University of the Pacific

Scholarly Commons

University of the Pacific Theses and Dissertations

Graduate School

2020

Caregiving for a Child with Multiple Disabilities: A Mother's Story

Shana Cole
University of the Pacific, girlymom143@live.com

Follow this and additional works at: https://scholarlycommons.pacific.edu/uop_etds

Part of the Educational Administration and Supervision Commons, and the Educational Leadership Commons

Recommended Citation

CAREGIVING FOR A CHILD WITH MULTIPLE DISABILITIES:
A MOTHER'S STORY

By

Shana C. Cole

A Dissertation Submitted to the

Graduate School

In Partial Fulfillment of the

Requirements for the Degree of

DOCTOR OF EDUCATION

Benerd College
Educational Administration

University of the Pacific
Stockton, California

2020

CAREGIVING FOR A CHILD WITH MULTIPLE DISABILITIES:
A MOTHER'S STORY

By

Shana C. Cole

APPROVED BY:

Dissertation Advisor: Christina Rusk, Ed.D.

Committee Member: Diane Carnahan, Ed.D.

Committee Member: Heidi Stevenson, Ed.D.

Senior Associate Dean of Benerd College: Linda Webster, Ph.D.

CAREGIVING FOR A CHILD WITH MULTIPLE DISABILITIES:
A MOTHER'S STORY

Copyright 2020

By

Shana C. Cole

DEDICATION

This dissertation is dedicated to my youngest daughter, who was my guiding light during this journey. It is because of her special needs and disabilities that I pursued a doctorate degree. As a mother first and educator second, I felt it my duty to learn more about my daughter's multiple disabilities and provide that insight to the conversation circle of children with disabilities. It is also dedicated to my ever supportive husband, who has encouraged me every step of the way and faced uplifts and hassles as my partner, and my eldest daughter, who has grown up with her mother always in school, always furthering her education, I only hope I am an inspiration to her. Last, but certainly not least, I dedicate this dissertation to my mother, who has been my family's backbone so many steps of the way while caring for our two daughters.

5

ACKNOWLEDGMENTS

It took a village to make this study a reality. I owe many thanks to Dr. McNair for helping me make it across the finish line. Your guidance in the final hour was most valuable. I want to thank Dr. Rusk for not only helping me through the first hurdle of this manuscript but also offering me a valuable read in *The Spirit Catches You and You Fall Down.* This book gave me inspiration to keep with this study and allow my journey to be heard. Dr. Skrla was instrumental in my choice to write an autoethnography. Her guidance and overwhelming support will never be forgotten. Dr. Carnahan has watched me grow as a teacher and student, having known me since my earlier academic years earning my teaching credential and Master's degree. It was an easy decision to ask her to be a part of my committee in this final academia journey. I am thankful to Dr. Stevenson for being my qualitative professor and seeing me through a very rough draft and vision of this study. I am appreciative that she accepted my invitation to be a committee member and see this to end. Finally, all of this would not have happened without my colleagues who sat in multiple classes working through literature reviews and rough drafts. Countless hours in the library will be a fond memory.

CAREGIVING FOR A CHILD WITH MULTIPLE DISABILITIES:
A MOTHER'S STORY

Abstract

By Shana C. Cole

University of the Pacific
2020

Multiple disabilities does not just affect the individual, it affects caregivers as well. Once a child and parent receives the diagnosis of multiple disabilities they find themselves in a new territory, a new mindset. This study is a longitudinal autoethnographic personal narrative of a mother of a child with multiple disabilities using an intimate inquiry framework. Intimate inquiry allowed me as the researcher to explore my experiences as a reflection of the culture of caregivers of children with multiple disabilities. The purpose of this research was to attempt to understand what it means to raise a child with multiple disabilities from the inside with regards to the positive and negative transformations associated with raising and educating a child with multiple disabilities while achieving personal growth. Findings from my autoethnography suggest that caregivers from all aspects of the child's life (family, home, school, child care, medical professionals) may share similar experiences and reactions addressed in the themes I identified. While this study specifically relates to caregiving for a child with multiple disabilities, it has the potential to relate to caregivers of any nature; those caring for their children, a spouse, or a parent or other family member.

TABLE OF CONTENTS

LIST OF FIGURES

Figure

CHAPTER 1: INTRODUCTION

On a typical morning with my daughter we wake up to prepare for school. Most days she complies, other days she runs from me. I tell her we need to go to the bathroom and I change her pull-up. She grunts and hands me the TV remote in order to ask for the Baby Channel. I change her from her pajamas to her school clothes. I sit her down to put on her shoes and socks. While she is sitting down I comb her hair and pull it back into a ponytail and braid. This lessens her pulling her own hair. I brush her teeth, though if you let her, she will chew on the toothbrush until the bristles have fallen out. My daughter is 9 years old and is unable to get herself ready for school.

Choosing to raise a child was not a decision that I made lightly. I understood that becoming a parent was a long-term commitment of a minimum of 18 years, yet once it was explained to me that my child had developmental deficiencies of her brain, I began to understand that parenting was going to be a lifelong commitment to my daughter's care and well-being (Rowbotham, Carroll, & Cuskelly, 2011). New mothers undergo a major life transition when becoming a parent. When the child has multiple disabilities, this transition is one mothers do not have control over, causing a strain in the sense of self-mastery (Ben Shlomo & Taubman-Ben-Ari, 2012). In comparison, it has been reported that parents of children with disabilities have higher levels of stress than of parents with typically developed children. Coping with challenges and care burden are greater caregiving demands that affect parents of children with multiple disabilities (Trute, Hiebert-Murphy, Levine, 2007; Woodman & Hauser-Cram, 2012).

Parenting a child with a disability changes the caregiving requirements in the home and the learning requirements in an academic setting. Additional attention and support is essential from parents and siblings as primary caregivers (Rowbotham, Carroll, & Cuskelly, 2011). At

times collaboration with formal and informal support systems as "the village it takes to raise a child" is necessary when raising a child with multiple disabilities. These support systems present themselves in academic settings, childcare settings, medical settings, and therapies. Family systems raising a child with multiple disabilities may cope with care burden, a cycle of stress and behavior, and challenges associated with raising such a child (Guralnick, 2006). Yet, the positive experiences, perceptions, and feelings of parenting self-efficacy, optimism, and self-mastery can be transformations of personal growth.

In this chapter I provide background into the culture of multiple disabilities. I discuss the research problem, my theoretical framework, and the purpose of my study. Finally, I describe my study through my research question, research design, researcher perspective and positionality, and significance of the study.

Background

How do families cope and grow when a child is diagnosed with one or more developmental delays? This autoethnographic study represents my coping with my daughter's diagnosis and my growth as a mother of a child with multiple disabilities as a model of the culture of multiple disabilities. Researchers have demonstrated the multiple layers associated with raising a child with multiple disabilities focusing on factual information such as medical concerns and needs and comorbid conditions and probable cause (Bolduc & Limperopoulos, 2009; Kuo, Cohen, Agrawal, Berry, & Casey, 2011; Shevell et al., 2003; Unwin & Deb, 2011). More importantly, there has been a focus on recognition of stressors and strains within families, identification of potential interventions and therapies, both formally and informally, and the functioning and adaptability of the family system (Barr, McLeod, & Daniel 2008; Guralnick, Hammond, Neville, & Connor 2008). Family practice literature has dwelled on the "negative

effects of childhood disability on family life, highlighting parental sorrow, marital discord, and family instability" (Trute, Hiebert-Murphy, & Levine, (2007). By the same token, positive dimensions associated with parenting a child with multiple disabilities such as a closer marriage bond, positive outcomes for siblings, stronger spiritual and ethical values, and a unified family unit are transformations that impact the family and more specifically, the mother (Abbott & Meredith, 1986; Trute, Hiebert-Murphy, & Levine, 2007).

Children with multiple disabilities are a growing community (McLeskey, Tyler, & Flippin, 2004) and parents, educators, and service providers find ways to help these children develop skills in the domains that are delayed. In doing so, parents, educators, and service providers become a part of the village raising the child, working together to help the caregivers of the child be the best they can be for the sake of the child (Kesselring, de Winter, Horjus, van de Schoot, & van Yperen, 2011). This autoethnography can serve as a reference and resource for stakeholders such as caregivers, educators, administration, and academic support staff, medical teams, and others who may need to contribute support, care, and resources for these children and their families, as well as fill in a gap of knowledge of this culture that is not able to be read in a report but may be understood from a personal account of positive and negative transformations.

According to the Individuals with Disabilities Act (2018) there are 13 categories of disabilities in which children can be evaluated for under section 300.8 (a). One of the categories, multiple disabilities (MD), describes concomitant impairments which causes educational needs that cannot be accommodated in a special education program solely for one of the impairments. According to the National Dissemination Center for Children with Disabilities (NDCCD), (2013), the term multiple disabilities is a broad term due to the fact that challenges make it difficult to identify how many disabilities a child has, how severe the disabilities are, or which

disabilities are involved. Additionally, the NDCCD fact sheet expresses that many combinations

of disabilities may be involved. Developmental delay is classified separately under IDEA

section 300.8 (b) for children aged three through nine experiencing developmental delays and

needing special education and related services as defined by the state and measured by diagnostic

instruments and procedures in one or more of the following areas: Physical development,

cognitive development, communication development, social or emotional development, or

adaptive development (IDEA, 2017). Global Developmental Delay (GDD) is defined by

Brothers, Glascoe, and Robertshaw (2008) as having two or more developmental domains that

are significantly delayed. They identify the domains that may be delayed as fine motor skills,

gross motor skill, expressive language (articulation), receptive (understanding) language, self-

help (e.g., dressing and teeth brushing) and socio-emotional skills. A delay diagnosed in two

developmental domains is typically associated with a higher chance that delays in other domains

will present themselves (Riou et al., 2009; Shevell et al., 2003). The terms 'Global

Developmental Delay' and 'multiple disabilities' may be used synonymously with some of the

literature referring to global delays and others referring to multiple disabilities. These terms are

based on the field in which the literature is directed and written for, either medical or academic.

In the medical field my daughter is classified and has been documented as Global

Developmental Delay, while in the academic field she qualifies for special education services

under multiple disabilities. With that being said, I use the term multiple disabilities when

referring to my daughter's disability. My daughter has an intellectual disability, a health

impairment, speech and language impairment, and vision impairment (due to surgery) as

classified under the multiple disabilities category of IDEA. Additionally, she has delays in fine

motor skills, gross motor skills, expressive language, receptive language, self-help, and socio-

emotional skills as described under the developmental delay subcategory of IDEA. Under the large umbrellas of developmental delay and multiple disabilities, a child and their family system does not have to have the same diagnosis to experience the same barriers and uplifts, the same challenges and love.

According to Shevell and colleagues (2003) 5% to 10% of children are diagnosed with development disabilities, 1% to 3% of which are affected by delays in multiple domains. These children and their caregivers experience a variety of diagnoses, prognoses, and daily living conditions. How each family responds to the challenges of their child with multiple disabilities varies greatly. Families can grow stronger and closer together or they can fall apart under the strain of the responsibilities and stress (Baker, Blacher, & Olsson, 2005). Marital satisfaction, parental stress, and child behavior problems have been linked together when discussing families affected by multiple disabilities (Robinson & Neece, 2015).

Description of the Research Problem

Raising a child with multiple disabilities may require that parents and caregivers acquire the ability to cope with challenges yet rejoice in the positive experiences in order to maintain a healthy family system (Hastings & Taunt, 2002; Orfus & Howe, 2008; Woodman & Hauser-Cram, 2012). The National Dissemination Center for Children with Disabilities, (2013) provides tips for parents in order to promote a healthy family system. First, families should learn about each of their child's delays and how best to help their child in their areas of needs. In addition, the family unit ought to allow the child to express their strengths, interests, and preferences while encouraging independence. Additionally, children with delays benefit from participation in family functioning such as having chores, experiencing social opportunities, and being treated as everyone else. Finally, the family system should love and play with their child with delays as

though they would their typically developed child. Park and colleagues (2003) describe family quality of life as conditions where the family's needs are met, family members enjoy their life together as a family and have the chance to do things which are important to them. Families with both parents can display positive family outcomes due to caregiving involvement of a second parent who may aid in house work, childcare, and parenting (Nolen-Hoeksema, Larson, & Grayson, 1999; Rosenfield, 1989). This can decrease the demands and needs of the child with the disability for the mother allowing the needs of other family members, such as typically developed siblings, and the household to be met (Davis & Gavidia-Payne, 2009).

Maintaining a healthy family system may require teaming up with formal and informal support systems (Dyson, 1987; Guralnick et al., 2008) and having social and psychological positive beliefs mind frames such as optimism, parenting efficacy, and self-mastery (Paczkowski & Baker, 2008; Scheier & Carver, 1992; Woodman & Hauser-Cram, 2012). There has been a focus on recognition of strains and stressors within families, identification of potential interventions and therapies, both formally and informally, and evaluation of the parents and siblings, both together and separately, within the family system (Barr, McLeod, & Daniel 2008; Guralnick, Hammond, Neville, & Connor 2008). These formal and informal systems can be in home or in an academic setting, accessed by family systems, academic stakeholders, and other caregivers. Additionally, there has been research regarding positive aspects of raising a child with a disability focusing on times of sadness and joy, positive perceptions of family systems that have a child with a disability, and the effects of optimism on parental well-being (Hastings & Taunt, 2002; Scheier & Carver, 1992; Trute, Hiebert-Murphy, & Levine, 2007).

There has not been a longitudinal autoethnographic study conducted that followed a mother and her child with multiple disabilities using an intimate inquiry framework with regards

to the positive and negative transformations associated with raising and educating a child with multiple disabilities while maintaining a healthy and functioning family unit. Being a mother to a child with multiple disabilities is a forever journey. Along the journey, a mother may also have additional obligations such as additional children, a spouse, and a career. How a mother is able to stay focused on the journey and not be derailed by emotions or situations is the inspiration for my study.

Theoretical Framework

According to Hastings and Taunt (2002) family research models do not specifically address positive experiences and perceptions of families with children with disabilities. Behr and Murphy (1993) state the absence of a conceptual framework for understanding perceptions as they relate to cognitive coping. My theoretical framework is intimate inquiry (Laura, 2011). Intimate inquiry is the concept that love has a place in social science and can be used as a framework for qualitative research. Laura explains that intimate inquiry is the notion that "each of us is an expert on the qualities of our own experiences" (p. 34). L'Abate (1998) explains that physiological processes are impacted by close, committed, and prolonged intimate relationships between and among people who are experiencing the same context. Physiology is the study of living organisms and the process in which they survive, grow, and develop. Laura explains the process for her dissertation, in which she formulated intimate inquiry, in which she began with a candid narrative that expressed the crisis her family was experiencing. Narrative inquiry is a way of understanding experience. It combines people's experiences as a phenomena and inquiring narratively as a methodology which "allows for the intimate study of individuals' experiences over time and in context" (Clandinin & Caine, 2008, p. 542). Laura describes the research tradition of family research as one of the methodological perspectives she drew from

while devising intimate inquiry. Family research uses narrative inquiry to study blood relatives through investigation of family artifacts and memories of experiences and observations. According to L'Abate (1998) "Intimate-relationships science studies the relationship between individual and family behavior" (p. 273). Autoethnography writing studies the researcher in relationships and situations through personal experience. The vulnerable self of the researcher is examined due to the nature of not being completely open with the people in their lives and how they see themselves or others relative to them (Ellis, 2007). As a caregiver of a child with multiple disabilities, my physiological processes have been impacted by the challenges and personal growth I have experienced. These impacts have had both positive and negative transformations throughout my daughter's life.

Another perspective discussed in Laura's dissertation (2011) is the act of witnessing versus the act of observation. When researchers *witness* they take note of what is meaningful within experiences up close and personal in order to validate the subject's story. As Laura expresses, I may not completely know my daughter, or be able to understand her, but I used the lens of family research and witnessing to pay attention, reflect, and learn about my daughter's life through her experiences. Ellis, Adams, and Bochner (2011) express that writing personal stories makes witnessing possible. As witnesses, autoethnographers invite readers to feel validated and/or better able to cope with their circumstances, and possibly make changes due to the pain and validation felt from the research.   Narrative inquiries should lead to positive change in an effort to make the world a better place, offering companionship to readers while attempting to establish meaning, healing, and/or growth in the life of the researcher (Ellis, 2007).

While intimate inquiry is a fairly new methodological framework, it has been used as in at least one additional study other than Laura's (2011). Melinda Westland (2016) wrote of a

foster system student who went from high school dropout to college scholarship recipient. She calls her dissertation a "qualitative life history" (p. 7) and a "narrative intimate inquiry that used a critical theory as its lens" (p. 7).

Throughout the chapters I maintained a level of intimacy as I research topics of concern for myself as a representative of family, such as care burden, the cycle of stress, behavior, education, and challenges. I related the narrative of my raising and coping experiences as a representative of my family unit through emotional uplifts and positive appeal. Using intimacy theory allowed me to write a qualitative life history about positive appeal in the face of challenges of raising and educating a child with multiple disabilities.

Readers are able to connect and make sense of my story through the narrative intimate inquiry of detailed personal accounts and positive and negative perceptions of my experiences of my daughter's multiple disabilities. Through my eyes as a parent with a background in education, I can represent the culture of caregivers of children with disabilities. No two children are alike, no two disabilities are alike, no two families are alike, and no two mothers are alike. The common thread is the caregiving journey, the small things in life that may be overlooked by others, the negative emotions associated by the inability to help your child or make them 'better', the positive emotions associated with the triumphs experienced by your child and the understanding that your child's disability is lifelong in nature. Readers can relate to the intimacy associated with my study regardless of disability diagnosis or the family member with the disability. The culture of caregiving can extend past caregiving for a person with a disability. Caregivers care for people that have terminal illnesses or people that are older in age and need support with their daily living. This framework is discussed in further detail in Chapter Three.

Purpose of the Study

This study provides a longitudinal, intimate, personalized account of the positive and negative transformations experienced by a mother raising and living with a child with multiple disabilities in a village support environment as a transformation of personal growth.

Research Question

My autoethnographic account of raising a child with multiple disabilities addresses one overarching question as it pertains to my personal story as a caregiver to a child with multiple disabilities that continues even as this study is being conducted: In what ways have I, as a mother of a child with multiple disabilities, transformed the impact of disability into personal growth?

Description of the Study

I conducted a longitudinal autoethnography in order to provide a personalized account that retrospectively and selectively discusses epiphanies that are made possible by being part of the multiple disabilities culture as a caregiver and educator for the past nine years. Qualitative longitudinal research (QLR) practice is used as a means to provide direct knowledge of the process of change over time. Ontologically, QLR allows the researcher to study and write about time as a given in the form of the past, present, and future. Longitudinal research conduct research under the assumption that the concepts of change, agency, and structure are unquestionable (Mauthner, 2015). For the purpose of this study longitudinal reflects the ten years that have past that are the basis of my study, understanding that I have experienced change from the beginning of this journey to the present.

Autoethnography is both process and product of research. The process of doing autoethnography requires the author to focus on past experiences, or epiphanies, both selectively

and retroactively (Ellis, Adams, & Bochner, 2011). Selectively suggests the author will discuss moments in their past that changed the trajectory of their life, while retroactively suggests that the past experiences serve as a statute for the author.

Ethnographies are a form of qualitative research that focus on a culture-sharing group (Creswell, 2013). Being a part of a culture and/or possessing a cultural identity presents opportunities to write about selective and retrospective epiphanies (Ellis, Adams, & Bochner, 2011). Belbase (2008) explains his study as being able to "explore upon my experiences for data as they are the ultimate sources of information for me to know the content" (p. 87). Autoethnography allows me to explore my experiences as a parent of a child with multiple disabilities, while also being an educator and student. Intimate Inquiry as a framework allows me to explore the experiences of myself as a representative of my family unit and the education system, who are caregivers to my child with multiple disabilities.

The lived experiences within the story I am narrating reflect the culture of caregivers of children with multiple disabilities. Researchers have focused on causes of delays and their effects on the child and the families that are the caregivers for the child (Bolduc & Limperopoulos, 2009). Coping strategies have been formulated as well (Paczkowski & Baker, 2007; 2008). The gap in the research is a personal longitudinal account of a mother raising a child that is multiple disabilities portraying positive appraisals and transformations evident in personal growth.

The intent of my study was to illustrate the caregiving of my daughter and her unique special needs and my personal growth as a mother. I focused on the stress of challenges as well as joys that I experience as positive appeal. Positive appeal is not a perfect picture or story. There are moments of frustration, disappointment, pride, and joy. It is both happy and sad,

ecstatic and excruciating. With this in mind, I discussed how I cope as a part of a family unit through the positive and negative experiences. This takes place with the mental comprehension that caregiving for my daughter may be a lifelong endeavor. I used personal accounts of the journey of raising a child with multiple disabilities, as well as my personal reflection of medical records and school records; including progress reports, Individual Education Plans (IEPs), physical therapy and occupational therapy goals and progress reports, and calendars and journals that I keep documenting the struggles she has overcome and how I have coped and celebrated.

I provided detailed descriptions the deficits of my daughter that are the most prominent in my daily life. These deficits are the challenge component of my research focus as they are what I am coping with on a daily basis. I described my personal growth that has resulted from coping with negative experiences. These negative experiences are the struggles that I have created strategies for in both my personal life and how I am able to advocate for her academics. On the other hand, I described in the same amount of detail successes in my daily life. These successes are the positive appeal component of my research focus as they are what I am celebrating on a daily basis. These successes illustrate a positive transformation and growth in my personal life and show the momentum of how I am able to advocate for her academics.

The data was analyzed using constant comparative analysis as outlined by Glaser (1965). First, I decided what to include from the data collection previously discussed. Second, I transcribed my voice recordings. Third, I put the data into chronological order. Fourth, I began a reflexive journal in which I provided detailed descriptions of the setting, experiences, and emotions in an initial review of the data. Fifth, in a second viewing of the data I created memos of reaction and emotions I experienced during the viewing. Sixth, in a third read of the data I began open coding fracturing the data into categories and concepts as shown in figure 1.

Figure 1. Theoretical frameworks components

Next, I utilized axial coding and theoretical memos as a process of connecting the data. Finally, I created a matrix and use selective coding to integrate the information using the intimate inquiry theoretical framework. During the matrix phase I used operation memos to facilitate the direction of the research design. The data analysis is discussed in further detail in chapter three.

Researcher Positionality

Laura (2016) clarifies her methodological theory as intimate due to the nature of the researcher's positionality with relation and connection to the kinfolk in the study. In this study the relation and connection is with my daughter. In terms of theoretical framing, intimate inquiry informed how I collect and relate the data in my study. Throughout the chapters I maintained a level of intimacy as I reveal topics of concern for myself as a representative of my family. I narrated my raising and coping experiences as a mother, wife, and professional. Topics of concern may be triggered by my background in education and the professional degrees I have achieved while furthering my academics in education. Caregiving for my daughter includes advocating for the best education she can sustain provided by her special education program. Using intimacy theory allows my readers to make sense of my story through my personal accounts of my daughter's disability as it represents the culture of children with multiple disabilities.

Intimate inquiry allowed me to maintain my positionality within the study. I was able to be a part of the study and include my feelings, reflections, transformations, and growth as data. I strongly believe in the words of Cindy Cook (2006) "I have never been intimidated by (her) disability" (p. 50). My roles within the study include being a Caucasian woman in her early forties that is married to an African American man. Being married means that I have a partner to share in the financial obligations, medical decisions and care, and family emotional needs of the family in addition to higher levels of martial satisfaction. I am a mother of two biracial children. My oldest daughter is a typically developing high school teenager and my youngest daughter is a child with multiple disabilities. Having a child with disabilities has had an impact on my relationship with my typically developed teenager (Barr, McLeod, & Daniel, 2008). She was an

only child for five years and has served as a caregiver to her sister early in her childhood. Finally, my spouse is also a college student, therefore there are evenings I am solely responsible for household responsibilities for myself and my children.

Parenting self-efficacy has been said to be an indicator of increased behavior problems three times higher in children with disabilities versus children without disabilities. (Paczkowski & Baker, 2007; Woodman & Hauser-Cram, 2012). Due to my background in child development from high school to the present as well as my teacher credential courses that taught me how to differentiate instruction, I feel that I have increased levels of parenting self-efficacy for both of my children. Self-mastery has been said to be an indicator of physical and mental health in stressful situations (Ben Shlomo & Taubman - Ben-Ari, 2012). Prior to my daughter's birth, I would have stated that my perceived self-mastery was high, that I felt in control of my life. Along the journey of diagnoses, I have not had control over my daughter's health and well-being, therefore threatening my caregiving experience and psychological parental well-being.

Academically, the fact that my daughter is half African American has led to her not being able to receive certain cognitive assessments according to the Larry P. et al. v. Wilson Riles et al. case of 1979, which deemed the assessments culturally biased (Harry & Anderson, 1994). I am a middle school general education teacher teaching core subjects to 8th grade students, a recent administration credential candidate, and a graduate student in a doctorate program. The nature of my roles with respect to my study with be discussed in more detail later. The data I provide needs to be as authentic as possible, free from bias. I looked at my data through an intimate lens as well as a witnessing lens.

Significance of the Study

There is much to consider when attempting to understand a child with multiple disabilities and describe what the mother copes with on a daily basis. My goal is to add to the circle of conversation by gaining an understanding of my daughter's disability while correlating the research to my experiences. Each member of the family system has their own experiences, insights, struggles, and coping strategies that they have used in order to be the best that they can be for the child with multiple disabilities. Park and colleagues (2003) acknowledges that disability may have a different meaning for each family member and multiple perspectives need to be taken into account. This is especially true for mothers. The mother tends to take on more caregiving responsibilities in addition to domestic responsibilities for the household and other children (Nolen-Hoeksema, Larson, & Grayson, 1999; Rosenfield, 1989; Rowbotham, Carroll, Cuskelly, 2008) and therefore has the most insight into the disability and the interests of the child with the disability (Park & colleagues, 2003). As part of the caregiving responsibilities, it is important that siblings of children with multiple disabilities still receive support and attention from parents. Feldman (2007) encourages families to have the outlook that raising a child with multiple disabilities can be a positive family experience, while Paczkowski and Baker (2007) explain that positive beliefs can influence the parent-child relationship. This can be accomplished through self-mastery, parenting self-efficacy, and dispositional optimism (Paczkowski & Baker, 2008; Scheier & Carver, 1992; Woodman & Hauser-Cram, 2012), something that I feel that I have demonstrated throughout my nine years with my daughter.

It was my intention to look beyond the negative aspects of coping and focus on what gifts children with multiple disabilities can provide to their families, educators, and society. Ellis (2007) discusses caregiving as a gift rather than a burden. This longitudinal intimate

autoethnography adds to the literature with respect to mothers and their role in the family systems as I describe the dynamic of positive and negative transformations associated with raising a child with multiple disabilities. The telling of my narrative fills in a gap in scholarship by allowing readers an inside perspective regarding the roller coaster wave of positive and negative emotions, the constant bombardment of thoughts, and the plethora of feelings associated with the caregiving experiences. From the telling of my narrative many themes emerged that caregivers, specifically those caring for a child or family member with a disability, may be able to relate to and find support in the strategies shared. Finally, this study addresses the academic outcomes of children with multiple disabilities, an aspect that strengthens the current research and education stakeholders. Principals' and teachers' perceptions of learning disabilities could benefit from more knowledge and a deeper understanding of student difficulties and the family system that is caregiving for the child (Kataoka, E. van Kraayenoord, & Elkins, 2004).

Chapter Summary

Children with multiple disabilities are a culture that needs understanding and awareness. Caregiving and raising a child with multiple disabilities can be challenging and stressful, yet it can also be rewarding, enriching, and a positive transformation that leads to personal growth. Multiple disabilities means that two or more developmental domains have been affected. Parents appraise the impact of the child with multiple disabilities as both positive and negative possibly relying on "village" support for coping strategies. This study was conducted from an intimate inquiry lens, allowing for the study of my experiences over time in the format of an autoethnography.

Chapter Two discusses the literature that has been reviewed in regards to what having multiple disabilities means to the child, the impact, well-being, and functioning of the family unit

raising a child with multiple disabilities, and the educators that support academics and therapies.

Negative transformations for mothers such as care burden and challenges were discussed in

addition to raising and coping with a child with multiple disabilities and the cycle of stress and

behavior. In retrospect, positive appraisal was a focus of coping strategies including the positive

beliefs of optimism and self-mastery, and parenting self-efficacy that families have within the

family system and through the use of formal and informal support systems, including the

education system. Personal growth of the self-system can stem from both negative and positive

transformations that develop as a result of caregiving for a child with multiple disabilities.

Chapter Three discusses the purpose for the study. I describe the methods, methodologies, and

theoretical framework used to conduct my autoethnographic intimate inquiry. I provide a

background of autoethnographic studies. I share my research design including limitations. I

explain my role as respondent and researcher. Finally, I explain my data collection and analysis

procedures. Chapter Four provides the narrative and interpretation of the personal documents

reviewed as an evocative reflection. Chapter Five provides the conclusions and discussions as

they relate to the culture of caregiving for a child with multiple disabilities. Finally, I explain

how this study fills in a gap of knowledge and provide recommendations for future research.

Definition of Terms

Through the course of my research and conducting this study many terms have been used

synonymously. For that purpose I have provided a list of words used to gain a perspective on its

meaning within the study.

Agenesis – failure of an organ to develop

Appraisal - a valuation of something such as emotions or an experience.

Caregiver - a family member or paid helper who regularly looks after a child or a sick, elderly, or disabled person. For the purpose of this paper; myself as a parent of a child with a disability.

Comorbid - the simultaneous presence of two chronic diseases or conditions in a patient.

Concomitant - Something happening or existing at the same time.

Efficacy – the ability to produce a desired or intended result.

Family system – the emotional unit of mother, father, and children.

Multiple disabilities - having two or more developmental domains that are significantly delayed.

Hypoplasia – underdevelopment or incomplete development of an organ or tissue.

Longitudinal - an observational study that follows particular individuals over prolonged period of time often years or decades to observe any changes in them.

Multiple disabilities – the combination of impairments found within the thirteen categories of IDEA.

Rumination – repetitively focusing on one's symptoms of distress.

Self-mastery – the belief that one can take active steps to control directly the course of an event or to prevent it from occurring.

Strain – enduring problems that have the potential for arousing threat.

Transformation – the act or process of changing, as through growth.

CHAPTER 2: REVIEW OF THE LITERATURE

This chapter reflects the literature that discusses multiple disabilities as a disability term for children who are delayed in two or more developmental areas or domains. Each diagnosis is as exclusive as the child themselves. Causes of the disabilities are inconclusive. Even therapies and treatments are not a guaranteed correction or minimization of the disabilities. The purpose of this study is to provide a personalized account of how a mother functions, responds to and grows from positive and negative transformations associated with raising and educating a child diagnosed with multiple disabilities.

With the challenges associated with the diagnosis, cause, and treatments of multiple disabilities there is much to consider with respect to the families of these children. For that purpose, I focus on my position as the mother in a family as a collective system that includes a typically developing sibling. The negative transformations may focus on the care burden and cycle of stress and behavior associated with challenges. The positive transformations may focus on therapy/intervention techniques, optimistic disposition, self-mastery, parenting self-efficacy, and a support system I deem a "village" that supports all members of the family system, both formally and informally. Cook (2006) concurs "We also had the support of a wonderful family" (p. 48), including a grandmother who helped whenever she could.

These components were looked at from personal selective, retrospective epiphanies, and past experiences with regards to how I perceive myself and my transformations regarding my daughter with multiple disabilities. I focused on the intimacy of my role in my family as a functioning system. This allowed my study to be a qualitative autoethnography through an intimate inquiry lens. Additionally, using an educator and parent lens I investigated my personal perspective of the education system as a component of the "village" of caregivers for my

daughter. I have used my privilege of being in education and understanding the system to advocate for my daughter's needs.

Multiple Disabilities Is Not Just a Label

There are 13 disability categories identified under the Individuals with Disabilities Education Act (Kemer & Sansom, 2013). These categories are disabilities related to impairments, disturbances, or conditions affecting developmental domains. These developmental domains are gross/fine motor skills, speech/language, social/personal, cognition, and activities of daily living. According to Brownstein (2015) having a shared definition of the disability is a starting place for the school districts' identification procedures.

Development delay in only one domain is a common occurrence that pediatricians witness in children during well-child visits and does not necessarily weigh significantly on the overall development of the child, however a delay diagnosed in two developmental domains is typically associated with delays across all domains (Riou et al., 2009). Concurrently, Shevell and colleagues (2003) explain that multiple disabilities is defined as having two or more developmental domains that are significantly delayed. Additionally, they explain, if a child has delays in at least two domains, there is a higher chance that delays in other domains will present themselves. Pediatricians identify the deficits of difficulty meeting developmental milestones in comparison to typically developed chronological peers. Significant delays are categorized as performing two or more standard deviations below the mean of the developmental milestone (Riou et al., 2009; Shevell et al., 2003). A deviation is apart from the norm, whereas a standard deviation represents a deviation for a group or a whole.

Diagnosis of Multiple Disabilities

Multiple disabilities is usually diagnosed in children five years of age or younger (Riou et al., 2009; Shevell et al., 2003). According to Brothers and colleagues (2008), parents are provided a multiple choice questionnaire which serves as an informal milestone checklist at monthly 'well visit check-ups' at the doctor's office. This is standard procedure for all children, regardless of normal development or potential delay. There are approximately six to eight questions on the survey, per age range, geared to determine age appropriate developmental milestones. The questions ask parents to reflect on the development in each of the developmental domains including; fine motor skills, gross motor skill, expressive language (articulation), receptive (understanding) language, self-help (dressing, teeth brushing, etc.) and socio-emotional skills. Parents and pediatricians discuss the development of the milestones recorded on the survey. This discussion is imperative as feedback from daily home life can be significant in understanding whether the delay is significant or not.

A delay in more than one milestone may be cause for clinical testing to assess why the delays are occurring (Shevell et al., 2003). This is a major concern to be taken into further consideration especially if the milestones have not been met by the time a subsequent visit has occurred. These delays may present themselves as challenges to the family experiencing the delays. Riou and colleagues (2009) assert language development and motor skill development tend to be the domains first identified as they are able to be observed by both parents and physicians as generally accepted norms without the aid of clinical testing. Developmental milestones that parents are asked about include motor skills such as crawling and walking and speech/language skills such as babbling and talking (Brothers et al., 2008). In these instances, parents may not have been aware of their child's delay in these domains or understood the

milestone associated with the age, domain, and delay. Speaking with the pediatrician for further assistance and clarification may be warranted.

According to Shevell and colleagues (2003), 5% to 10% of children are diagnosed with developmental disabilities, 1% to 3% of which are affected by multiple disabilities, being delayed in multiple domains. This means that 40,000 to 120,000 children out of 4 million born in the United States and Canada annually are diagnosed with multiple disabilities.

What Comorbid Conditions Exist?

While causes of multiple disabilities are unknown, neurodevelopmental outcomes have been studied. Bolduc and Limperopoulos (2009) conducted a systematic review of neuroimaging of children with multiple disabilities. It was noted that children with dysgenetic abnormalities of the cerebellum, it's two hemispheres, and the medial part known as the vermis displayed moderate to severe multiple disabilities. These areas can display hypoplasia, which is a decreased amount of the brain anatomy, or agenesis, which is the complete absence of the brain anatomy. Additionally, children with multiple disabilities may experience other medical conditions, usually described as a dual diagnosis, such as epilepsy or seizure disorder, visual and auditory impairments, and mental health or behavior issues (Shevell et al., 2003; Unwin & Deb, 2011). My daughter has a diagnosis of hypoplasia of the cerebellar vermis, hypoplasia of the Corpus Callosum, mosaic duplication of chromosome 15, and epilepsy.

Multiple disabilities is not the same as mental retardation. "A child with the clinical picture of multiple disabilities is not necessarily destined to be mentally retarded" (Shevell et al., 2003, p. 368). Mental retardation, according to Rauch et al. (2006), is a significant delay in the cognitive domain resulting in an intellectual impairment that can also effect adaptive functioning. Therefore, mental retardation is diagnosed through the use of intelligence testing.

Pediatricians and medical specialists may need to rule out or include comorbid conditions such as mental retardation, cerebral palsy, neuromuscular disorders, language disorder, autism spectrum disorder, metabolic disorders, cytogenetic abnormalities of chromosomes, and Rett syndrome (Shevell et al., 2003). My daughter's medical team ruled out Dandy Walker Syndrome and Down syndrome while she was in utero. Pediatricians and medical specialists, with the support of parents and family, would have to turn to laboratory investigations to determine etiology of multiple disabilities. Various types of screenings, such as molecular testing, chromosomal arrays, and neuroimaging, may take place to determine diagnostic yields in young children "with a Global Developmental Delay that is static, nonprogressive, and has no clear etiology" (Shevell et al., 2003, p. 368). My daughter has had MRI's, both in utero and as an infant and toddler, chromosomal array, and genetics screening.

The Functioning of the Family System

The family system, also known as the family unit, is the connection of the functioning and support systems of the child, parents, and siblings. The functioning system refers to how the family functions as a unit, whether cohesive or strained (Dyson, 1987). The support system refers to how the family supports each other internally and positively in the face of challenges. Experiencing a multiple disabilities in the immediate family has lifelong consequences for family well-being over long periods of time, whether conscious or subconscious (Barr et al., 2008; Trute, Hiebert-Murphy, & Levine, 2007).   "The developmental delays of children with established disabilities…tend to create enormous challenges requiring parents to acquire considerable information to both understand and address these issues" (Guralnick, 2006, p. 52). The unique strains related to the child's impairment can impact parents' adaptive functioning and parenting efficacy (Harper et al., 2013; Woodman & Hauser-

Cram, 2012). Pearlin and Schooler (1978) describe life strains as a synonymous term with stressors. For the purpose of this paper, both terms will be used in conjunction with one another. These strains are threats and challenges that may be harmful and for which people develop coping responses to in order to prevent, avoid, or control affected well-being.

Families can grow stronger and closer together or they can fall apart under the strain of the care burden and related stress of challenges. The impingement of the developmental delay has the capacity to ramify through the family and caregivers. The effect of the developmental delay can impact members of the family system individually and the interpersonal relationships inside and outside the family (Dyson, 1987).

According to Brown and colleagues (2011), a child's functioning includes their cognitive ability and adaptive functioning which are affected by their developmental delay. The delay status of the child directly affects the parental functioning and efficacy, which is presented in negative, intrusive parenting, higher perceived levels of negative family impact, and lower levels of family well-being (Brown and colleagues, 2011; Trute, Hiebert-Murphy, & Levine, 2007). Family functioning greatly impacts the development of high-risk children (Paczkowski & Baker, 2007). In the following section I expand upon burdens and challenges family units face when caregiving for a child with multiple disabilities.

Care Burden

Children with a multiple disabilities unintentionally create dysfunction in the home (Behr & Murphy, 1993; Orfus & Howe, 2008). Caregiver burden is defined as the load or strain a person bears when caring for a disabled family member. Burden, difficult aspects of caregiving, and negative impacts include physical, emotional, social, medical, and financial strains associated with caring for the family member with a multiple disabilities (Hastings & Taunt,

2002; Kuo et al. 2011; Trute, Hiebert-Murphy, & Levine, 2007). These strains are daily and can build in intensity from early childhood into middle childhood and adolescence.

Kuo and colleagues (2011) reveal that raising a child with multiple disabilities often means additional child care demands which could mean added costs to the family budget. Caregivers of a child with multiple disabilities spend more time coordinating care at school, daycare, and home care. Furthermore, childcare could take the form of cutting back on work or unemployment in order to care for the child. A child with comorbid conditions may require additional medical care as well which must also be coordinated. This requires time off of work for medical treatments, rehabilitation, or therapy sessions. Medical expenses could also require out-of-pocket costs which result in financial burden if not afforded by external respite care (Harper, Dyches, Harper, Roper, and South, 2013).

Children with multiple disabilities may have disabilities that are of a lifelong nature and may need to be assisted in their living for the entirety of their life which requires them to live at home with their parents or other family member, or placed in assisted living (Behr & Murphy, 1993; Rowbotham, Carroll, & Cuskelly; 2011). These are things that must be taken into consideration at all times for this child's entire life. Around 60 % of adults with developmental disabilities live at home with their parents and other trusted caregivers (Unwin & Deb, 2011). Parents have to plan their retirements accordingly to accommodate their child's needs and lifespan. Financial plans, such as the Achieving a Better Life Experience (ABLE) account, are available to caregivers for their children with multiple disabilities. These such accounts are a tax-advantaged savings account that subsidizes public benefits (Laise, 2017).

As previously stated, children with multiple disabilities, especially those with comorbid conditions, may need medical equipment, therapies, outpatient or inpatient procedures or

surgeries, frequent appointments with various medical professionals and specialists, and potentially serious medical decisions have to be made. Additionally academic/special education services, specialty care, daycare and/or homecare (respite) placement may be determined by the severity of the delay and medical conditions of the child (Kuo et al., 2011). These conditions are a snapshot of what the culture of multiple disabilities is on the surface. In a household with typically developed children it has been reported that the mother feels greater strain in a caregiving role, having more household chores, child care, and parenting responsibilities (Nolen-Hoeksema, Larson, & Grayson, 1999). In a household with a child with multiple disabilities, the family unit experiences differing responses to stressful situations and more variability in adjustments made in raising said child (Behr & Murphy, 1993; Woodman & Hauser-Cram, 2012). Caregiving in this culture of multiple disabilities can pay a toll on the emotional, financial and physical well-being of any family member at any given time and can impact the effective coping mechanisms of the family unit (Hastings & Taunt, 2002). This includes parents, siblings, and other relatives that may live in the household and share in the caregiving responsibilities.

Challenges: Caregiving and Coping

Orfus and Howe (2008) utilize the terms hassles and uplifts when referring to the positive and negative impact the multiple disabilities has on the family as a systematic unit. Miller, Wilcox, and Soper (1985) describe hassles as the frustrating, irritating, distressing demand put forth by the strain and malaise caused by care burden. Challenges are discussed first as it is human nature to describe negative aspects prior to analyzing the positive that can be gained from lived experiences. Studies on negative impacts on life such as damage and disorder have become the forefront in psychological studies due to a more thorough processing of negative events over

positive events. Humans process negative information and events more readily than positive information and events (Gable & Haidt, 2005). Previous research perceptions of the family impact of childhood developmental disability have focused on negative perceptions such as stress derived from the negative reactions to the child with the disability, family dysfunction, parenting efficacy, and depressive symptoms (Bandura, 2006; Behr & Murphy, 1993; Giallo & Payne, 2006, Woodman & Hauser-Cram, 2012). Dramatic events and taxing situations are the focus of modern stress research (Kanner, Coyne, Schaefer, & Lazarus, 1981). Each member of the family appraises their challenges and copes with the multiple disabilities and stress in their own manner (Guralnick, 2006). The caregiver's perception of the burden determines the impact the challenge has on his/her life (Oh & Lee, 2009; Orfus & Howe, 2008). The reverse of this sentiment could be that each family member appraises positive appeal, both for and from the child, and values their experiences in their own manner.

A Mother's Role in Sibling Related Adjustment

Parent and family factors such as problem-solving communication, family routines, management of stressful situations, and family coping resources can be predictors of how siblings of children with multiple disabilities adjust (Giallo & Gavidia-Payne, 2006; Hastings & Taunt, 2002). These predictors are part of a mother's role of traditional domestic caregiving responsibilities. Mother's typically take on the major share of childcare of children that are developing typically and children with multiple disabilities (Nolen-Hoeksema, Larson, & Grayson, 1999; Rowbotham, Carroll, & Cuskelly, 2011). In this manner, mothers restore the balance between demands and capabilities of the family as an interacting unit and as follows, creates a family schema. Such a schema reflects a family as an integrating unit, sharing beliefs, meanings, and values in order to adapt to the impact of the disability (Hastings & Taunt, 2002).

Siblings have a unique bond that is not easily identified or described by research. Siblings can influence and help each other adjust developmentally, emotionally, and spiritually (Orfus & Howe, 2008). Yet, it remains that siblings are rarely included in research conducted on family functioning of children with multiple disabilities (Orfus & Howe). Additionally, it is not reported how a mother, in her role of caregiver, helps nurture the relationship and bond between a sibling that is developing typically and a child with multiple disabilities nor has research determined clear findings to suggest positive perceptions and experiences are associated with raising a typically developed child versus raising a child with a disability (Hastings & Taunt, 2002). A limitation in research is understanding the mother in her role of raising both a child with a disability and a typically developed child.

Mothers should make sure the perspective of typically developing sibling is not overlooked as they have been in research (Hastings & Taunt, 2002; Orfus & Howe, 2008). Siblings of a child with multiple disabilities may experience similar feelings to that of their parents, but are less likely to have those feelings acknowledged (Barr et al., 2008). In addition to these feelings, siblings may withdraw from extracurricular activities and friends, feel pressured to achieve more academically in order to compensate for their siblings lack of ability, experience school functioning problems, or developed increased internalizing problems (Barr et al., 2008; Hastings & Taunt, 2002). Siblings tend to have friends based on who is accepting of the sibling with multiple disabilities and understands the delay and may even choose spouses based on the same requirements as their friendships in childhood (Barr et al.). Part of the reason being that they do not want to be embarrassed by their delayed sibling's behaviors and actions, such as crying and aggression, when around their friends. Siblings also expressed that they cannot

always do what they would like to do because of their delayed sibling. (Barr et al., 2008; Orfus & Howe, 2008).

Most important is the acknowledgment and acceptance that their sibling's multiple disabilities affects everyone in the family, regardless of the positive or negative connotation of the effect. Mothers may rely on older siblings to help care for their younger siblings (Orfus & Howe, 2008). When the family has a child with a multiple disabilities siblings may have more responsibility in order to help alleviate the family unit with caregiving burden. This can increase the stress levels of the sibling (Orfus & Howe).

Parents can play a part in how siblings feel about each other as well. Giallo and Gavidia-Payne (2006) developed a Sibling Daily Hassles and Uplifts Scale for their study. The results of this scale showed that siblings scored higher on adjustment difficulties and emotional symptoms and lower on pro-social behavior. Positive family experiences were thought to promote positive adjustment outcomes for siblings considering family characteristics are the most powerful influence on child development and well-being, with mothers providing social support and modeling coping skills (Giallo & Gavidia-Payne). In another study, Orfus and Howe (2008) interviewed siblings of children with multiple disabilities. Siblings reported a higher mean frequency of positive experiences than of challenges. Typically developed siblings enjoyed when they received affection from the delayed sibling. They also reported playtime and quality time with their delayed sibling as an example of positive appeal. Siblings also reported episodes of positive appeal when their delayed sibling shared with them, when they were able to help their delayed sibling, and when they heard good news regarding their delayed sibling (Orfus & Howe, 2008).

In these instances, positive perceptions can be portrayed throughout the family unit as the family works together to create a positive environment, assisting in individual family members adaptation to the child with a disability (Hastings & Taunt).

Cycle of Parenting Stress and Child Behavior

Stress can become a vicious, coercive cycle within the functioning of the family system. According to Neece (2013) the parent can be stressed because of the child's behavior, yet the child can demonstrate behavior problems due to the parent's stress and parenting. Brown and colleagues (2011) explain this pattern of parent-child interactions as bi-directional. Furthermore, research shows that parent stress is more associated with child behavior rather than the developmental delays of the child (Floyd & Gallagher, 1997). For the purposes of this study, the parent is myself, in the role of a mother, with additional responsibilities in the household, as a parent, and an employed woman and mother.

Another aspect of the cycle of stress or strain that mothers of children with disability may experience is parenting efficacy and depressive symptoms. Behavior issues associated with the child can increase depressive symptoms and lower feelings of parenting efficacy (Woodman & Hauser-Cram, 2012). Mothers that experience low parenting efficacy may also experience low self-mastery. This cycle contributes to rumination, repeatedly focusing on the negative perceptions and emotions of sadness or depression (Nolen-Hoeksema, Larson, & Grayson, 1999).

Finally, it should be noted that lower marital satisfaction has been linked with greater child behavior problems sourced from parenting stress, contributing to the cycle of stress that takes place within the family system (Baker et al., 2005; Robinson & Neece, 2015). Lower marital satisfaction has been reported by the wife and mother from the perspective of role strain

and burden in accordance with their partner's assistance with domestic and caregiving tasks (Rowbotham, Carroll, & Cuskelly, 2011). Cook (2006) explains in her anecdote "we knew the odds of a marriage surviving with a child with special needs…" (p. 48).

Parenting Related Challenges

Living with a child that is afflicted by multiple disabilities can elicit many feelings. Guilt, frustration, sorrow, crisis and helplessness are just a few emotions parents may feel when their child is diagnosed with multiple disabilities (Baker et al., 2005; Trute, Hiebert-Murphy, & Levine, 2007). Regardless of the link between parenting stress and child behavior problems there is a vast variability regarding the manner in which parents respond to the behavior and the child. Adding a child with a developmental delay to a family can significantly change the dynamics and the way the family unit functions. From this point on, there may no longer be time for "me" or time for "us" (husband and wife or parents and child). Parental and family well-being is most commonly associated with the level of stress the parent experiences (Oh & Lee, 2009; Trute, Hiebert-Murphy, & Levine, 2007). Most research has focused on the mothers of children with disabilities, with little focus on the father's experiences (Rowbotham, Carroll, & Cuskelly, 2011). Additionally, most research considers the family unit to be of heterosexual partners, with a mother and father in the roles of parents. Parents, especially mothers, are prone to poorer emotional and physical health than mothers of typically developed children (Feldman et al., 2007). This can make or break a family unit. "In the majority of world cultures, mothers, as opposed to fathers, appear to have greater responsibility for direct childcare" (Oh & Lee, 2009, p.151). Research suggests that mothers do not take care of their emotional and physical well-being due to the time consumption of daily care for their child. Depression, anxiety, and other mental conditions can affect maternal well-being as a

result of raising a child with multiple disabilities (Feldman et al., 2007; Oh & Lee, 2009). Additional factors that contribute to or affect parental well-being include dispositional (inherent quality of mind and character) factors such as a sense of self-mastery of one's environment, the ability to bond with their child, parent-child interactions, marital satisfaction, and child behavior (Baker et al., 2005; Brown et al., 2011; Ben Shlomo & Taubman – Ben – Ari, 2012; Guralnick et al., 2008; Paczkowski & Baker, 2007).

Bondy and Mash (1999) describe another aspect, parenting self-efficacy, competence to produce a desired result. The parents' perceptions of the failure and success related to managing their child can be related to child behavior problems. Paczkowski and Baker (2007), corroborate the link between parenting stress, parenting behaviors, child behavior, and active coping. If a parent has low levels of parenting self-efficacy child behaviors were reportedly higher than those of parents who had greater parenting self-efficacy and lower child behavior issues (Woodman & Hauser-Cram, 2012). Negative parenting techniques; abusive, intrusive (directive, overstimulation, and overprotective), coercive, permissive, inconsistent discipline, have been associated with lower parenting self-efficacy and increased parent-related stress. "Low parenting efficacy may lead to more frequent use of coercive discipline, which may lead to more misbehavior, which may lead to more coercive discipline, which may lower the sense of parenting efficacy" (Bondy and Mash, 1999, p. 163).

Parent-Related Stress

As previously stated, care burden of children with multiple disabilities causes struggles, challenges, strains and stressors such as financial costs, employment obligations and risk of unemployment, marital stress, parenting stress, and mental and physical stress (Kuo et al., 2011; Robinson & Neece, 2015). Sources of challenges can also come from disruption of family plans,

social isolation, and date nights for the parents. Parents with typically developed children also

have to continue to provide for their normal developed child as well and make sure they feel

included in the family unit (Barr et al., 2008; Guralnick et al., 2008; Paczkowski & Baker,

2008).

Parent-related stress can be alleviated by support systems, which can be thought of as

village support. Patrick Slattery (2013) refers to Hillary Clinton's 1996 book *It Takes a*

Village. The focus of Clinton's book was to expound the African proverb for families, churches,

educators and academic professionals, medical professionals, and the government to come

together as a means to care for all people, including developmental delayed individuals.

The village rhetoric is broken up into two categories, informal support and formal support

(Kesselring et al., 2012). Informal support is provided by personal social networks, which can

consist of nonparental adults such as grandparents or other extended family members or

nonfamilial adults such as friends, sports coaches, or neighbors (Ben Shlomo & Taubman – Ben-

Ari, 2012; Wheelock & Jones, 2002). Social networks offer emotional support; reassurance and

validation of beliefs, and instrumental support; practical tasks such as transportation or child

care. The benefits of informal support include family adaptation, feelings of parenting and

coping effectiveness, lessened stress and distress, psychological well-being, feelings of mastery,

and processing and handling the demands (Abbott & Meredith, 1986; Kawachi & Berkman,

2001; Pearlin & Schooler, 1978) of parenting a child with a multiple disabilities.

Formal support systems are agents of guidance and assistance in areas lacking knowledge

or know-how that provide the family informational support; directive advice, or normative

support; modeling behaviors (Guralnick et al., 2008; Kesselring et al., 2012). Formal support is

provided by professional organizations such as schools, regional centers, or family-centered agencies, to which I return later.

Behavior of a Child with Developmental Delays

Research suggests that child-related risk factors early in childhood and development have an impact on child behavior later in life. The risk factors of birth complications, infantile illness, health complications, and developmental delay status can create a temperament such as demandingness that can become an adverse situation for the parental and family functioning systems (Brown et al., 2011). Additionally, it has been reported that parents of younger children with disabilities report higher levels of stress suggesting a relationship between child behavior and parent stress (Behr & Murphy, 1993).

Children that have multiple disabilities are at a greater risk for developing internalized and externalized emotional, psychosocial, and behavior problems than that of typically developed peers. Neece (2013) reports that 26.1 % of children with developmental delay have behavior problems at clinical levels compared to 8.3% of chronological typically developed children. Children that are delayed may be unable to complete tasks and require modifications from educators and caregivers either at home or school. Children may have withdrawal symptoms (from social situations and sensory input), aggressive tendencies, and sleep problems. They may also have frequent bouts of crying, display defiance, and require more attention and time from their parents and educators (Brown et al., 2011; Robinson & Neece, 2015). Both principals and teachers lack awareness and training of issues related to learning disabilities, including teachers' teaching and management skills of said children (Katoka et al., 2004).

Related Stress of a Child with Developmental Delays

Learning how to communicate wants, needs, and desires can be complicated for any

typically developed toddler (Seefeldt, 2004). It can become a primary source of stress and

behavior problems in a child with multiple disabilities that increases during the early childhood

period (Hill & Flores, 2014). Orfus and Howe (2008) describes these stress occurrences as daily

adverse situations which include but are not limited to crying, demonstrations of upsets, hitting,

and pushing. Behaviors of children with developmental delay should be considered part of the

bi-directional cycle or child-risk factors described before. Negative parenting, lessened

parenting efficacy, maternal depressive symptoms, maternal intrusiveness, negative perceptions

and risk factors can present an additive effect for the child (Orfus & Howe, 2008; Woodman &

Hauser-Cram, 2012). These negative effects from the parents reinforce learned behaviors which

can attribute to negative and increased behavior outcomes in the child such as poor performance,

mood swings, demandingness, and aggression (Brown et al., 2011; Guralnick et al., 2008). As

these negative effects present themselves in a developmentally delayed child, the entire family

unit is affected. The entire family can be affected by positive effects as well as discussed in the

next section.

Education of a Child with Developmental Delays

The behaviors, stresses, and strains described above must be accommodated and adjusted

to by the teaching staff and administration of children with multiple disabilities. The purpose of

a quality special education program is to guide the student's positive self-image (Burrello,

Schnepf, & DeClue, 1988). This can be accomplished through academic and adaptive progress

of goals established in the student's Individual Education Plans (IEPs). It can also be

accomplished through providing students with a least restrictive environment (LRE) by

narrowing the discrepancy between mainstream (regular) education and special education. A quality special education program also focuses on the future of the student by providing opportunities to learn independent living skills and communication skills, work experience, and job placements. These objectives are achieved under the leadership of school administrators in collaboration with classroom teachers (both special day class and general education) and support staff on campus.

Principals need to collaborate with district directors of special education who work with special education teachers, support staff, and related personnel in order to advocate for students with multiple disabilities in need of special education (Bakken and Smith, 2011). Burrello and colleagues (1988) render a principal's authority to make decisions regarding special education an element of a quality special education program while Bakken and Smith (2011) acknowledge that the role of the director of special education is as liaison between the principal and other special education professionals on site.

Other elements of a quality special education program include three criteria. The first criteria is pre-instruction factors such as diagnosis, grouping, curriculum instruction and pacing, and measurement. The second criteria is during-instruction factors such as structuring engagement, time, and success, monitoring, and feedback. The third criteria is climate factors such as environment, expectations of the teacher, communication with parents, students and staff, and student exit criteria (Burrello and colleagues, 1988).

In order for these elements to be achieved administration and directors of special education need to ensure that special education teachers receive the same opportunities for in-service professional development, decision making, and curriculum as general education teachers (Bakken & Smith, 2011; Burrello, Schnepf, and DeClue, 1988). The overall program needs to be

reviewed for effectiveness of policies and procedures for the enhancement of students learning. In the event of unique problems of discipline, school personnel should be prepared to redirect and offer mild punishment (Burrello et al., 1988). Finally, Kataoka and colleagues (2004) conclude that support systems should aide in parent cooperation and understanding, classroom management, and teacher professional development and team teaching.

Positive Appeal: Coping and Positiveness

For the purpose of this paper, positive appeal is expressed as the product and perception of uplifts, or positive emotional experiences, (Hastings & Taunt, 2002; Kanner et al., 1981) that are a measure of positive aspects of caring. According to Turnbull, Blue-Banning, Turbiville, and Park (1999), unconditional love is a basic primary need that all children require from their family.

> Unconditional love is the knowledge that someone loves you with all your frailties as well as your strengths. This is the kind of love that is supposed to be given between parent and child, whether the child has a disability or not. (p. 165)

There is a cycle of positive and negative appeals associated with parenting. Appraisal of parenting a child with a disability and their impact on the family unit recognize that there may be times of sadness and joy. Positive and negative appraisals and emotions can coexist. Parents have reported both positive and negative ways in which they have responded to their child with a disability (Hastings & Taunt, 2002; Trute, Hiebert-Murphy, & Levine, 2007). Kanner and colleagues (1981) described in detail the relation of challenges and uplifts. Negative and positive emotions are connected. As burden and challenge decreases, emotional uplifts increase and vice versa (Unwin & Deb, 2011). Positive affect in the stress process can co-occur with negative affect during a given period and can also occur during chronic stress (Folkman & Moskowitz, 2000). Dyson (1987) asserts that the effect of the developmental delay on the family

functioning need not be negative while admitting the delay has an unequivocal effect on the family unit. Additionally, while there is heightened child-related stress due to developmental delay, the overall family functioning was reportedly no different from that of a family with typically developed children (Abbott & Meredith, 1986; Dyson, 1987). These family caregiving units learn how to use adaptive coping skills with the child who has multiple disabilities together, providing strength, well-being and cohesion within the family system (Orfus & Howe, 2008; Woodman & Hauser-Cram, 2012). According to Cook (2006) "when you have a child with special needs, it's important to make family life as normal as possible" (p. 49). All of this can be made possible through adaptive coping strategies, self-mastery, optimism, parenting self-efficacy, and positive appeal, reappraisal and reinterpretation all of which can lead to personal growth of the parent.

Coping Strategies of Parents

A vast amount of emotions, both positive and negative, involved in caregiving for a child with multiple disabilities has been researched. Unconditional love, as an emotion or product and action of mothering, is not so easy to research and document. Unconditional love may be felt for a variety of reasons including the bond between mother and child, feelings of increased meaning and enrichment, and the positive contributions of the child with the disability (Hastings & Taunt, 2002). Positive effects can stem from caring or helping the child with multiple disabilities (Unwin & Deb, 2011). Parents reportedly accept the multiple disabilities as a fact of life that cannot be changed as well as understanding that there are families that are worse off than they are (Behr & Murphy, 1993; Orfus and Howe, 2008). Abbott & Meredith (1986) explain that parents report accepting their child with a disability as they did their other children. Pearlin and Schooler (1978) explain that people in culture of coping have themes to aid in accommodating

stress without being overwhelmed by it. These themes include; accept hardship because it was meant to be, take the good with the bad, and everything works out for the best. This realistic, direct attitude and sentiment from parents can provide a positive acceptance model for the family as a unit by converting unavoidable hardships into moral virtue (Pearlin & Schooler, 1978). When presented with a problem families try to figure out a solution as soon as possible for the benefit of the family, not just the child with the multiple disabilities.

Practical problem-solving focus allows the family to make decisions and cope, lessening strains. Folkman and Moskowitz (2000) refer to this as problem-focused coping where one focuses on tasks, making this coping strategy instrumental in nature. When used, the individual feels effective and experiences self-mastery. Mothers who use problem-focused coping as a means to actively plan efforts to change the source of their stress have reported a decrease in child behavior problems and lessened depressive symptoms (Woodman & Hauser-Cram, 2012). Parents that utilize positive coping strategies individually and within the family system have reported greater marital satisfaction and disposition, lessened stress, lower incidents of negative child behavior, and personal growth. Cook (2006) continues from her anecdote "we were diligent in keeping the lines of communication open…keep ourselves rested…and enjoying time together when possible" (p. 48). In a study looking at caregiving for an adult child with a disability, Rowbotham, Carroll, and Cuskelly (2011) found that parents reported daily evidence of positive experiences in the forms of care-giving satisfaction and increased positive behavior in the adult child. In the following sections I expand on these positive coping strategies.

Positive Beliefs

Human beings face challenges daily. How one handles situations depends on their perceptions of the world and how they deal with the challenges they are faced with (Bath,

2005). When facing their problems, what people do or don't do can make a difference to their well-being (Pearlin & Schooler, 1973). Positive beliefs, positive reappraisal, positive reinterpretation and dispositional optimism are a few of the strategies used in challenging situations (Baker, Blacher, & Olsson, 2005; Folkman & Moskowitz, 2000; Paczkowski & Baker, 2008; Paczkowski & Baker, 2007; Scheier & Carver, 1992). Caregiving for a global developmentally delayed child brings challenges frequently, if not daily (Guralnick, 2006). Having a positive belief system is a strategy used by parents to reduce stress, increase well-being and self-mastery, and have a positive influence on child behavior (Paczkowski & Baker, 2008; Woodman & Hauser-Cram, 2012).

Positive psychology is the study of optimal functioning of people or a culture and the conditions and processes that contribute to the healthy families of the people or culture due to the protective nature of optimism and self-mastery (Gable & Haidt, 2005). Feldman (2007) encourages families with the outlook that raising a child with multiple disabilities can be a positive family experience, while Paczkowski and Baker (2008) explain that positive beliefs can influence the parent-child relationship, parent and child well-being, and health.

Self-mastery is a person's perception that they have control over the situation and their life. It is because of self-mastery that a person might feel secure and confident to accomplish most things they try therefore can be a prediction of physical and psychological well-being. People are more likely to be successful if they maintain a level of self-mastery (Ben Shlomo & Taubman – Ben-Ari, 2012; Hobfoll, 1989; Paczkowski & Baker, 2008; Paczkowski & Baker, 2007; Scheier & Carver, 1992).

Dispositional Optimism (Scheier & Carver, 1992) is a person's positive interpretation regarding what the future holds, regardless of the control they may possess. People tend to

believe in good versus bad in regards to their experiences in life and deal with problems head on, taking steps to make their situation better. In terms of psychological well-being, positive thinking is helpful because it makes people feel better and shows benefits in what people are able to do in times of crisis or adversity. In terms of physical well-being, optimism can produce fewer physical symptoms of distress. Optimists tend to use problem-focused coping because they perceive having the ability to control and accept stressful situations. In this regard, people choose to make the best of a situation and learn from the experience further reinforcing the reliance of optimism (Scheier & Carver, 1992).

Optimism and self-mastery are interconnected. Parents may feel more optimistic because they have a sense of control over situations regarding their child with a disability. Self -mastery and optimism are psychological adjustments that allows for the parent to initiate greater active, problem-focused coping strategies. Parents, mothers specifically, report lower levels of stress, beyond child behavior, when they have higher reports of positive belief attributes. Positive belief attributes are forms of optimism such as acceptance, belief in good future outcomes, and positive reinterpretation. The reason being that positive beliefs moderate the strains of parenting and educating a global developmentally delayed child (Ben Shlomo & Taubman – Ben-Ari, 2012; Paczkowski & Baker, 2008; Baker, Blacher, & Olsson, 2005). Having support resources in place can also alleviate the strains of parenting a child with a disability and increase positive beliefs.

Village Support

Throughout their lives children have opportunities to interact with a wealth of people, many of whom are professionals offering guidance and support in some fashion; medical professionals, teachers and academic professionals, counselors, coaches, pastors, boys and girls

scouts and/or clubs, Easter Seals, hospice care, etc. When both parents in a nuclear family have to work they may not be able to provide the type and amount of care they would like to. Childcare supports parents, mothers specifically, in providing for their families (Wheelock & Jones, 2002). This list provides examples of the "village" it takes to raise a child, disabled or not, as the old African proverb goes.

When faced with challenges, there comes a point in time when an individual person or the family unit needs more than internalized coping strategies (Dempsey & Dunst, 2004; Harper et al., 2011). Mothers, who reportedly suffer more from other people's problems, are much more likely than fathers to rely on another of their children, a close relative, or a friend as someone they can confide in and ask support from (Kawachi & Berkman, 2001). Resources are what are available to people looking for coping strategies during crises and challenges. Social resources present themselves as interpersonal networks people are a part of and can reach out to for support such as family, friends, coworkers, neighbors, churches, and voluntary associations or social services (Abbott & Meredith, 1986; Pearlin & Schooler, 1978). The resource deemed most valuable would be the support of the spouse. High marital satisfaction has been linked to internalized coping strategies, family functioning and well-being, and health (Abbott & Meredith, 1986).

Social support, defined as a system of interpersonal interactions, can have both cohesive and repressive impacts on an individual. It can increase self-esteem and self-efficacy but it also has the potential to make one dependent on others creating anxiety disorders. Social support interventions can provide informational and instrumental support while increasing emotional support perceptions and self-appraisal as was the focus for this paper (Ben Shlomo & Taubman – Ben-Ari, 2012; Kawachi & Berkman, 2001).

Family-Professional Partnerships

Family-professional partnerships are external resources that include professional organizations families can turn to for support, guidance, therapy, and interventions (Dunst & Dempsey, 2007). Families may ask for advice from religious figures, professionals or family-practice centers (Abbott & Meredith, 1986; Orfus & Howe, 2008). Regional centers, service providers, and family-centered agencies are organizations that can enable access to preferred community environments and offer guidance and assistance to parents and families. Similar to social support interventions, external support can provide guidance and assistance in instrumental and informational areas where families may be lacking knowledge or the know-how, in other words help-giving (Ben Shlomo & Taubman – Ben-Ari, 2012; Dunst & Dempsey, 2007; Turnbill et al., 1999).

In times of clinical level stress and behavior families of children with multiple disabilities may look to formal support such as resource specialists, therapists, and rehabilitation or intervention programs for guidance. The relationship between parents and formal support professionals has the potential to enhance or hinder the outcomes for families of a child with multiple disabilities (Dunst & Dempsey, 2007; Kesselring et al., 2012). For the purpose of this paper, enhancement, rather than hindrance, is discussed as a positive influence for the family unit as it relates to help-giving practices.

Dunst and Dempsey (2007) express enhancement as results of effective relationships between families and professional support that empower parents. Such empowerment, defined as accessing knowledge, skills, and resources that enable families to gain positive control over their own lives as well as improve their well-being, can increase positive beliefs such as competence, efficacy, and confidence. "Professionals can help families become empowered by creating

opportunities for family members to display competencies…to their own actions" (Judge, 1997, p. 473). Positive beliefs can empower parents to influence behavior, family unit functioning, parenting efficacy, self-mastery, and child- and parent- related stressors (Paczkowski & Baker, 2008).

Previous focus has been largely only on the parents and the child with multiple disabilities (Giallo & Gavidia-Payne, 2006; Orfus & Howe, 2008), however, siblings need to be included in these interventions as members of the family unit. As previously discussed, siblings have the potential to have a closer relationship with their sibling and therefore, should be included in interventions and therapy methods. The family should be viewed as a systematic unit when discussing intervention strategies or therapies (Barr et al., 2008; Roberts & Kaiser, 2011). Family-centered practices are such interventions that include the family as a whole caregiving unit when providing therapy.

As Barr and colleagues (2008) describes, services for families with a child with multiple disabilities are adaptable and individualized by each family's needs. They conducted research with regards to siblings, as an under-researched area of family practice centers. Four themes emerged from this study. The first theme was impact on the sibling relationship which discussed the personal relationship and understanding of the delay. The second theme was impact on relationships with non-familial people which discussed the sibling in the role of the protector and interpreter. The third theme was impact on self (typically developed sibling) and discussed jealousy and resentment emotions as well as worry and concern for the delayed sibling. The fourth and final theme was impact on the parent-child (typically developed sibling) relationship and discussed concerns regarding parents, taking on a parent-like role, and less parental

attention. The recommendation of this study was the importance of including siblings in the family-centered practice of therapy and interventions (Barr et al., 2008).

Family-professional practices should involve families in the decision-making process of their global developmentally delayed child's support to promote empowerment while enhancing the relationship for the betterment of the child (Judge, 1997). When parents feel they are responsible for the desired support and resources their child receives, it is correlated with positive beliefs about their parenting efficacy (Dempsey & Dunst, 2004; Dunst & Dempsey, 2007; Judge, S., 1997). Turnbull and colleagues (1999) express a move from parent education to partnership education in which family centeredness is enhanced through bidirectional education from professionals to parents and vice versus. Parents as providers enhance the family's capacity to help their child progress developmentally while increasing the perceived ability to work with and develop strong formal support systems. In closing, when parents and family units feel empowered they reciprocate support and positive beliefs with both informal and formal support systems.

Personal Growth/Self-System

An article written by d'Agnese (2016) discusses behind and beyond self-mastery. He referenced 'Dasein' which translates to 'presence' or 'being there'. The idea behind self-mastery is to reflect on experiences and move forward in new ways of thinking and acting, therefore pushing experience forward. In this regard, experience transcends the self; regardless of what a person will know, experience will always be behind knowledge and beyond oneself simultaneously. This is the essence of personal growth for an individual and their self-system, a term used by Hastings and Taunt (2002) to describe cognitive adaptation of responses to threats as a way to find meaning, gain mastery, and enhance oneself (Behr & Murphy, 1993).

Human agency (Bandura, 2006) is a theory of development, adaptation, and change. Humans possess the ability to self-regulate, self-organize, and self-reflect intentionally influencing their functioning and life circumstances through self-reactiveness and self-directedness. Humans are capable of developing an action plan and following through with it. Bandura's (2006) core belief of human agency is self-efficacy. One must believe that they have the ability to develop, adapt, and change. Self-efficacy is related to self-worth and self-esteem in that successful adaptation of challenges as an internal coping resource requires an upheld sense of positive self-view (Bandura, 2006; Trute, Hiebert-Murphy, & Levine, 2007). Human agency allows an individual to forge an identity through self-formation (Besley, 2005). For the purpose of this paper, my forged identity is one of a caregiver for a child with multiple disabilities. Besley (2005) discusses classical Greek and two known mantras 'care of the self' and 'know yourself' with the latter more prominent because it included that one should be concerned with themselves in order to improve themselves. In this paper I expressed how I have moved from caring for myself to knowing myself as a sign of personal growth. Self-mastery is evidence of caring for oneself by building on the strengths of the self for development, adaptation, and change (Besley, 2005).

Another aspect of the self-system is self-denial where a caregiver puts aside their own interests for the betterment of the interest of others (Besley, 2005). In this case, I as the mother, often put my own interests aside for my child. Situations of self-denial can lead to rumination because a mother may not feel that she can control these situations. Positive belief strategies help break the cycle of rumination and self-denial (Nolen-Hoeksema, Larson, & Grayson, 1999). Many everyday strains are not clearly positive or negative, making them open to interpretation and appraisal of the individual. Mothers who frequently use positive interpretation reported

higher levels of growth (Woodman & Hauser-Cram, 2012). Optimists use positive interpretation to allow them to accept the reality of the situation and actively cope creating adjustment and growth from experiences. This acceptance of the situation as a more accurate view of reality can be acquired from other avenues of life. Personal growth is a coping tactic used by optimists, especially in a situation of a child with a disability in the home and the strains associated with caregiving becoming longer in duration and chronic (Scheier & Carver, 1992).

Positive reinterpretation and growth has also been referred to as positive reappraisal and is linked to emotion-focused coping due to the nature of reframing situations, challenges, and crises in a positive light (Folkman & Moskowitz, 2000; Woodman & Hauser-Cram, 2012). Cognitive appraisal is the meaning that someone gives to a situation or crisis that challenges their well-being. When parents attach positive meaning and perceptions to the disability and caregiving requirements that has impacted their family they are utilizing positive appraisal in an effort to sustain over a long period of time. (Trute, Hiebert-Murphy, & Levine, 2007). Positive reappraisal has a positive correlation with parenting efficacy and lessened depressive symptoms in mothers of children with disabilities. In addition, self-mastery helps caregivers in the midst of distress having a motivational effect. Essentially, positive reappraisal takes the view of caregiving for a child with a disability as a painful, distressing, exhausting situation and changes it to a meaningful, worthwhile circumstance that creates a stronger purpose and appreciation for life and for the lives of the family impacted (Folkman & Moskowitz, 2000; Trute, Hiebert-Murphy, & Levine, 2007).

Hastings and Taunt (2002) report several themes of parent's positive perceptions of their caregiving experience. First, providing care for the child results in pleasure and satisfaction as the child becomes a source of joy and happiness. Second, having a sense of accomplishment in

doing one's best for the child, sharing love with the child, and an opportunity to learn and develop from the challenges associated with the child. Third, strengthened family and marriage, and development of new skills, abilities, or career opportunities. Fourth, becoming a better person internally in which personal strength and confidence has increased. Fifth, an expanded social and community networks. Sixth, increased spirituality, a changed perspective, a new or increased sense of purpose in life, and making the most of life. These positive transformations are due to positive contributions of the child with the disability (Behr & Murphy, 1993). Family reported perceptions of a deeper appreciation of family hardiness, closeness and enhancement, life satisfaction (individually and within the family unit), and happiness and fulfillment (individually and with the family unit). Parenting efficacy and strength were correlated with the positive contributions and learning experiences derived from the child with the disability as a member of their family unit (Abbott & Meredith, 1986; Behr & Murphy, 1993; Hastings & Taunt, 2002; Trute, Hiebert-Murphy, & Levine, 2007).

Transformational parenting experiences such as positive parental responses related to their child with a disability along with acceptance of their child's disability are evidence of personal psychological growth and experience in mothers. Positive beliefs aids in improved relations with other members of the household and positive transformations in philosophical or spiritual morals and values (Behr & Murphy, 1993; Trute, Hiebert-Murphy, & Levine, 2007).

Chapter Summary

Multiple disabilities is not just a label for a child, it affects the entire family unit. Once a parent receives their child's diagnosis of multiple disabilities they find themselves in a new territory, a new mindset. Through discovering and digging deeper into the care that must take place, the family unit may begin to flourish. Understanding the strains of care burden involved

in parenting allow families to function at a higher level. Multiple aspects need to be taken into account when understanding the family functioning system: parenting self-efficacy, marital satisfaction, child-risk factors and child well-being, as well as sibling participation and involvement are key components of family well-being.

The cycle of parenting stress and child behavior plays another role in development and caregiving. Not only for parents but for siblings as well. As siblings are not as often remembered, they are often turned to in time of need. As parent-related stressors seem inevitable, and child behaviors may change, children also find stress in these situations. There are many ways to cope in these situations. Positive appraisals of parenting self-efficacy, self-mastery, and optimism are positive coping strategies mothers can use throughout their family unit to guide their family to a more mindful and positive family system. Parents, families, educators, and all in a village should work cohesively in creating the perfect environment for the family to grow psychologically.

Children with Multiple disabilities have the unfortunate potential for a lifelong struggle. They may experience a plethora of difficulties surviving in the real world beyond their academic years. Challenges present boundaries and limitations for the delayed child into adolescence and adulthood. While the future may be unknown for a child with multiple disabilities, having a strong, positive family system and informal and formal support systems that includes the education system, can provide strength, compassion, and guidance that can enhance the child's well-being and interpersonal and intrapersonal relationships.

The purpose of this research is to attempt to understand what it means to raise a child with multiple disabilities. In addition, considering the family has such a large, prominent role in the child's life, coping was looked at from that perspective as well. Caregivers from all aspects

of the child's life including home, school, child care, and medical professionals should focus on positive beliefs, emotional uplifts, unconditional love support systems, and professional resources that are available within the community in order to help alleviate some of the aforementioned stressors and challenges found in home and public environments.

Chapter Three discusses the purpose for the study. I describe the methods, methodologies, and theoretical framework used to conduct my autoethnographic intimate inquiry. I share my research design including limitations. Finally, I explain my data collection and analysis procedures.

CHAPTER 3: METHODOLOGY

Deciding to become a parent was not a decision that I made lightly. I had many conversations about the future with my husband with regards to starting a family. While preparing for my second daughter I was told, in a doctor's office with my husband, that my long-term commitment had the potential to be a lifelong commitment due to medical complications. I learned that my unborn daughter had a brain deficit and the team of medical professionals could not give my husband and me a prognosis. Raising a child with multiple disabilities changes the caregiving environment and requirements necessary to care for the child. Collaboration with formal and informal support systems can help parents of children with multiple disabilities. These systems become the village it takes to raise a child especially when that child has multiple disabilities. Families may cope with care burden and cycles of stress and behavior as well as experience positive and negative transformations associated with raising and educating such a child. Parents have the potential for personal growth as they caregive for their child with a disability

My autoethnographic account of caregiving for a child with global development delay addressed the following guiding question as it pertained to my personal account as I focused on my journey, the stress and joys that I have experienced along the way, and how I have coped as a mother through the experience of caregiving for a child with multiple disabilities that continues even after this study was completed: In what ways have I, as a mother of a child with multiple disabilities, maintained a healthy family by transforming the impact of disability into personal growth?

In this chapter I provide the purpose of my study and explain my methodology including the history of autoethnography, research design and methods, and the respondent selection

strategies. I describe the data collection and analysis. Finally, I describe the limitations my study presents and offer a summary.

Purpose of the Study

The purpose of my research was to provide awareness of multiple disabilities and a detailed personal account of life with a child with multiple disabilities child. From within my family system I closely examined my efforts to raise and educate my child. I provided accounts and reflections of my daughter's diagnosis and medical history. I referred to the consultations, therapies, and interventions, both at home and in the school setting that I have gone through to help my daughter with her delays and support the cohesion of my family system in the role of the mother and wife. It was my intention to have this personal account fill in a gap of knowledge regarding children with multiple disabilities through an intimate lens. My story serves as a reflection for other caregivers that may be struggling with the unknown regarding their child's diagnosis of multiple disabilities, as well as a resource for educators, practitioners, scholars, and other stakeholders to understand the nature of a child with multiple disabilities in an academic setting.

Autoethnography as a first person, autobiographical account is a self-reflection writing experience that connects the personal to the culture being researched. More specifically, in reflexive ethnographies, it is the researcher's personal experience that is important to the study as it pertains to the researched culture (Ellis & Bochner, 2000). Wall (2006) adds, "The potential power of autoethnography to address unanswered questions and include the new and unique ideas of the researcher is inspiring to me as one who wishes to find my niche and make my own special contribution" (p. 149).

Methodology

This qualitative study was developed to provide an in-depth understanding of the daily life of a caregiver, myself, of a child with multiple disabilities. As early as the 1920s and 1930s qualitative research was used by sociologists to study human group life and ventured into other sciences such as social and behavioral, education, history, political science, business, nursing, social work, and communications (Denzin & Lincoln, 2000). Maxwell (2012) describes qualitative research as do-it-yourself research that does not proceed through a specified process or procedure. Additionally, he explains that qualitative research focuses on "interconnection and interaction among the different design components" (p. 3). Qualitative research situates the researcher as observer in the world in which a phenomena is being studied in its natural setting for the purpose of interpretation, representation, and connection (Denzin & Lincoln).

When the purpose of a study is to understand a phenomenon, there are multiple epistemological approaches a researcher can write from; interpretivism, phenomenology, constructivism, hermeneutics, and ethnography. Each of these paradigms focus on multiple truths and has an ontological approach that reality is subjective and constructed (Lather, 2006). Denzin and Lincoln (2000) explain that interpretivist epistemology is a branch of philosophy in which the knower and the known interact and shape one another whereas Schwandt (2000) express interpretivism as a means to understand a particular social action through grasped meanings by the inquirer that constitute that action.

Phenomenological analysis is one such notion of interpretive understanding. In this analysis, Schwandt explains that researchers attempt to grasp how we come to interpret our own and others' actions as meaningful through context of words or utterances and the understanding that such words or utterances are as much about doing something as they are about "something".

Interpretive practices as the *hows* and *whats* of social reality centered both in *how* people methodically construct their experiences and worlds and *what* the configurations of the meanings inform and shape into reality-constituting activities (Gubrium & Holstein, 2000). Therefore, phenomenological analysis deals with "how the social world is made meaningful" (p. 489). Interpretivist epistemologies from the view of hermeneutics emphasize the grasp one must have on a situation regarding human actions and the meaning derived of said action. Philosophical hermeneutics is not a "procedure- or rule- governing undertaking; rather it is the very condition of being human. Understanding is interpretation" (Schwandt, 2000, p. 194).

Social constructivism means that "human beings do not find or discover knowledge so much as we construct or make it" (Schwandt, 2000, p. 197). Jensen-Hart and Williams (2010) contribute that social constructionist are consistent with evocative autoethnography in which the researcher aims to encourage empathy for and connection with others. This is achieved by building analysis into the story turning the story into its own theory. The criteria for evaluating research under a constructivist paradigm as an interpretive paradigm includes credibility, confirmability, and transferability. Together these criteria refer to the criteria for rigor which analogs trustworthiness (Denzin & Lincoln, 2000). Trustworthiness is discussed in more detail later in the chapter.

An ethnography is one such qualitative paradigm which values culture. According to Creswell (2013) an ethnography is a form of qualitative research that focuses on a culture-sharing group. As defined by Chambers (2000), ethnos, or culture defines the research by subject matter, not its methodology. In addition, she states that culture has a variety of interpretations. For the purpose of this study the definition of culture that I refer to is Chambers'

(2000) view "culture is composed of those understandings and ways of understanding that are judged to be characteristic of a discernible group" (p. 852).

The multiple disabilities culture is a culture commonly unknown and underrepresented, making the topic a perfect candidate for a qualitative study with the support of extensive personal, medical, and academic records. I relived the experiences of my journey in order to provide an evocative account that subjectively discusses epiphanies discovered regarding caregiving for and educating a child within the multiple disabilities culture that Ellis and Bochner (2000) describe as a usual experience of autoethnography.

Theoretical Framework

Intimate inquiry is a methodological approach as well as a theoretical framework (Laura, 2011). Throughout the chapters I maintained a level of intimacy as I researched topics of concern for my family, and related the narrative of my raising, educating, and coping experiences as a mother. Using intimacy theory allowed my readers to make sense of my topic through my personal accounts of my daughter's specific case study as it represented the culture of disabled children as a whole. Using intimate inquiry allowed my readers to receive an in-depth, intimate understanding of my experiences (Ellis, Adams, & Bochner, 2011).

Intimate inquiry allowed me to maintain my positionality within the study. I was able to be a part of the study as both parent and educator. The data needed to be as authentic as possible, free from bias. I looked at my data through multiple lenses. I started with a parenting lens and educator lens as well as a disability lens, all of which are at the forefront of my daily life. As I began my reflection journey of the data I developed a personal growth lens. This is described in further detail in Chapter Five. The lenses are a part of my daily life. All decisions I

make regarding my daughter, family, and myself are based on the fact that I am a parent of a disabled child with a background in education and multiple professional degrees.

Intimacy theory itself is not a new concept. Rettus (2010) refuted previous theories of intimacy. She concluded that earlier accounts of intimacy theories failed to distinguish between intimate and non-intimate relationships. She also argued for relationship-centered focuses versus act-centered approaches to research. A relationship-centered focus affords the researcher a level of intimacy when conducting the study. Intimacy is desirable in autoethnography research because it connects relationships to culture. With regards to my study, intimacy is desirable because I am connecting the personal accounts of my journey to the caregiving culture.

Intimate Inquiry as a framework complements the use of autoethnography as a platform for an intimate narrative. As a researcher I am telling my story for the purpose of narrative inquiry research. Within my story I am telling about personal experience, observations, and intimate interactions (Ellis, Adams, & Bochner, 2011).

Background of Autoethnography

While an ethnography is the study of culture, an autoethnography is the study of the self as a member of the culture being researched (Ellis & Bochner, 2000). Autoethnography is a methodology that reflects on life experiences to generalize to a larger culture in the pursuance of social knowledge through social positioning (Ellis & Bochner, 2000; Jensen-Hart & Williams, 2010; Wall, 2006). Jensen-Hart and Williams (2010) describe social positioning as the researcher's position in social, cultural, and structural contexts as identities used to shape the writing. Muncey (2005) adds that autoethnography celebrates the individual story, and is as "personally and socially constructed as any form of research, but at least the researcher can say "I" with authority" (p. 10). Researchers who use autoethnography as their methodology have an

insider view of their own study, an essence of being "native", and accessing familiarity of the culture (Creswell, 2013; Ellis & Bochner, 2000).

Autoethnography has been utilized for over two decades beginning with Hayano (1979) as the originator of the term. With this being said, the application and meaning of the term may be different for each researcher. Wall (2006) explains that researchers have used such terms for their methods as personal narrative, heuristic inquiry, and autoethnography, while Ellis and Bochner (2000) have provided an extensive list in their chapter in The Handbook of Qualitative Research most of which relate to a narrative format, an ethnographic format, or an heuristic format (p. 739). Most of these methods utilize similar data sources. First, Wall (2006) acknowledges that personal documents, interview notes and transcripts, poems, and artwork are used as data for heuristic inquiry while discussions, reflection, and thought are the analysis for said data through which themes and meanings are able to emerge. Second, the data sources for an autoethnography, according to Ellis and Bochner (2000) include "short stories, poetry, fiction, novels, photographic essays, personal essays, journals, fragmented and layered writing, and social science prose" (p. 739). Analysis of these data may be done through various forms of cultural and perspective interpretation (Creswell, 2013; Ellis & Bochner, 2000). Finally, the data sources for personal narratives can come in what Muncey (2005) describes as techniques; snapshots, artifacts, metaphor, and journeys. These data are analyzed through feelings, experiences, emotions, and behaviors that portray a more complex view of one's life (p. 10). Ellis and Bochner (2000) caution that the autoethnographic genres have been blurred as distinctions are made between the personal and the cultural.

Research Design and Methods

Autoethnography as a research method allowed me to reflect upon my experiences as a parent of a child with multiple disabilities. The incorporation of intimate inquiry as a framework allowed me to explore my experiences as a caregiver to my child with multiple disabilities.

This study focused on the culture of caregivers. For the purpose of this study, the role of caregiver was for a child with multiple disabilities. With that being said, caregivers for any family member may share similar experiences shared in this study. The evocative experiences shared within the story I emotionally recalled connected the culture of caregivers of children with multiple disabilities to my personal life experiences. No two disabilities are alike, no two families are alike. The commonality of the caregiving culture of children with multiple disabilities is the journey, including the positive and negative transformations that the family experiences both as a family unit and as individuals within the family system, and the lifelong commitment caregiving may require when a child is not typically developed. Regardless of the disability diagnosis, caregivers experience positive and negative appeals. To date, researchers have provided insight to the potential causes of delays and their effects on the child and the families that are the caregivers for the child (Bolduc & Limperopoulos, 2009). Development of coping strategies and therapies have been formulated as well (Paczkowski & Baker, 2007; Paczkowski & Baker, 2008). The gap in the research is a personal, intimate, longitudinal narrative of a mother raising and caregiving for a child that has multiple disabilities and the growth she experienced and continues to experience even as the study concludes.

The intent of my study was to bring attention to the emotions, thoughts, and feelings associated with the caregiving of and educating my daughter and her multiple disabilities. I focused on the positive and negative transformations that I have experienced along the way, and

how I have coped as a family through the ongoing experience with the understanding that caregiving for my daughter may be a lifelong endeavor.

Researcher as Respondent

I was the main responder, explaining the caregiving experience of raising a child with multiple disabilities. It is my opinion that it takes a village to raise a child. The assets of the village include not only the education system but extracurricular clubs, groups, and associations that are citizen-based learning environments as well as local institutions such as businesses, not-for-profits, and government bodies (McKnight, 2015). These support systems provide incredible learning opportunities for children and their families. When a child has multiple disabilities, these added supports make the village that much larger, yet more tight-knit than would be considered the norm. For me and my family the village also includes my daughter's academic and day care facility as they are not mainstream facilities. For her preschool years my daughter attended a special school outside of a comprehensive elementary school that accommodates students from preschool age to age 22, when they age out of Free and Appropriate Education (FAPE) under Individuals with Disabilities Education Act (IDEA). She transitioned to a comprehensive school site with both general education and special education on the same campus. The school offers a special day class (SDC) for her age group and chronological grade level. She is bused from school to a special needs day care that is run by nurses and personal care assistants who attend to the children's medical necessities. Both the schools and day care are realities that families of the multiple disabilities culture may need help with raising and educating their child, as we have needed assistance.

Data Collection

Autoethnography is a self-study research method that adds to the knowledge by presenting personal accounts. Belbase (2008) confers the term autoethnography represents one's own personal experiences in his/her social, political, economic and cultural context.

Autoethnography is an approach used by researchers to acknowledge emotionality, subjectivity, and influence on research posed by the researcher. Autoethnographers use their qualitative methodological tools to analyze personal experience in ways that illustrate the culture while understanding that their readers may experience similar epiphanies related to their research (Ellis, Adams, & Bochner, 2011). Qualitative studies do not provide reliability or validity scores. Instead, as listed by Lincoln and Guba (1986) researchers utilize various strategies to ensure the trustworthiness criteria as merit of qualitative inquiry. These strategies include; credibility, transferability, dependability, and confirmability. Ellis, Adams, and Bochner (2011) address researcher's credibility as questions of trustworthiness. Are the experiences described really the narrator's own? Are the experiences 'factual evidence'? Transferability of the findings come in the form of thick, rich, descriptive data. Aesthetic and evocative thick descriptions of personal and interpersonal experiences are produced by researchers writing lifelike, believable experiences that the reader can feel is a representation of truth (Ellis, Adams, & Bochner, 2011).

Researchers using a self-narrative format tend to gather personal documents in order to establish a data source (Ellis, Adams, & Bochner, 2011). I have been keeping medical records dating back from when my daughter was in-utero and have two binders worth of after visit summaries, hospital visits, and various other medical records. These documents were an asset as they reminded me of the struggles I have overcome and the celebrations I have experiences. I

have also keep all academic records and have two binders worth of progress reports, Individualized Family Service Plans (IFSP) that were provided to my daughter during her preschool years, Individual Education Plans (IEPs) during her school age years, physical therapy and occupational therapy goals, academic progress reports. Due to the extensive nature of the documentation that I have been collecting during my daughter's life, I first identified which data sources were pertinent to my story. I specifically looked for data that provided support for my story of personal growth. I collected data sources that showed how I have grown as a mother, wife, educator, and scholar. Each of these roles that I have connect to each other and relate to my story of personal growth. I reviewed medical records including memos that were written during the reflection of these documents. I also reviewed school records including memos that I have written when I have reflected on these documents. I have also kept personal accounts of the journey of raising a child with multiple disabilities including videos, calendars, pictures, social media posts, and journals during my daughter's life documenting the struggles she has overcome and how my family has adjusted and coped.

After I chose the data sources to include in my story I put the written records and digital sources in chronological order in order to support the longitudinal study. Arraying events in chronological order in the data order phase facilitated easier data analysis and examination of process (Pandit, 1996). Prior to this study the medical records had been categorized in binders by hospital stays, specialist appointments, and diagnosis and accompanying explanation pamphlets. The medical records are also stored in my daughter's account through the medical facility. I did not have the need to request additional materials. The academic records had been categorized by early year home visits, preschool years, and school-age years. Additionally, my daughter's home care visits were videotaped with permission in order for my family to duplicate

what services the specialists were providing my daughter. I did not need to request additional materials from academic facilities. The social media posts, videos, and pictures were saved in an electronic folder on my computer. The voice recordings were saved in a folder on my computer. The voice recordings have the dates that I said them in order to include them in the chronological sequence of my study, though they were not started until I began this process. I listened to my voice recordings and transcribed them in order to include them in a reflexive journal. I was the only one with access to the computer used for this research. My log-in was the only log-in that activated the computer.

My review of these data sources were entered into the reflexive journal. I choose to use a reflexive journal because as an educator I keep notes about my work, about lesson plans and reflections after they have been completed. As a mother, I have always kept notes and scrapbooks and have 'cataloged' events in my family's life. It seemed only natural to utilize a reflexive journal for the purpose of describing my experiences, thoughts and feelings as a living document that continued to grow as the study progressed. I reread each academic and medical document while writing in the reflexive journal detailed descriptions recollecting the setting, experiences and emotions related to the event portrayed in the data source. I reviewed each digital data sources; pictures, social media posts, and videos and included detailed descriptions recollecting the setting, experiences, and emotions related to the event portrayed in the data source in the reflexive journal. During this initial review of the data sources I included the memos that had been previously written as support for trustworthiness and reliability. These memos showed the experiences were real and my own, can be considered "factual evidence", and allowed my readers to create connections and transform those connections to other settings due to shared characteristics.

Dependability and confirmability required the use of an external audit. My dissertation chair and I had consistent contact regarding content and edits that needed to be made. I kept an external audit journal of our conversations and action items that I needed to address (Creswell, 2013; Lincoln & Guba, 1986). The purpose and need for these criteria was to ensure that my study was accurate and implores acceptable documentation strategies for my readers.

Ethical consideration was examined regarding my daughter. This consideration refers specifically to the medical records, academic records, blog and social media posts, and my caregiver notes. Even though I am telling my narrative from these documents and notes, my narrative is directly connected to my daughter's story as these documents are hers as well. She does not have the capacity to provide her assent for my research to be conducted, therefore I, as one of her parents, provided the consent. Additionally, while my husband was not required to give consent he did agree to my use of data within my study. In addition, as my daughter's parent, I provided the consent to use the medical and academic records discussed in my findings. It was determined by the International Review Board that my study was not Human Subjects Research, see Appendix A and Appendix B.

Data Analysis

The analysis of the data began as soon as I started organizing the data sources in chronological order. While rereading the written documents and reviewing the digital sources my thoughts, feelings, emotions, reactions, and actions to situations that have been both positive and negative in nature surfaced. The multiple sources and methods of collecting data provided me with a more credible list of themes and conclusions (Maxwell, 2012). These documents were an asset as they reminded me of the negative appeals I have overcome and the positive transformations I have experienced. The school documents allowed me to connect the

caregiving experiences to that of my daughter's education. My daughter is currently ten years old and would be in fifth grade if she were in a comprehensive classroom. She is not potty-trained, is nonverbal, and not at grade level academically. Her teachers and I, with the support of the principal and multiple therapists that pull my daughter out of class for services, have created an IEP to address skill-ability appropriate goals. I have been her advocate in these meetings.

With all of my data sources collected and sorted in chronological order I reread all the academic and medical documents, transcribed voice recordings, social media posts and prior memos, and watch my videos. In this second viewing of the data I took notes, creating memos of my reactions and emotions related to what I have previously experienced. The memos written were code memos which according to Glaser (1965) conceptually label the data. This allowed me to visualize categories and relationships that I was hearing and seeing from and for myself in a third read. I decided to wait until the third viewing of the data to start coding in order make sure my personal reflections had a chance to form and present themselves as data. My method of analysis was constant comparative analysis which Glaser (1965) offers as an approach to qualitative analysis in order to provide joint coding and analysis. I started with open coding identifying concepts and categories in this third viewing of the data. The research question also helped guide my search of categories and themes within my data collection. According to Pandit (1996) open coding is an analysis system that labels and categorizes the phenomena as concepts recorded from the data collected. Pandit (1996) refers to open coding as 'comparative method'. During the open coding phase, Glaser (1965) suggests comparing the incident being categorized with other incidents already in the category as shown in Figure 2 "Since coding qualitative data takes some study of each incident, this comparison can often be based on memory" (Glaser, p.

439). This was another purpose for the multiple reads of my data. Due to the number of years of data, it was important to read multiple times in order to compare from memory.
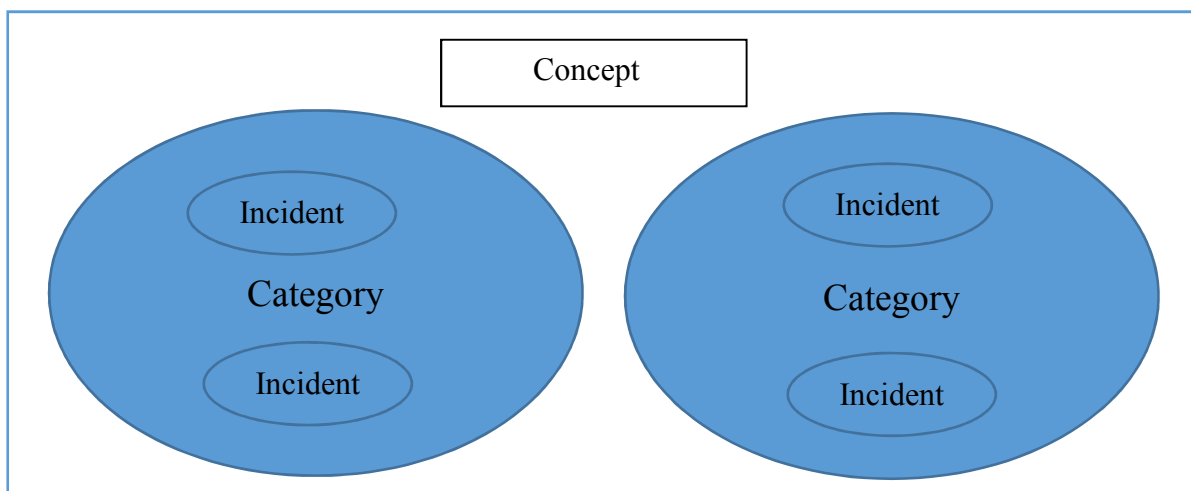
Figure 2. Constant comparative analysis – Open coding

Once I completed the open coding phase I analyzed the data using axial coding. Axial coding puts the data back together that was separated during open coding. Pandit (1996) explains that axial coding is the process of developing connections between the main categories and subcategories, as shown in Figure 3, from the collected data while Glaser (1965) describes axial coding as an integration of categories and their properties. I used connecting strategies to categorize my data collection into thematic analysis while I searched for positive and negative appraisals of my experiences and evidence of my personal growth in an attempt to understand the data. During the axial coding phase I found it necessary to use theoretical memos which according to Glaser (1965) guide the indication of the process of connecting categories to subcategories. These memos were included in the reflexive journal at the end of the chronological memos.
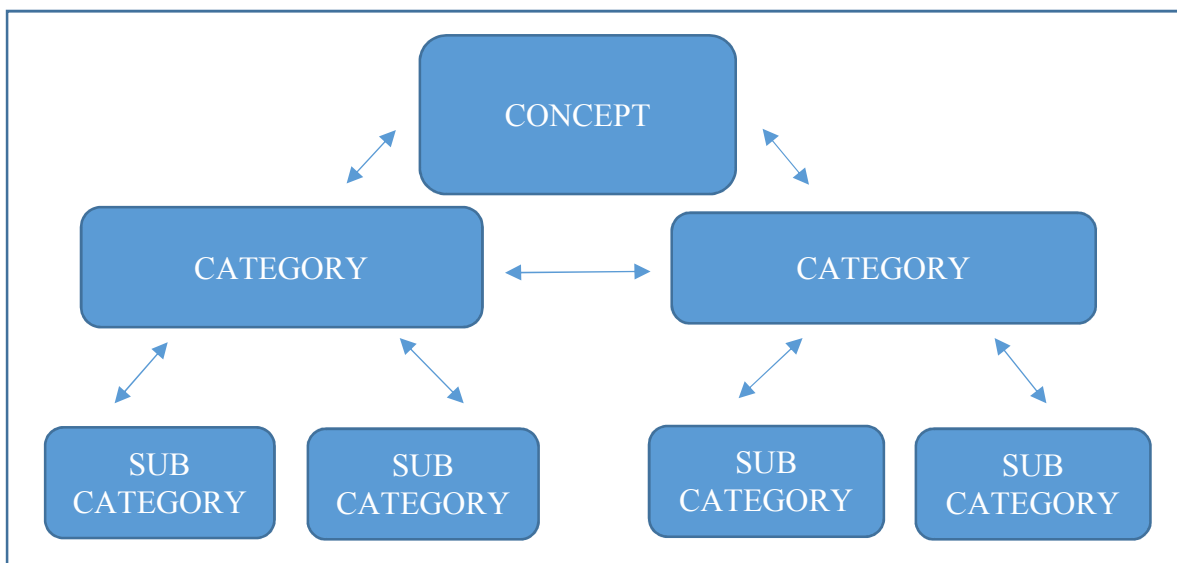
Figure 3. Thematic analysis – Axial coding

Finally I created a matrix that justified the themes and patterns found in the categories and their properties using selective coding (Creswell, 2013; Maxwell, 2012). According to Glaser (1965) the constant comparison of incidents starts to create theoretical properties for each category. Selective coding was chosen here to integrate the developed categories into the theoretical framework. During the coding phases I experienced conflict as I attempted to determine alternate ways to code and compare the incidents. For this reason, it was necessary to create operation memos during this phase as Glaser (1965) explains, to create direction to the evolution of the research design. These memos were included in the reflexive journal at the end of the theoretical memos.

In addition to telling about my personal experiences, I analyzed any turning points or epiphanies that my experiences and reflections of the documents showcased in order to corroborate my perceptions and share my understanding of the culture of multiple disabilities as a narrative summary and interpretation of the culture. Creswell (2013) professes that

corroborating evidence from various sources provides an insight to the theme or perspective presented in the study. This corroboration enabled me as the researcher to describe the culture of multiple disabilities and provide recommendations to caregivers, educators, medical teams, and others who may need to contribute support, care, and resources for children with multiple disabilities and their families, caregivers, and educators. In this regard I provided meaning to my study and my experiences within the culture of mothers of children with multiple disabilities.

Limitations

I am the main responder, explaining the caregiving experience of raising a child with multiple disabilities. It was my opinions, experiences, and reflections that represented the culture of caregiving for a child with multiple disabilities. The family members in my own household, nor those involved in my daughter's academics were consulted or included in this study. This culture is much larger than my story alone; I am a small piece in a larger schema.

Chapter Summary

How do families cope when a child is diagnosed with one or more developmental delays? The unknowns are endless with regards to this question. Each diagnosis is as exclusive as the child themselves. Causes are inconclusive. Even therapies and treatments are not a guarantee. Based on the discussion of some of the studies I have read I see a gap and the possibility for further research.

For this autoethnography I illustrated the caregiving of my daughter and her unique special needs as being a part of the culture of children with multiple disabilities as well as a positive contributor to my family. I analyzed and connected the multiple records that I have acquired throughout my caregiving and education experience as well as defined what it means to be a part of the multiple disabilities caregiving culture. I focused on the challenges and coping

strategies associated with this caregiving culture as well as the positive beliefs and growth experienced. Finally, I included my daughter's academics as part of the village support system and to fill in a gap of educating children with multiple disabilities.

Chapter Four provides the chronological narrative and interpretation of the personal documents reviewed as an evocative reflection. Chapter Five discusses the findings and analysis. I explain how this study fills in a gap of knowledge, why it is important to fill the gap and provide recommendations for future research.

CHAPTER 4: HER OWN BOOK, MY OWN BOOK

"She is writing her own book."
-Genetics Doctor

Excitement, anxiousness, optimism, anticipation, concern, happiness, and blessed are the normal and expected feelings, just to name a few, when one finds out they are pregnant. I found out I was expecting my second child on January 5, 2009. I experienced all of the above mentioned feelings as I had been trying for the better part of a year to conceive.

My first official doctor's appointment was on February 6, 2009. An ultrasound was conducted to determine the age of the fetus. I received a call while at work as a first year teacher a day or so later (timeline not written down). It was explained to me that I was being referred to a specialist because extra fluid was detected at the back of the baby's neck. I was told the specialist would conduct another ultrasound that could measure the amount of fluid. The fluid was problematic because it could be an indicator of Down syndrome, a condition that develops due to duplication of a chromosome. I went to the specialist in my hometown and the fluid was found to be within normal parameters therefore Down syndrome was ruled out. I was unaware that would be the only comfort I would experience for the remainder of my pregnancy.

At my gender reveal ultrasound appointment on March 31, 2009, I was told I was having a girl. My first reaction was disappointment, as I was hoping for a boy to compliment my first daughter. The ultrasound technician asked me to go back to the room because the doctor wanted to discuss the ultrasound with me. I asked if everything was alright and I was led to believe it was. The doctor came in and I was informed that a void was detected in my unborn daughter's brain, in the cerebellum, which is located at the back and bottom of the skull (Sweeney, 2009).

I was referred to a hospital in another city with advanced technology that could rule out Dandy-Walker malformation as the cause of the void. I had never heard of Dandy-Walker prior to that day and subsequently learned that it is a rare malformation of the brain that involves the cerebellum and fourth ventricle. I was nervous and anxious to find out if my unborn daughter had a disorder that I had never heard of and what that would mean for her, for me, and for the rest of our family. On April 9, 2009 I went to a lower level floor of the hospital to await a third ultrasound to understand what was going on with my unborn daughter. The ultrasound at the hospital confirmed the previous findings, a void in the cerebellum. On the same day I had to go to a different office on a different floor to undergo an amniocentesis for a karyotype analysis. A chromosomal array (molecular probe) was also conducted to obtain additional information regarding the void. Once again, I felt confused as I had never heard of these tests. The urgency of the medical staff was unnerving. I did not understand what all this meant. I wondered whether or not anything could be done if something was found in these additional tests?

The chromosomal array came back clear, while the karyotype from the amniocentesis noted two cultural artifacts that were deemed within normal parameters, yet there were two cultural artifacts identified as not significant to worry about regarding my unborn daughter's development. I had to take the medical staff's word for it because it was as if they were speaking a foreign language to me. I was bewildered at all that had taken place to check on my baby's development.

As if I had not already succumbed to enough tests, after the hospital ultrasound confirmed the specialist ultrasound, a void in the cerebellum; cerebellar vermis, I was scheduled for a fetal magnetic resonance imaging (MRI) test to get a different view of my unborn daughter's brain. An MRI was ordered since an MRI is a more conclusive test. I was told that

an MRI can view the brain from vantage points an ultrasound cannot. This would require me to

come back to this hospital at a later date to perform the MRI on my growing stomach in order to

scan my unborn daughter. I was scared but wanted answers. I was willing to do anything to help

my unborn daughter. I would travel to wherever I needed to, I would undergo whatever

tests/procedures the medical staff deemed necessary. It seemed unreal that this could be

happening to me. The date of the MRI was April 30, 2009.

Twenty-one painfully slow days passed before I had the MRI that would shed some light

on what the ultrasound had found, that my unborn daughter had a void in her brain. April 30,

2009 was a difficult day to say the least. I am an extremely claustrophobic person. I do not do

well in elevators, small spaces, or even tunnels. My husband came with me to the appointment

for support. I knew going to the appointment that a tube was involved though I was unsure how

much of me would have to be in the tube since this was a fetal MRI of my stomach. I laid on the

table and my arms were strapped down. Part of claustrophobia is knowing that I have limited

mobility and nowhere to go to escape. My husband sat at a chair at the opening of the tube that

my head would be at. The table slowly entered the tube. My eyes were closed. I made the

humongous mistake of opening my eyes. The tube was very close to my face and I panicked. I

panicked. My heart started pounding and my throat closed up. I felt that I could not breathe. I

tried to calm down but I could not and I had to be pulled out of the tube. The MRI attendant was

very patient. After about 10 minutes she said I would have to try again or reschedule the

appointment since there were other patients that needed to be seen. Because I wanted answers

sooner than later, I knew I needed to do this for my unborn child. I closed my eyes again and the

table entered the tube. I put my arm over my head in order to hold my husband's hand so I knew

the entrance was right there and there was open space just on the other side of my head. I then

envisioned the beach, my happy place, to keep my mind off of the fact that I was in a small

tunnel/tube. I got through the appointment this way.

April 30, 2009 is a day that I will never forget regarding the news I received. The MRI

found that there was not a void in the cerebellum; however, the cerebellar vermis demonstrated

"a slightly small appearance of the inferior and middle third of the cerebellar vermis with a slight

superior rotation of the vermis" (personal communication, MRI Impression report, 2009).
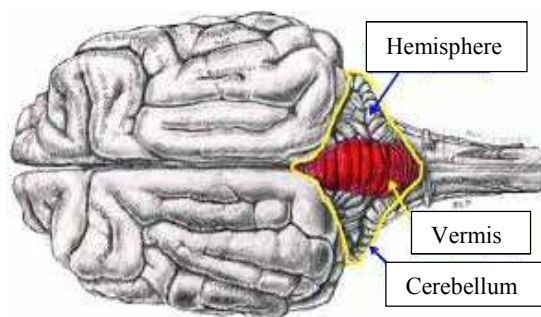
Figure 4. Cerebellar vermis located in the cerebellum

Sweeney (2009) explains that the vermis connects the two hemispheres of the cerebellum.

Unbeknownst to me, this statement was the beginning, and only a small portion, of my unborn

daughter's diagnosis of global developmental delay (GDD).

Pro-Choice

On that fateful day in April when I was given the findings of the in-utero (fetal) MRI, my

husband and I were asked a question I never thought we would hear. The conversation took

place in a small narrow consultation office, an office that was bare except for a large L-shaped

desk and two chairs. The doctor sat behind the desk and I sat down first, in the chair closest to

the wall. When I sat down I was not prepared for the conversation that was to take place. It was

explained to us that the vermis was tilted preventing it from growing properly. We were told that

while there was not a void in the brain, the vermis did in fact show showed agenesis (failure of an organ to develop). Due to the nature of the tilt of the cerebellar vermis as the midline connector of the two hemispheres, it was unclear to the specialists what skills my daughter would be capable of as she developed. Sweeney (2009) explains that the cerebellum acts as storage of motor sequencing, thought and action integration, movement and balance coordination, and sensory networks that can be accessed without awareness (muscle memory) or on demand as needed. He adds that the cerebellum has also shown on scans to contribute to emotion, such as love.

We were not given a prognosis. It was not known if our child would walk or run or maybe if she was mobile, they could not foresee her cognitive ability. For this reason, in not so many words, we were asked if we wanted to terminate the pregnancy, we were asked if we wanted to give up. But we had to make a rather swift decision, I was going to run out of time for the termination procedure to take place since I was already 22 weeks pregnant and approaching the point of no return. This decision, no matter whether I chose to terminate or continue with the pregnancy, was going to affect me for the rest of my life. If I chose to terminate, could I live with that decision, how would my mind and heart be altered? If I chose to continue with the pregnancy what would my child be like, what would parenting be like? In a moment of certain unity, my husband and I, without even consulting privately with one another, stated that we wished to continue with the pregnancy. In the brief seconds before responding I had a chance to reflect. To me, the thought to terminate had never crossed my mind. This was my unborn child. I had already told my five year old daughter that she was going to be a sister. I had already welcomed the fact that my family was expanding. I knew then that no matter what life presented

me with my daughter's development that I was going to be strong for her and my family and we would prevail as a family unit held together by compassion and support.

One more fetal MRI was conducted on June 4, 2009. The first MRI had given the doctors a baseline for the vermis. This second MRI was conducted to check on the growth of the vermis. Understanding my claustrophobia I was provided a calming drug that was safe for my unborn child. The results from this second MRI showed that the vermis growth was proportional to the time that had lapsed and the size it was at the baseline. Therefore, the vermis was growing in proportion to time, yet it would never catch-up to the size it should be according to chronological age. Also in June, on the 30th the hospital conducted one final ultrasound to check on the growth of the fetus. She was physically growing in proportion to her chronological age. It was suggested that a third MRI be conducted the following month but because my due date was approaching, the medical team decided that would not be necessary. Treatment and care returned to my obstetrician back in my home town.

Baby's First Year

I was scheduled for a caesarian section on August 18, 2009. At a check-up appointment my obstetrician informed me that I would not make it through that weekend. On August 14, 2009 I started having contractions around 1pm. Since I had eaten a little, I was unable to receive anesthesia for eight hours. Therefore, even though I was scheduled for a caesarian and should not have experienced labor pains, here I was at the hospital in the room for eight hours before I could receive anesthesia. At least football was on and my team was playing, that kept my mind occupied for a few hours.

Her Birth

My daughter was born that night at 10:07 pm. Unlike my first daughter (who was also

born via caesarian section for unrelated reasons) I was not able to see my newly born daughter. I

was informed that she was not breathing and was admitted to the neonatal intensive care unit

(NICU) for respiratory distress. My daughter spent the first five days of her life in the NICU.

While in NICU my daughter was given an ECHO to scan her heart. A heart murmur was

detected; this murmur is an open hole in the Patent Ductus Arteriosus and is referred to as a

PDA. This was something new that I was not aware of, something I was not able to prepare for.

The nurse notes stated "Mom coping very well" (NICU nurse notes, August 15, 2009) with

regards to the known concerns regarding my daughter's brain and newly developed concerns.

> The nurse notes that mom was very pleasant and good understanding of infant's current
> medical state. We discussed pregnancy complications and being followed by USCF for
> brain issues. The nurse notes state that mom was very optimistic as MDs are optimistic.
> It also states that mom has a good attitude with positive cognition. (NICU nurse notes,
> August 15, 2009)

Bring on the Specialists

My daughter was 12 weeks old when she had her first neurologist appointment on

October 26, 2009. This appointment was an introduction and baseline appointment due to the

known abnormality of her cerebellar vermis. The neurologist checked her reflexes and muscle

tone. I would come to learn more about these practices at subsequent appointments. My

daughter's second appointment with the neurologist was held on February 8, 2010.

At this time I was already experiencing concerns regarding my daughter's inability to

meet typical developmental the lack of milestones. According to National Institutes of Health

(2010-2014), a six-month-old child has started babbling at other people in a speech-like way.

The Pathways.org pamphlet *Assure the Best for your Baby's Physical Development* provided by

my daughter's pediatrician states a six-month-old should have developed the motor skills

necessary to roll over, balance their head, pull self to a sitting position, sit alone for a brief period

of time, and grasp objects from hand to hand. The lack of verbal and motor skills were already

concerning because even though I understood that no two children develop at the same rate, I

could not help but compare my younger daughter's development to that of her older sister. I

discussed these notable physical delays during the second appointment with her neurologist. He

did a couple of reflex tests on her, like raising her up in the air to see how her limbs responded to

being suspended in air. He diagnosed her as having hypotonia, meaning she had low muscle

tone. We discussed the possibility that the hypotonia could be the cause of my daughter not

meeting her motor development milestones; however, it was most likely because of the vermian

changes in her cerebellum that she had hypotonia to begin with.

> Shana Cole February 8, 2010 at 8:34 PM
> Here is (name omitted for confidentiality) doc update. We have to schedule an MRI for her sometime in March, early April. We have also been referred to the regional center for physical therapy. She is delayed in her motor skills, though not drastically. Sorry to those I said I would call.... I didn't feel like saying it over and over again (social media post).

The neurologist ordered an MRI to be conducted in an attempt to determine the cause of

the delays as well as providing me with a referral to a regional center in order to request therapy

support for my daughter's motor developmental delay. The local regional center was a facility

for persons with disabilities that provided plans to help support the needs of the person with a

disability.

Developmental delays were not the only concern. I had to stop nursing October 15, 2009,

which was only two months after she was born. That was difficult for me because I nursed my

first daughter for seven months. I wanted to provide for my second daughter, especially since

she had a rough start to life and nursing did not work out. In the moment I felt inadequate and

defeated but she needed to eat more than she currently was so we switched to formula. She was

not gaining weight so I had to do what was best for her and gave up trying to nurse her. Even

though nursing was unable to continue there were certain food celebrations to be had:

> Shana Cole February 9, 2010 at 9:06 PM
> My daughter loves carrots :) Homemade!! (social media post).

I was so excited that she liked food and would eat it. I had made homemade baby food

for my first daughter until she was able to eat more solid food and I was hopeful that my second

daughter would be receptive to homemade food as well. This was a milestone and celebration

towards progress.

While my daughter was seeing various specialists, therapists, and doctors for her inner

deficiencies, I began to notice physical differences as well. In December 2009, I began to notice

dark patches on my daughter's knees and her face had blotchiness. She was prescribed steroid

cream by her pediatrician. By February 2010, I noticed my daughter had light and dark marbling

and lines all up and down her legs and arms. Her chest developed a V-shape of light and darker

pigmentation, and her back developed an S-shaped whorl. I have been calling her my "Super

girl" since the appearance of the whorl on her back. At her six month check up with her

pediatrician, the doctor was concerned about the marbling on her calves and referred her to a

dermatologist that she would see later in March.

> Shana Cole February 24, 2010 at 10:01 PM
> Took (her) to her 6 month check-up yesterday. She is being referred to a dermatologist
> due to hyper and hypo pigmentation all over her body. Ohh and her MRI is scheduled for
> March 30th. We have not heard from the physical therapy people yet. My poor baby is
> going to see every area of specialty before she is one!! (social media post).

Feeling that my daughter was going to see every area of specialty at a young age was just the

beginning, therapy services started young as well. On March 18, 2010 when my daughter was

seven months old she was assessed for our school district's early start program. The assessors

came to my home and the assessment took place in my living room with my ugly, old brown

carpet and sectional L-shaped hunter green couch. The assessors brought their own bag of items

to assess her and asked me questions while conducting their assessment. This approach provided

a more detailed consult. This assessment meeting gave me mixed emotions. I was now one of

those moms whose child would need special services. This assessment fortunately qualified for

in home services. Her therapists have included an infant development specialist and a physical

therapist and she received services in the home twice a week until May 2012 when her services

decreased to a visit once a month until she started preschool. The therapists demonstrated

appropriate activities so that I could be the best teacher for my daughter when she was not

receiving the in-home services.

During the time of those weekly visits I was also provided support with infant massage so

I could help her with her low muscle tone and mild hypertonia in her legs. My daughter received

a series of five visits from the regional center to teach me infant massage as a form of therapy for

her hypotonia. I received a handout with instructions that I mulled over as if it were my college

homework. I was diligent in performing the massages as prescribed by the therapist. I felt as if I

was doing something to help my daughter so I was not concerned about how much time it took

out of my day.

March was a busy month for my daughter and me. We were receiving our in home

support from the early start program and we had two important appointments. On March 29,

2010, at her first dermatologist appointment, upon seeing my daughter's skin, he asked me if she

had neurological issues. After I explained her current condition to the best of our knowledge, he

diagnosed her with incontinentia pigmenti (IP), a rare genetic condition which creates

abnormalities of skin, teeth, eyes, and the Central Nervous System. I was baffled, I had no idea

that skin and neurology could be related to each other. I would later have a better understanding

of the relationship between her skin condition and her brain deficits. Since I was still in college

working on my teaching credential and master's degree, I did a research project for one

credential class on IP.

We stayed overnight at a hotel since the hospital where the test was taking place was out

of town. It was a restless night, experiencing anxiety over the fact that my daughter had to

receive anesthesia and go into the MRI tube without a parent present. Once at the office where

the MRI was conducted I was able to stay with my daughter while they put the oxygen mask on

her face that had the anesthetic in it. One of the worst experiences I have had to experience was

watching my baby's eyes roll to the back of her head as she fell asleep under the anesthesia. It

was all I could do not to burst out crying then. I was told it was time for me to leave the prep

area until the MRI was completed. I had to stay in the waiting room until she started to wake up

from the anesthesia. I cried while my husband hugged my shoulders. Waiting is excruciating,

trying to survive the unknown, the what-ifs. I did not cry for long as I realized my daughter

needed me to be strong.

> Shana Cole March 30, 2010 at 12:45 PM
> Everything went well with (her) MRI. I cried while they had the mask on her face seeing
> my baby like that.... She recovered very quickly, waking up almost immediately, where
> some sleep for 10-15 minutes. She was able to drink and eat within 1/2 hour. We are
> home and she is laying on her play gym yelling like normal :) (social media post).

That was a turning point for me. I silently vowed to be strong for her. Part of being her

voice is understanding her experiences. My daughter had to be put under anesthesia because she

did not understand what was happening and that she would have to stay extremely still. When I

had to undergo the MRI during the pregnancy, I understood what was happening yet, I could

hardly stay still. Her inability to understand the procedure must have been terrifying. After the

procedure, I wanted to be able to ask her if she was okay, to ask her how did she feel and I could not. Instead, I had to rely on body movement and facial expressions, and then be her voice, her advocate, her translator in order to help others around her understand what was happening.

April 5, 2010 is another day I will not soon forget as it was another gut-wrenching consultation regarding a medical diagnosis. My daughter's MRI found that her corpus callosum was thinner that it should be. She was diagnosed with Hypoplasia of the Corpus Callosum. The corpus callosum is the main communicative bridge between the left and right hemisphere.
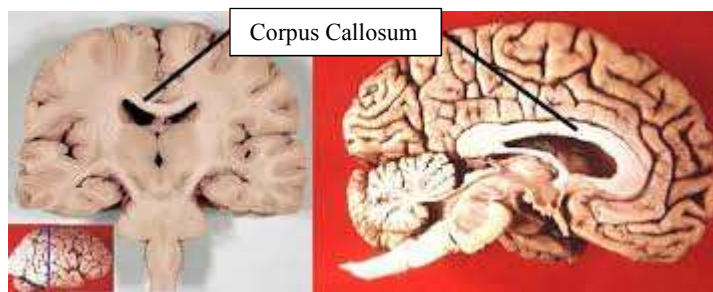
Figure 5. Corpus callosum

When the corpus callosum is thinner than is should be communication between the left and right hemisphere are compromised. Abilities that are affected by this are any that require the use of both sides of the body such as crawling, walking, and even clapping. The neurologist referred my daughter to an ophthalmologist to check for comorbid conditions, conditions happening simultaneously, and genetic testing to gain further insight into the possible cause for the diagnosis.

Then came the excessive vomiting so on April 15, 2010 we had to go see the ear, nose, throat doctor (ENT) because she would spray fluid out of her nose when she tried to have a bowel movement. She would vomit everywhere, without any advanced notice or indication that she may become sick. One defects the ENT was looking for was a cleft, which was not found.

This appointment explained that my daughter had an oral deficiency which contributed to her

inability to latch when I was attempting to nurse her. My daughter was referred to a

gastroenterologist for further testing.

Parent and Student

While attending to my daughter's various medical needs I was also a graduate student

working towards my master's degree. In April 2010 I created a website and Facebook page for

my thesis project. The introduction of the website follows:

> Agenesis of the Corpus Callosum - congenital brain disorder
> My daughter was diagnosed with a secondary type of Agenesis of the Corpus Callosum
> (ACC) known as Hypoplasia of the Corpus Callosum (HCC) when she was 7 1/2 months
> old. She is currently 20 months old. As a parent I wanted to know as much information
> as possible regarding HCC. As an educator I made it my mission to make this
> information as readily available to other HCC parents as possible. Follow my journey
> into understanding my daughter's brain as I share with you everything I have learned
> during my research of this complex condition.

The purpose of this project was to provide awareness of my daughter's brain abnormality

diagnosis to other parents and educators. The project also provided sections that discussed

family counseling, co-occurring conditions, local, state, and national resources and centers for

treatment, early intervention for daily living and academic settings, and long term school life and

social services. Finally, I offered a blog for which I provided personal narratives of my daily life

with my daughter.

Milestones

May and June of 2010 began the start of many physical milestones for my daughter.

Every accomplishment was a celebration because every accomplishment was not guaranteed.

> Shana Cole June 10, 2010 AT 11:34 AM
> Getting the carpet steam cleaned since she is rolling all over. You go girl!!
> The girls and I are away from the house out and about. Visiting daddy for lunch then
> shopping and the park (social media post).

My daughter was rolling at 10 months. This was such a happy day for me since I did not know what motor skills she would accomplish. She rolled back to front on May 4 when she was 8.5 months old. She held her bottle at nine months and slept on her tummy at 9.5 months. She sat at nine months and would crawl at 12.5 months. She pulled to a stand at 13 months and could cruise the couch at 15 months. She clapped at 14 months. She was still not walking at 20 months.

My daughter received devices from her physical therapist to help her with her muscle tone in an attempt to start having more mobility. The first device was called a TheraTog suit (see figure 6) that would be used to help bring her hips and feet more centered by training the muscles through constant oppositional stretching of the muscles. It would get strapped around her waist and then wrapped around her thighs and ankles as shown above. This device was worn under clothes.

Figure 6. Theratog suit

June 2010 was also the start of our genetic testing journey. The first of four genetic evaluation reports dated June 22, 2010 was done as a referral from her neurologist on the basis of her skin pigment anomaly and brain anomalies. At this appointment a chromosome analysis was

conducted and it was found that she had a duplication of one of her chromosomes. My daughter

was referred for additional chromosomal genetic testing; a chromosome array analysis to verify

the origin of the marker that was once said to be insignificant. These findings would become

clearer at her third and fourth genetic appointments.

Terrific and Terrible Two's

On October 6, 2010 when my daughter was 13 months old she received an Individualized

Family Service Plan (IFSP) early start review from the regional center. This is what early

detection and services look like prior to school age and an Individualized Education Plan (IEP).

Her qualifying conditions for the IFSP are stated as delays on motor development in which I, as

mom, had previously stated I wanted my daughter to improve. At this point she was almost 1.2

years and could only pull herself to a standing position. It was stated in the assessment review

that the parent/family concern was for my daughter to reach all her developmental milestones.

At the time of this review she was still below all domains, showing 25% delays in all

areas of development. Based on this review my daughter would receive weekly independent

development services (IDS) and physical therapy in the home. Her scores from the HOPE

assessment in the developmental domains were as follows with a goal that she would improve

overall developmental skills:

Social 8-9 months
Communication 9 months for both receptive and expressive
Adaptive self-help 8-10 months
Gross/fine 8-9 months
Cognitive 8-9 months

My daughter received her third and fourth genetic evaluation reports two months apart,

one on October 26, 2010 and the other on December 7, 2010. The first report confirmed the

large marker chromosome (described in more detail in the second report) seen prenatally. I was

told what was found in the amniocentesis was insignificant and yet here it is. The genetic report

from October 26, 2010 stated that my daughter had made good developmental progress but this

assessment was based on my anecdotal reports because I was wanting to explain everything she

could do at that time, no matter how insignificant it may have seemed. The report also stated

that IP is not the cause of her skin discoloration. Instead Hypomelanosis of Ito (HI) was the

confirmed diagnosis. HI is a rare birth defect that causes whirled, streaked, or mottled patches of

light colored skin in which clinical manifestations are variable; approximately 70% of affected

individuals have associated anomalies including intellectual impairment in two-thirds of patients.

This offered a more confirmed connection between the skin and neurological issues my daughter

was experiencing. I felt that this confirmation/diagnosis provided an answer for me but did

nothing towards a prognosis. The wind was out of my sails and yet I still held onto hope.

Pinball

The fourth genetic evaluation report on December 7, 2010, was done after another

microarray was preformed to determine the source of her marker chromosome. The microarray

revealed multiple mosaic duplications of varying size on chromosome 15q as shown in figure 4.
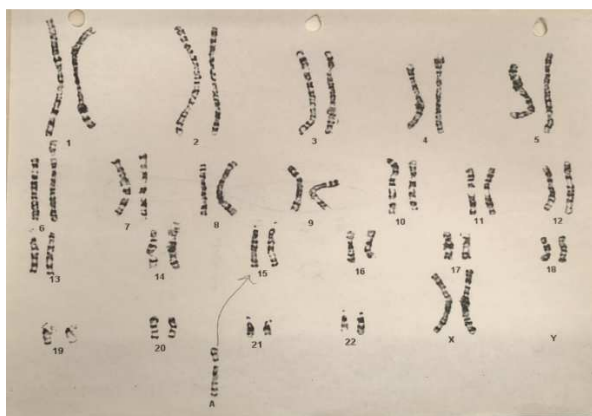

Figure 7. Chromosome printout from genetic evaluation

A parental analysis was suggested to see if it was inherited. No specific prognosis could be given based on the findings of the chromosome analysis though it was most certainly the cause of her current issues. I was told my daughter was at risk of developing associated issues, such as epilepsy, so she should be monitored closely and receive appropriate developmental interventions. Based on these findings I was back at my research. My daughter's duplication was mosaic, therefore once again, prognosis unknown. I began telling people that "the extra chromosome has played pinball in her body, affecting multiple areas of development". The doctors said "She is writing her own book." This description here has become my explanation to the outside world.

My daughter's life was filled with doctors, specialists, as well as case managers from the regional center. On January 7, 2011 my daughter had her annual Health Status Review from our regional center. The Wellness Screening Form stated:

> …speech and language delays, with no words but gestures, cooing, and pointing. Hearing and vision in normal limits. Child is generally hypotonic, but her legs are hypertonic, the left more than the right. Can get to a sitting position most of the time, almost crawling, gets around the house by rolling.

The Wellness Screening Form also acknowledged that my daughter is dependent on adults for all of her activities of daily living. Much of the information in this report came from my interview with my daughter's case manager at the regional center because I wanted to make sure her accomplishments were recorded in her reports. I wanted to make sure that her progress was documented.

On March 25, 2011 the IFSP report from the regional center which stated that my daughter was 25-50% delayed in all areas of development. Upon parent anecdotal statement my daughter's strengths included developing socially, she gives "hugs and kisses" and can entertain herself longer. Her needs were stated on the report as parents are concerned about the turning of

her feet outward. My daughter had not yet begun to walk at 18.5 months and my concerns were focused on getting the treatment and therapy she needs. I wanted her to improve her motor development and sleep patterns (she has always had troubling staying asleep throughout the night. At the receipt of this IFSP report she was sleeping better but still waking often at night though she could now comfort herself and search for her pacifier if it falls out of her mouth). She also had a renal ultrasound done to rule out kidney issues related to her skin's HI and one small gallstone was detected. I was worried about this diagnosis because I had heard how painful passing gallstones are. I was told not to worry, that this size would not affect her. I did not want any more diagnoses. Her current developmental domain scores based from the HOPE assessment at 18.5 months were:

Social: 10-11 mo. (up from 8-9)
Communication: 9-10 (up from 9)
Adaptive self-help: 9-12 (up from 8-10)
Gross: 11-12 (up from 8-9)
Fine: 10-12 (up from 8-9)
Cognitive: 9-11 (up from 8-9)

Based from this report my daughter received a walker (see Figure 6). I hoped this device would help her walk.

Shana @SweetlyUnique09 20 Apr 2011
My daughter's PT brought us a Kaye Reverse Walker today to try to help her walk. Anyone else use one for your child? (Blog post).

Figure 8. Kaye reverse walker

I kept it in the living room and monitored her. I just wanted her to be able to walk, I did not

know if she ever would and that concerned me. What if she got so big I couldn't carry her or

pick her up to help her? I am not that big of a person. Within a week of receiving the walker my

daughter was using her legs much better. It was amazing to see her fast progression after her

therapy and her use of the devices. She used to shuffle walk with a push toy while her feet

pointed outward and she would drag her feet across the rough old carpet. She did not seem to

have the ability to pick her feet and/or legs up in a walk stance. Because of her collapsed ankles

I did not believe the joint of the ankle was working properly. Since engaging with the therapy

and working with the devices her feet and hips had turned inward. Within a month my daughter

was able to lift her feet off the ground in order to have a more stable walk even though her foot

still flopped downward. At the end of the first month the therapist opted to take the walker away

because it was deemed more of a distraction than a help. My daughter was easily distracted and

wanted to explore and play instead of focusing on what she needs to do, such like therapy

exercises. She was distracted by the walker because she wanted to touch the components and

push it around, not necessarily use it for what it was intended. To this day a preferred activity of

hers is to push things around. I keep one of her old strollers in the house so she can push it

around.

The next regional center IFSP review came on November 10, 2011 showing delays of

25% in all areas of development. This allowed her to continue services and therapies. My main

concern at this appointment was her motor skills. I wanted her to make gains in her overall

development. I was also concerned about her weight and the fact that she spits out her food. I

was not sure if this was a behavior (was she being defiant?) or if she does not like the food or is full? Another concern was that she was still waking three to four times a night.

Speech development was the final concern at this point even though I was so very thankful that she had started walking. To me the two biggest necessities in life are mobility and the ability to communicate. Once she started walking I knew she was going to be okay with mobility. It was such a relief when she was able to walk on her own. I did not know at first if that would be possible. Speech, however, was not coming along and that frightened me. A friend tried to cheer me up and say her son did not start talking until he was four years old but deep down I knew there was more to it for my daughter. What if there was a part of her brain or physiology that was preventing her from speaking? What if she never could? These were questions that I tried to keep suppressed while focusing on what my daughter had been able to accomplish so far. I tried to keep hope that language was still a possibility for her. The therapists worked with us to develop a communication system that would work for my daughter. Pointing is a large part of communication for a nonverbal person paired with sounds.

> Shana @SweetlyUnique09 4 May 2011
> Pointing: Something that the therapists have been working on is getting our cupcake to point (Blog post).

At the time of this IFSP review my daughter was 26 months old and the report took place 7.5 months after the last report. Her scores in the developmental domains on the HOPE assessment were as follows:

> Social: 17-18 (up from 10-11)
> Communication: Expressive 9-10 (same) receptive 13-15 (up from 9-10)
> Adaptive self-help: 12-24 (up from 9-12)
> Gross: 14-16 (up from 11-12)
> Fine: 12-13 (up from 12-13)
> Cognitive: 15-18 (up from 9-11)

When my daughter was 22-months-old, the genetic evaluation report dated June 21, 2011 included that services received from the regional center should include speech therapy when she is was physically and cognitively able to participate in speech therapy. When I asked about this, I was told she was not cognitively ready to participate and benefit from speech services yet (personal communication, genetic evaluation report, 2011). I was concerned about the fluctuation in her skills. I did not understand why she made certain sounds and then appeared to forget them. I would later come to understand that children with corpus callosum disorders tend to learn and unlearn skills. Her current skills were documented as making some sounds, laughing, and smiling. She used gestures and facial expressions to get her needs and wants met, while pushing away items or food that she did not want. She demonstrated that she understood what the word hungry meant by rubbing on her stomach, and going to the kitchen if asked if she wanted a bottle. She demonstrated that she understood what night-night meant by going to the bedroom. Finally, she was able to follow simple commands. The emerging skills that the therapist and I worked on included using more gestures, signs, or simple words and sounds to express needs as well as pointing to get what she wants. My daughter was also working on identifying items when asked.

On June 28, 2011 in an effort to improve her collapsed ankles, which was the reason she was having difficulty walking, my daughter received plastic braces called Supramalleolar Orthosis (SMO) and twister cables. These devices were fitted especially for her feet and height. Her foot slipped into the SMOs like a young child's roller skate that fit around their shoe. The SMOs went up to her ankle for support and were held together by Velcro. The SMOs were worn inside a shoe.

Shana @SweetlyUnique09 29 Jun 2011
Orthotics: Our cupcake got her SMOs and twister cables yesterday. It is bitter sweet (Blog post).

Figure 9. Supramalleolar orthosis **(**SMO)

Figure 10. Twister cables with attached shoes

The twister cables had shoes attached to them that were a size too big for my daughter's foot in order to allow the SMO to go inside the shoe.   She wore the twisters for 4-6 hours per day from June to December 2011.

Casting Spells

The end of 2011 saw another devastating chapter in my daughter's story. My daughter developed seizures December, 2011, shortly after she turned two years old. It was a normal afternoon and my two daughter's and I were in the kitchen, while my husband was in the

adjoining backyard working. My youngest started to walk backwards stumbling toward the kitchen doorway. Thankfully I was behind her because in an instant that seems like a lifetime she fell backwards and began to tremble. I had never witnessed a seizure but I knew this was one. I yelled to my older daughter to go get her dad. By the time he came into the kitchen she was already coming out of the seizure. She looked very confused and sad. We immediately contacted her neurologist. He had anticipated such an outcome based on her multiple diagnoses. Because of the onset of seizures and her restless sleeping patterns my daughter began to sleep in my room so I could monitor her better. When the seizure activity increased she began to sleep in my bed so I could have an instant response time to help her. We began documenting her spells, another term for a seizure, in order to determine the best course of treatment. My daughter was put on an antiepileptic medication.

The Moment

It was February 2012. My daughter was thirty months old. I was driving to meet extended family members to pick up my oldest daughter after a visit. I was on the freeway and my youngest daughter would not stop crying. I tried to talk to her, sing to her, and coo her. I got frustrated, I yelled. I got so worked up, with my pulse racing, I had to get off at an exit and I pulled to the side of the road on a road I did not recognize with fields on either side, it was as if I was in the middle of nowhere. I called my husband at work and thankfully he answered. I started cursing at him with a raised voice, exasperatedly describing the situation. I could not handle it, the stress, I could not take it. I was beyond myself. He was able to talk me down and calm me. My daughter was always making noises, grunts and such. She would cry at red lights, because the car was stopped I am assuming because once the car started she would stop. And here I was in the front seat and she was in the backseat and there was nothing I could do. I felt

helpless and did not have control of the situation. It was a miserable feeling, I was used to being in control. I no longer had control with parenting or with my daughter. After talking with friends, I decided to see my doctor who prescribed me some medications to keep me calm. I took the medication every day for about eight months until I learned to focus and deal with stress differently.

My daughter also received treatments/therapies. One particular daily report from her OT and PT visits dated February 14, 2012 discussed her feeding therapy. Her tongue did not move to the sides of her mouth so she was given what is known as "chewlry." This particular chewlry was a textured T-shaped rubber chewing toy that was attached to a spiral necklace. The purpose of the chewlry was to help get the tongue to move from side to side by placing it on the sides of the cheek. She also used a gum massager to help with her texture tolerance. At home this was noticeable in the fight to get her to eat. I could not get her to swallow her medicine. She spit out foods. I had to do these daily activities with her. Although I tried to make the activities part of play time, the struggle to have her complete these activities put a strain on my relationship with her. Furthermore, the play time frequently occurred at the end of a long work day. That is, after working all day with students, then I had to come home, cook dinner and make sure my daughter received her daily activities as assigned by her therapists.

Preschool Years

Developmental assessments are age specific therefore on March 22, 2012 I received a new assessment that described my daughter's current level of development; this new assessment called the Battelle Developmental Inventory (BDI) was developed especially for older children. These scores were five months after the last assessment when she was 31 months old:

Social: 17-18 mo. (up from 10-11)
Adult interaction 14 mo. (new category)

Peer interaction < 24 mo. (new category)
Self-concept & social role 18 mo.
Communication: Expressive 9 mo. (same - no change since she was 13 months old) and receptive 17 (up from 13-15).
Adaptive self-help: 12-24 (up from 9-12)
Self-care 10 mo.
Personal responsibility <24 months (new category)
Gross: 16 mo. (from 14-16)
Fine: 16 mo. (up from 12-13)
Perceptual motor <24 mo. (new category)
Cognitive: 15-18 (up from 9-11)
Attention & memory 14 mo. (new category)
Reasoning & academic skills <24 mo. (new category)
Perception & concepts 9 mo. (new category)

These scores helped with her transition to preschool. On May 10, 2012 my daughter was preparing to exit out of the early education program and home visits and into a special day preschool classroom. I was very nervous. In the familiar environment of the early education program, she and I had learned consistency, the therapists knew her mannerisms, and she had learned the expectations and activities they did with her. I was afraid of the change and what it would mean for her. I did not know how she would react and behave. The transition to a special day preschool classroom would also mean that she would receive an Individualized Education Plan (IEP) where the team would consider the need for both a speech therapist and continued physical therapy for motor needs. In addition, a psychological report was used to determine special education eligibility. I had no doubt in my mind she qualified for special education. The report stated that my daughter:

> …met eligibility criteria for special education services as a student with intellectual disability, in addition, her diagnosis of ACC will also adversely impact her educational performance therefore she is also eligible as a student with other health impairment (OHI). The IEP team might consider her as a student with multiple handicaps. It appears that she will require a highly supervised classroom with a low student to teacher ratio.

The report also stated that she appeared younger than she was and that those working with her should keep this in mind in order to increase her overall skills. I knew and anticipated these

results, even if I did not know the terminology yet. Her doctor appointments showed global developmental delay which in the academic setting related to multiple disabilities. This was something I lived with on a daily basis all day, every day so I was fully aware of her needs.

Another aspect my daughter's preschool teacher would need to understand was her lack of expressive communication. My daughter's neurology check-up from July 9, 2012, when she was a month shy of three years old, added language delay to her hospital diagnosis list. I was definitely feeling the impact and effect of this diagnosis. The struggle of the guessing game associated with language delay was and continues to be daily over everything. I was always trying to figure out what she was trying to communicate, whether it be her needs or wants. She makes repetitive sounds constantly, which can become irritating.

That same month on July 23, 2012, my daughter received glasses for an astigmatism in her right eye. They were the rubber ones that have a strap that goes behind the head. They were light purple with rectangular lenses. Since being prescribed the glasses, she has never worn them full time. I do not know if she does not understand me when I say she needs to wear them or if they are uncomfortable for her or if she is just being uncooperative. She would also take them off and bite them.

First IEP

Once my daughter had been in her preschool class for a year we received our annual IEP meeting. The notes from April 29, 2013 stated that she was in a least restricted environment (LRE) in a moderate/severe special day class. A moderate/severe class is for those students that cannot participate in a general education classroom due to extensive delays. This meeting discussed her eligibility for summer school which was called extended school year (ESY) in order to not fall back on her goals. The IEP team wanted to keep her on a structured

schedule. She was going to be bused to school. That was scary for me because this meant that someone I did not know would be transporting my child.

When my daughter transitioned to school her plan with the regional center also changed. We no longer had an IFSP, my daughter had an Individualized Program Plan (IPP). An IPP is an action plan that talks about the assistance a person with disabilities needs to live the way they want. It identifies goals, services, and supports so a person with disabilities can be more independent and participate in the community. The services and supports developed in the IPP were meant to enable my daughter to live as independently and productively as possible. Sadly, I understood that independent and productive living were not necessarily attainable at this time. My daughter was capable of doing small tasks independently but usually required prompting and supervision I could tell her to use her utensil to eat, and she might for a few bites, but then she would revert back to using her hands. This behavior has continued as she has aged and is present even though she is now 10 years old. For example, I still have to prompt her not to stand so close to the television. I have to supervise her when she eats, otherwise she will stuff her mouth and choke. I have to supervise her when she goes up and down stairs. I have to prompt her to walk instead of run so she is safe and does not run into anything.

On August 1, 2013 my daughter received an Individualized program plan (IPP) from our regional center. It stated her long range goals; to develop to her greatest potential in the areas of communication, social, educational, and adaptive skills. Key words here were "develop to her greatest potential." Her potential is just one chapter in the book she is writing for herself. Additionally, the IPP stated:

> (My daughter) and her family would benefit from respite. Parents would like a break
> from her many care demands. She requires daily supervision to prevent injury and harm.

This was the first time that I ever saw someone acknowledge in writing that I needed a break. To my way of thinking, even if I got a break I was never fully off because in the back of my mind I worried and wondered and felt guilt.

My daughter's final preschool IEP dated April 7, 2014 stated that my daughter had increased her vocalization significantly over the last year, to gain attention, protest, or comment on what she is doing. She will point or lead you to what she wants. This means that she will grab someone's hand and adjust to fit her hand inside that hand and literally drag a person to what or where she wants. She definitely protests and will even make sounds to talk back. Because she has several types of grunt sounds, I have to translate the nuance of that sounds to interpret for others what she needs or wants. It becomes quite irritating for repetitive sounds. Similarly, if a person does not give her their hand right away she will pull at the person, often quite hard. For example she will tug at my arm and I just want to tell her to stop. Even though I understand that she gets frustrated that she is not able to communicate, the insistent repetition of her behavior has caused me anxiety.

This IEP also stated that my daughter was a "bubbly four year old that is full of energy." My daughter was and is always on the move. She has been full of energy all the time. She can go, go, go. That makes me an exhausted mom. My child is my form of exercise. "Full of energy" is an understatement. She does not sit still for any real length of time. She has a low attention span, it could be age appropriate, or she is bored or loses interest easily. She works well and can stay on task longer when someone sits with her one-on-one. She seems to prefer that attention which can be daunting when you are trying to accomplish household chores. She prefers someone watching her and will check to make sure someone is seeing what she is doing. Her love of books started somewhere around age four.

Finally, this IEP from April 7, 2014 stated:

(My daughter) can be IMPULSIVE. She can be disruptive during structured activities as she will flip, dump or mouth materials. She does need someone to be with her to supervise her during these activities. She does not do this all of the time but when she does she will continue the act until removed from the area. Her behavior impedes learning of self or others. Behavior goal is part of the IEP.

Impulsive was – and is – an accurate word to describe my daughter. The description that she did not always engage in impulsive behavior and that but when she did she could not seem to stop herself was – and is – also accurate. It is like she is a ticking time bomb and ones never know when she will go off. And there is not an obvious reason for her misbehavior. It could be attention seeking or boredom, it could be that she is antsy, or it could even be that she derives enjoyment from seeing our anger when she misbehaves. Art projects are interesting. She will dump and flip the tray of supplies and/or try to eat them. She loves to eat crayons and of course restaurants supply them for kids' meals. Even if we watch her very closely she is so fast she manages to get a crayon in her mouth and chew it so it is stuck in her molars and all over her tongue. I use a napkin and make her bite on it to try to get the crayon out of her molars.

School Years

Once my daughter started school I became more focused on her academics, abilities, and behavior, mostly because medical appointments were farther apart now. We had slowed down with new diagnoses and focused on therapies and treatments for existing diagnoses. This gave me a chance to go back to school as well. I enrolled in a Doctorate program and administrative credential program that would start in the fall of 2015 making me a parent and student once again.

On April 3, 2015 the Occupational Therapy Consultation Note from the school gave my daughter a diagnosis of PICA, which is a disorder associated with putting non-edible items into

the mouth. My daughter does not usually swallow anything non-edible but she chews on items

such as sand, bark, and even paper from the garbage. Anything she finds on the floor goes

straight to her mouth. Her chewlry that was provided for her he was causing a rash around her

mouth due to all the drool she was creating. This consult was to see if there were sensory

strategies that the school and I could use to help her. It was suggested that crunchy, intensely

flavored foods may be offered. She does like most foods and very flavorful types as well but

that has not prevented her from putting basically everything into her mouth.

Kindergarten

On May 18, 2015 my daughter's kindergarten IEP stated:

> Mom is concerned about (name removed for confidentiality) increased aggressive
> behaviors at home. She is also concerned with her safety on the playground and whether
> she gets enough supervision to prevent her from eating sand and bark.

I was very concerned with her eating sand and bark because she would eat so much sand

that it would come out in her bowels. That was not good for her internal system and also led to

external problems such as diaper and mouth rashes. I was concerned about splinters and germs

from the bark. Thankfully she did not normally swallow the things that she put in her mouth.

> This IEP also stated that my daughter: exhibits a severe disorder in the areas of language
> - morphology, syntax, semantics, and pragmatics in comparison to developmental
> level. This disability may not be corrected solely through modification of general
> education. She is primarily nonverbal however, observations during meal time reveal that
> her articulators appear to have adequate strength, range of motion, and
> coordination. (speech organs). She has a variety of vowel sounds and can produce /m, p,
> b y/ and the 1-2 syllable level. She uses hand leading and gestures to get most of her
> needs met. She still uses PECS for choices and an AAC (augmentative alternative
> communication) system to make requests for desires.

The discussion of her articulators made me question what was causing her to remain

nonverbal. I often asked myself, "What does not work?" I wished I could go inside her brain or

her voice box and see if something was not working. I could not tell whether or not her

communication issues stemmed from a cognitive dysfunction because she could make sounds,

she just could not articulate words. The picture communication exchange system (PECS) and

augmentative or alternative communication (AAC) are more village devices that are still used to

support my daughter. PECS are picture cue cards from a program. They can be used for a

schedule such as breakfast then toilet then recess or store then home then dinner. The PECS can

also be used as a choice board (toys, food, activity, and so on) providing my daughter an

opportunity to communicate her wants and desires. The AAC is a tablet that has picture cue

similar to the PECS but it voices the choice as well. This is a school device only. My daughter

has a tablet at home and I have tried using a program called JABTalk to get her to pick her

choices or tell me her wants and needs. She is currently a button pusher and will push multiple

items at once so it is unclear what her expectations are. It becomes more of a struggle and an

issue of consistency because I revert back to letting her pull me to what she wants and pointing at

it, while grunting.

Her IPP from the regional center dated July 16, 2015 discussed that she is followed by a

gastroenterologist for her low weight. She was also reported to be a fragile ambulatory child.

This meant that she was at a greater risk to harm while walking because she has a tendency to

walk very fast, and did not pay attention to cautious situation such as a curb by the road. She

would run into furniture and other objects and fall frequently. She has low stamina in her legs

and shows difficulty walking long distances for long periods of time. For these reasons I

requested a Convaid Cruiser, a stroller for children with special needs (see figure 11) at this

meeting.

Figure 11. Convaid cruiser

Behavior Support

It was also at this meeting on July 16, 2015 that my daughter's case manager documented that my daughter had a behavioral condition that was interfering with her development based on the parent interview. He and I also concluded that I would benefit from in-home behavioral assistance. I had to complete a required Hands on Behavioral Tools Class prior to being provided Behavioral Instructional Services (BIS) in-home. This parenting class was mostly meant for autistic (ASD) parents but there were many behaviors that my child also exhibited that they discussed in the parent class. In the behavioral tools class, I learned how to use applied behavior analysis and reinforcers in the form of positive reinforcement and antecedent, behavior, consequence (ABC). This helped me to understand how behavior works and is affected by the environment in order to decrease undesirable behaviors.

The BIS took place from August 19, 2015 to March 14, 2016 as a means to cope with behavior issues that included self-harm, harming others, and throwing things like her plate of food at mealtimes and toys when she is upset. When she self-harmed she did so by pulling her hair or head banging on the wall or floor. For the hair pulling I was instructed to walk away with no vocals, eye contact, or physical interaction. Additionally I was instructed to give her a high five for appropriate behavior. In stores I was to make my daughter the helper so she would not

pull my hair when I bent down at the shelf or to put something in the cart. I did this by handing

her items to put in the cart for me. For the head banging on the floor I was instructed to put a

pillow between her and the floor. I was given a communication system/visual schedule of

choices and tasks for the family to follow. Lastly, in an effort to lessen my daughter's

frustrations, I was instructed to avoid the word "no" and to use alternative phrases such as "we

don't jump on the couch." Outlined below are the targeted behaviors the therapist and I worked

on during these months and the strategies I learned to use in response to a target behavior:

> Target behavior #1 - decreased hair pulling
> Attention through soft hands not hair pulling. Walk away, no vocals, no eye contact, and
> no physical interaction. High five for appropriate behavior such as a hug. In stores make
> (my daughter) the helper so she won't pull my hair when I bend down at the shelf or to
> put something in the cart. Communication system/visual schedule - choices and tasks.
> Avoid the word "no", use alternative phrases such as "we don't jump on the couch".

Most of these were strategies that I could manage. Yet, it was so hard to refrain from

yelling "no" when she pulled hair. I had to remind myself to just get away and leave the

room. The communication system and schedule (PECS) worked for a while. Mostly I was bad

at keeping up with using the communication system and schedule even though I bought small

vertical clipboards and had one in the car so I could show her where we were going and what to

expect for our day. Now that she is older I think she understands the concept of first, next, then

as was taught with the PECS schedule system. I can tell her that after dinner I will read to her

and she leaves the kitchen. Fascinatingly, she will retrieve the book after dinner. She still has

PECS choice boards but again, I hardly use them. Instead she just hand leads me and points to

what she is interested in.

Another strategy that the behavior specialist recommended was to use "help" PECS icons

with her. These icons (an image of the ASL sign for "help") could be attached to a wall or

cabinet with Velcro so she could grab it with ease and hand it to me if she wanted help with

getting a preferred item or help with an activity. This way, she was able to develop a way to communicate her needs. Ultimately, I felt that this took a lot of commitment from me and from my daughter. Although I did use this strategy for the duration of her therapy, I stopped using it shortly after. It was just easier to revert back to speaking to her and her hand leading.

> Target behavior #2 - decreased throwing food & plate at meals
> Communication system during meal time including "more" and "all done".
> Parents encouraged to give smaller portions setting up the opportunity for communication vs. inappropriate behavior. Verbal praise for eating appropriately.
> At dinner she would chew her icons that were at the table. These icons were used so she

could make choices. Because they were damaged by the chewing, I would throw them away. I finally decided that using the icons at meal time had become a distraction rather than a benefit. I opted, instead, to provide small portions of food for her. She will still, on occasion, throw the food in addition to dumping the entire plate. When this happens, she will then eat the food from the table and even put food back on her plate without a prompt from me.

> Target Behavior #3 - Increased voiding in the toilet
> Take her during natural times - wake up, bed time, nap, before bath when arriving home.

I take my daughter to the bathroom during all the natural times described in the above note. Sometimes she voids in the toilet. Sometimes she pats her bottom and lets us know she needs to go to the bathroom. Because there are so many issues to focus on in relation to her behavior, I am not as concerned with toilet training at this time. I am confident that she will eventually learn to use the toilet.

First Grade

My daughter's first grade IEP from dated April 19, 2016 stated that her strengths included always having a smile on her face. It also stated that she is extremely "verbal" with correct intonations and levels to match her mood and she demonstrates multisyllabic jargon.

My daughter will babble up a storm. She makes many sounds, consonants and vowels, but I am unsure of what she is saying. At times it sounds like a true word comes out and I may say "did you hear that? She said ____." When she does that her face looks as if she is shocked as well that a word came out.

More Assessments

On July 18, 2016 my daughter had an annual neurology check-up. In addition to the routine exam, I requested a neuropsychological assessment. I wanted to know her developmental age because schools and regional centers do not have assessments for older children to determine how much farther she is behind chronological peers. At this point, my daughter was almost seven and other children would ask how old she is and why she could not talk. I try to give explain her situation so they can understand but I also do not want to go into too much detail without first confirming with their parents that this is okay.

The Psychological Reports dated September 7 and September 13, 2017 (when she was eight years old) stated that my daughter seems to test a new examiner because while walking with examiner outside of the office in the hallway my daughter ran away. When asked to come back, she looked back, smiled, and began to run faster in the opposite direction. I have often experienced this same behavior with her. When asked to do something, my daughter may just sit and look at me. I may have to repeat once, twice, or more times in order to get her to comply. Like most people in this kind of situation, I get impatient. Often I will get her and redirect her to what I need her to do.

Simple Abilities, Simple Pleasures

On May 11, 2018 I bought a fidget die for her. A fidget die is a six sided cube that has different activities on each side. For example, one side has a button to push, while another side

has a ball that can roll around. It was something that was brand new to her and I recall her picking it up and bringing it to me. The gesture was as if she was asking permission to play with it because after I told her it was for her she smiled and walked away with it.

That same summer she surprised me by showing that she had some long-term memory. I was cleaning my office and I had her with me. She came across a class photo from two years prior. She had become quiet, so when I turned to look at her she was sitting down with that picture pointing at her teacher and aides in the photo while smiling. When I asked her about the people in the photo, she made high pitched squeals and pointed at their faces more directly.

I also am noticing that she may be learning behaviors even if I do not expressly teach them to her. For example, she has learned to lay her finger on her nose to show "shhhh" after observing me put my finger to my mouth. Because I must cover my nose when I make the gesture for quiet, it seems that she has mimicked what she sees and she has adapted the motion in her way. This is consistent with the ways she has adapted sign language gestures to her own style.

For the Fourth of July holiday weekend in 2019, a month before my daughter's ninth birthday, my family went camping with friends. I purchased my daughter a separate air mattress because our air mattress was only a queen and we were used to co-sleeping in a Cal-King bed. Since my daughter did so well in her own mattress, I decided to give it a try at home as well. To date she is sleeping in her own bed, though the bed is in my room to monitor her seizure activity. This has allowed more restful sleep.

Current Events

At the conclusion of this study, my daughter is 10 years old. She still loves books and will often request the same book over and over again. This usually takes place during times

when I am trying to do household chores. While she can follow simple directions she does not always seem to understand what I want her to do. I can repeat myself several times but she will not respond to what I am telling her to do. It is often unclear if she is ignoring me, if she has forgotten an instruction, or if she is simply being naughty on purpose. I think to myself "you know this, you know how to do this." It is times like this that I wish she could better communicate with us.

My daughter is still unable, most times, to repeat a word or make other coherent words on a regular basis. She does not make two words together. I am in my daughter's world of nonverbal communication with sounds like "Buh," "mama," and "pees." Her signs include please, thank you, all done, more, eat, drink, excuse me, and "no more monkeys" which looks like the sign for "potty." She has been learning the signs for some colors as well such as "blue" and "yellow". My daughter has ways that help her communicate with us. For example, when she wants something specific she might point or make a sound, such as a grunt. She may also pull us to what she wants then point at it. If she is excited, she will often squeal and if she is happy she will laugh or clap. When she expresses displeasure she will grunt as in disapproval, self-harm or push items that are on counters, tables, and other furniture. Although it is difficult to describe, we have also identified the ways she might show some defiance in her attitude or talk back to us. This vast array of communication methods means I am constantly decoding her verbalization for mood, wants, and needs.

At 10 years old, she has begun to cover her eyes with her hands when she is in trouble, embarrassed, overwhelmed, shocked, scared, hiding, playing, or sad. Because she cannot communicate beyond gestures, it is difficult to determine if her behavior reflects an avoidance strategy for her or if she is trying to let us know that her head hurts due to

overstimulation. When I notice her behave in this way, I become more aware of the environment we are in so I can respond appropriately to her. Because of her sensitivity to different environments, I carefully consider invitations to functions to determine not only whether or not I will attend, but also whether or not I will bring my daughter. Knowing the type of function and the environment allows me to determine if this will be a situation that will place my daughter under stress and then how this could affect her behavior. This is similar to high level of awareness required when communicating with her and when attempting to manage her overall behavior.

The school experiences and activities have focused on developing her functional skills rather than her academic skills. Now that she is older there is an increased focus on academic skills, but even at 10 years old, she is unable to write her name or sing her ABCs or count. At school they have started having her wear regular underwear. Once she gets used to wearing the underwear at school it is my plan to start at home as well. Knowing that my daughter is usually a happy and content girl regardless of her severe academic setbacks and daily living limitations has given me a new perspective on life over the years.

Chapter Summary

This has been a story detailing how my book changed genres because my daughter's book was not a typical story. I thought the book of my second child was going to be very similar to the book I had created while parenting my first child. That was not how the tale was to be written. This is a book that will not end for a very long time. This story is only the beginning of a lengthy novel. I can only live it chapter by chapter. I cannot predict the ending. This story is my personalized narrative of caregiving for a child with multiple disabilities.

CHAPTER 5: ANALYSIS, FINDINGS, AND CONCLUSIONS

Excitement, anxiousness, optimism, anticipation, concern, happiness, and blessed are the normal and expected feelings, just to name a few, when one finds out they are pregnant. I found out I was expecting my second child on January 5, 2009. I experienced all of the above mentioned feelings as I had been trying for the better part of a year to conceive. As is the routine medical process when pregnant, I went every four weeks for my normal check-up with my obstetrician. During these visits my obstetrician would question me, asking how I was feeling and how I felt my pregnancy was coming along. He would then check my unborn baby's status by listening for the heart beat or measuring my growing belly. Through these observations my doctor was able to determine if my baby was growing and developing normally, or as normally as expected. This was the story of a mother who found out that her child was not developing as expected.

Analysis

My journey through the multiple records I have accumulated throughout the years was time consuming and emotional. I relived moments and felt the surge of emotions again and again. While many of the memories that I reflected upon happened years ago, I could imagine them as if they were just taking place. I felt warmth, sadness, love, anger, joy, frustration, pride, and anxiety again and again as I relived my moments and reflected on them in my reflexive journal. I laughed, I cried, I talked to those I consider my village, I stared into space in awe of this story I call life.

This study, my story, provided a longitudinal, intimate, personalized narrative of that journey through positive and negative transformations experienced by a mother raising and caregiving for her child with multiple disabilities with a transformation of personal growth. For

the purpose of this study, the term longitudinal reflected the past ten years as the basis of my study, understanding that I experienced change from the beginning of this journey to the present. Intimate Inquiry as a framework allowed me the ability to explore the experiences of myself as a representative of the culture of caregivers, which for my story, had a village that included my family unit, the education system, and medical scholars and therapists.

The goal of my research was to add to the circle of conversation by allowing readers to gain an understanding of my story and what it means to caregive for a child and her disabilities while correlating the research to my experiences. It was my vision to look beyond the negative aspects of coping and focus on the gifts children with multiple disabilities can provide to their families, educators, and society. I focused on the stress of hassles as well as the joys of uplifts that I experienced as positive appeal as a means for transformation of personal growth. It was beneficial to narrate both negative and positive experiences to allow the readers a chance to see within the culture of caregiving for a child with multiple disabilities. This painted a picture that cannot otherwise be obtained through quantified data.

Research in this area has quantified the data, but the missing component is the narrative. The narrative is just as, if not more, beneficial to this area of research because it allows readers to hear a voice and clarify what quantified data can only speculate. Quantified data can be left to interpretation making a narrative that much more valuable to the reader. It allows readers to understand the culture from the inside and it removes the *clinical* feel of quantified data. It was my intent to have readers, especially caregivers, acknowledge similarities in their own journey and understand that they too are writing their own book.

Autoethnography is both process and product of research. The process of doing autoethnography requires the author to focus on past experiences, or epiphanies, both selectively

and retroactively (Ellis, Adams, & Bochner, 2011). Selectively suggests the author discusses moments in their past that changed the trajectory of their life, while retroactively suggests that the past experiences serve as a statute for the author. It is my intent that this study contribute to the acceptance of autoethnography as a validated form of research. The narrative adds and extends quantified data as quantified data is left to the interpretation of the subject. Autoethnographies add to quantified data by allowing readers to experience intimate details rather than solely clinical data in order to connect to the stories and understand and relate to the data.

The theoretical framework for my study was intimate inquiry, created by Laura (2011). Laura explains that intimate inquiry is the notion that "each of us is an expert on the qualities of our own experiences" (p. 34). Narrative inquiry is a way of understanding experience. It combines people's experiences as a phenomena and inquiring narratively as a methodology which "allows for the intimate study of individuals' experiences over time and in context" (Clandinin & Caine, 2008, p. 542). Ellis, Adams, and Bochner (2011) express that writing personal stories makes witnessing possible. As witnesses, autoethnographers invite readers to feel validated and/or better able to cope with their circumstances, and possibly make changes due to the pain and validation felt from the research. Narrative inquiries should lead to positive change in an effort to make the world a better place, offering companionship to readers while attempting to establish meaning, healing, and/or growth in the life of the researcher (Ellis, 2007).

In this narrative I discussed personal details pertaining to caregiving for my daughter that have not only changed my life forever but I hope inspires readers to reflect on moments in their past that have changed their path. It is my hope that readers, caregivers specifically, find their epiphany of personal growth and understand that they are not alone. It is also my hope that

readers recognize that it is acceptable to have a village support system, caregiving should not be a solitary experience.

Answering the Research Question

As my story began my research question was as follows: In what ways have I, as a mother of a child with multiple disabilities, maintained a healthy family by transforming the impact of disability into personal growth? This research question guided my literature review and my research of the mother as the head of the family unit. And while I still believe that it is important to maintain a healthy family, I came to understand through the analysis of data and the writing of my narrative, that having a healthy family was an answer to the question I set out to answer. My epiphany was that I was more invested in me and how have I grown therefore my research question changed to: In what ways have I, as a mother of a child with multiple disabilities, transformed the impact of disability into personal growth? Through my analysis of the data I found multiple answers, which I refer to as themes, to this powerful research question.

Much like a classroom teacher creating lessons in a thematic unit this journey allowed me to recognize themes as the chapters in my story. Theme identification took place during the constant comparison of incidents as I wrote in my reflexive journal. This constant comparison created theoretical properties for categories I established throughout the data analysis. I established concepts in my first grouping of reflections and categories in my second grouping. While creating the categories in my second grouping I noticed that many of the concepts created in the first grouping overlapped similar categories found in the second grouping. I came to find out that many of my concepts could in fact relate to more than one theme. The themes are as follows; sacrifice, hope, factual vs. emotional, positive belief mind frames, coping, never-off,

parent trap, behavior battles, village, healthy family and personal growth. These themes were developed in response to my research question posed at the start of this study, my story.

Sacrifice

Sacrifice is the act of giving up something in order to provide or help another person. It would be reasonable to suggest that parents would sacrifice to provide for their children and many parents do. It would also be reasonable to suggest that parents would give up anything in order to rid their child of their disabilities or help them have the best possible life they can.

Throughout my story I shared moments of sacrifice I experienced. My largest sacrifice came in my first chapter making the choice to continue with the pregnancy and the birth of my daughter. In an instant I knew, but really did not know, what I was sacrificing, what I was agreeing to. I knew life as a mother would be different but I could not fathom what that would actually be like. My role as a mother of a child with a disability has been part of my sacrifice.

After that day my sacrifice has taken the form of what support I can provide to my daughter as she has received diagnoses and therapies throughout her life. Overnight trips out of town, sleeping in hotels, to see specialists and hospital visits. Learning how to properly use the devices provided to my daughter. Allowing therapists into my home in order to support my daughter. Countless hours on the computer researching.

I did not feel I could be a good mother, as good of a mother as I could be, if I did not understand what my daughter's diagnoses meant, what I could do for her, and what the future held for her. I poured over medical reports researching what I did not understand. This is not to discredit mothers of typically developed children. That is my role as well as I have a typically developed child that is five years older. I did research when my first daughter was an infant and toddler this included learning; how to make homemade baby food, how much tummy time

should she have, what activities promote milestones, and so on. The research is different with a child with disabilities and often requires outside village sources and much more medical terminology. Every time my daughter has been diagnosed with something I have done more research to learn about what that meant for her and what a prognosis was and what could I do for her. My role as a mother and educator is always learning more about my daughter's conditions and how they connect to each other.

There have been times when I have doubted my sacrifice because my daughter has been put through so much; testing, hospitalizations, therapy devices, appointments. I have felt that it was she who was sacrificing. I am a mother and an educator and I search for connections and answers, even if it means both my daughter and I sacrifice.

Hope

Hope is a feeling, an expectation, a desire for a particular outcome. The day I made the ultimate sacrifice to continue with my pregnancy, I also demonstrated the upmost hope for the future. I always hope for the best. I believe in things working themselves out. I believe in the law of attraction and having a positive belief mind frame. As a new teacher I was being laid off due to a reduction in force (RIF) each year, and each year, while staying positive, I managed to find work. I believed if I stayed positive then it would all work out. My daughter was born at the beginning of a new school year and I was able to have a job after the district's fall break in October.

My daughter's hospital discharge paperwork after her birth noted that her prognosis "depends on further evaluation". It was disheartening to think no one could tell me what to expect for my daughter, however, I had to take it one day at a time. I could not go down the rabbit hole of 'what-ifs'. I had to stay focused on her and the moment. That is what hope is for

me, not allowing myself to become overwhelmed while staying in the present and focusing on our time now. I have managed to maintain that mentality for the majority of the last ten years.

Hope also takes the form of not giving up. This was evident in my attempt to nurse my daughter who was not latching properly. Additionally, I have not given up hope that my daughter could progress with the therapies and treatments she received. Since my daughter was an infant I have received hope from village support. That included putting her in devices like the Theratog suit, twister cables, ad SMOs. I would do whatever it took to help her, I could only hope for the best and try to get her as much support as possible. Reflecting, I was sad and down that my child needed these services but excited for what the future could bring for her. And hope prevailed! She learned how to crawl and walk and use utensils to eat her meals. She can run and jump and hold a pencil correctly.

Scores from assessments also gave me so much hope. I had something to hold on to, my baby had been making progress. In my mind I felt that if she could maintain this progression she would be okay. Hope came in the form of goals. I have kept it in the back of my mind that anything is possible. Even when confirmations/diagnoses provided answers yet did nothing towards a prognosis the wind would be out of my sails and yet I still held onto hope. The doctors said "She is writing her own book." This description here has become my explanation to the outside world. But this explanation also provides hope, the book has not been finished yet.

What has given me the most hope is that my daughter always has a great smile, she is so friendly and loving. Part of having hope is understanding the differences between emotional responses and factual responses. My daughter responds in emotional ways, not that I do not but I have become very factual in my coping. In many ways being factual versus emotional is a way I deal with a loss of hope, inadequacies, or hassles I may come across on a daily basis.

Factual Versus Emotional

Being factual means that one is concerned with content instead of an interpretation of the content. Being emotional mean reacting in relation to ones emotions. When I think of caregiving for a child with multiple disabilities on a daily basis my mentality now is "I cannot change my situation, I cannot change my daughter's diagnoses, and I cannot change our daily living". This is not said to have a negative outlook on life, it is said matter-of-factly in order to understand that it (life, my daughter's diagnoses, so on) is what it is. As a mother I do what I have to do and I have gotten used to my life and the requirements of caregiving for my daughter. The fact of the matter was my daughter was already here in this world, I had made that choice and I had to accept her condition and think of how I could move forward by providing support and services, both medically and academically.

During my daughter's first year I was working on my master's project to finish my degree. The purpose of this project was to provide awareness of my daughter's brain abnormality diagnosis to other parents and educators. The project also provided sections that discussed family counseling, co-occurring conditions, local, state, and national resources and centers for treatment, early intervention for daily living and academic settings, and long term school life and social services. Finally, I offered a blog for which I provided personal narratives of my daily life with my daughter. While working on my project I was not full of emotion. I was completing something to help others and I was focused on the facts. While doing research for this project I began to reach out to the community and social media. I began a reflecting stage during this time. I had empathy, anger, sadness, anxiety, and peace. It was then that I understood that I was not alone in my caregiving for a child that was not typically developed, but I did not fully understand the stories of other parents and their children. I made it my mission to

talk to as many people as I could about my daughter's diagnoses. When I was asked about her condition I was not afraid to discuss, describe, and answer any questions. If my daughter was writing her own book than I would be an open book.

I experience sadness and an overwhelming sense of helplessness when I reflect back on everything my baby has been through yet when I speak about her journey and progress to others I am matter-of-fact without emotion. I have learned to focus on what my daughter can accomplish and I stray away from thinking about what could have been if things had been different. This has not been easy. I had to actually think of the things that could have been before I could actually move on from them myself. She most likely will never go to a school dance or prom nor will she graduate and have a job. She will never get married or have her own family. These are just a few of the thoughts I have had while also acknowledging that she will remain in my household for her entire life. There are future concerns as well that I just cannot bring myself to deal with just yet but these concerns have been spoken out loud and I have talked with people with adults with disabilities in their families.

Positive Belief Mind Frames

Through my research for my literature review I found many articles regarding psychological positive beliefs mind frames such as optimism, self-mastery, parenting efficacy, positive reappraisal, reinterpretation, self-compassion, and the self-system (d'Agnese, 2016; Paczkowski & Baker, 2008; Scheier & Carver, 1992; Woodman & Hauser-Cram, 2012). The opposite of those would be negative perceptions of sadness and depression, low parenting efficacy, and anxiety (Nolen-Hoeksema, Larson, & Grayson, 1999). When looking at the two lists it might seem that the positive list is the preferred option however the positive beliefs listed are not involuntary list such as breathing or blinking are.

Dispositional Optimism (Scheier & Carver, 1992) is a person's positive interpretation regarding what the future holds, regardless of the control they may possess. I deal with problems head on, taking steps to make my situation better. In terms of my psychological well-being, positive thinking has been helpful because it makes me feel better and has shown me what I am capable of in times of crisis or adversity. In terms of my physical well-being, optimism has produced fewer physical symptoms of distress and has been fundamental in sustainability.

Positive belief mind frames are not without conscious effort and it is that conscious effort that has helped my focus on personal growth. I stated in my story that I had an epiphany when I understood that I needed to focus on what my daughter could do, not what she couldn't. I applied the same mentality for myself. I had to focus on what I could do for my daughter and her disabilities instead of what I could not control or change. A family member gave me a book titled *The Secret*. This is a self-help book about the law of attraction which suggests that thoughts can directly affect a person's life. When I person has a positive belief mind frame then positive events should be forthcoming in their life. I choose to use the law of attraction for positive belief mind frames, I choose to have positive thoughts.

Coping

Coping is the state of effectively dealing with a difficult situation. Part of my role as a mother is to focus on not giving up which required me to discover and develop coping strategies. I have been learning how to cope since my pregnancy. I went to appointments as if they were part of the normal process of being pregnant. Once my daughter was born I demonstrated coping while she was in NICU. When my daughter was born with breathing complications and a heart murmur and had to be admitted to NICU in my heart, I told myself that this would pass. I did

not know if her breathing or heart problem was related to what I already knew about her brain but I felt these complications were not going to be significant to the rest of her life.

I believe part of the reason I have been able to cope has been because I am an informed mother. I take it upon myself to research and understand what my daughter's diagnoses are and what they could mean for her future. The more appointments my daughter has had the more I have learned about my daughter's conditions and how they connect to each other which has helped me accept and cope with what I cannot change. I have been an over analytical person in my life and even more so now. I learned to live in the land of no prognoses and adaptation. That has been my coping mechanism.

Another coping mechanism has been my connection to my village support system of family, friends, and my job. My family has supported me through my education and career endeavors. My family has supported me though my caregiving experiences with my daughter. My role of mother as the head of my family unit is not as strenuous because of the support of my family. I would be a different person, a different caregiver if I did not have my formal and informal support systems. I am a social person so keeping connected with my social network has helped me maintain my self-system and well-being. I have been able to confide in my social network and ask them for support.

Keeping a positive belief mind frame not only helps with hope but is a coping strategy as well. I am one who prefers problem-focused coping because I feel that I have the ability to control and accept stressful situations. I have also experienced emotion-focused by reframing situations, challenges, and crises in a positive belief mind frame (Folkman & Moskowitz, 2000; Woodman & Hauser-Cram, 2012). I have attached positive meaning and perceptions to my daughter's disability and caregiving requirements that has impacted me providing positive

appraisal in an effort to sustain over a long period of time. (Trute, Hiebert-Murphy, & Levine, 2007).

Part of my coping has been to simply see progress in her ability to adjust and improve, and how she has learned to cope with her surroundings and environment. It makes her disabilities not seems so bad when you see how she interacts with people and toys and food. At times, it is as if she is a typically developed little girl enjoying her way through life, and then I understand, she is enjoying her way through life her way.

Never-Off

This is a self-created term used to describe caregiving for my daughter. Parents of infants and toddlers can relate to the term. A parent of an infant or toddler tends to be more observant and cautious with their child as well as more attentive, whereas a parent of an older child may be more lenient and allow them to play without constant supervision, trusting in their decision making processes. Having a child such as my younger daughter means that I stay in the realm of infant and toddler parenting even as she gets older.

I am never off means that I am always responsible for two people. I am always rushing because I am behind in getting ready for anything. I am rarely relaxed. Taking care of her every minute she and I were together has created a very protective mommy out of me. I am a helicopter mom. Even when I talk to people I am looking at her, watching, observing, making sure she is okay, making sure she has not grabbed anything she should not, making sure she has not put anything in her mouth she should not. This has become a learned behavior for me. This gives me anxiety and has made me anxious.

I feel really sad when I see other children her age who can do things on their own, go places on their own, and generally take care of themselves. Seeing the other children makes me

acutely aware of her limitations. When children are interacting in a group, my daughter is the one who stays behind with the parents which means there is no time off even when other parents have a short break. For me, there is no relaxing on the beach while the children make sand castles, no walking hand in hand with my spouse while the children walk ahead at a theme park. I long for her to be able to be just a kid and not so reliant on me.

There are two other components of never-off experience; exhaustion and voice. As a parent of a child with multiple disabilities not only do I always have to prompt and supervise but I also have to stay on guard because she has such quick reflexes and needs constant supervision. She will hit, pull, push, and grab faster than most children I have come across. Part of the exhaustion I experience because I am never-off is due to a lack of restful sleep over the span of ten years. I frequently wonder if I am exhausted because I am experiencing sleep deprivation or whether I am exhausted because I am overloaded with multiple diagnoses, therapies, treatments, and days consumed with attention to a child with significant needs. I wonder if I would be as exhausted if my child had developed in a typical way and was playing with other children, entertaining themselves, using their imagination, saying "mom, look at me, look what I can do." I have become used to lack of sleep but that is not my only source of exhaustion.

Because my daughter does not have her own voice I have to be her advocate and translator. This inability to communicate represents another way in which I am never off as her parent. I have to constantly try to figure out how she is doing or what may cause her discomfort then respond to her needs without knowing if I have accurately assessed her need. It has been one of the biggest struggles in my role as her parent that I want to know what she is thinking and feeling, but it is impossible to bridge the gap in ways that could lead to understanding. Even more frustrating is that I have to always guess and try to interpret what she wants and needs,

what she is feeling and thinking. Sometimes I may guess correctly, while at others times I may not. Living with this constant uncertainty can be challenging because, like any parent, I want the best for my child; though unlike other parents, I have to work especially hard to ascertain her needs. My daughter expresses herself through grunts, squeals, pointing, and pulling you by the hand to what she wants. This vast array of communication methods means I am constantly decoding her verbalization for mood, wants, and needs.

Voice also includes interpretation. Like the time a beloved toy made her cover her face and cry. Why did this toy, this pink Leap Frog laptop make her upset? She did not have a sign or other sound to express this experience. What sounds could she make that could help me decipher what was wrong and how to best comfort her? A lot of the interpretation of her communication occurs in social situations. My daughter likes to go to complete strangers and hug them and grab their hands so she can look at their fingernails. I then have to explain to the strangers that she is non-verbal and loves to hug and likes looking at pretty shiny things such as painted nails. When we are in social situations I do not usually sit. I follow her around so I can gauge and intercept her behavior if necessary but also to let people know what she wants.

Additionally, I am always explaining my child, always explaining her actions, what she wants, what she is doing and why she is doing it. In her early years, I began to feel like a doctor explaining her condition. Most people in our life now know about her so I do not have to explain as much, but I do have people that ask. I am open to discuss my daughter and her condition, I do not shy away from it. I welcome questions from adults and children alike and try to answer them in a manner in which they can understand. I often get asked "what is she doing?" or "what does she want?" My favorite form of communication from her is when she squeals or dances; at these times I get to tell people that she is happy and excited because they offered her something she

wanted or they made her happy in some way. My least favorite experience of communication with her occurs during the drive to school. Most days it is a very quiet ride. She does not engage in sounds. Sometimes we can get a banter going. We play a game where we take turns saying "yeah." She seems to understand the concept of taking turns. Sometimes she cheats and says "yeah, yeah" and I will comment that she cheated and she will laugh. While it has been said "She can't tell you nothing," it is clear that she can. She just does it in her own way, a way that requires me to advocate and translate. Although many parents may feel this way, her disabilities have led me to a state of hyper-vigilance where I am never off, which is both daunting and exhausting.

Parent Trap

Similar to the twins in the Disney movie *Parent Trap* who were separated at birth only to discover each other later in life, as a result of this journey I discovered that where I thought I was one mother, I am actually two different mothers. I am one type of mother to my first, typically developed daughter, and I am a different type of mother to my second daughter with multiple disabilities. My parenting styles and strategies are different for each of my daughters. I am a mother that can correct behavior through a conversation yet I am also a mother that has to constantly redirect behavior. I am a mother that seeks out bonding opportunities with her teenage daughter yet also seeks some alone time away from her younger daughter who is always by her side. I am mother who has to provide permission for friends and outings yet I am a mother who has to schedule outings so that my younger daughter receives interaction. I am a mother that can provide a time to be ready to go yet I am also a mother that has to get her child ready. I am a mother that knows her child is safe when she is away from home yet I am a mother who is always worried whether her child has been injured and will not be able to tell me what

happened. I am a mother to a daughter who I can share and teach life lessons to yet I am a mother to a daughter who I am trying to teach daily living skills to.

And while all that may be true, I am also one mother who has unconditional love for both of my daughters, who can be proud of their accomplishments, no matter how small. Who can find the joy in the interaction I experience with each of my children. A friend once shared with me that I should thank myself every day. At first I could not understand the concept, thank myself for what exactly? After we continued the conversation, I began to understand. Self-compassion is an important part of the self-system. I began to thank myself for small things like exercising that day or making a dinner my family enjoyed. Then I started to think bigger picture. Now I thank myself for continuing my education and being an educator myself. I thank myself for helping others, my students especially. At this moment I thank myself for sticking with finishing my dissertation. I often times have people tell me that they do not know how I do it so I thank myself for 'doing it'. I thank myself because I am proud of myself. I thank myself because I never give up. I thank myself for having a positive belief mind frame. I thank myself for having a healthy family. I thank myself because those are parts of my life that I witnessed personal growth.

Behavior Battles

My daughter's behavior can also be exhausting. The behaviors take place in the home, at school or daycare, and in public. Sometimes the behavior battle is within me as I try to be consistent in my responses to her. Sometimes I would prefer to just give in and give up to keep her happy. Other times the battle is between her and me as I try to discipline or help her understand that her behavior is not acceptable. Other times she really just does not want to do

something that I need her to do, like wear her glasses. It is during these times that my parenting self-efficacy is tested (Bondy and Mash, 1999).

As an educator it is a hard pill to swallow when your own child has a behavior plan as part of her IEP. No one wants their child to impede the learning of others. She has also been known to hit peers. Is this a preventable behavior? Can she help it? Is she aware she is doing it? Why is she doing it? This is where the language barrier between us very much hinders my ability to communicate and reason with her. I cannot explain why she cannot do something or why her behavior is inappropriate in the same ways that I could with our first daughter. Another behavioral challenge is her insubordination. Like most people in this kind of situation, I get impatient. Often I will get her and redirect her to what I need her to do.

I feel like I am always being judged as a parent because others do not fully understand the enormity of parenting a child with severe disabilities. I even get upset when she is hurting herself. I take her to another room to sit somewhere else. I think that I am angry that I do not know how to help her and I wish she would not harm herself. The inability to correct her behaviors is directly related to the challenges of voice: I cannot reason with her to stop.

Constantly, relentlessly, repeating instructions to her connects various themes from this study, never off, communication, and behavior. The result is that I often feel like a broken record, stuck on repeating the same part of a song over and over again. It is during these times where I feel stuck in the cycle of parenting stress and child behavior (Neece, 2013). Part of my stress is more associated with my daughter's behavior rather than her developmental delays (Floyd & Gallagher, 1997). I struggle with understanding if the behavior is related to her developmental delays. I have received support services for her behavior where I was instructed

in strategies to help curb the behaviors. As she grows bigger and stronger I am concerned that I will not know how to prevent her behaviors. I may need to reach out for village support again.

Village

Hillary Clinton's 1996 book *It Takes a Village* presented the African proverb as a means for families, churches, educators and academic professionals, medical professionals, and the government to come together to care for all people, including developmental delayed individuals. The village rhetoric is broken up into two categories, informal support and formal support (Kesselring et al., 2012). Informal support is provided by personal social networks, which can consist of nonparental adults such as grandparents or other extended family members or nonfamilial adults such as friends, sports coaches, or neighbors (Ben Shlomo & Taubman – Ben-Ari, 2012; Wheelock & Jones, 2002). Formal support systems are agents of guidance and assistance in areas lacking knowledge or know-how that provide the family informational support; directive advice, or normative support; modeling behaviors (Guralnick et al., 2008; Kesselring et al., 2012).

I have been fortunate to have both formal and informal support throughout the chapters of my story. Friends and family are not the only ones who have helped me care for my daughter. I have had help from services, resources, and even therapeutic devices in order to better provide for her. I have been seeing doctors and specialists since before she was born and they continued to provide support from the moment she was born and taken to the NICU. I have previously described the plethora of specialists my daughter was referred in her first year of life alone. Once my daughter started school her village grew once again. She received support from additional therapists at school such as speech, visual, and adaptive physical education. In just the last two years my daughter received a 1:1 aid. This means that she has an adult presence for her

alone to help with her academics, recess, and other daily living skills. This aid is in addition to the classroom teacher and classroom aids that are a requirement for a special day class serving a specials needs population in the school.

Healthy Family

Adding a child with a developmental delay to a family can significantly change the dynamics and the way the family unit functions. When taking into consideration caregiving need not be an individual obligation, having a support system can greatly relieve the obstacles of stresses, challenges, and hassles when dealing with the impact of disability (Dyson, 1987; Guralnick et al., 2008). When the support system is a healthy family there is an increased rate of transforming negative appraisals into positive appraisals (Dyson, 1987). I have been fortunate to have my family support me as a parent and a student since my first child was born. Once my second child was born, the support from my family increased as did the capacity for acceptance and bonding.

My main goal has been to treat my family as normal as possible. I am not put off by my daughter's disabilities. I create memories even if I am not sure that my daughter understands what is going on or if she remembers through what I call family field trips. Sometimes these field trips are day trips or quick overnight trips and sometimes they are week long family vacations that include adventures. Some of these adventures have included four-wheeling to visit a green beach in Hawai'i, hiking uphill in the snow to visit Crater Lake, and a long exhausting hike to see Rainbow Falls by Mammoth Lakes. These memories have helped maintain my healthy family and have helped me focus on the positive aspects of having two children, regardless of their abilities. I do not let the disability define us and what we can accomplish.

Personal Growth

As I began my reflection journey of the data I developed a personal growth lens. Personal growth for an individual and their self-system, is a term used by Hastings and Taunt (2002) to describe cognitive adaptation of responses to threats as a way to find meaning, gain mastery, and enhance oneself (Behr & Murphy, 1993). My 'threat' has been my daughter's multiple disabilities. When I made the decision to carry on with my pregnancy, that decision, regardless of the actual choice, threatened my life as I knew it. My life would never be the same regardless of the path chosen. I knew I would have to learn to adapt and gain mastery by raising a child with a disability. The chapters of my story revealed that I had found meaning and enhanced myself in ways that I did not even comprehend until the completion of this manuscript. This personal growth lens represents my new perspective on life and I have to give thanks to my daughter.

Human agency allows an individual to forge an identity through self-formation (Besley, 2005). For the purpose of this paper, my forged identity was one of a caregiver for a child with multiple disabilities. Besley (2005) discusses classical Greek and two known mantras 'care of the self' and 'know yourself' with the latter more prominent because it included that one should be concerned with themselves in order to improve themselves. In this study I expressed how I have moved from caring for myself to knowing myself as a sign of personal growth. This is beneficial to readers because they can connect to my story of growth and understand that it is obtainable for them as well regardless of their identity be it parent, educator, or village support.

Although I have described in detail the many challenges my daughter and I have faced together, I am very thankful for what my daughter has accomplished in life. In the world there are children with worse conditions than her. There are children that are immobile or have to be

fed through a gastrostomy tube in their stomach because they have trouble eating. Some parents may not get to feel their children's arms wrapped around their neck. Some parents wish to feel that tug on the arm just once. This makes me realize I should never take life for granted. No matter the struggles in life there is someone dealing with worse in their life. Not that that should bring any solace but it should make a person count their blessings.

I changed my habits to remind myself that I needed to focus on what my daughter could do and not dwell on what she could not. I have come to understand that my daughter is not aware of what she is missing out on. She does not understand that there are skills or activities that she most likely will not be able to do such as driving, going to college or prom, or getting married and having children of her own. She did not get to make the choice to be who she is, yet she loves to interact and play and smile. My daughter is social, she will hug anyone, even complete strangers. She enjoys taking a person by the hand, even someone she just met and taking them to a preferred activity, which is usually reading a book. It is these positive interactions she has with people that makes my heart full.

Prior to having my daughter, I was one of those judgmental parents who would wonder why a child had not transitioned away from a stroller or pacifier. Having my daughter, however, offered me a new perspective on life. I learned to not be as quick to judge what others may be going through. A new perspective on life has also given me a heightened sense of awareness of other people, noise, and the environment. I have adapted this from my daughter because she too has a heightened sense of awareness.

Parents expect their children to outlive them. For those parents that have children who are typically developed they can expect that their children will turn into productive adults capable of taking care of themselves. I have accepted that my daughter will live with me forever

and have started to contemplate what will happen to her when I am gone. This is a perspective that is factual versus emotional. It will be my responsibility to make sure she is cared for after I am gone.

Recommendations and Implications

This autoethnography serves as a reference and resource for practitioners, scholars, and stakeholders such as caregivers, educators, administration and academic support staff, medical teams, and others who may need to contribute support, care, and resources for children with disabilities and their families.

Education has been a huge part of my village support system and essential to my caregiving. My daughter has been attending school since she was a preschooler. Parents of children with multiple disabilities do not conform to the normalcy of parenting and educating their child. Education has come a long way to ensure the rights of children with disabilities are educated to the best of their abilities. This has been made possible through combined efforts of practitioners, scholars, educators and parents. Principals, support staff, and teachers may lack awareness and training of issues related to learning disabilities, including teachers' teaching and management skills of said children (Katoka et al., 2004). The behaviors, stresses, and strains described in my story require accommodations and adjustments by the teaching staff and administration of children with multiple disabilities. Additionally, children need reinforcement with therapies, strategies and goals that are specific and unique to each child in the school setting. This can be accomplished through academic and adaptive progress of goals established in the student's Individual Education Plans (IEPs). It is in the best interest of students with multiple disabilities that school staff to go beyond the piece of paper or report that quantifies the child and learn from the child and family about their needs. This includes fostering a trusting

relationship with the child and family. It is not an easy task for a parent to leave their child at school all day, especially when the child is no verbal and cannot explain their day. It has helped me immensely to have trusting relationships with educators who understand my daughter's needs and my concerns.

Another large part of my village support system has been medical teams and the regional center. Practitioners, educators and scholars providing resources for respite or services for children and their families develop relationships with local agencies. This allows proper referrals for family concerns with therapies, devices, or behavior for the specific need(s) of the child. Through these relationships parents and educators are shown how to work with a medical device, therapy technique, or undesired behaviors in order to work together as a team. Family-professional practices involving families in the decision-making process of their global developmentally delayed child's support promote empowerment while enhancing the relationship for the betterment of the child (Judge, 1997). When parents feel they are responsible for the desired support and resources their child receives, they enhance the family's capacity to help their child progress developmentally while increasing the perceived ability to work with and develop strong formal support systems. This has helped me develop my parenting efficacy as a different type of parent to my second child.

I encourage parents to be proactive and advocate for any and all opportunities that their child may be eligible for. I encourage caregivers to get informed. Do research, ask questions of practitioners, educators, scholars, other parents and families, apply to be a client of a local regional center specializing in helping people with disabilities. I recommend staying factual when describing your child to practitioners, educators and even the stranger who asks a question. I even tend to stay factual when I talk to family and friends about my daughter's medical

necessities. The reason for this is due to emotions being what you feel about a situation versus factual being about the content being discussed. Emotions can get in the way of what message is trying to be conveyed, especially to practitioners and educators. A parent that sounds as if they know and understand what they are discussing versus showing emotional reactions have more credibility and can achieve desired results more frequently. I am not saying to not be emotional, just understand the time and place in which to do so.

Parents, as difficult as it may seem, it is vital to your mental health to take time for yourself, even if it is just shopping, or lunch for an hour or two. Parent guilt is the sense that a parent has done something wrong, that their child will be damaged by what they have done. What I have learned is your child will be okay if you take time for yourself and your spouse if you have one. It is just as important to spend individual time with your other children if you have them. I also encourage parents to take naps if their child naps; the laundry and dishes and vacuuming can wait. Take time to rest and rejuvenate for your mental health and your parenting efficacy.

Parents, understand that maintaining a positive belief mind frame is always a work in progress. Not every day will be a good day. Understand that trying again later or the next day is part of having a positive belief mind frame. Be willing to restart, to try again, to not give up, or to seek assistance from someone in your village.

Areas for Further Research

An autoethnography has limitations. It is a study from the view of only one person and that person's experiences. The gap in literature would benefit for continued research in the area of caregiving and personal growth; especially for that of children with multiple disabilities. As a

researcher I would appreciate learning about other's experiences with caregiving and associated negative and positive experiences and transformations.

Narrative research could add to the gap in literature as it studies a phenomenon, in this instance caregiving as the phenomenon. Narrative researchers could collect stories, documents, artifacts, pictures, and interviews. Literature would benefit from a biographical study or oral history in which the life and experiences of an individual are told from outside looking in, taking into account a caregivers reflections of events. Additionally, an understanding of the caregiving culture can benefit from an oral history narrative study from the extended family system of fathers, siblings, grandparents, and other family members. Their perspectives could add to the gap in literature by allowing readers and stakeholders the opportunity to understand varying points of view.

As my daughter has opened up the world to me and provided me with a new perspective it would benefit the literature to experience a life history narrative study from the accounts of a mother or other family member caregiving for an older, possibly adult child. This study represented the first ten years of my caregiving experience. I feel that it would benefit parents, practitioners, educators, and scholars to read a narrative about what to expect with a child reaches higher education and caregiving once the child is out of school. There is a new set of village support that happens after a child leaves the academic setting. The perspective of an older child or young adult with disabilities and their caregiving needs is different from that of a younger child with disabilities. Additionally, a collective case study could benefit the gap in literature as the researcher would select multiple cases to illustrate caregiving for a child or person with multiple disabilities.

As many stakeholders were mentioned as village support systems, it would benefit the gap in literature to experience a phenomenology study from an educator, therapist, practitioner, regional center case worker, or scholar working with children with disabilities. Educators in special education work with children many hours per week, often more in a waking day than families. To be able to connect the personalized home life and personalized academic setting could greatly benefit this area of research. Their subjective and objective experiences would add to the quantified data of these systems. Parents would benefit from reading phenomenological studies from village support systems to add to their repertoire of strategies. The gap in literature would also benefit from an intrinsic case study of the village support system of one child with multiple disabilities. The focus of this study would be on the case itself, interviewing and collecting documents from all the village system providing support to one individual.

Finally, as the culture of caregiving is a worldwide concern, an autoethnography from a mother or other village support member from another country could be beneficial. A study from another country could add to the literature by providing a personalized account of support systems and academic settings in another country as they may not be similar to those I have experienced in my country.

Conclusions

Choosing to raise a child was not a decision that I made lightly. I understood that becoming a parent was a long-term commitment of a minimum of 18 years, yet once it was explained to me that my child had developmental deficiencies of her brain, I began to understand that parenting was going to be a lifelong commitment to my daughter's care and well-being. I could never have understood what I would go through while caregiving for my daughter and I am elated to share my personalized account of my life with her for these last ten years. My story

does not end here. I have many more unwritten chapters, many blank pages to fill. I still have middle school and high school to experience with my daughter. I have caregiving once she is out of school to experience. My hassles and uplifts continue, my positive and negative appeals continue, my personal growth continues.

REFERENCES

Abbott, D. A., & Meredith, W. H. (1986). Strengths of parents with retarded children. *Family Relations*, *35*(3), 371–75.

Baby Center: Expert Advice. (1997-2017). Retrieved from https://www.babycenter.com/0_what-to-expect-at-your-prenatal-visits_9252.bc

Baker, B. L., Blacher, J., & Olsson, M. B. (2005). Preschool children with and without developmental delay: Behaviour problems, parents' optimism and well-being. *Journal of Intellectual Disability Research*, *49*(8), 575-590.

Bakken, J. P., & Smith, B. A. (2011). A blueprint for developing culturally proficient/responsive school administrators in special education. *Learning Disabilities: A Contemporary Journal, 9*(1), 33-46.

Bandura, A. (2006). Toward a psychology of human agency. *Perspectives on psychological science, 1*(2), 164-180.

Barr, J., McLeod, S., & Daniel, G. (2008). Siblings of children with speech impairment: Cavalry on the hill. *Language, Speech, and Hearing Services in Schools*, *39*(1), 21-32.

Bath, H. (2005). Our amazing brains. *Reclaiming Children and Youth: The Journal of Strength-Based Interventions*, *14*(3), 146.

Batshaw, M., Pellegrino, L, & Roizen, N. (2007). *Children with Disabilities.* Baltimore, Maryland: Paul H. Brookes Publishing.

Behr, S. K., & Murphy, D. L. (1993). Research progress and promise: The role of perceptions in cognitive adaptation to disability. 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* (p. 151–163). Paul H. Brookes Publishing.

Belbase, S., Luitel, B. & Taylor, P. (2008). Autoethnography: A method of research and teaching for transformative education. *Journal of Education and Research, 1*(1), 86-95.

Ben Shlomo, S., & Taubman - Ben-Ari, O. (2012). New grandparents' mental health: The protective role of optimism, self-mastery, and social support. *Journal of Family Social Work, 15*(4), 254–271.

Besley, A. C. (Tina). (2005). Self-denial or self-mastery? Foucault's genealogy of the confessional self. *British Journal of Guidance and Counselling, 33*(3), 365–382.

Bolduc, M., & Limperopoulos, C. (2009). Neurodevelopmental outcomes in children with cerebellar malformations: A systematic review. *Developmental Medicine & Child Neurology*, *51*(4), 256-267.

Bondy, E. M., & Mash, E. J. (1999). Parenting efficacy, perceived control over caregiving failure, and mothers' reactions to preschool children's misbehavior. *Child Study Journal*, *29*(3), 157-73.

Brothers, K. B., Glascoe, F. P., & Robertshaw, N. S. (2008). PEDS: developmental milestones—an accurate brief tool for surveillance and screening. *Clinical pediatrics*, *47*(3), 271-279.

Brown, M. A., McIntyre, L. L., Crnic, K. A., Baker, B. L., & Blacher, J. (2011). Preschool children with and without developmental delay: Risk, parenting, and child demandingness. *Journal of Mental Health Research in Intellectual Disabilities*, *4*(3), 206-226.

Brownstein, M. (2015). A 2e Parent's Journey: Persistence, Partnership, and the Provision of Unconditional Love. *Gifted Child Today, 38*(4), 223-225.

Burrello, L. C., And Others, Indiana Univ., B. D. of S. E., & Council of Administrators of

    Special Education, I. (1988). *The Principal's Blue Book on Special Education. Part II:*

    Principal Instructional Leadership and Supervisory Practices in Special Education

    Programs.

Chambers, E. (2000). Applied ethnography. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook*

    of qualitative research (2nd ed., pp. 851-869). Thousand Oaks, CA: Sage.

Clandinin, D. J., & Connelly, F. M. (2000). *Narrative inquiry: Experience and story in*

    qualitative research. San Francisco, CA: Jossey-Bass

Cook, C. (2006). Beating the odds: Parents choose to expand their family--despite the risks--and

    reap the rewards of their strength in the face of adversity. *Exceptional Parent, 36*(2), 48-

    50.

Creswell, J.W. (2013). *Qualitative inquiry & research design: Choosing among five approaches.*

    Los Angeles, CA: Sage Publications.

d'Agnese, V. (2017). Behind and beyond self-mastery: Risk, vulnerability, and becoming

    through Dewey and Heidegger. *Interchange: A Quarterly Review of Education, 48*(1),

    97–115.

Davis, K., & Gavidia-Payne, S. (2009). The impact of child, family, and professional support

    characteristics on the quality of life in families of young children with disabilities.

    Journal of Intellectual & Developmental Disability, 34(2), 153-162.

Dempsey, I., & Dunst, C. (2004). Helpgiving styles and parent empowerment in families with a

    young child with a disability. *Journal of Intellectual and Developmental Disability,*

    29(1), 40-51.

Denzin, N. K., & Lincoln, Y. S. (2000). The discipline and practice of qualitative research. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (2nd ed., pp. 1-28). Thousand Oaks, CA: Sage.

Dunst, C. J., & Dempsey, I. (2007). Family-professional partnerships and parenting competence, confidence, and enjoyment. *International Journal of Disability, Development and Education*, *54*(3), 305-318.

Dunst, C. J., Trivette, C. M., & Hamby, D. W. (2007). Meta-analysis of family-centered helpgiving practices research. *Mental Retardation and Developmental Disabilities Research Reviews*, *13*(4), 370-378.

Dyson, L. (1987). *Parent stress, family functioning and social support in families of young handicapped children*. Paper presented at the National Early Childhood Conference on Children with Special Needs. Denver, CO.

Ellis, C. (2007). Telling secrets, revealing lives: Relational ethics in research with intimate others. *Qualitative inquiry*, *13*(1), 3-29.

Ellis, C., Adams, T. E., & Bochner, A. P. (2011). Autoethnography: An overview. *Historical social research/Historische sozialforschung*, 273-290.

Ellis, C., & Bochner, A. P. (2000). Autoethnography, personal narrative, reflexivity. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (2nd ed., pp. 733-768). Thousand Oaks, CA: Sage.

Feldman, M., McDonald, L., Serbin, L., Stack, D., Secco, M. L., & Yu, C. T. (2007). Predictors of depressive symptoms in primary caregivers of young children with or at risk for developmental delay. *Journal of Intellectual Disability Research*, *51*(8), 606-619.

Floyd, F. J., & Gallagher, E. M. (1997). Parental stress, care demands, and use of support services for school-age children with disabilities and behavior problems. *Family Relations*, *46*(4), 359-71.

Folkman, S., & Moskowitz, J. T. (2000). Positive affect and the other side of coping. *American psychologist, 55*(6), 647.

Gable, S. L., & Haidt, J. (2005). What (and why) is positive psychology?. *Review of general psychology, 9*(2), 103.

Giallo, R., & Gavidia-Payne, S. (2006). Child, parent and family factors as predictors of adjustment for siblings of children with a disability. *Journal of Intellectual Disability Research, 50*(12), 937-948.

Gibbons, C. (2012). Stress, positive psychology and the national student survey. *Psychology Teaching Review, 18*(2), 22-30.

Glaser, B. G. (1965). The constant comparative method of qualitative analysis. *Social problems*, *12*(4), 436-445.

Gubrium, J., & Holstein, J. (2000). Analyzing interpretive practices. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (2nd ed., pp. 733-768). Thousand Oaks, CA: Sage.

Guralnick, M. J. (2006). Family influences on early development: Integrating the science of normative development, risk and disability, and intervention. *Blackwell handbook of early childhood development*, 44-61.

Guralnick, M. J., Hammond, M. A., Neville, B., & Connor, R. T. (2008). The relationship between sources and functions of social support and dimensions of child- and parent-related stress. *Journal of Intellectual Disability Research*, *52*(12), 1138-1154.

Harper, A., Dyches, T. T., Harper, J., Roper, S. O., & South, M. (2013). Respite care, marital quality, and stress in parents of children with autism spectrum disorders. *Journal of Autism and Developmental Disorders, 43*(11), 2604-2616.

Harry, B., & Anderson, M. G. (1994). The disproportionate placement of African American males in special education programs: A critique of the process. *The Journal of Negro Education*, *63*(4), 602-619.

Hastings, R. P., & Taunt, H. M. (2002). Positive perceptions in families of children with developmental disabilities. *American journal on mental retardation, 107*(2), 116-127.

Hill, D. A., & Flores, M. M. (2014). Comparing the picture exchange communication system and the iPad™ for communication of students with autism spectrum disorder and developmental delay. *Techtrends: Linking Research and Practice to Improve Learning*, *58*(3), 45-53.

Hobfoll, S. E. (1989). Conservation of resources: A new attempt at conceptualizing stress. *American psychologist, 44(*3), 513.

IDEA: Individuals with Disabilities Act (2018). Retrieved from https://sites.ed.gov/idea/regs/b/a/300.8

Jensen-Hart, S., & Williams, D. J. (2010). Blending voices: Autoethnography as a vehicle for critical reflection in social work. *Journal of Teaching in Social Work, 30*(4), 450-467.

Judge, S. L. (1997). Parental perceptions of help-giving practices and control appraisals in early intervention programs. *Topics in Early Childhood Special Education*, 17(4), 457-76.

Kanner, A. D., Coyne, J. C., Schaefer, C., & Lazarus, R. S. (1981). Comparison of two modes of stress measurement: Daily hassles and uplifts versus major life events. *Journal of behavioral medicine*, *4*(1), 1-39.

Kataoka, M., van Kraayenoord, C. E., & Elkins, J. (2004). Principals' and teachers' perceptions of learning disabilities: A study from Nara Prefecture, Japan. *Learning Disability Quarterly, 27*(3).

Kawachi, I., & Berkman, L. F. (2001). Social ties and mental health. *Journal of Urban health, 78*(3), 458-467.

Kemer, F. & Sansom, P. (2013). *California School Law (3rd. Ed.).* Stanford, Ca: Stanford University Press.

Kesselring, M., de Winter, M., Horjus, B., van de Schoot, R., & van Yperen, T. (2012). Do parents think it takes a village? Parents' attitudes towards nonparental adults' involvement in the upbringing and nurture of children. *Journal of Community Psychology*, *40*(8), 921-937.

Kuo, D. Z., Cohen, E., Agrawal, R., Berry, J. G., & Casey, P. H. (2011). A national profile of caregiver challenges of more-complex children with special health care needs. *Archives of Pediatrics & Adolescent Medicine*, *165*(11), 1020–1026. http://doi.org/10.1001/archpediatrics.2011.172

L'Abate, L. (1998). Discovery of the family: From the inside to the outside. *American Journal of Family Therapy, 26*(4), 265-80.

Laise, E. (2017). *Managing your finances: Create a plan for a special-needs child.* Kiplinger's Retirement Report*,* 9-10. Washington DC: Dennis Publishing Ltd Group

Lather, P. (2006). Paradigm proliferation as a good thing to think with: Teaching research in education as a wild profusion. *International journal of qualitative studies in education*, *19*(1), 35-57.

Laura, C. T. (2011). *Bad boy: My baby brother and the social ecology of difference*. Chicago: University of Illinois.

Laura, C. T. (2016). Intimate Inquiry: A Love-Based Approach to Qualitative Research. *Critical Questions in Education*, *7*(3), 215-231.

Laura, C. T. (2013). Intimate Inquiry: Love as "Data" in Qualitative Research. *Cultural Studies? Critical Methodologies*, *13*(4), 289-292.

Lincoln, Y. S., & Guba, E. G. (1986). But is it rigorous? Trustworthiness and authenticity in naturalistic evaluation. *New directions for evaluation*, *1986*(30), 73-84.

Mauthner, N. (2015). 'The past was never simply there to begin with and the future is not simply what will unfold': A posthumanist performative approach to qualitative longitudinal research. *International Journal of Social Research Methodology*, *18*(3), 321–336.

Maxwell, J. A. (2012). *Qualitative research design: An interactive approach* (Vol. 41). Los Angeles, CA: Sage publications.

McKnight, J. (2015). *The educating neighborhood: How villages raise their children*. Kettering Foundation Working Paper [2015: 01]. Kettering Foundation.

McLeskey, J., Tyler, N. C., & Saunders Flippin, S. (2004). The supply of and demand for special education teachers: A review of research regarding the chronic shortage of special education teachers. *Journal of Special Education*, *38*(1), 5–21.

Miller, M. J., Wilcox, C. T., & Soper, B. (1985). Measuring hassles and uplifts among adolescents: A different approach to the study of stress. *The School Counselor*, *33*(2), 107-110.

Muncey, T. (2005). Doing autoethnography. *International journal of qualitative methods*, *4*(1), 69-86.

National Dissemination Center for Children with Disabilities, (2013). *Multiple Disabilities*. NICHCY Disability Fact Sheet #10. Washington DC.

National Institutes of Health: National Institute on Deafness and Other Communication Disorders. *Speech and language developmental milestones.* (2010-2014). Retrieved from https://www.nidcd.nih.gov/sites/default/files/Documents/health/voice/NIDCD-Speech-Language-Dev-Milestones.pdf

Neece, C. L. (2014). Mindfulness-based stress reduction for parents of young children with developmental delays: Implications for parental mental health and child behavior problems. *Journal of Applied Research in Intellectual Disabilities*, *27*(2), 174-186.

Nolen-Hoeksema, S., Larson, J., & Grayson, C. (1999). Explaining the gender difference in depressive symptoms. *Journal of personality and social psychology, 77*(5), 1061.

Oh, H., & Lee, E. O. (2009). Caregiver burden and social support among mothers raising children with developmental disabilities in South Korea. *International Journal of Disability, Development and Education*, *56*(2), 149-167.

Orfus, M., & Howe, N. (2008). Stress appraisal and coping in siblings of children with special needs. *Exceptionality Education International*, *18*(3), 166-181.

Paczkowski, E., & Baker, B. L. (2008). Parenting children with developmental delays: The role of positive beliefs. *Journal of Mental Health Research in Intellectual Disabilities*, *1*(3), 156-175.

Paczkowski, E., & Baker, B. L. (2007). Parenting children with and without developmental delay: The role of self-mastery. *Journal of Intellectual Disability Research*, *51*(6), 435-446.

Pandit, N. R. (1996). The creation of theory: A recent application of the grounded theory

    method. *The qualitative report*, *2*(4), 1-15.

Park, J., Hoffman, L., Marquis, J., Turnbull, A. P., Poston, D., Mannan, H., ... & Nelson, L. L.

    (2003). Toward assessing family outcomes of service delivery: Validation of a family

    quality of life survey. *Journal of Intellectual Disability Research*, *47*(4□5), 367-384.

Pathways.org (2010-2020). *Assure the best for your baby's physical development.* [Pamphlet].

    Retrieved from https://pathways.org/wpcontent/uploads/2019/06/ AssureBrochure_

    LEGAL.pdf

Pearlin, L. I., & Schooler, C. (1978). The structure of coping. *Journal of health and social

    behavior*, *19*(1), 2-21.

Rauch, A., Hoyer, J., Guth, S., Zweier, C., Kraus, C., Becker, C., ... & Nürnberg, P. (2006).

    Diagnostic yield of various genetic approaches in patients with unexplained

    developmental delay or mental retardation. *American journal of medical genetics Part

    A*, *140*(19), 2063-2074.

Restak, R. (2001). *The Secret Life of the Brain.* Washington D.C.: Joseph Henry Press.

Roberts, M. Y., & Kaiser, A. P. (2011). The effectiveness of parent-implemented language

    interventions: A meta-analysis. *American Journal of Speech-Language Pathology*, *20*(3),

    180-199.

Robinson, M., & Neece, C. L. (2015). Marital satisfaction, parental stress, and child behavior

    problems among parents of young children with developmental delays. *Journal of Mental

    Health Research in Intellectual Disabilities*, *8*(1), 23-46.

Rosenfield, S. (1989). The effects of women's employment: Personal control and sex differences

    in mental health. *Journal of Health and Social Behavior, 30*(1), 77-91.

Rowbotham, M., Carroll, A., & Cuskelly, M. (2011). Mothers' and fathers' roles in caring for an adult child with an intellectual disability. *International Journal of Disability, Development and Education, 58*(3), 223-240.

Riou, E. M., Ghosh, S., Francoeur, E., & Shevell, M. I. (2009). Global developmental delay and its relationship to cognitive skills. *Developmental Medicine & Child Neurology*, *51*(8), 600-606.

Scheier, M. F., & Carver, C. S. (1992). Effects of optimism on psychological and physical well-being: Theoretical overview and empirical update. *Cognitive therapy and research, 16*(2), 201-228.

Schwandt, T. (2000). Three epistemological stances for qualitative inquiry: Interpretivism, hermeneutics, and social constructionism. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (2nd ed., pp. 733-768). Thousand Oaks, CA: Sage.

Seefeldt, C. (2004). Helping children communicate. *Early Childhood Today, 19*(1), 36-42.

Shevell, M. I., Ashwal, S., Donley, D., Flint, J., Gingold, M., Hirtz, D., & Sheth, R. D. (2003). Practice parameter: Evaluation of the child with global developmental delay report of the quality standards subcommittee of The American Academy of Neurology and The Practice Committee of the Child Neurology Society. *Neurology*, *60*(3), 367-380.

Slattery, P. (2012). *Curriculum development in the postmodern era: Teaching and learning in an age of accountability*. New York, NY: Routledge.

Spagnola, M., & Fiese, B. H. (2007). Family routines and rituals: A context for development in the lives of young children. *Infants & Young Children*, *20*(4), 284-299.

Sweeney, M. (2009). *Brain: The Complete Mind.* Washington DC: National Geographic Society.

Teaching students with disabilities: Developmental delays. (n.d.) Retrieved from

    https://sites.google.com/a/ucdavis.edu/teaching-students-with-disabilities/home/idea-

    disabilities/developmental-delay

Tedlock, B. (2000). Ethnography and ethnographic representation. In N. K. Denzin & Y. S.

    Lincoln (Eds.), *Handbook of qualitative research* (2nd ed., pp. 733-768). Thousand Oaks,

    CA: Sage.

Trakadis, Y., & Shevell, M. (2011). Microarray as a first genetic test in global developmental

    delay: A cost-effectiveness analysis. *Developmental Medicine & Child Neurology*,

    53(11), 994-999.

Turnbull, A. P., Blue-Banning, M., Turbiville, V., & Park, J. (1999). From parent education to

    partnership education: A call for a transformed focus. *Topics in early childhood special

    education, 19*(3), 164-172.

Trute, B., Hiebert-Murphy, D., & Levine, K. (2007). Parental appraisal of the family impact of

    childhood developmental disability: Times of sadness and times of joy. *Journal of

    Intellectual & Developmental Disability, 32*(1), 1–9.

Unwin, G., & Deb, S. (2011). Family caregiver uplift and burden: Associations with aggressive

    behavior in adults with intellectual disability. *Journal of Mental Health Research in

    Intellectual Disabilities*, *4*(3), 186-205.

Wall, S. (2006). An autoethnography on learning about autoethnography. *International journal

    of qualitative methods, 5*(2), 146-160.

Westland, M. A. (2016). *"I never seen myself going to college": An intimate inquiry of foster

    alumni in higher education.* (Doctoral dissertation). Retrieved from https://0-

    search.proquest.com.pacificatclassic.pacific.edu/docview/1803309382?accountid=1470

Wheelock, J., & Jones, K. (2002). 'Grandparents are the next best thing': Informal childcare for

    working parents in urban Britain. *Journal of Social Policy, 31*(3), 441-463.

Woodman, A. C., & Hauser-Cram, P. (2013). The role of coping strategies in predicting change

    in parenting efficacy and depressive symptoms among mothers of adolescents with

    developmental disabilities. *Journal of Intellectual Disability Research, 57*(6), 513–530.

APPENDIX A: HUMAN SUBJECTS RESEARCH DETERMINATION

UNIVERSITY OF THE
PACIFIC

March 29, 2019

Shana Cole
Curriculum and Istructions
Benerd School of Education

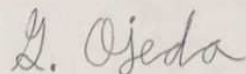RE: Human Subjects Research Determination, 19-87

Dear Cole:

Office of Research &
Sponsored Programs
3601 Pacific Avenue
Stockton, CA 95211
Tel 209.946-3903
irb@pacific.edu

Your Human Subjects Research Worksheet for research/activity, "**Cargiving for a Child with Multiple Disabilities: A Mother's Story of Personal Growth**", submission #19-87 has been reviewed. A determination has made that your project does not meet the Federal definition of Human Subject Research as outlined in The Code of Federal Regulations for the Protection of Human Subjects §46.102 : (d)"A systematic investigation, including research development, testing and evaluation, designed to develop or contribute to generalizable knowledge". (f)"Human subject means a living individual about whom an investigator (whether professional or student) conducting research obtains(1) Data through intervention or interaction with the individual, or (2) Identifiable private information."

Therefore, additional IRB review and approval for this research activity is not required based on the information provided in the worksheet.

Note: If the objective of this project is changed; it should be resubmitted to the IRB office for a determination of whether it still satisfies the exemption criteria.

Best Regards,

G. Ojeda

Gilbert Ojeda, IRB Program Specialist
Institutional Review Board