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"Joy for what it is": Narratives of two mothers on raising their children with disabilities

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University of Northern Iowa

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“JOY FOR WHAT IS”: NARRATIVES OF TWO MOTHERS ON RAISING THEIR
CHILDREN WITH DISABILITIES

An Abstract of a Dissertation
Submitted
in Partial Fulfillment
of the Requirements for the Degree
Doctor of Education
Approved:

Dr. Amy J. Petersen, Committee Chair

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ABSTRACT

The purpose of this study was to explore the experiences of two mothers of children with disabilities on parenting their children and navigating the world of disabilities. For many parents, the diagnosis of a child with disabilities represents a form of interpersonal loss through the loss of the imagined child. Mothers are often identified as the primary caregivers of their children with disabilities and are often at the front-end of seeking, providing, and advocating for medical, education, and social services.

Employing qualitative research methods, autoethnography and narrative inquiry were used to reveal the mothers' experiences. Through conversational interviews and journaling, data was collected for the scope of the study. The findings reaffirmed the educational and social challenges that stem out of parenting a child with disabilities. The mothers however, did not cease to address the myriads of joy and growth that they experienced as a result of parenting their children. The mothers discussed the different roles that they have assumed throughout their journeys indicating that their parental role always took precedence over all other roles.

The results of this study offer a number of implications for educators, service providers, and fellow parents. Of these implications, the need for educators and service providers to envision possibility and capability rather than be restrained by medical diagnosis and labels. Educators and service providers must view the child as a whole while valuing input from the parents on the children's needs and capabilities. Open, honest, and ongoing communication and collaboration among the educators, service providers, and parents is key in providing children with disabilities the services that best

meet their needs. This study also highlighted the need for parents of children with disabilities to see for their own physical and mental health for it is critical in maintaining their strength to resume their parenting journey. Finally, parents of children with disabilities are encouraged to seek support from support groups and networks that may provide them with assistance and help get rid of feelings of alienation in the unknown world of disabilities.

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Approved:

Dr. Amy J. Petersen, Committee Chair

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December 2016

DEDICATION

This dissertation is dedicated to my twins Omar and Kynda. Your birth has unveiled an experience I would have not known otherwise. Omar, forgive me. Kynda, you are a shining star in my sky. My love for both of you is immeasurable.

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CHAPTER 1

INTRODUCTION

According to the United States Census Bureau (2008), estimates of population size and distribution of disability types depend much on the definition of what it means to be disabled. Health professionals, advocates, educators and others use the term “disability” in different contexts, thus the term does not refer to a single definition. Medical models often consider disability as an extension of a physiological condition that requires treatment or therapy. Social models on the other hand view disability as a product of societal forces that define normal from abnormal. The International Classification of Functioning, Disability, and Health (ICF) attempts to bridge many of the definitions of disability by defining it as an umbrella term for impairments, activity limitations, and participation restrictions. The American Psychiatric Association (2000) labels individuals with disabilities as those with disabilities and states that those individuals might need accommodations and modifications to function with their disability.

Data published in the United States Census Bureau Report (2008) provides population estimates representing noninstitutionalized civilians living in the United States. Of the 303.8 million people in the U.S., 56.6 million had some level of disability and 38.2 million had a severe disability. Children under the age of 15 constitute 62.2 million of the U.S. population, 5.2 million of them had some sort of disability. Half of the 5.2 million (i.e. 2.6 million), were classified as having severe disabilities. Developmental delays or difficulty moving arms or legs were definitions given to children under the age of three to imply some sort of disability. About 300,000 of the

12.6 million children under three years old were classified as having one or both of these functional disabilities, while children aged 3-5 were defined as having developmental delays, difficulty walking, running, or playing.

Today more children are being diagnosed as having disabilities. This is partially attributed to medical advances made that provide better care to premature children or those with chronic or genetic conditions (American Academy of Pediatrics, 2007). Along with the increase in number of children being born and diagnosed to having disabilities, there are more interventions occurring in the medical, social service and educational communities (American Academy of Pediatrics, 2007; La Plante, 1998; Patching & Watson, 1993; U.S. Census Bureau, 2008).

The Centers for Disease Control (CDC); clarifies that the number of individuals with disabilities is higher in children because many of the disabilities have an early onset during childhood (1995). However, due to federally mandated birth to three intervention program that serves children who are found to be at risk for developmental delays or disabilities, services are being offered at no costs to the children's guardians. As a result, fewer children are being institutionalized due to their disabilities (La Plante, 1998; Patching & Watson, 1993). Not only does this federally mandated interventional program provide every identified child in each state the services they need, but it also projects future services needed. Services provided include and are not limited to: special education, occupational therapy, physical therapy, speech therapy, and audiology.

Parents, specifically mothers of children with disabilities serve as primary caregivers. For most parents, the diagnosis of disability in their child is a traumatic

experience (Green, 2002; Kearney & Griffin, 2001). Parents often feel bewildered as though they had been pushed into an unknown world with little warning (Scorgie, Wilgosh & Sobsey, 2004). The diagnosis of disability can shatter an entire family's understanding of who they are and what their life will look like. Parents realize that their life may change significantly. Parents question their child's current identity and future prospects as they also confront changes to their current and future way of life (Scorgie et al., 2004). The authors also report that

Parental responses to diagnosis of disability can be profoundly shaped by the images hospital personnel, agency workers, educators, extended family members and friends construct of disability, the meanings they ascribe to "being disabled" and the choices they afford persons with disability and their families. (p. 100)

Therefore, views of both the social and medical models contribute to the way we perceive the diagnosis of disability, and many of our views of disability are socially constructed. Hence, these views significantly impact the experiences of mothers as they navigate and become part of the world of disabilities. Much of the research highlights the challenges that mothers of children with disabilities face. However, the problem is that there is little research that articulates the lived experiences of the mothers.

While there is a need for more research on the experiences of parents of children with disabilities, Chapter 2 will discuss the body of literature currently in existence. This includes but is not limited to: Applequist (2009), Goddard, Lehr and Lapadat (2000), Green, (2002), Green (2003), Heiman (2002), Valle (2009), and Valle (2011). This literature addresses many areas related to parenting a child with disabilities including: challenges, social experiences such as stigma, psychosocial experiences including feelings of guilt, joy, and necessary supports for families.

Statement of Problem

Dominant bodies of research around the lived experiences of mothers of children with disabilities report that the mothers are often stressed and stigmatized, have their needs unmet, and seek ways of coping (Heiman, 2002; Green, 2007). Little is known about the daily life of these mothers because research on the subject is scarce, which is surprising, given the fact that mothers are often the primary caregivers of their children with disabilities. Caring for a child with disabilities means you are on the front end of seeking, providing and advocating for medical, educational and social services, therefore it is crucial to learn more about the lives of these caregivers and to portray their experiences as accurately as possible. Most of the studies on the subject are conducted by researchers and many of them are quantitatively conducted through observations and surveys (Dellve, Samuelsson, Tallborn, Fasth & Hallberg, 2006; Kieckhefer, Trahms, Churchill, & Simpson, 2009; Perkins, Holburn, Deaux, Flory, & Vietze, 2002). According to Green (2003), the community of people with disabilities has expressed a growing frustration with professionals from various disciplines who make them feel marginalized and pathologized rather than understood, respected and valued.

Valle (2011) states that much of the existing research on mothers of children with disabilities deems these mothers as: “(a) too subjective to contribute meaningfully and (b) in need of expert guidance” (p. 184). She challenged this notion by writing a dissertation which resulted in a published book *What Mothers Say About Special Education: From the 1960s to the Present* (Valle, 2009). In order to learn more about the authentic first hand experiences of the mothers of children with disabilities, opportunity must be given

to the mothers to lead the research and be involved in it. Green (2003), Jones (2011) and Valle (2011) have decided to use narrative inquiry to write about their own experiences as mothers of children with disabilities. Through their research on their own lives and experiences, they address 'joy,' autonomy, personal growth and the impact of race, class, culture and gender on parent and professional interactions which are often missing from the dominant quantitative literature on the subject. This illustrates the importance of providing the mothers with the voice and freedom to address what they deem as significant in their experiences.

Qualitative research and narrative is one method of learning about the first hand experiences. Richardson (2000) states that a narrative; is a way of telling about life and about knowing. This study is important because through narrative and reflection, mothers become empowered with knowledge on forces and factors that give them strength to walk the journey with their children and form their identity as mothers of children with disabilities. These forces and factors might perhaps be ones that empower a family to cope, adapt and advocate for their child's needs as they walk down the same road. It may also give them reassurance that they are not alone in their journey, for mothers of children with disabilities often report that they at times felt alone and estranged in their journey. In addition, this study may provide service providers and special educators with insight on strategies, resources, dispositions and skills that assist children with disabilities and their families through their journey. I hope that an experience once unknown to many will be re-lived by the readers. Goodley, Lawthom, Clough, and Moore (2004) note

Our belief is that life stories – our chosen form of narrative- tells us much about individual and collective, private and public, structural and agentic and real and

fictional worlds. Stories occupy a central place in the knowledge of societies... Narratives are always politicized, structured, culturised and socialized... Narratives may be our best hope of capturing structures that continue to shape, divide and separate human beings. (p. viiii-x)

Therefore, narratives provide us with first hand experiences by investigating the different factors that take part in the experience. A holistic, authentic experience is the subject of this study.

Context

“When a child is conceived, parents begin to imagine her or his life in accordance with the master narratives relevant to their familial and cultural context” (Green, 2002, p. 21). The imagined narrative of the child’s life is changed upon diagnosis of a disability and accommodations are made based on the reality of the disability. *Loss of the future* is often an initial feeling that parents experience upon the diagnosis of their child. The life of the child is reimagined and reconstructed.

Four years ago on November 26, 2011, I was suddenly propelled into the world of disability. Six and a half months into a healthy, joyous pregnancy my twins were born prematurely. A tiny boy and girl weighing 2 lbs each were born. The quietness of the room as the babies were born astonished me. “Why are they not crying?” I asked my husband Bilal as the doctors rushed the babies out of the delivery room. “They can’t cry,, their lungs are not fully developed just yet” he answered in a very low voice as if not to disturb the silence in the delivery room. I saw my twins 3 hours after I delivered them. They looked like fetuses in the process of becoming babies. I was startled at their size and their appearance. Their skin looked like translucent plastic. Countless tubes were hooked

to their mere bodies. Their eyes were still fused shut. One nurse explained to me, "In a few weeks, we would expect them to start taking their first peeks" she said.

Their physical appearance became my primary concern for the next two days. I wanted them to look like the normal babies I had imagined them to be before I delivered them. Little did I know about the reality and prognosis of delivering so early. Seven days following their birth, my son was diagnosed with a severe brain bleed that the doctors said would cause him to be severely disabled. Few months later, my daughter was diagnosed with hearing impairment and developmental and cognitive delays. It turned out that the day I delivered my premature twins, I had also started a firsthand journey in the world of disabilities, a journey that I did not expect to lead. This journey would be as much an education on the world of disabilities as a degree in it.

Prior to their birth, my husband and I picked out names that we deemed as perfect and as beautiful as we imagined our twins. Omar, a powerful Arabian name for the boy in hopes that he inherits qualities of his name. For the girl, Kynda a sweet name with a tune which represents a name of an Arabian tribe that existed in the second century B.C. Dreams, hopes, visions, and plans came for the twins even before they were born. Their cribs were assembled, their little bath tub, their car seats, stroller, and clothes were all clean and ready for their arrival. We were ecstatic and could not wait until we had our little bundles of joy. We even envisioned their appearance. Omar would be an olive-skinned, dark-haired boy with a strong and outgoing personality. He would enjoy soccer, look after his sister, and would be daddy's buddy. Kynda would be a sweet fair-skinned girl with light brown hair, so sweet, so pretty and warm. She would be

mommy's shopping buddy. Green (2003) states that when you give your child a name, you imagine them growing up in a certain way and then when you realize that your child will never be what you imagined, you experience the death of the imagined child.

“Will they be in the same classroom at school?” asked Bilal a few weeks before they were born.. “I think they will! It would be nice to have each other’s company and have each other’s back if something happens,” I answered. “But I want them to learn to make friends with other kids. I feel if they are in the same class they might not do so as much as if they were in different classes,” he said. “You have a point; let’s wait and see how their relationship will be as they grow up. We still have plenty of time before they go to school,” I answered. “My friends take their boys with them to the Friday prayer at the mosque. I can’t wait to take Omar with me,” said Bilal smiling as he dreamt of this moment. I on the other hand dreamt of Kynda’s wedding day where her twin brother would stand by her so tall and handsome and cheer for his sister and dance at her wedding. That was what my brother did for me on my wedding day. I wanted the same for my daughter.

Instead of our dreams for our children coming true, we were faced with a shockingly difficult decision to make for our son Omar following his premature birth and health prognosis. We were given the option to stop life support for Omar due to the very poor health prognosis that he had. Kynda was deemed more stable and seemed to have better chances of growing up to be close to normal in her abilities and functionality. We made the decision of stopping life support for Omar and he passed away after a short lived life of 23 days. Words cannot describe the difficulty of making that decision and

with living with the repercussions of having made that decision for an individual. Four years following this decision, my suffering is less, however it is not gone.

One of the things that I continued to wonder about after Omar's passing is how he would have been had he been given the chance to grow. Would he have had the disabilities the doctors speculated? How would they have impeded our life? I utilized my doctoral courses in searching for answers to my questions. I enrolled in classes where I studied about the lives of family of children with severe disabilities and managed to find and connect with a family in the area who agreed to host me and talk to me about their experience parenting their daughter with severe disabilities.

My initial purpose of the visit was for my own sake. I wanted to know what it was like to have a child in the household who has severe disabilities, just as Omar was speculated to have. I wanted to explore how the parents felt about their experience. I wanted to be provided with a glimpse of what my life could have been like if Omar lived.

What started off as a journey to realize what I missed out on with Omar's passing turned out to be a journey towards connecting with a family who shares similar experiences as mine through parenting our daughters with disabilities. Three and a half years into conversing with each other, we have shared tears and laughter regarding our experiences. We have established a relationship that is based on care and support for each other. We have agreed to document our experiences parenting our daughters in this dissertation therefore utilizing one of the roles that I currently assume in my life, the student.

As I grappled with my feelings and began to seek understanding through research, I came across the works of an associate professor and researcher in the field of sociology at the University of South Florida by the name of Sara E. Green. Green is the mother of Amanda who was born prematurely at 25 weeks gestational age just like my twins. At the age of one, Amanda was diagnosed with severe cerebral palsy. Amanda is now well into her twenties. Over the years, Green published extensively on her experience parenting Amanda. She also gave mothers of children with disabilities the opportunity to address their experience through story swapping.

Most parents of children with disabilities find themselves distressed as they cope with and adjust to the changes that occur in their lives and the roles that they assume. One of the forces that empowers mothers of children with disabilities is knowing that they are not alone. Reading Sara E. Green's work on her experience and the experiences of mothers was a form of therapy for me. Through her writings I found solace that some people share a very similar experience to mine. Most importantly they legitimized my thoughts and feelings as a mother of a child with disabilities. They were a virtual support system for me. As a result, Green's work is extensively cited in this research.

Statement of Purpose

The purpose of this study was to examine my own experience as a mother of a child as I enter/navigate the world of disabilities. In doing so, I also investigated and examined the experiences of another mother. Narrative inquiry was used to explore and understand our experiences. These stories offer insights into the impact of educational

practices, societal norms/views of disability, impact of disability on families, and parenting children with disabilities.

This study gives voice to my story and the story of another mother of a child with a rare brain formation disorder known as Lissencephaly which has left her daughter with severe disabilities. My goal for this study was to report shared first hand experiences of the two mothers of children with disabilities through a narrative form of inquiry. I hope that through this narrative readers will be able to see, hear and feel how mothers of children with disabilities experience motherhood with its painful challenges and joyous moments. My hope is that this study provides a lens through which insight on the details of the lives and the needs of mothers of children with disabilities is provided.

Research Questions

The research questions for my study are:

1. What are the experiences of mothers of children with disabilities as they raise their children and navigate the world of special education?
2. What roles do mothers assume throughout the process and how do they come to assume these roles? What societal and personal forces are influential?
3. How do mothers access, negotiate, and utilize special education services?

Theoretical Framework

Existing research on the experiences of parents of children with disabilities has used different theoretical frameworks to make sense of the experiences of the parents. Among the mostly used frameworks is the social model of disability, stress theory, transformational coping theory, family career model, and family systems theory. This

study will provide a different perspective to the field by examining the experiences of the participating mothers using Donald Super's Life Span and Life Space Approach to Career Development (1990). Super conceptualized career as "the life course to a person encountering a series of developmental tasks and attempting to handle them in such a way as to become the kind of person he or she wants to become" (Super, 1990, pp. 225-226).

Super labeled his theory as a differential-developmental-social-phenomenological career theory. Throughout a period of 40 years, he and his colleagues worked at revising and elaborating the theory so that it is developmental in nature and a synthesis of work from different disciplines such as psychology and sociology. The result was a segmental theory with three key aspects to it: (a) life span, (b) life space, and (c) self-concept.

The life-span, life-space theory builds upon 14 assumptions proposed by Super (1990). Briefly stated, they address people's differences in their abilities, personalities, values, interests, traits, and self-concepts. The assumptions state that people's vocational competencies change over time leading to self-concepts. Self-concepts change with time as a result of experiences. This process of change represents life stages that individuals pass through (growth, exploration, establishment, maintenance, and decline). The development through life stages is guided by two elements; the maturation of interests and abilities, and through reality testing and the development of self-concepts. Self-concepts are a product of inherited aptitudes, physical makeup, opportunity to observe and play various roles, and the extent to which role playing meets with the approval of superiors and fellows.

In his segment on life space, Super (1990) highlighted the life roles that individuals assume as they go through their busy life. He notes that people tend to play nine major roles in their lifetime and these are (1) son or daughter, (2) student, (3) leisurite, (4) citizen, (5) worker, (6) spouse (or partner), (7) homemaker, (8) parent, (9) pensioner. These roles are generally played in (1) homes, (2) school, (3) the workplace, and (4) the community. He states that life roles may occur simultaneously and may have different meanings to different individuals due to their different experiences. For instance, the meaning of my degree and dissertation in special education might be different from another individual who does not have a child with disabilities. Also, individuals may assume different roles simultaneously. For instance, I am currently a student, a parent, a homemaker, child, and a partner all at the same time. Super also maintains that adults often re-cycle through various career development stages and tasks throughout their life depending on their experiences. Environments of adults make an impact of them as they do on their environment. Meaning that environmental factors play in affecting and shaping interests, abilities, values, personalities and self-concepts of adults. At the same time, those traits in a person affect their environment.

Super (1990) maintains that conflicting life role demands may arise for individuals. Deciding which role takes priority is crucial. Sometimes a spillover from one life role occurs to another and this tends to create conflict. For example: as stated above, I currently am a mother, yet I am also the daughter of my parents. When I choose to speak of the challenges and feelings I experience as a result of parenting my daughter with disabilities, I do so to vent out to the people whom I trust the most in this world. By no

means does it mean that I am not able to fulfill my parenting role towards my children. However, because my parents are my parents, they perceive my venting out to them as a cry for help. They immediately assume their parental role towards me. They worry excessively about me and seek methods of sheltering me and assisting me in those challenges. As an adult and as a mother, this often leaves me upset that they are unable to step outside their parental role towards me which is driven by innate love and support. Conflict arises between my parental and homemaker roles towards my children and household and my role as a child towards my parents. My parent's love and need to parent and shelter me conflicts with my role of taking charge of my own life and my self-perception as a responsible and capable adult. Through experience, I have learned that while I am a mother, a homemaker, a partner, and a student, I still am a child for my own parents.

The third segment in Super's Life Span and Life Space theory is self-concepts. As defined by Super (1963) self-concept is a "picture of the self in some role, situation, or position, performing some set of functions, or in some web of relationships" (p.18). Personal and situational determinants shape the life roles that individuals play over a life span and the development of self-concepts.

Using Super's framework of the roles that people experience during a life-span this research seeks to investigate the roles that the mothers participating in this study have assumed throughout their experience with their daughters and how have these roles been shaped and/or changed as a result of the disability, societal, and personal forces. Donald

Super's Life space theory will also be the lens used at examining the third research question.

CHAPTER 2

LITERATURE REVIEW

This dissertation aimed to explore the experiences of mothers of children with disabilities. Mothers are often identified as the primary caregivers of children with disabilities; and hence most of the present literature on the subject is on mothers. This chapter provides an overview of literature on this topic, focusing on three areas: the general experiences of mothering a child with disabilities, including adjustment and coping issues; the challenges and joys associated with the experience; and some supports that are valued by the families, along with school and family partnerships. While there are both qualitative and quantitative studies on the topic, this review will particularly focus on qualitative studies that have given mothers the voice to narrate their stories since this study aims to do the same. However, a brief overview on some quantitative studies on the subject will follow.

Prior to the 21st century the primary bodies of research on experiences of mothering a child with disabilities came from the medical community and were quantitative in nature. Much of the nursing literature focuses on the tragedy, burden and pain of having a child with disabilities (Knafl, Breitmayer, Gallo, & Zoeller, 1996; Browne & Bramston, 1998; Glasscock, 2000; Monsen, 1999). Below are a few examples of research on families of children with disabilities that examined the stress that the families experience without considering other experiences such as joy.

Among the quantitative literature on the experiences of mothers of children with disabilities is a study by Dumas, Wolf, Fisman and Culligan (1991) where they assessed

differences in stress level among 150 families of children with autism, Down syndrome, behavior problems and typically developing children. Stress was measured using the Parenting Stress Index, which is a 120-item self-report questionnaire that is used to evaluate the quality and magnitude of stress that a parent is experiencing in relation to his or her child. It was found that parents of children with autism and behavior problems experienced significantly higher levels of stress than parents of children in the other two groups. Mothers of children with autism and behavior disorders experienced higher levels of dysphoria than fathers of the same groups.

Donenberg and Baker (1993) conducted a quantitative study that compared the impact on families of young children with externalizing behaviors, autism, or no significant behavioral problems on measures of family functioning. Parents of children with externalizing behaviors and autism reported more negative impact on social life, less positive feelings and more negative feelings on parenting and higher levels of stress related to the child than parents of typically developing children.

A related study by Johnston et al. (2003), addressing stress in mothers of children with Fragile X syndrome, found that maternal stress is related to child behavior, family cohesion, household income, and maternal psychology. Like in the study by Dumas et al. (1991) the Parenting Stress Index was used to measure the experienced stress among 75 mothers. The authors state that this finding would be useful in devising support systems for mothers of children with Fragile X syndrome in order to improve the well-being of the mothers.

Dellve et al. (2006) aimed at assessing stress, well-being and supportive resources described by parents of children with rare disabilities. Instruments measuring levels of stress, social support, self-rated health, optimism, life satisfaction and perceived physical or psychological strain were used. They found that high levels of parental stress and emotional and physical strain were present especially among mothers. Fathers showed a high level of stress related to incompetence of caring for the child. Levels of stress among single mothers were higher.

The studies cited above illustrate that the experiences of parents of children with disabilities were explored and assessed using quantitative measures that focus on the stress that the family experiences. This is not to negate that parenting a child with disabilities involves higher levels of stress, however stress is not the sole feeling that is experienced. Recently, there seems to be shift towards a narrative approach when exploring the mothering experiences of mothers of children with disabilities and there seems to be more to be said about the experiences of mothers of children with disabilities than those of sorrow and stress. The literature review below is organized based on the most common themes that arise when exploring experiences of parenting a child with disabilities. These themes were found to be (a) challenges, (b) social and psychosocial experiences, (d) positivity in parenting a child with disabilities, and (e) family supports and needs.

Challenges

Stress, Sorrow, and Loss

There is no question regarding the strong impact of the diagnosis of a disability in a child on the parents. Researchers describe this piece of news as the most frightening and confusing piece of news that parents will ever receive (Whitehurst, 2011). Some describe it as a unique and powerful form of interpersonal loss (Seligman & Darling, 1997). Feelings of pain, grief, and stress are very commonly reported by parents following a diagnosis of a disability.

In a study conducted by Kearney and Griffin (2001) on experiences of parents of children with significant developmental disability, the authors categorize the responses of their participants into two categories: sorrow and joy. This section will address the sorrow experienced by the parents. Joy will be explored in a later section of the literature review. The authors report that there were a number of elements that contributed to parents' sorrow. Amongst those elements were: facing the possibility of the child dying; learning about the child's changed potential; being treated by other individuals as though there has been a death in the family; being left on their own by people and the health system; being vulnerable as parents; feeling powerless; having many fears and worries, especially regarding the future; and grieving. Much of the sorrow experienced by the parents was reported to be due to the messages of hopelessness and negativity that other people bombarded them with. "All of the parents spoke of the message of 'no hope' being imposed upon them and were angry about a professional approach which left no room for hope" (p. 586). On the prognosis of her son, one doctor told the parents "he

won't do this, he won't do that, no, we can't do anything for him... I don't think anybody has the right to take away everything which is what happens just too many times"

(Kearney & Griffin, 2001, p. 586).

Some researchers have disclosed their own stories of pain while also studying the stories of others. Green is a researcher and a mother of a daughter with severe cerebral palsy and has written numerous articles on mothering her daughter Amanda. In one of her studies, she examines the benefits of narrative therapy among parents of children with disabilities. Green (2003) anecdotes feelings of pain, loss and sorrow upon the diagnosis of the child. On the moment of diagnosis of a disability, one parent who was involved in the study reports

We left the children with my sister for an hour to go out to dinner. I remember my husband and I sat there and cried. He cried for the child, his son, who would never throw a ball or run. I cried because of the speech. All I could think of was I'll never know this child because he'll never be able to tell me what's inside his head. (p. 9)

Given how parents experience an overwhelming sense of loss, Green describes the diagnosis of a disability in a child as death. She explains that when you give your child a name, you see them growing up in a certain way and then you find out that your child will never be that way. Therefore the diagnosis is the death of the imagined child. However, often when mothers are asked if they wish their child was dead rather than the way they are, mothers report that they certainly do not wish for them to be dead nor any different from the way they are. They explain that any change to their child does not make them who they are, it turns them to another child.

The evolution of grief among mothers is a factor addressed in Green's (2007) research on the benefits and burdens of mothering a child with disabilities. She reports that mothers participating in the research often describe their initial grief over losing their imagined child, a finding that is common amongst many mothers of children with disabilities. However, Green maintains that by the time the child is about five years of age, most mothers move beyond this grief. Green (2007) explains that several mothers describe a conscious and decisive moment after the trauma of the diagnosis where they were able to move on from the initial phase of shock and grief into loving and caring for the child who has come into their lives. This enables the mother to search for caring methods that will bring out the best of what her child can be and allow the parents to enjoy the child as he/she is.

Heiman (2002) explores how resilience of parents emerges in a family with a child with a disability. Thirty-two parents took part in the study and were interviewed by the researcher. Heiman's findings were that most parents react to the diagnosis of their child in an emotionally and psychologically negative way. Most parents initially experience considerable stress, as well as depression, anger, shock, denial, confusion, self-blame and guilt. However a few of the parents (n=4) report a positive emotional reaction. One parent said "We were prepared for a diagnosis like this. We weren't surprised. We expected it. We just wanted to hear from the doctors what we could do, what treatment we should provide him with" (p. 164). Heiman states that parents feel the need to strongly believe in their child and his/her future. She describes that as "an

optimistic outlook along with a realistic view and acceptance of the situation” (p. 169).

Therefore some parents longed for the positive outlook on their child’s future.

Coping and Adaptation

Parents report the need to cope and adapt to their new roles as caregivers and their new course of life due to changes resulting from the diagnosis of their child. Parents report having to assume multiple roles such as advocates for their child, nurse, and physical therapist, all deemed to be time and labor consuming. Some parents need to change houses or leave jobs as a means of adapting to their new family needs.

In Whitehurst’s (2011) study on parenting a child with fetal alcohol syndrome, one parent reports “I would cry day and night because I was really struggling with coping with ‘what is this’?...” (p. 190). Parents taking part in the study report feelings of fear and anxiety. A diagnosis of a disability means a lot of change to the family. Parents find themselves thrust into an unfamiliar world and are left to explore it as they become part of that world.

In a study by Whiting (2014) examining the effect of a child’s disability or complex health needs on the family, parents express that they are ‘time poor,’ meaning that caring for the child with disabilities requires a lot of time. Parents report that the extra care that is often needed by a child with disabilities is time consuming and thus affects their ability to engage in other activities such as caring for their partner, their other children and their social life. Parents also report that they need to take on multiple roles, some of which may be common to parents of non-disabled children. However, ones that are assumed only by parents of children with disabilities are: a nurse (administering

external feeds, clinical care tasks, constantly giving medications) and a physical therapist. The parents participating in the study report that a further challenge they experience is the inability of others, such as family members or babysitters, to provide cares to their child simply because they are too scared to take on the responsibility.

Appelquist (2009) examined parental experiences of those whose children received services under the Individuals with Disabilities Education Act (IDEA) through semi-structure interviews. She reports that “in the process of reliving their experiences several parents became emotional and cried acknowledging that their journeys were emotionally draining for them” (p. 9). On the impact of educational approaches on the family, most families addressed the federally mandated early intervention program whereby professionals visit the child’s home for services until they are three years of age. Most families report positive aspects about the home visiting models but several of them address how time and labor intensive it becomes to schedule all the medical and educational appointments for the child due to the numerous appointments for the child. One parent reports that she resorted to ‘self-imposed isolation’ as a way to cope with the ‘craziness.’

Amongst the researchers who investigated the experiences of mothering a child with disabilities are mothers of children with disabilities. Jan W. Valle is one of the mother researchers who advocates for using narrative research to learn about the impact of disability on the identities of the mothers and the experiences. Valle (2011) states that mothers who have participated in research on parenting a child with disabilities liken their experience of raising a child with disabilities to embarking on a journey not of their

choosing. Mothers describe a process of disorientation as they gradually gain bearings in an unfamiliar place. This is followed by a turning point where clarity and autonomy are regained. Mothers often allege their journey as the defining aspect of their motherhood and the most significant in their adult lives.

Heiman (2002) describes the diagnosis of a child with a disability as the most difficult and shocking experience that parents will experience. She says that in most cases parents' reactions are negative, and similar to reactions towards bereavement. She explains that "Families either adapt flexibly and mobilize into effective action or freeze in various degrees of rigid, ineffective reactions, whereas others tend to resist or even deny the diagnosis itself" (p. 160). For both groups, changes must ultimately occur in a family's routine in order to provide appropriate care for the child. This has been found to have significant effects on family functioning. Specifically, "Parents of children with disabilities experience greater stress and a larger number of caregiving challenges, such as more health problems, greater feelings of restriction, and higher levels of parental depression than parents of nondisabled children" (Heiman, 2002, p. 190). Increased needs of the child and challenges meeting those needs cause parents to feel stressed regarding the responsibility they have to fulfill their role.

Gray (2003) studied gender differences in coping mechanisms between mothers and fathers of children diagnosed with high functioning autism. He reports numerous differences between mothers and fathers that he bases on gender roles assigned to men and women in our culture. In other words, Gray argues that the coping differences that exist among fathers and mothers are not based on inherent genetic differences, but rather

on the experiences of the mothers and fathers. The most striking difference in coping between mothers and fathers was the personal impact that the disability had on the parent. Fathers reported that they did not experience any significant personal impact as a result of the diagnosis. They stated that the impact was mostly on their wives, which in turn had an effect on them. One father stated “I suppose the most detrimental effect I believe really is [my son’s] effect on [my wife] and her effect on me” (p. 634). In some cases, those effects created direct confrontations between the mother and the father and posed a threat to their marriage. Fathers acknowledged that mothers are the primary caregivers of their children and most admitted that their careers were unaffected by their child with disabilities. They did report considerable concern about the future of the child, especially in terms of economic independence and independent living did report considerable concern about was with regards to the future of the child.

Mothers participating in Gray’s (2003) study reported being severely affected in their emotional and physical well-being. Mothers were significantly distressed and the most significant effect on the mothers was related to their career. Half of the mothers participating in the study worked and most of them were employed part time or were working in a family business where they were offered flexible hours. Mothers stated that due to the extensive appointments that they had to arrange and attend for their child, career was something that they often sacrificed.

On practical coping methods of mothers and fathers most of them replied that they tried to anticipate difficulties that could likely arise and plan appropriate responses to deal with them. Others preferred to take things one day at a time and deal with

problems when they arise. On emotional coping methods, mothers often reported forcefully expressing their feelings of hurt, sadness or anger as a means for venting and fathers often reported suppressing their feelings. Mothers relied heavily on talking to friends or family as a way of venting. Support from other mothers of children with autism was something that mothers valued very much. Finally, religion was another important coping mechanism for several mothers. In some cases, mothers were already religious prior to having a child with disabilities, and in other instances, having the child increased their concern with spiritual matters and led them to find support through faith.

In summary, mothers of children with disabilities experience a significant amount of sorrow regarding the diagnosis of their child and the loss of their imagined child. The increased needs and the demanding caregiving roles that parents need to assume to care for their child often leaves them feeling stressed and seeking methods of coping and adapting to the abrupt change that has occurred in their life.

Social and Psychosocial Experiences

As stated in the introduction of the study, a social model on viewing disability exists and much of the view on disability is defined by societal forces that differentiate normal from abnormal. This section will look at experiences of parenting a child with disabilities that are largely defined by societal forces and expectations.

According to Goffman (1963), people who are poor, ugly, crippled or unsuccessful are viewed as failures and are stigmatized. The general view of having a child with a disability is that it is a tragedy that one may never recover from (Kearney & Griffin, 2001). Green (2002) describes the day her daughter was diagnosed with cerebral

palsy as the darkest day of her life. Green adds that the diagnosis thrusts parents into a stigmatized social category.

Goffman (1963) wrote a book on the impact of ‘stigma’ on family members of individuals with disabilities. He defines stigma as a discrediting attribute that transforms the bearer from a whole and usual person to a tainted and discounted one. He explains that stigma tends to spread to those who are associated with the stigmatized individual. Sometimes individuals can be stigmatized simply due to their close association with the discredited ones (Francis, 2012). Goffman distinguishes among three categories of people relevant to the social experiences of individuals with disabilities. ‘The own’ being composed of people who possess the discrediting trait, ‘the others’ being individuals who do not possess the trait and have little or no experience with people who possess the trait, and ‘the wise’ being people who do not possess the trait but “whose special situation has made them intimately privy to the secret of the stigmatized individual and sympathetic with it...” (Goffman, 1963, p. 28). Goffman states that interactions among ‘the own’ and ‘the others’ define the social experience of stigma.

Among the different categories of people that Goffman proposes, the own, the other and the wise, participating mothers specifically addressed the kindness and understanding that they often receive from the individuals labeled as the ‘wise’ which was often lacking in the outside world or ‘the others.’ Wise professionals who have laughed with the parents and the children and talked to them without appearing to be saddened or over-awed by the parent’s or the child’s situation were highly appreciated by the parents. Some participating parents who perceived themselves and their families as

stigmatized preferred to interact only with the wise group of people. While some parents who perceived themselves as less stigmatized or not at all maintained relationships with a wide variety of individuals.

Heiman (2002) examined experiences of parenting a child with disabilities among 32 parents. Twenty of the participating parents in her study report that the individuals who are mostly affected by having a child with disabilities is themselves, whereas 14 others report that it is the siblings of the child. Twenty parents report that the disability of their child strengthened their parental relations for they were able to communicate better than before having the child. Some others (n=7) report that their child's disability created new problems, conflict and impatience between the parents and so their dyadic relationship was weakened. Social isolation among friends was reported by nine of the parents participating in the study.

Psychosocial effects on parenting a child with severe developmental disabilities also emerged in a study conducted by Kearney and Griffin (2001). The parents participating in the study report that developmental disabilities hold multiple negative meanings primarily due to the dehumanizing societal attitude and practices towards it. Kearney and Griffin (2001) explain that having a child with a disability is a 'dreadful' experience for families due to the socially embedded responses to disability, including those given by the professionals. Therefore, much of the negativity experienced by parents was derived from "societal values and beliefs mirrored in words and behaviors of friends, family and professionals" (p. 588).

Goddard et al. (2000) conducted a qualitative study involving 15 parents to explore their experiences raising a child labelled with disabilities. Stereotypical views of what parenting a child with disabilities involves is among the most frequently experienced issues that parents report. Parents report that they were often perceived as stoic survivors for taking care of their child with disabilities, while others were subjected to horrible anecdotes on parenting children with disabilities. Other stereotypes that parents report are: being seen as in denial, unrealistic in their expectations and prone to abusing their children. It is, therefore, clear that professionals and the general population often view the parents of the child with disabilities as ones who are not in touch with reality regarding the diagnosis nor the true prognosis and capability of their child. Parents report that they often feared expressing their need for help in fear that they would be deemed as unable to cope and have their child taken away from them. One parent expressed fear over neighbors calling social services upon hearing the child cry when the parent was giving the child physiotherapy sessions or on seeing bruises on the child that were a result of the child falling down due to his/her inability to walk as well. This brings up the commonly expressed issue that parents of children with disabilities report and that is societal views on what is considered to be 'good parenting.' One parent asserted that the societal view on the parent being the sole champion of advocacy put so much strain and stress on the parent. On the subject, the parent states

The general population tells you- you're the parent, you're the advocate. You're the only one that will advocate for your child so you've got the guilt on your forehead so my God! If I don't do it. You're the continuity, because the professionals change. (p. 279)

Parents also discussed stories about how problems pertaining to disabilities are often attributed to social structures. These social structures often place social meanings on labels ascribed to individuals. In short, parents addressed issues related to cultural and systematic barriers to greater inclusion, tolerance and understanding of disabilities and parenting children with disabilities.

Among existing researchers who research their own life as they parent their children with disabilities is sociologist Sara Green. In her article, Green (2002), addresses how she expected that parenting her daughter who was diagnosed with cerebral palsy at the age of one would thrust her into a stigmatized social category. She says that most parents have no previous experience with individuals with disabilities nor any knowledge about disability. "They suddenly come face to face with the vagaries of public reactions to disability, which range erratically from extraordinary acts of kindness to bizarre expressions of sadness and even conscious avoidance" (p. 22). However, Green's fears of social stigmatization and isolation did not hold true for her and her daughter. In fact she says

The stigma we have felt is not at all what I expected when she was born. She has not been socially rejected. She does not lead an isolated life and she has never been cruelly ridiculed. She has been fully integrated into the life of our family, neighborhood, and community.... If stigma is an adverse reaction to the perception of a difference that is negatively evaluated (Sussman, 1994), then among people who know her, Amanda is not stigmatized. (p. 32)

Green (2002) gives an extensive account of her emotions and thoughts as she mothers her daughter. Green also acknowledges that due to her daughter's disabilities, she is much more involved in her life than other mothers of teenage children because Green has to provide a lot of basic care for her daughter that otherwise she would have been able to do

independently. She adds that despite this closeness, she feels that they will never truly understand each other because most of the basic aspects of their lives are vastly different. Green gives an example of when she took her daughter to attend a regional adaptive equipment fair.

As Amanda drove (her wheelchair), and we followed her, into the arena, her eyes lit up with delight- not only at the sight of all the cool equipment, but at the sight of all those adults in chairs. She wandered around in wide-eyed excitement until she found an adult friend of ours in a power chair. We were left on the sidelines to watch. I thought: “these are her people and we will never fully fit into this community.” I think this may be one source of the chronic sadness experienced by parents of children with disabilities. (p. 32)

A very powerful statement from Green indeed because she addresses how parenting her daughter made her see two different worlds. She claims that while these worlds have some interactions with each other, they will never be able to fully understand one another and call each other their own. She also makes a reference to the chronic sorrow that parents may feel upon the loss of their imagined child and upon not being able to truly fit in each other’s communities.

In another article also by Green (2003) that examines the benefits of narrative therapy among mothers of children with disabilities, she shares some of the social interactions that were significant in her experience as a parent. She starts off her article stating that in a room full of women, one of whom is pregnant, you are likely to hear giggles and stories on their happy ending births. However, for her, a mother of a child with severe cerebral palsy, the tale stops the conversation dead in its tracks. She states that with time, she learned to withhold or severely edit her birthing story in order to keep the conversation with other people going. Green (2003) also states that withholding

birthing stories happens with other mothers who have children with disabilities. Green maintains that they all have probably become so accustomed to withhold such tales to the extent that they sometimes withhold them from themselves.

Green also addresses the difficulty that parents have when giving their family the news of the diagnosis of their child. She reports that this often is one of the hardest parts of the birthing experience. Green goes on to explain that even when family members are willing to talk and listen, they are often unable to relate to the parents' concerns because they are so foreign to them. Also on the social struggles that parents of children with disabilities face, Green (2003) references the interactions among parents and medical professionals as they deliver the news of the diagnosis as one of the most shocking social interactions that parents are subjected to. Medical professionals are often cold, blunt, and completely blind to the child's strengths and their importance to their families. Horrific stories of diagnosis day and doctors delivering the news are shared in most of the stories told by parents.

The social experience of disability and the proponents of the Social Model of Disability maintain that due to children with disabilities not conforming to the predictable progress towards independence, economic production and adulthood, they are viewed as social problems (Green, 2007). On the same note, the social model also maintains that the burdens of parenting a child with disabilities have been imposed by the negative public attitude toward disability and its time consuming nature. In a more recent study by Green (2007), the daily hassles, emotional distress, and the benefits expressed by a group of mothers of children with disabilities were explored. Green (2007) was primarily

interested in exploring how much of the burden was perceived to be resulting from the socio-cultural constraints, which she calls objective burden, and how much was from emotional distress, which she calls subjective burden. The results indicated a significantly higher rate of objective burden than subjective burden. In other words, parental burdens were more likely to be viewed in terms of socio-cultural constraints than emotional distress. It was also found that mothers who work at least part time outside the home environment experience a higher level of objective burden than stay-at-home mothers. This is due to their being around people more and being subjected to the social view on having a disability or being involved with a person who is labeled as such.

Also in Green's (2007) study, issues pertaining to work expectations and duties conflicting with family-related caregiving were reported. Similar to the finding by Heiman (2002), some mothers report that their social and familial bonds, especially with their husbands, were strengthened. One mother says

One of the changes I've seen in (my husband) is he is more helpful to me...[and] with my children than ever before... we share roles and... its great and I don't know that it would have happened if there hadn't been a problem with (our son)... I think my husband and my relationship is probably grounded a lot deeper than it was before... (p.159)

In summary, Green (2007) found that a significant amount of the burden that mothers of children with disabilities experience was attributed to the society and that the more interaction that a mother had with the outside world the more she was likely to exhibit this kind of stress. On the other hand, mothers reported stronger social ties with the competent and the wise people in their life and their family.

In a current study by Francis (2012), the stigma experience of middle-class parents whose children have physical, psychological and behavioral problems were examined. It was found that parents (n=55) in the study experienced two types of stigma: courtesy stigma and stigma of being a bad parent. He reports that parents are subjected to shame and isolation due to their close social proximity to the stigmatized individual, their child. This is known as courtesy stigma. A typical example of courtesy stigma is when family members, friends or neighbors refrain from interacting with the parents of the child with disabilities because they do not feel comfortable being around the child. Another example is when parents are subjected to the same stare and funny looks as the child with disabilities. Moreover, bad parent stigma, also known as mother-blame as it is primarily geared towards mothers, holds parents responsible for their child's undesired attributes. In this kind of stigma, parents are often held culpable for their children's undesired traits and it is thought that parents also possess discrediting traits.

It is important to note that not all parents experience stigma and when they do they experience it to varying degrees (Green, 2001, 2003). Francis (2012) found that while some parents experience stigma without the element of parental blame, others report that parental blame is a central feature of stigma. Mothers more than fathers report experiencing bad parenting stigma. This may be due to the fact that cultures often hold mothers as the primary caregivers of their children. Courtesy and blame stigma may be experienced simultaneously by parents, and mothers more than fathers experience it due to social proximity to the child and due to greater ostensible culpability for the child's

problems. Sometimes bad parenting stigma is also demonstrated by family members, such as grandparents, of the child with disabilities.

Francis (2012) notes that “While people take women’s care work for granted, they celebrate fathers who participate in routine childcare” (p. 935). He adds that “the tendency to idealise involved fathers might result in a halo effect, making it less likely for people to view men are culpable for children’s problems, even when those men are in close social proximity to stigmatized children” (p. 935). The author also reports that parents of children with physical disabilities rarely experience bad parenting stigma; in fact, many times they were applauded for being good parents because they care for the child with disabilities. This is certainly not the case with children of behavioral and/or psychological challenges. The stigmatized child’s age also contributes to the stigmatization that the parents face. The younger the child is, the more parent blame and courtesy stigma that the parents receive.

Western culture assumes that a child is essentially good but vulnerable and lacking agency (Stearns, 2003). Therefore, when children cannot be held responsible for their poor behavior, it is the parents who are held responsible. As a result of the stigma that parents of children with disabilities receive, many times they find themselves seeking social isolation in order not to deal with the social psychological toll (Francis, 2012).

In a study on fetal alcohol syndrome, Whitehurst (2011) maintains that the parental psychosocial aspects involve experiencing stigma and isolation. Adoptive mothers of children with fetal alcohol syndrome who participated in the study report that

they found themselves explaining to people that they were not the biological mothers in fear that assumptions would be made about the mother. One mother reports

I said to them my one child has got foetal alcohol syndrome and do you know what... their jaws dropped and they all looked at me as if to say 'so you drank while you were pregnant?' ... and then you have to sit there and say well actually it wasn't my fault because my children are adopted and then you think to yourself I shouldn't even have to be explaining myself to these people. (p. 191)

This comment illustrates the impression that a judgmental society leaves on some parents as a result of their child's disability. This is accompanied by feeling the need to disclose information to people whom you are by no means obliged to in order to escape judgement.

Social and familial relationships, nuclear or extended family, and work opportunities are all aspects that are compromised when there is a child with disabilities in the family (Whiting, 2014). Families report social disengagement and general disruption of family life. Childhood disability impacts the family in several ways and is often significant because the care that a child with disabilities requires often persists while a typically developing child would be expected to become increasingly independent as he/she grows.

Applequist (2009) sought to explore parents' perspectives of special education by engaging in semi structured interviews with 32 parents of children who are receiving services under the Individuals with Disabilities Education Act (IDEA). She also looked into differences and similarities amongst what parents living in rural areas versus parents living in urban areas report. Among the common themes she found for both groups of parents is feelings of isolation from their families, friends and community. They even

express feeling of inadequacy and incompetency. They found solace in meeting with parents in the same position and described them as women who understand what it is like to have a child with disabilities.

Green (2001) uses Goffman's (1963) three categories of people relevant to the social experiences of individuals with disabilities to explore the experiences of parents of children with disabilities around these three groups of people: the own, the wise, and the other. These groups of people have been explained in an earlier section of the chapter. Research on the subject has generally shown that parents of children with disabilities seek and value relationships with the 'wise' category for they feel that they understand their mothering. Relationships that foster respect, information exchange, support, partnership and the ability to develop consistent and long term relationships are key in achieving parental satisfactions with professionals that work with the family. In the study conducted by Green (2001) on parental satisfaction with professionals, she reports that on average the mothers participating in the study took their child to the therapy clinic 3.7 times a week. She states that "mothers of children with disabilities face a confused world in which interactions with others are often a source of awkwardness and social distance" (p. 807). Green also talks about self-imposed isolation that is based on the modified labelling theory whereby mothers of children with and without disabilities have difficulty relating to one another and struggle to interact socially due to the latter's lack of understanding on disability. Some parents report instances of self-imposed isolation because they feel parents of typically developing children do not understand what having a child with disabilities entails. Other parents report that despite the differences, it was

important for the sake of their child to interact and learn to live in the world of the non-disabled others. Green (2001) maintains that therapy clinics are a popular place where parents of children with disabilities interact together. “Contact with other children with disabilities in the therapy centers can also help to increase maternal wisdom with respect to a variety of disabilities” (p. 810). This comment gives insight to the possible change and growth that occurs among parents of children with disabilities due to the extensive knowledge and exposure that they receive as a result of social interactions.

Blum (2007) conducted a study through in-depth interviews and fieldwork on 41 mothers of children with hidden disabilities such as AD/HD and ADD and how they understand and evaluate their own caregiving. Light was particularly shed on how they deal with the educational and medical systems. Many participating mothers addressed how the stigma attached to their children and themselves led to the loss of friends for both the mother and the child. One mother commented “I’m very, very isolated... I didn’t know one single parent in Brandon’s class” (p. 207). Another parent notes that disability seems to be some sort of taboo and people don’t want to “catch it,” therefore no one wants to be around people with disabilities. These findings reinforce the common finding of the imposed social isolation of both the child and the family.

A longitudinal study of families of children with autism was conducted by Gray (2003). The study started in the early 1990’s during the child’s early years after the onset of autism. Thirty five parents- 25 mothers and 10 fathers- participated in the study. At onset, a large majority of the parents reported the loss of typical family socializing experiences as one of the worst effects of autism on their families. Nearly a decade later,

parents report improved relationships with their extended families, especially the child's grandparents. Social rejection and stigma also were significant issues that parents reported at onset of the study. Frequent social isolation and severe socializing problems were frequently noted especially among mothers. The follow up research found that these problems still occurred and mothers were mostly affected by them however, their impact declined because their occurrence mattered less to the parents. In other words, parents were less sensitive to the reactions of outsiders. However, parents also reported success in finding friends who accepted their child's disability and helped them feel that they led normal social lives.

In her commentary about research on parents and special education, Valle (2011) maintains that mothers of children with disabilities often struggle with an experience of motherhood that does not conform to the cultural script of protecting their children, thus causing them feelings of guilt, shame, and failure. In other words, when mothers have children with disabilities, they feel that they have failed to fulfill vital roles which are protecting their children from any harm and raising them to become successful citizens in this world. As a result, mothers feel guilty and ashamed that they have not fulfilled their expected cultural role.

Feelings of blame and guilt and the need to ask forgiveness from the child are themes expressed in Whitehurst's study (2011) on parenting a child with fetal alcohol syndrome. One participating mother says

It's very hard to forgive yourself when you've actually damaged someone's life, irrevocably, you know, you can't turn the clock back... I've said sorry to him so many times and said I really, really wouldn't have wanted this life for you and I

really am so sorry..... but all I can do is be there for you to help you get through it, you know.(p. 191)

Blame is defined by Sher (2006) as an attitude that people take toward themselves or other individuals due to their not conforming to some moral standards. This parent demonstrates an example of parental blame whereby she assumes responsibility for failing to refrain from drinking while pregnant in order to maintain a healthy baby.

Some studies on insights of parents of children with disabilities on parental guilt and blame are by Broomhead (2013), Mickelson, Wroble, and Helgeson (1999), and Heiman (2002). The wealth of literature suggests that parents, especially mothers, are consistently blamed for their child's disability or difficulties in behavioral, emotional and social difficulties. Parents are often accused of ineffective parenting and lacking discipline. Moreover, most of the research, which has solely consulted parents about blame, has identified that parents feel blamed by educational practitioners for the onset of behavioral, emotional and social difficulties (Broomhead, 2013). This finding is similar to what Williams (2012) participating parents report the same findings except their children had a wide range of disabilities rather than focused solely on behavior, emotional, and social difficulties (BESD). On the same note, a number of studies have found that parents frequently experience self-blame or guilt regardless of the nature of their child's disability (Blum, 2007; Francis, 2012; Glogowska & Campbell, 2004; Holt, 2009; Moses, 2010; Peters & Jackson, 2009).

The findings of Broomhead's (2013) study were that parents of children with BESD exhibited much more parental guilt than parents of children with other disabilities.

Parental blame was also evident among the educational practitioners' responses. Phrases like "chaotic," "dysfunctional," and "no boundaries" were often used by practitioners to describe the homes of the children with BESD. However, many educational practitioners acknowledge that BESD was not to be blamed solely on ineffective parenting, but that it had to have some other causes, possibly medical issues. Parents on the other hand often attributed the child's needs primarily to biological causes. Broomhead (2013) suggests that parental attribution of their child's needs to biological factors may have been an attempt to identify an uncontrollable cause for their child's condition in an effort to reduce feelings of self-blame and blame towards their child. Despite acknowledging biological causes, "parents of children with BESD reported feeling intensely guilty for their children's special educational needs..." (p. 17). One parent expresses this guilt by acknowledging that "There may be elements that are down to parenting...I feel guilty, yeah I feel very guilty" (p. 17). Despite attributing the child's needs to biological factors, some parents still felt that they were partially responsible.

On the other hand, lack of guilt was commonly reported by parents of children with disabilities other than BESD (Broomhead, 2013). One parent states "...we know it's nothing we've done, so it's not because we've been drinking or smoking, it's just one of those things" (p. 18). Uncontrollable causes were viewed as the primary reason for the child's disabilities. A few mothers made sense of their child's needs through a religious explanation. Religious beliefs such as God's will, and being deemed by God as being able to cope were stated by mothers. This finding of attributing the disability to God's will and a test of faith was also supported by Mickelson et al. (1999).

Both groups of parents in Broomhead's (2013) study sought to receive labels for their children with disabilities, however their primary reasons for seeking the label differed. Parents of children with BESD sought the label to absolve their feelings of self-blame and excuse themselves for their children's difficulties. On parents reports that the diagnosis can be "a big relief and it's a big weight off your shoulders and you think well I was right all along" (p. 18). An educational practitioner observes that "...some parents want a diagnosis to say "it's not our fault because they've got this condition"... it's almost like an excuse...a devoid of responsibility" (p. 18). The words and the tone of the educational practitioner implies how critical he/she is of the parents and how parental blame is thrust on to the parents. Parents of children with disabilities other than BESD sought labels primarily for funding and support services for their children. In these cases, the label opens doors to services; one parent reports that "...without the label he wouldn't have the speech and language therapy" (p. 18). These services are crucial for the progress and the development of the child. They act as support services for both the child and their families.

Heiman (2002) conducted a study in which 32 parents of children with disabilities were able to voice their coping strategies, expectations and resilience through their journey. Parent report experiences of self-blame and guilt over the child's diagnosis. Heiman does not elaborate more on what the parents precisely mentioned in regards to those feelings. She suggests future research be conducted in a longitudinal manner whereby the emotional, social and behavioral adjustment of each family member is examined.

Mickelson et al. (1999) conducted a study that explored the causal attributions made by the parents for their child's cognitive disability specifically Down syndrome, autism, and developmental delays. The study also looked into differences in causal attributions based on different child diagnosis, physicians' explanations contribution to the parents' personal explanations for their child's disabilities, and the relationship between the parents' attributions and their adjustment to the situation. The authors found that most parents of children with Down syndrome attributed their child's needs to a genetic fluke; however, they also acknowledged that the event was random. This led parents to endorse the power of God's will and fate. In fact, most parents addressed both a random genetic fluke and God's will and power as strong causes of their child's disabilities. Many parents involved in the study stated that their child is a gift from God. Mickelson et al. (1999) claim that this is because the parents who make reference to God and His will and power tend to be more religious and found reason behind the randomness of the event that happened to their child. The authors also found that parents who attribute the disability to God's will tend to be less distressed.

The attributions made by parents of children with autism were heredity, genetic fluke, God's will/fate, and environment. However the ones that were most referenced were environmental factors (such as polluted waters) and heredity. Mickelson et al. (1999) state that attributions to environment and heredity both seem to have blame elements, one toward others and the other toward self. Parents of children with developmental delays, on the other hands made attributions to a genetic fluke, medical trauma, heredity and stress during pregnancy.

Regarding the Mickelson's et al. (1999) research interest on the relationship between attributions and coping, they found that attributions made to fate and God's will were the only ones that correlated with less distress and predicted decreased depression over time. On the other hand, attributions made to heredity, stress during pregnancy, and environment were related to greater distress. With regard to physicians' explanation, it was found that mostly parents with children with Down syndrome were ones that report receiving an explanation for the child's medical condition. This could have been due to the fact that parents tend to receive explanations from physicians when the causes for the condition are clearer. It was also found that parents who received explanations from physicians were less likely to create or search for their own attributions. This in turn may affect adjustment because it lessens an individual's personal search for explanation.

Goddard et al. (2000) study explored the experiences of parents of a child with a label of 'disability' through a qualitative study. It was typically mothers who expressed guilt over something they may have done during their prenatal period that led them to have a child with disabilities, suggesting a need to re-evaluate rigid social standards that portray parents as being the problem. One parent says "We have no other child so I would like to have another child to feel okay about me" (Goddard et al., 2000, p. 280). The parent clearly blames him/herself for having a non-typical child. Another parent says "Even when it's a genetic disorder, which is a total accident, you still want to prove something to yourself-that you could do it again" (p. 280). This parent's comment illustrates again the feelings of guilt and blame that they feel for their child's condition.

Both parents wish for a second chance to prove to themselves and perhaps society that they bear a healthy child.

In yet another study with a significant finding on maternal blame, Gray (2003) examines the role of gender and coping among parents of children with high functioning autism or Asperger's syndrome. In his study, Gray interviews 53 parents, 32 of which are mothers and 21 fathers. Mothers report that during the time it took for their child to be diagnosed they felt that they were charged and blamed by their husbands and other members of their wider family for parental incompetence. This finding was also supported in Singh's (2003) study of 39 New England mothers and 22 fathers of boys with ADHD. Gray states that this is primarily due to the attribution of responsibility for the child's behavior to the mothers, for society perceives the burden of raising a child to be on the mother. Once a child's diagnosis was in place, maternal charges of incompetence declined but mothers still experienced considerable guilt and depression about their child's disability. Gray (2003) states that "Certainly among the mothers in the present study, there was an overwhelming belief that they were viewed by both their husbands and people outside the family as the parents most responsible for their child's behavior" (p. 637). In summary, mothers much more than fathers were likely to experience a negative impact of their child's disability on their daily life, even from the closest people around them.

So far the literature that has been reviewed for the scope of this research has implied feelings of guilt and blame among parents of children with disabilities. However, through writing about parenting her daughter with disabilities, Green (2002) through

writing about parenting her daughter with disabilities, specifically says that upon the preterm delivery of her daughter and the diagnosis of severe cerebral palsy, she and her husband never experienced the need for blaming their daughter's disability on themselves or anybody. She explains that one never knows what's waiting for them and that life is full of twists and bends. She explains that in fact she continuously reimagines what her life will look like in the future and is often pleasantly surprised by what she finds. She says "Perhaps we have also been fortunate in that while both my husband and I have always had strong senses of personal mastery, we have been able to accept that sometimes, despite your very best efforts, bad things happen" (p. 24). While Green generally classifies her daughter's diagnosis as a "bad thing," later in the article she explains the positivity and the transformation that has happened to her family as a result of parenting her daughter. I discuss those ideas in the following section.

Positivity in Parenting a Child with Disabilities

Expressions of joy are given little credence in the literature on parenting a child with disabilities. Voysey (1975) observed that the positive, optimistic words that parents state are often dismissed by methodological artifact, statistically insignificant, or explained away by interpretations informed by the researcher's assumptions of pathology. The following section reports on incidents and feelings of joy that parents of children with disabilities experience and report.

Parental joy is a theme that has emerged in Kearney and Griffin's (2001) study on experiences parenting a child with severe developmental delays. The authors acknowledge that the parents' stories on their experiences address both joy and sorrow

and highlight the importance of the too often forgotten reality in the professional literature: joy. One participating parent says “The joy is defied by the sorrow which has come before” (p. 586). In the section that describes the element of joy being present in the study, the authors indicate that parents underwent growth into becoming ‘better parents’ and stronger as a result of their experience. One parent says “I wouldn’t miss what I’ve been through for anything” (p. 586), illustrating the gains that the parent has experienced as a result of parenting their child with disabilities.

Themes that contributed the parents’ joy were: the child surviving, the little things their child can do, becoming stronger in the face of adversity, and the new perspectives that follow overwhelming changes in personal beliefs and values. Parents spoke of their children with admiration, love and optimism. The children once labeled as ‘can do nothing’ can actually do things they explained. Parents claimed that “ their capacity to keep going in the face of sometimes overwhelming negativity was because of the inspiration they derived from the children who were described as ‘fighters,’ ‘survivors,’ and ‘gusty’” (p. 586). Their hope and ambition for their children was not proof that they were not in touch with reality as some may claim, in fact, the parents were well informed and understood their children’s impairments and their possible functional outcomes. However, they maintained a hope and a belief in possibilities. On the subject one parent said “a little is better than nothing, and you have to have some sort of goal or dream to work towards. I mean everything in life is, that has been done, has been done with a purpose or a dream” (p. 587). ‘Defiance’ is what Kearney and Griffin (2001) called as refusal to accept the verdict that went with the diagnosis. “Defiance of their children’s

prognoses enabled the parents to function with hope and optimism and to carry out therapeutic regimes which would be pointless if they paid heed to the predictions of ‘will do nothing’ and ‘will be a vegetable’” (p. 587). One parent illustrated this point with a very meaningful statement “And you are a million times more happy because he’s done it, because he wasn’t supposed to be able to do it” (p. 587). Therefore, the celebration of meeting a milestone among children who were given the prognosis of not being able to do it is celebrated more due to defining the expectation that was once set for the child.

In a study titled *Parents of children with disabilities: Telling a different story* by Goddard et al. (2000), parental joy, positivity, humor and optimism were among the experiences that parents of children with disabilities recounted. Parents engaged in processes of positively reframing or reconstructing the experience of having a child with disabilities. One parent says

You always have to keep saying you are doing your best and it’s going to get better, maybe not tomorrow, maybe not next year. So there’s that sense of optimism which is probably why I first spoke about positive things we experienced rather than negative. (p. 281)

Parents talked about sorrow and guilt in parenting a child with disabilities, but they talked about deconstructing those feelings and reconstructing them through a lens of acceptance, optimism and humor.

As Milo (2001) states, raising a child with a disability is a profoundly transformative experience. Heiman (2002) explored perceptions of coping, expectations and resilience among parents of children with disabilities. She reports that one characteristic present amongst most of the participating parents that clarifies the sense of

resilience in families was positive feelings towards the child such as joy, love, acceptance, satisfaction, optimism and strength. She states that these positive feelings were not present during the initial phases of diagnosis, in fact initial reactions were mostly negative ones. However, the parents demonstrated a transformation of those negative feelings into the positive feelings listed above. She notes that a small number of her participating parents (9 of the 32 parents) still feel anger, sorrow, frustration, guilt and pain especially when they compare their child with disabilities to other children. However, most underwent a transformation of feelings and thoughts to see the positive impact that the child gave them.

Among the researchers in the field who has written on her own experiences parenting a child with a disability is the sociologist Sara Green. She is a mother to a daughter who at the age of 1 years was diagnosed with cerebral palsy. Green (2002) talks about mothering her daughter and one of the first statements that she says on her experience is how transformative it has been. For her, transformation includes several dimensions. The first is the transformation of the dreams set for the child and the planned future that parents have for the child before the diagnosis, therefore the reimagining of the life that the child will lead. The second is the parental growth through which parents learn things through parenting their disabled child in which they might have otherwise never learned. She says

I can say unequivocally, however, that the experience of mothering Amanda has changed dramatically, irrevocably, and in very positive ways who I am and the way in which I view the world. It has created in me a willingness to share my emotions with others in ways that I would have found uncomfortable in the past. It has also broadened my image of what it means to live a good and worthwhile

life and has entirely redefined for me the meaning of dependence and independence. (p. 30-31)

Green (2002) explains that her understanding of interdependence and dependence have changed through mothering her daughter also with what it means to have “a good life.” She says “In short, it has made me a better person and a better sociologist. I am profoundly grateful for this transformation. I have much yet to learn” (p. 33). Green’s statement illustrates the impact of the new experience that she was thrust into upon the diagnosis of her daughter.

Growth was another theme that parents participating in Kearney and Griffin’s (2001) study addressed. They explained that their experience was a challenging and a growing experience for them which made them stronger and led to their grief being transformed to joy. The authors state “The parents were also clear that their experience was strengthening. They constructed meaning and developed new perspectives on life as a result of their experiences and challenges” (p. 588). Hence, through their experience parents gained a wider perspective on life and gained personal strength through managing their experience.

In a study on the benefits and burdens of mothering a child with disabilities, Green (2007), found that mothers gain exposure and experience to the world of disability through which their level of comfort with people with disabilities increases. On the subject one of the mothers participating in the study states

...I think, one of the things you learn is that these children are so normal—they’re just in a chair. When you looked at them before, you used to not know what to do. You were standoffish because you had no idea... then, you have a child and you’re not afraid... so, I think that... it changes you...(p. 158)

Another participating mother extended the comfort level of the parents to reach the siblings of the child with disabilities. She says

My children... are so much more tolerant of people with handicaps and I'm very thankful for that because... it's something you can't teach them... They'll play with anybody anytime...children with handicap, children of another color... if you wanna play, you're fine with me... (p. 158)

Mothers also expressed personal growth among themselves due to their parenting experiences. They acquired information in an array of fields; medical, educational and social areas. Their knowledge and skills increase their confidence and self-esteem. One mother reports that she has become more assertive and stronger as a result of her experience. "Mothers also report an increased awareness of what's really important to them. They've learned to focus on those things that give life meaning for them and to let other things slide" (Green, 2007, p. 158-159). This illustrates that parents experience personal growth by learning about what matters most in life.

Family Needs and Supports

This section will examine parents' perspective on missing supports in the educational and medical system that parents have significant experiences with as a result of parenting their child. Also, this section will shed light on what parents perceive as valuable supports and services provided to them during their experience.

In Whitehurst's (2011) study aimed at hearing the parent voice among children with fetal alcohol syndrome, reported that parents perceived life as a battle on behalf of their child. Meeting the educational needs of the children was particularly difficult. Parents addressed concerns about the lack of knowledge among educational practitioners

on the disorder, its implications and the provisions it needs. These differences left many parents feeling unsupported and vulnerable.

In another study done by Applequist (2009) that examines the parents' perspectives of special education, she reports that most parents indicate that prior to receiving IDEA services, they were unaware of its existence. "Many parents were quite surprised to discover early intervention existed and expressed gratitude that they did not have to pay for the services" (p. 9). Often parents were critical that their child's physicians had not informed them about these services and facilitated a referral. No reference has been made on how the parents eventually learned on the federally mandated early intervention program. In reference to this finding, the author suggested that physicians receive training pertaining to early intervention so that more timely referrals are made.

Heiman (2002) reports in her study that aims at examining parents' of a child with disabilities coping, expectations, and resilience found that parents valued different types of supports such as psychological services, psychiatric consultations, support groups, social workers, educational advisors and others. They also valued support that came from family members, grandparents and relatives. Heiman says "Seeking for support, can enlighten on how informed resilience is expressed, that is, by doing something actual or practical about the situation. Singly and together, these may help construct their resiliency" (p. 169). Many parents expressed concerns on their child's future, such as their physical and financial independence, education, acquiring a profession, and some even express worry over how their children will manage without them. Of those parents

who expressed the concerns stated above, 30% of them were already looking for hostels' information, examining vocational facilities and seeking advice from different organizations regarding their fears and worries. Among Heiman's implications is the need to enhance coping strategies that are related to the future of the child's welfare and the importance of social resources and effective programs of intervention.

A qualitative study conducted by Goddard et al. (2000) on the deconstructed view of disability with parents of children with disabilities yield results pertaining to meeting the children's needs and bureaucracy. Several narratives by parents involved in the study address the invasiveness of intended help and the lack of appreciation towards the parents' personal context. One parent made a comment about feeling that her child belonged to the system rather than to her. She explained that she had numerous appointments scheduled with different professionals for her child, "You had speech therapy, physiotherapy, occupational therapy. I never had so many people in my life at one time and you felt like this child did not belong to you" (p. 282). Parents also spoke about medical professionals objectifying their children. The most troubling system for the parents involved in the study was the bureaucracy. The authors report "It was not particular professionals per se who represented a problem in their lives, but a bureaucratic discourse that set the context of supports" (p. 283). In short parents described interactions with professionals as invasive and the system as "invasive, lacking contextual understanding, overly bureaucratic and impersonal, and often dominated by an unquestioned adherence to traditional medical models" (p. 283). It was only when parents felt that professionals saw them as equal contributors to the goals set for their

children that parents reported positive experiences and relationships with the professionals.

Green (2003) reports that parenting a child with disabilities is costly in terms of time and money spent on attending to the child's needs. Parents report stories of financial crisis due to paying for the medical services and interventions needed for the child. Issues with insurance covering the services, and a decreased household income due to the need of one parent quit their job and care for the child. In another study that was conducted by Green (2001), on the interactions between parents of children with disabilities and professionals, the findings suggest that parents value interactions with professionals who are able to laugh and interact with their child without feeling sad or awed at their condition. She reports that those professionals who highlight the strengths of the child, their interests, and were more interested in the child achieving his/her potential were highly valued by the parents. On the other hand, parents were very frustrated with medical professionals who failed to guide them on the practical aspects of helping their children live life to the fullest. Green (2001) reports

If nothing can be done to cure the problem, they want help in figuring out how to make the best of it. Most of all they want to hear that they and their children are doing well within the parameters with which they must live. (p. 806)

In other words, parents report appreciating guidance on how they can live with and handle the situation they are in the best- on how to make the best of what they have.

In a recent study conducted by Benzies, Trute, and Worthington (2013), they found that measures of general self-efficacy among mothers of children with disabilities predict overall family adjustment over time. Mothers who demonstrate high levels of

self-efficacy show stronger family adjustment abilities. Parental self-efficacy in particular is a paramount service goal in family centered support services. These services give high priority to empowerment practices among parents. When parenting a child with disabilities, the parents often assume many roles which include, the information seeker, problem solver, political activist committee member, educator, and spokesperson for the child. Therefore, a paramount product of the disability services that families get is to empower them and increase their self-efficacy in order to take on the roles that they need to for their child.

Williams (2012) studied the experiences of teacher candidates as they took part in a Families as Faculty (FAF) program whereby teacher candidates visited families of children with disabilities. The purpose of the experience was for teacher candidates to gain personal and authentic knowledge on the journeys that parents take on from the discovery of the disability to accepting and understanding their child. On the immersive experience, one teacher candidate states “I never realized how many families with children with disabilities there really are in our community” (p. 243). Sometimes families of children with disabilities are overlooked unless a conscious effort to acknowledge their presence is made. Williams reports that 21% of the 33 participating teacher candidates addressed professional bias when reflecting on their visit to the family. One teacher candidate reflects on his/her preconceived ideas and bias on the family by saying

When I first pulled up to the house I made the mistake of judging the family. The house was small, older and a little run down. For a moment I expected a family that was uneducated and dull; however, before I reached the door I corrected myself. (p. 244)

Williams explains that professional biases are present early on in the lives of teacher candidates for they are often a cultivation of cultural socialization practices.

Williams (2012) found that 49% of her 33 teacher candidate reported feeling apprehensive to the assignment at first especially that they felt that they were going to intrude in details of the lives of families. They were surprised to learn that parents were overwhelmingly willing to disclose and share their experiences with them. Teacher candidates learned that among the greatest needs of families of children with disabilities were legal and financial resources. They also learned that one family member's disability impacts the life of all the family members. One teacher candidate explained "Because he has a variety of disorders he has several pharmacological interventions, the family often worries about how to pay for everything" (p. 243).

In a study that looked into mothers' lived experiences of support as they parent their child with congenital heart defects, Bruce, Lilja, and Sundin (2014) express that one important need of mothers (and parents in general) at the point of diagnosis is providing them with relevant information on the condition in simple and understandable lay person terms. They need to be able to know what it means, what to expect and what treatment options or interventions there are. Social support that consists of emotional support, advice, consolation, and caring from people who have a close relationship with the mother are also vital. Social support from close family and friends continue to be reported as a vital form of support for others children with disabilities.

Mothers participating in the study express the need for support in four major areas. The first area is needing support to inhibit limitations such as maternal fatigue,

stress, burnout, frustration helplessness, grief, and vulnerability. The second area is desiring coordination of care within the society as support. Mothers wish to avoid responsibility for being the link between service providers and professionals that the child receives services from. The third area is requesting privacy as mothers wish to cherish their personal integrity and need time to themselves after being notified about their child's medical conditions. "Mothers lack strength to answer questions in the early days of their children's diagnosis, which may collide with relatives' wishes to display their participation by keeping in touch" (Bruce et al., 2014, p. 60). The fourth area is needing supportive confirmation whereby mothers receive specialized care for their children from healthcare providers and are taken seriously by being listened to and offered explanations and gracious amounts of information on their child's condition. Mothers feel empowered when they are involved in the care of their child and when they have knowledge on their child's condition and can share knowledge and advice with other parents. An important aspect in this area is support from parents of other children with similar conditions. Mothers have a desire to get in touch with parents in similar experiences. This makes them feel that are not alone in the situation and creates a sense of community spirit.

In a similar and current study on caring for parents who are preparing for a child with disabilities, Lindsey (2011) reports that the art of caring must be employed by all child care providers and childbirth educators. "Actively listening, spending face to face time, and allowing expression of fear, anxiety, and grief will be beneficial to these families" (Lindsey, 2011, p. 18). Fostering hope and a positive image of the child is beneficial for parents along with connecting them with support groups of families with

similar experiences. While the future of the child cannot be predicted, but providing the parents with concise, clear, and realistic information that is laced with hope is an imperative support that parents appreciate.

There has recently been an affirmation of the need for parents and families to be involved in planning and implementing their child's educational plan. Engaging parents as co-educators and key players in the design and implementation of interventions is currently the trend (Carpenter & Egerton, 2005). Dunst (2002) notes that family based educational practices will require treating families with dignity and respect while providing individualized and flexible services to meet the children's needs. Viewing the parent-professional relationship as the bedrock for improving outcomes of children is going to be an integral change.

Applequist (2009) conducted a narrative study on the parenting experiences of families of a child with disabilities. She reports that parents address the importance of collaboration and communication between the home and the school. They stress that creating a learning environment that promotes inclusion and is designed so that their children can participate alongside other students in the class. Parents also address the issue of transitioning their children into new settings. They also express their fear of the transition from early intervention to center based programs for they felt their role changed and professionals became less accessible. Therefore, ongoing communication is vital when is child is transitioning. Most parents report support and validation of their children's needs from professionals, however, there were some who report resentments due to confrontations between them and school staff and administrators. Positive

experiences related to transitions were mostly credited to planning and preparation prior to the actual transition and qualified personnel who approached their work with genuine dedication. Parents living in rural communities express frustration with scarcity in qualified personnel, while parents living in urban communities expressed unhappiness with the intensity of the services offered. This leads us to believe that having enough services to benefit from rather than stress about by qualified and dedicated professionals is key.

A number of recent studies have underlined the importance of building strong partnerships between the home and the school environment. One of those studies is by Edwards and Da Fonte (2012), whereby the authors outline a 5-point plan for teachers to use in developing parent-teacher relationships that “potentially benefit families, students, and all involved in a student’s educational process” (p. 7). The central elements in the 5-point plan are effective communication and collaboration with families of students with disabilities. The authors accentuate the importance of teachers providing support to families that will allow them to “be independent and develop a sense of control in their lives in terms of raising and supporting their children with disabilities” (p. 8). The ability to be independent and empowered with knowledge on supporting one’s child seems to be a recurring method of recommendation for supporting parents.

The plan consists of firstly being positive, proactive and solution oriented. The authors advise that focusing on student growth and success with the families is crucial along with identifying areas of need and finding specific ways to support these needs. Seeking information from parents on what has worked with their child previously, their

interests, areas of need and any information that families deem important for teachers to know is important. The second step in the 5-point plan is to respect families' roles and cultural backgrounds in their children's lives. Parents are the experts on their children's strengths and needs, therefore seeking their input for solving or preventing difficulties and listening to their perspectives is key. It is imperative to address cultural differences in the classroom and in communicating with the parents. Paying close attention to whether the parents may need interpreters for efficient communication and collaboration with the teacher is an example. Thirdly, on the 5-point plan is to communicate consistently, listen to families' concerns, and work collaboratively. This constitutes using a wide range of methods to promote communication and collaborative opportunities. Families of children with disabilities report a need for consistent feedback and information on the progress of their child. Inconsistent or delayed communication is to be avoided. Fourthly, consider simple, natural supports that meet individual needs of students. "Families often articulate a desire for natural supports that meet their children's individual needs, such as considering the effect of physical disabilities on fine motor skills or of language impairments on students' communication" (p. 10). Natural supports are often ones that can be employed at the school and at home such as practicing mealtime routines. Asking parents whether they are in need of supports at home or information is appreciated and beneficial. Reporting to the parents areas which their child may need accommodations with, sharing proposed supports, and soliciting input is vital in this stage. The fifth and final stage in the 5-point plan towards greater parent-teacher partnership is to empower families with knowledge and opportunities to be involved in the context of students'

global needs. Among the most reported challenges that parents of children with disabilities report is the feeling of loss of control. This feeling can be battled by empowering the parents with the knowledge and information pertaining to their child's needs, services available, parental rights, and other relevant information that is necessary for them to feel they can regain their sense of control and power.

In another current and similar study by Sawyer (2015), the BRIDGES (Build, Recruit, Individualize, Dialogue, Generate, Empower, and Strengthen) framework model through which teachers can develop and implement strategies to facilitate different levels of parent involvement was outlined. As cited in Sawyer (2015), Dunst and Dempsey (2007) maintain that parents become involved when they feel they will make a difference in their child's schooling experience and have a high sense of self-efficacy. The components of the different levels of the BRIDGES framework include:

1. Building meaningful relationships based on trust and understanding
2. Recruiting input, choice and voice, from the child's family by employing methods that the input is collected
3. Individualizing parent involvement strategies to accommodate and embrace differences
4. Dialoging effectively through ongoing and easily understood formats and languages by parents while appreciating parental input
5. Generate ideas and support parents in the identification and implementation of evidence-based practices in the home and community

6. Empower parents through equipping them with knowledge and skills that will optimize parent-child interactions
7. Strengthen partnerships between teachers and parents by celebrating small accomplishments and acknowledging involvement

In summary, Sawyer (2015) maintains that one size does not fit all when considering parental involvement. This model is meant to be a flexible framework for teachers to use towards helping parents embrace their role as advocates of their child. Sawyer affirms the importance of reaching out to parents with children with disabilities because many times the parents are overwhelmed, intimidated, and frustrated by involvement in advocacy oriented activities for their child such as Individualized Education Programs (IEPs).

Positive and negative experiences in home-school partnerships were amongst the things that the families addressed in Williams's (2012) study. The study explored reflections by teacher candidates who visited families with children with disabilities in their home environment. Positive experiences with home-school partnerships addressed the common issues of positive communication, respect, trust, competence, and commitment. However, 48% of the reflections by the teacher candidates were on parents expressing the lack of positive teacher interactions and acceptance of their child. One teacher candidate reported "The teacher thought she knew what the child needed and didn't listen to the mother about his learning problems. This was very frustrating to the mother, so she sought advice from a lawyer and filed Due Process" (p. 243). Williams (2012) states "parents discussed their frustrations that teachers often don't value parental

prior knowledge and experiences in educating the child in question” (p. 244). In short, parents of children with disabilities have sometimes felt unheard in the schools and it was useful to see parents in their most comfortable zone- their home. This will hopefully lead the prospective teachers to understand the behavior and motivational factors exhibited by their students.

Respectful two way relationships has been an important recommendation towards achieving a positive home-school partnership. Schischka, Rawlinson, and Hamilton (2012), also stress the significance of these elements among adults in both settings. The authors primarily investigate factors affecting the transition to school for young children with disabilities. They maintain that a positive start to school sets the child for continued positive schooling experiences. Also, evidence exists on children with disabilities needing longer time to become familiar with classroom routines and environments before they start school. On this basis, some researchers recommend a greater number of pre-entry visits of the children to the school environment and the first year primary teacher to visit the children at their Early Childhood Centre prior to the transition. Others commend on the presence of a liaison between the family and the school to provide the family and the child a form of continuity.

In addition to the above, ongoing communication and collaboration between the families, the Early Childhood Centre, the school, and all other professionals were valued. Schischka et al. (2012) aimed at interviewing parents and teachers of children with disabilities on their retrospective views on the child’s transition process. Findings concurred on assembling a team of personnel to plan the transition along with involving

the parents, personnel and the child in the transition. The benefits of pre-entry school visits were recorded. “For families who were offered transition meetings and multiple school visits, this had provided them with the possibility for more family input, thereby increasing levels of communication between home and school” (p. 21). It was also found that the levels of communication and collaboration that occurred between the family and the school prior to school entry tended to continue in the period following school entry. Positive transition processes typically were characterized by strong respectful collaboration and communication between both parties.

The implications stated by authors for this research include: encouraging family involvement in every step of the process, assembling a collaborative team of personnel to coordinate the transition and discuss the child’s needs, plan numerous pre-entry school visits at varying times while gradually increasing in length, differentiation in teaching, consistency in communication and collaboration among parties.

Summary

Mothers of children with disabilities are the primary caretakers of their children. Their experiences, as reported in this literature include parents (a) experiencing stress, loss and sorrow, and working through adaptation and coping methods, (b) managing stigmatization and social isolation from the society, (c) experiencing feelings of guilt and blame, (d) undergoing personal growth and transformation as a result of their parenting experience, (e) seeking service and supports that benefit the child and the family. In addition, this literature review indicates a shift in the type of research employed from quantitative to qualitative studies. This shift illustrates the importance of understanding

the experiences of families from a narrative or qualitative framework. Due to the mere number of research that has given mothers of children with disabilities the voice to address issues they deem significant and worthwhile to share, it seems that there is a need for more research on the subject that adopts this approach.

CHAPTER 3

METHODOLOGY AND METHODS

Study Design and Rationale

The purpose of this study is to explore the experiences of mothers of children with disabilities as they raise their children and navigate the world of special education. The study entails exploring societal and personal factors such as attitudes and expectations towards children with disabilities and their families, particularly mothers, and the roles that the mothers assume throughout journey. It also aims at delving into the process that mothers go through to access, negotiate and utilize special education services by service providers and professionals. These areas are explored through narrative, autoethnography and the storytelling of my journey with my daughter who has disabilities along with conversations and story swapping with a second mother of a child with disabilities.

To accomplish these goals, I am drawn to qualitative research as a method for conducting and analyzing my research interests for they will elicit a full description of the mothers' experiences. This study aims at giving mothers of children with disabilities the voice and the freedom to address what they deem as significant and pertaining to parenting their child and navigating the world of special education. A qualitative study will allow myself and another mother to describe experiences and feelings rather than respond to structured questions. This chapter will present the research method used, the data sources, and the procedures of data collection and analysis.

Qualitative Inquiry and Research Methodology

Qualitative inquiry will be the big umbrella that encompasses the design of the research to meet its objectives. In this study, narrative inquiry will be used to capture the story of a mother of a child with disabilities and autoethnography to capture my own story. The aim is to delve deeper into the needs and intricate experiences of families of children with disabilities along with the interactions and supports present and lacking among professionals in the field of special education. Narrative inquiry and ethnography will serve the purpose of providing the mothers with the flexibility and freedom to address any experiences that had an impression on them.

A characteristic of qualitative research is making sense of personal narratives and the way they intersect by creating categories and finding relationships between them. Qualitative researchers “seek to understand and interpret how the various participants in a social setting construct the world around them. To make their interpretations, the researchers must gain access to the multiple perspectives of the participants” (Glesne, 2006, p. 4-5). This involves being aware of what is said, how it is said, silence and bodily gestures. Asking how questions about the narrative will also initiate further reflection from the participants. As Riesmann (1993) suggests, a performative approach in qualitative inquiry shifts from the ‘told’ language to include both the ‘doing’ and ‘telling.’ In other words, the focus is on both what is being said and how it is being said, therefore taking note on behavior demonstrated while telling the story, the sequence in which the events are told, the time spent addressing certain issues and so on so forth is vital.

“We are a storying animals; we make sense of things commonly in story forms; ours is a largely story-shaped world” (Egan, 1991, p. 96-97). For humans, narrative is the primary framework for constructing meaning (Polkinghorne, 1988). This means that we make meaning of experiences through telling about them and hearing stories. Romanoff (2001) addresses the benefits of narrative construction for individuals coping with loss or other traumatic life experiences. She points out that while the goal of qualitative research is to study human behavior and the goal for narrative therapy is to facilitate change and personal growth, both have therapeutic benefits for both the interviewee and the interviewer.

Narrative inquiry has become increasingly visible within disability studies (Smith & Sparkes, 2008). It holds assumptions that a person constructs stories out of life (Josselson, 2006) which is heavily shaped through social and cultural forces (Riesmann, 1993). This is due to meanings and expectations associated with the situations individuals are placed in and not being merely a production of their personal and independent mind. In other words, meanings are developed and nurtured through what culture and society deem as appropriate and normal. Atkinson (1997) explains that personal events may be exclusive to the individuals but are structured according to socially and culturally shared conventions of telling and the narratives that one has access to. In other words, while experiences differ, the constructed meaning of the experience would be similar due to socially and culturally shared values. Despite all the social and cultural factors embedded in the meanings assigned to our experiences, narratives also provide a structure in selfhood and identity (Smith & Sparkes, 2008). Therefore, narratives promote active self-

shaping thoughts and revisions of the self and identity in different roles and contexts by investigating the role of agency and structure. On the topic, Goodley et al. (2004) state: “Narratives may be our best hope of capturing structures that continue to shape, divide and separate human beings” (p. viii-x). While one kind of qualitative research seeks to interpret and analyze participants’ construction and perspective of social interaction through the researcher acting as story analyst, another kind seeks to include the researcher as a participant- the storyteller. The latter is a characteristic of autoethnographic research.

Autoethnography

Autoethnographies are “highly personalized, revealing texts in which authors tell stories about their own lived experiences, relating the personal to the cultural” (Richardson, 2000, p. 931). In other words, an autoethnography is an experience retold. Ellis, Adams and Bochner (2011) explain that “As a method autoethnography combines characteristics of autobiography and ethnography. When writing an autobiography, an author retroactively and selectively writes about past experiences” (para. 5). Ellis (2004) states that in autoethnography, the story is the analysis whereby the story is retold through systematic sociological introspection and emotional recall. Multiple layers of consciousness are displayed by the author in an effort to understand the experiences. Ellis (1999) composed a list of characteristics of a heartfelt autoethnography. These include

the use of systematic sociological introspection and emotional recall; the inclusion of the researcher’s vulnerable selves, emotions, body, spirit; the production of evocative stories that create the effect of reality, the celebration of concrete experience and intimate detail; the examination of how human experience is endowed with meaning, a concern with moral, ethical, and political consequences; an encouragement of compassion and empathy; a focus on helping

us know how to live and cope; the featuring of multiple voices and the repositioning of readers and “subjects” as coparticipants in dialogue; the seeking of a fusion between social science and literature, the connecting of the practices of social science with the living of life; and the representation of lived experience using a variety of genres-short stories, poetry, fiction, novels, photographic essays, personal essays, journals, fragmented and layered writing, and social science prose. (p. 210-211)

A key criteria in autoethnographies is that the readers be able to reflect on their own lives in relation to that of the author. In other words, although the story is that of the author, it has an implied audience. McLeod (1997) states “so it is as if to some extent the recipient(s) of the story draw it out of the teller.... Even a story written alone, such as a novel, has its implied audience” (p. 3). Although autoethnographies are rare within the realm of disability studies, a number of scholars have produced them (Frank, 1995; Green, 2002, 2003, 2007; Murphy, 1990; Neville-Jan, 2004; Sparkes, 2002; Valle, 2011). Choosing a research method(s) is dependent on both the nature of the research and what it aims at investigating.

For the scope of exploring the experiences of parenting a child with disabilities, I have chosen to break the traditional stand on maintaining an objective stand as the researcher by merging my narrative into the narrative of another mother who belongs to the same group as mine, a mother of a child with disabilities. Through this method I am able to be both a researcher and a participant. I am able to “swap stories” as described by Green (2003) with the other mother. Green (2003) states that she hoped that swapping stories would be therapeutic and enjoyable to her participants. As a mother of child with disabilities, I predict it will be for me, and as a researcher I hope it will be the same for my participating family. Finally, Green (2003) reports that “there is a growing concern

that the “objective stance” and “privileged voice” of academic expertise have often, unintentionally, served to marginalize and alienate the people whose lives we study” (p. 2-3). My hopes for this research are to minimize if not eliminate all objective stands and provide the participating mother and myself the freedom of addressing what we want to address on parenting our children.

According to Neville-Jan (2004) who presented autoethnography in the form of a quest narrative, autoethnography has many benefits for example: it is a method of breaking the silence for individuals with experiences because the experience is re-presented to the public. As a result, communities are built among individuals who share the similar experiences and “produce change in the political process by challenging the dominant narrative” (p. 123). It acts as a manifesto to build communities among people who share the same or similar experiences. She also states that autoethnography can inform and develop an embodied disability theory that would benefit disability studies through informing the public on every day life experiences within a disabling society. According to Smith and Sparkes (2008), other benefits of autoethnography are the connection, empathy and solidarity that are encouraged amongst readers and the population. Powerful insights and emancipatory moments are generated, these “can inform, awaken and disturb readers by illustrating their involvement in social processes about which they might not have been consciously aware” (p. 25). They add that “a valuable use of autoethnography is to inspire in someone critical reflection” (p. 25). In summary, advantages of autoethnography include: building community and support ties among populations with similar experiences, shedding light on the involvement of

readers in the lives of people with disabilities through social process interactions, providing information on embodied disability theories, and promoting critical reflection among the author and the implied audience, as these advantages relate to my research.

Like all research methods, autoethnography also has some potential risks and limitations. Several risks and limitations are stated in Smith and Sparkes (2008). Due to the sensitive nature of the experiences being exposed and the disclosure of details required by autoethnographies, one may experience levels of uncomfortness in inner feelings and emotions. This risk increases when the research includes others such as family members. Another risk is one of change to individuals, for when an autoethnography strikes a chord in readers, a change is expected, however, the direction of the change is unpredictable. Furthermore, the process of writing an autoethnography is a difficult one for it requires creative and evocative articulation to portray the story. Finally, autoethnography is often viewed with suspicion as a method of inquiry and often criticized as being self-indulgent. However, as Sparkes (2002) argued, autoethnographies encourage acts of witnessing, empathy and connection that extend beyond the self of the author and contribute to our self-knowing. In summary, the risks and limitations of autoethnographies include uneasy feelings and vulnerability that are demonstrated as a result of providing intimate details on human experience, difficulty in engaging in an autoethnography due to the elements of writing that it demands, and the criticism and suspicion that autoethnography is treated with amongst some researchers. I will discuss these challenges in the section titled ethical considerations.

Case Study

The use of case studies varies from involving a single person to involving entire communities and nations. The common denominator in all case studies Glesne (2006) explains is a bounded integrated system with working parts. Stake (2000) states that there are three types of case studies: intrinsic, instrumental, and collective. Intrinsic case studies involve studying a particular case in order to better understand that specific case. An instrumental case study is when the aim of the case study is to provide insight on an issue or to redraw generalization. A collective case study is when the instrumental case study involves looking at several cases to investigate a phenomenon. Qualitative case studies gather data through ethnographic tools of participant observation, in-depth interviewing, and examination of relevant artifacts. In summary, case studies investigate real-life experiences using a variety of sources as data.

When this research started my experience in the world of disabilities was a mere one year. Adding on the experiences of another family who has been immersed in this foreign world for a much longer time would make the research more rich and diverse. The participating family's contribution is vital and very rich due to the greater amount of professionals they worked with, their bigger social circle and the milestones that they have reached with their daughter given her age. Therefore, adding a case study to this study would add depth and breadth to the research.

Methods

This section will present information on the two participating families in this study. Since this work is a combination of narrative inquiry and autoethnography, several

methods of data collection were employed; journaling, conversational interviews, and document and artifact reviews.

Participants

Two mothers will be participating in this research. The first is myself, a 29 year old mother of two children, 4 year old Kynda, and 3 year old Omar Jr. I am also a wife, a homemaker, a doctoral student, and a daughter. My husband Bilal is a physician at one of the local hospitals in town. My daughter Kynda was born prematurely at 25 weeks gestational age. As stated in an earlier chapter, Kynda had a twin brother, Omar. One week following their birth, brain ultrasounds were done on the twins and we learned that Omar was suffering from a severe bilateral brain bleed. The doctors told Bilal and I that the prognosis of that would be a high chance of developing severe disabilities. The doctors told us that if we wanted we could stop life support due to the poor health prognosis Omar had. It was the toughest decision of our life. The thought of losing my baby broke my heart, yet I feared the change that would come to my life as a result of his disabilities. Three days following his first ultrasound, a second brain ultrasound was done on him. We learned that his brain bleed got worse and was at the worst degree it could get to. His blood pressure was three times higher than normal and he was on morphine to ease off pain he might be feeling due to his extremely high blood pressure. It was then that we decided to stop life support for Omar. He passed away in my arms 14 days later. The decision to let him go probably will be the most difficult decision that Bilal and I had to make. It was partly driven by his suffering as a result of his health condition, and partly due to our fear parting a child with disabilities.

Kynda's health prognosis was brighter. She did not suffer from a brain bleed, yet she was not immune to developing disabilities as a result of her premature delivery and her hospital stay. Surely, as Kynda grew older she was diagnosed with developmental and cognitive delays and bilateral moderate to severe hearing loss. She currently wears hearing aids to supplement her hearing and aid her in acquiring language and the ability to communicate with others. Kynda receives numerous services such as physical therapy, speech therapy, audiology, itinerant hearing, and special education. She started attending an inclusive daycare with the rest of her typically developing peers since she was two years old and continues to do so. One year following the birth of my twins, I was blessed to give birth to another boy whom I named Omar Jr.

The mother that is participating in this research was referred to me by a common friend who had contacted the family and asked permission to pass their contact information to me. An email that debriefed the mother on the purpose and the scope of the study was the initial contact I had with the family. Following consent to participate in the study, I visited the family for the first time in their home in rural Iowa in December 2012 and have remained in contact with them by email. Visits resumed again in November 2015. The family is comprised of a married couple, Sarah and Evan Sailor. Evan was a retired construction worker and the Sarah is a part time physical therapist. Sarah and Evan have two children together, a son, Sammy, in his mid-20s and currently in college and a daughter named Tammy who is in 19 years of age and has just graduated high school. Sarah and Evan were initially told they could not have children but few years into their marriage they had Sammy who is a typically developing boy and four

years later had Tammy, who at the age of five months was diagnosed with a rare brain formation disorder known as Lissencephaly. Sarah explains that her pregnancy was very healthy and they took home a girl whom they thought was a healthy typical baby.

Lissencephaly is a disorder that primarily and severely affects psychomotor functions and causes the person to have seizures. Tammy has been left with severe disabilities as a result of the disorder. When the time came for Tammy to go to school, Sarah and Evan explored all schooling options, segregated and inclusive. They decided that Tammy's best needs will best be met in the general education school of their local school district and so Tammy has always been school in a general education setting. In May 2014, a year and a half after I connected with the family and met them for the first time, Evan passed away to cancer at the age of 71. Sarah was left with the full responsibility of caring for a child who needs 24/7 care, a large ranch house, and a part time job.

Data Collection

Journaling. One key data set for this research was my journal writing. Perhaps one way of dealing with chaotic and transformational life events is writing about them especially when one feels uncomfortable to voice them to other individuals. Journaling as a therapeutic aid has long been acknowledged by schools of therapy (Janesick, 1999). Therapists view journaling as a method of making sense of one's life. Journaling about life events that took place in my life, as a result of my daughter's diagnosis of disability and the passing of my son who was deemed by doctors to develop severe disabilities, certainly relieves some of the stress and the flood of emotions that I was experiencing. It allows me to make sense of the situation I was in. My feelings concur with Janesick's

(1999) reports that journaling refines ideas and beliefs. She explains that journaling is “a type of connoisseurship by which individuals become connoisseurs of their own thinking and reflection” (p. 506). Most importantly, journaling allows me to acknowledge my feelings and thoughts. My journal allows me to write whatever I wish without judging me, without undermining me and without pitying me. In fact, journaling makes me grow and find strength from what I once called a weakness- my son’s health prognosis and my daughter’s disability. It is a way by which I gain insight on my experience, actions, and thoughts. Janesick illustrates that journal writing enables one to “experience in a full and open-ended way, the movement of our lives as a whole and the meaning that follows from reflecting on that movement” (p. 507). She adds that this is the means by which a story becomes public text.

I journal mostly prior to and after an important event, such as a medical appointment, an IEP meeting, or a birthday. Journaling took place after everyday routines for sometimes a memory was recalled or meaningful incident took place. A big chunk of my journaling took place as I was conducting my literature review for this study for as I read other parent’s anecdotes on parenting their child with disabilities, my memories were revived. I often journal when I am in solitude for at those times there is serenity in my environment. My emotions and thoughts often turmoil when I am in solitude and that is when I head to my notebook to write them down. More journaling took place prior to and following my meetings with the participating family. Data analysis of the journal involved the regular elements of qualitative data analysis which typically include comprehending, sorting and coding.

Conversational interviews. Ellis (1998) proposed the research method of interactive interviewing. She maintains that this method provides opportunities for both the interviewer and the interviewee to move back and forth between expression/disclosure and protection/restraint in a mutually supportive atmosphere. Therefore, there are numerous benefits to learning about the lived experiences of mothers of children with disabilities through narrative inquiry. Therefore, the study procedures included extensive interactive and conversational interviewing. Sarah, the mother, was asked to share stories about the birth and the diagnosis of her daughter and interactions with family, friends and professionals during and following the diagnosis. She talked about how her parenting experience has affected her and her family. Structured questions were not be used in this study. In fact, Sarah was encouraged to lead the conversation as she deemed. She was encouraged to voice her feelings and experiences mothering her child with disabilities. I started the conversation by telling Sarah more about myself, my family and my daughter with disabilities and the forces that have compelled me to conduct this research. Opening questions such as “Tell me a little about your daughter and about parenting her,” “If you were asked to describe your experience parenting your daughter and navigating the world of disabilities and special education, what would you say?” “Thinking back on your experience of parenting your daughter, what were the most significant memories that you hold?” and “How has parenting your daughter affected you and your family?” were used if the need arose. Why and how questions will be asked to illuminate feelings and thoughts of the mother on statements she makes.

I swapped stories between Sarah and myself on similar and different experiences that we have shared parenting our daughters. As the conversations took place more data collection methods emerged such as observations, examining of artifacts and school work or other relevant material. The multiple in-depth narratives that took place were audiotaped. Field notes were noted throughout the interviews and served as a data points for this study, particularly ones that addressed emotions of the participating mothers. Observations of bodily and facial gestures along with interactions among family members and setting details were also be noted. Multiple interviews were conducted yielding a total of over 12 hours of audiotaped conversations. Each meeting lasted about 120 minutes. The settings at which the interviews took place were divided among the Sailor's home and restaurants.

Document and artifact review. Documents and artifacts available by myself and Sarah that were deemed significant to the scope of this research were reviewed. Document and artifact review validate and verify observations, interviews and journal entries and make findings more trustworthy. Documents and artifacts included letters, essays, emails, pictures, videos, IEPs and so forth. Glesne (2006) states that document review may raise questions that may shape a new direction for the research along with provide personal information that may be unavailable from other sources. She adds that the use of unobtrusive documents provides a historical and contextual dimension to the observations and interviews. This will ultimately enrich what is heard and said by participants through supporting, expanding and challenging portrayals and perceptions, thus the understanding of the topic in research grows.

Data Analysis

Case study and autoethnographic collection. Each interview was transcribed including any sounds such as sighs, pauses, laughter or cries made by the mothers or other family members as they told their narratives. Perakayla (2005) recommends that qualitative researchers transcribe their data as naturally occurring as they can. Written language feels flat on paper but spoken language is full of emotion, life and inflection. Transcribing the interviews to reflect those elements was an important task.

Emerging themes that rose from the narratives that Sarah and I engaged in or journaled about were documented. Marshall and Rossman (2006) suggest that “emerging analytic insights and clues that focus data collection” be noted (p. 99). Strauss and Corbin (1998) maintain that “by putting our analysis immediately into notes” we begin the inductive process of open coding (p. 120). Therefore, personal connections in relation to what Sarah was sharing with me during the conversational interviews were noted. The data that was produced through transcriptions of the conversational interviews, journaling, artifacts, and documents were periodically read and re-read. Each time, I jotted down my thoughts, notes, emerging themes, and possible interpretations on the margins of the documents, in order to make sense of the data and begin the process of coding and analysis. I also listened to the recorded audios of the conversational interviews multiple times to pick up on the influx of tone and language used by Sarah and myself. As I engaged in this process, I realized the challenge of formulating clear cut categories of what the narratives were addressing and the means of presenting the data. I struggled with the idea of whether or not to fragment the data into small ideas or portray

them as a short story, each addressing an experience. My fear of fragmenting my data into small pieces was that I lose the bigger picture and the impact of the words that the mothers had expressed.

Chenail (1995) suggested several strategies of presenting findings in qualitative research including

- Quantitative Informed: data is presented in ways typical of quantitative studies; along lines of central tendencies, ranges, clusters and frequencies.
- Theory Guided: data arrangement is governed by the researcher's theory or theories regarding the phenomenon being presented in the study.
- Dramatic Presentation: researchers order their data presentation so as to save the surprises or the unforeseen discoveries for last.
- Narrative Logic: data is arranged with an eye for storytelling. (para. 35)

Based on Chenail's suggestions for presenting data in qualitative research, I chose to present my data utilizing the "narrative logic" method portrayed as vignettes. Chenail (1995) states that the strength of the "narrative logic" method is that the researcher can "plot out the data in a fashion which allows them to transition from one exemplar to another just as narrators arrange details in order to best relate the particulars of the story" (para. 35).

Chang (2008) has also written on how autoethnography, like all qualitative research methods requires construction and interpretation. She recommended several formats for writing up autoethnographic data and these include: imaginative creative writing, descriptive emotive writing, or even creating one's own style. The imaginative

creative writing format allows the researcher to express the data in an unstructured method such as a story or a genre. This format is focused more on interpretation of the data than on the analysis. The descriptive emotive format removes any interpretation and asks the researcher to simply describe with the intent of only using descriptive passages that elicit emotion. When a researcher chooses to mix and match any of the formats that Chang recommends then it would be creating one's own style in presenting autoethnographic data. Ellis (2004), recommended that autoethnographic data be presented as a narrative story such as fiction, poetry, or performance and only theorizing the context of the narrative. Based on the above recommendations, I have chosen to present the narratives that Sarah and I put forth through vignettes illustrating significant experiences on mothering our children. These vignettes utilized elements from the narrative logic method, descriptive emotive format, and imaginative creative writing format thus, creating my own method of presenting the data. The vignettes illustrate experiences, thoughts, and emotions that Sarah and I lived through.

One of the purposes of this study is to investigate the roles that the mothers assume as they parent their daughters with disabilities. The data analysis included roles assumed by Sarah and I as we walked through the path of parenting our daughters with disabilities. Donald Super's nine Life Span Life Space approach, existing themes in the literature, such as challenges faced, positivity experienced, social and psychosocial experiences, and family supports and needs were explored throughout the data analysis.

A method to ensure credibility measures in qualitative data is through member check (Brantlinger, Jimenez, Klinger, Pugach & Richardson, 2005). Member checking is

the process by which the participant, Sarah, checks the researcher's data analysis and interpretations for accuracy and inaccuracy prior to publication. In other words, validation of the researcher's analysis and interpretation is checked by the participant. This process has been out for this research to ensure validity and credibility of the data analysis and interpretation.

Ethical Considerations

Moral and ethical considerations were formally addressed through the human participant review application and through acquisition of approval from the Institutional Review Board. Since this study emerged in a previous course, Advanced Qualitative Research Methods, an IRB is currently on file and up to date. Participating individuals were made aware of the purpose and the nature of the study along with their rights and possible psychological risks. All participants consented to participating in this study and were free to withdraw at any point in time with no penalties.

Due to the sensitive nature of this research, I built rapport first before delving deeper into intricate details of the family's life. Free flowing conversations followed whereby Sarah led me to areas they would like to shed light on and bring out to the public. Smith and Sparkes (2008) highlight that "it is important that the moral and ethical importance of listening to disabled people's stories is not sidestepped" (p. 23). It is important for the researcher to be sensitive to and respectful of diverse stories and contradictions and tensions that result within them. Thus, I approached these conversations with utmost respect and understanding.

Potential risks that apply to myself and my family as well as I engaged in this autoethnography. Some of the potential risks include; the feeling of vulnerability as intimate details will be publicly shared, the lack of anonymity, and the emotional turmoil of intimate recall of events and emotions experienced throughout the past four years.

Confidentiality is key in the nature of this study for it aims at exploring intricate details on the lives and experiences of the family of a child with disabilities. All information was kept in a safe and secure place. With the exception of my own name and my children's, pseudonyms were given to all family members when writing up the data and reporting it.

As stated earlier, I struggled with the means of reporting the Sailor's part of the story in a way that reaches the hearts of the readers. I knew that to do so, it would be best if I presented her story in first person. For many months, I struggled with the idea of doing that, primarily because I felt I have no right to assume her identity. I was afraid to report or interpret events that she would make sense of differently than I did. After careful thought and consideration, I chose to do what would best illustrate the Sailor's experience in parenting their daughter Tammy. I chose to utilize the 12 hour audiotaped conversations in addition to the numerous email exchanges that we shared to report her story using first person and as accurately as she described it to me. As a means of clearing any misinterpretations or representations that I may have engaged in during reporting and analyzing my data, I chose to send Sarah a copy of my research prior to submitting it to my committee members and have her amend or delete any pieces of her story that may have been misrepresented or analyzed.

CHAPTER 4

FINDINGS

The purpose of this dissertation was to explore the experiences of two mothers of children with disabilities through narrative inquiry. The mothers shared stories on their experiences parenting their children and the impact that the children had on the family. The data collection methods for this dissertation included narratives of descriptive and reflexive journaling, conversational interviews, and document and artifact review. The existing literature on the subject reports that mothers are the primary caregivers of their children with disabilities and are at the front end of seeking, advocating, and providing services to their children. Therefore, the experiences of two mothers of children with disabilities was studied for this research.

The outcome of the data collection methods yield vignettes representing the experiences of Sarah and me. A selection of vignettes were chosen to be presented in this chapter. It is by no means that the presented vignettes cover the entire experience of Sarah and me, however, they seek to convey to the readers a sample of experiences that we deem as significant ones. The vignettes describe experiences, thoughts, and emotions that Sarah and I experienced as we worked our way through the world of disabilities.

The Beginning

Dreams: Zeina

Only two months into being married, I learned that I was expecting twins. Thrilled is an understatement of what I was experiencing during that time. I had gotten married in May 2011 and for a few months afterwards, I was busy showing people my

wedding video and recalling experiences that I treasured of the beautiful wedding celebration that I enjoyed. My wedding party was spectacular because it was filled with love and joy from family and friends. The joy of having my tall handsome brother at my wedding filled my heart with warmth and happiness. The feeling of love, happiness and security offered to me by his presence was vast, for he was my brother, my only sibling, and always had my back. As I recall the events and the emotions I experienced in the summer of 2011, I get overwhelmed with feelings of blessings, love and joy. A beautiful wedding filled with love and support, followed immediately by the thrilling news of expecting twins, a boy and a girl.

My first dream of my twins was of my daughter's wedding day. This dream represents the notion of constructing an image of my child that is relevant to my cultural and familial context (Green, 2002) for it is related to my wedding experiences. I could almost feel how happy and how emotional I would be on the day my daughter got married. In the dream, I always imagined my son standing by me so tall and handsome like his uncle before him, cheering for his sister and dancing at her wedding. I imagined him carrying her over his shoulders just like my brother did for me at my wedding. Yes, my dreams were very similar to the experiences that I had shortly before I knew I was expecting my two bundles of joy. If I pictured any change in what I wished and dreamed for regarding my children's future, it would have been that they lead a more prosperous and joyous life than mine. It is only normal for a parent to wish the same or better for their children. Right? I imagined and wished for a strong everlasting sibling bond

between my twins. A breach of the meticulously and perfectly constructed dream for my twins would mean shattering my world.

Six months into a healthy and joyous pregnancy, six months into living a life of completeness and blessings, my world shattered. On November 26, 2011, at a mere 25 weeks into gestation, I delivered my twins preterm. Three weeks later, on December 19, 2011, my son Omar passed away. My perfect and complete world shattered. My constructed dreams, my hopes, and my wishes for my twins were crushed- TWICE. First, when Omar was diagnosed with a brain hemorrhage that would leave him severely disabled. The diagnosis of Omar certainly was the death for our imagined twins and family. The idea of my perfect child and my perfect family was breeched (Lindsey, 2011). The diagnosis of Omar put a death statement on my constructed images and dreams and a deep sense of interpersonal loss followed (Goddard et al., 2000). My world shattered yet again when Omar passed away three weeks after his birth. Oh how PAINFUL the death of a child is- unimaginable pain. The death of a child is one of the biggest fears and stress factors for parents, especially those of children with disabilities (Kearney & Griffin 2001). The diagnosis of Omar certainly was the first death of dreams that I experienced, and his passing was the second, and will forever remain a scar in my family. For many months, or perhaps years following his death, I struggled with the fact that Omar's heart stopped beating while mine continues. I struggled with accepting my altered dreams of the eternal sibling bond for my twins; a dream that was shattered too soon. The parental sorrow that I experienced was deep. Sorrow is an inevitable feeling that parents of children with disabilities experience (Green, 2002; Heiman, 2002; Taylor-

Bourke, Howie & Law, 2010; Yousafzai, Farrukh & Khan, 2011). The diagnosis of Omar and his death caused an unfathomable amount of sorrow over the imagined child, the imagined future, and the actual child.

Prior to my preterm delivery, I dreamt of taking my daughter shopping with me. My husband, Bilal, dreamt of a buddy to dress alike, and to play with. Bilal had bought himself and Omar identical clothes to wear, prepared and assembled the twins' room as I took pictures of him do so for the twins to see when they grow up. Bilal's smile was wide and big in that picture. His joy and pride as he prepared for fatherhood were indescribable. He was eager to assume the role of a father and took on the responsibility of preparing the room for the twins.

On Omar's burial day, Bilal dressed himself and Omar in one of the identical outfits he had bought for them to wear when the twins would be born. He put it on Omar as we were getting ready to go to the cemetery. Bilal took pictures of Omar wearing that outfit and sobbed like a baby. He said, "This is the only chance he will have to wear it." Oh how profound and scarring the pain of losing a child is, oh how sorrowful these times were (Goddard et al., 2000). I wanted to apologize to Bilal for his pain, I wanted to apologize to Omar for not being able to keep him healthy and alive in my belly. I wanted to apologize to my daughter Kynda for losing her brother, for breaking the eternal bond between them, for changing her life in such a significant way. I as a mother, felt responsible for the loss and pain of my family and the death of my son. I experienced feelings of guilt and self-blame for failing to maintain a healthy pregnancy that would yield healthy babies. I failed at my maternal role of sheltering and protecting my children.

Parental duties are characterized by successfully fulfilling the roles that are socially and culturally imposed. Failure to meet the societal expectations means failure to be successful in assuming the role and its embedded duties. My self-blame thoughts and feelings of guilt are consistent with Francis (2012), Heiman (2002), Mickelson et al. (1999), and Valle (2011) who report these feelings among parents of children with disabilities. Valle (2011) explains that mothers feel guilty and ashamed that they feel they have not fulfilled their expected cultural role of protecting and rearing healthy individuals and this was certainly a strong feeling I experienced and continue to do so at times. I failed to grow my children healthily. I failed to protect them.

One of my coping mechanisms for the loss, sorrow and guilt that I was experiencing was through God's grace and will. One of the first thoughts that I experienced following the traumatic preterm delivery of my twins was the urge to apologize to God for any sins I had committed in the past and for that He might be punishing me for. I also confided in God in effort of trying to make sense of the unfortunate events that took place. Why me I asked constantly. Why did my life have to change so drastically? Why did my son have to be deemed as severely disabled? My thoughts fluctuated between believing that the experience was a test from God and the belief that God was bestowing upon me a punishment that I deserved due to past sins. The excruciating pain that I experienced as a result of my preterm labor led me to seek and wonder about coping mechanisms. I thought that coping through God's grace and will were exclusive to me and my religiosity, however it seems that this coping mechanism for parents of children with disabilities has been verified by Broomhead

(2013), Mickelson et al. (1999), and Thwala, Ntinda, and Hlanze (2015). Finding meaning and spiritual support through God's will was one that helped me sustain my strength during my journey, however, I often wondered why I had to have such an experience. Till this day, I wonder, yet I have no answer.

My father is a person who has strong faith in God. Throughout my experience, he has never ceased to remind me of the power of God's will, fate and how merciful God is. I am a Muslim by faith and in Islam, God's will is very eminent. "You want, I want and God does what He wants" is a very popular religious statement that Muslims believe in. What that statement means is that despite all the wishes that man has, God will do what He has planned for man. The statement serves as a reminder to those going through crisis that no matter what we wish or plan for, things will be the way God wishes them to be. A verse from the Holy Quran (30:4) explains that the decisions of matters are first and foremost to Allah (God). During many different occasions over the past years, my father continuously repeated these two phrases to me. He reminds me that God is more merciful on mankind than mankind on himself, and that while we might not instantly see the purpose or the good in what has happened, we will understand it later. He reminds me to be patient and not complain of the situation which I am in and always ask God for His mercy. Dad continuously pushed me to surrender things to God and to ask mercy from Him. A prayer he taught me to say is "Lord, I do not ask You to stop what is predestined but I ask You to be kind and merciful in it." This belief is called fatalism, the belief that everything that happens is predestined to happen.

Surrendering the logical interpretations of why this experience happened in my life was the easiest coping method, and I have employed it throughout the past years. One might think that I am exaggerating or being very harsh when I say that my coping mechanism has made me go far in thought to believe that had Omar lived to be healthy and well, he might have grown up to be an evil person who harmed people, and so God did not want that for me or him. Crazy it might sound, yet a real thought it is. The experience of my preterm delivery and all its consequences altered my values, dreams, perspectives, status, and roles. A new me was born.

I have examined and noted my self-perception over a period of three years starting from the summer of 2011 to spring of 2014. In summer of 2011 I viewed myself as a young normal and successful individual. I was working towards a doctoral degree in special education, had a graduate assistantship assignment, was newly married, and pregnant with healthy twins. I felt happy, thankful and blessed. Could I have possibly been taking things for granted? Yes, possibly because my self-perception a few days after the delivery of my twins was very different than the one I had a few months earlier.

I no longer perceived myself as successful, blessed or thankful! I'm no longer felt successful nor happy. The loss that I experienced with the altered image of my twins left me feeling unhappy and a failure. At the time I was not consciously aware of my fear of being thrust into the stigmatized category of a parent with a child with disabilities; however my feelings and thoughts reflected that fear. I was thankful for my doctoral degree in special education for I would need it to mother children... but I did not want to mother a child with disabilities! I did want my image to change. I did not want the

dreams that I had for my twins to be altered. I despised the new social category I was going to be part of; a parent of a child with disabilities. It sounds harsh and selfish, but the truth is that I chose to let go of my child partly due to the fear of the being part of the world of disabilities. The doctors suggested stopping life support for Omar because of this health condition and because of his future prognosis. The decision was excruciatingly difficult because after all he is my son, the apple of my eye. However at the time, this option did give me a sense of relief because it opened up a way to escape the world of disabilities. The doctors speculated an 80% chance of him developing mild- moderate disabilities and a 60% chance of developing severe disabilities. That's not what I imagined for my child, for me, for my family! I was SCARED of parenting him, of the change that parenting him was going to bring about to our family and our identity.

I even went far enough to worry about who would care for him when I pass away. Parents of children with disabilities are often thrust into a stigmatized social category due to their close relation with the stigmatized individual, the person with disability (Francis, 2012). Fearing the dehumanizing societal attitude towards individuals with disabilities has been reported by parents of children with disabilities (Kearney & Griffin, 2001). Perhaps this is why I feared parenting Omar and I worried about who would care for him when I pass away. My main fear was stemming out of society and their attitude towards Omar. I wondered if he would he be treated kindly and with respect or would he be mocked and viewed as less fortunate? Given all the information I had at the time, I let Omar go. I hoped the label of a parent of a child with disabilities goes with him.

Several years later, I still wonder if I made the right decision or not. I seek to realize what I lost with the loss of Omar. I experience TREMENDOUS amounts of guilt and blame. I am a mother who wishes to go back in time and change things. I am a mother who WANTS to know what life could have been like with her son being alive. Anyone has a crystal ball?

The love for my first born never ceased or diminished. It grew with his loss. I still wonder about the unknowns and the uncertainties that came with his diagnosis. Whitehurst (2011) claims that parents become fearful and anxious when they are thrust into an unfamiliar world that will bring a lot of change to the family. I still experience guilt and self-blame on failing to protecting him from harm and giving up on him. These feelings are not uncommon amongst mothers of children with disabilities. They are often attributed to perceived failure in protecting and sheltering the child (Francis, 2012; Gray, 2003; Green, 2002; Sher, 2006; Myers, Mackintosh, & Goin-Kochel, 2009; Thwala et al., 2015; Whitehurst, 2011). My feelings of guilt and self-blame is an area that I cannot delve deeper into for I fear not being able to assume its psychological repercussions. Instead, I choose to visit his grave often and tell him all about his family and siblings, tell him how much I love him, ask for his forgiveness for failing to protect him, and letting him go.

In spring of 2012 I chose to put my degree on hold and assume another home that was 90 miles away from my real home. I rented an apartment on the territories of the hospital that Kynda was at and decided to stay there for the duration of her hospitalization which was 4 months. I became a bereaved mother waiting upon her

daughter to grow and develop in order to speculate her health prognosis and the future. I chose to put aside all roles other than my parental role in order to assume it and fulfill its duties. I was blessed with the support of my husband, my advisor and my employer to support me in my decision to make my parent role a priority over all others. Super (1990) states that individuals may assume more than one role during a time period, however conflicting life role demands arise for individuals which leads them to decide which life role takes priority. My priority was mothering my daughter and being by her side as she grew from a 2 lb. fetus into a 7 lb. newborn size. Applequist (2009) maintains that parents of children with disabilities acknowledge how emotionally draining their journeys were and since I was still immersed in grief over the outcome of my twins and filled with apprehension on my daughter's future, I too was drained from my energy.

A few months after Kynda's birth, she was diagnosed with hearing loss and developmental and cognitive delays. I became a bereaved mother AND a mother of a child with disabilities. I thanked God that her disabilities are not very obvious. Very few were able to identify her hearing loss as a baby, especially that she did not wear hearing aids at the time. Few picked up on her delays and I always justified them with her prematurity. The social impact of disability was one of my major fears at the time and this is illustrated in my worry on how exposed Kynda's disabilities would be. I believe that I stressed over Kynda's disabilities getting exposed because that meant that my identity as a mother of a child with disabilities would get exposed as well. I was concerned with how society will perceive my children and my capability of bearing 'healthy' off springs. This is a sad truth that illustrates how much society's perception has an effect on me.

Broomhead (2013) and Whitehurst (2011) found that parents feared they be assigned responsibility for their child's disability. This is consistent with my feeling and is illustrated in the fact that I blamed my daughter's disabilities and my son's diagnosis on prematurity.

In spring of 2014, Kynda's disabilities became more obvious for she started wearing hearing aids. Her disabilities became more serious and a brain MRI showed damaged parts of the brain. My world shattered when I learned the news of her brain damage. Her disabilities were now documented in the medical world. I felt disillusioned at the moment of my daughter's official diagnosis of a brain damage. I feel on paper and through tests, she is an imperfect girl with deficits and brain damage. In real life, she is the most lovable, cutest and smartest girl I have known! I choose to let Kynda define who she is and not her tests. She will be the person responsible for telling us who she is and what she's capable of and not machines and individuals who haven't had more than a few moments of experiences with her. I wondered about the impact of that on her educational world.

I found myself asking the why question again. Why me again? Why does Kynda have disabilities? Was God punishing me again for letting go of Omar because of his health condition and prognosis? I tried to run away from assuming the identity of a mother of children with disabilities once with Omar but it followed me again with Kynda. I was meant to be a mother of a child with disabilities. Stigma experienced from society is very hurtful. It represents an identification mark on the stigmatized individual's forehead that marks them as an outlier of the society. I thank God that Kynda is a girl.

Perhaps her hair covers her hearing aids and society by kinder to her than a boy. Link and Phelan (2001) define stigma as the co-occurrence of labeling, stereotyping, separation, status, loss, negative emotional reactions, and discrimination. I was again left with fear of the unknown future. My heart wept at my daughter's diagnosis. Soon afterwards I realized that grief over what has been lost will not yield me any good. I needed to provide Kynda with the best opportunities that could shape who she becomes in life. This evolution of grief from pure sorrow, to why me questions and then to a decisive moment in time whereby the parent realizes that these thoughts and feelings will not do any good to the family are reported by Green (2007). Following that decisive moment, the parent realizes that what needs to be done is to provide care and opportunities to the child that foster opportunities for optimal development and growth. My role as her mother is to do everything and anything in my power to assist my child in developing in the best way she can.

As stated above, I often struggle with defining who Kynda is; for my view of her is very positive and capable, yet on paper and through assessments and evaluations she is deemed as a girl with significant deficits. My perceived image of who Kynda is implies a positive outlook of her. Parents of children with disabilities speak of their child using words of love, optimism, and admiration (Goddard et al., 2000; Heiman, 2002; Kearney & Griffin, 2001). Perhaps it was my innate motherly love for her led to a positively constructed image filled with perfection, love and hope. However her assessments paint

an image that highlight her differences and deficits as defined by the medical model on disability.

With time and experience on parenting Kynda, I have learned to adopt MY perception of my children rather than the ones stated by assessments and evaluation. I have learned to reject perceptions and evaluations that I strongly believe do state my daughter's real potential nor her strengths. I am her parent, and I am by the far the person who has spent the most time with Kynda. Nobody except herself will be able to describe who she is better than me. I chose to reject Kynda's definition that is imposed by society and adopt my own understanding of who she is based on her strengths and capabilities.

A parent of a child with disabilities is often subjected to the turmoil of adopting a personalized and fair definition of their child's abilities and identity. As stated above, I experienced this commotion through the discrepancy between my views on who Kynda is and what her capabilities are and how Kynda is defined on paper through her assessments and evaluations. Sadly, society and service providers often adopt the label and the definition provided by the medical model on the identity of the child. This model often defines individuals by highlighting their areas of deficits and continuously seeks to provide the individuals with interventions in order to 'fix' their deficiencies. Since children with disabilities are viewed through the deficiency lens, they and their families experience stigma from society.

Experiencing the loss, sorrow, pain, and stress of having to drastically alter dreams of our children that are based on personal, cultural, and familial contexts is profound. Motherly self-blame is an instant by-product that I experienced and a powerful

coping mechanism that I employed throughout my experience. Up until this day I find solace through God's will and grace.

Diagnosis day for children with disabilities is a significant and often unforgettable painful day for parents. That day is when dreams are shattered, hopes are crushed, expectations are altered...only for new ones to form. Sarah illustrates her experience during diagnosis day and her re-bonding experience with Tammy in the vignette below.

Cheated: Sarah

At the age of five months Tammy, my precious daughter was diagnosed with Lissencephaly, a congenital brain malformation that results in severe physical and cognitive disabilities along with a shortened life span. The comfort I find in that is that if I live my normal expected life span I will outlive her by a number of years which will enable me to care for her all her life. The news of our perfect child having an imperfect brain was devastating. Parents normally pray that their children bury them, however parents of children with disabilities pray for the opposite. This is because in the case of our death, we worry about guardianship, institutionalization, and money for the care of our child; a notion supported by Jones (2011). However, because life has an unpredictable nature, my husband Evan and I, have made plans and secured funds that go into providing Tammy with the care she needs in the case that we would no longer be able to care for her. Parental responsibilities of a child with disabilities may be lifelong with everlasting dependency of the child rather than the typical increase of independence.

My typical life disappeared when the doctor said “Mom we have a problem.” People would try to comfort me by saying “oh, you’ll meet people and have experiences you never would have otherwise.” True, but no real comfort when I didn’t want to be there in the first place! I was thrust into an unknown world that I did not want to be in in the first place, what comfort will that do? This is a common feeling among parents of children with disabilities as stated in Yousafzai et al. (2011) and Green (2002, 2003). This world is fearful to parents of children with disabilities because of the change of roles and lifestyles that come with it.

Four and a half years prior to having Tammy, I had my oldest child, Sammy. I am one of five children, and so I wanted Sammy to have a sibling who he could play, fight, share experiences with and reminisce just like I did with my siblings. My dreams for my children are ones that are similar to what I experienced in my familial context. When I became pregnant with Tammy, I was overjoyed to know my wish for him would come true. What I thought was a healthy pregnancy and a healthy baby did not hold true. Sammy now has a sibling, just not in the way I imagined for him. I grieved his loss as much as my own. While I may have felt cheated by life, Sammy on the other hand did not. He loves his sibling and she adores him. He plays with her, sometimes, much to his father’s dismay, jouncing her all around. As a child, he often assured me that it’s okay Tammy is in a wheelchair because people in wheelchairs can do lots of things. He accepts Tammy for who she is, when sometimes I fail to do so. I wish people viewed Tammy using the same positive outlook he viewed his sister, one that highlights capability rather than deficits. This is the difference between the social model and the medical model on

disability. Acknowledging the possibilities and capabilities of a child with disabilities along with the joy that is experienced as a result of parenting the child is something that I would have never experienced had it not been for Tammy.

Given the devastating news of our perfect child having an imperfect brain we coped in the usual ways: utter shock initially, but with support from family and friends and our belief that God provides for all we coped. I am a crier by nature and right after Tammy's diagnosis I cried every day. Upon the diagnosis of a child, grief certainly becomes the parent's companion (Bruce et al., 2014; Myers et al., 2009; Seligman & Darling, 1997; Thwala et al., 2015). It is grief over what has been lost and the changed future. Tammy's diagnosis day was characterized by feelings of emptiness and darkness, as though I was thrown into an abyss. Oh how much tears I shed on that day... I believe God cried as much as I did. During that day, I felt that Evan, Tammy and I were held by the hands of God. This is what God does when there are no words to be said. I KNOW that God did not mean to do this to us, and this is part of where I live. Things happen in life and good things can come from that. As reported in Gray (2003) and Thwala et al. (2015) solace in God was and continues to be one of the most powerful and most useful means of support that I utilize. Social support from friends and family was another means of support that I utilized very often. As Bruce et al. (2014) and Green (2007) explain, social support consists of emotional support, advice, consolation, and caring from people who have a close relationship with the mother. Luckily, I was overwhelmed with those and continue to day. The feelings of sorrow, emptiness, and darkness that surrounded me on diagnosis day maintained a strong grip of me for about a week. I then decided I need to

come out of the deep dark bottomless hole that I was thrown into and start caring for my two children.

Initially, one of the oddest parts of adjustment for me was re-bonding with my daughter. I had her and cared for her for five months before her diagnosis but all of a sudden she was a different person to me. She was not the daughter that we thought we were going to have. It was weird- the realization that she was not the same yet is the same person. I love her dearly and would not trade her for the world. Still, I sometimes fight with myself to let go of what might have been and fully appreciate the child I have. I mourn the deep loss that I experienced, yet my love for my daughter is ever so strong and I have learned to savor the joy for what is.

I no longer cry everyday now but I still have days when I am more susceptible to tears. Things that will make me cry include having to tell someone of her diagnosis for the first time, thinking about losing her, and unexpected acts of kindness from people. There are days when sorrow weighs heavily and others when it seems typical. I no longer use the word normal because it is no longer part of my life for I am a parent of a child with disabilities. The grief and sorrow that I have experienced has evolved throughout the years to take on a variety of forms and move across several stages. This evolution was addressed by Green (2007) who states that grief initially starts off as sadness and sorrow over what has been altered. However, with time mothers like myself move beyond this grief and describe a conscious and decisive moment after the trauma of the diagnosis where they are able to move on from the initial phase of shock and grief into loving and

caring for the child. This was evident when I realized that my feelings of sorrow and grief were not going to do anybody any good.

Grief can also be characterized by why me questions on the changed future along with parental guilt towards the child's changed potential. Like many mothers, I most certainly experienced that, for I have experienced a wide array of emotions and thoughts the past two decades. I have learned to keep some of my thoughts and feelings in a box locked away. The box contains feelings of guilt towards Tammy's disorder and "why me" questions. I keep this box hidden and locked away for I cannot deal with those feelings and thoughts. For a period of time, I was entrenched with them... but then, I realized that they did not do me any good...they did not help.

An experience that sets my emotional trigger on is Tammy's diagnosis day. Despite the decades that have passed since this experience, I still fail to withhold my tears and sorrow as I recall this day. On Tammy's diagnosis day, I went down to the lobby area in the hospital that we were at and called my mom to tell her about the news we received. I can take you to the phone booth where I was, I can still see it in front of my eyes. My mother was saying why why?! I said its okay, God gave her to us, and she said well why did God give her to YOU?! I said well WHY NOT?! WHY NOT? The conversation was filled with lots of tears, but I'm grateful that I was right way able to my mom. It took me a year before I asked the why me question. I did eventually, but it took me a year.

And I very definitely did the guilt thing as well. Because I grew her, right? I grew her... but I didn't grow her right so...my fault... I know that the feeling of parental guilt towards a child's disability is not a feeling that is exclusive to my experience and has

been reported by other parents of children with disabilities such as Blum (2007), Francis (2012), Gray (2003), and Heiman (2002). In my family, both Evan and I blamed ourselves for Tammy's disability. Several years after Tammy's diagnosis, Evan and I had this conversation about guilt towards our precious daughter's diagnosis. Turns out that he always blamed himself...because he was 52 when we had Tammy. So surely it was his old sperm that was the problem! When I learned about how he too felt guilty, I was surprised because it wasn't only me who was entrenched in this feeling. Now, I laugh as I recall this conversation. Each one of us blamed themselves. Much of the feelings of guilt are due to the cultural script on the parent's responsibility towards protecting their child. When parents have a child with the disability, they feel they have failed to protect their child.

For two weeks following diagnosis day, I was deeply entrenched in guilt and then I realized that that was not productive that it didn't help me, it didn't help my children- it didn't help anything. So I figuratively took that guilt and the 'why me' and put them in a box and I don't look at it. It's not gone, it's there. I just don't look at it. I can't... I can't. It's just there...

I have learned to accept and live with the changes I have endured to my once typical dreams for my children. Adapting is typically one of the early struggles that parents experience upon the diagnosis of the child, for it includes adapting to a new roles and expectations (Heiman, 2002). I have learned to realize the beauty in what is and let go of anguish for what has been lost by Tammy's diagnosis. An instance that would illustrate this would be one that occurred during the spring of 2004. The Land's End

overstock catalogue came and as usual, at my earliest opportunity, I leafed through it looking for those too good to pass up deals. I lingered over summer sandals looking at a pair for in the girls section. There were some lovely purple ones. Tammy's colors being pink and purple, they were worth perusal. I evaluated the sandals for ease of donning (doffing is usually not a problem; actually coming off too easily is generally a problem). My thoughts then turned to "will Tammy like these?" or perhaps more appropriately will her peers like these and will they help her be 'one of the girls' or just prove she has a mother who has no fashion sense. Tammy was 7 years then; we were quite adjusted to her limited abilities but it suddenly stuck me as I sat trying to decide on what sandals to buy, the pure joy of having a child be able to pick for themselves. To say "mom, I don't like those" or better yet, "mom I really like these."

I remember the first time I bought some shoes for my son and he announced they were okay but he didn't really like them (translate: I won't wear them). Back to the store they went and I never bought him a pair of shoes without his being present again. Tammy gives me no such trouble. She gladly wears anything I put on her. But oh the simple joy of having a child express a personal preference. Mourning the loss of independence of a child was also reported by Green (2002), as she parented her disabled daughter. The independence of a child from his/her parents marks the beginning of separating from mom and dad; of expressing themselves as individuals; of deciding on their own. Often times those decisions can be quite frustrating for the parent, but again, one of life's simple pleasures as in a rite of passage. My heart weighed heavy for the little girl who would be stuck with her mother's choice instead of her own. My heart rejoiced in the

little girl who was free from decision-making and all the burdens therein. It is an ever present struggle though no longer a constant one that wages in me. My sorrow over what has been lost continues to linger every now and then and has become a typical part of my life (Heiman, 2002; Kearney & Griffin, 2001; Yousafzai et al., 2011). Tammy is who she is and I am blessed to have the opportunity to care for her. She has triggered personal growth in our family by instilling values of cooperation, compassion, and tolerance. The sandals? I didn't order them. I decided to take her peers shopping with us so they can help this old, fashion-less mother make a good decision for her daughter.

Yes, parenting a child with disabilities is marked with immense changes to dreams, roles, expectations, and more, however people who are unfamiliar with the world of disabilities often perceive this change to be one that is characterized solely by loss and sorrow. When in fact, what starts off as bitter and sorrowful, later transforms into joy and personal growth. I like many other mothers have realized the positivity and interpersonal growth that my family has undergone as a result of having Tammy in our life (Kearney & Griffin, 2001; Myers et al., 2009).

Children with disabilities are not any less than typically developing children. Sammy realized this about his sister in a wheelchair at a very young age and much faster than I did, for it did take me a few years to make this realization. Several years after I had Tammy, I sat in a soccer field and watched a tall young man holding the hand of a dark haired little girl, both of them in soccer garb, as they ran along the edge of the 'big' field headed toward the U8 field. It was, no doubt, big brother and little sister with big brother making sure sis got to the correct playing field. Unbidden came the thought, 'that

could've been Sammy and Tammy'. Could've been because the age and sizes looked about right. Sammy is 4.5 years older than Tammy; he plays U12 (under age 12); she would be playing U8 (under age 8) if she played soccer. Would be playing- if she could run- or even walk for that matter. But that is not our reality. Tammy cannot run or walk or stand or even sit without a lot of assistance. One might think the scene of brother hand-in-hand helping litter sister get to her soccer game would be painful for me to watch, or at least elicit sadness for what is not to be for my children. But it didn't. The relationship between Sammy and Tammy is no less because of Tammy's limited abilities- and perhaps it is more. While I may on occasion wish for more that is not where I live. I can't. That would be too awful a place and life is definitely too short for that. Instead, I enjoy the camaraderie and caring that obviously exists between the soccer playing brother and sister knowing that the relationship between my children-brother and sister- is the same. One of love and trust and enjoyment in time spent together. I can do no less but offer my thanks to God for the privileged of being mother to children such as Sammy and Tammy.

The above vignettes illustrate some experiences, thoughts, and emotions that Sarah and I have had regarding our altered dreams and expectations for our children. Without a doubt, sorrow and grief over the loss that we experienced were our sole companions when we learned of our children's altered future. Mourning what we had lost was inevitable and deep. Our coping mechanisms included shock, denial initially, solitude, and self-blame. However, soon after that we realized that these mechanisms did

not do anybody any good. We sought support and meaning of our experience through God's grace and will and through support from family and friends.

Positivity, joy, and interpersonal growth were outcomes of parenting our children with disabilities. The fear that we initially experienced during diagnosis day was replaced with a positive outlook on our child's capabilities and potential. This outcome has been expressed in multiple studies; namely Goddard et al. (2000), Jones (2011), and Kearney and Griffin (2001). These authors state that in spite of the seemingly obvious challenges and changes that are part of parenting a child with disabilities, positivity and love along with joy are also existing elements.

Throughout the Years

Social Aspects

Evaluations and opinions: Zeina. In 2014, my husband and I decided to take our daughter Kynda to a pediatric neurologist to seek an evaluation of her development. She had been relatively healthy and catching up with her milestones however, she was still significantly physically, developmentally, and cognitively delayed. Kynda walked at 25 months and when she did she seemed to drag her right foot. We were concerned that there be an issue that we are missing. Her Area Education Agency (AEA) therapists and pediatrician acknowledged this observation yet they assured us that Kynda was making progress and that is what really mattered. Despite their re-assurance, we chose to go for an evaluation by the medical provider specialist.

Our decision to get her evaluated by a medical professional came out of our desire to provide her with the best medical and interventional care in order to ensure the best

opportunities for optimal growth and development. One of my greatest fears in parenting Kynda has always been coming to a point in time when I regret I had not done more for her when she was younger. For the first three and a half years of her life, Kynda's needs and interventions took precedence over ANY and EVERYTHING else in my life. They even took over mothering my newborn baby Omar Jr. that was born 12 months after Kynda's birth. The psychosocial repercussions that a parent experiences as they parent a child with disabilities are immense. The concern about the time and energy being consummated by the child with disabilities and the fear of neglecting the typically developing children siblings is often experienced and has been expressed in research studies by Myers et al. (2009) and Thwala et al. (2015). Typically developing siblings often miss out on a fair share of time and attention because the parents are consummated with the needs of the child with disabilities. Feelings of guilt towards "neglecting" Omar Jr. and not providing him with the ample amount of patience, enthusiasm, effort, as I did for Kynda was something that drained me emotionally and psychologically. I recall expressing those feeling to Kynda's AEA service providers who assured me that I was doing a wonderful job by managing my time and energy between both kids. They pointed out that in addition to the attention and interactions that I was providing Omar Jr., he was getting some from his sister.

I believe feelings of guilt, fear, and worry are much more entrenched when parenting a child with disabilities than a typically developing child. In a study by Goddard et al. (2000), the feelings of guilt among parents of children with disabilities extends to attribute the child's performance to the mother. If the child is doing well that

means the mother is doing a good job at parenting her child and the opposite holds true. As a result, when a child is lagging in some areas, the mothers often feels guilty as though this deficiency is her fault. This possibly occurs because of the socio-cultural expectation that the mother must do everything in her capability to positively influence and shape the future of her child. Perhaps this notion explains my fear of not providing Kynda with the best opportunities to progress. I feared acquiring the bad parent stigma which defines the parent as incompetent and lacking responsibility to fulfill the parental role successfully.

There was a time in my life, when I felt I no longer enjoyed a mother-daughter relationship with Kynda because I was overly consumed with conducting evaluations and assessments for her Individual Family Service Plan (IFSP) and Individualized Education Program (IEP) goals and taking her to therapy sessions. The stress that was inflicted on me by assessments, evaluations and appointments for my child was high. I felt outraged that I was no longer enjoying my daughters because of evaluations and interventions. That was not right! I was even more outraged when I found that many parents feel this way because of the stress of assessments and evaluations (Green, 2007; Myers et al., 2009; Ogston, Mackintosh, & Myers, 2011; Thwala et al., 2015; Whiting, 2014). Kynda's appointments and evaluations were for her pediatrician, speech therapists, physical therapists, audiologists, special educators, and more. The worst time was around the time of her Individual Family Service Plan (IFSP) or Individual Education Program (IEP) review. The stress of conducting many assessments and evaluations to evaluate her progress and formulate new goals made me feel like I was missing out on enjoying my

child. I felt that I was her examiner rather than her mother. One parent in a study conducted by Goddard et al. (2000) said she felt her child belonged to the system rather than to her. I was feeling the same way.

Coping with my role as an examiner was not easy to adjust to, because it felt like it was taking away from my role as a mother. On many occasions, the role of the examiner conflicted with my role of a mother. This notion of conflict among roles has been described by Super (1990). He states that when conflict exists among roles assumed by an individuals, stress is experienced. As a mother, all I wanted was to cuddle with my child and read stories with her. My examiner role however asked that I bring out the checklist provided to me by her therapists on the concepts she should be mastering and completing assessments to see where she was at with those concepts. The time that Kynda and I spent together was filled with frustration from both ends. I was frustrated when she would not show signs of understanding what I was teaching her. As a parent, I wanted my daughter to strive but I was doing all that I could for her. As a toddler, Kynda was frustrated with her mom who wasn't playing with her and instead was getting upset at times for reasons that her toddler mind could not understand. The educational and medical evaluations done on her deemed her as deviating from the norm and in need of interventions. My joy of parenting her and experiencing her as she is resulted in a perception of her as a whole and as a human. This positive perception is supported by the social model of disability. These events and feelings represent challenges that I faced mothering Kynda due to her disabilities.

When we arrived to the neurologist's office on March 17, 2014, the waiting room was empty. That was a good sign because we won't have to wait too long before we get admitted. Few minutes later we get called into the examination room. A very kind nurse escorts us inside and gets some information about Kynda and the reason behind our visit. We explain to her that we would like an evaluation done on Kynda to make sure we are not missing anything significant that may hinder her development. Soon after she leaves the room, the neurologist walks in. He is a very kind man, very humorous, and very friendly. He knows how to handle children. He was able to examine Kynda while making her think it was all a game. His examination was filled with play and so the room was filled with laughter and joy- big smiles on everybody's face.

Now came the time for the word of truth from the doctor. Oh how I longed for this word of truth. Oh how I wished I owned a crystal ball when she was an infant to tell me if she will develop normally or not and what problems she would have.

Interestingly enough, I describe what the doctor will say as the 'word of truth,' despite the fact that he only spent few minutes evaluating her. In a sense I was giving his opinion on Kynda a higher value than my own opinion. I describing his opinion on her after a few minutes of interaction as 'a word of truth' and my opinion on her after 28 months of interaction as a perception that I am fighting for! This perception could be the effect of what society conditions us to give high value to. We are brought up to give

medical professionals very high value on what their opinion is on our physical and psychological state of health.

The doctor looked us and said “I read over Kynda’s medical history over my lunch break today and as I was reading I was thinking to myself oh my God what kind of child am I going to see. When the nurse walked out of your room, the first thing I asked her was, how is the girl? She said: she’s very cute. So tell me, why are you here? Yes your daughter has some delays but so what? She’s doing great. Count your blessings! Go outside and look at the kids waiting in the waiting room and then you will realize how blessed you are.” Bilal and I smiled happily at this words. It was as though the Supreme Court has ruled for us! “Your daughter is doing very well. She might have delays here and there and maybe if we look deeper we will find a diagnosis, but why will that matter. Look at what she CAN do, she can eat, run, walk, and talk! Take your daughter home, enjoy her, and before you leave here look at the kids that are in the waiting room and then you will realize your blessing.” The three of us left his clinic very happy. The waiting room was empty. There was no one to compare Kynda to.

What this doctor said to us represents the general view of people on individuals with disabilities. They are people who are less, less fortunate and probably not blessed. Perhaps this is the definition of stigma as per Goffman (1963) for he defines it as a discrediting attribute that transforms the bearer from a whole and usual person to a tainted and discounted one. Francis (2012) explains that stigma tends to spread to those

who are associated with the stigmatized individual. In other words, both an individual with disabilities and his/her family become stigmatized. What the pediatric neurologist said about Kynda in comparison to other children in the waiting room represents the stigma that individuals with disabilities face. The immediate feeling I got as a result of the doctor's words is superiority towards a group of people and that was possibly why Bilal and I were happy to hear the doctor's words. His judgement on our daughter was that she was not less, others were, but not her.

For some time this feeling of superiority made me feel good about my daughter and my parental status. It was only when I started reflecting on my experiences in the world of disabilities that I realized the idea that was embedded in me by the doctor. This realization made me conscious of the stigma that even the most educated amongst us forces upon individuals with disabilities. On the influence that the doctor may have had on my interpretation of the diagnosis of a disability, Scorgie et al. (2000) states that

Parental responses to diagnosis of disability can be profoundly shaped by the images hospital members personnel, agency workers, educators, extended family members and friends construct of disability, the meanings they ascribe to "being disabled" and the choices they afford persons with disability and their families. (p. 100)

This explains the feeling of superiority that I experienced when the neurologist addressed Kynda's health status in comparison to other children who visit the same clinic. The way the neurologist explained to me Kynda's health status was through undermining other's health status in comparison to her. Thus, this left me with the feeling of superiority over the population of individuals with more significant needs. The doctor's attitude on disability represents the medical model of disability whereby the

individual's deficits are highlighted to form their identity. As articulated by Lenny (1993), disability is a problem not of the individual but of the disability society, meaning that the societal attitude and systematic barriers are what create this disability.

Perhaps in a very naïve and superficial context, the words of the doctor are true- compare your daughter to others and you will realize your blessings- however upon mindful examination of children of all abilities, one realizes that individuals often count their blessings regardless of what they can do and cannot do. Every individual is special in his/her own way. If the doctor characterized an individual's cup as half empty, the individual may characterize the cup as half full.

Notable is the pediatric neurologist's words of optimism and positivity. Throughout our visit he treated us and Kynda with utter kindness, and used words of optimism and hope. His interaction is one that I valued and appreciated. I appreciated his question to the nurse How is the girl, and her answer she's very cute. I felt that Kynda was viewed as an individual rather than a patient. Our visit to their office was joyous filled with smiles on all faces. He provided us with ample time and attention. He answered all our questions honestly, yet added optimism to his answers. (Green, 2001) states that parents value interactions with professionals who are able to laugh and interact with their child without feeling sad or awed at their condition. She adds that parents don't want professionals to cure their children, they just want to hear that they and their children are doing well given the parameters they must live in and that was truly what I heard from the doctor. He did not ask us to seek more physical therapy or speech therapy. He told us to take our child home and enjoy her as she is.

Unlike what has been reported by Goddard et al. (2000), I did not feel that this neurologist objectified my child. In fact, his time and interaction with us portrayed that he valued us and Kynda as an individual. Did he objectify other children who would have been categorized as having obvious disabilities? Perhaps he did and continues to do so especially for individuals who can “fake” normal.

One of the most hurtful and destructive things that an individual can experience is a judgement, a negative attitude, a low perception of ability towards oneself or a loved one. A close family member of mine frequently checks in with me on Kynda’s health and progress. She is always happy to hear of the improvements and growth that Kynda is demonstrating yet always manages to throw in the sentence “Don’t forget that Kynda has a special situation.” This statement irritates me because it declares that despite all the progress that Kynda is making, she still cannot see beyond her “special situation.” Yes Kynda does have disabilities but she can certainly fall for a typically developing child because in so many ways she is very typical. I have perceived my child as a typically developing child much more than I’ve described her as a child with disabilities. Over the years and through the experiences that I have gained, I have made an informed decision to let Kynda decide who she is and what she wants and not what her assessments, educators, professionals, friends, or family. Nobody can tell us more about Kynda’s abilities and needs than her own self.

Every time this family member reminds me of Kynda’s “special situation,” I realize how society often times cannot let go of the child’s label and the stigma that is

attached to it. Some people are just over consumed with Kynda's labels that they are unable to see beyond them. Many times, a label attached to an individual will obscure others to vision potential and this seems to be happening with the family member of mine. I believe this is an example of the effect that the medical model of disability has on society, whereby a person's deficits are highlighted and become the prominent subject of discussion.

To illustrate my point further on how people can be overconsumed with a label to be able to objectively see the true potential and capability of the child I recall an experience with Nadine, one of my childhood friends who is a special educator and a school psychologist in Lebanon. Every summer when my family goes to Lebanon for a vacation, Nadine spends so much time with my children; playing and interacting with them. There was a time when I had asked her to reviewed Kynda's IEP and health assessments to see what services she would need if we were to move to Lebanon.

She told me that she could not believe that the reports were addressing Kynda's issues. She said "Zeina, I feel we are talking about two different people. In her assessments and IEP, her deficiencies are very much highlighted and you get the impression that her deficiencies are significant. However, in real life, she is just like any other child!" Nadine's comment illustrates the perception and the stigma that affects perception of the capabilities of a child who once received a label.

If you see through my eyes, you will see Kynda defined as a strong willed, patient, observant, perseverant, sweet girl. None of this is highlighted in her IEP report, nor do our conversations during her IEP meeting dwell on her strengths or capabilities

such as her outstanding memory or her good behavior, or the fact that she identified all her alphabet by the age of three! Kynda's labels and assessments SHOULD NOT define her more than she defines herself. She should be in charge of showing people her personality through ongoing face to face interactions that take place in authentic settings. To get the best potential in a child, the child must be comfortable with the activity he/she is engaging in and comfortable with the people around him/her. Assessments are often administered by people whom the child does not know very well and in settings where the full potential of the child is not unveiled. Those same people who spend a few minutes with the child write up evaluation reports that forever affect the child, let alone the fact that the evaluation is deigned to pinpoint deficiencies rather than strengths.

Kliewer and Biklen (2007) wrote on the significance of constructing local understanding of the student to formulate a closer to accurate idea of his/her understanding and knowledge. They reject the use of objective practices of assessments and state that "These practices can reduce a child to various categories of impairment within 90 minutes of a first-ever meeting."(para. 9) This is confirmed by the demeanor of my friend on Kynda's IEP for she is a person who has interacted with Kynda in multiple settings all of which were filled with lots of love, fun, and laughter. Therefore, she has constructed a different perception of Kynda than what her IEP communicates.

As with my struggles on how people perceive Kynda, Sarah has also had similar struggles. One of the most notable experiences was with a teacher in Tammy's school, who also happens to be a very good friend of Sarah.

Evaluations and opinions: Sarah. This is an incident that happened when Tammy was about 6 years old. There was a boy in Tammy's classroom who once asked the classroom teacher if Tammy can nap whenever she wanted. He had asked that question because Tammy often takes short naps during the day as she is sitting in her chair. The teacher said yes she could. The boy answered "She is so lucky she can do that."

That afternoon, the teacher shared the story with me. She did not tell me who the child was. A few days later, I share the story with one of my friends whose boy goes to Tammy's class. She tells me that it was her son who made that comment and had shared the story with her as well. She tells me "But I said to him, oh honey but she's unlucky in so many ways" and she explained to him that Tammy can't do this and can't do that. I was in utter shock! I told her "WHY?? WHY would you do this to Tammy?? Why would you take away this image he created of her?!"

The conversation between my friend and I certainly spurred a great deal of anger from my side. I was angry that she took away the positive image that this boy had of Tammy! I was angry that she altered the beautiful picture he drew of Tammy. That conversation did not change my relationship with the friend (who is a teacher in the same school). It really was an opportunity to educate; it became an opportunity to provide another perspective.

Years down the road, when Tammy started doing volunteer work at the elementary school, it was this teacher/friend who introduced Tammy to each grade level in the school. In fact, she did an excellent job with introducing her. This experience also gave me some insight and opportunity to think about how to respond to people's comments in a way that would allow them to vision possibility instead of just seeing limitations. It was just another learning experience by which my values and my thoughts matured and refined. What was special about this experience is that it also created an opportunity to teach others about taking on a positive perception of a child with disabilities.

Not only do mothers of children with disabilities have a different perception of their children's abilities and identities that lay people or service providers, but they also experience situations where they realize the importance of 'perspective'. Incidents or characteristics that are of greater significance than others. This notion may receive criticism by groups of people, however, I have chosen to report it because it has been experienced by both Sarah and me. Mothers of children with disabilities acquire a realization on things in life that matter the most to them. Sarah Green, the sociologist that is frequently cited in this dissertation is also a mother of a daughter with disabilities. On the subject of perspectives she states that mothers "have learned to focus on things that give life meaning for them, and let other things slide" (Green, 2007, p.159). This means that they may not dwell on issues in life that seem trivial to them. This notion will be

explained in two mini-vignettes illustrating an incident from my experience and an incident from Sarah's experience.

Perspective: Zeina. Following the birth of my twins, their diagnosis, and Omar's passing, I remember being very irritated at things that my friends complained about; in laws being nosy, trying to decide on a venue to spend New Year's Eve at, and complaining about expecting a baby boy rather than a baby girl. I just wanted to scream at them and tell them WHO CARES, SO WHAT, IT REALLY DOESN'T MATTER. What matters in life is that your family members be in good health, because if they are not, you have lost a priceless blessing. I wanted to explain to them that in the grand scheme of things those are minor things in life that don't make or break life. Instead I said nothing, I just realized my growth and appreciated it.

Perspective: Sarah. I had a co-worker who had a teenage son with some digestion problems. As a result, temporary food modifications had to be implemented to figure out the food that was irritating his digestive system. Every day she would come to work whining about her son's food modifications and a possible food allergy. Day after day, the same thing over and over again whining and more whining. One day I looked at her and I said count your blessings. Your son can eat, my daughter can't! I just had enough of the whining and I had to say it. The coworker did not say anything to me at that moment, but she was obviously not happy with my comment. She flung my words back at me a number of months later stating she couldn't even talk to me about her son. I had just asked her about her son so didn't know what she was referring to; she had obviously

hung onto that conversation and missed my point. She took my comment as unfeeling/unsympathetic. She tends to be a Negative Nancy and I should have known better but perspective seemed to be in order. She didn't see it that way.

The experiences that Sarah and I describe above depict the perspective and growth that parents gain as a result of their experience. In a study by Myers et al. (2009) one parent addresses the realignment of priorities that her son with disabilities had brought to the family. She states

He has made us 'see the light' and reprioritize. Things we used to think were important are no longer important. Our goals are no longer career oriented. We enjoy life a little more. Our biggest priorities are being happy, having fun, and doing what ever it takes to make that E will be a self happy and sufficient adult. (p. 678)

This can strain the relationship between the mother and others who are possibly forming the core of the mother's social world. This was particularly evident in Sarah's story with her co-worker because she was uneasy with Sarah's comment for a while. When examining the perspectives that Sarah and I have learned through our experience we realize that these were gained due to lived experiences or different realities than families of typically developing children. This can impose some isolation between mothers of children with disabilities and others due to their different experiences and different perspectives. The two groups of parents may find that they do not share common experiences and perspective on issues of life.

The above vignettes illustrate social and psychosocial experiences that Sarah and I have experienced throughout the years parenting our daughters. More often than not,

our social experiences with individuals perceived our daughters as outliers and atypical. The deficient view on our daughters with disabilities was expressed by medical professionals, educators, friends and family. It makes me wonder what to expect from lay people who are complete strangers and have barely had any experience with individuals with disabilities. This pessimistic view on individuals with disabilities stems out from the medical model on disability which highlights the disabled individual's weaknesses and attempts to "fix" them through interventions. Sadly, the people who spread the vibes of the need to diagnose and "fix" individuals with disabilities stems from people in authority such as medical professionals and educators.

Interestingly though is the growth and maturation that both Sarah and I address to be a byproduct of parenting our daughters. Our growth and maturation has enabled us to view our daughters with a lens that emphasizes their strengths, the joy that they bring to our family, and a view of highlights what they are capable of doing rather than what they lag behind on. Parenting our daughters with disabilities has also refined our values and thoughts to be more compassionate, tolerant, and appreciative of all humans. Individuals with disabilities are not less and are joyful.

Professionalism:

Zeina. I am flabbergasted, I am amazed, I am in awe, yet I am in a great amount of turmoil. This morning as I was dropping Kynda off to her class, Laura, her teacher came to me and said: "I made Kynda a doll and we called it Kynda's doll. Kynda loved playing with it and was very happy to see it." How cute I thought. In my mind, I

imagined a pretty doll that looks like typical dolls – maybe with black hair and dark eyes instead of blond hair to represent Kynda. Laura leaned over to Kynda and told her do you want to show mom your new doll? Kynda smiled excitedly and ran to get the doll. She brought a dark old doll that had absolutely no clothes on, and no hair. My first thought was at how unattractive the doll was. Why would this be Kynda's doll?! Why did it not even have clothes on?

As I was trying to figure out my thoughts on what is so special about this doll for it to be Kynda's doll I saw it. The doll had hearing aids drawn on the back of its ears. Two hearing aids just like Kynda's. The ear mold was silver and the actual machine was pink. You could tell that the hearing aids were for a girl. The doll also had earrings drawn on the ear lobes because Kynda wears earrings. Laura was the one who drew the hearing aids and the earrings on the doll. She was very happy and proud of her creation. Kynda was elated, jumping from excitement and very happy with her doll. I smiled at Laura and put on a happy face despite the turmoil of emotions that was going on inside of me. I was truly very happy for Kynda's happiness. I was happy that Kynda had a buddy with hearing loss too in her class, a doll that she related to. But I was sad too because I felt that the doll identified Kynda's difference and did not represent Kynda's appearance well. I left the daycare with mixed emotions. Positive parental perception of the child despite any deficits is often reported parents of children with disabilities (Heiman, 2002; Green, 2002; Goddard et al., 2000; Myers at al., 2009). Therefore, I expected that the doll to be as pretty and as normal as I perceived Kynda to be. Feelings of shock and negativity towards the doll represents proof that I do not perceive my daughter in the way she was

represented. Perhaps it could be interpreted as living in denial, or perhaps I truly hold a very positive and normal perception of my daughter that I don't often think of any identifier of her that does not fall within the normal realm. If you ask me to describe Kynda I would say she is a coquette who is very smart, patient, and observant. She is a girl with an outstanding memory and a very strong will. Hearing loss along with cognitive and developmental delays are not amongst the instant identifiers that come to my mind when I think of Kynda. I believe this is because through mothering her I am privileged to have constructed an accurate local understanding of her capabilities through a myriad of first hand experiences under different conditions Kliever and Biklen (2007). As a result, I have formed an image that I highlighted by strength and capability of my daughter.

Laura has been Kynda's teacher for two years now and she is one of the sweetest, most loving, and most considerate people I've met in my life. She loves Kynda dearly and actively seeks what's best for her. What a priceless characteristic in a teacher.

During the day, my thoughts on the doll with hearing aids were going back and forth between admiring it and hating it. In the afternoon I told Bilal about it. I told him exactly what happened and then I asked him "Why is part of me hating this doll and this idea?" Bilal was very appreciative of Laura's initiative. He described it as creative and courageous thinking. He saw the positive effect it had on Kynda. He reassured me by validating my negativity about the doll. He explained that I was probably feeling that way because I was reminded of Kynda's difference. I was relieved by his acknowledgement. I was also reminded of the importance of the support received from a partner when

parenting a child with disabilities. Empathy, advice, companionship, and common interests are things that Bilal and I have shared the past five years as we parented Kynda.

Soon after I got that affirmation, I was able to see all the positivity in the initiative that Laura took. I call it an initiative because she was the first person in Kynda's 4 years of life who had the courage to put out Kynda's disability to the public as something that exists between people. Amongst the characteristics of a praiseworthy educator is the ability to provide the child with individualized and flexible opportunities that foster a positive parent-professional relationship which in turn serves as the bedrock for improving outcomes in children (Dunst, 2002). Laura demonstrated her ability to courageously think outside the box and envision possibility of altering a figure of a doll to represent my daughter. I thought of the courage that Laura had to have to be able to do that. It was heartwarming to me that she wanted Kynda to feel that she was not alone in needing to use hearing aids.

Laura's initiative made me feel supported and this according to Whitehurst (2011) is a fundamental need of parents of children with disabilities. Parents of children with disabilities appreciate interactions with professionals who are able to laugh and interact with their child without feeling sad or awed at their condition (Green, 2001). Laura was able to do that by courageously altering the doll and adding a book on hearing aids to the classroom's book shelf. This demonstrates how she feels about Kynda's condition; believing in the need to normalize hearing aids for Kynda. I thought of Kynda's peers and the kids who are going to come into the classroom next year and the year after and see the doll and be educated and familiar on hearing aids. What great

exposure and education. Perhaps with this kind of exposure, this new generation would not be as close minded and as judgmental as the older one.

I know for a fact that I will NEVER forget Kynda's doll in my life. I will never forget the example of how a teacher can make all the difference in the world for the child and for many generations to come by simple drawings on a doll. Laura had also ordered a book by the title "Oliver gets hearing aids" to the class. It is about an elephant named Oliver, who gets diagnosed with hearing loss. The book describes the process that Oliver went through to get his hearing aids. Laura often read the book to the class. This book has become one of Kynda's favorite ones to read. How lucky am I and Kynda to have such a considerate teacher for our child, one who think outside the box!!!

Meeting the family needs and providing supports through parent-teacher partnerships, interactions, and collaboration are crucial in shaping or breaking the educational experience of a child at the school setting. Above was an example of a teacher who employed those characteristics to make Kynda's experience a positive one. However, not all professionals do the same.

Kynda's hearing loss was stable at unilateral mild/moderate hearing loss for the first two years of her life. In November 2014, we got news that Kynda's hearing dipped significantly. She was diagnosed with bilateral hearing loss at the mild/moderate level. It is needless to explain the devastating impact that the news had on our lives. We had to live with uncertainty probably for the rest of our lives because that dip meant that

Kynda's hearing can forever take further dips until it is all lost. As a result, her ENT doctor advised hearing re-checks every three months.

In February 2015, I chose to do her hearing test at our local AEA agency rather than at a private clinic. The AEA audiologist who is also a member on her IEP did her test. The results indicated a further dip in Kynda's hearing. Based on the results of that test, Kynda's hearing loss was now at a moderate/severe level in both ears. My heart was set on fire. I was in desperate need for an excuse so that I don't believe those results. I found my excuse. The room and the facilities at the AEA were old and run down. They are probably not accurate. Uncertainty towards a child's future due to medical diagnosis is a fearful event due to its unknowns. I was flooded with feelings of sorrow and grief over losing the blessing of hearing.

My initial method of coping was denying the accuracy of the results by seeking excuses to dismiss the results. Denial is one of the coping mechanisms that parents of children with disabilities use to deal with initial stages of shock and grief (Heiman, 2002). What added hurt to the wound is the apathetic attitude that the audiologist had towards the news. She made me feel like its normal that Kynda's hearing drops. She reported the news to me almost like reporting the weather, making it sound like it was not surprising and okay. How could she not see sadness through my eyes? How could she portray an image that it was okay for a toddler to be suffering from progressive moderate/severe bilateral hearing loss?! Empathy was missing in her tone of voice and facial expression as she delivered the devastating news to me. It is very hurtful for a mother to be receiving unpleasant news on her child's health as the professional

delivering the news portrays an image of indifference to the impact and meaning of the news. She gave me an impression that the news she was delivering to me is not so serious when in fact it is! I instantaneously decided that I will go for another hearing test at the ENT's doctor's office and I told her of my intention.

A week later the results were confirmed by the audiologist at the ENT doctor's office. She was very kind and empathetic when she told me the news. She told me that she was sorry to have to confirm this news. She acknowledged that over the past three months Kynda had big dips in her hearing. Instead of making me feel that it is okay that Kynda's hearing loss is now down to a moderate/severe level, she pointed out that the good news is that Kynda's speech is developing well and she's progressing. She made me realize the strength and capability of my daughter in developing speech despite the changes in her hearing. Viewing and describing the child's strength and including elements of hope and optimism are things that parents of children with disabilities appreciate from a professional (Green, 2001). Thankfully, the audiologist at the ENT's office demonstrated those characteristics for I needed them to raise my morale amidst the bad news that I was receiving.

In the afternoon of that same day, I sent the AEA audiologist an email in which I told her that the audiologist at the ENT's office found the same results as she did and her response was: I'm so glad that the results were verified. **THIS IS NOT SOMETHING YOU TELL A PARENT** whose child lost 30 decibels of hearing in three months!! You may tell a co-worker that you are glad the test was verified as reliable, however to a parent that is just plain harsh. Her response made me feel that she viewed my daughter

merely as a patient and not as an individual or a child whom she cared about. Had she perceived us a fellow family and took the time to develop local knowledge about our feelings, thoughts, and needs she would have certainly been more empathetic and understanding.

What is even more difficult than her lack of local knowledge and understanding as defined by Kliwer and Biklen (2007), is that she is one of the IEP members of Kynda and I have to listen to her input and advice on how to “best serve Kynda.” One hopes to have people on the IEP team who have the needed local knowledge and understanding of the child and the family to be able to perceive them as fellow humans rather than patients or clients. I would have much more appreciated a response of: I’m sorry the results were verified. However, empathy is not something that can be taught can it?

A year later, that same AEA audiologist did a hearing test on my son Omar Jr. as part of the regular three year old hearing screening that governmental agencies offer. I was left a note in my son’s mail box that he has failed his hearing test and that he needs to be retested. No further information was provided. Was it both ears? Were the test conditions and Omar Jr. reliable? Which frequencies did he fail? When will he have another hearing screen? No information except her name and phone number were provided. Given the history we have with Kynda, I was very worried about Omar’s hearing. Could the hearing loss then be due to genetic factors? I called her office to ask for verification on all my questions. Her response was it was not her who did the hearing screen but her assistants and that she did not have answers to any of my questions except that she is looking back at re-testing in a month. My immediate thought was at how

unprofessional of her to send such a note home without having any further information. In my opinion, she has never taken time to think about her patients as individuals with feelings, or else she would have shown more signs of empathy at their needs.

On the same note of unprofessionalism, right after Kynda's hearing dipped significantly to be bilateral moderate/severe hearing loss, I decided to consult with the cochlear implant team at a big university hospital 100 miles away from my home. I went in with a few questions on cochlear implants and Kynda's eligibility for one. My biggest question was: if Kynda were to lose all her hearing, would she qualify to be implanted? I wanted to know the answer to this question because I could no longer live in uncertainty. I wanted to know if I should start teaching Kynda sign language or continue with spoken language. I wanted to know if Kynda would ever be able to hear my voice again if she lost all her hearing.

I prepared my list of questions, and headed off to the university hospital. I took Kynda's brain MRI with me so that the doctor can review it and see the area where the brain has been damaged as a result of her premature birth and decide whether that affected the ability to implant Kynda or not. I waited for about an hour before the doctor came in. He walked in and stood right at the door. He looked at me and said "If your daughter were to lose her hearing I would happily implant her." I asked him "Did you take a look at her brain MRI?" "That doesn't matter" he answered. "Dr. Smith is a fellow in our department and he will be here to answer questions you may have" and he left. The time he gave me did not exceed 30 seconds. One month later, I received a \$1,000 bill for the precious 30 seconds that he gave me. I left the hospital very angry and crushed. This

doctor was the head of the cochlear implant team at the hospital. If he treated me this way, how will the rest treat me? What if one day Kynda does lose all her hearing and she gets implants under his supervision, how would he treat us?? Would he give us our rightful time and explain to us the procedure? I pray that we never have to go there again.

Similar to the need to view and describe the child using words of optimism that highlight strength and capabilities, providing the parents with ample time and explanations of the child's diagnosis, implications and interventions, while listening to their concerns and answering their questions is amongst the characteristics that foster a positive parent-professional relationship. This should be particularly true when the professional sends in a bill for the time and effort they have spent with you. When the characteristics that foster positive parent-professional relationships are missing, respect and trust is lost between the members.

The above vignette is characterized by the characteristics that parents appreciate and seek in professionals who are working with their child. Like several other vignettes in this chapter, statements expressing the challenges that parents face as they embark their journey are expressed. Sarah too experienced some challenges with professional in the educational world. The next section presents some of those experiences.

Sarah. Transition can be a scary time in the life of a soon-to-be preschooler and parents. Particularly when the child has disabilities. If you are experiencing this feeling, know that it IS OKAY! You are not alone in feeling the way you are, in fact families in

similar experiences have reported feeling apprehensive of this change (Applequist, 2009). This fear may be stemming out of role change and professionals being less accessible. My fear was driven by two aspects; the first being my parental duty of assuming responsibility for her my daughter and providing her with the best opportunities and the second through the emotional tie to my child and the need to nurture and shelter her. The decision of where to have your child attend school is a big one, and can be complicated. The questions seem endless. Where will my child's needs be best met? How will the teachers and other students receive her? Will she be okay? Will she get the services she needs? Will mom and dad be okay?! How will we know if we are making the right choice for our child and our family? What if we change our minds?

We struggled through all of those questions and more in making the decision of where to send our daughter to preschool. She was in Early ACCESS from the age of 6 months and the thought of changing from a home-based to a school-based program was, indeed, scary. We visited schools, asked questions, visited more schools, asked more questions. The significance of continuous and honest communication and collaboration amongst the school and the family is crucial for a successful school transition and is supported by Applequist (2009), Edwards and Da Fonte (2012), Sawyer (2015), and Schischka et al. (2012). Continuous and honest communication facilitates collaboration between the school and the home setting to best meet the needs of the child.

At last the decision was made. Not everyone agreed with it, but it was our choice, based on what we know to be best for our daughter, her older brother, and our whole family. It was a decision we were comfortable with, and, in our hearts, we felt was the

right one. Some AEA members did not feel that an inclusive school setting would be the correct placement for Tammy. However they knew that they could not stop parents from making the choice of placement and could do nothing more than let us know how they felt about our decision. The AEA feared that the teachers at the local school district did not have enough experience with students with disabilities and that's why they advocated for a segregated school placement rather than an integrated one. I on the other hand, knew that if Tammy were to be placed in a segregated school setting, she would have been placed with children with the most significant needs, so all kids in wheelchairs and all non-verbal. Her primary interactions would be with the adults in the room and some with the other kids but that would have been very limited just because of the limitations of all of the kids that she would have been placed with. This is not what I wanted for Tammy. Instead, I wanted Tammy to be subjected to as many experiences as a typical child would be and that was a decisive factor in choosing a school setting for her. Therefore, I strongly believed and advocated for an all-inclusive general education school setting.

Monthly team meetings and lots of conversations closely followed the transition to preschool. When all was said and done, it was a successful year. Now we are ready for the transition to pre-kindergarten- five half days a week. It was far less painful. All the preparation that went into our family's transition from Early ACCESS to Tammy's preschool paid off. We finally knew the answer to at least some of the questions! No doubt, each year, with its own transition, will bring new questions and challenges. And each year our first question will be, "Where are Tammy's needs best met?"

As you think about transition for your child/family from Early ACCESS to a school setting, consider all the possibilities. Visit the schools. Observe. Ask lots of questions. If you are unsure, go back and ask more questions. Talk to other families whose children have moved from Early ACCESS to preschool. The importance of support that is acquired through families with similar experiences is vital, seek families who have been there and done that prior. It will provide you with a feeling that you are not alone in your journey and creates a sense of community between you and other families in the same boat (Green, 2002). Know what you want for your child, for your family. Go with your heart and know that, gradually, the bleeding does stop. Yes bleeding, because it hurt me to pass on a chunk of what I considered to be my parental responsibilities to her teachers. I am a person who likes to be in control, sending Tammy off to school meant entrusting other people to carry out her cares for her. It is now almost two decades after Tammy's first schooling experience and I still struggle with letting go of the control.

My experiences throughout Tammy's school years were a combination of supportive and accusing ones. A negative one that I recall happened when Tammy was in second grade was regarding one of Tammy's one on one associate who just needed to NOT be working with children. The classroom teacher had A LOT of concerns, the school nurse had concerns- she was just someone who just should have not been there. She was a last minute hire. There was a time when she had medical appointments that she could not change. So I volunteered to be Tammy's one on one for those days that she was gone. So on one of them they were doing their spelling pre-test, it was 2nd grade and with

Tammy how we did it was hand over hand with her so marker to paper. We did it. The teacher goes around and she's checking their tests and she came to ours and puts a star on ours and says "very good Tammy" and I said "well, we were a little worried about penguin but I was pretty sure we had the rest of them" so she leans down and says to me Tammy doesn't always get her words correct- which means the associate couldn't spell at 2nd grade level! This is what we were dealing with.

This associate was at me about thinking that Tammy didn't weigh enough.

Tammy was tube fed, she got her feeding tube when she was four years old. And she kept saying that, and my response to her was always well we are on our physicians care, we are doing what our physicians direct. I don't want her to be too heavy and she's healthy. I said to the nurse one day I'm ready to say to her just report me to the DHS. JUST report me! LET'S JUST get it over with!! The nurse said "DON'T SAAAY THAAAT!!" and I said well I'm ready to be done! And so we didn't end up doing that. And in the spring they asked me if I would write a letter to the next level up in the AEA to say why I didn't want to have this person come back. And I thought about it and I didn't do it. I said "I'm gonna trust that the system is gonna work. I shouldn't have to, as a parent put my foot in the middle. I was already labeled a demanding parent."

This associate did not have simple knowledge needed to be able to assist a second grader in her spelling test. However, what is more significant is the invasiveness that this associate demonstrated in our lives when she was on to questioning Tammy's weight and health. As Edwards and Da Fonte (2012) recommend through their 5 point plan , parents should be treated with respect and dignity and respect must be shown to the roles of the

family members and cultural backgrounds for they are the expert on their child's needs. Williams (2012) also stresses the importance of listening to the mother with regards to the needs of the child because she knows the child best. Therefore, it is important to take the mother's perspective and opinion seriously and respectfully.

The associate made me feel guilty and responsible for Tammy's weight. She made me feel that she was unhealthy! She insinuated that I was the person to blame for Tammy's "unhealthy figure" by implying that I was not doing a good job at feeding Tammy and nourishing her. What was even more hurtful is her persistence in blaming me! Bad parent stigma is also known as mother-blame as it is primarily geared towards mothers and holds them responsible for their child's undesired attributes (Francis, 2012). I wanted to just scream at her "JUST REPORT ME!" and let us get this over with.

I was already labeled a demanding parent. When I walked into the school I felt that I had the word 'demanding' imprinted on my forehead because that was what some educators and AEA members perceived me as. The school principal confessed to me one time that she was told by some AEA members that I was a demanding parent. This was because I let nothing take precedence over the best interest of Tammy. When thinking of an action plan for services and goals for Tammy, I did not accept the excuse of "I don't know what to do in this situation" from an educator or a professional. I realized that the local school district which Tammy was placed in did not have a student with significant needs like Tammy's before and so lacked experience. However, I too am new to parenting a child with significant needs, so my response was "This is my first time as well, so let's figure this out together." As a physical therapist, if I have a patient that I'm

not sure what to do with, I would not tell the patient go seek another PT. Instead, I would seek assistance and advice from fellow therapists on a plan of action.

The above vignette is one that highlights the professionalism that needs to be present among educators and professionals to ensure a positive home-school partnership. The relationship should be fostered by respect, dignity, and acknowledgement that the mom knows the child best. The vignette also addresses the impact that the role of a parent has on seeking what is best for the child for it is filled with responsibility in determining what helps meet the child's best interests.

Leisure

Zeina. During the first week on January, 2012, Only 10 days after Omar's passing, Bilal told me he had a surprise planned for me in the next few days. Knowing Bilal's love for travel, I had a feeling that he booked us a ticket to go somewhere. I couldn't imagine it though. Kynda was still at the hospital, relatively stable but yet the roller coaster ride was not done yet with her health issues. Omar passed away a mere 10 days ago. A couple of days later Bilal tells me that he has booked us a trip to visit the west side of Mexico, Puerto Vallarta. His only request was that we don't tell anybody that we are going there. Despite my shock at his plan, I did not question it. Knowing the person he is and the pain he was going through, I knew that he NEEDED that trip to revive his morale. I agreed to the trip. I agreed primarily for his sake because I knew that he was going through an emotional turmoil that an OB/GYN father would towards an

unsuccessful pregnancy. I knew he was grieving for many reasons. First, for the loss of his son. Second, for the unknown future of his daughter. Third, for failing as a father and as an OB/GYN to ensure a healthy pregnancy for his family. We told the nurses at the hospital that we were going down to Texas to visit my brother. Our friends in town thought we were 90 miles away with our daughter who was in the hospital, but we were actually in Mexico.

For me, that trip was dominated by tears. Tears at the airports, tears at restaurants, tears in the middle of the ocean as I was snorkeling... the tears I shed were primarily for the loss of my son Omar. I grieved his death and thought of the irony of me being on a leisure trip as his short lived life ended. I grieved what could have been a family trip. For me that trip was like diving against the current towards land. That trip was a struggle on its own for it was filled with sadness, yet it gave me a sense of the continuity of life. Life did not stop with Omar's passing. Life continued, and at that point I saw hope of life being beautiful again with Kynda's presence.

Four years following this trip, I conversed with Bilal on the reason behind him booking that trip and not wanting people to know about it. "What had happened to us was life a train wreck and so we needed a change of mood. We were very depressed and sad... living in the hospital for many months. I feel like we need the change, to take a break, because when you are in the hospital all the time you don't see anything else. You just see the sorrow and the pain of the hospital- so this gives you an idea of how life still exists, things still go on, things can change and there is hope. This will not continue as is. This is the main reason why I booked...to...umm...and it was more for you than for

me...because YOU were staying in the hospital all the time. I was going to and from work. It was also for me because I too wanted to take a break.” On the reason behind not telling people we went to Mexico Bilal said “Part of it was that I felt that people will not understand what we are going through and people judge and their first reaction will be ohhhh they have a child in the hospital and they are going for a trip! How irresponsible! They don’t care about their child! This is the perception so unless someone is in your shoes, they will not get it. Probably if it was someone who has been through the same experience then I would be comfortable sharing this with them because they would get it.” He continues to say “It’s okay to take a break. It’s okay to leave the responsibility on someone else for some time. The most common thing is people know that parents in general deserve some time alone without children as a couple. So this is something common in society and acceptable.” I then asked him if four years later he would be comfortable telling people about our trip and his response was “I care less about people now but I still don’t feel comfortable 100% because this is society. Society has not changed for the past four years, I might have changed that’s why maybe I care less but how people think is still the same for the past years. I would still not tell them but I care less than before.”

The reason behind us telling the nurses that we were going to Texas to visit my brother was that we wanted them to know that we are not around if something happens. The nurses were very surprised with our travels plans. We feared they would think that we did not love our child enough and care for her. We feared they care for her less thinking about why they should care for her the best they could if her parents left her.

Perhaps their train of thought is logical but at that point there was nothing we could do for our child that the medical system allowed other than to pump milk for her and watch her through the incubator.

Looking back at this leisure trip that Bilal and I took, I do not regret it, however I am surprised at the courage and strength we had to go through it. I do acknowledge that if our daughter was not in very safe hands and in stable condition, we would have never left her bedside. However, given all the factors, a little joy wouldn't hurt our hearts.

Our trip to Puerto Vallarta explains an attempt for adding leisure to our life following the birth of our twins. Engaging in leisure activities is one of Donald Super's (1990) nine roles that one assumes in a lifetime. Prior to having children, leisure was a vital pillar of our life. We knew that once we have children, leisure was going to be compromised for some time.

What had happened to us was like a train wreck indeed, and we needed a change of mood... I feel like we need the change, an escape to take a break. Engaging in the leisure activity of traveling was the break and escape that we sought. Due to Kynda's medical condition and our status as bereaved parents, it seemed inappropriate for us to announce our trip to people. We knew we needed this trip for our own sake, for our own morale, yet we could not explain this to society. Therefore, we chose to keep it from them. It is expected that the parents are the primary caregivers of their children, especially when they are not in optimal health. I believe, it was due to this expectation that we chose to keep our leisure trip a secret.

Another role from Super's life span and life space roles that is addressed in this vignette is the partner. I accepted to go on the trip because knowing the person he is and the pain he was going through, I knew that he NEEDED that trip to revive his morale. I agreed to the trip. I agreed primarily for his sake because I knew that he was going through an emotional turmoil that an OB/GYN father would towards an unsuccessful pregnancy. Four years later when I asked him why he booked the trip, he claimed that it was for both of us, for our morale, for us to realize that life still holds hope, however he stated that he booked because he felt I needed the change more than him ... "it was more for you than for me...because YOU were staying in the hospital all the time. I was going to and from work. It was also for me because I too wanted to take a break." He explained that when at the hospital all the time one sees nothing but sorrow and pain and so he wanted me to see that positive things in life do still exist. It was interesting to me to see that each one of us thought he agreed to the trip for the other person's sake. This brings me to realize the importance of the support from your partner during difficult times. As a partner, you seek to support your significant other, to make things more pleasant and easier for them. This is what we were both doing to each other- nurturing each other through our crisis.

To follow up with the idea of the need for a leisure trip for Bilal and me, comes the needs and supports for parents of children with disabilities. As stated above, the most common thing is that people know that parents in general deserve some time alone without children as a couple. Likewise, for parents of children with disabilities, especially shortly following a diagnosis, time is needed to assimilate and make sense of the

information that was showered upon them. It was also a time to rejuvenate, inhibiting fatigue, stress, grief, and vulnerability. It was like an escape for a short period of time...where you can forget your pain for a while and try to recoup and have time alone for yourself. The hope was that it would lift your morale, our spirit and give you another perspective... It was a time needed to find the strength to continue our journey, for life continues.

As with many other vignettes that I have written on my experience birthing my twins and their diagnosis, sorrow and grief are constant integral pillars of my experience. Sorrow for what is lost, yet joy for what has become. I do not know that sorrow will ever go away. I do know that it gets better. For me, that trip was dominated by tears. Tears at the airports, tears at restaurants, and tears in the middle of the ocean as I was snorkeling... the tears I shed were primarily for the loss of my son Omar. I grieved his death and thought of the irony of me being on a leisure trip shortly after his short lived life ended. I grieved what could have been a family trip. Grief over what has been lost for our family was extremely strong during those days. Grief is typical amongst parents of children with disabilities (Bruce et al., 2014; Green, 2007; Myers et al., 2009; Seligman & Darling, 1997) and amongst bereaved parents. That was certainly a dominant feeling that I experienced during that trip.

Despite the pain and the grief that we were in, societal forces still drove our decision. We feared society's response to our trip. Part of it was that I felt that people will not understand what we are going through and people will judge me for leaving my daughter at the hospital and going on a trip. I can hear them say: "How irresponsible!

They don't care about their child!" This is the perception so unless someone is in your shoes, they will not get it. We feared being judged, being stigmatized as uncaring and irresponsible parents. We were already coping with the grief we had over the loss of our imagined family and the guilt for not being able to bear healthy babies and with the decision of stopping life support. We could not bear being thrust into another stigmatized category of irresponsible, unloving, and uncaring parents. In short, we feared society's judgement and perception on what kind of parents we were. This illustrates the impact that society has on individuals, shaping their actions in relation to what is perceived as appropriate, what is not, what is normal and what is not.

In Green's (2007) study examining the weight of burdens resulting from socio-cultural constraints (objective burdens) versus burdens results from emotional distress (subjective burdens) on parents of children with disabilities, she found that objective burdens were more significant. Therefore, burdens that are as a result of socio-cultural constrains outweigh those that are due to emotional distress. It seems that Bilal and I feared the stigma of a bad parent as per Francis (2012). Mothers more than fathers tend to be subjected to bad parent stigma due to their role as the primary caregivers of the children. We feared they would think that we did not love our child enough and care for her. We feared they care for her less thinking about why they should care for her the best they could if her parents left her. Looking back at this experience, I feel that our logic behind taking this trip was that Kynda is in very safe hands with professionals, and since she was going to be sent home on monitors and oxygen tubes, our family and friends would not be comfortable caring for her because they were unfamiliar with those

equipment and her needs. Therefore, this truly would be our only opportunity for travel a very long time. This brings us to an issue that has been addressed by Whiting (2014). It is the challenge for family, friends, or babysitters to care for the children with disabilities due to their complex medical needs and their unfamiliarity with them. Looking back, I know that would have been the case for our family.

“Society has not changed for the past four years. I might have changed, and that’s why maybe, I care less but how people think is still the same for the past years.” This statement, even though made by my husband Bilal, implies personal growth and transformation as a result of parenting Kynda. We have come to realize, only people who are in the actual situation can make a judgement about what’s appropriate and what’s not, and even then, to each his own. We have learned a lot about the world of disabilities through our experience. We have learned how the medical and educational system thrusts individuals with disabilities in a stigmatized category where it’s impossible to free themselves from. We have learned that no matter how much progress a labeled child makes, a parent will be stressed and stigmatized by society. We have learned to brush aside the labels and the stigma to reduce the stress we experience as a result of the perceived image of our child with disabilities. Our comfort level around individuals with disabilities and their families has increased tremendously. We have learned that individuals with disabilities are just another variation of life, they are people who have strengths, weakness, interests, and it is society’s attitude and barriers that disables them. We have learned that families value and enjoy talking about their child with disabilities

as much as their typically developing child. These changes have been a result of our parenting experience.

In short, this vignette is characterized by our need for leisure during difficult times as a means of recouping our strength and our morale. Bilal and I have been each other's support through the difficult time we have passed through. The need for leisure and time for us to revive ourselves is stated as need for parents of children with disabilities. This vignettes, like many other included elements of grief and sorrow over what is lost implying that it is a strong factor of my experience, along with personal growth and transformation experienced as a result of parenting our child. Socio-cultural restraints and expectations have also been addressed through the fear we expressed on society's view of our parenting.

Sarah. Ever since Tammy was little we have traveled around. Initially it was by plane but then I realized that planes are barely comfortable for individuals without disabilities and so if you do have disabilities and special equipment then it gets real uncomfortable. Since that realization my family has decided to travel by car. We have a customized van that we ordered specially for Tammy and it serves us well when we travel. The vehicle fits her wheelchair and locks it in place to avoid any movement. The van also has plenty of open space for equipment that we need for Tammy. Using that van that fits our needs and Tammy's needs, my family has gone on numerous trips. Thankfully, Tammy travels well and that just why we travel so much with her.

Much of our traveling was more for Sammy's sake. When Sammy was a child, I she spent a lot of time parenting Tammy and doing hospital time with her which often left Sammy behind with his father. Both Evan and I wanted him to know that he was as important to us as Tammy, that he garnered our attention as well. I felt as responsible for my parental duties towards Sammy as much as I did for Tammy. Evan and I always feared that Sammy gets neglected as a result of us attending to his sister's needs. In fact, this is a parental concern reported by parents of children with disabilities regarding raising their typically developing child (Myers et al., 2009; Thwala et al., 2015). We wanted to ensure that we provide to Sammy as much as we provided to Tammy. There were a couple of times when I traveled with Sammy alone and left Tammy behind with her father. Leaving Tammy was HUGE for me! It involved passing over my parental responsibilities to her father, and as I noted earlier, passing on parental responsibilities is NOT something I handle well. I am a controlling and attached mother who wants to be the one who cares for her children, who is there when the school bus drops them off, and who gets called by the school if something comes up with her children. To leave Tammy behind with Evan caring for her and while I was miles away from them with very limited contact was very big for me.

Before I had kids I went to the third world part of Jamaica and it was a different world and culture. I made a decision that one day, if I have children, I want to bring them here in order for them to experience the difference in culture and lifestyle. Sure enough, when Sammy was about 15 years old, I took him to Jamaica for community work. As I

stated earlier, I wanted Sammy to experience the different culture and I wanted him to know that he garnered our attention as well.

That trip was HUGE for me because I didn't have contact with home. Evan had an emergency number that he could use get hold of me if he needed to. Not being able to call home and check on Tammy and Evan was VERY HARD for me! That meant I could not check on how they are doing as frequently as I wanted.

The other trip that I took with Sammy was to Europe. It was for two and a half weeks. We visited friends in England and Germany during that trip. I would call home at least twice a day to check up on Evan and Tammy. Evan would say he that when he and Tammy went to the airport to pick us up, I counted Tammy's fingers and toes to make sure she had them all! Those trips were HUGE HUGE for me. During both of these trips, I had respite lined up and Evan would come up to me and say "you know you don't have to have respite come in everyday." I said "it's not for you, it's for me." I knew Evan would be very well capable of caring for Tammy and I trust his care, but knowing the respite was lined up for them gave me reassurance that they will be okay. Perhaps the reason behind why mothers often assume the primary caregiver roles for their children with disabilities is due to their need to be in control of their child's welfare. This stems out from parental unconditional love for the child.

Our leisure activities have also involved the four of us in trip across the nation. Both Sammy and I like to hike and so we would go on hiking trips where he and I went up trails and mountains as Evan and Tammy stayed behind in a park.

Leisure trips have always been a big part of our life and in the family I am the traveler more than Evan is. He even once told me, you make being married to you fun. These activities are integral in providing the family with fun and diverse experiences. Tammy's needs have never hindered our travels and she was always a part of them. Thanks to her for being a great traveler, she makes traveling so easy for us.

Roles

I'm not a child: Zeina. Throughout the past four years, I have remained the child in my parent's eyes. When I was pregnant with my twins, and was going through the nauseating first three months, my mother flew over from Lebanon to help me. She helped with cleaning the house and cooking. Mom came for a month and we made arrangements that she would come back when the twins are born. It is in our culture that the female's mom comes to help out with the newborn for the first month or two. So typically, my mom would come a week or two before my due date and stay with us for a couple months to help out with the new born. I was a wife, a mother expecting twins, a full time doctoral student, and had a 20 hour graduate assistantship.

Things did not go as planned and I delivered 15 weeks early. Mom and dad were VERY worried about me. They were worried about my well-being, my morale, my feelings, and my ability to cope. That was understandable for they were parents who were worried about their daughter. Dad would tell me, let your mom come over and stay with you. And mom would tell dad "Go visit Zeina, you are the only person who calms her down and makes her feel better." My answer to them both was that I don't want anyone here with me for I was staying at the hospital all the time and the twins were going to stay

at the hospital for another 3 or 4 months at least. There was nothing you could do for me, except play the waiting game like I did.

In spite of the eight hour time difference, Mom and dad would call me over 5 times a day. On days when they wanted to give me more space, they would text me. Dad was better at cheering me up. He would try to be funny and would tell me all about his day so I had something to think about other than the health of my twins and the hospital stay. He would send me prayers to read for my babies. He would remind me that whatever God has planned for will happen and that God is more merciful on people than their own mothers. He gave me hope, he motivated me to believe in the power of prayer and God's will. He was always there to calm me down. He convinced me that my twin's premature birth and Omar's death was all for a bigger and better purpose. He reminded me that this may be a test from God to see if I will be patient and believe in God's better plan/ purpose or if I will fail to endure.

Mom on the other hand is more of a worldly person. She was vocal about questioning why this had to happen to us? She was as bereaved, as sad, and as touched as we were by the premature birth of our twins. More than anything else, she was WORRIED about me. She would tell me, "God be with you. I don't know how you are enduring." She even told me once, "I am afraid this event will break you forever." Her worry about me was beyond what words can describe. There were times when I wanted to speak to someone, to tell them about what I was going through with the kids' health, my worries about them, my feelings... someone to vent out to. Through experience I learned that I should not vent out to mom and dad- especially mom. When I voiced out

my feelings and the events that were taking place in my life, they got worried to the point that they added stress to my life. I did not need more of that, so I decided not to vent out to them anymore. It was not out of any malicious intentions, only out of deep parental love for me. Despite being married and a mom now, they were still mothering and fathering me. There were times when I wished they would be more objective and offer me words of advice and wisdom on how to handle things since they have more experience in this life than I do. However, mom and dad could not step outside their mom and dad shoes.

In spite of all the roles that I was assuming when I delivered my twins, I was still a child in the eyes of my mother and father. They were still busy mothering and fathering me when I was busy mothering my own children. There were times when I wished they would be more objective and offer me words of advice and wisdom on how to handle things since they have more experience in this life than I do. However, mom and dad could not step outside their mom and dad shoes.

The stress that I experienced out of their inability to step outside their mom and dad shoes was because how their worries clashed with my needs as I mothered my twins. I wanted someone to empower me and to provide me hope and optimism that joy does return and that things will be okay. However, most of the time, their worries about their daughter conquered their ability to provide the support that I needed from them.

I appreciated my father's proposed method of coping- religion. That was exactly what I wanted from my parents throughout the months and years that followed the birth of the twins. If only they could have supported me without worrying about me. I did not

want to ask why questions, my emotional and mental state could not afford asking these questions. They were going to drown me further in my grief for no good reason. As with the health prognosis of my twins, there were many unknowns regarding the reason of premature delivery. I chose to utilize religion and faith in God as a mechanism for making sense of what happened and accepting it. Thwala et al. (2015) report that parents of children with disabilities seek spiritual support in God's grace when facing the challenging situation of a change in the imagined child and family. I have utilized this spiritual method of coping throughout my experience.

As stated by Super (1990), conflicting life role demands may arise for individuals. Deciding which role takes priority is crucial. Sometimes a spillover from one life role occurs to another and these tend to create conflict. In my case, the spill over between my child role towards my parents and my other roles at the time of the delivery of my twins created conflict and tension in my life as to which role takes precedence. This vignette also addresses a coping mechanism that was introduced by my father and that is religion.

Cutting the umbilical cord: Sarah. For some people it is, as the old expression goes, cutting the apron strings. For me, I think it was more like cutting the umbilical cord. Tammy was four years old on her first day of preschool. She was fine, but I cried like a baby. I had promised myself I wouldn't cry until I was in the privacy of my van. knew I would never make it until I got home! But as I bent over to kisses her goodbye and tell her I would see her later (our usual parting ritual), the tears came and there was no return.

First day of schools tends to be for most parents an emotional day because it involves letting go of some responsibility of your child for a number of hours each day to another adult and that was certainly not one of my strengths. First day of preschool also represents a first step in subjecting the child to the real world through interactions from different people and I was apprehensive on how that would look like for Tammy.

The associate kindly offered to let me stay for a few minutes to see that tammy was okay. I declined. I knew tammy would be okay. This was a Mom thing. The awful wrenching of that umbilical cord! I knew I needed to make a clean break or cut as the case may be. Standing around sobbing, letting the blood flow is not a healthy way to sever the cord. It needs to be a quick, precise cut; clamped quickly and discarded.

For Tammy, the moment passed quickly. For me it will take several days (weeks?) for the stump of that cord to heal. But heal it will, hopefully without infection, and we will all be better for it. Especially Tammy, who is being allowed to move on to a new phase in her life. As in the literal cutting of the umbilical cord between mother and child, she will now move forward, guided by others, distinct and separate from her mother. (At least for 3 hours a day, 3 times a week!) I am so happy for her! It is as it should be. Striving towards greater independence is something that I have always set as a goal for Tammy.

The thing that makes this particular severing of the cord even more momentous is the little girl and the school environment she is in. Tammy has severe/ profound developmental delays, physically and mentally. The preschool she is attending is a typical

preschool. All of the other kids are typical kids who will run and hug their Moms when they come pick them up, and will tell them about their morning.

Tammy will show her love in a different way, but I know she will show me she is happy to see me. I will know how her morning went by how the rest of the day goes, and by the report I will hear from her associate and from her teacher. Tammy is capable of proving me with the same information but in non-conventional ways. Don't mistake my thoughts about the capabilities of my daughter for living in denial for parents of children with disabilities have been stereotypes previously in such ways (Goddard et al., 2000). I in fact have learned through first-hand experiences that Tammy's differences should not be mistaken for deficits. After all, human differences are typical. Parenting a child with disabilities and a typically developing child are like eating cheese cake and a chocolate cake, both are sweet and savory, each in its own way.

We have worked hard for this day and moment of separation to occur, as have numerous professionals. We are on the road less traveled and, I believe, everyone will be better for it. Certainly Tammy, her classmates, and her teachers will. And Mom, with her severed umbilical cord, which oozed less blood as time went by, surely will be too. I believe Tammy's inclusion in the school district, at church, and the community triggered some personal growth and change in individuals who met her. Can we sit back and say we've made this gigantic change, no but we have made ripples. We've made ripples and we've changed- SHE'S changed individual lives. Any student whose life was touched by Tammy' - if someday they have a child with a disability or a niece or nephew or a neighbor or whoever, that they can share those positive stories with them. Green (2001,

2003), Jones (2011), Myers et al. (2009) and Valle (2011) have addressed parental growth and transformation as a result of mothering children with disabilities. Contact with children with disabilities helps increase wisdom with respect to the variety of disabilities. Change and growth are often achieved due to acquiring an extensive amount of knowledge, exposure, and awareness that automatically leads to increase comfort levels with individuals with disabilities. In fact, one of Tammy's teachers once said to me that students in the classroom have learned to cooperative help each other without being prompted to and that was triggered by Tammy's presence in the classroom.

School and home partnership in making the schooling experience successful, pleasant, and positive to the child and the family. The importance of collaboration, open and honest communication, and placing the child's needs as the top priority when devising an educational program for them (Sawyer, 2015; Whitehurst, 2011; Whiting; 2014; Williams, 2012) is not to be taken lightly. To work towards a successful educational experience requires extensive work from both parties, however, it facilitates a smooth and successful schooling discourse. To facilitate the success of my daughter in the educational setting, I have alternated between wearing three different hats that signify three distinct roles; the mom hat, the PT hat, and the advocate hat.

I am by profession a physical therapist. I was working full time before Sammy was born. When he was born it was very easy to quit my full time job. My plan was to go back to work part time when he went to school. By then, Tammy had come along. They are four and a half years apart. I was intending to go back to do per Diem work when Tammy was six months old. However, at five months of age, she had a tonic colonic

seizure that blocked her airway. It was this event that got us to diagnosis. So then I didn't work for another year and a half. Now Tammy is 19 years old and I have continued to do per Diem work throughout the years. This would not have been possible without Evan's support. He was working full time and was supportive of my decision to be home with the kids. He was willing to take on the responsibility of the kids and the house solely by himself to enable me to devote my time and energy for the kids. Financial crises have been reported by parents of children with disabilities (Green, 2003) due to the high medical and interventional costs utilized by the child. So I KNOW how big of a responsibility Evan had on his shoulders when I quit my job, and I will forever be grateful to him willingly taking on the responsibility.

Over the years I have used my PT hat in the medical world because I know how to navigate that world in terms of looking for good doctors or appropriate drugs for Tammy's seizures. I have often introduced myself to Tammy's doctors as a physical therapist so that they know the background I am coming from, so that they know I have some medical knowledge. I felt that my medical knowledge provided me with power when interacting with the healthcare providers because we have the same medical background. That background often enabled me to be the translator of those medical terms to my husband who would need lay person terms to understand the diagnosis and the implications of Tammy's disorder.

When Tammy was evaluated by a PT at the Early Developmental Intervention Center at four months old, I knew that the minute she touched Tammy, she knew something was not right. I know had I been wearing my PT hat when Tammy was a few

months old, I would have been alarmed a lot sooner that something was not right. Definitely when Tammy was little I wasn't wearing my PT hat at all... but now as she's growing I certainly am, especially in the health care system because I understand it.

At work, I was lucky to have employers who are flexible and understanding. They knew I had a child with disabilities and if she is doing hospital time then I'm doing hospital time with her. I will honor my work commitments to the best I can BUT my first responsibility goes to my children. When I went for Tammy's four month checkup I knew it would be an issue that she was not rolling over yet, but I was wearing my mom hat and not the PT hat in terms of her lack of development and missing her milestones. I was doing the mom thing of every kid does their own thing own pace and I had Sammy whom I was busy with as well. If she was my first one I would have been like ahhhhhhhh because I read the book with my first one. I wasn't reading the book by the time the second one came along.

I worked when my kids went to school. We had respite workers when Tammy was younger and so I worked with the amount of respite hours we had a month. And as with a per diem job, sometimes it was regular hours and sometimes not, so it was a hit or miss whether I could work those hours or not. I would get the kids off to school, tear off to wherever I was working, work for 4-5 hours and then come flying back home to be there for the bus. I am a PRN physical therapist because my mom hat always comes first.

So when Evan retired there was a role change in that he was the one that was doing the person who was home. The controlling mother that I am though, I would like to be the one who was home when the bus came to get my daughter of the bus. So that was

a big change for both of us, because I was the one who did all her feedings, did all her medicine, I was the person who got her on the bus, got her off the bus, if something happened in school I was the one to go there. I will say the umbilical cord has never been really cut. It's had to stretch a really really long way sometimes, and I can't say I am any better about that with my typically developing child than I am with my child with disabilities, so that's who I am as a mother. I am pretty attached to my children. You want them to grow and be independent, as independent as they can be. That's our goal for her as well, although obviously she's a kido who will always need, 24/7 care.

It was very important for me that Sammy knew he was as important to us as his sister. It was also very important to me when he was younger that he gets what he needs and that he knows what was gonna happen when I was doing hospital time with Tammy. During one of Tammy's hospital stays for a surgery, Sammy was about 6 or 7 years old and I was driving him to school that morning and going through the schedule with him. This is what you are going to do. Dad is going to take you and you are gonna go to Janet's and you go to this and you go to that, and that I was gonna call him every day. Then I would ask him if he had any questions and he goes "If I had to be in the hospital would you come and stay with me too?" I said "Of course honey I would!" Biggest grin on a child's face. That's what he wanted to know, that he was equally as important to me. So this has also been one of my roles, to make sure he realizes this.

My advocate hat has been assumed in both the medical and educational settings, however more so in the educational setting. One example of where I had to use my advocate hat in the medical system is when I searched for and got Tammy a non FDA

approved drug for her seizures which thankfully kept her seizure free for 51 weeks. I look at those 51 weeks as a blessing and a gift a HUGE gift that allowed us to figure out the rest of the stuff that we needed to do for her. I have used my advocate hat in the educational setting when I have called for academic goals to be added to her IEP rather than just have social and communication goals. It was not until Tammy was in 3rd grade and it was time for the standardized tests that the school freaked out and realized the need for academic goals on her IEP. My advocate hat is one that I wear all the time, even when working with my patients and considering their needs.

In a similar experience, my husband was the figure of power during my twins' hospitalization for he was the one with the medical background. On the front page of Kynda's chart, right in the center of it there was a very large font statement that said "Dad is an Ob/Gyn at a nearby hospital." Had this piece of information not been relevant to the hospital staff, it would not have been important to write it right on the cover page of the chart. Medical staff and professionals were very conscious of Bilal's status. During one incident when Bilal asked the nurse about the care that she was performing on Kynda which he truly did not know anything about it because pediatrics and especially neonatology were out of his realm of experience and knowledge. The nurse laughed and said "You are a doctor, you know why I'm doing this." He was surprised with her answer and said "No, I don't. I am an Ob/Gyn and not a neonatologist." The nurse had a look of confusion on her face, she then went about and explained to him what she was doing for Kynda. This incident along with Sarah's feelings about the power that her PT hat

provided her are strong indicators of things that empower parents as they work with service providers and medical professional to explore the world of disabilities.

My live-in support: Sarah. Parenting takes a lot of time and energy. Parenting a child with disabilities takes a lot more time and energy. The stress and time consuming nature of a parenting a child with disabilities has been verified by many research who studied the lives of parents of the parents (Browne & Bramston, 1998; Dellve et. al., 2006; Dumas et. al., 1991; Johnston et al., 2003). Having a supportive spouse or partner to share parenting responsibilities with is important regardless of the child's level of need. Given the time, energy, and emotional demands of caring for a child with disabilities, the support of a spouse becomes even more crucial. My husband and I shared parenting responsibilities for both of our children. That partnership became even more important after our daughter was diagnosed with severe developmental delay and a host of medical issues. He allowed me to focus on getting the care our daughter needed while providing for our typically developing son as well. In fact, had it not been for his support, I would not have been able quit my job and then go back as a PRN when Tammy started school. When a child is diagnosed with a disability, one parent often has to quit work or have a flexible job that would be understanding of the family's situation. The need to either quit a job or have a flexible one has been supported by Gray (2003). I was thankful for employers who understood that my first responsibility was going to be for my family and my daughter specifically. I could not have taken on a job had they not been flexible and understanding.

Family is always a balancing act but becomes even more so when a child struggles with health and learning issues. Because we worked in tandem, we were able to give each of our children the time and attention they needed. He also gave me the time I needed to recharge; sometimes to take a nap, sometimes to go off by myself and work on a project, sometimes to get household chores done uninterrupted, on occasion to give me the opportunity to spend one-on-one time with our son or time with friends. My husband provided physical support by assisting in our daughter's care, monetary support allowing me to work part time or not at all when needed, emotional support and a listening ear, literally a shoulder to cry on, support with decision making regarding her care and her education. We sold a beloved old farmhouse and built a wheelchair accessible house; something I could not imagine having done without him. He was the anchor that allowed me to be able to do what I needed to for my children and for myself.

My life has changed in many ways in the almost two years since his death. I am discovering it doesn't matter how old your child is (my son is 24), you continue to parent which takes energy. My 19 year old daughter will always require 24/7 care. While I used to share that with my husband, her care is now 100% my responsibility. I am always tired. At times I am overwhelmed. Maternal fatigue, stress, burnout, and frustration are not exclusive feelings to my situation only, for mothers of children with disabilities frequently report such feelings (Bruce et al., 2014). However, after the passing of Evan and as a result of the responsibility of Tammy and the house resting solely on my shoulders, these feelings have rooted deeper into my bones.

Decisions about her care now rest solely on my shoulders. As she is growing older, her medical problems are growing. I know that I will face her death one day which is something I have always anticipated but also always thought I would be able to share with my husband. I have lost my live-in support. I continue to work only part time so that I can care for my daughter as well. I don't have any 'back up' when a caregiver cancels. If I need a nap, I have to hope my daughter does too! It takes me much longer to get household chores and yard work done. Finding time to run errands can be challenging. I realized that after Evan's passing, I have assumed all the life roles needed to care for my children; a parent, a worker, a housekeeper and more. Following Evan's death, I have become torn between fulfilling all those roles and this leaves me tired... very tired. Super (1990) states that when an individual is consumed with many roles that conflict with each other, they become stressed and fatigued and this is what I am currently experiencing as a result of the death of Evan. This is because there is always a struggle between which role takes precedence over the other.

While I continue to grieve the loss of my husband, I also know that the solid foundation we built together to support our children is still strong. Even though I continue on alone, when I need it, he is the voice in my head telling me I am strong enough to do it on my own. For that, and for the gifts that are my children, I will always be grateful.

CHAPTER 5

SUMMARY

This dissertation was shaped by the research questions and the literature on the subject and the methodology of data collection that Sarah and I engaged in. The research questions for this dissertation were:

1. What are the experiences of mothers of children with disabilities as they raise their children and navigate the world of special education?
2. What roles do mothers assume throughout the process and how do they come to assume these roles? What societal and personal forces are influential?
3. How do mothers access, negotiate, and utilize special education services?

The findings of the study extend upon the literature in reporting the challenges, social and psychosocial experiences, and the positivity of parenting a child with disabilities. It also confirms the need for support through positive school-home partnerships and from service providers and the community. Sarah and I express challenges in parenting a child with disabilities, which are characterized by the loss of the imagined child and the family's altered future. We express sorrow and grief over what has been lost. We express some coping and adaptation methods that were beneficial to us during our journey. We express feelings of guilt and self-blame on the diagnosis of our children. Parenting any child is not easy, but parenting a child with disabilities is even more difficult. Despite the challenges that we express, our determination to continue fighting strong. Our purpose was and continues to be clear. We seek what is best for our daughters. We want to provide them with the best opportunities to grow and develop.

Unconditional love has fueled our drive to seek, provide, and advocate for Tammy and Kynda needs, supports, and existence. In spite of the labels and the descriptions provided to our daughters, we never cease to describe them with positive and beautiful descriptors such as “sweet, beautiful, and capable.” We experience joy for what is and for what has become. We experience personal growth and transformation in our families and our daughters’ acquaintances. All become more compassionate, tolerant, and comfortable, and all learn the value of collaborative work.

In the vignettes that describe my experience parenting Kynda, I am often left with the struggle of determining who Kynda is? Her medical and educational evaluations along with the service providers and professionals define her using terms of deficits. I on the other hand, define her with words of optimism and capability. I constantly have a feeling of dissociation when a service provider or a professional talks to me about Kynda. Our views do not overlap. I constantly have the feeling that they are talking about someone else, someone who is characterized by deficits, someone who is lagging behind, someone who needs continuous intervention, and someone is clearly deviating from the norm. The image that they provide me of her resonates in my head until the minute I see her again. With her determination, her patience, her strong will, her humor, her intelligence and much more she brushes their implanted image away. I am then reminded that she is who she is, a girl with interests, a strong personality and will, and like all humans with some weakness. Kynda’s character reminds me that she is the one in charge of defining herself and her capabilities. I concur.

Sarah, on the other hand, does not seem to be immersed in this struggle as much as I am. This could be probably due to her maturity for she is a couple of decades older and has much more experience in the world of disabilities than I. She explains her experience as one where her primary goal is providing Tammy with the opportunities that would best meet her needs. She does not care about proving Tammy's abilities to service providers and professionals. She does make an effort to educate people around her Tammy's needs and capabilities, however she is at peace with the course that life takes her. A significant satisfaction for Sarah is the positive change that Tammy has not only brought upon her immediate family members, but also her community, her peers, and her educators. In our time story-swapping together, Sarah has how much change Tammy has brought upon the community. As Sarah shares these with me, her eyes light up with joy and pride.

The role that we assumed primarily throughout our experience parenting our daughters was the parent role as per Super's (1990) nine roles assumed in a lifetime. Our parental role was driven by two forces: our unconditional love for our children, and our perceived societal and cultural obligation for rearing them. These two forces drove us to advocate for services and supports that benefit our child the most. As a result of her advocate role for Tammy's needs, Sarah was labeled as a "demanding parent" by the AEA and was subjected to "bad parent stigma" by one of Tammy's associates due to Tammy's light weight. I, on other hand, was always fearful of assuming a "bad parent stigma" as a result of the decision I made of stopping life support for Omar, the leisure trip I took with Bilal during the hospitalization of Kynda, and Kynda's continuous lag on

her cognitive and developmental milestones. Being labeled or fearing being labeled may have altered some face value actions that we took; however, they did not change our core values nor our plan for our children.

We come about accessing services for our children through seeking knowledge from our support groups who share similar experiences with us or those who are willing to offer us insight on services available to our family. We negotiate a special education service by observing, asking questions, learning more about the service and evaluating if and how this service would meet our child's needs. We utilize special education services by providing service providers with insight and local understanding on our child's needs, strengths, and interests. We also learned to choose our battles with our children's service providers.

In summary, parenting a child with disabilities is not an experience which parents pass through feelings and thoughts in a longitudinal way. On the contrary, the experience is like roller coaster. It constitutes a repetition of feelings and thoughts of joy and fear and all that lies between. Below is an analogy titled Welcome to Holland written by Emily Perl Kingsley in 1987 which helps people understand how mothers of children with disabilities experience transformation and consequently redefine joy.

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

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

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

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

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

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

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

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

But... if you spend your life mourning the fact that you didn’t get to Italy, you

may never be free to enjoy the very special, the very lovely things... about Holland.

Implications

Challenges

Sorrow and grief over what has been lost for the child and the family will be experienced. Learning and developing coping and adaptation methods will help parents get through the experience. Journaling has helped both Sarah and me by providing us time to reflect and rejuvenate. We encourage parents to adopt that method, or find another one that works for them.

Acknowledge parents' feelings of the loss and be empathetic towards them. Parents do not want to be pitied, but would rather be understood and assisted in finding services and supports that the child and the family would benefit from.

Social and Psychosocial Experiences

Seeking and accepting help from family and friends along with those who have been there, done that is crucial in helping parents. See to your own physical and mental health, you will need to do this to keep your strength in resuming your parenting journey. As often as they come and as painful as they are, feelings of guilt and self-blame are often unrealistic and will not help the family. Instead of immersing one's self in such feelings, use this energy to seek, negotiate, and utilize services for the child and the family. Provide families with references to support groups or networks that may provide assistance to the family. These support groups help parents get rid of feelings of alienation and isolation.

Positivity

Mothers included in this study love and value their children very much and they find significant joy and benefits in the experience raising them. While the future of a child cannot be predicted, however lacing the information with hope is imperative. View the child as a whole, as capable, and not as less fortunate tainted. Describe the child with words of hope, optimism, and capability rather than through deficits and weakness.

Acknowledge the joy for what is and what has become for it does exist.

Needs and Supports

Always ask yourself, how will my child's needs be best served? Ask questions and more questions. Communication is key. Be prepared to challenge the status quo if necessary. Take a friend or other advocate to meetings with you as they may hear things or pick up things that you don't. Parents would like to be fully informed about special education services and the choices that they have. Listen to the voice of parents, they are the ones with the experience. Through listening to them you will be able to match their needs and provide them with the support that they and their child needs. Parents value professionals who care about the child and the family and who sincerely seek making a difference in their lives. Parents appreciate positive partnerships that are based on honest, open communication and collaboration while taking the parents' input into perspective. Envision possibility and think outside the box. Take initiative in learning new techniques that could work for the child. After all, it's the parent's first time parenting a child with disabilities and they are learning too.

Donald Super's Life Span Life Space Roles

Parenting a children with disabilities involves being the primary caretaker, information seeker, problem solver, committee member, and spokesperson for the child. These are often characterized under one role stated in Donald Super's Life Span Life Space Roles (1990): the parent. This role was significantly assumed in the parenting experiences of Sarah and me. To avoid conflict with other lifetime roles that we were assuming at the time of the diagnosis of our daughters, all other roles were put on hold and our parental role took precedence over all.

We also describe the significance of assuming a partner role, because in our experiences a partner has proven to provide support in times of hardship. A partner provides strength, an objective second opinion, support, a shoulder to cry on, help with caregiving responsibilities to the child and much more.

Leisure activities are defined as time spent doing something of your own liking. Sarah and I have addressed the significance of engaging in leisure activities for they represent a time to unwind, re-coupe, and rejuvenate. They represent a time to find the joy that still exists in life despite all hardship.

Research Considerations

The Social Context

The social context of the study is an important factor to consider for it is through that lens that the participating families make sense of their experience. In other words, social context plays a vital role in the social meaning of disability and the construction of social identity in a family of an individual with disabilities. The two participating

families in this research are classified as white middle/upper class with good education and status at hand. The fathers are a construction worker and a physician and the mothers are a physical therapist and a special education doctoral student. Becker (1963) and Schur (1971) have both stated that disability can serve as a master status and can carry stigma with it. Therefore, often times one's social identity changes when a label of a disability is attached to them or a direct family member such as a child. Often being labeled as disabled can have a profound impact on a person's identity (Taylor, 2000). In short, the meaning and the experience resulting from a label of a disability may vary from one social class to another. What holds true for Sarah and I through our experience parenting our daughters with disabilities may not hold true for other families. This could be due to difference in perceived meanings of disability, responsibilities towards the child, social status and financial means of seeking and utilizing needs for the child and the family. Therefore, caution should be exercised in assuming that the findings of this study can be generalized to other demographic subgroups. To illustrate the significance of the social context in how disability is constructed, Taylor's (2000) study is presented below.

Taylor (2000) investigated how disability is constructed in the Duke's family wherein each of its members as well as its friends and kin have been defined as disabled, handicapped or retarded. At the time of the study Taylor explains that he has known the family for ten years and he has become a good family friend and a lawyer to them. He explains that every single family member and friend of the Duke's family has a label attached. After following the family thoroughly for 10 years, he concludes that they have constructed a world in which disability is not stigmatizing nor problematic for their

identities. They have shared a meaning on disability that “acts as a buffer against abstract cultural meanings attached to disability” (p. 61). In short, they do not attach the same meanings to disability labels as the broader society would. In his study, Taylor (2000) portrays to the readers examples of how the family’s definitions of their labeled children stand in contrast with how they have been defined by schools, agencies and government reports. Taylor attributes this dissonance to four factors. The first is being how the family stands between individual members, agencies and programs by providing their own set of meanings and interpretations of their experiences. Second, their constructed world is reinforced by an extensive network of kin and friends who are much more influential to them than typically described families in much of the existing literature. Third, their deinstitutionalization and their roles within their family play a vital role in enabling them to establish a positive identity. Finally, as per Goode and Ben-Yehuda (1994), competence is a relative concept. They might not perform well on standardized tests but they are able to get about their day-to day life as they experience it. In summary, and as Taylor (2000, p. 89) states, “Culture is experienced, to a large extent, through face to face social groups and especially through those groupings we refer to as families.” Therefore, the social and cultural status of families is an important factor when looking at constructed meanings and experiences of disability in a family.

Recommendations for Future Research

First, it would be useful to find and follow a group of mothers who have recently received news of the diagnosis of their child and follow their experiences longitudinally. Second, as a result of the benefits of journaling and narrative therapy that are stated by

the mothers participating in this study and by researchers in the field, it would be useful to explore the effect of narrative therapy and journaling on mothers of children with disabilities. Third, it would be important to include data from service providers on their experiences with families of children with disabilities. It would be interesting to compare perspectives of different parties.

Epilogue

Navigating special education is a whole world unto itself. Many people have no experience with the special education system, yet it seems people get swooped into it at once. It can be hard to sort out everyone's role and what is in the best interest of the child and the family.

This dissertation sought to provide myself and another mother of children with disabilities the voice to address their experiences parenting their children. Both Sarah and I have engaged in journaling and story swapping to fulfill the purpose of this narrative research. We have both experienced and identified the benefits of these activities. Journaling was therapeutic for it provided us with time to self-reflect and make sense of our experience. Story swapping created a sense of community between us for despite the difference in diagnosis, age, and many aspects of our experiences with our children, the commonalities we shared in thoughts and feelings were greater than the differences.

Through parenting our daughters, we have experienced challenges, sorrow and grief, yet the personal strength and growth along with the exposure to the world of disability and the joy that has come along outweighed the challenges. The personal growth and exposure that we gained ultimately led to increased levels of comfort with people with disabilities and a redefined meaning of a good life.

For parents who are on similar journeys to ours, it is hoped that this study assures them that they are not alone in their journey and that there is joy for what is despite the loss that has occurred. Hopefully, parents benefit from some supports that benefited Sarah and me. For educators, service providers, and medical professionals, this study

may help them to better understand the needs and supports expressed by the participating mothers and to empathize more fully with the families. For everybody who has engaged in this dissertation and read it, may it open the door to empathy and understanding which would lead to transformation and action.

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APPENDIX

GUIDING QUESTIONS

Some guiding questions that will be used in the interviews are:

1. What was your experience like as a family navigating the world of special education.
2. What are roles that you assumed as a result of your experience in the world of disabilities?
3. Have any societal, cultural or personal forces made an impression on your experience? What are they and how have they made an impression?
4. Tell me about supports and services that you have received during your journey. How were they helpful and how were they not?
5. What is missing or needs to be changed in the world of special education?
6. What is missing or needs to be changed in the world to make special education less stressful?