

THE JOYFUL EXPERIENCES OF MOTHERS OF CHILDREN WITH
SPECIAL NEEDS:
AN AUTOETHNOGRAPHIC STUDY

A DISSERTATION
SUBMITTED TO THE GRADUATE SCHOOL
IN PARTIAL FULFILLMENT OF THE REQUIREMENTS
FOR THE DEGREE
DOCTOR OF EDUCATION

BY

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Dedication

I dedicate this dissertation to my very special and amazing boy, Will. You *are* my sunshine, my joymaker, my muse. You have taught Mommy the most important lesson of life—live your joy. You continue to prove your name because your will is the greatest I have ever known. I am so grateful that I was chosen and that God gave you to me.

Abstract

DISSERTATION PROJECT: The Joyful Experiences of Mothers of Children with Special Needs: An Autoethnographic Study

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The purpose of this study was to examine the joyful lived experiences of mothers of children with special needs (CSN). Mothers, who are most identified as the primary caregivers of children with special needs, are subject to marginalization because of the societal perspective that having a disability is wrong and that care giving for a child with a disability is dominated by challenge or burden. This study gave voice to mothers of children with special needs so the joys of being a mother of a CSN can be better known and understood by medical, educational, and social service practitioners. The findings resulted in a reflective transformative adult learning model that practitioners can integrate into their discourse with mothers of a CSN.

The qualitative research method *autoethnography* was used to reveal the mothers’ joyful experiences. Both internal and external data were collected from five mothers who were purposively sampled from a support group that is located in suburban Indianapolis, Indiana and from the researcher, also a mother to a child with special needs. External data in the form of transcribed interviews including personal writings of the mothers and

internal data in the form of reflexive researcher field notes and personal writings were subject to analysis using the constant comparison method.

The findings revealed that mothers of a CSN do experience challenges, but they have learned to find joy through the unique strengths of themselves and their children. They have discovered a purpose and have been transformed by their children. As a result of that transformation, they recognize that their children's joy is their joy and that joy is defined as the "simple things" they and their children engage in. These simple and unique joys, however, require planning and collaboration. The researcher called those practitioners in the medical, educational, and social service communities to use the reflective practice of writing as a way to better understand how important joy is for mothers of a CSN so practitioners can transform their treatments, education, and services to include joy.

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CHAPTER ONE

INTRODUCTION

Introduction to Study

According to the United Census Bureau's most recent report, of the 291.1 million people in the population, "54.4 million or 18.7 percent had some level of disability" (2008, p. 3). More than 1 in 6 of Americans living in this country have a disability. Of that 18.7 percent living with a disability, "35 percent (12 percent) had a severe disability" (p. 3). An increase in those living with a disability was not only recorded in senior populations but also in children under age 15. For children under the age 5, parents reported that, "228,000 children under 3 years old (1.9 percent) with a disability and 475,000 children 3 to 5 years old (3.8 percent) with a disability" (p. 9). Of the 36.4 million reported children between the ages of 6 to 14 years old, "4.7 million (12.8 percent) had a disability and 1.6 million (4.4 percent) had a severe disability" (p.9).

Often individuals with a disability are referred to as persons with *special needs*. The term *special needs* is used in clinical diagnostic and functional development to describe individuals who require assistance for disabilities that may be medical, mental, or psychological. For example, individuals with visual disabilities, physical disabilities, or cognitive disabilities are included as those individuals with special needs. Individuals with disabilities are identified as *individuals with special needs* as it refers to any

accommodations and modifications those individuals might require in functioning with their disability (American Psychiatric Association, 2000). A report compiled by the Centers for Disease Control (CDC) supported the Census Bureau's statistics clarifying that "an estimated 48.9 million persons or 19.4% of the total U.S. population" had a disability (1998, para. 4). Of those 48.9 million, the CDC (1998) noted that 3.8 million of those persons were under seventeen years old. The number of individuals with disabilities is "disproportionately higher among children because disabilities with onset during childhood account for approximately one third of the years of disability" (para. 6). The CDC calculates the years of disability by multiplying the number of persons with new cases by the expected lifespan of each person with a disability per year. Because of a federally mandated birth to 3 intervention program and better pediatric home health care and therapy services, fewer children are being institutionalized as a result of their special need/s and therefore remain in the home (LaPlante, 1998; Patching & Watson, 1993).

The federally mandated birth to age 3 intervention program provides every child identified with special needs in every state in the United States both interventional medical and educational services and can successfully project future services needed. Because of this federal requirement, education of those in the medical field to recognize and diagnose those disabilities has improved and more children in the United States are being identified as having special needs. The increase can also be attributed to medical advances that are being made in all areas of the medical sciences including the medical care of children born prematurely or children born with chronic or genetic conditions (American Academy of Pediatrics, 2007).

There are more children being born and diagnosed with disabilities; there are

more children being identified as requiring special needs; and there are more interventions occurring in the medical, social service, and educational communities (American Academy of Pediatrics, 2007; LaPlante, 1998; Patching & Watson, 1993; US Census Bureau, 2008). Diagnosing and providing services is only half of the picture. A child with special needs, like any child, requires a caregiver. The studies and literature on caregivers of children with special needs are few and mostly quantitative. From this limited work, the research supports that more mothers than fathers of children with special needs remain at home to care for the child and are identified as the primary caregivers of children with special needs. Within that small pool of research on mothers of children with special needs, there are two primary bodies of research. One body focuses on the psychological stress and coping mechanisms of mothers who have children with special needs. (Dellve, Samuelsson, Taliburn, Fasth, & Hallberg, 2006; Donnenberg & Baker, 1993; Dyson, 1991; Hastig, Allen, McDermott & Still, 2002; Kiekhefer, Trahms, Churchhill, & Simpson, 2009; Olshanky, 1962; Olsson & Hwang, 2001; Phetrasuwan & Miles, 2008; Redmond & Richardson, 2003; and Robinson, 2008; and Tway, Connolly, & Novak, 2007). The other body presents the mother as stigmatized because of her role as a mother to a child with special needs (Craig & Scambler, 2005; Farrugia 2009; Gray, 2002; Green, 2003a, 2003b, Davis, Karshmer, Marsh, & Straight 2005; Perkins, Holburn, Deaux, Flory, Vietze, 2002; Ryan, 2005; Wornoski, 2008). Both bodies of research acknowledge that there are more challenges for mothers of children with special needs, that the stress levels for these mothers is higher, that the stigma is greater, and that the need for coping strategies and support is critical for mothers as they are most often the parent who remains home to take care of their child with special needs.

These disadvantages outlined by the literature coupled with secondary findings in much of the literature about the “domestic role” of the mothers of special needs children are concerning. Because so many mothers then have to remain at home to care for their children, those mothers are deprived of the “gratification that comes with being employed” (Breslau, Staruch & Mortimer, 1982, pp. 682-683). While social isolation for any caregiver staying at home to raise a child may be typical, this study noted that it is worse for mothers of children with special needs. Because the level of care required for children with special needs may be greater and occur for a longer time—associated more with the kinds of employment patterns mothers of infants or very young children face—these mothers are more often excluded from the workforce or have unsatisfactory employment patterns. They work only part-time or are unemployed because of the limitations their children present on their ability to work. This exclusion can lead to even greater social isolation (Lewis, Kagan, Heaton, & Cranshaw, 1999; Kuhltau, Kahn, Hill, Gnanasekaran, & Ettner, 2010; Ryan & Runswick-Cole, 2008). In addition, this further domesticated role can lead to increased stress, stigma, and the use of coping mechanisms required for them not only as mothers to a child with special needs, but also as women (Breslau, Staruch, & Mortimer, 1982). In Lewis, Kagan, Heaton, and Cranshaw’s (1999) study about the economic and psychological benefits derived from employment, a predominant theme was that lack of employment led to social isolation and stigma for the mother of a child with special needs.

Much then is known about diagnosing, intervening, and treating children with special needs, as well as the challenging lives of the mothers of these children. But what is not known is the actual lived experiences of these mothers whose responsibilities,

again according to the dominant bodies of research, include finding ways to “cope” to overcome additional stress and stigma so they can continue to care for their children with special needs.

Problem

The number of children being diagnosed as having special needs is increasing, but the research about the lives of these mothers who are the primary caregivers of children with special needs is deficient. In the two primary bodies of research regarding mothers of children with special needs, they recognize and suggest repeatedly that the mother’s actual lives should be researched. For example, in findings that emerged from a key quantitative study, Hentinen and Knygas (1998) noted several reasons to understand and support mothers as primary caregivers including mothers being at home more with the child and being responsible primarily for the constant skilled medical, educational, and intervention care the child requires. They cautioned and revealed that parents or caregivers who are adapting poorly to their role typically suffer from a lack of “emotional and instrumental support” (p. 323). They recommended further research to study the needs of the caregivers so those in the medical field can cope, adapt, and intervene in the lives of the caregivers—not just the children—if necessary.

The theme that emerged from these dominant bodies of research is that the lived experience of a mother of a child with special needs is one of stress, stigma, needs being unmet, and coping. It reflected a bleak view for those in the educational, medical and social service world who already view disability or having a child with special needs as a deficit (Behr & Murphy, Summers, 1992; Dowling, Nicoll, & Thomas, 2004; Green, 2003, 2007; Hastings, Allen, McDermott, & Still, 2002; Lassetter, Mandelco, & Roper,

2007; Mandelso, Olsen, Dyches, & Marshall, 2003; Rocque, 2010; Patching & Watson, 1993; Stainton & Besser 1998; Summers, Behr, Turnball, 1989). These dominant bodies of research on mothers of children with special needs assume and place individual mothers of special needs children into one group, painting them into the same corner, and revealing that the predominant and accepted view is one of suffering. The researchers or “intellectuals” who created this deficit view can, according to philosopher Gramsci (1929), dominate our understanding of the mothers and add to the social hegemony of mothers of children with special needs. This study seeks to break that hegemony and reveal a different perspective of mothers of children with special needs.

For the purposes of this study, the definition of *special needs* earlier outlined by the American Psychiatric Association will be used to define those children who are ages birth to 18 and who require assistance for disabilities that may be medical, mental, or psychological. Mothers of the children with special needs will be identified as the primary caregiver. From this point on, the following terms will be used to denote a mother of a child with special needs as a “mother of a CSN” and a child with special needs as a “CSN” (Robinson, 2008). For comparison, the term *neurotypical* will be used to identify those children who are typically developing and who have no special needs and will from this point forward be referred to as a “NT” child (Pappas, J. MD., personal communication, June 15, 2003).

Because mothers are more often identified as the primary caregiver, I chose to focus my study on women. As suggested earlier, little is known about the individual mother and her daily lived experiences and what is known represents the mothers in only a “challenging” light. Because mothers are providing and advocating the majority of the

services for their children on many fronts in the medical community, the educational community, and the social service community, it is imperative that we have a better understanding of the mothers' lives. In a study conducted by instructors in a pediatric residency program where the residents were required to go into the homes of families of children with special needs for an hour to observe and talk with the families, the residents overwhelmingly described the visit as the most "powerful educational experience" they had as medical students, and that it "changed their insight about special needs children" (Sharma, Lalinde, & Brosco, 2006, p. 185 & p. 188). Individuals in the medical, educational, and social service institutions who educate and program plan for mothers of children with special needs would benefit in understanding a diverse view of these mothers. While mothers of children with special needs do suffer and live with well-documented stress and stigma, and according to the literature, they adapt and cope, how do the mothers experience those adaptations and coping? Considering all of the challenges that must be adapted to and coped with, do mothers of children with special needs experience any other emotions that are not challenging—for example, joy? Does joy play a role in experiencing their CSN? And if so, what are the joyful experiences of those mothers with a CSN?

Discovery of Problem

My original research interest into this area began with a journal review of a study conducted by a group of nurses to identify parent needs of children with Cerebral Palsy and their purpose was to evaluate the reliability of the quantitative Family Needs Assessment Tool (FNAT). According to the nurse researchers, Buran, Sawin, Grayson, and Criss (2009), most healthcare needs assessments do not reflect the needs the family.

Mothers completed 75% of the surveys in that study. The results of the FNAT mostly identified many challenges for the caregivers, including accessing information and service and obstacles to treatment. The argument of the study was that being aware of parental perceptions was critical in understanding the satisfaction of services provided and in considering program planning in any kind of clinical setting that specializes in disability specific care.

After reading and reviewing their study, I found myself asking what the challenging experiences were of the mothers who answered the survey. As a mother to a CSN, I wanted to know more about their specific individual challenges. The quantitative research survey tool used did not and could not answer those questions with numerical data. Wanting to know more about the mother's individual stories, which I did not hear in the survey results but I knew had shaped those mother's answers, prompted me into a qualitative research course where I was able to conduct two focus groups of mothers of children with special needs and reveal those challenges in more detail. One of the themes that resonated and something the mothers qualified their statements of challenges thought with how much joy their child gave them. That journey from that one piece of literature to a formal study to this dissertation proposal has led me to my final query, what are the joyful experiences of being a mother to a child with special needs?

Statement of Purpose

The purpose of this study was to examine the joyful lived experiences of some mothers of children with special needs to better understand the joy they experience in their role as a mother of a CSN. This study will give a voice to mothers of children with

special needs so the joys of being a mother of a CSN can be better known and understood.

Research Questions

- How do the joyful experiences add to the complexity of the emotions of being a mother to a CSN?
- How do mothers of a CSN define joy?
- What are the joyful experiences of a mother of a CSN?

Subjectivity Statement

Mothers of children with special needs can be identified as a marginalized culture because of the stigma of having a special needs child, gender shifting, and lack of inclusion. Having a CSN is seen as operating from a point of deficit. Consider the negative connotations of the language surrounding the disability culture. We ask what is “wrong” with a child with special needs. When a person with special needs uses a wheelchair, we say they are “confined” to a wheelchair. Consider the term *disability*. The prefix *dis* means the *opposite of*. So to be *disabled*, means to be the opposite of being *abled*. In a recent study conducted by Sunderland and Catalano (2009) on the missing discourses of joy and happiness in disability, they initially explored official government publications and interview transcripts from academic qualitative studies. The goal was to “compare and contrast discourses of disability that are presented in official texts” (p. 705) using a software system called Wordsmith to generate the words used by individuals versus those presented. The individual interview transcripts overwhelmingly generated more terms associated with joy and happiness, while the official government publications generated more negative terms associated with challenge and coping.

Consider that expecting mothers excitedly anticipate the delivery of their healthy neurotypical or NT child. A child with special needs is not anticipated or welcomed but something feared and attributable to something that has gone “wrong” with the pregnancy or delivery. Vohs’ (1993) summed up reactions of the community in response to her daughter’s diagnosis of Cerebral Palsy, “To be disabled or to have a child with a disability is a tragedy” (p. 52). Caregivers and families of special needs children are discussed as being stigmatized individuals whose best hope is to find ways to adapt and cope. Vohs (1993) explained that:

Coping can be empowering or disempowering. If the source of the problem is that the person is defective, coping, even at its best, can only convey a sense of putting up with a situation that is inherently bad and about which nothing really can be done. (p. 60)

Even a seemingly positive term, like *hope*, connotes that there is something negative or wrong in which a person needs or should seek this positive perceptive idea of *hope*. “If disability is an ordinary part of life, there is no longer a need to cope with the obvious and inherent tragedy of disability” (p. 60). Language is power and Vohs (1993) supported that a language change can mean a shift in power. She suggested that those who supported families of children with special needs “learn to speak differently” (p. 63). She continued by suggesting that changing our language is a critical tool in helping to “empower and ennoble” the families and can lead to a social institutional changes in how we perceive those persons who have special needs and for those who care for individuals with special needs (p. 65).

Like Vohs' (1993) who wrote as a mother of a child with special needs, I chose this topic for my dissertation for personal reasons. I too am a mother of a CSN. My son, Will, has Cerebral Palsy and autistic tendencies. I have always wanted to share my story—to tell the world about how hard *and* how wonderful it is having a child with special needs. My husband and I dreamed of a child, yet we grieved, not celebrated, his death, which came before his birth. We suffered along with him as he struggled to survive. When we were warned to not name him because he was not expected to live, we named him “Will” for will to live. Will is now living beyond expectation, but like his birth, is still struggling to survive. Because of his Cerebral Palsy, he remains non-ambulatory, non-verbal, and has a feeding tube, which all present significant challenges for him and for me, but he attends school, plays, laughs, and loves just like any other neurotypical seven-year old boy.

The dominant literature presented regarding mothers of children with special needs is too simple and in reading it, I find myself questioning methods, findings, and even purpose. This study will provide an authentic and complex perspective. This study will give voice to not only my story but to other mothers of children with special needs. My goal in this study is for those who read it to gain meaning from a larger social context and enhance their sense of common humanity and community which will help them to better understand not only these mother's joyful experiences but also their own perceptions, assumptions, and responses to the joyful experiences revealed in the study.

I want people to see, hear, and feel how mothers of children with special needs live with challenges that are, yes, lived painfully and differently than what most people outside of our world understand, but also generously, fully, and joyfully. While our lives

may be unique, they become typical for us and in our “typical,” we experience joy. In a study about how mothers mediate for their children with special needs, the author, Rocque (2010), noted that we have to directly challenge and resist the stigma of the “hegemonic norms of embodiment that produce the lack of understanding and exclusion of those with embodied differences” (p. 486). The joy of mothers of children with special needs is worthy of understanding, which can only happen by listening and learning. I believe in the power of story, as story is indigenous to every culture in every historical time. Story transforms. My hope is that these mothers’ stories and mine will present a veritable view and can become a transformative agent for those who know, love, serve, educate, or treat mothers of a CSN.

According to Patching and Watson (1993), the research that has been conducted in the culture of disability has assumed that there is a “set social reality” that is depicted through “researcher-developed questionnaires, surveys, structured interviews and observation schedules; all of which reflect the values, beliefs, and biases implicit in the functionalist paradigm” (p. 116). I want those in the medical community who educate mothers in clinics, individual doctor’s appointments, and at conferences to assume more than stigma and stress when constructing the narrative they deliver. Patching and Watson warned that mothers of children with special needs are “at risk of social processing and control since they become targets for treatment and are victims of the medical model, which emphasizes diagnosis, classification, labeling, placement, and prescription” (p. 116).

I would like for those who work in the school system and sit across the table from mothers at the annual Individual Education Plan (IEP) case conference to reconstruct

their meetings so mothers can highlight the joys as well as the challenges of their child's home and school environments. I hope that social service agencies who provide services such as respite, home health care, and community rehabilitation to take joy into account when program planning for those mothers and their children.

Limitations

Some readers may view my role as both researcher and participant as a limitation, but I view it as strength because I am in a unique position to give voice to this marginalized culture. Coloma (2008) explained that “The desire to speak-for-oneself is especially important for marginalized individuals and communities that have been imagined and represented by those who occupy dominant positions of power” (p. 11). For example, I am a mother to a child with special needs; therefore, I know well and can speak with the culture of the women who will be the participants in my study. Behar (1996) in the seminal text *The Vulnerable Observer: Anthropology that Breaks Your Heart*, mocked researchers who say they are a participant observer but as soon as the grant money runs out or the dissertation is complete or the project is over, the researcher moves on to the next culture to embrace. For me, this serves as a rationale for my insider and full membership position. I cannot and will not leave my culture because I will always be a mother to a child with special needs.

In any qualitative research, the researcher must practice reflexivity and analyze that reflexivity throughout all stages of research. In reviewing my years of writing and work in education, I clearly saw that being a mother to a child with special needs was reflected in everything I had written and practiced professionally since Will was born—it pervaded my thinking, writing, and even talk. I could not stop myself from entering that

world even when I tried to remain in what I thought was my “scholar” culture. I had always acknowledged that my son, Will, had changed my personal life. But, I had never considered how it might influence my academic life. In researching my own culture of mothers of children with special needs, I realized that in all of this research about mothers of children with special needs, the voice of the insider and individual mother was missing. Like writer and educator, bell hooks (2003), while researching this topic, I felt like an academic “working within institutional structures that are designed to contain ideas, to repress imaginations, and indoctrinate the mind” (p. 186). Feminist researcher Kanuha (2000) aided my reconciliation reminding me that, “as a student and scholar, I sought a theoretical and conceptual framework for comprehending what seemed at least to be some very commonplace but rarely elucidated phenomena” (p. 441).

What led to me ultimately choosing the position of insider researcher can best be described by Burnier (2006) as “a sense of displacement” (p. 412). Researchers in social science research find traditional outside research to be “abstract, detached” (p. 412). “Where is the lived experience of individuals in the research? Where is the context, place, situation? Where are the actual voices of the researcher and the researched?” (p. 412). In reading the literature on mothers of children with special needs, I found myself asking the same questions. Where is the voice of the mother, the primary caregiver? Where is the voice of the researcher who has lived it? Nonscholarly work in the form of family genre reveals the voice of the mother. Scholarly, academic work predominantly reveals the voice of detached researchers. I understand now that I can do both and provide an authentic, yet analytical voice for the culture of these mothers. By remaining an insider in my research, I can bridge “the gap between our narrow academic world and our wide

cultural experiences” (Tedlock, 1991, p. 80) and close “the illusionary gap between researcher and researched and between the knower and what is known” (Etherington, 2004, p. 32).

Because I am an academic in education, I believe it is imperative that social science and educational research speak to those individuals in and outside of academia. Because I have one foot in both worlds, I can do that. My “insider voice,” as Reed-Danahay (1997) illustrated, is “more true” (p. 3) than a voice from the outside. In conducting insider research, I can confront and overcome those ethical considerations of disclosure to my participants and reveal incidental data through strategic positioning. If an insider researcher remains too scholarly in tone, the reflexive advantage gained through the incidental data is lost and can alienate the participant. However, if the researcher does not disclose the research project fully and relies on incidental conversations, then the evocative voice of the researcher might drown out the data.

Because I am a full member of the culture I am studying, I speak the same language and share many of the same experiences as the mothers. This insider advantage allows me greater control over the research questions and the ability to practice what anthropologist Clifford Geertz (1973) referred to as “thick description,” which is where the ethnographer does not just observe, record, and analyze a culture but also interprets the signs of the culture which allow the researcher to gain all of the meaning of that culture. (p. 3). Thick description, according to Denzin (1989), creates verisimilitude and maintains rigor by providing context, stating the organizing “intentions and meanings, tracing the evolutions and developments, and presenting a text that can be interpreted. “Thin description,” on the other hand, “simply reports facts” and is independent of

intentions or circumstances” (p. 33). The mothers I interviewed know me and through my data collection and analysis process, they know they can trust that I will not misinterpret, misconstrue, or misrepresent the data they reveal.

Definitions and Terms (Operationally Defined)

The following terminology will be used throughout this study:

Special Needs- The term “special needs” is a clinical term to describe individuals who require assistance for disabilities that may be medical, mental, or psychological (American Psychiatric Association, 2000). For example individuals with visual disabilities, physical disabilities, or cognitive disabilities are included as those individuals with disabilities or individuals with special needs.

CSN- A Child with Special Needs refers to any child ranging in age from 0-18 who has a disability and who has special needs (Robinson, 2008).

NT- Refers to any neurotypical developing child ranging in age from 0-18 who has no disability and requires no special needs (Pappas, J. MD., personal communication, June 15, 2003).

Marginalization-Refers to any groups of people who are considered part of an emerging or growing underclass of individuals who suffer deprivation and are isolated and expelled from a typical social life. (McLaren, 2003).

Mother of a CSN- A mother of a Child with Special Needs.

These terms will allow the reader of this dissertation to understand and use the cultural vocabulary of a mother living with a CSN and the medical terminology used by academics who write and research on the special needs community.

CHAPTER TWO

LITERATURE REVIEW

Summary of Study

This dissertation's purpose was to examine the joyful experiences of mothers of children with special needs. Problems identified were that more children are living and living at home with a disability and have special needs. Mothers of a CSN or a child with special needs were more often identified as the primary caregivers of their children with a disability. According to the literature, mothers experienced significant challenges, which led to stress and stigma and require coping. Mothers of a CSN, like children with special needs, were often viewed as a deficit and are marginalized. The language used to describe these women and their children illustrates that deficit and marginalization. This dissertation sought to find out if having a CSN means that mothers of CSN can experience joy and what that joy is.

Review of Literature

The literature on the topic of mothers and their special needs children is not extensive, is mostly quantitative, and has been conducted primarily by researchers in the medical community. What research has been conducted focuses on the psycho and social deficits that make up of the mother instead of understanding how to access, serve, and educate the needs of those mothers of children with special needs. As the literature review that follows reveals, mothers are identified as the primary caregivers and more information about how those mothers experience their life with their CSN is needed, and

those in the medical, educational, and social service communities do have an interest in educating and supporting mothers of a CSN.

Mother of a CSN as Primary Caregiver

In a study comparing 132 caregivers who were functioning “okay” versus those who needed more help, every single caregiver included in the study was a woman. This was not by design, but because no men responded to participating in the study (Leonard, Johnson, & Brust, 1993). A sample quantitative study that measured parent-child shared management of chronic illness included 129 participants and 85% of those who participated in the study were identified as mothers of those children (Kieckhefer, Trahms, Churchill & Simpson, 2009). Only 13% of the 189 parents surveyed to identify adaptive factors of parents of a chronically ill child were fathers (Henteinen & Kyngas, 1998).

While these studies were conducted in the United States, mothers as the primary caregiver were actually identified even across international lines. In a study conducted by Roll-Petersson (2001) in Europe, of the 46 parents of 38 children interviewed, only mothers participated in 29 interviews and both parents participated in 8 interviews and only one father participated by himself in one interview. In the findings, the researcher speculated that because mothers of children with disabilities are often less active in the workforce than other mothers with children the same age who are typically developing, they were more available to be studied. In Schwartz and Hadar’s (2007) study conducted in Israel on parents caring for children with physical disabilities, they noted that 85% of the participants were mothers.

In Rocque's (2010) very recent study on mothers of children with autism spectrum disorders functioning as mediators for their children, the researcher called to attention the noticeable "imbalance" (p. 488) of mothers versus fathers in the study as only two men responded to an invitation to participate. Finally in a comprehensive meta-analysis of caregivers of children with special needs, author Beresford (1994), noted that most of the research has supported mothers and not fathers because "in the majority cases, mothers are responsible for the child's care" (p. 183).

Mother of a CSN: Stress and Coping

After reviewing the literature verifying that mothers were the primary caregiver, I then wanted to know what these mothers who were providing the data in the research were sharing with those in the medical, school, and social service communities about their lives as mothers of children with special needs. What did the mothers communicate about their experiences as a mother of a CSN? And in my personal experience as a mother to a child with special needs and the facilitator of a writing support group of mothers of children with special needs, did I agree or did I see gaps, stories untold?

The primary body of research regarding mothers of a CSN focuses on the stress and coping mechanisms of the mother of a CSN. A quantitative study conducted by Olsson and Hwang (2001) with both mothers and fathers of children with intellectual disabilities found that mothers experience more distress than the fathers because the mothers "take on a larger part of the extra care and practical work that the child with disabilities requires" (p. 540). In a study measuring parent-child shared management of chronic illness where 85% of the participants were mothers, the findings illustrated that the greater the demands of the child's care, the more stress and coping required by the

parent (Kieckhefer, Trahms, Churchill & Simpson, 2009). The authors encouraged additional investigation of parent perception to better understand the factors contributing to the parent's stress and experience. The study identified that there is stress and that coping skills are necessary for dealing with that stress. Unfortunately, the researchers did not reveal what those necessary coping skills are, only the challenge of stress.

In a study designed to measure the coping strategies used by both mothers and fathers of children with autism, Tway, Connolly, and Novak (2007) discovered that parents of children with special needs use coping strategies to better “tolerate or minimize stressful events” (p. 253). After analyzing the data, they discovered that fathers scored higher than mothers, illustrating the father's ability to cope with the demands of their child with special needs better than the mothers of the same children with special needs. It is important to note, however, that the study did not discuss how much time each parent spent everyday caregiving for the child. But, the researchers did note that the level of resources known to be available for a CSN were proportionate to the mother's intellectual ability, skill level, health, and personality. So the more personal, economic, and educational resources available to the mother, the less stress for both mother and father which illustrates an important rationale for understanding the needs of the individual mother as primary caregiver. They recommend that those who are working with the families of children with special needs “listen to the parent and acknowledge their concerns” (p. 258).

An intervention study exploring the stress and well-being of parents of children with rare diseases found higher stress and emotional and physical strain among mothers as compared to fathers (Dellve, Samuelson, Taliborn, Faseth, & Hallberg, 2006). The

researchers warned, “especially mothers run an increased risk of poor health and lack of well-being” (p. 393). A limitation that emerged from the study is that “little is known about family and life-consequences” in families with special needs children and that this topic is worthy of exploring in more detail (p. 393).

In Redmond and Richardson’s (2003) study exploring the service needs of mothers of children with severe medical special needs, they explained that traditionally there has been less emphasis on what these mothers themselves suggest would be helpful for them in the care of their child and how well they feel that the services presently being offered to them to meet their needs. (p. 206)

The mothers in that study revealed the following self-perceptions as dictating their daily lives, “concentrating, sleeping, feeling useful, feeling stressed, being able to function and participate in daily activities, and feeling happy” (p. 208). Because this study was limited to a survey and included only a small sample size, the findings revealed that further research is warranted to give “legitimization of the mothers’ own perspectives” (p. 217).

In another current study conducted by Robinson (2008) where families of children on the autism spectrum were compared, a significant finding was that the parent perception of need was strongly correlated to the parent’s perception of stress. Those parents who had no outlet for their stress such as respite care for their child, therapy for themselves, or other forms of support such as a support group were more stressed than those with those outlets. The findings recommend further research to be conducted with individual caregivers to better understand their unmet needs so information and resources can be better prepared and provided for those caregivers.

In a different but also recent study evaluating the parent stress in mothers of children with autism spectrum disorders, Phetrasuwan and Miles (2008) rationalized that successful interventions for a child can only happen if the needs of parents are understood because “less attention has focused on the needs of parents” (p. 158). As well, this same study notes that equal to the stress the mother of a CSN feels, there are also feelings of positive growth and greater meaning and those stories are often not understood or revealed, yet the study never revealed those positive growths. In their conclusion, the authors recommend that future studies “should focus on the context of the lives of mothers” (p.163).

Mother of a CSN as Member of a Marginalized Culture

As shared in the operational definitions, Maclaren (2004) defined marginalization as any group of people who are considered part of an emerging or growing underclass of individuals who suffer deprivation and are isolated and expelled from a typical social life. Tucker (1990) maintained that marginalization is a “complex and disputatious process by means of which certain people and ideas are privileged over others at any given time” (p. 7). hooks (1990b) reiterated that those who are part of a marginalized group live in a space of marginalization sometimes with and sometimes separate from their oppressors where “sites of repression” and also “sites of resistance” can occur (p. 342). Finally, Lorde (1990) argued that marginalization is more than “dominant/subordinate, good/bad, up/down, superior/inferior” (p. 281). It is a complex process in which some group is made to occupy an “inferior” or “dehumanized” space (p. 281).

Ryan and Runswick-Cole (2008) maintained that “mothers of disabled children have occupied a complex, contradictory and marginal position within disability studies

and the disabled people's movement" (p. 199). For women, according to Lorde (1999) marginalization is *typically* defined only in terms of differences in "race, sexual preference, class, and age" (p. 282). However, it has been well-established in the research that mothers of children with special needs face stigmatization which contributes to the marginalization of the mothers as a cultural group. In Rocque's (2010) very recent research of mothers of children with autism spectrum disorder (ASD) acting in the role of mediators, he defined the "unfamiliar" as those who do not understand the mother's child and who have to be informed and taught not only about the child but the special need the child has. This role of constant mediation with "unfamiliar" creates a "social chasm" not only between the children and the "unfamiliar," but also between the mother and the "unfamiliar" (p.486). As well, he shared that the mothers frequently express that the only way anyone can really understand their child and his or her ASD is to immerse themselves into that child's world which is of course impossible. This isolation of being immersed in a world that the "unfamiliar" do not understand forces mothers of children with special needs to live in the margins.

In Wnorski's (2008) study of the stigma of mothers of children with special needs, she warned that "being an individual with a stigmatized identity does not come without its costs. There can be many cognitive, affective, and behavioral implications" (p. 7). Mothers of children with special needs are at risk for exclusion and "feelings of inferiority" (p. 8). Two dominant themes emerged from Wnorski's study, both fraught with challenges. Every mother in the study expressed more "negative" stigmatic experiences than positive ones, including "rude comments and harsh treatment from strangers" (p.19). As well, each mother expressed "feelings of personal isolation" and

those feelings of isolation in addition to “the socially imposed feelings of guilt” that mothers of special needs children often feel again forces mothers to feel stigmatized and marginalized (p.19).

A hypothesis proven to be true from Green’s (2003b) study on the stigma of families of children with special needs revealed that “mothers who feel that individuals with disabilities are devalued and discriminated against by others in the community are more likely to feel embarrassed, guilty, ashamed, resentful, worried, trapped and/or emotionally upset by the fact that their children have disabilities” (p. 1365). Gray (2002) clarified that families of children with special needs experience what is referred to in Goffman’s (1963) seminal text on stigma as *courtesy stigma*. Goffman (1963) explained that courtesy stigma happens to the “individual who is related through the social structure to a stigmatized individual” (p. 30). Courtesy stigma, according to Gray (2002), is the “stigma of affiliation that applies to people who associate with stigmatized groups rather than through any quality of their own” (p. 735). Ryan and Runswick-Cole (2008) reiterated this concept by noting “we argue that the mothers of disabled children are more than allies to their disabled children, as they experience directly and by proxy many of the discriminatory practices and attitudes their disabled children face” (p. 202).

hooks (1990) explained that “to be in the margin is to be part of the whole but outside the main body” (p. 341). Consider a single sheet of composition lined notebook paper where the body of the main text is always written after the red margin line. No one except for perhaps a teacher providing feedback would dare write in the margin. When we write on lined composition paper, we remain in the center, never starting or crossing that red line. Anyone who wrote outside the margins was breaking the rules. hooks

explained that in her experience growing up as an African American girl in a small Appalachian Kentucky community, the railroad tracks were the “reminder of our marginality” (p. 341). And while she could enter that world by crossing the literal and proverbial tracks, she could not live there because, “We had always to return to the margin” (p. 341). This crossing though allowed her perspective, “We looked both from the outside in and from the inside out” and “we focused our attention on the center as well as the margin” (p. 341). This attention to the larger more complex view “provided us an oppositional world view—a mode of seeing unknown to most of our oppressors that sustained us, aided us in our struggle to transcend poverty and despair, strengthened our sense of self and solidarity” (p. 341). hooks explained that this position of marginality then presents itself as not a “site of deprivation,” but a space of “radical possibility” (p. 341.).

Perhaps then those who live and write in the margins have the opportunity to break the hegemony of marginality and see instead their position as a “site of resistance” (hooks, 1990, p. 341). During my first year of teaching, I had a 12th grade student in Composition who was considered at-risk because of his poor performance in his academic subjects. He filled his lined paper with words and images when he wrote. I used to remind him to not write in the margin, that space beyond the red line. He used to tell me that he did not see that line, he only saw the white page waiting to be filled. As a rookie teacher, I did not understand that then, but I do now.

Long-time and well-known disability researcher, Tom Couser (2006) explained that for too long, those living and functioning in the disabled community have been marginalized and consequently isolated and subjected to well-meaning but often missing

the mark medical experts and nonprofit organizations. Hammel et al. (2008) agreed noting that even the label of being disabled which is “created and institutionalized by public health, medical, rehabilitation and other professionals” can “perpetuate disability ideologies related to deficit and dysfunction, and further promote professional dominance” (p. 1446). Couser recommended that “disability communities are ripe for ethnography investigation” (p.123). The mothers of children with special needs bring to their new identity as special needs mothers, their own diverse background. That diversity and current identification and the benefit of being marginalized are valuable and worthy of understanding and studying.

Mothers of a CSN and Joy: Impetus for Research

Stothers (1995), an adult advocate living with special needs’ wrote an article titled, “Maybe it’s time for ‘The Joy of Disability’” (p. 50). I agree. And maybe it is also time for the joy of the mothers who care for children with special needs. Accepting the paradigm that mothers of special needs children are challenged and marginalized leaves little room for any other understanding that the actual lived experience of the mothers is—as it is with all human beings—a much more complex socio-cultural process than it appears. Researchers Patching and Watson (1993), who included parents in the negotiation and construction of the qualitative tool used to measure how parents of children with special needs construct their reality, explained that their reason for including parents in that dialogue and process was to better understand those “emergent” or experiences not understood or known by those who operate only under a limited “network of assumptions” (p. 117). For example, Hastings, Allen, McDermott, and Still (2002) explained that in terms of families of children with special needs, “Studies are not

typically designed explicitly to address positive perceptions, but are a part of the family stress literature” (p. 269). Again, Rocque (2010) informed us in his findings that mothers mediate, interpret, and translate their children with special needs for the “unfamiliar,” and that process is part of how mothers identify their self-hood. And while his findings focused on only those challenging behaviors and translations those mothers encountered with the “unfamiliar,” (p. 495), I ask, is not joy also a possible interpretation and identity for these mothers? Wnorski (2008) in her research of mothers of children with special needs insisted that we must “change or eliminate the assumptions” we hold about mothers (p. 23).

There are very few studies that provide information on the positive impacts of having a child with special needs, and in my research; I could not find a single study that talked simply about the joys of having a child with special needs. Hasting and Taunt (2002) revealed only five studies published in 2002 on the positives of having a child with disabilities. They questioned the influx of literature regarding the challenges. “Although many researchers have found that families of children with disabilities report more stress than do other families, there is no clear evidence that they also report fewer positive feelings or perceptions” (p. 121). Problematic for me is this language or idea of “positive impact” remains ambiguous though and supports the generally accepted view that in order for there to have been a “positive impact,” children with special needs must also have negatively impacted their mothers.

In discussing the perception service providers have regarding families caring for a child with special needs, a study conducted by Summers, Behr, and Turnball (1998) surmised that those providers “cast doubt” that families can cope with the “emotional

implications or daily demands that are placed upon them as a consequence of the disability” (p. 27). Families who have children with special needs are seldom perceived or even presented to the medical, educational, or social service community as positively coping or adapting with having a CSN. In a seminal work conducted in the 1960’s, Olshanky (1962) revealed to us that society thinks of caregivers of children with special needs as living in constant turmoil and crisis. The majority of current literature continues to reflect that historic view. Sunderland, Catalano, and Kendall (2009) concurred explaining that the “missing discourses of joy and happiness in relation to disability is culturally and historically entrenched” (p. 703).

However, in a study on the siblings of children with special needs, researchers found that the stress differences between families with and without special needs’ was not significant as related to family functioning (Mandleco, Olsen, Dyches, & Marshall, 2003). Patching and Watson (1993) supported this finding in their study explaining that families of children with special needs “have just as much in common with mainstream families as they do with each other” (p. 130). Behr and Murphy (1993) criticized the methods used by researchers to research families with a CSN. In their review, they found that there is no discernable variation in the family perceptions of stress. In fact, they suggest that if asked, most families will speak of the positive contributions of the child with special needs to their family.

In a qualitative study, Lassetter, Mandelco, and Roper (2007) asked parents to take photographs of their special needs child and followed up the content analysis of the photographs with parent interviews. The findings surprised the researchers because almost all of photographs and interviews revealed activities and joyful moments. The

parents did not take images related to the care or challenges of raising their child. When asked about which photos they wish they had taken more of to reveal their child, the parents answered—more joyful images. The researchers encouraged additional research on understanding the positive outcomes associated with having a CSN and noted that while most of the research on families of children with a CSN are quantitative, “the richness of these parent’s experiences can best be understood through qualitative research” (p. 456). According to their findings, parents *unanimously* revealed that “children with disabilities fulfilled special purposes within their families and were frequently viewed as blessings” (pp. 464-465).

In Stainton and Besser’s (1998) study designed to qualitatively measure the positive impacts of a child with special needs on the individual family, nine core themes were identified including “source of joy and happiness” and “positive impacts on others/community” (p. 57). The researchers advocated for more research so those in the medical practice can improve their practice in working with families to counter the “disabling effects of negative attitudes and assumptions” (p. 65).

A key study completed on the positive contributions of children with special needs was conducted in development of the Kansas Inventory of Parental Perceptions (KIPP) by Behr, Murphy, and Summers in 1992. “The KIPP was designed to measure four domains: positive contributions, social comparisons, causal attributions, and mastery/control” (p. 5). In the creation of this tool, which was based initially upon 268 interviews using open-ended questions, positive contributions were included because “206 items for Positive Contributions, 25 items for Social Comparisons, 24 items for Causal Attributions, and 24 items for Mastery and Control” were identified (p. 9).

Positive contributions were defined as “perceiving that the family member with a disability is a source of positive contributions” (p. 5). However, the theoretical frameworks used to measure the domains were from cognitive adaption theory where family stress and coping theory reign and again assume there is family stress in which coping is necessary.

In Myers, Macintosh, and Goin-Kochel, 2009’s study titled, “My Greatest Joy and My Greatest Heartache: Parents’ Own Words on How Having a Child in the autism spectrum Has Affected Their Lives and Their Families’ Lives,” 493 parents completed an online questionnaire where one open-ended question was posed, “How has your child in the autism spectrum affected your life and your family’s life?” (p. 670). Their researchers primary support for their question came from what they identified as a gap in the research where most of findings regarding mothers of special needs children have “poorer mental health, poorer physical health, and lower quality of life” (p. 671). And while they opened up their study to any parent of a child on the autism spectrum, 92% of the 493 participants were mothers. The words of the parents were analyzed through content analysis and the researchers found three times as many negative themes as positive themes regarding child’s behavior and five times more negative themes regarding impact on the family as a whole. But, they found an equal number of negative and positive themes related to the impact on personal well-being. Their findings supported that “parents had more to say about the difficult parts than the positive aspects of raising their children” (p. 681), but they recommended additional study to reveal the meaning making parents participate in for arriving at these positive themes. They admitted that the

research question invited both challenges and joys and they were surprised by how many joys were revealed.

In a study titled, “We’re tired, not sad: Benefits and Burdens of Mothering a Child with a Disability,” the researcher warned against the “pathologizing” of mothers of children with special needs. The researcher, Green (2007), a researcher and mother of a child with special needs, supported studies focusing on joys rather than challenges, noting that “many parents of children with disabilities identify positive aspects of their experiences” (p. 151). In that same study, author Green (2007) argued that “the majority of research on parenting children with disabilities has emphasized the Subjective Burden (emotional distress) and de-emphasized, if not completely ignored, both the Object Burden (socio-structural constraints) and the benefits involved” (p. 151). She recommended further studies that will present “the benefits derived from loving and living with individuals with disabilities” (p. 161).

In a different study with the same researcher, Green (2003a) used interactive interviewing to “swap stories” with other mothers of special needs children. While the stories shared were mostly on the challenges and grief, the Green (2003a) reflected upon her experience with her daughter by saying, “Amanda is not a disastrous outcome” (p.2). As well, in highlighting one story exchange at the end both she and the participant agreed that “they are beautiful and they are mine!” (p. 11). Green (2003a) encouraged additional qualitative research where stories can be gathered so that others can understand that “while our mothering is certainly different and often fraught with difficulty, it is nonetheless as ‘real’ as mother can possibly be” (p. 12).

The literature that *is* available specifically on the joys of mothers is non-scholarly work, written in the genre of memoir by mothers themselves and often self-published, published by small Christian publishing companies, or by publishing companies committed to disability awareness (Griffin, 2005; Kennedy, 2001; Schwartz, 2006; Sharp, 2003; Soper, 2007; and Zimmerman, 1997).

Summary of Literature Review

Mothers of children with special needs are the primary caretakers and decision makers for their children. Because they are living with more documented challenges, stigma, and stress than mothers of neurotypical developing children or fathers, they are part of a marginalized culture. The literature supported further research to better understand the range of individual mother's experiences, including the positive emotions and joyful feelings associated with having a CSN.

CHAPTER THREE METHODS

Summary of Study

This dissertation's purpose was to examine the joyful experiences of mothers of children with special needs. More children are living with a disability and have special needs. Mothers of a CSN or a child with special needs are more often identified as the primary caregivers of their children with a disability. According to the literature, mothers of children with special needs are the primary caretakers and decision makers for their children. Because they are living with more documented challenges, stigma, and stress, they are part of a marginalized culture. The literature supported further research to better understand the range of individual mother's experiences, including the positive emotions and joyful feelings associated with having a CSN. This dissertation sought to find out if having a CSN means that mothers of CSN experience joy and what that joy is.

Mother of a CSN: Insider and Insider Researcher

What is missing in the research and the literature on mothers of children with special needs is the individual voice of a mother of a CSN on her joyful experiences and the voice of the researcher. There are many considerations that a researcher with insider status must negotiate in order to answer his or her research questions and also remain true to the culture in which he or she claims membership.

Goodenough (1970) explained that social and behavioral sciences categorize "emic" descriptions as those that come from persons living within the culture of study

and “etic” descriptions as those coming by someone living outside of the culture. Merton (1972) explained this “insider” versus “outsider” argument as two opposing doctrines. The insider doctrine assumes that the insider researcher has “privileged” access to the group in which the researcher belongs (p. 11). The insider is viewed as an “insighter” because the researcher can share the “deepest concerns of the group” (p. 15). Outsiders may research relevant problems to the group but they cannot access the same depth of information because they “occupy different places in the social structure” (p. 16).

The insider doctrine, which can be “monopolistic,” assumes then that the outsider researcher has the intellectual “incapacity to comprehend alien groups, status, cultures and societies” because the outsider has not been “socialized in the groups nor has engaged in the run of experiences that makes up its life, and therefore cannot have the direct, intuitive sensitivity that alone makes empathetic understanding possible” (Goodenough, 1970, p. 15). Outsiders often engage in research of marginalized cultures in which they are not members because as outsiders, they understand the “systematic frustration” of being an outsider (p. 29).

Merton (1972) urged insiders and outsiders to “in the domain of knowledge, unite” because neither doctrine is useful for researchers to in the “pursuit of truth” (p. 44). Both insider and outsider can be equally incompetent and ill-trained. We are all insider members by different degrees in many cultural groups, “occupants of certain statuses which thereby exclude us from occupying other cognate statuses” (p. 22). However, as researchers valuing our work as valid, we “transcend extraneous group allegiances” (p. 42). See Figure 1 for an illustration. For example, I am a member of the academic culture, of the feminist culture, and of the mother of children with special needs

culture. I can stand in the larger macro societal culture that houses my individual micro cultural memberships. I can even move in and out of these cultures changing the degrees of my membership. As an educated and trained academic researcher studying the culture in which I am a member; however, I can practice being more than a member. I can practice being an insighter. Consider the famous image of Leonardo daVinci's Vitruvian man whose feet are grounded where he physically resides but who is reaching upwards, gesturing his desire to know something greater than himself. In Figure 1, the researcher's feet represent the many cultural stances in which the individual retains membership. But as a researcher studying those cultures, she is able to open up her metacognitive brain to understand how she knows what she knows of the practices of her culture. And because she is grounded in them, she can access them moving through them, passing as a native.

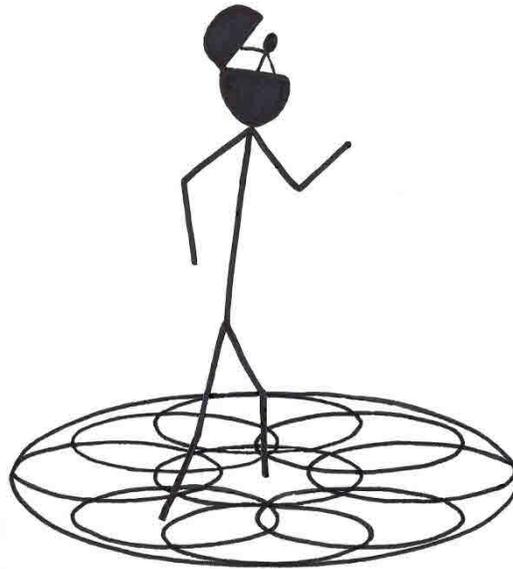


Figure 1. Jones/Bruewer Insider/ Insigner researcher moving in and out of cultural memberships.

Additional definitions of membership in qualitative research include Adler and Adler's (1987) definition of three levels of membership including: (a) peripheral member researchers, who do not participate with the group (b) active member researchers, who are involved but not fully committed to the group, and (c) complete member researchers, who are already members of the group (p. 33). Banks (1998) offered a practical continuum for understanding the positioning of the insider/outsider researcher. The "indigenous-insider" (p. 7) is one "who endorses the unique values, perspectives, behaviors, beliefs, and knowledge of his or her indigenous community" and "who can speak with authority about it" (p. 7). The "indigenous-outsider," (p.8) on the other hand, "has experienced high levels of cultural assimilation into an outsider or oppositional culture" but is one who remains committed to the indigenous culture (p. 8). The "external-insider" (p. 8) no longer identifies with the indigenous culture and the "external-outsider" (p. 8) is "socialized within a community different from the one in which he or she is doing research" (p. 8).

Costley and Gibb's (2006) research on "others," mimic Merton's recommendation to unite, reminding us that all social science research is political and that the "virtuous researcher would, in all humility, seek to undertake research not just to present harm to others but to do good" (p. 93). Caring for those we research is what motivates and often drives our research and that "engrossment with others, the process of setting aside one's own self- concern" allows the researcher to "make decisions regarding their research which dissolves the subject/object divide of unengaged research" (p. 93).

For example, a qualitative researcher reflecting upon her insider membership as a White parent of an adopted Asian child studying White parents of Asian children shares,

“I do not think being an insider makes me a better or worse researcher; it just makes me a different type of researcher” (Corbin, Dwyer, & Buckle, 2009, p. 56). In the same article, a different researcher Buckle (2009) shared that even though she is a parent, when she was studying bereaved parents, she had not experienced the death of a child; therefore, she could not identify with her participants. Her outsider status was actually noted by several of her participants as a disadvantage, “it’s different if you’re a member of the club and I never want you to be a member of the club, don’t get me wrong, but you talk different to people who have lost somebody” (p. 57). “Positionality is thus determined by where one stands in relation to the other” and those positions are always in “flux” depending on our “loci” (Merriam, Lee, Kee, Ntseane, & Muhamand, 2001, p. 411). For all qualitative researchers regardless of our insider or outsider status, “the researcher’s power is negotiated, not given” (p. 409).

According to Mercer (2007), the insider researcher is faced with two ethical dilemmas:

- How to disclose the research objectives to those in the culture in which the researcher is a full member and
- How to use the “incidental data” in the research (pp. 11-13).

Bias from participants, according to Mercer (2008), is possible in both insider and outsider research because participants may not want to share reality but a “distorted image” (p. 13) of what they want their reality to be. This bias can be a concern in insider research as well, because a relationship with the researcher and participant who are in the same culture may continue and understanding that realization may prompt participants to distort that image even more. While the insider researcher can “enjoy freer access, stronger rapport and a deeper, more readily available frame of shared reference with

which to interpret the data they collect,” they also have to “contend with their own pre-conceptions, and those their informants have formed about them as a result of their shared history” (p. 13). However, outsider researcher Rowling (1999) discussed the extreme “emotional reactions to interviews” she experienced while conducting her research (p. 175). “Nothing that I read in planning this study prepared me for the emotionality of the research process” (p. 175). She referred to her reaction as traumatic and difficult to incorporate into her analysis and interpretation. McConnel-Henry, James, Chapman, and Francis (2009) noted the wide spread literature questioning whether “neophyte researchers should conduct research that elicits sensitive data” because of the potential inability to process and maintain trust and rapport with the individual being interviewed (p. 7).

Because I am fully disclosing my insider status and because I have experience as a mother to a CSN, I will have trust and rapport already with my group and I will be prepared for whatever data is disclosed in the interview process. In Green’s (2003a) research as an insider, the researcher fully disclosed her “stake in the topic so that readers could judge for themselves the degree to which my involvement might influence my interpretations” (p. 2). Because she knew she would be “swapping stories” with her participants about a topic, which was also about her experiences, she clearly identified herself as an insider and that revelation was “critical to the study’s success” (p. 3). Green (2003a) weaved the incidental data into her reflection, which created a lens through which she analyzed and interpreted the data (p. 4). Similarly, in Voloder’s (2008) study, the author discussed how friends and family began to “encroach into research territory” and trying to “maintain artificial boundaries” between those two cultures was “proving to

be counterproductive” (p. 33). The author embraced her engagement as an insider researcher, sharing that “my claim to insiderness stemmed from my deep involvement in the social world under study” (p. 30).

Because I am a mother with a special needs child; I know well, and therefore, can speak for the culture of the women are my participants in this autoethnographic study on the joyful experiences of mothers of special needs children. Tedlock (1991) proposed, “Ethnographers who have learned not only the language but also appropriate behavior . . . have been transformed, sometimes quite radically, by their fieldwork experience” (p. 70). Based upon his fieldwork in New Guinea from 1914 to 1918, anthropologist Malowski (1960) recommended researchers “to grasp the native’s point of view, his relations to life, to realize his vision of this world” (p. 25). Because I am an insider researcher and a full member of the culture I am studying, I do not have to worry about “going native,” because *I am a native*. Again, I cannot and will not leave my culture because I will always be a mother of a child with special needs.

Acknowledging that my son, Will, had changed my personal and academic life and choosing then to cross borders in this study, I have answered a question that represented a gap in the available literature—what are the joyful experiences of being a mother to a child with special needs? Baumbush and Clark (2010) declared that “we are often drawn to research questions that arise in our own lives” and that because we are trained as researchers, we can address that need (p. 255).

Insider research gained momentum and definition through feminist research. A key piece of research and literature, *Women’s Ways of Knowing: The Development of Self, Voice, and Mind*, helped to shape positionality in feminist research. The authors of

this text categorize the epistemological voices of women into five ways of knowing: silent, received knowledge, subjective knowledge, procedural knowledge and constructed knowledge (Belenky, Blythe, Goldberger, & Tarule, 1997). The inside researcher must remain a constructed knower.

Received knowers understand the value of listening but they do not trust their instincts when it comes to speaking. They believe knowledge is something everyone else has to offer, but not them. This prevents them from sharing and from activating and using their own prior experiences in creating new thoughts. Subjective knowers believe in their intuition. They believe they have some authority, as valuable as those they listen to. However, subjective knowers still do not trust their instincts enough to say with conviction I am equal to the authority and they cannot with any clarity define why they feel the way they do or how they arrived at those intuitions. They voice their opinions but not with conviction. And, they voice them defensively because they know what they know but they do not know *why* they know it.

Procedural knowers take risks. They are able to think “outside of the box,” but not just any box, their box. The authors (Belenky, Blythe, Goldberger, & Tarule, 1997) liken procedural knowing to the German word “kennen.” As a former German instructor, I know that linguistically it is difficult to translate individual words and the connotations associated with those words from German to English. In English, we use the word “understanding” on many different connotative levels including understanding how to drive a car to understanding how someone is feeling. But “auf Deutsch,” or in German, the word “lernen” means to understand something objectively and “kennen” means to know and be personally familiar with—an understanding representative of a deeper

level— and German native speakers use the words appropriately. Procedural knowers know not only the objective idea, but the subjective factors associated with the idea as well. Procedural knowers are both connected to what they know but can separate themselves from it as well. They are interested in experiencing and are interested in other people's lives. They are nurturers and understand that life and humans are complex. Procedural knowers often rebel or redefine who they are differently than from where they come or what they once knew to be true.

The final voice is constructed. A woman who is operating with a constructed voice understands that knowledge is constructed and that the individual woman's voice and experience is an innate and integral part of knowledge. Constructivist women understand that they must self reflect, analyze, and use context to arrive at answers. They understand that situations in life change and we must respond to those and as a result change what we believe to be true. The authors colloquially define the constructed voice as "letting the inside out and the outside in" (Belenky, Blythe, Goldberger, & Tarule, 1997, p. 135). The constructed voice is one that reflects metacognition. This woman not only listens and connects; she can objectively analyze who she is, why she is, and how she best learns and thinks. She has successfully integrated her voice with other voices and can express with conviction and confidence her views and thinking. The woman with a constructed voice is always reflecting and evaluating her thinking and her practices and adjusting those as necessary (Jones, 2007).

The constructed voice must be the dominant way of my knowing in my role as the insider researcher because my primary role as a researcher is to give the participants a voice and to do that honorably, respectfully, and authentically. Chang (2008) explained

that “in a conventional ethnography, insiders and outsiders are different people; therefore, it takes outsiders a considerable number of border-crossing experiences to decipher the cultural meaning of data collected from insiders” (p. 127). I do not have to spend my energy moving myself and in and out, *because I am in*. I am close and more importantly and to my advantage, will be able to get close to the participants in the culture I am interviewing because of the common language and experiences we share. Word data gathered from an insider perspective is critical because:

Language is how social organization and power are defined and contested and the place where one’s sense of self- one’s subjectivity- is constructed. Understanding language as competing discourses—competing ways of giving meaning and of organizing the world—makes language a site of exploration and struggle.

(Richardson & St. Pierre, 2005, p. 961)

Insider research is immersed in culture and sociological study. It is complex. It is messy. It is hard to do. And that can scare researchers away from researching topics in which they are an insider, but it is the messy and complex that make the research authentic. With full disclosure to participants in my study as to how incidental data will be integrated, I can, as Merton (1972) reminded, pursue the truth and win “a world of understanding” (p. 44).

In order to fill this research gap and to include myself as insider and insider researcher, I have explored the joyful lived experiences of being a mother of a CSN. My research reveals how joy is defined, practiced, and lived. Unlike the dominant literature pervading the academic community of mothers of children with special needs and based upon recommendations in many of those studies, joy was the primary focus. It was not on

the challenges or joy as a positive “perception,” but on joy as a reality. My study reveals how having a CSN is a joyful experience for the mother instead of the pervading negative view that being mother of a CSN is all challenging and stressful and something that has to be adapted to. Because mothers are more often recognized as the primary caregiver and are the primary decision maker, better understanding of the joyful experience of mothers of a CSN will allow those in the educational, medical, and community institutions to better understand and more effectively educate mothers of a CSN. Green (2007) warned us that “pathologizing, and thus discouraging parental ability to find benefits in having a child with a disability is potentially very problematic for parents” (p. 151).

A good research study can be viewed as a photograph, waiting to be set up, taken, and developed so that it will most closely illustrate what the photographer saw and experienced at the scene. One mistake amateur photographers make when taking a photograph is that they look directly through the viewfinder and try to frame the subject in the center. It is referred to in photography as the "bull's eye syndrome." The amateur photographer is so focused on the center of the subject that they rarely look to see what else might appear in the photograph or how the subject in the center will appear with what else is present in the scene.

More seasoned and/or professional photographers know to look all the way around the viewfinder, investigating all four corners to see if anything that will appear in the photograph might distract from the subject and focus of the photograph. By examining the entire scene and looking all the way around the viewfinder, the photographer may see in the corners something more interesting to capture or something

distracting to avoid. At this point, the photographer adjusts the angle and zoom of the camera, so it includes or excludes what was discovered. For example, if the photographer decides that he or she wants only the individual's face in the photography, he or she can fill the frame with that subject's face by moving physically closer and/or adjusting the zoom of the camera.

My study has produced more than just a single photograph about the joyful experiences of mothers of a CSN; it is a photo album articulating what else is possible regarding our perceptions on mothering a child with special needs. Metaphorically speaking as a researcher for this study, I zoomed in on and framed joy in my viewfinder since it is a subject or landscape not typically photographed or portratized. My qualitative research method included the interviewing the mothers of children with special needs using semi-structured questions, the collection of personal writings, and my field notes. These three sources allowed me to look all the way around the viewfinder for that subject, taking and developing many "photographs" so those in the medical, educational, and social service communities will better understand the complexity of the joys of mothers to a CSN. These many developed photographs can provide better information, education, and programming for the mother of a CSN.

Bauman (2005) in "Afterthought on Writing: On Writing Sociology" warned us that "To diagnose a disease does not mean the same as curing it" (p. 1096). While my study does not cure this "social ill" or the well-documented stress and stigma of being a mother of a CSN, it will as Bauman recommended, provide the reader the ability "to see through—explain and understand" (p. 1096). I do not anticipate revealing any new truths, just truths that need to be told and heard. Well-known writer and activist Toni Morrison

(1990) explained that marginalized slaves in the United States wrote narratives to reflect two important ideas:

One: This is my historical life—my singular, special example that is personal, but also represents the race. Two: I write this text to persuade other people—you, the reader, who is probably not black—that we human beings worthy of God’s grace and the immediate abandonment of slavery. (p. 299)

To reveal those truths, my study has generated word data through individual interview sessions using semi-structured questioning along with writings shared by the mothers. The results of this study provide rich insights into the types of education and programming needed for mothers of children with special needs.

Design Framework: Autoethnography

Learning from experience requires being open and willing to participate in new experiences, requires being able to observe and reflect, and requires being able to analyze and integrate new ideas and concepts from those observations and reflections. To reveal the mother’s joyful experiences, I used the qualitative research method *autoethnography*. Autoethnography is a qualitative method whereby a particular social phenomena is examined from an insider’s perspective (Merriam et al. 2001). Muncey (2010) defined autoethnography as “postmodern, where provocative modes of discourse, writing and criticism” challenge those “traditional boundaries between art and science” (p. 95). Wall (2006) defined autoethnography as, “an emerging qualitative research method that allows the author to write in a highly personalized style, drawing on his or her experience to extend understanding about a societal phenomenon” (p. 1). Wall explained that “the intent of autoethnography is to acknowledge the inextricable link between the personal

and the cultural and to make room for nontraditional forms of inquiry and expression” (p. 1). The key to autoethnography is the “auto” or “self.” In ethnography, the researcher studies the beliefs and values of the cultural group he or she is studying and there is distance between the researcher and those being studied. In autoethnography, the researcher must have membership in the culture and the subjective voice of the researcher to interpret that culture is required. Often in autoethnography research, the researcher is the only subject. To collect data, the individual researcher can analyze internal data such as personal journals, memorandums, or interview others about him or herself. Similar to all qualitative research, in autoethnography, the researcher must decide how he or she will participate in the study, how the data will be collected, how the data will be analyzed, how the data will be written up, who the benefitting audience is, and which disciplines should be targeted for contribution. The researcher must also decide how he or she will present him or herself in those findings.

Autoethnography requires the researcher to write in the first person because autoethnography researchers choose an area of needed research by looking both outwardly to their shared culture in finding a focus of study and then inwardly on their own experiences with that focused area. By bringing their individual experiences and data to the research, they can share their personal cultural perspective on that area of focused research. Burnier (2006) explained that “Autoethnography, different from other qualitative research, offers a way to situate the self within the research process and its written product, by making the self the object of research” (p. 410). According to Hayano (1979), autoethnography researchers must have prior and/or current knowledge of the “people, their culture and language, as well as the ability to be accepted to some degree,

or to pass as a native member” (p. 100). Recall Figure 1 of the Insider/ Insider researcher moving in and out of cultural memberships.

Autoethnography is couched in both ethnography and narrative inquiry. The focus on ethnography allows the researcher to study, critique, and analyze the participants within a cultural context. The narrative form allows the researcher to organize and shape those interpretations along with the participant’s experiences into a written structure, which reflects meaning for not only the researcher, but for others. Bruner (2002) reminded us that the most poignant and omnipresent symbolic activity in our culture and in every culture is the narrative form. Writing and telling about our lives is just a strategy for recording events, but it helps us define as human beings. “It is the narrative gift that gives us the power to make sense of things when they don’t” (p. 28). A story, “is a locution, but it also has a specific purpose: what a speaker intended by telling it to his listener in this setting” (p. 24). The researcher using autoethnography must provide space for participants to share their stories, and because the researcher in autoethnography is also a required participant, then he or she must also share his or her story.

Autoethnography supports the primary purposes of qualitative research, which according to Marshall and Rossman (2006), include exploratory, explanatory, descriptive, and emancipatory. Autoethnography is unique in that it moves through these stages simultaneously.

- For the exploratory purpose, as an autoethnography researcher, I can “discover important categories of meaning.” (p. 34)
- For the explanatory purpose, I can “explain the patterns related” to my research questions.” (p. 34)

- For the descriptive purpose, I can “document and describe the phenomenon.” (p.34)
- For the emancipatory purpose, I can—and this is the most important to me personally—“create opportunities and the will to engage in social action.” (p. 34)

According to Chang (2008), data collection for autoethnography can include internal and external data. Whether the researcher chooses to collect either internal or external data or both depends upon the purpose of the study, the discipline employing the method, and how the data collected will be presented. External data includes interviews, textual artifacts such as historical documents, official documents, personally produced texts such as journals, letters, even travel diaries, and other artifacts including photo and video. Interviewing remains the “staple” form of external data collection in autoethnography because of autoethnography’s ethnographic roots (Chang, 2008; Denzin & Lincoln, 2000). Studies using autoethnography often only include internal data, meaning the researcher’s only data is self-produced through interviews with the self and/or by analyzing personally produced documents. For example, when I attended and presented at the autoethnography strand at the International Congress of Qualitative Inquiry (ICQI) conference in 2010, I read and listened to studies where individual researchers had analyzed only internal data on everything from surviving an eating disorder to learning to assimilating as an immigrant teaching in an American university to watching their mother die.

Internal data can, according to Chang (2008), include self-observation and self-reflection. Self-observation asks the researcher to “record actual behaviors, thoughts, and emotions as they occur in their natural contexts” (p. 90). Self-reflective data, on the other

hand, “result from introspection, self-analysis, and self-evaluation of who we are and what you are” (p. 95). Self-observation (internal data collection) can happen systematically in logs, notes, or in journal entries and is typically focused only on the researcher’s role in the culture or the researcher’s interaction with the culture. However, self-reflective data can be collected before, during, and after the administration of external data collection such as a field journal that a researcher completes before, during, and after an interview or before, during, and after the reading of textual artifact like a piece of journal writing. Chang (2008) encouraged autoethnography researchers to keep a field journal because “autoethnography is a highly self-reflective and introspective process” and the field journal is a “metacognitive activity” and “methodological way” that help the researcher “move into and out of the self reflective state” (pp. 95-96).

Heider (1975) illustrated the importance of the field journal when he studied the native New Guinea people in the Grand Valley Dani of Irian Jaya, Indonesia. He deviated from the list of complex interview questions created by himself and his fellow outsider researchers and asked a native to help him ask one question to the Dani people, “*akhuni nena hakakhatek? –What do people do?*” (p. 3). The answers the Dani people generated were rich and provided more information than any other data they had been collected. He kept a field journal on his method of access including how and why he chose to use this process as well as his reflections to those answers generated. He discovered that because ethnographers typically spent so much time learning the culture and language of the group they are studying, it would seem more natural to consider having a trained native member conduct that research so more time could spent on gathering data than on learning how to access the data. But if that trained native researcher is not available, then

using a field journal will help the researcher move in closer. The work he produced about the Dani people is recognized and accepted by most as the first use of the autoethnography method and is even sometimes referred to as the “Dani Auto-Ethnography.”

David Hayano defined autoethnography in 1979 in his seminal work, “Auto-Ethnography: Paradigms, Problems, and Prospects” where he explains the criteria for using the autoethnography method as being one that includes the researcher having prior knowledge of the culture and language of the people being studied and being able to be “pass as a native member” which he acknowledges can be on a continuum (p. 100). His call to using autoethnography includes the argument that “fieldwork can no longer be conducted under the wing of friendly colonial authorities” (p. 99). Part of what led to the use of autoethnography as a research method was “a sense of displacement” by researchers who according to Burnier (2006) found traditional social science research to be “abstract” and “detached” (p. 412).

According to Reed-Danahay (1997), autoethnography combines autobiography, the story of one's own life, with ethnography, the study of a particular cultural group. The concept of autoethnography synthesizes both a postmodern ethnography, in which the realist conventions and objective observer position of standard ethnography have been called into question, and a postmodern autobiography, in which the notion of the coherent, individual self has been similarly called into question. The term has a double sense—referring either to the ethnography of one's own group or to autobiographical writing that has ethnographic interest. Thus, either a self (auto) ethnography or an autobiographical (auto) ethnography can be signaled by “autoethnography” (p. 2).

According to Couser, (2005), autoethnography is “slippery, ambiguous, but useful” because it is defined differently by the varied disciplines, such as anthropology, literary studies, or sociology, who use it. (p. 126). Ellis and Bochner (2000), leading scholars on autoethnography include a long list of titles that have been used to refer to autoethnography which again reflect the diversity of how the method can be employed.

Find a sample below which include:

- Autobiographical ethnography
- Autobiology
- Auto-observation
- Autopathography
- Collaborative autobiography
- Ethnographic memoir
- Critical autobiography
- Indigenous ethnography
- Narrative ethnography
- Reflexive ethnography
- Enthobiography. (pp. 739-740)

Autoethnography research is both a process and a product. During the collection of autoethnography data, the researcher has a choice of how to interact with that data, whether internally or externally collected. Similar to all qualitative, social science research, the data and interaction with the data can be presented on a continuum. For autoethnography, on the right and more conservative end of that continuum is analytical

autoethnography and on the left or more liberal is evocative autoethnography. Analytical autoethnography, according to Anderson (1996) can be explained by understanding that the researcher engages in dialogue with participants from his or her own culture but remains committed to the theoretical analysis of what the participants and the researcher's dialogue with those participants reveal in a socially constructed context. The researcher's story is either an equitable or subordinate component to the story of the other members of the cultural group.

Anderson (1996) defined the role of the researcher in the far right or use of analytical autoethnography as one in which the researcher is:

(1) a full member in the research group or setting, (2) visible as such a member in the researcher's published texts, and (3) committed to an analytical research agenda focused on improving theoretical understandings of broader social phenomena. (p. 375)

Those operating on the right or analytical end of the continuum identify themselves as a full member which is required in autoethnography, but primarily as a researcher studying his or her own cultural group. They distinguish between those two voices (member of the group and researcher) when they present their findings and discussion. Typically on the analytical end of the autoethnography continuum, the researcher may collect internal data, but the primary data collection comes from other members in his or cultural group through interviews or content analysis of text or other media. For internal data collection, the researcher may interview him or herself as part of this process to include his or her voice or the researcher may simply explain results using his or her personal experiences to help interpret what those other cultural group members are revealing.

Evocative autoethnography, on the other hand, can be presented as drama, dance, visual, or literary representations. The goal of evocative autoethnography's scholarship is to invoke emotion and move the reader or viewer to not only understanding the experiences (sympathy), but feeling the experiences as the individual felt them (empathy) (Ellis & Bochner, 2000). The reflexive voice of the researcher may be the only voice, the dominant voice, or the indistinguishable voice from any other cultural participant voices in the study. On the evocative end of the autoethnography continuum, the research provides an opportunity to confront, embrace, or simply reflect on those shapemakers. Chase (2005) reminded us that when using autoethnography, researchers can "write, interpret, and/or perform their own narratives about culturally significant experiences" (p. 660). As with any narrative and social science research, autoethnography research is based upon in-depth interviewing of a specific culture whose voices interact with the researcher who is identified as having membership in that culture. Autoethnography meets my goal as a researcher because I am a full member of the group in which I am studying; I am a mother of a child with special needs. During the design of this study, I had a choice of how to position myself in that continuum.

Reed-Danahay (1997) emphasized that when considering how we should position ourselves, we need to be mindful of the connection of the self to the social and cultural. She summarized the three potential roles of the autoethnography researcher as:

- (1) "native anthropology," in which members of a previously studied cultural groups become ethnographers of their own groups;
- (2) "ethnic autobiography," in which personal narratives are written by members of ethnic minority groups; and

(3) “autobiographical ethnography,” in which anthropologists interject personal experience into ethnographic writing. (p. 2)

For the purposes of my study, I took on two of these three roles. I was both autobiographical ethnographer and ethnic autobiographer. Through interviewing, I studied the joys of the cultural group—mothers of children with special needs. Specifically, to access the cultural data, it was proposed that four to six mothers of children with special needs from the Indianapolis Special Needs Moms Writing Group would be interviewed using semi-structured questions addressing what the mothers perceive as joys of being a mother of a CSN. In the interview protocol, the mothers were invited to share any personal writings on the topic of what they perceive as joy regarding their role as a mother to a special needs child. I collected my own data through my reflexive field journal where I reacted and responded before, during, and after each interview and again after each transcription using a qualitative field journal. The personal notes in my field journal took on both an analytical and evocative tone. I used my cultural stance as both insider and insider to analyze the data and present findings that elicited emotion from the reader. For example, as Anderson (1996) suggested I used my personal experiences to help interpret the data. But as Reed-Danahay (1997) recommended, I also interjected my personal experience as data. Padilla-Goodman (2010) in discussing her insider role as a researcher explained that “understanding the complexities of my own stance in this project has been essential in trying to predict the complexities of the stances of my participants in order to remain sensitive” (p. 318). Both the internal and external data were subjected to analysis.

The style of qualitative field journal that I used was modeled after one created by Carsaro (1981) where the researcher first describes and then reflects. For example, prior to the interview, the researcher writes Observational Comments (OC) regarding the location, scene, and details about the upcoming process. During the interview, the researcher takes notes describing Theoretical Notes (TN)—key ideas or themes that surfaced. After the interview, the researcher continues describing with Methodological Notes (MN) whereby the researcher critiques his or her research methods during the interview process. Finally, the researcher moves into the act of reflexivity and completes Personal Notes (PN) where the researcher writes down connections, responses, and reactions to what was said during the interview. Bodgan and Biklen (2007) explained this reflexive addition as “think pieces” (p. 122). Glaser and Strauss (1967) referred to this field journal exercise as a memo. I chose this model because it allowed me as the researcher to again situate myself in the middle of that autoethnography continuum where I can identify myself as researcher, but also include my data and voice with the other mother’s voices. See the Appendix A for an outline of the field journal I used in the data collection process.

The use of the method autoethnography required that I was both a researcher and a subject. By both describing and reflecting, I remained both analytical and evocative. While writing the Observational, Theoretical, and Methodological notes, I maintained my role as a researcher of the study. While writing Personal Notes, I presented myself evocatively, sharing my own stories of my son as they related to or connected to what the members of cultural group had presented as data and interpreting what the participants

said. Self-reflexivity before, during, and after the interview, transcription, and data analysis stages were employed in this study using autethnography.

By positioning myself in the middle of the continuum, I sought to elicit emotion and move my reader but also wanted to insightfully speculate on what those emotions and experiences meant. While I argued for the voice of the missing researcher in the study of the joys of mothers of a child with special needs, I also argued for the voice of the mother. I disagree with Anderson's (2006) argument for the right of the continuum when he said that the analytical autoethnography researcher should primarily be "committed to an analytical research agenda focused on improving theoretical understandings of broader social phenomena" (p. 375). Having an "agenda" could lead to misinterpretation or analysis of the data. As a student in a Adult, Higher, and Community Education, I am equally committed to both theory and practice and my goal in this study was to present my work in the most accessible representation so that I can affect educational, program, and practitioner applications of what I discovered. In autoethnography, just like in any qualitative research, the researcher—not the survey or the data collection tool—is the instrument, which is why autoethnography research is so culturally significant. It is situated in how the individual researcher perceives the person and because humans are fallible, autoethnography research is subject to those human limitations.

Autoethnography's focus is on the individual's experience in his or her cultural group and that purpose of presenting the individual as part of a cultural group must prevail. In order to retain that focus, I have presented my findings in a traditional five-chapter qualitative research dissertation format where each of the voices of the mothers

of a CSN and the collective cultural voice of mothers of children with special needs has an opportunity to be heard, analyzed, and interpreted into meaning.

Benefits and “Limitations” of Autoethnography

“The problems of auto-ethnography are the problems of ethnography compounded by the researcher’s involvement and intimacy with his subjects” (Hayano, 1979, p. 99). But Barbara Tedlock (1991) reminded us that, “Ethnographers who have learned not only the language but also appropriate behaviors have been transformed, sometimes quite radically, by their fieldwork experience” (p. 70). Again, because I am part of the culture I am researching, I do not have to worry about *going native* because I already am a native. I can focus less on my transformation and more on the transformation of those who read and apply my study.

This insider advantage allows me greater control over the research questions and the ability to practice what anthropologist Geertz (1973) referred to as “thick description,” which is where the ethnographer does not just observe, record, and analyze a culture but also interprets the signs of the culture which allow the researcher to gain all of the meaning of that culture (p.3). My insider position allows me greater insight into the culture being studied. Traditional research often requires that we distance ourselves and try to make ourselves as neutral as possible which is impossible and why in autoethnography, according to Tedlock (1991), we announce our insider advantage and encourage “the native’s point of view” (p. 69).

By writing in first person, I had the opportunity to take complex data and interpret it into comprehensible, accessible, and applicable information to multiple audiences. Autoethnography is not just research for other researchers. Because of its undertones of

social justice and call to action, autoethnography is not just read, but is experienced. Autoethnography requires full engagement and results in an active communication.

My method required my own participation. Throughout this study, I have related and connected my personal experiences with my fellow participants during the reflexive part of my field journal and included it as data. With my required insider participation, I was in a better position to interpret and make connections because as a member, I understood the culture and language of the mothers I studied. I had to be mindful of the potential blurring of the line between my roles, which is why I created a consistent system of description and reflexivity during my data collection process that addressed my role and membership during the data collection process.

A general argument against autoethnography is that if it is not done well, it loses its analytical or theoretical edge. Ellis (2004), a leading expert on the method of autoethnography, noted that “knowledge and theory become disembodied words on the page and I lose connection” (p. 431). Yet, I refute that idea of “losing connection” because as Bauman (2005) suggested “there is no difference between engaged and neutral” (p. 1097). I was able to get close to the participants in the culture because I am close to them. I interviewed these mothers because there was a well-defined need to study and illustrate their experiences. And, because I am one of them, I shared some of their experiences and can positively contribute to the data and study’s results. Fraenkel and Wallen (1996) suggested that during interviewing, the researcher respect the cultural background of the individual being researched, respect the individual being interviewed, and to act naturally, which I could do because of my insider membership. As well, during the reflexivity stage of writing field notes, Fraenkel and Wallen (1996) explained that:

Learning to understand, and where appropriate, [the researcher] speak the vocabulary of the group being studied. If researchers do not understand what informants mean when they use certain terms (especially slang) or if they take such terms to mean something that they do not the, the recording of invalid data will surely result. (p. 462)

Worthen, Sanders, and Fitzpatrick (1997) likewise recommended that while interviewing, the researcher use a common language of the subject, including words that mean the same for everyone participating in the interview. I knew what my participants meant and did not misunderstand because I spoke the same language. The most important thing I had to remember as an autoethnography researcher was to announce my participation as a researcher and a subject and to give my participants a voice and to do that honorably, respectfully, and authentically. Padilla-Goodman (2010) explained that in autoethnography, “burden lies in my personal commitments to my community; about not commodifying people’s stories” (p. 321). Narrative researcher, Gornick (2001), advised that we often cannot write if we get too far away from our subject but if we are too close, we can suffocate, losing oxygen.

Word data gathered from an insider perspective is critical because as Richardson and St. Pierre (2005) illustrated,

Language is how social organization and power are defined and contested and the place where one’s sense of self—one’s subjectivity—is constructed.

Understanding language as competing discourses—competing ways of giving meaning and of organizing the world—makes language a site of exploration and struggle. (p. 961)

Because I am a native and cannot leave my culture, I take my ethical role seriously and my work in this area of research will be ongoing, long past this project. Behar (1996) asked that we understand autoethnography as being a micro study as opposed to a study of the macro (p. 21). “The tendency is to depersonalize one’s connection to the field. . . and to accumulate masses of data that can be compared, contrasted, charted and serve as a basis for policy recommendations, or at least as a critique of existing practices” (p. 25).

Sample Selection

Purposive sampling (Patton, 2000) was used to identify the mothers of children with special needs. Purposive sampling, as the name indicates, is purposeful because it required a specific population for this study— mothers of children with special needs. Purposive sampling allowed me to identify mothers who I knew would be rich in information for this study. I used purposive sampling to recruit participants from the Indianapolis Special Needs Writing Group, a writing support group for mothers of children with special needs who gather voluntarily for the purpose of writing about their experiences as mothers to a CSN. The mothers in this group are and were, for this study, comfortable talking openly and giving voice to their experiences.

I used purposive sampling to recruit four to six mothers from the group. I delivered a one-time communication face-to-face with the mothers who participate in the Indianapolis Special Needs Writing Group where I read from a consent form script explaining the research study and asking for four to six participants. I followed that face to face communication with an email communication restating the script requesting again. I emailed participants from an email contact list I maintained as the facilitator of

the Indianapolis Special Needs Moms Writing Group in order to establish the purposive sample. I am a full member of the Indianapolis Special Needs Moms Writing Group and this group is not part of any other organization; therefore, I did not have to seek permission from any other organization or sponsor to gain access to the mothers. The mother's participation was completely voluntary and beyond the one face to face and email consent script, there was no other communication requesting participants. Five mothers responded and five mothers participated in the study.

Data Generation Methods

Data collection in autoethnography can include external data including textual documents such as photos or journal entries or the interview process itself or internal data including the reflexive writing or personal memory of the researcher about the findings. Data analysis within autoethnography reflects the typical qualitative forms of analytical inductions, comparisons, sorting, and coding. I used data generated from each semi-structured interview, self selected personal writings on joy the mothers shared, and my reflexive field journal notes for each interview and personal writings.

As explained earlier, internal data for this study were collected through a reflexive field journal before, during, and after each semi-structured interview. As Marshall and Rossman (2006) reminded us, "Field notes are not scribbles" (p. 99). Researchers and writers must have "explicit note-organizing and note-management strategies" (p. 99). Before each interview, I described observational comments regarding the location, scene, and any relevant details regarding the upcoming interview. During and after the interview, I described and reflect upon any theoretical notes—key ideas or themes that surfaced. And after the interview, I continued by describing, critiquing, and reflecting

upon any methodological notes of the interview process. The final component of the field journal was reflexive only and occurred after the interview and again after the transcription process and allowed me, as the researcher, to write down any personal connections, responses, and reactions to what was said during the interview. Marshall and Rossman (2006) suggested that the researcher include “emerging analytic insights and clues that focus data collection” (p. 99). Those connections, responses, reactions may and did include my own personal writings on joy. Strauss and Corbin (1998) explained that “by putting our analysis immediately into notes,” we can begin the inductive process of open coding (p. 120).

See Figure 2 for an illustration of how both external and internal data were collected in this study.

External Data	Internal Data
Semi Structured Interviews	Reflexive Field Notes: Observational, Theoretical, Methodological, and Personal Notes
Transcribed Interviews including words and sounds	Personal Writings on Joy
Readings of Personal Writings on Joy	

Figure 2. Chart of external and internal data collection in the study titled, “The Joyful Experiences of Mothers with Special Needs Children.”

Each interview was transcribed including sounds made by the mothers as they answer the questions such as sighs, pauses, laughter, and crying. In Ansay, Perkins, and Nelson’s (2004) study of at-risk children of military families, the sessions were recorded,

transcribed, and coded for certain responses such as affirmative behaviors and statements. Mostyn (1985) explained that it is important that qualitative researchers “give an indication of both the direction and intensity of feelings expressed by respondents” (p. 142).

Perakyla (2005) recommended that qualitative researchers transcribe their data as naturally occurring as they can. Perakyla (2005) warned against those who use written texts as their data and do not “follow any predefined protocol in executing their analysis” because textual material on its own cannot give a clear view of the cultural world (p. 870). Perakyla (2005) asked researchers to employ an analytical methodology including discourse analysis, which takes into account how the language was spoken as much as what was said. “The capacity of language to convey ideas” is critical in analysis (p. 875). To access how the language was spoken, she encouraged the use of conversational analysis where the researcher using video or audio recordings, notes “naturally occurring interactions” (p. 874). Perakyla (2005) presented several detailed charts showing different researchers symbolic methods for translating talk in transcription. The symbols presented were for researchers only analyzing conversation, not what was actually said. For example, “WORD” means that the word was said with a “creaky voice” and “(2.4)” means there was a pause of exactly 2.4 seconds and “wo(h)rd” means that a laugh occurred during the speaking of that word (p. 882).

Prior to the transcription process, I developed a simpler system of coding the sounds. Long pauses, more than three seconds, were noted with three ellipses points. Em dashes were used for run-on sentences. The sixth edition of the *Publication Manual of American Psychological Association*, recommended using an Em dash in writing to “set

off an element added to amplify or to digress from the main clause” (p. 97). While we write using very clear end notation and writing is flat on a page, when we speak, we bring those words alive with inflection and emotion. I wanted to show how the mothers did not respond in any kind of a robotic fashion but as individuals who would often think of another way to say or explain or illustrate an answer. I never purposefully ended a sentence with an end mark unless it was ended and complete. I placed any parenthetical notations directly after the word spoken. For example, if a mother laughed, I noted as (laugh) turned into laughter, I noted it as (laughing). If the mother sighed, I noted it as “sigh.” If the mother asked a question, I ended the interrogative with a question mark. See three excerpts from my transcription and Figure 3 for a more complete visual of my system.

Interview Text Examples

K: He came up with that himself as an infant and self moistens which is a HUGE, HUGE benefit because most kids with Moebius have some significant issues with the dry eyes along with an explanation of the system.

K: Yea, and we have the NGTube hanging and he was double cast at the time and he had two casts on his feet and he had a splint—they were trying to straighten his finger deformities so they had this splint on just one hand and (laugh) and I just go walking in—I have to go to work! I am sure she just loved me! (cynically). I just didn’t know any different—I just had to go to work like everyone else.

L: I got in the car and I was just like I said to Matt, “that was so much fun.” Matt said, “Had fun with Issac, my friend Issac” and it was a big full moon and I was driving home (cry) like that was just pure joy. . .(crying)

Sound	Transcription Symbol
A laugh noise made during or after speaking	(laugh)
Laughing that continues after speaking	(laughing)
A cry made during or after speaking	(cry)
Crying that continues after speaking	(crying)
Run-on sentence	— Em Dash
Long pause as defined as three seconds or more	. . .
Inaudible	(inaudible)
Appropriate end punctuation to signify a close to the interrogative sentence posed	?
Appropriate end punctuation to signify a close to the declarative or imperative sentence posed	.
Appropriate end punctuation to signify a close to the exclamatory sentence posed	!
Intonation of cynicism	(cynically)
Intonation of sadness	(sadness)
Sigh	(sigh)
Said with emphasis or louder	WORD IN ALL CAPITAL LETTERS

Figure 3. Chart of symbols representing how sounds were transcribed in the study titled “The Joyful Experiences of Mothers with Special Needs Children.”

The participants—mothers of children with special needs who participate in the Indianapolis Special Needs Moms Writing Group— were interviewed in a private

Sunday School classroom of the church where the writing group typically meets. Semi-structured questions (Patton, 2000) were used to facilitate an individual interview session with each of the mothers who participated in the study. Semi-structured questioning begins with general questions and allows for additional questions to be used in the interview process based upon the participant's response to what was asked.

Each individual interview session was approximately least sixty minutes in length and was no longer than ninety in order to respect each mother's time. Each interview session was digitally recorded to ensure accuracy. I provided pseudonyms for all of the mothers, as well as any organizations, children, or people they name within their responses for confidentiality. Those pseudonyms were used in the remaining chapters of this dissertation and will remain being used for future transcripts, reports, and publications related to this study. After all of the individual interview sessions were transcribed, I analyzed and coded the data to reflect topics or themes revealed from the individual voice of a mother of a CSN.

The Interview Guide

The interview guide was developed through a series of steps including drawing upon the literature regarding qualitative interviewing, input from my chair and doctoral committee, results from a previous focus group study on the challenges of mothers of children with special needs, an external panel of mothers of children with special needs not participating in the study, and the researcher's professional experience as a creator of writing prompts.

Sandelowski (2002) identified one-to-one interviewing as the most commonly used tool to collect data in qualitative research. According to Ryan, Coughlan, and

Cronin (2009), “The individual interview is a valuable method of gaining insight into people’s perceptions, understandings, and experiences of a given phenomenon and can contribute to in-depth data collection” (p. 309). Ryan et al. placed interview types into three categories: the standardized interview or structured, the semi-standardized or semi-structured interview, and the unstandardized or unstructured interview. The standardized or unstructured interview “employs the use of an interview schedule which contains structured and explicit questions that do not allow for veering off the topic in question” (p. 310). The semi-standardized or semi-structured interviews “offer a more flexible approach” and “while they may use an interview schedule for predetermined topics, they allow for unanticipated responses and issues to emerge through the use of open-ended questioning” (p. 310). Unstandardized or unstructured interviews “do not engage in a specific framework for questioning” (p.310).

DiCicco and Bloom (2006) explained the key features of a semi-structured interview as including one that is “organized around a set of predetermined questions” and where “other questions emerge from dialogue” (p. 315). According to Siedman (2006), in research, we choose interviewing as a qualitative data collection tool because we are “interested in other people’s stories” and those stories are a “meaning-making process” for the researcher (p. 7). Vgotsky (1987) reminded us that when we tell stories, we select the words carefully because those stories represent a microcosm of our consciousness. The purpose of interviewing is not first to get answers or to test a hypothesis, but to “understand the lived experience of other people and the meaning they make of that experience” (Siedman, 2006, p. 9). How a researcher uses the interviewing tool to access those stories in qualitative research depends on the data collection

requirements of the specific qualitative method used. For example, a structured interview protocol might keep the interviewer from digressing from the questions and if closed answers were necessary, then a structured series of questions should be what the researcher would choose. Warren (2001) pointed out that in ethnography, “qualitative interviewing has long been linked to ethnographic fieldwork” (p. 85). In autoethnography, Chang (2008) explained that unstructured and semi-structured are preferred because they “allow flexibility in questioning and responding” (p. 105). Interviews are useful in autoethnography because they help “stimulate your [the researcher’s] memory, fill in gaps in information,” and “gather new information” (p. 106). Because flexibility in questioning and responding are required to access those lived experiences in autoethnography, in-depth interviewing is required. In-depth denotes what it says and seeks “deep” information. Johnson (2001) explained “deep” as “deep understandings held by real-life members or participants” (p. 106). And it is the researcher’s role to “seek to achieve the same deep level of knowledge and understanding as the members or participants” (p. 106). In-depth interviewing “involves a greater involvement of the interviewer’s self” (p. 109). Johnson (2001) warned that in-depth interviewing requires some form of complimentary or strict reciprocity between the researcher and the interviewee, which is only possible “if the interviewer is a former or current member of the group under study” (p. 109). My insider status provided that reciprocity to my participants. They knew I shared some or all of their “own views, feelings, or reflections on the topics being discussed” (p. 109).

In-depth interviewing, according to Siedman (2006), required the researcher to use “primarily, open-ended questions” to “build upon and explore the participants

responses to those questions” (p. 15). Open-ended questions in a semi-structured interview format, in particular, and according to Siedman, are ideal for accessing the lived experience because it creates the opportunity for the interviewer to “ask questions,” “to follow up,” “to ask for clarification,” “seek concrete details,” and “request stories” (p. 81).

DiCicco-Bloom and Crabtree (2006) concurred that the in-depth interview is one that is a “personal and intimate encounter in which open, direct, verbal questions are used to elicit detailed narratives and stories” (p. 317). The most important skill an interviewer can have when using semi-structured questioning is not to ask all the semi-structured questions on the guide, but to “listen actively and to move the interview forward as much as possible by building on what the participant has begun to share” (p. 81). Marshall and Rossman (2006) likened in-depth interviews to “conversations than formal events with predetermined response categories” (p. 101). According to Marshall and Rossman (2006), in-depth interviewing may also be “supplemented with journal writing,” but only in so far as the writing helps to “capture the deep meaning of experience in the participant’s own words” (p. 55).

Establishing and maintaining rapport between the interviewer and interviewee is critical during the in-depth interview process (DiCicco-Bloom & Crabtree, 2006; Johnson, 2001; Marshall and Rossman, 2006; Ryan et al., 2009; Siedman, 2006; Warren 2001). While in-depth interviewing is an interviewing research method, Siedman (2006) stressed that it is also a “social relationship,” that occurs in a “social context” (p. 95). As with any relationship, it must be “nurtured” and “sustained” (p. 95). That social relationship is enhanced by the face-to-face interview. Conducting interviews face to

face, noted Ryan et al. (2009) “offer the researcher the opportunity to interpret non-verbal cues through observation of body language, facial expression and eye contact and thus may be seen to enhance the interviewers understanding of what is being said” (p. 310). It is this social interaction coupled with the semi-structured questioning format that “permits the researcher to probe and explore hidden meanings and understandings” (p. 310). Siedman (2006) suggested that because of the social forces at play, researchers try to gain as much understanding of the cultural aspects of the individual they are interviewing. DiCicco-Bloom and Crabtree (2006) warned that when interviewing women, it is important that the social roles between the interviewer and interviewee are equal and to not “ignore social differences” (p. 317). Again, in the method of autoethnography, the goal is to gather the cultural data. Because my interview questions were designed to learn more about the joys of the culture of mothers of children with special needs and because I am an insider, a mother to a CSN myself announcing my membership, I had a greater ability to maintain those equitable social forces. Chang (2008) reminded that while a “wide variety of techniques fall within the continuum of individual and group, structured and unstructured” interviews, in autoethnography, the most commonly used techniques involve an individual participant in a face-to-face interview using open-ended questions in a less structured, meaning a semi-structured or unstructured interview format (p. 104).

Ryan et al. (2009) insisted that rigor is maintained in the unstructured and semi-structured interview process through a consistent approach and well-designed questions. Fraenkel and Wallen (1996) explained that when writing the interview guide for the semi-structured or unstructured interview, “sequence and wording are determined

throughout the course of the interview” so that the interview remains “fairly open and conversational” (p. 448). According to Chang (2008), creating questions for the less structured or semi-structured interview guide, “generally begin with a grand-tour questions in casual conversational settings and progress to mini-tour questions seeking more detailed and focused information (p. 105).

Patton (1990) identified six types of questions that the interviewer can ask including background or demographic, knowledge, experience or behavior, opinion or value, feelings, and sensory. Each provides the researcher with different but necessary data. Background or demographic answers provide routine demographic data. Knowledge questions provide factual or informative data. Answers to experience or behavior questions provide personal experiences and activities as data. Answers to opinions or values questions provide personal opinions or ideas as data. Questions regarding feelings provide data regarding the interviewee’s attitude about a topic or idea. Finally, sensory questions provide data about how the interviewee uses his senses in interpreting a topic.

In Baumbusch and Clark’s (2010) discussion on writing the interview guide for semi-structured questioning they recommended prompts, probes, and sub questions such as, “tell me about...” or “can you tell me more” or “what was that like for you” (p. 256). Ryan et al. (2009) explained that open-ended descriptive questions such as “Tell me what happened” or “How did you feel when” are useful because they “encourage interviewees to talk and expand on their stories” (p. 311). As well, the authors also suggested the use of prompting such as “what happened next” because it is “useful in permitting the interviewee to expand on a particular issue or in getting them to re-engage with the interview process if they lose their train of thought” (p. 311). Finally, they recommended

probing questions such as “can you tell me more about that please” which “allow the researcher to uncover deeper levels of meaning and seek clarity on the topic of interest” (p. 311).

DiCicco-Bloom and Crabtree (2006) asserted that after asking the basic research question as your first interview question, “between 5 and 10 more specific questions are usually developed to delve into different aspects of the research issue” (p. 316).

Regardless of the questions created in the semi-structured format, “the interviewer should be prepared to depart from the planned itinerary during the interview because discussions can be very productive as they follow the interviewee’s interest and knowledge” (p. 316).

Warren (2001) recommended ethnography interviewers “develop 10 to 12 specific questions” from the research question or questions (p. 86). Johnson (2001) disagreed, recommending instead five to eight main key questions so the researcher in the semi-structured format can then digress and “follow the informant’s interests or knowledge” because such “diversions are likely to very productive” (p. 111).

While Patton advocated for different types of questions and different experts on writing the interview guide weigh in on how many questions should be asked, Baumbusch and Clark (2010) recommended building the interview guide by asking the questions in stages. For example, in stage one, the researcher allows the interviewees to ask questions about the study. In stage two, there is a shift to questions with a factual focus. Reminiscent of Patton’s knowledge type questions, these questions are more in-depth than questions about the study but are still not yet accessing any emotions or values. In the third stage, the researcher asks more difficult questions that may have emotional responses. In the fourth stage, the authors recommended shifting away from

the emotional and returning to what Patton would refer to as an opinion or value question. In the fifth stage, the researcher closes the interview by talking casually and thanking the interviewee for his or her contribution. By following this stages, according to Baumbusch and Clark (2010), the researcher can maintain rapport, rigor, and remain ethical.

As noted in the beginning of this section, in writing my questions for this study, I drew upon not only the literature on how to write qualitative semi-structured interview questions, but also what little literature is available on the joys of having a child with special needs. For example, only one open-ended question was asked in the study about the joys and challenges of having a child on the autism spectrum: “How has your child in the autism spectrum affected your life and your family’s life?” (Mackintosh, 2009, p. 670). In the Kansas Inventory of Parental Perceptions or KIPP (1992), the questions posed by researchers in this quantitative study, which measured both positive and negative perceptions, were presented as partial statements that parents ranked possible complete answers. For example: “My child is _____ I consider my child to be _____, The Presence of my child _____, or Because of my child _____” (pp. 29-31). There were also individual statements which again parents could agree or disagree using a Likert scale noting whether or not they strongly agreed, agreed, disagreed, or strongly disagreed. Examples include:

I seem to manage better than other people who have children with special needs.

When I compare my child with other children who are doing better. I feel bad that my child isn't making better progress. In most ways my family is pretty much like other families who have children with special needs. (p. 33)

In addition to the research literature available on the joys, non-scholarly publications written as memoirs or self-help books by mothers of children with special needs also provided an expert “word bank” from which I could access in building each question. Each of us has a “word bank” from which we deposit and withdraw words for communication. We encounter, learn, and deposit new words from our community, including family and friends, through reading, and from the educational system in which we participate, whether formally, informally, or nonformally. Once we have a word or a better word to communicate something that has been deposited, then we can draw out that word from our word bank and spend it in our communication forms such as speech and writing. For example, consider some of the following book titles written by mothers of children with special needs. Each one presents new words for the word bank on the culture of the joy for these mothers: Marie Kennedy’s (2001) *My Perfect Son has Cerebral Palsy*, Mary Sharp’s (2003) *An Unexpected Joy: The Gift of Parenting a Challenging Child*, Elizabeth Griffin’s (2005) *Fragile X Fragile Hope: Finding Joy in Parenting a Child with Special Needs*, and Jane Jennings (1978) *Why Joy? Learning to Love my Special Child*.

In addition to examining the literature on writing interview questions, what few questions have been asked or written and presented in academic research on joy, and individual memoirs, I also drew upon my experience as a writing instructor and prompt writer. While interview questions are answered orally and writing prompts are used to prompt writing, both require the individual to be engaged and provide the best answer to the question or prompt posed. I have been teaching narrative writing formally since 1992. In my professional work as an instructor and the co-creator of The Memoir Project at the

Writer's Center of Indiana, I have created writing prompts for children ages 3 to senior citizens ages up to 90. I have taught individuals to write who consider themselves to be writers, individuals who are both illiterate and alliterate, and individuals who can write but who proclaimed to hate it. This is what I know from my nineteen years and hundreds of students: A good writing prompt invites the writer to write by motivating him or her to not only want to write, but creates a need to write. For example, when provided with the right writing prompt, the person has to write—they experience an urgency, a need to expel the words out of their head and onto paper. Likewise, a well-written interview question prompts the interviewee to feel like they need to answer because they have something to say.

There are three key parts in creating a good narrative writing prompt: “cloze” it or provide some of the words so the writer can fill the rest in with his or her own, use the personal pronouns “I” or “you” so the writer can draw upon the self, and finally narrow the prompt so the writer can zero in on one person, place, or time. These can be written as questions or as statements. The following are tried and true examples I have written and used for various writing courses or workshops: “Before I had _____, I dreamed of _____ . After I had _____, I dreamed of _____”; “I remember a good day. It started out . . . and continued. . . and ended with. . .”; “What have I lost?”; or finally, “I remember a special place. Repeat the phrase I remember. . . . over and over to both describe and explain why it was special”. Whether I presented these prompts to adults living or dying with cancer, senior citizens wanting to access and write about a legacy memory, or girls in prison writing to heal, these prompts invited and encouraged the individual voice to answer.

My interview questions are listed below along with a description of how my doctoral committee chair, my doctoral committee, the literature— both academic and professional—and my writing prompt experience each played a role in the design of the questions. Note that I have posed eight questions, which follow the literature guidelines of writing a range of five to twelve questions that build upon or reflect the research questions. Again, my word bank for the design of my interview questions for this study drew upon the academic and non-scholarly literature I read, my committee's expertise, and my experience as a mother and as a writer.

To establish and verify that the mothers were qualified as a mother to a CSN, I will begin with the following question:

1. What is your name? What is/are the name(s) and age(s) of your child/children with special needs? What is your child/children's special needs or diagnosis?

Patton (1990) recommended this question to establish that the individual is a part of the study and to establish that he or she is knowledgeable about the topic. Baumbusch and Clark (2010) recommend that at stage two, after the researcher introduces him or herself and the study, that a demographic or factual question is posed. My doctoral committee chair, Dr. Glowacki-Dudka, along with a former member of my committee, Dr. Joseph Armstrong, supported my additional purpose for this question, which was to illustrate the diversity in age and disability types of the children from which the mothers share their experiences as a mother of a CSN. My goal in researching the joyful lived experiences of mothers with special needs children was to help inform those who love, serve, educate, and treat mothers of children with special needs and their children. It is

important that this study did not just reflect the experiences, for example, of only mothers of children with autism or only mothers of children with cerebral palsy. A seminal study conducted by Hammel et al. (2008) included people with “diverse social, geographic, and disability backgrounds” so the data was “based on shared life experiences” and individuals reading would respond to the commonality instead of an individual diagnosis or label (p. 1448).

My guide then continued with the semi-structured interview questions meant to generate data to support my research questions.

2. Do you have any personal writings on the joys of being a mom to a special needs child or the joys of your child that you would like to read or share?

During my dissertation proposal meeting, all members of my doctoral committee suggested that in addition to the interviews, I also collect the personal writings. Because I used a population of mothers of children with special needs who participate in the Indianapolis Special Needs Mom’s Writing Group and personal writings are a form of data used in autoethnography, we agreed that this addition would help to triangulate the data. The Ball State Institutional Review Board (IRB) reviewed my modification to the study of collecting personal writings, and recommended that I include it as a question in the interview guide. They were concerned about the collection of the writings as they consider individual writings such as journals or diaries personal properties. Along with my chair, we concurred with IRB. This compromise still allowed me access to the writings without keeping any personal properties. The readings of these writings generated knowledge answers, behavior or experience answers, opinion or value answers,

or feeling answers (Patton 1990) and could be in any of the potential stages as outlined by Baumbusch and Clark (2010).

3. How does it feel to be a mom of a child with special needs?

Chang (2008) suggested that autoethnography researchers create questions that “generally begin with a grand-tour questions in casual conversational settings and progress to mini-tour questions seeking more detailed and focused information (p. 105). As well, my chair, Dr. Glowacki-Dudka, suggested this question to ease interviewees into the specific topic of joys. In stage two of asking interview questions, Baumbusch and Clark (2010) recommended shifting to questions with a factual focus to prepare interviewees for the more emotional questions that will come next. Reminiscent of Patton’s (1990) knowledge type questions, this question is in-depth but was still not yet accessing any experiences or behaviors, emotions or values. It is not a feeling question because it is not first asking the interviewee about an experience or behavior in which to assign feeling to. It is simply asking for information that only a member of this individual cultural group can establish. Again consider the individual memoir titles listed prior which illustrate potential words for this answer.

4. Being a parent encompasses a range of emotions, so how do you find moments of happiness, playfulness, or peacefulness?

This question was recommended by my committee during my dissertation proposal meeting and serves the same purpose as the question above. It supports the research question: “How do the joyful experiences add to the complexity of the emotions of being a mother to a CSN?” And, it provided yet another opportunity for the interviewee to provide in-depth knowledge on the topic, but not yet provide any

emotions, values, or feelings. It is similar to the questions and statements posed in the Kansas Inventory of Parental Perceptions (KIPP) where the parents were asked to find a statement that best completed a prompt. My question though allowed the mothers to complete their own answer instead of providing one from a list.

5. How do you celebrate joys with your child with special needs and family?
What kinds of unique experiences do you have with your child with special needs?

I wrote this question to mirror the research question, “What are the joyful experiences of a mother of a CSN?” DiCicco-Bloom and Crabtree (2006) recommended using a similar version of the research question as a question on the interview guide to directly ask what is driving the study. Baumbusch and Clark (2010) recommended that researchers in the third stage ask more difficult questions that may have emotional responses and this stage coincides with Patton’s (1990) suggestion of asking experience or behavior questions that provide the researcher with individual personal experiences and activities as data. Again notice the use of words like “unique” and “celebrate joys”.

6. What has surprised you or been unexpected about having a child with special needs? How is it different or unique being a mother to child with special needs?

I wrote this question to maintain the momentum of stage three and continue to ask another in-depth and emotional question. However, this question, according to Patton (1990) asked the interviewee for more than just their experience or behaviors but to direct their feelings to that experience or behavior hence it is regarded as a feeling question. This question presented the potential to addresses all three of the research questions posed in this study:

- How do the joyful experiences add to the complexity of the emotions of being a mother to a CSN?
 - How do mothers of a CSN define joy?
 - What are the joyful experiences of a mother of a CSN?
7. What are the good things about being a mom to a child with special needs?
 8. What else would you like to say or add....?

I wrote the final two questions so that participants could move to stage four, where Baumbusch and Clark (2010) recommended the researcher shift away from the emotional and return to what Patton (1990) would refer to as an opinion or value question. As well, it was a final opportunity for participants to answer the research question, “How do mothers of a CSN define joy?”

It is important to note that this semi-structured interview guide was just that—a guide. Open-ended questions in a semi-structured interview format, according to Siedman (2006), are ideal for accessing the lived experience because it creates the opportunity for the interviewer to “ask questions,” “to follow up,” “to ask for clarification,” “seek concrete details,” and “request stories” (p. 81).

As the participants answered questions, I did have the opportunity to use additional prompts recommended in the literature including “tell me about...” or “can you tell me more” or “what was that like for you” or (Baumbusch & Clark, 2010, p. 256). The use of prompting such as “what happened next” because it is “useful in permitting the interviewee to expand on a particular issue or in getting them to re-engage with the interview process if they lose their train of thought” (Ryan et al., 2009, p. 311).

Siedman (2006) recommended testing the interview process and questions with another peer or a team of peers. Marshall and Rosmann (2006) explained that a pilot study can be useful in refining the research instrument, particularly questionnaires or an interview guide. A pilot study helped the researcher “foreshadow research problems and questions, highlight gaps and wastage in data collection, and in considering broader and highly significant issues such as research validity, ethics, representation” (p. 57).

Per the literature and my committee’s recommendation, I did submit my questions to a panel of three mothers of children with special needs who would not be participating in my study and who also work in the special needs community. I explained my study and invited their input as well as answers so I could better understand how they would be received. Everyone concurred that the topic was a necessary one to study and that the questions invited experiences and feelings of joy to be documented. They also noted that they were easy to understand and that answers would be easy for individuals to access. All three on the panel felt that question number three regarding how one feels being a mother to a CSN was too broad and worried it might invite more challenges than joys. Because of three of the mothers who served on the panel worked in the role of advocacy, all three suggested that individual mothers might share experiences regarding support or services in framing any joyful experiences or behaviors. Finally two of the three talked about including a question on dreams, however, my chair felt that was addressing a different topic than one of joy. Their participation and analysis did improve the interview guide instrument. My goal with this instrument was to follow the literature’s recommendation of moving from factual to descriptive to emotional question, to both broaden and narrow as emotions were stated. So their contribution of analyzing the

specific questions and they types of responses they thought might be provided helped in the creation of the order of the questions.

Warren (2001) expressed that while “asking” is certainly important in the interview process, equally important is “listening, talking, and hearing” as are “seeing and feeling as means of apprehending the social world” the researcher is studying (p. 98). Fraenkel and Wallen (1996) summarized that the most important idea to remember when creating questions for the interview guide is to remember that interviews are used to “discover a respondents opinions, beliefs, or knowledge about a particular topic” (p. 448).

Confidentiality of Data

I personally conducted each individual interview session. I recorded each interview using a digital recording device and verbatim transcripts of each interview were typed by me. All paper representation of the data were stored in a locked filing cabinet in my home. After data was analyzed, the paper transcription were shredded and all the electronic data files are password protected on my personal computer and will remain indefinitely.

Confidentiality was addressed during the transcription process and in these and any subsequent submission of the findings by using pseudonyms in place of the participants’ real names. Only myself and my faculty supervisor had access to the raw data. After subject checks and final correspondence were completed, personal identifying information (real name, email address, etc.) were removed to de-identify the subject data. I destroyed the coding sheet that pairs the subject’s name with the assigned pseudonym, but all other data were securely stored indefinitely. These coding documents were destroyed by shredding to additionally address confidentiality. The findings will be used

for the development of manuscripts for publishing and conference presentations and will be shared with colleagues in a classroom setting.

Data Analysis

A data analysis process was used whereby an inductive system of open, axial, and thematic coding (Strauss & Corbin, 1998) was employed to arrive at the findings. Strauss and Corbin defined open coding as the “analytical process through which concepts are identified” or “discovered” in the data (p. 101). Axial coding is defined as the “process of relating categories” (p. 123). The goal of open coding is to open up the data to possible interpretations and the goal of axial coding is the “process of reassembling the data that were fractured during open coding” (p. 124). In the inductive open, axial coding of data, our interpretation of the data, our experiences, our analytical memos and field notes, and the literature regarding the topic participate in helping to relate the categories to produce themes.

To induce, I moved through the data differentiating between the chaff, “that data which is determined to be non-significant or redundant” and the wheat, “that data which is deemed significant or exemplary” (Chenail, 1995, para. 14). Once the repeating themes of “wheat” were identified, I allowed the data to be the “star” in terms reporting exactly which themes were revealed in understanding the joys of being a mother to a CSN (para. 12).

Chang (2008) recommended ten strategies for analyzing autoethnography data, which include “(1) search for recurring topics, themes, or patterns and (2) look for cultural themes” (p. 131). After transcribing the interviews and writings shared during the interview, I listened again to each recorded interview session. Then to analyze the data

for those recurring themes, I used the Constant Comparison Method and assigned each line of each transcript a code (Dye, Schatz, Rosenberg, & Coleman, 2000). During induction, I employed Denzin's (1989) semiotic reading analysis method. After assigning each line a code using the constant comparative method, I then semiotically organized key words as codes. After that initial culling or assignment of code, I then grouped common or similar answers to the questions posed (Glaser & Strauss, 1967). An interpretive interactionist approach was used where data was analyzed using a multistep deductive process including (a) relistening and rereading the transcripts (b) line-by-line coding (c) collapsing and expanding codes into themes (using the mother's words where possible) (Chenail, 1995; Denzin, 1989).

In grouping those common answers, derived from the codes, and finding recurring themes, I listed and read for what Mostyn (1985) described as the five most important guidelines in interpreting qualitative research including the incidence of occurrence, attitudes presented by participants, what is not being said, indication of salience, and meaning. Making meaning out of what was said, how it was said, and in what context it was said are critical for qualitative data analysis. In the method of autoethnography, what I had to say about what was said is also part of that meaning making process.

I highlighted, copied, and pasted those parts of the exchanges, including my responses, which reflected repeating or recurring themes. Those data points then were subject to axial coding or "culled," where I then followed Mostyn's (1985) suggestion of "condensing, excising, and even reinterpreting the data, so that it could be written up as a meaningful communication" (p. 138). Those recurring themes were refined and clarified. Mostyn (1985) advised us that, "there is no easy formula to aid the researcher in the

interpretation of qualitative research data as opposed to merely reporting the findings” (p. 140). The researcher must be able to “understand basic motivation and apply them, see behind rationalizations; ask and try to answer the question” (p. 140).

Because I studied the mothers of special needs children as a culture and interjected my own voice as part of that culture, I conducted my analysis understanding that equitable to that analysis was the cultural interpretation of the data because according to Chang (2008), this process “transforms bits of autobiographical data into culturally meaningful and sensible text” (p. 126). My insider perspective allowed me the advantage of being able to make meaning. “In a conventional ethnography, insiders and outsiders are different people; therefore, it takes outsiders a considerable number of border-crossing experiences to decipher the cultural meaning of data collected from insiders” (p. 127). Mostyn (1985) explained that in trying to find meaningful relationships in qualitative data, “the analyst must also understand the roles, values, and life styles of respondents in order to interpret the data” (p. 118) of which I do as a mother to a CSN.

Reliability and validity were addressed through the systematic collection and analysis of the data points. Golafshani (2003) in a comparison of reliability and validity in quantitative and qualitative research explained that terms such as “reliability and validity are treated separately” in quantitative and qualitative studies and that we should use terms that “encompasses both, such as credibility, transferability, and trustworthiness” (p. 600). Reliability and validity, according to Golafshani (2003) equate to or can be interpreted in qualitative research as “trustworthiness, rigor, and quality” (p. 604). In autoethnography, Ellis clarified (2004) “validity means that our work seeks verisimilitude” and that “you can judge validity by whether it helps readers communicate

with others different from themselves or offers a way to improve the lives of participants and readers” (p. 124).

Witcher (2010) in an article titled, “Negotiating Transcription as a Relative Insider: Implications for Rigor,” argued that a transcription is “merely one representation/re-presentation of this event” (p. 124). However, “being a relative insider contributes to transcription quality” which has “implication for research rigor/trustworthiness” (p. 124). Witcher (2010) warned researchers that to ensure rigor and trustworthiness during an interview where participants use “nonstandard meaning” or a dialect or slang particular to their culture data, those words must be transcribed in the same language and analyzed in that language or they could be “misrepresented and misinterpreted” (p. 127). However, to minimize bias during the interview, I made sure that the interviewing was conducted “nondirectionally” whereby the interviewer “must leave it [the answers] entirely to the informant to provide answers to questions” (Brenner, 1985, p. 151). My system of sound transcription illustrated in Figure 3 maintained that saliency in meaning.

Fraenkel and Wallen (1996) recommended several specific procedures for researchers to follow to ensure validity and reliability in qualitative research including:

- Using a variety of instruments to collect data
- Checking one informant’s descriptions of something against another informants descriptions of the same thing
- Learning to understand and speak the same vocabulary of the group being studied
- Writing down the questions they ask
- Documenting the bases for interferences they made

- Describing the context in which questions re asked and situations are observed
- Using audio tapes and videotapes when possible and appropriate
- Drawing conclusions based on one's understandings of the situation being observed and then acting on these conclusions. (p. 462)

My data collection and analyses addressed all of these procedures systematically and consistently through my multiple forms of data collection: interviews, writings, and my field notes. My protocol for collecting, transcribing, and analyzing those interviews, writings, and my field notes ensured validity and reliability.

Site of Research

The individual interview sessions were held in a private Sunday School classroom at a church where the mothers meet for the Indianapolis Special Needs Writing group and the location was both private and centrally located.

Ethical and Political Considerations

Prior to beginning each individual interview session, I reviewed the Introductory Letter/Informed Consent Form and secured the appropriate agreements/signatures. I explained that the mothers were free to discontinue participation at any time, for any reason, without prejudice from the myself as the principal investigator (see email communication in Appendix B and introductory letter/informed consent form in Appendix C).

Timeline

The individual interviews were conducted in the fall semester of 2010. Following my IRB protocol strictly, I sent a one-time email communication to the group as well as delivered a one time face-to-face communication. Five mothers responded and five

mothers were interviewed and of that five, three of the mothers shared their personal writings with me during the interview.

Representation

The findings will be used for the development of manuscripts for publishing and conference presentations and will be shared with colleagues in educational, social service, medical classroom, and institutional settings.

Institutional Review Board

I sought modification to a successfully obtained Institution Review Board (IRB) expedited approval from February of 2010, which allowed me to proceed with the study in the spring semester of 2011. I closed the protocol in early February as all data had been collected and analyzed. I did this under the direction of both my chair and the IRB director, Chris Mangelli.

Summary of Chapter Three Methods

Purposive sampling was used to identify mothers of children with special needs from the Indianapolis Special Needs Mom's Writing Group. Autoethnography requires the researcher to also be a subject in the research. Insider and insighter positionality is critical for the method. For this research study, data was collected from internal and external sources. Data was collected externally through semi-structured interviewing with five mothers.

During the interview, if the mothers chose, they could select and share any readings of personal writings they had on joy. As the researcher, I included my own or internal data in the form of descriptive and reflexive field journal notes taken before, during, and after each interview. The interview guide was created using research

recommended interview guide and protocol methods, with input from my chair and committee, from an external panel of mothers of children with special needs, and from the researcher's experience as a prompt writer. Data collected was analyzed using the Constant Comparative Method. Institutional Review Board (IRB) approval was satisfied.

CHAPTER FOUR

FINDINGS

Summary of Study

This dissertation's purpose was to examine the joyful experiences of mothers of children with special needs. More children are living with a disability and have special needs. Mothers of a CSN or a child with special needs are more often identified as the primary caregivers of their children with a disability. According to the literature, mothers of children with special needs are the primary caretakers and decision makers for their children. Because they are living with more documented challenges, stigma, and stress, they are part of a marginalized culture. The literature supported further research to better understand the range of individual mother's experiences, including the positive emotions and joyful feelings associated with having a CSN. This dissertation sought to find out if having a CSN means that mothers of CSN experience joy and what that joy is.

To find data to satisfy whether or not there was joy and what that joy was, the method autoethnography was employed. Autoethnography requires the researcher to also be a subject in the research. Because this researcher is also a mother to a child with special needs, this method was the most appropriate one to generate data because insider and insighter positionality is critical for the method. For this research study, data was collected then from both internal and external sources. Data was collected externally through semi-structured interviewing with five mothers. Data was collected internally in the form of descriptive and reflexive field journal notes taken before, during, and after

each interview. The interview guide was created using research recommended interview guide and protocol methods. Data collected was analyzed using the Constant Comparative Method. Institutional Review Board (IRB) approval was satisfied.

Method for Presenting the Findings

Chenail (1995) suggested several strategies for researchers to present their findings in qualitative research including:

- Most simple to most complex—For sake of understanding, start the presentation of data with the simplest example you have found.
- First Discovered/Constructed to Last Discovered/Constructed—The data are presented in a chronicle-like fashion, showing the course of the researcher’s personal journey in the study.
- Theory-Guided—Data arrangement is governed by the researcher’s theory or theories regarding the phenomenon being represented in the study
- Narrative Logic—Data are arranged with an eye for storytelling. (para. 35).

I have presented my data in this chapter data utilizing the “Narrative Logic” strategy recommended by Chenail (1995). I am both an academic and a narrative writer, so creating a flow between the themes so the reader can see how they not only fit together but how they support or refute the literature is key. While each theme is a part, those parts are part of a much more complex picture. Recall the metaphor I illustrated in chapter two comparing a good research study to the setting up, shooting, and development of a photograph. For this dissertation, I have taken and developed many “word” photographs and my goal in this chapter is to arrange those photographs in an album for you so you can see how each one of those photographs together illustrated a

much larger image. I was not interested in handing you a disorganized stack of every single photograph taken in this research study, but instead have presented to you the dominant images that developed so you can see how those photographs addressed my research questions. Chenail (1995) insisted that the “narrative logic” strategy’s strength is that the researcher can “plot out the data in a fashion which allows them to transition from one exemplar to another just as narrators arrange details in order to best relate the particulars of the story” (para. 35).

Chang (2008) who has written one of the few conclusive texts on how to use the method autoethnography reminded us that autoethnography, like all qualitative research, is a constructive and interpretive process. Chang recommended several formats for writing up the data in autoethnography research including imaginative-creative writing, confessional-emotive writing, descriptive-emotive writing, and analytical interpretive writing, and even suggested creating your own style. The imaginative-creative writing style allows the researcher to express the data in any kind of unstructured story or genre including poetry, fiction, or drama. This style’s goal is more focused on interpretation of the data than analysis. In the confessional emotive writing, the researcher uses the data as a secondary element to incite empathy and uses primarily the researcher’s data to show the reader what the researcher has come to learn or understand about only his or her role as a member of that culture. The descriptive-emotive writing removes any interpreting writing, asking the researcher to simply describe with the intent of only using descriptive passages that elicit emotion. The author recommended that if the researcher chooses mixing and matching these styles, the researcher should create one’s own style in presenting autoethnographic data. In my discussion in chapter three on the continuum of

how to present the data within autoethnography method, the “create your own style,” the “imaginative-creative,” the “confessional-emotive” data presentation writing styles would present themselves on the left or more liberal use of the method, while the “descriptive-emotive” and “analytical interpretive” writing present the data on the more conservative or right end of that continuum.

Muncey (2010) maintained that regardless of what form the data takes that it must be “organized around certain features: portrayal of the self, one’s positioning in the field, and the interaction of the experience of self in a particular world and the ways in which we come to organize experience and our actions” (p. 23). A leader in the field of autoethnographic research, Ellis (2004), recommended only presenting autoethnography as a narrative story and presenting those stories as fiction, poetry, or performance and theorizing only within the context of the narrative form. However, she argued as well for the right or more conservative end of that continuum by insisting that “stories are analytical” and we use “analytic techniques to interpret” those stories (p. 196). Denzin and Lincoln (2005) in the *SAGE Handbook of Qualitative Research* present poetry, performance, online, and analytical examples contributed by individual researchers as examples of how autoethnographic data can be revealed and presented.

While I am presenting my data using “narrative logic,” that logic is based upon the more conservative method of “analytical-interpretive” writing. In analytical writing, “essential features transcending particular details are highlighted and relationships among data fragments are explained” (Chang, 2008, p. 146). Using this discourse allows me as the researcher to use my insider/insighter positionality to “see interconnectedness within the data” and to not only transcend but to interpret and translate the data (Chang, 2008, p.

146). You will see in the findings that I present the data and then present my interpretation of that data which came through my Personal Field Notes. I save my voice for last and use my experiences and positionality as the interpretation of the data presented.

In traditional qualitative research, the dominant position of the researcher is outsider. When reading this research, often the researcher uses quotes from the participants to reveal the data. Those selected quotes reveal the theme poignantly but then the abrupt voice of the outside researcher emerges trying to summarize up and analyze those thoughts. For a moment though—before that interruption—through the participant’s words, we are immersed. We understand the message from the participant’s direct experience and how that message supports the findings. We may even connect that understanding to our own. But then we hear the analytical voice of the researcher who jerks us away from the quote and sets us back into academia and away from the very thing the study sought for us to know. As the reader, we quickly lose the human connection and view those individuals as human subjects or participants instead of as human beings. We replace the story with data. By using autoethnography and the analytical-interpretive paradigm, I can ease the reader down from the rich data revealed by the participants and into the analysis, so you better understand that these are not just subjects but individual human beings whose voices should be heard.

Consider the following example of what I have avoided doing in my presentation of data from a study titled, “What does participation mean? An Insider perspective from people with disabilities?” The researcher sets up quote from an individual in the study avoiding his narrative voice or use of first person, creating semantic distance by stating,

“Participants recognized that many people were limited by inaccessible housing and built environments” (Hammel et al., p. 1452). Following that researcher statement is the individual voice of the person interviewed who shared, “If you have don’t have access to transportation, you don’t have access to a whole lot of things. You don’t have the opportunities to do very much” (p. 1452). I was drawn and better understood the human experience of inaccessibility and the importance it has for that one person and potentially all those persons who identify with him. But the researcher then resumes his researcher distant voice following that individual statement with, “Accessible information was also identified as a key environmental resource for participation” (p. 1452). That abrupt move and switch in tone forces me to view that individual as a “subject” again and not as a human being.

Denzin’s (1989) critical text titled *Interpretive Interactionism*, defined interpretivism as “the clarification of meaning” (p. 120). We create meaning through a “triadic process” of interacting and interpreting “(1) a person, (2) an object, event, or process; and (3) the action taken toward that object, event, or process” (p. 32). “Understanding is the key in the process of interpreting, knowing, and comprehending the meaning that is felt, intended, or expressed by another” (p. 120). When we interpret, according to Denzin, we must blend both emotion and cognitive understanding. We cannot base our interpretations solely on “self-feelings” or “shared experiences” but neither can we remove or “detach emotional feeling” (p. 121). Denzin (1989) clarified that we can evaluate or judge our interpretivist acts or analysis by several criteria including, “Are they based on thickly contextualized material?, and “Do they cohere and produce understanding?” (p. 63).

He recommended that rigor can be maintained by utilizing multiple forms of data, connecting the experiences of each voice, presenting the data in the “language, feelings, emotions, and actions of those being studied,” and most importantly by following the six steps of interpretation (p. 27). Those six steps include:

- (1) Framing the research question;
- (2) Deconstruction or critical analysis of prior conceptions of the phenomenon;
- (3) Capturing the phenomenon, including locating and situating it in the natural world and obtaining multiple instances of it;
- (4) Bracketing the phenomenon or reducing it to its essential structures;
- (5) Construction or putting the phenomenon back together in terms of its essential parts, pieces, and structures; and
- (6) Contextualization, or relocating the phenomenon back in the natural social world. (p. 48)

In Chapters One and Two, I have framed my research questions and deconstructed the literature illustrating the dominant thinking on mothers of special needs children, captured the data in my outlined data collection process, bracketed the data using the constant comparative method of data analysis, and have reconstructed the data using the narrative logic form. In discussions with my chair, Dr. Glowacki-Dudka, she recommended that I “determine the parts, examine the relationship between the parts, and connect that relationship of the parts back to the whole.” As well, she reminded me that analysis is what is broken down and then expanded upon (Glowacki-Dudka, Personal Communication, September 2010). My hope is that this presentation contextualized the data and the women not just as marginalized or as stigmatized but as mothers, like all

mothers, who experience joy even though they are faced with well-documented challenges. Remember that the reading of any text is transactional and that the reader plays a critical role in the interpretation and presentation of data (Denzin 1989; Rosenblatt, 1994). “A reader brings meaning to and creates the text that is read” (Denzin, 1989, p. 131). As you read the following narrative, I encourage your interaction and interpretation of any meaning you find.

One unique finding and six themes emerged and they will be presented to you in a series that allows you, the reader, to first understand who these women are, that yes they do have significant challenges as supported by the dominant literature, but through their CSN, they have come to understand and redefine joy. Once that joy is defined through the data, then you will see how the mothers experience and know joy. Again, I am not presenting these to you in terms of dominance of codes in the data. Quotes from the individual participant’s transcribed interviews, writings, and my field notes will give shape, definition, and color to each photograph or theme.

Diverse Demographics

The first finding, not theme, that emerged was one that genuinely surprised me. While my study only allowed for four to six interviews and five participated from one purposively selected group, the diversity of the participants and their children’s special needs presented itself as a dominant finding. Initially when designing this study, I wanted to include more participants in my study. Under the direction of my chair and members of my committee, I was encouraged to keep that number between four and six. As seasoned qualitative researchers, members of my committee were concerned with the amount of

data that would be generated. I am grateful for their guidance because the external data—five interviews and personal writings—along with my internal data—field notes—generated 161 pages of text word data. The depth of the questions, the length of the interviews, the personal writings, and my coding process made for a time intensive, but valuable, transcription and memoing process. It is often the practice of qualitative researchers to hire out the transcription and after this experience, I know I would not do that. I found much value in hearing it over and over as I worked to type not only what was said, but how it was said.

While I knew these women as members of my group, it had never occurred to me how diverse a population they represent. My first demographic question was really designed only to show the diversity of the ages and disabilities. However, either while answering that question or while answering other questions, more demographic information was revealed. While the number of participant mothers in this study were small, and the women came from a common geographic area, the central Indianapolis community, the diversity was significant and much greater than one might consider that five participants could reveal.

To better understand this significant diversity and the consequent data presented, consider the following demographic and biological profile of each of the participants:

(Participant 1) Lisa is a 45 year-old stay at home mother to two children. David is 14 years old and is neurotypical. Matt is 11 and has autism. Lisa is married and is originally from the East Coast. She moved to the area with her husband following his transfer to the community. She was formally educated as a social worker and worked prior to having her children. As a social worker, she worked with adults

with mental illness and with children in the foster care system. She has been seeking part-time flexible employment so that she can be home to get Matt off the bus every day by 3:15. She defines herself as living in the upper middle class.

(Participant 2) Barb is a single mother who works part time as a classroom teacher. She has four children who are Japanese-Americans. She was raised an hour north of the Indianapolis area. She is formally educated and prior to marrying and having children, worked overseas in corporate America. Three of her four children has special needs. Haley is 11 and she has Attention Deficit Hyperactivity Disorder (ADHD) and Asperger's Syndrome. Elijah is 10 and has Asperger's Syndrome and Juvenile Diabetes, Type 1. Issac is 6 and he has Autism. Mia is 5 and is neurotypical. Barb lives below the poverty line and despite being employed and receiving assistance from her ex-husband, she relies on public assistance. Barb's ex-husband, a Japanese native, was abusive to her. It took her many years to leave the domestic violence that reigned in her home.

(Participant 3) Mary has only one child, Johnny, and he is 16 and has Cerebral Palsy. She is married to a musician. Mary was born in Texas, but grew up in the Indianapolis community and considers herself an "older mom" at age 49. Before Mary had her son, she worked as a car salesman, as a registration clerk for the Bureau of Motor Vehicles, and as a licensed insurance and real estate agent. She now works part time as a writer and speaker for several community foundations.

(Participant 4) Kay is an American born Cuban American from New York who moved to the area with her husband's work. She is a stay at home mother with three children. Jack is 11 and has Moebius Syndrome, a chromosomal or genetic disease, as well as a secondary diagnosis of Autism. Ann and Gayle are fraternal neurotypical 10 year old twin girls. Kay is a fluent native Spanish speaker who worked as a social worker with children with disabilities before she had Jack. She defines herself as living "okay" and does not have to work.

(Participant 5) Bonnie is a 42 year old mother to 7 year old Kristie and 5 year old Ron. Kristie has Cru Du Chat, a chromosomal or genetic disease, and Ron is neurotypical. Bonnie, along with her husband, moved to the area following both their careers. Bonnie is formally educated and had a professional career as a medical sales representative who worked closely with heart surgeons demonstrating her companies' technologies in heart surgeries. Bonnie was adopted and grew up with her adoptive family in Chicago. She recently met and found her birth mother and discovered that she has inherited Huntington's Disease, a genetic progressive and terminal neuromuscular disease. Bonnie defines herself as "living comfortably" and fortunate to have a nice home, be able to go out, and not have to work.

(Researcher) I am the researcher and also a mother to a special needs child. I am a 41 year old mother to Will who is 7 and has Cerebral Palsy. I am married and also moved to the area with my husband following our careers. I am from southern

Indiana. I consider myself living a middle class lifestyle. I used to live an upper middle class lifestyle, but now live more in the middle because of my lack of employment opportunities and my son's extensive medical bills. I am formally educated and have worked as a classroom English teacher, education consultant, writer, a doctoral teaching fellow at a university, and as an Education Director of a nonprofit organization.

During the interviews, the mothers revealed themselves not only as mothers but also as women living with the same challenges faced by many women who may not have children with special needs. They and their lives are complex. The five mothers in this study and myself come from all walks of life. The mothers are rich, poor, from a different country of origin, educated, seeking employment, and facing death. The mothers ranged in age from 36 to 49 years old. The age range of the children of these five mothers were from ages 5 to 16. The total number of children represented, both neurotypical and those with special needs, including my son, Will, is 13. The number of children with special needs represented in that total group of 13 is 8. The age ranges of those children with special needs were from ages 6 to 16 years old. Of those 8 identified with special needs, the following seven diagnoses were represented: Autism, Asperger's Syndrome, Juvenile Diabetes Type 1, Attention Deficit Hyperactivity Disorder (ADHD), Moebius, Cru Du Chat, and Cerebral Palsy. See Figure 5 for a detailed chart outlining the mothers and their children for reference as you read through the remaining findings.

Mother's Name	Mother's Age	CSN's Name	CSN's Age	Diagnosis
Lisa	45	Matt	11	autism
Barb	36	Haley	11	autism and Attention Deficit Hyperactivity Disorder (ADHD)
		Elijah	10	Juvenile Diabetes Type 1 and Asperger's Syndrome
		Issac	6	autism
Mary	49	Johnny	16	cerebral palsy
Kay	37	Jack	11	Moebius Syndrome and autism
Bonnie	42	Kristie	7	Cru Du Chat
Researcher- Lyn	41	Will	7	cerebral palsy

Figure 4. Demographic chart illustrating the diversity of age and range of disabilities of children of the participants in the study, “The Joyful Experiences of Mothers of Children with Special Needs Children.”

I did not ask for any detailed information about the diagnosis or disability of the child with special needs as it was not the intent of this study to define a complex diagnosis such as autism or cerebral palsy. I asked simply for the name, age, and diagnosis of the child for two reasons—to establish that the child of the mother I was interviewing did have a child with special needs and to show that I was not just focusing on mothers of children with only type of diagnosis. However, after asking for the child's name and age and diagnosis, two of the mothers gave in depth details about their child's

special needs. For example, consider Kay's explanation of her son Jack's diagnosis of both Moebius Syndrome and Autism:

Kay: Moebius is a paralysis of the 6th and 7th cranial nerve and Jack has what is called "the sequence" which means he has more nerve involvement than most. . . the criteria [for Moebius] is that there is a facial paralysis so there is no smile and they are known as the "kids who can't smile." It's a very rare condition. With the sequence, you will often get hand and foot anomalies as well as other anomalies along with other conditions. And, so we have been blessed with (laugh) (cynically) the whole lot of it! Jack is a right foot amputee; has had club foot repaired and has what is called brachydactyly which is the shortened fingers. And, there is like a 20 to 30 percent of the Moebius population will also have Autism.

Bonnie shares information regarding her daughter, Kristie's, diagnosis of Cru Du Chat:

Bonnie: Cru Du Chat is a chromosomal disorder where Kristie was born with her 5th chromosome or the P arm of the 5th chromosome deleted and some children have their whole arm deleted of the P arm or the 5th chromosome P arm and some people have a partial deletion. Kristie has a total deletion which means she has global delays which means she has delays in speech, you know—she had trouble with gross motor delays—with orally speaking and she is still very nonverbal and umm. . . besides the global delays of like speech and gross motor and fine motor and all of that—she also had holes in her heart and other things that when she was born that were incorrectly put together. So like she had a single kidney when she was born.

I have an eight page updated medical narrative that I keep for Will. I give it out twice a year to all of Will's doctors, schools, therapists, and home health nursing staff. See a very small portion that I wrote in my field notes after listening to Kay talk about her son, Jack:

Researcher: Will is seven and has Cerebral Palsy (CP). Cerebral Palsy is a neuromuscular disease caused by injury to the brain which can happen in utero or at birth. CP presents itself on a spectrum and Will is on the severe end of that spectrum because of his medically fragile condition. Will is nonambulatory, nonverbal, moderately to severely mentally handicapped, and has a gastrointestinal tube. He has had 22 surgeries, 10 hospital stays, and 32 hospital procedures. Johnny, Mary's son (Mary is participating in this study), also has cerebral palsy has an above average cognition and is medically stable, but he still requires the assistance of canes or walker to walk as well as assistance with some fine motor skills.

An outside researcher or reader of this study might not understand this impulse or need to explain such details about one's child. Each child with disabilities is very different. All disabilities present themselves on a spectrum and someone who does not know that individual child might assign traits or definitions to that child based upon their experience or knowledge of that disability. For example, when I first told a colleague that Will was diagnosed with cerebral palsy, she said to me, "Oh, don't worry. My nephew has cerebral palsy and now you can't even tell and he is in college!" My son's brain injury that caused his cerebral palsy was very different than her nephew's and/or manifested itself very differently. So, saying a name and labeling something does not

necessarily make one understand what that means. Lisa, a participant in this study, has a son, Matt, with autism who attends a classroom where he is in class with other children who also exhibit moderate mental handicaps. He was just potty trained at age five and still engages in parallel play or play alongside others, not with them. Barb's son, Issac, on the other hand, who also has Autism functions cognitively above average and is in a neurotypical classroom, but faces more behavioral issues than Matt.

It is important to note the complexity of the mothers and their answers to a seemingly straightforward question. No one in the study who also had neurotypical children chose to elaborate on any traits or characteristics of their neurotypical children even though they gave their names and ages. The demographic discussions emerged as the mothers revealed the following four themes of challenge, finding perspective, purpose, and planning for joy presented below.

Challenges: Sometimes It Sucks...

The dominant literature regarding the challenges, stress, and stigma were confirmed and despite my semi-structured questions that prompted discussions of joy, those "challenge" discussions were evident in the data. The quote headlining this first theme, "Sometimes it sucks" was from Lisa, a mother in my study and it framed the findings well because while it is sometimes hard and does "suck," the mothers talked in the same breath about fighting those challenges and finding a way to make the best of it.

Below find those stories of challenge, which include the challenges faced in the constant medical care of our children, taking our children outside of the home to do seemingly "normal" things such as attend worship or a family vacation, and the fear associated with the future care of our children.

Bonnie talked about Kristie's multiple medical problems:

Bonnie: She had four heart related [surgeries] and she had six surgeries before the age of three and four were heart related and two weren't. And the two that weren't were the bowel surgery when she was five weeks old and the other one was a Bronchoscopy because she had really small airways and she had so many problems during her five month old heart surgery that they worried—or I worried about—the open heart because she had to be reintubated so many times. . .

In reading her writing, Barb, and in the interview, Mary, shared their medical challenges.

Barb: When he was 15 months old- just after his booster shots- he started to have seizures. The last seizure he had was so bad that afterwards he remained unconscious. Seeing his tiny body on a stretcher in back, my mind was racing and I truly thought we had lost him.

Mary: I mean I almost blackout his surgery where he had his ankles stapled and his tendon's lengthened. And we thought he would be running afterwards but it was almost a year before he walked. Those were probably my darkest days.

Mothers of children with special needs have a medical story. Sadly most of them are not happy ones. People always say that having your child in the hospital or sick or dying is the worst thing one can imagine. We do not have to imagine it. We live it. Every time our children are admitted into that medical world, it is a death. Each time Will is hospitalized, I liken it to a part of me that dies and while it does grow back, it takes times and that new generation of that part of you is never quite the same as the old one. Susan Zimmerman (2002) talked in her book *Writing to Heal: Transforming Grief and Loss Through Writing* about feeling like one open large seething wound covered with a

hundred bandaids attempting to cover up the gaping hole so visible to everyone else. Four years ago, my son's pediatric gastroenterologist was also teaching a course for pediatric residents in the medical arts and asked me if through my writing group, I could access and share those stories of medical mishaps. The stories I collected from the ten mothers and shared with those residents that day in class had many in tears because they were so horrific. No textbook can highlight the human story and ours is sometimes quite dark.

My son's birth was a death. He was never born. He came out dead. There was no happy delivery, no photos, no taking the baby out to see the grandparents with a blue or pink hat on, wrapped in a striped hospital baby blanket. Will was born prematurely at 33 weeks via an emergency C-section. While he weighed 6 pounds and was 18 and ¼ inches long, he was not alive. The ethical line for saving a hypoxied baby is 15 minutes as the ability for a newborn to make a meaningful recovery with no oxygen source for 15 minutes is rarely possible. Because the doctors were unclear of how long Will had been deprived of oxygen, they proceeded to attempt to save his life. Had my husband been present (he was on assignment for the military, desperately trying to get to the hospital) or had I been conscious, we would have been asked whether or not we wanted this dead baby to be revived. Will was born with an Apgar score of 0 and was given two blood transfusions before he could be revived. Apgar stands for appearance, pulse, grimace, activity, and respiration and is the standard criteria used to assess a newborn's health at delivery. Will had bled out in utero and had lost 75% of his blood into his mother. His blood crit level was only 16, normal is within the range of 82-98. Will was on full life support and intubated. His initial brain scan showed Burst Suppression Syndrome, meaning no brain activity. Through some miracle, he did survive and has thrived more

than anyone thought possible, but his birth will always be framed for me as a death and the moment I knew that many challenges lie ahead. Kay framed it well when talking about her son's medically fragile needs which she knew prior to his birth and the additional challenge of being what she defined as a younger mother, "You just grow up in an instant."

While everyone could agree that the medical stories presented above are challenging, would one consider something as simple as going to church to be difficult? In the interview Kay, and through her personal writing, Barb, each talked about the challenges of doing this seemingly simple task that thousands participate in every week.

Kay: Is God going to think less of me because I didn't have it in me to take him, like we get there and we have an accident or people stare at us because Jacob is screaming the entire time—it's not their fault—you can't help but look. I used to be fearless. I used to say, I don't care who looks at me in church, we are going. But now, I don't have the energy to take it on. My freight train is slowing down.

Barb: To say Issac does not do well at Mass is an understatement. He is everywhere at once, constantly moving and making noise. If I bring snacks, he spills them. If I bring trains, he crawls around the sanctuary on his knees. If I bring books, he scoffs at me. I am constantly retrieving him from the windows, the Narthex, and the statue of Mary surrounded by candles and flowers. I often have to manhandle him back into our pew and am frequently hit and screamed at. Worst of all, though is the tackling of his siblings in the Communion line, only to shout, "I'm hungry! I'm thirsty! I want some too!!" and then fall to the floor in

front of the Extraordinary Minister of Holy Communion when he realizes that – yet again – he will not receive the Body of Christ today.

It takes me a minimum of an hour to get out the door to take Will anywhere. Gastrostomy tube or Gtube feedings, medicine that must be given or else a potentially cause a seizure, incontinent supplies, and orthopedic equipment are all time suckers. During my church service, the children leave for Children's Church. My child cannot go unless I go with him. I tried to take him a few times, but the loud music and unstructured environment was overwhelming and terrifying for him. And of course, besides the children's minister, I was the only other adult in the room. So instead now, I try to keep him with my husband and me in church. We have to sit at a pew by the choir in front so we have more open space in the front to navigate him. As if Will's braces, wheelchair, excessive drooling, screeching, and the fact that he is the only child in the congregation do not make us stand out enough, we also have to sit in the front for everyone to see throughout the entire service. I worked very hard to organize a special needs ministry at my church, but it was not well-received. I do not make the same effort to attend church as much as I used to. I feel closer to God than I ever used to but often alienated by His people.

Mary shared how she was raised a devout Catholic, even attending Catholic school. She stopped attending when she walked into church with her son, Johnny, for the first time and everyone stared at him. She said after that incident, she attended a spiritual retreat and was able to make peace with God but she never went back to church again. Kay's son, Jack, uses facilitated communication to write and he and Kay write together. This is something she shared that sums up our children and our feelings of isolation,

“Lepers come in all shapes and sizes. A leper is someone who is like an outcast. They may look or act different than most. I sometimes feel like a leper.”

Lisa talked about trying to go on vacation with her family where she and her large family all convene every summer. After Matt was diagnosed with autism, this anticipated ritual proved difficult.

Lisa: We always gather in one condo to celebrate always an occasion—a party or a birthday. There was a time when I had Matt in his wagon and I would put him in the wagon and we were doing laps around the whole complex. Because he couldn’t be in there [in the condo because of the noise] but I didn’t want to go home because I guess I just didn’t want to give up. And I kept picturing everyone else having fun and drinking wine and you know I just told my husband to stay in the condo because I was in a place if I stayed it wouldn’t have been any good anyway. I remember thinking, “is this it?” Everyone else is having fun and I am walking around pulling Matt in a wagon? I mean talk about a metaphor – he’s my weight and I am carrying him behind me dragging him. You know. . . And now it’s fine. Now he does better. And now it’s a given. One of us is going to go first. One of us will go with our other son for awhile and one of us with Matt a little bit. And if it’s one of the condos that has a playground outside maybe we will. . . I mean it’s not that it’s. . . it still sucks— it’s not that it’s better, but we have adjusted.

Whenever Mary is out with her son, Johnny, inevitably people will stare at Johnny, and Mary is prepared, always looking over her shoulder for who is looking. She noted that she just wants to say to people, “He’s got Cerebral Palsy” so quit looking at

him, quit trying to guess!” My husband and I took our very first vacation with Will when he was five. It took that long for him to be healthy enough to travel and for us to be brave enough to attempt it. We rented a beautiful ranch home on Lake Michigan. The three-hour drive took us almost five, but we made it with our mobility van loaded with the five days of necessary supplies and equipment. After day three and figuring how to carry a forty-five pound boy onto the beach, how to keep the sand out of his stoma site, and restaurants were accessible, we finally started to relax and even feel like a “normal” family on a vacation. As we went out for a sunset walk, an old man with a dog approached us and asked, “What’s wrong with his legs?” My husband, more quick-tempered than me, retorted, “I don’t know. What’s wrong with your legs?” Knowing that he had offended us, he then asked if our son would like to pet his dog, trying to make some kind of amends. My husband and I, both astounded, just walked away, defeated once again by this constant reminder that we too are not “normal” and nor would any vacation ever be again.

The greatest challenge and worst “suck” is the future of our children. Kay shared her fears of Jack outliving her.

Kay: It’s terrifying. I mean we have been working on the will and the Letter of Intent and we are really focusing on this transition to adulthood stuff and it’s terrifying to think . . . Who will ever take care of him as well as us . . . ? I can’t imagine—I can’t fathom anyone loving him anymore than I love him. And who is going to know every little . . . noises or . . . Who is going to know that . . . ? Who is going to learn that . . . ” Who will want to . . . ” ONE DAY LONGER! I pray that

all the time and sometimes I feel so badly but I do – I just say- God if I could just live one more day . . .

My response to Kay was that I understood because it is my prayer too. And my exact words to her were, “That’s a hell of thing to pray for, isn’t it?” Most people pray that their children will bury them, not the other way around. But the fear of guardianship, institutionalization, and money are a constant for mothers of children with special needs. Because we are so much more isolated and excluded, our families and friends cannot or will not accept the future care of our children. Lisa said that this fear keeps her up at night. My husband and I have taken significant steps to secure guardianship tempting our wonderful friends with enough insurance money to be able to secure twenty-four hour day care for Will. But our lives are what they are and we have to keep moving forward. We have to keep living and find a way to overcome those challenges.

The challenges shared in this study represented that were equal to discussions of how these mothers continue to find the strength and challenge the challenges presented to them. After Kristie survived her early medical challenges, Bonnie was faced with new challenges, but instead of caving to those, she was determined to find people who could help her helped her daughter. She categorized those who did not help her as “takers” and those who helped she and her daughter as “givers.”

Bonnie: But that’s what surprised me—how hard it was to learn how to be a mom with disabilities or to be a mother to a child with disabilities—it was harder than you realize- it is like learning a foreign language in a lot of ways because you know, it’s not like anything you or I went through because we went through neurotypical classrooms and then you don’t even have any idea how to do it well

because no one is trying to help you along the way—they are just trying to take from you—like the school districts so it's like we rely on each other- which is why the special needs moms group is so important for me because I feel like it is people who get it and who want to help you find the best things and the best for your child . . .

Kay shared her determination to lead a typical life in the face of those challenges and as a young mother with a son with special needs and twin girls on the way:

Kay: I mean I was so young— just twenty-five, and you know you just grow up in an instant. Yea, and we have the NGTube [Nasogastric Tube used for feeding] hanging and he was double cast at the time and he had two casts on his feet and he had a splint—they were trying to straighten his finger deformities so they had this splint on just one hand and (laughing) and I just go walking in to the sitter like, I have to go to work! I just didn't know any different. But it wasn't foreign to me so I didn't think it was foreign to anyone else. I didn't think it was a big deal. We went everywhere with Jack. I had family out east and we used to stop at restaurants and tube feed him at the table and we would get looks but it didn't register to me what the big deal was. Just like you hand your baby a bottle—you know—no big deal. I fought for him. He will go to regular preschool damnit. He will go and do. He has done 4-H, every Gymboree class, every Kindermusik . . .

During the interview, Bonnie talked about how her own personal condition of Huntington's Disease which is terminal and of course, has affected her perspective in raising a child who has special needs.

Bonnie: I have had to stay in the present because she needs me so much. I still feel extremely blessed every single day—extremely blessed—because I just feel like, God— even for all the sorrow—I have Kristie who is this bundle of love who is this love bug—I feel loved—I do—I feel blessed. Do I have moments where I feel guilty? Yeah. A lot. And do I have moments where I am like, I can't believe I am going to be so sick that I am not going to my kids graduate or get married or any of that stuff and do I feel like that's not fair to them or not fair to my husband.

Consider Mary talking again about those earlier darker early days when Johnny was recovering from surgery:

Mary: I am surprised by Johnny's uh. . . resilience . . . We thought after the surgery that he would be running afterwards but it was almost a year before he walked. Those were probably my darkest days. And he had to relearn everything. And as mad as I was, Johnny was never mad. He taught me that.

Or Barb talking about the challenges of raising three children with special needs:

Barb: Well, first of all, it feels tired. I am always tired. Um . . . there is a lot to do and a lot to stay on top of—a lot to keep track of. That is the first thing and the second thing is that is an overwhelming responsibility because um... with kids with special needs, the future is such a big question. It's not an 18 year old job—not that parenting is . . . But you know—their dad was abusive so not having him there everyday is a gift—now that he is not there anymore so . . .

Lisa shared the well intentioned and often shared clichéd wisdom of her sister who tried to explain that things will be easier or better. Lisa, found her own source of wisdom to follow:

Lisa: My sister has three boys – they are grown now and in college. She always says, “Just when you don’t think something will stop, Laura, it’ll stop.” Whether it will be them not sleeping well or behavior at school and then you move to something different. It’s really not true. It’s Ground Hog Day [referring to the movie about a man who wakes up and has to relive the same day over and over again]—the Sonny and Cher song (cynically)—it’s Tuesday all right—we are going to therapy and Matt is going to want to read *Click Clack Moo* again like he does every single night. So it’s maddening but if you can flip it and you really have to flip your own attitude. I mean at least I know what to expect—at least I know he is going to love that. He still wants us to sit there and he still enjoys reading to us- I mean you just have to keep finding the joy and finding the perspective.

Overcoming the challenges and finding that joy and perspective is so freeing. I do not measure my joy by anyone else’s now but my own. Will taught me that too. I do not have to worry about his standardized test scores, saving for college, or signing up for every art class, T-ball, or soccer league. All I have to do is love him, take care of him, and make him happy while he is here.

According to the dictionary, the word “joy” has several denotative definitions including the “expression or display of glad feeling,” an “emotion of great delight or happiness caused by something exceptionally good or satisfying” and “pride and joy”

(“Joy,” Dictionary.com). For mothers of a CSN, their child was very much a cause for joy and is defined as their pride and joy. Understanding that children with special needs are a source of joy allowed the mothers to define and ultimately express that joy. Mothers of children with special needs children were not shaken by imperfection. Instead mothers of a CSN celebrated and experienced the lessons their child taught them and the pure joy their child gives.

As noted prior in the literature review, in a study conducted in Australia titled, “Missing Discourses: Concepts of Joy and Happiness in Disability,” through content analysis and software called Wordsmith Tools, the authors created word lists of repeating words used in policy texts regarding disability and in individual and focus group interview transcripts given by and about people with disabilities, and in focus group transcripts (Sunderland, Catalano, and Kendall, 2009). While I did not have access to this tool, nor did I use content analysis, there is no question that the following words and phrases were repeated over and over in the identification in the coding process and inevitably established themselves as deposits in my word bank: “purpose,” “get it,” “chosen,” “simple things,” and “his or her joy is my joy.” The mothers defined their joy by explaining how their child with special needs has given them a purpose and it is through that purpose that they have come to be transformed and get “it.” Many shared that they feel chosen and all of the mothers expressed transformation and have redefined joy in terms of their cause for happiness—their child with special needs.

Purpose: I learned my own power; I get “it.”

Lisa explained that her child with special needs has given her “clarity about what’s important.” In response to the question asking Mary how she felt about being a mom to a child with special needs, she shared how Johnny has helped her “learn her own power” and “empower” her:

Mary: Empowering . . . um . . . but at the same time . . . horrifying. Learning my own power. Just depends on the day and what I am doing. It’s not like you have the same job everyday or the same feelings everyday. But overall, I think it has made me a stronger person so that is why I say empowered because there is very little that I can’t do because I have already done with Johnny. Where before somebody might have said—I need you to go in there and talk to that room full of doctors and I’d be, “Noooo!” But now I’ll march in and say this is what I need if that is what I need.

Barb shared that her experience with her children with special needs have given her a “purpose” and now she “gets it” or what is really important.

Barb: It’s also um . . . given me purpose. And this is the part that is my experiences and just I think a lot of people when you become friends tend to be superficial for a long time and always tend to be your best foot forward and a lot of times — a lot of days— I don’t have a best foot to be forward—when we have bad days, they can be really bad days and to be able to have friends that share that experience. I mean I just think we are a lot less superficial and a lot more real—I mean we [mothers of children with special needs) get it—we get what’s important.

The mothers explained how this purpose has shaped how they live and they question what would have come of them had they not had this child with special needs. Mary talked about living a prioritized life, Kay questioned who she would be if she were not Jack's mother, and Bonnie shared how Kristie has made her a "better person":

Mary: Knowing and actually living your true priorities. It's one thing to say this is important to me. It's another if you have to live it. I mean you know?

Kay: Don't you wonder? Where would I be? What would I be doing? Would I have been as good of a mom—to all of my kids.

Bonnie: I am super proud to be Kristie's mom—Kristie has made me a better person! She has. I feel like she has softened my edges—she did. She softened my edges. I feel like now I look for the person walking through the door in the wheelchair, I look for the person needing help in the parking lot—I do. She has taught me a lot about . . . I never had any contact as a child with any children with disabilities except for that they were all in another room—they never even brought them over. So I was never around them so I just thought they were extremely different from me. I realize how much you want people to know about—that this isn't so different and this is someone's life and how accepting I want other people to be and so Kristie has definitely made ME a more accepting person of differences . . .

Lisa explained how having Matt has transformed her by "sharpening the good and the bad" she brought to motherhood and how that transformation is practiced.

Lisa: It [having a CSN] has definitely made me who—I mean I am not much different than I was before but it has sharpens the good and the bad you know—

some of my downfalls are worse now like my issues with what's going to happen next, lack of security, abandonment issues some of those things I am dealing with from my childhood are probably worsened. But on the other side, I am more thoughtful than I have ever been. I try to help other people because I know how much I need that—a kind word—you know just kindness . . . thoughtfulness—I think sometimes from the inside it's impossible to know how much it has transformed how I think. I do . . .

Lisa continued by sharing how because of this transformation, she wants to be with others who also “get it.”

Lisa: I have been transformed through Matt. And I know I get annoyed with people who don't appreciate—I see—like especially moms out with their kids who have 2 or 3 typical kids, dragging them around Target, yelling at them and I always say, maybe at home they have a crappy home and no husband or money and they are stressed out but I don't know to me like I think you have it so easy why can't you just enjoy your kids? You know? I don't have patience anymore for people who are inauthentic and who put on heirs. I would rather be anywhere than sit among a few people who are all about themselves who don't get it.

In the interview, Lisa, and through reading her writing, Barb, continued to explain how transformation then leads to the experience of joy:

Lisa: I have not just survived but triumphed. I feel like I have triumphed. I feel like I have triumphed. I really do. I have seen the deepest of the deep. I have been down that hole. Once you have been in the depths of despair and I have been there

– have been so low—like frighteningly low...But once you have been there (crying) . . . Nothing. That’s why when you are joyful . . . you get it.

Barb: There are many challenges to having a kiddo with special needs, but sometimes the perspective they give you on the world is amazing. Nothing tops their determination. While my son is an amazing artist, he actually struggles with fine motor skills. He has always struggled with tying shoes, and so he was so disheartened with his new shoes. But instead of pouting, he sat down, he let me show him several times and after about at least a 100 times of trying, he did it. Some people say they can’t imagine how hard my life is. I’m wondering if those people walked in my shoes, if they would miss the miracles.

All of the women talked about the writing group they participate in and having other moms who have been transformed and who get “it.” Barb explained how comforting it is to just be able to jump right into the middle of a story and talk about her children’s special needs to those who get it without having to give them a context because we all have similar or shared stories or experiences. Bonnie concurred sharing, “The special needs moms group is so important for me because I feel like it is people who get it and who want to help you find the best things and the best for your child.” Lisa explained that being part of the group is “comforting” and “normalizing” for her because it says to her, “you are not alone.” It is one place that we do not have to translate our children or our experiences.

For example, we can talk about the Individualized Education Plan Case Conference without explaining what that is and why it is typically a tense and challenging process because we all experience it and get “it.” Lisa shared in the interview that when

Matt was diagnosed, she accessed books about having a child with special needs and the books always related something similar:

Lisa: Your friends will be the people that have special needs kids and she notes that at first, she did not believe that. She assumed her close girlfriends would remain in that role. And I still have some of those friends . . . but they don't get it either and these are great, great women—really good women but I don't talk to them about Matt much anymore because it's impossible. I will mention stuff and they will ask and I appreciate that but you just can't really get it unless you know and you walk those shoes and walk in those shoes.

When my son, Will, was one year old, I searched for a support group, desperate for resources and to be able to talk my new medical and special needs vernacular that had permeated my normal speak. All of the support groups I attended had guest speakers and were designed really to give information. What I noticed is how long the mothers, including myself, would stand around after and talk, sometimes even moving onto a coffee shop. Hours would pass as we talked, cried, and laughed about the topic presented, our current challenges, and our fears and joys. I learned more from these “mother experts” than I did any of the guest expert presenters. I decided to begin my own informal support group and to try to access that “thing” that was happening after those meetings. I did not know what it was yet, but I knew that for me it was so as Lisa said, “comforting” and “normalizing” and I wanted to share that with others. As a writer, I thought that what we refer to in education as “think and ink” or thinking about a question or a topic and then writing about it would provide a format for the structure of this support group. So the Indianapolis Special Needs Moms Writing Group was born. I started out with five

women and now have fifty women on my list, twenty-five who actively participate. We think about a topic or writing prompt, which I present, we write, and then we share. It is through the gathering and sharing of that writing that we are able to not only share resources, but our challenges, joys, and purpose.

Providence: Why was *I* chosen?

Another theme that arose was being “chosen” to be the mother to a CSN. Barb talked about how having her children has helped her to understand who she is and what she is supposed to be doing. She talked about God’s plan and being chosen.

Barb: I get just really surprised by the awesomeness of it—why was I chosen to do this? You know- there must be a reason that I got to be their mom. Umm . . . So the times it is really hard I remember that if someone had a different mom they wouldn’t . . . I don’t know what the right word to say is but you know—I would just be their mom because I have a special set of something that is particularly geared towards their needs and so when I get most disheartened that is when I remember that I have them for a reason and you know I can do it.

While Kay waivered on whether or not she was chosen in a spiritual sense, she relayed that being Jack’s mother is a “huge” part of her identity, more so than even her identity as a mother to two neurotypical children.

Kay: I don’t know. I don’t know any other way. I have never known just being a mom. I have always been a mom with a kid with special needs. I am Jack’s mom. That is a huge big part of our identity. I don’t think it’s that God got together and you know with the angels and said, “Let’s give all the special needs kids to the . . . I feel like it’s—because we are able or empowered or have that . . . I don’t know.

I have gone back and forth. Sometimes I think if someone out there is going to have this kiddo—I am glad it’s me. If Jack had to be born with these issues, I am glad it’s me.

Lisa shared that she does not believe she was chosen and her reasoning is, “why would anyone choose this?” She continued by explaining:

Lisa: I don’t believe that [being chosen]. I think it can happen to anyone. I think some people handle it better than others and I think in this group we are blessed with meeting incredible parents who are very proactive who look for support and look for those resources but I think there are people who have fallen apart. I don’t believe I was chosen. I don’t believe Matt was chosen to have Autism. Why would God choose that? Why would anyone choose that for a child? We do the best we can. That’s my personal opinion.

Barb shared a selection from a piece that she wrote titled “Profundity.” In that selection, she shared, “My children give others the opportunity to be Christ—to show kindness, gentleness, and patience.” Barb felt that she was born with certain traits like being positive and calm and those traits made her worthy of being chosen for her children with special needs. Bonnie explained that she too is glad to be Kristie’s mom because she had the education and the resources to give her everything she needed:

Bonnie: I really feel like I was supposed to be Kristie’s mom cause you know I was in the medical industry and was super comfortable calling on doctors and super comfortable calling on the OR [operating room]—I mean I called on the OR people for 9 years of my career . . . I did heart stuff and so I saw all that all the time and I was not – I did not think doctors were God and I know that some

people leave with a doctor degree that are the best in their class and some that were the worst in their class and they are still called “Doctor” so I realize that you know—I always had to find the best for Kristie and that made me ask the right questions and taught me to not be afraid to ask the right questions and find the right doctor and go to another doctor and get second opinions and it made me comfortable in that environment.

The mothers shared different answers to whether or not they feel like they were chosen, but everyone was grateful to be their child’s mother. I concurred. I used to think that having a child with a disability was the worse thing that could happen to me. When trying to get pregnant, I would even vocalize this. I would justify my argument with the fact that I had grown up hard. And I did. I grew up poor and from an abusive family. I worked hard to put myself through school and to make it. And when I met my future husband, Jim, a person I loved more than I thought possible and we moved into that upper middle class lifestyle, I thought this is it. I deserve this—I have worked hard for this. I will have perfect normal children because I have paid my dues. My burden of the past is no more. In the interview, Lisa talked about this as well, “I mean I wish I could say—Okay, this is our burden—nothing else is going to happen—but I mean I am not naïve.” When you become a mother to a child with special needs, “everything becomes crystal clear about how fragile life is how fragile family is and things can turn on a dime.”

I realize now what a ridiculous way that was to think. Who is it okay for this to happen to? My friend Bea used to say that having a baby is like a crap shoot—you never know what you are going to get. Amen, sister. But what I perceived as the worst thing has

been in fact, the best thing. I do not think now in terms of “what did I do to deserve this?” But rather “God, what did *I* do to deserve Will?” I have been able to get it now—now while on this Earth. God has shown me what life is really supposed to be about. I see that lesson every day in Will’s face. I always tell people that when I look at Will, I see God and his plan. Jim left corporate America, took half his salary, so he could be home more. I left my job and worked from home part time so I could devote my energy to Will. We sold our upper middle class home and traded our life for a working middle class lifestyle. We put ourselves in debt covering medical and other expenses for Will. But, we love our work now. And we love our community. We love our God. We love each other more. And we love Will, more than we ever thought loving a child was possible. And this *is* so much more than coping or learning to adjust, it *is* transforming. Like Lisa, I no longer make small talk. Will changed my world, my thinking, and my speak. And my studies, my research, and the future publications of my dissertation will allow me to change other people’s speak to stop seeing mothers of children with special needs as tragic. Will is the greatest lesson and I have had the honor of learning. I was reminded of and wrote the following in my field notes after hearing Barb talk about being chosen:

Make a joyful noise unto the LORD, all the earth: make a loud noise, and rejoice, and sing praise. Sing unto the LORD with the harp; with the harp, and the voice of a psalm. With trumpets and sound of cornet make a joyful noise before the LORD, the King. (King James Version, Psalms 98:4-6)

Will is my muse, my joyful noise—the noise that woke me up and has allowed me to experience the extreme pain and real joy. I rejoice in him and in this gift God has given

me. His death and birth has changed me—indelibly and forever. I see, hear, celebrate, live, dream, love, and hope differently now.

Pure Joy: Their joy is my joy!

Pure joy was another revealed theme. Below hear Lisa and Barb read from their writings and Mary from the interview sharing illustrations of how joyful their children make them and how they have come to define joy as a pure joy because it comes through their children:

Lisa: I am grateful for so much when I think of Matt. First of all, just to be his mom and to know that I can love him the way he needs to be loved. I am just grateful for the chance to start over each day because there are some days when I don't do a good job and he is so forgiving and sees me as the center of his world.

Barb: We rejoice each new skill—greater independence, riding a bike, finally mastering pronouns—and celebrate who we are NOW, not who we may or may not become.

Mary: I am a big cryer. And I told Johnny— and I believe it's true—that I cry because my heart is so full. When my heart is so full, I can't breathe so the tears have to come out so I can breathe.

Kay shared an excerpt from something she wrote titled, "The Perfect Day" where Jack had been working as the manager of the football team and the entire team came out to support and raise money for Autism awareness.

Kay: Then up pulled an RV [recreational vehicle] filled with the entire 6th grade football team! Out they poured sporting their team jersey's and shouting "go team Jack!" Immediately the boys began high-fiving Jack and other team members, and off they went pushing Jack in his wheelchair. I never pushed that wheelchair again until the end of the walk when those same 6th grade boys encouraged Jack to get up out of that wheelchair and walk to the finish line. With arms around Jack's shoulders, the boys escorted him to the finish line where they created a human tunnel with arms raised. Not only a victory for the 6th grade team but a victory for Mom and Dad who stood with tears in their eyes as they witnessed the "perfect day."

In the interview, Kay and Bonnie both shared the same ideas of their child's joy being their joy.

Kay: Jack's joy is my joy. What he loves what he needs and seeing him enjoy all the simple things— that's my joy. At the end of the day, I am going to fight hard for him, but at the end of the day, that's not what really brings me joy—what brings me joy is just seeing him truly content (cry) and okay—you know?

Bonnie: And I know if she feels that joy, then...I feel that joy. But I can still feel her love without her ever verbalizing it you know—by squeezing her face against mine—or just yelling for me or something like—just jumping up and pointing to everyone...

Barb helped shed light on this as well explaining that with her children, she finds joy in their progress. So much is placed not on progress, but perfection. Effort and

progress are in the very end so much more important than perfection. “We rejoice each new skill- greater independence, riding a bike, finally mastering pronouns—and celebrate who we are NOW, not who we may or may or may not become.”

Mary shared that she was used to filling out medical and information forms regarding Johnny and after years of doing that, she was so tired of talking about what she calls all the “no, no, no’s” or deficits her child with special needs presented with so instead at his initial evaluation for preschool when prompted to describe him, she simply wrote, “pure joy.”

Mary: And it said, “describe your child” and it had several lines and I usually take up all the space but I just wrote two words, “pure joy.” And they said, “We’ve never had anyone answer it like that.” And I said that’s the easiest way to say it. I mean I can’t look at him without saying, LOOK AT HIM! Yea! I mean you know normally I would take up every little bit of space but I just said, “pure joy.”

Lisa also had a story where she defines a rare spontaneous moment of what she also describes as “pure joy.”

We went to Barb’s like a month ago now—maybe more- um . . . you know just my husband was out of town with our other son and she said come over we’ll have some pizza and you know she understands with Matt because she has kids of her own with these issues. So I said, all right I’m coming but I don’t know how long I will stay . . . you know . . . (laughing). But you know we were there for like 3 hours! It’s kids all over and there were even neighbor kids over too so there were like 6- her kids plus 2 more plus Matt. He was upstairs, downstairs—I mean he was building something with another little girl. I just sat there having pizza

with Barb hanging out for hours. Even at one and a half he was just having a lot of issues like being other places so I just like like—so happy—happy for myself and happy for Matt and it was such a simple thing but that joy . . . I got in the car and I was just like I said to Matt, “that was so much fun.” Matt said, “Had fun with Issac, my friend Issac” and it was a big full moon and I was driving home (crying) like that was just pure joy . . .

Lisa went on to explain that when her husband travels out of town she misses him and that friends will invite her over but she just makes up an excuse because Matt would not have any fun and that makes it not only not fun, but sometimes even difficult for her. “I should be able to do this” but you know I am way past that—I am just happy when I have those moments happen.” Those moments of being able to go and do activities normally, she said, are like being plugged into a charging station—they help sustain her. She compared those moments to her neurotypical son, “when Matt does something that makes me joyful, it feels more, it definitely feels more because with my other son, I expect it.”

Mary expressed that she tires of the pity she receives with Johnny. She wanted people to understand that “the joy which way outweighs anything else.” Barb defined joy as something that comes from “deep inside” and that her children are always joyful. Bonnie also shared that “we are all born with joy – I just think some people lose it . . .” and I added to that interaction but “our kids keep it.”

Something that really surprised me was how when the mothers talked about their children being their joy, how much joy they illuminated in how they said it and with their body language. See an excerpt directly from my transcriptions below from Kay and

Bonnie to get a glimpse of how the mothers just light up and share such touching sentiment when they talk about their children. I actually interacted with Kay as they talked because I also could not contain my joy. I have listed myself as PI for principal investigator and K for Kay and B for Bonnie.

PI: So how can a kid who can't smile show his joy [in reference to Jack's Moebius Syndrome which has paralyzed his face]?

K: Pause . . . OHHHH . . . Happy noises. We are fluent in "Jackobese". Jack is non verbal, completely but his happy noises are just clear to just anyone who would meet him. You would know in an instant whether he is happy or mad or sad. (making roof raising motion).

PI: Yes! We call it . . . "The roof!" (Kay joining me as we both sing it and laugh.)

PI and K: "The roof. The roof. The roof is on fire!" (both making the motions)

B: Cause they say she is always a jumping bean- totally- she is a jumping bean and she jumps up and down to show her joy . . . yeah . . . (laughing)

PI: What is it that you always call her?

B: Kristie bug, lady bug . . .

PI: That's right . . .

B: My Kristie bug . . .

PI: That's so sweet . . .

B: Yeah, I just love her. She is the sweetest thing.

PI: She jumps to show her joy!

I wrote following in my journal two years ago and I think it summed up the themes of purpose, providence, and pure joy.

Some days the challenges outweigh the joys but when those joys come along, they are so amazing. You feel them so intensely. The challenges are always present. When someone has a child with a broken arm, it is a challenge but that challenge is fixed and eventually life returns to what it was before that broken arm. Our children are never fixed so after awhile of living with so many challenges, we almost become numb to them. I liken administering food down Will's G-tube to doing laundry. I do it many times a day, every day. It is routine. It is not a challenge anymore, just my "normal." I think sometimes people in the school or medical community think I am being callous when I recite Will's medical history without becoming emotional, but I have to recite that damn script a thousand times. Every nurse, doctor who enters a procedure room for one procedure—pediatric resident students, new therapist, new instructional assistants, new teachers, etc . . . It is hard to hear, but not when you have lived it and told it over and over and over. It loses its effect on you—thankfully because I would not want to remain there. When we have to cancel something because Will is sick or we have been up with him for thirty-six straight hours and then go to our jobs or hold him down while they try to find a vein in his weak arms or watch him endure painful recovery from surgery, people will say to us, "I don't know how you do it." I do. You just do it. One moment at a time; one step at a time; one day at a time. So when those joy moments come—Will finally making a sign to communicate, Will taking a bite of real food, Will loving the zoo—you realize what a gift that is and do not just observe it, you feel it. When I emerge from that darkness and feel the joy—it just runs through your body so intensely that you

feel as though you can make it— that it will be okay and that he will be okay and that you will be okay.

Consider that all of the words in our word bank present themselves on a word continuum. We have many ways to talk about joy in our language. See figure 6 below for an illustration of how we might place words of joy on that continuum.

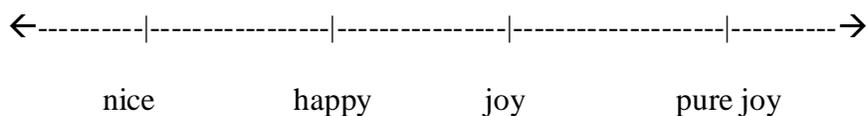


Figure 5: Joy word continuum explaining how mothers of children with special needs define the word “joy” when defining their joy of having a child with special needs.

We talk a lot about being happy, but rarely do we talk about joy or pure joy. What fills our heart? What makes us feel the rapture of pure joy? According to these mothers of children with special needs, it is their children and it is more than just “joy”—it is pure joy.

Joy? It’s The Simple Things.

Another important theme to emerge from the study was that joy is the “simple things” or the “little things.” The mothers repeatedly used those two phrases when referring to joy and gave multiple examples of what those “simple things” or “little things” are. Mary illustrated that joy was as simple as a new pair of non-orthopedic shoes. Lisa explained it as reading and playing the same books and games every day with Matt and having no agenda filled with school, therapy, or respite rehabilitation. Barb shared a story of one of her sons being able to watch an entire movie and as a successful

sledding adventure down the street from where they live. Kay defined it as a tickle game with Jack and him joining the Christmas family celebration and enjoying it. Bonnie told stories about Kristie's Bert doll, playing with a new kitten, and being surrounded by the people she loves. There were so many stories and this dissertation study does not allow me to share them all so below find key examples.

Mary: Umm . . . Johnny had been walking with his braces—I guess he was close to five and umm . . . and he is . . . um . . . His doctor said Johnny is doing really well and I think he could probably get regular shoes without his braces and not have to wear them everyday. So we went to the store and Chuck [Mary's husband] found a pair that I am pretty sure was blue and yellow— like the Pacers and that's who Johnny was liking then. And I just remember Johnny just stood up and put his hands on his hips like Superman and we said go ahead and walk and he was almost running— he was marching and everything—I am going to cry (crying). Anyway, he was just so proud of himself . . . That's a joy story.

Lisa: Anyway he is so into the story *Click, Clack Moo* and he like reads it with intonations because you know he had the CD/DVD and it's Randy Travis so he speaks it with a southern slang and Matt is so good at imitation—you know it's part of his echolalia [a trait of children with autism who parrot back words or phrase that they have heard] and all that stuff. But he is like “Duck was a neutral party” (speaking as Matt would say it) and he reads it like an adult and he looks at you for your reaction and it is so funny. . . I can really just enjoy those simple things. He will want to play three little pigs and he'll just get his blocks and build

three houses and his little pigs. It's just the simple things. Simple days. No expectations.

Barb: Well okay, Saturday they . . . we got to go to a lights up, sound down movie and we didn't have to pay because it was a special needs event and it was the first time that Issac had ever sat down through a movie and that was just you know—joyous. Come home and ate lunch and it just snowed and snowed and snowed and I live five minutes from a huge sledding hill and I thought I am just going to try it—I am going to take them all and Elijah was complaining because you know that is the thing, whenever we go anywhere, it's just me. You know so . . . if someone needs to go to the bathroom, it's just me. They are all scared of public toilets—they don't go by themselves and if Elijah's blood sugar takes a dive—it's not like I can send him home—it's just me and so sometimes it's hard to get up the nerve to just do it. So I am like alright, let's go for it. We went and no one was there and we had the best time—the best time— there were like only three other families there and I was able to take them all up and give them all pushes. A lot of people live like they are waiting for the next big thing—waiting for vacation or waiting for summer or you know whatever it is. We don't live that way.

Kay: But when we tickle him or something and he loves that—he loves to be manhandled and he thinks that is the best but you have to wait for his cues and he has this way— his mouth will actually go down which is sort of his smile or he opens his mouth (demonstrates) which he does have the ability to do which is nice

because he will open his mouth. He is very simple—you know—I think that is neat to see ummmm typical kids versus kids like Jack or like Will. He just wants to love (crying). The attention is worth more than a gift that we can get him or a thing we can give him- ummmm like Christmas mornings...we would beg him, “please Jack, open a present!” He could care less . . . He could care less what’s in the package—he could care less—and it’s overwhelming for him and always every year it’s always a disaster Christmas morning until finally like 2 or 3 years ago, we decided to let it go and we let him come down the stairs when he was ready and sometimes he would just sit and just listen (crying) and he loves to listen to the girls’ joy and that’s his joy (crying) and then he will walk right by us and we are all opening gifts and the girls are going bananas and he will sit in the kitchen with his back to us and just sit and listen—but he can’t come in—it’s too much to be there—so his joys are so simple— his Christmas morning is me rereading the same book literally since the day he was born titled- ironically—*The Day You Were Born*. We have gone through several of them. He knows every word and he is thirteen and we still read it every night and I can do the whole thing without looking—we just pull the book out for giggles and we have this little routine where I touch his knees and we have this whole little thing where we act it out—you know and he knows the line before and he covers his ears because he knows I am going to tickle his ears— and that— that is his joys—right there—the simple, simple things . . .

Bonnie: At Halloween we had a Frankenstein outside and she would look at it and point and when it would light up, she would go “ooooo” and make this scary face and I would say, “You are not scared of the Frankenstein- you aren’t scared” but when it wasn’t on when she got home off the bus cause she knew I needed to turn on the switch and she knew it was a blow up Frankenstein . . . And she would look at me and go, “(blowing noise).” She was trying to convey that she wanted the blow up Frankenstein and she would be so happy that she would jump up and down in front of Frankenstein and go outside in the cold and kiss Frankenstein. It’s not about the presents and stuff—it’s all about the lights and happy things around her. The simple things . . . and she is just blown away from it- like her sitter took her home to meet her cat and it was the greatest thing on earth . . . she wanted to chase it and this cat would be around the corner and it’s tail would be sticking out and Kristie was on the floor laughing.

Bonnie went on to tell stories of how because Kristie is nonverbal, she jumps and “belly laughs” to show her joy. And what makes her jump for joy are flipping through books at the library, grandpa tickling her, and being with her brother. Bonnie reiterated that joy is the simple things.

Bonnie: I never knew she could be so happy and convey she could be so happy and it takes such a little amount to make her happy and I mean if you just tickle her or play peek-a-boo or walk around the corner, I can make her laugh, I can make her world, make her life and with a typical child, it is not like that—you gotta take them to the movie, do these parties, and do this but with Kristie or with any child with disabilities—it takes so little to make them happy.

Lisa concurred with Bonnie in her discussion about Matt:

Lisa: He loves to be outside, going for a bike ride with us or going to the park just kind of where he can be himself and there is no agenda placed upon him and no expectations of you know whatever we are doing therapy. He can be himself and be silly and say his silly things and um... and he knows now he is being silly. He will look back at me and say "So silly" or "You are so fresh" because I used to say to him when he was little, "Matt, you are so fresh" when he would say something (laughing) just how he can be himself which I think how any kid feels but for Matt so much of his time is spent trying to be what everyone wants him to be and live up to their goals and being at school is so stressful for him that really just being at home is so delightful and so simple. It is so simple to make him happy which is a huge plus. You know? He is so simply pleased and it makes it easier in some ways to be his mom than a typical kid. He's easier to please.

Each time I interviewed one of the women and I heard them sharing their stories of simple joys, I wrote down the simple things that brought Will and I joy: grandma and grandpa, friend Ann, Raffi music, Cat in the Hat, trotting on a horse, Will napping with Daddy, help me push the buttons on the DVD player, watch football, walk outside with Mommy, bath time, and the sound of the water coming in on the shores of Lake Michigan. These simple things are Will's greatest joys and they are my joys. His joy is my joy. Similar to the other mothers in this study, it is not the material things that bring Will joy, but nursery rhyme songs, games that include particular sounds, and his favorite people. As Bonnie explained, neurotypical children require material items and social events, while our children just want to be loved and as Kay clarified, love back. Barb

shared that with her three children with special needs, “They know at a really young age that life is too short to not to get bogged in the stuff that is really not important . . .” Is this because children with special needs suffer from deficits in their cognitive and social abilities or because of their intuitive and clearer understanding of this purpose they are here to teach their mothers?

Planning for Joy: They just want to play!

A final theme that emerged which is critical and adds to the layered complexity of how mothers of children with special needs define and experience joy is that joy takes time, effort, and planning on the part of the mothers.

Barb explained how she has to prepare her children with special needs with an exit plan for what she hopes will be a joyful experience.

Barb: I think that because I have all these kids with all these diagnosis, I expect or anticipate the worst possible circumstances and so often I am pleasantly surprised. Like I think we are going to go and everyone is going to have a meltdown and it’s going to be a nightmare and very often I am pleasantly surprised by kids that are calm and I think—you know—I could change the way I think about it but because I think this is going to be a nightmare, I sit down with them and I say, “We are going to do this and then we are going to do this and this is what you should expect”—and by giving that set of expectations that when it comes at them, they know.

The following is an example of exit plan that Barb wrote about regarding her son Elijah trying martial arts.

Barb: The first night I prepped him. “We are going to this class and we will meet the teacher and you can watch and you don’t have to participate. If you don’t like, you’ll never have to go back. If you behave, afterwards, I will take you to the library” which is a treat for him. He said, “fine.”

“I’m not gonna like it”

“I’m weak”

“I can’t do Karate”

“I’m not strong”

“I’m weak”

“Weak”

“eek”

“k”

Once this litany began, it repeated—before dinner, after dinner, in the van, and even in the dojo. And then the miracle began. As soon as the Sho-Han [instructor] started speaking, it was like he was the pied piper. Elijah participated and asked to go back!

Bonnie and Mary shared how much their children loved people so they celebrate the joys with all of the people who their children love and who love them. Bonnie had to rent ramps for her house so the children in Kristie’s class who are in wheelchairs could attend, seek permission from the school to send home invitations because the school prohibits this sharing of personal information, and hope that Kristie’s “fan favorites” came.

Bonnie: We try to surround her with people. Like last year, I invited her class.

People [parents of other children in her class] called me crying saying “this is the first party he has ever been invited to.” And I am like, “Oh, my God—this is why we should do this (crying) we should be doing this for our kids! Kristie kept jumping up and down and going over to her favorite aide—Miss Connie—and she was so excited to see Kristie and Kristie was so excited to see her. I invited the aides, the teachers, and everybody from her class and when they came, everyone came and Kristie was like jumping up and down and jumping for joy.

Mary said they wanted to have a party to celebrate all of the progress Johnny had been making in therapy and when he was able to start walking on his own, they went all out. It was the biggest party they had ever had and over 100 people who knew the family or Johnny came to help celebrate.

Mary: When he started walking on his own without crutches and a walker, we had the Big Boy USA party. We had a big banner made that said, “Big Boy USA” and had it in the back yard and my husband’s band played and I bet we had over 100 people there—bunch of family and friends and the music and had like a cook out. It lasted for hours and he was so tired and he said, “I am done having fun now.”

Bonnie shared how Kristie has no one to play with and how Kristie has no “extra curricular” options outside of therapy.

Bonnie: People come over for play dates with her brother or whatever and they aren’t nice to Kristie—they don’t become a play date forever because they have to include Kristie. There are a lot of people who were playing and were locking Kristie out. Some people come over and say, “Well, Kristie keeps trying to do this

and Kristie's trying to do this" so I say remember that Kristie is a special needs child— she is doing the best he can. And you know when he was younger, I was really worried about it because I didn't want him [her brother] to think that it was okay to treat Kristie that way or to leave her out—even though she is different or doesn't play the way typical kids play. (crying) It's the hardest thing about it— like she chases Ronnie [her NT brother] when she sees the soccer ball—she says, "Ro, Ro" because she knows she is running around the soccer ball because she doesn't think of herself as a soccer player. I have worked really hard this past year to find her something—like we are doing a little bit of the Indiana Elite Cheerleading for special needs cheerleading program. I just wanted something for her that wasn't therapy and wasn't doctor's visit.

Kay also talked about how hard she has worked to make sure Jack is included in activities, even something as simple as riding the bus to school.

Kay: I fought for inclusion. He will go to regular preschool damnit! He will go and do. He has done 4-H, every Gymboree class, every Kindermusik. I developed my vision for him at that young age when he was still a toddler—we are not going to miss a thing—we are going to do everything everyone else is doing. I paved the way for him—I think—or have tried to anyway because part of his joy is riding the bus . . . or not having a stressful day at school which is all designed much in part by what you have to do and so . . . And my ultimate goal is keeping him in this world with us because if left alone, he would very easily slip into a—his little autism world—where I can't go. I can't go with him but I can keep him in our world as long as possible. When I say I am going to ride it out— that's what I

mean—I am going to keep in our world—keep him typing—keeping him functional in the grocery store, at the movie theater. I want him in my world . . .

Lisa talked about protecting time because so much of it is dominated by school, therapy, or respite rehabilitation. She urged that “he just wants to play!”.

Lisa: We have gymnastics on Mondays and horseback riding on Tuesdays and we have swim lessons either Wednesday or Thursday depending on how we schedule that. That means he is in the door at ten till three and we are out the door in fifteen minutes or less. That means grab your snack, grab your milk, here’s your DVD player—let’s go. He doesn’t know the difference because that is what we do. But on those other days, I try hard to not schedule anything. I try hard not to you know have doctor appointments and stuff. I would rather pull him out of school then waste an afternoon. Cause to me school is just one more thing he can do without a day at school but not an afternoon. I try to protect those times. Even if we have our aide through our waiver [for rehabilitation therapy at home]. I try really hard to not have her come after school. “I can come at 3:30.” And I always say, “let’s do 5:30 or 6:00.” I just want him to have some time because once she comes and as much as she is great, there are those expectations, “What do you want to do? How was your day at school?” She has goals for him too. We all mean well. Gosh, he just wants to left the freak alone . . . you know? He just wants to play and play is so important. He used to live in his play. He is just playing now like he did when he was four or five you know. So it doesn’t mean too bad—he has to go through those stages. He needs to go through that. He wasn’t pretending when he was four and now he is pretending. We aren’t going to

nip that in the bud just because it's not appropriate to play three little pigs when you are eleven—I don't care. I don't care. I try to protect those two days after school that we don't have any therapies. And on the weekends, I just really, really think twice about everything we are doing. I just like have to decide what's the benefit versus what's "let's get out of our pajamas and let's go!"

Children with special needs face more time and people in the medical, school, and social service world. I used to overdo everything with Will. I would get another specialist opinion, do more therapy, try out every activity for kids with special needs, and even try out new "miracle" cures. I felt I could fix Will or at least what I thought his life should be to be tolerable. But he is who he is and forcing him out and thrusting him onto new people or activities all the time was hard on him. He used to cry and cry. To him, it just meant more chaos, more uncertainty, and more fear. It took me a few years to figure that out. For example, I used to invite anyone who would come to his birthday parties where I provided too much food, too many expensive noisy toys, and he hated it. Now we invite only his "fan favorites," which include Grandma, Grandpa, his Godmother, his main nurse, and our two family friends. We eat a quick brunch because Will is less tired in the morning, open only a few toys, which he has preselected at the toy store, and then we all sit in the garage and swing him in his swing—all of us around him smiling. And then, I send everyone home and take a nap with him. I doubt anyone would plan a birthday party like that unless they knew Will and this planning took me several years to perfect.

I thought by giving him more and curing him, I could then make him more joyful when the truth was—he too just wanted to be at home and play. I finally listened to my teacher, Will, and learned. Now I do not let the doctors and therapists and educators each

speaking from their own narrow discipline dictate what I “have to do.” Will and I figure that out together and then we plan what we will do. The following is a piece I wrote two years ago to explain the complexity of being able to plan joy for Will.

It’s both hard and wonderful having a special needs child. My husband, Jim, and I dreamed of a child, yet we suffered at our child’s tragic and simultaneous birth and death. We suffered along with him as he struggled to survive. When we were warned to not name him because he wasn’t expected to live, we named him “Will” for will to live. We each “own” or live up to our names and Will is no different. He continues to “will” amazing things to happen.

While Will is non-ambulatory, non-verbal, and has a feeding tube, he smiles, he laughs, and he loves. My husband and I have been committed to providing for Will as many normal activities as we can—swimming on Lake Michigan with adaptive flotation devices, biking with an adaptive trailer, running with a lightweight wheelchair with all-terrain wheels, and swinging with an adaptive swing. When you use a wheelchair, you don’t get to feel the same kind of vestibular input that those of us who can walk and run through space can. And when Will gets the chance to really move, he wants to move faster. If he trusts you, he has no fear.

Winters have been hard for us in Indiana. Even with all terrain wheels, we often can’t get his wheelchair through the snow, ice, and slush. We have tried to adapt sleds, but carrying a fifty-pound boy up a hill each time is difficult and our hills

around Indianapolis are pretty short. Will spends a lot of time looking out the window, longing to go outside. When a friend told me about the Adaptive Snowsports Program at Perfect North Slopes, I couldn't visualize it. Even with her photos, I couldn't figure out how Will could truly "ski" and how it could possibly be safe. I had been skiing a few times and loved it. My husband lived out west when we were dating and we had these great dreams of moving back and learning how to ski better. But all of that was dashed when Will was born . . . until Perfect North.

I called and spoke with the director of the Adaptive program, Tommy, and he very thoroughly explained how it worked and the safety precautions and yes, they were used to kiddos who had significant special needs. As well, he added, they would be teaching me to ski so that we could enjoy skiing as a family. That stopped me in my tracks. The night before, I almost called the whole thing off. When you are the primary caregiver of a child who requires constant medical care, you are terrified of getting sick or being broken in any way, especially falling. The next morning, Jim and I opted to go under the condition that if we felt it wasn't safe or a good idea; we would turn back toward home.

Of course, Will loved it immediately. He was making the sign for more and smiling from ear to ear in one run. And, he wanted to go faster and longer. As soon as the run was over on the small hills, he wanted the team to hurry him back up so he could go down again. So despite my mommy worry, I let Tommy take

him to the big hills while I remained on the green falling my way down in an attempt to hurry my skills so I could see that smile more often. While at the bottom of the bunny hill, trying to learn how to stop without falling, I looked up and there was Will, stories above me, riding the lift with Tommy and Lawrence. It was a Jesus moment for me. I had to trust that he was safe and happy and that he would be okay because I couldn't get to him. I couldn't ski where he wanted to go and my husband was at the bottom trying to take photos and keep track of our mountain of orthopedic and medical gear we travel lightly with. Of course, Will was fine and in fact cried when we left because he wanted to keep moving . . . fast. That's the beauty of adaptive skiing—freedom. Freedom to feel the wind and the cold on your face and to feel that rush of being scared and excited all at the same time.

This is our second year at Perfect North. We have had to buy our own helmets and boots and get up at 5:00 a.m. in order to get Will ready so we can drive the two hours to get there and ski early when the slopes are not busy. I now ski the blue hills with ease and am working on the black diamonds. I ski alongside with Will with the adaptive team. As soon as we turn onto Interstate 74 from Indianapolis, Will knows where we are going and he starts clapping. And when we arrive he offers face pats (his way of hugging and showing love) to all his friends in the adaptive trailer where we meet to gear up for two hours of skiing which is all the time Will has the energy for.

This year, Tommy paired Will with two exceptional young men, Alec and Wally. I was concerned about having Will ski with someone else because he had only skied with some of the older and more experience skiers. Alec and Wally are high school seniors. I know Tommy takes his training regiment with his team seriously, but I was just worried about how two young boys themselves were going to ski my young boy. Will is 50 pounds, and the Monoski [the adaptive ski equipment] is 50 pounds. Slowing down, stopping, lifting Will and his ski onto the lift are not easy. I almost asked Tommy if we could please have someone else but again chose to trust his judgment. I am so glad I did.

Will's boys, as we call them now, are superior skiers and more importantly extraordinary young men. Wally and Alec treat Will like a regular boy. They greet him with "Hey Will—good to see you buddy!", laugh with him when he laughs, and take him to the runs and hills they know he likes most. But most importantly for Jim and I, they nurture. They put Will's gloves back on each time he removes them which is often, they wipe his nose with a tissue when he has snot flying, and they let him lean his head against their shoulder on the lift when he gets tired.

It's impossible to explain to anyone else what that means to Jim and I. The entire Adaptive Snowsports team at Perfect North, and particularly, Alec and Wally, have helped to restore my faith that yes, there are still wonderful people in the world, who don't just talk about being compassionate but who live it.

I bring as many people and groups as I can to Perfect North so they too can witness it and each time, those folks are equally amazed of the amount of time, energy, and love this group offers to not only Will but to every child and adult who wants to experience freedom.

Helen Keller said, “Alone we can do so little; together we can do so much.” Be a part of something miraculous—ski, volunteer, give, or teach with the Adaptive Snowsports program at Perfect North Slopes. Give freedom.

Summary of Findings

The mothers of special needs children who participated in this study represent a diverse population in terms of age, marital status, ethnicity, and ages and diagnosis of their children. They do experience well-documented and researched challenges including dealing with the medical community, doing typical activities with their children, and worries of the future. However, they have learned to find joy through the unique strengths and gifts of themselves and their children. In learning to find the joy, they have also found a purpose and have been transformed by their children. In that transformation, they recognize that their children’s joy is their joy and that joy is defined and demonstrated in simple measures including a successful run down a ski hill and an afternoon of uninterrupted play. But even these simple and unique to their child measures take planning on the part of the mothers.

CHAPTER FIVE
CONCLUSIONS, LITERATURE, THEORY TO PRACTICE, AND FURTHER
RESEARCH

Conclusions

This dissertation study has been focused by the research questions, the method, and the literature. The research questions posed were:

RQ 1: How do the joyful experiences add to the complexity of the emotions of being a mother to a CSN?

RQ 2: How do mothers of a CSN define joy?

RQ 3: What are the joyful experiences of a mother to a CSN?

What conclusions can be drawn from the answers/findings to those research questions? We heard challenge and pain when the mothers talked about their child's medical interventions. We heard challenge and anger when the mothers talked about how isolating and difficult it can be to access typical public services such as school or church with their child or children. We heard challenge and sadness when the mothers worried about the future welfare of their child or children. But we heard determination and resilience when the mothers talked about fighting those challenges. We heard solidarity when they talked about their purpose—being chosen, about “getting it ” and being transformed through their child's or children's lives. We heard love when they talked about their child's or children's simple joy also being their joy. We heard how they now define joy as pure joy. We heard their plea that this simple joy is what they want, seek,

and plan for their child. As Lisa shared, “Sometimes it sucks . . . but you have to keep finding the joy.” There is joy, but you have to learn it, name it, seek it, plan it, and then live it. See figure 6 below, an illustration of the themes of joy revealed in this study.

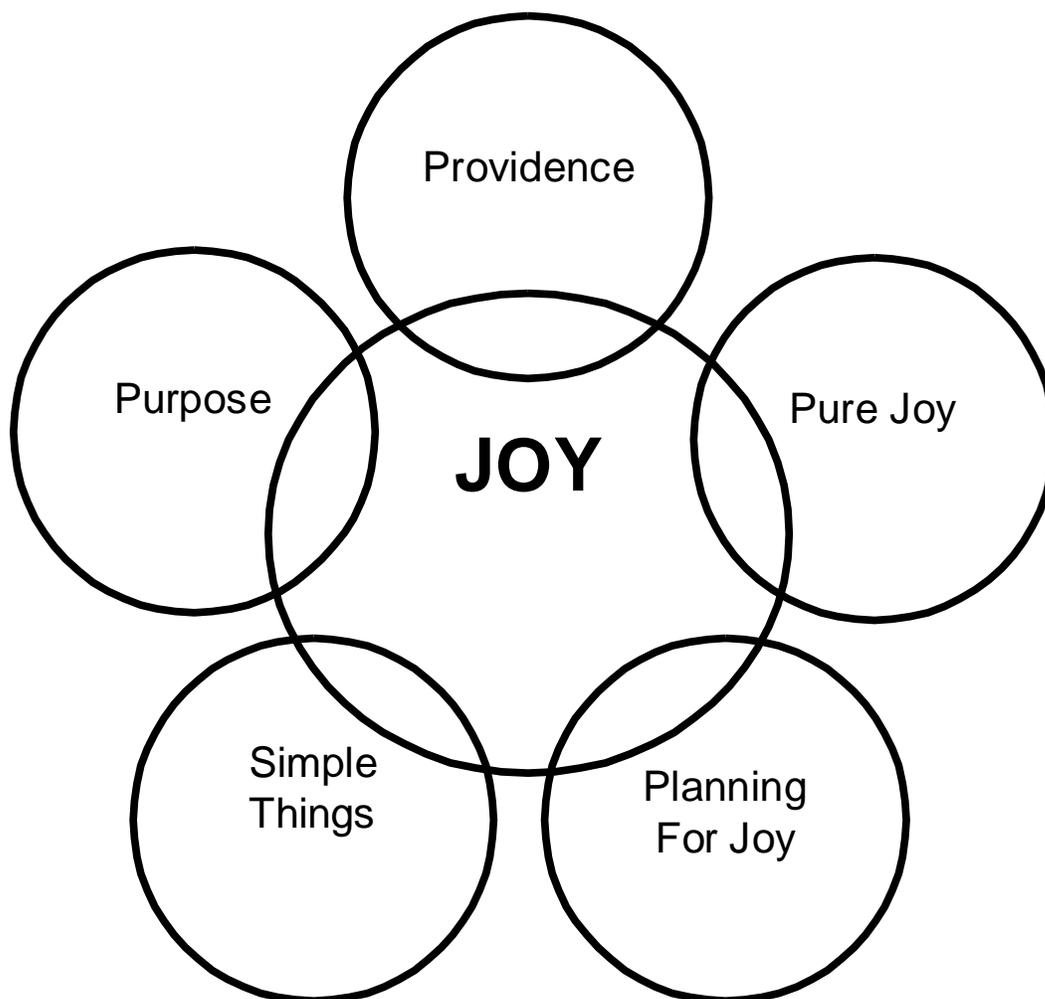


Figure 6. An illustration of the themes of joy revealed in the study, “The Joyful Experiences of Mothers of Children with Special Needs”

Scholarly Literature: Challenge and Joy

Joy is defined very differently for a mother of a special needs child. It is defined individually for their child, not on a societal idea of what joy is for a neurotypical child.

In their experienced feeling of purpose and transformation, the mothers have learned to find the joy and can now accept the simple joys of their child as their joy. Their joyful experiences are those that their children have taught them, and because of that, understanding and definition, the mothers seek and plan those joyful experiences.

In the next two sections, I return to the literature. The reader will find both scholarly, academic articles focused on joy as well as non-scholarly memoirs written by individual mothers of children with special needs. The addition of the non scholarly work is different from the literature presented in Chapter Two and allows the reader to understand that the themes presented in my findings are consistent and supported by voices of mothers of children with special needs outside of this study. This meta-analysis of the new literature reveals the importance of the final theme revealed in the findings, planning for joy, which is an implication for supporting and continued educational practice for those who treat, educate, and serve mothers of children with special needs.

A metasynthesis study conducted by Nelson (2002) on mothers of children with special needs, found that the studies conducted were mostly on the challenges of caregiving. Themes of daily care regimes, searching for normalcy, lack of support, and grief dominated the scholarly literature. However, along with those themes, Nelson (2002) also identified enriched life, revised constructions of the self, and reaffirmation on the part of the mothers. “Mothers repeatedly expressed great love for and commitment to their children placed great value on their relationship, and found reward in caring for their children” (p. 524). It is interesting to note that in this metasynthesis, the participants

or mothers from the studies he analyzed also represented diverse demographics. Similar to my study, the mothers had children representing a wide range of ages and diagnosis.

In a study on the joy and sorrow of having a child with special needs, authors Kearney and Griffin (2001), identified that the mothers expressed great sorrow when they found out their child had a disability, feeling isolated after the diagnosis, and the fear and worry that permeated. However, they also expressed equal joys and they defined that joy as the “little things, new perspectives, and becoming stronger” (p. 585). “It was clear,” according to the authors, “that their children were a source of joy” (p. 586). The participants emphasized that they are “better people” and spoke of their children using terms like “beautiful,” “affectionate,” “generous,” and “cheerful” (p. 586). The participants “claimed their capacity to keep going in the face of sometimes overwhelmingly negativity was because of the inspiration they derived from the children who were described as ‘fighters,’ ‘survivors’ and ‘gutsy’” (p. 586). “The depth and profoundness of coming to terms with the child’s disability” are, according to Larson’s 1998 study, “powerful enough to generate an enduring commitment to maternal occupational patterns and to generate profound internal spiritual and emotional changes” (p. 873). Recall the mothers in my study also used words and phrases like “pure joy,” “resilience,” and “empowered” when talking about their children with special needs. The mothers in my study overwhelmingly noted that they could not imagine not being their child’s mother or that their child had made them a better person.

Fischer (2005), mother to a child with special needs, in an article from the journal titled the *Archives of Disease in Childhood*, acknowledged, “We know he is a joy and an obligation at the same time. He is emotionally and physically draining. He tests us to the

limits and pushes us further than we would have gone without him” (p. 433). But, “our son has taught us the real meaning of service, and the triumph of human survival, and spirit. We are also much less tolerant, of prejudice, ignorance, and discrimination” (p. 433). Schwartz and Hadar’s 2007 study found that the participants, 85% of which were identified as mothers, expressed, “developing a deeper sense of self” as a result of the caregiving they provided for their children with physical disabilities (p. 278). In my study, Lisa, shared her metaphorical example comparing pulling her son Matt in the wagon to the actual burden of caring for him. She understood her burden but has since learned to not only bear it but find agency and joy in it as well.

In a 2009 study conducted by Larson, the researcher studied indicators of the well being of caregivers of children with disabilities. The indicators identified by caregivers in a mixed method study presented a higher percentage of challenges including capacity to manage life demands, mental health, and opportunity for recuperation. However, new learning and growth along with maintaining a positive outlook or keeping perspective were also identified as indicators of well-being. “Certain feelings, perspectives, and attitudes were all mentioned as important to caregivers’ well-being” (p. 36). And while “achieving a positive outlook on life or keeping perspective” was expressed in the study as an “effort,” it was expressed as an important “effort” and equal to that effort was feeling “peaceful about their situation” (p. 36). Schwartz’s (2003) study on the gratification of caregiving for parents of children with chronic disabilities found that the parents receive gratification in “learning about themselves” (p. 576). According to Schwartz, caregiving a child with special needs moves the caregiver beyond the traditional perspective of “acceptance” and into “a stage beyond acceptance, which

involves appreciation of a positive aspect of life” (p. 583). In Read’s (2000) study of the “Midland Mothers” of children with special needs, her final notation was from one of the mothers in her study who shared, “Our children are the ones who teach us about the issues. They give us the opportunities to learn and understand. They give us determination and confidence. They give us hope and courage. They show us how it can be done” (p. 122).

According to the mothers in my study, their children have taught them to know their own power, to engage in only those activities or conversations that are positive and have meaning for them. In Victor Frankl’s (1959) *Man’s Search for Meaning*, an important book I read many years before I had my son, Will, Frankl chronicled his survival of the Nazi death camps during the Holocaust. A psychiatrist by training, he suggested that the way to find meaning is in the attitude we choose to take toward that suffering: “A man who becomes conscious of the responsibility he bears toward a human being” will learn the “’why’ for his existence, and will be able to bear almost any ‘how’” (p. 127). The mothers in my study understand their responsibility for their children. Some understand why they were chosen and some do not but they all bear their “how” by perceiving their children as more than a responsibility but as a gift of “pure joy.”

Larson (1998) explained the emotional complexity of mothers of children with special needs as the embrace of the paradox, defined as

The management of the internal tension of opposing forces between loving the child as he or she was and wanting to erase the disability, between dealing with the incurability while pursuing solutions and between maintaining hopefulness for

the child's future, while being given negative information and battling their own fears. (p. 865)

Hasting and Taunt (2002) in their metasynthesis of five publications that studied the positive impacts of caregivers of children with special needs explained that parents arrive at this positive state by the "attempts to derive meaning from the situation," the "development of a sense of personal control," and the "need to form new identities" (p. 118).

Corman (2009) found the following in the study on the positives of mothers caregiving children with autism: "when mothers saw their child happy, they were especially happy" (p. 441). A participant in their study explained, "without the joys, without those moments of connection," she continued "you'd go stir crazy. These are the things that feed you. I get a huge amount of strength from the 'tiniest little thing'" (p. 442). The mothers in my study explained their joyful experiences as the "simple things" and how those "simple things" are unique to their child. And those simple things their child finds joy in also gives the mothers joy and sustained the mothers until the next joyful moment occurred.

Non-scholarly Literature: Challenge and Joy

The experiences of the mothers in my study were similar to the voices of the mothers in the non-scholarly writing presented mostly in the genre form of memoir. While each mother's experience is unique, the mothers speak with a common cultural voice. Griffin (2006), a mother to a child with special needs, put words to and explained her mechanism for combating what Larson (1998) presented as this idea of "paradox" or the tension of reconciling the challenges with the joys. Once Griffin (2006) lowered her

expectations and realized that Jacob was happier with less than she understood, “the less we expect the happier and more fulfilled we are” (p. 128). Jane Jennings (1978) in one of the earliest memoirs written by mother to a CSN, explained her experiences with a child with severe autism in 1944. Ironically, her child’s name was Joy. Joy was self-destructive, socially difficult, and struggled with traditional education. She and the family suffered from several medical conditions and failed interventions. Jennings explained how she found no support from the medical or school community and suffered mostly hardship in her years trying to raise such a unique child as Joy. Yet, Jennings titled her book, *Why Joy: Learning to Love my Special Child*. She explained in the Prelude, “Today is important—vitaly important to me. It is Joy’s birthday, and she is happy. Happy! I want to shout my thanks to God. He gave us this special child. He gave us a seemingly insoluble problem, and then solved it” (p. 5).

Susan Zimmerman shared in her memoir this same paradox regarding her daughter who had Rett’s Syndrome, a rare chromosomal disease that disrupts the nervous system. Zimmerman (1996) talked in depth about procedure after procedure performed on her daughter as they sought to find a diagnosis, thousands of dollars spent on alternative therapies, and the relentless energy it took to feed her, change her, and treat her. She shared that “the loss of Katherine couldn’t be mourned and put in its proper place” (p. 146). Despite challenges and the grief, she explained that through that greatest pain she was able to experience a joy like no other. In her book, she tried to answer that very question, “How can it be that the greatest pain gives us the greatest ability to experience joy?” (p. 148). Sharp (2003), a mother of a CSN, summarized it well when expressing, that despite the challenges, she is looking toward the future to see what

“joyful anticipation” her son Nic will bring (p. 140). Each of the mothers in my story shared stories of medical, school, and social service. But louder than those stories, they shouted stories of pride and joy. Mary expressed how perfect and wonderful her son was, adding she is sometimes so happy and in love with her son that the tears just come out. Barb talked about how she feels sorry for those who miss the miracles of having a child with special needs. And Kay expressed how she cannot imagine her son Jack belonging to anyone but her.

Joy anticipated is joy experienced, joy defined, and joy sought after. Mothers seek and find that perspective of the “why” and “how” in the small joys. Joy is “the small joys” (Sharp, 2003, p. 94). As mothers she expressed, we have learned to be both happy and “thankful for the simplest things” (p. 95). She continued, “The growth, beauty, and simplicity Nic has brought to our lives bring me joy every day” (p. 140). Jennings (1978) described her joy at seeing her daughter learn in school, communing with God in her own way, and playing. Joy’s joy, her joy, is the “flashing lights of a ladybug, the whir of a hummingbird, the antics of a squirrel” (p. 160).

In a book written for caregivers of children with special needs in the United Kingdom titled, *To a Different Drummer: A Practical Guide to Parenting Children with Special Needs*, under a chapter titled, “Attitude,” the authors share an individual mother to a CSN response to her daughter who has special needs:

We believe Keziah has come to us for a purpose, which we all have chosen. We also share a faith that is right. It is what we all need, although sometimes our small selves reject the handicap as a mistake, as “wrong” and say “no” and “Why us?” This faith, combined with love for each other, brings us through the rough

patches and give us contentment in the good phases (Clarke, Hofsky, & Lauruol, 1989, p. 27).

In an excerpt from a collection of writings by parents of children with special needs, one mother writes, “I am truly blessed to have been chosen to be the mother of Monica Grace” (Enright, 2004, p.202). Knowing her daughter she says, she can now “honestly say I know love” (p. 202).

Below read an analogy that was written by Emily Perl Kingsley in 1987, which has been cited and shared often in the community of mothers of special needs children. Some find it cliché and others find it comforting. I found it referenced often in the non-scholarly memoirs written by mothers (Downing, Nicoll, & Thomas, 2004; Kennedy, 2001; Schwartz, 2006;). It is worth sharing here to understand how the mothers of a CSN have come to be transformed and consequently redefine joy.

I am often asked to describe the experience of raising a child with a disability—to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this . . .

When you're going to have a baby, it's like planning a fabulous vacation trip—to Italy. You buy a bunch of guide books and make your wonderful plans. The Coliseum. The Michelangelo David. The gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, "Welcome to Holland."

"Holland?!?" you say. "What do you mean Holland?? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy."

But there's been a change in the flight plan. They've landed in Holland and there you must stay.

The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine and disease. It's just a different place.

So you must go out and buy new guide books. And you must learn a whole new language. And you will meet a whole new group of people you would never have met.

It's just a different place. It's slower-paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around. . . and you begin to notice that Holland has windmills . . . and Holland has tulips. Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy . . . and they're all bragging about what a wonderful time they had there. And for the rest of your life, you will say "Yes, that's where I was supposed to go. That's what I had planned."

And the pain of that will never, ever, ever, ever go away. . . . because the loss of that dream is a very very significant loss.

But. . . if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things . . . about Holland.

This perspective is supported by Voh (1993), a contributing parent perspective author in a text about cognitive coping for families living with disability. She explained, “Creating a place for me to stand called ‘I belong’ caused a major shift in the world. My fundamental belief about who I was shifted and that altered the way I saw the world” (p. 55). In Zimmerman’s (1996) memoir she shared her challenges and joys of her daughter Katherine, who was born with the rare Rett Syndrome. The book is titled *Grief Dancers: A Journey into the Depths of the Soul*, and her purpose for writing, she explained, is to present a “story about the need we have to take our sorrows and our losses and find a way to move through them” (p. xiv). Zimmerman talked of how her experience with her daughter transformed she and her husband because they were “able to transform the pain into the expression of our very souls” (p. xiv). A large scale study conducted by Read (2000) in England with mothers of children with special needs explained “several talked of feeling that they and their lives had been enriched in unanticipated ways through their relationships with their disabled sons and daughters” (p. 49).

Transformation is part revelation perhaps and part necessity to combat the challenges and to find perspective. Again as my participant Lisa shared in the study, explained, “Sometimes it sucks . . . but you have to keep finding the joy.” And that can happen according to Stothers (1995) in a “joyful flash,” which “dissolves problems with amazing simplicity” (p. 50). Once transformed, Nicoll (2004) explained that “laughter,”

“delight, and “happiness” are what “children with disabilities afford parents many opportunities to experience” (p. 222). Griffin (2005) agreed explaining, “There’s a deep sense of love and joy I’ve found in parenting a special needs child that I never expected, and I’m grateful to have it in my life” (p. 16). Even in her sorrow as her tears fell and hit her son Jacob’s face, Schwartz (2006) shared, “he was smiling. I was sobbing—feeling as low and full of self-pity as I have ever experienced in my life—and he was grinning from ear to ear as if my sobbing was the most hilarious joke in the world. Everything was going to be okay, his smile said” (p. 26).

Scholarly and Non-Scholarly Literature: Impetus for Planning for Joy

Both the scholarly and non-scholarly literature supported the conclusive theme of my finding, which was that the joy of mothers of a CSN must be supported and that support can come through a collaborative planning effort with the mother to create more of those joyful experiences. After understanding the unique joyful experiences to a mother of a CSN, we must then learn to plan for more of them. Sharp (1993) called for the rules to be rewritten. We have to as mothers of a CSN “rewrite the rules” (p. 93). According to disability advocate Stothers (1995), “the joy of disability is a daily requirement of planning and action” (p. 50).

Kearney and Griffin (2001) who clearly identified as many joys as sorrows of mothers of children with special needs, asked why so many professionals neglect the idea of joy and why so often they leave caregivers with “no hope” (p. 586). They (2001) recommend that “parents require alliances and effective partnerships with professionals which support their determination” not just their sorrow (p. 589). In Turnball and Turnball’s (1978) historic text titled *Parents Speak Out: Then and Now*, the editors

requested action on the part of those who serve families: Families “need to be told about the joy, love, challenge” of having a child with special needs but also the “opportunity for growth and fulfillment that such a situation can offer” (p. 97).

Larson (1998) stressed that the reasons these actions are not always met is because “health professionals, despite their professions, may feel unable to fully meet the needs of the families and their children with ongoing disability and may harbor some of the same prejudices about disability” (p. 865). The mothers in this study expressed their desire for more people outside their culture to get “it,” so they can work with them and not against what only they truly understand regarding their child’s joyful experiences.

Schwartz and Hadar (2007) speaking to the health care profession, urged that it is “essential for practitioners to help care giving parents realize that despite the burden they bear, there are some benefits or rewards to their situation” (p. 280). Parents, they explained, “express positive thoughts and feelings about their experience of caring for their disabled child and need to be encouraged to do so” (p. 280). They even recommended that practitioners use a strength-based approach where they ask parents to “mention the good things in life rather than spend a lot of time dealing with what is wrong” (p. 280). Corman (2009) agreed, suggesting, “it might be beneficial for services and supports to facilitate the joys of caregiving by drawing attention to the strengths of the caregiver and the positive contribution their child with a disability makes to their family” (p. 443).

Beresford’s (1995) national survey found that “the greatest need” for parents with a child with special needs is for “the child’s needs to be met” (p. 33). Those needs included not just a break from the challenges, but for social planned quality time with

their children and more time for their children to engage with other children. Read's (2000) study with mothers of children with disabilities noted that the majority of the mothers "pointed out that they had a lot of good times with their children, something that they suspected was not readily appreciated by those who had not had the experience" (p. 49).

Sunderland and Catalano's (2009) study revealed that part of the problem in not meeting the positive aspects is because of the permeation of negative discourse. As a result of their findings, the authors (2009) recommended that a "full range of positive, negative, and in-between human emotions, experiences and aspirations" be reflected and encouraged in "officially disability discourses" (p. 713). Read (2000) discovered in her study, "when others make reference to your experience, they frequently show that they misunderstood it quite fundamentally" (p. 121). Language is power and that power should be shared among mothers and practitioners who educate or serve the mother of a CSN. (p. 713). The discourse should make "room for sorry and joy," (Lindblad & Sandman, 2007, p. 242).

Sunderland and Catalano (2009) agreed, stating, "There is a lot of personal, political, and social freedom in the free use of language. Researchers, policy-makers and others who are involved in shaping and reshaping disability discourses, institutions and practices should remember this discourse" (p. 713). They warned that those who communicate discourse in the disability community need to remember that "we have a duty to care" and a duty to "ensure that our genres of engagement with them are open to the possibility of positive discourse and that the full spectrum of human aspiration and flourishing is not silenced" (p. 713).

Summary of Literature Supporting the Findings

After the data were analyzed and the findings written and represented in themes, additional research was conducted and literature both in the form of scholarly and non-scholarly works were discovered that support the themes of challenge, purpose, and simple things. The academic literature supports the view of challenge but also acknowledges the positive transformation that mothers experience as a mother to a CSN. The non-scholarly literature, mostly written in the literary genre of memoir, joins the voices of the mothers in my study in giving voice again to those same themes of challenge, purpose, and simple things.

Both the scholarly and non-scholarly literature discuss how critical discourse is in changing the language and perspective paradigm used by those in the medical, educational, and social service fields, particularly when it comes to understanding how mothers of a CSN seek joy. Collaboration between mother and those in the medical, educational, and social service fields was recommended for changing that paradigm.

Theory to Practice

How can those practitioners in the medical, educational, and social service first change their discourse and ultimately their paradigm for how they understand the joys of mothers of a CSN? How can they learn from the mothers on how to better plan for joy? Those who treat and support mothers of a CSN are not just practitioners of their discipline, but learners as well. For example, a doctor who during an office visit, talks with the mother about her child's interventions and treatment is not only educating the mother, but also learning from the mother about that child so he or she can tailor that intervention or treatment. The early childhood, elementary, or secondary education team,

who with the mother, develops goals, accommodations, and modifications for the child's Individualized Education Plan's (IEP) is learning about the child's home and educational history. The social service agency and social worker who meets with the mother in or out of her home to provides respite, rehabilitation, and community outreach is learning from the range and type of programming the mother thinks might best meet their child's needs. It is important that they identify themselves equally as both a practitioner of their discipline and as a learner. Mothers of a CSN are too often viewed as marginalized, yet this study and the findings support that mothers are self-directed towards joy, they do bring a wealth of experiences about they and their child's joy, and they are motivated to plan for that joy.

Theory: Transformational learning

In the findings, while challenges emerged, the mothers also shared how they overcome those challenges. They explained how in those challenges, they have emerged transformed and have learned to find, redefine, and access joy. How can practitioners hear and learn what the mothers know? A construct that might be useful in assisting practitioners in the medical, educational, and social service field is transformational learning theory. Mezirow (1991), a key theorist of transformational learning, defined transformational learning theory as “habits of expectation and meaning schemes” that “determine the scope of our attention and hence perception and arbitrarily determine the way we categorize objects and events, make associations and attribute causality within a value system (p. 50).

Transformational learning theory, represents “our need to understand our experiences” (Mezirow, 1991, p. 10). This need is “the most distinctively human

attribute,” because “making meaning is central to what learning is all about” (p. 11). In order to change those meanings which dictate our habits or structures, learners must tacitly be “reviewing and making interpretations based on prior experiences” so that later in the process we can incorporate those into our new understanding and ultimately experience transformation (p. 16).

According to Mezirow (1991), in order to undergo transformation in learning, learners or practitioners of the medical, educational, and social service field must work through the following phases of transformation:

1. A disorienting dilemma
2. Self-examination with feelings of guilt and shame
3. A critical assessment of epistemic, socio cultural, or psychic assumptions
4. Recognition that one’s discontent and the process of transformation are shared and that others have negotiated a similar change
5. Exploration of options for new roles, relationships, and actions
6. Planning of a course of action
7. Acquisition of knowledge and skills for implementing one’s plans
8. Provisional trying of new roles
9. Building a competence and self- confidence in new roles and relationships; and
10. A reintegration into one’s life on the basis of conditions dictated by one’s new perspective. (pp. 168-169)

By working through these phases, which can happen sequentially or non-sequentially, the goal of transformational learning theory is to emancipate adult learners, in this case, those practitioners of the field of medicine, education, and social service who

are learning from the mother. Emancipation, Mezirow (1991) clarified, is “to help learners move from a simple awareness of their experiencing to an awareness of the conditions of their experiencing” (p. 197). In this case, to help those in the medical, educational, and social service field who learn from the mothers of a CSN understand not just that the mothers can experience joy but why and how they experience joy.

Transformative learning is “learning through action” and that action can only happen by deciding to choose an alternative meaning perspective (Mezirow, 1991, p. 36).

Transformative learning requires “mindfulness,” not passivity on the part of the adult learner (p.116). To be an agent of change, the learner or the medical, educational, or social service practitioner must participate in his or her own emancipation.

Practice: Reflective practice

As shared earlier in Chapter Five, language is power. Because of its power, it is an emancipatory and transformative tool. Freire (1993) in his critical text, *Pedagogy of the Oppressed*, reminded us that the “essence of dialogue” is “itself: the word” (p. 87). Words are two dimensional, according to Friere, presenting both reflection and action. Each culture has its own unique vocabulary creating a language, a collection of words, or what I refer to as “speak.” For example, those who work in the medical, educational, or social service fields have their own professional speak. As demonstrated from the study, the mothers of children with special needs are also part of a distinct culture with a distinct speak. We can use language, our speak to bridge both cultures. Language is a critical component of the acculturating process required in transformational learning theory because in order to interpret, perceive, and

transform learning, we have to comprehend and articulate through a common cultural sign and symbol system, language.

According to Mezirow (1991), it is through language that learners can attach themselves to meaning from which to emerge, grow, and ultimately change, which is the goal of transformative learning (p. 36). Mezirow (1991) stressed that, “we do not live through language so much as language lives through us” (p. 38). We hear language, we speak in language, we write in language, and we think in language. And when we are transformed, we repeat that cycle with new language because our new language of transformation replaces our old language. An example of that has been illustrated in this study with the mothers of a CSN who themselves have learned to redefine joy and use a different discourse.

Transformation requires reflection and reflection is represented through language. Mezirow (1991) explained that, “Dialogue or communicative action allows us to relate to the world around us, to other people, and to our own intentions, feelings, and desires” (p. 65). Mezirow (1991) explained that reflection frees the individual learner to explore distorted and authentic language and choose an interpretation to then articulate and shape. Hoggan (2009) suggested that it is “through symbolic knowing, we are able to see alternative perspectives” which allow for transformation in learning (p. x).

By reflecting, practitioners in the medical, educational, and social service who treat, educate, and serve mothers of a CSN can learn to move through or move past, for example, the “disorienting dilemma” which can dominate their perception of mothers of a CSN (Mezirow, 1991, p. 168). And instead begin exploring “options for new roles, relationships, and actions” which can lead to “planning a course of action” (p. 169). By

reflecting on what the mothers of a CSN share in their language, practitioners can learn about the joys of mothers of a CSN and with the mothers plan for more joyful experiences.

Practice: Writing as a reflective practice

Mezirow (1991) supported writing as a method of reflection suggesting “life histories, journal writing, and literature” (p. 219) as possible tools. Cranton (2006) asserted that “engaging in critical self-reflection that may lead to changes in a perspective,” is “itself, a process that requires self-awareness, planning, skill, support, and discourse with others” (p. 117). The key action words in that statement are “self-reflection,” “planning,” “support,” and “discourse.” How can writing be used as a self-reflective tool by the mothers to educate the practitioners in the medical, educational, or social service field to help change their discourse, support their joyful needs, and plan for joyful experiences?

I know from my personal experience with my son, I am typically *not* provided the opportunity to self-reflect on joy prior to meeting with those medical, educational, and social service practitioners. Because I am not prompted and the discourse in that appointment or meeting is dictated by the practitioner and not me, joy is never a part of our speak exchange. For example, when I attend Will’s Annual Case Reviews (ACR) for his Individual Education Plan (IEP), I come with what I call “fighting” words. Prior to our meeting, I am typically provided a copy of Will’s goals and services and asked to “jot down” any new goals, services, or accommodations I think Will needs. I attend Will’s doctor’s appointments with treatment words. Prior to doctor’s visits with major medical pediatric specialists, I am asked to complete medical forms that ask me to list not only

demographic information but also any new “limitations” Will has. After seven years and nine pediatric specialists, our conversation always begin and end with his treatment, not his joy, which is also my joy. I meet with Will’s social workers with need words. Will’s social service agency who provides respite and rehabilitation send me a form asking me to “list” my needs. The forms sometimes even come with recommendations asking me to circle needs such as “sleeping” or “running errands” while they are in the home providing rehabilitative services to Will. The nursing staff is not allowed to accompany me on any outings besides doctor’s visits. But the social service agencies never ask me what brings Will joy. If so, I would ask them to come with me to help me take him skiing or adaptive bowling or to the pool so he and I could manage the tasks involved in having fun together. If joy were a consideration on those reflective writing prompts given prior by those practitioners, the conversations or discourse could maintain authenticity and help to transform those practitioners by reading or discussing the mothers orientation to joy and transformation already experienced.

According to Hogan (2009), the process of writing supports and facilitates transformative learning because “through story, ideas are given meaning and relevance as they bring abstract concepts into concrete and personal terms” (p. 51). “Through words, people are able to express multiple understandings” (p. 51). And finally, “writing can reveal one’s assumptions” (p. 68). Words have different connotative meanings for each of us depending upon our experiences which have shaped our use and interpretation of that word. As well, words elicit images of personal associations and memory and those images are powerful in helping us to choose the words we place on paper in the writing process. For example, if I shared my writing about Will’s heroes on the hill about adaptive

skiing, one of our joyful experiences, with our educational, medical, and social service communities, could they better get “it”? Would they be able to connect their own joyful experiences to mine and remember how wonderful and important that is for anyone? Would that piece of writing teach the practitioner and lead to his or her transformation?

Noted memoirist Thomas Larson (2007) shared that writing has “led me to two of my greatest sensibilities: the psychology of adult development and the art of critical discovery” (p. 8). He even referred to writers as “archeologists” who “excavate for truth” and once discovering it, make sense of it (pp. 67-69). With writing, the practitioner has a structure to read and explore his or her’s assumptions, beliefs, and values. Literacy researcher, Mannion (2001), suggested that writing as a learning aid or practice in transformation has the ability to reach out to a “diverse range of disciplines and even more diverse ways than of interpreting knowledge” (p. 97).

According to Graves (1985), “writing is a medium with which people communicate with themselves and with others at other places and times” (para. 16). When we write, we show what we know. Graves (1985) explained “Then I see . . . and know. Writing makes sense of things for oneself, then for others” (para. 16). Through writing, the writer and the reader brings his or her own lived experiences to the transaction. It is in that exchange that we come to understand and know what the writing means and we have the opportunity then to act on that transaction. Recall my word bank metaphor illustrated earlier in this study. Through writing, the mothers of a CSN can add words to the word banks of the practitioner from which those practitioners can withdraw and spend a new discourse, engage in a new speak.

Writing program model. Writing can be used easily in informal settings. One does not have to be a writing instructor to use writing. We too often think of writing as a formal tool, while really its greatest potential for learning is as an informal writing to learn tool. While formal education is defined by Woods and Judikis (2002) as the “systematic planned and operationalized teaching-learning activities or processes for which some sort of credit or credentialing is awarded,” informal education is the “intended teaching-learning processes that take place outside of formalized programming” (pp. 113-114). Formal education requires “a planned curriculum, trained teachers, and credentialing outcomes” and informal education does not (p. 112).

According to Maxwell (1996), there are three levels of writing. At level one, the purpose of the writing is to “to organize thoughts, to aide memory, to keep track of information, to generate ideas” (p. 37). The format of level one writing is informal because the only audience for level one writing is the writer. For example, level one can include lists, notes, or an outline. At level two, the writer must generate complete responses and thoughts that can be read by someone else, but again that readership is informal. Level two can be represented as any complete response to a single idea such as summary, a crafted idea as part of a larger idea in development, or a reaction to be used in conversation or discussion. When the writer reaches level three, the writer must then present his or her ideas formally in a fully developed format such as an essay, a research paper, or an argument. In an informal learning setting where a medical, educational, or social service practitioner is working with mothers of a CSN, level one and two joyful writing prompts would be the natural goal.

The following writing prompts are ones I recommend for those in the medical, educational, and social service communities to present to mothers prior to the meeting time. I recommend that practitioners either ask the mothers to share their writing or read their writing prior as a way to engage in discourse in their meeting together. Friere (1993) reminded us that while literacy, acts of reading and writing, are liberating, it is the dialogue or the “encounter between men” of that reading and writing that allow us to come to an equal power base from which communication can create change. It is in that exchange where one individual names his or her world and listens as the other individual names his or her world that a shift can happen. For example, the mothers of a CSN, can give voice to, explain their world, which includes joy and the medical practitioner can listen and name or explain his treatment plan. In that exchange, these two worlds, can perhaps create a better plan and rename this new world where each contributes equally. In creating these prompts, I have drawn not only upon the findings of this study, but also my experience as a writing instructor and prompt writer working with writers in both formal and informal learning settings.

Medical. In the mandatory paperwork that is mailed or delivered electronically prior to each appointment or is given in the office prior to the appointment, I would ask medical practitioners such as doctors, therapists, or nurses to ask mothers of a CSN any combination or all of the following:

1. What brings your child joy? He or she finds joy in/with/through/by...
2. How do you and your child experience joy together? We....
3. What steps do you have to take to make those joyful experiences happen for you and your child? When we _____, I have to ...

4. What medicines, devices, therapies, or treatments are we currently using with your child that hinder or prevent that joy from happening? When he or she takes/uses/attends _____ he or she or we
5. What treatment ideas do you have that we could use to help facilitate that joy? We would like _____ to be added/ changed/ adapted because...

This list is just a recommendation of possible topics that can be used to better understand and access the joyful experiences of mothers of a CSN. By soliciting level one and level two responses to these closed writing prompts, the medical practitioner can perhaps take joy into consideration. For example, talking with the mother about which medicines are given and if when they are given hinder access to joy and if there are any alternatives. For example, my son takes a medicine that after it is given, makes him very tired so we have to move his activity schedule around this medicine schedule. There are other medicines that might be as effective but do not cause this kind of reaction and would not hinder our access to joyful activities. As well, perhaps recommended therapies that allow for more joy could be integrated into the treatment plan so mother and child could combine therapeutic treatments with joy.

Educational. In the educational setting, paperwork sent home prior to the Annual Case Review (ACR) for the Individualized Education Plan (IEP) could include the following:

1. What brings your child joy at school? He or she finds joy in/with/through/by...
2. How do you and your child experience joy together outside of school? We....

3. What steps do you have to take to make those joyful experiences happen for you and your child? When we _____, I have to ...
4. What happens during school or in the school setting that hinders that access to joy? When he or she takes/has/needs _____ he or she
5. What services or goals can we include that would bring more joy and success to you and your child? We would like _____ to be included/ changed/ adapted because...

By better understanding how the mother and her child experience and access joy, learning could be better facilitated for the student and would promote the mother being more involved in the educational experiences of the child. And by having joy as a consideration in the educational dialogue, those “fighting words” can be replaced with a more potentially positive interaction between school and parent.

Social service. Those social service agencies that provide case management, respite, rehabilitation services, and home health care services could include the following prompts in their paperwork as they apply to their specific agency’s services:

1. What brings your child joy? He or she finds joy in/with/through/by...
2. How do you and your child experience joy together? We....
3. What steps do you have to take to make those joyful experiences happen for you and your child? When we _____, I have to ...
4. What services are we currently using with your child that hinder or prevent that joy from happening? When he or she takes/uses/attends _____ he or she

5. What service ideas do you have that we could use to help facilitate that joy?

We would like _____ to be added/ changed/ adapted
because...

If the social service agent included the mother in the design of these service, those services could be better implemented and utilized. Funding and access remain a constant concern for these agencies so by including the mothers of a CSN's joy, those services could be perhaps more fiscally and developmentally implemented.

These prompts would encourage and ensure the reflection necessary to transform the practitioner's discourse and paradigm. Certainly there may be disagreement, but there will be dialogue. hooks (2003) reminded us in her work, *Teaching Community: A Pedagogy of Hope*, that we need to drop cliché sentiments such as "we are all just human" and instead "engage our differences, celebrate them when we can" and confront and address any tensions that result in the exchange (p. 109). Those in the medical field have taken an oath whereby they agree to practice in the best interest of those they treat. Mothers are a critical component in that care. These prompts have the opportunity to engage both mother and practitioner in dialogue and potentially transform practitioner. And, they also could provide assistance to practitioners in helping mothers of a CSN practice and program plan for joy.

Summary of Theory to Practice

Those in medical, educational, and social service field who treat, educate, and serve mothers of a CSN are learners as well as practitioners of their discipline. They would benefit from learning from mothers of a CSN what their joyful experiences are so they can better collaborate with the mother to plan more joyful experiences.

Transformative learning theory, an adult learning theory, supports the reflective practice of writing as a way for the learner or practitioner to use in his or her collaboration with the mothers of a CSN. By asking mothers to include level one and level two informal writing on their required forms, the discourse gap can be bridged and aid the medical, educational, and social service practitioner to learn from the mother. By integrating “joy writing” prompts into required forms, practitioners can not only come to a deeper level of understanding of the mothers of a CSN’s joy but also help the mothers integrate and plan for more joy. This transformation could possibly lead better treatment and program development.

Recommendations for Further Research

There are so many ideas for future study that emerged from this study. After completing this study, I find my thinking flooded with questions. For example, in considering the prior section, could transformative learning theory be a construct for studies of mothers of children with special needs? What other reflective tools are being practiced in the medical, educational, and social service agencies with mothers of a CSN? Is transformation a goal of those reflective tools? What is being done by those in the medical, educational, and social service agencies to understand caregivers of a child with special needs?

And what about the fathers of a child with special needs? How would they define joy? What are their joyful experiences? Are they similar or different? Does being primary caregiver make a difference in how joy is experienced? What about the siblings of children with special needs? How do they define and experience the joy of their sibling?

Would they also talk about the challenges? Would either fathers or siblings express transformation? Would their transformational learning be practiced differently?

And while my study's participants were diverse, they do all live in a suburb of Indianapolis near two major children's hospitals, Riley Hospital for Children and Peyton Manning Children's Hospital. Would the data present differently to mothers living in a rural area where medical, educational, or social services are not as easy to access. While my participants talked about the priority of therapy and school dictating time, would someone who did not have this access experience joy the same or differently?

While I propose Mezirow's idea of transformational learning theory as a model for accessing and changing discourse, I am wondering how my study would be impacted by other discipline's theoretical models? For example, in psychology, there is a concept called "benefit finding" where the individual who has suffered a trauma finds benefit in what has happened. This is something we see often with individuals who have experienced the trauma directly but what about those who have experienced nondirectly like mothers of children with special needs. The mothers themselves do not have special needs, their children do. But according to the literature and ideas presented in this study, mothers are marginalized due to what Goffman (1963) defined as "courtesy stigma" so is benefit finding also a useful term in explaining this sense of purpose and agency and transformation experienced by the mothers?

Also, the spiritual discussion of being chosen is an interesting potential study. How does spirituality relate to the mothering or care giving of children with special needs? If attending church is difficult, how is spirituality practiced or is it not? And for those who do or do not, are their differences in attitudes or practices directly related to

the care of children with special needs? How do those leaders in the spiritual community weigh in on this idea? In fact, how do different religions such as Muslims, Christians, or Jews view and participate with families of children with special needs?

According to Wiggins and McTighe (1998), the design and creative process should begin with what is worthy of enduring understanding. They suggest that we begin with what we really want our audience to remember and then work backwards to fill in what they need to know and be familiar with. What is worthy of further research is perhaps contingent then upon what caregivers of children with special needs want those in the medical, social service, and educational communities to know. Including caregivers or family members in the design of a study is an implication for further research. What is worthy of enduring understanding? Once those topics are generated then perhaps research studies addressing those topics could be addressed both quantitatively and qualitatively.

Another important potential study is one that examines different models of joy to see which models are being represented and practiced within the medical, school, and social service community. Dr. Elizabeth Kubler-Ross' well-documented grief cycle for those experiencing the death of a loved one is used as a key component in social services when educating families who have children with special needs (Larson, 1998). Is there a model of joy that could also be suggested? Does the adaptation of an act change attitude and long-term practice and language? Intervention reigns in the disability community and that intervention is typically precipitated by an individual or individuals without a disability. What if activities were designed to include caregivers of individuals with disabilities or individuals with disabilities themselves? How would those practices be different? What would that model look like and how would joy be incorporated? Are

those typical models of practicing joy even applicable in the disability community because the joy is so unique to the individual with disability? If that is true, then is an individualized social plan instead of an individualized education plan one that therapists, teachers, and respite workers need to consider when designing joyful experiences for children with special needs?

In the higher education model at Ball State University, students with disabilities who come to the university are taught to advocate for themselves. While there are supports and accommodations in place, students are expected to explain and seek out solutions for their independent and unique needs. I wonder if we taught encouraged caregivers of children with special needs or children with special needs to advocate for joy what the care and treatment and education or children with special needs would look like.

I read a very recent study about the impact of care giving for mothers of a child with a disability and in the article, employment patterns and what positions the mothers have taken as a result of their care giving responsibilities was noted (Bourke-Taylor, Howie, & Law, 2010). A few of the mothers in my study talked about their current work in advocacy whether paid or not, they feel that the job of advocacy beyond even their child is important. I wonder if there is a connection or a relationship between employment choices after having a child with disabilities? Do mothers take on more social service or education roles? Do their lived experiences as mothers to a CSN influence that decision? A feminist study on employment and mothers and those influences could yield interesting data.

While all of these studies warrant additional literature review and study, my first action step after the completion of this dissertation might include opening another study through the Institutional Review Board (IRB) and pilot these questions with one medical, one educational, and one social service agency to collect not only what is written on the forms but also interview those practitioners before and after a period of time working with the prompts to find out if language, practice, and transformation have occurred.

A second action step is to study the joyful experiences of fathers of children with special needs. I hope to review the literature regarding fathers and interview fathers. I will be operating in that study as more of an outsider because of my gender. I am hoping to partner with a researcher who is also a father to a child with special needs child to aid in the interviewing process. That study would employ ethnography instead of autoethnography.

I will continue to work tirelessly as a researcher and educator, partnering with those in the medical, school, and social service community to study these topics. As I shared from the very beginning, I will always be a part of this culture of being a mother to a special needs child, and my insider status can serve the gaps in the research in the greater disability culture. As Hammel et al. (2008) shared, “The concept of full participation in society is becoming increasingly important and represents a key goal and vision for many stakeholders, including constituents with disabilities, disability advocacy organizations, rehabilitation providers, community organizations, and policy makers” (p. 1445). The authors urged that methods that “deepen the understanding of how participation is contextualized, experienced, and valued” are critical to information

authentic assessment and social change. (p.1445). I concur with the authors and hope to include more individuals living in the disability culture in studies about them.

While the goal of this dissertation was to give voice to the mothers of a CSN, I think the most important practice that can come from this research is for those in the medical, educational, and social service community to take my study and put it into action and to *continue* giving voice to the mothers. I urge others toward future study in the community of children with special needs. I invite both insiders and outsiders to consider my list of recommendations posed as questions and to answer them. As noted in my study, there is a distinct and disparate need for further qualitative studies that focus on the individual and unique voice the individual speaks in his or her culture. As Lisa in my study shared during her interview, “They just don’t get it.” My hope is that this study opens the door to empathy and understanding, which then leads to transformation and action.

References

- Ainge, D., Colvin, G., & Baker, S. (1998). Analysis of perceptions of parents who have children with intellectual disabilities: Implications for service providers. *Education and Training in Mental Retardation and Developmental Disabilities, 33*, 331-341.
- American Academy of Pediatrics: Council on Children with Disabilities (2007). Role of the medical home in family-centered early intervention services. *Pediatrics, 120*, 1153-1158.
- American Psychological Association. (2010). *Publication manual of the american psychological association*. Washington, DC: American Psychological Association.
- Anderson, L. (2006). Analytical autoethnography. *Journal of Contemporary Ethnography, 35*, 373-396.
- Ansary, S., Perkins, D., & Nelson, J. (2004). Interpreting outcomes: Using focus groups in evaluation research. *Family Relations: Interdisciplinary Journal of Applied Family Sciences, 53*, 310-316.
- American Psychiatric Association (2000). *Diagnostic and statistical manual of mental disorders, DSM-IV-TR*, (4th ed.). Washington, DC: American Psychiatric Publishing, Inc.
- Banks, J. A. (1998). The lives and values of researchers: Implications for educating citizens in a multicultural society. *Educational Researcher, 27*, 4-17.

- Bauman, Z. (2005). Afterthought on writing: On writing sociology. In N. Denzin and Y. Lincoln (Eds.), *The SAGE handbook of qualitative research* (3rd edition) (pp. 1089-1098). Thousand Oaks, CA: Sage Publications.
- Baumbusch, J., & Clark, L. (2010). Semi structured interviewing in practice-close research. *Pediatric Nursing, 15*, 255-258.
- Behar, R. (1996). *The vulnerable observer: Anthropology that breaks your heart*. Boston: Beacon Press.
- Behr, S. (1990). *Literature Review: Positive Contributions of persons with disabilities to their families*. Robert Hoyt (Ed.) Lawrence: Beach Centre on Families and Disabilities.
- Behr, S., & Murphy, S. (1993). Research progress and promise: The Role of perceptions in cognitive adaption to disability. In A. Turnbull, J. M. Patterson, S. Behr, D. Murphy, J. Marquis, & M. Blue- Banning, (Eds.), *Cognitive coping, families, & disability* (pp. 151-163). Baltimore, MD: Brookes.
- Behr, S., Murphy, D., & Summers, J. (1992). *Users manual: Kansas inventory of parental perceptions (KIPP)*. Lawrence: Beach Centre on Families with Disabilities.
- Belenky, M., Blythe, M. C., Goldberger, N. C., & Tarule, J. M. (1997). *Women's ways of knowing: The development of self, voice, and mind*. New York: Basic Books.
- Beneken, D., Kolmer, G., Tellings, A., Gelissen, H., Garretsen, H., & Bongers, I. (2008). Ranked motives of long-term care providing family caregivers. *Scandinavian Journal of Caring Sciences, 22*, 29-39.

- Beresford, B. (1995). *Expert opinions: A national survey of parents caring for a severely disabled child*. University of Bristol, UK: The Policy Press.
- Beresford, B. A. (1994). Resources and strategies: How parents cope with the care of a disabled child. *Journal of Child Psychology, 35*(1), 171-209.
- Bogdan, R. C., & Biklen, S. K. (2007). *Qualitative research for education, 5th edition*. Boston, MA: Pearson.
- Brenner, M. (1985) Intensive interviewing. In M. Brenner, J. Brown, J., & D. Canter, (Eds). *The research interview: Uses and approaches* (pp. 147-162). London: Academic Press.
- Breslau, N., Staruch, K. S., & Mortimer, E. A. (1982). Psychological distress in mothers of disabled children. *American Journal of the Disabled Child, 136*, 682-686.
- Bronfenbrenner, U. (1997). *The ecology of human development*. Boston, MA: Harvard University.
- Bruner, J. (2002). *Making stories: Law, literature, and life*. Cambridge, MA: Harvard University Press.
- Buran, C., Sawin, K., Grayson, P., & Criss, S. (2009). Family needs assessment in cerebral palsy clinic. *Journal for Specialists in Pediatric Nursing, 14*(2), 86-93.
- Burnier, D. (2006). Encounters with the self in social science research: A political scientist looks at autoethnography. *Journal of Contemporary Ethnography, 35*, 410-418.
- Centers for Disease Control. (August 25, 1995). Disabilities among children aged less than or equal to 17 years -- United States, 1991-1992. *Morbidity and Mortality*

- Weekly Report (MMWR)*, 44 (33), 609-613. Retrieved from <http://www.cdc.gov/mmwr/preview/mmwrhtml/00038522.htm>.
- Chang, H. (2008). *Autoethnography as method*. Walnut Creek, CA: Left Coast Press.
- Chase, S. (2005). Narrative inquiry: Multiple lenses, approaches, voices. In N. Denzin and Y. Lincoln (Eds.), *SAGE handbook of qualitative research* (3rd ed.) (pp. 651-679). Thousand Oaks, CA: Sage Publications.
- Chenail, R. (1995). "Presenting qualitative data." *The Qualitative Report*, 2(3), <http://www.nova.edu/ssss/QR/QR2-3/presenting.html>
- Clarke, P., Hofsky, H., Lauruol, J. (1989). *To a different drummer: A practical guide to parenting children with special needs*. Waldrige Stroud, UK: Hawthorn Press.
- Coloma, R. S. (2008). Border crossing subjectivities and research: through the prism of feminists of color. *Race Ethnicity and Education*, 11(1), 11-27.
- Corbin D. S. & Buckle, J. L. (2000). The space between: On being an insider outsider in qualitative research. *International Institute for Qualitative Methodology*, 8(1), 54-63.
- Corasaro, W. (1981). Entering the child's world: Research strategies for field entry and data collection in a pre-school setting. In J. Green and C. Wallach (Eds.), *Ethnography and Language in Educational Settings*. Norwood, NJ: Ablex Publishing.
- Costley, C., & Gibbs, P. (2006). Researching others: Care as an ethic for practioner researchers. *Studies in Higher Education*, 31(1), 89-98.
- Couser, T. (2005). Disability and (auto)ethnography. *Journal of Contemporary Ethnography*, 34(2), 121-142.

- Cranton, P. (2006). *Understanding and promoting transformative learning: A guide for educators of adults*. San Francisco, CA: Jossey-Bass.
- Cranton, P. (2009). Foreword. In C. Hoggan, S. Simpson., & H. Stuckey, (Eds.) *Creative expression in transformative learning: Tools and techniques for educators of adults* (pp. vii-x). Malbar, FL: Kreiger Publishing Company.
- Corman, M. (2009). The positives of caregiving: Mothers' experiences caregiving for a child with autism. *Families in Society: The Journal of Contemporary Social Services*, 90, 439-445.
- Dellve, L., Samuelsson, L., Tallborn, A., Fasth, A., & Hallberg, L. (2006). Stress and well-being among parents of children with rare diseases: a prospective intervention study. *Journal of Advanced Nursing*, 53, 392-402.
- Denzin, N.K. (1989). *Interpretive interactionism*. Newbury Park, CA: Sage Publications.
- DiCicco-Bloom, B., & Crabtree, B. F. (2006). The qualitative research interview. *Medical Education*, 40, 314-321.
- Dickens, C. (2005). *A Christmas carol*. Delaware: Prestwick House, Inc.
- Donnenberg, G., & Baker, B.L. (1993). The impact of children with externalizing behaviors on their families. *Journal of Abnormal Child Psychology*, 21, 179-198.
- Dowling, C., Nicoll, N., & Thomas, B. (Eds.). (2004). *A different kind of perfect: Writings by parents on raising a child with special needs*. Boston, MA Trumpeter.
- Dye, J. F., Schatz, I. M., Rosenberg, B. A., & Coleman, S. T. (2000). Constant comparison method: A kaliedoscope of data. *The Qualitative Report*, 4(1/2), <http://www.nova.edu/ssss/QR/QR4-1/dye.html>

- Dyson, L. (1991). Families of young handicapped children: Parental stress and family functioning. *American Journal on Mental Retardation*, 95, 623-629.
- Ellis, C. (2004). *The ethnographic I: A methodological novel about autoethnography*. Walnut Creek, CA: Altmira Press.
- Ellis, C., & Bochner, A. (2000). Autoethnography, Personal Narrative, Reflexivity: Researcher as Subject. In N. Denzin and Y. Lincoln (Eds.), *The handbook of qualitative research*, (2nd Ed.) (pp. 733-768) Thousand Oaks, CA: Sage Publications.
- Enright, C. (2004). Something much bigger than all of us. In C. Dowling, N. Nicoll, & B. Thomas (Eds.), *A different kind of perfect: Writings by parents on raising a child with special needs* (199-202). Boston, MA: Trumpeter Books.
- Etherington, K. (2004). *Becoming a reflexive researcher: Using ourselves in research*. London: Jessica Kingsley Publishers.
- Fisher, F. (2005). Our life with jonathan. *Archives of Diseases in Childhood*, 90, 433.
- Freire, P. (1993). *Pedagogy of the oppressed*. New York: Continuum.
- Frankl, V. (1959). *Man's search for meaning*. Boston, MA: Beacon Press.
- Garland, C. (1993). Beyond chronic sorrow: A new understanding of family adaptation. In A. P. Turnbull, J. M. Patterson, S. K. Behr, D. L. Murphy, J. G. Marquis, & M. J. Blue-Banning (Eds.), *Cognitive coping, families, & disability* (67-80). Baltimore, MD: Paul H. Brookes Publishing Co.
- Geertz, C. (1973). Thick description: Toward an interpretive theory of culture." In *The Interpretation of Cultures: Selected Essays*. (pp. 3-30). New York: Basic Books.

- Glaser, B. G., & Strauss, A. L. (1967). *The discovery of grounded theory: Strategies for qualitative research*. Chicago: Aldine Publishing Company.
- Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity*. New York: Simon & Schuster.
- Golafshani, N. (2003). Understanding reliability and validity in qualitative research. *The Qualitative Report*, 8, 507-607.
- Goodenough, Ward (1970). *Description and Comparison in Cultural Anthropology*. Cambridge: Cambridge University Press.
- Gramsci, A. (1971). *Selections from the prison notebooks*. London: Lawrence and Wishart.
- Graves, D. (1985). *All children can write*. LD online.com. Retrieved from <http://www.ldonline.org/article/6204>
- Griffin, E. (2005). *Fragile X fragile hope: Finding joy in parenting a child with special needs*. Lynnwood, WA: Emerald Books.
- Gray, D. E. (2002). 'Everybody freezes. Everybody is just embarrassed': Felt and enacted stigma among parents of children with high functioning autism. *Sociology of Health and Illness*, 24, 734-749.
- Green, S. (2003a). They are beautiful and they are ours: Swapping tales of mothering children with disabilities through interactive interviewing. *Journal of Loss and Trauma*, 8, 1-13.
- Green, S. (2003b). "What do you mean 'what's wrong with her?': Stigma and the lives of families of children with disabilities. *Social Science & Medicine*, 57, 1361-1374.

- Green, S. (2007). We're tired, not sad: Benefits and burdens of mothering a child with a disability. *Social Science & Medicine*, 64, 150-163.
- Griffin, E. (2005). *Fragile X: Fragile joy*. Lynnwood, WA: Emerald Books.
- Goffman, E. (1963). *Stigma*. Englewood Cliffs: NJ: Prentice-Hall.
- Padilla-Goodman, A. (2010). When "you" become one of "them": Understanding the researcher's identity dialectically. *International Review of Qualitative Research*, 3, 315-329.
- Gornick, V. (2001). *The situation and the story: The art of personal narrative*. Farrar, Straus, and Giroux, NY.
- Gower, R. M. (2004). Happiness wears a cheesy grin. In C. Dowling, N. Nicoll, & B. Thomas (Eds.), *A different kind of perfect: Writings by parents on raising a child with special needs (184-186)*. Boston, MA: Trumpeter Books.
- Hale, N. (2004). The making of an honest woman. In C. Dowling, N. Nicoll, & B. Thomas (Eds.), *A different kind of perfect: Writings by parents on raising a child with special needs* (pp. 203-205). Boston, Massachusetts: Trumpeter Books.
- Hammel, J., Magasi, S., Heinemann, A., Whiteneck, G., Bogner, J., & Rodriguez, E. (2008). What does participation mean? An insider perspective from people with disabilities. *Disability and Research*, 30, 1445-1460.
- Hastings, R., Allen, R., McDermott, K., & Still, D. (2002). Factors related to positive perceptions in mothers of children with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 15, 269-275.
- Hastings, R. P., & Taunt, H. M. (2002). Positive perceptions in families of children with developmental disabilities. *American Journal on Mental Retardation*, 2, 116-127.

- Kupfer, F. (1985). Severely and multiply disabled children. *Equals in partnership: Parents of disabled and at-risk infants and toddlers speak to professionals*. Washington, DC: National Center for Maternal and Child Health.
- Hayano, D. M. (1979). Auto-ethnography: Paradigms, problems, and prospects. *Human Organization, 38*, 99-104.
- Hentinen, M., & Kyngäs, H. (1998). Factors associated with the adaptation of parents with a chronically ill child. *Journal of Clinical Nursing, 7*, 316-324.
- Hoggan, C. (2009). The power of story: metaphors, literature, and writing. In C. Hoggan, S. Simpson, & H. Stuckey (Eds.). *Creative expression in transformative learning: Tools and techniques for educators of adults* (pp. 51-74). Malabar, Florida: Kreiger Publishing Company.
- hooks, b. (1990a). Talking back. In R. Ferguson, M. Gever, T. T. Minh-ha, & C. West, (Eds.), *In Out there: Marginalization and contemporary cultures* (pp. 337-340). New York: The New Museum of Contemporary Art.
- hooks, b. (1990b). Marginality as site of resistance. In R. Ferguson, M. Gever, T. T. Minh-ha, & C. West, C. (Eds.), *In Out there: Marginalization and contemporary cultures* (pp. 341-344). New York: The New Museum of Contemporary Art.
- hooks, b. (1993). *Teaching community: A pedagogy of hope*. New York: Routledge.
- Jennings, J. (1978). *Why joy: Learning to love my special child*. Chappaqua, New York: Christian Herald Books.
- Johnson, J. M. (2006). In-depth interviewing. In J. F. Gubrium & J. A. Holstein (Eds.) *Handbook of interview research: Context & method* (pp. 103-119). Thousand Oaks, CA: Sage Publications.

- Jones, D. (2006). *Memoir project curriculum*. Indianapolis, IN: Writers' center of Indiana publication.
- Jones, D. (2007). *When you know better, you do better*. Unpublished work.
- Kafka, F. (1996). *The Metamorphosis and other stories*. New York: Barnes & Noble.
- Kanuha, V. K. (2000). Being "native versus "going native:" Conducting social work research as an insider. *Social Work, 45*, 439-447.
- Kearney, P. M., & Griffin, T. (2001). Between joy and sorrow: Being a parent of a child with developmental disability. *Journal of Advanced Nursing, 34*, 582-582.
- Kennedy, M. (2001). *My perfect son has cerebral palsy: A mother's guide of helpful hints*. Bloomington, IN: 1st Books Publishing.
- Kieckhefer, G., Trahms, C., Churchill, S., & Simpson, J. (2009). Measuring parent-child shared management of chronic illness. *Pediatric Nursing, 35*, 101-127.
- Kingsley, E. P. (1987). *Welcome to Holland*.
<http://www.ourkids.org/Archives/Holland.html>
- Krishnam, K. (2004). A gift of lessons. In C. Dowling, N. Nicoll, & B. Thomas (Eds.), *A different kind of perfect: Writings by parents on raising a child with special needs* (pp. 189-191). Boston, MA: Trumpeter Books.
- Kuhlthau, K., Kahn, R., Hill, K. S., Gnanasekaren, S., & Etter, S. L. (2008). The well being of parental caregivers of children with activity limitations. *Maternal Child Health Journal, 14*, 155-163.
- Kupfer, F. (1985). Severely and multiply disabled children. In *Equals in this partnership: Parents of disabled and at-risk infants and toddlers speak to professionals*. (pp. 19-25). Washington DC: Maternal Center for Maternal and Child Health.

- LaPlante, M. P. (1998). *Data on disability for the national health institute, 1983-1985*. Washington, DC: National Institute on Disability and Rehabilitation Research.
- Larson, E. (1989). Reframing the meaning of disability to families: The embrace of paradox. *Social Science & Medicine*, *47*, 865-875.
- Larson, E. (2009). Identifying indicators of well-being or caregivers of children with disabilities. *Occupational Therapy International*, *17*(1), 29-39.
- Larson, E. (2010). Ever vigilant: Maternal support of participation in daily life for boys with autism. *Physical & Occupational Therapy*, *30*(1), 16-27.
- Larson, T. (2007). *The memoir and the memoirist: Reading and writing personal narrative*. Ohio University Press: Swallow Press.
- Lassetter, J. H., Mandelco, B. L., and Roper, S. O. (2007). Family photographs: Expressions of parents raising children with disabilities. *Qualitative Health Research*, *17*, 456-467.
- Leonard, B., Johnson, A., & Brust, J. (1993). Caregivers of children with disabilities: A comparison of those managing OK and those needing more help. *Children's Health Care*, *22*, 93-105.
- Lewis, S., Kagan, C., Heaton, P., & Cranshaw, M. (1999). Economic and psychological benefits from employment: The experiences and perspectives of mothers of disabled children. *Disability & Society*, *14*, 561-575.
- Lindblad, B. M., Holritz-Rasmussen, B., & Sandman, P. O. (2007). A life enriching togetherness-meanings of informal support when being a parent of a child with disability. *Scandinavian Journal of Caring Science*, *21*, 238-246.

- Lourde, A. (1990). Age, race, class, and sex: Women redefining difference. In R. Ferguson, M. Gever, T. T. Minh-ha, & C. West (Eds.), *In Out there: Marginalization and contemporary cultures* (pp. 281-288). New York: The New Museum of Contemporary Art.
- Lusthaus, E., & Lusthaus, C. (1993). A normal life for Hannah: Trying to make it possible. In A. P. Turnbull, J. M. Patterson, S. K. Behr, D. L. Murphy, J. G. Marquis, & M. J. Blue-Banning (Eds.), *Cognitive coping, families, & disability* (pp. 43-50). Baltimore, MD: Paul H. Brookes Publishing Co.
- Mannion, G. (2001). Journal writing and learning: Reading between the structural, holistic, and post-structural lines, *Studies in Continuing Educaiton*, 23(1), 95-115.
- Maxwell, R. J. (1996). *Writing across the curriculum in middle and high schools*. Upper Boston: Allyn and Bacon.
- McConnell-Henry, T., James, A., Chapman, Y., & Francis, K. (2009). Researching with people you know: Issues in interviewing. *Contemporary Nursing*, 34(1), 2-9.
- Malinowski, B. (1960). *Argonauts of the Pacific: An account of native enterprise and adventure in the archipelagoes of Melanesian New Guinea*. Lowe and Brydone Printers, Ltd.: London.
- Mezirow, J. (1991). *Transformative Dimensions of Adult Learning*. San Francisco, CA: Jossey-Bass.
- McKie, F. (2005, 15 July). Have we done enough? *Macleans*, 118. Retrieved from http://www.macleans.ca/article.jsp?content=20050718_109144_109144
- Marshall, C., & Rossman, G. (2006). *Designing qualitative research*, (4th ed.). Thousand Oaks, CA: Sage Publications.

- Mandelco, B.L. Olsen, S. F., Dyches, T., & Marshall, E. S. (2003). The relationship between family and sibling functioning in families raising a child with a disability. *Journal of Family Nursing, 9*, 365-396.
- McLaren, P. (2003). *Life in schools: An introduction to critical pedagogy in the foundations of education*. Boston, MA: Allyn & Bacon.
- Meredith, D. A., & Meredith, W. H. (1986). Strengths of parents with retarded children. *Family Relations, 35*, 371-375.
- Mercer, J. (2007). The challenges of insider research in educational institutions: Wielding a double-edged sword and resolving delicate dilemmas. *Oxford Review of Education, 33*(1), 1-17.
- Merriam, S. B., Johnson-Bailey, J., Lee, M.-Y., Kee, Y., Ntseane, G., & Muhamad, M. (2001). Power and positionality: Negotiating insider/outsider status within and across cultures. *International Journal of Lifelong Education, 20*, 405-416.
- Merton, R. K. (1972). Insiders and outsiders: A chapter in the sociology of knowledge. *The American Journal of Sociology, 78*(1), 9-47.
- Mezirow, J. (1991). *Transformative dimensions of adult learning*. San Francisco, CA: Jossey-Bass.
- Mostyn, B. (1985). The content analysis of qualitative research data: A dynamic approach. In M. Brenner, J. Brown, & D. Canter (Eds.), *The research interview: Uses and approaches* (pp. 115-144). London: Academic Press.
- Muncey, T. (2010). *Creating autoethnographies*. Thousand Oaks, CA: Sage Publications.
- Myers, B. J., Mackintosh, V. H., & Kochel-Goin, R. P. (2009). My greatest joy and mygreatest heartache: Parents' own words on how having a child in the autism

- spectrum has affected their lives and their families lives. *Research in Autism Spectrum Disorders*, 3, 670-684.
- Morrison, T. (1990). The site of memory. In R. Ferguson, M. Gever, T. T. Minh-ha, & C. West (Eds.), *Out there: Marginalization and contemporary cultures* (pp. 299-305). New York: The New Museum of Contemporary Art.
- Nelson, A. M. (2002). A metasynthesis: Mothering other than normal children. *Qualitative Health Research*, 12, 515-530.
- Nicoll, N. (2004). Introduction. In C. Dowling, N. Nicoll, & B. Thomas (Eds.), *A different kind of perfect: Writings by parents on raising a child with special needs* (pp. 221-223). Boston, MA: Trumpeter Books.
- Olshanky, S. (1962). Chronic sorrow: A response to having a mentally defective child. *Social Work*, 43, 190-193.
- Olssen, M. B., & Hwang, C. P. (2001). Depression in mothers and fathers of children with intellectual disability. *Journal on Intellectual Disability Research*, 45, 535-543.
- Patching, B., & Watson, B. (1993). Living with children with an intellectual disability: Parents construct their reality. *International Journal of Disability, Development, and Education*, 40, 115-131.
- Patton, M. Q. (1990). *Qualitative evaluation and research methods* (2nd ed.). Newbury Park, CA: Sage Publication.
- Perakyla, A. (2005). Analyzing talk and text. In N. Denzin and Y. Lincoln (Eds), *Sage handbook of qualitative research* (3rd ed.) (pp. 869-886). Thousand Oaks, CA: Sage Publications.

- Phetrasuwan, S., & Shandor Miles, M. (2009). Parenting stress in mothers of children with autism spectrum disorders. *Journal for Specialists in Pediatric Nursing, 14*(3), 157-165.
- Read, J. (2000). *Disability, the family, and society: Listening to mothers* (1st ed.). Buckingham, UK: University Press.
- Reed-Danahay, D.E. (1997). *Auto/Ethnography: Rewriting the self and the social*. Oxford: Berg.
- Redmond, B., & Richardson, V. (2003). Just getting on with it: Exploring the service needs of mothers who care for young children with severe/profound and life threatening intellectual disability. *Journal of Applied Research in Intellectual Disabilities, 16*, 205-218.
- Richardson, L., & St. Pierre, E. A. (2005). Writing: A method of inquiry. In N. K. Denzin and Y. S. Lincoln (Eds.) *The SAGE handbook of qualitative research* (3rd ed., pp. 959-978). Thousand Oaks, CA: SAGE.
- Robinson, P. (2008). *An investigation of child and parent needs for students with Asperger Syndrome (AS), as compared to those with high functioning autism (HFA)*. Retrieved October 1, 2009, from Dissertations & Theses: A&I. (No. AAT 3352024).
- Rocque, B. (2010). Mediating self-hood: Exploring the construction and maintenance of identity by mothers of children labeled with autism spectrum disorder. *Disability & Society, 25*, 485-497.
- Roll-Petersson, L. (2001). Parents talk about how it feels to have a child with a cognitive disability. *European Journal of Special Needs Education, 16*(1), 1-14.

- Rosenblatt, L. M. (1994). *The reader, the text, the poem: The transactional theory of the literary work*. Carbondale, IL: Southern Illinois University Press.
- Rowling, L. (1999). Being in, being out, being with: Affect and the role of the qualitative researcher in loss and grief research. *Mortality, 4*, 167-181.
- Ryan, F., Coughlan, M., Cronin, P. (2009). Interviewing in qualitative research: The one to-one interview. *International Journal of Therapy and Rehabilitation, 16*, 309-314.
- Ryan, S., & Runswick- Cole, K. (2008). Repositioning mothers: mothers, disabled children and disability studies. *Disability & Society, 23*, 199-210.
- Sharma, N., Lalinde, P. S., & Brosco, J. P. (2006). What do residents learn by meeting with families of children with disabilities? A qualitative analysis of an experiential learning module. *Pediatric Rehabilitation, 9*, 185-189.
- Sandelowski, M. (2002). Reembodying qualitative inquiry. *Qualitative Health Research, 12*(1),104-115.
- Siedman, I. (2006). *Interviewing as qualitative research: A guide for researchers in education and the social sciences* (3rd ed.). New York: Teacher's College Press.
- Schwartz, C. (2003). Parents of children with chronic disabilities: The gratification of caregiving. *The Journal of Contemporary Human Services, 84*, 576-583.
- Schwartz, C., & Hadar, L. (2007). Parents caring for adult children with physical disabilities: The impact of hope and closeness on caregiving benefits. *Families in Society: The Journal of Contemporary Social Services, 88*, 273-281.

- Schwartz, E. (2006). *Lessons from Jacob: A disabled son teaches his mother about courage, hope and the joy of living each day to its fullest*. Toronto, Canada: Key Porter Books.
- Sharp, M. (2003). *An unexpected joy: The gift of parenting a challenging child*. Colorado Springs, CO: Pinion Press.
- Snow, K. (2005). *Disability is natural: Revolutionary common sense for raising successful children with disabilities*. Woodland Park, CO: Braveheart Press.
- Stainton, T., & Besser, H. (1998). The positive impact of children with an intellectual disability on the family. *Journal on Intellectual & Developmental Disability, 23*(1), 57-70.
- Stothers, W. G. (1995). Maybe it's time for the joy of disability. *Mainstream, 20*, 50-50.
- Soper, K. (2007). *Gifts: Mothers reflect on how children with down syndrome enrich their lives*. Woodbine House: Bethesda, MA.
- Strauss, A., & Corbin, J. (1998). *Basics of qualitative research: Techniques and procedures for developing grounded theory* (2nd). Thousand Oaks, CA: Sage.
- Sunderland, N., Catalano, T., & Kendall, E. (2009). Missing discourses: Concepts of joy and happiness in disability. *Disability & Society, 24*, 703-714.
- Summers, J. A., Behr, S. K., & Turnbull, A. P. (1988). Positive adaptation and coping strengths of families who have children with disabilities. In G. H. S. Singer and L. K. Irvin (Eds.) *Support for caregiving families: Enabling positive adaptation to disability* (pp. 27-40), Baltimore, MD: Brookes.

- Taylor-Bourke, H., Howie, L., & Law, M. (2010). Impact of caring for a school-aged child with a disability: Understanding mothers' perspectives. *Australian Occupational Therapy, 57*, 127-136.
- Tedlock, B. (1991). From participant observation to the observation of participation: The emergence of narrative ethnography. *Journal of Anthropological Research, 47*(1), 69-94.
- Tepper, R. (2004). Outside of the norm. . In C. Dowling, N. Nicoll, & B. Thomas (Eds.), *A different kind of perfect: Writings by parents on raising a child with special needs (1876-1888)*. Boston, MA: Trumpeter Books.
- Turnball, A. (1985). *Positive contributions that members with disabilities make to their families*. Paper presented to the AAMD 109th Annual Meeting, Philadelphia.
- Turnball, H. R. III, & Turnball, A. (Eds.). (1978). *Parents speak out: Then and now*. Columbus, Ohio: Charles E. Merrill Publishing Company.
- Twoy, R., Connolly, P., & Novak, J. (2007). Coping strategies used by parents of children with autism. *Journal of the American Academy of Nurse Practitioners, 19*, 251-260.
- US Census Bureau. (December 2008). *Americans with disabilities: 2005*. (Publication No. P70117). Washington, DC: US Department of Commerce Economics and Statistics.
- Veenstra, C. (2004). The woman in the mirror. In C. Dowling, M. Nicoll, B. Thomas (Eds.), *A different kind of perfect: Writings by parents on raising a child with special needs* (pp. 172-174). Boston, MA: Trumpeter.

- Vohs, J. (1993). On belonging: A place to stand, a gift to give. In A. P. Turnbull, J. M. Patterson, S. K. Behr, D. L. Murphy, J. G. Marquis, & M. J. Blue-Banning (Eds.), *Cognitive coping, families, and disability* (pp. 51-66). Baltimore, MD: Brookes.
- Vygotsky, L. (1987). *Thought and language*. Cambridge, MA: MIT Press.
- Wall, S. (2006). An autoethnography on learning about autoethnography. *International Journal of Qualitative Methods*, 5(2), 1-12.
- Warren, A. B. (2001). Qualitative interviewing. In J. F. Gubrium & J. A. Holstein (Eds.) *Handbook of interview research: Context & method* (pp. 83-102). Thousand Oaks, CA: Sage Publications.
- Wiggins, G., & McTighe, J. (1998). *Understanding by design*. Upper Saddle River, NJ: Merrill Prentice Hall.
- Witcher, C. S. G. (2010). Negotiating transcription as a relative insider: Implications for rigor. *International Journal of Qualitative Methods*, 9, 122-132.
- Wnorkski, A. (2008). *Uncovering the stigma in parents of children with autism*. Thesis, Miami of Ohio Honors Program Project, May 2008). Available from http://etd.ohiolink.edu/view.cgi?acc_num=muhonors1209350362
- Worthen, B. R., Sanders, J. R., Fitzpatrick, J. L. (1997). *Program evaluation: Alternative approaches and practical guidelines*. New York: Longman.
- Woods, G. S., & Judikis, J. (2002). *Conversations on community theory*. West Lafayette, IN: Purdue University Press.
- Zimmerman, S. (1996). *Grief dancers: A journey into the depths of the soul*. Golden, CO: Nemo Press.

Zimmerman, S. (2002). *Writing to heal: Transforming grief and loss through writing*.

New York: Three Rivers Press.

Appendix A

Field Journal

Before Interview:

Observer Comments (OC): Record your direct observations. You can record who is being observed, what is being done, why it is being done, and specify as to how it is being done.

During and After Interview:

Theoretical Notes (TN): Annotate theories about what you are observing during the data collection process. They may be insights or references of theories that you may have explored in the literature.

After Interview:

Methodological Notes (MN): Explain observations about the type of methods you are using and how it is affecting the information you need for your study. You may want to record where you are completing the data collection, how it is being completed, the people involved and what is working or not working with that method.

After Interview and After Transcription:

Personal Notes (PN): Reflect upon contextual factors that may be influencing what you are seeing. You may want to record events outside of the classroom, moods, family issues, and health issues of either yours, your students, or others influenced by you or your students.

Appendix B

Introductory Email Script

To: Indianapolis Special Needs Mom's Writing Group

Subject: Opportunity to participate in a study

Ladies- Darolyn "Lyn" Jones emailing you with a request to participate in a study. As many of you know I am working on my doctorate at Ball State University. This semester, I am working on my dissertation, and I have the opportunity to find out more about your individual joyful experiences as mothers with special needs children and write up those findings and give voice to what it is you experience as the joys of having a child with special needs. Please read the letter below, which outlines the study's details and let me know if you are interested in participating. Your participation is completely voluntary. The one on one approximately 60 minute interview session will be held at a date and time convenient for you prior to January 15, 2011. The interviews will take place in the Sunday School classroom where we meet for our writing group. If you would like, feel free to bring any personal writings you have related to joy to the interview. If you have any questions or concerns, feel free to email me at ljones2@bsu.edu or call me at 317.697.4843.

Thanks all and have a wonderful week!

Lyn

Introductory Letter/Informed Consent Form

Title

The Joyful Experiences of Mothers of Children with Special Needs

Purpose of the study

The purpose of this study is to examine the joyful experiences of some mothers of children with special needs to better understand their experiences and to investigate the implications of their unmet needs.

Inclusion/Exclusion Criteria

The population used for this study will be mothers of children with special needs.

Participation Procedures and Duration

For this project, you will be asked to participate in one individual interview session for a period of approximately 60 minutes. The interview will be held in the Sunday School classroom where the writing group typically meets. The individual interview sessions will use semi-structured interview questions.

Audio or Video Tapes

For purposes of accuracy, with your permission, the interview will be digitally recorded. Any names of people or organizations used on the audiotape will be changed to pseudonyms, including the names of the participants, when the sessions are transcribed. The recordings will be stored in a locked desk drawer in the researcher's office.

Data Confidentiality or Anonymity

All data will be maintained as confidential and no identifying information such as names will appear in any publication or presentation of the data.

Storage of Data

The principal investigator (PI) will personally conduct each individual interview session. The interviews will be recorded using a digital recording device and verbatim transcripts of each interview will be created by the PI. All paper representation of the data will be stored in a locked filing cabinet in the PI's home, and all the electronic data files will be password protected on the PI's personal computer indefinitely. Confidentiality will be secured in the transcription process and in any subsequent submission of the findings by using pseudonyms in place of the participants' real names. Only the PI and the Faculty Supervisor will have access to the raw data. After subject checks and final correspondence have been completed, personal identifying information (real name, email address, etc.) will be removed and de-identify the subject data. The PI will destroy the coding sheet that pairs the subject's name with the assigned pseudonym, but all other data will be securely stored indefinitely. These coding documents will be destroyed by shredding. The findings will be used for the development of manuscripts for publishing and conference presentations and will be shared with colleagues in a classroom setting.

Risks or Discomforts

There are no foreseeable risks. Subject data will be de-identified and the PI will destroy the coding sheet that pairs the subject's name with the assigned pseudonym, but all other data will be securely stored indefinitely.

Benefits

Having a child with special needs is not typically perceived as a welcoming or joyful event. This study could reveal if there are joys and illustrate how they are experienced with a child with special needs. As well, it could give a voice to mothers of special needs children so the joys of being a special needs mother can be better understood and so the unmet needs of the mothers can be identified.

Voluntary Participation

Your participation in this study is completely voluntary and you are free to withdraw your permission at anytime for any reason without penalty or prejudice from the investigator. Please feel free to ask any questions of the investigator before signing this form and at any time during the study.

IRB Contact Information

For one's rights as a research subject, you may contact the following: Research Compliance, Sponsored Programs Office, Ball State University, Muncie, IN 47306, (765) 285-5070, irb@bsu.edu.

Study Title

The Joyful Experiences of Mothers of Children with Special Needs

Consent

I, _____, agree to participate in this research project entitled, "The Joyful Experiences of Mothers of Children with Special Needs." I have had the study explained to me and my questions have been answered to my satisfaction. I have read the description of this project and give my consent to participate. I understand that I will receive a copy of this informed consent form to keep for future reference.

To the best of my knowledge, I meet the inclusion/exclusion criteria for participation (described on the previous page) in this study.

Participant's Signature

Date

Researcher Contact Information

Principal Investigator:
Darolyn "Lyn" E. Jones, Doctoral Student

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Appendix C

Introductory Letter/Informed Consent Form

Title

The Joyful Experiences of Mothers of Children with Special Needs

Purpose of the study

The purpose of this study is to examine the joyful experiences of some mothers of children with special needs to better understand their experiences and to investigate the implications of their unmet needs.

Inclusion/Exclusion Criteria

The population used for this study will be mothers of children with special needs.

Participation Procedures and Duration

For this project, you will be asked to participate in one individual interview session for a period of approximately 60 minutes. The interview will be held in the Sunday School classroom where the writing group typically meets. The individual interview sessions will use semi-structured interview questions.

Audio or Video Tapes

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shredding. The findings will be used for the development of manuscripts for publishing and conference presentations and will be shared with colleagues in a classroom setting.

Risks or Discomforts

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Benefits

Having a child with special needs is not typically perceived as a welcoming or joyful event. This study could reveal if there are joys and illustrate how they are experienced with a child with special needs. As well, it could give a voice to mothers of special needs children so the joys of being a special needs mother can be better understood and so the unmet needs of the mothers can be identified.

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To the best of my knowledge, I meet the inclusion/exclusion criteria for participation (described on the previous page) in this study.

Participant's Signature

Date

Researcher Contact Information

Principal Investigator:
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