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Parents of children with disabilities in public schools often do not advocate for their child and frequently lack the knowledge of how to advocate. There are, however, some parents who are successful advocates for their children. This study collected life stories of six parents who are engaged in their child's education and pursue advocacy with passion and determination, not just in the public schools, but in all aspects of their child's life.

The selection of narrative inquiry methodology for this study allowed the selected participants to share richly detailed life experiences that were constructed into stories that (1) produced insight into the complexities of their life and (2) shaped their identities as advocates. The narrative analysis of this study revealed five over-arching themes from the participants' life stories including *suffering, family, faith, motherhood, and advocacy*.

The findings in this study indicate that each participant's identity was shaped by life experiences that have influenced their advocacy for their child with a disability and that of others.

LIFE STORIES THAT SHAPED
ADVOCACY IN PARENTS
OF CHILDREN WITH
DISABILITIES

By

Timothy Joel Peddle

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Approved by

Committee Co-Chair

Committee Co-Chair

This dissertation is dedicated to my Aunt Jane, who has always loved me, inspired me to make a difference, and has never complained about life circumstances. I look forward to the day where you and I will leave our earthly bodies and reunite with each other in our heavenly bodies. It will be a glorious day.

To my wife who patiently endured my absence in her life during the writing of this dissertation. Thank you for sticking with me through thick and thin.

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To my brother and sister who have provided me with support, encouragement, and the example of achieving your dreams.

To my parents who believed in me and never questioned my human ability. Thank you for everything. We did it!

Finally, to my Heavenly Father and Savior Jesus Christ, for without you I am lost. With you, I am heaven bound.

APPROVAL PAGE

This dissertation has been approved by the following committee of the Faculty of
The Graduate School at The University of North Carolina at Greensboro.

Committee Co-Chair _____
Kathleen Casey

Committee Co-Chair _____
Ulrich Reitzug

Committee Members _____
Carl Lashley

Glenn Hudak

Date of Acceptance by Committee

Date of Final Oral Examination

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CHAPTER I
INTRODUCTION

Until I did this interview, you know, I thought that I had failed as a mother. I felt like no one was listening to me and so, like I really never thought of myself as an advocate, you know. But I am.

- Cindy, Parent Advocate

This research study is a narrative inquiry into the life experiences of parent advocates. This study is based on (1) interviews conducted with parents of children with disabilities who advocate by actively engaging in improving the quality of education and life experiences for their child and that of others, and (2) my professional experience in the field of education for the last two decades. In this chapter, I begin by presenting the statement of the problem, followed by the purpose, questions guiding study, background and rationale of the study, key terms defined, importance of the study, organization of this dissertation, and conclusion.

Statement of Problem

I have worked in the field of special education and have witnessed first-hand the inequality, discrimination, and the process of categorizing that many students with disabilities undeservingly face in our public education system. It has been my experience that students with disabilities are not self-advocates, nor are their parents. In fact, even during an era when parent advocacy was heavily influencing the shape of landmark

legislation, such as PL 94-142 and the reauthorization of the Individuals with Disability Education Improvement Act (IDEA) in 2004, the majority of parents of students with disabilities during my professional experience either were absent from the meetings or sat quietly unengaged when present. Yes, it is true there are parent advocates and other disability activists who have pursued justice, but based on my professional experience of working with parents of children with disabilities and from a perspective of academia and supported by Kalyanpur and Harry (2004) special education services will continue to be shaped by a community of educators, researchers, and policymakers, rather than parents engaged in the process.

Even though I observed a lack of parent-school collaboration, it is my desire that there would be better teamwork between the school and parents of children with disabilities. Schools can benefit from the knowledge that parents have, as they can provide a “first-hand experience with their children and their needs” (Friesen & Huff, 1989, p. 1). By having synergy between the school and parents of children with disabilities, partnerships are established, parents feel respected, and school barriers disappear. According to Lo (2012), a partnership between the school and parents of children with disabilities must be formed at the moment the child is enrolled in the school. Lo (2012) further states that partnerships with parents of children with disabilities are even more crucial because “parents are the advocates for their children and are the ones who can speak for their children regarding what services and supports are suitable to address their needs” (p. 19).

Purpose of Study

The primary purpose of this research study is to identify and understand life experiences that have shaped the identities of parent advocates. In order to obtain this information, I have collected life stories of six parent advocates who have a child with a disability. I also believe that it is important to make a contribution to special education literature, in order to catalyze a broader movement of parent advocacy and to recognize the importance of being engaged as a parent in the landscape of their child's education.

Questions Guiding Study

- 1). What are common life experiences of parent advocates?
- 2). For what do parents of children with disabilities advocate?
- 3). What experiences and or motivations lead parents to advocate for their children, but also for other children with disabilities?
- 4). What are the barriers that prevent parents from advocating?
- 5). Why should schools teach parents on how to advocate?
- 6). What can schools learn from parent advocates?

Background and Rationale of Study

Throughout my professional experience, parents of children with disabilities in public schools have lacked the encouragement, education, and discussion of how to advocate and be engaged in their child's education. As a professional educator, I have not witnessed nor heard of any schools providing parents of children with disabilities

training on how to advocate. In fact, if advocacy training did take place, it perhaps would justify changing the existing autocratic public school systems (Bradley, 1996).

Even though current educational law encourages parents to be active participants at schools, our culture within public schools can create an atmosphere that discriminates, overlooks, and judges based on the disability rather than looking at the potential of the individual. Thomas Hehir (2002) and Gregor Wolbring (2008) refer to this atmosphere, along with many disability activists as *ableism*. In *Teaching for Diversity and Social Justice*, Laura Rauscher and Mary McClintock (as cited in Adams, Bell, & Griffin, 1997) defines *ableism* as:

A pervasive system of discrimination and exclusion that oppresses people who have mental, emotional, and physical disabilities...Deeply rooted beliefs about health, productivity, beauty, and value of human life, perpetuated by the public and private media, combine to create an environment that is often hostile to those whose physical, mental, cognitive, and sensory abilities...fall out of the scope of what is currently defined as socially acceptable. (p.198)

It is the continual presence of *ableism* in our public schools and the lack of parent advocates that has drawn me to this research study. While schools follow the letter of the law in having parents sign their child's Individualize Educational Plan (IEP), I have observed schools fail miserably in listening to parents, engaging parents, and educating parents in advocacy skills. It is my belief that parents of children with disabilities have a world of information and knowledge that can benefit the school. However, many times as I have witnessed, the type of questioning in parent meetings often discouraged parent

feedback and active participation. Casey (1995) states “the problem, after all is not with the voices that speak but with the ears that do not hear” (p.223).

This research study focuses on parent advocacy for children with disabilities from the perspective that there is a connection between the life experiences of parents of children with disabilities and their identities as an advocate. My inquiry is grounded in McAdams (as cited in John, Robbins, & Pervin, 2008) *narrative identity theory*, which refers to “an individual’s internalized, evolving, and integrative story of the self” (p. 242). Drawing on McAdams (as cited in John, Robbins, & Pervin, 2008) *narrative identity theory*, I have pursued identifying life experiences of parent advocates that have influenced what I refer to as their, “*identity as an advocate.*” Utilizing a narrative format, I am able to identify how parent advocates construct and make sense of their life. Fundamentally, according to McAdams (as cited in John, Robbins, & Pervin, 2008) how people construct the stories of their life is based on “our struggle to reconcile who we imagine we were, are, and might be in our heads and bodies with who we were, are, and might be in the social contexts of family, community, the workplace, ethnicity, religion, gender, social class, and culture writ large. *The self comes to terms with society through narrative identity*” (p. 243).

This study explores the parents’ identity and understanding of self as advocates through the construction of life stories.

Key Terms Defined in Study

It is important to define the following terms, as they will be used in this study.

Advocacy

There are many forms of advocacy and can take shape in a variety of ways. For example, advocacy can take the form of letters, phone calls, boycotts, presentations, speeches, or marches. Historically, disability rights literature has defined advocacy as the ability to speak or act on someone's behalf so that their strengths, preferences, and needs are voiced (Wolfensberger, 1977, Dalrymple & Hough 1995). On-line dictionaries such as Merriam-Webster (2009) define advocacy as the act or process of advocating or supporting a cause or proposal. The Free Dictionary by Farlex (2009) defines advocacy as the act of pleading or arguing in favor of something such as a cause, idea, or policy. YourDictionary.com (2009) defines advocacy as the act of advocating, or speaking or writing in support of something.

While current legislation such as the No Child Left Behind Education Act of 2001 (NCLB) and the Individuals with Disabilities Education Improvement Act (IDEA), mandates educational professionals to include parents of children with disabilities in the decision making process, the language in such laws hesitates to identify parents as advocates (Turnbull, 2005). The term 'advocacy' is absent in NCLB and IDEA, unlike the term 'parent participation' which is used exclusively to describe the role of parents (Trainor, 2010). For this study, I utilize Turnbull and Turnbull's (2000) description of advocacy as it relates to IDEA, in that 'advocacy' is implied by the language used in IDEA when describing parent participation. This point is illustrated in sections of IDEA

that describe parents' rights and responsibilities; for example, Section 615 (b) (7) (A) (ii) (III&IV) of IDEA states that parents filing a complaint should describe "the nature of the problem of the child relating to such proposed initiation or change, facts relating to such problem [and] a proposed resolution of the problem to the extent known to the party at the time."

Parent Advocate

A parent advocate has traditionally been defined as someone who speaks up and acts in support of their child's education. For clarity, this research study utilizes the language in IDEA (see above definition of advocacy) to define a parent advocate. For the purpose of this study, a parent advocate is defined as someone who actively and unarguably participates in the educational decisions for their child that are guaranteed by IDEA (Trainor, 2010). While the term 'advocacy' under IDEA implies that parents secure appropriate educational services through 'parent participation,' Turnbull and Turnbull (2000) noted that Congressional testimonies referred to parents as acting accountability mechanisms or agents that monitor a school's implementation of IDEA's requirements.

IDEA

The Individuals with Disabilities Education Improvement Act of 2004 (IDEA) is a federal law that provides states with federal funding on the condition that states ensure equity, accountability, and excellence in education for children with disabilities (Cohen, 2009). IDEA consists of four parts. Part A declares the barriers, solutions, and national policy for educating students with disabilities. Part B authorizes funds to educate

students ages 3-21. Under Part B of IDEA, students with disabilities are guaranteed a free appropriate public education (FAPE). Part C authorizes funds to educate infants and toddlers, ages 0-3. Finally, Part D authorizes national research, training, demonstration, and technical assistance activities (Turnbull, Huerta, & Stowe, 2009).

IEP

An IEP is defined in the North Carolina General Statutes, Article 9, Chapter 115C-106.3, subsection (8)(2006) as an Individualized Education Program or IEP that is in the form of a written statement for a child with a disability that is developed, reviewed, implemented, and revised consistent with IDEA and state law.

PSAP

Parent School Advocacy Plan (PSAP) is a document that is created by a school that outlines how the school is going to train parents of children with disabilities on advocacy skills. A PSAP is created by individuals from the school including parents, teachers, administrators, and related service personnel. Similar to an IEP, the PSAP is a document that states goals and objectives. The school will also be required on the PSAP to establish dates for parent advocacy training sessions, including how they plan to invite parents to the training sessions. Each school will receive a video to be viewed by the school team prior to completing a PSAP along with other supporting advocacy material. It is important when developing the PSAP that schools and parents work together as partners.

LEA

LEA is defined in the North Carolina General Statutes, Article 9, Chapter 115C-106.3, subsection (11) (2006) as a Local Education Agency (LEA) which includes any of the following that provides special education and related services to children with disabilities:

- a. A local school administrative unit
- b. A charter school
- c. The Department of Health and Human Services
- d. The Division of Adult Correction of the Department of Public Safety
- e. The Division of Juvenile Justice of the Department of Public Safety
- f. Any other State agency or unit of local government

Importance of Study

The importance of this study identifies the need for public schools to educate, train, discuss, and to engage parents of children with disabilities in how to advocate for their child, as well as identify what schools can learn from parent advocates. As an educator in North Carolina for over nineteen years, I propose that an amendment be made to Article 9, Chapter 115C-109.3 (2006) of the North Carolina General Statutes, requiring public schools to train parents in advocacy. I suggest that each local educational agency (LEA) be required to submit to their Board of Education a parent school advocacy plan (PSAP). A portion of the plan could replicate the advocacy plan designed by a grassroots organization called Beyond Welfare located in Ames, Iowa. Amending Article 9, Chapter 115C-109.3 could reshape the future of parent advocacy in North Carolina

Public Schools. In Chapter VI, I discuss my proposed PSAP and Beyond Welfare's advocacy plan and how such a plan could be constructed to fit North Carolina's Public School System for parents of children with disabilities.

The stories shared in the narratives of the parent advocates in this study reveal self-defining memories (Singer & Salovey, 1993) or life experiences that represent emotionally intense events that reflect on one's identity (McAdams as cited in John, Robbins, & Pervin, 2008). Although each parent in this study is different, they share the life experience of having a child with a disability. What is important in this study is how each parent revealed in their narratives the life experiences that influenced their identity as advocates.

Finally, this study and the narratives of parent advocates could inspire other parents of children with disabilities to advocate, engage, and participate in their child's education rather than continuing to take a back seat. I believe, based on my professional experience, that this dissertation can provide relevant information to parents of children with disabilities, public school educators, administrators, and grassroots advocacy organizations, especially since we continue to live in sectors of a society that continue to promote ableism and that is "torn apart by self regard and lack of care and violation of all sorts" (Greene, 1991, p. 551).

Organization of Dissertation

This study is organized into six chapters. Chapter II explores relevant literature on special education, parental involvement, and advocacy. Chapter III describes my perspective as a researcher, clarifies the interview process, and details the methodology of this study including theoretical framework and design. Chapter IV begins with a brief overview of how life experiences can shape an individual's identity, an introduction to each participant, and finally an analysis of the participants' narratives. Chapter V discusses the theme of advocacy which was the core of the mothers' narratives. Finally, Chapter VI provides the conclusion, limitations of the study, and implications for further research.

Conclusion

The participants interviewed in this study have a long history of advocating and welcomed the exploration of developing a narrative of their life story. In this dissertation, I discovered the identities of the parents through their life stories by identifying key themes that have shaped their advocacy. McAdams (2001) explains that the identity of an adult takes the form of a narrative or life story that combines interpretations from the past to the present self and provides meaning and purpose in one's life. McAdams, Josselson, and Lieblich (2001) believes that our life stories "tell about the major transitions in our own lives, contribute to our identities, help us cope with challenges and stress, shape how we see the future, and help to determine the nature of our interpersonal relationships and our unique positions in the social and cultural world" (p. xv.).

I invite readers to join me on a narrative journey formulating a life-story model of the identity of a parent advocate.

CHAPTER II

LITERATURE REVIEW

To provide a context for this study, I reviewed information on the history of the disability advocacy movement, special education law, parental participation and advocacy in public education. The review of literature will be presented into four sections. The first section provides a brief overview of the evolution of the disability advocacy movements. Sections two and three are a brief overview of special education law and parent participation in public education and finally, the fourth section is an overview of parent advocacy for children with disabilities in public education.

Brief Overview-Evolution of Disability Advocacy Movement

The story of disability advocacy began during the mid 1800's by early pioneers Jean-Marc-Gaspard Itard, Dorothea Dix, Edouard O. Seguin, Samuel Gridley Howe, Hervey Wilbur and Thomas Hopkins Gallaudet. They believed that individuals with disabilities could be protected from abuse and neglect by providing them a place to live while receiving a specialized education (Mock, Jakubecy, Kauffman, James, Devery, Sindelar, Brownell, Ackerman, Jaeger, & Smith, 2002). All across the United States, with the support and persuasion of Samuel Gridley Howe and others, states were opening special schools for children with disabilities (Trent, 1994), including North Carolina.

On January 9, 1845, North Carolina General Assembly approved an act “to provide for the education of the poor and destitute deaf-mutes and blind persons in this state” (NC, Session 1844-45, p. 59). This act paved the way for the construction of one of the south’s first state supported educational program for children with disabilities (Powell & Mazzocchi, 2006). According to Simpson (2001), in North Carolina, white children in 1845 who were deaf and blind attended The North Carolina Institute for the Deaf and Dumb and the Blind, in Raleigh, North Carolina. However, by the end of the Civil War, there were efforts made to address the need for a school for African American children with disabilities as well. On January 4, 1869, African American children who were deaf and blind attended a separate school rented from the American Missionary Association in Raleigh, North Carolina. This was the first school in the United States for African American children who were blind and deaf (Crockett & Dease, 1990), until the Civil Rights Act of 1964, which ended racial segregation of schools. The North Carolina Institute for the Deaf and Dumb and the Blind would not have been built and approved by state legislature, if not for the advocacy of North Carolina Governor, John Motley Morehead (Powell & Mazzocchi, 2006).

In 1890, advocate Edward McKee Goodwin of North Carolina persuaded state legislatures to have separate schools for deaf children and blind children. He would later serve as first superintendent of the new School for the Deaf in Morganton, North Carolina from 1891-1936. The school for the blind remained in Raleigh, North Carolina as the Governor Morehead School.

While opportunities were improving for educating children who were deaf or blind in North Carolina and across the United States, the educational outcome for other children with other disabilities were not so promising. By the late 1800's, educational institutions for children with disabilities unfortunately turned into custodial institutions. These institutions had even reached a point where they begin separating the boys from the girls in fear they might produce disabled offspring (Beirne-Smith, Ittenbach, & Patton, 1998).

In 1869, influenced by the ideas of Charles Darwin, Francis Galton published a book called *Hereditary Genius*. Galton adopted a theory that individual traits were inherited and coined the term *eugenics* (Lombarado, 2008). Eugenics is defined by Galton as “all influences that tend in however remote a degree to give to the more suitable races or strains of blood a better chance of prevailing speedily over the less suitable” (Galton, 1883, p. 17). At the turn of the century, individuals with disabilities were no longer considered victims of environmental circumstances, but were viewed as members of an inferior race. Galton's theory of eugenics were popularized and reinforced by an American psychologist named Henry Goddard. In 1912, Henry Goddard published a book titled *The Kallikak Family: A Study in the Heredity of Feeble-Mindedness*. The publication reinforced the belief that mental retardation had genetic implications and fueled the movement to control the feeble-mindedness genetically (Beirne-Smith, Ittenbach, & Patton, 1998). In 1907, the state of Indiana passed the first law requiring sterilization of all criminals and institutionalized “imbeciles” (Keely as cited in Null & Trent, 2004). Over the next two decades, evidence suggests that the

movement of eugenics was strengthening as more than twenty-two states had enacted laws of sterilization (Beirne-Smith, Ittenbach, & Patton, 1998), including North Carolina.

On March 11, 1919, the North Carolina General Assembly passed its first public law granting, under Section 1 of Chapter 281, medical staff at any state penal or charitable hospital or institution the power to perform surgical procedures that would be considered beneficial to the mental, moral, or physical condition of an individual or “inmate,” (North Carolina General Session Laws of 1919, Chapter 281, p. 504). The law is quite brief with three remaining sections, including Section 2, the identification and role of a consultation board in the event an actual procedure would be performed, and Sections 3 and 4, repealing any laws that are in conflict of such law and the enforcement of the law. It is worth noting that eugenics and sterilization is not mentioned in the wording of the law of 1919, but its intent is implied.

Between 1910 and the 1930’s, twenty-nine states had enacted laws permitting the involuntary sterilization of the “feebleminded, as well as the mentally ill, the epileptic, and sometimes the criminal” (Castles, 2002, p. 850), including North Carolina.

According to, *The Preliminary Report To The Governor Of The State Of North Carolina* (2011), *On Compensation for Victims of North Carolina’s Eugenics Board*, North Carolina’s first sterilizations did not occur until the law of 1919 was changed during North Carolina General Assembly Session of 1929. The law of 1929 was enacted two years after the United States Supreme Court ruling of *Buck v. Bell* in which sterilization was ruled permissible under the U.S. Constitution. Under North Carolina’s new law of

1929, which now included the term sterilization in Chapter 34, forty-nine individuals were sterilized (NC Preliminary Report, 2011).

While sterilization was taking shape in North Carolina and throughout the United States during the 1930's, parents of children with disabilities, especially mothers, sought to protect their children, perhaps from fear of involuntary sterilization and searched for advice and guidance for their children. In fact for years, mothers who cared for their child with a disability had little or no educational materials to help them. Mothers in particular did most of the teaching and caring of the child and bore much of the frustration. Recorded letters written between 1915 and 1932 by mothers seeking advice and guidance regarding their child with a disability were sent to the Children's Bureau, a federal agency in charge of programs for mothers and children (Ladd-Taylor, 1986). One mother in particular stated in a letter that she was told by a child specialist her son would always be backward and mentally disabled. However, the mother was determined to give her child every opportunity to develop mentally through special training (Ladd-Taylor, 1986). Like many mothers to follow, the voice of hope was ever present in the letters. This was an early indication that parents of children with disabilities were dissatisfied with the current assumptions of the capabilities of children with disabilities and the educational practices that accompanied them.

Individuals with disabilities and their positive contribution to society became visible to society when injured soldiers returned home from World War I and wanted to contribute to the economic system. This led to the Vocational Rehabilitation Act (PL 66-236) established in 1920, allowing injured soldiers to benefit from vocational

rehabilitation. This law proved to be one of the most important laws enacted in protecting the rights of individuals with disabilities (Beirne-Smith, Ittenbach, & Patton 1998). Unfortunately, individuals born with a disability continued to be treated differently by members of society. In an effort to address society's perception of the disabled, parents of children with disabilities in the late 1930's and early 1940's organized on a local level within their communities and laid the foundation for advocating for individuals with disabilities.

The end of World War II brought a renewed prosperity to the United States and created a means in which parents of children with disabilities could voice their child's human rights. By the late 1940's and early 1950's, efforts from grassroots organizations spearheaded by parents of children with disabilities, led to the formation of national advocacy organizations such as the United Cerebral Palsy Association, Inc. and the Association for Retarded Citizens (ARC) (Turnbull & Turnbull, 1990). Advocacy organizations were established by mainly parents of children who were developmentally disabled. The parents of these organizations served as lobbyists, researchers, and social reformers.

Influenced by parent advocates of children with disabilities and advocacy organizations including the ARC of North Carolina, the General Assembly of North Carolina in 1947, enacted Chapter 818 of the Public School Laws requiring the education of children with physical and mental disabilities. This law helped establish a state-wide Special Education program for children with disabilities (NC Proceedings, 1954 p. 23). It was the belief of the North Carolina Department of Public Instruction and its Division of

Special Education, that “Special Education must be a part of the regular program of the public schools; it has too many problems in common with general elementary and secondary education to justify its standing apart from these” (NC Proceedings, 1954, p. 23).

As a result of continued advocacy and awareness for children with disabilities across the state, North Carolina held its first conference on children with disabilities on May 27, 1954. The conference was sponsored by the North Carolina State Board of Health, North Carolina Department of Public Instruction, and the North Carolina Health Council. The objective of the conference was to:

[1] study the conditions which cause handicapping in the children of the state; [2] determine program, services and facilities now available in the state for meeting the needs of handicapped children; [3] consider those programs, services and facilities which should be developed in order to meet these needs more adequately, [4] develop the understanding, interest and support necessary to attainment of the goals which the conference may formulate (NC Proceedings, 1954 p. v).

While fundamental changes were taking shape in public schools across the United States, parents of children with disabilities pressed forward for equal opportunities inside the classrooms. Utilizing newly developed intelligence testing, the public schools began creating special classes for children with various disabilities (Sacks, 2001). By the 1960’s, the field of special education had been shaped by constantly evolving or redefined beliefs, conditions, and understanding attributed to science, culture, society, and education (Osgood, 2005). Additional laws were made to improve educational opportunities for children with disabilities including the passing of The Head Start Act in

1965. The Head Start Program began during the summer of 1965, serving children in low-income communities that would enter public schools in the fall (Kagan, 2002). Initially, children with disabilities were not present in The Head Start Program, but were eventually included after 1972 Amendments to the Economic Opportunity Act which stated, “not less than 10% of the Head Start enrollment opportunities nationwide be made available to handicapped children” (Ensher, Blatt, & Winschel, 1977, p. 202). In 2009, North Carolina enrolled 23, 316 children in Head Start, of which 3,031 were children with disabilities (CLASP, 2010).

A major shift of thinking toward individuals with disabilities was validated during the normalization movement popularized by Wolf Wolfensberger, an American academic scholar who influenced disability policy. For parents of children with disabilities, the normalization movement created a sense of hope that society would change and learn to accept, include, and have a better understanding of their child. The normalization principle was powerful in that it indisputably improved the quality of life for individuals with disabilities (Harry, Rueda, & Kalyanpur, 1999). Wolfensberger was an advocate for the mentally retarded and along with Bengt Nirje, one of the originators of normalization, believed in the essential right of “making available to all mentally retarded people patterns of life and conditions of everyday living which are as close as possible to the regular circumstances and ways of life of society” (Nirje as cited in, Kugel & Wolfensberger, 1969. p. 181). The work of Nirje and Wolfensberger proved to be highly influential, causing a widespread discussion on normalization and deinstitutionalization. These efforts brought normalization and integration to the forefront of special education

in public schools. By the 1970's, the principals of normalization continued to spread, allowing for further discussions of inclusion and advocacy for children with disabilities, and paving the path for legislation (Osgood, 2005).

North Carolina has made great strides to improve the lives of individuals with disabilities, including the development of advocacy organizations led by parents of children with disabilities and individuals with disabilities. These organizations include North Carolina Association of the Deaf founded in 1908, The National Federation of the Blind of North Carolina founded in 1940, United Cerebral Palsy Association of North Carolina founded in 1949, the ARC of North Carolina founded in 1953, the Autism Society of North Carolina founded in 1970, the Brain Injury Association of North Carolina (BIANC) founded in 1982, The Down Syndrome Association of Charlotte (DSAC) founded in 1986, and the Alliance of Disability Advocates of North Carolina founded in 2004. However, the scar that was left behind by our states Eugenics Program will continue to have detrimental effects and has the potential of overshadowing many of our states accomplishments for individuals with disabilities. By 1974, North Carolina had sterilized nearly 7,600 individuals, including men and women as well as boys and girls as young as ten-years old (NC Preliminary Report, 2011). The Eugenics Program in North Carolina has left a reprehensible memory for many individuals and their families who were sterilized. It is in my eyes, one of the most shameful periods of our state's history (NC Preliminary Report, 2011).

Brief Overview- Special Education Law

Over the past twenty-five years, the rights of students with disabilities have significantly advanced, thanks to legislation mandates. Prior to 1975, the majority of students with disabilities were not allowed to attend public schools with their peers. The Congressional Record of 1975 indicated that 1.75 million students with disabilities did not receive educational services at all and the 2.5 million students with disabilities who were fortunate enough to attend school, did not receive an appropriate education that met the student's educational needs (Yell & Katsiyannis, 2001).

Major legislation mandates marked the beginning to an end of continued discrimination for individuals with disabilities. In 1973, Section 504 of the Rehabilitation Act was passed, but was not fully enacted until 1975. Section 504 of the Rehabilitation Act was the first major effort to protect students with disabilities from discrimination (Yell & Katsiyannis, 2001). By 1975, advocates for students with disabilities including advocacy organizations and parents began suing states for violation of the students' right to an equal education opportunity under the U. S. Constitution (Turnbull & Turnbull, 2000). As one would imagine, numerous challenges mounted for parents and students with disabilities during their efforts to access educational services. Following two landmark court cases, *PARC v. Commonwealth of Pennsylvania* and *Mills v. Board of Education*, the United States Congress enacted a series of laws to secure the educational rights of students with disabilities (Turnbull & Turnbull, 2000).

Each law that was passed provided students with disabilities more opportunities, more accessibility, and more possibilities. The Education for All Handicapped Children

Act of 1975 (EAHCA) or also known as PL 94-142 was the first major legislation that was passed. EAHCA mandated a free and appropriate public education for all handicapped children (Suelzle & Keenan, 1980). In addition to a free and appropriate public education (FAPE), EAHCA was also designed to protect the rights of students and their parents as well as assist states and local education agencies in their efforts to provide services (Yell & Katsiyannis, 2001). The Education for All Handicapped Children Act had hoped to change the public's perception of students with disabilities as a "separate or less qualified" group to participate in the mainstream of society (MacGugan, 1989). Since then, this law has been renamed the Individuals with Disabilities Education Act (IDEA) and has been reauthorized in 1990, 1997, and 2004. The impact of this law not only opened the door to equality, but it also provided a voice to parents of children with a disability (Valley & Aponte, 2002). IDEA provides states with federal funding on the condition that the states adhere to the requirements established by the law (Cohen, 2009). Unlike IDEA, Section 504 of the Rehabilitation Act is a civil rights law and is not funded by federal government (Yell & Katsiyannis, 2001).

In order for a student to be eligible for special education services under IDEA, the student must meet at least one of the categories of disability determined by a series of evaluations carried out by trained professionals (Cohen, 2009). IDEA provides key rights for parents and students with disabilities, including first, the basic law of making sure all students with disabilities receive an appropriate education no matter how severe the disability may be. Second, the concept of free and appropriate or referred to as (FAPE)

creates the need for adapting an education to the specific needs of the student. Third, IDEA establishes a support system of related services for each student with a disability. The related services could be a physical therapist or an occupational therapist, all of which is dependent on the individual needs of the student. A fourth basic entitlement to students with disabilities is the mandate of a least restricted environment. Whether students with disabilities want to be in the classroom with their regular educational peers or not, the law requires them to do so to the maximum extent appropriate. Least restricted environments can be achieved through related services that are designed to support students with disabilities so that every opportunity for educational success is available. A fifth key concept of IDEA is for each student with a disability to have an Individualized Education Plan (IEP). An IEP is a written legal document for each student with a disability which provides the student's present level of academic performance, both short and long term educational goals, and information on related services received and or modifications that are needed in the school environment. A sixth concept is the elimination of fees to parents. Under IDEA, parents of students with disabilities are guaranteed to a free education including physical therapy, speech therapy, occupational therapy, and other related services. Finally, IDEA ensures parents the educational rights for their child through notification and parent participation (Weber, 2009). I believe this final concept of IDEA is of most importance, as schools no longer can make decisions without the consent of a parent or legal guardian.

Brief Overview-Parent Participation in Public Education

Parental participation has undergone lengthy discussions and research in the last decade, especially as it applies to children with disabilities and the Individuals with Disabilities Education Act. The original vision of The Education for All Handicapped Children Act (PL 94-142) was to increase parental involvement through informed consent. As discussed in the previous section, informed consent by a parent is mandated by IDEA. No longer are schools the final authority in determining what is appropriate for a student with a disability (Hoff, Fenton, Yoshida, & Kaufman, 1978). However, earlier research on parental involvement of children with disabilities suggests that only 50% of the time parents understand and are aware of the decisions being made on behalf of children's education (Hoff, et al. 1978 correct). Other major legislation such as the reauthorization of the Elementary and Secondary Schools Act and Goals 2000 require parental involvement as a component of a school's reform initiative, ultimately giving the parent a productive voice in their child's education (Nicholson, Evans, Tellier-Robinson, & Aviles, 2001). One has to believe that even without the mandates of IDEA, which gave parents a right to be informed, a right to participate, a right to challenge, and a right to an appeal, that schools would welcome parental interaction and collaborative decision making, but this is often not the case.

Based on my professional experience, parents who challenge the system are often perceived as troublemakers and implications suggest that these types of parents are too intense to fully participate in a meaningful conversation regarding their child's education, despite their right to do so (Valle & Aponte, 2002). The responsibility to engage parents

of students with disabilities to actively participate in the IEP process is primarily left up to the school and the Local Education Agency (LEA). Ultimately, IDEA requires all LEA's to notify parents of children with disabilities of their legal rights. In North Carolina, parents are provided information on their legal rights in a thirty-two page document titled, Procedural Safeguards: Handbook on Parents' Rights (NC Department of Public Education, 2008). The Procedural Safeguard Handbook provides parents of children with disabilities with information about their legal rights, such as filing a due process petition or attaining an independent educational evaluation.

It has been my experience that parents of children with disabilities have more difficulties than parents of a non-disabled child (Nicholson, et al. 2001). For example, I remember a parent of a child with a disability terribly upset that her son, who was diagnosed with muscular dystrophy, had been recently confined to a motorized wheelchair and could not find any after school childcare. These types of frustrations and other difficulties that parents of children with disabilities face in day-to-day life are inevitably carried over into their involvement in their child's education (Nicholson, et al. 2001). During school meetings such as an IEP, parents are consistently shut out of the decision-making process by simply lacking the knowledge and understanding of their child's rights. Many times unclear explanations of psychological reports along with pre-prepared IEP's make parent involvement even more difficult to achieve (Goldstein, Strickland, Turnbull, & Curry, 1980). Parents of children with disabilities typically accept their child's educational recommendation and never voice their opinions. For example, Sonnenschein (1981) states, "Too frequently, observations and suggestions

made by parents are given little weight and concerns are dismissed without investigation” (p. 64). Elsie Aponte, a mother of a child with a language learning disability describes her frustrations in an IEP meeting that left her crying. Ms. Aponte stated that during the IEP, they were constantly being interrupted by knocks on the door. At one point, she had no idea what the scores meant on the evaluation given her by the psychologist. Finally, feeling a heavy lump in her throat, she recalls flash forwarding to the future and asked the school’s educational experts if they believed that her daughter would be able to attend a college in the future. “Anybody can go to college,” was the response, however, they explained that her daughter was more capable of a technical job such as a receptionist rather than a scientist (Valley & Aponte, 2002). The experience that Ms. Aponte shares is a sad reality that continues to exist in our public schools, unless you are your child’s strongest advocate. Parents sometimes lack a voice in their child’s education due to their own school experiences, feelings of inferiority, language barriers, or cultural differences (Nicholson, et al. 2001).

In my experience, many parents of a child with a disability sit quietly in school meetings relying on the recommendations and advice from school professionals rather than sharing their knowledge on their child. After attending several hundred meetings, I realized that many of these parents were just grateful that their child had a public school to attend and someone to give them a rest from their daily responsibilities, and perhaps didn’t want to “rock the boat.” Based on my experience, I believe the parental “silence” that occurs in IEP meetings have cheated many children with a disability from having opportunities to be successful in public schools. However, not all of the parents sit

quietly. Some question decisions and opinions of the school and district. Parents that question decisions are always treated somewhat differently. I remember many meetings where school officials were always prepared for parents that may challenge their decisions. Official documents such as the district's code of conduct, student work samples, formal testing, along with other documents were easily accessible for review in hopes to squash a possible disagreement with a disgruntled parent.

Brief Overview-Parental Advocacy in Public Education

Advocacy is a word that is defined differently in various public discourses including education, society, research, and policy. An advocate can be described as an individual who acts and expresses ideas, explores causes, and voices concerns (Reid, 2000) that are profound and have far-reaching effects. For many parents of children with disabilities, advocating represents hope, equality, and justice. Research shows that the intensity and frequency (Ryan & Cole, 2009) of advocacy for parents of children with disabilities is greater than parents of non-disabled children, due to their determination to navigate, negotiate, and collaborate with the professional community (Ryan, 2005). Unfortunately, many parents do not perceive themselves as advocates even though they intercede on behalf of their children in sports, in churches, in schools, and even in their neighborhoods.

Given the fact the language of IDEA excludes the term parent advocate, IDEA in a sense recognizes that parents are their child's best advocate. For example, procedural safeguards are placed in IDEA requiring schools to involve and notify parents at various stages of their child's education including identification, evaluation, and development of

an IEP (Phillips, 2008). IDEA also gives parents the power to request a due process hearing if they perceive the school is not providing their child with a free and appropriate education (Phillips, 2008). While IDEA assumes that advocacy is represented by a parent's ability to participate in seeking appropriate educational services (Turnbull & Turnbull, 2000) the how, when, and where continues to be controlled by the school (Deslandes & Bertrand, 2005).

According to Phillips (2008), without a rubric that evaluates the success or failure of IDEA, barriers to parent advocacy will continue to arise. For example, IDEA assumes that parents have the knowledge to effectively advocate because they know their child's strengths and weaknesses, yet they lack the ability to classify their child's abilities based on the diagnostic criteria for disabilities (Phillips, 2008). Also, while parents are able to recognize the success of a corrective educational program, they lack the experience of working within educational systems and learning about other educational options and services available to their child. Finally, parents must not only be the expert on the child's disability, but also an expert in IDEA's multiple procedural requirements, so that they can confront and challenge school decisions (Phillips, 2008).

Advocating is important to parents of children with disabilities because it balances the power and control that exists in public schools, yet many parents find it stressful, uncomfortable, and time consuming. In fact, some parents perceive advocacy as a challenge that decreases their quality of life, whereas other parents who advocate find it a source of comfort that actually reduces stress, resulting in an increase in their quality of life (Wang, Mannan, Poston, Turnbull, & Summers, 2004). Parents of a child

with a disability experience a full range of emotions including denial, anger, guilt, and sadness. For many parents, advocacy is an opportunity to channel these emotions to better the life of their child. Parent advocating can make a difference, whether it is through a political platform that stimulates social change or in the school, volunteering and engaging in the everyday school life of their child. While the journey is long and at times difficult, parents who advocate must remember through their frustrations, challenges, and temporary barriers, they stand side by side with others who have made great strides in human rights throughout our history.

CHAPTER III

RESEARCH METHODOLOGY: NARRATIVE ANALYSIS

In this chapter, I explain the chosen methodology for my research. I also describe my perspective as a researcher, clarify my interview process, and finally discuss the methods of analysis. Let me first make clear the terms I use when describing the research participants. In this chapter, when I use the term advocate, parent, or parent advocate, I am referring to the participants, who are all female and mothers of children with disabilities. Each mother I interviewed for this study, actively and unarguably participate in the educational decisions that are protected by IDEA (Trainor, 2010) as well as oversee the overall health and well-being of their child. When I refer to the word child, son, or daughter with a disability, I am referring to the children that were born to the mothers that I interviewed. The children discussed in this dissertation range in disability and age, and all live at home with their mothers, except one son who lives in a supervised group home setting. The mothers in this study have similarities and differences. While they may differ in ethnicity, age, and place of residence, they share a common vision of advocating for equal educational and life rights for their child.

My Selection of Research Methodology

I have chosen narrative analysis as the method for this research because I want to uncover within a mother's story what life experiences has shaped their identity as an advocate. Within my search, I hope to discover common life experiences, common behaviors, and common barriers that parents have experienced. While quantitative research may provide statistical information on how many parents engage in active educational participation in a particular school system, it will not provide an array of richly detailed life experiences that are constructed into stories that produce insight into the complexities of life. Campbell (1995) notes that many research methodologists believe that qualitative research is superior to scientific methods, especially when the task is to understand the life experiences of women.

By looking at how one's identity is constructed through one's life experiences, we will gain a better understanding of how a parent is able to handle the complexities and challenges that are associated with advocacy. McAdams (as cited in John, Robbins, & Pervin, 2008) states that the identity of an individual is internalized, evolved, and integrated from life experiences. Darling (1988) states that life experiences evolve based on natural development. In fact, Darling (1988) explored the natural development of activism among parents of children with disabilities from a symbolic interactionist perspective, and concluded that parents of children with disabilities learn about their roles as parents from past and present experiences that are observed from "their own parents, the parents of other children," (p.141) and models within society. Darling (1988, p. 141) attaches natural development to "predisposing conditions and situational contingencies"

that influence activism. While I agree that parents of children with disabilities can learn from a symbolic interactionist perspective, my study focuses more on the life stories that connect advocacy to one's reaction of life experiences. In other words, I want to know how each parent's interpretations of life experiences may have shaped their decisions, perspectives, and role as advocates. Not all life experiences define who we are, but they do provide a way for humans to organize and make meaning out of their life (DuBois, 1979).

The choice of narrative is also influenced by my past interactions with parents of children with disabilities and the public school system. My interest lies not only within the political territory of the public school system, but beyond. Therefore, it is imperative that I listen to the voice of the advocate because they have experienced the reality of discrimination that continues to exist in our world. The experiences shared through the mothers' life stories have the capacity to change conversations, shift the political landscape, and remove barriers that exist personally and socially. Casey (1995) states that when an individual's stories move from private to public, the narratives shift from the individual into the political realm. In fact, one of the parents that I interviewed believes that her story could impact state legislation. Her belief is grounded in her desire to have her voice heard within a political atmosphere. The future of special education law can be changed, as history has shown, but requires a collective voice of parents to pursue improvements.

Finally, I am attracted to narrative research because it helps me to look at the outside appearance of individuals and to acquire a better understanding of one's true

identity (Riessmann, 1993). There is not a right or wrong way of expressing a narrative, nor does one's financial, educational, or social status enhance its meaning. Casey (1995, p. 220) states that the "lack of academic learning does not preclude expertise in narrative knowing or skill in narrative expression," therefore, the narrative in itself is important politically and socially. By listening to the narratives, I was able to dissect each layer of the advocate's "collective" self from the themes that surfaced. These similarities of experiences can identify a common ground among the community of parents of children with disabilities. When special education policies are written, they are usually in the presence of the professionals, while lacking the voice of the "true" expert. The experts are the parents who have lived through real life experiences with their child. Not all of the parents I interviewed are necessarily at a place in their life where they can effectively penetrate the larger political realm, but their stories can.

The Purpose of Narrative Research

My research is not about making predictions on narratives that are based on hypothetical situations, but rather based on actual lived experiences that take shape in the form of a story. The narratives purpose is to "see how respondents in interview impose order on the flow of experience to make sense of events and actions in their lives" (Riessman, 1993, p.70). Connelly and Clandinin (1987) describe narrative research as "a study which is historical, personal, factual, causal in an interpretive sense, and designed to reveal what is meaningful in a person's history" (p. 130). While it is important that I look for specific themes, I must also pay careful attention to not limit unexpected stories that may present themselves. Finding the voice of the narrator is especially important as I

analyze the story in the context of a particular time, place, or setting (Connelly & Clandinin, 1990).

The significance of my research lies within the stories shared from the participants in this study. It is in the course of sharing their life story in the form of a narrative that parents of disabled students begin to open up and discuss the difficulty of raising a child with a disability. Riessman (1993) states, the details of an individual's life experience can be modified based on who is listening, the interest of the listeners, and their reasons for sharing, which may or may not in fact be consistent from one setting to the next. Many of the stories I heard were remarkable and would be considered by others too private or too personal to be shared. I was surprised at their level of trust, and was indebted to the participants' sense of security and honesty. Following the recommendations of Oakley (as cited in Roberts, 1983), Riessman (1993), and Casey (1995), I began my time with each interviewee telling them some of my own story. We talked about my childhood, how I am connected to individuals with disabilities, my role as a parent, my faith, and my future direction upon completion of my research. I believe by sharing parts of my life story and the purpose of this research helped the participants gain my trust. Finally, I found at times the participants' stories were incredibly moving, especially during their stories of suffering. It was during those moments in the interview that I felt their suffering and shared their tears. I embraced all aspects of the narratives shared with me, regardless of their emotional impact.

Myself as a Researcher

In a narrative class that I took under the direction of Dr. Kathleen Casey, she emphasized that I must understand myself as a researcher so that I can be aware of my identity within the relationship between interviewer and interviewee. Casey (1995), states the precondition of understanding others is achieved by understanding yourself. Following Casey's (1995) direction and Kleinman and Copp (1993), I analyzed my values, emotions, motivations, and attitudes throughout the research, especially since I have a personal connection with the disability community. Peshkin (1988, p. 17), states that the researcher should "systematically identify their subjectivity throughout the course of their research." Obviously, my own life experiences have shaped my personal identity and have provided a sense of continuity and balance in the completion of this research study (Pasupathi, Mansour & Brubaker, 2007). In the following section, *A Story Worth Living*, represents my past experiences that have influenced my subjective awareness.

A Story Worth Living

In truth, all lives are worth living no matter how difficult it may seem. Pinar (1981, p. 184) simply states that individuals are "not mere smudges on the mirror. Our life-histories are not liabilities to be exorcised, but are the very precondition for knowing. It is our individual and collective stories in which present projects are situated, and it is awareness of these stories which is a lamp illumining the dark spots, the rough edges." My journey as an individual has taken many paths and I have often reflected on the stories that represent my life. Grumet (1987, p. 322) states, "our stories are the masks

through which we can be seen, and with every telling we stop the flood and swirl of thought so someone can get a glimpse of us, and maybe catch us if they can.”

This section titled, *A Story Worth Living*, reflects a self-navigating experience that I share below which has lead me to a much fuller understanding of my subjective self as a researcher. The experiences that I share are collective stories that represent the *Story of My Life* and were originally written within a document titled the *Story of My Life* (Peddle, 2007) for a graduate course. Since then, the original document has changed due to a continual reflection of my past experiences. Paz and Weinberger (1990) describes the process of self-reflection as an act of walking inside yourself. Again, this section represents my subjective awareness of experiences from my past and their claim on my identity. Riessman (1993. p. v) explains that “the construction of any work always bears the mark of the person who created it.” Alan Peshkin (1988, p. 17), reminds us that in analyzing one’s subjectivity, the researcher becomes “aware of how their subjectivity may be shaping their inquiry and its outcomes.” In reflecting back some of my life experiences are clearer than others, especially those that have had an influence on my identity as a professional educator for students with disabilities.

My Beginning

Before I begin, I believe it is important to state that both my parents have shared with me only fragments of their childhood. Like my memories, their selection and rejection of stories depend on who they are, when, where, and why they were willing to share their memories with me (Casey, 1993).

My mother was born in Winston-Salem, North Carolina on January 6, 1950. She grew up in a small, shingled white house on a dead-end road. My mother was the middle child and had a brother who was eleven years older and a younger sister who was born with a developmental disability. My father was born in Kannapolis, North Carolina on August 18, 1948. His family moved to Baltimore, Maryland and remained there eight years, before returning to North Carolina in 1957. My father had an older sister and was the oldest of five boys. His closest brother in age died in the Vietnam War when my father was twenty-three, which made a lasting impression on my parents. I remember them sharing with me that they believed the Vietnam War was a bloody, political mess.

Many stories my mother has shared with me reflect back to her childhood, like the afternoons she spent singing songs with her parents. My mother's father was a self-taught banjo musician and her mother, who played the piano, would often have jam sessions in the evening after dinner. My mother has never forgotten the words and melodies to the songs she sang, nor has she forgotten the sounds of coins hitting the top of the kitchen table. Those sounds were a reminder of her father's night life that included gambling and partying. On one occasion, my mother recalls an unusual event when she was around four-years old. She tells the story of her father who was dressed up in a tuxedo with his hands and face painted black. She remembered screaming as he entered through the kitchen door, unsure of who he was. Later on, she learned that her father had appeared at a variety show that night for Sears and Roebuck, and had performed a tap dance act with his late night friends. Nonetheless, my grandfather had a hard time explaining to my mother why he was a black man. My mother had few opportunities for

personal growth. She was often reminded and distracted by the advancing age of her parents, her sister's disability, and the poor conditions of her home environment.

My father's childhood memories are sketchy. Much of this is due to very cruel, physical, and verbal abuse he suffered as a child at the hands of his father. He remembers his mother stating on many occasions that his father wanted to keep her "barefoot and pregnant." On another occasion, my father remembers his dad telling him to jump from a ladder and he would catch him. As he jumped, he didn't catch him and my father landed on the ground. After he looked up in disbelief, his dad told him that this experience would teach him not to trust anyone. In the fifth grade, my father and his younger brother were walking to elementary school only a few blocks from their home. As they crossed the street, a driver failed to see my father and knocked him to the ground, luckily, only breaking his leg in several places. Due to this unfortunate event, my father was able to go to college, using the money that his mother had set aside from the car accident settlement. My father recalls after years of abuse, his dad began to practice a religion called the "Truth." The "Truth" originated in Wales and was brought over and was introduced to my father's family who resided in St. John's, Newfoundland. My grandfather's conversion offered some relief from the abusive taunts my father and his family endured. A few years past, my father and mother went to Newfoundland in search of his ancestral home place located in Bristol's Hope. While there, they searched for a possible link between his family's cultural background and a reason for the extreme harshness my dad suffered as a child.

I remember as a child traveling to Kannapolis, North Carolina to visit my father's grandparents and climbing the long smooth limbs of a crepe myrtle tree. I remember hearing the coo coo clock and sitting down at dinner watching my dad enjoy the company of his grandparents. His grandparents offered stability and a refuge.

My Childhood

My childhood memories begin on a gravel road in rural Winston-Salem, North Carolina. It was a place to discover hidden paths that stretched deep into the woods near my home. It was a place where imagination and play collided and produced many of my childhood memories with my brother. The freedom we experienced together as we roamed abandoned quarries, old sheds, and sandy farm roads created a bond that we will forever share.

My older brother and younger sister were more academically gifted than myself. At one point in high school, my brother received numerous academic and art awards given out at the end-of-the-year awards day ceremony. As a student, I was fidgety and anxious, excelling more in sports than in academics. In the second grade, my teacher told my parents that I had a learning disability. My mother and father did not accept the label, because they believed that it would limit my potential and just didn't believe it. What was my potential? Sadly, not one teacher took a special interest in me to help improve my academic development. Today, I see the importance of believing in myself and not allowing other people to determine who I am and what I am able to accomplish. My educational journey is not in whole the *Story of My Life*, but yet is an integral part of my struggle for significance.

Shaking Hands

“*Shakings Hands*,” begins in a seat on a bus in route to North Forsyth High School in Winston-Salem, North Carolina. What moves would I make? What counter moves would he make? I was always nervous before a wrestling match, getting the usual butterflies deep down in my stomach. The locker room at North Forsyth bled with the smell of sweaty athletes. There I was, standing in line half naked, waiting to be weighed in. I hated wrestling, but I did it anyway to please my parents. I weighed in that night, a light 112 lbs. I quickly slipped on my uniform, laced my shoes, gathered my head gear, and lined up to enter the gym. I was the third wrestler in line. I felt a sense of importance by being on the team, hoping that my presence would make me more popular in school. We entered the gym as a team circling the mat, grunting our intimidation chant. The gym was unusually packed that night. During the stretching routine, I looked over to size up my opponent. I would compare his stature to mine and would predetermine the outcome of the match based on what I saw. Was I stronger, quicker, and smarter? That night I breathed a deep sigh of relief. My opponent was nowhere to be found and I anticipated a forfeit.

The buzzer sounded as my teammate quickly pinned his opponent. We were up 2-0 and I was next. I waited nervously on the bench for my name to be called. “Joel, let’s go. You’re up,” the coach shouted. I approached the edge of the mat. The audience stood to their feet and began cheering. Obviously, they knew something I did not. I looked across the mat and there was my hopeful forfeit. I was speechless. My opponent had legs, but could not walk. He used his arms to hold himself upright on the floor. My

heart was beating faster and faster, no longer in anticipation of a forfeit, but how to stomach such a match. I could not imagine myself pinning a student with a disability. I looked back at my coach, hoping he would take me out, seeing that I was in shock. I looked up at my parents in the audience, hoping they would take me out of the match or at the very least give me a signal indicating that everything was going to be all right. No signals, but only a plastered look of disbelief were on their faces. I could neither run, nor hide. I had no choice but to wrestle and to win. To lose would mean humiliation and ridicule by my teammates. I was damned no matter what. As I walked to the center of the mat, I met my opponent dragging himself to the center. We reached out and shook hands. His firm hand grip was an indication of his upper body strength and suddenly, I had a thought that he might just pin me. The buzzer sounded and off we went. Within a few seconds, I was able to quickly circle him and put him on his back. He struggled to move as I squeezed harder and harder, pressing down on his chest. Finally, the referee slapped the mat and our match was over. I remember standing over him thinking “what did I just do?” The referee raised my hand in victory as I held my head down. There were no claps, no high-fives, not even a “way to go, Joel.” While the audience and my teammates remained in complete silence I walked off the mat and went back to the locker room. It wasn’t long after this event that I decided that wrestling was not for me. This experience affected me deeply.

Alex

During my seventh year of teaching, I met Alex as a frail sixth grader in the fall of 1997. He had a rare bone disorder, unable to move his upper body except for his fingers, and was confined to a motorized wheel chair. He was a brilliant student and loved the social interaction with his peers. However, he was unable to participate in physical education class because the gym was not accessible. The gym lacked a handicap ramp. Alex and I often talked about developing a plan to get a ramp so that he could join his peers in the gym. Finally, toward the end of the year, Alex and I had written a proposal to submit to the school administration for a ramp. It received no attention, so during his seventh grade year, we submitted the proposal to the school system's exceptional children's director. During that year, the school system sent their construction director to the school where we, Alex and I, laid out the best location for a ramp. A few weeks later, the director called me and stated that it would take over \$8,000.00 to construct a ramp. He also stated that there were no funds for the project for that school year. I expressed to the director that next year would be Alex's last year in middle school and it would mean a lot to us if the project would be considered for the following year's budget. Alex and I never got to see the construction of a ramp during his eighth grade year, however, during his tenth grade year in high school, a ramp was finally constructed at the middle school. Alex and I were proud of our determination and for raising the level of awareness for the rights of students with disabilities.

Jesse

On a brisk Monday morning, I got Jesse and walked to the track. “Mr. Peddle, what is our plan for today?” Jessie asked. “Today we are going to ride a bike together,” I stated. “How?” Jesse asked. “You will see,” I replied. I snapped on Jesse’s helmet and guided him to the bike. “Mr. Peddle, don’t let me fall,” Jesse stated nervously. I remained confident, assuring Jesse not to worry. “Ok, Jesse, on the count of three I would like for you to push off with the leg that is on the ground and begin pedaling with the foot that is on the pedal.” I took a deep breath, “One, two, three,” and off we went. We rounded the first lap together, feeling the cool air against our faces. Jesse was having the best time of his life. “This is awesome,” Jesse replied over and over. The tandem bike proved to be a dream come true for Jesse. As we finished our last lap, a heavy-set man approached the track and held out his arm motioning for us to stop. I told Jesse to begin slowing down. This man who identified himself as the school’s athletic director, ordered us off the track stating that the bike was damaging the surface. I refused to leave, informing the athletic director that Jesse was a blind student at the high school and this was his adapted physical education class. A week later and after several conversations with the school administration, Jesse and I returned to the track to once again feel the wind against our faces.

Jane

“Hey Joel,” is the first comment that my Aunt Jane usually responds to when I call her on the phone. Jane is developmentally disabled and has been fortunate to have never lived in a state-run mental facility. She now resides with two other ladies who are

also developmentally disabled. I have many memories of Jane which include her jumping over imaginary “dead” people in our backyard, soulfully dancing in our living room, and laughing uncontrollably during our family’s Thanksgiving dinners. More recently, I remember Jane doodling on a writing pad, while the court decided whether or not Jane should remain her own guardian. We were all present that day, my mom, her brother, my father, Jane’s two nieces and I waited anxiously to speak to the court on Jane’s behalf. At one point, I interrupted the court hearing and stated that this was not fair to Jane. The court asked me what I meant by that statement. I replied that once again I believed that others were making decisions for what is in Jane’s best interest, other than her family. I learned that day the court was not interested in her family’s advocacy, but more interested in why she was able to sign off on refinancing the mortgage on her home. This was the question posed by the guardian ad litem assigned to Jane by the court. The caseworker that filed the petition, based on her professional opinion, believed that Jane was not able to make safe and sound decisions about her welfare and needed a court appointed guardian. The court decided to postpone the decision until further notification and communication from CenterPoint. CenterPoint is North Carolina’s state-mandated local management entity in charge of overseeing the delivery of publicly funded mental health, developmental disabilities and substance abuse services in the county where Jane resides. Following several meetings with CenterPoint, the case resumed and it was the opinion of the court that Jane could remain her own guardian, since she was a homeowner and signed off on the recent refinancing of her home. It was evident to me

my mother's voice was secondary to the agencies who assumed they knew better.

However, it was also clear that our family's advocacy had been noticed.

Conclusion

These stories from my own personal history and others I have not noted are at the root of my particular interest in the subject of disability education. These narratives formed my own subjectivity as well as the direction I have taken in this study. Peshkin (1988) describes the importance of disclosing to the reader the writer's subjectivity, so that there is an understanding of self and subject.

Finally, having been in the field of special education and having sat through hundreds of IEP's, I witnessed first hand parents sitting and signing rather than questioning and engaging in active participation in the educational decisions for their child. The reality of this experience has left a lasting impression on me and is the center of my research. What is surprising is that change is rarely suggested, which is why I want to propose the development of a Parent School Advocacy Plan (PSAP) at the state level. I expand on this initiative in Chapter VI.

Selection of Participants

In my introduction, I stated that I wanted to interview parents of children with disabilities who advocate for their child. Unless you have worked in special education and have witnessed the lack of parent advocates, as I have, you might think that finding parent advocates would be a simple task, but this was not the case at all. My initial attempt was to contact local agencies that worked with individuals with disabilities, in hopes of locating parent advocates. After several emails and unanswered phone

messages, I thought that I may have to attend the next Law and Advocacy conference conducted by Wrightslaw in Greensboro, North Carolina in order to find willing parents. The task of finding parent advocates proved to be a challenge and so I decided to seek advice from my dissertation chair who overlooked this study. It was recommended that I contact a former University of North Carolina at Greensboro doctoral student who serves as an executive director of a local ARC organization. I contacted the executive director and explained my research study. She found my research to be very relevant to our current disability community and agreed to support and assist me in recruiting parent advocates for my research. I initially contacted potential participants by email and followed up with a personal phone call. During my conversation, I identified myself and explained why I was interested in doing a study on the life experiences of parent advocates. I also explained the interview process. The six participants I selected agreed to be a part of my research study. The participants are all female and have a child with a disability. Four of the mothers were born in United States, while the remaining two mothers were born in Mexico and are fluent in Spanish. Rather than involve a third-party translator, who may have threatened the intimacy of the interview, I chose to accept the mistakes and struggles communicated in “broken” English. To protect the mothers’ privacy, I used pseudonyms for each parent and their child in this study.

The Interview Process

I offered to meet each parent at a convenient location to conduct our interview. One parent requested that I meet them at their house. Two of the parents requested that I meet them at their place of work and the remaining three parents requested that I meet them at a local public library. All of the libraries provided me a private conference room, however, at my last meeting with a parent, the library informed me that there was a \$100.00 charge for use of the room. Unfortunately, I was unable to pay for the conference room and had not prepared a back-up plan. I had traveled almost two hours to meet this parent and I did not want to reschedule our meeting. Feeling a bit pressured, I remembered seeing a nearby church that I had passed on my way to the library and so I asked them and they graciously agreed to let me use a small room.

Five of the six interviews were conducted in an office or private room and provided a quiet and relaxing location. The final interview took place at a parent's home and was conducted outside on her patio, along with her dogs, cats, and a pet bird. At first, I thought the atmosphere may be distracting, however, the parent seemed relaxed and forthcoming during the interview. When I met with the participants for our in-depth interview, I formally introduced myself, provided further information about the research study, and explained my connection to the disability community. I also reviewed issues regarding confidentiality, the length of the interview, and the recording process. Oakley (as stated in Roberts, 1983) states, "the goal of finding out about people through interviewing is best achieved...when the interviewer is prepared to invest his or her own personal identity in the relationship" (p. 41). Prior to the interview each parent knew I

was going to use a tape recorder to record their conversation. Once the parent was settled and appeared to be comfortable, I began the recording session by asking them to tell me *the story of their life*.

The story of their life represents an open-ended structure of questioning that is meant to illuminate the life experiences of an individual's identity (Casey, 1993). Spradley and McCurdy (1972) refer to this type of question as a "grand tour" question. Quantz (1992) defines it as one which is designed to be directive enough to require concrete and precise responses, yet open enough to allow the interviewee to go in any direction and recall anything that is meaningful to one's life. In *I Answer With My Life: Life histories of women teachers working for social change*, Casey (1993, p. 24), states that by asking the question "tell me the story of your life," a story is transformed into an "interrogation for social significance" which is further interpreted into "what is the meaning of your life."

Method of Analysis

The narratives collected in this study were highly constructed texts (Popular Memory Group as cited in Casey, 1993) filled with words that "have taken meaning and shape at a particular historical moment in a socially specific environment" (Bakhtin as cited in Casey, 1993, p. 26.) Each narrative was filled with knotted, embedded, and interwoven stories (Riessman, 1993). In this study, the experiences shared in each narrative are presented through a "storied landscape." The "storied landscape" creates a way to understand how the context in which an individual lives is shaped by their experiences and their understandings (Clandinin & Connelly, 1995). The narratives that I

have collected from parent advocates embody a way to connect, investigate, and understand their human experiences while providing an opportunity for parents to tell their stories in their own terms.

Narratives are constructed within a three dimensional space, “with temporality along one dimension, the personal and the social along a second dimension, and place along the third” (Clandinin & Connelly, 2000, p. 50). The three dimensional space is represented in all narratives where the storyteller shares stories of their past that frames their current positions, while moving forward and backward from social to personal, which is then situated in a place (Clandinin & Connelly, 2000). Temporal dimensions are shaped according to an individual’s past, present, and future. The personal and social dimensions refer to inward and outward conditions such as one’s feelings, desires, and reactions to moral experiences or existential conditions such as family, community, or self. The third dimension is the place in which the narrative is situated (Clandinin & Connelly, 2000).

For this study, I followed Riessman’s (1993) method of narrative inquiry which is divided into three stages, namely telling, transcribing, and analyzing a story. First, telling was captured through interviews that I recorded using a digital recorder and was listened to repeatedly. Not only did repeated listening to the recorded stories prove essential in hearing all of the nuances that could have been easily overlooked, it also identified pauses, speed, and contours in the storyteller’s speech (Riessman, 1993).

Second, the recorded interviews were transcribed into a written text or 'crunchable form' so that analysis of each story can take place (Riessman, 1993). Third, final analysis of each narrative occurred by:

- (1) Implementation of Richmond's (2002) "storymap" model of narrative analysis
- (2) Identifying themes grounded under thematic analysis (Braun & Clarke, 2006)
- (3) Examining each narrative according to Popular Memory Group's (as cited in Casey, 1995. p. 234) presumption that every narrative's principal value comes "complete with evaluations, explanations, and theories" which are identified through silences, slippages, and selectivities.

Detailed Steps of Analysis

Once I completed the interviews and transcribed the recordings into a written text, I used Richmond's (2002) storymap model to identify main themes and sub-themes in each narrative. Richmond (2002) explains "the storymap organizes the learners' recounting of past and present experiences and future intentions under the rubric of character, setting, events, conflicts, incidents, and resolutions. This "map" gives shape to individual stories and allows for a more penetrating analysis in relation to the objectives of the research" (p. 3). Utilizing Richmond's (2002) storymap framework, I designed a similar rubric which consists of self, family, community, suffering, conflicts, and reflection with each of these categories being situated in an individual's past and present experiences, as well as future intentions. Further, the storymap rubric that I designed (see Table 1) supports each of the three dimensional spaces which represent the core of a narrative (Clandinin & Connelly, 2000).

Table 1. Story Map Rubric

	SELF	FAMILY	COMMUNITY	SUFFERING	CONFLICTS	REFLECTION	RESOLUTION
PAST EXPERIENCES	▪	▪	▪	▪	▪	▪	▪
PRESENT EXPERIENCES	▪	▪	▪	▪	▪	▪	▪
FUTURE INTENTIONS	▪	▪	▪	▪	▪	▪	▪

Second, a thematic examination (Braun & Clarke, 2006) of the transcribed narratives occurred following completion of the storymap model. The thematic examination identified themes and sub-themes amid the parents’ narratives and allowed for cross examination between them from each of the categories represented in the storymap. Riessman (2003, p. 2) states when utilizing a thematic analysis, emphasis is placed “on the content of the text, “what” is said more than “how” it is said, the “told” rather than the “telling.” Bell (1994) explains that by studying the sequence of stories and identifying the thematic connections in a participant’s story, researchers are able to help connect significant events and important relationships in their lives. To identify themes across each storymap, a thematic rubric was designed (see Table 2).

Table 2. Theme Rubric

PAST EXPERIENCES	SELF	FAMILY	COMMUNITY	SUFFERING	CONFLICTS	REFLECTION
MAIN THEMES	▪	▪	▪	▪	▪	▪
SUB-THEMES	▪	▪	▪	▪	▪	▪

Finally, I identified silences, slippages, and selectivities that may in turn shape how the narrative is portrayed in the text (Popular Memory Group as cited in Casey, 1995, p. 234). Silences refer to what the participant chooses to leave in or out of their life story, for example, the divorce from a spouse or the death of a relative may or may not be revealed. Narrative researchers must attend to the silences in a story, as suggested by Kermode (1981), since people do not hear the stories that they themselves are sharing. Slippages in a story occur when one part of a participant's story contradicts another part of their story or were not meant to be told or just "slipped" out. Merrill (2007) refers to narrative slippage based on how the participant attempts to avoid expected story lines. Further, slippage reveals how individuals make decisions on what stories they will share and for what reasons. Selectivity refers to a participant's discretion of what experiences they reveal or not reveal from their life story.

CHAPTER IV

ANALYSIS OF THE LIFE STORIES OF PARENT ADVOCATES

In this chapter, I begin with a brief overview of how life experiences can shape an individual's identity. I also introduce each participant so that the reader develops a sense of who this person is. In addition, during the analysis of each narrative, five themes emerged providing me an opportunity to theorize on the significance of those themes and their broader meanings and implications (Braun & Clarke, 2006) as they relate to each advocate. In this chapter, I introduce four common themes that were identified within the narratives. The fifth and final theme is discussed in Chapter V. For clarity, in this chapter when I use the term mother, advocate or parent advocate, I am referring to the mothers that I interviewed.

Identity and Life Experiences

The narratives collected from parent advocates are a response to being asked to tell "*the story of your life.*" The open-ended structure allowed the parents to introduce subjects that are of major importance (Casey, 1993). These subjects are in the form of stories which are central to the identity of the self. Polkinghorne (1988) explains the self is constructed into a historical unit which includes not only "what one has been but also the anticipations of what one will be" (p.150). Additionally, my inquiry follows that of what one has become through one's life experiences. Personality psychologists in their

attempt to understand human behavior have turned to life experiences that are in the form of a “story” or “narrative” to be useful when finding consistency and meaning of human lives (McAdams, 2001). The identities of parent advocates are situated along temporal dimensions that connect personally, culturally, and socially. The identity of each parent advocate is shaped over a course of a life-time and constitutes the individuality of that particular person (McAdams, 2001). Narrative identity theorists Dan McAdams (2006) draw correlations between individuals and how they connect their life experiences into the construction of one’s identity. McAdams (2006) suggest an individual’s narrative is comprised of life transitions or events that shape the personalities of the self.

Studying human personalities is complex with varying degrees of theories including prominent historic researchers, Sigmund Freud and Erik Erikson. Freud’s theory of personality development is grounded under early life experiences. Erikson expands Freud’s theory by incorporating the impact of later life experiences on an individual’s personality (McAdams, 2006). A person’s identity can change from one life experience to the next, but what is consistent is the core of the individual self. Drawing from McAdams (2001) identity theory, the narratives in this study were complete with themes, characters, and plots.

When I began my interviews, I really didn’t know what type of stories I would encounter. I didn’t know how the story would begin or where they would end, after all each story is a continual work in progress (McAdams, 2006), but what I observed was that each story definitively shaped the identities of the mothers in one way or another (McAdams, 2006). The identity of each of mother is different, yet they share a common

core story, the birth of a child with a disability. Their path to advocacy is also different, yet they share common storied themes. Each story was delivered with passion, as I sensed urgency in their telling. Perhaps I was the first to hear *the stories of their life* or maybe the stories are representative of a triumphal spirit within each mother. The mothers in this study do not represent parents who are fearful to confront or engage and consequently just show up for IEP meetings, doctor visits, or parent teacher conferences. Instead, I am talking about mothers that are resolute yet cooperative, firm yet kindhearted, resistant yet resilient, invincible yet vulnerable. I am talking about mothers who convey a committed and steadfast message of equality for their child and other children with disabilities.

Introduction of Participants

Out of all the words that describe the mothers, I found the word resilience to resonate strongly in the context of their past experiences and public school experience. I found this resiliency to launch their systematic plight to improve the quality of life and education for their child and that of others. The names of each mother and their children have been changed to insure anonymity. The mothers in this study are currently in their thirties, forties, and fifties and live in different cities within the same state. In addition, at the time of the interviews, all of the mothers were married except for one.

Cindy

I met Cindy in [city], at the [county] public library. She was a tall woman with short, brown hair and glasses. Cindy had a beautiful smile and a slight, southern drawl. She grew up in [city] with her mom, dad, and older brother. Her mother and father have been married for over thirty years. Cindy grew up in a very happy home and attended church regularly with her family. Her father was a musician and deacon in the church and would read the Bible to her every night. Cindy remembers thinking as a child that her family was poor because she wore clothes purchased from Family Dollar. During much of her childhood, Cindy was picked on at school.

When she entered high school, she slimmed down and started dating. Cindy made A's and B's in high school and by her senior year had been accepted into several colleges. She chose the University of [state] and wanted to major in psychology. During Cindy's senior year in high school, she dated a boy for six months who was four years older and ended up getting pregnant. Cindy graduated from high school and was married at seventeen to the father of her child. Cindy had a healthy pregnancy and delivered her son, Luke, determined to be a responsible mother. Cindy believed that her pregnancy was a wake-up call from God.

Her new husband was a truck driver and turned out to be physically and verbally abusive. After two painful years of marriage, Cindy decided to file for divorce. Cindy's fight for custody of Luke was a pivotal time in her life. She feared losing Luke, but after a lengthy court battle, Cindy eventually prevailed and won custody. Cindy and Luke became a family, but Luke struggled with his behavior and was considerably behind

developmentally. Luke's slow development went unnoticed by Cindy who thought his multiple outbursts were normal. It was during this time in Cindy's life, with the remnants of an ugly divorce and the early stages of Luke's educational struggles, that her faith in God kept her balanced and prepared for a long puzzling journey ahead understanding the abyss of autism.

I do know that I'm going to be judged and I feel like God did give me Luke for a reason...I know I'm going to have to look and say every decision pretty much is about Luke.

Dora

I traveled to [city] to meet Dora on a Saturday morning. We were scheduled to meet at a public library located in a highly populated urban area. I secured a private conference room for our interview, but was told when I checked in that there was a hundred dollar charge for use of the room. The meeting had been rescheduled several times to accommodate Dora's busy schedule and since I did not have a hundred dollars, I decided to ask a nearby church for a small room to conduct the interview. The church was more than happy to comply and so Dora and I began our interview. Dora was born in [city], Mexico in 1972. She is the youngest of nine siblings. Dora's parents, while they struggled in their marriage, provided her and her siblings with a safe, loving home. At an early age, Dora understood the meaning of compassion and the reality of life and death after the sudden loss of her best friend. Dora finished high school in Mexico and after two years of college, she married her high school sweetheart.

While in college, her husband who was a United States citizen, decided to join the United States Marines. Dora dropped out of college, left her family in Mexico, and moved to [city]. After two years in [state], Dora and her husband separated. Previous to the divorce, Dora's sister had followed her sister's footsteps and as fate would have it, ended up living in [city], providing a place for Dora to live for a short time. It was during this life transition that Dora questioned her purpose as a human being. The reality of learning a new language in a new culture with an empty wallet began to shape her dependence and trust in God. "Is this it? Where am I my going? Who am I?" Dora's quest to understand who she was soon was answered. After several months of working in [city], Dora decided to go back to school at a nearby community college and began volunteering at Hospice.

Not a crossroad, but a very important point in my life. Like, you go this way or you go this way. So when I started volunteering for Hospice, I felt like whoa... this is, you know, this is where I am supposed to be.

Dora remarried, graduated with an Associate in Business Administration, and eventually became pregnant with twins. Dora's pregnancy was difficult both physically and emotionally. After seventeen weeks, Dora was admitted to the hospital and was restricted to bed rest. After six long weeks in the hospital, Dora ended up losing one of her twin boys. It was during this time in the hospital that Dora's life would change dramatically and her faith in God would be tested. For the next several years, Dora and her husband experienced major life changes, including their son's diagnosis of cerebral palsy and an unexpected new pregnancy. They moved back and forth from Mexico to the

United States. It was the diagnosis of Down's Syndrome of their newly born daughter that exposed Dora's weaknesses, her strengths, and God's direction for her life.

Lisa

Lisa and I met at her place of work in [city]. We walked to a small conference room and sat down to begin our interview. Underneath Lisa's small stature is a woman with passion, persistence, and a feisty personality. She is the oldest of four siblings. Her mother is still married to her father even after suffering from his physical and verbal abuse. Lisa grew up in [city] while her father drove a bread truck and her mother worked in the tobacco fields. Her family was poor, yet her abusive father always found time and money to drink to excess. Lisa excelled in school. She was popular, smart, and was nominated as an outstanding senior in her class. Much of her time in high school was spent being involved in extracurricular activities, perhaps, in an effort to avoid going home. After years of physically fighting and protecting her mother and siblings from her father, Lisa graduated from high school, left for college, and never returned home to live. Prior to Lisa leaving for college, she met a young disabled boy in church who would make a lasting impression on her life and career forever. Lisa dated in high school and became engaged in her first year of college. The engagement was short-lived and so was her college experience.

Lisa dropped out of college and went to work as an assistant in a developmental center for children with disabilities. As an assistant, she met an autistic student who was non-verbal and behaviorally aggressive and needed transportation to the center. Lisa agreed to transport the student back and forth to the center and developed a "motherly"

relationship with him. The director did not like her style of disciplining the young boy and advised Lisa to stop defending him, unless she had a degree to back up her disciplinary theory. Lisa remained as an assistant until the autistic boy graduated from the school. She also returned to college to earn degrees in Psychology and Special Education. Prior to graduating from college, Lisa started dating a hang gliding pilot she met in the mountains of [state]. They dated and were married within a short time. Adventure and recreational activities were the core of their relationship, and Lisa welcomed the challenges. All of the activities came to a screeching halt when Lisa discovered she was pregnant. Lisa went into premature labor at twenty-five weeks while at work and delivered her son a few hours later. Tate weighed one pound, eleven ounces and was eleven inches long. The hospital staff advised Lisa not to get attached due to a possibility that her son may die within an hour, but Lisa relied on her faith in God. “I said I’m already attached. I’m going to love him and I said, God makes those decisions not man, so I went in there and I about passed out.” Tate did survive, but was born blind. Lisa’s husband could not handle the restricted lifestyle of having a child with a disability and so Lisa and her husband got a divorce. Even though there was a day to day struggle within the community and in the public school system, Tate and Lisa created a legacy of opportunities for blind children. Lisa states that Tate has been her “founding purpose for twenty-five years of doing more,” for children with disabilities.

Elsa

I traveled to [city] to meet Elsa for our interview. We met at the public library where I secured a small conference room. Elsa was born in [city], Mexico. She is the

youngest of four siblings. Her father died when she was three, leaving her mother financially responsible for the family. Elsa's mother finally decided to leave [city] and move to [state] with some friends after Elsa was shot in the arm in a crossfire between two gangs in their neighborhood. At a young age, Elsa struggled to learn English and adjusted to the American culture.

After a short time in [city], her mother met and married a man who lived in [city]. The man turned out to be physically and verbally abusive and required her mother to file for welfare and her older siblings to go to work. The food stamps and money earned went to the man while Elsa, her siblings, and mother were only allowed to eat tomato and banana sandwiches. "That's the only thing we could have and water and so, to this day I cannot eat tomato sandwiches or banana sandwiches, because that reminds me of that time." Elsa and her family began to rebel from her stepfather's control and eventually left. The police were contacted and arrested Elsa and her family because they thought they were illegal aliens. After spending a day in jail, the police released Elsa and her family because her mother had proof of legal residency. Needing a place to live, Elsa and her family accepted help from another family. Their trust was again shattered, as this family did not allow them to eat the food that Elsa's mother had purchased with food stamps. Elsa and her family eventually returned to Mexico, but were treated as Anti-Mexicans.

We went back to Mexico...but it was like, in Mexico...we were not Mexicans no more. They treated us different. Our accent changed a little bit. So there was one time that they....one kid told me that I was retarded or something.

After six months, Elsa and her family returned to [city] to live with her oldest sister. Elsa's mother got a job, found a place to rent, and established a loving home in a city where they had been taken advantage of earlier. While in high school, Elsa started dating a young boy she had met volunteering at church. Prior to graduating from high school, Elsa eloped and got married. Elsa became pregnant and delivered her first child with the intention of being a loving and caring mother. When her child entered public school, Elsa volunteered in various ways, including translating school documents from English to Spanish.

Elsa encountered problems with her second pregnancy and delivered her son Omar prematurely. Omar came home after a month in the hospital, but Elsa sensed that something was wrong. Omar had difficulty eating, sleeping, and appeared to be in pain while being transported in his car seat. After several trips to the doctors and having many questions left unanswered, a year later, Omar was diagnosed with quadriplegic cerebral palsy. The effects of having a child with a disability were overwhelming for Elsa. Omar and Elsa faced many life challenges including those within the public school experience. She resisted the temptation to give up and raised Omar to be an independent thinker. She established herself within the disabling community as a persistent parent. "Every time they needed anything for Omar, IEP's, anything, I'm always there. I'm always asking what did I need to do? What did I need? If he's out, I'm always asking what stuff does he need?"

Sara

I traveled south down the winding roads of [state] to meet Sara in [city]. About ten minutes into my journey, I was interrupted by the sound of a police siren. The police officer said I was speeding and gave me a ticket. Needless to say, I was not in the greatest of moods when I showed up at Sara's place of work for our interview. However, it only took a few minutes of listening to Sara's story to erase my earlier speck of misfortune. Throughout Sara's office were multiple pictures of Sara's family along with memos and to-do lists scattered on her desk. Sara is a middle-aged mother of three children and grew up thinking that her role in life was to get married and have children. Sara's parents instilled in her that faith in God and commitment to family should be top priorities in her life.

Sara met her husband on a blind date and was married a year later. Focusing on starting a family, Sara and her husband found out they were pregnant with their first child after their second year of marriage. Sara had a healthy pregnancy and delivered their son Jack without complications. According to Sara, Jack was a perfectly healthy baby meeting all of his milestones in the first nine months. However, at ten months old, Jack started showing signs of some delay. Sara really didn't think too much about the delay and thought that he would catch up within a few months. At eighteen months, Jack was not standing or showing any developmental progress, so Sara decided to have Jack tested. The Developmental Evaluation Center conducted tests on Jack and delivered one of the most devastating comments that Sara and her husband would ever hear. Sara states,

“They told us that Jack was mentally retarded and that the best thing we could do is possibly put him into a institution.”

At that moment while her heart was shattered in disbelief, Sara’s inner resiliency emerged with much determination. “Well, my husband was pretty devastated. I was devastated, but I was mad. I don’t know if it was part of my upbringing or what, but it really ticked me off.” Sara’s grit would carry her through many of life’s trials, including those faced in the public schools and within [state’s] Department of Developmental Disabilities.

Beth

I met Beth at her log cabin that she shares with her husband and two children in [city]. The cabin sits near the end of a graveled road surrounded by wild flowers, herbs, bird houses, and a nearby stream. As I drove up to her home, I was greeted by two barking dogs looking to pounce on me at any moment. Actually, both dogs were pretty playful and have been professionally trained by Beth. Her home had several outdoor sitting areas including an architecturally designed patio and screened-in gazebo with hot tub.

We began our interview on the patio accompanied by the dogs, cats, and birds. Beth had a soft voice which served her well when training animals. It was obvious that Beth was passionate about animals, a love that began as a child. During high school, Beth volunteered in veterinarian offices and pursued a degree in animal science in college. After college, Beth took several internships in veterinarian offices, but eventually landed a job as a zoological veterinarian technician at the [state] zoo.

Beth was born with a genetic condition and prior to getting pregnant, Beth and her husband sought genetic counseling. After consulting with the experts and feeling confident about the positive information that was given them, they pursued the hope of starting a family. Once Beth became pregnant, genetic tests were conducted as planned on the fetus to determine if any genetic disorder existed. Unfortunately, the tests were unable to determine if any genetic defects were present. Beth was left with disappointment and unanswered questions. Beth gave birth to a healthy baby boy and left the hospital showing no signs of any disorder.

For the first two years, Beth's baby was typically developing, but after three years his development took a nose dive, raising red flags for Beth and her husband. Their son, Joey, was tested and determined to be a "genetic mosaic." His development then followed the trajectory, typical of children who are on the autistic spectrum disorder. No one is prepared for the birth of a child with a disability. However, Beth possessed a unique ability of channeling her energy and time on the needs of their son Joey, while providing a home for foster children, respite care for parents of children with disabilities, and a home for rescued pets.

My son being disabled has been a blessing to the family. People have expectations for their children. Everybody has the same. You want your child to grow up healthy, happy, and wonderful and then you get that diagnosis. If your child isn't going to follow that path, then you have to adjust to the new path.

Introduction of Themes

We are not content as adults to construe lives as dispersed and fragmented, especially when the life is our own. We search for coherence, meaning and purpose in the dusty archives of our remembrances of things past and in our anticipation for the days to come. And we find coherence by consciously and unconsciously constructing for ourselves and for others a self-defining life story (McAdams as cited in Frantz & Stewart, 1994, p. 158).

I approached this research believing that the identity of an advocate is shaped by life experiences that occurred prior to and after the birth of a child with a disability. By asking the mothers to tell me *the story of their life* in the form of a narrative, I was able to identify who they believe they are, where they thought their life was going, and what constituted their individuality (McAdams, 2001). Not only did their life story represent the “history of their lives, where political naming, doing, and (re)interpreting create personal identity” (Casey, 1993, p. 24), it also demonstrated how people put their lives together into self-defining stories (McAdams, 2001).

A cross-examination of each narrative during the analysis revealed five overarching themes and twelve sub-themes. The emergent themes were inherent in the way each story was told and were represented through acts of *suffering, family, faith, motherhood, and advocacy*. For clarity, the mothers’ shared commonalities among the themes, as represented in their narratives and are indicated by their pseudonymous names.

Identity Shaped by *Suffering*

Within the narratives, stories of suffering were significant in terms of the profound impact it had on the mothers' lives. Black and Rubenstein (2004, p. S23) states that issues of suffering "are ultimately issues of identity." The nature of suffering as an experience, is "bounded and unbounded, immeasurable and paradoxical" and yet its outcome forces the question "When will this end?" or "Why me?" (Black & Rubenstein, 2004, p. S23).

The mothers in this study experienced a variety of suffering including the impact of death, divorce, physical abuse, sexual and emotional abuse, depression, loneliness, and bullying. Feelings of helplessness, the birth of a child with a disability, and fears of the unknown also contributed toward experiences of suffering. The stories that exposed scenes of suffering clearly challenged the mothers to reevaluate themselves and to understand how these experiences contributed to their roles, their identity, and their interpretation of life. There are moments in the narratives when remembering events of suffering invoked tears from the mothers and while I tried not to let their story influence my subjectivity, its enormity was overwhelming.

The Experience of Death

The death of someone who is older seems natural, but for a parent who loses a child or has a near death experience of their child, it seems unnatural or out of order and has the potential of having lasting effects on their identity and psyche (Rando, 1985). In the narratives, suffering caused by death was experienced and was shared differently by each mother. For Dora, suffering was associated with the death of her first son, while

the near death experiences of Lisa and Sara's sons, left them grasping for their faith in God as discussed in *Identity Shaped by Faith*. Unlike Dora, Lisa, and Sara, Beth's experience of death was not associated to mortality, but rather the hope of having a normal child. In Beth's narrative, she viewed the birth of her son with a disability as "the death of the normal child." This is further discussed in a later section under *The Experience of Disability*.

The suffering that is experienced from death is one of many similarities that the mothers share in their narratives, yet its impact on their life is expressed differently for each mother. For example, in Elsa's narrative, although she does not indicate whether her early life events were altered as a result of her father's death, the fact that she begins her narrative with his death could possibly explain the magnitude of the events that followed his death.

As the narratives indicate, death had in fact affected the mothers in one way or another from influencing their identity to providing them with a sense of reality and an appreciation for life.

Dora

Dora's narrative begins by describing her family, but quickly transitions to the death of her best friend. The selectivity of describing this early life experience in the beginning of her narrative perhaps has become more than a childhood memory. In fact, it possibly serves as a continual reminder of the suffering that is caused by death. Dora's early experience with death triggered philosophical thoughts about heaven and awakened feelings of compassion especially toward her best friend's mother.

One of the first experiences that I had, you know, that I had a chance to feel compassion for other people was when I was in the fifth grade, my good friend died. She had an accident and she died and that was the first encounter like with, like wow, it's not just me. The world is this, you know people feeling something else, like when I saw her mother at the funeral, I thought, like my heart just poured out to her.

Like I can't imagine...she was my best friend. But it was the first encounter I felt, like her mama said, she's not going to ever see her again. I remember going to the roof of my house and wait for the heavens to open and see her, like say hey I'm here. I don't know it was just like a cartoon to me. But I truly was expecting her to just say hi or I'm here. But she never showed up. That kind of, like shaped my heart, you know and through the years she's always been in my mind.

Unlike many individuals who would avoid watching others suffer at the time of death, Dora's compassion led her to Hospice where she surrounded herself with people who were suffering. Hospice played a pivotal role in Dora's life. It exposed an ability or gift that she believed was from heaven. According to Dora's narrative, this gift allowed her to see the soul of the sufferer, which enabled her to connect and help transition individuals and families through the death experience.

This is, you know, where I am supposed to be. So, when I started volunteering for hospice, I felt like whoa, this is it! I started meeting people and then I started seeing the pain of the family. Remember, this has a lot to do with what I felt for my friend and for my friend's mom mostly. So I got some patients like Hispanic patients that didn't speak English. That was a great blessing for me because I met so many great people at their raw feelings. Like you know, you don't see what they wear. You don't see what they're trying to show you. You see them.

This is me, I'm sick, I have cancer. They were angry. They didn't want to die. I saw many people die. I don't want to die or some people so surrounded by love they were like, this is the way I want to go. I saw their feelings. You can see their

souls. I can see this without all the layers and all the things. This was like a gift to me, like the heavens opened and they let me see people. This is my call, this is it.

After several years volunteering and working at Hospice in [city], Dora met her present husband and moved to [state]. There, Dora became pregnant with twin boys, Fernando and Marco, and I believe it is at this very point in Dora's narrative where the experience of death shapes Dora's identity.

I don't know what happened to my first son [Fernando], but they took Marco. They put him in this bed and I didn't see him. I was so bloody. They took me to where my husband was. He [Dora's husband] is never cold, but he was like holding something like this. Really! It was something like this. I say he's cold. He's never cold. He had a blanket and so I was there and then I realized that it was my first son, which we called Fernando and he had him in his arms. He was so little. He was 500 grams and he wasn't going to make it because he had stopped growing and he was 19 weeks old and I was 23 weeks by the time I gave birth.

So he stopped and they said ok, he's just there to give life to his brother. He's just doing his job. So they gave me him. I say God, let me remember his face. Let me remember because I was drugged. Let me see all that I can and I say, oh these drugs clear my mind and I passed out. I woke up and I wanted him again and so he survived for five hours. They came to check to see if his heart is still beating. They checked him and it was like one, two in the afternoon. They just took him. They say he's dead. It was so hard, and they took him away and we cremated him.

The death of Fernando left Dora in a state of shock and brought her misery, pain, and depression that pierced the deepest parts of her heart. Her suffering was overwhelming and at times exhausting. Her healing from this event has been a long journey, leaving scars of depression, loneliness, and denial, all of which has been influential in shaping her identity. Even though Dora experienced the death of her best friend, the suffering

associated with the death of her own child was more than she could ever have imagined or prepared for.

We cremated him and had a funeral. We kept the ashes. This year we went to Mexico, my home town and we put him in a mausoleum and then it was kind of hard, you know to hold onto him all this time, but I said this is not the place for him. I know he's not here but it was really hard to grip. I thought am I going to let go? So if it wasn't for my son that survived, I probably, you know kind of like lose it.

Elsa

While death emerged as a major life experience for Dora, its subtle impact on Elsa was a bit foggy. At the age of three, Elsa's father died. Although her narrative exposed the silences of her father's death, the impact of growing up without her father was critical to the safety, stability, and well-being of her family.

I was born in Mexico, in [city]. As you know is the worst place in Mexico to live in. My father died when I was three-years-old. So my mother did not work before my father passed away. So my mom had to get a job. After my father died, my oldest brother got into gangs and stuff like that. My mom was the only one working. We were literally starving. It's kind of hard, you know, she was like dependent on my dad for everything. Many times my mom would have jobs at night and she would have to lock us in the house because we lived in really bad neighborhoods. Several times there were gang wars in our neighborhood.

One incident that really sticks to my mind was when I was playing tag with some of the children and all of sudden two gangs start shooting each other and shooting at people. I can see in the back of my mind dirt, you know like when you shooting in the ground and like, smoke coming out of the dirt. I can see that. I froze. My mother was yelling at me and yelling to run. I can't run. I just froze. Something hit me. It was a bullet that hit me. People were trying to knock the doors and try to get inside our house. My mom, just say that we can no live like this no more.

Elsa's narrative would not have begun with the loss of her father if the selectivity of the experience did not demonstrate the impact it had on her development. As a result of her father's death, Elsa's early life development ultimately hinged on the decisions that her mother made for their family. Social and behavioral scientists who study human development believe "the experience of parental death during childhood has been discerned as a poignant and pivotal life event with long-term consequences" (Schafer, 2009, p.76). The death of a parent is devastating to a child and may subconsciously shape the individual's future life choices including "the correct time to marry, to bear children, and to leave home" (Schafer, 2009, p. 78). Elsa's narrative in fact shares selective life choices like getting married prior to graduating from high school and rebelling from her stepfather.

In church is where I met my husband volunteering. He was a shy person and I had never been shy. Well, when I was young I was always outgoing. I guess I changed as I started dating my husband. I eloped and got married my senior year in high school. November 30th is we going to be 20 years married, which a lot of people thought that we were not going to make it, because we were so young.

In summary, Michelangelo recognized death's influence on one's identity when he states, "no thought exists in me which death has not carved with his chisel" (Kubler-Ross, 1975, p.2). Experiencing death, especially that of a child, leaves you in a state of suffering that is at times unbearable (Huntley, 2001), and yet somehow a person's identity will emerge like in the case of Dora, with a renewed sense of purpose.

You know I felt that emptiness like I want to go, you know, help people who's alone. I have these thoughts but I understand that this is my like my assignment now. This is it.

The Experience of Divorce

When we were little, fairytales taught us that sad stories have happy endings. They also taught us that good people are rewarded while bad people are punished. In an ideal world, this all may be true, but take a step in the real world and you will quickly learn the difference between fantasy and reality. This is especially true of marriages. Marital dissolution has been the focus of considerable social science research, and much of that research has determined the end of a marriage is considered a major life experience or turning point (Young, Stewart, & Miner-Rubino as cited in McAdams, Josselson, & Lieblich, 2001).

In the narratives of Lisa, Cindy, and Dora, divorce was a shared life experience which had an impact on their identity. Is there a common “divorce” denominator between the three mothers? Ironically, yes. Lisa and Cindy were divorced after the birth of their child with a disability, whereas Dora was divorced from her first husband prior to having a child with a disability. According to Poller and Fabe (2009), the divorce rate in the United States is between forty and fifty percent and if you add the strain of a child born or diagnosed with a disability, the divorce rate percentage increases between eighty-five and ninety percent (Kraus, 2005). Unlike Lisa, Cindy's narrative did not indicate whether the disability of their child played a role in either their marital strain or divorce, but it is highly likely.

A second similarity indicated in the narratives was that each mother was in their early twenties when they were married and divorced. Young (et al as cited in McAdams, Josselson, & Lieblich, 2001) claims that “women who divorced in their 20’s emphasized a period of self-questioning, uncertainty, and depression surrounding the time of their divorce, which eventually led to a dramatic restructuring of their plans for the future” (p. 210). While a period of restructuring holds true for each mother, a strong sense of self was also discovered.

Lisa

Lisa was beautiful, vibrant, and smart. Shortly after graduating from college, she met John, a hang glider instructor, who provided her with a sense of protection and companionship. He was insistent that they get married and live a life of adventure.

So I met John and he said, don’t go, come back to [city], come back and marry me. So I never moved back to [city] and we did all kinds of activities. We did boating. We were just, you know, little daredevils. We did hang gliding. I did off sand dunes but he was a Level IV hang glider pilot who could fly off [-] mountain.

For Lisa and John, adventure was their connection to happiness and contentment, but Lisa got pregnant and John began to question their future. It was not until their son was born and diagnosed with blindness, that John became distant, resentful, and more concerned for only himself, while Lisa became focused only on Tate and his needs for survival.

When I got pregnant he was afraid. He said, having a baby is not going to come in between us or keep us from doing our stuff and I was like no. A child, no, he

can go with us on the weekends, you know put a backpack on him, just like you know whatever...when Tate was sick, he [husband] would go out hunting and fishing and do his thing with the guys and I would stay at home with Tate. When Tate was five years old, his dad left and said that he couldn't handle the blindness anymore...that it had interrupted our lives. So I raised Tate as a single mother from that point in time.

Lisa conceptualized her marriage and divorce in terms of her own development as evident in the silences and selectivity of the marital experiences shared within her narrative. Divorce many times leaves one with an enhanced sense of self (Young, et al as cited in McAdams, Josselson, & Lieblich 2001) or in the case of Lisa, a strong will.

Cindy

At seventeen, Cindy was pregnant and married her twenty-two year old boyfriend, who she had only dated for six months. Cindy represents a rarity, as most teens today do not get married before their baby is born (Boonstra, 2002). In her narrative, Cindy silences any feelings she has toward her boyfriend, leaving me to believe that perhaps she did not want to marry him or she did not love him. Relationships in high school can play a pivotal role in helping youth define their sense of identity and develop a capacity to understand committed relationships in adulthood (Sorensen, 2007). Cindy's early identity had been shaped mostly by the ridicule she experienced from being unattractive and overweight. "I was made fun of a lot. I was fat, freckled face, glasses, and short hair. I was called a lot of names you know, like dike."

By her senior year in high school, Cindy slimmed down and started dating. Cindy indicates in her narrative that dating and saying "no" to being sexually active was difficult. Sorensen (2007) explains that feeling pressure to engage in sexual activity is

significant for teens and according to a survey conducted by Teenage Research Unlimited in 2006, one out of four teens believe that having sex is expected, while one-third of girls who did engage in sexual activity feel pressured to do so when they did not want to. Did her boyfriend put pressure on Cindy to have sex? The selectivity of the experiences in her narrative points more toward the influence of her peers and a willingness on her part.

Then it was, you know peer pressure to have sex and I know what I'm doing was not right. But you're a teenager, your doing it anyway, and so I went down that wrong path.

Cindy graduated high school, was married within the same year, and filed for divorce after two years. Whether or not the decision to get married was based on the "right thing to do," perhaps in hindsight it was the "wrong thing to do."

I graduated high school and then I got married the same year. The guy turned out to be really horrible, abusive, verbally, physically, just you know completely changed. Just turned out to be not a good situation and so I remember you know, after arguing and fighting, I remember thinking I really need to get out of this situation because this is not good for my son at all. So when my son was two we separated. During this time there was so much turmoil because my husband was trying to get custody of Luke and that was horrible.

For the next three years Cindy was in and out of court, prolonging her suffering which stemmed from her desire to have full custody of Luke and not joint custody.

My husband, that you know I was separated from, was trying to get custody of Luke and that was horrible because I felt like...you know that is something that no parent wants to have, custody completely taken away. I just thought it would be so devastating to my child. We went through court battles and that was horrible, court battles, terrible you know.

Devastating, horrible, terrible, are words that Cindy used when she reflected on the custody experience. However, the experience of divorce left Cindy with a sense of urgency to figure out what she was going to do with her life and how she was going to provide for her son.

I decided I want to go back to school. I'm still living by myself, me and my son...So I go to school and get my CNA and I get my CNA 2's, and then I start going to PCC, which is [-] Community College out in [city], and I go to get my associate in human services.

Dora

As indicated in her narrative, Dora's reasoning for divorce was more related to being too young rather than from other circumstances.

I never lived outside my mom and dad's home. In a new country, a new language...I didn't know nothing, so when I moved here, so many changes, married, living with a man and without my family so far away...So there were too many things and we were kind of immature. I was like twenty one, so we decided to separate and go different ways.

At the age of twenty one and living in a new country, divorce left Dora questioning her life and leaving her with existential questions about her future. In her narrative, loneliness and feeling lost as a human being was a turning point in how she defined her identity.

I had, I mean zero. I had nothing and I don't know anything. I did not know English...I was kind of lonely ...there's a word...Is this it? Where am I going? Who am I?

Dora could have returned to Mexico, but in her narrative, the silence of a reason to stay in the states is left unanswered, however, self-will and determination to survive was evident.

All that crisis goes in through your mind, so I decided to start...well, I get a job. I was a cashier and you know it was kind of hard because I didn't speak the language and then I started making new friends. I didn't have a car. I didn't have anything, but the help of my friends. A lot of people offered me, like you know what, you can work for me or you can work here.

I eventually got another job in [city] working in a wipe company. Than I say, well this can't be all this. There has to be something. I mean, is this my purpose to just be folding wipes. No! I want to go to school. Ok, so I validated the classes I had from college. I enrolled in [city] Community College. So I finished my associates there.

Perhaps Dora was looking for a new start after getting divorced or maybe she was looking for new opportunities in a new country. More importantly, Dora began focusing on her identity through a new career. The dissolution of a failed marriage had no implications on her new sense of self.

In summary, divorce is an experience that can affect a person's identity. In the mother's narratives, we saw how each of them became more determined and more focused to not allow the experience to derail their role as a provider and as a loving parent. Finally, as in the case of Dora, the experience of divorce forced a sense of self-discovery and understanding of her development.

The Experience of Abuse

When children are young their primary source of love, safety, security, nurturance, and support come from their mom and dad. When this primary relationship is

betrayed in the form of abuse, it scars virtually every facet of their life in one shape or another. The effects of childhood sexual abuse on an individual's identity development is profound (Brown, 2008) and such an event can affect one's identity throughout their life, serving as a basis for perceiving, thinking, and reacting to life events (Najman, Nguyen, & Boyle, 2007).

In the narratives of Cindy and Elsa, an ex-husband and a stepfather were the perpetrators. Their encounter with abuse was selectively shared, while the silence of its effect left much for interpretation. However, in Lisa's narrative the selectivity of physical and sexual abuse shared was instrumental in her life development and its effect on her identity was revealed.

Lisa

Lisa's narrative describes a painful memory of the abuse she suffered from her father, both physically and sexually. Lisa is a fighter, a survivor of sorts and her narrative is indicative of both.

I didn't know until later in my life that I was [paused]. Until as earliest as I can remember, but I was a victim of sexual abuse, incest in my family by my father. I did not want it to happen to my sisters or my brother and with my dad being an alcoholic I learned to fight him, to save, to try protect my mom. I could remember times jumping on his back and telling mama to get away.

Lisa indicates in her narrative that her mother and father are still married and when the scars of abuse taunted her self-worth, her mother reminds her that she has always been a survivor and a guardian of her family. Children like Lisa, who take on the role of

protector or guardian, are referred to as the family hero (Vernig, 2011) and look after the well-being of the family. Usually the “hero child” comes from a dysfunctional family and assumes an almost adult role (Glover, 1994) as Lisa did, while attempting to be a model student, hard worker, and all around good person inside an abusive home environment.

So my mom brings back occasions to me all the time, whenever I start feeling down and blue...She said, you took a beating for your sister and brother before you let them take it or you know, when daddy would have one of his fits and I would wake up and hear him hollering, I would know what would come next.

Lisa’s mother knew about the physical abuse, and with Lisa’s selective sharing of her mother’s pre-marriage wishes to find “somebody different,” led me to believe that her mother was also a victim of abuse. This slippage in her narrative explains her mother’s reasoning for not acquiring a divorce.

My mother was the oldest of four, who had alcoholic parents, so she made it through high school and married my dad. She thought he was somebody different then her family...but my dad was also an alcoholic, so that’s why I said my mom thought she was marrying somebody different when she married my dad.

Lisa’s attempt to disassociate herself from the abuse was evident in her narrative. As a survivor of sexual abuse, her early coping strategies remarkably transcended into re-defining a tattered self-esteem and a strategic way of removing herself from the situation.

In high school, I was into everything that a teenager could be into and to not be at home. I was a cheerleader. I was a majorette. I was in gymnastics. I kept stats for the boy’s baseball team. I was having to go to all the marching bands practices and just anything to keep from going home. I can never remember

doing homework. I can only remember doing athletics, but I was a straight “A” student. It just came easy. I was nominated one of the ten outstanding seniors. My senior year was the best year of my entire life. I don’t know if it was because I was popular, or if it was because I was just so happy. I was going all the time. I did not want to graduate. I wanted to stay right there in that time of life.

Maybe, Lisa wanted to stay in that time because she was fearful of the future or maybe the experience of abuse indelibly began to shape the core of her identity (DeFrain, Jones, Skogrand, & DeFrain, 2003). I sensed in her narrative that this was the first step to her recovery as she recognized her strengths as an individual. Lisa became a survivor and not a victim of her past abuse.

So, I overcame a lot of odds to get to where I am...I mean you know, all the things that happened to me and being able to stand up and fight and not fight...for what I believed in whether it was in my personal life or in any other child’s life.

Cindy

Cindy’s narrative does not indicate childhood abuse but she does selectively describe domestic abuse. Velzeboer and Novick (2000) describe domestic abuse as one of the most pervasive human rights abuses in the world today. Women who have suffered domestic abuse have a fragile sense of identity due to its emotional, physical, and psychological effects (Crawford, Liebling-Kalifani, & Hill, 2009). Cindy’s early identity had been stained by the ridicule she endured as a child, along with feelings of guilt and shame that resulted from an unexpected pregnancy as a teenager. Did her past overshadow or influence her acceptance of domestic abuse? Unfortunately, there is not a clear answer in her narrative, but her tolerance was short-lived.

The guy turned out to be really horrible, abusive verbally and physically, just you know completely changed...just turned out to be not a good situation. Well, we argued and fought when he [their son] was a baby, but I remember when he got older, he was like two, I remember thinking I really need to get out of this situation because this is not good for my son at all.

Cindy's protective instincts to remove her son from the situation provided her with a sense of hope and direction. For Cindy to leave her abusive husband wasn't just a one time event, it was a prolonged process (Lempert, 2006) that brought fear for the next three years as she fought for custody of her son.

Elsa

Elsa suffered abuse from her stepfather that was both mentally and emotionally devastating. Elsa states in her narrative that after her mother married her stepfather, his behavior changed from being nice to being "awful." She described a man who lured her mother to [city] so that he could profit financially by marrying her. It is unclear in her narrative how bad the relationship became between her mother and stepfather, but clearly control and deception was key to his abusive nature.

This man wanted for my two brothers and my sister to work and give him the paycheck...We went to get help from the government, like food...but we're not allowed to touch the food. We were surviving on tomato sandwiches and banana sandwiches. That's the only thing we could have and water. So, to this day I cannot eat tomato sandwiches or banana sandwiches, because that reminds me of that time.

Elsa may have been more of a witness to the abuse that her mother endured while married, due to the absence of the details. Although the marriage was short lived, the experience of her stepfather's control and witnessing her mother suffer from an abusive

relationship contributed to her identity. Fisher (as cited in Fisher, Primožic, Day, & Thompson, 2002) states, “the pressure on our identity is not restricted on solely to the confines of our own “first-hand” experience of suffering. The suffering... of those we love...can act as a trigger to undermine the confidence we have in ourselves as persons” (p.1).

In summary, the effect of abuse on one’s identity intertwined with feelings of fear and doubt, hopelessness and loneliness, repression and desperation, sometimes redirect the focus away from their suffering and onto something or someone in greater need.

The Experience of Disability

When parents realize their newborn child is born with a disability, future dreams and expectations drastically change (Graungaard & Skov, 2006) causing many parents to go numb or become emotionally paralyzed. It is not the end of the world, but at that moment of discovery, the joy of life is overshadowed by blame, jealousy, and disappointment leaving parents desperate for answers. Many parents go on a prognosis “hunt” in an attempt to discover what the future may hold, especially when normalcy has been shattered (Graungaard & Skov, 2006). While the perception may be that of crisis for many parents, ultimately the child’s ability to survive hinges on the parent’s ability to accept, protect, and provide sustenance to their child.

As stated earlier, the identities of each mother are different, yet they share a common core story, the birth of a child with a disability. All of the mothers have journeyed on different paths in understanding and accepting their child’s disability, but

along the way each have encountered moments of suffering with their child, which has had a lasting effect on their identity.

Sara

Sara's life goals since childhood was to get married and have children. Everything seemed to be going as planned. She graduated from high school, got married and two years later was pregnant with her first child. Sara didn't indicate in her narrative if she ever worried about having a healthy or "normal" baby, as many parents do. Sara delivered Jack with no complications. He appeared to be, as she stated, "pretty typically developed...and you know there was nothing...except he was a perfectly healthy baby, we thought." At ten months, Sara was told that Jack was not meeting his milestones, and while this may be a red flag for some parents, Sara blamed it on her husband's genetic background.

Because my last name is [pseudonym]...it is a German descent name and...sometimes babies don't develop at the same rate as other babies and he would probably catch up. So I really took that with a grain of salt. Just felt that things would kind of work out and wasn't really concerned.

At eighteen months, Jack's development had gotten progressively worse and required tests to identify what was wrong. In her narrative, Sara was very detailed in describing the moment she learned her son's disability diagnosis. It was not so much the confirmation of a disability that caused Sara's suffering, but how Jack's "less than human" description was given by a diagnostic specialist.

I will never forget. I can tell you what color of the wallpaper was...the person what they looked like. I can repeat every word that they said that day and one of the things they told us...that Jack was mentally retarded and that the best that we can do was to possibly put him into an institution and that he probably shouldn't live at home and he was pretty severely mentally retarded and the best thing we can do is possibly think about having other children and just kind of forget Jack...that we could see him on the holidays, but other than that, we pretty much needed to just give up.

Perhaps, Sara's determination to prove her son's diagnosis was wrong had overshadowed the reality of having a child with a disability. The suffering was silent throughout Sara's narrative until Jack became deathly sick, hospitalized, and diagnosed with spinal meningitis at the age of eight.

He got meningitis. Very devastating, caused a lot more brain damage than what we already knew. But, this was pretty devastating blow. They really didn't think he was going to make it. They didn't think he was going to live. If I showed you pictures of him, as he was younger, you would be able to tell me exactly when the change is, that he didn't have the illness here and he had it here. It was that much of a drastic change. He survived for whatever reason...They air lifted him from [-]to [hospital] and so, we kind of knew that it was very, very serious.

In Sara's narrative, when Jack was diagnosed with meningitis, her earlier determination and unwavering focus was overshadowed by feelings of discouragement and hopelessness. Not only could Jack die, but if he lived, all of Sara's earlier efforts to help Jack advance, could be lost. While this setback put Sara in a state of depression, her identity as a persevering, determined mother eventually returned.

I could not believe I had fought and really pushed...for Jack to be where he was at, and everything was gone in twenty-four hours. You know, it was just gone and so I was the one that had a little bit harder time coming back around.

Elsa

Elsa's journey of suffering had been shaped by early life experiences of abuse, the death of her father, and the birth of a child with a disability. While the experience of abuse and death had exposed her vulnerability as a human being, it also heightened her desire to find people she could trust. "I don't know why we were easy targets or something...or we just believe in people."

For Elsa, trusting the professionals was of utmost importance, especially when she noticed that something was wrong with her newborn son. However, it was not until several months later that she would eventually discover that the doctors, whom she had trusted, had in fact discounted her concerns and made a misdiagnosis. Their deception left her confused, angry, and hurt.

It was a really rough pregnancy and he came early and I was in the hospital for about two months prior to having him. He was premature. He was three pounds and five ounces...which they told me everything was fine...and at that time nobody told me that you know, he had cerebral palsy or anything was wrong with him. They told me he was fine. He was there for...I think a month or maybe a little bit over month in the NICU.

I brought him home like a normal baby...they said everything was fine. He would keep on throwing up his food. With babies, you usually put them on their stomach, they'll be happy. He was not happy. He would be like crying. Car seat, he would be like, like something was pinching him or something. He was terrified of car seats. I keep on telling the doctors. The doctors say, no everything fine.

It is unclear in her narrative why the doctors continued to overlook the seriousness of Elsa's concerns. This experience left Elsa with bitterness and resentment toward the

health professionals. This experience also fueled the confidence she needed to confront the “so-called experts” in the future. In her narrative, the selectivity of Elsa’s pain is not from the prolonged delay of her son’s prognosis, but more from her misunderstanding of “cerebral palsy” and its implications.

First of all they say...oh he has acid reflux. That’s what’s wrong with him. That’s why he’s...you know squirming and I was like...I still say no, something still wrong. At eleven months... they did more x-rays...they did head scans, ct scans...they found out that he has cerebral palsy. I have never heard the word cerebral palsy. How the doctors explain to me was...oh he can go to physical therapy, occupational therapy and he would be ok.

In my mind, was like a person that breaks their body, you know, their leg...has a cast and help them how to walk and they’ll be fine with therapy...then she [case worker]realized that I did not know what cerebral palsy meant. So she sat down with me and explain to me. That’s when I broke down. I was like what did I do [crying]? What did I do wrong? I mean all this doctors, you know, I had them for almost a year after the baby was born and nobody explain to me [crying]. You know I wanted an answer and they never told me anything. I felt betrayed because I trusted the doctors and they never told me anything [crying].

In a period of uncertainty, especially during the diagnostic stage of a child’s disability, information is vital to parents (Graungaard & Skov, 2006) especially for someone like Elsa who was not proficient in English. She relied on the professional and was not informed properly on the extent of her son’s disability. Even though Elsa suffered from her son’s delayed diagnosis, her tenacious spirit would give her confidence to challenge the opinions of the professional.

They told me that he's not going to be able to walk. He was not going to be able to talk. He basically was going to be vegetable. I told them they were wrong and I proved them wrong. So I was determined that my son was going to be capable of doing stuff...even though they said no.

Beth

Beth thought she was prepared for the possibility of delivering a child with a disability. She had researched her own genetic disorder and trusted the doctor's opinion before she got pregnant. In Beth's narrative, there were no indications of emotional suffering, feelings of shock and disbelief, or discouragement when she learned that her son had a disability. However, as she completed her narrative, there is a moment of slippage where she describes the act of having a child with a disability to that of experiencing death, not in the sense of death and the grave, but her hope for a normal child.

I see other people now, who are on different parts of the journey that I was on. Because when you first find out that your child is, has a disease or is disabled...people have expectations for their children. Everybody has the same. You want your child to grow healthy, happy, wonderful and then you get that diagnosis of... If your child isn't going to follow that path, then you have to adjust to the new path.

We've gone through the whole cycle with that. You know, I think it is sort of like a cycle of people who are dealing with death, because you are dealing with the death of the imagined child and then you have to go through you know, your anger, your denial, your guilt. You know, all the phases of mourning.

Beth along with many other parents of children with disabilities had a mental image of their baby prior to birth (Bristor, 1984). The imagined baby, as Beth has described, is a

composite of impressions and desires (Bristor, 1984) which are connected to the parent's past. The imagined baby, perfect in every sense, has now become a dream. Beth did not dwell on the imagined child, but believed they were on a new journey. Beth states, "my son being disabled has been a blessing to the family."

Dora

We have discovered thus far from Sara, Elsa, and Beth's narratives, suffering from having a child with a disability is experienced, expressed, and interpreted differently. The experience of suffering expressed in Dora's narrative is not only a reaction to having one child born with a disability, but having two children with disabilities.

Prior to the birth of Fernando and Marco, Dora had envisioned helping others, which she thought was God's will for her life. But after the death of Fernando and survival of Marco, "His" purpose had obviously changed for her, leaving Dora with a sense of disillusionment. Parents who have difficulty accepting that their child is disabled usually experience a variety of emotional reactions including grief, denial, and anger as well as feelings of emptiness or thoughts that "nothing seems to matter" (Hadjiyannakou, Ioannou, & Tziogkourous, 2007, p. 147). For Dora, the reality of not fulfilling what she had perceived as God's calling on her life to help those in need, left her to redefine and reorganize her life.

It was so weird because I was consumed by him [Marco]. I had quit my job since I was pregnant...I felt that emptiness. I said I'm not going to hospital to help. I'm not going to do any things I thought I should be doing because I was with my son all day...day and night. He slept with me...to change, you know his head. I

have to move it because his head was completely flat. Because he was always connected to the machine.

Was a whole year...was like that every night, every hour I have to check him and the oxygen is not blocked. You know I felt emptiness...like I want to go, you know, help people who's alone. I have this thoughts, but I understand that this is my, like assignment now. This is it. I felt you know that emptiness, but then he started to do better.

Under my earlier section, The Experience of Death, we learned that Dora had a traumatic experience dealing with the death of her first son Fernando. We also learned that through Fernando's death, Marco was able to survive, which in turn helped Dora to believe that Fernando's death was God's will and he ultimately had a bigger plan for her life.

So if it wasn't for my son [Marco] that survived, I probably wouldn't...you know kind of like lose it for while...then he came home and... you know he was on oxygen for like a year and he didn't walk. He didn't make the milestones [crying]. They said ok, he's going to have cerebral palsy because he can't walk. He can't use his hands and all this, but we started the therapy.

Perhaps Dora understood and accepted her new assignment in life, as signs of any emotional distress from having a child with a disability were minimal. However, an indication of Dora's suffering magnified greatly after her daughter Arlene was born and diagnosed with Down's Syndrome.

While research suggests that parents of a child with Down's Syndrome are more understanding of the initial diagnosis (Quine & Rutter, 1994) than other parents with a child born with a disability, Dora on the other hand was shaken by her daughter's

diagnosis and used the word “Hell” and the act of drowning to describe the emotional suffering she felt.

She was so little. You couldn't tell. Then the next day the doctor just came and say, you know what....we need to check something because we might suspect that she [Arlene] has Down's Syndrome. I said, you checked whatever you want. She doesn't have anything, I was thinking. I said ok, go ahead and I signed everything. The next day they say...your daughter has Down's Syndrome. Whoa! You know, I felt like I went through hell and I stayed for a few minutes and came back....whoa, where does this come from? I mean nine months and I didn't do anything. What is the deal?

I went through a very dark, like depression [crying]. I mean it was so different...and then...I made decision, I said I can't. My son needs me and she needs me. So I need to snap out of it. So I kind of like...when you fall in the water and you go up...I felt exactly like that. So from that point on it was different again. My mind was renewed again.

As quickly as Dora experienced the feelings of shock, denial, anguish, grief, and sadness (Nunes & Dupas, 2011), she also felt a renewed spirit. Even though her once battered spirit felt like it had visited Hell, Dora would remain resilient and found strength to weather the storms ahead.

Lisa

Lisa's journey with disability and suffering began on a Sunday morning at church when a young boy with a disability stole her heart. He was small and unable to talk and as Lisa described, “nobody really knew what to do with him.” For some reason he took an interest in Lisa, maybe because the little boy sensed that Lisa was caring and

compassionate. Perhaps he thought that Lisa would take time to listen to him, even though much of his words were unrecognizable.

So I sat down and just pulled out some crayons, and he was like grrreeeeeeeeeeennnnnnn and he was trying to say green. Well, he picked up green. When I figured out what he was trying to say, he picked up the green crayon and matched a forest green to my lime green dress and he went to the bulletin board and matched it to like color of the tree.

You know, like a, you know, lighter color green and I started crying and just tears would come to my eyes. He saw my tears... and he didn't understand why I was crying. I went to school the next day and I can remember clear as day walking in my guidance counselor's office and said, What do I need to do... to work with children like this? I said, just like you know, it had just hit me...this is what I needed to do.

While most seniors were planning their graduation beach trip, Lisa was planning her future. Although there were twists and turns in her journey, Lisa pursued a degree in special education. Lisa's earlier experience with a child who had a disability became an ominous beginning to her identity as a future advocate.

Up until the birth of her son Tate, Lisa had endured many forms of suffering, including abuse. Through her shared selective stories, I learned that Lisa had a resilient spirit, a spirit that was capable of facing any type of storm or battle, including the birth of a child with a disability.

At twenty-five weeks, Lisa delivered her son Tate. He was eleven inches long and weighed only one pound and eleven ounces. Lisa remained strong, even though she was not able to hold her son for the next four weeks. The hospital staff attempted to

prepare Lisa for the worst. Tate could in fact die and at one point in Lisa's narrative, she indicates that his heart had actually stopped beating. Soon her optimism faltered.

He was laying beside ten pound baby, which you know is really a normal...a little bit heavier, but it was like a Barbie doll next to a regular size baby and it just...the shock of it...just about drove me sick [paused].

There are approximately 40,000 babies a year that are born between twenty-two to twenty-five weeks of pregnancy, and while many premature infants do well, many die. Those that do survive, many times are left with brain damage, behavioral problems, vision and hearing loss, and other disabilities (Grady, 2008). Lisa was aware of these likely outcomes, but never feared them. Even though this brief moment of slippage in her resiliency was exposed, it actually demonstrated how strong her spirit was. For the next twenty-two years, Lisa never shares another moment in her life where her spirit was broken. For Lisa, she did not suffer as a result of having a child with a disability, her suffering occurred from being unable to bond with her son in the early stages of his life.

I could sit beside him but I couldn't you know, touch him. Then the nurse would come in and they would lift him up and would hold him...and I said...after a month I said, why come I hadn't held my child yet...they said you can go look at him, but don't get attached because he won't live through the hour and I said I'm already attached. I'm going to love him.

Cindy

Learning your child has a disability is an emotionally charging event, but an undiagnosed disability can leave parents emotionally drained for a substantial time. This

was the case for Cindy. Her son Luke was born healthy and showed no signs of any delays or disabilities. However, the more time Luke spent around his peers in daycare, Cindy realized something was not right. His daycare workers constantly complained about Luke's unusual and at times aggressive behavior. Cindy's experience of suffering from an undiagnosed disability is common, especially with parents of children who fall under the autism spectrum disorder (Watson, Hayes, & Radford-Paz, as cited in Hodapp, 2011). Cindy also experienced suffering from her feelings of guilt of not noticing Luke's behavioral problems.

During this time, my son does not have any diagnosis...I didn't really know, you know that his behavior would be considered not really normal. Then when he gets to daycare...people start saying...you know he's not talking like he should be...he's way too hyper...and you know something going on with him. So I'm like really? Then I feel really horrible because you know, I didn't even notice. I didn't know he wasn't on level...and I feel bad because now it's like, I wasn't looking where I was supposed to be looking.

In the course of securing help from a behavioral specialist, Cindy learned that Luke fell under the autism spectrum disorder, but was put on a waiting list before Luke could be tested. Like Cindy, parents of children with disabilities seek a diagnosis for several reasons including, "access to interventions, knowledge regarding learning challenges and strengths, and information regarding medical or mental health risks and resiliencies" (Watson, et al, as cited in Hodapp, 2011, p. 32). Luke was now in the first grade and after waiting over a year, Luke was tested and the results were not what Cindy had expected.

So we go to TEACH and so I was just so unhappy with them because really all they did was talk to me and they talked to Luke and they did not do, you know, they didn't do any test. They didn't do any evaluations for autism. They didn't do anything. Anyway they did not diagnosis him with autism. They said that it's more of his IQ is low. He's mildly mentally retarded and he has, you know like, the cognitive issues and it's not autism.

In Cindy's narrative, the selectivity of Luke's undiagnosed autism is frustrating. Her bewilderment grew as Luke's behavior became more difficult to handle at home and school.

I don't know what is...what's going on with him, but something more than that is going on, because it is autism. I know it is, because he's got all the symptoms. I think he got suspended fifteen times and I think that's because they didn't really know what to do with him.

Cindy's slippage of "he's got all the symptoms," confirms Cindy's intent to understand autism and to unconsciously reduce added psychological suffering (Bromley, Hare, Davison, & Emerson, 2004). An undiagnosed disability left Luke vulnerable to his teachers' rigid thinking and inability to handle children with behavioral problems. The average age for a child to be formally diagnosed with autism spectrum disorder is between five and six-years old, however, many children like Luke experience longer delays before a formal diagnosis is made (Howlin & Moore, 1997). Luke was finally diagnosed with autism at the age of eight and while the official diagnosis was hard to bear, it was also proof of Cindy's pursuit for closure. Cindy states, "So, I was like, you know, it was devastating to hear that. At the same time you feel validated because you're like...I knew...I knew something wasn't right."

In summary, the experience of having a child diagnosed with a disability and its impact on one's suffering is complex. All of the mothers in the narratives experienced different levels of suffering when they learned their child had a disability. Dora felt numb and even sensed herself going to *Hell and back*, while Beth experienced the death of the "normal" child.

Summary on Suffering

Each mother's interpretation of suffering, whether it was from death, divorce, abuse, or disability had indeed shaped their identity. Solomon, one of the wisest, richest, and most powerful men in the Bible wrote Ecclesiastes. Ecclesiastes seems to be the kind of book that reflects life experiences and painful lessons that are learned. Solomon also knew how suffering shapes identity when he wrote, "Sorrow is better than laughter for sadness has a refining influence on us" (Ecclesiastes 7:3). Suffering is part of the human experience and as Fisher (as cited in Fisher, Primožic, Day, & Thompson, 2002) states, "becomes a question about the complex interpersonal relationships we build and develop; and a person's identity exists...in response to all the fluctuating circumstances and events which constitute human life" (p. 1).

Identity Shaped by *Family*

Throughout our lives we are influenced by our family. Our family is designed to be a sanctuary, where our emergent and fragile identity is kept safe, where protection allows us to explore possibilities and where our foundations are formed. Our interactions with those that raised us during our childhood can have a lasting effect on our identity (Dean, 1988) and subsequently shapes our memories and experiences. We look to our

family for trust, support, and guidance especially during times of crisis. Our relationships with family members, including grandparents, parents, siblings, husbands or wives, and our children can influence areas of our identity. While there are healthy family relationships, there are also unhealthy and dysfunctional relationships, as described by Lisa, Cindy and Elsa, in my earlier section, *The Experience of Abuse*.

Several mothers in this study identified stories that reflect on their family. Those stories, however, do not include if the birth of their child with a disability had affected their family, except for Lisa. In my earlier section, *The Experience of Divorce*, Lisa did not state specifically whether or not her son's blindness contributed toward her divorce, however, it is highly possible because their son's disability interfered with her husband's hobbies. The fact is, more children born with disabilities today are living at home than ever before and are attending their neighborhood schools due to advanced medical technology, de-institutionalizing, and the passing of the Individuals with Disabilities Education Act (Reichman, Corman, & Noonan, 2007). The mothers' silence of any negative effects on the families, perhaps suggest that these mothers embraced and accepted their child's disability and believed they were a blessing to their family rather than a burden.

In *Identity Shaped by Family*, three sub-themes emerged from the mothers' narratives, including the size of the family, the absence of their husbands, and the role of a mother. The stories shared serve as a vehicle in understanding the difficulties, joys, and complexities that a family has on one's identity.

A Large Family

According to social scientists, there are many variables that influence an individual's development, including the size of the family (Hawkes, Burchinal, & Gardner, 1958). The dynamics of the family are individually unique and "the influence of birth order on personality would change" as the size of the family increases (Dixon, Reyes, Leppert, & Pappas, 2008, p. 120). Dora, Lisa, and Elsa came from a large family and the selectivity of their stories demonstrated how their family has affected their identity.

Dora

Dora begins her narrative immediately describing the size of her family and then discloses a slippage in her story. The impact of the slippage does not necessarily have a first-hand affect on Dora that we know of, but perhaps it did on her parents' marriage, although the details are silent.

I have three brothers and three sisters and I am the youngest of all...and my mom has a son outside the marriage and my dad had another...daughter outside the marriage, so that makes nine of us. My parents were there, both of them, even though their marriage wasn't all that, but I felt safe and I think that shaped my life.

Dora does not go into details describing how a large family affected her childhood, but it is evident that family size did not interfere with Dora's happiness as a child.

I had a very, very, very happy childhood. I was very loved and I was very happy to have my brothers and sisters to play with...so I was very happy.

In Dora's narrative, the word "happiness" describes her family and childhood experiences, but is absent in her remaining life stories. Perhaps "happiness" has been silenced by the shock of having children born with disabilities. More importantly, the word "happiness" in Dora's narrative is now replaced with "advocacy." Dora has found happiness maybe not expressed in the form of a word, nor from the size of her family, but from the passion and love she provides for her children.

Lisa

There are multiple family experiences that Lisa shares in her narrative. For example, we learned in *The Experience of Abuse*, that Lisa grew up in a dysfunctional family. Her father was an alcoholic and abused Lisa, her mother, and siblings. Lisa was the oldest of four siblings, and always assumed the role of protector, nurturer, and mediator. Lisa does not describe her family as a loving home, but a poor home. Research indicates that children who grow up in poor homes have an increased risk for future negative outcomes that may in fact follow them into adulthood (Moore, Redd, Burkhauser, Mbwana, & Collins, 2009). Lisa does not indicate in her narrative if being poor had any negative effects on her as a child or adult. Perhaps the selectiveness of sharing her family's poor background was more of a way to confirm her childhood roots and what she had overcome.

As long as I can remember, we grew up in a very poor family and we used to have a bread truck and my mother used to work in tobacco field. The story of my life begins with a very, very poor family of six and where we had lots of beans and potatoes.

For Lisa, having a large family played a role in growing up poor (Bradshaw, Finch, Mayhew, Ritakallio, & Skinner, 2006), however, Lisa did not allow the size of her family or being poor to affect her self-esteem. Under the extreme conditions that she lived in, Lisa remained unbelievably self-confident, achieving many accomplishments such as head cheerleader, head majorette, and as she describes herself, an “overachiever.”

Elsa

Elsa grew up in a large family, but at the age of three we learned in, *The Experience of Death*, that Elsa’s father died. In Elsa’s narrative, family has always played a pivotal role in her life from her mother’s protection to her brothers and sister’s effort to get a job and provide food for their family.

I have two brothers and one sister...which I’m eight years younger than my, my sister. So I’m the youngest of four and my brothers, they were like you know fifteen, fourteen, fifteen somewhere around that age when they had to start working and helping out...because we were literally starving.

We learned in *The Experience of Abuse*, Elsa’s family was desperate for loyalty, friendship, and help. Perhaps other families may have grown apart, yet the experiences Elsa shares of growing up poor, living in a dangerous neighborhood, the death of her father, the abuse of a stepfather, and acts of vulnerability, have all influenced Elsa’s family to remain strong and united. Strong families like Elsa’s have a history and are affected by that history, while providing them a sense of belonging and identity.

In summary, having a large family affected the mothers in different ways, from feelings of happiness and protection to recognizing their poor living conditions.

However, Dora, Elsa, or Lisa did not allow the size of their family or their family's economic conditions to negatively impact their identity, as indicated in their narratives.

A Husband's Absence

Under my earlier section, *The Experience of Disability*, we learned that parents who have children diagnosed with a disability experience a broad range of emotions such as denial, anger, isolation, helplessness, and guilt (Fortier & Wanlass, 1984). We also learned that sometimes mothers experience a sense of loneliness from having a child with a disability. Perhaps this loneliness was felt because the husbands have abandoned their role as a supportive partner in the care of their child. While research suggests there are husbands that do interact with the day-to-day care of their child, thus relieving the mothers of stress, anger, and depression (Simmerman, Blacher, & Baker, 2001). This was not the case as interpreted from the narratives of the mothers in this study.

Even though the mothers do describe experiences with their husbands or ex-husbands, they provide selective experiences describing how their husbands responded emotionally to their child's diagnosis and or their level of engagement and support with their child's disability and overall development. Perhaps the husbands' absence is due to their child's diagnosis of a disability and their diminished hope of having a "normal" relationship with their son or daughter. It could be argued the mothers' silence of their husbands' involvement is a reflection of their focus on the family's financial burdens and less on the daily care of their child. It would be hard pressed to believe otherwise, but the silence of the husbands' response and engagement of their child may in fact support the mothers' reasoning for their absence in the narratives. For example, in Beth's narrative

she does not mention her husband at all other than to include him occasionally as “we,” when decisions were made about adopting and fostering children, or rescuing animals. Yet once their child was born and diagnosed as a genetic mosaic, Beth’s husband is silent throughout the remaining narrative and “we” is replaced with “I,” especially as her narrative leads us toward her role as an advocate.

Like I said, you have to have so many hours of parenting education to be a foster parent. So, you know, I started going to those things and I just began, began to get more and more interested in children overall, but especially in special needs kids and beside the fact I have one of my own. So after a long career at the zoo, working with animals professionally and privately, I began to sort of move toward children and started working with the ARC of High Point serving on their board now.

The lack of mentioning a “husband” is also true of Sara’s narrative. Unlike the other mothers, Sara selectively describes her husband’s response to the diagnosis of their son’s disability as “devastating” and briefly provides a scene where Sara and her husband are committed to help their son improve and gain access to a gymnastics program.

You know, we heard about gymnastics program in [city]. We had to go through all kinds of paperwork because you know he was very low tone. Had a lot of issues and they were really worried about the liability that they would have. But we went through all the paperwork they required us to go through, so they couldn’t say no, you can’t. You can’t bring him and so my husband and I worked with him and got on the floor and everything that they did. We really pushed his body to do and he learned to walk.

This would be the only scene in Sara’s narrative where she specifically describes an act where her husband shares the responsibility of their son. Like Beth, as Sara shifts her

experiences toward advocacy, her husband's absence becomes more apparent for no other reason other than, as Sara states "he was not the one to push." It is not indicated in Beth or Sara's narratives that their husbands abandoned them emotionally or from the day-to-day care of their son. It's hard to imagine any father totally absent in the care of their child, but perhaps Beth and Sara's silences, as well as the other mothers in this study, were more satisfied (Simmerman, Blacher, & Baker, 2001) than dissatisfied with their husbands' interaction with their child.

In Cindy's narrative, her level of satisfaction is reflective of her ex-husband's absence and non-participatory role in their son's life.

I ended up getting primary custody. In the end, he's getting you know supervised visitation with his father every other weekend, which is not exercised at all, because he will go a year at a time without even talking to our son, which I think is fine because I think he's not a good influence. So he shouldn't be in his life anyway. So that works for me.

Cindy and Lisa are the only two mothers in this study who are divorced from their child's father and they represent a growing statistic in the United States. According to a report in the Wall Street Journal in November of 2008, parents who have a child with a disability divorce at a higher rate than the national average (Barr, 2010).

We learned in my earlier sections, the Experience of Abuse and the Experience of Divorce that Cindy and Lisa did not allow the absence of their child's father to negatively impact how they were able to meet the needs of their child. More importantly, the narratives of Cindy and Lisa painfully remind us that "children with disabilities are more likely to live with single parents, and especially their mothers, than are other children"

(Cohen & Petrescu-Prahova, 2006), leaving mothers like Cindy and Lisa self-confident and persistent in their role as the primary caregiver.

In the narratives of Elsa and Dora, the absence of their husbands may in fact reflect more of their Hispanic heritage than a desire to be non-engaged in the day-to-day care of their child. In the Hispanic tradition, the role of husband is viewed as the authoritarian, making all the decisions for the family, while the wife is more submissive and assumes the role of mother and wife (Galanti, 2003). Traditional behaviors of Hispanic men are viewed as cold and overbearing, due to their cultural emphasis on their role as the financial provider for the family. Elsa and Dora's narratives do not portray their husbands as overbearing or domineering in the least, nor are the mother's roles typical of traditional Hispanic women. Elsa is very much aware of this cultural difference and explains the distinction is mainly due to her husband's inability to speak English.

Tradition Hispanic women supposed to be shy, supposed to be back, just yes, yes, don't speak up. Usually, it's the husband the leader, but because of my husband not speaking as much English as I do, I was the one responsible for doctor's appointments, special appointments, teacher's conferences...taking [children]to school, signing them up, anything for the children I had to do that. So the role is a little different in my household, because I'm in charge of the bills.

My husbands the one that works and I'm the one that does the checking account, pay bills, doctors, school, anything like that. So, but other culture [Hispanic] of course, you know the mother is the caregiver but the parent, the father is usually the...head of household. The one that makes the decisions, all stuff. In my case I'm the one that has to do the decisions. I discuss it with my husband, but I'm the one that do the decisions.

Dora and Elsa understood and embraced their roles as the sole caregiver of their child. They were appreciative of not being burdened to contribute financially to the family. Rather, they could concentrate on meeting the needs of their child. Dora explained, “thank God, I have all the resources to, you know, stay at home with them and give them the therapy and give them everything they need.”

In summary, even though the mothers in this study were silent about any feelings of frustration due to their husband’s absence, mothers of children with disabilities experience high levels of stress (Simmerman, Blacher, & Baker, 2001) from the everyday care of their child. The stress of caring for a child with a disability may affect a mother’s overall well-being, causing psychological suffering and possibly straining the quality of their marriage. Parenting a child with a disability can be demanding, and exhausting (Glidden, Bamberger, Turek, & Hill, 2010), leaving the mother with a never ending role as caregiver. For the mothers in this study, this never ending role becomes central to their identity and overall life satisfaction (Glidden, et al, 2010).

A Grandmother’s Endless Support

Lisa

Out of all the narratives of the mothers in this study, Lisa was the only mother that selectively described experiences where her mother provided her with support and encouragement in her life. We learned in *The Experience of Abuse*, that Lisa was a victim of sexual abuse by her father. The horrific experiences described by Lisa might leave someone struggling to make sense of the relationship she had with her mother considering the abuse they endured. While many daughters blame their mothers for

being a passive bystander, Lisa silenced any feelings of hatred or blame toward her mother. Their mother-daughter bond was strong as evidenced in how Lisa protected her mother and siblings from their father. Perhaps her role as protector was key to helping Lisa recover from the abuse she had already endured. Berliner, (Berliner, 1990, as cited in Schonberg, 1992) after interviewing children who were victims of abuse, stressed the key to helping children cope emotionally was not in the form of counseling, but from the support of their mothers. Lisa's mother was there for her during several pivotal life experiences, including when she decided to go back to college, but financially could not afford it.

So I got my first credit card, but my mom said if you want to go back to college, she said, I will take over the debts and you can pay me back when you get your first job and I said ok.

There is a bond between a mother and a daughter that ties the two together. Lisa and her mother's bond were shaped by the experiences they shared and the storms they overcame. Perhaps Lisa looks at her mother as an extension of herself by persevering through life's challenges, even as a mother of a child with a disability.

Summary of *Family*

Our family can influence our identity, from those that raised us, to those that provided support and guidance for us. Family helps us identify our roots and shape our values, beliefs, and ideas. We discovered in the narratives, that the identities of the mothers were influenced by their families and were "ever-changing" as they experienced

new roles in their life (Terry & Campbell, 2009, p. 25). These new roles, like those described in the mothers' narratives, reflect a strong bond with family members such as a parent, sibling, or husband and can provide a sense of security and support that is constant, familiar, and stable during life's hardest challenges. Finally, we learned while the family can shape our identity, it is never fixed. Our identity has the ability to be constructed and reconstructed based on past, present, and future experiences.

Identity Shaped by Religious *Faith*

At several turning points in my life, I have thought about what my purpose is. Why was I born? Why did this happen to me? For many individuals including myself and several of the mothers in this study who question their purpose in life, their existence, or their understanding of life challenges, they often turn toward religion for answers, for guidance, and for strength especially during times when their world feels punctured or collapses (Fowler, 1995).

In the narratives of Sara, Lisa, Dora, and Cindy, they identify life experiences in which they turned to God, particularly when they faced adversity or challenges concerning their children. Monaghan and Just (2000) state that, "it seems apparent that one thing religion or belief helps us do is deal with problems of human life that are significant, persistent, and intolerable" (p.124). McAdams (2006) notes that research in life stories shows that women in their middle adult years construct a narrative identity based on their "steadfastness and deep belief...that religious or spiritual sensibility provides a prime source for...depth and clarity" (p. 145).

The mothers that share experiences of their faith do not emphasize what religion they were brought up in as a child or which religion they practiced as an adult, but they do provide through their narratives an understanding and justification for their existing spiritual dependence on a higher being, which they describe as God. Faith in God, in fact, compliments the mothers' identities as advocates in the challenges they faced with their children. In *Identity Shaped by Faith*, two sub-themes emerge that explain the root of the mothers' faith and their commitment to trust God through life's toughest challenges.

Childhood Faith

Sara, Cindy, and Lisa shared early life experiences where faith in God reflected a component of their family's structure and ultimately would influence their identity as an adult. Sara's opening response to "tell me the story of your life," immediately began with a description of her childhood home that of being "very religious." However, the majority of Sara's narrative silences any further indication of her faith until after her son was diagnosed with a developmental disability. Perhaps the silence is not an indicator that she abandoned her faith, but more of a steadfastness and continuity of trusting her faith in her daily life.

In Cindy's narrative, the first description of her family reveals the happiness of her mom and dad's marriage. The second description of her family describes their commitment to God and to their church. Cindy shares in her narrative that her early years as a child were spent attending church every "Sunday morning, Sunday night, Wednesday evening, choir practice, you know, every function." It is not until the life

experience of getting pregnant at seventeen when Cindy's narrative moves beyond her childhood faith in God, and shifts more toward having a relationship with God that is personal, enduring, and spiritual. As a young married adult, Cindy experienced early struggles in life that ranged from physical abuse, divorce, and court custody battles. Each of these experiences was very difficult to overcome, but as she states, "...I just prayed and prayed." Throughout the remainder of Cindy's narrative, she draws upon her religious faith to overcome many challenges that involved the well-being of her son.

Lisa's life story began with memories of growing up poor, living in a large family, and being abused physically, sexually, and emotionally by her father. Her religious faith does not enter her story until she reaches an age of moral understanding. She stated, "At some point...I became to know the differences of right and wrong and going to church and knowing things and knowing some things were right and not right." Unlike Sara and Cindy's family life that incorporated the whole family around their religious faith, Lisa's narrative describes a family that centered on protection and avoidance of an abusive alcoholic father. Unfortunately, Lisa's narratives does not indicate if her mother attempted to protect her children, but it is likely that Lisa's mom leaned on her faith in God to help her endure the abuse her family experienced. For Lisa, her mother, and siblings, the church provided a safe haven and time away from their dysfunctional home. The church also, as we learned in my earlier section, The Experience of Disability, provided Lisa at a young age the opportunity to advocate for a child with a disability. Her religious faith helped her stand up to her father's abuse.

Faith through Adversity

The mothers who expressed their faith shared a common response when faced with experiences of adversity. In today's world, many individuals including those that are religious, want answers, want results, and will go wherever or do whatever to get what they want. The mothers who shared experiences of faith did not communicate any sense of extreme urgency in their narratives, but rather they relied on God being in the midst of their trials.

An example of trusting God came at a point in Lisa and Sara's life, where life or death was at stake for their child. In both experiences, the hospital staff had little hope for the newborns, and warned the mothers of possible bad news. Sara's response to the hospital staff's warning was persistent prayer for her son's recovery. Sara states in her narrative that her son had survived spinal meningitis, "...for whatever reason that I can't explain other than God just wasn't finished yet." Lisa recalls the hospital staff stating, "...ma'am you don't understand. Your son is probably not going to live." Many parents may have given up hope, but Lisa was grounded in her faith and responded to the staff by stating that "God is in charge of this." Lisa never hesitated in believing that God had given her son to her for a special reason and knew he wasn't going to let him die. In fact, Lisa's faith never wavered while describing experiences of adversity in her narrative, including the experience of having her son on life support as an infant and his life threatening seizures as a young adult.

Out of all the mothers who shared experiences of religious faith, Dora's narrative embraces a relationship with a "living" God. The story of Dora's life begins by

describing her family and childhood. Dora then proceeds by sharing that her faith in God should be at the top of her priorities in life. She states, “first is God and then your family is the most important thing.” We learned in my earlier section, under *Identity Shaped by Suffering*, that Dora’s religious faith in God was present and active. She illustrates this throughout her narrative by statements like, “it was amazing, you know, you could feel God,” “like the heavens opened up and they let me see people,” “God let me remember this,” “God let me remember his face...let me see all that,” “I mean God, are you kidding me?” “Thank God I have all the resources,” and “I don’t do it... then that to me it’s as bad as sin...it’s just you say no to God.” It is likely from the evidence in Dora’s narrative that she shared her religious faith and trust in God with others. For example, Dora describes a doctor who was in charge of her son’s critical care as a very “devout Catholic,” who went to church and as she states, “prayed all night for wisdom to know what to do,” to keep her son alive.

Like Lisa, Cindy believed that her son Luke was a gift to her from God. Her role as an advocate is as she states, “a responsibility that God gave me.” For Cindy, trusting God is a part of her identity which affects every facet of her life.

Every decision you know, whether you know it was the medicine or to see this specialist or to see that one, whatever I have had to pray about it and I had to say, you know is this the right thing and I have to live with the consequences. If I don’t do anything and I let, you know, whoever make the decision, then he’s going to be looking at me and I know God’s looking at me. So, I have to make my decisions based on that. So, I think that’s a huge part of how I live my life.

From the beginning of Cindy's narrative, she shared experiences that always pointed toward her faith in God. By the end of her narrative, Cindy had shared many experiences where her faith in God and her responsibilities as a mother were priorities in her life.

But you know I have a personal relationship with God and I pray about things and I ask God to have his will done in my life and I think everybody and all the parents, everything gets caught up you know, in you know, what you're doing here, your job, your car, your house, your clothes, everything and really I think in the end, what is important is when I die that I do know that I'm going to be judged and I feel like God did give me Luke for a reason.

Summary of *Faith*

The mothers in this study who shared their religious faith in their narratives believed that God had a purpose and plan for their life. Their faith facilitated coping when experiencing adversity (Treloar, 2002). Religious faith was beneficial to the mothers as it provided them with a source of reasoning and emotional understanding. It was not surprising to have learned through the narratives that the mothers drew on early traditions of faith and spirituality from their childhood, which was then carried over to their adulthood. Ultimately, their faith played a significant role in shaping their identities as advocates. The mothers' stories of faith supported their belief that it is better to be joyful for the life of their child, in spite of the adversity that is associated with having a child with a disability.

Identity Shaped by *Motherhood*

Landsman (as cited in Layne, 1999) states that mothers of children with disabilities are often viewed by society in a separate category from other mothers.

Mothers of children with disabilities are either blamed for their role in the birth of the child, or they are looked upon as special mothers chosen by God (Landsman as cited in Layne, 1999). The mothers in this study as indicated in their narratives did not look at themselves differently from other mothers. In fact, statements in the mothers' narratives like "God gave me this child for a special reason," or "I feel like God did give me Luke for a reason," or "He survived for whatever reason," are indicators that the mothers interpreted the birth of their children, as they were meant to be here.

The model of motherhood continues to be redefined in an ever changing political, social, and cultural landscape. *Identity Shaped by Motherhood* is not intended to be a debate of cultural and social ideals of motherhood, rather it is about life experiences shared in the narratives of the mothers where they have defined their identity through acts of motherhood such as "nurturing," protecting, and "self-sacrificing" (Austin & Carpenter, 2000, p. 380).

In the narratives, the mothers describe experiences where listening to their instincts was important to the survival, protection, and the well-being of their child. For example, in Elsa's narrative, she describes an experience where she sensed deep down that something was wrong with her son during his first year, even though the medical doctors had insisted for ten months that her son was developing normally. Elsa's persistence in listening to her instincts while identifying her son's needs medically, socially, physically, and educationally are consistent throughout her narrative. Lisa also listened to her maternal instincts insisting that her son, who was born prematurely and stayed in the hospital for four months, would thrive better under her care rather than in

the care of the hospital. Lisa states, “I just kept on and on...they never had a parent so determined to get their child home and I kept saying, just let me get him home, he’ll be so much better.”

The mothers’ narratives also shared acts of selflessness. For example, Cindy who had for months challenged the public schools and advocated for her son’s educational rights, decided to forego aspirations to pursue a degree in human resources and chose to be a stay-at-home mother and home school her son instead. Dora, Elsa, and Sara also decided to forgo career opportunities to be stay-at-home mothers as well. This was difficult at first for Dora, especially since she felt her call in life was to serve people, but Dora accepted her new role, stating “you know I felt that emptiness like I want to go, you know, help people who’s alone. I have this thoughts, but I understood that this my, like my assignment now.” Lisa and Beth, on the other hand, chose careers that kept them close to their children. Lisa, who was a single parent, became a visually impaired teacher and mobility specialist, which allowed her to closely monitor her son’s education throughout his public school experience. Beth also shared an act of selflessness in that she retired from an earlier career as a veterinarian technician at the [state] zoo, in order to work as a special educational classroom assistant at her son’s school.

In my early section Identity Shaped by *Suffering*, Lisa shared that she was a victim of incest. According to Kritsberg (1993) mothers who have been victims of incest often have difficulty protecting their children from potentially dangerous situations. This type of behavior is definitely not an attribute of Lisa. Not only did we learn in Lisa’s narrative that she protected her siblings and mother from abuse, but she also displayed

protective instincts while working as a teacher's assistant at the developmental daycare, as a mobility specialist for visually impaired students, and as a behavioral intervention specialist in middle school. Lisa states, "I can remember being pregnant with my son Tate and two kids in middle school fighting and me stepping in the middle. It's just something about people fighting that just, it just drives me crazy and I feel like I've got...place to step in and stop it or keep somebody from getting hurt." Protective instincts were natural for all the mothers. Elsa and Cindy also describe in their narratives public school experiences where they sensed a need to protect their child. Elsa describes herself during those experiences where, "the lion... came out."

Summary of *Motherhood*

According to Prilleltensky (2003) motherhood is an important part of a women's present and future identity. Even though the mothers in this study didn't necessarily equate giving birth to a child as a narrative definition of motherhood, the life experiences of being a mother and the characteristics described above were important components to their personal identity as mothers. For example, in Lisa's narrative she describes a scene of joy from being a mother, despite there was a chance that her son would not survive his birth.

I said I am not leaving this hospital until Mother's Day and when I leave, I want my big blue bow out at my mailbox. They said ma'am you don't understand, your son is probably not going to live. I said...I want my big blue bow. I said when my family members come up here you will tell them...my big blue bow on my mailbox and I want everyone to congratulate me for having a son.

CHAPTER V

IDENTITY SHAPED BY *ADVOCACY*

In this chapter, I discuss the theme of advocacy which was the core of all the mothers' narratives. I describe early life experiences of the mothers that are shared in their narratives that played an important role in influencing their identity as advocates. I also describe experiences the mothers share that illustrate advocacy for their child. Finally, I discuss how Sara, Lisa, and Beth's role as advocates provided further opportunities to help parents of children with disabilities.

As I defined earlier in Chapter II, this study refers specifically to a parent advocate as someone who actively and unarguably participates in the educational decisions for their child that are guaranteed by IDEA (Trainor, 2010). The mothers that I witnessed as a professional educator in public schools typically just showed up unengaged or were absent at their child's IEP meetings. However, the mothers in this study were engaged in their child's education and pursued advocacy not just in the public schools, but in all aspects of their child's life with passion and determination.

Early Signs of Advocacy

In the narratives of Lisa, Dora, Elsa, and Beth, early signs of advocacy are evident as described in life experiences such as protecting members of their family from abuse, providing support for individuals at their church or at their place of work, and rescuing

abandoned animals and fostering children. Their early advocacy experiences created a foundational memory that helped each parent during experiences that would test their advocacy skills.

Lisa

When asked to tell the story of her life, Lisa paused and then proceeded justifying why her life experiences would be difficult to share. After hearing her stories of sexual abuse, divorce, and the diagnosis of her son's disability, I understood her reasoning, but it was apparent that her life story, regardless of her struggles, needed to be heard (Avery, in Corker & French, 2009). The role of an advocate typically begins as an adult, but according to Lisa's narrative she has been an advocate since she was a child. In fact, her statement, "I have been an advocate for children as long as I can remember," speaks true of early life experiences where she advocates against abuse and educational equality for an autistic child.

In my earlier section under The Experience of Abuse, Lisa shares that she was a victim of incest by her father. The suffering she endured eventually reached a point where Lisa began to question her father's authority, especially after she understood the difference between right and wrong. It was at this point in Lisa's life when she became an advocate for her siblings and mother.

But as I became to know the differences of right and wrong and going to church and knowing things and knowing some things were right and not right, I learned that if you don't question authority, the same thing keeps happening over and over. I did not want it to happen to my sisters or my brother...I learned to fight him [father] to save, to protect my mom. *So I became an advocate for our family.*

The more stories of her life that Lisa shared in her narrative, the more I realized that her damaged identity had actually produced a resilient and energetic spirit of advocacy that she drew on to help other children who were physically and emotionally abused.

I've been an advocate for kids in all kinds of ways without really realizing it. Like one time when I was a teenager, well, really about twelve or thirteen years old, our family had gone out to [-] lake and went swimming. There was a man out there that was trying to teach his daughter to swim and he was being loud and boisterous and there was all these families laying around the shoreline at the lake and all these adults that were out there and he was like, I'm going to teach you to swim, GD [vulgarity], and you know, your bla bla bla and I just could not believe that another adult out there could not say or do something.

This man was totally embarrassing and humiliating this child and so I go up and my daddy said, you better not get in the middle of it, and I said I am. I said, this is ridiculous and I walked out to that water and I told that man I have worked as a lifeguard and I have worked with children. I said...I was only twelve...and I don't even remember where I came up with the stuff I was saying to him. I said, well I was a lifeguard, but I said, ... if you'll let me have her for at least five or ten minutes, I guarantee you she will be swimming and he didn't have a choice because there was, you know, people were seeing and hearing...and that little girl was swimming, but she was so happy to be swimming...and not be beaten up over it.

At the age of twelve, not only was Lisa protecting her siblings and mother from her own abusive father, but had the courage to protect other children from their abusive fathers. The experience at the lake demonstrated that advocacy was now as much a part of her identity as was the memory of the abuse she suffered as a child. Standing up against abuse was just one area of advocacy that Lisa initiated. Similarly, education for the rights of children with disabilities became another important advocacy issue.

In my earlier section, The Experience of Disability, Lisa shared that getting a degree in special education and working with children with disabilities was something she felt “a need to do.” Her vision was clear, however, college life was not what she had anticipated. Midway through her fall semester, Lisa became dissatisfied and dropped out. While her goal of earning a degree in special education was put on hold, her goal of working with children with disabilities began when she landed a job at the Child Development Center as a teacher’s assistant.

So I dropped out of college after my first year, and I started working. I didn’t want to leave the field [crying], *so I started working as a teacher assistant* and worked with some autistic adolescents and autistic preschool kids. Absolutely fell in love. Had a director that was just an “A” type, anal person. We had a student that was in the town... and I was outside of [city] in the [city] area, and he [student] needed transportation.

So I said, well, I’ll take him back and forth to school and so he was what I know now as autistic and was non-verbal and he did a lot of hand biting and I took him back and forth to school everyday and it was about a thirty-five minute ride, if there’s no traffic...so some days we might be together for forty, forty-five minutes and *I would talk to him and I would sing to him and I’d call his name all the time*. His name was Dewayne.

Lisa advocated for Dewayne, not just by singing to him or giving him a ride to school, but by gaining his trust in a non-threatening way. Dewayne’s non-verbal and aggressive behavior was challenging, however, Lisa was learning skills in dealing with autistic children.

I had started working with this little boy [Dewayne] one day on the way home. I had to pick my mom up and I had flipped through a book and we had tried to teach him to speak and to be verbal to us and to say things and he couldn’t say

things and not carry on a conversation or even say one word, but I turned to a page and he flipped the page over and he started hand biting and screaming and started flipping his ears and he goes...Wesson al n d, Wesson al n d!

It was a picture of Florence Henderson...a can...a thing of Wesson oil. I said yes, that's from the Wesson al n d commercial. I said, but this says Wesson oil. He said Wesson oil, Wesson oil, and so from that point on I started showing him words and he would speak any word, any word, it didn't matter about phonetically. Anything, he could read any word we gave him. So then he became print driven. That was one of the things which we didn't know that was cycling the hand biting was the print.

Lisa describes this experience with Dewayne, as "a major breakthrough." From then on, when Dewayne would have behavioral outbursts, he would seek out Lisa for comfort, support, and understanding. However, this close relationship was not received well with the director of the center. As a result, Lisa was asked to stop responding to Dewayne's behavioral needs. Lisa did not listen to her director, but listened to her inner voice of advocacy, even if it meant losing her job.

The director did not have a degree in education. She had one in business. She said well, he's you know, not having to be accountable for his actions. He's just running to you and your kind of feeding into it and she said, you can't do that anymore and I said, I'm not going to turn my back to him when he comes to me for help or if he's frustrated. She said, well, you're going to have to or that will be your job...so, like I told her...after all of this, I am leaving here when he graduates, so I don't care if you fire me, but I am not leaving until he graduates.

It was like in the summer, so the graduation was just a couple weeks away and she said to me, she said, *what do you have for your basis of your feelings*, because I told her that was not right, that I did not believe in what she was telling me to do, and *I said my "heart."* She said, unless you have a degree to back that, she said, you cannot come to me with anything else. She said, you need a degree and I said, you don't have to worry about that, I said, because when I go home today, I'm going to find out what I can do to get back into college, because no one will

tell me that what I feel in my heart is wrong again. So I did, and I went back to school and finally graduated [laughing] with two degrees and one minor in psychology.

There are two powerful remarks that are selectively shared in Lisa's narrative above. I believe each is critical in understanding Lisa's early identity as an advocate. The first statement, "I'm not going to turn my back," and the second, "No one will tell me that what I feel in my heart is wrong," are a direct result, I believe, from the suffering of abuse that Lisa endured as a child. Lisa knew firsthand how it felt for someone, perhaps her mother, to turn their back on her when she needed help. I also believe that Lisa knew that listening to her heart was important and significant to her recovery from the abuse she suffered as a child and the direction she would take in her future.

Dora

Dora's early advocacy experience began as a result of a language barrier. After moving from Mexico to the United States with her first husband, Dora was faced with dependency on his English for translation of everyday needs, including routine doctor visits.

Ok, this is the shot you have to have. This is the checkups and you need to have this and this...my ex-husband had to take off work and come, and it was kind of hard for him. I didn't understand the doctor.

Not understanding the English language left Dora feeling helpless. This sense of helplessness for Dora was a result of, lacking fluency in English, and also adapting to and living in a new cultural environment. The feelings of disorientation and shock motivated

Dora to learn English and advocate for other Spanish speaking adults in health care facilities.

But, one of those days...one of those visits....I sat by myself and waited for the doctor to come and I said, for as long as I live and *if I have the power to speak* English or translate or I don't care I learn sign language. I will help the people that's in my place. I will never allow this to happen, if it's within my reach. You know, people to suffer...they don't understand or they miss communication and they get sick...that was, that was the big thing for me.

Dora's pursuit to help others led her to a job as a translator in the emergency room at a hospital. There, she was able to advocate for Spanish speaking families and provide them with the support they needed. The experience also opened Dora's eyes to what she believed was discrimination of the Hispanic community within the hospital. In fact, hospitals and other medical facilities could face governmental sanctions, if they are found to have discriminated against someone because of their race (La Veist, Rolley, & Diala, 2003). The discrimination that she perceived provoked a strong desire to encourage people to see others as human beings and not as a drain on society.

I was working as a translator in the hospital. That was the thing in the ER and all this people came like at three in the morning, and I was just happy to help...like ok, you know what, like, lets just...and I talk to them and you know I had a chance to meet all this people...all this doctors, all this nurses, all this PAs...Ok, well you have this and this and this [medical diagnosis] and ok, then they go...like woa, mostly you know. I am not racist at all, but I can see the difference when they treated somebody, like Hispanics. You can see [Hispanic families] very humble...ok, well you have this and this [medical diagnosis]...that make me angry because they don't speak the language. They don't know what's going on or with their kid or anything.

You know, *people in the world needs more compassion* and then I would sit with them...and if they needed something...ok you know what, let's call my church. You know, be the connection because, been there done that, and I felt the same way. Well, they come to the states...they didn't speak English, bla bla bla, ok whatever. That's their opinion, but you know that helped me a lot to, you know, to advocate for this people. I said no! [referring to discrimination] They don't have a voice. *We're still human* and they still have needs. They [Hispanics] need more help when they don't speak English. They don't have the communication. They don't have family.

The similarities that Dora shares with the Hispanic families were important to the relevancy of her advocacy. For example, Dora didn't have her family nor did she know English when she moved to the United States. This connection allowed her to share frustrations and understand discrimination. For Dora, her early advocacy experience is important to her identity as it helped prepare her to have a strong voice in her future role as a parent of a child with a disability.

Elsa

At an early age, Elsa witnessed her family being taken advantage of on multiple occasions. The death of her father left her family vulnerable to those who prey on the defenseless and who are desperate for help. In her narrative, there is no mention of any individual who stepped in and advocated on behalf of her family. However, once Elsa and her siblings reached an age where they could protect themselves, they not only advocated for themselves, but also for others who were overlooked and lacked a voice. For example, Elsa describes in her narrative there was no Spanish mass at the Catholic Church they attended due to a lack of a Hispanic presence. After being ignored for years,

Elsa and her family decided to bring to light discrimination that prevailed within an English speaking church.

We started here in [-] Catholic Church, in [city]. We find out that there is not a Spanish Mass...and they say the reason because there were not many Hispanic people in here. Well, there were a lot...it's just the people did not know where to go. So, my brother-in-law and sister, my two brothers, and my mom...we got our cars and start bringing, going into the fields and picking up people...that they, you know, do tobacco and stuff like that.

We would pick them up early in the mornings and bring them to church and we established to have Sunday Mass for the Hispanic people. So, that's one of the things that I saw. We saw something wrong and we started helping out...actually, we have a priest that were sent from [city] that spoke Spanish, because there was the priest that we had...it [priest] was American...and he would just read from a book, and they saw that we were having more Hispanics, so that's when they started bringing a priest for us.

Elsa's sensitivity to the needs of the Hispanic community directed her to bring attention to and rectify the situation at the church. Although this was the only example in Elsa's narrative of an early experience of advocacy, it provided her with an opportunity to learn how determination and a committed vision can impact not just one individual, but a whole community. This experience would help Elsa gain the confidence needed to advocate for her son's educational opportunities.

Beth

Beth's life is defined as she states, "by those around me probably and probably defined by animals and children." Beth's opening statement in defining her life story is an excellent example of how individuals interpret their lives differently. For Beth, past

memories of her parents, siblings, or childhood are absent in her narrative. The silence of these memories does not necessarily mean they are unimportant to her identity as an adult, however, the silence reveals the significance of animals and children and their impact on Beth's life. In fact, her love for animals led her to a career as a veterinarian technician at a zoo where she worked for twenty-two years, while her love for children led her to foster care and adoption. Beth's early advocacy experiences emerged from her desire to improve the quality of life for children and rescued animals.

The first part of my life, totally dedicated to animals. Started out with a great interest and love of animals and I took that and channeled that all through high school working in vet offices and then through college getting a degree in animal sciences...then, I went to work for the [state] Zoo as a zoological vet technician and I did that for twenty-two years...then I got into animal welfare issues and worked through the Humane Society and animal advocacy groups and held presidencies and vice presidencies and sat on boards for animal advocacy for a long time. So, I was always an active participant and an advocate for animals.

So, we did a lot of rescued animals and ...we opened up our home further to other people's children and animals, as I said, have defined my life. Eventually, we did adopt one of our foster children, who is our daughter now and she is ten...and then we have another foster child who we never adopted, because she aged out of the system before we could, but she calls us mom and dad and she's thirty. She's thirty-one almost and she has two kids of her own who like to pretend to call me, who have threatened to call me grandmother...but anyway, so after we were foster parents, I did also do advocacy for fostering children and adopting children and joined a few of those groups, and of course, in order to be a foster parent, you have to keep up your educational license.

It is evident in Beth's narrative that she is adamant about being a part of a solution to the problems that she encountered, either with animals or with children. Her early advocacy led her to serve on various boards, associations, and committees in which her voice could

be heard. The experience in foster care provided an opportunity to expose her to children with various needs including children with disabilities.

Like I said, you have to have so many hours of parenting education to be a foster parent. So you know, I started going to those things [meetings] and I just began, began to get more and more interested in children overall, but especially in special needs kids.

It is clear in Beth's narrative, fostering children and caring for animals provided early advocacy opportunities. Beth chose to embrace advocacy, as it became the core of her identity prior to and after the birth of her son with a disability.

Advocating for their Child

The core of the mothers' narratives in this study is advocating for their child. While there is no guarantee that advocating will get a parent of a child with a disability what they want, speaking up regardless of the outcome, allows your voice to be heard. The mothers in this study were not afraid to speak out and were effective in their advocacy experiences. Other parents of children with disabilities can learn from the mothers in this study from their experiences and strategies used to be effective advocates.

Sara

Sara's journey as an advocate began at the moment her son Jack was diagnosed as developmentally disabled. As stated in my earlier section, *The Experience of Disability*, Sara became angry, not from the diagnosis of her son's disability, but from what was communicated following the diagnosis. The message, which came from an evaluation specialist, suggested placing Jack in an institution. The idea of placing Jack in an

institution literally shocked and infuriated Sara, especially since she assumed that institutionalizing individuals with disabilities ended many years ago.

Part of it was that *it really ticked me off*, the way that they said that... and I'm think that we're in 1990. That you hear about different things that have happened over the years...that we have come way past putting someone in an institution that had a disability. So that's where you know, I really had that fight and that urge to make it different and do something different.

The initial trigger for Sara's advocacy was the suggesting of institutionalizing Jack. Sara's statement, "We have come way past putting someone in an institution that had a disability," illustrates the perception that deinstitutionalizing had occurred with the disability rights movement. In fact, June of 2012 marked forty-five years that "deinstitutionalization of persons with intellectual and developmental disabilities began as a national phenomenon in the United States" (Scott, Lakin & Larson, 2008). What is also revealing in the experience that Sara describes is the evaluation specialist's negative opinion of families of children diagnosed with a disability. Perhaps, the message reveals that the Developmental Evaluation Center assumes parents do not want the responsibility of caring for a child with a disability, however, Sara embraced the idea of caring for her son.

So I started *at that point, fighting* what they said. I was going to prove them wrong and I've just started looking for services. There was something called the infant toddler program that was through the mental health centers, but the waiting list was two years long and so we would need to just kind of hang on and wait for two years and when our name came up then we would get services and I was really the one who said no. That's not good enough.

Sara began advocating for Jack by putting pressure on the mental health center and within three months Jack was accepted into the infant toddler program. Sara's determination to prove to the system that Jack was much more capable than the system had given him credit for led her to advocate for alternative programs such as gymnastics to help Jack's motor skills.

We were told he would never walk. He walked. You know, we heard about the gymnastics program in [city]. We had to go through all kinds of paperwork, because you know he was very low tone...had a lot of issues, and they were really worried about the liability that they would have. But we went through all the paperwork they required us to go through, so they couldn't say, no, you can't.

We really pushed his body to do and he learned to walk. He did excellent. We found out, though, that our county...didn't really have a lot of things going for people with disabilities, for kids with disabilities.

Sara realized to advance Jack further developmentally she would have to make plans for his future. After realizing their residing county lacked resources and opportunities for children with disabilities, Sara began researching educational programs that were geared specifically toward children with disabilities.

We heard about an excellent program in [county] that was an inclusive daycare and at that point in time, inclusion was not a word that you used very much. We really didn't understand all of those things, but we really pushed to get Jack in that program and we drove fifty miles round trip every day...so that he could be in that program. We arranged our work schedules so that we could do that and that program benefited him greatly...and we felt like, that things were great.

Sara saw progress in Jack's development and was pleased with the inclusive developmental daycare. At first, Sara was unaware of the changes that were taking place

in mental health funds for individuals with developmental disabilities, but she began to hear that North Carolina was making changes. In fact, in 2001 North Carolina's General Assembly passed House Bill 381, an act to phase in implementation of mental health system reform at the state and local level. The changes affected North Carolina's funding allocations for individuals with developmental disabilities which would eventually become a roadblock for many children like Jack who were not residents in the county of the developmental daycare they attended. Sara realized that the funding issues would eventually impact Jack's future opportunities, so Sara became more aware of legislation and policies affecting individuals with disabilities.

Really, funding wasn't necessarily something that was talked about. We knew that part of the reason he got to go to the center that was in [county] was because of mental health funds...but Jack was a success story in our book, because of all the strides he had made.

About the time that he hit seven, that's when sort of changes were coming along. A lot of the mental health funds were changing. A lot of state legislation was changing and so we started hearing these rumbles and I'll tell you...my husband...he is very supportive, but he was not the one that would push. I started going to all the meetings. I heard that, you know, you need to contact your legislator. You need to do this or do that and I just really--. It was a passion, because I wanted there to be things out there for Jack and so, I really started pushing.

Sara's advocacy had reached a level where she would practically do anything to support Jack's developmental progress, even if it meant changing careers or moving to another county to live. Her passion for advocacy was perhaps at its highest peak when Jack became eligible for public schools.

We started hearing about the IEP meetings...you really didn't have to get involved with the school system quite so soon. Now you have to at age three, but when he was there you did not and that was a really big deal for us, because we were bringing Jack these fifty miles and doing this...but when he turned the certain age, the school system was going to start taking over funds. The school systems don't play nice between each other, and counties don't play nice, and so that also happened and we had to really start pushing.

They told us that, you know, basically if we lived in [county], he would not be able to change counties...to continue to go to [inclusive developmental daycare] unless we had an address in that county. So, we put our house up for sale and moved and truly, our case manager, cause we had a case manager at that point, never believed we would do that and said, you know...I just think that's an awfully big step to think about doing when you have this child with a disability, and is it really going to be beneficial?

Sara continued to face professionals who doubted Sara's willingness to totally sacrifice herself to help Jack reach his full potential. Through Sara's steadfast advocacy and with the support of her husband, Jack began making significant progress even so much that it was highly likely that Jack would enter kindergarten in a regular educational setting.

I had really gotten involved in doing a lot of advocacy for Jack. I asked all kinds of questions at the IEP meetings. They hated it. I wanted to know what every checked box was. I wanted the very best for him, and so I was really determined, and so we also decided that maybe we were going have another child. You know, Jack had come to a point to where he was walking and doing a lot of things...Had a lot of daily living skills that he needed for his age and things were going pretty well.

Up until that point, we had already been in touch with the school system...we had already kind of arranged for him to possibly have an assistant with him during the day and things were going pretty well. He was going to be in a regular kindergarten class. We had really pushed for that, because they really wanted him self-contained. We did not. I did not want that and I had become real involved in the ARC and really got into a lot of committees and groups and saw other kids who were older than Jack and how successful they had been and really wanted

that for him, and so I pushed the school system and really, really advocated to get him into a regular classroom.

Everything up until this point in Sara and Jack's life were moving in the right direction. Sara continued to grow as an advocate by attending advocacy meetings at the ARC, a nonprofit organization that supports individuals with developmental disabilities. In preparation for Jack's kindergarten year, Sara had questioned every aspect of the public school's educational plan for Jack and pushed for a regular classroom setting. However, a few days prior to Jack starting kindergarten, Sara learned she was pregnant. The next day, Jack became deathly sick and was air-lifted to a nearby hospital. This experience would prove to be a turning point in both Jack and Sara's life.

So I found out that I was pregnant one day and he got meningitis...was diagnosed with meningitis the next and he was eight. Very devastating, caused a lot more brain damage than what we already knew...but this was a pretty devastating blow. They really didn't think he was going to make it. They didn't think he was going to live. He survived for whatever reason that I can't explain other than God just wasn't finished yet. I mean we prayed a lot through that.

If I showed you a picture of him, when he was younger, you would be able to tell me exactly when the change is, that he didn't have the illness here and he had it here. It was that much of a drastic change...we kind of knew that it was very, very serious and we weren't sure he was going to walk after that and at that point the roles changed.

Sara's passion for advocacy was built around her belief that Jack could overcome obstacles through hard work and providing him with the right resources. Sara proved she was selfless and dedicated her life to Jack's well-being. Any signs of weakness or doubt were silent in Sara's narrative until Jack became sick. Perhaps, through all of her

advocacy for Jack, she had pushed herself physically and emotionally too far. Her statement, “I could not believe I had fought and really pushed and advocated for Jack to be where he was at, and everything was gone in twenty-four hours,” supports why she was willing to change roles so easily as Jack’s advocate with her husband.

Jeff became the advocate and I became the mom. I was devastated. You know it was just gone and so I was the one that had a little bit harder time coming back around. The school system automatically said he could not go into a regular classroom. It was going to be self-contained and ...here’s the IEP it’s already wrote. You will agree to this. You will do this.

For the last eight years, Sara was not willing to take advice or follow anyone who doubted Jack’s abilities, until Jack became sick. While Sara remained distant from advocating, the public schools had made arrangements for Jack to be in a self-contained classroom. Perhaps, the idea of a self-contained learning environment reminded Sara of the previous suggestion of institutionalizing Jack, which fueled her passion for advocating for Jack once again.

I kind of got my fighting spirit back at that point and really pushed to make sure that--. He may have to be in self-contained, but I want him to have as many opportunities as possible and I pushed every limit that I could push for him...to at least do art, music, a lot of different things. Things went pretty well for a couple of years...and he was like twelve when we talked about transition plans. I knew of other kids that got to explore a lot of different things.

We knew that Jack probably wasn’t going to get a diploma...so I was very interested in getting Jack in the community as much as possible and not having him sit in the classroom. The school system really fought and pretty much told us that he could not be in the regular classroom anymore. They would not allow that because they felt like it was a distraction from the other kids... So I really thought that, kind of lost that fight.

Throughout Sara's narrative, her goal to provide and advocate for Jack was her primary focus in her life, but toward the end of her narrative, her role had changed slightly. With two additional children, Sara's role as Jack's primary caregiver became so difficult to the point where she realized that Jack's needs could be better served in a group home setting. Sara's identity as an advocate was not affected by this decision, in fact, her advocacy continued even in the group home setting.

His needs had gotten to the point to where I was not able to take care of him at home and he had to move into a group home and I was pretty devastated by that. But he really transitioned very well...when things start getting on his nerves at my house, he starts calling different staff names. So, I knew that it was the right thing.

So now, he does different vocational things and I have found out the group home experience really pushed my advocacy as well. Because the system would have you to believe all the professionals, but I knew that deep down inside, Jack's just a person and I want him to be treated as a person and have those opportunities and because he lives in a group home doesn't mean he doesn't enjoy going to Pizza Hut...and so I really pushed to be involved in every aspect.

Sara's identity as a wife, mother, and person has been shaped by her advocacy for Jack. Her persistence began at the moment of Jack's diagnosis and has continued through many life trials. Sara always believed that to insure a better life for Jack, she needed to be "involved" in his life. For Sara, it was not about controlling Jack's life, but as his guardian, Sara will always push for what is best for her son, even if it does not comply with the opinions of the professionals.

Elsa

Under, *The Experience of Disability*, we learned that Elsa's role as an advocate began when she believed that she had been deceived by the health professionals. If anyone is credited for teaching Elsa how to advocate, it would be Omar's first caseworker that was assigned to him through a program called BABIES. To Elsa, Omar's caseworker was more than just an assigned employee, but a friend who not only recognized Elsa's misinterpretation of the meaning of cerebral palsy, but took time to teach, educate, and to encourage Elsa. She was as Elsa states her, "guardian angel."

To this day, I thank that lady [caseworker] *because she opened up my eyes*. I think that's the first person that actually told me and explained to me how to speak up...I told her that she had been my guardian angel, because we still keep up with each other [crying].

It was through their friendship that Elsa was able to gain the confidence needed to speak up in the early stages of Omar's development. Elsa never identifies the name of the caseworker other than referring to her as a guardian angel, but it was evident in Elsa's narrative the impact she had on Elsa's role as an advocate.

I learned my tricks... by her. I think she's the one that started teaching me how to do that. Every time I needed anything, anytime, she will be there. Physically and emotional, she will help me...I think that's when I started learning that I have to start speaking up.

Elsa started speaking up first at Omar's doctor's office, where she believed she had been deceived and felt betrayed. Her confidence as an advocate for her son was not hindered

by past memories of perceived deception. In fact, she embraced her new role and was determined to prove the doctor's negative outlook to be wrong.

From that day, every time I went to doctor I ask questions, and I ask questions, ask questions. There is certain point that sometimes the people will get sick and tired of me...because I will stand by the door and I would not let the doctor go out, until I have all my answers.

So, every time I go to doctors, I mean I know they know me, that I ask a lot of questions. They told me that he's not going to be able to walk. He was not going to be able to talk. He basically was going to be vegetable. *I told them they wrong and I prove them wrong.* So, I was determined that my son was going be capable of doing stuff that even though they said no.

Elsa made the decision to enroll Omar at the age of three in public schools based on advice from his caseworker. Within several months, Omar showed significant growth in learning how to sign for things that he wanted. His nonverbal communication at home had now been replaced by a language that at first Elsa did not understand.

So when she [caseworker] told me about that school, I say yes...I enrolled him that school. *My baby learned how to sign language.* At first, [laughed] it was so funny because he wanted milk and he was saying milk, please, and he was saying with his hands, sign like a cow, like milking a cow and rub his chest...please. I did not know what that meant and I thought like something is wrong with him [laughed] and...they taught me a few sign language words. I was starting using it more at home.

The absence of communication between Elsa and Omar was now replaced with words that brought joy to Elsa. She saw progress and knew that Omar was capable of much more. In fact, Elsa pushed for assistive technology and an electric wheelchair that would give Omar independence and confidence.

As he got a little bit older, assistant technology started help me out with him, because *I keep on asking, I know he's capable of talking. I know he's capable of talking. I said no, we need to try this.* You know, I said this computer that would talk for him so he would not have to use sign because he has cerebral palsy, so his hands are going to get worse as he get older.

I wanted him to be independent and so I ask, what can I do to get a wheelchair [electric] for him. Oh, it's very hard to get a electric chair for him, because you have to go through, jump through hoops. I say, I'll jump through hoops. The person came to my house to interview me for wheelchair. They say that Omar was not needy enough. I say you know what, I love the words that you're saying. That he's not needy enough. That makes me wonderful, you know, he's not [laughing] special needs like your saying, but...are you blind or something [laughing]? He has quadriplegic cerebral palsy. What else you needed for him to be needy?

Through Elsa's advocacy Omar received an electric wheelchair and a boost in confidence, so much so that other areas of his development flourished. His ability to speak without an assistive device was improving. Elsa was excited, laughing and smiling, when she described in her narrative the progress that Omar had made.

After Omar got the wheelchair, nobody could keep up with him [laughing]...and he started speaking more and more. That it got to the point, that he did not need that machine to speak...So, sometimes he speaks [smiling] really fast and some people don't understand him. So when he speaks slower, he's able to be understood better. His nickname was Muhammad Ali, because he would speak up [smiling]...I'll beat you up in this wheelchair.

Elsa believes that Omar's self-confidence and his sense of independence in his electric wheelchair was a way for him to be free and to feel more like other children who are able to go places on their own. Omar's spirit of independence was important to Elsa, as it provided opportunities for Omar to learn how to speak up for himself.

Up until Omar was in third grade, Elsa's primary role as an advocate focused on Omar's education and preparing him for the future. However, she never expected to use her advocacy to protect Omar from verbal or physical abuse.

I think the time that actually the lion of me came out is when...his one-on-one was abusing him and emotionally abusing him. Like, telling him dumb...telling him shut up, you not supposed to talk. Stuff like that... but the thing is, nobody listened, nobody listened.

Elsa's statement, "nobody listened" proves that Elsa contacted someone and reported the misconduct of Omar's one-on-one. However, it is unclear in her narrative whom she contacted and whether there was any disciplinary action. Omar's change in personality was obvious to Elsa and should have been obvious to school officials, but perhaps they turned a blind eye. Elsa states, "Omar would come home and he would be just crying and he didn't want to go to school and he loved school. I knew something was wrong."

Omar's school is not the only school to ignore a parent's claim of abuse. In fact, school districts and officials across United States have ignored forms of abuse, even when according to Sullivan and Knutson (2000), "children with disabilities are 3.4 times more likely to be maltreated than nondisabled peers" (p. 1). Sorensen states (2002), "studies consistently show that the level of violence and other major crimes against children and adults with substantial disabilities is four to ten times higher than against the general public" (p. 1).

Unfortunately in Omar's situation, it took a terrible incident to occur before any changes were made with the one-on-one. After listening to Elsa describe the act of

physical abuse that Omar sustained, one would assume any school official or school superintendent would be contacting their school board's attorney in fear of being sued, but surprisingly that was not the case at all.

Omar came home with his bottom, was like hurting. It was red. His bottom was red and he was--. I smelled urine really bad. I said what happened? He explained to me...and he was smelling like Lysol, too...I mean his underwear was soaking wet and smelled like Lysol. Omar mentioned that in early in the morning he had little bit of an accident and the person [his one-on-one assistant] sprayed him with Lysol, because he didn't want him to smell like urine. So, he sat all day long with that Lysol spray in his bottom. So, when he came home he had burns in his, in his bottoms. I took him. I took pictures and I should have taken him to the hospital.

I didn't take him to the hospital...I gave him a bath and I the next day, I took him...I took him to the doctor and I took the, the underwear in and clearly they saw there was burns. I try to sue the school. It was his word against the person's word, that worker's word. He was terrified to go back to school. Of course, I didn't want to send him to school. They threatened me that if I didn't send him to school I would be going to jail. *I say go for it.*

What is most revealing in Elsa's narrative is the threatening statement that the school made to her. The school's statement doesn't make sense, unless the school was trying to intimidate Elsa and shift the focus on the legalities of Omar's attendance and away from her claim of abuse.

My husband was afraid of me going to jail, so he say, you go school with him. As we were going to the school, Omar was begging me not to take him school. He was shaking and crying. I say baby, I'm going to be all the time with you. You know...I'm not going separate from you. He was like, I don't want him near me...I say, he's not going to be near you.

For the next several months Elsa's advocacy would change, from speaking up for appropriate educational resources for Omar, to protecting and advocating for someone to hear and acknowledge their story.

The principal from that school saying that my son was lying. I say you telling my son is lying? You have not seen any of his chemical burns in his bottom. Oh...that could have happened anywhere [principal's response]. We don't know. We don't carry Lysol. I had gone to that bathroom and I saw there was a Lysol bottle in there. I took pictures of it. I went to the school...for like that day and then he was out for about three, four days and again they threatened me that he doesn't go to school...again, I was going to go to jail.

So I decided to call the police. You know the police, since we were outside the city limits the sheriff had to come. The principal called me a liar and called my son a liar and Omar was there. I put that lady on speaker phone and the sheriff was there and the sheriff say you know, I see the chemical burn. I see he's [Omar] the one telling me, it's not you telling me...he's the one saying what had happen in details. I tried to get a lawyer, nobody touch, would touch this.

Elsa reached out to local lawyers, but it is unclear as to why they would not take her case. In fact, the abuse that Omar experienced was similar to a child with developmental disabilities who was abused by his teacher in Fulton County, Georgia. According to the Office of State Administration Hearings in the State of Georgia, and Administrative Law Judge (ALJ) ruled that Fulton County School District denied a free, appropriate public education (FAPE) to a student with a disability, because the district failed to stop a teacher's known prolonged abuse of the student when he was in middle school and failed to inform his parents of the abuse (Chapman, 2012). In addition, the nurse at the school reported in 2004 to the principal that the teacher had sprayed a child with Lysol and placed her in the hall after she had passed gas. The court document further states that the

parents had procedural rights to be fully informed of their child's education and that the school district had violated those rights. Finally, the ALJ believed that failure to inform had in fact impeded the parent's opportunity to fully participate in the IEP process due to the parent's distrust in the district and feared further harm to their child. This was exactly how Elsa felt. Not only was Omar fearful of returning to school, but Elsa also believed that Omar was susceptible to further verbal and physical abuse. In the case against Fulton County School District, the ALJ ordered the school district to pay for five school years of intensive, integrated, home and community-based instruction to compensate the student for the five years he did not receive an appropriate education (Chapman, 2012).

What is perplexing in Elsa's narrative is her rather quick decision in not seeking a second opinion from a different attorney. Her narrative is silent of any indications of reaching out for further assistance from anyone, excluding the sheriff. Perhaps, Elsa's being taken advantage of as a child played a role in her lack of confidence to seek further assistance. Elsa was experienced at advocating at Omar's school, but advocating beyond that was out of her element. It is evident in Elsa's narrative that she lacked someone like her past "guardian angel" who guided her through difficult experiences. Finally, it reached a point where Elsa's defense was to invoke threats back at the school system, if they were unable to remove his one-on-one from him and allow him to go to another school.

So, I decided to change him to another school. They said that cannot happen. I say, yes it can happen. No, it cannot happen in the middle of the school year. I say, well, you don't do that... I'm going go to my story and put it in...you know go to the news. They got mad at me because I say that. Finally...from a Friday

to Monday, he was changed to another elementary school because *I threatened them that you don't...I was going to call the news.*

They changed his one-on-one of course...had another person...I found out that he [the abusive one-one-one] became a teacher for SSI [paused]. So Omar told me, mommy just drop it, that's fine as long as we know we telling the truth, it doesn't matter, as long as that person is not near me, I'm ok. So he started a new school and everything just started blossoming.

The core of Elsa's identity has been shaped by her efforts to advocate for Omar and his educational rights. She states, "My son is going to be treated equally as my other kids, as the other children in the world." She further believes in teaching others including her family that Omar is unique and not "special." According to Elsa, "Special is for people that are going to be treated special, different, and my son is not going to be treated special." Elsa ends her narrative by emphasizing how each life experience, whether good or bad, has taught Omar the importance of self-advocacy.

One of his [Omar] goals is for him to be self-advocate, but when he speaks up, they say that he's...not a good student...that he supposed to mind his elders. Yes, he supposed to mind his elders, but it takes respect you know to get respect and Omar throws that at the people. You want respect, respect me...*don't be quiet, don't be quiet.* You think they doing something wrong to you, speak up.

Beth

Beth began advocating for her son by volunteering and serving on various boards of organizations like the Autism Society of North Carolina that supports individuals with disabilities. Through these organizations, Beth was able to understand and become familiar with the politics of disabilities. Her creativity, passion, and determination

expanded opportunities for her son, Joey, and other individuals with disabilities to be further engaged in their community. At the ARC where Beth volunteers and serves as vice-chair of the board, she has incorporated the arts as a way of letting individuals with disabilities share their talents with others.

I like to deal with the arts and I like poetry and so I've tried to incorporate that. *Because a lot of times the disabled community gets defined by the label of their disability and they don't get defined by the label of their humanism* and so arts is a way to say no, this person is first and foremost a human who likes to paint a beautiful tree and you see the beautiful painting of the tree before you see the fact that this person is disabled and so anyway...I like to work with that.

The tone of Beth's advocacy is different from the other mothers in this study. In fact, Beth is silent about any public school experiences where the educational rights of Joey were either compromised or neglected. Beth's style of advocacy is optimistic and she sees herself impacting the bigger picture of the disability community. From her narrative, the key to Beth's advocacy is being in tune to policies, being engaged in the process, and being active in all aspects of Joey's life.

So, I finally took the big leap and left my career...to try get a job working with the school system, the [state] school system in the capacity as a teacher assistant for the developmentally delayed special needs children and I began pursuing that right when the economy tanked. So what I've been doing is doing substituting teaching at the school [where Joey attends] for special needs kids and I love it.

Of course, in the summer I volunteer...I've been coordinating the summer camp for the disabled children through the ARC and I did that last summer and I'm doing it this summer as well, scheduling all their outings and all their extracurricular activities and that was a huge learning curve for me...all kinds of things I never knew like big wheelchairs do not go in fresh poured gravel.

Beth describes her life experiences with her son Joey as a “journey.” Towards the end of the narrative, Beth becomes frustrated because of the vulnerability that parents of children with disabilities sometimes demonstrate. She counters this movement by advocating from a political social angle rather than attacking the source.

Things that frustrate me are the many organizations and institutions out there that are making a profit off of the disabled. Oh, it just irks me, especially autistic kids. When you have a child who is disabled, there’s always some government funding, CAP funding, Easter Seals funding and you get your child and you need funding cause disabled children take a lot of money, but you get funding and then immediately you’re bombarded by organizations who are going to help you spend your money and there are a lot of those that are for profit and I am very uncomfortable with that.

I think if you get financial funding for your disabled child in any way, shape, or form, I don’t care where you go, just go somewhere that is not for profit. Do not let someone make a business out of your disabled child...there are a lot of people out there who because the parent of the disabled child is going through the stages, feeling anger, remorse, rebellion, they will play on those emotions and they will take your money...*One of the things when I do go out and do speaking engagements with the March of Dimes, Civitans, or to the parents of the Rotary clubs, or whatever, and I’m also going to use my platform of the PTO at my son’s school to talk to other parents and say you know, I know you’re looking for help. Just look for it in places where people are not making money off of your child.*

Beth believes that society has become more aware of individuals with disabilities such as autism and other developmental disabilities. This awareness encourages opportunities to remove barriers and change the way people think of others who are different.

It used to be...twenty years ago when a person was autistic you know, they would, could be publicly ridiculed...now, that could still happen, but I don’t think it’s as likely. People that I encounter are much more likely...oh autism, yes I know somebody or I saw a show or I read a book or I saw a newscast and so yea,

I feel like the fact that people are more aware and more accepting of people with disabilities.

But it's still a fight... you know right now the current fight in the disabled community is to, as they say, retire the word retard. Because it has become a slang insult, just as much to the black people...hate to say it, nigger. But it's bad and we don't say that anymore. We want to get it out of the vocabulary and they're trying to remove the word retard from the collective vocabulary and I think that's a good thing. I think it's showing public awareness. I think the overall face of disabilities is becoming more accepted in our community. That's good. That is good.

The story of Beth's life as indicated in her narrative is an overarching theme of advocacy.

Beth believed in reaching out to the community in order to increase opportunities and awareness for individuals with disabilities. Her positive outlook reinforces continual belief that the more our society is aware of disabilities, less discrimination will exist.

Cindy

Cindy's journey as an advocate for her son Luke did not begin until she realized that she was allowing her mistakes to get in the way of meeting his needs. She states, "I wanted him...to have the best childhood that he could have and you know, I just felt that instantly because I did not want the child to suffer for, you know for me." Prior to her advocacy efforts, Cindy blames herself for not noticing Luke's behavioral difficulties and decides to listen to the advice of Luke's teachers to have him tested and put on medicine.

I go to school full-time and I'm working part-time on the weekends, so I put my son in daycare. Then people start saying...you know he's [Luke] not talking like he should be talking and...he's way too hyper. Have you considered giving him medicine and you know something going on with him. So, I'm like really? Then I feel really horrible because you know, I didn't even notice...I wasn't looking

where I was supposed to be looking. Cause, you know, I was looking at all these other places and I wasn't looking at my son.

So, you know we get him tested, originally in [city] and he's like three and they diagnosed him with ADHD and then they put him on medicine.

Perhaps the reason for allowing Luke to be put on medication at such an early age was due to Cindy's naiveté. Cindy reached out for advice from many professionals, including a psychiatrist that Luke saw on a monthly basis. She also took the advice of a behavioral specialist who was assigned to Luke from the school system who believed that Luke was autistic.

You know, that his behaviors, hitting, acting out, you know you could just tell. They saw that something wasn't right and Fran [behavioral specialist] immediately thought ok, you know he's got some type of autism and...I'm doing, you know, other workshops too and...in the meantime, we're still going to a psychiatrist. Fran, she was like you know, helping me and she was like, let's get him tested at [evaluation center].

It is obvious in Cindy's narrative that she was desperate for answers. In fact at this point in her life, she is following many people's advice, rather than relying on her own instincts and what she believed was best for Luke. According to Cindy, her confidence in others was necessary because at that particular time in her life, as she states, "I didn't really know any better I guess you would say." Luke's behavior in school continued to be challenging which prompted the school system to suggest to Cindy that Luke not only should repeat kindergarten, but he should also transfer to another school. Cindy agreed to the new school because she was told they had excellent special educational resources.

At his first school, I think you know was substandard, because I think many times they were not trying to teach him anything. They were just there. They would just let him kind of do whatever. They weren't really trying to teach him, you know, and so many things were going on and somebody I think should've seen more of what was wrong.

Like he [Luke] couldn't stay in the lunchroom because of all the stimulus. He couldn't do it. So they were, you know, bringing him in a room by himself and letting him eat and I'm like...don't you think there something wrong with that...I just don't think he got the help that he needed.

Cindy's patience was wearing thin from the advice of the professionals. Luke remained on the waiting list at the Evaluation Center, while Cindy stepped up her level of advocacy of awareness by observing Luke's developmental progress more. Much of Cindy's early advocacy was engaging with the school's development of Luke's IEP plan and reinforcing behavioral strategies at home. However, Cindy admits she was unsure if she was applying the behavioral strategies correctly. Midway through Luke's second year in kindergarten, the Evaluation Center called to evaluate Luke. Cindy thought the evaluation would bring closure to Luke's undiagnosed disability and would help him progress further with specific strategies to meet his developmental and behavioral needs.

So we go to [Evaluation Center] and so I was just so unhappy with them because really all they did was talk to me and they talked to Luke and they did not do, you know, they didn't do any test. They didn't do any evaluations for autism. They didn't do anything.

Even though Luke continued to have difficulty in school, his new school decided to promote him to the first grade anyway. Cindy's frustrations continued to mount,

especially since the Evaluation Center did not diagnose Luke with autism spectrum disorder (ASD), but rather with a low IQ and a mild developmental disability.

The setback of the diagnosis from the Evaluation Center did not deter Cindy's advocacy for Luke to remain in an inclusive educational setting. By Luke's second grade year, the IEP team believed Luke would benefit from additional time with a special education resource teacher. Unfortunately, the additional time meant that Luke would attend a third school and be placed in a separate setting.

Everything went wrong in second grade. The teachers, I don't think they were trying to help him...*I think he got suspended like fifteen times* and I think that's because they didn't really know what to do with him and so they just called me and I just came and picked him up...So anyway, I don't know how many meetings that I have had with the principal, with the teachers, or the Special Education teachers at the IEP meetings.

I remember calling meetings, going and talking to the principal and you know saying something's not right, something's going on. We have to do something because he keeps getting suspended. This is not good and she's like, well, I'm not an autism expert and I'm like, well, you know I'm not either, but somebody in this county is. So somebody needs to be here for a meeting...you know that just really frustrated me.

Cindy's advocacy eventually led her beyond the school system for help. She reached out to Monarch, an agency that supports individuals with disabilities and their families.

Monarch assigned Luke a case manager, who immediately advised Cindy that Luke needed intensive in-home therapy. The case manager also believed that Luke showed autistic tendencies and wanted him re-evaluated at the Evaluation Center. The support that Cindy and Luke received from Monarch was a huge boost in confidence.

I was talking to his case manager, she was very good. She was you know, she was, like I see autistic tendencies off the bat. Well, I'm like you know, me too and I was like, let's get him tested again because [Evaluation Center] said he wasn't. So we did and finally we got the diagnosis of...mild mental retardation, ADHD, anxiety disorder, and aspergers, autism.

So I was like, *you know it is devastating to hear that*. At the same time, you feel validated because you're like, I knew, I knew something wasn't right because you're telling me to do these things and they're not working and you're looking at me like, I'm not doing what I'm supposed to do and I am.

Through the help of Luke's case manager from Monarch, he was able to get twenty to thirty hours of CAP services that included intensive in-home therapy and respite care.

While Luke's official diagnosis of autism spectrum disorder was a relief to Cindy, it presented new challenges to Luke's school. These challenges became more difficult and were not embraced by his teachers or the administrators at his school, especially after Luke hit a teacher assistant. In fact, the assistant from the school filed assault charges against Luke.

So yeah, *I was like really upset and surprised and shocked* that she would do that to him [Luke] and he was eight-years old at the time... You know, so I go talk to the principal, which actually ended up talking to the assistant principal...but I just remember like talking to him about what can we do. It's like you go straight to the court system. He didn't say, let's have a meeting. Let's see what else we can do. Let's bring in the social worker from school. Let's do something instead of running to the court system...he hit a teacher in the face and we're not equipped to handle that and I'm thinking, well, why did everybody tell me to bring him to this school?

The statement the assistant principal made is a common excuse that is often repeated when the educational rights are not enforced for students with disabilities. The school

system could have assigned a specialist similar to the one that was assigned to Luke during his kindergarten year to reinforce behavioral strategies, but instead they intimidated Cindy by using fear.

Well, he had already had you know the fifteen suspensions and then, you know, he saw the doctor maybe once a month or once every two months...then the principal tells me after...the assault charges that if he misses another day of school, they're going to take me to court for truancy and I was like are you kidding me.

In less than four years, Cindy reached a point in her life she believed the public school system was more of a hindrance to Luke rather than a source of help. She also feared the school may file additional assault charges if another incident occurred, which she believed possibly could prompt the court to have Luke removed from her home. Ultimately, fear consumed Cindy to the point where she decided to home school Luke, while continuing to receive support services from CAP and Monarch. At this point in Cindy's life, she made decisions as to what she believed was best for Luke, rather than listening to the advice of someone else.

I just think I'm where I'm supposed to be... doing the right thing and it's not what I expected to be doing, but I think it's what I need to do for Luke...I mean, you know I've had people all along telling me he shouldn't be in the home. He should be somewhere else and I'm like no, he's going to stay with me because he's my son...but that is my worst fear that somebody's going to take your child and then you know to a place like that, all they're going to do is drug him up so they don't have to deal with him.

Perhaps, Cindy's early life experience of going to court to gain full custody of Luke was a contributing factor in the overwhelming fear that Cindy felt. Cindy's identity as an advocate for Luke has been as she describes a "roller coaster ride." In the early part of Cindy's narrative, she admits to overlooking Luke's needs and relied on the advice of professionals. By the end of her narrative, Cindy saw herself as a strong advocate for Luke relying on her faith to provide her with the confidence she needed to help Luke meet not only his developmental needs, but also his emotional needs.

What makes me an advocate...maybe is just that I felt that sense of responsibility and I think every parent does have. They should. I just think that I'm being a good parent, you know.

Dora

Throughout Dora's narrative, her questioning of her faith, the meaning of her life, the why of her children's disabilities is just a glimpse of her existentialistic nature that I found to be very revealing and fascinating. In fact, in my earlier section, Identity Shaped by Suffering, Dora's narrative reveals her existentialism from the trauma she experienced in the birth and death of her children. Dora's advocacy didn't begin until she realized that she needed to allow her mind, as she states, "to snap out of it" and be "renewed again." The selectiveness of these statements emphasize that the health and well-being of her son and daughter was dependent on Dora's emotional, mental, and physical stability. With a renewed mind and spirit, Dora began to focus more on advocacy by becoming the expert on her children's disabilities.

I didn't know anything about Down's Syndrome...I mean you know, I knew people like that and they couldn't do certain things the way you and I do, but I didn't know anything. I didn't know how to feed her. I didn't know how to hold her...I started you know reading all these books and reading everything and going places...and I got into the computer and I said ok, how, who?

Anyway, so [crying] I got more informed...and involved with the, you know, the other moms that have Down's Syndrome [children] and are going through the same thing.

During the majority of Dora's interview, she appeared emotionally drained from telling the story of her life. The experiences of suffering that she shared in her narrative and the birth of her children with disabilities evoked many sad memories including how society reacted to her daughter's disability.

You know what...really was hard for me was all the people look at me at the mall, like when they [Marco & Arlene] were little. When Marco starting to walk or they were looking like it was my fault, you know [crying], I say no...I have to do something about this...They see Arlene has Down's Syndrome...like you must have done something bad or better you than me. You know what is the point? Like, that's how I felt and some people, really I mean they...they just look like or how old were you when you had him.

The looks of the people that they give us, mostly Arlene. They like wow, ooh! You know that kind of looks and I'm like no, no, that has to change! Something has to be done, and so you know, I think for me to advocate for them is to...to show the world that it's ok.

Much of Dora's advocacy after the birth of Marco and Arlene was focused on educating and demonstrating to society that children with disabilities are loving, intelligent, talented, caring, and deserving of experiencing the same things as normal children. Dora admits that the "stares" or "gazes" coming from individuals negatively affected her in the

beginning, but as time passed she viewed their curiosity as a lack of knowledge, rather than being rude.

My daughter goes where I am going and I show the people and I think very simple way to advocate for her...not so much for my son because you see him, you see him normal, you see him typical, but for my daughter...I take my daughter anywhere I go, anywhere! I think this simplest way to advocate for her. *The easiest is when I, when I treated her with respect in front of people.* You know, like when we're in restaurant and she starts to yell or throwing things. You know it doesn't matter, this is my daughter and I give her a lot of love and I'm always hugging her and my son, too.

I always like to have contact with them and when I see people, like when I'm doing that in the restaurant or wherever, they like, you know, this is kind of weird. All kinds of looks and you know for me, is teaching them this is okay. I mean what is the difference? It's just you know, maybe she don't know how to count like your daughter...but you know she still has it right and when she doesn't have it right, I will give it to her. I mean, she's my daughter.

Parents of children with disabilities who have experienced rude behavior from the public (Ryan, 2010) often decide to leave their child at home rather than face humiliation.

However, some parents believe in changing society's perception by giving out literature, labeled t-shirts, or using identification badges that explains their child's disability (Ryan, 2010). In Dora's case, she chose a more direct approach.

I noticed the first time. I noticed a lot of people don't bring out the kids. The special kids, they don't take them out. Like, I said where are all the people with Down's Syndrome? There so many kids with Down's Syndrome, where are they? I don't see them at the mall. I don't see them at the fair. I don't see them at my church. I mean...the people take their dogs out to the mall. Their dogs and they don't take their kids, you know. I don't see kids with special needs like you know, interacting with other kids and I don't know...it's just and I know they're there somewhere.

So I decided to make a point to take my daughter wherever I go...anywhere I go, you know, *not try to disguise or, or hide what she is*. You know, she has Down's Syndrome and...let's talk about just Down's Syndrome...they need to be educated. Many people don't mean any harm.

Dora's confidence in advocating for her children was not hindered by the public's perception in the least. In fact, Dora's advocacy was enhanced by interacting with the public and attending conferences on her children's disabilities. The information she learned at the conferences helped Dora become an expert on her children's disabilities and taught her how to advocate and communicate more effectively within society, the public schools, and with her children's therapists.

Another way I advocate for them [Marco & Arlene] is you know, like the Down's Syndrome association...they give us a lot of information, like conventions to know how, you know, how to train the tongue so it doesn't pop out or whatever...how to walk better because they cannot walk fast.

Like when I go to my child's school, Marco, I say you know what, I go eat lunch with him and then I see they put him in a chair that he sit like...I say no, he doesn't need to bend over...physical therapist, say no, no. Look at him, I mean just look at him. He sits like this...He can't...He doesn't have much trunk strength. Say, he needs to be in one where he's like this. I mean, we need to work on that. You want me to bring something or and they kind of don't like when I say things like that, but I don't care.

Dora's style of advocacy is unique. She has a very hands-on approach and is not afraid to share her knowledge with others. Her statement, "you want me to bring something," demonstrates her creativity and willingness to design a chair that was more appropriate for her son.

The people [professionals] that go to school, they don't tell us anything like, what can I do to Arlene so she can walk better. Well, she'll walk better when she gets older. No, No, No! Let me see what I can do and we have to find out through the internet. We have to find out through other parents. We have to just do it ourselves. Ok, maybe if we stretch this way or maybe I have to read a lot of books.

You know, I came up with the little thing she, she, she goes likes this walking. So, I kind of sewed together, like pants so she can't open the legs. So that's working a lot better. She walks much better. I mean nobody told me that and it's something simple and people who go to school...and then I thought ok, I didn't go to school to study that...I think that you know, its more that you put your heart in it and it comes to you. So, I have to read a lot of books. I have to read a lot of this.

Parents, who advocate like Dora, have an acute awareness of how to meet the needs of their children. Dora exemplifies her awareness through examining and engaging in her children's education and therapies. Dora's strong commitment earns respect rather than demands respect from the professional community, which is key to the success of her advocacy. Dora believes in sharing her advocacy skills with other parents of children with disabilities and encourages them to be fearless when speaking up for their children.

I think that, like if we open the eyes of the people, the parents, for example, that had a special kid...if we open their minds...let's say, ok you have a right to say...it's [child] still a human and you can say, I want this many times of therapy because this is the reason...I think, not a lot of parents are advocates, but it's not because they don't want to. I think most of them is because they don't know how and they don't feel that they have the power to say it. Like who am I...really or ok, can I say that, or can I ask for one more day of therapy.

Toward the end of Dora's narrative, she states, "The kids are the ones that's going to have to face it, the world." Dora never explains what "it" is, but perhaps for Dora and

other parents of children with disabilities, “it” refers to society’s continual ignorance, lack of compassion, and lack of understanding of the needs of individuals with disabilities.

Finally, Dora’s advocacy for her children kept her grounded, committed, and focused on being prepared for the future, whereas earlier, existentialistic thoughts kept her questioning the past, her faith, and the reality of her circumstances.

Lisa

When I think of Lisa, I think of a captain of a ship navigating through the rough waves of the sea, a captain who steers through storms and around storms, a captain who understands every detail of his ship and his job, and finally a captain who is not afraid to face the unknown. Lisa is used to navigating through storms, as we learned in my earlier sections, *The Experience of Abuse*, *The Experience of Divorce*, and *The Experience of Disability*, yet Lisa never once complained nor abandoned her goal. She faced each storm with an optimistic attitude and was resolute in finding solutions. Lisa’s longest journey has been advocating as she explains, “in what I believed in, whether it was in my personal life or in any other child’s life, especially my son.”

Lisa’s advocacy for her child began at the moment she realized that her son Tate, who was born prematurely, responded to her voice while he remained in critical care in the Neonatal Intensive Care Unit (NICU). Lisa approached the hospital with a desire to be hands-on during the critical stages of Tate’s life. The fact that Lisa advocated to be physically engaged with her infant son while he remained in the hospital encouraged other parents to want the same opportunities. As a result of Lisa’s advocacy, NICU

policies would eventually change at the hospital, allowing mothers to hold their babies during the early critical stages of their child's life.

So, I sat beside his bed and started humming and singing and when I wasn't there playing, playing a cassette tape. Well, one of the nurses noticed that his TOM, the oxygen meter reading, whenever I would talk to him and or when I wasn't there, I would leave a tape player on of my voice, that Tate's oxygen meter reading was higher, even though he was on a ventilator his little cheeks were redder, and...they were saying, it's like when you get embarrassed or you get real red, that you've got more oxygen circulating through your body and then if you're cold or you're shocked, your body doesn't oxygenate as well, you get that grayish color. You get pale and they were noticing that as I was talking to him, she [nurse] was showing me how the different things worked that he was understanding... that it was my voice and so I even stayed there even more.

He was wired everywhere...they had blood...because they have to stop and start different IV's and what not and...I am well, why can't I pick him up? I've never held my son. Why can I not pick him up and hold him and you know, I know it's not going to be the same kind of hold, but...well they said, we'll ask the doctor. So they asked the doctor. So the doctor said, yes, and so other parents saw me hold Tate, so they starting saying, why can't I hold my child. So they started changing NICU rules, that was in 1986 about involving parents more in the care of their children.

Lisa's intuition played an important role during the early stages of advocating for Tate.

She sensed deep down that Tate, even with his continual need for oxygen, a nasal cannula, and a feeding tube, would flourish *in her care* rather than in the hospital.

He had a hundred foot oxygen cord, but they said they'd never had a parent so determined to get their child at home and I kept saying, *just let me get him home*, he'll be so much better...I just kept on and on.

He was on the ventilator for two and half months, so I became his little advocate from the get go, in the hospital and then we took him to the doctors to see what they thought might be wrong and the doctor...he just came right out and said that

he was totally blind and I got him an appointment at [-] Hospital for you tomorrow.

At the point Lisa discovered that Tate was completely blind, her narrative is silent of life experiences with Tate until he reached three-years old and became eligible for services with the public schools. Lisa's advocacy experiences are also silent during those years, until Lisa was told that Tate would have to attend the School for the Blind, rather than attend a nearby regular preschool program within the public school system.

I said that doesn't make any sense whatsoever. So, I contacted my doctor and said do you know of any other children that are visually impaired and he said yeah, but I can't give you their name and I said that's ok, you give them my name and tell them that I'm having a meeting at the library and I made up a little flyer and went from there and started the first parent support group.

With her support group by her side and after learning her rights as a parent through the National Association for Parents of the Visually Impaired, Lisa lobbied her state's General Assembly to add additional preschool programs for children with visual impairments. Lisa's advocacy and determination had reached a political level where she received support from various individuals and groups, but also encountered critics along the way.

I mean I literally took them [children] to [city] and *practiced saying to Senator Right* that I needed school, because I got an anonymous phone call, if you bring the children to [city], this bill that's before the Senate for the preschool programs might just pass and people were calling the town wanting to know what it would do to take me to shut up.

And so we started...we got funding. [University] gave us the building and the office space for the classroom and the parent support group, we did enough fundraising that we got the playground equipment and then the local Lion's Clubs and anybody else I could write, electrical energy companies, whatever, donated money. They bought, like the microwaves and the furniture and the adaptive equipment, any of that kind of stuff.

Lisa's resiliency and hard work produced successful results, enabling Tate to become completely independent in the preschool setting. However, for Lisa, the barriers that existed within the K-12 public school environment proved to be very challenging and required persistence in advocacy.

It was time to go to the public schools and by then they were letting them [children with visual impairments] come into the school and I have never had such a hard time of advocating my entire life...so anyway, so here we are, we go to the public schools and then they have him in a basement. He was able to go to the bathroom by himself. He was able to do all these things and they put him in a basement and they put him in and where you had to go down around the building...the kids would have to come down the steps here and then trail along the side of building and then there would be this big drop off...No handrails, nothing, no nothing...and I said you guys got to be crazy.

Well, they had one other child that was there that was one year older than Tate and his mother never complained, she was just very thankful that he could come to the public schools, and so from then on I was noted as a parent that was never satisfied, that I always complained and was always bucking the system to get what my child needed.

Although Lisa shares that the public school experience challenged her advocacy the most, Tate's inappropriate kindergarten classroom setting would be the only public school experience that Lisa shares in her narrative. It is unclear as to why this is the only experience she shares, however, the selectiveness of this experience sheds light on two

related issues revealed within this context. One, parents of children with disabilities are often complacent when it comes to the decisions that are made within the public schools. Second, parents of children with disabilities often do not speak up because they do not want to be perceived as troublemakers (Trainor, 2010). There is no indication in Lisa's narrative that she perceived herself as a troublemaker, but rather a mother who advocated as she states, "against the school system for what [I] thought was right for Tate and as well as for other students."

Advocacy for Others

I discovered in the narratives of Sara, Lisa, and Beth that their advocacy has not only impacted their own children, but also other parents of children with disabilities. For example, Lisa and Sara both have careers in which they are able to support and advocate for children with disabilities. Lisa works as a visually impaired itinerant teacher and mobility specialist in the public schools. Sara works as a parent advocate and quality management coordinator at a non-profit organization that supports people with intellectual and developmental disabilities. Both mothers have used their advocacy skills to educate and inspire other parents. Lisa states, "I feel like I have enabled and invited other people to step up to the plate." In fact, Lisa encourages all of her students' parents to learn Braille so that they are able to transcribe their child's homework. The parents of two of her students became Brailleists and worked for their local school system, while another parent became Lisa's teacher assistant. Lisa's bravery to speak up and take action was contagious. Her commitment to advocacy is unstoppable. Lisa's latest advocacy project is again political. Her son, Tate, who is now in his twenties, wanted to

become more independent in daily living skills, and has traveled to California to acquire the skills through a special program. According to Lisa, her residing state lacks such a program and would rather “pay for someone to come to our house for three hours a day to cook for him, to bring groceries to him, but not to teach him to get his own groceries, do his own cooking or any of those skills and so we started advocating.” Eventually, Lisa’s residing state paid for Tate to attend the independent living facility for three months in California, but Lisa is advocating for funding so other students from her state can attend the program as well. Lisa does not clarify in her narrative why her state lacks an independent living program. However, I wouldn’t be surprised to see a program similar to the one in California in the near future, due to Lisa’s vision and advocacy.

Finally, Beth’s advocacy has also attained new heights within the disability community by volunteering as a parent advocate at the ARC. She has plans to get a job as a teacher’s assistant at the school where her son attends. Each of these mothers are confident in their abilities, are knowledgeable of the political and social challenges, and are unwavering in their continual efforts to create a better community and a better world for their children and for other children with disabilities.

Summary of *Advocacy*

Advocacy is the core of all the mothers’ narratives. The stories shared by each mother identified their unique style and understanding of how to advocate for the needs of their child. Lisa chose a more political direction to advocate for her son, while Dora’s approach was more hands-on. We learned through the mothers’ experiences that advocacy can be challenging, especially when each mother sought to protect the rights

and freedoms for their child. For example, Dora and Elsa faced language barriers which hindered their advocacy, however, it did not silence their voice. In fact, many Spanish speaking parents of children with disabilities feel that while they want to be involved in the educational decisions of their child, they are silenced or marginalized by what Silas (2004) refers to as overt or covert messages that imply their opinions are not valued.

Finally, we learned that social and professional intimidation, negative remarks, life threatening medical diagnoses, and educational discrimination motivated the mothers to advocate for their child. The mothers in this study overcame the shock of their child's diagnosis and the intimidation of public school officials. They learned how to educate people that stared at their children in public places and how to transform the political landscape.

CHAPTER VI

CONCLUSION

This study has examined the identity of parent advocates through their life experiences. In this chapter, I discuss my summary of findings and themes that emerged as they relate to the questions guiding my study. Finally, I discuss what advocacy strategies the mothers shared in their narratives that can help other parents of children with disabilities, my proposed design of a parent school advocacy plan (PSAP), limitations of the study, implications of the study, and participant summary of themes.

Question 1. What are common life experiences of parent advocates?

Some of the common life experiences among the participants in this study are:

1. They identified early life experiences that exposed acts of *suffering*.
2. They shared experiences where *family* played a role in their life.
3. They identified life experiences where seeking religious *faith* was a source of strength and stability.
4. They shared life experiences that uncovered their identity as *mothers*.
5. They shared life experiences that demonstrated *advocacy* skills prior to and after the birth of a child with a disability.

Acts of Suffering

Suffering is an universal experience that all individuals face at some point in their life. According to Black and Rubinstein (2004), many individuals when describing their life story, lack the ability to share experiences of suffering, thus leaving their narrative interrupted or silenced at the point in which the suffering occurred. This type of narrative experience did not occur with the participants in this study. In fact, the findings from my analysis suggest the narratives of the mothers in this study shared acts of suffering, such as death, abuse, and divorce, but each mother spoke differently when describing the experience. For example, Lisa and Cindy when describing the abuse they suffered spoke with a fervent voice that demonstrated a strong inner resiliency, whereas, the suffering that occurred in the lives of Dora and Elsa was expressed with a passionate voice that was often interrupted by tears and pauses. While the mothers expressed their suffering differently, understanding and giving meaning to their suffering were significant to their individual identity as an advocate. Lisa illustrates my point when she refers to her suffering as a source of strength in her advocacy.

I mean, you know...all the things that happened to me and being able to stand up...to advocate for what I believed in.

Black and Rubenstein (2004) state that stories of suffering can reevaluate and reintegrate the self. The findings in my study suggested that experiencing suffering in one form or another reintegrated the self in the mothers and also left a lasting impact on

their individual identity. The mothers in this study breathed life into their experiences of suffering by sharing them in their narratives. In fact, Lisa and other mothers in this study used the experience of suffering as a source of motivation to develop a resilient voice of advocacy for their child and for other children with disabilities.

Role of Family

The findings from my study indicate that *family* can affect an individual's identity. We learned in the narratives that family was a source of love and protection, a backbone to face exceptional challenges, and a voice of reasoning. The opportunity to share their life experiences gave these mothers a sense of connection to their roots, where memories of their family provided them with joy, dreams, and hope, but there was also experiences shared that were painful, like the abuse Lisa endured or the absence of Elsa's father in her life.

What was also revealed in the mothers' narratives was the absence of their husbands in sharing the life experiences of having a child with a disability. The mothers' narratives focused more on their role as the primary advocate and caregiver for their child. The absence of their husband from the life experience of the day-to-day care (Simmerman, Blacher, & Black, 2001) may have affected the mothers psychologically and emotionally. What was present in the narratives of Dora, Cindy, and Elsa was an appreciation of their husbands' support in their decision to be stay-at-home mothers and rely on their husbands as the primary financial provider for their family.

The findings in my study indicate that each mother's identity as an advocate for their child continues to change based on life experiences. Yet, while their identities are

continually being shaped, the role of the family experience whether good or bad, surface in the mothers' narratives when decisions, actions, or positions are made on education, health, and finally their role as advocates.

Religious Faith as a Source of Strength and Stability

The mothers in my study were no strangers to expressing their *faith* in God. The findings in my study suggest that religious faith was a source of strength and stability, provided hope and clarity, and generated meaning and purpose in their life. The mothers in my study experienced their faith in God during extraordinary circumstances such as the birth of a child with a disability, or near death experiences as expressed in Sara and Lisa's narrative, or during life transitions as expressed in Cindy's narrative. Faith helped shape the identity of the mothers which is grounded by early life experiences as well as their trust that their lives were "sanctioned and supported by God" (McAdams, 2006, p. 135).

Religious faith not only was an important facet in the development of the mother's identity, it also aided the mothers in gaining an understanding to the complexities of life (King, 2003). This perspective is illustrated throughout Dora's narrative, especially during experiences where she relied on her religious faith to counter her own existential questioning.

I learned in the narratives of the mothers that faith was personal and present in their life. Faith provided them with a sense of security and direction in coping, managing, and facing the challenges of having a child with a disability. Finally, the findings from my study identify the mothers' religious faith was a source of explanation,

and provided hope and reassurance in having a child with a disability. Statements from the mothers like, “God gave me this child for a special reason,” or “I feel like God did give me Luke for a reason” illustrates my point.

Identity as a Mother

From my findings, each mother shared life experiences that embraced their role as *mothers*. For example, Dora who at first questioned God after giving birth to two children with disabilities, honored their individuality as human beings, instead of looking at their births as a regret.

We also learned from the narratives that each mother possessed different maternal instincts, fostered by early life experiences. Lisa, for example, possessed a protective instinct at an early age that easily carried over to her adult role as a mother of a child with a disability. Beth’s identity as a foster mother, prior to the birth of her son, demonstrated selfless care for children as a central theme to her life. Cindy described in her narrative that motherhood was a gift from God which should not be taken lightly.

The findings in my study suggest that the mothers reoriented themselves after learning that their child was born with a disability. Their maternal identity merged with their already existing identity, providing them with the strength and resolve to accept a more challenging role as a mother.

Demonstrated Advocacy Skills

The mothers in my study recounted experiences where *advocating* was an important part of their identity as a child and as an adult. The findings suggest that their willingness to stand up and fight for a cause was an innate part of who they were as

individuals. The mothers had a history of volunteering and being engaged in their children's education, identifying community resources, and supporting disability awareness.

The mothers were self-learners who became familiar with the educational system, educational laws and policies, and educational opportunities. The mothers also learned that ableism can exist within our schools as evident in the experiences revealed in the mothers' narratives.

From the mothers' narratives, you could easily identify these mothers as leaders within their churches, schools, and community. For example, they possessed leadership skills that gave them the ability to network for social and policy change, to hold positions on various boards including organizations like the Autism Society, the ARC, Parent Teacher Associations, or the National Association for Parents of the Visually Impaired.

The mothers in my study maintained a positive spirit to create the best learning experience for their child and in the process improve learning opportunities for all children with disabilities. Finally, the findings from my study suggest that the mothers understood their role as an advocate is ever changing and ever increasing due to the demands that society places on individuals with disabilities who continue to be discriminated against and are marginalized.

Question 2. What do parents of children with disabilities advocate for?

The parents in this study advocated for:

1. Identifiable disability diagnosis
2. Appropriate, attainable, equitable, and individualized education
3. A safe educational environment
4. Expanded life-long learning opportunities beyond public education
5. Timely medical diagnoses
6. Supporting resources within public schools and the community

We learned in Chapter V, *Identity Shaped by Advocacy*, that the mothers in my study began advocating at different ages, for different reasons, and with different outcomes. Based on their narratives, my findings indicate the mothers were not initially trained in how to advocate. They were not surrounded by adults who were advocates and served as role models. They lacked the professional discourse in advocacy and finally, they lacked knowledge on advocacy. While many parents of children with disabilities find personal obstacles such as those mentioned above as a reason to not advocate, the mothers in my study did just the opposite. Each mother in my study had the courage to speak up and the confidence to engage in the community of professionals.

Mark Mlawer's (2012) article "Who Should Fight?: Parents and the Advocacy Expectation" argues that parents of children with disabilities that are "forced into the advocacy role" (p. 106) by school systems are really creating a more difficult life for parents of children with disabilities. Mlawer (2012) also claims that parents are not

always empowered through school workshops and literature on how to advocate, rather they should be guided by a philosophy of normalization where the parent assumes their role in as “typical a manner as they desire and as is possible”(p.107).

While I agree with Mlawer’s point in the article that advocacy for children with disabilities is frequently needed, I disagree with his view that parents of children with disabilities should just assume the normal role of parenting. I also do not believe that parent’s lives would be more difficult if schools required and provided advocacy training. In fact, parents who do advocate find it as a coping strategy reducing their stress while increasing their quality of life (Wang, et al, 2004).

Finally, I have been a public school teacher for over nineteen years and I have never heard of a school or school system within my state that trains parents of children with disabilities on advocacy skills. Consequently, the voices of parents of children with disabilities in my professional experience have been silent and are continually replaced by a non-collaborative authoritative voice.

Question 3. What experiences and or motivations lead parents to advocate for their children but also for other children with disabilities?

The parents in this study were motivated to advocate for their child and for other children with disabilities because:

1. They received misguided medical diagnoses.
2. They recognized and experienced inequity and unsafe practices in public school education.

3. They learned from school experiences they could not trust the professional including school administrators, classroom teachers, one-on-one assistants, and related service personnel.
4. They received offensive and ableistic remarks from members within society and the professional community.
5. They have a desire to educate society on their child's disability.
6. They want to encourage advocacy within the disability community.

Graham and Weiner (as cited in Berliner & Calfee, 1996) define motivation as the “study of why people think and behave as they do” (p. 63). In my research, I have learned from the mothers' narratives the specific things, as listed above, which motivated the mothers to advocate for their child. I also learned that motivation was used as a tool to create life experiences where they could engage, participate, and understand the outcomes. Due to the mothers' motivation, my findings indicate that decisions were made, resources were contacted, meetings and conferences were attended and books were read, subsequently changing the focus and direction of their advocacy.

The findings from my study indicate the mothers in my study were motivated to advocate for their children and for other children with disabilities for safe and quality learning environments, timely medical information that could improve their child's quality of life. For example, Dora was adamant in changing society's perception of individuals with disability within the community, including malls, public libraries, recreational parks, and restaurants. The mothers in my study were also motivated to

advocate because they found other children with disabilities in the same situation as their child.

While some parents may have difficulty sustaining a motivational reason to continue advocating, the mothers in my study continued to be fueled by an ever-changing system of ableism in education, acts of continual discrimination in society, and a desire to improve the quality of life for their child's future.

Question 4. What are the barriers that prevent parents from advocating?

The barriers to advocacy as expressed in the parents' narratives were:

1. Lack of knowledge of medical and disability diagnoses
2. Lack of educational degrees
3. Feelings of incompetence
4. Complete understanding of the English language (i.e. English terms used during an IEP meeting)

The effectiveness of parents acting as advocates for their children is logical, practical, and natural. Parents understand their children better than anyone else, and most maintain a close relationship with their children throughout their life. The mothers in my study represented a source of advocacy that is constant, while professionals can be seasonal and disposable.

The findings in my study indicate that while the mothers desired a role as an advocate for their child, they faced barriers such as those listed above that made them question their abilities. Most of the barriers that were expressed in the mothers'

narratives, other than an external barrier shared in Lisa's narrative, are what I call internal barriers. I chose to not list Lisa's experience as a barrier, because it did not hinder her ability as an advocate. In fact, Lisa became more determined to remove the external barrier through social and political means of communication.

There were many occasions where I sat in IEP meetings, prior to the arrival of the parent, and the conversations amongst the professional educators consisted of blaming the parent for their child's difficulties in school, rather than strategizing on how to help the parent. The tone of those meetings, needless to say, did not encourage parents to speak up and act as an advocate, rather the parent was reluctant to engage in conversations and sat quietly listening to decisions made by the school. This type of behavior during meetings can produce doubt in a parent's mind as to their desire or ability to be an advocate.

The findings from my study suggest that internal barriers like feelings of incompetence or the ability to understand the language used during professional meetings, can be counter productive and hinder a parent's ability to successfully advocate for the needs of their child. I also believe internal barriers are the hardest of barriers to overcome, due to their emotional and psychological impact on the parent's self-belief. Finally, while the mothers in my study experienced barriers to advocacy, they were short-lived and it did not have a long term effect on their future abilities as an advocate.

Question 5. Why should schools teach parents how to advocate?

The answer to this question in my opinion is simple. Schools that teach parents how to effectively advocate for their children are ensuring that parents and their children

have a voice and are fully involved in the important decisions made regarding their child's education, while in the process establishing a supportive and non-authoritative environment. In addition, by having parents serve as their child's advocate, schools are held more accountable for the individualized educational programs (IEP) that are designed to meet the needs of the child.

While schools may state they desire increased parental involvement and parent advocacy, they contradict themselves by lacking a parent advocacy or parent involvement plan. School curriculum nights, parent conferences, music performances, spring flings, and IEP meetings all serve as a vehicle in getting parents to schools. On the surface, these programs or meetings make it appear that schools are involving parents, but in my opinion they actually are not. At most of these meetings or programs that I have attended as a professional educator over the course of nineteen years, parents sit back and watch and listen instead of being engaging participants. I refer to this type of school behavior as an "educational mirage" that exists four to five times during a school year.

Question 6. What can schools learn from parent advocates?

Schools can learn from parent advocates by:

1. Listening to parents' knowledge, awareness, and understanding of their child's emotional, physical, cognitive, and developmental needs, strengths, and weaknesses
2. Collaborating with parents and their connections to community resources that can offer educational support

3. Adopting behavioral and educational strategies in the classroom that are designed and used by parents in the home setting
4. Listening to parents' honest feedback

I strongly believe that school professionals and parents of children with disabilities must work as a collaborative team in order to improve the educational success of the child. It has been my experience as a professional educator, as I have stated throughout this study, while schools acknowledge that parents are important stakeholders in their child's education, schools do not always seek parents' "active involvement, expertise, connections, and especially, leadership" (Carter, Swedeen, Walter, & Moss, 2012, p. 10). What is important, especially for schools that serve children with disabilities, is to incorporate the knowledge and expertise that parents of children with disabilities can provide. According to Henderson and Mapp (2002), "When schools build partnerships with families that respond to their concerns and honor their contributions, they are successful in sustaining connections that are aimed at improving student achievement" (p. 8).

The mothers in this study were more than willing to collaborate with their child's school in order to help them gain a better understanding of their child's needs, however, in some cases the schools not always welcomed the parent's input. For example, after several visits to her son's school, Dora reached out to the school in an effort to improve how Marco was sitting in his chair. Her recommendations were based on her research and knowledge of cerebral palsy, his physical development, and observations made from

their home setting. Evidently, Dora's knowledge of her son's needs was not welcomed because she stated that the school, "kind of don't like when I say things like that." In this example, it appears the school was unwilling to listen to Dora's advice, thus furthering the distance between themselves as collaborative partners.

Parents of children with disabilities like the mothers in this study want schools to listen to their opinions, acknowledge their information, and respect their input. In fact, I believe that parents of children with disabilities are the experts on their child and have a wealth of knowledge that is worth accessing. There is not an easy solution to eliminate existing barriers in schools that prevent collaboration. However, it begins with a change in the attitudinal atmosphere within schools, as well as changing preconceived thoughts of parents, where school professionals are not looked at as their enemy, but are on their side and are doing the best they can for their child.

Parents' Demonstrated Advocacy: What Can Other Parents Learn?

In this dissertation, there was a landscape of passion, courage, sadness, anger, fear, and joy (McAdams, 2006), that unfolded in the stories that the mothers shared. Statements like, "I don't know why we were easy targets," "I really had that fight to make it different," "I say God, let me remember his face," "I was devastated," "I kind of got my fighting spirit back," "The lion [in] me came out," and "I have never had such a hard time of advocating my entire life" are all representative of the mothers' suffering, their adversity, and their setbacks. However, the mothers in this study have moved forward, have picked up the broken pieces, and have become victors instead of victims.

There were stories represented in this dissertation that other parents of children with disabilities can relate to, draw on for encouragement, and can learn from to bring about their own advocacy, as evident in the following strategies that the mothers used.

(1) Persistent Phone Calls & Cell Phones

Making contact by phone and being persistent makes known the seriousness of the situation. Sara, in fact, did just that. She states, “I started calling the mental health center. So I started pushing and pushing and within three months we had him in that program.” Elsa used the phone to call the sheriff to report her son’s abuse by his one-on-one. She then placed the principal on speaker-phone so that the sheriff could hear the principal’s comments. Elsa does not indicate if she used a cell phone during their conversation, however, cell phones are a great source of documenting and accessing quick information. With advanced technology, cell phones can aid the advocate by providing speaker phone, camera, digital recorder, and video capabilities, as well as access to the internet.

(2) Access the Internet and Informational Books

Becoming an expert on your child’s disability establishes confidence, knowledge, and can provide the ability to discern critical medical information. For example, after learning that her daughter was born with Down’s Syndrome, Dora began seeking information about her child’s disability through books and the internet. Her desire to become an expert on her child’s disability was evident as she states, “I started you know reading all these books and reading everything...and I got into the computer.” Accessing

information and becoming an expert on your child's disability is important in your role as an advocate.

(3) Volunteering, Attending Meetings, and Serving on Boards

Becoming involved as an active volunteer at your child's school or serving on boards of various disability organizations in the community, provides opportunities to become familiar with the educational environment, learn first-hand information, and keep up-to-date on changes in laws and policies affecting individuals with disabilities. The mothers in this study volunteered, served on boards, and attended meetings that helped them gain skills to be effective advocates. For example, Sara and Cindy attended meetings at their local ARC organization. Beth served on the Autism Society board and was president of the board of her local ARC organization. Elsa volunteered at her children's school, Dora attended meetings for the Down's Syndrome Association, and Lisa became active with the National Association for Parents of the Visually Impaired.

(4) Networking with Parents

Communicating with other parents of children with similar disabilities can be a source of support, can provide new ideas and strategies, and can even lead to grassroots advocacy organizations that impact disability laws and policies. For example, Lisa created flyers and organized a meeting with other parents of children with visual impairments with the support of her child's pediatrician. Lisa states, "I contacted my doctor...and I made up a little flyer and went from there and started the first parent support group." Lisa and other parents from the support group eventually lobbied their state's general assembly to add additional preschool programs for children with visual

impairments and were successful. Also, Dora reached out to other mothers of children with Down's Syndrome for support. She states, "I got more informed and involved with the, you know, the other moms that have Down's Syndrome [children] and are going through the same thing." Dora's interaction and communication with other parents created opportunities for her to exchange ideas and find creative solutions. A great example of this is illustrated in Dora's narrative when she described taking her daughter's pants and sewing the inside seams together in an effort to help her daughter's gait.

(5) Asking Questions

Parents of children with disabilities should not be afraid to ask questions, because this is the first step in understanding more about their child. Asking questions also provides clarification and promotes collaboration. For example, asking questions was important to Sara, especially during her son's IEP meetings. She stated, "I asked all kinds of questions at the IEP meetings...I wanted to know what every checked box was." In Elsa's narrative, she emphasized the importance of asking questions and getting answers during her son's medical visits. Elsa stated, "Every time I went to the doctor I ask questions, and I ask questions...I will stand by the door and I would not let the doctor go out, until I have all my answers." Asking questions sometimes can be difficult especially if a parent is intimidated by the professional. Parents of children with disabilities must remember *they* are the "experts" on their child, and asking questions reinforces their knowledge and awareness.

(6) Educating Others

By utilizing various speaking platforms, such as a church, parent school teacher (PTA) meetings, or rotary clubs, parents of children with disabilities can increase public awareness, influence politicians, stimulate conversations, create opportunities, develop partnerships, and eliminate assumptions on disability issues. For example, in Beth's narrative, she is relentless about exposing organizations and companies that are making a profit from individuals with disabilities. Beth's frustrations are voiced at speaking engagements at her son's school, the Civitans, the March of Dimes, or wherever she can "use [her] platform" to make a difference. Dora, however, takes a different approach. Her desire to educate others stems from the *stares* and *gazes* that she and her daughter receive out in public. Rather than hide her daughter, Dora takes her out wherever she goes and finds opportunities to talk with individuals at the mall, in restaurants, or at the library and educate them on her daughter's disability.

The mothers in this dissertation recognized injustice, took action, and demonstrated bravery and commitment to react to discrimination that is present in their lives, their child's lives, in society, and in the school setting. Parents of children with disabilities should not feel they are alone in raising a child with a disability, no matter how hard at times it may feel "*to just give up.*" I believe the stories the mothers' shared can elicit responses from other parents of children with disabilities to, (1) listen and react to their parental instincts, (2) share with others their expert knowledge of their child, (3) be engaged in their child's public school setting, and (4) support efforts to increase social awareness on issues of disability.

Finally, this dissertation and the life stories that were shared can be a great starting point for parents of children with disabilities to reflect on and share their own life story to a friend, a family member, or written down for a later time to be read at moments of struggle and triumph.

When people talk about their lives, they tell *stories*. It is through stories that we often learn the greatest lessons for our lives--lessons about success and failure, good and evil, what makes a life worth living, and what makes a society good. It is through stories, furthermore, that we define who we are. Stories provide us with our identities (McAdams, 2006, p. 13).

My Parent School Advocacy Plan (PSAP)

The findings in my study support my position that schools are not educating parents in advocacy. In fact, I believe unless schools are held accountable to train, educate, and support parents in their role as advocates, children with disabilities will continue to be excluded from advanced educational opportunities, face an increase in discrimination, and have limited opportunities to reach their fullest potential as an individual. My proposal to combat this continual problem is in the form of a parent school advocacy plan I call (PSAP). In order for local educational agencies to be held accountable in the development of a PSAP, I propose:

- (1) An amendment to be made to Article 9, Chapter 115C-109.3 *Access to records; opportunity for parents to participate in meetings*, which states the following:
 - (a) Each local educational agency shall provide an opportunity for the parents of a child to examine all records relating to that child and to participate in meetings with respect to the identification, evaluation, and educational

placement of the child, and the provision of a free appropriate public education to that child.

- (b) Local education agencies may release the records of a child with a disability only as permitted under State and Federal law. The parents of a child with a disability may have access to the child's records and may read, inspect, and copy all and any records, data, and information maintained by a local educational agency with respect to that child. Parents, upon their request, are entitled to have those records, data, and information fully explained, interpreted, and analyzed for them by the staff of the agency, unless specifically prohibited by court order. If a request is made under this subsection, the local educational agency shall honor the request within not more than 45 days after it is made or in time for the individual who made the request to prepare for a meeting under subsection (a) of this section, whichever is sooner.
- (c) The student and the student's parents may add written explanations or clarifications to the records, data, and information and may request the expunction of incorrect, outdated, misleading, or irrelevant entries. If a local educational agency refuses to expunge incorrect, outdated, misleading, or irrelevant entries after having been asked to do so by the parent, the parent may appeal that decision under G.S. 115C-45© (2). (1977, c. 927, s. 1; 1981, c. 423, s. 1; 2006-69, s.2).

I chose Section 115C-109.3 in the North Carolina General Statute as an appropriate section to be amended, due to the description of parent rights that are established in subsections (a-c) of this section. Although the words “parent advocacy” is absent in the law, North Carolina clearly recognizes parents as advocates because of the language used in subsections (a-c) to describe the role of parents as they pursue the rights of their children that are guaranteed by North Carolina law. Additionally, the language in Section 115C-109.3 in the North Carolina General Statute is similar to the language used in IDEA when describing parent participation (Turnbull & Turnbull, 1982). Further, I suggest that Chapter 115C-109.3 should add a subsection and preferably should be the first subsection under section 115C-109.3 which would state (a) that each local educational agency shall submit a yearly parent school advocacy plan (PSAP) to their local Board of Education.

I also believe Section 115C-109.3 is the appropriate section for the PSAP, because in order for parents to fully participate as suggested in Section 115C-109.3, they must first (1) feel they can trust the school, (2) feel comfortable within the school, (3) be available, and (4) be knowledgeable through a series of parent conferences. Finally, if amended, I propose a more appropriate title of Chapter 115C-109.3 to state, *Parent advocacy; opportunity for parents to participate in meetings; access to records.*

(2) A portion of the PSAP could replicate the advocacy plan designed by a grassroots organization called Beyond Welfare, located in Ames, Iowa. Beyond Welfare is a program that helps women in poverty develop self-sufficiency through a variety of programs including leadership development training, and advocacy training, and practice

(Bloom, as cited in Burch, Haberman, Mutua, Romeo & Duffield, 2001). Beyond Welfare and a group of single mothers designed an advocacy plan that would improve their relationship with their children's schools. The plan focused on meetings with the mothers and school staff. Bloom (as cited in Burch et al, 2001) states the goal of their advocacy plan had two parts, (1) to educate staff on the perceptions of the mothers so that they could change the design of parent/school meetings and how they were conducted, and (2) sensitize staff to the needs of their children and themselves (i.e. living in poverty). The mothers then designed an advocacy activity in the form of role play. The role play would provide a neutral ground between the mothers and school to discuss these difficult topics that were interfering with their desires and effort to be better advocates for their children (Bloom, as cited in et al, 2001).

Finally, for the purpose of my study, the PSAP and the evolution of role play is an excellent way to stimulate discussion, address ableism in education, create opportunities, and foster improvements in the field of special education while advancing parent advocacy for children with disabilities. My suggestion is to require the school staff that is preparing the PSAP to watch a video that simulates parents of children with disabilities and the difficulties they face within the school environment including attitudes, perceptions, barriers, parent teacher interaction, and school communication. Building from Beyond Welfare's advocacy plan, a role play video will shed light in a non-confrontational format that exposes the realities that exist between schools and parents of children with disabilities.

Limitations of the Study

I selected participants with the help of a local advocacy organization. The criteria set were based on their role as an advocate which was defined as someone who actively and unarguably participates in the educational decisions for their child that are guaranteed by IDEA (Trainor, 2010). My interest in recruitment of participants for this study was not limited to gender or ethnicity. However, a limitation in this research study was that each participant turned out to be all females. Since the participants are all mothers, it does not tell the story of advocacy from a father's perspective.

Implications of the Study

It was apparent in my study the themes of suffering, family, faith, motherhood, and advocacy served as powerful influences in the development of the mothers' identities (McAdams as cited in John, Robbins, & Pervin, 2008) and each of these areas are worthy of further exploration as they relate to identity formation (Singer, 2004). Additionally, the stories from the mothers in my study and my analysis of them were "not attended to show that specific [life] experiences determine whether an individual will become an [advocate] (Ginsburg, 1998, p.141-142). Rather, my interest was in listening to the "stories of their lives" and identifying through their life story, experiences that shaped their identity as parent advocates. McAdams (2006) states that "along with dispositional traits and our motives and goals, internalized life stories make up important aspects of our personality" (p. 14).

My study reinforced the need for schools to make a commitment in helping parents of children with disabilities learn how to advocate for their child through a series

of training opportunities. While it is highly suggested that parents receive advocacy training from schools, it is also equally important that future school administrators and special education teachers receive training in advocacy so that they can create the best education for students with disabilities. I also believe that my study will continue to raise awareness for children with disabilities and their parents. Finally, the following questions below could expand future research.

1. How is a parent advocate influenced in their life by “themes of suffering, redemption, and personal destiny “(McAdams, 2006, p. 5).
2. How does support or lack of support of a mate, parent, sister, or brother affect a parent advocate?
3. How has religious faith influenced advocacy/activism, and more importantly, what role does faith play in parent advocacy?
4. Does the emotional and psychological role of motherhood (Knowles, 1990) affect a mother’s role as a parent advocate?
5. How does parent advocacy differ for minority parents and is their motivation different by context, for example living in an urban vs. rural area, or their socioeconomic status?

Participant Summary

After listening to each mother share the “*story of their life*,” I observed a release of emotions. Their stories were motivating, inspirational, educational, and at times entertaining (McAdams as cited in John, Robbins, & Pervin, 2008). We are reminded

through their life stories that *life* is complex, messy, and cluttered with experiences that engage our emotions, directs our steps, and creates stability in our lives. During each ride home from the interviews, I could not help but to replay their experiences in my mind, as each story shared had meaning, significance, and purpose. The life stories from each mother were crafted (Singer, 2004) and expressed, as though the experiences had just happened, which made the narratives powerful, moving, and ultimately distinguishable in their role as advocates. The following is a summary of the themes and sub-themes that surfaced from each participant's life stories.

Cindy

Theme / Sub-Themes

Chapter IV- Identity Shaped by *Suffering*

- The Experience of Divorce
- The Experience of Abuse
- The Experience of Disability

Chapter IV- Identity Shaped by *Family*

- A Husbands Absence

Chapter IV- Identity Shaped by *Religious Faith*

- Childhood Faith
- Faith through Adversity

Chapter IV- Identity Shaped by *Motherhood*

Chapter V- Identity Shaped by *Advocacy*

- Advocating for their Child

Dora

Theme / Sub-Themes

Chapter IV- Identity Shaped by *Suffering*

- The Experience of Death
- The Experience of Divorce
- The Experience of Disability

Chapter IV- Identity Shape by *Family*

- A Large Family
- A Husbands Absence

Chapter IV- Identity Shaped by Religious *Faith*

- Childhood Faith
- Faith through Adversity

Chapter IV- Identity Shaped by *Motherhood*

Chapter V- Identity Shaped by *Advocacy*

- Early Signs of Advocacy
- Advocating for their Child

Lisa

Theme / Sub-Themes

Chapter IV- Identity Shaped by *Suffering*

- The Experience of Divorce
- The Experience of Abuse
- The Experience of Disability

Chapter IV- Identity Shaped by *Family*

- A Large Family
- A Husbands Absence
- A Grandmother's Endless Support

Chapter IV- Identity Shaped by Religious
Faith

- Childhood Faith
- Faith through Adversity

Chapter IV- Identity Shaped by *Motherhood*

Chapter V- Identity Shaped by *Advocacy*

- Early Signs of Advocacy
- Advocating for their Child
- Advocacy for Others

Elsa

Theme / Sub-Themes

Chapter IV- Identity Shaped by *Suffering*

- The Experience of Death
- The Experience of Abuse
- The Experience of Disability

Chapter IV- Identity Shaped by Family

- A Large Family
- A Husbands Absence

Chapter IV- Identity Shaped by
Motherhood

Chapter V- Identity Shaped by *Advocacy*

- Early Signs of Advocacy

Sara

Theme / Sub-Themes

Chapter IV- Identity Shaped by *Suffering*

- The Experience of Disability

Chapter IV- Identity Shaped by Family

- A Husbands Absence

Chapter IV- Identity Shaped by Religious *Faith*

- Childhood Faith
- Faith through Adversity

Chapter IV- Identity Shaped by *Motherhood*

Chapter V- Identity Shaped by *Advocacy*

- Advocating for their Child
- Advocacy for Others

Beth

Theme / Sub-Themes

Chapter IV- Identity Shaped by *Suffering*

- The Experience of Disability

Chapter IV- Identity Shaped by *Family*

- A Husbands Absence

Chapter IV- Identity Shaped by *Motherhood*

Chapter V- Identity Shaped by *Advocacy*

- Early Signs of Advocacy
- Advocating for their Child
- Advocacy for Others

Final Word

Throughout this research study, I have addressed the need for schools to train parents of children with disabilities in how to advocate for their child. While my position remains unwavering on the issue of improving parent advocacy for children with disabilities in public schools, I have not examined the resistance and criticism of parent advocacy. In this study, we learned from the mothers' stories that advocating is not easy and requires a tireless steadfast commitment to improving the life of their child. On one hand educational policies such as IDEA encourages parents of children with disabilities to participate and to be actively involved in their child's education, yet schools are not prepared to handle the "parent entitlement" or "parent power" that many schools may fear. In this case a parent advocate can be viewed by the school as a *hindrance* rather than an educational partner.

I believe criticism of parent advocacy lies within three areas including *practice resistance*, *fiscal resistance*, and *political resistance*. I refer to *practice resistance* as the school's inability to train parents in effective advocacy skills including how to collaborate, how to communicate, and how to navigate the system, due to their lack of knowledge on advocacy. In many cases, if a parent does advocate for their child they are looked upon negatively by the school because of their obsessive behavior and lack of patience and perspective (Gibbs, 2005). *Practice resistance* also refers to the school's lack of material and training opportunities that informs, educates, and assists administrators and teachers in parent advocacy. Schools that are committed to a parent-

centered philosophy considers advocacy as a priority outcome of parent participation and collaboration.

Fiscal resistance refers to a school system's reluctant attitude toward the financial cost associated with complying with a parent advocate's request to either correct a physical barrier, buy additional equipment to aid in instructional support, or provide a one-on-one for a child with a disability. I learned first hand of *fiscal resistance* when I requested a paved concrete ramp to be installed to allow a student with a disability to access the gymnasium. The initial response from the school's administrators and the school system's maintenance director in charge of construction stated that it would cost over \$8,000 and it was not a part of the current school year's capital improvements. Even though I am sure they were aware of ADA (Americans with Disabilities Act) regulations, I reminded them that the cost of a lawsuit would outweigh the cost of meeting ADA regulations. A year later the ramp was built!

Political resistance refers to the school or public school system's fear of "parent power." Parent advocacy can be looked at in having the ability to go beyond one particular program or service for an individual child, to seizing control of an entire school. An example of this type of "parent power" is demonstrated by California's Parent Trigger Law (Bacon, 2011). This type of power allows parents of children attending failing schools to make a transformative decision regarding the future of the school. Trigger laws and other reforms initiated by parent advocates can ultimately, if not carefully planned, promote greater inequity in the system.

My perceptive of the three types of resistance mentioned above promotes *ableism* in our society and in our schools. During this time of limited funds and limited resources, schools and parents of children with disabilities must not resist each other, but become reliable allies (Wang, et al, 1004) in the quest to improve the education for all children with disabilities.

As a result of this study and the analysis of the mothers' narratives, I designed my own vehicle, i.e., PSAP, in which I can improve parent advocacy in North Carolina public schools. My final step is to form a team that consist of parent advocates, professional educators, members of the community who have a disability, and agencies that support parents of children with disabilities to edit and finalize the organization of the PSAP. The final product will be submitted to North Carolina's Council on Educational Services for Exceptional Children for consideration. In accordance with Article 9, Section 115C-112.1 of North Carolina General Statutes, subsection (a) states that the Council on Educational Services for Exceptional Children be an advisory council to the North Carolina State Board of Education.

My dissertation has been an exciting journey where I have discovered how individuals tell stories, how individual identities are formed from life experiences in the structure of a narrative, and ultimately, how individuals apply their life story to help understand their self, others, and society (Singer, 2004). As rewarding as it was to listen, document, and share the mothers' life stories, I also discovered myself as a researcher (Casey, 1993) which has given me confidence to further address parent advocacy politically and socially. I remember as a child sitting down with my mother and

struggling to tell my story. Back then “*my story*” was in the form of an answer to my mother’s continual prompting of “Joel, why did you do that?” This was her way to get me to reflect on my experience and my actions. Now, *my story* is full of purpose, is ever-changing, and continues to help me make sense of my life.

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APPENDIX A

DESCRIPTION OF PARTICIPANTS

Participants	Description
Cindy	<ul style="list-style-type: none"> • Grew up in a very religious home • Was overweight and was picked on as a child • Became pregnant and was married at seventeen • Had a healthy pregnancy and delivered her son Luke • Luke’s father was physically and emotionally abusive which eventually led to a divorce • Luke was diagnosed with Autism • Got remarried • Removed Luke from public schools after second grade • Luke is currently home schooled • Relies on her religious faith for strength, wisdom, and guidance
Dora	<ul style="list-style-type: none"> • Born in Mexico in 1972 • Is the youngest of nine siblings • Best friend died when they were in the fifth grade • Got married to high school sweetheart and moved to the United States, but was divorced after two years • Remained in the United States and met her new husband • Became pregnant with twin boys and delivered Fernando and Marco prematurely • Fernando died a short time after birth • Marco was born with cerebral palsy • Had an unexpected pregnancy and delivered Arlene • Arlene was diagnosed with Down’s Syndrome • God and her family are priorities in her life
Lisa	<ul style="list-style-type: none"> • Is the oldest of four siblings • Endured abuse from her father while living at home • Dropped out of college after freshman year • Became an assistant at a developmental daycare • Went back to college with the support of her mother • Met her husband while in college and got pregnant • Delivered her son Tate prematurely • Tate was on life support for several months and born visually impaired • Tate’s father wanted a divorce due to the marital strain associated with having a child born with a disability • Works as a visually impaired teacher and mobility specialist

Elsa	<ul style="list-style-type: none"> • Born in Mexico • Father died before she turned six • Is the youngest of four siblings • Mother remarried a man living in the United States • Endured abuse from her step-father • Was married prior to graduating high school • Got pregnant and had a healthy pregnancy with her first child, but had difficulty with her second pregnancy and delivered Omar prematurely • Omar had difficulty within his first year and was later diagnosed with quadriplegic cerebral palsy • Has two additional children without disabilities
Sara	<ul style="list-style-type: none"> • Grew up in a very religious home • Met her husband on a blind date • Was pregnant after their second year of marriage • Had a healthy pregnancy and delivered their son Jack without complications • Jack showed developmental delays within his first year • After making developmental progress during his first five years of life, Jack developed spinal meningitis and regressed considerably • Has two additional children • Jack currently in his twenties, and lives in a group home setting
Beth	<ul style="list-style-type: none"> • Went to college and earned a degree in animal science • Got married and became a foster parent • Worked at her state zoo for twenty years • Sought genetic counseling prior to getting pregnant • Got pregnant and delivered a healthy baby boy • After three years, Joey’s development took nose dive • Joey was diagnosed as a “genetic mosaic” and his development follows that of children with autistic spectrum disorder • Has an adopted daughter, continues to rescue animals, and provide respite care to parents of children with disabilities • Serves on various boards, including the ARC organization