm sure I must have had the "Why me, God?" thoughts during this time, but then I just got on with the business at hand. However, I definitely think that God knew that Diane was not going to have the intellectual or developmental capabilities to make choices about her life on her own. He knew that she needed a family that was organized, educated, and knowledgeable about the system. So, Diane got to live with a family who could meet her needs; she got to live with us.

So, that was the beginning. That was the first two years. First, we had a baby with a disability; then we had a baby with chronic health issues. “Oh my god, now is she gonna die?” So you see, the battle with leukemia just made the Down syndrome diagnosis fall into the background. It’s not that it hasn’t been important in my journey as a mom; it has been! It’s just in the early years, my concerns were more existential: “I didn’t want my baby to die.”

Denise. I had my son, Jermaine, in the 1980s. I was only in my 20s when he was born, but I’d started my family early, so I already had several children by the time this beautiful little boy came along. He was so handsome to me; had all his fingers and toes, weighed over eight pounds and had a headful of hair. The doctor on call came around and said, “There’s something wrong with your baby.” When I asked, “What’s wrong with him?” the doctor said he would send the pediatrician around and he would explain everything, then he left. Well, I had Jermaine on a Saturday, so it was a couple of days before the pediatrician came by. For those few days, I’m just looking at this perfectly beautiful baby and thinking, “What in the world’s wrong? He’s breathing, crying and eating.” Finally, the pediatrician comes in and tells me Jermaine has Down syndrome. It was information overload, and I started crying out to God. I wanted to know “Why did You give me this imperfect baby?” Everyone was so excited about this baby; what was I gonna tell my kids, my mom and dad, and my husband? Well, the nurses saw me boohooing, so they started offering their input, “Oh it’s gonna be okay, they have facilities for babies like this.” Some people were telling me, “Put him in an institution.”

Even when the pediatrician talked to me, he said we had to figure out his level of deformity and mental retardation. Well, I didn't even know there were severe and mild cases of Down syndrome; I just didn't know anything about it. They didn't give me no pamphlets or books or anything so that I could inform myself, and there wasn't Google back then. I was feeding off all their negativity. It was confusing, discouraging, and I was just in a panic. And my mom thought I had that post-partum depression, and I may have been trying to get a little depressed, maybe, probably. That's when I had to turn to my spirituality, I mean, well, I had to pray.

I remember praying so hard for answers. I didn't do drugs, I didn't drink or smoke. I'd been adequate on my part. So why was God punishing me? You know, I came from a big family and my mom was my idol. I admired her work ethic, the way she took care of us kids, and I wanted to grow up to be just like her. So when I was a teenager, I didn't think about finishing school or going to college; I went straight to starting my family. At first, I thought God did this to punish me, because I went about having my family the wrong way. But, I had this preconceived notion I got from my dad who was a minister, that we're all part of God's plan. My dad's been gone 20 years now, but I still hear him saying "God don't make mistakes."

So, I'm praying and God starts answering my prayers. I started hearing stuff about kids with Down syndrome like they don't live very long and they have all kinds of problems like heart and respiratory issues. So when I had a question, God had me writing it down. It so happened, Jermaine's follow-up appointment came, and it was a different pediatrician from the one in the hospital; this one was older. Well, I had all these questions and he sat there and answered every one of them. Some questions had him dying laughing and some questions, you know, he felt my heart. That was a turning point for me in understanding Down syndrome. He connected me with people and support groups that had experience. I knew in my heart that I wasn't gonna give Jermaine away; I was gonna keep him. And once things started falling into place and I had the support group, people who could help me and a doctor who was on my side, I started accepting the journey we were on, and I understood that God gave Jermaine to me for a reason. He trusted me to take care of him. God knew Jermaine would keep me grounded and connected to Him. As I got further into my journey with Jermaine, I realized it was about more than me and my son; it was about the next young mom who comes along with a kid who has Down syndrome and feels like I did. And I thank God for all of that. If He hadn't been in it from the beginning, it could a turned out totally differently.

Felicia. My mothering journey began in the 1980s when I gave birth to a baby girl named Rose. At the time of her birth, I was in my 30s and my husband and I were working professionals. Rather than beginning my story at Rose's birth, I'll start just shortly after her birth. The hospital where Rose was born suggested she might have Down syndrome, but they couldn't confirm the diagnosis. So, at only a few days old and weighing under five pounds, we had to take Rose out of the hospital and travel to a larger medical facility in another town that was equipped to diagnose Down syndrome.

The doctor we saw had a good reputation, but she was just a hideous person. She scolded me harshly for not having prenatal testing and an abortion. She just lit into me and made it very clear that my child would do nothing. Maybe we could take her for a car ride; she might enjoy that, but otherwise, nothing. At best, she might have the intelligence of a 7-year-old. It was a horrible prognosis and a terribly low point for us, but it didn’t last long.

With the support of friends and family, I eventually read enough to know that what the doctor said was nonsense and a very inaccurate and outdated view of Down syndrome. By the time Rose was born, there was a recognition that children who had Down syndrome could thrive in regular, non-institutionalized settings, and they could learn. So, I decided that Rose would have opportunities to learn and develop physically, intellectually, spiritually, and in all areas where she showed interest. My husband helped make sure this was a reality for our daughter.

In fact, my husband was my greatest source of support raising Rose. Without his strength and insight, I don’t think I would have survived. It was my husband who questioned the doctor’s prediction that the most we could hope for was that Rose would have the intelligence of a 7-year-old; “Which 7-year-old?” he asked me, because they’re all different. At the time, we knew a 7-year-old who was a pretty interesting and creative guy; his mind was always working. If that was the best Rose could be, that wouldn’t be bad. In fact, it was better than many adults we knew.

Ultimately, I guess I came to believe that this doctor could not and did not know my daughter’s future, and neither did I. But I had this faith, this hope, that the doctor would be wrong, and she was. Still, when I think of the pain that doctor caused me and my husband, and the damage she may have done to other families, I feel bitter sadness. That doctor saw my daughter more like a vegetable rather than a human being with a spirit that thrives from pursuit. Apparently, she had not read or understood Tennyson’s poem, Ulysses; it is the pursuit of life, not the mastery of life, that matters.

Sabrina. During the 1970s and not yet 20 years old, I gave birth to my first child, a baby girl named Bea. When I first saw her, I knew something was different, but I didn't know what it was; mother's intuition, I guess. About an hour later, the doctor came into the room to share the news with me and said, "Your baby is Mongoloid. She'll never be able to walk, talk, feed herself, do for herself, she'll be a vegetable. So the best thing you can do as her mother is to put her in an institution." Oh, what a shock! I had just come out of delivery and was still recovering. What was this doctor saying to me? Was he telling me I would not be able to take care of my baby? Could an institution take better care of her than I could? Was that the only hope for her? The doctor told me to think about it, and he would come back for my answer later. By the time the nursery brought Bea in for her feeding, I was scared to death. I thought maybe she wouldn't be able to eat right and she might choke, but I did the best I could with a bottle, the whole time wishing she would hurry up and eat so the nurses could take her back to the nursery. I was scared and so afraid that I was going to hurt her. Once they took her back to the nursery, I starting doing a lot of thinking. My family was there and we were all just so excited, but at the same time, we were facing something we did not understand. I was young and naive and I knew nothing about Down syndrome; neither did my family. So we prayed together as we searched for the right decision.

I've always been a spiritual person; my family raised me that way. So when Bea was born, I had my doubts and I wondered why God would to this to me? Why would He do it to her? I felt so guilty and so sorry for Bea. I was young and immature and I thought it was my fault; for some reason I was being punished. I wondered if I had not lived like I should and God was trying to set me straight. I had so many conflicting emotions; guilt, fear, anger, and happiness. There was happiness there; I had just delivered a baby girl, but I wanted a child that could run, play, and laugh. So all these emotions were running together at the same time as I prayed with my family.

After the doctor shared the bad news, the first thing I did was think about the negative possibilities he suggested; I didn't focus on the positive. But as I prayed with my family, my doubts were lifted. I thought God was not punishing me. I didn't need to feel guilty. He chose me to be Bea's mother for reasons I might never fully know, but He picked me! Having that faith, my heart just opened up to her, and I wasn't scared anymore. The next time the nurses brought her to me for a feeding, I did much better and I thought "I can do this." After that, she was just like a newborn to me.

My family felt the same way, and we decided this baby was going home with us; she wasn't going to any institution. I think we knew that all along, but prayer reassured us we were making the right decision. So when the doctor came in later and wanted to know what I had decided, I told him, "She's going home with me." He asked if I understood the challenges that would be ahead. I told him not really, but we're going to try it anyway. It was the right decision. "Oh my goodness. What a joy she was to all of us. And she still is."

Mary. I may be the oldest mother telling her story here, but I was only in my 20s when Angel was born back in the 1960s. She was our first child, and my husband and I were looking forward to the birth; the whole family was really. In those days, babies weren't kept in the hospital room with the mother; they went to the nursery. The hospital gave you a card that identified your baby so they would know which one to show you at the nursery. The doctor that delivered Angel suspected something was wrong, but he couldn’t get ahold of the pediatrician, so he didn’t come by to talk with me and he didn’t have the nurses bring the baby around. Even though this was my first child, I knew this was unusual and I worried that maybe my baby had died. But I saw the card on the dresser mirror, and I thought surely they wouldn’t go to such trouble to keep it from me if she was dead. So that was the day Angel was born; it was a Saturday afternoon.

The next morning, the pediatrician came by to talk with me. My mother and husband had gone home for the night, so I was alone when he told me that Angel had Down syndrome and she would never be able to do anything. The way we laid her down would be the way she stayed until we picked her up. He said we should never take her home from the hospital, and that we should send her to an institution. He painted the bleakest picture and told me if we took her home, our lives would be terrible. I had never heard of Down syndrome, and it was scary. After he left, I was in shock. This was totally the opposite of what you expect when you go in to have a baby. You expect it be wonderful, but it was not wonderful, at least not in the beginning; not because of Angel, but because of the dark picture the doctor painted.

When I started crying, the nurse asked if I wanted some medication, but I said, “No, this is something I’m gonna have to live with the rest of my life, and I might as well start now.” Of course, I started praying, and I prayed and I prayed. By the time my mother and my husband got there, I was at total peace, no more tears, no more anxiety, no more fear. I didn’t have any answers; I just knew that we were gonna take her home, we were gonna love her, and whatever was in the future, we were gonna be able to deal with it.

The day after she was born, they finally brought her to me and that was the first time I got to see her. When I held her and looked at her, well, she was beautiful and precious to me, and I felt such joy and happiness. So, once I got over the initial shock of her diagnosis, I recognized her for what she was; our blessed, loaned gift of love from God. I just knew it was gonna be okay because the Lord was with us. About a week after she was born, someone gave me a book written by Dale Evans called *Angel Unaware*. It was about Dale's baby who had Down syndrome, and this was the first I ever really knew about Down syndrome. That book reminded me that God sends angels to be among us, and He brought Angel to me and my husband because He knew she was going to be loved and cherished. And what a joy it was to take her home, you know. We were so proud of her.

Of course, she was nothing like this doctor had predicted. She's bubbly, outgoing, fun, and she was all of that from the time she was big enough to start giving back. The first few months of a child's life, as a parent, you do all the giving. Then all of a sudden, they become a personality that starts laughing and smiling at you, grabbing your finger, and all of those things. They give back. That doctor didn't think Angel would be able to give back, but she's been a joyful and giving blessing all of her life.

Research Questions

Sub-question number one: Why us? To understand how spirituality and/or religiosity influenced the meaning these mothers attributed to their child's diagnosis, the following sub-question was explored: How does spirituality or religion create or reduce meaning with regard to the child's diagnosis of Down syndrome? Several factors contribute to the complexity of these mothers' responses. When responding to the interview questions related to this research sub-question, mothers offered insights grounded in their spiritual and religious beliefs, but they also presented information that contributed to the meaning of their child's diagnosis that was unrelated to these constructs. In addition, some meaning-making contributors were both spiritual and secular. For example, mothers consistently spoke about love as an important element that influenced their understanding of Down syndrome. In some instances, the word love represented the spiritual love of God; in other instances, love represented compassionate caring for others. Finally, mothers acknowledged that their understanding of Down syndrome was not static and changed over time. Despite the convoluted nature of understanding a meaning that is ever changing and contextually situated, mothers consistently responded to this question with two primary thematic ideas: (a) I am a God-chosen mother of a child-gift, and (b) my child has purpose. The latter of these, purpose, has several subcategories as mothers discussed their child's purpose in relation to themselves, their family, and their community.

God-chosen mother of child-gift. Of these six mothers, five of them believed their role as a mother of a child who has Down syndrome was God-ordained. They did not claim to know why they had been chosen as most of them did not initially feel particularly well equipped for the task. Sabrina described this unknowingness when she said, "He [God] did give me this child for some reason. I didn't know yet, but I was chosen to be her mother for some reason I may never know." The only mother who thought perhaps God had chosen her because she was prepared was Helen who described herself as an older, more educated and knowledgeable mother who had access to valuable resources, benefits many younger mothers might not have. Some mothers believed God's choice in delivering this child to them was intended to help them deal with personal challenges. Denise said “I could have went and been wild and crazy. I coulda did a lot of things, you know.” Unlike many of her friends who did not have a child with a disability, Denise avoided most of life’s destructive temptations, and she attributed this to God and her son: “Jermaine was given to me for the purpose of keeping me grounded, keeping my connection with God. I believe that! You know it wasn’t nothing that I did; it wasn’t nothing that I deserved. It was just God’s plan.” Sabrina and Isabella shared similar stories about hardships and challenges in their younger years. They believed God rewarded their faithful endurance during these earlier years through the blessed gift of a child, which provided them with guidance and direction. Sabrina described this chosen perspective as a re-scripting of an initially negative view of God’s intercession in her life when she said, “Well this happened for a reason, not that you are being punished; you don’t need to feel guilty. God has chosen you to be Bea’s mother, ya know, to be my child’s mother. I was chosen!” Isabella engaged in a similar re-authoring as she described her mental transitioning: “I just thought oh, I have an unhealthy child. I have a child that… is gonna be different than everybody else…But this is my gift. I thought this was what He [God] gave to me. I came to the conclusion that, okay, this is my gift for all that crap I had to go through as a child.” Yet, for these mothers, the gifted-child was about more than God extending a helping hand to them; it was about them caring for God’s blessed gift.

Regardless of their status as young or older, experienced or inexperienced, and formally educated or not, each of these mothers believed they were chosen because of the love and care they could offer their child. Mary expressed this when describing her daughter as “an intentional gift. I think God knew that we were gonna love her, and that she was going to be loved as much as [she] possibly could be loved. I think God said, ‘that’s a good place for Angel.’ ” Similarly, Isabella claimed, “God chose me as her parent ‘cause He thought I could handle it and He thought I would be good for her,” and Sabrina described feeling blessed by God for being chosen to be Bea’s mother as though she were given a special task to fulfill. Denise reiterated this idea of vested safekeeping when she said, “He [God] trusted me enough to give me Jermaine because He knew that I was gonna take care of him. You know, Jermaine could have been anybody’s kid, but He gave him to me!” In her practical fashion, Helen believed God chose her and her husband to parent Diane not only because they would love her but also for pragmatic reasons “because we had what she was gonna need.”

Felicia was the only mother who did not describe her mothering role as God-ordained. Felicia had a deep spiritual faith and a committed relationship with her church, yet her faith orientation was not grounded in pre-deterministic ideologies. She relied on God, prayer, and the sainted to offer divine wisdom and guidance, but she did not presume her circumstances to be pre-scripted by God. Consequently, she did not recount her daughter’s birth or diagnosis from this perspective. However, she did conceptualize her mothering role and her daughter’s interactions in the world as purposeful.

Purpose. All these mothers described the meaning of their child’s diagnosis in terms of purposefulness, and every mother told a purpose-filled story of their child’s life. Some of the purposeful living was linked to spiritual and/or religious ideas, but other instances of purposefulness were not. The child’s purpose benefitted the mother, the family, and the community. The child’s purpose also had an indirect ripple effect whereby the child's influence on the mother and others resulted in more profound changes as these individuals interacted with the larger community. Across these domains, the most frequently identified purposes were related to a child's ability to influence others through: (a) unconditional love, (b) inspiration and modeling, and (c) teaching and advocacy. Although related, it would be inaccurate to imply these mothers found meaning in their child's diagnosis of Down syndrome without first explaining how this diagnosis was an acknowledged and significant component of their life story but also an element that fell into the obscure backdrop of their child's personhood. In other words, the meaning derived from purpose was descriptive of the child's uniqueness, not the diagnosis. Felicia described this conceptual absence of a Down syndrome diagnosis when she said:

> This label, Down syndrome, is something I forget about most of the time...I just don't think about [it] very much. She is who she is, and the label doesn't explain it, it doesn't help, it doesn't do anything. She's Rose; that's who she is.

Unconditional love. All of the mothers said their children genuinely loved people. The mothers did not necessarily believe their children loved more deeply than others did; rather, their expressions of love were less inhibited and held fewer judgements and expectations. Unconditional love was considered a spiritually caring act of soulful connection and an extension of God's love for us. For these mothers, love was a worldly experience of the human form and it was also an existential experience that unites us spiritually. Mothers were often the recipients of this unconditional love as Helen explained: "Being a parent's hard, but there's so much more that's positive…you still have unconditional love, and she's 23. If she opens that door, she'd run in here, 'Mommy!' So those are the great things." Sabrina repeated this narrative when she said her daughter "is full of love and just a joy. That girl loves me with all of her heart…That's a blessing, when you have someone in your life that loves you so much, unconditional." This unconditional love was not reserved for mothers; fathers were recipients too. Isabella narrated how her daughter, Chloe, expressed her spontaneous request for her father's affection when she looked at her dad and said "kiss me dad, kiss me right here," gesturing toward her check. But according to her mother, Chloe's love of people was infinite.

In fact, most of these mothers described how their child's love was not bound by familiarity. People outside the family, even strangers, benefited from this love. Isabella said Chloe "loves everybody; she can't help it." Then she adds, "Maybe she has an impact more than we know [because] some people don't get the time of day, and that might be the person she chooses to hug." Denise contributed to this communal love concept when she described her loving son: "If he came in here now, he'd wanna give you a hug or kiss on the jaw…Them older ladies at church, oh, they love it, cause…Jermaine's gonna pass hugs around to everybody, or blow you a kiss." Felicia added to the loving narrative through her admiration of her daughter's ability to get along with and affect so many people stating, "I have people coming up to me and saying, 'Oh, is Rose your daughter?' And then they go on about how nice she is, and how sweet she is, and how much they like her." Mary's account is similar,

> Everybody talks about Angel's gift, and her gift is love. And they talk about it all the time because they say she loves everybody. And she shows her love, you

> know. If you're gonna be around Angel, you're gonna get hugged, okay. And, she impacts the world with love, and it's an unconditional love.

Mary goes on to describe her daughter's love of others as Christ-like, an idea other mothers described as neighborly love.

Inspiration and modeling. Mothers depicted their children as inspirations for their own and others' spiritual development as well as models for living a full and mindfully-present life. Sometimes others, such as family, friends, teachers, parishioners, and even strangers, bore witness to the inspirational role the child held in their life. At other times, mothers made assumptions about their child's inspirational influence by observing their interactions with others. Inspiration influenced spiritual development as these children magnified their mothers' and others' acknowledgement of the active presence of God in their lives and intensified their spiritual connections. Their children kept them focused on God as they endeavored to teach them about the family's religious faith beliefs. For several mothers, the certain belief that God unconditionally loved their "imperfect" child translated to a deeper understanding that God loved them too, even with all their imperfections. This awareness inspired most of these mothers to forgive and love themselves with more grace.

For some mothers, the prayerful examples their children set encouraged them to have greater faith, or at least try. Sabrina said she sometimes struggled with prayer and thought that her simple prayers may not be heard, yet, "Bea prays a lot. I hear her praying in her room all the time. She has more faith than I do." Sabrina's faith in prayer was renewed because she believed God heard and responded to Bea's prayers. Speaking of her daughter, Mary claimed, "She's made my prayer life much deeper," then added, her "prayers go through when sometimes ours don't, because they don't carry the baggage that we carry."

For other mothers, spiritual inspiration evolved as they cared for their child. Felicia, like many mothers, labored to develop the unique parenting skills and responses needed to care for a child with a disability. Through the stumbling process of parenting ineffectively then getting it right, Felicia believed "that's what's made me a more spiritually rich person. That you're concerned enough to do what you have to do to [get] it right, even though it's a whole lot of work." Denise explained that her mothering struggles made her recognize the need for God in her daily life and encouraged her to listen for God's guidance. "When I had Jermaine, it changed my whole focus, and I knew I needed God." Helen reiterated this recognition that God influenced all aspect of her life as a mother; and although she had always pursued a spiritual relationship with God, her daughter shaped her thoughts about God's guiding presence. "She's probably the reason why I think that God just plays a hand in how things are supposed to be….I guess we've had so much to deal with that I just had to let some of it go." Like the other mothers, Mary turned to God daily to request forgiveness, guidance, and support, but Mary's faith was strongly tied to her parents' beliefs, particularly her father's. Consequently, when Angel inspired Mary's father, this was especially moving for Mary. As Mary explained, her father was excited about the birth of a grandbaby, and when he initially learned about her diagnosis of Down syndrome, many of his grandfatherly dreams were shattered. However, it did not take long for him to realize he had been mistaken. With tears in her eyes, Mary recalled her father's words as he said, "she's the greatest gift we've ever gotten. I’ve never questioned God again with anything He’s done, because He has blessed me with Angel. Angel taught me never to question God again.”

Mothers reported their children inspired them to develop a more positive outlook and resilient character. All mothers thought their child had helped them become better people by expanding their compassion, empathy, patience, and tolerance for others. Mothers stated their child encouraged them to live life more fully and meaningfully and that others were inspired by interacting with their child. Helen said her daughter taught her to live with greater freedom and a mindful presence in the moment. Helen said, Diane “helps me live for today, look for the fun things, and realize that life is not all about planning and organization and stuff like that, because she doesn’t plan; she’s fun today.” Helen was inspired by her daughter’s spontaneity, affectionate nature, and achievements. Isabella said Chloe inspired her to let go of material acquisitions, the need for orderliness, and to live in the moment with the people she values most. Isabella believed others reframed their own circumstances after learning about the many life challenges young Chloe had already faced. “They think, well, look at Chloe, what all she’s been through, and I’m really complaining over this!?!” Sabrina was inspired by her daughter’s ability to fit in to diverse social settings, her physical and mental aptitudes, her spiritual faith, and her independence. Denise was inspired by her son’s ability to overcome barriers, appreciate music, never stop learning, and by his loving personality. Felicia was inspired by her daughter’s determined perseverance, her hard work ethic, her brave endurance even when afraid, her ability to get along with others, her caring nature, her talents, and even her political interest and savvy. Mary was inspired by her daughter for many of these same reasons but most notably because of her deep and personal relationship with the Lord.

The most direct examples of a child's inspirational influence on others were related to career. For some, the child's influence inspired mothers and others to choose careers that allowed them to work directly with children or adults who had disabilities. For others, the inspiration motivated them to pursue a variety of helping professions, such as nursing or counseling. Helen was recently contacted by one of her daughter's grade school tutors, who told her "one of the reasons [I'm] in nursing school is because of Diane." Felicia shared a similar story about her daughter's art instructor who "told me one of the main reasons she got her rehab degree after she finished the art program was Rose." When speaking about her son's influence on her and her sister's career plans, Denise said he "was the catalyst for our business plan." She and her sister returned to school to obtain degrees that would help them open a day facility program for adults with disabilities, a need Denise became aware of once her son graduated from school.

Teaching and advocacy. Although no single purpose rose to the top as most significant in understanding the meaning of Down syndrome, the influence these children had on teaching and advocacy is demonstrably present, particularly for the mothers. Every mother shared examples of how her child taught her and others important life lessons or motivated them to become teachers and advocates. In fact, the role of teaching was as integral as love in understanding how these mothers conceptualized Down syndrome. Mary conveyed this interwoven purpose when she explained,

> I believe Angel was given to me and Don [her husband] as a gift of love, ‘cause He knew we were gonna love her and cherish her. But she was also given to us to teach us something and to use us to teach other people.

Mary believed, through the gift of her daughter, she learned how to love and accept others unconditionally, something she viewed as a Christ-like love. She was tasked with teaching others this lesson by modeling these behaviors. Denise felt a responsibility to teach as well. She did this by mentoring a young mother of a child who had Down syndrome and sharing the wisdom that she had learned mothering Jermaine. Denise drew great satisfaction as a mentor to this young mother, explaining, “I was placed in her life to give her direction so she wouldn’t make some of the mistakes that I made. And I’m like, ‘Thank you God,’ because that was the whole plan for me to be there.” Sabrina described herself as an indirect participant in her daughter’s unintentional teaching and advocating. Sabrina described her daughter, Bea, as a role model whom many admired. She was often asked to watch over younger children, which she did happily. During these occasions, Bea encouraged others to engage in new activities and role modeled her own accomplishments; in doing so, she demonstrated the possible. Through this unintentional advocacy, Bea broke down stereotypes and taught others how to overcome barriers. Sabrina described one notable occasion when Bea’s modeling was particularly significant for two young parents-to-be.

> Bea was probably 8 to 10 years-old and she [teacher] asked if Bea could come home with her one afternoon. She had a friend that was pregnant and they just found out that their baby was gonna be born with Down syndrome. She said I would love to take Bea to their house so they can see what can become of their

> baby. And, I said sure you can! She took Bea to their house, and when I went and picked her up they were so blessed and so thankful that they got to spend quality time with Bea [and] to see what chances their baby could have at a normal life situation. So that, of course, made me so happy.

Bea took these moments in stride, but her mother did not. Sabrina was proud that her daughter was able to teach others what children with Down syndrome could achieve, unraveling the irritatingly persistent narrative that focused on limitations, barriers, and anticipated failures.

Isabella's experience with her daughter's teaching was closer to home. Isabella said, Chloe "teaches me about priorities. She teaches me don't sweat the small stuff." Before Chloe was born, Isabella was a working woman with an established career who liked a tidy and orderly home. Now, she says, "Before her, I would have never sat with this junk here; that would have freaked me out! Now, I'm like, whatever, it's not important, it's just paper. She knows what's important, and some people don't get that." Isabella's words reflected several other mothers' opinions; recognizing one's personal priorities, and attending to these needs before other less important demands, led to a more fulfilling and meaningful life experience.

Helen was an advocate who used teaching as a tool. Consistent with her self-described practical character, she was a "list maker, organizer, get-her-done kind of person." Helen was proactively involved in her child's integration into her school, her church, and her community. Helen's identity was interwoven with her daughter's. If Diane was not happy, Helen was not happy. If Diane was not accepted, Helen was not accepted. Because Diane did not have the ability to advocate on her own behalf, Helen acted as the voice of her daughter. However, in advocating for her daughter, she was also advocating for herself. Other mothers shared some of these same close emotional connections with their children, and their experiences of child-linked acceptance or rejection were similar to Helen’s, but each mother responded to these situations uniquely. For Helen, it was about planned and strategic advocacy. She advocated for her daughter’s integration into the school system. She advocated to secure a suitable tutor for her daughter during grade school. She advocated for equal access in the church when barriers prevented her daughter’s spiritual and physical engagement. She taught numerous in-service training classes in an effort to inform people about Down syndrome and other disabilities. As Helen saw it, “I’m her voice. I make sure that I have provided her everything that I can that’s going to make her have the best quality of life possible, because if I don’t do it, who’s going to do it?”

Mary was also an advocate, but of a quieter sort. She did not like to cause disruptions or call attention to herself, but she wanted her daughter, Angel, to have opportunities. Like Helen, Mary became involved in her community and church in order to create an accepting space for Angel. For Mary, prayer was also part of her advocacy practice as she asked the Lord for guidance, support, and intercessions when needed. Mary also invested her money and her time to raise money for programs that facilitated her daughter’s integration and participation in their community.

Felicia was another quiet advocate as was her daughter, Rose. Like the other mothers, Felicia advocated for her child’s place in the school, church, and community, and she believed that opportunity and education were important. As Felicia expressed it, “I think even that intellectual aspect is, in part, spiritual. If you can read, you can empathize with others. I think that's a part of spirituality too, and so that's something that we try to encourage her in." However, there were barriers to these goals, and Felicia challenged them through advocacy. Some advocacy occurred in the school with one teacher who believed her daughter could not and should not be taught to read. Other advocacy was aimed at the church. Felicia described a challenge she encountered during a campaign drive to raise funds for religious education programs that would fail, once again, to create an inclusive environment for her daughter. In her view, her donation would signal her endorsement of segregating practices. When she asked the clergyman, "Why should we support some place that has historically discriminated against individuals with disabilities?" he had no answer for her. Felicia was troubled by the historical patterns of discrimination, but what she had really challenged was the church's current practice of denying children who had disabilities admission into their private school.

Felicia, like Sabrina, believed her daughter was an advocate through her character and achievements. Rose was gifted in many ways and her resolute determination was admirable. Felicia hoped her daughter's example would erode stereotypes about Down syndrome and allow individuals to be seen without biased assumptions.

> What I hope her influence on others does is get them beyond stereotypes of people with intellectual disabilities to perhaps recognize what people with disabilities can do, and perhaps the ways in which they are more like us than different.

All of these mothers were advocates and teachers in their own way, and they all agreed that advocacy is just part of the mothering journey. Some mothers advocated loudly, others quietly, others through modeling, others through teaching, others through their child's character and achievements, and others through their wallets.

Sub-question number two: Blessed are the meek, sometimes. To understand how religiosity and the church influenced these mothers' conceptualization of their child's diagnosis, the following sub-question was explored: How do the systemic patterns within organized religion influence positive or negative perceptions of Down syndrome? Mothers' perceptions of Down syndrome within the context of the church were not bound to the label of the diagnosis, but they were bound to the manner in which a child with this label was accepted and included in the church. For these mothers, the positive and negative narratives the church created about Down syndrome hinged almost solely on the thematic constructs of acceptance and rejection. This acceptance or sense of belonging versus exclusion or rejection were communicated to mothers through four primary sources: (a) religious scripture and stories, (b) the community of the church, (c) the institution of the church, and (d) religious leaders. Scripture, church culture, church bureaucracy, and religious leadership were overlapping and interwoven constructs that influenced these mothers' stories, but were often difficult to distinguish. Similarly, there were blurred lines when talking about the church as the body of Christ, house of God, the body of congregants, or an organized institution. Felicia described these intersecting but distinct conceptualizations of the church, when she said,

> I tend to think of the church as more than just the bureaucracy of the church and more than just the [religious leaders]...They're human, they're frail, and they're error prone, and I think the church is more than that. I remember when [one religious leader] was here, he said to the congregation, "You are the church; It's

> not me. You are the church." And I think, in part, that's true. It's the people that [are the church]… If there are some narrow-minded, bigoted individuals that are part of the bureaucracy, that's a problem, but the church is greater than that.

The ambiguity and overlapping meanings of some religious terms (e.g. church as body of Christ, house of God, collection of parishioners, or institutional bureaucracy) did not hinder these mothers' storying. In fact, these conversations provided rich sources of meaning that contributed to how these mothers understood their child's position within the church, and consequently Down syndrome in the context of the church.

Religious scripture and stories. For several of these mothers, biblical scriptures and stories were sources of positive messaging that affirmed their child's place within the church of God. Mothers' interpretations varied among the Christian denominations, but all mothers relied on some form of biblical narrative for support. A few of these scripture-inspired beliefs included: God does not make mistakes; my child is beautiful and perfect in [God's] eyes; children are a gift from God; nothing is impossible with God; children and persons with cognitive disabilities automatically receive God's grace and salvation at birth; God's Holy Spirit guides us; and the heavenly angels and saints watch over us. Some mothers contemplated, "What would Jesus do?" under their circumstances. Helen said the scripture, "Do unto others as you would have them do unto you" (Luke 6:31) positively guided her behaviors and her expectations of others' behaviors toward her and her daughter. For Helen, this scripture proclaimed that kindness and acceptance was the Christ-like response to people with disabilities.

Many of the scriptures mothers relied on for support had a larger backdrop in a biblical story. One example was the saga of the prophet Elisha and God's army of angels. As Mary told the story of Elisha heading to battle with his servant, she said,

> When they looked out, the enemy was huge compared to the men that they had. The manservant was totally frightened, you know, almost scared to death, and the [prophet] was totally at peace. [The servant] asked him, 'How?' [The prophet] said, 'They're there protecting us.' [The servant] said, 'Who?' And [the prophet] asked the Lord to let him see. And there were legions of angels surrounding them, and they were protected; and I believe that! I believe there are angels that protect us.

One story Isabella turned to for strength was the passion of Christ, or, as Isabella described it, God's sacrifice of his only son. When Isabella was faced with the possible, perhaps even probable, death of her baby daughter due to a life-threatening condition, this story resonated with her internal struggle to give up or survive. In her most despairing moments, the story did little to alleviate her agony, but at other times, the story helped Isabella imagine her own endurance of the seemingly impossible. Reflecting on this difficult time, Isabella recounted,

> I thought why in the world would you [God] give me this child? It's probably the most bitter I've ever been at God. At that time [I thought], "Why would You give me this child, and then I accept that she's mine and I love her, and then take her away from us six months later?" I mean, I know you can't figure everything out, but I'm a person that tries to sometimes, and I just could not make absolutely any sense of it…Since then I've learned of some ways to think of things like that. I

> think, you know, God gave up his son for us, so why can't we give up our child for Him?

Though some biblical narratives provided mothers with solace, other scriptural accounts were a source of angst, guilt, and indicative of deserved punishment. Several mothers experienced moments of self-blame and questioning about the birth of their baby who had Down syndrome. They believed, at least for a time, that their child's diagnosis was God's punishment for the sins they had committed. Although short-lived, Sabrina initially responded to her daughter's diagnosis with guilt: "I did feel guilty; like why did this happen? Did I cause this? Did this happen because of something I did? Was I being punished?" Denise's thoughts were similar as she recalled, "At first, when Jermaine was born, I thought, well, this is God's way of getting back at me because I had this mixed up notion that I wanted a bunch of kids, but I didn't go about it the right way." Consistent with this script, Isabella questioned God's retribution following her daughter's birth and near-death experience: "It just felt like I was being punished. Like, why would You give me this child who has special needs anyway and is not so-called healthy, and You're gonna take her away from me now?"

Some mothers also experienced guilt about their angry hurt at God's unjust betrayal, abandonment, and failed protection. They wanted to know "Why?" but even this questioning produced guilt, because they believed scripture suggested true faithfulness demands no explanations or validating evidence. Isabella described this early questioning as her immature Christian faith, whereas a mature Christian would never question and never doubt God. Fortunately, these mothers resolved this birth-associated guilt early in life.

The community of the church. All of these mothers described their feelings of acceptance or exclusion as interwoven with their child's experiences to some degree. Mothers' religiosity was often dependent on their child's success in securing an accepting space within the church community, which some also called the congregation or body of the church. These mothers conceptualized the church community's perception of their child's disability from two perspectives: the first conveyed acceptance and a sense of belonging, and the second projected messages of exclusion or outright rejection. Acceptance and a sense of belonging were gleaned from parishioners who overtly welcomed and actively included mother and child into the church family and activities. Sabrina and her daughter, Bea, experienced this open encouragement when,

> We were invited to a Christmas dinner with Gentry Church and I thought, okay, we should do this and just see if it might be something that we're interested in; and we did. And then, of course, Bea just took right off with it, and I knew this was our place. I was like, this is too cool! There's all kind of stuff going [on with] all these people, you know, and I could go to another class. I don't have to go to Wonderfully Made Ministry, but that's where I belong.

Supportive tolerance was another way parishioners communicated a sense of acceptance. Sometimes, although rarely, parishioners communicated their tolerance to mothers by verballing telling them they need not be concerned about their child's nontraditional or unchurched behaviors; their child was accepted and welcomed in the church just as they were. For instance, Sabrina said parishioners told her, "Oh, she'll be okay; don't let that bother you. We're used to children not sitting still." At other times, parishioners communicated this acceptance not in words but in actions. Denise described an instance when parishioners demonstrated their acceptance of her son's boisterous behaviors.

> We were doing the offering and Jermaine would always turn the lights off. He would always, every Sunday, he would turn the lights off. And my pastor would be like, "Denise, get your boy." But, everybody, that would be funny to them. That would break the whole church monotony, 'cause everybody be laughing. He'd be laughing! And they wouldn't stand there and block it, you know, so he wouldn't do it. They let him do it every Sunday.

Sabrina, Isabella, and Mary shared similar stories of parishioners' acceptance, which were powerfully-reassuring messages for these mothers. Because mothers often anticipated negative judgment from others, overt welcoming was important in creating a sense of inclusion and belonging. Like other mothers, Felicia thought inclusion was equivalent to acceptance and belonging, and she sought to identify and access accepting environments for her daughter, Rose, in all areas of her life including the church. What she found was that acceptance was inconsistent among parishioners: "Kids accepted her. They knew her…They were fine; they supported her. Adults who were older and who had stereotypes, they were the problem." Still, some adult parishioners and educational instructors accepted Rose and facilitated her integration into the church. When Helen felt accepted by parishioners, she did all she could to facilitate her daughter's successful integration into the church community in hopes of establishing the family's church home. Despite Helen's repeated efforts at multiple churches over the years, it did not always work out; in fact, it never worked out for long. Isabella experienced a similar struggle in finding a church home for her family because the smaller church community created a more accepting cultural fit for her daughter, Chloe, but her other children benefited from the diverse services offered at a larger church. In her attempts to meet all of her children's spiritual needs, Felicia sent Chloe to the smaller church with her grandmother and the rest of the family attended the larger church. Consequently, Sundays created a spiritual divide and sense of incompleteness in the family.

Even the most basic gestures of simple kindness communicated a sense of belonging for these mothers and their children. It was particularly inclusive when parishioners normalized their child and treated them like other children. Isabella expressed this appreciation when she described how the parishioners interacted with her daughter. "They just…hugged her and kissed her and all that…I got good stuff from the church, and it was probably just the fact that they loved her like she was and didn't treat her any different." Mothers also experienced acceptance through caring outreach offered by parishioners in the form of prayer, babysitting services, and sometimes even financial assistance. However, the outreach of prayer and financial support was typically reserved for critical situations such as sickness, injury, or death. Sabrina and her family were the recipients of her churches' emergency outreach support following a house fire. With gratitude, Sabrina said, "My church just spread the word [and] you would not believe how much stuff started coming in…It was enough to get us our own place and set up house again." Unfortunately, other mothers received no support because they became disengaged from the church during difficult times when their child was most seriously ill. When these mothers were again able to return to routine church involvement, the situation was not deemed critical, so no support was offered. The church, and sometimes the mothers, considered the routine care a child with a disability needed as unwarranted of special assistance, although they all agreed there were unique challenges in this mothering experience. When addressing this issue of church support, Helen said,

> We didn’t have death or a severe accident or hospitalization or sickness or any anything which is when everybody [brings] a casserole thing, and comes by to visit, and all of that. So, I know that the church plays that role and I saw it happening with other families, but we never had a need.

For those mothers who were involved in smaller church communities or smaller church groups within a larger church, prayers and other outreach supports were more likely to be offered during times of crisis as well as during times of routine daily challenges. Though these affirming experiences were important in helping mothers positively understand their child’s disability in the context of the church community, some parishioners covertly and overtly ostracized their child.

The community of each church had a distinct culture that was perpetuated by its members. The unspoken rules and expectations of social and religious etiquette were difficult for many children to adhere to, and they were especially challenging for people who had Down syndrome, intellectual disabilities, or sensory disorders. In most churches, there was an expectation that one sit still and remain quiet while the religious leader delivered the daily message, which was typically constructed for and delivered to an adult audience. Meanwhile, sensory distractions abounded as lights and stained-glass windows glittered, people and papers rustled in the pews, voices and music reverberated from the speakers, bodies and smells permeated the senses, and the sermon lingered on and on. Mothers reported their children’s unchurched behaviors were sometimes exacerbated by these circumstances. Some parishioners understood, some looked on with questioning misunderstanding, and others were clearly hostile toward non-traditional behaviors even when they presented only minor non-disruptive oddities. Sometimes, being different meant one did not belong. Mary shared her experience of being physically ostracized, when other parishioners were “talking and blocking where we [couldn’t] get through. Now it’s obvious that we’re standing there, but they’re not moving. And, when they do move, they don’t smile and say how are you or excuse me,” they just discounted her and her daughter’s presence as unworthy of acknowledgement; they were invisible members of the church. Her overall conclusion of some parishioners’ attitudes toward members who had disabilities was that, “They don’t wanna be bothered, you know. They take them [people with disabilities] and put them somewhere where we don’t have to be bothered with them.” Helen reiterated this idea of invisible presence when she described how her and her daughter’s church absences went unacknowledged by many of the parishioners suggesting that they were unimportant and unmissed.

Only rarely did Sabrina report a lack of perceived support from her fellow parishioners, and even then it was more about differing viewpoints rather than unsupportiveness. In contrast, Helen and Isabella reported disappointment that church members did not occasionally offer to care for their child during church services, which would have allowed them to focus fully on the service.

These mothers’ perceptions of parishioners’ support were quite different. Sabrina felt overwhelmingly embraced by the church because her daughter was. Felicia had some disappointments with individual parishioners, but, like Denise, her tribulations with the church focused more on the bureaucratic institution of the church that was insensitive to the needs of persons with disabilities. Isabella’s struggle was primarily about finding a suitable church home to meet all her family’s needs. Mary found acceptance within the church but was troubled about unequal access and recognition within the church community. Helen’s negative experiences were more pervasive. As a child, she found church to be an accepting environment that provided a sense of belonging. As an adult, Helen found her fellow parishioners were often “cliquish,” judgmental, and not as accepting of her and her daughter as were many other people in their daily lives, such as family, friends, and coworkers. For Helen and her daughter, the search for acceptance and “that sense of belonging or being a part” was easy to secure in some relationships, but “the hardest part [was] in a church.” When reflecting on equal access and accommodations, Helen said, “I think church and acceptance for individuals with disabilities is the last frontier.”

The institution of the church. As described by these mothers, the church is comprised of many components including the parishioners, holy religious leaders and program ministers, religious rites of passage, church doctrines and traditions, and bureaucratic systems founded on rules and guidelines that set the stage for the actual practice of their religious faith. Some of these faith practices followed written protocol, others traditional commitment, and others socially-scripted religious decorum. Though the people of the church and religious leaders certainly contributed to the practices within the institution of the church, when discussing these issues, mothers did not focus on individual parishioners or leaders but rather the overarching practices of the church that either supported them or failed to support them. The mothers were divided in how they believed the institution of the church could most effectively serve their child, and these different perspectives influenced what these mothers hoped to receive from the church.

Some mothers believed that church ministries or Sunday school classes created for people who had disabilities offered a more accepting environment and camaraderie with others who had shared experiences. Other mothers believed this segregated approach further devalued their child, something they had doggedly tried to overcome in all domains of their child's life. Regardless of where these mothers fell on this spectrum of religious mainstreaming, they all recognized pros and cons of each position and understood that whichever situation one chose, they were sure to experience some degree of exclusion and that their child's spiritual needs would likely be only partially addressed, if acknowledged at all. In a broad sense, mothers' concerns about the institution of the church centered on one issue: inclusion.

Church structure. Church size was one factor that mothers repeatedly mentioned when discussing inclusion. Smaller churches tended to offer higher levels of inclusion through social acceptance, interpersonal interactions, and some participation in traditional rituals and practices. However, they offered less spiritual inclusion as the religious messages and materials (e.g. sermons, homilies, scripture readings, lessons) were typically too abstract and complex. Although larger churches also presented spiritual barrier in their collective church services, if they offered ministry services designed to meet the needs of individuals who had neurocognitive disorders, they were more likely to present religious material in a user-friendly format for these individuals enhancing their spiritual engagement. While creating materials and spaces to meet the specific needs of individuals with disabilities, larger churches tended to ostracize these members physically, socially, and spiritually. As all of these mothers attested, cognitive engagement was important in their child's religious development and spiritual experience, but emotional and social connectedness was just as important, if not more important, in facilitating their child’s relationship with God. Smaller churches provided this relational component through association with other non-disabled parishioners and church leaders. Smaller churches also tended to be more tolerant of children’s non-traditional church behaviors and treated these children who had Down syndrome just as they did other non-disabled children.

Although smaller churches seemed to more readily integrate children with Down syndrome into the social network of the church community through regular Sunday school classes and services, they were less likely to provide the empathic understanding support that other families with children who had disabilities could offer. Larger churches that served multiple individuals who had disabilities were better positioned to create opportunities for these children and their mothers to develop reciprocally-accepting relationships with caring peers who had shared experiences concerning disability, but the cost was often associated with exclusion from the larger body of the church. In fact, these mothers reported that it was more difficult for their child to fit into the social culture of larger churches and that finding a space even among other non-disabled children was more challenging, and became increasingly difficult as their child aged. It seemed no church offered these mothers and their children all that they needed and wanted. Instead, these mothers chose church homes based on what they believed best met their child’s needs, understanding that the decision was made with great compromise. Unfortunately, some mothers were simply unable to find a church that met their child’s needs, leaving them and their child, in a sense, spiritually homeless.

Religious practices. Regardless of size, some churches were more adept at creating inclusive spaces for these mothers and their children. When churches created opportunities for children to engage actively, mothers perceived the church as accepting of their child. A few of these engaging activities mothers discussed included participation in children/adult ministries, Sunday school activities, singing in the choir, candle lighting ceremonies, acolytes, baptism, and confirmation.

Baptism and confirmation were particularly significant for these mothers, but church doctrine and tradition sometimes complicated these religious rites. Mothers who attended churches that offered baptism at birth were comforted by the belief that their child was protected and ensured salvation, at least until they could one day accept the church as an independent adult. Felicia said her daughter was "baptized fairly soon after [her birth] because she did have a heart defect and she had heart surgery. I wanted the baptism to come fairly quickly because I was worried about the heart." Even this reassuring holy sacrament was tainted with trepidation because Felicia "grew up in the days when baptism was necessary for salvation." Though Felicia rationally acknowledged that the church has since revised their view on baptism as preferable but not an exclusive requirement for an infant's salvation, that was not the case when her child was born. Consequently, the baptism of Felicia's daughter was immersed in polarizing emotions: fearful anxiety and thankful relief as this sacrament signaled "not just inclusion in the church, but inclusion in the divine."

Helen's experience with her daughter's baptism was different. For her, "you are born a child of God, you are baptized in a church, and the church looks out for you until you take your own personal stand of faith." Helen viewed the baptism ritual as her proclamation of her daughter’s spiritual relationship with God and the church, and it was comforting to her. Helen’s anxiety emerged when her daughter, Diane, entered middle school and was expected to personally proclaim her profession of faith. The confirmation process required preparation, reflection on abstract concepts, independent responsibility, and a public affirmation of the baptismal covenant. Helen knew this would be difficult for Diane, yet it was important that her daughter achieve this spiritual milestone. Helen modified instructional materials, coordinated tutors, created mock practice scenarios, and even delayed Diane’s confirmation so she could be confirmed with her younger brother. “I waited until [her younger brother] was old enough, because I thought maybe she’d get it more when she’s two years older. But even waiting the two years didn’t make a difference, ‘cause it was all above her head.” After much angst and effort, Helen was eventually rewarded when Diane completed her confirmation, which further validated her membership in the church.

At Mary’s church, baptism was not performed at birth. Instead, to receive baptism, one had to independently claim the Lord as savior. Mary could not act on her daughter’s behalf to claim Angel’s membership in the church; Angel would have to do this herself. From infancy, Mary took Angel to church and used books and movies to teach her about their faith. Though Mary hoped her daughter would develop a spiritual relationship, she was uncertain. “It was very important to me to make Angel understand what it was to be saved. Now, did I really believe that was ever going to happen because of her limited mental ability? No.” So, Mary had great pride and relief when one day while sitting in church, Angel looked up to her and said, “Momma, I want to be saved. I want to give my heart to Jesus.”

Accommodations. In theory, these mothers viewed the church as a place of inclusion. They believed the religious doctrines of their churches promoted loving acceptance. Some churches were overt in their efforts to promote inclusion by asking parents what they needed for their child or, more generally, for parishioners who had disabilities. If not proactive, some churches were responsive to requests for accommodations and modifications for members who had disabilities. However, in practice, churches often failed to meet the needs of these mothers and their children. Sometimes financial constraints contributed to churches' inabilities to meet individual needs, sometimes blind disregard for needs hindered churches from responding effectively, and sometimes intentionally excluding persons through systemic practices marginalized persons with disabilities within churches.

Sabrina was the only mother who indicated the church had successfully meet her expectations for her daughter's religious and spiritual needs. For Sabrina and Bea, the church was home and they both seemed to find their place within the church with relative ease and little conflict. Other mothers thought that the church services and accommodations were inadequate and did not meet their child's needs. Helen and Mary spoke directly about funding as a limitation. Both mothers explained that churches, like other organizations, had to make decisions about program funding, and services for people with disabilities were often not a priority. Mary reported funding efforts directed to meet the needs of persons with disabilities were sometimes less than expected and often less than needed. At the same time, Mary was grateful her church made an effort to provide accommodations to meet the needs of their members who had disabilities when she knew many churches were unable or unwilling to do so. Helen's church offered some accommodations to her daughter, Diane, when requested, but it had to be balanced with the needs of other non-disabled children. Consequently, Diane never received full access to her church. Additionally, the approved accommodations were often left to Helen to coordinate or provide and the church offered little to no funding to support programs for her daughter and other children with disabilities.

Barriers. More frequently, mothers spoke about the church's failure to meet their child's needs because of a thoughtless disregard for the full inclusion of people with disabilities within the church. Funding was not considered the primary barrier, but failing to consider the unique needs of their child was a significant problem. Denise explained how the church unintentionally ostracized her son by not considering his sound-sensitivity when they built a new church:

> The new sanctuary came [with] all this sound system and everything…it would hurt Jermaine's ears, where we would have to take him out of the sanctuary and put him in a classroom…Sometimes that even bothered him, because it's just loud and it's intercomed out through the whole building. So, I think in that way they were insensitive to his disability because it caused us to pull him away from church...We'd have to pick and choose services. He did good in Sunday school because it's quieter, but then in regular service, he couldn't stand it.

Not all noises bothered Jermaine; he loved the singing, but intense sounds were problematic. Helen reiterated this sound-focused concern when talking about Diane's sensory-avoidance behaviors in church. Like Jermaine, Diane loved the singing, but when the music stopped and the undercurrent of wrestling bodies and muffled whispers began, it was too much for her to tolerate. Helen explained, "If there's too much talking, if people are sniffing their nose or coughing, those little noises are irritating to her…There were lots of times we would just leave church in the middle." It was simply too uncomfortable to stay once Diane became agitated by the persistent noises. Similarly, Isabella said her daughter did not tolerate loud microphones, which was not an issue in the smaller church, but it was in the larger church. The very foundation of the church's construction created a barrier for these children as sounds echoed and reverberated through the space.

Occasionally, the church's systemic practices overtly ostracized individuals with disabilities. Some specific examples these mothers described included physical access, corporeal placement within the church, and segregation from church affiliated educational resources. The church, for the most part, ensured physical accessibility to the building through ramps, wide entry doors, and accessible bathrooms, but this accessibility did not extend to all parts of the church and the accommodations tended to focus on physical disabilities but not emotional or cognitive disabilities. Denise said of the parishioners, "they treat them nice and kind," but the church had "no activities for them; they have no outreach for…people with developmental disabilities." Helen described her perception of the church's physical, cognitive, and spiritual segregation of people with disabilities when she said,

> So we've had the ADA [Americans with Disabilities Act] around for 25 years, and churches are physically accessible, but …there is still this unseen barrier within churches for families who have an individual with any kind of disability. Granted, you may get in the building with your wheelchair or your walker, [but] chances are your pews are…in the back, 'cause they're not gonna put you up in

> the front. So, you’ve got a physical barrier, but… it’s very difficult to take concepts of religion and break them down when you’ve got such…a disparate gap between how old she is and what she understands. There just was no place for her.

In her determined effort to advocate for her daughter’s place in the church, Helen defied these barriers, and she and her daughter sat in the front of the church. Mary reiterates this purposeful segregation of the mentally and physically “rich” from the mentally and physically “poor” when she described the church as blinded toward persons who have disabilities as though they were unseen. Mary stated, “the Bible says, don’t treat the rich man different than you treat the poor man,” yet she saw the church responding differently. Mary observed a hierarchical placement of people within the church with the wealthy, able-bodied positioned at the front where they were easily seen and those with limited financial, physical, or cognitive resources were positioned in the back where they remained unseen.

Felicia experienced covert and overt othering of her child from the church. On a covert level, Felicia spoke with frustration about the church failing to engage her child in the day-to-day religious traditions and practices. On an overt level, Felicia was pained to witness the conflicted reality of some core foundational beliefs within the church. “I go to a church that talks about the right to life, but when my daughter wanted to go to [parochial] school, the principal wouldn’t even meet with us.” The church’s conceptualization of the right to life seemed not to extend to the right to receive a religious education. Somehow, the church’s avid advocacy of a fetus’ inherent right to life did not extend to her daughter’s right to live fully in the church.

Overcoming obstacles. Exclusion and inclusion were not binary. Most of these mothers experienced inclusion and exclusion as cohabitating partners within the institution of the church. As Felicia phrased it,

> There is at once exclusion but there's also inclusion…in terms of her ability to be part of the worship service the same way that I am, sitting in the pews and going to communion. She has received the sacraments, she went to penance and now reconciliation, she made her first communion and goes to communion regularly, [and] she made her confirmation. So, [she has] inclusion in that way, and I think that's the important way.

Similarly, Denise described her son's inclusion in the church through the recording of the pastor's sermons that he enjoyed watching in the quieter spaces of his own home. Mary said that through prayer, she had come to peace about the marginalizing practices of persons with disabilities within the church. In the end, Mary described the church as a collection of God's people who she believed "were all brothers and sisters in Christ."

Religious leaders. Of these six mothers, five addressed the positive and negative influences religious leaders had on their understanding of Down syndrome within the context of the church. The overwhelming narrative about religious leadership was perhaps not surprising: their position of privileged power within the church garnered them authority over their congregations and they had the power to sway opinions. Consequently, the views and attitudes of religious leaders shaped the views and attitudes of parishioners. Through a variety of religious rites, such as baptism, communion, confirmation, and even marriage, religious leaders had some control over who became a member of the church and to what extent they participated in the life of the church.

Mothers generally perceived religious leaders who celebrated these rites as having contributed positively to their child’s religious life by signaling their inclusion in the community of the church.

Several of these mothers shared their observations that religious leaders who publicly supported members who had disabilities positively inspired other parishioners to respond with greater compassion and acceptance. Religious leaders who supported persons with disabilities were more likely to consider these members’ needs when developing the church’s strategic plans and annual budgets. Religious leaders also positively influenced the donations of funds, goods, and services that supported programs benefitting members who had disabilities. In contrast, when religious leaders failed to model accepting attitudes toward parishioners who had disabilities, it was a signal to others that this group was not important. This negatively affected the psychological, emotional, and physical space persons with disabilities held in the church.

Most mothers believed that to effectively offer support, religious leaders needed to have some knowledge of their child and have insight into their life as the mother of a child with a disability. Otherwise, the support was perceived as disconnected, lacking in genuineness, and failed to provide the validating assurance that their child was accepted. Consequently, familiarity was an important factor that contributed to how these mothers perceived their religious leaders understanding of their child’s disability and their life situation. Isabella described the significance of this personal relationship, or lack of, when her infant was about to undergo life-threatening surgery. At the time, she was not affiliated with a religious community, so the only religious outreach she received was from a hospital chaplain whom she did not know. Isabella did not believe this man could understand the value of her child when so many others had already indicated they did not. “I didn’t have anybody to guide me through that, other than a stranger; nobody I really trusted that said the right words to me at the time. I mean, yea, I had a chaplain there that I didn’t know,” but he was useless to her. Isabella did not believe she could count on this religious leader to understand her or her child’s plight because he did not know her. Instead, her own overwhelming grief deafened her ears to him.

Several mothers communicated a sense of frustration and anger that their religious leaders were naïve, ill-informed, or unconcerned about their child’s need for an inclusive spiritual and religious experience. One mother shared her frustrations about the lack of understanding religious leaders had with some members of their congregation stating, “I think there are a lot of problems when you have priests who have no family life, who aren’t married and don’t have children who might have disabilities.” In her view, this disconnect prevented religious leaders from fully comprehending the challenges of families who had children with Down syndrome or other disabilities. If the religious leader could not understand them, then how could he contribute to their understanding of Down syndrome? Informed awareness and empathy were prerequisites for helping families positively conceptualize disability within the religious narrative, and some religious leaders had neither.

Although all mothers acknowledged the presence of positive religious leaders in their life, there was one mother, Helen, who recounted immense gratitude for one particular religious leader. This religious leader initiated their relationship through a personal invitation at her home. Helen had called the church office to inquire about their resources. When the pastor delivered the information to her home, she was moved and accepted his gesture as an invitation. “Well, I just was like oh my god, that’s just amazing. And so, we went to church that Sunday.” Some months later, the pastor further reassured Helen of her and her daughter’s place in the church when she verbalized her concerns that her daughter’s behaviors were a disruption to other parishioners.

> It was certainly evident to me that day that I talked to the minister, and he said, ‘You don’t pay attention to what anybody else thinks.’… You know, for him as the minister, as the senior pastor of the church, to say to me, ‘Don’t you worry about what anybody else thinks. Nobody’s said anything to me and rest assured if they had, I’d tell ‘em they need to walk a mile in your shoes. And if anybody says anything to you, you come tell me who they are, and I will take care of that for you.’ So that, to me, was this standing force of this church.

Certainly, this religious leader gave Helen an important sign of acceptance through his overt outreach, empathy, and support. Other mothers indicated a longing for this same affirmation from their religious leaders. Mothers wanted to know their religious leaders understood the challenges they faced mothering a child with Down syndrome. They wanted to know their religious leaders valued their child’s participation in the community of the church and they would promote their child’s access to and inclusion in all aspects of the church. According to these mothers, religious leaders communicated this most effectively from an informed position and through their words, their actions, and their advocacy.

Sub-question number three: Peace be with you, or not. To understand how spirituality and religion influenced these mothers’ coping resources and strategies, the following sub-question was probed: How does spirituality or religion alleviate or aggravate the stress associated with raising a child who has Down syndrome? Mothers' responses to this inquiry yielded five primary sources of spiritual and religious support: (a) spiritual narratives, (b) prayer, (c) the church community, (d) finding peace with God, and (e) mindful optimism.

Spiritual narratives. Mothers relied on a variety of religious and spiritual narrative mediums for support, including biblical scriptures, daily devotionals, inspirational books and songs, and some mothers pondered the WWJD (What would Jesus do?) inspirational phrase for spiritual guidance. These narratives guided some mothers' prayer lives, directed decision-making, offered solace and peace, were sources of encouragement and hope, and helped them make sense of the senseless. For some mothers, these narratives fostered worldly and divine relationships.

Mary was the only mother who reported reading the Bible consistently. Scripture readings brought Mary comfort and offered her wisdom, guidance, and a peaceful reassurance that God made her daughter just as she should be: "she is beautiful and perfect in [His] eyes." The Bible also set standards for Mary's behavior, which offered varying degrees of latitude but always personal responsibility. Based on biblical stories about Jesus and the moneychangers, Mary concluded anger had a rightful and productive role in her life. However, she believed spiritually-acceptable anger must be constructive, not vengeful. For Mary, scripture challenged her to balance anger and avoid judgment; a difficult task because anger involves some judgment of the wrongfulness of a situation. Nevertheless, Mary felt obligated to follow the Bible's teachings: "The Bible tells us if we don't want to be judged, we better quit judging others. So, it's okay to see something that is wrong and become upset…, but not to the point where we act like an idiot." Mary acknowledged this was not easy but said she had a responsibility to strive for balanced moderation in her behaviors and in her life.

Isabella said inspirational readings helped her make sense of the senseless when she painfully contemplated the eventual death of her daughter: “I read God picks. He don’t just pick old people, He picks all kinds of people to come to His kingdom early.” For Felicia, reading was a conduit for spiritual growth and enlightenment that “helps you ultimately identify with people [and] identify with your emotional, spiritual life.” Her reading materials included religious texts and secular texts that resonated with her and comforted her spiritually.

Other mothers relied on religious leaders or church practices to direct religious readings. These mothers were familiar with scripture but reported they did not routinely read the Bible. Helen said she had some daily word books and a women’s Bible that she read occasionally, but these were not part of her regular spiritual practice. However, Helen enjoyed reading, and like Isabella and Felicia, she found spiritual connection in the quiet times spent with a good book.

> I get [spiritual connection] from my quiet time in the morning when nobody else is up. I’ve always been an early riser before everybody else. I’m an avid reader, and so I think I get some of that from that activity. It doesn’t have to be a spiritual book that I’m reading; it’s just the fact that I’m meeting an internal need myself to learn something new or to escape and just relax and read. I think that feeds [my spirituality].

Several mothers spoke about the influence of song to bring them joy, peace, and strength. For Sabrina, singing created connections with other parishioners and offered a sense of belonging that alleviated her anxiety. The relationships she developed by singing in a choir created a space for Sabrina to face challenges in the companionship of other religious families instead of on her own. Mary described song as a source of reassuring peace that God would always forgive her transgressions stating, “He keeps forgiving me over, and over, and over, and there’s a song that we sing that talks about that; when we get to heaven, we’ll sin no more.” Isabella referenced songs as a source of strength and reassurance. Moving beyond the religious genre into pop music, Isabella said Celine Dion’s song, *Fly*, held spiritual power for her. The lyrics described her feelings about her daughter as a happy, pure, and gentle spirit whom she would never forget. The song reminded Isabella that her angelic daughter’s death, though surely sad, would be a day of reunion when she would fly back to the light of her heavenly home with God.

Isabella again relied on a secularly-positioned but religiously-oriented narrative through her use of the acronym WWJD (What would Jesus do?) as a moral guide. Most mothers talked about Jesus as a model for Godly living, but Isabella used this pop culture religious phrase to help her make decisions that were consistent with her moral values. Isabella said. “Well, to me being Christ-like would be trying to be like Him, which I don’t think any of us can be…because there’s only one of Him.” Yet, WWJD offered her reassuring guidance and direction as she questioned, “How would He react? What would He do?...I hear that in my head, and I try to think what would He do? What is the right thing to do?”

Mothers’ stress was, in some instances, diminished with the use of biblical scripture, daily devotionals, songs, and books. However, mothers used many coping strategies to access divine support. One frequently reported practice was prayer.

Prayer. Each mother described their prayer practices uniquely and they all used prayer in multiple ways. Prayer was conveyed through a distinct dialogue spoken aloud and through quiet thoughts shared with God. Prayers included intentional petitions, expressions of thanksgiving, requests of forgiveness, or reverent adoration. Sometimes prayer was meditational, void of any words or specific message, and intended solely to connect with the spirit of God. At other times, prayers were casual conversations with God that were integrated into mothers' daily activities. Some mothers had specific times and places they prayed, some prayed throughout the day, and some prayed inconsistently but as needed. Isabella described the versatility of her prayer life when she said, "Yeah, I pray before our meals and stuff like that, but my best God times is when I'm just talking to Him inside my head or feeling Him in my heart, and it's not some designated time."

Some mothers prayed to God, some to the Lord, some to a Higher Power and some to deceased family members and the heavenly saints. Felicia described her prayers to deceased family members and saints as a request for their intercession to God on her and her daughter's behalf.

> I believe in the community of saints. I believe that my family who is no longer with me, those who are dead, are still there to help, so I lean on them. So, whenever there have been problems…I've asked for their intersessions to help her and to help me.

All of these mothers reported using prayer when faced with extreme difficulties such as behavior challenges, limited access to social and community resources, and medical and health concerns. Denise relied on prayer to moderate her son's independent, sometimes stubborn, behaviors. "In my morning prayer, I would always ask God to regulate Jermaine… before I wake him up [so] that our morning would go smoothly." Sabrina used prayer to find resources for her daughter after her graduation from school. "So I had a really hard time finding placement for her…I prayed about that 'cause I didn't want her to just sit at home.…I wanted her to have the socialization." For mothers whose children had experienced significant health problems, prayer was used to request healing and to direct the medical staff as they delivered curative treatments. Mothers also used prayer as a source of guidance, strength and peace while they provided care to their sick child. Helen's daughter was seriously ill for the first two years of her life. During that time, Helen said, "Obviously we were offering up whatever prayers we could to make sure we got through this hospitalization and we got through this sickness." Mary found peace in prayer with the Lord when her young daughter's life was in peril as she lay alone in the hospital's intensive care unit. Distraught with anxiety and fear, Mary sought quiet time with God in the hospital chapel as she asked for His protection, wisdom, and peace. Mary described her prayerful experience in the chapel saying,

> Well when you walk in you're just anxious about everything, all these fears and anxieties are going through your mind, and your body is all uptight and everything. And when you leave, that's all gone. You know that it's all gonna be okay and that you don't have any fears, you don't have any anxieties…It's just like a calm comes over you.

Denise described a similar hospital chapel experience when she fell to her knees asking for God's support during her son's critical illness. "God gave me such peace. [When I] went in the room, I was nervous [and] shaky. All of the sudden it felt like some…physical experience …that God was getting ready to do something…and I was calm."

Mothers' prayers included requests that God help their child be successful and watch over and protect their child. Mothers spoke about their prayer requests for wisdom and guidance in decisions-making, strength to endure challenges, help to mediate their emotions, and for peace and comfort. Mothers also prayed that difficulties would pass quickly and that better times would be ahead. Isabella said she asked for the power of endurance and optimism in her prayer conversations with God: "Can You help me get past this moment? Can You help me see the joy in this?" Mary described her morning prayers before participating in this research interview stating she began by "thanking Him, asking Him to give me wisdom, and sometimes I ask for patience… I asked God this morning to give me wisdom that I would say what He wanted."

Mothers reported prayers were generally helpful, but prayer did not ensure their wishes would be granted nor did it always offer answers to their problems. However, prayers could offer insight and alleviate sadness, despair, fear, distress, and anger. Sometimes God responded to their prayers by placing people or opportunities into their life to help mediate a problem. Most of the time, prayer provided a sense of comfort, peace, and protecting support. Helen shared an example of how she used prayer to request knowledge and people who could help her and her daughter.

> I made prayers [to] God…I want her to get through whatever this crisis is. Help me do that, God. I'm old and…I need to know that she's going to be okay after I'm dead and gone. So You have to help me put all that together…Give me the knowledge that I need, help me meet the people I need to meet. So it's prayer

> through thought…and I just know that that Higher Power is involved in helping all of those things happen.

Still, there were times when prayer was less effective than at other times. Sometimes mothers said they were not ready to turn their concerns over to God; they were still trying to resolve challenges through worldly resources and actions and had not yet exhausted their own efforts to settle a problem. At other times, mothers said prayer did not alleviate their worry and provided little or no comforting reassurance. Sometimes mothers believed their prayers were not enough. When discussing the inadequacies of her own prayers, Sabrina said,

> Sometimes if I feel like I'm not quite as close to God as I should be, then I will ask people that I know…to help me…I know that…the Bible will tell you just a simple prayer [is enough]. But sometimes a simple prayer doesn't make me feel good about myself; it feels like it's got to be deeper.

Sabrina, as did several other mothers, believed that though she prayed, she did not always pray with adequate conviction and God was more likely to hear and respond to communal prayers or prayers sent by someone who had a closer relationship with Him. Similar to Felicia's outreach to the saints for intercession on her behalf, some mothers made requests for prayerful reinforcements from the living, which mothers sometimes found reassuring.

Mothers expressed gratitude for the prayers others made on their behalf, specifically family, friends, and their church community. Knowing others supported them through prayer reassured some mothers that God would hear and respond to their prayer requests. In fact, several mothers routinely requested prayerful support from family and fellow parishioners believing the power of prayer was increased with numbers. Some mothers also believed that parishioners who had disabilities offered purer prayers and were more likely to be heard by God. Finally, the laying on of hands as a communal prayer practice was especially powerful for some mothers. Sabrina described the miraculous support of communal prayer and laying on of hands from a group of parishioners prior to her surgery. She had postponed this recommended surgery for several years because the recovery time was rather extensive, an estimated six to eight weeks, which was longer than she was prepared to be off work. “They prayed for me, laid their hands on me, I had my surgery [and in] three weeks I was back at work. It was pretty amazing.” Sabrina said the medical staff told her they had never seen someone recover so quickly, but Sabrina “thought my group prayed for me, that’s why it happened!” Similarly, Mary pronounced her faith in the practice of laying on of hands with a group of parishioners who had disabilities. As Mary explained, the group gathered around her in prayer and each laid a hand on her body. Those who could not reach her, touched someone else’s body whose hand was upon her. Mary said, “It’s peaceful…Their prayers go through [to God], when sometimes ours don’t, us quote normal people, because they don’t carry the baggage that we carry…so you…feel the peace or the spirit when they touch you and pray.”

Certainly, prayer alleviated stress for these mothers, at least sometimes. Through prayer, mothers received guidance, support, protection, comfort, and prayer deepened their spiritual relationship with the divine. Communal prayer from fellow parishioners offered mothers additional encouragement and established important, supportive bonds with their church communities.

The church community. The church community refers to individual parishioners, the collective congregation, and the overall social, cultural, and religious practices of the church. In sub-question number two, the community of the church was identified as a contributing source to mothers' conceptualization of their child's diagnosis of Down syndrome. In that section, discussion about the community of the church was aimed at describing how systemic patterns within the community of the church positively and negatively influenced mothers' perceptions of Down syndrome. In this section, the focus on the church community, although overlapping in content, is aimed at describing how the church community aggravated or helped to alleviate mothers' stress. Parishioners' prayers were a source of support that helped diminish mothers' anxiety. Because prayer was addressed previously under this sub-question (see Prayer), it will not be included again here. In addition to communal prayer, mothers focused predominately on two elements of the church community that influenced their stress: the actions of fellow parishioners and participation in the church.

Parishioners offered varying degrees of support to mothers. Some were beneficial and helped to alleviate stress; other support was offered infrequently or did not meet the mother's and child's needs, so was less helpful. From a practical perspective, parishioners sometimes offered helpful assistance with childcare during church services. When childcare was offered, it was appreciated and it allowed mothers to engage in church services with fewer distractions. The availability of childcare allowed some mothers to participate in Sunday school classes with other adults, which offered an opportunity to develop valuable supportive relationships. Developing positive relationships with other parishioners and engaging in the religious service reduced mothers’ stress. Some larger churches offered childcare for young children, but this was not always a viable option for mothers of children who had Down syndrome because of unique care needs and sometimes because of behavior challenges. As children aged, the availability of childcare diminished and the needs of their child became increasingly disparate from other children, adolescents, and eventually young adults. Therefore, childcare support, particularly for adult children, was unfortunately rare. For some mothers, the lack of suitable childcare created a circular pattern of diminished involvement that reduced opportunities to create relationships with others who could offer support. Without relationships, there was no support; without support, there was diminished involvement in the church.

Two mothers reported that the church community offered them financial support and one mother received donated goods (e.g. furniture, dishes, and clothes) in response to emergency situations. During these times of crises, supports offered solace and addressed immediate physical needs for food, housing, and safety. However, the supports mothers identified as most helpful in reducing stress were not related to tangible goods; the supports most valued communicated acceptance of and appreciation for these mothers and their children. These supports included comments that conveyed approval of their mothering skills and acceptance of their child. Isabella said some people told her they believed God gave her daughter to her because she would be a good mother adding, “people that I think were very genuine Christian people say that she is precious, she is an angel,” and that made her feel good. When Denise was searching for a new family home following a move, she said the parishioners, “embraced us like they had been knowing us forever.” Sabrina described the supportive sense of camaraderie she experienced with her fellow parishioners when they gather for dinner on Wednesday nights. “We’re meeting in the cafeteria for dinner, oh my goodness, you’d think we hadn’t seen each other…in forever. You know, they’re always so welcoming and they let you know that they love you.” These moments assured Sabrina that she was not alone and that she and her daughter were important and supported. Another example Sabrina described involved parishioners’ support of her daughter in the choir. “We went into this choir and Bea knew where to sit, she had her music, …[and] if she couldn’t find her robe, people would help her out just like anybody else.” This was a great relief to Sabrina because she was anxious about her daughter’s participation in the choir and unsure how they would accept her. Witnessing other choir members’ support of Bea was reassuring and reduced Sabrina’s anxiety.

For most mothers, reassuring outreach from parishioners was inconsistent and the lack of support added to their stress rather than mediating it. Helen said she found her friends to be enthusiastically interested in her daughter’s life and accepting of her individuality, but she did not receive that from the church community. For Helen, church required persistent effort to secure and maintain a position of social acceptance among the parishioners, which contributed to her stress. Helen, like Isabella and Denise, said even planning for church attendance could be stressful.

> I have almost like a cost-benefit analysis in my head, and say well, I want to go, but it takes this much to go and it’s just easier not to go…Trying to pick the right service that I think would be the best for Diane, contemporary versus traditional; I didn’t want her to be disruptive to everybody else. I don’t want to get up and walk

> out. So, if I’m thinking that maybe we might not make it through the whole service, then I just won’t go. So, it’s a cost-benefit thing for me.

Ironically, though church attendance sometimes increased stress, not attending church was stressful too. Several mothers experienced guilt about their inconsistent church attendance, guilt for claiming their child as an excuse for church absences, guilt for having a child whose behaviors were disruptive and disparaged by parishioners, and guilt for being inadequate mothers who failed to properly teach their child socially-acceptable behaviors. Other mothers experienced guilt for their preoccupation with their child’s needs during church services. Helen’s comments offer an example of her self-blaming thoughts. Though Helen was actively involved in her daughters’ integration into the church community, her self-deprecating comments reflected her perception of self-blame and social inadequacy within this group.

> I couldn’t go to Sunday school on a regular basis, which I think was a major detriment to my ability to make a bigger social connection to the church ‘cause I focused so much on Diane and Sunday school and how to get her connected. I was teaching a class or I was with her in the class, so I didn’t make as strong a connection as an adult with the church as maybe I could have.

There was no shortage of guilt for some mothers, but not all mothers felt guilt; some mothers were angry with a church community that failed to be inclusive, which significantly added to their stress.

Attempting to address the needs of these mothers, children, and their families, some churches offered ministry groups created for parishioners who had disabilities. Typically, these groups were designed to serve individuals with cognitive disabilities, which included persons who had Down syndrome. Some mothers did not want their child segregated from non-disabled parishioners because they viewed this as socially isolating and limited their child's spiritual development and involvement with the church's traditions and practices. Of these mothers, four attended churches that did not offer segregated classroom activities for adults with disabilities. Of these four, one mother did not want this service for her child, another mother wanted services that offered specialized support and also opportunities for religious integration, and two mothers believed this segregated support of their child might have increased their ability to more successfully participate in the church and reduced stress associated with church attendance. One mother, Helen, advocated for and created a mentoring program to help her daughter participate in age-appropriate classes, but this was effective for only a short time. Because the church had not initiated this program, when the peer-mentor ceased her participation in the program, the church did not offer to find a mentor replacement. Helen found the mentor program helpful, but she abandoned it because she was tired of the effort required to maintain it. The church supported her ideas, but the work was left to her and sometimes it was just too much responsibility. The two mothers whose children attended religious education classes designed for individuals with disabilities considered the service supportive, which reduced their stress. Mary believed the group benefited to her and her daughter because it provided a place where they could interact with others who understood them. Speaking about her daughter and her peers, Mary explained, "They enjoy being together, they understand each other, and they care for each other." Sabrina reiterated this sentiment when she said, "They involved [her] in so many things and I just felt like that's where we needed to be. She needed to be involved." This genuine, reciprocal relationship was important for these two mothers. They believed friendships with similar peers added quality to their child's life. They also believed other families who had lived similar parenting experiences could offer them more insightful support.

All mothers agreed that their child was a source of inspiration and enlightenment for others and that segregating them from other parishioners had negative consequences. When other church members were unable to interact with their child, mothers believed they missed an opportunity to receive their child's unconditional love. Some mothers also believed that this segregation denied parishioners, especially younger members, the opportunity to learn about people with disabilities and develop compassion. Some mothers added that this segregation denied parishioners the opportunity to witness the committed spiritual relationship their child had with God.

Finding peace with God. Mothers reported multiple stress-reducing benefits from having God in their lives. Mothers believed God helped them mediate difficult emotions by increasing patience, reducing doubt and fear, alleviating worries and anxiety, and decreasing frustrations and anger. Having a relationship with God helped some mothers develop greater tolerance, empathy, and compassion for others including themselves, and it gave them a sense of calming comfort and peace, and sometimes joy. The supportive guidance mothers received from God improved their decision-making skills and increased their confidence. Although mothers talked about God's presence in their lives from various perspectives, the preponderance of descriptions fell into three thematic categories: (a) relationship with God, (b) guidance from God, and (c) faith in God.

Relationship with God. Each of these mothers described God as a divine entity with whom they had a relationship. This relationship was maintained through prayer, spoken dialogue, internal thoughts, and quiet presence. Having an active relationship with God offered assurance that God would be present when he was most needed. When describing how her relationship with God comforted her during her cancer diagnosis, Denise said,

> It keeps me calm. It keeps me from worrying, anxious and panicky about situations. I mean when I got my diagnosis for cancer and not knowing if I was gonna survive it or not…it gave me a sense that it was gonna be okay, that it was gonna work out for my good, and it kept me from losing it, you know.

Mary said her relationship with God filled a void others could not: "He's the only one that can give you that inner peace and that comfort. People can't do that. They can be there for you, and that helps, but they can't go inside you, and He does." Felicia described her relationship with the divine as a spiritual connection with God through light. Felicia used Hildegard's metaphor of viriditas ("life force animating the natural world" [Mews, 2014, p. 78]) to explain how "everything in life needs light, just as Hildegard was going on about how everything needed this green force…of God that heals and protects, light is essential. And I get that feeling." Some mothers acknowledged that though they considered themselves to be religious and spiritual, sometimes these aspects of their lives were pushed into the background as they were busy living. As Helen explained, "I think spirituality or that Higher Power is something [we] sometimes take for granted, until we're actually faced with something that really has an impact…and then we're forced, we're really forced to think about it." Helen was a spiritual woman, and she was also a self-reliant, task-oriented person. She recognized her tendency to try to resolve challenges on her own before turning to God, yet she was comforted in her belief that God was with her and He knew what she needed better than she knew herself.

> If I'm making it known that this is what I want to happen and it's for her, that it's what's in her best interest, then this Higher Power is going to help me achieve the things that I want for her. God is going to put the right people in my path…the right services in my path, and He's gonna put them there when He thinks they're supposed to be there.

Guidance from God. Most of these mothers believed that God interceded in their life providing wisdom and guidance in daily decision-making and during times of crisis. Several mothers believed God delivered guidance to them through unspoken messages, whispered suggestions or signs, and some believed guidance was communicated to them through dreams. Mothers reported this guidance made them more thoughtful, insightful, and more open to listening to others because they might be God's messengers. Although answers to mothers' questions were not always forthcoming, the act of asking and anticipating guiding support was comforting. Though Helen was a planner who liked to have control of her life, she experienced a "sense of calm…that there is a Higher Power that helps [me] make the right decisions about things." Sabrina prayed for guidance during difficult times, but at other times, she believed God provided signs that influenced her daily decision-making. Sometimes the signs seemed to evade her, but she believed God would provide answers eventually. Sabrina found comfort knowing that God was available to support her whether she prayed or not, whether she watched for the signs and listened or not; she knew He was there. Isabella relied on her intuition to know when God offered her guidance. When contemplating decisions, Isabella said, “I know that whatever He tells me, that [if] I feel it’s the right thing to do, it’s Him.” For Isabella, experiencing a sense of rightness indicated God supported her decisions and actions, and this was reassuring for her.

Most instances of God-delivered guidance mothers experienced were positive and stress reducing, but not always. Mary described a warning premonition she received from God prior to a family death, like “something that comes into your mind, you know you’re being told something…You feel in your mind. You know you’re receiving a message about something but you don’t know [what], preparing me for [something]…and it isn’t peaceful.” Denise described another guiding moment that was anxiety inducing but also problem resolving. During this time, the home’s electricity had been disconnected due to temporary financial hardships, and the family was using candles and a gas stove for lighting and heat. Denise was asleep and dreaming when she received God’s message.

> I’m dreaming that Jermaine had drank poison, but in my dream when he turned this bottle up, you could see his mouth puckering and blistering up. It was something hot in his mouth, and I’m going towards him and I’m seeing this. And I see him screaming. I don’t hear him screaming, I just see him screaming. And so I’m trying to get to him, and when I got to him, I woke up. When I woke up, it immediately made me want to go make sure he’s okay. I go in the front of the house, and he has this Lion King puppet…on his hand, and he had it over the light and it was burning. He’s just sitting there watching it, and he’s not saying a word. That was God. God showed me that in my dream, that he was in danger.

Faith in God. In the end, after the relationship building, the prayers, the times spent conversing with God, the search for signs and answers to guide life decisions, most mothers expressed that their unconditional faith in God was enough to bring them comfort. They wanted a relationship with God and they longed for answers to their troubles, but having faith in God's love for them and for their child was sufficient. Isabella said, "believing that everything's gonna be okay and for the good without really knowing it for sure" was comforting to her. Mary expressed this same sentiment when she said she was comforted just to "know that the Lord's gonna be there no matter what the outcome." Felicia described faith as an intermingling of trust, belief, and hope that contributed to her "sense that the divine is watching, supporting, [and] moving things to[ward] some kind of divine culmination." Denise described her faith as "believing in something that you can't see, don't know where it's coming from, [and] don't know when it's coming. Faith is knowing that God's got your back, in any situation." With faith, Denise was assured that she could deal with whatever challenges came her way and that "God's grace is sufficient; it's enough."

Mindful optimism. All of these mothers engaged in various strategies to focus on the positive and discard the negative. Some mothers used reframing to adjust previously-held views to outlooks that were more palatable and congruent with how they wanted to see their life and their child's life. Several mothers practiced mindfulness techniques that allowed them to connect spiritually with their surroundings, with God, or with their Higher Power. Some mothers used aspects of mindfulness, specifically, intentionality, to engage in activities and develop character traits they viewed as spiritual.

Helen used reframing strategies when, after years of effort to teach her daughter about her religion, she realized the concepts were too abstract for her to understand. Therefore, Helen amended her spiritual goals for her daughter and considering her strengths, concluded,

> She doesn't need to be in a structured house of worship to have [God's grace]… Whether she sits on a pew at church or not, she still feels that she's a child of God. She can't tell you that. Does she know who God is? No. Does she know what God is? No. But I know, and I know that she is in a good place.

This new perspective was more congruent with Helen's spiritual beliefs and with her view of her daughter as a person who lived in the spirit of God's love. All of these mothers implemented cognitive reframes as they transitioned from their initial conceptualizations of their child's diagnosis of Down syndrome to their eventual belief that their child had purpose and could contribute meaningfully to their world. Denise initially thought her son's diagnosis was punishment for her sins, but with time, she came to believe his diagnosis had a meaningful purpose that transcended either of them.

> Since I've gotten older, I feel that I have accepted that purpose. At the time [of his birth], I thought it was about me and Jermaine. I thought it was about me being young and having a disabled kid. But now, since I've gotten older and I've grown in Christ, I believe that our situation was for somebody else. What I did and how I got through it, it wasn't just for me and Jermaine, it was for the next young person.

The thought of having a spiritual purpose to serve others was comforting for Denise. Like Denise, other mothers used reframing to redefine how they spiritually conceptualized their child’s birth, which reduced stress by identifying purpose and developing an optimistic outlook. Isabella reduced stress through her optimistic attitude and her choice to see the positive. As she explained, when “I talk to people these days, I have to try to take the good of what they say and know that they probably mean well, and throw the rest out. That’s just how you have to do in life.” Focusing on the positive and anticipating optimistic outcomes from social interactions and life experiences reduced stress for these mothers.

Several mothers used mindfulness practices to reduce stress. Typically, mindfulness, for these mothers, meant alone time or quiet moments shared with God. Some mothers sought out quiet time to commune with God so they could sense his comforting and guiding presence. For some mothers, quiet time was spent in the garden with a good book, wandering the aisles of a grocery store alone, relaxing in nature, or petting their dog. These mothers described quiet time as physically, mentally, emotionally, and spiritually renewing. Isabella said, “My time out is my quiet time when I talk to God.” When Denise was anxious about a problem, she said, “I go to my quiet place and I pray about it, and then I feel this peace that it was answered, that it was done.” Felicia described her quiet time swimming laps in the pool as a relaxing experience when “the rest of the world is on hold for a little bit.” For her, the water and especially the sunlight were spiritually connecting: “Where the pool is you’ve got one side [that is] all windows and another side [that has] windows and just that light coming in, [it] just does something for me. I guess I think it’s a spiritual experience.”

Intentionality, a component of mindfulness, was important to several mothers as they sought to reduce stress. As previously noted, mothers were intentional in their use of prayer, their engagement in religious practices, their church attendance, and in maintaining their relationship with God. Intentionality was also used to develop character traits, such as patience and being nonjudgmental, and participating in works they deemed spiritual. Denise found purpose and comfort when presenting herself to others as a spiritual inspiration. This approach helped her mediate her interactions with others and reduced her stress: “I got to be careful how I dress, I have to be careful, you know, what I say [in] my conversations I have with people, because I want people to see God in me. That’s my spirituality.” Felicia used intentionality to help her and her daughter fully connect with life spiritually. Felicia believed that spirituality was about more than receiving the spiritual gift of God’s loving forgiveness; it was also about seeing beyond personal needs and giving back to the community. For Felicia, “Spirituality allows us to go beyond ourself…I think volunteer work is important; it takes you out of yourself to recognize what others need. You’re not being selfish; you’re giving of yourself to others.” Felicia was intentional in her efforts to involve her daughter in volunteer work to donate her time, money, and talents. Through this spiritual connection of giving, she and her daughter received fulfilling peace. Intentionality was woven throughout these mothers lives as they learned what reduced stress, what supported them, and what contributed quality to their lives.

Sub-question number four: When I think about the future. To understand how spirituality and/or religiosity influenced these mothers’ outlooks on their child’s future life, the following sub-question was posed: How does spirituality or religion create or thwart hope for the future of a child who has Down syndrome? The mothers’ responses fell into three primary thematic categories: (a) fear of loss and death, (b) faith in God's divine plan, and (c) planning and self-reliance.

Fear of loss and death. All of the mothers expressed anxiety and fear when contemplating their child's future, and, although the interview questions were not framed to encourage consideration of death, five of the six mothers responded to questions about the future with somber hesitation as they cautiously, and sometimes tearfully, shared their fears about death. These mothers' future-oriented concerns included the sad possibility that they might lose a beloved child, something they all viewed as an unnaturally-occurring order in the life-death cycle. Yet just as concerning was the possibility that their child might outlive them and no longer have the mother's care and oversight. These future-oriented fears included recognition that limited support services might be available to their child, and that, even if available, services were unlikely to meet their child's physical and emotional needs in the same way they lovingly provided for their child. Denise exemplifies this concern in her slow, rhythmic Delta accent when she uses the word *spoil* to describe her efforts to provide a quality and joyful life for her son.

> It's that uncertainty of what if? If I go before he does, then me thinking about what is Jermaine gonna do without me? You know, I'm his primary caregiver, and if I'm removed out of that, who's gonna take care of him? Who's gonna do this? But, I usually give him his way, so they say I'm the spoiling parent, you know. Who's gonna spoil Jermaine when I'm gone? Somebody's still gonna have to spoil him. He's 30-years-old. He ain't gonna change.

Denise's concerns were framed by the painful memory she stored away about another mother who cared for her child her entire life until one day she became ill and died. Upon this woman’s death, the daughter was placed in a facility, and within two months, she too had died from what Denise described as a “broken heart.” Denise worried this might be Jermaine’s fate should she become unable to care for him. Denise had already lived with this concern when she was diagnosed with cancer. During that time, it was difficult for Denise to focus on her own health care needs and treatment because she was so concerned about who would take care of her son. Rather than question the management of her own health, Denise’s first response was to worry as she questioned, “What if? What if I don’t overcome this? What if I don’t survive this? What’s gonna happen to Jermaine?”

Similarly, Felicia concisely conveyed her death-centered concerns by stating, “Well, when I think about her future, I think of her future without us. And that has to strike terror in your heart.” Helen repeats this internal struggle saying,

> I wrestle with, I don’t know, do I wanna outlive her or not? Parents aren’t supposed to bury their children. So, the fact that she might die and I’m still alive would just be horrible! But the flip side of that is, she’s still alive and we’re dead, and who’s looking out for her?

With a splintered voice, she adds, “I’m terrified of her being here and we’re gone.” Mary’s teary eyes and pain-filled, squeaky voice affirmed this conflicted turmoil as she admitted, “I realize I can’t ask God to let me outlive her if I’m not willing to give her up, which will be very hard. But, you know, it’s what’s best,” adding that she did not want her daughter to suffer the devastating grief of her mother’s death.

Although these mothers expressed agonizing distress when contemplating the potential loss of their child, only the youngest mother, Isabella, assumed her daughter’s death would likely precede her own. This position of assumed survival seemed to give Isabella permission, even a sense of responsibility, to imagine and plan for her daughter's death. In fact, Isabella was the only participant who shared thoughts about her child's eventual funeral.

> I already know that when that happens, I'm playing that song (Celine Dion's *Fly Away*) at her funeral because it's about flying back to heaven after being an angel. When I heard it, I'm like, oh my gosh, that's so how I feel about Chloe. I can't hardly stand to listen to it because it upsets me, for when that time comes. But when that happens, that's gonna be one of the songs that I play because that's how I feel. Like okay, she came down here, she taught us what she came to teach us and, now she's going back.

Throughout the interview it became clear that time had changed Isabella's thoughts about losing her daughter. Early in Chloe's childhood when health conditions threatened to take her life, Isabella thought she would not survive and wondered,

> Why would [God] give me this child and then I accept that she's mine and I love her and then take her away from us six months later? I just could not make any sense of it. Course, if I lost her tomorrow, I would be very sad, I would be upset, but I have enough faith now to say, hey, I got to spend some time with her, [and] she changed my life.

Sabrina, the only mother whose future-oriented concerns did not include a death scenario, was also the only mother among these six whose child had not already experienced at least one life-threatening health condition. Other mothers' children had collectively faced multiple health complications including serious injuries, hospitalizations, heart surgeries, cancer, and near-death experiences. These mothers knew the overwhelming agony the potential death of their child created for them. This was not a hypothetical possibility; for them, it was a lived experience. Instead, Sabrina's concerns centered on loss, not through death, but through change. Each of these mothers were uniquely bound to their child's life, and most considered these relationships life-long commitments of shared companionship. Only one mother, Helen, had considered her child's independent living in any tangible way. The other mothers were committed, at least to this point, to living with their adult child indefinitely. This was the case for Sabrina who considered her daughter a friend and lifetime companion. Sabrina was fearful of losing her daughter through change as she continued to develop increasing independence. She was also fearful of the changing and conflicting dynamics this might create for her family. By death or physical separation, concerns of loss lingered in the corners of these mothers' minds, yet they all looked to the future with optimistic determination.

Faith in God's divine plan. When considering the future of their child, there was an overarching faith in God's will among all of these mothers. This future-oriented faith was not a fatalistic attitude, but it did include a belief that God influenced life's direction and that their child's life was part of His divine plan. This God-influenced destiny was interwoven with mothers' responsibilities to be thoughtfully informed, create opportunities for their child's development, and be responsive to the opportunities God placed before them. When discussing God's divine plan in their child's life, mothers focused on three points: (a) their daughter/son was a child of God who had an inherent relationship with Him now and for eternity, (b) the child was an instrument of God who would positively influence others, and (c) sometimes mothers' spiritual faith wavered when contemplating their child's uncertain future.

A child of God. At the most fundamental, spiritual level, mothers believed their child's eternal future was with God. In fact, most mothers described their child as having a unique relationship with God. Sabrina reported frequently overhearing her daughter's prayers and described her daughter's relationship with God as a prayerful and reciprocal connection, adding, "She has more faith than I do." Denise said her son was "a child of God and that even in his disability, he's still aware of God." When describing this special relationship, Isabella was certain her daughter was guaranteed a place with God in the afterlife stating, "Chloe has a free ticket to heaven." Mary expanded on this idea by describing all children with Down syndrome and intellectual disabilities as "angels unaware" sent to us by God and uniquely special to God. Helen spoke about her daughter's relationship with God a bit differently. Helen believed that we all have God's saving grace but not everyone accepts it. Because Diane had difficulty understanding theoretical concepts, she did not grasp religious doctrine or abstract relationships. Yet, Helen said, she knew her daughter was "in a good place [with God]" because she had accepted God on behalf of her daughter. Although Helen believed it is an individual responsibility to accept God's grace, she also believed that for a child who has an intellectual disability, the bridge to saving grace could be facilitated by someone else, such as a mother. Felicia's description of her daughter's spiritual relationship was even more global than the other mothers. Felicia described Rose's spiritual connections as one with not only God but also with the community of saints and deceased family members all of whom offer guidance and "continue to watch over her."

When contemplating an uncertain future, Felicia described “a sense that the divine is watching, supporting, moving things to some kind of divine culmination” and that “things are perhaps moving in the direction they should [for] some larger end.” Mary confidently proclaimed her belief that her daughter would “live as long as God wanted her to” concluding “that it’s gonna be okay. Everything that’s happened in our lives, the good and the bad, He’s always taken care of us.” Mary’s faith allowed her to not “worry about it because I know in His time, He will take care of it.” Sabrina reiterated this belief that God “has a plan and a purpose” and that “when the time is right, God will let me know.” Sabrina just needed to be watchful for His sign. Expounding on this, Sabrina added that wherever she is in life “I feel like that’s where God has called me and led me” and that He would continue to lead her in the future. Helen echoed this philosophy which she had seen evolve in her life - “I just believe that God plays a role in all of that, to make things fall in place like they’re supposed to fall in place.” When considering the future, Helen said,

> Hopefully she’s gonna outlive me and I have to know that I’ve done everything I can to make her life be as comfortable and as safe and as supported as it can be, and the only way that can happen is because God’s hand is in there somewhere.

Similarly, Isabella was uncertain about the future, but she was reassured by her belief that God is “dependent on me to do this. If He thinks I can do it, I can do it!” Several mothers spoke about God’s sacrifice of His own son for others’ salvation suggesting this brought them some solace knowing that the loss of their own child was bearable and could have purpose. Denise frequently spoke of “God’s plan” as a guiding power and her child was the catalyst for her educational aspirations and plans to open a group home for people with disabilities. “It’s coming full circle. It’s still coming, you know,” said Denise. Faith in God’s guiding influence reassured these mothers their child’s life was purposeful and that intentional awareness and proactive efforts could help actualize God’s plans.

An instrument of God. Like Denise, other mothers had already witnessed their child’s influence on others, and they believed this influence was part of God’s divine purpose, which would continue into the future. Although mothers identified no single life purpose, there were overarching themes of perpetual, unconditional love and inspiration that positively altered their lives and the lives of others who interacted with their child. Certainly, all of these mothers believed their child’s life had purposeful meaning divined by God that contributed positively to the world. Mothers also believed they and/or their child would pass on life lessons to others as models, mentors, or advocates.

Even though these mothers identified a variety of challenges their child presented, all of them viewed their child who had Down syndrome as exceptionally loving. Mothers who had other children were quick to explain that it was not that the child who had Down syndrome loved them more, but rather the love was uninhibited and free of judgmental conditions. Sabrina said her daughter “keeps me happy” and “that girl loves me with all of her heart. [It’s] a blessing when you have someone in your life that loves you so unconditionally.” Mary repeated this sentiment recounting, “Everybody talks about Angel’s gift, and her gift is love. She impacts the world with unconditional love.” Helen reiterated this perpetual, unrestrained affection when she described her daughter’s “unconditional love. You know she runs in with her arms up in the air. How many moms have [an adult child] who comes running in the door like that!” Isabella described the loving joy and laughter her daughter brings to others as “just little stuff that she does that cracks people up and makes them love her. She loves everybody." Similarly, Denise said, "Jermaine is so loving. If he came in here now, he'd wanna give you a hug or he'd wanna kiss you on the jaw." For these mothers, this unconditional love was a past, present, and future gift their child would continue to give.

In addition to the gift of love, mothers also described their child who had Down syndrome as an inspiration for others. For some, this inspiration influenced career choices, for others it inspired advocacy, and for some it inspired changes for improved quality of living. Whichever the case, each mother believed their child was here for a God-divined purpose and that purpose often included elements of teaching. Isabella said her daughter was "put on this earth to teach others compassion" and that "she teaches me what's important in life, she teaches me about priorities." Helen said her daughter taught her to "live for today and look for the fun things; [it's] not all about planning and organization and stuff like that." Mary believed her daughter was "sent for us to learn something" and that she was responsible for passing these lessons on to others.

Felicia, Helen, and Denise shared stories of how their child had inspired others to pursue helping careers such as nursing, personal care provider, and rehabilitation counseling. Several of these children influenced their mother's careers and volunteer work. Helen, Mary, and Sabrina worked in service positions assisting other disadvantaged people. Denise pursued an advanced degree to better meet the needs of her son and other adults with disabilities. Denise clearly understood her son's influence in her educational pursuits stating, "If I wouldn't had a son with a disability, I just don't think it would a went in that direction."

Each mother developed advocacy skills to some degree, and all the mothers used these skills to obtain services for their child or to create more integrative spaces for their child. Some mothers used these learned advocacy skills to benefit others. Mary used her gentle persuasion and her wallet to advocate for the needs of adults with disabilities within her church community. Helen advocated for children through educational sessions offered to parishioners aimed at helping people understand Down syndrome and other developmental disabilities as well as promote the effective integration of these children into their communities. Denise was a mentor of another young mother who had a son with Down syndrome. Sabrina and Felicia supported their daughters' efforts to act as role models and advocates. Sabrina described with pride the hope her daughter brought to a young couple who learned their baby would be born with Down syndrome. The couple was frightened by the diagnosis, but after meeting the joyful and accomplished Bea, their hope was renewed as they began to imagine new possibilities for the future of their unborn baby. When sharing her frustrations about the church's failure to effectively integrate people with disabilities, Felicia explained her hopes that her daughter's active participation might influence others and deconstruct some of the stereotypes that define people with disabilities as different from others. Felicia believed that despite the slow pace of progress, people would eventually recognize the value people with disabilities offer to our communities. Felicia speculated that "maybe Rose plays a small part in that by having an impact" on others.

Wavering faith. Regardless of these mothers' faith in God's divine plan, the inability to maintain a satisfactory amount of control created a sense of apprehensive uncertainty and powerlessness among these mothers. This resulted in a faltering faith that provided little comfort or reassurance about their child's future. When questioned about the future, mothers' responses were often pragmatic, yet interlaced with avoidance strategies of what each mother perceived to be a fearfully uncertain future. Sabrina expressed her fear-avoidance strategies following her daughter's birth stating, "I really didn't pray, I don't know why. I guess I thought what good's it gonna do, the damage is done, and it was. But I didn't look toward the future. I was scared, I was scared to death." With her mater-of-fact, present-mindedness, Felicia suggested she is still unable to evade the insidious concerns of an uncertain future - "You're in the routine and you get through the routine, and sometimes that's all there is is getting through today. But in the back of your mind you're still worried about tomorrow, and the next day, and beyond that." This uncertain questioning was repeated in Helen's nighttime reviews as she pondered, "My practicality steps in that says that I have to go to bed at night knowing, if I were to die tomorrow, have I done everything I can today to make sure she has what she needs?" Isabella expressed her pragmatic perspective of a troubling future when, with a sigh, she said, "It's not my favorite thing to talk about, but I know it's gonna happen one day, more than likely I'm gonna outlive her." The future, although uncertain for everyone, included an underlying note of child-focused anxiety for these mothers, which is not typical among parents of children who do not have disabilities.

Although mothers reported they often relied on planning and faith to assure them all would be well, doubt persistently lurked in the corners of their worried minds as they each recognized they could not plan for nor control all that they wanted for their child. Felicia expressed these conflicted concerns when she said, "Part of me says there's a point at which I've got to realize it's out of my hands," adding that "There are things that are simply in God’s hands, but it’s hard to say that and to stop worrying.” Sabrina described her internal struggle between two troubling options. Even though she thought she should turn her troubles over to God, she did not want to; but when she did not give them to God, she felt guilty. In mediating these uncomfortable options, she tried to delay decision-making by waiting for a sign from God. But, still, she vacillated from waiting to see “the right sign from God,” to feeling a sense of relief when she believed she had received this sign, and then, when taking a step back, becoming consumed with doubt once again. It was a frustrating cycle of indecision and stagnation that Sabrina said “robs me of my joy because I won’t just hand it over to Him and not worry about it anymore.”

Denise grappled with this same turmoil as she described her deep faith in God to guide her decisions, yet sometimes, when she thinks about the future of her son living without her, her faith wavers. At other times, Denise thought she was too independent, trying to do things on her own and in her own way, especially if she did not yet understand God’s whole message. Denise described herself as divided spiritually and physically; her spiritual self had unwavering faith in God’s plan, but her physical self remained stuck in worry about the future. Sometimes Isabella described her view of life as one of God-ordained destiny; but at other times she questioned God’s role in her daughter’s life, wondering if perhaps He is not involved in at least some of their day-to-day activities and worries.

Helen suggested that her spirituality, at times, brought her tremendous comfort including comfort in her daughter’s successful future as long as she was a living witness to this success. However, her faith did little to alleviate her anxiety about her daughter’s future after she died. Instead, Helen imagined that she would have to reconcile her fears upon her deathbed with little choice left but to let it go to God. Helen also wrestled with her historical pull toward the church and her perceived failure in finding a church home to meet the needs of her and her daughter. Often this left Helen feeling guilty, unsatisfied, and searching for a way to fill this spiritual void. At other times, she felt content in the everyday spaces in which she connected with her Higher Power – the outdoors, the quiet aisles of the grocery store, or even the pages of a good book. By the end of the interview series, Helen concluded that perhaps she might let go of her guilt-fueled need to find God within the walls of a church, and, instead, appreciate the Higher Power's presences in her day-to-day life and the life of her daughter.

For Mary, the uncertainty centered on prayer. She accepted that she could not know or control the future, but she felt a need to pray and often received comfort through her prayers. Still, she questioned her prayerful intercessions wondering how to reconcile her conflicted prayers for her daughter's healing with those that asked Him to protect Angel from living in grief without her mother's support. Mary worried about these prayers and asked God to "forgive me if I'm interfering with your plan." Overall, these mothers concurred that the human condition created a rift in faith regardless of the intensity of one's devotion to God. Mary admitted that "even though my soul belongs to the Lord, there are times when Satan can still [lead me astray]." In this same spirit, Denise said, "Even though we have faith and believe, this human side of us still will cast doubt or make us feel like, what if God don't…?"

Planning and self-reliance. As these mothers looked toward the future, they tried to balance their reliance on God and their wavering faith with personal responsibility. Mothers believed passivity was not adequate and they all engaged in proactive long-term planning to some degree. The nature of plans varied but centered on increasing skills, maintaining ongoing care, and assuring the child had a fulfilling life. Future-focused planning included strategies to increase the child's quality of life while the mother was still living and, for some, plans for ongoing care once the mother was no longer able to care for her child. Specific planning strategies included developing trust funds, identifying potential guardians or caretakers, expanding support networks and services, and increasing independent living skills.

As part of Denise's planning, she identified her daughter, Kiatta, as her son's guardian upon her death ensuring that Kiatta "would take care of Jermaine [and that] he would not go to a facility. He would live with her until God saw differently." Sometimes planning was not orchestrated in advance but evolved when a crisis occurred. That was the case when Denise sustained a temporary, but disabling, injury and had to call upon her mother to help care for her son. During her recovery, Jermaine's grandmother helped him learn some basic daily living skills that, Denise said, "set him up to where I didn't have to worry. Jermaine would get up in the mornings, and take his shower, he brush his teeth, he eat his breakfast, [and] he pick out his clothes." Acquiring basic daily living skills assured Denise that Jermaine could help with his care, lessening her concerns about his future.

Felicia's planning and self-reliance included establishing trusts, working to expand her daughter's network of supports, and persistently pursuing efforts for her daughter to acquire independent living and adaptive socialization skills. As Felicia stated, "You set up the trust funds, you do the kinds of things you have to do, that you can do, so that she can manage, and you give her the skills, as many skills as you can manage." In her holistic approach, Felecia "wanted to make sure that all the aspects of her [Rose], the physical, the intellectual, the spiritual, everything, she had opportunities to learn and develop and thrive in the areas that she was interested in." Felicia also focused on prolonging her ability to provide care for her daughter by maintaining a healthy lifestyle stating, "I'm trying to take good care of myself. I am exercising so that I can be there longer."

Sabrina was a reluctant planner because the changing landscape of the future was frightening to her, as it was for most of these mothers. Sabrina's daughter, Bea, wanted an independent life with a romantic significant other, and this concerned Sabrina. It was not that Sabrina did not want her daughter to be independent; she did, and she always had. But, she also wanted Bea to be successful in her relationships, and this was a new area that Sabrina did know yet know how to negotiate. Nevertheless, Sabrina prepared her child for the future by helping her develop daily living skills, socialization skills, and increasing her independence. Sabrina recognized early in her daughter's life that she had a choice that would influence her daughter's ability to grow independently.

> I can do everything for her and sit back and say, 'Oh she can't do that, no, she can't do that.' No, I did not! I thought yeah, it's up to me. We're gonna do it together, and that's what we've done.

Sabrina, like other mothers, realized that increasing social skills, daily living skills, and overall independence increased their child's likely success in the future.

Isabella's thoughts of the future of her daughter were focused on immediate goals rather than long-term goals. Isabella wanted Chloe to have a job, and so effortful planning was invested in considering which jobs might best fit Chloe's interests and skills, what job opportunities were available in their community, and what supports might be needed to secure and maintain her employment. Planning for her daughter's integration into the church was also important to Isabella. Until now, Chloe has participated primarily in a small, rural church with the support of her grandmother. Isabella anticipated this situation would eventually change and she was uncertain how she might effectively integrate her daughter into the larger church, which the rest of the family attended. At the time of the interview, Isabella had evaluated her limited options with no resolutions.

When planning a family move, Mary considered her daughter's future needs when selecting a new hometown. She and her daughter could live where resources were plentiful, or she could live closer to family support where resources were limited. Though neither option provided everything, Mary made this decision, and other life decisions, based on what she believed would most benefit her daughter.

In addition to planning for their children's future physical care, mothers attended to their children's spiritual future. Mary was actively involved in her daughter's religious development as a component of her spiritual future by reading biblical stories and using Christian movies to teach religious and moral lessons. Similarly, Denise used recorded sermons to teach her son about religion. Rose's godfather was an important contributor in Felicia's plans for her daughter's ongoing spiritual and religious support. Several mothers used a variety of reading and educational approaches to facilitate their child's spiritual and religious development. Mary and Felicia used their personal powers through donations and tithing to ensure services were available to support their child's spiritual needs in the future.

Helen's practical approach to problem solving was similar to Felicia's. Helen described herself as a planner, a "list maker, organizer, get-her-done kind of person [who gets] on with the business at hand." Helen was also an analyzer, assessing the supports and services her daughter needed to achieve desired outcomes. If the appropriate supports were not available, Helen searched for a way to create these supports. Helen is the only mother of these six who, at the time of the interview, was currently transitioning her daughter out of the home and into an apartment with assisted living supports. This was part of her planning strategy as she explained,

> One of the reasons we're in this apartment complex and Medicaid Waiver is to get Diane connected organizationally to a bigger system that hopefully could step in as that directing force if Ron and I were to get hit by a bus tomorrow.

Overall, mothers looked toward the future with a sometimes-tentative faith in God, an unwavering certainty that their child had divine purpose, and a sense of personal responsibility. As Helen said, although she believed her Higher Power is a guiding presence in her life, that did not assure she would get what she wanted, but she gained some comfort in believing that, "I've done everything I can to make sure that whatever supports…she needs are in place if we were to drop dead tomorrow."

Additional Research Findings

The semi-structured interview format provided a framework for the conversations that unfolded with these mothers. In establishing a safe environment in which mothers could talk freely and openly, I did not limit what they chose to share during their interviews. Information that sometimes initially appeared to be tangential often intersected with these mothers' conceptualizations of spirituality and religion. At other times, although relevant to these mothers' experiences, the information was unrelated to spirituality or religion. Qualitative interviewing involves developing rapport, reflecting empathy, and listening for the unexpected as the pursuit of knowledge (or in the case of phenomenology, understanding) is balanced with respect and an ethical responsibility to represent participants' uniquely individual perspectives (Kvale, 1996). Consequently, some of the findings revealed during these interviews were not clearly linked to spirituality or religion. Yet it seems inaccurate to say that any part of life was unrelated to spirituality because these mothers viewed human existence as a spiritual experience and spirituality was intertwined into one's existence whether they were conscious of it in the moment or not. Nevertheless, this data is relevant to these mothers' experiences and this information has been retained in the final analysis to accurately and completely describe their stories. Some of the findings included in this section were included in previous sections because they bridge a space that is spiritual and secular. These additional findings are described as they relate to: (a) coping and support, (b) pride and admiration, and (c) changes over time.

Coping and support. Mothers utilized a variety of coping strategies and accessed multiple sources of supports that were unrelated to spirituality and religion. Sources of support included family, friends, coworkers, support groups, Special Olympic teammates and families, medical professions, teachers and school personnel, day program staff, and patrons and employees of various community establishments. Denise found support groups to be especially helpful, sharing, "They were like my other extended family, and by the time we got to the really hard stuff, I already had the answers."

Mothers were self-reliant as well and engaged in independent strategies to cope by educating themselves through books, literature, pamphlets, online resources, and television. Most mothers were task-oriented problem-solvers who identified barriers and actively utilized resources to pursue resolutions. All mothers engaged in advocacy as needed whether to protect their child in social situations, obtain medical care, or request access to educational and community services. For example, Helen knew what her daughter's educational rights were, and sometimes these were provided as requested, but at other times, they were not. "I've been in schools where we've had very inclusive, accepting principals, and then we've had principals in schools who didn't give a damn about special ed and wished there wasn't a single kid with a disability in their school." Helen understood the principal set the tone for the school, and that was where her advocacy efforts were initially targeted. When all else failed, they would change schools to ensure her daughter received what she needed. Sabrina was a subtle advocate. Yet she understood the importance of belonging and she negotiated spaces that appreciated and affirmed her daughter, stating, "You have to have that acceptance; if you don't, you really are gonna have a mountain to climb."

Mothers employed several cognitive techniques to navigate stress such as developing an optimistic attitude, focusing on the positive and rejecting the negative, engaging in mindful retreats for rejuvenation, accepting what they could not change, and reframing to create a more appealing narrative. For example, when Felicia was searching for a private school for her daughter, she met with an educator who asked a series of questions she found degrading and unappreciative of her daughter's strengths. Felicia said, "That person I was dealing with was not very intelligent. She was asking questions like can she walk…It told me that I didn't want her there, because I didn't want her around people with those attitudes." Isabella employed a bit of restorying when she considered the challenges she and her husband sometimes had with Chloe, "Parenting is one of those jobs that's the hardest job you'll ever love, you know" and concluded that her "life is crazy good."

Mothers also relied on their past successes as a measure and guide for their current and future mothering successes. Dealing with and resolving previous challenges gave mothers additional tools and strategies to tackle new problems. Past successes allowed them to rely on their intuition with greater confidence. Experience provided increased insights about what worked and what did not work for their child. For example, Isabella employed the voice of a beloved cartoon character to persuade her daughter when behavior challenges arose, and it was an amazingly effective strategy for Chloe. When Felicia considered future challenges she and her husband would encounter caring for Rose, she knew they would "ultimately get through it because we've gotten through the other things before."

Pride and admiration. Mothers expressed pride and admiration of their children across multiple areas of life. Some of these mothers had children in addition to their child with Down syndrome, and when that was the case, mothers said they were proud of all their children, just in different ways. Isabella expounded on this when describing Chloe's early childhood accomplishments in comparison to her other children. "When she learned to walk, it took her four years to take her first step; my other kids, around one year. Both were wonderful milestones, but with her it's just bigger…'cause it took her so long." Overall, mothers were just proud of their children, and when they shared these stories of their child’s successes, they were typically accompanied with bright eyes, beaming smiles, and sometimes tears. Mothers’ pride in their children centered on the child’s (a) ability to develop meaningful relationships, (b) character, and (c) achievements.

Meaningful relationships. Mothers expressed pride in their child’s ability to develop deep spiritual relationships, relationships with other people, and the ability to contribute positively to their social community. Mothers admired their child’s ability to be authentic and honest in their relationships. Some mothers admired their child’s ability to develop relationships that exceeded their own capabilities.

Several mothers expressed awe at their child’s ability to develop deep spiritual faith, committed participation in religious practice, and their genuine relational prayer life with God. Mothers expressed pride in their child’s ability to achieve religious milestones such as baptism, confirmation, and communion, or to participate in other religious rites and practices. Sabrina wistfully admired Bea’s prayerful relationship with God, which exceeded her own, as she contemplated her struggles with prayer: “To tell you the truth, it robs me of my joy because I won’t just hand [my concern] over to Him and not worry about it anymore.” Sabrina saw her daughter’s faithful relationship with God as beneficial and inspirational. When Mary reflected on her pride of Angel’s ability to understand salvation and maintain a prayerful relationship with the Lord, she said one of her most joyous rewards as a mother was to see her daughter’s faith and spiritual understanding blossom until she became “more Christ-like than I am.”

All mothers admired their child’s ability to be open and honest in their interactions with others. Some mothers believed their child was less encumbered by social expectations and inhibitions, which enabled them to express themselves to others with greater authenticity and to lovingly accept others with fewer judgments. Other mothers believed that their child’s character traits, such as their sincere friendly nature, nonjudgmental acceptance, and unconditional love, allowed them to develop important social relationships. When describing Chloe’s open expressions of love, Isabella said, “She is not afraid to show her [love]. We have limits, we have ways you should act and you shouldn’t act. She just tells it like it is.” Isabella added that she sometimes wished she felt the freedom to express her emotions like her daughter, but social etiquette and her own fears limited her. Felicia, who is comfortably situated in her introverted nature, observed her daughter’s social interactions with respect: “I admire her ability to get along with so many different people and to know so many people, and to, I think, have an impact on so many people.”

All mothers expressed pride in their child’s contributions to others and to their community. Sometimes these contributions were delivered through work, volunteerism, advocacy, or other acts of kindness and caregiving. Felicia shared a long list of community activism Rose participated in each year. Isabella, Denise, and Mary shared stories of their children’s loving outreach toward others, and Sabrina shared stories about Bea’s caregiving supervision of other children. Mothers also expressed pride in their child’s ability to inspire others to experience life with greater gratitude and appreciation. Sabrina and Felicia shared numerous instances of their daughters’ inspirational role modeling and advocacy. Denise, Helen, and Felicia offered specific examples of how their children had inspired others’ career choices and advocacy efforts. Each mother was undoubtedly proud of her child’s ability to develop reciprocal relationships with others and to contribute positively to the community, and mothers recognized that this ability was due largely to their child's character.

Character. Mothers lovingly heaped adjectives into the conversations about their child, and many of these reflected qualities they found admirable. Mothers described their children as loving, forgiving, non-judgmental, kind, friendly, funny, happy, bubbly, joyful, sweet, caring, and giving. Some mothers talked about their child's tendency to love animals, babies, other children, and people in general. Some mothers talked about their child's here-and-now appreciation for life, their novel approach to each day, and their fun-loving character. Some mothers described their child as slow to anger and less likely to respond defensively when others acted unkindly toward them. Yet, they also consistently described their child as determined and stubborn. These last two character traits were sometimes a source of frustration and angst for mothers; it was also deeply admired because this unyielding grit propelled their children toward accomplishments. Felicia described the polarizing experience with her child's stubbornness when she said,

> They talk about stubbornness as being a characteristic of Down syndrome, and it really is. I mean, there's no way I'm gonna go head to head with her and win. She will outlast me; she will be stubborn. But there's also a positive side of that, and that's what I think of as determination. She puts her feet down, plants her feet down, says she's gonna do something, [and] she'll do it.

Achievements. This determined spirit of perseverance produced an independent attitude among most of these children. Mothers were proud of the diligent efforts their children made to achieve what they wanted, how they often learned more than others expected, and how they overcame obstacles that might have thwarted others.

Achievements included reading and academic successes, creative talents such as art, singing, and dancing, developing independent living skills, and getting a job. Achievements also included overcoming challenges such as personal fears, physical and social barriers, temporary impairments, and even surviving cancer. Helen was proud when she proclaimed her daughter was a cancer survivor, and she was proud when she shared the successes her daughter had made toward obtaining an independent living apartment. Sabrina was proud when Bea's singing instructor expressed surprise at how quickly she learned to sing, saying "she picked that right up and the director…was like, well, I didn't know you could do that, but…[Bea] just ran away with it." In addition, Sabrina was immensely proud of her daughter when she was able to inspire hope for a young couple whose unborn child had been diagnosed with Down syndrome. When Denise broke her ankle and was unable help her son get ready for the bus, he surprised her with his independence. "He pick[ed] his clothes out, even down to the socks! That wasn't happening before. So that was God showing me that, baby, you can step back, 'cause Jermaine knows how to do more than you give him credit for." Isabella said even now that Chloe is an adult, when she learns something new, and she does, "it's just as exciting [as when the other kids] bring home a good report card. It's different, but it's as exciting because her expectations are different." Mary's pride in Angel is captured succinctly in a phrase her father said to her years ago: "If the world had more Angels in it, it'd be a better place." Felicia's heartfelt expression of awe for Rose's achievements was striking:

> I think she's an incredible person in many ways and I really admire so many things about her. I admire how hard she's been willing to work [and] how hard

> she worked getting through school. She got a regular diploma, she was in regular classes, and it wasn't easy, but she did it. I admire the way she went out and registered to vote, because she was determined to do it! And I'm just amazed at the way she will get on stage and [perform]…It would be so hard for me to get out and do some of the things she does.

Changes over time. Because this study focused on mothers with adult children who have Down syndrome, these mothers told their stories from the perspective of experienced motherhood. They had years of retrospective insight that contributed to their storytelling because they had long passed their child's initial birth and infancy, the early toddler years, grade school, high school, and puberty. Now, their child had reached adulthood, and the challenges and successes encountered in those earlier years had passed by and been replaced with new ones. Mothers acknowledged this was the case with any child, but because their child was uniquely different from other children, they were not initially certain change would happen, when it would happen, or what it would look like. These mothers still did not know what changes might lie in their child's future, but they were no longer mystified by change; they knew life would change. These mothers understood life was fluid and their children would continue to mature; and they knew they would survive it because they had before. Just as in the past, some changes would be difficult and others would be exciting.

The research questions and interview guide did not include any questions that prompted mothers to share how their mothering experience had changed over the course of their child's life, but they all offered insights about how change was transformative. Their discussions about change focused on themselves, their child, and their social environment and included changes in the following areas: (a) view of Down syndrome diagnosis, (b) child's development, (c) increased resilience, (d) spiritual shifts, and (e) societal changes.

View of Down syndrome diagnosis. All of these mothers reported an initial period of shock when their child was first born and diagnosed with Down syndrome. In fact, most mothers viewed the diagnosis as an unfair twist of fate and some even thought it was punishment from God. Certainly, in the beginning, they were not perceiving their child as a gift from God or a grounding center in their life. However, negative perceptions of their child's diagnosis, and certainly of their child, were brief. Despite some mothers' initial confusion responding to their baby's diagnosis, all these mothers quickly decided that they would take their child home, and for some, even despite pressure from doctors, institutionalization was never considered. Digesting the diagnosis took a bit more time and required education and experience. Family support was a critical factor for most of these mothers. Spousal and family support assured them they would have the emotional and physical assistance needed to take care of their child. For these mothers, their faith in God, the acquisition of knowledge, practical experience, and time helped shift their initial perceptions of their child as a hardship to a joyful blessing. Isabella shared her perceptual transformation of her daughter when she said, "Well, today I see her as a gift…At that time [birth], I didn't realize that I would think, in the future, that she was a spiritual gift." After all these years, Isabella now considers her daughter to be a spiritual gift of thanks and a sign that God trusted her to care for Chloe.

Initially, mothers did not consider how their child could positively contribute to their life by influencing career paths, advocacy work, and core character traits. Too often, the initial and sometimes persistent narratives these mothers heard about Down syndrome focused on worst-case scenarios, limitations, barriers, and the hopelessness of the situation instead of the potential possibilities and the unique personality their child would bring to their family. No doubt, sometimes it was difficult parenting a child with Down syndrome, but it was also wonderful. Helen captures this emotional shift as a mother of a child with Down syndrome when she said,

> No matter how bad things sound when you first hear something, once you get past the initial diagnosis, you get on your journey, [and] you're gonna find the good things along your journey. Not that we haven't had our dips and our struggles, but look where we are! I have said all along that Diane needed to live in the community and that she could do that with the right supports. So, look where we are now. It's not the end of the journey, but this is a big station for her. So, I think that [for] parents who have kids with disabilities, they need to realize that even though it's rough and tough in the very beginning, there are lights along the way.

Developmental changes. All mothers identified developmental changes that were challenging. Certainly, mothers proudly shared stories about their child's developmental growth that helped them become more independent, develop social skills and peer relationships, explore personal interests and talents, graduate from school, or become employed. However, challenging changes accompanied positive and normal developmental maturation. Puberty was sometimes accompanied by mood swings. Aging was accompanied by increased desires to be independent and self-determining. No longer could Isabella swoop up her daughter when they needed to get to an appointment; now Chloe was a grown woman who made decisions about how and where she moved her body. Mary now had to balance decision-making on behalf of her daughter with opportunities that allowed Angel to make independent choices because she wanted to be treated like the adult she was. With each passing year, Helen became increasingly concerned as she vacillated about whether or not Diane could live successfully in her own apartment. In the end, she decided, "she needs to be in her own apartment so things are the way she wants them to be." Sabrina struggled to balance her motherly instincts to keep her daughter safe with Bea's right to make adult choices as she ventured into a romantic relationship. Parents of nondisabled children have these same concerns, but having a child with Down syndrome added a complexity to the process that other parents did not encounter. Nevertheless, each of these examples are normal developmental life changes, they just evolved differently and a bit later for some children.

Increased resilience. Through experience, mothers increased their resilience to situations that once caused them distress. For some mothers, this meant they employed greater patience and delayed decision-making until action was required. For example, Sabrina believed if she was patient, God would provide the answers to her worries. She had utilized this practice previously, and it worked. So, when she found she did not know how to resolve a problem, she waited for a sign from God knowing He would provide guidance at the right time. Other mothers found that choosing how they responded to a circumstance was more effective than trying to change the situation. Mary now laughs about things that once angered or pained her on behalf of her daughter. Now, when others act unkindly toward Angel, Mary just "write[s] it off; it's your loss fellow," believing the other person is truly missing an opportunity to experience her daughter's loving spirit. Other mothers found that redefining success allowed them to focus on the positive achievements rather than perceived failures. Helen said she has amended the criteria she set to measure herself as a successful parent, and these adjusted goals allowed her to recover from setbacks more quickly.

Spiritual shifts. All of these mothers reported that their child had influenced their spirituality and that this process of change continued to evolve over time as their faith deepened and their relationship with God shifted. For some mothers, this meant their relationship with God was integrated into their daily routines more than it had been in the past. Denise prayed to God every morning as part of her routine with her son; this was not her practice before he was born or even in the early years of his childhood when God was more often reserved for emergency situations. Other mothers reported their spiritual shifts moved away from traditional religious practice and increasingly toward their spiritual relationship with God, which they found meaningful. Helen's view of her faith was initially strongly attached to the church. Over time, she believed her Higher Power was present with her outside of the church perhaps even more than inside the church. She amended her longtime belief that church attendance was central for practicing her faith and now believed that spirituality was something she experienced everywhere, including watching her child grow. Isabella said her faith had strengthened since her daughter was small, and she anticipated that it would continue to grow. When considering how her daughter had influenced her spiritual life, Felicia said, being Rose's mother "made me a better person." She believed many of the personal qualities she had developed mothering Rose made her more spiritual.

Societal changes. Only a few mothers talked directly about societal changes that had altered their mothering experiences in recent years, and some of those conversations were directed toward the future as they hoped for greater inclusion. The internet and social media platforms created opportunities for inclusion that were not previously available to mothers or their children. Through the internet, mothers had access to information and support networks that increased accessibility to resources and better prepared them to meet their child's needs. Institutionalization was no longer seen as the most appropriate placement for children with disabilities, and social movements to integrate children into community settings had slowly been increasing.

Several mothers referenced support programs for adults with disabilities, and although these community-based programs had increased over the decades, they were still inadequate and choices were limited. Similarly, educational opportunities had improved for people with disabilities, but mothers often found inconsistencies among schools, and parental advocacy for a child's educational needs was too often necessary.

One mother, Sabrina, talked about changing social dynamics in public spaces. When her daughter was younger, children sometimes stared rudely. Sabrina said her daughter was not bothered by the stares. In fact, Bea didn't even notice them; Sabrina did, and it hurt. With relief, Sabrina said, "Years ago, it was so different than what it is today. We don't have all the staring anymore."

Felicia addressed changing social dynamics more than other mothers, perhaps because she had witnessed significant change within her church. Felicia knew change was possible and probable, eventually; she looked forward to progressive changes that would create a more inclusive culture for her daughter and others. As Felicia reflected on change, she said, "I don't know how long it's going to take. I think maybe the process of change is beginning, but…I think it's slow because change…in ways we see things takes a long time." When considering how her daughter influenced her world spiritually, Felicia thought perhaps Rose's interactions with others encouraged them to be more accepting of people who were different from themselves. By encouraging an inclusive attitude, Rose inspired social change that benefited all people. With hopeful optimism, Felicia said, "I think it will happen eventually for people with disabilities, and you know, maybe Rose plays a small part in that."

Summary of the Findings

This chapter described the findings of this study within the framework of four sub-questions related to the spiritual and religious experiences of six mothers of adult children who had Down syndrome. The sub-questions aimed to describe how the spiritual and religious beliefs of these mothers affected their reported (a) meaning of their child's diagnosis (b) perceptions of their child's disability, (c) coping behaviors, and (d) sense of meaning and hope for their child's future. In the final section of this chapter, additional findings unrelated to spirituality and religiosity were included to fully describe these mothers' reported experiences as shared during their interview series. These finding described additional coping behaviors and resources, mothers' pride and admiration of their child, and changes throughout their mothering journey. Overall, mothers' spirituality was a beneficial source of support that provided solace and guidance. For most mothers, religious institutions, doctrines, and practices were both supportive and rejecting. Yet despite the challenges, most of these mothers persevered in their pursuit of religious inclusion for themselves and their children.

In the following chapter, these findings will be discussed in relation to the literature. This last chapter includes a discussion of the limitations of the study, implications for professions, and recommendations for future research. Chapter 5 concludes with some advice from these mothers and my final thoughts about my work with these women.

Chapter 5

Conclusions

The purpose of this study was to explore and describe the experiences of spirituality and religion in the parenting processes of six mothers of adult children who have Down syndrome. This overarching inquiry was guided by four sub-questions that focused on understanding how spirituality and religion influenced these mothers': (1) perceptions of meaning or purpose in their child's diagnosis; (2) positive or negative perceptions of Down syndrome within the context of the church; (3) coping resources and strategies; and (4) perceptions of hope for the child's future. A phenomenological approach was used to describe these mothers' experiences as shared through a series of individual interviews. A phenomenological study aims to offer insight into the lived experience of a phenomenon through rich, thick descriptions, but it does not seek to provide causal explanations about the phenomenon. Nevertheless, some measure of reasonable, explanatory understanding is gleaned when considering the findings from this study with other research and in the context of the current social and political environment. This chapter includes a discussion of research findings in relation to the literature, followed by implications for professionals, limitations of the study, and recommendations for future research. The chapter concludes with advice from these mothers and my final comments about my research journey.

Discussion

The four sub-questions are as follows and the findings are discussed in relation to the research literature and current social and political issues.

1. How do spirituality or religion create or reduce meaning with regard to the child's diagnosis of Down syndrome?

2. How do systemic patterns within organized religion influence positive or negative perceptions of Down syndrome?
3. How do spirituality or religion alleviate or aggravate the stress associated with raising a child who has Down syndrome?
4. How does spirituality or religion create or thwart hope for the future of a child who has Down syndrome?

Sub-question number one. The first sub-question was, “How do spirituality or religion create or reduce meaning with regard to the child's diagnosis of Down syndrome?” Although there were variations among the mothers’ responses, there was consensus that God chose them to be the mothers of their children. Some mothers believed that being chosen was related to their individual needs or the child’s needs, and other mothers conceptualized the choice as God’s divine work toward the culmination of a greater cause that was not necessarily related to them as individual mothers. This perspective is consistent with the findings from a study conducted by Bennett et al. (1995) with parents of children who had a variety of disabilities, in which parents reported a belief that God had chosen them and that He would support them during their parenting journey. Similarly, other researchers have reported parents were comforted by their social community’s perception that they were distinctly special or God-chosen because they parented a child with a disability (Brasfield, 2008; Lawrence, 2008b; Nugent, 2011). Isabella expressed this sentiment when speaking about her friend: “When they told me that they thought God chose me as her parent ‘cause He thought I could handle it and He thought I would be good for her, I think that made me feel good.” Some parents believed raising a child with a disability was a spiritual experience that was divinely offered to them by God (Marshall et al., 2003).

Other studies have highlighted the inconsistency in this God-chosen perspective. For example, Lalvani's (2011) study found that some parents felt burdened when other people ascribed heroic labels to their parenting role. Mary, one of the mothers in this study, said when she was younger she did not like it when people viewed her as exceptional or a perfect parent because she knew she was not, and it placed unrealistic expectations on her. Now that she is older, Mary is bolder and corrects others' erroneous assumptions as she explains she too has good and bad parenting days: "Some days we make it through and it's a really good day, and then the next day, it might be we've blown it completely."

In this study, the mothers who perceived their child as a God-given gift were from various Christian denominations, including Baptist, Catholic, and Methodist. Interestingly, Bryant et al. (2011) reported that 30% of respondents in their study with Pakistani parents of children who had Down syndrome said they believed their child was a gift from Allah. These parents were Muslim, so it appears this God-given child perspective is not exclusive to Christians.

Another consistent theme regarding meaning among the mothers in this research study was that their child's life had a spiritual purpose, which was fulfilled as they interacted with others in their communities. Several other studies have found similar results where spiritual faith positively shaped parents' perceptions of the meaning of their child's disability (Haworth et al., 1996; Heaman, 1995; Lalvani, 2008; Poston & Turnbull, 2004; Rogers-Dulan, 1998; VanSolkema, 1997). Blair's (2003) research with parents of children who have disabilities revealed that some mothers used religion to create positive meanings of their child's disability. Similarly, Treloar (2002) found that families and caregivers of children who have disabilities believed that God helped them find meaning and life purpose in the child's disability. In Bennett et al.'s (1995) study on family adaptation and the use of religious coping resources, some parents reported that religious beliefs offered an explanation of the purpose and meaning of their child's disability. In a qualitative study with Asian Indian parents of children with disabilities living in the United States, Zechella (2014) reported that some parents thought their child had a predetermined purpose in life, which was consistent with their Hindu religious beliefs. Again, the use of religion to find purposeful meaning in the life of a child who has a disability is not unique to this study, and, in fact, exists in faiths other than Christianity.

In a study by Stainton and Besser (1998), some parents said having a child with a disability increased their sense of purpose, which is consistent with the mothers in my study who reported that their child influenced their careers and advocacy efforts. For example, during Denise's interview, she described her son's influence on her, her sister, and her daughter.

> It's like his disability opened the doors to a lot of our lives… I think it was part of God's plan, because…it's kind of like it was the catalyst for our business plan [to create an independent living center]…And my daughter…has a heart for people with disabilities, and she's become such a great advocate.

The findings that address this research question indicate that mothers believed God chose them to parent a child with Down syndrome and that the child's life had divine purpose. Considering these findings, how do these beliefs function in a society that has the ability to make choices about which babies are born? We live in a world with medical professionals who promote the use of prenatal screening and genetic testing, a culture where abortion is not uncommon, a scientific community where the attempts to modify human DNA are well underway, and an era in which the idea of genetically-modified babies is no longer just an idea. It is unclear how these last two developments will alter the future of babies who have Down syndrome and other disabilities; however, debates about social, ethical, and religious concerns regarding genetic engineering of human life are already underway.

Prenatal screening and testing are not new and advancements continue to develop. However, prenatal screening cannot detect Down syndrome with complete accuracy and prenatal testing has a small risk of miscarriage. Yet, advancements in noninvasive genetic testing continue to evolve and, although expensive, are more accurate than older methods of prenatal screening (Zolotor, 2014). According to the American College of Obstetricians and Gynecologists (Caplan, 2015), genetic screening and counseling are recommended for all women who are planning a pregnancy or who are pregnant. Though genetic counselors have historically been encouraged to use value-natural language when sharing genetic results with parents, this position of neutrality fails to adequately inform parents of the benefits of having a child who has Down syndrome, and most parents know very little about this disorder prior to a diagnosis. In 2014, Pennsylvania enacted Chloe’s Law, also known as the Down Syndrome Prenatal Education Act, which aimed to address this deficit in prospective parents’ informed decision-making. This law requires the Department of Health and medical care providers to share information about treatment options, support services, and Down syndrome resources. Chloe's Law aims to ensure women who receive genetic testing hear about the positive outcomes associated with having a child who has Down syndrome. The passage of Chloe's Law has promoted ongoing discussions about the ethics of value-neutral genetic counseling that, though perhaps unintentional, presents disability from a negative perspective with little normative, disability-friendly messaging (Caplan, 2015).

According to the National Down Syndrome Society (n.d.-c), there are many reasons one might choose to have prenatal screening including: (a) advanced awareness and the opportunity to access appropriate prenatal care; (b) have time to plan for the infant's adoption; or (c) terminate the pregnancy. Choosing to have prenatal screening or testing is a personal decision, and although many mothers have prenatal screens and tests, some parents decide against prenatal testing because they have determined the information will not change the course of their pregnancy. Notice that institutionalization is, thankfully, not among this NDSS's list of reasons one might choose to have prenatal testing. Three of the mothers in this study said medical professionals suggested institutionalizing their child, and one mother was chastised for not having an abortion.

Option number three, abortion, is a choice some mothers select. However, the actual rates of abortion among fetuses diagnosed with Down syndrome is unknown because the U.S. does not track this information. Nevertheless, similar to the estimates of children born and living with Down syndrome in the U.S., there have been attempts to estimate the numbers of abortions following prenatal diagnoses. These estimates vary greatly, with termination rates in the U.S. projected to be as high as 92% to a low of 30% (Charlotte Lozier Institute, 2015) with other estimates indicating the termination rate is closer to 67% (Natoli, Ackerman, McDermott, & Edwards, 2012). Regardless of which number is accurate, the mothers in this study indicated their child facilitated their spiritual growth, improved some of their personal character traits, and made them better people. Genetic engineering, gene modification, and abortion based on prenatal tests that identify Down syndrome have the potential to alter future generations and eradicate Down syndrome. The ethical considerations surrounding these issues are complex. However, for people, like these mothers, who believe children who have Down syndrome positively influence their lives or are God-given gifts with divine purpose, the possibility of losing the inspirational and spiritual benefits these children offer to families and communities is a significant consideration.

Sub-question number two. The second sub-question was, "How do systemic patterns within organized religion influence positive or negative perceptions of Down syndrome?" When probing this question, mothers' responses indicated that the church's acceptance or rejection of persons who have Down syndrome was critical in communicating the church's perception of this diagnosis as positive or negative. If the church accepted and supported people who had Down syndrome, mothers' believed the perception was positive. If the church rejected or ostracized people who had Down syndrome, mothers viewed this as indicative of the church's negative perception of the disability. Mothers identified four religious sources which conveyed their sense of acceptance or rejection: (a) religious scripture and stories; (b) the community of the church (aka. parishioners and the social culture of the church); (c) the institution of the church (aka. doctrine, tradition, practices, and structure); and (d) religious leaders.

Several of the mothers in this study reported they initially believed God was punishing them with their child's diagnosis, an internal narrative that was acquired through religious teachings. However, these mothers also reported that biblical scriptures and stories helped them reframe their view of the child who had a disability from a personal punishment to a gift from God. Sometimes biblical stories helped mothers endure difficult times, such as the serious illness of their child. Some mothers also reported that the effects of religious stories are dependent, in part, upon the context of the situation. Recalling Isabella's story about God's sacrifice of His son, Jesus, Isabella said the story brought her comfort now, but it did not in the early days when her infant daughter was faced with heart surgery.

The literature includes reports of parents' differing and conflicting perceptions of religious narratives about disability. Bennett et al. (1995) reported that church doctrine and religious scripture helped parents develop an optimistic outlook of their child's disability, but other research has been less positive. Like some of the mothers in this study whose initial perceptions of their child's disability was that of punishment, Zechella (2014) found that Asian Indian mothers living in the United States believed their child's disability was a curse, bad karma, or an intentional endowment from God, but they also believed there was purpose in the child's life. Perhaps the mothers in this research study and other similar studies did not directly attribute their conflicted feelings about their child's disability to religious text or doctrine because these messages were sometimes contradictory and confusing; they did not know if they should express gratitude for these supportive messages or resentment about disparaging narratives, when, in fact, they experienced both. Treloar (2002) reported that parents and caregivers in her study used the Bible to provide meaning about their children's lives, but they expressed a need for the church to establish clearer theology about disability, specifically because some biblical narratives were conflicting and unclear. Although not related to religious texts, other researchers have found that parents' personal spirituality helped them transform their initial perceptions of their child's disability from grief to gratitude (Scorgie et al.,1999) or from a shameful punishment to a thankful blessing (Marshall et al., 2003).

Religious involvement has been found to be an important coping resource (Gupta et al., 2012), which is strongly associated with the child's acceptance and integration within the church community (Merrill, 2010; Pillay et al., 2012; Treloar, 2002). However, Bennett et al. (1995) reported that parents' successful use of their spiritual and religious faith was only attainable if the church community was accepting and supportive of their child. These findings were consistent with the mothers in my study who identified acceptance and inclusion within the church community as critical prerequisites for their successful engagement. These mothers understood that participation in the church created a sense of belonging that was crucial for their communally-shared celebration of faith. If their child did not fit into the church's culture, was denied access to spiritual engagement, or faced barriers to participate in the church's practices, cognitively or physically, it created a spiritual barrier for the mother as well. Helen expressed this sentiment when she said,

> I did a myriad list of things to try to help Diane be connected and integrated and a part of [the] church, finding where she fit, [and] where she was comfortable.

> ‘Cause if she’s comfortable, then I’m comfortable. And if she’s not, well, then I’m not either.

In addition, Hughes (1999) found that a process of reciprocal enhancement increased parents’ participation in religious activities, which resulted in greater support from the religious community. Several of the mothers in my study said reciprocal peer relationships contributed to the perception that their child was accepted within the church community and that their child’s contributions to the church community increased their sense of inclusion. However, mothers also talked about the barriers their children encountered, which limited their engagement. One mother said the robes the acolytes were required to wear were roughly textured and intolerable to her daughter. The church accommodated this by permitting her child to disregard this required dress code. Unfortunately, most churches did not offer other modifications and accommodations that mothers believed might have been helpful to their child. For example, accessible and age-appropriate religious education materials were not available, and, in most cases, classes were not designed to meet their level of development. Isabella addressed her frustration about the lack of an appropriate religious educational space for her adult daughter when she said,

> I could send her with her little sister, but that’s with 5- and 6-year-olds, and they just look at her like, ‘Why is she so big?’… And so you’re like, where do I send her? Do I send her with the bigger kids where she don’t fit in? Do I send her with the little kids where she sticks out like a sore thumb?…It becomes complicated.

Maul and Singer (2009) reported that families appreciated helpful modifications that encouraged religious inclusion, specifically Sunday school classes that were designed to meet their child’s developmental needs. These classes offered children opportunities to interact with developmentally-similar peers. Families’ perceptions of the church community’s acceptance of their child was critical to their own sense of inclusion, and if the child was not well-integrated into the church community, parents often felt rejected (Gaventa, 2012). Two of the mothers in my study reported this same sense of satisfaction and inclusion through their child’s participation in ministries designed for adults who have developmental disabilities. Two other mothers indicated they would have appreciated this service if it had been available at their churches. However, two mothers were not interested in segregated services, but they did want their children to have opportunities for inclusive participation, and all mothers experienced varying degrees of exclusion and rejection when their child was not accepted. This experience is consistent with Speraw’s (2006) overall conclusion that although some parents felt supported, many felt the needs of their child were not adequately addressed by the church, and this left them feeling unsupported and rejected by the church community. This view is consistent with Turnbull and Ruef’s (1996) previous findings that some parents thought churches did not offer adequate or effective supports for their children. This is particularly important because sometimes the perception of available support is more important to parishioners’ overall well-being than the actual support (Weiss, 2002)

Like the mothers in my study, Marshall et al. (2003) reported that parents were fearful that their child would not be accepted by the church and that their child would not be able to meet certain expectations deemed necessary for full participation in church practices. All of the mothers in my study expressed various concerns as they worried about their child’s ability to tolerate the hard pews, the noisy rustling of bodies, the loud microphones, or the requirement that they sit still and be quiet. Mothers also worried about their child's ability to attain important religious rites of passage and participate in religious traditions. These worries created stress for these mothers, and sometimes worries turned into realties that resulted in barriers preventing their child from participating in church practices.

O'Hanlon (2009) further contributed to this idea when she reported that parents gained a sense of appreciation and belonging when they had opportunities to share their expertise on disability to educate others. Some of the mothers in my study initiated efforts to educate their church parishioners about children with disabilities through in-service trainings. Others advocated through teaching activities, such as Sunday school, where they had greater opportunities to voice disability-affirming messages, and this was rewarding. For example, Helen was happy to contribute her expertise through in-service trainings to other religious teachers and parishioners, as she stated,

> So nobody knew anything really about kids with special needs. So I did a little in-service stuff…We talked about disabilities in general, and we talked about people-first language. We talked about proactive, positive ways of presenting material…I loved it, because I just thought it was so important… I mean I wanted the church to be a place where other families who had kids with special needs would feel comfortable in coming…So it made me feel good; it was an important thing.

At the same time, these in-service trainings were temporary, and though Helen appreciated the opportunity to educate and advocate, even in her position as expert mother of a child with a disability, she retained her sense of aloneness, and the benefits derived through her contributions were short-lived.

The mothers in this study seldom included religious leaders in their discussions about effective sources of support. Churchill et al. (2010) found this to be true in their study of parents who had children with special healthcare needs; only 16% of parents reported they sought advice from a minister. Some of the mothers in my study talked about religious leaders, but they had mixed views of these clergymen. When religious leaders advocated for their child or for parishioners who had disabilities, mothers perceived the clergymen positively. In a study with parents of children who had disabilities, Bennett et al. (1995) reported a similar finding that indicated religious leaders could serve as a coping resource when they openly accepted and supported children who had disabilities and their families. However, the mothers in my study frequently spoke about religious leaders with frustration as these clergymen too often seem disconnected with their families' and their children's needs. This is consistent with Blair's (2003) study in which mothers sought support from religious leaders but sometimes reported discontentment with their clergy. Speraw (2006) described how parents experienced disheartening outcomes when they approached religious leaders for guidance and were told the church was not prepared to meet their child's educational needs; instead, it was expected that the parents would have to teach their child on their own. This view is consistent with most of the mothers in my study who repeatedly reported inadequate religious education materials, environmental barriers, unrealistic expectations for their child's participation in religious practice, and a general disregard for their child's spiritual needs. Yet these mothers persisted in their use of religiosity and spirituality in spite of the lack of support they received from clergymen.

When considering how this data was situated in our social and political environment, I am reminded of Helen's comments about the ADA's lack of influence within the church as she said, "I think church and acceptance for individuals with disabilities is the last frontier." Although most church doctrines and religious beliefs claim to promote an inclusive environment and encourage compassion toward others, there is a disconnect when churches unintentionally and intentionally exclude some groups of people from participating in the church. As Helen suggested, as a society we have made some advances to meet the needs of children and adults who have disabilities through the Americans with Disabilities Act of 1990 and the Individuals with Disabilities Education Act (IDEA, 1990). Unfortunately, religious organizations are not required to comply with ADA, and private religious educational institutions are not required to comply with IDEA in the same way that public schools must (Jackson, 2016; Tucker, n.d.). Felicia extended this discussion of the church's practice of exclusion beyond disability when she said,

> You know, I was thinking that it's not just people with disabilities who are segregated and discriminated against by the church, obviously sexual orientation [is]. There are a lot of problems in the church, and I think maybe 50 years from now, a 100 years from now, I don't know how long it's going to take, [but] I think maybe the process of change is beginning; but I think it's slow.

Some churches make an effort to create inclusive spaces for people who have disabilities; unfortunately, some do not. Additionally, when churches do provide services for people with disabilities, families have reported these services were inadequate to meet the needs of their child. There are many reasons churches may offer limited resources to people with disabilities (e.g. lack of funding, limited space, privileged able-bodied culture of the church). Yet there are many more reasons why churches should strive to improve the services they offer to parishioners with disabilities. For example, statistics indicate that church attendance is steadily decreasing while the number of people in the U.S. who have disabilities is steadily increasing (Newport, 2018). Moreover, modeling compassionate caring and brotherly love are consistent with church values. Clearly, churches have a long way to go before they are welcoming and inclusive to all people who wish to practice their faith within the walls of the church. For the sake of families such as those in this study, I hope Felicia's speculation is not correct, and that it does not take another 50 to 100 years for religious institutions to embrace all people regardless of what they look like, how they live, or what label has been cast upon them.

Sub-question number three. The third sub-question was, "How does spirituality or religion alleviate or aggravate the stress associated with raising a child who has Down syndrome?" The mothers in my study reported using a variety of spiritually-oriented texts to cope with stress, including the Bible, devotional readings, inspirational books and songs, religious stories, and the "What would Jesus Do?" (WWJD) slogan as a moral guide. Only one of these mothers reported regularly reading the Bible, two referenced the WWJD slogan, four read inspirational books, five mothers referenced the healing power of songs, and five included religious stories in their interviews. None of the literature addressed the use of devotional readings, inspirational books and songs, or the WWJD slogan directly, but the literature did address the use of biblical stories and scripture as family-coping practices.

Mussett's (2012) study with parents of children who had Down syndrome focused on spiritual struggle following the initial diagnosis of their child, and although he inquired about parents' use of biblical scripture in his assessment, he did not report his findings on this specific issue. However, Marshall et al. (2003) reported that families of children with disabilities found strength in the moral foundation of and the shared beliefs they derived from biblical scripture. In another study with parents of children who had disabilities, Bennett et al. (1995) reported religious scripture created a sense of hope for these families as it offered an explanation of the purpose and meaning of their child's disability, and one parent reported reading a religious book to reconcile her incongruent spiritual and religious feelings. Treloar's (2002) work with people who had disabilities and their family members found that the biblical scriptures and stories helped them find meaning in their circumstances and respond positively to life with a disability. The mothers in my study reported a similar use of biblical stories to reframe their understanding of their child's diagnosis, which resulted in greater optimism and increased purpose in their mothering experiences.

Treloar also reported the people in her study expressed frustration about scriptural messaging that were ambiguous and failed to clearly supported people who had disabilities. Speraw (2006) reiterated this perception when reporting findings from her study that parents used biblical stories and scripture to shape their behavior, but the lack of scriptural clarity was frustrating, and the incongruence between their perceptions of biblical messaging and the negative behaviors of clergy and parishioners was distressing for families.

All of the mothers in my study reported using prayer to alleviate stress, seek guidance, receive comfort, and to request strength, wisdom, and protection. Mothers believed prayer mediated their stress and sometimes helped them resolve problems, but mothers reported prayer did not guarantee they would get what they wanted. Nevertheless, prayer offered these mothers some assurances that God would guide them toward an appropriate outcome, which supported His divine plan.

Literature reflects the findings that prayer can be a source of comforting support. In a study conducted with Latter Day Saint parents who had children with disabilities, most families said there was power in prayer (Marshall et al., 2003). VanSolkema (1997) reported that 16% of the parents in her study with families of adult children who had developmental disabilities reported that prayer was one of the three most helpful coping supports they relied upon (the other two were faith and God). Fox et al. (2002) reported that families of children who had disabilities accompanied with behavior challenges indicated prayer was a primary source of support for them along with the help of other key family members. In a study conducted with African American caregivers of adult children with disabilities, parents reported that prayer offered them comfort and guidance (King, 2001). Other studies replicated the findings that parents were comforted through prayer and this practice improved their emotional and existential well-being (Poston & Turnbull, 2004; Willis, 2007).

The mothers in my study reported using prayer for many reasons in addition to comfort, such as seeking guidance or support when their child was sick. Prussing et al.

(2004) reported similar findings from their study with parents of children who had Down syndrome who used prayer as a supplement to traditional medical care during their child's illness, not necessarily for a cure but for the overall well-being of their child. Mary shared her prayerful efforts to balance her wishes for her child to remain healthy with God's divine plan when she said, "There've been times when she's been sick, and I would pray for her healing. But then I'd say, but 'Lord, I'm asking You not to let me die before her, so, forgive me if I'm interfering with Your plan'."

Prayers have also been reported to help reappraise situations concerning a child's disability (Heaman, 1995), and the power of communal prayer via the telephone has been reported as beneficial among rural mothers of children who had disabilities (Brasfield, 2008). This last point is consistent with some of the mothers in my study who reported that shared instances of communal prayer were especially powerful, even miraculous, for them. Regardless of the potential benefits one might gain from prayerful practice, if a mother's child is not well-integrated into the church community, her ability to be renewed through communion with God in prayer can be diminished (Speraw, 2006).

When considering how the church community alleviated or aggravated their parenting stress, the mothers in my study reported fellowship with other church parishioners was important to their sense of inclusion and helped them develop supportive, social bonds with others. However, not all mothers reported consistent social support from their church community. In fact, only two of the mothers described social supports from parishioners in any meaningful and consistent manner, and both of these mothers participated in groups that were designed to support the needs of persons with disabilities and their families. Two other mothers had been Sunday school teachers and occasionally participated in other church functions, which offered social connections as long as they were able to fulfill these roles. However, if mothers were not actively engaged in service to the church, parishioner support fell into the background of their overall religious experience. Unfortunately, the demands of caring for a child who has special needs often prevented mothers from routinely participating in church activities or engaging in service to the church, which limited their opportunities to engage in beneficial fellowship. Overall, the results from my study were mixed. Some mothers received support and a sense of shared camaraderie with other parishioners, whereas other mothers remained on the social periphery.

These findings are comparable with previous research that demonstrates an inconsistent pattern of social acceptance within the church community. Churchill (2010) reported that parents of children with special healthcare needs indicated that attending and participating in church were important coping resources but not nearly as important as spiritual faith. In O’Hanlon’s (2009) study of parents accessing religious education for their children who had disabilities, most parents considered the church’s support of their child to be positive, but this was most significant when the church parishioners and clergy accepted their child and their child participated in religious education and formal church practices and ceremonies. Nevertheless, almost one-third of the families in O’Hanlon’s study said their child had minimal contact with the church community and almost as many expressed some dissatisfaction with the religious education their children received.

When addressing church attendance, Poston and Turnbull’s (2004) findings were similar. Some families experienced a sense of acceptance through their participation in church attendance, and other families found the experience to be challenging, unaccommodating, and sometimes even full of rejection. Even worse, Haworth et al. (1996) reported that some mothers in their study said that parishioners and ministers discouraged their active participation in the church, and some refused to accept or support them. The mothers in my study conveyed this polarizing experience as well. Recall Sabrina's comment about her and her daughter's church experience: "We've been accepted everywhere we go, even in the big choir with no other disabilities, we were accepted." Compare Sabrina's experience of acceptance with Helen's struggle to find an inclusive space within her church community: "Outside of church, or outside of religion, I fit in just great…[with] my circle of friends [and] my family. So the sense of belonging or being a part, the hardest part is in a church."

In addition to fellowship, several mothers said pragmatic support through childcare would be helpful, but, like other instrumental care (e.g. cooking and cleaning), it was seldom offered. These types of supports were reserved for crisis situations. Caring for a child with a disability did not qualify as an emergency in their view, even though these mothers acknowledged caring for their child had unique challenges not typical for other parents of non-disabled children. Several of the churches these mothers attended did not provide childcare services. However, even when churches offered this service, the childcare often did not meet these mothers' needs regardless of the child's age. Consequently, childcare remained the mother's responsibility. Additionally, several mothers expressed a sense of obligation to provide for their child and were reluctant to burden anyone with this task even when others volunteered. For example, Isabella was grateful when a parishioner joyfully offered to take care of Chloe during church services. However, even though Isabella was appreciative, she was hesitant because she said,

> When she’s not acting good, I don’t want anybody else to have to deal with her because it’s not fun at all. When she’s having a meltdown, I feel like I’m the only one that really knows how to handle her when she is like that.

Instrumental (e.g. cooking, cleaning), emotional (O’Hanlon, 2009), and financial supports can be beneficial, but this is often dependent on families making these needs known to others (Pillay et al., 2012). This may be part of the reason why most of the mothers in my study reported they received little, if any, instrumental or financial support. The only reported instances of this type of support came from Sabrina and Mary who said the church had responded with instrumental and financial supports (e.g. housing goods, foods, and money) during times of crises (e.g. house fire, family death). In a study conducted by S. V. King (2001), she reported that some parents of adult children with disabilities were appreciative of the instrumental supports they received from the church, but others were dismayed and disappointed by the lack of support they received.

All of the mothers in my study reported they experienced a sense of peace, comfort, guidance, and support through their relationship with God or their Higher Power. In fact, as committed as most of these mothers were to their church homes, their spiritual relationship with God far exceeded any solace the church might offer. Churchill et al.’s (2010) study with parents who had children with special healthcare needs reported that parents’ spiritual faith was their most frequently accessed coping resource and exceeded their use of religious engagement. In Pritzlaff’s (2001) study with parents of children who had disabilities, she too found that parents rated their faith in God as their most important coping resource. Similarly, the mothers in my study believed God could give them a peace that transcended the capacity of any parishioner or clergyman. As Mary described it, God "gives us the peace that passes all understanding, and, you know, I have felt that peace." Scorgie et al. (1996) found similar results in their study with parents of children who had disabilities that reported their faith in God was a source of support that provided a sense of purpose in their circumstances. These parents believed that their spiritual faith fortified them and gave them the strength to endure the parenting challenges they encountered.

Several of the mothers in my study attributed their close relationship with God to their child because they believed their child made them more spiritual. Helen explained how her parenting experience contributed to her spiritual growth when she said,

> I believe the reason that [spiritual connection] I have, that is because of Diane! If you had asked me all this when I was [in my 20s], I don't think I would have had that non-traditional viewpoint. I think that I have that non-traditional viewpoint in a retrospective manner looking back over the last…years after Diane was born. All the things that we've had to do to make sure she had the best quality of life that she could have, as I look back, I'm thinking we couldn't possibly be where we are today without some guiding hand in there.

Similarly, Hughes (1999) found that parents frequently attributed their spiritual growth to the experience of raising a child with a disability. Skinner et al. (1999) reported Latina mothers of children with Down syndrome living in the U.S. believed their child strengthened their relationship with God and made them better people. In the same way, one of the mothers in my study, Felicia, said mothering her daughter had made her more spiritual and “probably a more humble person…a more tolerant person, a more accepting person,…but, I think, maybe, it’s made me a better person.”

The mothers in my study indicated that focusing on the positive and rejecting the negative was a helpful coping strategy, although they all employed this optimistic outlook in varying degrees. Regardless of how much mothers were able to embrace this positive perspective, they all suggested it was a choice and sometimes a daily struggle to remain positive. Nevertheless, making a mindful effort to be positive alleviated worry and stress. Isabella described this positive-choice process when she said,

> I try to pick the positive stuff that I want to hear, and throw out the negative; let it go in one ear and out the other, because you have to be like that. You have to choose what you want hear.

Other research suggests that having a child with a disability promotes an optimistic perspective on life (Taunt & Hasting, 2002) and having an optimistic outlook is a positive parenting trait that helps sustain parents during challenging parenting moments (Scorgie, 1996). In addition, spirituality and religiosity have been found to increase optimism, which is associated with greater overall well-being (Baker et al., 2005; Friedrich et al., 1988; Greenberg et al., 2004). As Denise explained, when she is faced with a challenge, “I face it with optimism. You know wherever God’s fixin’ to take me…I’m gonna be willing to go. I’m not gonna be screaming and hollering, kicking and fighting, because I want to see God in this.”

Sub-question number four. The fourth sub-question was, “How does spirituality or religion create or thwart hope for the future of a child who has Down syndrome?” As previously stated, the format of this interview process allowed mothers to present their stories as they chose, and I did not redirect their storytelling when they ventured into areas that were unrelated to spiritual and religious issues, which happened throughout the interview and in relation to all of my research questions. Still, in this section mothers' discussions were deeply divided as they vacillated between a committed faith regarding God's divine role in their child's life, to a wavering use of faith as they planned for their child's future, and finally to a faltering faith when considering the eventual death of their child. Interestingly, when probing the topic of mothers' use of spirituality and religion as they contemplated their child's future, I did not pose any questions that suggested mothers should address their child's death; yet all but one mother did. When considering the child's future, mothers' responses fell into three primary thematic categories: (a) fear of loss and death; (b) faith in God's divine plan; and (c) planning and self-reliance.

A pattern arose during the interviews with the mothers in my study; they all expressed concerns about loss through separation or death. Five of the six mothers emotionally addressed their concerns about their child's eventual death. These five mothers' children had each faced life-threatening health conditions. Only one mother's loss concerns were not centered on death; instead, her worries about loss focused on the potential loss of companionship should her daughter eventually move out of the home. This mother's child had not experienced significant health concerns. Considering this unsolicited discussion about death and loss among the mothers in my study, it is surprising this was not present more often in the literature.

Mussett's (2012) study examined parents' posttraumatic growth following the death of a child, but few studies questioned how parents coped with the eventuality of their child's future death. S. V. King's (2001) study with African American parents of adult children who had disabilities reported that some parents avoided thinking about the future, but other parents acknowledged that their caregiving would likely end when their child died or they became unable to provide care any longer. S. V. King (2001) also reported that one mother prayed her child would die before her so she would not have to worry about his care should she die first. Leyser and Dekel's (1991) study with Israeli parents reported that mothers and fathers expressed little concern about their child's future because they trusted God would provide what their child needed.

When contemplating the future of their child, the mothers in my study believed God had a plan and that life would work out just as it should. They all said their spirituality had grown overtime and been positively shaped through their mothering experiences, which was consistent with Hughes' (1999) study with parents of children who had disabilities. Ninety-four percent of parents in that study reported their relationship with God had deepened since the birth of their child.

In Bennett et al.'s (1995) study with parents of children who had disabilities, participation in the religious community promoted a sense of hope for their child's future, and one mother whose child was over the age of 21 reported that her spirituality contributed to a sense of empowerment and confidence that she could create a happy future for her child. However, the Bennett et al. (1995) study included children ranging in age from 15 months to 30 years-old, and this optimistic hope for the future was reported by parents whose children ranged in 6 from six to 12. Only one mother who had an adult child over the age of 21 reported an optimistic, future-oriented outlook. As mentioned previously, Leyser and Dekel's study (1991) with Israeli parents and S. V. King's (2001) study with African American caregivers reported that parents trusted God to provide for their child. This is consistent with several of the mothers in my study who believed God would guide and provide in His own time, and that, as Denise put it, “God’s grace is sufficient.”

The mothers in my study believed God had a special relationship with their child and He would protect their child. Protection did not necessarily ensure the child would not experience illness, an accident, or death, but mothers believed a spiritual protection was present through God, the Holy Spirit, angels, or the saints. Mary conveyed her faith in God when she said, “I knew she was in God’s hands and that He was gonna…protect her, you know. I’d given her to Him, and He was gonna take care of her.” Additionally, most mothers in my study believed their child was guaranteed a place with God in heaven and that their child’s relationship with God and prayer life was more authentic than other people’s devotional commitment. Speraw (2006) reported that the parents in her study believed their child had an enhanced spiritual connection with God. Even after death, Marshall et al. (2003) reported that some parents believed their child who had a disability was guaranteed life after death. Some of the mothers in my study conveyed this same belief that their child was guaranteed salvation. For example, Isabella said, “I think all special needs kids go to heaven, I just do.”

The mothers in my study believed their child had a divine, future-oriented purpose and would continue to positively influence the people in their lives. Zechella (2014) found Asian Indian parents living in the Unites Stated believed their child had a predetermined purpose in life. Cho et al. (2005) reported that Korean American parents tended to view their child’s disability as part of a transformative, divine plan that ultimately benefited the family.

Although not reported as future-oriented findings, the following studies support these mothers' view that their child contributed to their social network. Stainton and Besser's (1998) study reiterated this view that parents believed their child had a positive impact on their family and on their community. Taunt and Hastings (2002) confirmed the idea that parents believed their child with a disability contributed positively to siblings and extended family by increasing sensitivity, providing opportunities to learn, inspiring optimistic perspectives on life, and improving family relations. Finally, Bryant et al. (2011) reported that parents thought knowing a person who had Down syndrome was enriching. The mothers in my study believed that the benefits family and community members received through their interactions with a child who had Down syndrome would continue to occur throughout the child's life.

The mothers in my study said their faith in God was consoling and reassuring, but sometimes faith was not enough; sometimes they doubted. Some mothers occasionally wondered if God would really be there for their child. For other mothers, the doubt was about letting go and turning it over to God. At other times, the doubt was about how to practice their faith, how to pray, what to pray for, and how to balance faith with personal responsibility. It was a complicated quandary for some mothers as they tried to get faith right. The literature did not discuss faith in terms of doubt. Outcome data was typically presented by parents' degree of use of particular coping resource, but not about doubt or uncertainty of their use of a resource, in this case God. Consequently, none of the studies included in the literature review directly addressed doubt.

However, the literature review identified planning and optimism as beneficial coping strategies. The mothers in my study believed that optimism fortified them during difficult times and planning prepared them for the future. Scorgie (1997) and Scorgie and Sobsey (2000) reported that optimism was an effective parenting trait that promoted other positive parenting responses during difficult times, such as hopefulness, strength, and confidence. In a study conducted by Churchill et al. (2010), parents reported proactive coping strategies, such as seeking advice and facing problems to find resolutions, were helpful when addressing challenges. Sullivan (2002) found that mothers’ use of planning activities as a coping behavior increased over time. The mothers in my study responded similarly. Initially, they were surprised by their child’s diagnosis of Down syndrome, but for most, it did not take long until they began to learn how to acquire knowledge and initiate problem-solving strategies. Experience helped these mothers develop their problem-solving skills as they became more familiar with available resources and support systems.

The prognosis for children who have Down syndrome has changed dramatically over the past decades. Currently, the average life span of an individual with Down syndrome is 60 years old, with many living on into their sixties and seventies (NADS, n.d.). As recently as 1983, the life expectancy was estimated to be only 25 years. This significant increase is due largely to advanced medical treatments and deinstitutionalization, which has resulted in improved care and quality of life for people who have Down syndrome (Global Down Syndrome Foundation, 2018). Though this is good news, other concerns arise as people with Down syndrome are living longer and experiencing additional health concerns, such as Alzheimer’s disease. Consequently, family care planning is likely to expand as children are expected to increasingly outlive their parents. Although it is unclear exactly what this might mean for the future care needs of people with Down syndrome and their families, it seems certain that change is ahead. One possible result could be an increase among caregiving by siblings, and program policy changes may be required to help meet these shifting needs (Taylor, 2017).

Implications for Professionals

The following conclusions were drawn from three sources: (1) findings that were directly related to the research questions, (2) findings that were unrelated to the research questions but emanated from the mothers' interviews, and (3) findings that emanated from my reflective journal. My reflective journal included my reactions to the research as I contemplated my previous work in rehabilitation with persons who had disabilities and their mother, which included data related and unrelated to spirituality and religiosity. Because I did not limit what these mothers chose to share during their interviews, some information was unrelated to spirituality and religiosity but was important in their mothering journey. The conclusions from these findings, combined with data from my reflective journal, are presented in the next two sections specifically for professionals in the helping fields and medical professionals. Information directly related to spirituality and religiosity is presented at the end of each of these two sections. Lastly, conclusions are presented for the clergy and parishioners, which focuses solely on the spiritual and religious findings from this study.

Professionals in the helping fields. A myriad of professionals work with children and adults who have Down syndrome. Which professionals work with a person who has Down syndrome varies greatly depending on the individual's specific care and developmental needs. During the early years, some children with Down syndrome work with physical therapists, occupational therapists, speech therapists, or daycare workers. As the child grows, they may work with special education teachers, regular classroom teachers, and school counselors. Later in life, case managers, vocational rehabilitation counselors, mental health counselors, and community-based program staff may offer beneficial services. This research identifies three points that helping professionals can draw from to improve the delivery of services to these children and adults and their families.

First, families of children who have Down syndrome perceive and interact with the child as a unique, contributing family member. The diagnosis of Down syndrome is an external label that contributes little to their daily functioning as a family. As Felicia said, “This label, Down syndrome, is something I forget about most of the time. She’s Rose; that’s who she is.” Professionals operate within ethical boundaries that limit personal relationships, and interactions with people who have Down syndrome are typically service outcome driven. Eligibility criteria (i.e. a diagnosis) frame the foundations of these relationships. Ironically, most professionals promote a person-first approach, yet their positions as professionals create barriers to person-first relationships. The first step toward appreciating the individuality of someone who has Down syndrome, or any other disability, is to recognize and understand the inherent limitations professional relationships present. While conceptualizing the person from a service delivery perspective, professionals should strive to understand this individual as a person first recognizing the intersectionality of all their life roles (e.g. child, brother/sister, aunt/uncle, spouse, student, employee, etc.).

It takes effort to balance one's professional expertise with a humble approach that signals to an individual and their family that they are the experts of their own life, not the professional. The mothers in this research study repeatedly used the phrase "blah, blah, blah." When I asked about the meaning of this phrase, one mother explained that it meant she had heard all she wanted to hear from someone who thought they were the expert. Developing and maintaining professional humility should not lessen the quality of one's work, but it might reorient the focus away from labels and goal outcomes toward a perspective that more fully embraces the unique individuality of persons with disabilities.

Secondly, a prevalent message throughout these mothers' interviews was the importance of acceptance and inclusion as a contributing factor in the worth of their child as perceived by the community. Developing academic, work, and daily living skills are important, but mothers believed that to live a quality life, their child needed to be accepted and included as a participating member in the community to whatever degree was possible. As service providers, it is important to remember that acceptance and inclusion may be the most important goal professionals help a child achieve.

Finally, as the life expectancy of children with Down syndrome continues to increase, it is likely families will need expanded program options, supplemental supports, and life care planning to attain and maintain quality of living throughout the life of their child. Professionals who work with persons who have Down syndrome and their families should consider these future needs and advocate for legislative changes that expand these services. In a time when Medicaid, which is the primary funding source for service programs for people with disabilities, is continuously threatened with budget cuts, innovative planning and advocacy will remain an increasingly important professional responsibility.

For some families, spirituality and religion are important coping resources, and advocacy may be needed within that domain as well. I was a rehabilitation counselor for approximately 25 years. During that time, I advocated with, and on behalf of, persons who had disabilities. I also worked with churches when developing plans of care when requested by individuals or families. Unfortunately, it never crossed my mind to advocate within the church. For some reason, I stopped at the church door believing that referring someone to a place of worship that best matched their faith beliefs was enough. Based on these mothers' stories, I now realize that it was not enough. They needed more than to simply step inside the church; they needed to be a part of the church.

This research highlights the importance of religious engagement for some families. Although none of these mothers suggested their helping professionals should have advocated on their behalf within the church, none of these mothers reported that any professional had ever offered to do so. Today, many helping professionals strive to work from a person-centered and holistic perspective. With that in mind, it seems more than reasonable to suggest that professionals include the community of the church and faith practices in their plans to help individuals achieve equal access to resources and a good quality of life.

Medical professionals. The findings in this study are relevant for persons working in the medical professions. Based on the mothers' birth stories presented in Chapter 4, it seems obvious there is a need to improve the delivery of postnatal diagnoses. However, considering these birth stories collectively, it appears some changes are already underway. The stories told by Mary, Felicia, Sabrina and Denise all contained elements of hopelessness regarding the diagnoses and prognoses of their babies, all of whom were born approximately three to six decades ago. Isabella and Helen gave birth to their babies just over two decades ago and, although still troubling, the birth story narratives about the medical staff were quite different. These two mothers had a more positive view of their physicians and medical care professionals. A number of studies have evaluated effective practices for physicians to follow when presenting a postnatal diagnosis of Down syndrome to parents. Researchers' recommended practices for physicians include the following:

- Obstetricians and pediatricians should jointly inform parents of the diagnosis.
- Physicians should inform parents of the diagnosis as early as possible.
- Parents should be together when this news is shared.
- The infant should be present during this conversation.
- Physicians should use positive language and avoid communicating pity, sorrow, or tragedy.
- Information should be presented in practical terms and relevant resources should be provided to the parents.
- During the first conversation, physicians should limit medical information to the conditions they suspect the baby may have.
- The physician should provide information about local support groups.
- Follow-up appointments with the appropriate medical care experts should be coordinated (Skotko, Capone, & Priya, 2009).

The experiences of the mothers in this study indicate these physician recommendations are accurate. They wanted to know what was happening with their child as early as possible, they wanted to have the support of their spouse or family when they received the information, and they wanted the information to be cohesive, clear, and consistent. As previously reported, when too much information was shared, mothers became overwhelmed, and all they heard was “blah, blah, blah.” Additionally, the mothers in this study considered providing encouragement through positive language, physical resources, and referral to local support systems helpful.

Although these guidelines were developed for physicians, other medical professionals can benefit from these recommendations. All medical care providers can use positive, person-first language that affirms the value of parents’ infants. Becoming familiar with local resources that support families who have children with Down syndrome provides medical care professionals with the information they need to effectively assist these families. Helping families coordinate services by providing contact information or making appointments assures them that they will have caring support as they begin their journey parenting a child who has special needs. Understanding that some families benefit from spiritual and religious supports can prompt medical professionals to offer this resource to families when appropriate.

Clergy and parishioners. Based on these mothers’ stories, spirituality and the community of the church can be a source of consoling support, but not all clergy and church parishioners respond with equally affirming and inclusive words and actions. It seems likely that most religious communities do not intentionally reject children who have disabilities. However, claiming to be inclusive and actually being inclusive are not the same. As Dan Vander Plaats (Becker, 2018) describes it, inclusion is a process. Vander Plaats is the Director of Advancement at Elim Christian Services and he is an avid advocate for persons who have disabilities, particularly within the religious community. According to Vander Plaats (n.d.b), this process of inclusion begins from a position of unawareness when clergy and parishioners are essentially blind to the needs or presence of persons with disabilities. This is followed by pity, then care. The forth step is friendship established through meaningful relationships. The fifth and final step is co-laboring as persons with disabilities are actively included and recruited to participate with other parishioners as they practice church traditions and rituals and work for the overall good of the church (Becker, 2018, Vander Plaats, n.d.b). In this study, mothers indicated that acceptance and inclusion in the church community was a powerfully-validating signal of the church's perception of their child's worth, and inclusion directly contributed to these mothers' ability to successfully practice their faith within the walls of the church.

During a time when church attendance is diminishing, people are moving away from formal religious practice, and the number of people living with disabilities is increasing, it is in the interest of church communities to ensure they were welcoming all people. As a follow-up to the five stages of inclusion previously outlined, Vander Plaats (n.d.a) has identified seven signs that a church community is stuck in their lack of awareness. Recognizing these signs can help a church community transition from blind unawareness to the insightful and intentional inclusion of persons who have disabilities. These signs include: (a) shunning individuals with disabilities; (b) using insensitive language; (c) feeling annoyed by the presence or needs of people who have disabilities; (d) lacking the spiritual maturity to share God's church; (e) lacking awareness of the prevalence of disability; (f) physical inaccessibility to all church resources and practices; and (g) general insensitivity toward the needs of others. For clergy and parishioners who want to create an accepting church environment for people with disabilities, including the mothers and children who participated in this study, there is hope; but their compassionate and informed advocacy is needed.

Limitations and Recommendations for Future Research

Some of the strengths of this study contribute to its limitations. The goal of a phenomenological study is to offer rich, thick descriptions of a phenomenon that are captured through a variety of means such as observation, written documents, pictorial images, and interviews. To describe a phenomenon accurately, the source of the data should be similar. In this research study, individual interviews were conducted with mothers to understand how spirituality and religiosity permeated their lives as the parents of adult children who had Down syndrome. Though generalization to other populations is not the intent of a qualitative study (Esterberg, 2002), transferability to other cases is possible if the reader determines the environment and situations are similar enough to justify the use of the research findings (Shenton, 2004).

The focus on mothers' experiences in this study is intentional as it draws data from a similar pool of participants, but it fails to address fathers' encounters with spirituality and religion as they parent a child who has Down syndrome. This is noteworthy because previous research documents that gender-based differences in stress exist between parents (Bristol et al., 1988; Glidden & Floyd, 1997; Heller et al., 1997; Lawrence, 2008a; Morris, 2014; Noh et al., 1989; Oelofsen & Richardson, 2006; Olsson & Hwang, 2001, 2008; Scott et al., 1997). Sanders and Morgan (1997) found that mothers and fathers perceived problems with their child and the family differently, so their responses to potentially troubling circumstances were not the same. Some of this may be attributed to the different roles mothers and fathers hold in caring for their child, which influences stress and wellness (Grant & Whittell, 2000; Heller et al., 1997; Manor-Binyamini, 2012; Roach et al., 1999). Fathers' experiences of caregiving are likely quite different from their spouses' experiences because mothers typically function as the primary caretakers of children who have Down syndrome (Pelchat et al., 2003). Additionally, mothers are more likely to report religion as a source of support (Grant & Whittell, 2000) and are more likely to view their child as a "blessing from God" than are fathers (Marshall et al., 2003, p. 68) suggesting these gender-based difference would be noticeable in a similar study with fathers. Understanding how fathers experience and use spirituality and religion in their parenting of a child with Down syndrome would be helpful.

The mothers in this study all resided in Southern states situated in what is commonly referred to as the Bible Belt. Mothers who live in other parts of the country may experience spirituality and religion differently. For this study, mothers were asked to self-identify as spiritual or religious, but there was no systematic measure that determined how engaged these mothers were with their religious faiths, and, although they were all Christian, there were denominational variances among them. One mother was Catholic, one was Methodist, one reported she was non-denominational, and three were Baptist. Certainly, these mothers' church doctrines influenced their religious beliefs. According to Gutierrez et al., (Gutierrez, Hale, & Park, 2018) religious differences influence one's likelihood of perceiving spiritual and religious events as life changing, such as the birth and rearing of a child with a disability. Research aimed at exploring the differences between mothers’ religious denominations would be enlightening.

The interviews with these six mothers produced thick, descriptive data that contributed to understanding these mothers’ spirituality and religious experiences. Although I attempted to interview mothers who had similar experiences, the participants differed in various ways that likely influenced how they experienced spirituality and religion. Only one mother was African American; the other five were White. Religious affiliations differ among ethnic and racial groups, with more African Americans associating with Protestant faiths and fewer associating with Catholicism (Frame, 2003). Additionally, according to some studies, African Americans’ are more likely to employ deferring coping strategies (leaving their problems to God) than their White counterparts (Ark, Hull, Husaini, & Craun, 2006), suggesting that a study that included women of one race and one faith denomination might yield different results from this study. This study did not include any non-Christian participants, so examining how spirituality and religion influences the parenting experiences of parents living in the U.S. who practice non-Christian faith beliefs, such as Judaism or Islam, might reveal different findings.

The mothers in this study differed in age ranging from the early 40s to the mid-70s. Previous research has reported that older parents are more likely to utilize spiritual supports as a coping resource (Grant & Whittell, 2000; Hayden & Heller, 1997; King et al., 2006; Sullivan, 2002; Willis, 2007). This finding was not supported in my study, however, only one mother was in her early 40s; the others were in their late 50s to mid-70s. Additionally, the mothers in the current study gave birth to their children in different decades ranging from the 1960s to the 1990s, a span of over 30 years. During that time, the social shift in our country's ideas about institutionalization, education, and integration of children who have disabilities likely influenced these mothers' experiences. Conducting a similar study with mothers of children who have Down syndrome that have been born more recently might reveal a positive shift in the diagnosing process, maternal adjustment, and the use of spirituality and religion as a coping resource.

In addition, previous research indicates that parents' stress and coping are linked to the severity of a child's diagnosis, particularly as it relates to behavior challenges and social skill development (Hodapp et al., 2003; Keller & Honig, 2004; Roach et al., 1999; Saloviita et al., 2003; Wang et al., 2004). The mothers in this study had children who represented a diverse range of abilities; one child was non-verbal and had limited independent living skills, whereas other children were accomplished athletes, artists, held jobs, and voted. I did not consider this variable during my recruitment efforts or in the analysis of the data, however, it may contribute to mothers' use of spirituality and religion as a coping resource. Conducting research to explore the differences among mothers' use of spirituality and religion based on the severity of their child's disability could provide helpful insights.

As previously noted, only a few of the studies in this literature review explored parents' concerns, planning, or coping strategies about their potential or eventual separation from their child due to the child's increased independence, the parents diminished ability to provide care, or their child's death. When developing my research questions, I did not ask these mothers about their potential separation or death of their child, but they all addressed this issue with grave concern. Given the intensity with which these mothers discussed this subject, I believe this is another area worth researching.

Lastly, some of the mothers in this study offered their input regarding future research. One mother suggested more information was needed about parenting non-disabled children along with a child who had a disability. This mother was concerned about how the unequal distribution of childcare time and the additional demands placed upon other children who have a sibling with a disability might influence their development. Another mother suggested research on holistic approaches for programs serving adults with disabilities following high school would be beneficial. This mother recognized her daughter had ongoing intellectual and emotional developmental needs that were not being met by day programs, and she believed a holistic approach that effectively integrated art, music, healthy life choices, and physical fitness would improve the overall health and wellness of adults who had disabilities. These mothers offered some insightful recommendations regarding future research; however, that doesn't really surprise me because some of the best advice I have heard came from mothers.

Advice from a Mother

During the interviews with these mothers, there were times when they shared insights that were particularly important and they wished someone had shared this with them when their child was younger. Toward the end of the interview series, as I began to debrief with the mothers, we talked about what the interview process had been like for them, what their favorite stories had been, and what takeaways they thought might be most helpful to other mothers. The intentionality of their comments struck me, and I realized they were not sharing their stories to benefit me or themselves; there was a greater purpose. In fact, these mothers likely had many reasons for electing to participate in this study, but one clearly-communicated reason was to help other mothers of children who have Down syndrome. The following include some of these shared moments of mothering advice. Similar to the presentation of these mothers' initial birth stories in Chapter 4, this advice is presented from a first-person perspective. Unlike the birth stories, each piece of advice represents more than one mother's voice; therefore, the advice is not attributed to any single mother. Although this content does not represent direct quotes, I have made a deliberate effort to retain the voice(s) of these mothers to convey the cognitive and emotional elements of their experiences.

Don't tell me you're sorry. When my baby was first born and people came by the house to see her, they would tell me, "I'm so sorry." I mean, when we first learned that she had Down syndrome, it was a confusing time; but she was so precious, how could they be sorry for me? "I'm sorry" is what you say when someone you love dies, not when they're born. She wasn't dead, so what were they saying to me? Were they sorry that she wasn't healthy, or were they sorry that she was different? To me, it felt like they were saying, "I'm sorry you had a kid like that." It was just negative, like this child must surely be a big disappointment to me; but she wasn't. To me, she's a beautiful child, sweet, funny, and gorgeous. So, don't tell me you're sorry! Instead, say, "Oh my gosh, I'm so happy for you. She's so cute and sweet," just like you would any other child. I mean, she's not dead; she's here, and she's lovely.

Don't take advice from ignorant people. When my child was born, and still to this day, people want to tell me what they think they know about Down syndrome. I'm not talking about the people who actually know what they're talking about. I'm talking about all those other people who really don't know anything about Down syndrome. It's not that they're stupid; they're just ignorant of the facts. I remember when my kid was little, people told me stuff like, “Kids with Down syndrome don’t live very long,” “They can’t learn,” “They won’t have any friends,” and on and on. It really had me down. Thank goodness, I was able to educate myself. What really helped was getting connected with support groups and other families who had kids with Down syndrome. They told me what it was really like, told me the good stuff, and shared information that prepared me for the future. When I met their kids, I saw they were friendly and social and could learn. I mean one of those kids even played the piano like Mozart, and another one was over 60 years-old; it was awesome! By relying on people who knew what they were talking about, I learned that just because my kid had Down syndrome, that didn’t mean my child couldn’t live a long and happy life.

Give yourself time to grieve. After I had my baby and we learned about the diagnosis of Down syndrome, I was overwhelmed with conflicting emotions. I felt scared and happy, angry and guilty, proud and disappointed, thankful and resentful, and grief. I couldn’t understand how it was possible to feel all those opposing emotions at the same time, about the same event, when at the center of it all was my precious newborn baby. I spent a lot of time beating myself up about some of those emotions, especially about the grief and guilt. I guess I didn’t understand that I could feel grief and happiness at the same time, but I did. I mean, I was in love with my baby from the very beginning. But that grief; I kept trying to pretend like it wasn’t there, that I hadn’t lost my baby, so it was wrong, even selfish of me, to feel grief. This just made me feel even guiltier than I already did. Somehow, I thought my baby’s Down syndrome was my fault; I had done something wrong to cause this. It didn’t take long for me to realize this wasn’t true. Down syndrome didn’t have anything to do with my actions; it was genetic. So, I was off the hook about that guilt, but I still felt guilty about feeling sad. It was a mess, and in hindsight, it seems like I wasted a lot of time punishing myself for my emotions when, in truth, I had a right to feel sad. All the dreams and assumptions I had about my baby were shattered with the diagnosis. I hadn't yet rebuilt my dreams, so the future looked so unknown, and it was scary. You know, at the time, I didn't even realize that my sadness was grief, and that grief about lost dreams is a real thing and it's okay. I also didn't realize that grief, guilt, and all those other emotions were just part of a process that I had to experience before I could start imagining all of the wonderful possibilities about my baby's future. So, I guess what I'm saying is give yourself time to get through whatever emotions you are feeling. You can feel scared, angry, disappointed, and resentful, and you can grieve your lost dreams at the same time you are loving your baby with all your heart.

Forge your own path. It all boils down to this, you have to forge your own path; the one that is right for you, your child, and your family. I know several families with kids who have Down syndrome, and we're all doing different things. All of our kids are a little different developmentally and intellectually, so these boys, girls, men and women with Down syndrome, they're all living different lives. No matter how many pictures other people paint about what your child's or your family's life should look like, there are a million good options and different paths you can follow. And why shouldn't you?!? Your kid, just like other kids, is unique, and your child's talents, aptitudes, and interests will be as well. So be prepared for a journey of discovery as your child evolves into his or her own unique person. Granted, no two families are the same, and we can all learn from each other; just be sure you follow the path that is right for your child and your family.

Never stop learning. I think this applies to all of us, but as a mother of a child who has Down syndrome, I want to encourage you to start early and never stop exposing your child to new experiences and opportunities to grow intellectually, emotionally, physically, and spiritually. I believe we thrive when we learn, and opportunities to learn are all around us. Children who have Down syndrome are curious just like other children. Their developmental readiness for some learning activities may occur at different times, but if children have new and stimulating opportunities, they can learn. I can't imagine the lack of fulfillment I might feel if I were not continuously learning new things. I want my child to experience the same excitement from personal growth that I do. If your child can learn to read, then encourage her to read. If your child in interested in music, find opportunities for him to play an instrument. Unfortunately, some people will tell you "she can't," or "he won't be able to," but don't believe them. No one knows what your child can do until she has the opportunity to do it. So plant the seeds of learning and watch your child grow.

Trust God with your child. Here's what I've learned over the past decades: God loves your child more than you do. I knew this when my child was born, but knowing it and living it are two different things. I knew if God loved me, He would love and bless my baby. But even after all these years, I'm still learning this lesson as doubt sometimes seeps into the cracks of my faith. It's an ongoing experience of understanding that God loves your child and wants what's perfect for your child. I mean, mothers want what's good for our children in the human ways of wanting, but God wants all of His children to have a perfect life, spiritually speaking. Our human concerns don't have the same magnitude as His eternal hopes for our children. If we trust Him, He will provide. At least that's the way I see it. So when my humanness makes me doubt, I ask God to reassure me, "All of this is gonna work out in the end, right?" God always says, "Yes."

Final Comments

My research journey with these mothers has been an unexpected blessing for me. I thought I would learn from this experience, and I did. What I did not anticipate was the raw truthfulness I heard in these mothers' stories, which sometime struck me quite personally. More than once, I recall mothers sharing their frustrations about attempts to access care for their adult child through a seemingly impenetrable barrier of bureaucracy, paperwork, and waiting lists. In my previous work, I had been part of that system, and I wondered if I could have done more for the people with whom I had worked. I thought I had understood, but as I listened to these mothers, I realized that my awareness was often limited. Even in those instances when I worked with families for many years and had acquired greater insight, this knowing was from the perspective of an outsider looking in. I knew this before, but hearing these mothers' stories made me even more aware of how important it is to recognize and acknowledge the limits of how much I can ever understand about someone else's experience. This is my greatest lesson from this journey: to know that I can never fully know. I have been humbled through this experience, and this humility gives me freedom. I no longer feel pressured to be the knowing expert. Instead, I feel that I have a renewed freedom and responsibility to inquire and to listen.

Another unanticipated outcome for which I am grateful is the emotional component of this journey. I had no idea that I would so often laugh until I cried or simply cry because the stories hurt. Even now, when I reread these stories, I find myself once again laughing and crying with these mothers as they retell their stories from the pages of the transcripts. This experience bonds me to these mothers because their stories are now a part of my own.

As I ended the interview series with these mothers, it was sometimes especially difficult to say goodbye. The relationships established between us through their storytelling was like a good book that we did not want to end. Concluding these final pages of my dissertation, I find I am feeling this same hesitancy about ending. However, I am comforted by the hope that I have told their stories well, and that it will be as they wished: their stories will help other families of children who have Down syndrome.

Perhaps this is already happening. When I think about my aunt's experience with her little boy, my heart now has more compassion for the difficult decision she made almost six decades ago. Ever since I was a little girl and first saw Rex's picture hanging on my grandmother's sewing room wall, I wondered how my aunt could choose to place her child in an institution; but I never asked. I did not question this family secret. After hearing these mothers' stories, my wondering perspective shifted. The mothers in this study relied on their spiritual faith for guiding comfort; but just as importantly, maybe even more importantly for some of these mothers, they had the support of family who looked at the baby as a God-given gift, and they had hope for the future. My aunt did not have this support nor this hope. Now, when I think about my aunt and her little boy, I no longer wonder how she made her decision; I wonder how she survived the pain and loss she surely suffered in the wake of that decision. I also wonder about the joy my family missed by not having Rex in our lives.

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Appendix A
Recruitment Flyer

Mothers of children who have Down syndrome!

Want to make a difference?!?!
Join a research study on
spirituality and religion in the
experience of mothering a child
who has Down syndrome.

You may be wondering…

1. What do I need to do to participate?
    - Talk about how **spirituality or religion** impact your experience as a mother.
2. Why should I do it?
    - Your story can help other mothers of children who have Down syndrome!
3. How do I know I am eligible?
    - You are eligible if:
        - ❖ *You are the mother of a child who has Down syndrome who is 18 or older and is no longer attending high school.*
        - ❖ *Religion OR spirituality is important in your life. (You do not need to attend a church, synagogue, mosque, or other religious institution to participate.)*
        - ❖ *Your child lives with you at least 6 months of the year.*
        - ❖ *You live in the Mid-South region of the United States (Arkansas, Mississippi, Missouri, or Tennessee)*
4. Is it safe to participate?
    - Yes, participation is voluntary, and your identity will remain confidential.

If you are interested, please contact Stephanie Gotay, MRC, CRC at sggotay@memphis.edu or (870) 243-2885.

(This research is conducted under the supervision of Dr. Lustig at the University of Memphis.)

Appendix B
Consent Form

Consent to Participate in a Research Study

(Mothers of Adult Children who have Down Syndrome: Understanding the Meaning of Religion and Spirituality in Perception, Hope, and Coping)

Introduction: Why are you being invited to take part in this research?

You are invited to take part in this research study about religious and spiritual coping of mothers of adult children who have Down syndrome. In order to participate in this study, you must be 18 years of age or older, consider yourself a spiritual or religious person, and be the mother of an adult child who has Down syndrome who lives with you at least half of the time. Adult child means your child must be age 18 or older and no longer enrolled in high school.

Who is doing the study?

The person in charge of this study is Stephanie Gotay of the University of Memphis, Department of Counseling, Educational Psychology, and Research. As a counseling doctoral student, this research is guided by her dissertation chair, Dr. Dan Lustig.

What is the purpose of the study?

The purpose of this study is to learn about the spiritual and religious coping experiences of mothers of adult children who have Down syndrome.

What will I be asked to do?

If you agree to participate in this study, you will be asked to complete a demographic questionnaire and participate in two interviews lasting approximately 1 to 2 hours. During the interview, you will be asked questions about your religious/spiritual coping experiences as a mother of a child with Down syndrome. The two interviews will take place in a private location of your choice over the course of one month. The interviews will be recorded to ensure your story is accurately represented. You will have an opportunity to review your transcribed interviews to make sure they represent what you want. I will meet with you a final time to collect the interview transcripts. There are no costs associated with your participation in this study.

What are the risks involved in this study?

The risks associated with this study are minimal and are not greater than risks ordinarily encountered when participating in self-reflection of personal coping strategies and spiritual or religious supports. The University of Memphis does not have funds for compensation for injury, damages, or other expenses. However, if you experience distress, a referral to an appropriate counseling resource can be provide to you.

What are the possible benefits of this study?

The possible benefits of participating in this study are increased personal awareness of your coping strategies and spiritual and/or religious support systems. Providing information regarding your personal experience as a mother of an adult child who has Down syndrome may contribute to the literature which guides professionals responding to the needs of mothers. In addition, your story may help other mothers of children who have Down syndrome.

Do I have to participate?

No, your participation is voluntary. You may decide not to participate at any time with no negative consequences. If you decide not to take part in the interviews, there are no other choices except not to take part in the study.

Who will know about my participation in this research study?

Other than this consent form, you will not be asked to provide any identifying documentation. I will make every effort to prevent anyone who is not involved in the research analysis from knowing that you gave me information. My research committee from the University of Memphis may see parts of your interview transcript, however, a pseudonym will be used to maintain your privacy and conceal your identity. Research records will be stored securely in a locked cabinet and all recordings will be destroyed after transcription and data analysis has been completed. I will keep private all research records that identify you to the extent allowed by law. However, there are some circumstances in which I may have to show your information to other people. For example, the law may require me to share your information with authorities if you report information about the abuse of a child or an adult who has a disability or if you pose a danger to yourself or someone else.

Whom do I contact with questions about the research?

If you have questions regarding this study, you may contact the lead researcher, Stephanie Gotay, at sggotay@memphis.edu or 870-243-2885, or my dissertation chair, Dr. Daniel Lustig, at dlustig@memphis.edu or 901-678-3941.

Whom do I contact about my rights as a research participant?

This research study has been reviewed by the Institutional Review Board (IRB) at the University of Memphis. For research-related problems or questions regarding your rights as a research participant, contact Beverly Jacobik, Administrator for the IRB for the Protection of Human Subjects, by phone at 901-678-3074 or by email via irb@memphis.edu.

Your signature below indicates you are age 18 or older, and you are agreeing to take part in this study:

______________________________	______________________________	____________
PRINT Full Name	Signature	Date

Appendix C
Abbreviated Interview Sample Questions

Pseudonym: __________________________ Date/Time: ________________________

Researcher: __Stephanie Gotay___________ Location: _________________________

The following are some potential topics that might ask about in your interview. These statements are presented to you now just to give you time to begin thinking about how you experience religion and/or spirituality in your life as a mother. You don’t need to figure out any answers to these points before our interview. Maybe some of these don’t even apply to your life. However, you may have something you really want to share regarding some of this points. Just let these thoughts simmer over the next few days. We can explore them together when we meet for your interview.

1. Tell me about a time when religion or spirituality impacted your life as a mother.

2. Tell me about a time when religion or spirituality influenced your thoughts about Down syndrome.

3. Tell me about a time when religion or spirituality guided your impression of your child’s disability in positive or negative ways?

4. Tell me about a time when your religion or spirituality influenced how you felt about your child’s future?

5. Tell me about a situation when you turned to your religious or spiritual supports for guidance during a challenging time with your child?

Appendix D
Semi-Structured Interview Guide

Pseudonym: _________________________ Date/Time: ___________________________

Researcher: _Stephanie Gotay___________ Location: _____________________________

1. As a mother with a child who has Down syndrome, **what is it like to have religion and/or spirituality in your life**?
   1. Tell me about a time when religion or spirituality impacted your life as a mother.
   2. What did it feel like to have that spiritual/religious presence during this time?
   3. How did it change the situation?
   4. What did you do in response to this experience?
2. What does your religion/spirituality **tell you about your child's diagnosis of Down syndrome**?
   1. What does it mean, why did it happen, how does it make sense of disability?
   2. Tell me about a time when religion or spirituality influenced your thoughts about Down syndrome.
   3. How did it feel to understand your child's Down syndrome from this perspective?
   4. How was it beneficial/detrimental to the way you thought about Down syndrome?
3. How does your experience of religion and/or spirituality contribute to your **view of your child's disability**?
   1. Tell me about a time when religion or spirituality guided your impression of your child's disability as positive and/or negative?
   2. What did it feel like to hear these spiritual/religious narratives about your child?
   3. How did it change the situation?
   4. How has this changed the way you live with your child (e.g. what you let your child do on their own or with others, expectations you have of your child, responsibilities you give your child)?

4. How do you experience or feel about **<u>the messages</u>** religion and/or spirituality convey to you about **<u>your child's future</u>**?
    a. Tell me about a time when your religion/spirituality influenced how you felt about your child's future?
    b. What did it feel like to receive these messages or ideas about your child's future?
    c. How did it change the situation you were in at that time?
    d. What did you do in response to these messages?
5. What is it like to have **<u>religion and spirituality in your life as you cope</u>** with the daily challenges of raising a child who has special needs?
    a. Tell me about a situation when you turned to your religious/spiritual supports for guidance during a challenging time with your child?
    b. What did it feel like to have this religious/spiritual presence during this challenging time?
    c. How did it change the situation?
    d. What did you do in response to the supports or lack of supports provided to you?
6. Is there anything I should have asked you, but I did not?
7. (Ask LATER) What has it been like to share your story (to be asked in the final interview)?

Miscellaneous Notes:

Appendix E
Excerpts from Reflexive Journal

My reflexive journal included reflexive entries and analytic memos. The following excerpts offer a sampling of these journal entries. The information in italics was added to contextually situate these entries in the data. Additionally, some entries were linked to specific interview content. In those instances, the letters and numbers in parentheses identify the location of the data within the transcripts. For example, (S.1.760) means Sabrina, interview number one, line 73.

10-17-14 (Reflexive thoughts on initial meeting with Sabrina prior to first recorded interview.) I asked Sabrina if she had any questions regarding the interview questions, and she said no, she would try to do her best and answer them correctly. I assured her that she was at a tremendous advantage as there were no correct answers and that only she knew how to answer the questions in a way that would best represent her story. She seemed content with my response, but I sense the uneasiness. I feel it myself - the pressure to “get it right.”

10-20-14 (Reflexive thoughts on Sabrina’s dialogue about being obstinate with God and her assurance that He still loves and supports her.) This section strikes me as quite beautiful - the struggle with letting go of one’s daughter; recalling and understanding her father’s tears when he let her go to the marriage alter; the laughter as she talks about resisting God, not wanting to hear Him; accepting that she is knowingly standing her own ground, even with God, and still feeling safe in her relationship with Him. This is so human to me; I find this a wonderful example of our existence as one who is simultaneously independent and dependent of/on God. (S.1.760)

1-20-15 (Understanding Sabrina’s desire to create a more balanced representation of life with her daughter.) I sense this is important to Sabrina, understanding there was hardship among all the good times. To portray a life of blessed answers from God, comfort, and ease would be inaccurate and leave her feeling as if the story was not fully told; as though it were a sham of sorts. (S.3.98)

6-11-15 (Observing patterns in Felicia’s discussion about Down syndrome.) Felicia emphasizes the positive (have, potential, opportunities). She understands Down syndrome in terms of what one has, not what one does not have. (F.1.580)

6-11-15 (Planning questions for the next interview session with Felicia.) We spent some time in this interview talking about the conflict/disconnect between the church’s position on right to life and their practice of inclusion/exclusion of persons with disabilities both in the church rituals and in the school. But, I never really heard what message this conveyed to Felicia about disability, other than some people are not intelligent/informed. There is something unsaid here. Explore this next time. (F.1.177)

6-15-15 (Analytical considerations and planning future questions for Isabella.) She mentioned when Chloe was first born that she didn't see her as a gift yet. Does that mean that she later saw her as a gift? If so, when and how did this happen? (I.1.199)

6-23-15 (Balancing research with respect/care as Felicia tells me I ask hard questions.) Something has told me I am pushing beyond Felicia's comfort zone. I feel guilty for invading her private thoughts and "demanding" such detailed explanations. I don't want to create discomfort, but I want to understand even more. I am torn between letting her feel comfortable and my pursuit of understanding. (F.2.488)

7-17-15 (Analytic consideration when Isabella initially suggests guilt is part of the healing process; plans for future questions.) Does she mean she had to go through the experience of guilt to get through it? Guilt is not something that can be avoided? Ask about this? (I.2.744)

7-17-15 (Analytic consideration as I begin to see commonalities across mothers' interviews.) Here is a repeated meaning unit with Helen's story – peers outgrow a child who has Down syndrome. (I.2.1168)

7-17-15(Reflexive thoughts and planning future questions when Helen describes her efforts to find a space where she and her daughter were accepted within the church.) It was so very important that Helen attempt to find/retain her place in this space, a space where she felt she and her daughter were accepted. Where were other places in her life where she had experienced this type of acceptance/belonging? (H.1.610)

7-17-15 (Analytic considerations and planning future probes about dueling use of the words-"God" and "Higher Power.") Helen is choosing this new word "Higher Power." How is this different or more fitting to use here than the word she used before – "God?" Does she have two belief systems; one about the God of the church and another about a Higher Power that exists outside of the church? (H.1.1110)

7-31-15 (Reflexive thoughts and noting future questions to probe during next interview.) These words, "God's got your back," are Denise's words, not mine. I think I know what she means when she says this, but these aren't words I might likely use. I am not sure what she means here. Is it the same as how I think? That if I don't believe I have God to lean on or have God to walk beside me during difficult times in life, I might stumble, might not make it, might make poor decisions, might suffer more than is needed – is this what it means to have God at your back? (D.1.901)

8-13-15 (Reflexive thoughts when Helen talks about ensuring her daughter has some autonomy and decision-making power in her life.) The depth of personal giving and sacrifice that a mother will make for her child strikes me. This mother's world centers on making her daughter's life good. That is her purpose, at least one purpose. (H.2.866)

8-13-15 (Reflexive thoughts on Denise's inquire about her first interview transcript: "Are you as satisfied with it as I am?") I love that she is concerned about how I perceived her story. She wants to make sure I think her story is great also. As a researcher, I am concerned that she be satisfied; as a storyteller, she is concerned that I am satisfied. The sharing of stories even in research seem to, at least in this instance, appear to be a product that serves to meet multiple needs – the needs of the storyteller to voice what they have experienced but also to convey it in a way that satisfies the listener. (D.2.124)

8*/20/15 (My thoughts while writing/reading Mary's transcript about the doctor's dark prognosis for her child.)* I am think about my cousin, Rex, and my aunt. If my aunt were alive today, she would be almost the same age as Mary – maybe one year older. I wonder if my aunt heard these same words from her doctor when Rex was born. Did this contribute to her decision to place him in an institution? Hearing Mary's words make me think of my aunt and Rex from a new perspective with sadness. (M.1.214)

8-20-15 (Analytic consideration as Mary introduces her birth story with only this prompt: How has your religious foundation translated into your mothering experience?)
This may answer one of the questions I have been wondering about. Why have each of these mothers started with the birth of their child in their storytelling about their S&R *(spiritual and religious)* experiences? Mary is saying it is because it begins when you become a mother. The S&R is likely in her life before this. It was in hers and has been for some other mothers; so when you become a mother, you become a S&R mother. (M.1.191)

9/22/15 (Checking my curiosity; reminding myself this is about Mary's story, not my tangential curiosity.) I am so wanting to ask more about religion at this point. I am wondering if she thinks Jesus is the only way to God/heaven. This is what she says; so what happens to non-Christians? But, I don't ask. This is my curiosity and not a point of my research inquiry. (M.2.779)

12/5/15 (Reflexive thoughts) I have so many reactions to this process. Today, I read a mother's words, "I think that's one of the better things I am, Rose's mom." I am struck by the beauty of these words. It seems these words are perfection; the epitome of mothering a child with Down syndrome, of mothering any child. As I consider why these words resound so loudly in my heart, I realize this is a position of betterment that I can never claim. I am no ones' mother. The mothering words that were flitting around in my heart suddenly evaporate leaving an empty void.

4-12-16 (Reflexive thoughts on static truths and accurate representations.) I am repeatedly surprised by how these mothers' stories impact me not only in the moment they are told but again and again as I continue to read them. This week as I read Denise's cancer story I experienced her story in a new way in relation to my dad's cancer struggle. Her words and concerns were so much more real to me as I contemplated my dad's cancer. Cognitively, I know our perceptions of a story change as we change and the factors most relevant to our life in that moment influence this perception. Yet, experiencing this is so different from knowing it. I suppose the same is true of this research. No matter how accurately I attempt to represent these mothers' stories, the experience of it will be different from the telling. In some ways, this is freeing for me. I was so concerned about getting it "right." Now, I think there is no single "right" way, so I will just do my best.

7-15-16 (Reflexive thoughts on presentation) In the midst of Daddy's dying, several truths struck me. During the last two weeks, Hospice provided helpful support with supplies, medications, and literature about the dying process. Although literature was helpful, as I grappled to understand this dying event, it did not explain the emotional turmoil and angst I and my family experienced…During this time as I faltered like a bird with broken wings, I spent a lot of time contemplating. I thought that I did not want my dissertation to be like the Hospice books. It would not be bad if it were; the books were helpful. But…I wanted to convey more in my writing. I wanted readers to feel what they read not just understand what they learned…I thought about the words these mothers had told me and understood through my own experiences that these words were sometimes only tiny windows into an expansive and tumultuous sea of emotion. I wanted to pass on these mothers' experiences through a cognitive lens of confusion and understanding, an emotional lens of despair and gratitude, and a spiritual lens of conflict and comforting grace. So, let it be...Let me share these mothers' experiences as they lived them, felt them, and wrestled with their own spiritual supports to survive.

7-31-16 (Analysis.) I can see that my potential themes/meaning units will be transforming as I go, taking on new identities/descriptions. For example, what I originally called S&R definitions has become S&R foundational constructs. They aren't concrete definitions; that is too solid a descriptor. These notions are the foundation of guiding beliefs that help these mothers make sense of their lives, but they are sometimes hard to define. The words can be flimsy attempts to define a visceral experience of understanding. So, I think to call them definitions is misleading, but constructs seems more accurate.

5-24-18 (Reflexive thoughts on disability positions in the church.) I stopped to look at the Grace Church website to see how PWD *(persons with disabilities)* really were positioned. I know they have a sizable group, but it is not listed on the website, or if it is, I can't find it. I wonder why. Maybe Mary is right; the church prefers these folks be unseen.

12-17-18 (Contemplating presentation and anonymity.) In an ideal world, I would provide rich, thick descriptions of each mother, but I am intentionally not because I want to conceal their identities as much as possible. I have given this thoughtful deliberation and concluded there are other methods to personalize these mothers without demographic data. I will use their birth stories to facilitate this connection with the reader creating an emotional link while concealing identifying information.

Appendix F
Excerpts from Field Notes

The interviews provided verbal and non-verbal data. The verbatim interview transcripts record verbal data; field notes document non-verbal information and observations not captured in the transcripts. The italicized information contextually situates these field notes in the data. The parenthetical information identifies the location of the data within the transcripts. For example, (S.1.73) means Sabrina, interview number one, line 73.

10-20-14 [As Sabrina shares her story of feeding her infant for the second time with greater confidence.] I perceived Sabrina's smile as sweet, gentle and loving when she says this. The smile, for me, feels humble while she recalls these memories. (S.1.73)

10-20-14 [Noting positive language patterns.] Interesting that I say "ability" rather than "disability" at this point. The absence of disability talk is one of the things I have noticed in this group, and in this interview, and here I am doing it as well – leaving the "dis" out of the discussion. (S.1.486)

10-20-14 [Noting emphasis in Sabrina's description of her daughter's dedicated effort.] The emphasis on "so hard" suggests, to me, that Bea's hard work was more than the words convey. (S.1.806)

6-11-15 [Noting significant emphasis as Felicia described her efforts to create opportunities for Rose to thrive.] This section of the interview contains more speaker emphasis than other sections possibly suggesting this is important to Felicia. (F.1.103)

6-11-15 [Observations as I listen to Felicia talk about advocating for her daughter's rights to be included and to thrive.] I sense Felicia is proud of the fight she has made for her daughter's rights, not only in education, but also in her spiritual life, her creative life, and her life as a person, not a person with a disability. (F.1.231)

6-11-15 [Felicia's voice as she discussed Rose's independent move to become a registered voter.] I can hear surprise in Felicia's voice as she says this - as though she was innocent and completely taken by surprise by these evolving events. (F.1.407)

6-15-15 [My observations of Isabella watching me during the interview.] Isabella sees that I am taking some notes. My perception is that her attention is distracted by my note-taking; perhaps she is questioning me – what am I doing, what am I writing? (I.1.207)

6-15-15 [Isabella's gestures as she describes when she knows she needs a break and it is time to call on her husband for respite.] Isabella indicates how far up she's HAD it by moving her flattened hand across the front of her forehead. Like an umpire striking out a batter, her hand motion indicates she is out! (I.1.1128)

7-15-15 [As Isabella guides me through corrections on her first interview transcription.] I can still hear Chloe's consistent talking in the background. I can't make out her words most of the time, but I continue to believe that she is echoing her mother's words. For instance, at this point, it sounds like she says the words "trust" and "faith." (I.2.490)

7-17-15 [While Helen tells me about her minister's support when she believed other parishioners perceived her daughter as disruptive.] During this section of Helen's dialogue, tears begin to spill out of her eyes and roll down her cheeks. She wipes them away as she speaks. (H.1.595)

7-31-15 [Observations of physical and emotional air around Denise's words "God is good."] She has a wide smile and bright eyes when she says this, then she begins to laugh. My perception is a physical feeling - I can feel her belief in God's goodness when she says this. It is so present; I feel His goodness in her words and emotions. (D.1.280)

8-13-15 [Helen shows me a picture of Diane and her friend.] Helen hands me a piece of black paper. On the paper is pasted a handwritten letter to Diane from Mindy bookended by two pictures of the two of them. (H.2.420)

8-13-15 [As Helen is describing her mothering journey with Diane.] She has reached for Kleenex and I move the box closer to her setting it on the coffee table. (H.2.768)

8-20-15 [As Mary describes her father's kindness toward others.] This is an emotionally touching story for Mary to recall. Her eyes that are moist with tears. The words Mary uses to describe her father remind me of words one might use to describe Jesus. It is reminiscent of the Christ-like living she has mentioned of her parents. (M.1.164)

8-20-15 [When Mary shares her daughter's decision to accept Christ as savior.] Mary's voice is strained with emotions as tears fill her eyes. (M.1.499)

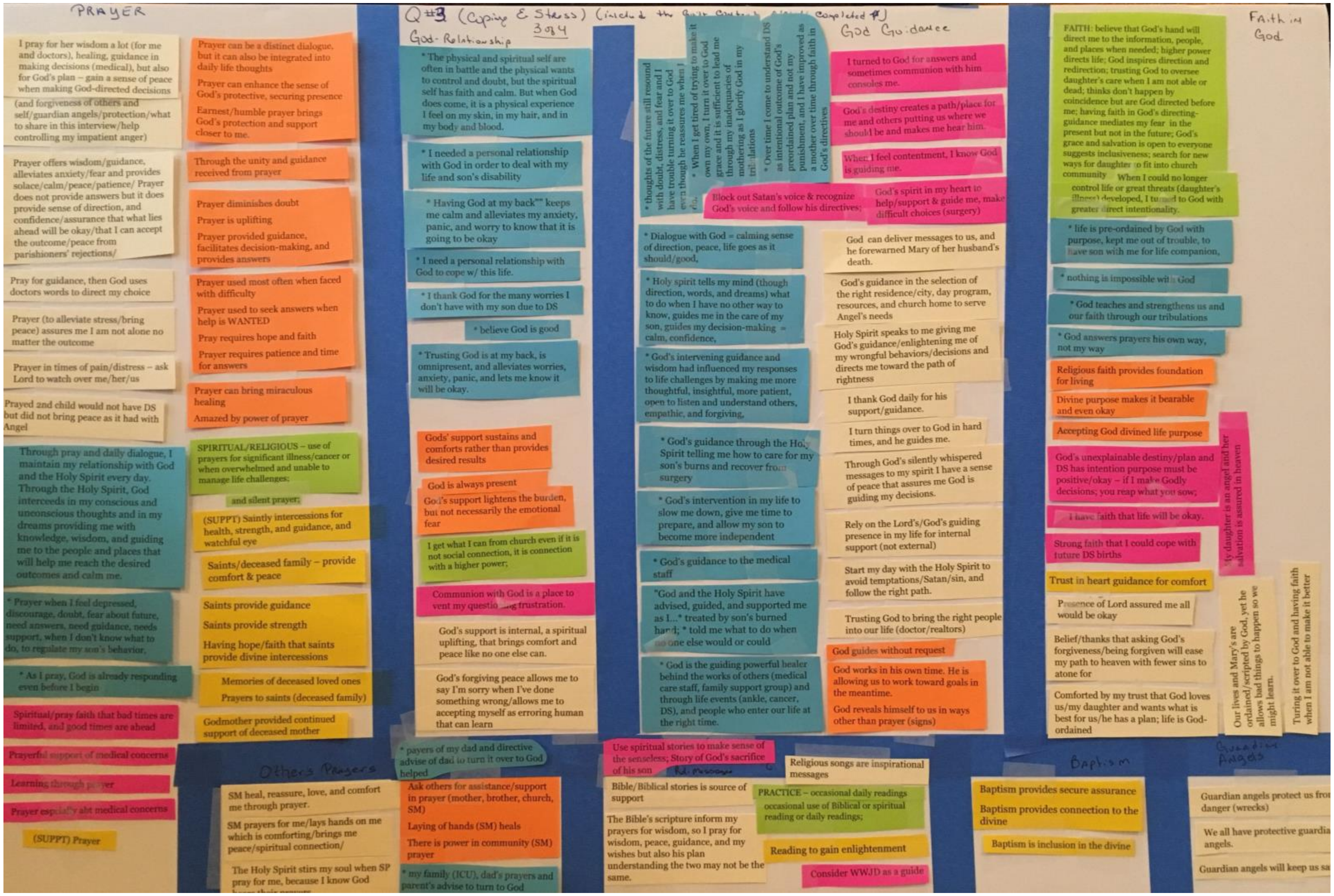
8-28-15 [Denise describes son's near-death experience.] Denise's voice volume remains steady, but the words are spoken with power, each one distinct from the next. (H.2.506)

8-28-15 [Denise describing the presence of God.] Denise grabs a piece of paper from her desk and begins to fan her face demonstrating the feeling of wind or breeze. Her curls fly away from her forehead as the fanning breeze pushes against her face. (D.2.533)

9-22-15 [While Mary is sharing her corrections of the first transcript.] Mary continues to look over her words questioning what more to mark out. As we sit quietly, the muffled sound of the TV can be heard in the background with Angel's voice occasionally contributing her thoughts to the TV's dialogue. (M.2.152)

Appendix G
Analysis Board

(One of four analysis boards for sub-question number three.)



PRAYER

I pray for her wisdom a lot (for me and doctors), healing, guidance in making decisions (medical), but also for God's plan – gain a sense of peace when making God-directed decisions

(and forgiveness of others and self/guardian angels/protection/what to share in this interview/help controlling my impatient anger)

Prayer offers wisdom/guidance, alleviates anxiety/fear and provides solace/calm/peace/patience/ Prayer does not provide answers but it does provide sense of direction, and confidence/assurance that what lies ahead will be okay/that I can accept the outcome/peace from parishioners' rejections/

Pray for guidance, then God uses doctors words to direct my choice

Prayer (to alleviate stress/bring peace) assures me I am not alone no matter the outcome

Prayer in times of pain/distress – ask Lord to watch over me/her/us

Prayed 2nd child would not have DS but did not bring peace as it had with Angel

Through pray and daily dialogue, I maintain my relationship with God and the Holy Spirit every day. Through the Holy Spirit, God intercedes in my conscious and unconscious thoughts and in my dreams providing me with knowledge, wisdom, and guiding me to the people and places that will help me reach the desired outcomes and calm me.

* Prayer when I feel depressed, discourage, doubt, fear about future, need answers, need guidance, needs support, when I don't know what to do, to regulate my son's behavior,

* As I pray, God is already responding even before I begin

Spiritual/pray faith that bad times are limited, and good times are ahead

Prayerful support of medical concerns

Learning through prayer

Prayer especially abt medical concerns

(SUPPT) Prayer

Prayer can be a distinct dialogue, but it can also be integrated into daily life thoughts

Prayer can enhance the sense of God's protective, securing presence

Earnest/humble prayer brings God's protection and support closer to me.

Through the unity and guidance received from prayer

Prayer diminishes doubt

Prayer is uplifting

Prayer provided guidance, facilitates decision-making, and provides answers

Prayer used most often when faced with difficulty

Prayer used to seek answers when help is WANTED

Pray requires hope and faith

Prayer requires patience and time for answers

Prayer can bring miraculous healing

Amazed by power of prayer

SPIRITUAL/RELIGIOUS – use of prayers for significant illness/cancer or when overwhelmed and unable to manage life challenges:

and silent prayer;

(SUPPT) Saintly intercessions for health, strength, and guidance, and watchful eye

Saints/deceased family – provide comfort & peace

Saints provide guidance

Saints provide strength

Having hope/faith that saints provide divine intercessions

Memories of deceased loved ones

Prayers to saints (deceased family)

Godmother provided continued support of deceased mother

Others Prayers

SM heal, reassure, love, and comfort me through prayer.

SM prayers for me/lays hands on me which is comforting/brings me peace/spiritual connection/

The Holy Spirit stirs my soul when SP pray for me, because I know God

Q#3 (Coping & Stress) (include the [illegible] completed #)

3 of 4

God-Relationship

* The physical and spiritual self are often in battle and the physical wants to control and doubt, but the spiritual self has faith and calm. But when God does come, it is a physical experience I feel on my skin, in my hair, and in my body and blood.

* I needed a personal relationship with God in order to deal with my life and son's disability

* Having God at my back"" keeps me calm and alleviates my anxiety, panic, and worry to know that it is going to be okay

* I need a personal relationship with God to cope w/ this life.

* I thank God for the many worries I don't have with my son due to DS

* believe God is good

* Trusting God is at my back, is omnipresent, and alleviates worries, anxiety, panic, and lets me know it will be okay.

Gods' support sustains and comforts rather than provides desired results

God is always present

God's support lightens the burden, but not necessarily the emotional fear

I get what I can from church even if it is not social connection, it is connection with a higher power;

Communion with God is a place to vent my questioning frustration.

God's support is internal, a spiritual uplifting, that brings comfort and peace like no one else can.

God's forgiving peace allows me to say I'm sorry when I've done something wrong/allows me to accepting myself as erroring human that can learn

* payers of my dad and directive advise of dad to turn it over to God helped

Ask others for assistance/support in prayer (mother, brother, church, SM)

Laying of hands (SM) heals

There is power in community (SM) prayer

* my family (ICU), dad's prayers and parent's advise to turn to God

* thoughts of the future still resound with doubt, distress, and fear and I have trouble turning it over to God even though he reassures me when I do.

* When I get tired of trying to make it own my own, I turn it over to God grace and it is sufficient to lead me through my inadequacies of mothering as I glorify God in my tribulations

* Over time I come to understand DS as intentional outcome of God's preordained plan and not my punishment, and I have improved as a mother over time through faith in God's directives

Block out Satan's voice & recognize God's voice and follow his directives;

* Dialogue with God = calming sense of direction, peace, life goes as it should/good,

* Holy spirit tells my mind (though direction, words, and dreams) what to do when I have no other way to know, guides me in the care of my son, guides my decision-making = calm, confidence,

* God's intervening guidance and wisdom had influenced my responses to life challenges by making me more thoughtful, insightful, more patient, open to listen and understand others, empathic, and forgiving,

* God's guidance through the Holy Spirit telling me how to care for my son's burns and recover from surgery

* God's intervention in my life to slow me down, give me time to prepare, and allow my son to become more independent

* God's guidance to the medical staff

"God and the Holy Spirit have advised, guided, and supported me as I...* treated by son's burned hand; * told me what to do when no one else would or could

* God is the guiding powerful healer behind the works of others (medical care staff, family support group) and through life events (ankle, cancer, DS), and people who enter our life at the right time.

Use spiritual stories to make sense of the senseless; Story of God's sacrifice of his son

Rel. Messages

Bible/Biblical stories is source of support

The Bible's scripture inform my prayers for wisdom, so I pray for wisdom, peace, guidance, and my wishes but also his plan understanding the two may not be the same.

God Guidance

I turned to God for answers and sometimes communion with him consoles me.

God's destiny creates a path/place for me and others putting us where we should be and makes me hear him.

When I feel contentment, I know God is guiding me.

God's spirit in my heart to help/support & guide me, make difficult choices (surgery)

God can deliver messages to us, and he forewarned Mary of her husband's death.

God's guidance in the selection of the right residence/city, day program, resources, and church home to serve Angel's needs

Holy Spirit speaks to me giving me God's guidance/enlightening me of my wrongful behaviors/decisions and directs me toward the path of rightness

I thank God daily for his support/guidance.

I turn things over to God in hard times, and he guides me.

Through God's silently whispered messages to my spirit I have a sense of peace that assures me God is guiding my decisions.

Rely on the Lord's/God's guiding presence in my life for internal support (not external)

Start my day with the Holy Spirit to avoid temptations/Satan/sin, and follow the right path.

Trusting God to bring the right people into our life (doctor/realtors)

God guides without request

God works in his own time. He is allowing us to work toward goals in the meantime.

God reveals himself to us in ways other than prayer (signs)

Religious songs are inspirational messages

PRACTICE – occasional daily readings

occasional use of Biblical or spiritual reading or daily readings;

Reading to gain enlightenment

Consider WWJD as a guide

FAITH: believe that God's hand will direct me to the information, people, and places when needed; higher power directs life; God inspires direction and redirection; trusting God to oversee daughter's care when I am not able or dead; thinks don't happen by coincidence but are God directed before me; having faith in God's directing-guidance mediates my fear in the present but not in the future; God's grace and salvation is open to everyone suggests inclusiveness; search for new ways for daughter to fit into church community

When I could no longer control life or great threats (daughter's illness) developed, I turned to God with greater direct intentionality.

* life is pre-ordained by God with purpose, kept me out of trouble, to have son with me for life companion,

* nothing is impossible with God

* God teaches and strengthens us and our faith through our tribulations

* God answers prayers his own way, not my way

Religious faith provides foundation for living

Divine purpose makes it bearable and even okay

Accepting God divined life purpose

God's unexplainable destiny/plan and DS has intention purpose must be positive/okay – if I make Godly decisions; you reap what you sow;

I have faith that life will be okay.

Strong faith that I could cope with future DS births

Trust in heart guidance for comfort

Presence of Lord assured me all would be okay

Belief/thanks that asking God's forgiveness/being forgiven will ease my path to heaven with fewer sins to atone for

Comforted by my trust that God loves us/my daughter and wants what is best for us/he has a plan; life is God-ordained

My daughter is an angel and her salvation is assured in heaven

Our lives and Mary's are ordained/scripted by God, yet he allows bad things to happen so we might learn.

Turing it over to God and having faith when I am not able to make it better

Faith in God

Baptism

Baptism provides secure assurance

Baptism provides connection to the divine

Baptism is inclusion in the divine

Guardian Angels

Guardian angels protect us from danger (wrecks)

We all have protective guardian angels.

Guardian angels will keep us sa

Appendix H
IRB Approval for Initial Exploratory Case Study

Beverly Jacobik (bjacobik)
on behalf of Institutional Review Board

Stephanie Gayle Gotay (sggotay);
Alison Anne Happel (aahappel)

Hello,

The University of Memphis Institutional Review Board, FWA00006815, has reviewed and approved your submission in accordance with all applicable statuses and regulations as well as ethical principles.

PI NAME: Stephanie Gotay
CO-PI:
PROJECT TITLE: The spiritual coping experience of a mother of a child with Down syndrome: A phenomenological case study
FACULTY ADVISOR NAME (if applicable): Alison Happel
IRB ID: #3427
APPROVAL DATE: 10/10/2014
EXPIRATION DATE: 10/10/2015
LEVEL OF REVIEW: Expedited
RISK LEVEL DETERMINATION: No more than minimal

Please Note: Modifications do not extend the expiration of the original approval

Approval of this project is given with the following obligations:

1. If this IRB approval has an expiration date, an approved renewal must be in effect to continue the project prior to that date. If approval is not obtained, the human consent form(s) and recruiting material(s) are no longer valid and any research activities involving human subjects must stop.

2. When the project is finished or terminated, a completion form must be completed and sent to the board.

3. No change may be made in the approved protocol without prior board approval, whether the approved protocol was reviewed at the Exempt, Exedited or Full Board level.

4. Exempt approval are considered to have no expiration date and no further review is necessary unless the protocol needs modification.

Approval of this project is given with the following special obligations:

Thank you,
James P. Whelan, Ph.D.
Institutional Review Board Chair
The University of Memphis.

Note: Review outcomes will be communicated to the email address on file. This email should be considered an official communication from the UM IRB. Consent Forms are no longer being stamped as well. Please contact the IRB at IRB@memphis.edu if a letter on IRB letterhead is required

Appendix I
IRB Approval for Current Study

Christopher Wayne Whitehead (cwhitehd)
on behalf of Institutional Review Board

Fri 5/8/2015, 3:05 PM
Stephanie Gayle Gotay (sggotay);
Daniel Charles Lustig (dlustig)

Hello,

The University of Memphis Institutional Review Board, FWA00006815, has reviewed and approved your submission in accordance with all applicable statuses and regulations as well as ethical principles.

PI NAME: Stephanie Gotay
CO-PI:
PROJECT TITLE: Mothers of Adult Children who have Down Syndrome: Understanding the Meaning of Religion and Spirituality in Perception, Hope, and Coping
FACULTY ADVISOR NAME (if applicable): Daniel Lustig
IRB ID: #3739
APPROVAL DATE: 05/08/2015
EXPIRATION DATE: 05/08/2016
LEVEL OF REVIEW: Expedited

Please Note: Modifications do not extend the expiration of the original approval

Approval of this project is given with the following obligations:

1. If this IRB approval has an expiration date, an approved renewal must be in effect to continue the project prior to that date. If approval is not obtained, the human consent form(s) and recruiting material(s) are no longer valid and any research activities involving human subjects must stop.

2. When the project is finished or terminated, a completion form must be completed and sent to the board.

3. No change may be made in the approved protocol without prior board approval, whether the approved protocol was reviewed at the Exempt, Exedited or Full Board level.

4. Exempt approval are considered to have no expiration date and no further review is necessary unless the protocol needs modification.

Approval of this project is given with the following special obligations:

Thank you,
James P. Whelan, Ph.D.
Institutional Review Board Chair
The University of Memphis.

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