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Bryannyagara Barboza The Role of a Mother's Childhood Trauma in Parenting her Child on the Autism Spectrum: A Case Study

### **ABSTRACT**

This single case study explored the experiences of a white, middle class, lesbian, single mother, with history of childhood trauma, raising her child on the autism spectrum. This was a qualitative exploratory study with semi-structured interviews as a way to collect data. The participant mother was interviewed a total of four times, one hour each interview. The interviews took place at public and private spaces, (e.g., public library, museums, coffee shops etc.). Due to unfinished data collection and the limitations present in the study, the results are inconclusive. Although the current literature on parenting children with a diagnosis other than autism link childhood trauma with negative parenting practices, more research needs to be done on the area of childhood trauma and parenting autistic children.

# THE ROLE OF A MOTHER'S CHILDHOOD TRAUMA IN PARENTING HER CHILD ON THE AUTISM SPECTRUM: A CASE STUDY

A project based upon an independent investigation, submitted in partial fulfillment of the requirements for the degree of Master of Social Work.

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I dedicate this work to my family and friends.

Much gratitude and appreciation is also owed to my thesis advisor, Michael Murphy, and his untroubled patient, consistent enthusiasm and unchanged compassion and humanity. Thank you! I am most fortunate to have had an opportunity to work with such a "super-human" such as you. I give you my respect, admiration and my gratitude, for your support during this metamorphosis. Thank you.

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I also dedicate this work to my Field Faculty Advisors and internship supervisors, (first and second year's placements). Thank you for believing in me.

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Cheers,

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# ABSTRACT

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### **CHAPTER I**

### Introduction

Experiencing any form of childhood trauma and abuse can have a big impact on an adult's quality of life. It can make basic day-to-day activities, such as eating, sleeping, working and studying difficult, and it can also affect mental and physical health as well as relationships. Research has found that childhood trauma contributes to the likelihood of depression, anxiety disorders, addictions, personality disorders, and so forth. The effects of childhood trauma have also been linked to negative parental practices.

Childhood trauma is defined by the Center for Disease Control and Prevention (CDC) as any act or series of acts of commission or omission by a parent or other caregiver (e.g., clergy, coach, and teacher) that results in harm, potential for harm, or threat of harm to a child. (CDC, 2015). The CDC refers to Acts of commission as those with deliberate and intentional acts, where harm to a child might not be the intended consequence. The CDC illustrates this with the following example, "a caregiver might intend to hit a child as punishment (i.e., hitting the child is not accidental or unintentional), but not intend to cause the child to have a concussion." It also provided the following types of maltreatment as example of acts of commission: physical abuse, sexual abuse, and psychological abuse. The acts of omission referred to by the CDC are those acts in which the parent fails to "provide for the needs or to protect [the] child from harm or potential harm". It is illustrated by the parent's "failure to provide for a child's basic physical, emotional, or educational needs or to protect a child from harm or potential harm." As

with acts of commission, harm to a child might not be the intended consequence. The CDC also uses the following types of maltreatment as acts of omission: "physical neglect, emotional neglect, medical and dental neglect, educational neglect, inadequate supervision, and exposure to violent environments." (CDC, 2015).

As for the effects of childhood trauma on parenting, studies have also found a link between childhood trauma and negative parental practices. These findings suggest that parents with reported childhood trauma were more likely to engage in negative parenting practices. (Chu, & DePrince, 2006). Other studies have also found maltreatment to be more likely to be present in new generations if it was present in the parent's childhood. (Riser, D., 2009).

Although many studies have linked parenting style with the negative outcomes of childhood trauma, there is currently no literature exploring the outcomes of childhood trauma on parenting practices for children with special needs, and particularly in regards to parenting autistic children. Research on parental childhood trauma as it relates to parenting behaviors is essential to inform us to the outcomes of childhood trauma on parenting. This single case study hopes to aide in the research needed to better understand these influences and how to best support positive parenting of autism. In addition, further knowledge is needed in understanding childhood trauma as it relates to parenting. Research is also needed to address the current gap in the literature in how childhood trauma may affect parent's raising children on the autism spectrum.

### **CHAPTER II**

### **Literature Review**

The effects of childhood trauma have been widely studied, and the findings have linked childhood trauma with many mental health issues in adult life. (Agorastos, Pittman, Angkaw, Nievergelt, Hansen, Aversa, Parisi, Barkauskas, and Barker 2014; Tsoory, Guterma, & Richter-Levin, 2007). As suggested by these findings, the consequences of childhood trauma can be very serious and, unless dealt with, can manifest in various ways. These manifestations can be debilitating and chronic, such as those seen in people suffering with mental health illnesses such as depression, anxiety, and Post-traumatic stress disorder (PTSD), or quietly insidious, such as those seen in people suffering with dissociations, and social isolation. Childhood trauma has been linked to many adulthood addictive behaviors as well. Alcohol abuse, tobacco consumption, and drug addiction are just a few of the possible outcomes of childhood trauma. (Eames, Businelle, Suris, Walker, Rao, North, Xiao, Adinoff 2014; Giordano, Ohlsson, Kendler, Sundquist, & Sundquist 2014).

### The Effects of Childhood Trauma

Many recent studies on the effects of different childhood trauma types found a strong correlation between childhood trauma and chronic mental conditions (Agorastos, Pittman, Angkaw, Nievergelt, Hansen, Aversa, Parisi, Barkauskas, and Barker 2014). One study associated the effects of childhood trauma with "higher rates of both mood and anxiety disorders in adulthood" (Tsoory, Guterma, & Richter-Levin, 2007, p. 378). This study investigated what where the effects of childhood trauma in the limbic system of young rats. The study found that

exposure to stressors during juvenility results in altered emotional responses in adulthood, that is, a marked reduction in novel-setting exploration, impaired avoidance learning, and more escape failures in the two-way shuttle avoidance task exposure to stressors during juvenility alters the maturation of the limbic system, and potentially underlies the predisposition to exhibit stress-related symptoms in adulthood. (pp. 387-388)

Childhood trauma has also been linked to drug and alcohol abuse. A study found strong indicators linking childhood trauma to abusive alcohol consumption. In their study, Eames, Businelle, Suris, Walker, Rao, North, Xiao, and Adinoff, (2014), found that

A study by Giordano, Ohlsson, Kendler, Sundquist, & Sundquist (2014), found that

Children aged less than 15 years who experience a second-hand extraordinary traumatic event, such as a parent or sibling being assaulted, diagnosed with cancer or dying appeared to have approximately twice the risk of developing a drug addiction when compared to those who did not have a traumatic experience. (p. 1125)

These and other findings points to a strong link between childhood trauma and substance abuse. However, it is important to account for factors that could be influence in each individual predisposition to such outcomes.

### The Effects of Childhood Trauma on Attachment

Attachment theory is the result from the joint work of John Bowlby and Mary Ainsworth in the middle of the twentieth century. "Both Bowlby and Ainsworth were heavily influenced by the work of Freud and other psychoanalytic theorists." (Shilkret & Shilkret, 2011, p. 187). Attachment is described by Blaustein and Kinniburgh as "one of the most basic human needs in connection to other human beings. We begin to connect from our earliest moment, and we

continue to rely on relationships throughout our lives. The attachment system provides a model for all other relationships. It provides the earliest training ground for coping with and expressing emotions." (2010, p.49). It implied that, "a mentally healthy infant should experience a warm, intimate, and continuous relationship with his mother (or permanent mother substitute) in which both find satisfaction and enjoyment." (Durrani, 2014, p. 101).

Trauma and adversities in early childhood shape many areas of development, and like all other areas it is also believed to have an effect on a person's attachment style. As it is described by MacDonald, Sciolla, Folsom, Bazzo, Searles, Moutier, Thomas, Borton, and Norcross (2015) "a person's attachment style is rooted in recurrent interactions between children and their primary caregivers. Once internalized as relational memory networks, these interactions form a blueprint for future adult relationships." (p. 82). Because attachment-type relationships form during early childhood and become increasingly more complex and sophisticated during the process of development towards adult maturity, it is believed that when traumatic events such as child abuse and neglect occur, they can interrupt the attachment cycle—leading to serious problems in the formation of the personality and most likely affecting and individual throughout adulthood. (Blaustein & Kinniburgh, 2010, p.11).

In their study, MacDonald, Sciolla, Folsom, Bazzo, Searles, Moutier, Thomas, Borton, and Norcross (2015) looked at individual risk factors for physician boundary violations and the role of attachment style, childhood trauma and maladaptive beliefs among individuals reporting history of childhood trauma, and found evidence supporting "a potential link between childhood adversity and boundary difficulties, partly mediated by insecure attachment and early maladaptive beliefs" (p. 83). Their findings suggested a positive link between childhood trauma and insecure/avoidant attachment style.

Another study, conducted by Aspelmeier, Elliott, & Smith (2007), investigated the link between attachment, childhood sexual abuse (CSA), and adult psychological functioning. This study expanded on previous works by assessing the degree to which attachment security moderates the relationship between a history of child sexual abuse and trauma-related symptoms in college females. This study found that "women's reports of childhood sexual abuse are consistently associated with higher levels of trauma-related symptoms and lower levels of attachment security in close-adult, parent-child, and peer relations." (p. 560). The study suggests that childhood history of sexual abuse "was consistently associated with higher levels of trauma-related symptoms and lower levels of attachment security in close-adult, parent-child, and peer relations". The authors found attachment security to be "consistently associated with trauma-related symptoms." (p. 560).

### The Effects of Childhood Trauma on Parenting Style

Aside from the effects of depression, anxiety, higher predisposition to drug abuse, and its possible effects on attachment style, childhood trauma has also been found to negatively affect parenting style. Parents who have been exposed to childhood adverse experiences are believed to be more likely to use negative parenting practices and behaviors. In their study the "role of maternal childhood trauma on parenting among depressed mothers of psychiatrically ill children", Swartz, Cheng, Cyranowski, and Zalewski (2013), found that "mothers with a history of emotional abuse may be at elevated risk to exhibit lower levels of child-focused acceptance and rely on parenting tactics that use psychological control." (p. 797). This study showed that "maternal depression and maternal history of childhood abuse conferred the risk for impaired parenting. (p.792).

Another study, by Collin-Vézina, Cyr, Pauzé, and Mcduff (2005) took into account history of childhood trauma such as physical abuse and emotional trauma and current depressive symptoms to evaluate parental functioning. Results to this study found a strong association between childhood maltreatment (physical and emotional abuse and neglect) and inconsistency in applying discipline. (71-97). Ruscio (2001), also explored the relationship between childhood sexual abuse and parenting styles. The results of his study indicated that sexual abuse survivors reported greater rates of permissive parenting practices than those mothers in the community sample. (pp.69–387).

### Childhood Trauma as a Predictor of Parenting Style

Aside of its effects of parenting practices, there is also the concern that traumatized parents are at a greater risk of becoming abusive parents themselves. Schuetze & Eiden (2005) investigated the association between childhood abuse and parenting outcomes, including parenting stress and feelings of competence and discipline. The level of stress experienced by the parent played a role in the way the parent responded to his/her child. This study hypothesized that maternal depression and partner violence were mediators of the association between childhood trauma and parenting. The study found that maternal depression and current partner violence were associated with more negative parental perceptions and higher punitive discipline. (pp. 645-659).

As these studies suggest, childhood trauma may play a big role on parental style and/or practices. But if so, what does this "effect" look like when parenting a child with autism?

### **Childhood Trauma and Resilience**

Although childhood trauma has been linked to many negative factors later in life, factor such as resilience *h*owever is also to be accounted for when speaking of the possible response to traumatic events in early childhood. As it is described by Bartone (1999),

"The ways that children respond to [traumatic events], vary considerably depending upon other moderating factors, including resilience. Constitutional hardness, sociocultural factors, family and community support, and preparation/education regarding trauma-related effects may all mediate the potentially negative effects of trauma." (as cited in Basham, 2011, p. 448).

As Basham puts it further, "individuals who have coped with traumatic events approach their lives with optimism and sound functioning." (p. 449).

A study by Sexton, Hamilton, McGinnis, Rosenblum, & Muzik, (2015), found that "resilience was associated with reduced psychopathology... in "4-months postpartum mothers.." The study investigated the influences of resilience and childhood history of maltreatment on posttraumatic stress disorder (PTSD), major depressive disorder (MDD), parental sense of mastery, and family functioning. (562-568).

Resilience has also been found to be an important factor mitigating the risks of suicidality associated with childhood trauma. A study by Roy A., Carli, V., & Sarchiapone, M. (2011), examining whether resilience worked as a protective factor in relation to suicidal behavior, found that results that suggested that resilience can indeed be a protective factor mitigating the risk of suicidal behavior associated with childhood trauma. (591-594).

As it is shown by these studies, there are factors that should and must be accounted for when exploring the possible effects of childhood trauma.

### **Autism**

Autism was defined by Andrew Solomon in his 2012 best seller *Far From the Tree:*Parents, Children, and the Search for Identity, as a "syndrome that encompasses a highly variable group of symptoms and behaviors, [which] we have little understanding of, where is located in the brain, why it occurs, or what triggers it". [Kindle DX version]. Autism spectrum disorder (ASD) may result in lifelong disability with pervasive impacts across multiple domains of development (American Psychiatric Association 2013). However, since ASD includes such a spectrum of symptoms, many people with the label aren't disabled by it. Autism was once considered a rare occurrence, but is now being recognized as the second most common serious developmental disability, occurring in approximately 1 in 68 children nationwide (Centers for Disease Control 2014). In first place is intellectual disability, which is considered to be the most common serious developmental disability in the United States; it is estimated that one in ten families are affected by Intellectual Disability in the United States alone. (CDC 2014).

Autism is a syndrome deemed pervasive, meaning it affects multiple aspects of one's life. Autism spectrum disorder symptoms vary widely in their severity in four core areas. These include difficulties in social-interactions, communication challenges, a tendency to engage in repetitive behaviors, and difficulty with sensory integration. Taken together, these symptoms and their severity may result in relatively mild challenges for someone on the high functioning end of the autism spectrum; however, for others, these same symptoms may present themselves as more severe, such as when behavior challenges and communication issues interfere with everyday life.

### **Autism Treatments**

There is currently no cure for autism; however, there are currently a wide variety of treatments focused on the reduction of the behaviors and attainment of social-learning skills. Behavior and communication approaches, dietary, medication, and sensory integration are just a few examples of the variety of treatments widely used to address the many symptoms of autism today. While autism is known to be a life-long condition, it is believed that the benefits of these interventions continue throughout life and that the earlier the intervention takes place, the better for the individual's overall quality of life later in life. Among the many popular treatments for autism, floor time therapy and Applied Behavior Analysis are among the most currently used treatments. ABA is described by Kilroe, Murphy, Barnes-Holmes, & Barnes-Holmes, (2014), as

"the application of Skinner's (1938, 1957) basic research on the principles of behavior to address a wide range of human problems. This scientific approach has been found to be efficacious over many decades, and successful behavioral treatment areas include emotional disturbance. Children with autism and related language difficulties have benefited greatly from the application of behavior analysis to establish or enhance verbal skills, and the efficacy of ABA with populations with autism has been widely reported even by sources outside and independent of behavior analysis. ABA focuses on the principles of learning theory—that is—to improve socially significant behaviors to a meaningful degree, and to demonstrate that the interventions employed are responsible for the improvement of behavior." (p. 60).

There are many providers of ABA services, and frequently, a parent will choose a qualified provider with whom they share similar philosophical approaches in the application of intensive behavioral interventions. Aside from the use of ABA for the treatment of Autism, "DIR/Floortime approach has also been used to treat children on the autism spectrum. "The DIR/Floortime approach was developed as an alternative to behavioral approaches, such as Applied Behavior Analysis, which have historically been commonly used for children with autism." (DeWaay, 2010, p. 10). This model offers children with a variety of developmental delays a new and improved way to treat them. It "focuses on helping children to master core developmental competencies such as relating, communicating, and thinking, rather than focusing strictly on symptom alleviation." (Greenspan & Wieder, 1998; Wieder & Greenspan, 2005, as cited in DeWay, 2010, p. 11). Overall, DIR/Floortime has the goal to help children reach their developmental milestones. "The six developmental milestones which the DIR/Floortime model promotes include (a) self-regulation and interest in the world, (b) engagement and intimacy, (c) two-way communication, (d) complex social problem solving, (e) emotional and creative ideas, and (f) logical reasoning. As it is proposed by this model, "when children are functioning on all six levels, they are expected to develop and thrive appropriately. (DeWay, 2010, p. 11).

### **Autism and Attachment**

One of autism's hallmarks is a diminished ability to create and maintain socioemotional connection, so much so that the

"cliché about the syndrome "is that it impedes the ability to love... The earliest theories of autism linked it directly with attachment, either claiming that inappropriate parenting actually caused autism... or, conversely that autism resulted in a fundamental inability to form attachments (Solomon, 2012, {Kindle DX version}).

As it is put by Solomon (2012), "Autistic children often seem to inhabit a world in which external cues have limited impact." {Kindle DX version}, this and other factors, may be the root to which, the belief that autistic children are unable to form secure attachment is originated from. In a study examining attachment in children with autism spectrum disorder, In their study, (Grzadzinski et al, 2014), utilized a qualitative approach to examine attachment behaviors in young children with autism spectrum disorder. Based on the results of previous studies, the researchers looked at (a) parental gender, (b) child diagnosis, and (c) child cognitive skills to examine the role of these three factors on attachment behaviors elicited during a modified strange situation paradigm. The results suggested that "parental gender, child diagnosis, and child cognitive skills each had significant main effects on attachment." (p. 85).

Autistic children have deficits in social skills, and often enough, the parent-child relationship for an autistic child and their caregiver reflects the impact of such deficits. Because children on the autism spectrum appear mostly disengaged with their surroundings, "tending to them can be gravely frustrating because the distinction between deficit of emotion and deficit of expression is often opaque". (Solomon, 2012, {Kindle DX version}).

### Conclusion

Given that there are not many studies exploring the possible effects of childhood trauma on parenting style among mothers of autistic children, this literature review served as a gateway to understand what already has been published and what these studies have said about the effects of trauma on parenting children with disabilities other than autism. In an attempt to answer the question proposed by this study, I have chosen to do a case study. A case study is often defined in psychology research methods texts as an "intensive" or "detailed" description and analysis of one single individual. (Goodwin, C.J. 2010, p. 308; Shaughnessy, J. J., Zechmeister, E.B., Zechmeister, J.S., 2009, p. 440). This case study was based on

"grounded research theory, a research approach that focus initially on unraveling the elements of experience. From a study of these elements and their interrelationships, a theory is developed that enables the researcher to understand the nature and meaning of an experience for a particular group of people in a particular setting." (Glaser & Strauss, 1967 as cited in Moustakas, 1994, p. 4).

By using grounded research, I was able to identify the theory that best supported my hypothesis, (i.e., relationship of traumatized mother to child), trauma and attachment theories served as the base to the conclusions made in this study.

### **CHAPTER III**

### Methodology

### Introduction

This case study explored the possible effects of maternal childhood trauma on parenting a child on the autism spectrum. The purpose of this study was to examine the dynamics (e.g., relationship, attachment and parenting style), between a mother who reports that she herself experienced childhood trauma, and her autistic child - and attempt to gain insight into the question: How might maternal history of childhood trauma affect a mother's parenting style while raising a child on the autism spectrum?

# **Recruitment of Participant**

Recruitment for this case study was obtained through a recruitment flyer posted in a large social media network site. The publication listed the following criteria - mother with reported childhood trauma, parenting a child aged 3-12 years old, non-gender specific, needed for research study. Potential participants interested in participating in the study initially contacted the researcher through email, which was followed by a face to face meeting. Informed consent forms were signed by the participant mother prior to the interviews. The participant mother received a monetary compensation for her participation.

### Sample

The sample was limited to one participant. The participant was a white, highly educated, in her mid to late twenties, lesbian, single mother, from middle class.

### **Data Collection**

I anticipated I would have informal interviews and observation of mother and child interacting during a routine time. But, because of unexpected circumstances which prevented us—both the researcher and the participant—to meet and facilitate better continuity in the collection of data; the process was interrupted and only four interviews were possible as a result. Each interview lasted approximately 1 hour. The interviews were semi-structured and took place at different settings, (i.e., participant's office, shopping mall, coffee shops, etc.). The questions were open-ended and explored themes of motherhood, parenting style, parenting a child diagnosed with autism, single motherhood, sexual orientation, autism services and childhood trauma.

I had hoped to be able to interview and possibly observe other members of the primary participant's social support network, but because the participant mother did not agree that I could interview other members of her family or supports, data collection was limited to the mother and child. Given that the participant mother didn't agree to be audio-recorded, data were based on my ability to take precise notes, ask the right clarifying questions, and on the details I was able to recall after each interview. These notes and personal audio-recordings made after interviews ensured that the data could be accessed at any time and reviewed for any missing content.

### **Data Analyses**

Data were analyzed by me from notes taken during the semi-structured interviews.

Three types of coding were used to analyze the data collected: Open coding - so as to limit the data to a small set of themes that appeared to relate to the phenomenon being discussed (childhood trauma and parenting autism); Axial coding was used to make connections between the themes being explored; and theoretical coding was used to guide me with the data collected.

### **Rights to Human Subjects**

Approval for this study was obtained on January 24, 2015 from the Smith College School for Social Work Human Subject Review Committee (see Appendix A). In order to comply with the thesis guidelines set by the HSRC, the participant mother was shown the consent form which stated the main goals and methods of the study, the potential risks of the study, and the right to withdraw from the study at any time (see Appendix B). A list of local mental health resources was also provided to the participant mother at the time of the first meeting. For confidentiality, identifying information was removed and a pseudonym was assigned to the participant and her child. Confidentiality was strictly kept by this investigator. Informed consents were signed at the time of the first meeting with the participant mother.

### **CHAPTER IV**

# **Findings**

**Merida: The Case Study** 

Merida is the central figure for this single case study. She is a white, middle class, lesbian, single mother, living and attending a Ph.D-level graduate program in the outskirts of the greater Boston area. Merida has a four year old girl, Ariel, who was diagnosed with Pervasive Developmental Disorder--Not Otherwise Specified (PDD-NOS) when she was about 18 months old. She received early intervention services until the age of three. Ariel is currently enrolled in a mainstream classroom and has an Individualized Education Plan, (IEP) which includes occupational therapy, or OT, speech therapy, and a paraprofessional is assigned to work with her. Aside from the IEP, Ariel also receives applied behavior analysis (ABA) therapy through private health insurance.

Merida identifies herself as Lesbian. Although we did not closely explore Merida's experiences around her gender identity and parenting, Merida does not think that her sexual identity affects her parenting style.

Merida has a history of brief involvement with the foster care system when she was a child, and has no relationship with her foster parents currently. Although she lives and attends school outside Boston, Merida reports she does not have any blood relatives living nearby. Her involvement with the foster care system was due to the death of both her biological parents at the age of four. Because we didn't explore this aspect of Merida's life, I was unable to understand the transition out of the foster care system after the death of her parents.

History of sexual abuse and childhood neglect were the types of trauma reported by Merida. Although we didn't explore the reported trauma, Merida refers to these adverse experiences as essential to the development of her identity and personhood.

Merida was in a committed relationship for about five years and, due to the stability of the relationship, Merida and her wife decided to have a child. Merida got pregnant through in vitro fertilization (IVF), a process by which an egg is fertilized by sperm outside the body: in vitro (in glass), then inserted into the uterus of the receiving mother. The process of getting pregnant took approximately 13 months, and resulted in a healthy pregnancy and a non-problematic delivery of a healthy 8 lb. baby girl. Although the pregnancy had been the decision of the couple, five months after the baby was born, Merida was left to be the sole caregiver to her five-month-old-daughter.

### **Emerging Themes**

The themes explored in the four consecutive interviews were as follows: motherhood; parenting style; parenting a child diagnosed with autism; autism services; single motherhood; and childhood trauma.

### **Motherhood**

The first theme explored with Merida was motherhood. This theme captured Merida's early experiences and her perspectives as a mother.

When we explored the role of motherhood Merida reported she does not see herself primarily as a mother; she listed motherhood in third place on an identity list of one to three. Merida explained that although she loves and cares for her child very much, she sees herself more as "a teacher and coach, a student, and then a mother." Merida believes that too much credit is given to motherhood. "Anyone can be a mother, but few can finish a college degree."

Merida recalled the day that she gave birth to her daughter and described how much praise was given to her reproductive capacities, yet such praise has not been given when she earned her two master's degrees. "All it took was to get pregnant." She added.

# **Parenting Style**

Parenting style was also a theme explored. When asked about her parenting style, and given the choices between "permissive and/or restrictive parenting style" (Swartz, Cheng, Cyranowski, & Zalewski, 2013, p.793), she identified herself as being neither. "I am more in the middle". Merida illustrated her parenting style by contrasting her parenting style with those of other parents. She referred to the amount of television she allows her daughter to watch as an example of her not being permissive or restrictive. Although Merida does not believe that television is the appropriate stimulation for her daughter, she also explained that restricting television completely will also not be beneficial to her; thus, she allows her daughter to watch one hour of television per day.

As we continued to explore parenting style and practices, structure was an important concept to which Merida continuously returned. "All children need structure and everything has to have a place and time," she explained. Merida described with much detail the importance of a consistent environment for the child's development. As we explored Merida and Ariel's daily routine, structure seemed to be the fuel for the family's busy schedule. The structured environment, as Merida described, helped Ariel manage her anxiety.

### Parenting a child with Autism

Parenting a child with autism emerged naturally as we explored parenting style. Ariel was about eighteen months old when she was diagnosed with pervasive developmental disorder not otherwise specified; PDD-NOS. Merida recalled that shortly before receiving the diagnosis she

noticed some delays in her child, but because Merida had also had been developmentally delayed as a child, she didn't think much of it. Merida recalled noticing Ariel seemed to have delayed speech, inability to discriminate between left and right, and some delay in other developmental milestones around fine and gross motor movements. As a result, Ariel was referred by her pediatrician to see a specialist. The specialist then made the PDD-NOS diagnosis.

The Diagnostic and Statistical Manual of Mental Disorders (DSM IV) defines PDD-NOS as "a severe and pervasive impairment in the development of reciprocal and social interaction associated with impairment in either verbal or nonverbal communication skills or with the presence of stereotyped behavior, interests, and activities." (p. 84). However, as with any form of autism, PDD-NOS can occur in conjunction with a wide spectrum of intellectual abilities and a wide range of delays. The label, as Merida sees it, seems to be too broad, and it encompasses too many aspects of a person's life. The CDC predicts that on average, 1 out of 88 children in the United States have an ASD (CDC, 2012).

Soon after she received the diagnosis, Ariel started receiving early intervention (EI) services. EI consists of services provided to children of school age or younger who are at risk of developing a handicapping condition or other special need that may affect their development. Early intervention can be remedial or preventive. It remediates existing developmental conditions or strives to prevent their occurrence. EI may focus on the child alone, or on the child and the family. EI programs may be center-based, home-based, hospital-based, or a combination of them all. Services range from identification, that is, hospital or school screening and referral services, to diagnostic and direct intervention programs. The service may begin at any time between birth and school age; however, it is believed that the earlier intervention begins the better the outcome.

One of Ariel's delays was related to her ability to produce speech; thus if she needed to communicate something she would throw tantrums. As Merida described it, the tantrum became the main method that Ariel used to communicate her needs. Nonetheless, crying never stopped the family from going on outings. Merida described going to public spaces such as museums, parks, restaurants, and libraries as events in themselves. "But she would stop after five minutes." Merida added.

As we explored the difficulties Merida had with Ariel during her early years, Merida explained that she does not believe that keeping the child in the house is beneficial for the child's development. She reported knowing parents who will avoid going out with their special needs children just because the parents cannot tolerate the child crying. She also noted that some parents will take their child away from stimuli even before the child has had the time to adjust to the environment. "It takes time for the child to learn, to adjust. You have to give her the time." Merida reported that Ariel is excelling academically, and that ever since she developed the ability to produce speech, she no longer uses crying as a way of communicating her needs.

Merida puts great energy and focus into keeping a structured routine for her child. Since very early on, and as part of her structured routine, Merida has limited Ariel to one hour of screen time per day, has maintained consistent meal and bedtime routines, and provides continued exposure to social interactions, such as those provided by the school. They take weekend trips to different places, such as libraries, museums, parks, or shopping. Those are just a few of the activities that are a constant in Ariel's life.

### **Autism Services**

Soon after Ariel received the autism diagnosis she started early intervention services. Merida describes the experience with EI services as being very negative. Merida reports feeling judged by the providers. As she explained, although they had qualifying certifications, the providers did not seem well prepared for the job. Merida also described an instance in which she witnessed a staff—who was certified in Applied Behavior Analyses (ABA)—running a program with her daughter, and when she asked questions about the program, the staff didn't seem to understand, or know what it was Merida was talking about.

Poor training, lack of supervision and poor communication (between the family served and the agency providing services), were just some of the problematic issues Merida reported having during the months in which her daughter received EI services. She said that poor training was evident: there was a lack of ethics in some staff, which were very judgmental and visibly lacked understanding of basic concepts of child development. Such issues, as Merida explained, contributed to her frustration with the EI services.

Merida narrated an incident in which an ABA-certified staff was trying to run a program with her daughter, but because of the lack of logic behind the program, Ariel refused to cooperate. And because the staff clearly lacked training, so much pressure was put on Ariel that she had an accident: "She peed all over herself. They [EI staff] are not capable of going beyond the piece of paper." Merida also recalled another instance, in which a service provider was trying to have her daughter put on a pair of socks, as part of an ABA program.

She kept on telling Ariel to put on her socks, but Ariel didn't want to. And I am sitting there thinking – she can do it, just give her a reason. Give her a reason. And the staff person didn't think. If only she (the EI service provider) had said, put your shoes on, let's go outside. But she just continued to ask her to put the shoes on. I was so mad. Although Merida was frustrated

with the situation, she explained that she didn't intervene at the time. But this was another of many examples she provided to describe how unprepared she felt staff providing EI services were.

But poor training was not her only issue with the services being provided. As Merida explained, aside from being poorly trained, staff providing EI services at her home would go for weeks without having supervision, which was another factor contributing to Merida's dissatisfaction with early intervention services. This frustration contributed to decreased or lack of communication between Merida and the agencies providing services. Merida felt that because the providers delivering services had poor training and lack of basic understanding of child development, she could not communicate with them about her own concerns. And, due to lack of supervision, she also felt they were not as good with communication.

But even though she felt the services were not of great quality, Merida stated that she was glad that her child received them. "At least she got the social stimuli," she reported.

### **Single Motherhood**

After her almost five-year relationship with her partner the couple split and Merida was left as the sole caregiver to her then five-month-old daughter. Between her new roles as single mother and graduate student, Merida described having to quickly adjust to it all: "It is not easy." Merida explained how easy it can be to get overwhelmed with all the responsibilities. As a result, she has to constantly divide herself to fit into the domains of school, parenthood, and household provider. There is a great deal of pressure being a single parent. She said that all the responsibilities lie on the one parent. The child needs to be fed, secured, kept healthy, loved, cared for. "You don't get to take a break and leave, because if you do, who will take care of your child?"

Although Merida currently has a live-in nanny, she explained this was not true until very recently. The paid help has paid off, she explains. Knowing that she doesn't have to worry about meeting her child's basic needs, such as hunger, she can provide her with other needs, such as emotional connection and opportunities to grow in other areas, including emotionally and socially.

The hired help takes a great deal of pressure from Merida; as a consequence, she is able to enjoy quality time with her child. But the lack of support from a partner is not the only challenge Merida faces. Because her immediate family (mother and father) has passed away, and she was an only child, Merida also lacks the networks of natural supports that an extended family could provide her with. The lack of such support, as Merida described it, plays a big role in the way she parents her child. Because there is no other family involved in Ariel's care, Merida puts great effort into assuring that her child is independent and self sufficient.

The lack of natural supports is difficult, but not impossible. Although she doesn't have natural supports to help her raise her child, Merida understands that her socio-economic status (middle class), enables her to have a better quality of life (e.g. she is able to afford paid help, where the reality of many single mothers is much different then hers). According to U.S. Census Bureau report, in 2014 alone, more than 80% of single parent families were headed by single mothers, nearly half of which live below the poverty line. As Merida explained, being able to pay for the nanny surely helps.

As a single mother, Merida has struggled with many other challenges of single motherhood. As she described in our interviews, being the only person her child can rely on puts a lot of pressure on her. Not having the parental support of her ex-wife is also something Merida describes as being difficult. Although she is present, she is not involved. "Ariel sees her

once a month and she says she misses her" Merida said. She continues by explaining the extent to which her ex-partner has been involved in the life of their child.

### Conclusion

The themes motherhood; parenting style; parenting an autistic child; autism services; single motherhood; and childhood trauma emerged and were explored in the three consecutive interviews I had with Merida. These themes were inspiring and provided me with a rich learning experience. Although, these interviews and my observations of Merida may not be sufficient to confirm or disagree with the already existing literature, the process of conducting this research provided me with a great deal of learning.

### **CHAPTER V**

### **Discussion**

### Introduction

Childhood trauma has been linked to a wide range of negative outcomes in later adulthood. Studies have linked it to chronic mental conditions (Agorastos, Pittman, Angkaw, Nievergelt, Hansen, Aversa, Parisi, Barkauskas, & Barker, 2014), to abusive alcohol consumption, (Eames, Businelle, Suris, Walker, Rao, North, Xiao, & Adinoff, 2014), and to symptoms of anxiety, depression, PTSD, (Nierop, Viechtbauer, Gunther, Zelst, de Graaf, Have, Dorsselaer, Bark, & Winkel, 2014). Childhood trauma has also been found to increase the risk of developing a drug addiction, (Giordano, Ohlsson, Kendler, Sundquist, & Sundquist, 2014). Likewise, childhood trauma has been found to underlie "the predisposition to exhibit stressrelated symptoms in adulthood." (Tsoory, Guterma, & Richter-Levin, 2007). Childhood trauma has also been found to affect attachment. Studies, looking at specific risks factors such as type of trauma have linked childhood trauma to attachment style. (Aspelmeier, Elliott, & Smith, 2007; MacDonald, Sciolla, Folsom, Bazzo, Searles, Moutier, Thomas, Borton, & Norcross, 2015). Aside from its effects on the above mentioned aspects of one's life, childhood trauma has also been found to affect parenting style. (Collin-Vézina, Cyr, Pauzé, & Mcduff, 2005; Ruscio, 2001; Swartz, Cheng, Cyranowski, & Zalewski, 2013), and to be a predictor to parenting style. (Schuetze & Eiden, 2005). As suggested by the findings of these two studies, the level of stress experienced by the parent appears to play a role in the way a parent responds to her/his child.

Finally, as it is suggested in the literature review, childhood trauma appears to have a variety of negative effects on adulthood, so much so that these effects may play a role in the parent/child relationship. But if so, how does this potential negative effect manifest itself, when parenting a child with autism?

This single case study explored the perspectives and experiences of a mother who has a history of childhood trauma and who is raising a child with autism. This study attempted to answer the question: Does history of childhood trauma affect a mother's parenting style while raising a child on the autism spectrum?

### Merida

The main figure for this single case study is Merida, a graduate student who is white, middle class, lesbian, and a single mother who lives in the outskirts of the greater Boston area. Merida has a four year old girl, Ariel, who was diagnosed with Pervasive Developmental Disorder--Not Otherwise Specified (PDD-NOS) when she was about 18 months old.

The first time I met with Merida was on a windy Friday afternoon. We agreed to meet at a coffee shop nearby her office, outside the greater Boston area. I had arrived earlier to our meeting place, and was anxious to get started. I saw her when she walked in. "Hi, I am the person you agreed to meet with. How are you? I said with a big anxious smile on my face. "Hi, I am Merida." She responded briefly. After we signed the informed consents, and discussed the logistics of our upcoming meetings, we began to discuss Merida's motherhood experiences.

During the interviews I had with Merida, motherhood, parenting style, parenting autism, autism services, single motherhood, and childhood trauma were the themes emerged and became the major point of the exploration; this discussion will address all themes as a whole in the analyses of Merida's experiences.

Motherhood was a theme that was very enriching and provided me with great insight.

Although Merida did not identify herself primarily as a mother (since she listed motherhood in third place on an identity list of one to three) it was clear from how she reported her experience, parenting seemed to play a bigger role in her life than she describes.

"All it took was to get pregnant." She said in one of our interviews. Motherhood has been often associated with "a strong source of fulfillment and success for women (Rittenour & Colaner, 2012), but such fulfillment may come at a great price. As described by Rittenour and Colaner, "Entrance into motherhood can bring post-partum depression, work/family conflict. (p. 352). As we explored motherhood, Merida contrasted her experience of mothering with that of earning a graduate degree. As put by Merida, "anyone can be a mother, but few can finish a college degree." However, because of the overrated accreditation that is given to motherhood, from her perspective, Merida stated feeling more accomplished around her work and study areas, and less so with her motherhood role. "The accounts of student-parents reveal that tensions between conflicting identities can be managed by drawing on the positive aspects of one identity to diffuse the potential damage to the other." (Estes, 2011, p. 200).

But motherhood did not come naturally to Merida, or by accident for that matter. It took a lot of planning. As it she described it, all the little details were taken into consideration, "the health risk factors, families' histories, and all else were discussed, before the pregnancy. In the end it made sense for me to be the biological mother." The literature refers to this process as *negotiation* where factors such as the relationship of the donor to the offspring are negotiated before the pregnancy. (Hassen, 2015, p. 277). Although Merida was not driven primarily by the desire to be a biological mother, being able to give her child a sense of belonging was the reason for the couple to seek donors with the same ethnic background of her at the time wife.

"We wanted her to look like us, like we were a family." (Ariel, the four year old girl, has long curly dark hair. From pictures, I assumed, with my limited understanding of what an Asian/White-American children are supposed to look like), that the child indeed looked like her and the non-biological mother. She is a beautiful girl.

"The transition from being a student to student-parent came as a shock. It took some adjusting to it. At first was really hard, but you get used to it after a while." This was Merida's words to describe the difficult, yet, "doable" transition that she went through as she transitioned from being solely a graduate student, to being a graduate student and mother. As it is noted by Estes (2011),

Due to the high demands of both parenthood and graduate school, these two concepts often clash. The ideal parent is often portrayed in media and popular culture as financially stable, married, educated, and supportive. On the other hand, the ideal student is portrayed as young, single, impressionable, and free from outside responsibilities. When the roles of parenting and student are paired, however, the value we attach to either of these identities diminishes. (p. 200)

Estes also noted that the accounts of student-parents reveal that tensions between conflicting identities can be managed by drawing on the positive aspects of one identity to diffuse the potential damage to the other.

## **Gender Identity**

Despite the fact that we did not explore in depth her gender identity, some time was given to discuss the topic. "Being a single mother is easier than a gay parent." Merida stated when asked to speak of her gender identity. Merida added that her gender identity has not affected her parenting, or parenting practices, so far. But as she described it, the struggles of single parenthood are far easier to deal with than those related to her gender identity. Not identifying her, and not presenting with the "stereotypical" characteristics of a lesbian woman, Merida stated, has made her life much easier. "I don't have to explain it." Merida added.

Lesbian mothers still have to deal with the consequences of not agreeing with what is considered the "normative" or "natural" expectations family. Acts such as the Defense of Marriage Act, (DOMA), enacted in 1996 during the administration of Bill Clinton, curtailed the rights of gay and lesbian families. DOMA was passed in the same year in which welfare reform also passed, The majority of what was at the time considered a "bipartisan Congress, passed the act banning federal recognition of same-sex marriages and allowing states to refuse to recognize such marriages performed in other states." Cahill, (2005, p. 864).

In the years that followed, especially during the Bush administration, the promotion of "heterosexual marriage and the reinsertion of fathers into single mother-led families." was seen "as a key solution to child poverty." It has been reported that the Bush administration spent over 1.5 billion on 2004 alone in promoting the "heterosexual" ideals of marriage (Cahill, 2005, p. 865).

The marriage and fatherhood movements may be accountable for the main forces driving these ideals. These groups have advocated heterosexual marriage and fatherhood promotion policies including privileging married couples with children in the distribution of

limited supply benefits such as public housing units, requiring mutual consent for divorce, and banning access to fertility clinics by unmarried couples (Bradford et al., 2002; Cahill and Jones, p. 2001). Yet, marriage and fatherhood promotion policies aimed at poor women also assume that all poor women are heterosexual and are both capable of and desire to marry a man. In fact, many poor women are bisexual or gay. There is also the concern that these policies are more likely to disproportionately hurt African American and Latino parents, who are more likely than white non-Hispanic parents to be single or unmarried.

But Lesbians have not always had all this fervor and passion driven against them. It was not since 1970, when the women's right movement gathered steam; that the defense of the traditional family beliefs became a main center of attention. Gutterman, (2013), in her dissertation, explored the many ways in which heterosexually married women with "lesbian desires," had to operate in secrecy in order to get satisfaction for their desires. Due to how of society regarded homosexuality that time, (1945-1979), "wives who desired women" had to confine their desires to the opportunities provided by that society. In many cases, such wives, in an attempt to "balance married life with lesbian relationships, often used the straight (heterosexual) spaces—work, church, the family neighborhood, even the household itself—to engage in lesbian relationships, typically with wives and mothers like themselves."(p. 3).

Not until decades after the women's right revolution has society begun to wake up to a new and more flexible way in which we see the family structure, but there is still a long way before progress can be considered complete.

### **Single Motherhood**

Merida's maternal experiences encountered a twist when, five months after her child was born, her relationship with her wife of approximately five years ended. If getting used to the new role of parent while still performing as a student was difficult, it got yet more difficult when Merida was left to be the sole caregiver of her 5 month old child. Merida was in a committed relationship when she got pregnant. And although her pregnancy did not come through conventional means, (i.e., Merida got pregnant through in vitro fertilization), if her maternal identity didn't fully develop when she delivered her baby, perhaps it developed when she was left to be the sole caregiver of her infant child. Although we did not discuss the details of Merida's separation, Goldberg & Sayer (2006), described the transition to parenthood as a time "of stress for many couples, and such factor can be counted as a predictors of change in relationship quality (love and conflict) during the transition to parenthood' (p. 87). In their study, the authors used factors such as, "personality variables, work context variables, social context variables, and couple characteristics" (p. 87), as predictors to such change. As a consequence to such change, many lesbian couples split.

But single parenthood was not exactly in Merida's plans. When asked about her experiences as a single mother, Merida explained that it was not easy. "It is all you." She said. After the couple split up Merida took upon herself the role of mother and household provider. She stated that it can be easy to get overwhelmed with all the responsibilities, so she is constantly dividing herself into school, parenthood, and household provider. As Merida described, there is a great deal of pressure being a single parent. All the responsibilities fall on the one parent. The child needs to be fed, secure, healthy, loved, cared for. "You don't get to take a break and leave, because if you do, who will take care of your child?" She added.

Although single parenthood was not part of her initial plans, Merida found ways to continue on with her graduate studies while parenting as a single mother.

If for a short period of time, she was afforded with the support of her ex partner, soon after the birth of her child; Merida finds the hard truth of being a single mother student. But as she puts it, "break ups happen and you got to move on." Although the ex partner contributes financially with child support and health insurance, Merida described, with a degree of disappointment that the involvement is limited to that, and the monthly visits.

If the lack of support from a partner makes single parenting difficult, single parenting without the support of extended family is specially challenging. Merida has no extended family, or blood relatives leaving in the area. Perhaps, her history of brief involvement with the foster care system may have contributed to her current lack of natural support networks. Merida stated she did have any relationship with her foster parents, and she currently lives and attends school in the greater Boston area, she has no blood relatives living nearby.

Merida currently has a live-in nanny, although this was not true until very recently, the help has paid off. The hired help takes a great deal of pressure from Merida. The lack of natural supports is difficult, but not impossible, and being able to pay for help facilitates Merida's ability to negotiate between her priorities. Although she doesn't have natural supports to help her raise her child, Merida acknowledges her socio-economic stratum and is thankful that she can afford help, so she can enjoy her child without the stress.

But being structured and organized has also become a factor contributing to Merida's current experiences. This new, organized lifestyle is the way, Merida finds, to allow her to deal with all the pressure put on her by all the expectations that result of her single motherhood and graduate student role. Yet, she is capable to sustain both roles successfully. If on one hand, Merida holds protective factors, such as level of education achieved, socio-economic location, which may contribute to her success, on the other hand, the lack of a natural support networks

makes her, as vulnerable as other parents, under similar conditions, to the same vulnerabilities and stresses brought on by single parenthood.

#### **Parenting Autism**

Parenting an autistic child is described by some, as "challenging", due to the child's perceived lack of interest/appreciation in the wellbeing of the relationship" (Solomon 2012). Ariel was about eighteen months old when she was diagnosed with pervasive developmental disorder not otherwise specified, PDD-NOS. Taking care of a child with an ASD can be difficult, time consuming and very stressful. Likewise, being a single mother of an ASD child is all the above, but to the power of 10. Because single mothers lack the emotional, psychological and financial support provided by a partner, single mothers, in many cases, must rely or create other support networks such as family, friends or social agencies. Merida also, as a single mother, struggles with the difficulties of parenting a child on the autism spectrum, alone. As a consequence, assuring that her child has her needs met is a constant and continuous struggle.

Because autistic individuals tend to be less socially engaged and/or interested, guidance is crucial for their continued development. Likewise, the support of those such as family and friends become indispensable the key for the success of autistic individuals. Merida puts great energy and focus into keeping her child connected to the community. Since very early on, exposure to social interactions, such as those provided by the school, weekend trips to different places, such as libraries, museums, parks, and stores were part of Ariel's intellectual stimulation and growth. But such activities are not solely with the intent of socialization, as Merida explained it, because Ariel is so energetic, outings help her to calm down.

It would be easy, you know, to let her sit at home and watch television all day, but it would not be good for her. That is not good stimulation. Children don't learn like that. I

have noticed that she learns from exposure, so I make sure she is exposed to these social situations.

Merida explained however, that although she doesn't let her child sit and watch television all day, she believes that taking it away completely, would also not be beneficial; as a result, she allows Ariel to one hour of screen time per day. Merida speaks of the importance and role of her community while raising her child as a single mother.

When asked if her parental style would be different if parenting a typically developing child, Merida stated that her parental style would not be different. "All children need structure, and everything has a place and time" she explained. Thus, her parenting style would not change if her child was not autistic.

#### **Autism Services**

Learning about the availability and quality of autism services available was one of the most important learning experiences she had, Merida reported, during the period that followed diagnosis and thus a great amount of time was dedicated to the exploration of this theme.

As Merida described it, soon after her daughter received the autism diagnosis, the EI services begun. What was expected to become a solution became yet another issue Merida found herself dealing with in order to assure that her child was receiving the appropriate type of intervention.

"Judgmental, they were very judgmental." Merida said when expanding on her experiences with Early Intervention services. Aside from the judgment Merida reported experiencing; she also reported on other, as important, issues with communication between the agency providing the services and the family being served, and the lack of supervision for the staff providing the services. As described by Merida, staff providing DIR/Floortime, or ABA

services, would go for many weeks without having a supervisor, or a clue of what they were doing.

#### Childhood Trauma

Merida is not certain if and how her childhood adversities have affected her life in any manner. "I haven't had the time to peel it apart. So I don't really know" she said, when asked if her early experiences had had any effect on her parenting style. Merida stated she was trying to explore it, "to process my early experiences in therapy" and it was not until very recently that she started noticing the benefits of such. But much of her self-analysis was dedicated to aspects of her life other than motherhood. Merida stated that, nonetheless, her experiences with therapists, especially female clinicians, have been very questionable, from the part of the therapists. As described by Merida, her therapists tended to relate to her in a way that made her feel uncomfortable. Merida gave an example in which one of her therapists had acted inappropriately towards her by "befriending" her on a social network.

Merida concluded however, that although she has had questionable relationships with some of her therapists, she acknowledged that because of her time in therapy she is now able to comprehend some aspects of herself.

# **Single Motherhood and Mental Health**

Aside from the many difficulties single mothers have to deal with every day when raising their families, mental health problems seem to be yet another potential factor affecting this population. Although single mothers' mental health has been widely studied, researchers across all disciplines have focused mainly on depression as the main outcome to childhood adverse experiences. Nonetheless, a study by Summels-Dennis, Ford-Gilboe and Ray (2015), exploring the possible outcomes of early childhood trauma on single mothers with

posttraumatic stress symptoms found that a "level of exposure to psychological and assaultive traumas... impacted both the patterning and severity of mothers' current PTSD symptoms" (p. 9); these findings suggest another area to take into consideration, when exploring the effects of childhood trauma on parenting and child with autism.

### **Possible Factors influencing Parenting Style and Practices**

Although childhood trauma has been found to negatively impact the quality of life of adult survivors, (Agorastos, Pittman, Angkaw, Nievergelt, Hansen, Aversa, Parisi, Barkauskas, and Barker 2014; Philippe, Laventure, Beaulieu-Pelletier, Lecours, & Lekes, 2011; Tsoory, Guterma, & Richter-Levin, 2007), factors such as resiliency, may a play a role in guiding the direction of such outcome.

In a study investigating how "ego-resiliency" can play a mediating role in the relationship between childhood trauma and psychological symptoms," Philippe, Laventure, Beaulieu-Pelletier, Lecours, & Lekes, (2011) found that "ego-resiliency was a significant mediator of the relationship between childhood trauma and these three types of symptoms {anxiety, depression, and self-harm behaviors}." Although it is not yet clear whether resilience develops as a consequence of trauma (resilience as an outcome) or if resilience is innate to some, (Philippe, et al, 2011, p. 583), from my impressions of Merida, it seems that resiliency has been a strength as she navigates her complex life and roles.

# Recommendations for future research in this area

Future research with more diverse samples (mothers, fathers, single families, and families of different socio-economic classes), can help to determine how childhood trauma affects the relationship between mothers (with history of childhood trauma) and their autistic children. Because the middle-class status can be viewed as a protective factor, it is also

important to look into lesbian families of low income class, for that such factor may also influence the direction of the findings. In addition, racial, class, and economic diversity exists within this group, and it is a role for future research to determine how to best capture it. Finally, the area of effects of childhood trauma on parenting an autistic child is still well under explored. Future research should include these groups in order to contribute to a slowly growing literature on gay and lesbian couples and families.

# **Study Limitations**

While the single case study methodology is well used across disciplines in psychology, because case studies don't allow for control groups, conclusions made on the observations of a single case study may not be generalized to any other population. (Goodwin, 2010, p. 443). Although case studies limit researchers from making generalized statements, a case study allows researchers to "develop new ideas and hypothesis, opportunities to develop new clinical techniques, and a chance to study rare phenomena." (Shaughnessy, et al., 2009, p. 440).

Aside from the limitation of this being a single case study, other limitations such as less data collected than anticipated, and the researcher's first language and nationality (Portuguese), were also limiting factors to this study.

Less than anticipated quantity of data collected was one of the major issues with the reliability of this study. Because the participant did not agree that I be able to interview other members of her family and support network, data collected were limited to the mother alone.

The participant's discomfort in being audio-recorded also was a limitation. Thus, the collected data was limited to the researcher's understanding of the topic being discussed, ability to take precise notes, ask the right clarifying questions. Although the study was anticipated to have informal interviews and observations of mother and child interacting during a routine

time, due to unexpected circumstances, the study was stopped after only four interviews and before I was able to meet and observe the child.

The language barrier was presumed to be a significant obstacle in conducting interviews. Because the researcher was raised speaking another language than English, such barrier impacted the conversations and I tended to speak with a stronger accent, impacting the participant's ability to understand me. This contributed to the continued request that I repeat a question, or a word. My own bias toward parental values and practices may have influenced the research and present a conflict with the findings. I have tried to be mindful of my biases as a way of increasing transparency about my role.

Another limitation of this study was the researcher's own knowledge and relative inexperience in doing research. As a researcher conducting my first qualitative study, I do not have the technical knowledge of qualitative research and analysis methods that could provide me with the appropriate tools to enhance study validity.

Although there were limitations to this study, there were also strengths. One of the strengths of semi-structured interviews is that it provides the opportunity for the participant to make in-depth statements, ask clarifying questions, and respond to researcher follow-up questions. As a researcher, interviews also allowed me flexibility to respond to the participant's questions and ask for clarification. The study's qualitative, exploratory aspects allowed me to capture the narrative and descriptive accounts of a mother with history of childhood trauma raising a child with autism.

### Implications of this study to other research or scholarly work

The implications of this study should be considered in light of its limitations. Size of sample, (one mother), and the characteristics of such sample (highly educated, lesbian, single

mother, raising a child on the autism spectrum), and the socioeconomic location of such, (middles class), limits ability to determine how childhood trauma has affected the participant's relationship to her autistic child. However, these are factors to be considered in future investigations when looking at this phenomenon. Hopefully, this study will contribute to the understanding of the challenges of parents with history of childhood trauma.

Because a single case study methodology results in very limited generalizability, further research is needed so that the experiences of caregivers from diverse groups can be examined and compared and reliably represented. Additionally, it would also be beneficial to look at the experiences of "all" parents, with history of childhood trauma understand how these experiences affect their relationships with their autistic children. Understanding such may allow clinicians to get a better understanding how to work with families with trauma and autism.

# Implications of this study to theoretical framework

A continuation of the current research and further sampling is needed in order to reach theoretical saturation and create a truly grounded theory that can more thoroughly represent the effects of childhood trauma on parenting an autistic child. Merida's reflections on the shortcomings of the early intervention program's staff may provide valuable insights into how practitioners might improve care to clients, as well as support and supervision of direct care staff.

### Implications of this study to social work practice

The findings of this study will hopefully enhance social work practice by deepening our understanding of the possible effects of childhood trauma. With such, social workers have the unique opportunity to be a pivotal role in identifying the effects of trauma on parenting autism, and create new interventions.

#### Conclusion

Although no reliable conclusion can be made by this single case study, its implication can be used to inform other researchers, mental health practitioners and counselors, of the current lack of research investigating the effects of childhood trauma on parenting a child on the autism spectrum. This study also serves to inform agencies providing Early Intervention services of the importance for competent training and supervision of autism providers. Although studies have shown that parental childhood trauma may affect parental style, it is rather too soon to assume that such results can be generalized to parents of children on the autism spectrum, thus the need for more studies in the area of parental childhood trauma and autism.

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# Appendix A

# Research approval letter

Smith College School for Social Work

Northampton, Massachusetts 01063

T (413) 585-7950 F (413) 585-7994

January 24, 2015

Bryannyagara Barboza

Dear Brya,

You did a very nice job on your revisions. Your project is now approved by the Human Subjects Review Committee.

*Please note the following requirements:* 

**Consent Forms**: All subjects should be given a copy of the consent form.

**Maintaining Data**: You must retain all data and other documents for at least three (3) years past completion of the research activity.

*In addition, these requirements may also be applicable:* 

**Amendments**: If you wish to change any aspect of the study (such as design, procedures, consent forms or subject population), please submit these changes to the Committee.

**Renewal**: You are required to apply for renewal of approval every year for as long as the study is active.

**Completion**: You are required to notify the Chair of the Human Subjects Review Committee when your study is completed (data collection finished). This requirement is met by completion of the thesis project during the Third Summer.

Congratulations and our best wishes on your interesting study.

Sincerely,

Elaine Kersten, Ed.D.

Co-Chair, Human Subjects Review Committee,

CC: Michael Murphy, Research Advisor

# Appendix B

Informed Consent to participate in a Research Study (Participant-mother)

Smith College School for Social Work - Northampton, MA
<b>Title of Study:</b> The Role of a Mother's Childhood Trauma in Parenting her Child on the
Autism Spectrum: A Case Study
Investigator(s): Bryannyagara Barboza, MSW Student, XXX XXXX
Door
Dear,

You are being asked to be part of a case study that investigates how/if maternal childhood trauma affect a mother's parental style when caring for an autistic child. You were selected as a possible participant because you meet the two criteria necessary for this study, which is that you report childhood trauma, and you have a child or children on the autism spectrum, (ages between 3 and 12 years old). We ask that you read this form and ask any questions that you may have before agreeing to be part of the study

# **Purpose of Study:**

The purpose of this study is to investigate how/if a mother's own childhood trauma affect her parental style when caring for her autistic child/children. This study is being conducted as a

research requirement for my master's in social work degree. Ultimately, this research may be published or presented at professional conferences.

### **Description of the Study's Procedures:**

If you agree to be in this study, you will be asked to do the following things: meet with me for informal interviews exploring aspects of your life as a mother of a child or children on the autism spectrum and discuss if and how the "reported trauma" may have influenced your parenting style in any manner.

You are asked to meet with me for a total of 6 hours divided into several meetings. Note that the length of each meeting, place and time of meeting are to be discussed, and will be based on your availability and preferences.

I will also ask you to complete the Adverse Childhood questionnaire at a later point in the study (second or third meeting). I anticipate interviewing only you, but if you agree to it, I would also be interested in observing and speaking with other members of your family including your child/children, so to better understand their perspective of autism. Note that, I will NOT be discussing your trauma history with anyone else other than you.

# **Risks/Discomforts of Being in this Study**:

This study has the following risks: given trauma is one of the topics being explored, and that raising a child on the autism spectrum is also something of that can be seen by many as something stressful, there is the possibility that exploring such subjects may cause you to

experience negative thoughts and/or feelings. It is important for you be aware of your own limitations and to acknowledge to me if something is too upsetting to discuss. We can take a break or even stop talking about the topic that is upsetting you,

Please feel free to ask me any questions at any time in the study. Along with a copy of this Consent, I will provide you a list of local resources and supports.

#### **Benefits of Being in the Study**

Benefits include the following: the opportunity to voice your personal experiences (positive/negative) around raising a child on the autism spectrum, which may impact the development of research in a neglected area, while addressing the need for MSW programs to prepare future social workers to support autism with a trauma informed perspective.

## Confidentiality

Your participation will be kept confidential and in order to protect your confidentiality, I will take the following measures:

I will use a code name on documents, such as the completed questionnaire, transcribed recordings, and my notes to protect your identity; I will keep any identifiable information in a secure location., away from the coded documents and questionnaires; none of the information you provide will go into your ServiceNet record, and no employee of ServiceNet besides the REACH program clinical director, will know of your participation, or have access to any information you give me. The REACH program director has signed a Confidentiality Agreement, promising that she will keep your participation confidential

I have also changed aspects of the other informed consents, so to assure that your personal history is kept confidential.

All research materials including recordings, transcriptions, analyses and consent/assent documents will be stored in a secure location for three years according to federal regulations. In the event that I need materials after this period, I will keep them secure until I no longer need them, and then will destroy them. All electronically stored information on my computer will be password protected. I will not include any information in any report I may write that would make it possible to identify you.

# Payments/gift

You will receive a 75 dollar honorarium for your participation in the study.

### Right to Refuse or Withdraw

The decision to participate in this study is entirely up to you. You may refuse to take part in the study *at any time* without affecting your relationship with the researchers of this study or Smith College.

Your decision to refuse will not result in any loss of benefits (including access to services) to which you are otherwise entitled to.

You have the right not to answer any single question, as well as to withdraw completely up to the point noted below. If you choose to withdraw you *must notify me by email at*(bbarboza@smith.edu), or by phone at (XXX.XXX.XXXX). If you choose to withdraw, I will not

use the information collected. You must notify me of the decision to withdraw by email or phone by April 18 2015. After that date, the information collected will be part of the thesis, dissertation or final report.

# **Right to Ask Questions and Report Concerns**

You have the right to ask questions about this research study and to have those questions answered by me before, during or after the research. If you have any further questions about the study, at any time feel free to contact me, [Bryannyagara Barboza] at [bbarboza@smith.edu] or by telephone at [XXX XXX XXXX]. If you would like a summary of the study results, one will be sent to you once the study is completed. If you have any other concerns about your rights as a research participant, or if you have any problems as a result of your participation, you may contact the Chair of the Smith College School for Social Work Human Subjects Committee at (413) 585-7974.

#### Consent

Your signature below indicates that you have decided to volunteer as a research participant for this study, and that you have read and understood the information provided above. You will be given a signed and dated copy of this form to keep. *You will also be given a list of referrals and access information if you experience emotional issues related to your participation in this study*.