

## ABSTRACT

SHEVACK, ROXANA MANRIQUE. It is *Something Else: An Autoethnographic Journey of Working Mothers Parenting a Child with HFA*. (Under the direction of Dr. Julia Storberg-Walker).

The purpose of this modified autoethnographic study was to gain a better understanding of the parenting and work/life balance (WLB) experiences of working mothers whose first born child was diagnosed with High Functioning Autism (HFA). The study focused on this subculture (first-time mothers of an HFA child) to align with my lived experience as the researcher and full member of this sub-culture, and adopted Chang's (2008) suggestions for multi-perspective autoethnographic studies. I interviewed four co-participants for the study over a twelve-month period—each of us raising a beautiful child with HFA. I embarked on this journey of self-discovery and learning with the dual purpose of finding answers not only for me but for other working mothers out there, who like me, are in the search of the self-discovery, sanity, and peace. The research questions that guided the study were: 1) How do working mothers perceive the experience of raising their first child with HFA? And 2) How do these working mothers perceive the experience of balancing their work and care-giving responsibilities?

My study found that the co-participants (including myself) experienced a three-phased process that is iterative and non-linear. The three phases are 1) undergoing the demands; 2) coping; and 3) seclusion. Depending on which phase a mother is in, she described different work/life balance challenges and workplace issues. In general, the study found that we, the co-participants, faced particular challenges (due to HFA) and work/life balance obstacles (due to becoming mothers while working full time). Further, participants and researcher together highlighted that there are a number of cultural misconceptions about

autism in the lay population—including employers-- and this contributes to the difficult journey of raising a child with this disability while working full time.

This study contributes to both research and practice. While there is a large amount of literature on autism, on parenting a special needs child, and work-life balance, there was no literature on the experiences or culture of this group of women. This study contributes to that gap. The co-participant working mothers in this study offered a unique perspective on how employers (and co-workers) currently provide for their needs, and offered suggestions that could help them navigate this intricate new world of balancing two worlds: work and family's special needs.

I have hope that other mothers out there who feel alone like I once felt will find this research comforting and reassuring. They are not alone. I believe that that if we unite and fight for our beautiful children we can make a better world for them, for us as their caregivers, and for the teachers, employers, and co-workers who may want to help but don't know what to say. This study will give them a glimpse into our world. Additionally, it provides insight into the needs of these workers and how organizations can use this information to reduce turnover and provide a better workplace for them.

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It is *Something Else*: An Autoethnographic Journey of Working Mothers Parenting a Child  
with HFA

by  
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## **DEDICATION**

This work is dedicated to the most important person in my life, to that handsome little fellow who fills my life with joy and a happiness that is not possible to describe with words; to my wonderful son Tristan.

I was fortunate to become a mother in 2008 and I could have not asked for a better child. Always a good baby, only crying when it was absolutely necessary, he arrived to this world with a beautiful bold head and gorgeous hazel eyes. He has a great personality, the most contagious laugh and he even dares to be a photogenic little man for her amateur photographer mother.

I am indebted to him for tolerating my absences for the past 3 and a half years and I hope one day, when he understands, he will be proud of my accomplishments. He is my constant source of motivation, I learn for him and from him. He is my foundation of love and more than anyone gives me the inspiration and purpose for life.

Pipis...I love you more than words can say!

## **BIOGRAPHY**

I was born and raised in Mexico and immigrated to the US in 1999. I started off living in Florida then moved to North Carolina. I have been living in the Raleigh area since 2004 with my husband, my mother and my son.

I earned a B. S in Mass Communications from the University of Monterrey in Mexico. During my career I have worked in several industries such as telecommunications, aviation and the jewelry business. I am currently employed at North Carolina State University as an HR Manager for the College of Textiles. Always interested in learning, I attended a training called Pathways Leadership which led to an interest in adult education and I enrolled at NCSU to pursue a M.S in Human Resource Development and I will graduate in May 2014.

I am a bilingual individual with a keen interest in learning from other cultures. On a personal level, I am a party planner, a cook, an amateur photographer, a scrapbooker, a Zumba instructor, movie fanatic but most of all a hopeless romantic. These personal traits have guided me all my life, and were pivotal in this little adventure called graduate school.

## ACKNOWLEDGMENTS

First I would like to thank my committee members. Dr. Julia Storgberg-Walker for making the completion of this thesis possible. She provided guidance and support throughout the whole process and it was a delight to work with her. To Dr. Brad Mehlenbacher for his guidance and willingness to be part of this committee, and last but not least, a very special thank you to Dr. Kate Guerdat for helping me ground my passion and making it a workable thesis topic. Her mentorship during my time in graduate school is invaluable and is a memory I will always treasure.

To my mother, thank you for teaching me the values of family and life leading by example and not just words. For raising me as an independent woman and to believe that any endeavor is possible if you work hard for it. For teaching me concepts such as strength, perseverance and tenacity; such ideas were pivotal for my desire to go back to school and guided me until the end allowing me to graduate. Thank you Mami!!!

To my husband David for helping take care of my son during the endless hours of work that graduate school requires.

To my friends and family for always giving me words of encouragement, for the endless days of allowing me to complain about the one more article I had to read.

Finally, I would like to express my wholehearted thankfulness and indebtedness to the participants on this study. To Lynne, Martha and Fiona, those working mothers who like me are parenting a child with HFA and who shared with me the desire of helping others in our situations by sharing our experiences.

It was my honor and privilege to have work with you and I will always be grateful for your help in completing this research. I have called you the “Supporting Actors” in this project, and for your performance you deserve an Oscar.

Thank you all for your support during this challenging but highly gratifying experience.

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## CHAPTER 1: INTRODUCTION

*“As a mother of a child with autism sometimes I feel defeated with a constant reminder that my life is not “normal”. I am always tired; there is a lot to do and a lot to stay on top of; a lot to keep track of. Like benefits’ policies or how to stay employed while you parent a child with special needs. I learned the process of applying for Family Medical Leave last December when I visited New Jersey for a 5 week intensive feeding treatment as suggested by my son’s therapist. Going north during the winter is not an attractive idea; however I did not hesitate for a second. My son has dysphagia, a condition where individuals who has it don’t know how to chew so they just swallow their food. My son can’t eat in a regular restaurant, a birthday party or a family cookout, I always have to feed him before we go out or bring his “special food” with me. If we are in a restaurant, people stare. One time someone went as far as to ask “Isn’t him too old to eat pureed food?” to which I retorted, “Aren’t you too old to speak without a filter?” I try not to let things like these get to me but it is hard. Needless to say, feeding him it is not an easy task, so when someone presents a possible solution for this problem you jumped right to it. But to think about leaving work for 5 weeks it’s scary, especially in this economy. Not long before that some people were laid off so I was scare to even ask for the time off but I had to do it. I felt awful! It is exhausting to be scared of “something” ALL the time. It is like someone told me I am doing an aerobics class for hours and hours until I drop. So I just keep going and going, trying not to but wondering when am I going to drop”.*

I delivered my first and only child in 2008, and at age two he was diagnosed with HFA. I am his primary caregiver and although we don’t have a “normal” life, I could not

imagine my life without him. I am also a working woman, and like many I struggle with balancing the often competing demands of working and mothering, as illustrated in the story above. My struggle is not surprising, as research has confirmed that “attempting to work and provide care to a child with special needs appears to be particularly difficult” (Freedman, Litchfield, & Warfield, 1995, p. 509).

In addition to the normal and customary challenges of balancing work and a new role as worker mother, I also live with and learn about my son’s autism and special needs. And over the last five years, I have learned many things. Amongst them, that the U.S. Centers for Disease Control and Prevention (CDC) identify around 1 in 110 American children as on the Autism Spectrum, this is a 600 percent increase over the past two decades. More children will be diagnosed with autism this year than with cancer, diabetes or pediatric AIDS.

I learned that defining and living with autism can be daunting. I have learned that children with autism are characterized by impairments in communication, social interactions, and repetitive and restricted behaviors and interest (APA, 2000). For some, the term provokes intense emotional reactions, bringing to mind such politically charged concepts as “Americans with disability act”, “equal opportunity” and “diversity”. These reactions may stem, in part, from a narrow focus on protected groups covered under affirmative action policies.

I learned about the benefits within The No Child Left Behind Act (NCLB) for students with disabilities. The NCLB is a federal law that offers incentives to schools with progress for students with disabilities and punitive measures for schools not meeting the needs of the disabled population. Children in the Autism Spectrum are considered to have a

disability, and this federal law provides various types of relief for parents who otherwise would need to find specialized education in the private school system.

However, the issues that I and other parents have to deal with in a daily basis are not just about education. The demands for working parents of children with autism go far beyond this one part of life. These demands can tax the resources, strength, and hopes of parents, and often can take their toll on what many people call ‘work/life balance’. For instance, the amount of appointments, medical evaluations, and therapy sessions that are normally required for a child with autism can exhaust vacation time pretty quickly, and we are not even talking about how that time away from the office can put a dent in your productivity as an employee.

Social life and friendships can get a toll as well, loud noises and crowds are not a good combination for a child with autism, and therefore social events are most times out of the question. Even a simplest thing like going to church can be problematic. My son has High Functioning Autism (HFA) and is able to verbally communicate and pretty much function like a typically developed child, but I always have to make concessions when it comes to socialization. You cannot go through life with a sign that reads “My son is autistic” and yet you feel the need to explain it to those who stare whenever an “episode” occurs.

The demands are overwhelming and they never end; they never will. And one of the biggest challenges is to try and balance caring for him along with my work. I am of the opinion that you should always leave your personal life at home, but when you have to go to work after taking your son to the zoo for the first time while he didn’t seem to notice or care where he was, and you have to pretend everything was fine when your coworkers ask “how

was your weekend?”, it is really hard to accomplish. Inside, I wanted to vent out and tell her it was bad, that I was looking forward to this outing because lately my son has shown interest in animals so I thought he was going to enjoy the zoo, but he just wanted to play his video game most of the time, and it was not until the last 30 minutes that he showed a remote interest in his surroundings. Instead, I just responded “My weekend was fine, how about yours?” To respond to this simple question and others like them, has become a monumental task. So I keep going to work like there are no struggles in my life. I keep going to work like I am fine. But I am not and I don’t know if I ever will. The mixed emotions of moments like these are intense, and I work extremely hard to keep my feelings on some kind of equilibrium because my husband is not able to do it. I try to keep myself positive and focused. This is what my study is about.

Prior to the birth of my son, I was always been interested in how people create meaning from their experiences. I have been so busy working and providing care that I have not had a chance to stop to understand this new mothering role in my life. This modified autoethnographic research study granted me the opportunity to look closely at this process, and thus cope with the existentialist and cultural aspects of my own experience. As a working mother of a child with autism who is trying to balance family and work, I feel blessed to have my son and would not trade my experience for anything in the world, but I wonder, is this true for others as well? What aspects determine the level of difficulty of this experience? What is the process to cope?

Not all disabilities are the same or affect the individual in the same manner; therefore I imagine the experiences should not either. How do parents understand the experience of

raising a child with autism? Does every parent experience the same challenges? Is having your first-born child diagnosed with autism different from having your second or third child diagnosed? And, what do we already know about how working mothers deal with providing care for an autistic child?

As many people already know, autism is a broad term and the severity can range from high functioning (i.e. Aspergers), to extremely low functioning where individuals need to be hospitalized for life. When conducting the literature review for this study, I found an extensive body of research regarding parenting children with disabilities that focuses on coping mechanisms and stressors (Donnenberg & Baker, 1993; Dyson, 1991; Kiekhefer, Trahms, Churchill, & Simpson, 2009; Olsson & Hwang, 2001; Phetrasuwan & Miles, 2008; Redmond & Richardson, 2003; and Tway, Connolly, & Novak, 2007).

There are a few studies that provide information from working mothers of children with special needs (Parish, Rose, Swaine, Dababnah, & Mayra, 2012; Gordon, Cuskelly, & Rosenman, 2008; Chou, Fu, Pu, & Chang, 2012), but in my research I could not find a single study that talked simply about first-time mothers or worker-mothers and their experiences of parenting a child with High Functioning Autism (HFA) or any type of autism. Extensive research does exist on special education of children with disabilities (e.g. Aron & Loprest, 2012; DiPipi-Hoy & Steere, 2012; Ford, 2012; Nartgün, 2010; Santos, 2012; Sindelar, Dewey, Rosenberg, Corbett, Denslow & Lotfinia, 2012), or parents of children with autism and their perceptions on education (Starr & Foy, 2010). Other studies are centered on treatments for autism such as social skills interventions (Rao, Beidel & Murray, 2007), or at the coping skills for parents of children with all types of disabilities including autism

(Hughes, 1999; Benson, 2010). The literature on the topic of mothers and their children with autism I did find is generally quantitative, centered in both parents (e. g. not focused on mothers only), and has been published in medical journals.

For example, in a study conducted by Itzchak & Zacho (2011) they examined what specific child and family factors were related to treatment outcomes in adaptive skills. Interestingly, a significant finding was that advanced maternal age resulted in better outcomes. This finding made sense to me. It is hard to imagine a younger mom dealing with having a child with a disability, better than a more experienced woman.

The researchers suggested that “it is possible that more experienced and mature mothers may enable better implementation of their children’s potential in daily living skills” (p.349). These findings suggest there may be a difference between novice and experienced mothers as they provide care for their autistic child. Great, I thought. As a first time mother, this study and its findings generated some discomfort in me, but also highlighted the importance of understanding the experiences of first-time mothers to help them navigate the early years and to also create organizational policies and practices supportive of the working mother with a HFA child. As first time mother, I was always fearful of how my inexperience can lead me to make bad decisions for my child, or not provide him with proper care. If we add the fact that my child has HFA, the uncertainty and discomfort is even greater.

Other research suggests that it is likely more difficult for parents of an autistic child to achieve work/life balance (Jang & Appelbaum, 2010; Sevon, 2011) than parents of children with other types of disabilities. The researchers state “work-life balance must be particularly challenging for these parents, but little is known about how they balance work

and family demands” (Jang & Appelbaum, 2010, p. 313). This study explored coping mechanisms of these parents of children with chronic conditions and examined the resources that workplaces had to offer them. According to the study, parents of children with chronic conditions use more unpaid leave than parents of typically developed children, and the mothers are more likely to apply for a job that offers FML (Family Medical Leave) benefits. Participants in the study also reported that after the diagnosis they wanted to know everything related to the condition but as the demands piled up, they had less and less time to do it. The authors reported that with a “few workplaces benefits available to families with these responsibilities, parents face many difficulties in coping with their situations” (p. 322).

In another study that evaluated the stress in mothers of children with autism, the authors concluded that successful interventions for a child can only happen if the needs of the parents are understood and they recommend that future studies “should focus on the context of the lives of mothers” (Phetrasuwan & Miles, 2008, p. 163). Working mothers of children with autism are usually the primary caretakers and decision makers for their children. They live with more challenges and demands than mothers of typical development children therefore they are part of a somewhat marginalized culture.

Other literature exists that focus on the experiences of first-time mothers raising children without disabilities. Related to my experience as a first-time mother, but not focused on autism or a child’s disability, I found that Sevon’s (2011) study focused on mothers making sense of parenthood. This study found that many western women believe being a ‘good mother’ requires intensive mothering, taking responsibility not only for the baby but for the home and her partner. This study also found that first-time mothers have additional

stress and conflict just by adding the factor of being “new” to motherhood. Western women are also concerned about other issues such as mothering, gender ambivalence and couple disruption.

As the numbers of children diagnosed with autism increase in an alarming rate, and as their mothers in the workforce seek work-life balance, the topic increasingly presents a challenge for organizations, policy makers, medical providers and the public school system to better understand this phenomenon as they develop programs tailored for this specific population. How do parents sustain their multiple care-giving and work roles? Is it more difficult than caring for a typically developing child? Empirical answers to these questions are difficult to find in the current literature; this study is a step toward rectifying that problem.

### **Problem Statement**

Research suggests that being a working mother presents a series of challenges that can create stress and anxiety all by itself (Savon, 2011). However, when the first born is diagnosed with autism, the demands become even greater. While much is known about diagnosis, intervening and educating children with autism, little is known about the lived experiences of these mothers struggling to balance work and family in the field of Human Resource Development (HRD). The HRD literature does contain work/life balance (WLB) research in general (Kahnweiler, 2008; Pitt-Catsouphes, Matz-Costa & MacDermid, 2007; Polach, 2003), and even targeting working mothers (Schultz & Higbee, 2010; Thinnam, 2011), but I have not been able to locate any research on working mothers with an autistic child. From my experience, combined with my review of the disability literature, I suspected

that there is a qualitative difference in this situation than in other disability types. This is a topic that organizations and the discipline of HRD will greatly benefit from learning more about.

A greater understanding of these issues will also be important as the upward trend in diagnosis continues. While there is a growing emphasis on providing special education to these children (i.e. No Child Left Behind Act), I know from my experiences that there are several other issues that are not being considered. The literature targets more general umbrella of the Autism Spectrum Disorder (ASD), or deals with parents of children with other disabilities but does not specifically examine the work/life issues of working mothers. There is a need for examining and understanding all of the multiple demands of parenting children with High Functioning Autism (HFA) while in the workforce. These mothers need guidance from formal and informal sources on ways to manage their lives so they can focus on their children's development and at the same time stay sane and employed. Yet, many times they only encounter barriers and marginalization and nobody to talk to.

### **Purpose and Research Questions**

The purpose of this qualitative modified autoethnographic study was to gain a better understanding of the work/life balance (WLB) experiences of working mothers whose first born was diagnosed with High Functioning Autism (HFA). This study covered a twelve months ethnographic research on a mother's subculture composed of working females whose first born was diagnosed with High Functioning Autism and who live in the Raleigh Durham area. Having no other children in the household presents an added difficulty in parenting due to inexperience. There are a number of cultural misconceptions about autism and this

contributes to the difficult journey of raising a child with this disability. Being one of those mothers, and having travel on this road for five years now, I am still surprised at the lack of research covering this topic.

Overall, I was hoping to gain a better understanding of these parenting experiences, which can be valuable data for HRD practitioners and scholars as they develop programs for this population.

The research questions that guided the study are:

1. How do working mothers perceive the experience of raising their first child with HFA?
2. How do these working mothers perceive the experience of balancing their job/work and care-giving responsibilities?

The sub-questions that will be addressed that I hope will contribute to the literature on parents of HFA child are:

1. What are the positive and negative experiences of parenting a child with HFA?
2. What are the barriers to successfully maintaining work-life balance (WLB)?

### **Significance**

Is the experience of raising a child with High Functioning Autism (HFA) important?

Is it worth doing empirical research on it? How is it relevant in today's world and society?

There are a number of factors that need to be considered as we measure the importance of this study and the current literature covering the topic, such as cultural understanding of autism, the parents' experience, the current services provided at state and federal level to this population, and the added work when it is the first born. I believe a comprehensive understanding of the parenting experience will not only benefit parents but will also

contribute to both theory and practice in three ways.

First, it contributes to the field of Human Resource Development (HRD) by providing privileged information on how organizations are structured and how they build upon individual and organizational change. Working mothers have a unique perspective on how the organization provides for them in terms of tools that can help them navigate this intricate new world of balancing two worlds: work and family. This study can provide insight into the needs of these workers and how organizations can use this information to reduce turnover, and they could do this, by providing a more customized workplace for these mothers who are in a unique situation when compared to other employees.

Second, this study will add to gender perspective in organizational literature. Current work from feminist scholars has led to a gendered analysis of organizational structures and provides an insight into how organizations operate. Worker mothers as females have a unique perspective about being an employee, and most certainly add a different perspective on what is needed from these organizations. This study was built on that strong gender perspective.

Lastly, and most importantly, this research will fill the gap in the literature regarding working mothers and their lived experiences on raising children with HFA while trying to balance family and the workplace. While there is a wealth of literature regarding WLB in general (e.g. Jyothi & Jyothi, 2012; ten Brummelhuis & van der Lippe, 2010; Doble & Supriya, 2010; Sturges & Guest, 2004; Waumsley, Houston, & Marks, 2010), they are not centered on women's experiences. And although this is a significant body of literature that focuses on special needs children and their disabilities in some shape or form; there are no studies that combine working mothers with special needs children specifically HFA.

This study builds on the existing literature that is focused specifically on women. It examined working mothers of a child with HFA and their experiences making life decisions, such as responding to work-life conflicts as they discover if organizations are prepared to offer special accommodations for their *special needs*, and how do they respond to marital and family conflicts that can arise from the stress of raising a child with HFA. The project is unique in that it followed four working mothers whose first born was diagnosed with a form of HFA, allowing for and capturing how their world changed radically since the diagnosis and thus; promoting individual learning by reflecting on their experiences.

### **Theoretical Framework**

“Qualitative research is an inquiry process of understanding based on distinct methodological traditions of inquiry that explore a social or human problem. The researcher builds a complex, holistic picture, analyzes words, reports detailed views of informants, and conducts the study in a natural setting” (Creswell, 1998, p. 15). I have never been interested in statistics, or numeric facts. On the contrary, I have always been attracted to stories in general but specifically in life stories, and this quote complements my idea of research design, a type of inquiry where I can explore the lives of the participants and learn from their experiences.

The goal of this study was to rely on the participants points of view, to make sense of what it means to raise a child with High Functioning Autism (HFA) and what effect has on work-life balance (WLB); therefore, it is based on a social constructivism worldview. In qualitative research, according to Creswell (2009), the term worldview, or paradigm as called by others, is a “general orientation about the world and the nature of research that a

researcher holds” (p. 6). Further, Creswell explains how these types of beliefs held by the researcher will lead him/her to the most appropriate method such as qualitative, quantitative or mixed methods.

The social constructivism paradigm is consistent with qualitative research. Followers of this worldview are individuals who seek to understand the world they live and work, and “the goal of the research is to rely as much as possible on the participants’ views of the situation being studied”. Because I am interested in give meaning to the experience of parenting a child with HFA while trying to find balance between work and life; I interviewed this sub-culture and listened carefully to what they have to say about their life settings and I focused the study in the context in which these working mothers live as I sought to understand “the historical and cultural settings of the participants”, hence adopting this worldview. (Creswell, 2009, p. 8).

To describe the frameworks used in this study about these working mothers’ lives, I used an ethnographic approach with a gender perspective on their perceptions of parenting a child with HFA while trying to balance work and life. In addition, I utilized a feminist lens according to Bierema & Cseh (2003), which is to “look at the world from a woman’s perspective honoring the common experiences and histories of women in society” (p. 8). My intention with this study was not to fight for the equality of women’s rights or use a radical feminist approach, but in my experience as a married women I do believe that man and women’s perceptions on raising a child with HFA, as well as seeking work-life balance, are different; therefore I am defining it as a *gender perspective* and it was the lens leading this study. In most societies, women carry on their shoulders most of the responsibilities of the

home and raising the children (Doble & Supriya, 2010), they juggle several things and in some cases are even expected to do it. In feminist research, “the goals are to establish collaborative and non-exploitative relationships, to place the researcher within the study so as to avoid objectification, and to conduct research that is transformative” (Creswell, 1998, p. 83). As a result, I explored the changing nature of these mothers’ care-giving responsibilities and the balances they attempt to maintain and manage their personal and professional life.

It is common in qualitative research and in ethnography in particular, to utilize a flexible inductive approach on the idea or topic being studied. To illustrate this concept, this study did not fend for a definite idea of what it means to raise a child with HFA, instead, it approached the topic with questions like “I wonder what it is to be a mother of a child with HFA”...”I wonder what the experience is...”. This research had the potential to discover some of the answers to those questions and more specific details during the data collection process. This is consistent with what Bogdan & Biklen (2003) suggest about qualitative studies: “While people conducting qualitative research may develop a focus as they collect data, they do not approach the research with specific questions to answer or hypotheses to test”(p. 2).

### **Limitations**

There are limitations to any research study that must be identified and discussed as a background for the analysis of findings and their meanings. One significant limitation to the study was my dual role as a participant and researcher. Since I am part of the sub-culture I am studying, I am a biased source where my responses are influenced by my perceptions and beliefs, and it was important to take this into consideration in data analysis. Biases of the researcher often play a role in the qualitative research process, however, the nature of

qualitative studies is precisely that; share, describe or understand the perceptions of individuals who voluntarily share such information. As a researcher, I am aware of the fact that I need to keep a constant check on my positionality.

Another limitation was the inexperience of the researcher which can lead to unexpected problems in the process in aspects such as data collection and data analysis. Further, this study was a part of a Master's degree thesis and it was time limited. The results of this study are not generalizable but are consistent with qualitative research, however; they can serve to inform what may be observed in regards to the topic and as a guide for future research, which based on the current literature, is an area that has not been studied yet.

Despite these limitations, this study has a significant advantage: the dual role of researcher and participant have the potential to produce valuable data which will help explore the lived experiences of working mothers of a child with HFA, and therefore understand and learn from their experiences as they try to find work-life balance (WLB).

In general, the findings may offer a foundation for the development of strategies to modify the work environment to foster improvement for relationships between the employees and the organization. Parenthood is widely considered to be essential to human existence and is related to quality of life. The findings of this study can underline this importance, and suggest that concepts such as special accommodations for parents of children with special needs need to become more accepted and included in the organizational vocabulary.

### **My Story**

Individuals with a disability are referred to as persons with special needs. This term, although not a medical diagnosis, is commonly used to describe individuals who require

assistance for disabilities that can be medical, mental or psychological in nature. My interest in this topic comes mostly from my personal experience as a member of the culture I am researching. I am the mother of a 6 year old boy with High Functioning Autism (HFA). I work full time and attended graduate school in a part time basis. My relationship to this study is shaped by a desire to contribute toward the support of other working mothers who are uncertain on how to proceed once their first born child has received a diagnosis of Autism. After reading several journal articles, I found myself asking what were the challenges and experiences of those mothers. Where did they get the information they needed? How did they learn to cope? A survey with numerical data results was not the answer for me. I wanted to hear the stories.

Choosing to work in my life story is convenient in a way. I am a full member of the research group I am studying; therefore I have a having a full understanding of the phenomenon, and can speak to the participants in this study in their same *language*. Because of my background as a working mother of a son with HFA struggling to maintain a work-life balance, I was interested to examine this particular population in more depth. Being participant and researcher allows me to take advantage of familiar surroundings to collect and interpret the data.

It is imperative to acknowledge subjectivity in qualitative research and specifically in autoethnography. Because I have a dual role of participant and researcher, it is necessary to address my own subjectivity that may impact perceptions of the data and to understand future findings. I am an only child of a divorced mother who had to work all her life to support me. This made me an independent child since an early age. My mother had to go back to school

in her late thirties and her father who barely finished elementary school was able to provide for a family of six, therefore education was highly valued in my family. Aside from this, family values were intrinsically connected to my upbringing and this had a significant impact on my perspectives of life and family. As a female, I must also pay attention to how gender impacts this study. I do not see myself as a working mother being better or worse than a working father, however, I do realize that there is an expectation of mothers being the primary caregivers for children and therefore sometimes being judged more for their parenting skills. While I do not believe that my gender has anything to do with being able to provide for a child, I do realize that others may differ in their opinions.

When I was told I was having a boy, I imagined myself as a mother who will spoil her son while at the same time direct him through life with the same family values and principles I was raised. I imagined myself teaching him the love for culture I have and take him on many vacations to experience life. Having a child with autism, even in the high functioning form does not combine well with all those hopes and dreams I once had. Autism is a complicated disease that have no definite medical or behavioral interventions, and families that live with it, are always in the “trying” stage: trying a new therapy, a new elimination diet, the newest behavioral approach; all in the hopes of finding if not the best tactic, the *right* one. I feel that there is an overall lack of support in organizations for parents of a child with autism.

Disability rules apply for an actual employee who may suffer from this disease, but not to the parents of a future employee. I am currently a forty-two year old female working in an organization where I have the luxury of having an understanding and supporting

supervisor, one who allows me the flexibility I need to attend the many appointments and therapies my son requires, but mine is an isolated case that it is not too often repeated throughout the organization. I also understand that my gender potentially plays a role in how I am perceived by staff and colleagues, will a father of a child with autism have the same, more or less privileges I have? These factors discussed in my own subjectivity contribute to my lens as a working mother with a child with autism as they are interpreted as part of my own perceptions of my “self” and my experiences. I seek to understand if my own experience is unique or if other women in similar situations are challenged the same way I am. How do they cope? How did they assign meaning to their lives? How do they balance their work and family obligations?

Having attended numerous conferences, doctor appointments, and all types of academic and medical evaluations, I still encounter parents in the waiting room that have no idea of the long road of adjustment is ahead of them, and it is inconceivable that there is no easy path to alleviate the anxiety that produces a diagnosis of Autism. I have personally experience the angst of not knowing what to do, who to see, what to do next, the special needs world is very tricky to navigate and after all these many years of research, there should be an easier way.

These personal and professional experiences have led me to choose this topic. The number of children being diagnosed with autism is in the rise, but the research about the lives of these mothers who are the primary caregivers is deficient. To immerse yourself in other’s world is a learning process; it is how you learn about others, particularly in the culture sense. By examining the lives of these mothers, the focus of this modified autoethnography was the

everyday experiences and events they have navigating life, and the perceptions and meaning attached to those experiences as expressed by them. This study will give a voice to the mothers of children with High Functioning Autism (HFA) so their lived experiences and joys can be better known and understood.

### **Definition of Terms**

The key terms employed in the study are as follows:

#### **ASD- Autism Spectrum Disorder**

Autism spectrum disorder (ASD) and autism are both general terms for a group of complex disorders of brain development. These disorders are characterized, in varying degrees, by difficulties in social interaction, verbal and nonverbal communication and repetitive behaviors. Examples of this are Autism (299.00), pervasive developmental disorder-not otherwise specified (PDD-nos) (299.80), and Asperger syndrome (299.80). (Diagnostic and Statistical Manual of Mental Disorders IV, text revision-DSM-IV TR)

#### **No Child Left Behind Act (2002)**

Federal legislation increases accountability for public schools by requiring academic standards for all students, establishing annual assessments for students in grades 3-8, requiring schools to publicly report on performance data for all identified student groups (i.e., race, gender, disability, English language proficiency, and socio-economic status), and requiring teachers and paraprofessionals to be highly qualified, among other regulations. The purpose of this title is to ensure that all children have a fair, equal, and significant opportunity to obtain a high-quality education and reach, at a minimum, proficiency on challenging State academic achievement standards and state academic assessments.(NCLB,

2002, § 6301 (3)).

### **Special Education**

Specially designed instruction, at no cost to parents, to meet the educational needs of an eligible exceptional student, including classroom instruction, out-of-school instruction, instruction in a special school or residential setting and instruction in other settings, including the workplace and training center. (IDEA, 2004, § 2647).

### **Individualized Education Program (IEP)**

A legal document that details the specific performance levels of performance and academic needs of a student who is eligible and in need of special education services. The IEP is developed by a team of school personnel and experts, the parents, and the student when appropriate Developmental Disability-Lifelong disabilities attributable to mental or physical impairments. (IDEA, 2004, § 2647).

**HFA- (High Functioning Autism)** - Autism is a complex disorder of brain development with a broad range of severity. HFA is on the end of the spectrum where individuals present language and cognitive abilities in the average range. (Freitag et al, 2013).

**Work-Life Balance (WLB)** - The stability characterized by the balancing of an individual's life complexity and dynamism with environmental and personal resources such as family, community, employer, profession, geography, information, economics, personality or values. (Crooker, Smith & Tabak, 2002)

### **Human Resource Development (HRD)**

A series of programs and activities that positively affect the development of the individual and the productivity and profit of the organization. Some of those programs are training and

development, organizational development, employee assistance programs, career development, and performance appraisal. HRD is a process for developing and unleashing human expertise through organization development and personnel training and development for the purpose of improving performance. (Swanson & Holton, 2001; Khan, Khan, & Mahmood, 2012; Allameh, Pool, & Davoodi, 2012; Benjamin, Naimi, & Lopez, 2012)

## **CHAPTER TWO: LITERATURE REVIEW**

### **Summary of Study**

According to Creswell, we “conduct qualitative research when we want to empower individuals to share their stories, hear their voices, and minimize the power relationships that often exist between a researcher and the participants” (2007). This was the purpose of the present modified autoethnographic study: to hear the voices of working mothers and their parenting experiences having a child with autism, for a better understanding of their work-life balance. The literature identified that these mothers experienced significant challenges which lead to stress, sometimes stigma, and require coping. These mothers along with their children are often seen as a deficit and are marginalized. The level of care that a child with special needs require is greater than a typically developed child and occur for a longer time, therefore the employment patterns of these mothers are significantly different that other female workers, and as a consequence, they are often excluded from the workforce as they voluntarily decide to stay home a care for their child. This thesis sought to understand the perceptions of working mothers, both positive and negative and what it means to be a working mother with a child with High Functioning Autism (HFA).

### **Literature Review**

A major concern I had undertaking this literature review was to ensure that it was coherently bounded, without being too extensive, to the purpose of this research. Due to the extensive literature available on autism, it was an overwhelming task to narrow it down to the appropriate themes to include. Therefore, a scheme was developed for organizing this chapter, first, into autism definitions and symptoms; second, in the literature and frameworks

on mothering and the mother culture; third, in the literature that addresses the unique demands for parents with children with autism; fourth, in the HRD literature on work-life balance (WLB), and lastly what is the cultural meaning of all these. For the purpose of this literature review, the focus was to concentrate on academic literature and I was primarily interested in finding empirical qualitative research on the parenting experiences of working mothers who have children with a form of High Functioning Autism (HFA). As the literature review that follows reveals, mothers are usually the primary caregivers and more information about how these mothers experience their life with their children with autism is needed for those interested in understanding and supporting the work/life struggles of this cultural group.

### **Autism**

One this study's main topic is autism, therefore the goal of this chapter was to create a basis for understanding that concept. Both professionals and individuals have difficulty describing or even conceptualizing what autism really is, where it came from, what causes it and how to cure it. There is a vast amount of literature on autism that is not relevant to this study. For example, medical and alternative medicine trials (Scahill, Hallett, Aman, McDougle, Eugene Arnold, McCracken, & Vitiello, 2013; Carter, Messinger, Stone, Celimli, Nahmias & Yoder, 2011; Lee, Choi, Shin, & Ernst, 2012), laws and legislation (Aylott, 2011; Yen & Mao, 2011), and teaching children with autism (Mintz, 2013; Magyar & Pandolfi, 2012; Constable, Grossi, Moniz & Ryan, 2013). For this study, two issue areas surrounding autism seem to be the most relevant: symptoms and interventions. This is due to the fact of how they can illuminate the context within which the working mothers in this study will act.

The working mothers as primary caregivers become deeply connected and responsive to HFA symptoms and are also key ‘actors’ in the play that is intervention. This section will describe the literature on these two areas, and will provide a focus on HFA when possible.

The word autism derives from the Greek word *autos*, referring to self. In the early 1940’s Leo Kanner adopted the term “autistic” to characterize the self-contained world of a group of his patients. In the beginning, there were marked similarities between autism and schizophrenia but also a distinct difference that ultimately lead to the separation of the terms. More than twenty five years after schizophrenia became a formal diagnosis, academia began working to accurately separate the two conditions in the literature (Ghaziuddin, 2005).

The literature states that diagnosing autism is a difficult task. This is due in part of the multitude of possible presentations or subtypes as included in the Diagnostic and Statistical Manual of Mental Disorders (Verte et al, 2006). Three of these subtypes are associated with normal intelligence. “The development of standardized tests to assess autism, particularly in young children, is a topic of considerable interest in the research community” (Matson, Nebel-Schwalm & Matson, 2007, p. 38). The term Autism Spectrum is a colloquial and educational term rather than academic or medical and can refer to different types of developmental disabilities such as Disintegrative Disorder (CDD), Rett’s, Autistic Disorder, Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS), Asperger’s Disorder and High Functioning Autism; and with the May 2013 publication of the new DSM-5 diagnostic manual, these autism subtypes will be merged into one umbrella diagnosis of ASD (Autism Speaks website). There are different methods to give a diagnosis but most of them employed the help of a neurodevelopmental pediatrician and the use of standardized

diagnosis tools such as ADOS (Autism Diagnostic Observation Schedule) which is a semi-structured questionnaire design to assess social and communicative functioning to classify children into categories of autism; or ADI-R (Autism Diagnostic Interview Revised), a semi-structured interview administered to parents (Itzhak & Zachor (2011).

### **Symptoms and Characteristics**

In an article by Kanner & Eisenberg (1956) on early infantile autism, the authors explained how severe autism can be associated with extremely low functioning but it is not necessarily representative of low intelligence. They suggest that autism is stamped by sensory impediments that generates from a neurological base and affects an individual's ability to connect with people. The ability to respond to others is one of the most valuable forms of language and individuals with autism lack this ability impacting their social development in a dramatic way (Goldsmith, LeBlanc & Sautter, 2007).

Matson, Nebel-Schwalm & Matson (2007) describe that “given the many opinions and rapid changes in notions about how to best label various disorders relative to core symptoms of autism, it is no wonder that a number of scaling methods have been developed to help clarify these major controversies in definitions and diagnosis” (p. 39). Autism is a neurological impairment and does not appear to be emotionally based; it is statistically more prevalent in boys than girls being the male-to-female ratio of approximately 4:1 (Dworzynski, Ronald, Bolton, & Happe, 2012).

Classic autism presents a highly recognizable set of cognitive and behavioral characteristics, especially on the severe end of the spectrum, and they can include: limited verbal expression, limited receptive language, severe sensory disintegration (Grandin, 2006),

self-injurious behaviors, sleep and eating disorders, violent behaviors, and repetitive physical movements (Sabbagh, 2004). Autism generally presents before the age of three with parents normally the ones noticing repetitive activities, difficulty with change or transition, sensory challenges, delayed speech, and sensitivity to noise which is an inability to normally process sensory stimuli (Exkron, 2005). Some of these sensory issues for a child may include hypersensitivity to light or sound, which leads the child to cry or yell which in turn, can lead to a misunderstanding from “outsiders” if there is lack of awareness about the child’s sensory problems (Goodman & Williams, 2007).

On this note, and with social problems existing for these individuals, other children may not understand the child’s behaviors, and this can lead to discrimination and bullying (Attwood, 2007). When it comes to medical needs of the child with autism, Attwood (2007) suggests that neurological and biological aspects of the disorder must be considered to account for some of the problems children face developmentally, such as metabolism issues in regards to food intake that can affect the brain’s development. Furthermore, the author points out that with these issues, there may be a high need for the child to be provided with adequate medical screenings, neurological testing, and proper pediatrician evaluation, not only in childhood but throughout adolescence and adulthood.

According to Verte et al (2006), High Functioning Autism (HFA) is a subtype of autism characterized by three main symptoms: (1) impairment in social interactions, (2) impairment in communication, and (3) restricted, repetitive and stereotypic patterns of behaviors, interests and activities. Their study results showed that children with autism, regardless of the subtype they belong to, presented pragmatic communication problems and

they recommend finding intervention programs that can focus this type of language skills. According to Goin-Kochel, Myers, & Mackintosh (2007), these treatments options can include behavioral interventions, different types of therapy, special education, gluten free diets and some medications. The authors found that the parents of children with autism are using a variety of treatments simultaneously, and some without supportive scientific evidence.

### **Interventions**

“When there is no cure, there are 1000 treatments.” - Donald Coher

There is an increase in awareness of autism and thus, the amount of treatments and interventions have risen. The entire fifth issue volume 32 of the Journal of Autism and Developmental Disorders is devoted to reviews of behavioral treatments. Matson, Nebel-Schwalm & Matson (2007) describe that there is an advantage in diagnosing a child before the age of 2, and that is the “belief that treatment programs based on applied behavior analysis can dramatically help afflicted children, and that the earliest possible recognition of those at risk will result in the best long term treatment results” (p. 39). Deciding which treatments to follow or what therapy is the best is another issue, one that can be a daunting subject for professionals but specifically for parents who may feel overwhelmed with the variety of options.

In a research by Goin-Kochel, Myers & Mackintosh (2007), the study explored the use of treatments and therapies for children in the autism spectrum disorder. Families reported that they are always on the look-out for a new therapy to try in the hopes they don't miss the one treatment that can really help their child. The authors then conducted a follow

up study in 2009 to investigate the efficacy of treatments and therapies and looked at some of the challenges that can determine this aspect. The decision of determining the effectiveness of these evaluations was delegated to the parents in the study as they can be seen as the in-house experts in their own children's development. "They care for and interact with them every day and in multiple settings. Parents are also those most invested in their children's development and quality of life. They care about whether a treatment works, not for scientific reasons, but because they want the best possible outcomes for their child" (Goin-Kochel, Myers & Mackintosh, 2009, p. 530).

It can be difficult to determine the effectiveness of individual treatments when most often than not, families try multiple therapies and interventions simultaneously (Goin-Kochel, Myers, & Mackintosh, 2007). Another factor that can affect the perception of success is the fact that these treatments sometimes only affect self-help skills and/or other functioning areas. "For example, a child with autism on an elimination diet might have fewer bouts of diarrhea, but no change in communication or social skills" (Goin-Kochel, Myers & Mackintosh, 2009, p. 534). These authors conclude, however, that parent's insights are valuable tools for professionals and perhaps a better approach would be to try one therapy at a time, and to request the appropriate tools to objectively assess the response from their children to such interventions.

In another study by Itzchak & Zachor (2011) the authors agree with the literature in that the age of the child at the time of the intervention has a significant importance in predicting the results. Their results suggest that the younger the child at the intervention, the better the response in the cognitive area. In the study by Goin-Kochel et al (2007), some

categories of interventions were described as pharmacological treatments (with the use of antidepressants, mood stabilizers, and stimulants); diet related (gluten free, casein free, dairy free); and educational and behavioral (early intervention, floor time, music therapy, occupational therapy, picture exchange system, physical therapy, sensory integration and speech therapy). These authors studied a large sample of families and the treatments used which in average and depending on the diagnosis, most children were trying between four and six different treatments at a time. In terms of age related trends, Goin-Kochel et al (2007) suggests that younger children are using more diet and behavioral/educational/alternative treatments than the older ones, and that adolescents used more pharmacological treatments than children of early ages.

To determine the efficacy of these treatments is a difficult task according to a follow up study from Goin-Kochel et al (2009) as children show fluctuations in behaviors from one day to another. “For example, a child might sleep poorly, be agitated, and have meltdowns on one day, and the next day be calm and cooperative. These fluctuations make it difficult to assess what changes-if any- are the results of a given intervention” (p. 529).

## **Literature Frameworks**

### **Mothering and Mother Culture**

In this study, the research participants were working mothers who identified themselves as the primary caregiver of the child with HFA. Consequently, the identity of “primary caregiver” is relevant to this study. In Sevon’s (2011) recent study on mothers making sense of the gender perspective when it comes to parenthood, the researcher call to attention that most western women believe being a ‘good mother’ requires intensive

mothering, taking responsibility not only for the baby but for the home and her partner. The study identified different phases in the women interviewed starting with an optimistic beginning, transitioning to a relational turbulence and passing a phase of adaptation and reorientation.

All participants were first-time mothers relatively well educated and within a heterosexual relationship. This study points out how first-time mothers have additional stress and conflict just by adding the factor of being “new” to motherhood, they are also concerned about other issues such as mothering, gender ambivalence and couple disruption. The author concludes that the “ideal of shared parenthood may be also difficult for new mothers to identify with because the focus and argumentation is on gender equality rather than on the wellbeing of the child” (Sevon, 2011, p. 78). If this is true for most first time mothers, it is only natural for them to miss out on early signs of autism or other developmental disabilities.

Green (2007), a researcher and mother of a child with special needs supports studies with a focus on joys rather than the challenges and she argues that the “majority of research on parenting children with disabilities has emphasized the Subjective Burden (emotional distress) and de-emphasized, if not completely ignored, both the Object Burden (socio-structural constraints) and the benefits involved” (p. 151). Further, most studies look at parenting the entire autism spectrum without making distinctions between mild, moderate, severe or high functioning autism.

In constructing a framework for understanding this study, I found few articles on women and the role of mothering, or on working mothers of children with disabilities (Lewis, Kagan, & Heaton, 2000; Porterfield, 2002); and even fewer articles that directly addresses

the mother's experience but they were covering a variety of severe disabilities including developmental disabilities and genetic abnormalities rather than focusing on just one such as High Functioning Autism (HFA) (Lawrence, 2008; Read, 1991). Read's research (1991) is extensive in the impact of raising a child with disabilities and it looks at the women's lived experiences but does not center in one disability in particular.

There is a growing literature supporting the notion that birth of a child with a disability generates intense emotional distress for the family (Hughes, 1999; Pelchat & Lefebvre, 2004). Parents of children with disabilities "must continually adapt to changing circumstances and needs of the child, with stress being a frequent consequence of these demands" (Hughes, 1999, p. 271). Parents who are raising a child with a disability experience care giving demands that go beyond the typical demands of parenting; for instance, they attend a significant number of medical appointments, which likely reduce the time they have to spend together or at work. As a result, they struggle to find time to incorporate support when their family and work life balance is disrupted.

A main stress point for mothers is the emotional exhaustion of taking their children out to the world. The frequently need to have to respond to inquiries or disapproval faces from the public who don't know the difference between a child with special needs versus a child missing disciplinary actions at home. Mothers juggle a host of generated expectations and stigmas as they navigate their life with their child, they are required to reframe their parenting perspectives and embrace who their child is.

### **Work-Life Balance and Workplace Accommodations**

The idea of balance is a central issue for working parents and there is no doubt that

handling the work life as well as family commitments can be a delicate balance. “Applied professionals in business and policy arenas struggle to find solutions to the “challenge” workers face in combining their work and family lives” (Grzywacz & Carlson, 2007, p. 455). When any working adult is single, or without children, they have more choice over how they spend their time. Spending numerous times a week apart from spouse and children, can result in a burnout and a high turnover. In some phases of life, and certain professions, 50 hours per week may be acceptable; however, with a spouse and children involved this is no longer an option. When a profession occupies most of a person’s time and attention, the effects flow over into the family life. In some cultures, work demands are often seen as an obligatory priority and family is viewed as an optional choice, leaving it third or fourth on the priority list.

In an online article from the U. S. Department of Labor, I found their introductory paragraph to be a great preamble of a major point of interest in this thesis: “the stress and the tension between work and family are increasing. Major changes in American families-and the lack of corresponding changes in many workplaces policies and practices- are the causes. Balancing work and family responsibilities, particularly the responsibilities of child and elder care, will remain issues in the workplace of the future, touching each of us at some point in our work lives” (U. S. Department of Labor, 1999, p. 28).

Work-life balance is a term to describe “those practices at workplace that acknowledge and aim to support the needs of employees in achieving a balance between the demands of their family (life) and work lives (Jyothi & Jyothi, 2012, p.35). Working mothers in general have this component added to their career when they become mothers and

balancing these two highly demanding responsibilities is a difficult task that can lead to conflict between work and family. “Work-family balance is at the core of issues central to human resource development (HRD). Indicators of balance have been associated with greater employee commitment” (Grzywacz & Carlson, 2007, p. 456). Research on the needs of parents of children with special needs is limited and indicates that, what employers are offering to balance their work/life, is not comparable with their demands. Not widely implemented or studied, are the specific demands -and consequently, what employers have to offer to help with the WLB -of parents with children in the ASD (Autism Spectrum Disorder).

When parents have to deal with care giving responsibilities during work hours, they can have consequences on their productivity and/or their ability to handle their work responsibilities. “Attempting to work and provide care to a child with special needs appears to be particularly difficult” (Freedman, Litchfield, & Warfield, 1995, p. 509). Much of the literature, as evidenced by the great amount of journal articles and books have been written about this topic (Doble & Supriya, 2010; Freedman, Litchfield, & Warfield, 1995; Jang & Appelbaum, 2010; Jyothi & Jyothi, 2012; Ogston, Mackintosh, & Myers, 2011; Sturges & Guest, 2004; ten Brummelhuis & van der Lippe, 2010; Waumsley, Houston, & Marks, 2010), examines the work/life balance of parents with children who develop typically, and some about children with severe mental disabilities such as down syndrome, or even workers without children, however, few are developmental disorder specific. Therefore, little is known about how parents of children with an emotional or behavioral disorder, such as Autism, are able to juggle their work and family lives when an extra “weight” is put on them,

or what type of workplace accommodations they receive from their employers. Freedman, Litchfield, & Warfield completed an exploratory study in 1995, where they gathered information from parents of children with developmental disabilities about the impact of care giving on work and family roles. Although their findings are helpful, there seems to be a large gap of studies between their research and the last seventeen years. Their research findings showed how many parents “chose to work part time instead of full time, because appropriate, affordable, child-care programs, particularly after-school programs, were unavailable” (p. 509).

Women in particular, who may or may not decide to leave the workforce and care for their children, represent a specific niche in the organizations that this study seeks to investigate more. The field of HRD can benefit from learning about these working mothers and their attempts to balance work and life, to provide the necessary tools for organizations to be able to retain these valuable workers and avoid high turnover costs. Research in retention and turnover shows the significant impact that has on organizations when employees leave the workforce voluntarily by estimating that it takes between 25-200% of an employee’s annual salary plus the cost of benefits to replace and train their substitute (McKinney, Bartlett, & Mulvaney, 2007; Linhartová, 2012). Due to the never ending demands that working mothers of children with HFA have, the possibility of quitting or losing their job in higher frequency than other employees only seems a fitting statement.

In assessing the relationship between the demands those parents of children with special needs have and the offerings from their employees to balance their work/life, the literature suggests that there are several organizational factors that might be influential, as

well as a possible disconnection between them. When it comes to talk about child care solutions, few studies have examined the dilemmas that working parents of children with disabilities face, “particularly those with emotional or behavioral disorders” (Rosenzweig et al., 2008, p. 78). For example, a parent can be faced with the decision to choose between attending an important meeting and a doctor’s evaluation. If they miss the meeting they risk retribution from work, but if they miss their child’s appointment they risk missing to find a possible intervention for one (or more) of their child’s medical and/or behavioral issues. In addition to these problems that we face as parents of children with HFA, and as a result of trying to balance work and family, there can be serious consequences on health and well-being. For instance, it can lead to increased occurrences of alcohol consumption and poor physical health (Frone, Russell & Cooper, 1997). Evidence that directly assesses the difficulties these parents go through show how the lack of child care accommodations “adversely affect employees performance and well-being, as evidenced by increased absenteeism, interference with concentration on job tasks, lower marital and parental satisfaction, and increased stress-related health problems” (Rosenzweig et al, 2008, p. 78).

When demands are coming from every direction, emotions will start running their decisions, then is time to stop and bring all the stakeholders into the “big picture”. Employers should be aware of the demands these working parents face- in contrast to working parents with children who develop typically -this way, it can be easier to understand their employees’ issues and not just judge on their absences due to endless doctor’s appointments, or other life disruptions. The HRD function of support and advocate for all employees is somewhat short when it comes to mothers of children with HFA. There is literature about worker mothers in

general struggling to find WLB but none with the specifics of having the additional “weight” of caring for a child with HFA.

### **Making Sense**

In a study from Samios, Pakenham & Sofronoff (2008), they investigated the nature of sense making in parents who have a child with autism. They explained how sense making “was first given significance as a meaning reconstruction process by Assumptive Worlds Theory proposed by Janoff-Bulman and colleagues” (p. 517). This theory goes to explain how traumatic events can compel an individual to confront the meaning of their own lives. Having a child with autism, which is an unexpected event in particular for a first-time parent, can certainly qualify as a traumatic event as it has the power to possibly destroy one person’s views of the world and adopt a sense of meaninglessness. Restoring meaning into life can be an arduous road. The results for this quantitative study show that parents make sense of having a child with autism by getting closer to spirituality, identifying the causes and people with the disorder, and reframing it as luck of fate or difference rather than a disorder.

There is no denying that raising a child with autism is a stressful process and just about every study I have read has touch the topic one way or another, however, the severity of the disorder plays an important role on the levels of such stress. Having identified this issue, does not tell us how or why this happens. On a study by Myers, Mackintosh & Goin-Kochel (2009), the authors embarked on the task of finding out how are the lives of parents of a child with autism are affected. The purpose of their study “My greatest joy and my greatest heart ache: Parents’ own words on how having a child in the autism spectrum have affected their lives and their families’ lives” was to listen to the parents voices and to discover the parent’s

views on the big picture. With an in depth analysis, some of the themes discovered were how time demands for care and therapies is an important aspect to consider when it is time to identify the overall tone of *joy* or *ache*, along with sleep problems, exhaustion, financial strain, social life, impact on siblings and other family members, and struggles with school and services. Their responses provided an opportunity to hear what these parents have to say about their parenting experiences, but are these experiences the same regardless of the conditions of the household? Regardless of the severity of the disorder? Can we compare the experiences from a parent of a child with severe autism with one with Asperger?

The demographics of this study showed that the participants were mostly mothers (92.2%) and the diagnoses varied from autism, Asperger syndrome or PDD-NOS but it was not specified if the respondents were working mothers or stayed at home. It will be interesting and beneficial if future researchers can differentiate from one side of the spectrum to another. One father from Myers et al. reported “Autism does one of two things, it drives families apart, or makes them stronger” (Myers, Mackintosh & Goin-Kochel, 2009, p. 682).

The findings of this literature review support the implementations of future research where some key issues need to be addressed such as, how does having a child in the Autism Spectrum influence your decisions about work? How does having a child in the Autism Spectrum influence your career choices and career development? What supports and benefits do parents with a child in the Autism Spectrum receive in their workplace?

Researchers are just beginning to understand the implications of balancing family and work in groups of parents of children with disabilities; however, disorder specific research- such as autism-is still in the development stages. Future research is needed to both to

replicate and most importantly, to extend these findings. It should consider more behavioral in nature disorders such as autism to broaden the knowledge of the stakeholders.

### **Summary**

Autism is a complicated disorder and raising a child with it is a monumental task. The severity affecting each individual has a tremendous range that can go from severe (where individuals are mostly institutionalized) to high functioning (where most individuals have a great prognosis of an independent adult life). This condition is ruled by sensory impediments generated from a neurological base and affects an individual's ability to connect with people. Individuals from autism can suffer from a number of symptoms such as limited verbal expression, limited receptive language, severe sensory disintegration, self-injurious behaviors, sleep and eating disorders, violent behaviors, and repetitive physical movements.

Deciding which treatments or therapies to follow can be a daunting subject for professionals but specifically for working parents who may feel overwhelmed with their multiple responsibilities from both fronts: family life and the workplace. These demands present a challenge for these parents in their ability to juggle them attempting to find a "balance", and they could benefit from employers being aware of these demands to provide them with better tools to help with the balancing.

In order to better understand life with this challenge, outsiders need the correct background and the specifics on what is this disorder and how to conceptualize parenting, and specifically motherhood, in relation to it. The literature supported future research to better understand the range of individual mother's experiences on parenting a child with HFA, positive, negative and everything in between. The next chapter will explain the

rationale for the methodology use to conduct this study with details on data collection, analysis and trustworthiness and ethical considerations.

## CHAPTER THREE: METHODOLOGY

### Summary of Study

*“On a cold night in December 2008, I was watching my son play with his first train set my husband just built for him. We sat him inside the rail and watched him happily how he transition from a shy smile to a contagious laugh as he scrutinized how the train would go around him. Then suddenly, he started flapping his hands up and down harder and harder. First we thought it was just normal excitement of a baby, little did we know this was a sign of autism. How are you supposed to know if this is your first child and you have no experience as a parent? Since then, my life as a working mother has not been easy: to discover that your son has a “condition” that there is no medical detection or cure. Nevertheless, I will not trade this experience for anything in the world. How could I? I have so many wonderful memories: his first steps, his wonderful laugh, and the first time he said “I love you Mama”. Those words and the echo of his laugh are what keep me going. You think you have left behind those images, but they accompany me throughout my life and sculpt a place in my memory to which, sooner or later- no matter how many books I read, how many trips I make, how many worlds I discover- I will always return.”*

Expecting parents are normally asked many questions: “Have you chosen a name yet?”, “Is the nursery ready?”, “Do you want to be surprised by the sex of the baby?”, and depending on the culture, age, region of residence and other factors the responses will vary, however; one common wish for all parents, regardless of socioeconomic status, religion, or ethnicity; is the aspiration of having a healthy child. When a child is born with serious health problems, parents need to adapt and cope soon to be able to provide for that child who needs

instant care. When a child is born with autism, the diagnosis sometimes does not occur until two or four years after the child is born, which sometimes can affect these families more as they are already established and organized. These parents face an additional set of challenges compared with parents of typically developed children, from special education schooling, to toilet training, to socialization; these daunting tasks seem to grow more and more by the minute. As a mother of a child with autism; these are the experiences I am interested in as a researcher. Listening to the stories of other mothers and presents them to a wide audience of researchers, administrators and educators, in the hope to improve future interactions between them and the parents who have a strenuous road ahead of them.

### **The Qualitative Approach**

There are compelling reasons why I choose qualitative research over other designs, as Creswell (1998) points out, qualitative research should be choose because the topic needs to be explored, because “variables cannot be easily identified, theories are not available to explain behavior of participants or the population of study, and theories need to be developed” (p. 17). Understanding how a working mother of a child with autism navigates through life is not something that can be done with statistics and a graphic. Qualitative researchers tend to collect data in the field where participants are experiencing the phenomenon, in other words; in their natural setting. This information is gathered “by actually talking directly to people and seeing them behave and act within their context” (Creswell, 2009, p. 175). A qualitative researcher is the key instrument of the study as it collects the data through multiple sources such as interviews, observations or by examining documents. Qualitative research is descriptive, holistic, and interpretative. After data

collection, the researcher uses inductive analysis to build their themes and present a thick descriptive interpretation of the problem by exploring the stories of the participants. It uses an emergent design that evolves from field notes and observations; it is not a restrictive process that has to be adhered to a firm plan and each and every one of the phases “of the process may change or shift after the researcher enters the field and begins to collect data” (Creswell, 2009, p. 176).

I firmly believe that stories are meaning-making methods, and to make sense of an issue; is to give it meaning in a cultural environment. Always a follower of nontraditional anything, I found that autoethnography provides a unique connection between the reader and the subject. The readers can feel more involved and curious about a case like this as the distance between the writer and the reader is reduced. The first person expression of the writer provides a space of intimacy. “Autoethnography represents a significant expansion in both ethnographic form and relational potential. In using oneself as an ethnographic exemplar, the researcher is freed from the traditional conventions of writing. One’s unique voicing—complete with colloquialisms, reverberations from multiple relationships, and emotional expressiveness—is honored. In this way the reader gains a sense of the writer as a full human being” (Ellis & Bochner, 2002, p. 14). This quote clearly exemplifies the interest driving this research: to present the lived experiences of mothers of a child with autism-including mine- in a non-traditional way of writing.

The purpose of this qualitative modified autoethnographic study was to gain a better understanding of the work/life balance experiences of working mothers whose first born was diagnosed with High Functioning Autism (HFA). The primary objectives were to understand

the challenges these mothers have, the influences on their work, and how to they manage to balance family and work in their demanding life. Qualitative research can accomplish this task and autoethnography as a design; can provide a significant insight into the lives of the participants being that the researcher has a dual role in the process.

I was interested in providing not only a “surviving guide” to working mothers who are shattered with the discovery that their child has a long life disability, but also and insight of this world to practitioners so others in this culture can obtain better resources provided by organizations and government agencies. “Autoethnography is an excellent instructional tool to help not only social scientists but also practitioners—such as teachers, medical personnel, counselors, and human services workers—gain profound understanding of self and others and function more effectively with others from diverse cultural backgrounds” (Chang, 2008, p. 13).

Ellis and Bochner (2000) states that some good examples of autoethnographic research can include short stories, fiction novels, journals and personal essays amongst others. Personal narratives can, and should, expose the intrinsic details about the individuals we are studying, and how those details can help us make sense of their lives and culture. Telling stories is an ancient practice and I have always been a storyteller, so the idea of presenting my study in this approach is highly interesting for me.

After collecting the data, I analyzed the stories and key life moments that gave me the start the process of cultural interpretation. As Chang (2008) describes, autoethnographers “attempt to achieve cultural understanding through analysis and interpretation. In other words, autoethnography is not about focusing on self alone, but about searching for

understanding of others (culture/society) through self” (2008, p. 48-49). Using interviews and field notes, the data produced a rich description of the parenting experiences of working mothers of a child with High Functioning Autism (HFA), the findings will be presented in Chapter 4 in a constructed narrative where data is weaved together from all corroborated sources.

The present study addressed the following research questions:

1. How do working mothers perceive the experience of raising their first child with HFA?
2. How do these working mothers perceive the experience of balancing their job/work and care-giving responsibilities?

The sub-questions addressed that I hope will contribute to the literature on parents of HFA child are:

1. What are the positive and negative experiences of parenting a child with HFA?
2. What are the barriers to successfully maintaining work-life balance?

These questions were the starting point for the study; however, I expected the research to evolve once the stage of data analysis was reached and to follow the flexible tradition of qualitative research.

### **Research Design**

This study used a combination of autoethnography and focused interviews (Chang, 2008). Data collected from my own experience as a mother of a child with HFA was use in this study in conjunction with the data from interviews from other working mothers in order to triangulate data and construct a narrative to report the findings describing parenting experiences. This autoethnographic account of my parenting experiences, coupled with the

data gathered from the interviews, sought to extend the understanding of the central issue (How do working mothers perceive the experience of raising their first child with HFA? How do these working mothers perceive the experience of balancing their work and care-giving responsibilities?), by providing a realistic account with actual stories from the experts. I served as the fourth interviewee; this auto narrative can illustrate significant events in a unique form when compared to other designs of qualitative research.

### **Autoethnography**

This methodology is most often described as a personal narrative of the researcher and as both a process and a product. Culture and individuals have a history of being intertwined and in autoethnography there are many examples that can show this, such as native ethnographies (ethnographies conducted by ethnographers on their own people); anthropologist's memoirs; ethnobiography or critical autobiography amongst others.

For the purpose of this study, I define autoethnography as a methodology that combines cultural analysis and interpretation with narrative details following the anthropological inquiry approach rather than descriptive storytelling. Further, as Chang (2008) explains, autoethnography should be “ethnographic in its methodological orientation, cultural in its interpretive orientation, and autobiographical in its content orientation” (p. 48).

This last aspect is what separates this type of ethnography from others and one of the reasons I became interested in this design in the first place: autoethnographers use their personal experiences as main data. As part of the group I am researching, I have unlimited access and thorough experience to provide a rich and thick description of the phenomenon.

The research process for autoethnography does not differ significantly from ethnography.

Raising children with HFA is like two different worlds colliding, it is as if they are coming from another country, one that we don't know anything about and are completely unfamiliar with their habits, their culture, their cuisine and most importantly their way of interpreting the world. I called this the "Cultural Clash Analogy", and it has been a helpful tool that has guided me to communicate with those unfamiliar with autism how is that world compared to ours, and it has been very helpful for them to understand the experience.

In the analogy, when you meet someone from that "country", you don't understand many of the behaviors, and you cannot fathom the idea of them only eating certain things. You cannot understand why the noise bothers them, isn't there music in their "country"? How can you help them if you don't even understand where they are coming from? How can you help them if their country is completely the opposite of yours? We need to start by recognizing we are being subject to a "cultural clash" and in order for us to help them, we need to learn their "language". This analogy endorsed the decision of using autoethnography as a method.

Data collection involves multiple methods such as observations, interviews, and document analysis and field notes. Data analysis will interpret the meaning of the findings, and the data will be validated via triangulation of sources and member checks. At the end, the researcher will write the report of findings hoping to gain an understanding of the group, with the difference of including him or herself in the analysis. Focusing on the lives of the participants, this study examined the perceptions of parenting and work-life balance (WLB) experiences of working mothers of a child with HFA using interviews and observations. I

inquired into their lives and attempted to discover how they try to find a balance between their work and family responsibilities.

### **Participant Selection**

A culture sharing group is the unit of analysis for the ethnographer as he or she attempts to understand and interpret the behavior, language, and artifacts of people. The ethnographer typically focuses on an entire group—one that shares learned, acquired behaviors—to make explicit how the group “works” (Creswell, 1999, p. 245). The unit of analysis for this study is the working mothers of a child with High Functioning Autism (HFA). Autoethnography is not a study of self alone, there are others connected directly or indirectly. Self and others can be positioned in different ways, accordingly, I have chosen for this study to be the main character with others (mothers with similar experiences) as co-researchers. Therefore, and because this study was center on a sub-culture (working mothers of a child with HFA), and it is not following the traditional path of autoethnography (one person) and it included others, it is referred to as a modified autoethnography throughout the paper.

The rationale of why I have chosen this path is because I want my voice to be heard, not only as a coping mechanism, but to serve the purpose of this study: to describe, as an insider of the group I am studying, how do working mothers perceive the experience of raising their first child with HFA and how do they perceive the experience of balancing their job/work and care-giving responsibilities. I realized that there is no research done on this particular group and in the studies that are similar to this one (with mothers of children with special needs and not necessarily HFA), the voice of the insider is missing.

For triangulation purposes I wanted to include the voices of other mothers so they can be heard, better known and better understood and in searching for a method that can allow me to bridge the gap between my group and the academic world, I came across autoethnography. As an *insider researcher*, I am part of both worlds: academia and the real world. I can be true and ethical to my culture of working mothers of children with HFA, and at the same time avoid being too scholarly in tone and alienate the mothers from the real world.

This study was conducted in the Raleigh-Durham area in North Carolina. The focus of the study was to tell the lived experiences of working mothers of children with autism, therefore I had to first establish a list of similar attributes that each participant must have in order to compare similar experiences. I used a purposive sampling and the criteria for participant selection will be intentionally similar to myself: (a) must live in the Raleigh-Durham area; (b) must be a full-time working mother; (c) have a child diagnosed with some form of High Functioning Autism (HFA), because the experiences from a child with a severe case of autism cannot be the same than a child with High Functioning Autism (HFA); and (d) preferably the child with the diagnosis, if not the only child, to be their first born.

The rationale for this criterion was to ensure that the parenting experiences are similar. Studying women in similar circumstances to my own will provide me with an entry point and shared aims as my interviewees. Marshall & Rossman (2006) recommendation for qualitative researchers is to choose topics they are familiar with because “closeness to the people and phenomenon (one studying) through intense interactions provides subjective understandings that can greatly increase the quality of qualitative data” (p. 62).

Purposive sampling allowed me to identify working mothers who in my opinion can provide me with the stories I need to compose a rich description of this culture. I used this purposive sampling to recruit participants from two places I attend with my son: a company that provides occupational therapy, and from Brain Balance, a private non-medical company that provides an individualized approach to help children with neurobehavioral and learning difficulties. However, I was only able to recruit one person with this method and had to postpone the research for almost five months. By using a snowball sampling process, from key individuals who possess personal knowledge of rich-information cases such as the owner of Brain Balance, I was then able to secure the second participant and was able to resume the research.

These initial recruitment places were selected based on the researchers' access due to the relationship with the owner(s). I sought permission from management in both locations to post a sign in the lobby soliciting participants and explaining briefly the nature of the study, and did it by emailing both companies to explain the nature of the research (Appendices A and B). In my experience as a member of this culture, I have met several other working mothers of children with HFA in the last five years, either personally or through other acquaintances, and this was how I was able to secure the third and last participant.

Even though I had to recur to this snowball sampling and had to interview participants I have never met before; nonetheless they were still selected based on the criterion specified previously. Consistent with qualitative research and to ensure confidentiality, I used pseudonyms for all participants, as well as the actual place where the participants were recruited. Purposive sampling as described by Creswell (2009) is used to

“best help the researcher understand the problem and the research question. This does not necessarily suggest random sampling or selection of a large number of participants and sites” (p. 178). Based on this, I aimed to have a sample size of three to four participants including the researcher.

Once I was contacted by the participants, I sent them an email (Appendix C) describing in detail what their participation will entail to, what the study is about, the duration of the interview (between 45-60 minutes), and particularly how do I intend to keep confidentiality. The interviews were schedule based on the availability of each participant at a convenient location for them as well. I recruited a colleague of mine to formally interviewed me using the same questions I used with the other mothers, following a recommendation from one of my professors who has extensive experience as a researcher (T. Bowles, personal communication, November 2012).

Due to the nature of this study, and in order to safeguard the protection of human subjects in research, I sought approval from the Institutional Review Board (IRB) before I started soliciting participants. The IRB application was send after the preliminary defense of this thesis and approved shortly after.

The IRB requires the researcher to disclose several details such as potential risks for the participants, the purpose of the research, the expected duration of the study, and expected benefits for the participants amongst other. This is done through an informed consent (Appendix D) that all participants must sign and that I provided to each participant prior to conducting the interview. I then explained the contents of this document before securing their signature. The focused semi-structured interviews were utilized to gather data from

participants and were recorded through an app called “iTalk” in the researchers’ password protected smartphone. An overview profile of each participant is provided next:

Lynne: Caucasian female, age 49 married. Have two children, ages 11 and 9 and works as an Office Manager.

Martha: Caucasian female, age 44 and married. Have two children, ages 9 and 6 and works as a nurse.

Fiona: Caucasian female, age 45 and married. Have two children, fraternal twins age 6 and works as an Office Support until recently.

Roxie: Hispanic female, age 42 and married. Has one child age 6 and works as an HR Manager.

Additionally, the diagnosis and characteristics (if more than one) of the child diagnosed with HFA are important when trying to compare similar experiences from parents with similar characteristics. The following is an overview of the demographic data and diagnosis of the children to provide a better sense of each participant’s life environment.

Jack: Diagnosed at age 9 with ADHD and Aspergers, currently he is 11.

Patrick: Diagnosed at age 6 with ADHD and HFA, currently he is 9 years old.

John: Diagnosed at age 2 with Autism and Apraxia, currently he is 6 years old.

Tristan: Diagnosed at age 2 with HFA and SID (Sensory Integration Disorder), currently he is 6 years old.

### **Data Collection**

In the analytical side of autoethnography, the researcher collects internal data but the primary data collection comes from the co-participants. In this study, data was collected from

January 2013 through February 2014. Consistent with qualitative research and its use of multiple data collection techniques, this study included field notes and a 45-60 minute recorded semi-structured interview with the participants. The audio interviews were transcribed by the researcher as the cost to do it professionally was not affordable. I then managed the data by creating a filing system by interview question. To assist in the data collection phase, I utilized a field log to record a detailed account of my observations during the interviews as well as my own thoughts, feelings and experiences throughout the research process. In addition, I also included a reflexive comment after each interview to describe any personal connections I found to what was said during the interview. It was during this exercise that I decided to create a segment on Chapter 4 called *Final Impression*, where after describing in detail who I called my *supporting actors*, I proceeded to include my final impressions of each participant which were mainly guided by these reflexive notes collected during the interviews. The participants are the *experts* in the subject of raising a child with autism, and my goal was to collect their knowledge regarding this topic they know so well. The core of the interview was based around the following questions that are part of my interview guide. They were created to seek a recount of how they understand the experience:

1. Thinking back to when you first found out you were pregnant, what were your thoughts about the child you were carrying?
2. Tell me about the experience of going back to work after your first pregnancy?
3. Tell me about your experiences in the workplace, how do you juggle the demands from being a full time worker and a mother? Do you think your gender influences your experiences?

4. How is your support system at home and amongst friends?
5. How do you feel about this situation that you are in as a mother with a child with Autism?  
Do you feel rejected?
6. Do you feel that your demands as a parent of a child with Autism are different and/or harder than that of parents with typically developed children?
7. Is there enough information available that can help you deal with these demands?
8. Considering all the challenges that you must cope with, what emotions do you experience?

### **Data Analysis**

Chang (2008) recommends ten strategies for analyzing autoethnography data: (1) search for recurring topics, themes, and patterns; (2) look for cultural themes; (3) identify exceptional occurrences; (4) analyze inclusion and omission; (5) connect the present with the past; (6) analyze relationships between self and others; (7) compare yourself with other people's cases; (8) contextualize broadly; (9) compare with social science constructs and ideas; (10) frame with theories" (p. 131). This went hand in hand with Strauss & Corbin's open coding system that I utilized during the initial analysis after I transcribed the interviews and listen again to the recorded sessions.

Merriam's advice (2006), is to analyze while collecting the data and not waiting until having a mountain of interviews to go over, and when the memories of the process are no longer fresh. Data analysis was guided by the research questions at all times:

1. How do working mothers perceive the experience of raising their first child with HFA?
2. How do these working mothers perceive the experience of balancing their job/work and care-giving responsibilities?

The sub-questions that I hoped to also address and to possibly contribute to the literature on parents of HFA child were:

1. What are the positive and negative experiences of parenting a child with HFA?
2. What are the barriers to successfully maintaining work-life balance?

Once initial codes begun to emerge, I used the constant comparison method to accomplish saturation of the data. Each question had sub-folders with the initial coding emerging themes. The most relevant stories and epiphanies were the second level of coding, and once identified they had their own classification within the data. Once everything was compiled, I identified the recurrent themes in all questions by re-reading the data, made margin notes and memos to myself to help me create the final codes. To present the findings in Chapter 4, I wanted to create a table to reflect the categories and sub-categories emerging from the analysis, however, I decided to make a change and instead presented them in a narrative way and stay closer to traditional autoethnography.

### **Trustworthiness**

The rigor of my study was safeguard by a quality control that guided my research at all times and I avoided the three major pitfalls that can be done in autoethnography. First, culture is a group concept and it should not be delegated to a second level in the study. The notion of culture, according to Chang (2008) “predisposes the co-presence of others even in a discussion of individual culture”; therefore autoethnography should reflect the interconnectivity of self and others (p. 54). Self-indulgent introspection is not research.

Second, autoethnography and its flexible writing style can lead to a pure self-narration and ignore the true mission of cultural interpretation of autobiographic narratives.

Self-narration is very engaging to writers and appealing to readers, but I was careful not to settle for “elaborate narratives with underdeveloped cultural analysis and interpretation” (Chang, 2008).

According to Creswell, a “rich and thick description allows readers to make decisions regarding transferability” (2007). All stories that were accounted in this research were described in great detail to comply with this suggestion, it is with “such details descriptions that the researcher enables readers to transfer information to other settings and to determine whether the findings can be transferred” (2007). Last, multiple sources of data were provided for a basis of triangulation and to help enhance the content accuracy and validity of the study. This protocol that I used for collecting and analyzing the data, which follows the rigor of qualitative research procedures, ensured validity and reliability of the study.

### **Ethics**

There is a notion that confidentiality does not apply to autoethnographies because the researcher is using his or her own story, but as stories are constructed, there are also “supporting characters” to the “protagonist”. Autoethnographers should not claim full authorship for their stories, they should also protect the confidentiality of the other people in the story and this task can be extremely difficult as the researcher reveals his or her main identity. Autoethnography requires the researcher to adopt creative strategies to protect confidentiality such as using pseudonyms for some characters of the story, “create composite figures based on actual facts to obscure their identities, or let their voices tell the researcher’s story” (Chang, 2008, p. 68). If none of this applies to the topic, the researcher can use the real identities of the participants with their written consent.

By analyzing my own story in addition to the data collected from interviews of other mothers such as myself, the parenting experiences of working mothers of a child with High Functioning Autism (HFA) were depicted in a meaningful way, this has the potential to provide tangible data to the readers with actual experiences from which they can form their own interpretations. For the purpose of this study, the findings were presented in a narrative writing in the form of a story or reflection, a sort of “a day in the life of” that each participant wrote containing a detailed account of a day of these mothers and their children. This was included after a detail description of what I call the “supporting actors” of this study. This section included the background of each woman, and my final impressions on each.

It is important to check with the IRB of the learning institution about the requirements for autoethnographic research and I did that for this study. Written consents were obtained from the participants on this study after I explained to them the purpose and how the interview was going to be conducted, and this was done before they signed the document. According to Chang (2008), although “perfect protection of privacy is not always possible, you should model an honest and conscious effort to adhere to the ethical code of research” (p. 69). I followed all standard considerations at all times such as confidentiality, informed consents, and treat subjects with respect.

### **Summary**

This chapter contains the methodology I used for my study. The research questions and the purpose statement have been included to remind the reader of the focus of the study: to understand the parenting experiences of working mothers of a child with High Functioning Autism (HFA). Data was collected through observations, interviews and field notes with the

intention of triangulating the information. The sample was purposeful with specific criteria for choosing the participants. Data was analyzed through the constant comparative method to look for emergent themes. For the presentation of the findings, I included a narrative in the form of a story or reflection, a sort of “a day in the life of” that each participant wrote. The data that emerged from the interviews provided a rich description in the form of a story of how we, working mothers of a child with HFA, navigate life *one day at a time*.

## CHAPTER 4: FINDINGS AND THEMES

“Does an emotional response lessen or enhance intellectual understanding. “

Ruth Behar

### Summary of Study

Generalizability is an issue that sometimes arises in qualitative studies and is sometimes related to validity. However, in this particular ethnography, we are not using this sample of participants to represent the larger population. It could be interesting to compare experiences of working mothers of children with severe autism to mothers with children with mild symptoms, or even with other completely different conditions such as Down syndrome, but the goal for this ethnographic research is not to find commonalities between cultures, but rather to understand the culture of study in depth.

A researcher can have an idea of what one is looking for, but the beauty of the process comes in the inductive rather than the deductive approach, the surprise of what the final product will look like. I started this process with a general idea of finding other working mothers like me, wondering what these individuals have experienced when raising a child with autism; do we share the same hopes, fears and dreams? How different are our experiences? Do we all have the same support systems? How much support we have from our workplace? Are there any other benefits/policies out there that we are still not aware of? I wanted to find others who were experiencing my same feelings but I was open to what I might find. For this particular study, I purposely weighed the psychological effect of the questions I asked the participants of the pain involved in disclosing very personal challenges

and feelings and how this disclosure might exacerbate the trauma these women were already experiencing, and I did that by first answer the questions myself. I imagined that these women might benefit from being able to talk about their experience, especially to someone who was experiencing something similar. After the original recruiting phase, I was able to secure only one participant, therefore I had to postpone this research for approximately 5 months until I was able to secure two more participants via a snowball sampling process. As a full member of the culture I am researching, I have a deep understanding and knowledge for all these topics, having put myself on their position, I asked one of my co-workers to interview me trying to recreate the experience of answering those deep personal questions to a stranger who knew nothing about my situation.

The present study addressed the following research questions:

1. How do working mothers perceive the experience of raising their first child with HFA?
2. How do these working mothers perceive the experience of balancing work and caregiving responsibilities?

The sub-questions that will be addressed that I hope will contribute to the literature on parents of HFA child are:

1. What are the positive and negative experiences of parenting a child with HFA?
2. What are the barriers to successfully maintaining work-life balance?

After all interviews were completed, I gathered all the pieces of my puzzle from interviews, to field notes, autoethnographic writings and field notes then I laid them all out on the floor and started the review process. This chapter is an overview of what I discovered in the data gathering stage of this research and is organized in three sections. In the first

section, I start by first describing what I call ‘the supporting actors’ of this study. This section includes the background of each woman and the demographics, specifics on the child with autism, a personal reflection from each woman, and my final impressions on each. The second section describes the three main themes and six sub-themes that emerged from my data analysis. The third and final section synthesizes the participants and themes and provides answers to the two research questions guiding the study.

### **Meet the Supporting Actors**

For the purpose of this study, I decided to interview four women that are “experts” on the subject of raising a child with autism. My goal in conducting the interviews was to harvest their knowledge and understanding of a topic they know profoundly, and share it with the world for others to benefit from it.

#### **Lynne**

##### **Background and demographics.**

Lynne is a 49 year-old Caucasian woman with dark blond hair. She works as the office manager for one of the companies where my son receives therapy. She was the only one who responded to my recruiting ad and was the first one I interviewed. She was very pleasant to be around and took her time to respond to each question, she really seemed interested in help other mothers like us by providing all the details she could remember. She has 2 children, Jack who has an Aspergers diagnosis and a daughter who is typically developed. She went back to work gradually as her kids got older and it was not full time until 2011. Her socioeconomic level did not allow her to stay home much longer and only doing odd jobs here and there (i.e. babysitting) but she held as much as she could afford. She

is very well articulate and intelligent. She is very religious but did not share her affiliation during the interview.

**The child with autism.**

I only saw Jack briefly at the beginning of the interview but I could tell he is a very tall and good looking boy. Jack was diagnosed when he was nine with Aspergers and ADHD. He is about to turn eleven. His symptoms were so mild that his parents always assumed were part of his personality. He has not been diagnosed by a doctor, only by therapists and psychologists. Most of his struggles reside on his social skills or lack of. His previous teachers and parents of friends had never picked up on it before because his symptoms were so mild until he started to grow up. He had hit all of the milestones therefore doctors did not notice either, he was not a picky eater, he didn't have any stemming or autistic tendencies. He is not receiving any type of treatment currently as his parents do not feel the need to send him to therapy at this point.

**Personal reflection.**

I do remember a conversation with my mom a month or so ago, a month before Jack was diagnosed or I figured out what was going on. I remember my mom saying when I was done venting, "I don't know what to do." Over the years of parenting, I've been a parent now for a little over 13 years, I remember hearing over and over again, "Whenever you have a parenting question you're supposed to ask your mom or your dad, someone older than you, your grandma." My mom actually said at the end of that conversation, "I don't know what to do. I've never dealt with this." That really hit me, like; my mom doesn't know what to do. I had to find another way to deal with

this. My mom didn't know what to do. I didn't expect that. Your mom was supposed to have the answers to parenting questions or at least have an idea. She didn't know what to do. I didn't know what to do. (Lynne, personal interview, September 2013).

### **Final impressions.**

Lynne talked repeatedly about how she is grateful that she now has a job that allows her the flexibility to be a mom with many demands. She talked about how she is still figuring out how to navigate the world of special needs, the amount of daily mental labor she is exposed to, about how some days are incredibly frustrating and others seem like it is very easy. She talked about her feelings of peer and family pressure of "Oh you have to do this," "You should sign up for this," "I bet your kids would love this!" but she has a goal of try not to overschedule her family on too many things. My perception is that she might still have difficulty in accepting his diagnosis as she recognizes how her son struggles with the social aspects of his condition, especially now that he is a teenager, and yet she does not want to seek any medical or other therapy treatments. Jack does not even have a medical diagnosis and she is not looking to get one either. She sees kids with Autism and other developmental conditions in her job all the time and hears stories of other parents on how their children have outgrown their diagnosis so I wonder if this is her thinking behind it. She did a great job describing her day to day struggles and was very kind to even accept to do this interview, but had a harder time expressing her feelings. Everything was about the child, or the incident, or work. Not so much about how she feels as an individual or how it affects her. She did not elaborate on feelings past the stage of the diagnosis and I felt as if there was a something beneath the surface. A subtext she was not able or willing to talk about it

## **Martha**

### **Background and demographics.**

Martha is a 44 year-old Caucasian female who was born and raised in Poland. She has been married to Jacob for over 10 years and English is not their first language. She has light brown hair and is always smiling. Martha came to this country several years ago and is now an American Citizen but she still keeps several of her European traits. They are both from a European country and they reflect it on their interest for culture and good food, she prepared quite the feast for our interview and was very sweet throughout. Warm and engaging but always appears tired and worn out. Perhaps due to her job, she is an emergency room nurse and has 2 children, Patrick who is her first born and was diagnosed with High Functioning Autism (HFA) at the age of seven (he is currently nine); and Adam who is six years old and typically developed.

This is an upper- middle class family who does not seem to struggle with money. Their house is large and very well appointed nothing overly expensive but well equipped, like nice furniture, high-end electronics, etc. Patrick and Adam are both in public schools, but Patrick requires additional therapy that they contract from private settings as they are able to afford it in combination with their insurance. Her husband has his own business and even though travels for work; he is able to spend a lot of time with the family.

Martha is very thankful that her job allows her the flexibility to be home for long periods of time, as well as providing her with a generous health insurance plan that has helped her tremendously with the coverage needed for Patrick's treatments. Martha is an intelligent, well spoken and well read individual, whom at the end of the interview shared

with me her desired to go back to school and get a master degree. She has gained a great deal of knowledge about autism by researching articles and books, and is always interested and aware of her surroundings, always looking for competent staff that is able to provide the care her son needs. She is Catholic and very religious and feels this has helped her cope with her current situation.

### **The child with autism.**

Martha and Jacob waited nine years to have a child. Since week 25 in the pregnancy, she was put in bed rest and had to take a lot of medication to stop the contractions until week 35 when Patrick was born. Patrick is a very handsome 8 years old with light brown hair and beautiful green eyes. At first sight he does not show typical autism behaviors as his struggles mostly reside on the social aspects.

He was diagnosed first with ADHD when he was six and Martha believes the medication she took during pregnancy has been found to have a secondary effect that caused this. Patrick has been in therapy since then, some being occupational and speech and his mother reports how big of an improvement she has seen since then. Patrick never showed any of the typical symptoms of autism, he hit his milestones at the right age, was speaking fluently since age 2 and was always seeking friendships.

Martha believes that childhood vaccines are to blame for his autism diagnosis that came after the ADHD. Martha reports that she always thought Patrick's behaviors were part of his personality and that he was going to outgrow them at some point. It was not until he started Kindergarten that she realized there was something more and thus the testing began. He is currently in medication for his diagnosis and his parents feel good about their decision.

**Personal reflection.**

Not necessarily rejected, but...what is the word I'm looking for... Oh my goodness is not rejected because nobody can reject me I would hope so, but definitely put in this category... Like people feel sorry for me and I hate that. Maybe there is not even a category but I am definitely not one of everybody... I don't know, nothing negative, I don't want this to sound like this is something negative... Or maybe is my need to feel like everybody else and because I want my kids to be like everybody other kids and maybe that is my need for that feeling. So I also feel my 2<sup>nd</sup> son I feel he is missing on too much, we don't do certain things like group sports because with Patrick we were doing that but it was such a failure because he was not able to participate. And because we are always so busy...so if there is any guilt is the fact that we don't spend as much time as we do and did for Patrick. So there is definitely the guilt there (Martha, personal interview, February 2014).

**Final impressions.**

Martha discussed a number of topics such as her pain and constant tiredness, and her feeling of guilt towards her youngest son. "He is missing out a lot; there are a lot of situations we avoid for both our children" (Martha, personal interview, February 2014). She has not given him the same attention than Patrick and this bothers her tremendously. She recognizes that Patrick requires more attention but nevertheless feels is not a fair situation. She feels bad of not practicing sports as an example, Patrick is not a "team player" therefore he has not been enrolled on any sports, but the youngest constantly asks when is he going to be able to play them. She feels bad of enrolling one and not the other and hence her dilemma on what to do.

“We take Adam for granted” (Martha, personal interview, February 2014). The experience has really taken a toll on her but especially on her family life. She feels her husband is still in denial and it was not until recently that he has seemed to accept Patrick’s diagnosis somewhat. She seems optimistic, mainly because of the progress she has seen so far.

During the interview, Martha’s feelings and expressions fluctuated from happy to sad to hopeless to resigned. She does have a very strong thinking that carries her through this experience, such as not feeling any guilt associated with the medicine she took while pregnant, she made her peace with that decision and feels that if she had not taken it, Patrick would have been born an even more premature baby with all types of medical risks associated. However, she does feel guilty of not seeking a diagnosis sooner. Another topic she discussed in her interview was what it means to be a mother and her gratitude to the job she has as it allows her to spend the time she feels her son requires.

## **Fiona**

### **Background and demographics.**

Fiona is a 45 year-old Caucasian female married to Kevin. She has three full blood siblings and 2 half siblings from her father’s first marriage. Fiona is a very kind individual and is very eloquent and polite when she speaks. During our interview, she talked very openly and was very friendly, just happy to be doing the interview and possible helping others through her experiences. Her family is middle class and at the moment she is not working, Kevin supports them as Fiona stopped working to be home full time with the twins. She is from a Jewish faith but her husband is an atheist, however, both children are being raised Jewish. At the beginning of the pregnancy Fiona was carrying triplets but lost one of

the babies early on. They were trying to get pregnant for years and were only successful on the last try via in vitro fertilization. She gave birth to fraternal twins six years ago and even though one of them, Patrick, was diagnosed early on with a form of a developmental delay, he has progressed so much that is now considering a typical developed child. John on the other hand has a diagnosis of autism. Fiona used to work as an administrative assistant for a State agency but as she decided to go back to school, she is now a stay-at home mom.

### **The child with autism.**

John is a handsome 6 year-old with blond hair and gorgeous blue eyes. He is extremely tall and has a wonderful smile. Fiona first noticed problems with John around 9 months old when he was not developing any language like his twin brother. Testing started on both kids at age one and he was diagnosed with a developmental delay shortly after, since then he has been receiving services from the CDSA first and now through the Special Education branch of the state of North Carolina. He is currently attending Kindergarten in the CCK program and also receives external services such as occupational and speech therapy.

John is a very sweet boy who also has a diagnosis of apraxia, which is a disorder that causes an individual to have difficulty putting sounds and syllabus together in the correct order to form words. This interferes with his constant need to interact with other kids as they cannot understand what he is saying becoming a real frustration for him. This in particular, has present John's parents and added stressful element to their lives as it prevents him from socializing with other kids without adult intervention. He also has difficulty sleeping by himself but he is fully potty trained, and has not eating difficulties other than the typical picky attitudes of kids his age

### **Personal reflection.**

In our family's case, we do attempt to include our unique little man in all things environmental and educational, but mostly fun activities. We do this for the exposure combined with learning what our child's boundary really is. In many instances, if one does not try something new, then our family believes that one might miss the opportunity to experience/sense something outside of their comfort zone. Do these interactions lead to failures? Sometimes yes, so we try again later. Contact with friends and family are dependent upon what activity or family gathering is going on. For instance, when our son's entire family gets together, and I mean the immediate family for Thanksgiving, there is close to forty people including children in attendance. The children go one way and the adults the other. Later on the children are looked in on; you will spot one or two little boys playing independently, or alongside their relatives, but not directly with them. It is not because they are not included; it is because of their unique qualities interfering with their ability to play. For instance, our child is unable to process the activity quick enough, so his interaction becomes limited. Another example for our child is the noise level. With so many family members, there is an abundance amount of over stimulation occurring at once, for our child to feel comfortable to participate. Therefore, we do avoid certain engagements with family ... yes, but not because of the lack of wanting to. There are many instances, when enough becomes enough for our child and if we attend all the family gatherings or large crowds our child shuts down emotionally and loses his connection to those around him (Fiona, personal interview, January 2014).

### **Final impressions.**

Fiona is very devoted to her children. Additional areas discussed by her in our interview was her feelings of helplessness, her love for her children, her pain and suffering and her fears of affect them by showing some of these emotions in front of them. To paraphrase from my notes, she stated:

Rejection is more a personal matter to me as the parent. If I become too emotional my child can sense it, and I can see fear creeping up in him, which can hinder him, which in turn hampers my emotions of not having a “normal” child. Rejection is hard enough as an adult to contend with, but when a child smiles and wants to play with others, and those others do not which to play with him, yes I feel rejected as a parent for not maybe doing something different that could have lead me to have two normal children. Being rejected is a personal demon for me (Fiona, personal interview, January 2013).

Although she identifies herself as being exhausted, she keeps going. As with most mothers in this study, Fiona had no trouble talking about her experiences which I found extremely refreshing and gratifying to find other people who like me, is willing to share their experiences to possibly help others. She was willing and did talk in length about her feelings and how the situation affects her. She has worked extremely hard for her children to make progress and has done an excellent job to stay afloat and well informed. I believe she had difficulty to accept the diagnosis in the beginning just like the rest of us, but has moved on in her search for coping ever since.

## **Roxie**

### **Background and demographics.**

I am a 42 year-old Hispanic female married to David. I am an only child and came to leave to this country full time about 15 years ago and English is not my first language. We are a middle class family and both of us work full time. In addition, I am a part time student about to graduate with a master's degree. My husband did not go to college and is currently employed in the technical support business. We live a comfortable life without too many luxuries but we are able to provide for our son and ourselves with not too many monetary constraints. He is from a Jewish faith but does not practice, I consider myself a Catholic "light" individual, one who believes in God and was raised Catholic but not necessarily go to church every Sunday. Our son is being raised Catholic as it was agreed early on the relationship. The first time I got pregnant, it was not successful and lost the baby, and then it took about three years to get pregnant again. There are no other cases of autism on my side of the family; there is one case of autism on his side of the family.

### **The child with autism.**

Tristan is a handsome 6 year-old with beautiful hazel eyes. He was born healthy and reached most of his milestones up to age two except for feeding. He never transitioned from pureed foods to foods with more texture. He gagged every time and shortly we realized he was not chewing and instead was swallowing the food in whole. He also displayed real sensitivity to noise, textures and crowds. He was diagnosed with a Sensory Integration Disorder (SID) and a developmental delay at age 2 and started receiving services from the CDSA since then. To their suggestion, an autism test was applied and he was diagnosed

when he was 2 and a half with High Functioning Autism (HFA). He is currently attending Kindergarten in a Special Education program of the state of North Carolina and we hope he can move to mainstream school soon. He also receives external services at school and a private setting for occupational and speech therapy. Tristan displays the typical symptoms of a child with High Functioning Autism; he has very high points (such as an excellent set of academic skills) and some low points (such as poor social skills). He is an extremely bright boy who learned how to read since he was about a year old, his expressive language is not to par to his receptive side but he is making a tremendous progress. At school, he is reading and doing math at a first grade level but still struggles with the social aspects and pretend play that other six year-old ones have no issues with.

**Personal reflection.**

Autism has taught me many things, but the most important? To appreciate the little things. I wear my heart on my sleeve; always have and always will. This has caused me many heartbreaks but I will not change this trait of mine for anything. I am devoted to my child and I wear my feelings for him on my sleeve with proud. Every day is a new day and every day there is a new challenge. It is getting through that day and to the end of the day. You just do what you got to do! My life is a constant juggling act and a constant struggle to keep a healthy routine as best as possible but without making it the same either, kids with autism respond well to routines and my child is no exception but he also needs a variety, hence the difficulty to balance both needs. I am often being pulled in two different directions between the expectations of my “normal” life and work, and my duties as a mother and my child’s needs

generated by autism. It was not easy but I finally got to a decision of throwing all the expectations out the window and live a different life than the one I imagined when I was pregnant. Once I did that, it was like if a big weight lifted off my shoulders and I feel much lighter now. Meeting the needs of my son generated by autism often get confused as I try to do too much for him and bypass the fact that he is almost a “normal” child, and as such, I need to also punish him when he is being a brat, and help him be as independent as possible so he can have a future “normal” life (Roxie, autoethnographic writing, October 2013).

Each interview occurred in the participants’ homes and in every case; there was a small period of informal discussion at the beginning of the meeting in an effort to establish rapport. I used a casual but structured interview guide that sought to create a narrative of how the person understands their experience. For instance, some of the questions were derived from my own autoethnographic writings where “support system” and “demands” were recurring themes, and I was interested if others had similar experiences and or similar perceptions. The following questions carried each interview for the scheduled time and generated rich descriptive data. Additionally and give the length and complexity of the interviews they were tape recorded for accuracy. They were created to seek a recount of how they understand the experience:

1. Thinking back to when you first found out you were pregnant, what were your thoughts about the child you were carrying?
2. Tell me about the experience of going back to work after your first pregnancy?
3. Tell me about your experiences in the workplace, how do you juggle the demands from

being a full time worker and a mother? Do you think your gender influences your experiences?

4. How is your support system at home and amongst friends?

5. How do you feel about this situation that you are in as a mother with a child with Autism?

Do you feel rejected?

6. Do you feel that your demands as a parent of a child with Autism are different and/or harder than that of parents with typically developed children?

7. Is there enough information available that can help you deal with these demands?

8. Considering all the challenges that you must cope with, what emotions do you experience?

### **Their Stories**

Autoethnography is often considered outside of the traditional research methods due to the inclusion of the self, which challenges previously established norms regarding the researcher's objectivity. Qualitative research and ethnography in particular, has utilized participant observation and interviews as the primary sources of data collection. Ellis (2004) writes that "good autoethnographic writing is truthful, vulnerable, evocative, and therapeutic" (p. 135). I agree with Ellis specifically in the therapeutic value of this research method, being that this particular characteristic is what attracted me to it in the first place. But how does autoethnography can be therapeutic? There are several ways I could conceptualize the therapeutic value of self-disclosure both for me as the author as well as the reader. First, the process of forcing myself to dig within my deepest thoughts and feelings that I may have or may have not shared in the past, and bringing them to the surface for a conscious examination can be in fact therapeutic. After I shared this concept with my co-

participants, and I showed them some of my “stories”, they all agreed to complete a similar one for this study. Most of them felt the therapeutic concept I was describing just by answering the questions of this interview, and they were eager to continue the journey by writing their own story. Another way to conceptualize this notion, is to have a clear understanding of what happened and how it happened, this has the potential of helping others who are experiencing the same circumstances and are looking for answers.

In the hope that this autoethnography can meet these therapeutic criteria for the readers, I present the following essays from my co-participants where they address in their own words how “a day in the life of...” is about. Each participant chose the title and length of their sharing; they were only given a single instruction of describing how is a day in their life of working mothers of a child with autism. These living situations are imperative to understanding the struggles and joys and everything in between that we experience while raising our children.

### **Lynne’s Home: “The Support System”**

I’m still trying to figure out how to juggle everything. One of the biggest challenges we have is, because we’ve learned about food sensitivities that Jack has dinner is a challenge. I don’t especially enjoy cooking. So I don’t I’m not very good at planning ahead, so a lot of times when I get home from work the question will be, “What’s for dinner?” and I’ll just want to put my head down on the table like, “Oh my gosh I forgot about dinner!” I have a tremendous support system in that my husband is wonderful and has gone along with me on this journey in discovering Jack’s borderline for Asperger’s and mild ADHD. I just try to get through the days sometimes. Some days it’s incredibly frustrating, other days it seems like

it's very easy. I try not to overschedule our family on too many things. That's one way that I'm able to juggle because there's a lot of things that my kids would like to do. They want to do soccer, my daughter wants to do piano lessons and there are things in the cultural center that they would love to, like a certain type of class on how to build a robot and I could sign my kids up for that type of thing but I work full time. The money that I earn needs to go to more important things like groceries.

So although I would like to do all sorts of things and take my kids to this class and that class and this type of lesson and soccer practice and this game on the weekends, our schedule is packed full of school and giving them time to do homework and church and we have our bible study group and allowing time for other things that come up like birthday parties and just being kids is important to us too. I don't want to overschedule my kids because I don't want to turn into somebody that's rushing everywhere certain nights of the week because we made a commitment to soccer practice and then you get less time with your family. So over scheduling is something I'm really against.

My husband, when he grew up, he was very much into sports and enjoyed doing at least one sport during one point of the year: soccer, hockey, basketball, everything. I've told him several times I do not want to spend my weeknights and weekends shuttling our kids from one sporting event to another and they really don't seem that interested in doing it anyway. I fight over scheduling a lot. It's hard because we get a lot of peer pressure, family pressure of "Oh you have to do this," "You should sign up for this," "I bet your kids would love this!" and saying no is hard and sometimes people stop calling to, "You should get together with us for this," "You should do this," "Oh, your kids would love this!" Some

friendships have faded because of it but I just fight it. Until I can have better handle on it.

I do have a tremendous support at work because our office is small and a very personal feel. When I need to take my kids somewhere and my husband's not available, when I have to bring in Jack for his reassessment in a few weeks I know that I'm going to very likely when he's done back home. He cannot stay at work with me all day, he'll be tracked out from school but I do need to bring him home after it's over. I know that my boss will not mind if I do that because she knows that I'll be gone for a half hour and I'll have to come back. I don't know too many places of employment or too many supervisors that think that's permissible, that that's okay; I get tremendous support for that. Sometimes if I've gotten a phone call at work about Jack's behavior from the school they're supportive when I needed to take a few minutes and take some deep breaths and calm down if it wasn't a great phone call or if I need to take a personal call if something happened at home and I needed to step outside for a minute to take a phone call. If the phone rang at work someone else picks it up if they hear that it rang a couple times and I was not able to pick it up. So the support at work, although they understand what I'm dealing with, they support me in other ways which is really great.

### **Fiona's Home: "My Every Day...Creak"**

I acknowledge Leonard Tolstoy's few moments of thought: I have two cities so simplistic that *A Tale of Two Cities* existed because "it was the best of times, it was the worst of times." So today, I sit back rocking and thinking about the basic nature of human kind. Subscribing myself to these moments or even those wonderings of what will and what will be in an in-between life. I choose to open the window before me to remind myself of the

importance of freedom and forgiveness. I feel no absolution to expel from my embrace my children. My sons were born as a combination of love and medical science, three equal gifts and peace. Unfortunately, science and love are never perfect.

To imagine the perfect family and the perfect home in many instances is just a “thing.” Early on during my bliss, a premature death occurred to one of my children, a sadness that still lingers ever so, like a whisper. As my morphine haze released my senses I learned that in giving birth I nearly lost my own life but not that of my children. What was the breath of life to mean except to give you another breath? I instead yearned for more morphine through my veins so I would castrate myself from my pain. In one moment, I went from woman, wife, and mother, to a shroud of mental silence. Outside myself, I had two precious moments that astounded me. Time passed and little incidences eventually led up to monsters, empty dreams, and fear. To hear two specialists later that their patient, my child suffered some forms of a stroke, that would leave him with multiple disabilities. As taken aback as I should have been, I was not. I understood quickly that fairies were short on hand to accept my wish and prayers were too simplistic for my beliefs. The type of surprise I felt for myself were similar to me receiving my positive pregnancy results: questions!

Questions arose on whether the freedom I experience with and for him is going to necessitate his crash and his inevitable burn, or whether I can hold onto my son long enough to let him fly solo and unsteady in order for his lessons for finding a freedom occurs. What secures my sanity is the creaking of my chair as it lists back in forth outside a void. Maintaining my equilibrium is watching as his double soars independently and determined, whilst remembering the one missing. Validation from my quickening rocking movements

shakes me towards my foothold.

Enough of my fear, I say to myself, the time has come to unzip my second self universally and rise off this rocker. At this moment, before you, I wear the face of someone who has the vigor and energy to move forward. While looking back over my shoulder at the person sitting back in the chair, I realize that the mussed hair, hunched shoulders and dark circles enveloping that shell is the other me. My rocker slowly stills itself within the stale air choking my shell until the seams slip open. The awakened me move on.

Reaching for my keys I watch how one shuttles himself down the steps and pulling the car door open to start his day. while the other waits for me to grasp his hand so we can count for the one hundredth time the nine steps down to the car where I open his door settle in his book bag and lock him into his seatbelt. I mentally make note to question the tailor within my mindset and request tighter stitches for the day. I will need to preclude arguments over who won getting into the car, initiate conversations between music and electronic vices, what fears one or the other may have at that moment. Before the door closes and the independence seeps into my sons I remind both boys to do their best is to be their best. All the while, I can hear my chair creaking for me, reminding me that I am still waiting someplace else. With a smile and a nod to a complete stranger, I offer my boys one last wave goodbye. Even with a determined smile on my face, I think about what comes next and pray one or the other does not realize what I hide. I unroll the window down feeling the fresh air awaken the fake me, the pretend smile on my face me.

For others I have noticed that he or she question their own capabilities in doing what I do and wonder how “I do it.” What is it? Is it the person who represents herself as the friend,

mother, or wife, or is it the warrior who spares no others in order to maintain the chaos that ensues my son. Right now, I am only part of me, later I might be the navigator of endless medical paperwork, or director of household responsibilities. If the day suits my son, I may be his cheerleader or his restraints. Holding back gritted teeth while bearing the smirk of sarcasm I advocate against the stupid with a ticker tape parade, all in the name of my son, and for others. Where is that note I wrote myself on how not to let my days bleed seamlessly into others, oh yes, it is in my rocking chair where it appears the tailor has done a good job on my stitches.

**Martha's Home: "Just like any other day, except it is not"**

Today started like any other day, my husband, Jacob, got up first and showered I lay there and listened to the water running while thoughts of today's IEP meeting lay ahead of me, not really knowing what to expect. Our son Patrick was diagnosed with Autism. I felt nervous about the meeting because I knew it was about my child. After my husband showered, I proceeded to go into the bathroom and let the daily routine occupy my thoughts. Going through the motions, we fixed breakfast made sure Patrick was ready to go to school and to not let anything distract him from missing it.

My meeting was scheduled in the afternoon, I proceeded to say goodbye to my husband as he went off to work, he didn't really think much of the meeting and seemed carefree. He is the most amazing and outspoken husband in the world, when it comes to expressing his feelings, not so much. He holds it all in. Today was no different. I took our son Adam to preschool and gave him kisses and hugs, he cried like he had done every other day and with my own emotions today was hard to say goodbye to him. I went to work trying

to be involved and do my job at 100%; I work at a hospital as a nurse and today was not the day to be at work. When I left work, it hit me that I needed to be at this meeting because my daughter needed me to be. I walked in and around the table were 8 people and none of them were familiar with the exception of one, her classroom teacher, Mrs. Bryant. What I couldn't say in that meeting for fear I would cry in public, that lady did. She was able to get Patrick the help he needed for academics. After an hour and a half, we were done and finally my son would get the exact help needed. I don't know what tomorrow will bring, but today ended on a good note.

### **THEMES**

This section describes the themes that emerged from the analysis of interview transcripts. These are the 'parts' of the study that interact to generate the 'whole' experiences of the mothers described above.

There are several factors that can influence the way that mothers can make meaning of their lives. The relationships that these women have to the experiences of raising children with High Functioning Autism (HFA) are dependent on their past histories, their individual circumstances and their perception of those circumstances. All these meanings and perceptions translate into their own ideas and feelings, their own unique way of thinking, feeling, responding and empowering. However, in this study, those perceptions and meanings as different as they are also interconnected forming the themes that applied to this group. The ideas and feelings expressed by these mothers including myself generated the data that were analyzed and boxed in several initial categories or "open codes" (Corbin & Strauss, 1990). These codes were then further analyzed and condensed into a fewer major categories that

were chosen to be the main themes of the study findings. Each co-participant was very unique in their way of sharing their feelings, thoughts and fears, but their experiences contained such similar elements that the main themes blended beautifully and effortlessly. The most predominant themes were Undergo the Demands, Coping and Seclusion.

When writing about these themes, I think about them retrospectively questioning how they came together and it was then I realized that one is the succession of the next. It appears that in this research, dealing with the demands derived from autism, who all mothers agrees are different than our peers of children typically developed, was a consistent theme in all interviews and that none of them had any trouble explaining in detail. If one was to compare demands from a parent of a typically developed child vs. the demands of a parent of a child with autism, and regardless of how can they be interpreted by an impartial party, the perception that us parents of children with autism have is that they are bigger, underwhelming and critical. This is the way we assign meaning to the experience, the way we make it “our own”, and by accepting this simple but powerful fact; we cope.

All women responded to the overwhelming duty of dealing with these demands while trying to balance work-life, which they “graduated” from the denial phase and moved to coping in order to push through. However, it does not necessarily means these mothers are super women with no feelings or robotic attitudes, this test of coping with both the physical and emotional demands of their situations, has led them to an undeniable status or seclusion sometime self-imposed and sometime not.

These themes highlight and understanding of the research questions: How do working mothers perceive the experience of raising their first child with HFA? How do these working

mothers perceive the experience of balancing their job/work and care-giving responsibilities? And the sub-questions of: What are the positive and negative experiences of parenting a child with HFA? What are the barriers to successfully maintaining work-life balance?

### **Undergo the Demands**

The most dominant area of impact these mothers and I have in our lives, and that it was discussed at length and in great detail, is the physical and emotional challenge of undergoing the demands of taking care of a child with autism. This theme had some sub-categories including: handle developmental delays and marathon of appointments.

#### **Handle developmental delays.**

To more specifically understand what it is to take care of a child with HFA, let us first conceptualize these demands. The children of this study range in age from 5-11 with the majority in the 5-6 year range. Like most children with High Functioning Autism (HFA), they are fully verbal, usually toilet trained but with some difficulties to engage in basic self-care activities such as feeding, bathing, dressing, tooth brushing and hair brushing. The levels of help needed from each child vary from child to child, and some might present deficiencies in one or more areas but not necessarily in all. They are able to communicate their needs, wants and/ or areas of fear but sometimes they are “shy” about it. They need constant supervision but no more than any other typically developed child. Their main trouble area is the social skills and their trouble to balance their sensory issues. The data included many descriptions such as the following from Fiona: “You will spot one or two little boys playing independently, or alongside their relatives, but not directly with them. It is not because they are not included; it is because of their unique qualities interfering with their ability to play.

For instance, our child is unable to process the activity quick enough, so his interaction becomes limited” (Fiona, personal interview, January 2014).

These women are routinely adapting and performing specific tasks for their children specific needs such as making schedules, follow a routine, not disrupting the routine, preparing special meals. Lynne describes life with Jack by saying “One of the biggest challenges we have is, because we’ve learned about food sensitivities that Jack has dinner is a challenge. I don’t especially enjoy cooking. So I don’t I’m not very good at planning ahead, so a lot of times when I get home from work the question well be, “What’s for dinner?” and I’ll just want to put my head down on the table like, “Oh my gosh I forgot about dinner!”(Lynne, personal interview, September 2013).

### **Marathon of appointments.**

The world of autism creates for these mothers a part time job. The suddenly gained all this extra labor in relation to extra paperwork, doctor and therapy appointments, learning new equipment (sensory spoons? what are those?), educating themselves on autism and trying to “cure” or at least improve their children’s life. After the diagnosis, nobody tells you that you have just been register for a “marathon of appointments”, or that you are in a race to try different therapies, drugs, different special education options, meeting with social workers and educators, hundreds of evaluations, designing Individual Educational Plans (IEP), fighting with the insurance company to cover your expenses. We go to different appointments and the amount of paperwork to fill out seems endless, all requiring extra time and energy from your other multiple duties as a wife and a worker. Other than Lynne (Jack does not go to any therapy or special education school), all the other mothers agreed that

there is a plethora of appointments they need to attend, Fiona states:

I no longer work as a full time person, and instead became a full time stay at-home mom. With my son, the demands related to his unique qualities, or in this instance demands of an autistic child. Our family denotes John's special needs as being unique. Thus, limiting the stares, questions, and outside opinions, which are seventy-five percent personal and inappropriate. However, there are those few moments when people insert their similar situation, and his or her experiences with also having or knowing a child with unique characteristics who similarly experience, or have gone through comparable medical procedures and so forth. Although, these same demands represent more trips to doctors or specialists every few months for check-ups, blood work, EEG's, sleep tests, and cognitive development testing. Add in the speech therapist twice a week, an occupational therapist twice a week, and a personal tutor. In additions, to the previous sentence, in my child's case, there are visits to a Developmental Psychologist and a Social Behaviorist who targets educational aspects. All these persons are now part of my support system and in many instances ... family. This in our case indirectly affects our support system (Fiona, personal interview, January 2014).

From my autoethnographic writings, "I don't think that I will be going to so many appointments if Tristan was a typically developed child. And that is not really what bothers me, is the fact that for every time you change a provider, or go to see a new doctor or therapist, they have to do an evaluation. I have a special filing cabinet just to be able to have all the hundreds of evaluations performed in the last 5 years, it's ridiculous! Why can't they

use some of his past's reports? Are they that different? It is definitely like having a second job. I used to joke that I knew so much about autism that I could write a dissertation about it, so here I am in graduate school, writing a thesis about autism. Not so funny anymore huh?" (January, 2014).

Martha talked at length about the her experiences on how she feels that the demands she has are absolutely harder than her peers of typically developed children,

Between the appointments we go with Patrick and the worries, and the doctor appointments we go to, the psychologist, the occupational therapist, the meetings in school, making sure his homework is done, getting ready for tomorrow...tremendous! I have a youngest son and I don't have to worry what is he going to wear, what is he going to eat, Adam is six years-old and he is perfectly capable of getting his breakfast, and brushing his teeth, I don't have to say a word to this child and he does everything. He makes a mess with the cereal and he is not allowed to do it, but he is capable of doing it (Martha, personal interview, February 2014).

### **Coping**

Having established a general picture of the circumstances surrounding the demands that these mothers are coping with, the next question is how are they coping? How are they surviving the experience? One day at a time. The women in this study all have examples on how they are doing it but two sub-themes were overarching in this attempt: realizing or conceptualizing the fact that their children's "odd" behaviors were not part of their personalities and that most likely were not going to outgrow them, that there was something else; and the hard and strong decision of not living anymore in denial.

**It is something else.**

All these mothers have a rational way of conceptualizing the experience. They all share a point in time when they realized that all those different and odd behaviors they were observing in their children were not part of their personalities; they were part of something else. Lynne states,

I only figured it out by putting the paper work from Brain Balance with what I know of him at home as a parent and when I filled out the paper work after noticing kids in the waiting room at Brain Balance I started to realize maybe it's not just a personality thing and I filled out the paper work as a parent and I realized that he's borderline for Asperger's and ADHD and it was like somebody hit me on the side of the head with a brick. I had no idea that it was anything other than his personality. So it was so incredibly enlightening to realize that not an excuse, but to realize the reason why he act the way he does sometimes and why his social skills were the way they were and why he struggled with those (Lynne, personal interview, September 2013).

Fiona furthers the concept by explaining the following:

After my son's diagnosis and the initial shock wore off, I called a few of my friends who currently have children with different types of autism, or a combination of learning disabilities. With family, I only had one who experienced similar testing and the earlier diagnosis of their child being on the autistic disorder spectrum. Attempting to define the "situation" of an autistic child also meant discovering if there was something within our family that could lead to or link up any answers as to why, and how do both of our children end up as part of this disorder (Fiona, personal interview,

January 2014).

I also felt the need to define my own situation by contacting other parents of children who I knew were having similar issues, “basically I have two ways of looking at this-either I block myself and pretend is not there or I face it and confront it and move on. What is more beneficial for my son? What is going to help him? So I decided to confront it and move on. This is my new life, this is my new situation and I am going to push through. That became my new attitude” (Autoethnographic writing, October 2013).

### **No more denial.**

Another conceptualization that these mothers share including myself, is that they all reached the decision unconditionally to stop being in denial, mostly because of the love and devotion they have for their children. There is a belief amongst these women that nobody can start to heal and move forward without “graduating” from the denial phase, and they conceptualize most everything they do as their responsibility, the child is their responsibility as primary caretakers. They see themselves as lone agents in the equation of who can and should be the caretaker. This is evident in much of their discourse and stories such as Fiona’s when she states,

Could my spouse handle these same daily experiences, yes, but not in the same instance that I have. This does not mean I did not believe my spouse was unable to do the same as me, but we are two different people with different abilities in handling certain fluxes in life. For instance, my spouse is capable of dealing with small nuances while maintaining calm. On the other hand, I go straight to the point, and do not pass go, until answers are explained or dumber down. So I can explain it to those

who handle my son's medical care and needs on a consistent basis. Is it the feminine in me that could do this ... possibly, but even science is still working on that explanation (Fiona, personal interview, January 2014).

Based on their various beliefs and individual circumstances, all the women engage in a variety of behaviors in order to attempt to cope with their situations. Lynne's belief that over-scheduling is not beneficial for her son or her, leads her to live a more simple life and thus allowing her to relax, "My husband, when he grew up, he was very much into sports and enjoyed doing at least one sport during one point of the year: soccer, hockey, basketball, everything. I've told him several times I do not want to spend my weeknights and weekends shuttling our kids from one sporting event to another and they really don't seem that interested in doing it anyway so that is a relief" (Lynne, personal interview, September 2013). I on the other hand, the busiest I am the better and thus I try to find all types of activities for me and my son that will keep my mind in a constant state of work, hence why I decided to enroll in graduate school and do this research study about my son. From my autoethnographic writing, "I just weary sometimes of not doing enough. I exercise, I do scrapbooking, I organize my house, I do homework, organize my son's birthday parties from the invitations to the thank you cards and all in an effort to always stay afloat" (October 2012).

Fiona feels that family support is important when dealing with her situation, "family, appear as the foundation which build the stabilizing structure of one's family. However, there is also the reality of people who do not have a child with special needs and therefore are unable to offer emotional support, or even understand that with a child with special needs

does require a bit of finesse” (Fiona, personal interview, January 2013).

There are a myriad of behaviors -consciously and unconsciously- engaged in by these mothers that fall into categories of working hard, escape and family support, but in general, these mothers work hard at jobs or at life in order to escape and survive. For the most part, none of these women addressed directly the topic of isolation or depression but it was palpable in certain comments they made that shall remain anonymous as they requested it, such as “I will just hit the liquor cabinet after a long day”, or “When me and my husband got hold of pot we thought we were going to die of happiness”. This is related to the inability to fully cope and thus the need to use other means of escape reality. The next theme will address this inability to cope and it’s resulting in isolation.

### **Seclusion**

Even with all the coping mechanisms in place these women have, again including myself, they frequently hover near a breaking point, but they work really hard and most of them are pretty successful at keeping themselves from getting too close to that edge, “I get to the edge and start to think I am not going to make it, I need to find me a new project, keep my mind occupied. That is the key! Sometimes I just need a glass of wine and go to bed, then I wake up and it is another day and I have more strength and a new attitude” (autoethnographic writing, March 2012).

### **Gender role.**

One sub category that came up to light on this seclusion theme was the gender role. These mothers feel their gender is some sort of involuntary confinement and Fiona was very vocal about her opinions on the matter.

Gender roles, in my opinion can compete with role responsibility concerning who works, monetary expenses, and one's flexibility to be not only a parent, but mental caregiver, nurse and especially the new role as advocate. At first returning to work, I presumed would be as easy as it was the first time around. In this instance, it was not. Going from automatic parent and adolescents to older parent attempting to raise twins, and one with special needs was conflicting. Due to such a change, attempting to work and manage multiple therapists, numerous trips to doctors, and later specialists combined with hospital stays, made full – time job responsibility unmanageable for me personally and emotionally (Fiona, personal interview, January 2014).

Lynne describes how her gender isolated her from the workplace for many years,

The reason why I avoided full time until a few years ago is because I didn't want to have a job where my boss needed to feel as though he or she could not depend on me if my kids were sick and I needed to stay home I would have felt very badly about being considered full time but I have to take off because my child is sick. So I needed either an extremely understanding boss as my kids were young and in preschool or toddlers or that age and then once they got out of the preschool age and they got older and their immune systems got better and they were sick less often I was able to work more but I did not consider full time until a few years ago when they were both older and I was able to understand that working full time is something we needed to consider financially because part time was okay for spending money, pocket money, helped pay for groceries, but it really wasn't making a significant contribution to our

household finances. So we needed to consider full time now that the kids we were older (Lynne, personal interview, Septembers 2013).

Martha describes her gender isolation in terms of quality motherly time that was taken away from her by her employer, “honestly I blame my work for not being able to breastfeed my child, this country does not allow you to stay home more time in the beginning, and it takes a week or more just for the baby to latch on so...yeah, there is not enough time. When I went back to work and being a nurse, there is always the risk for infection so I didn’t feel comfortable pumping in my job in an office next to the surgical floor” (Martha, personal interview, February 2014).

### **Fading relationships.**

All the mothers expressed melancholy at having lost friends, and jobs and some even family members, and not being able to participate in certain social events. The state of isolation shared by these mothers generated copious amounts of crying in some of these interviews, It was very surprising to see by the amount of emotions displayed by these mothers Lynne describes her experience on how she needs to be more “alert”,

Um... during our bible study group study last week there was a situation I didn’t know about that happened until a few days later and um, Jack didn’t know at the time that he had caused some, um what’s the word, he had been playing noodle tag with the boys in the backyard and he’s one of the oldest kids. And he was very excited because he likes to play that game and the other kids are a couple of years younger, they’re shorter, they’re not as strong, they’re not as old as he is, and one of them asked him to stop. And he didn’t because he was excited and he forgot and he didn’t

back off. And he didn't follow the rules. The rules were supposed to be below the waist and he kept this other kid on the arm. But he just didn't understand. This other mom emailed me upset about it and I didn't know about it until a few days later and when I discussed with him he didn't seem to remember that incident at all which bothered me and I wished I had known about it. So it's incidents like that where I need to be more aware of things and we do have a babysitter that takes care of the kids in the backyard and I always ask her, "How was everything," "Did anyone get in trouble?" and to the babysitter everything was fine, but I tend to forget and take for granted just because there were no injuries, nobody got hurt, everything to the babysitter was fine (Lynne, personal experience, September 2013).

Martha described how repetitive incidents of rejection with an old neighbor were her main reason to move from her old home and how now she is happier and relaxed not having to deal with it; however, she misses the other neighbors who she had a great relationship with. She further describes how she is not afraid anymore of cutting up those ties with people, who cannot accept her child,

"I avoid some of our friends who have older kids but mostly because they have shown a dislike of Patrick. Their children do that and the parents don't say anything to their kids and I think is a form of bullying. Life is too short so we have eliminated three or four sets of friends for that reason, kids should not be exposed to negativity. Some people have even expressed their desire to have Adam but no Patrick (Martha, personal interview, February 2014)"

Isolation and faded relationships are a result of the caretaking and coping experiences

of this group of women. Caretaking a child with autism results in a very particular lifestyle for these mothers, one that is isolated from typical life and from the rest of the world. This isolated state forces them to try and cope, but coping still can result in feelings of loneliness and sadness. These mothers, including myself, often feel pushed to the edge by this experience, wondering if coping is really possible, fearing to reach a point of being unable to successfully handle the demands of their lifestyle and resulting in depression, a state that further compromises the abilities to take care of their children and that even though none of them experience it or have experienced in the past; they are well aware that is a possibility.

### **Study Findings: Answers to Research Questions**

This section synthesizes the gestalt/wholes (mothers) and parts (themes) to offer detailed answers to the research questions guiding this study. Specifically, the research questions were as follows:

*RQ 1:* How do working mothers perceive the experience of raising their first child with HFA? They perceived the experience as a process that involves several elements that were clearly reflected as the themes and sub-themes that emerged in the data analysis section of this study and they were: Undergo the Demands (Sub-themes were Handle Developmental Delays and Marathon of Appointments), Coping (Sub-themes were It is Something Else and No More Denial) and Seclusion (Sub-themes were Fading Relationships and Gender Role).

Their lives are usually hectic and they feel as if they are running a marathon, hence why this emerged as a main theme throughout the research. Fiona states “Although, these same demands represent more trips to doctors or specialists every few months for check-ups,

blood work, EEG's, sleep tests, and cognitive development testing. Add in the speech therapist twice a week, an occupational therapist twice a week, and a personal tutor (Fiona, personal interview, January 2014).

Even with all the coping mechanisms in place these women are always close to a breaking point. They all expressed melancholy at having lost friends, and jobs and some even family members, and not being able to participate in certain social events. The state of isolation shared by these mothers generated copious amounts of crying in some of these interviews and the sharing of some of those experiences where sensitive and highly emotional. "I avoid most of our friends who have older kids mostly because they are more aware of the "differences" in our son and they are in an age where they have not mastered the "filter" technique so they show their dislike of our son and I can't handle it. The parents just avoid the confrontation as if it's ok so we decided their friendship is no longer valuable to us. Some of those kids have gone as far as expressing their desire to play with our daughter but not our son...in front of their parents, in front of other people, in front of us, but most importantly in front of Jack! And what do you think that is going to do to his self-esteem?" (Lynne, personal interview, September 2013).

*RQ 2:* How do these working mothers perceive the experience of balancing their work and care-giving responsibilities? In one word, the general consensus was there is no magic formula or "recipe" to follow to be able to accomplish the monumental task of balancing work and life. These mothers recognize how their life changed and how different is from what they envisioned while pregnant. Overall their perception on this balancing act is highly personalized and dependant on each families own circumstances, but at the same time they

share such feelings and anxieties. “I live by the calendar. I just can’t live without it, every step, plan or wish I have has to be done according to my calendar: can I go on vacation on this month? Well that depends on how many therapy appointments we can miss (autoethnographic writing, March 2012)”.

### **Summary**

This chapter presented the study findings and themes by looking specifically at the content of the interviews and field notes. My goal was to present the data in a way true to autoethnography so I decided to first use a condensed and understandable form of describing each woman on the group, then presenting their stories with their own words in the form of “A day in the life of...” I highlighted various subjects as expressed by these mothers such as having in common experiences and fears and feelings related to their children who have some form of High Functioning Autism (HFA). The ways in which the individual women interpret them, were portrayed in vivid emotional detail throughout their interviews and I included them here in the section called Personal Reflections.

Raising these children is like two different worlds colliding, two different realities merging together. Sometimes I think of children with autism as if they are coming from another country, one that I know nothing about and I am completely unfamiliar with their habits, their culture, their cuisine and most importantly their way of interpreting the world. How can you help them if you don’t even understand where they are coming from? How can you help them if their country is completely the opposite of yours? You cannot fathom the idea of them only eating certain things. You cannot understand why the noise bothers them, isn’t there music in their “country”? We need to start by recognizing we are being subject to

a “cultural clash”, then we need to learn their “language”, but this is only the beginning steps of learning about them, perhaps with time and as we gain knowledge we can learn how to “help” them.

Looking at these findings and how the women present themselves as a group, I am struck by their willingness to share their experiences. In addition to being their mothers, they also see themselves as their advocates. This role, I feel is a response to their children’s frailties and it seems to reinforce a deeper sense of commitment to their children. I could not help but being impressed by the positive attitude of all these women. They recognize how their life is not what they envisioned while pregnant, but at the same time they remain hopeful and optimistic about their children progress and future. All these positive attitudes cannot be other than helpful for these children who can learn from their mothers and be independent like them. I feel there is a bond between these women, like being inducted into some sort of a mother’s hall of fame or special club that is not experienced by our peers parenting typical children. A club that is exclusive in the sense that your beautiful child with HFA is the one who granted you access. And I am proud of being part of the “club”.

## CHAPTER 5: ANALYSIS AND IMPLICATIONS

### Summary of Study

*“I took him to a Disney on Ice show last Sunday...First he was all excited to go and see Mickey when I told him where we were going the day before, but as soon as we started driving to the arena he wanted nothing to do with it. I was able to get him out of the car but he kept saying “I don’t want to go in Mommy...I don’t want to go in”. I keep telling myself he will be fine as soon as he sees Mickey and all the other characters he likes so much. I had his snacks in my purse and his noise canceling headset, so I thought to myself “we will be fine”. It was a “Mommy and Child” event so I invited a good friend of mine and her daughter whom my son loves. After handing our tickets to security, we started walking in the crowd to find our seats, and that just proved to be too much for my little man. My friend went in and I stayed behind with a very frightened boy that all he wanted to do was to go home. As we are standing by the door, several people walked by and looked at us: a crying child and mother with a face that went from desperate, to angry, to sad in a matter of minutes. I felt helpless of not being able to calm my child. I felt angry of not being able to tell sooner he was not ready for this experience. Once I realized he was not going to change his mind, I sat with him on a staircase to wait for the intermission to get my friend’s car keys. As we sat there, and he realized I was not going to “force” him to go in, his attitude changed and he started to play, to sing, go up and down the stairs, just passing the time as a “normal” 5 year old will do. I was trying to pretend I was not frustrated. I kept talking to him like if I was not feeling defeated and I almost succeeded on my attempt to convince myself that I was “ok” until an older gentleman from the peanuts stand- who had been witnessing the whole experience*

*without me noticing- approached me. He smiled, said “hi” to him, and then he walked by and squeezed my arm; that was it. It was like as if he understood that there was value in this child, that we were not freaks for not wanting to see Mickey, because most of the other people who walked by looked at us exactly like that, like freaks! Like “what is wrong with you?”, “Why aren’t you inside watching the show instead of sitting in the stairs?” I wanted to scream at them that just because I didn’t have a total nervous breakdown does not mean I am “ok”. As my tears starting to flowed, I looked back at the old man with gratitude. I then hugged my little man and reminded myself that it is ok not to be “ok” sometimes”.*

### **Conclusions**

This research study has been focused and guided by the research questions at all times. The questions posed were:

1. How do working mothers perceive the experience of raising their first child with HFA?
2. How do these working mothers perceive the experience of balancing their work and care-giving responsibilities?

The sub-questions that were addressed and that may contribute to the literature on parents of HFA child were:

1. What are the positive and negative experiences of parenting a child with HFA?
2. What are the barriers to successfully maintaining work-life balance?

Based on my analysis of the data, the answers to the two guiding research questions are:

*RQ1:* How do working mothers perceive the experience of raising their first child with HFA? All the participants of this study, including myself, expressed the common theme

of being overwhelmed by the experience of raising your first child who was diagnosed with HFA. The diagnosis just adds to the uncertainty and anxiety of being an inexperienced mother dealing with all the duties and tasks associated with motherhood for the first time. They perceived the experience as a process that involves several elements that were clearly reflected as the themes and sub-themes that emerged in the data analysis section of this study and they were: Undergo the Demands (sub-themes were Handle Developmental Delays and Marathon of Appointments), Coping (sub-themes were It is Something Else and No More Denial), and Seclusion (sub-themes were Fading Relationships and Gender Role).

These mothers survive the experience day by day by coping in many different ways that vary according to their backgrounds and beliefs, but one common trait is the physical and emotional challenge of undergoing the demands of taking care of a child with autism, and these demands we all agree to be a common denominator amongst us. Through the stories told in the interviews, I was able to compare my personal struggles with theirs and discovered how close and similar our experiences are. My co-researchers show little to no awareness of the impact their words can have on other mothers and their lives, but once they realized how I was being affected by them, they were even happier to be participants in this study than originally.

*RQ 2:* How do these working mothers perceive the experience of balancing their work and care-giving responsibilities? In one word, the general consensus was there is no magic formula or “recipe” to follow to be able to accomplish the monumental task of balancing work and life. These mothers recognize how their life changed and how different is from what they envisioned while pregnant. They are fully aware that their “mommy duties” are

just the newest addition in the already long list of hats they wear on a regular basis. These mothers agree that just by being aware of this fact helps with the realization of searching for methods to be able to balance their hectic lives. The endless responsibilities, the stressful feeling of the situation, and the added emotional charge to their lives could be an unquestionable reason to send anybody into a depression state of mind, however, and in spite of all of this, they remain hopeful and optimistic about their children progress and future.

Women's responses to demanding circumstances such as the ones these mothers go through vary from person to person and in this group of mothers is no exception. Nevertheless, these mothers often sacrifice their family time when they cannot find a way to manage both "jobs", and they struggle with feelings of guilt, stress and being overworked. Overall their perception on this balancing act is highly personalized but at the same time they share such feelings and anxieties.

Given the lack of research that included experiences and stories about working mothers of children with HFA, this study was a way to rectify the omission and give a "voice" to these mothers, as well as myself, to have them express and share their feelings and thoughts about the balancing act between both their main responsibilities: motherhood and workplace.

### **Final Thoughts**

If there was a segment of this study I was the most afraid to write about, it was this one. I wanted to make justice to all the working mothers out there that may benefit from reading this research, therefore making meaning of the data was in fact an extremely daunting task for me. What conclusions can be drawn from the findings on these research

questions? I heard the challenge when these mothers talked about having to juggle numerous tasks in order for them to take care of their children. I heard the sadness when these mothers voiced their fear and worries about what can the future bring to their children. I also heard determination, resilience and above all unconditional love when they talk about their children and what they mean to them. We heard how do they define their experiences of raising their children with HFA, and how without saying it with all the words, these mothers define their experience of balancing their work and care-giving responsibilities.

My personal struggles with raising a child with HFA is what led me to a place that generated the idea for this thesis. If I was going to spend six to twelve months of my life researching a topic to graduate, I might as well do it on a topic I am passionate about. And what a better topic for a mother than her own child. I needed a better understanding of what this experience of raising a child with HFA is all about, but mostly, I wanted reassurance that I am not the only one who feels this way. The feeling of isolation does not sit well on any scenario especially on this particular one. This need for answers has led me in this journey from the proposal stage, to the research, to the writing of this autoethnographic project.

Additionally, and due to the fact that in my search for solutions I barely found any qualitative research that could give me any answers to my several questions, I embarked on the journey of self-discovery and learning with the dual purpose of finding answers not only for me but for other working mothers out there whom like me, are in the search of the same. This study, therefore, offers some ideas and recommendations for mothers as well as for employers who wrestle with significant work/life issues. Towards that end, this final chapter is organized into three sections: first, the implications of this study's findings are discussed in

light of the existing literature as presented in chapter two. Second, and holding true to the autoethnographic method, the findings are re-presented in terms of questions and answers that are important to mothers of HFA children as well as employers seeking to provide W/L balance options for this type of employee population. Third and finally, the chapter concludes with implications for future research and practice.

### **Implications**

This section offers connections between the existing literature and the findings of the study. Specifically, and as presented in chapter 2, literature on autism, mother culture, and work/life balance is addressed. The purpose of this chapter is to illuminate any new contributions to the literature that could be proposed as a result of the study. This chapter is organized by research question for ease of reference. Because the two research questions drew from different literature streams (e.g., question 1 primarily focuses on mother culture, and question 2 primarily focuses on W/L balance), organizing by research question rather than literature stream seemed most appropriate.

#### **Implications for Research Question 1**

How do working mothers perceive the experience of raising their first child with HFA? To create a basis for the understanding of this study, it was necessary to devote a section in the literature review and talk about Autism from different angles. Both professionals and individuals have difficulty conceptualizing what it is, where it came from but specifically what causes it and how to cure it. For this study, the areas that seemed the more relevant to cover were symptoms and interventions. The literature states that diagnosing autism is a difficult task due in part of the multiple possibilities of presentations

as well as the variety of symptoms that can be present and the level at where that symptom is. “The development of standardized tests to assess autism, particularly in young children, is a topic of considerable interest in the research community” (Matson, Nebel-Schwalm & Matson, 2007, p. 38). There is a connection found between this concept in the literature and the data from this study. In two of the participants cases (Lynne’s and Martha), it took them years to realize the traits they were seeing in their children were related to Autism and not to their personalities. The symptoms in Jack for example (Lynne’s son) were so mild that neither his teachers, parents nor medical practitioners noticed until he was almost nine years old. Autism is a neurological impairment and does not appear to be emotionally based; it is statistically more prevalent in boys than girls being the male-to-female ratio of approximately 4:1 (Dworzynski, Ronald, Bolton, & Happe, 2012). This proved to be another connection to our study where all the children who participated are boys.

The research participants of this study were working mothers who identified themselves as the primary caregiver of the child with HFA. Consequently, the identity of “primary caregiver” is relevant to this study. In Sevon’s (2011) study, the researcher call to attention that most western women believe being a “good mother” requires intensive mothering. This study points out how first-time mothers have additional stress and conflict just by adding the factor of being “new” to motherhood, but they are also concerned about other issues. If this is true for most first time mothers, it is only natural for them to miss out on early signs of autism or other developmental disabilities. This proved to be true on the participants of this study, Martha states: “I was so concentrated on trying to be a good mother, prepare fresh food for the new baby, and make sure everything in the house is clean

and safe that I was not able to see the signs. I go back to the first years of Patrick's life and they symptoms were there; I just didn't see them" (Martha, personal interview, February 2014).

There is no denying that raising a child with autism is a stressful process and just about every study reviewed in the literature touched this topic one way or another, however, the severity of the disorder plays an important role on the levels of such stress therefore, and for consistency issues on this study, a sub-culture of only parents of children with HFA were recruited to participate. Most studies currently in the literature look at parenting the entire autism spectrum without making distinctions between mild, moderate, severe or high functioning autism.

There are only a few articles on women and the role of mothering, or on working mothers of children with disabilities (Lewis, Kagan, & Heaton, 2000; Porterfield, 2002); and even fewer articles that directly addresses the mother's experience but they were covering a variety of severe disabilities including developmental disabilities and genetic abnormalities rather than focusing on just one such as High Functioning Autism (HFA) (Lawrence, 2008; Read, 1991). The data from this study will be a contribution to the literature on the specific sub-culture it was focused on: working mothers and their experiences on parenting children with HFA.

### **Implications for Research Question 2**

How do these working mothers perceive the experience of balancing their work and care-giving responsibilities? The idea of balance is a central issue for any employee but in particular to working parents. "Applied professionals in business and policy arenas struggle

to find solutions to the “challenge” workers face in combining their work and family lives” (Grzywacz & Carlson, 2007, p. 455). Work-life balance is a term to describe “those practices at workplace that acknowledge and aim to support the needs of employees in achieving a balance between the demands of their family (life) and work lives (Jyothi & Jyothi, 2012, p.35). Working mothers in general have this component added to their career when they become mothers; the participants of this study have an even additional component added to their workload: the special needs of their child.

“Work-family balance is at the core of issues central to human resource development (HRD). Indicators of balance have been associated with greater employee commitment” (Grzywacz & Carlson, 2007, p. 456). There was connection found in this study between this concept and one of the participants, Fiona expressed her discontent with the system by saying “it was so difficult for me to come home after 9 hours of a stressful job and find out that I needed to fill out a 20 page evaluation in order for my son to receive the services he needed. Then cook dinner, clean the kitchen, finish laundry, prepare lunches for me and my husband for the next day and prepare myself for the meeting in the morning. I ran out of time constantly; forget about trying to talk to your husband to see how his day was, and how about some little time to play with the kids? I was exhausted all the time, I had to stop working” (Personal interview, January 2013).

The field of HRD can benefit from learning about working mothers who like Fiona, failed at her attempts to balance her career and life and decided to leave the workforce. This disconnects between the literature and the life of these mothers can be remedied by looking closely at the added demands these worker have when parenting a child with HFA versus a

typically developed one. Research in retention and turnover shows the significant impact that has on organizations when employees leave the workforce voluntarily by estimating that it takes between 25-200% of an employee's annual salary plus the cost of benefits to replace and train their substitute (McKinney, Bartlett, & Mulvaney, 2007; Linhartová, 2012).

### **Autoethnographic Answers: Implications for Mothers of HFA Children**

The previous chapter of the study findings does encapsulate the data that came out of this research study and speaks directly to the original intent of finding the answers to the research questions, however, given my personal incentive for this research to provide me and other working mothers out there with a better understanding of our own personal experience with a therapeutic intent, it seems important to view that experience in relation to the findings. What did conducting this research study meant to me and what did I learn? The central aspect to Human Resource Development (HRD) is to “focus on the central goal of developing human potential in every aspect of lifelong learning” (Swanson & Holton, 2001). On average, the work-family policies seems to represent that organizations are providing a supportive working environment for working mothers even though they were mostly created by men. Work-life balance is usually a program that is the responsibility of the human resource function within organizations. The HRD function supports and advocates for all workers and as a working mother, one of my goals was to acquire individual learning from my experience of raising a child with HFA, and having shared this experience with three wonderful loving mothers, I can say that the objective was met and then some.

“Autoethnography represents a significant expansion in both ethnographic form and relational potential. In using oneself as an ethnographic exemplar, the researcher is freed

from the traditional conventions of writing. One's unique voicing—complete with colloquialisms, reverberations from multiple relationships, and emotional expressiveness—is honored. In this way the reader gains a sense of the writer as a full human being” (Ellis & Bochner, 2002, p. 14). This quote clearly exemplifies the interest driving this research: to present the lived experiences of mothers of a child with autism-including mine- in a non-traditional way of writing.

As Chang (2008) describes, autoethnographers “attempt to achieve cultural understanding through analysis and interpretation. In other words, autoethnography is not about focusing on self alone, but about searching for understanding of others (culture/society) through self” (2008, p. 48-49). From the data collected in the interviews, a rich description of their parenting experiences generated the following narrative where data is weaved together from all corroborated sources. Staying true to the world of autoethnographies, where one's voice is honored and there is flexibility in the writing style as is atypical from other forms of research, I present the answers found as a conclusion segment for this study.

**Question: Am I Alone?**

Answer: You are certainly not alone. The most important and more satisfying of my discoveries was that in fact, I am not alone in this experience. I used to think that because I am fortunate that my child is in the high functioning side of the spectrum I was probably “making a big deal” about how I felt about my struggles and maybe I just was not working hard enough. Therefore my pleasant surprise to find others like me, struggling with the same concerns, living with the same fear of what the future holds for our children, dealing with the

myriad of appointments and therapy sessions, hoping to find the best way to balance life with work and trying to “survive”.

Finding this was a welcoming feeling of gratitude for these women who were kind enough to share their deepest thoughts and feelings with me. It generated a deep satisfaction effect that validated my resolve to do research on this topic and reinforced that my quest to give the best of this world to my son and to myself by pushing through the challenge and allowing myself to be happy about it is applicable outside my family.

**Question: Is Raising a Child with HFA Hard?**

Answer: Yes it is. I always wonder if I was allowed to complaint about the experience. I felt I was not allowed to “suffer” like my peers who have children with severe autism. Who was I to complain when I have a child who can talk to me and tell me he loves me? Who is aware I am his mother and misses me when I am gone? A child who for the most part is aware of his surroundings and makes a tremendous progress day by day? The feeling of over-dramatizing my situation haunted me. I now feel a great deal of support and validation that my perception of raising a child with HFA is hard on its own and I that I am allowed to feel that way as it is my own experience, and the meaning that I assigned to it is what makes it real for me.

**Question: Should we be Forced to Always Segregate our Children?**

Answer: Absolutely not. Prior to this research, more than often I consented to the idea that I could not expose my child to mainstream situations and experiences and that I have to always find him activities with the words *special needs* in the title. And even though I have been told many times by the specialists (doctors, social workers, therapists) that this is not necessary at all times, I often did it thinking it was the best for my child, because he was not ready to

mainstream in the world. But supplementing from the other mothers testimonials; isolation is not the key. I want him and me to be included on all activities from the world outside autism, but most of all I want him to feel welcome. How will this happen if he grows up not being expose to the world? He is at an age where he is still not fully aware of rejection, but once he gets to that point I want him to be prepared. I want him to be included and he has the right to be.

**Question: Should we Constantly Live in Fear of the World Outside Autism?**

Answer: Absolutely not. Living in fear of what is outside the world of autism is paradigm that needs to change. The culture is changing and more and more there are places from restaurants, to theme parks that are changing their policies when it comes to making accommodations for children with special needs. If the culture is changing we need to change along with it. We need to allow ourselves to be proud of our children and think that we have equal rights to live in the world just as our peers of children typically developed even if we cannot participate fully or 100% on the dominant cultural norms.

Every Friday we go out for dinner and we tend to choose the same places my son is familiar with and does not struggle with the noise or the crowds. Last week we decided to try a different one and the wait just to get a table was of 1 hour. We debated if to leave or not but the place had a fish tank that entertained him for at least 20 minutes, the rest of the time he asked for his iPad and we gave it to him. I used to feel guilty about letting my child play with his electronics but after hearing the stories of the mothers in this study, I decided that I will not feel guilty anymore. There were other children in the restaurant also waiting on a table and they were not as well behaved as my son, even when their parents also gave them their

electronics to play with. After all, isn't the same when our parents used to let us bring a stuffed animal or a book to a restaurant so we could entertain ourselves while they dined in peace? So why are we in constant fear of what society will think about the world we live in plagued with iEverything? We should not!

**Question: Can we Truly Balance Life and Work or is it Just a Myth?**

Answer: It depends. What made me think that this was going to be easy? Ok I get it, is not. But it is not impossible either. I found myself in conversations with other mothers thinking about how different our lives are compared to our peers of typically developed children, and we all agreed that even though we believe our workloads are bigger and heavier, this is our reality. They have their own too and to them, it is the same struggles and fears we have. We have therapy evaluations; they have annual evaluations. We have IEP meetings; they have PTA meetings. We have therapy sessions; they have soccer and baseball. We have jobs; they have jobs as well. And we all have to eat, do laundry and clean our homes. We all have hectic lives and the key to correctly balance our work and life does not rely on our children and how they are or how they are not; that sole responsibility depends on the type of person we are as an individual. The sooner and faster we entertain this idea, the better off we will be and that distant utopian dream of work-life balance will be not so distant anymore.

**Question: Can the Barriers to Work-Life Balance Overpower our Happiness of Motherhood?**

Answer: Only if we let them. We have the power; not them. I left this question to last for the simple reason of individuality. As human beings we are all unique in the way we process our thoughts and emotions, therefore, an answer to this question can be *it depends*. But if we look

further, past the appearances of the impossible we will realize that things can change and these mothers I interviewed share yet again one more trait: we believe in ourselves. And when you have enough self esteem as a mother, you can make miracles. We have the power to change, we have the power to adapt, and we have the power to be happy.

Every single one of my co-participants shared with me the tremendous and non-measurable love they have for their children with HFA, and how regardless of how hard the experience of raising them is, they will not change it for anything in the world. All we have to do is let those exact same words sink in deep in our brains, this way we will believe once and for all that there are solutions to these issues, they just have to be taken up and executed.

### **Summary of Findings**

The three overachieving themes that came out of the findings were: Undergo the Demands, Coping and Seclusion. This research was intended to be an investigation into the way working mothers create meaning from their experience of raising a child with High Functioning Autism (HFA) and how does these experiences contribute to their capabilities to balance work and life, therefore, a work-life balance lens can be used to further understand them.

The experiences of these working mothers create some feelings of despair and isolation that forces them to cope with their role of caretakers, in part because the culture does not readily incorporate the children casting these mothers into specific lifestyles. This level of work that their roles require, coupled with the isolated lifestyle, segregates them from a regular interaction from the world creating a disconnection and making it harder for them to balance both of their worlds: work and life.

## **Work-Life Balance Lens**

Within the theoretical literature there is an abundance of material that looks at the process of work-life balance. Although these women did not specifically say “I am trying to find a work-life balance”, in essence they are. They are more inclined to say how are they trying to “survive” the experience, or to cope, and they do this in their own way by conceptualizing the experience based on their individual backgrounds and beliefs. There are obvious differences but also several similarities in how these women understand their situations and how they frame their lives translating into the meanings they give to their experience of raising a child with High Functioning Autism (HFA).

## **Recommendations for Further Research**

During the course of this research study I experienced the desire to work towards changing the current system of raising a child with HFA. There are so many ideas for future research that emerged from this study. After completing this study, I find my brain flooded with questions. For example, can reflective tools help in any way these working mothers to help them with work-life balance? What is being done by those in the medical and educational fields to understand the mothers of a child with HFA? And what about the fathers, how do they perceive the experience of parenting a child with HFA? Are they similar or different? What about the siblings? How do they define their experience of living with a child with HFA? While the participants of my study were a small representation of the culture, they were diverse enough to project a very close concept of the group as a whole. Would the data represent differently to mothers of children with severe autism? On this note, and given that there is almost no research done on raising a child with HFA, it would be

beneficial to conduct further studies but in a variety of areas and perhaps a bigger sample population. It would be interesting to redo this same study with a bigger and different group of women and then compare outcomes. Further, this study can be expanded by addressing mothers from a different geographical area or target specific ethnic populations.

Even though there was a briefly spiritual discussion of being able to cope due to the guidance of a superior being named God, it is an interesting potential study: how does spirituality relate to the mothering of children with HFA? How do different religions such as Muslims, Jews or Christians view and participate with families of children with HFA? I believe it will also be interesting and worthy to hear what these working mothers of a child with HFA want those in the medical and educational fields to do research on. Once the topics are selected, and then perhaps the next question will be, do we want qualitative or quantitative research? Again, given the lack of studies on this population in general, the field is wide open for further contribution.

I firmly believe that the best way to make changes on any system is to show how the system affects the individuals, something to which I hope this study will contribute to. In the process of demonstrating what it is to raise a child with HFA while trying to balance work and life, I find it important to ask both my co-participants and myself for recommendations for future action. My goal was to compile the vast knowledge these mothers have as they are consider the experts on the topic and share it with the world, and they happily complied with my request all the way to the last part of writing a small essay on their experience. The following section includes all our suggestions combined.

### **Implications for Practice, or ‘The To Do List’**

At the end of each interview, I asked each mother to share with me some final thoughts that could include everything from a story to a list of things they would like to see change. Most of them chose the *to do list*. The primary areas they would like to see change in the way the educational system handles their politics and policies, and second; the aid the government provide to children diagnosed with autism in general

#### **Education.**

It is not an easy road to navigate through and is not personalized enough for children in different areas of the spectrum; you cannot expect to serve children with HFA properly when you put them in a room with other children with severe autism. The literature discusses how critical it is for all the parties involved to be in the same page. The educational team who these mothers develop the goals and accommodations for the child’s Individualized Educational Plan (IEP) is learning about the child’s home and educational history. The pediatrician not only provides information to the mother but also learns from her about the child so he can tailor his intervention. The social worker who provides community outreach services to these mothers is learning from them the type of programming the mother thinks might best meet her child’s needs. It is imperative that each and every one of these individuals identify themselves as both, provided and learner.

#### **Government help.**

Most of these mothers shared their discontent on how there is still no law that forces insurance companies to provide coverage for these children. There are not even enough medical specialists in this area capable of treating them. Martha shared with me her

frustration of having to wait months to be seen by a neurodevelopmental pediatrician, and we live in an area where we have access to specialized care in many areas, unfortunately autism is not one of them. Perhaps if the government provided the necessary findings, there will be more therapists in school; there will be more teachers and more programs to cater to this population of children with HFA with no “cookie cutter” approaches and more individualized methods.

### **Implications for Myself**

After I honored the typical format for this Chapter 5, I feel the need to add a last and final section to honor the research design as well, so in a true autoethnographic format, a new layers needs to be included: what are the implications for me as a working mother of a child with HFA? I decided to write a short paragraph to illustrate what this study has give me as no other in the literature did and one word can summarize my thoughts: hope.

I am leaving this research experience with hope that just like I was able to find these three mothers for this study, there are several others out there who have the same feelings, thoughts and experiences and are ready to share them with the world. I have hope that medical practitioners, education and government leaders and organizational administrators will benefit from research like this by opening their eyes to the world of autism in a more personal and raw way than with graphics and percentages. I have hope that other mothers out there who feel alone like I once felt, will find this research comforting and reassuring that they are not, and that if we unite and fight for our children; we can make a better world for them and for us as their caregivers.

## **Summary and Personal Thoughts**

This research study was conducted in order to fulfill the requirement of a master's degree. It was done to explore the lives of working mothers raising children with High Functioning Autism (HFA) in a specific geographical, and created following the format of qualitative research to be able to gather their thoughts, ideas and perceptions on the experience of motherhood and their ability to balance work and life. This final chapter encapsulated the major findings and revisited the questions that carried the whole study. Recommendations for future research and desired changes were included at the end. Overall this research was a personal and difficult endeavor very close to my heart, and I hope it contributes to the public perception of what working mothers experience while raising children with HFA.

While the main goal of this study was to provide a "voice" to those working mothers of a child with HFA, including myself, I feel the most important practice that came from this research is for the medical and educational community to also give voice to these mothers. I urged others to continue doing qualitative research on the juggling acts of balancing work and life by the mothers in their community of children with HFA. As noted in this chapter and the literature review, there is a distinct deficit of qualitative studies where mothers of a child with HFA are able to express in their own words what is like to have a child of special needs. So I feel there is a desperate need for future research that focus in the unique voice these individuals have in regards of his or her culture. My hope is that this study opens the door for all of those possibilities.

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## APPENDICES

## Appendix A

### **Email to Companies for Initial Recruitment**

To whom it may concern,

My name is Roxana Shevack and my son is currently receiving occupational therapy/other therapy in your center. I am currently enrolled in NC State University in a Master's program that requires me to write a thesis, for that purpose I have chosen to study one of the groups I belong to: working mothers of a child with autism.

In order for me to accomplish this task, I am looking for volunteers to participate in a research study that seeks to understand the parenting experiences of working mothers who are trying to find balance between work and family. For that reason, I would like to ask for your permission to post the attached document in the lobby of your office to possibly recruit participants for my study.

Please let me know if you have any questions about the study itself or anything else about the process.

Hope to hear from you soon;

Thanks!

Roxana Shevack

(phone number)

(email)

## Appendix B

### Sample of Recruitment Flier

#### **“OUR” 1 IN 88 CAN’T WAIT!!!**

Every 11 minutes, a child is diagnosed with an autism spectrum disorder. 1 in 88 children in the United States is on the autism spectrum; 1 in 54 boys.

Are you the mother of one of these boys or girls? If yes, I am looking for you!!!

I am a master student at NC State University conducting a research study to learn about the experiences of working mothers of a child with High Functioning Autism (HFA) and how do they balance their work life with their family life.

If you are:

- Over the age of 18
- Have a child diagnosed with any form of HFA (preferably the first if you have more than one child)
- Currently employed

Please contact me and share your story. I only need 2-3 hrs. of your time.

It is not easy to have work and family responsibilities, and if you have the added component of parenting a child with special needs, then life just became even harder. Sometimes it is not easy to confide in someone close to us such as family and friends, and talking to a stranger can be easier. This is your chance to have a “free” counseling session where you will be able to complaint, share happy thoughts or just talk about your experience and be LISTENED!!!

Not sure if you can participate? Contact me for more information, and then decide. Your participation is voluntary and confidential.

Let’s make a change for our children!

Roxana Shevack  
(phone number)  
(email)

Appendix C  
**Sample Email Response to Participants**

Dear Participant,

First of all I would like to thank you in advance for accepting being part of this study. As a working mother of a child with autism myself, I can relate to many of your life situations and would like to provide you with an opportunity to voice your opinions and experiences on balancing work and life. Now let me explain what your participation will entail to.

I am currently enrolled in a master program of Human Resource Development at NC State University and this research thesis is one of my requirements to graduate, but to me is much more than that. My son is my inspiration along with mothers like you who are struggling like me to balance our multiple demands from both fronts: work and home. I would like to share with the world our experiences as working mothers in special circumstances, with the hopes than organizations can understand our roles better in order to provide better accommodations and support systems in the workplace.

Your participation in the study will be a twofold: first I will need to interview you for about 1 hour to 1 hour and a half, and then I would like to meet a second time after I have sent you a transcript of the interview to discuss any questions or last comments you may have. I know we all have busy lives so I will make my best effort to accommodate your needs into the scheduled meetings. The transcripts from your interview will include ONLY your aliases. Data will be recorded digitally and will be stored on a password-protected laptop where only I have access to it and the data will be permanently destroyed five years after the study concludes.

I hope that this experience will also be helpful for you and gives you the opportunity to express your feelings as much as you desire. Sometimes it is hard to confide in someone close to us such as family and friends, and at least on my case, I feel as I don't want to impose on my friends bothering them with my fears or concerns, and I have found that it is easier and sometimes even more productive to talk to a stranger, so you can look at this experience as a "free" counseling session where you will be able to complaint, share happy thoughts or just talk about your parenting experiences in general, with someone who is not only familiar with most of what you are going through, but also an ally on your side.

Please let me know if you have any questions and I will do my best to explain. Thanks so much and I look forward to be working with you.

Regards;  
Roxana Shevack

Appendix D  
**Informed Consent**

**North Carolina State University**  
**INFORMED CONSENT FORM for RESEARCH**

Title of Study: It is *something else*: An autoethnographic journey of working mothers parenting a child with HFA

Principal Investigator: Roxana Shevack

Faculty Sponsor : Dr. Julia Storberg-Walker

**What are some general things you should know about research studies?**

You are being asked to take part in a research study. Your participation in this study is voluntary. You have the right to be a part of this study, to choose not to participate or to stop participating at any time without penalty. The purpose of research studies is to gain a better understanding of a certain topic or issue. You are not guaranteed any personal benefits from being in a study. Research studies also may pose risks to those that participate. In this consent form you will find specific details about the research in which you are being asked to participate. If you do not understand something in this form it is your right to ask the researcher for clarification or more information. A copy of this consent form will be provided to you. If at any time you have questions about your participation, do not hesitate to contact the researcher(s) named above.

**What is the purpose of this study?**

The purpose of this study is to gain a better understanding of the work/life balance (WLB) experiences of working mothers whose first born was diagnosed with High Functioning Autism (HFA). At this stage of the research, Autism will be generally defined as a complex disorder of brain development with a broad range of severity, where HFA is on the end of the spectrum where individuals present less severe symptoms.

**What will happen if you take part in the study?**

If you agree to participate in this study, you will be asked to first fill out a questionnaire to determine eligibility and collect preliminary information. In addition, you will be asked to participate in one semi-structured interview lasting approximately 1 hour. I will make a reasonable effort to accommodate your schedule and will provide you with a copy of the protocol that I will follow during the interview process. The research will take place in the Raleigh Durham area; I will make a reasonable effort to find a convenient place for all parties involved to meet for the interview.

**Risks**

There are no risks associated with your participation in this study. Your identity will be kept anonymous through this research process. Data analysis will be performed using pseudonyms for the participants, and only the researcher will have access to the password protected list that triangulates names with pseudonyms. You will be given the opportunity to read the transcripts of your participation in the interview before they are used in the study.

**Benefits**

There is no direct benefit to participants. As an indirect benefit, we anticipate the results from this study to have the potential to help organizations, policy makers, medical providers and public school systems to increase a better understanding of the culture of working mothers raising children with High Functioning Autism (HFA), as they develop programs tailored for this specific population.

**Confidentiality**

The information in the study records will be kept confidential to the full extent allowed by law. Data will be stored securely in a password protected laptop computer owned by the researcher. No reference will be made in oral or written reports that could link you to the study. You will NOT be asked to write your name on any study materials so that no one can match your identity to the answers that you provide. Any data that includes your name or identity will be kept in an undisclosed location inside a locked cabinet.

**Compensation**

You will not receive compensation for participating in this study. If you withdraw from the study prior to its completion, you will not be penalized.

**What if you have questions about this study?**

If you have questions at any time about the study or the procedures, you may contact the primary investigator, Roxana Shevack at [roxana\\_shevack@ncsu.edu](mailto:roxana_shevack@ncsu.edu) or 919-515-6642.

**What if you have questions about your rights as a research participant?**

If you feel you have not been treated according to the descriptions in this form, or your rights as a participant in research have been violated during the course of this project, you may contact Deb Paxton, Regulatory Compliance Administrator, Box 7514, NCSU Campus (919/515-4514).

**Consent To Participate**

*"I have read and understand the above information. I have received a copy of this form. I agree to participate in this study with the understanding that I may choose not to participate or to stop participating at any time without penalty or loss of benefits to which I am otherwise entitled."*

Subject's signature \_\_\_\_\_  
Investigator's signature \_\_\_\_\_

Date \_\_\_\_\_  
Date \_\_\_\_\_