The Experience of Being the Parent of a Child Diagnosed with an Autism Spectrum Disorder:

A Qualitative Study

Jessica L Federowicz

A Clinical Research Project presented to the faculty of the Hawaiʻi School of Professional Psychology at Chaminade University of Honolulu in partial fulfillment of the requirements for the degree of Doctor of Psychology in Clinical Psychology.

Honolulu, Hawaiʻi
July, 2019

The Experience of Being the Parent of a Child Diagnosed with an Autism Spectrum Disorder: A Qualitative Study

This Clinical Research Project by Jessica Federowicz, directed and approved by the candidates Clinical Research Project Committee, was approved by the faculty of the Hawai'i School of Professional Psychology at Chaminade University of Honolulu in partial fulfillment of the requirements of the degree of Doctor of Psychology in Clinical Psychology.

Sean Scanlan, Ph.D., Program Director
Hawai'i School of Professional Psychology

Clinical Research Project Committee:

Joy M. Tanji, Ph.D.
Chair

Lianne T. Philhower, Psy.D, MPH
Committee Member

July 15, 2019
Date

© copyright 2019

by

Jessica L. Federowicz

All Rights Reserved

The Experience of Being the Parent of a Child Diagnosed with an Autism Spectrum Disorder:

A Qualitative study

Jessica L. Federowicz

Hawai’i School of Professional Psychology at Chaminade University, Hawai‘i – 2019

Caregivers and immediate family members of an individual diagnosed with an Autism Spectrum Disorder (ASD) can experience a tremendous amount of stress and distress. The experience can be personally overwhelming and put strain on many aspects of the family and parental unit. The effects of ASD span across not only the individual diagnosed but the families that love and care for them. Research by Van Hecke and Karst (2012) shows the pervasive and severe deficits often present in children with ASD are associated with a plethora of difficulties in caregivers, including decreased parenting efficacy, increased parenting stress, and an increase in mental and physical health problems compared with parents of both typically developing children and children with other developmental disorders. By neglecting to acknowledge the parent and nuclear families emotional and support needs, we as providers and educators are missing a very important piece of treating the child with special needs. Research on families with developmentally disabled members has been poorly represented in terms of looking at the dynamics from a systems perspective. This study is dedicated to coming closer to understanding the experience as expressed by those who live it. The information gathered is intended to expand and add depth to the current literature and serve to inform practitioners and educators who work with this population by providing insight into the experience of parenting a child diagnosed with and autism spectrum disorder.

Dedication

This work is dedicated to individuals diagnosed with an Autism Spectrum Disorder and their families. May service providers and educators gain useful and salient insight into the struggle and joy that ripples through those who love and support a child on the autism spectrum.

Acknowledgments

This project was one that I had been incubating in my head for over a decade but had never taken shape until now. I would like to acknowledge the guidance and incredible insight of my research chair and mentor, Dr. Joy Tanji, who helped me to refine and focus the work. I am beyond thankful for her organizational strengths and editing wizardry.

Additionally, I would like to acknowledge the time and candid expression the participant agreed to commit to this project. It is the hope that this project will help other families on their journey of parenting a child diagnosed with an Autism Spectrum Disorder and that she can add it to her long list of influential advocacy work.

This journey has been made possible by many people who have selflessly taken on many of my other responsibilities so that I could focus on its development. My husband has taken on more than his share of our parenting responsibilities, allowing me to work late nights, while only forfeiting a portion of his sanity. I love you Doug and could never have walked this path without your support and encouragement. Also, I would like to acknowledge my mother who took her 29th trip to Hawai‘i from New York to help my husband with the kids, organize my life, and comfort me.

The meaning of hard work that was instilled in me by my father was put to the test throughout this experience. His example has been an image of inspiration and has given me strength in moments of weakness. I would like to acknowledge and thank my father for all he has given me which has prepared me to take on this feat.

I choose this path but could never have walked it without you. Thank you.

Table of Contents

APPENDICES

CHAPTER I. INTRODUCTION

Becoming a parent is a transformational experience. It requires individuals to shift focus from themselves to the offspring they bring into the world. For many parents, this is a shift for which it is difficult to imagine or plan. It is a shift that changes who they are as people and what they value as individuals. The uniqueness and complexity of this experience is sometimes difficult to define. Caring for oneself when simultaneously caring for children can be difficult and often neglected. It is not uncommon for any parent to neglect their own mental health and self-care needs, but it may be more common for parents with special needs to do so. Parents who have children with developmental disabilities and special needs spend an enormous amount of time caring for their children's special needs and coordinating their services. This leaves less time to care for themselves and a higher likelihood that they will become physically or emotionally unwell due to this neglect and emotional strain.

Situating the Study

Situating a study involves a discussion of the personal interest of the researcher in studying the topic as well as detailing the disposition and skill base of the researcher. It helps the reader to understand the inception of the inquiry and the degree to which the researcher is likely to be reflexive, process oriented, and relational when conducting the study (Rossman & Rallis, 2017).

As a parent, I personally experience stress and heightened emotionality relating to the caregiving of my children. I also admit that I neglect my own needs more often than I would like, resulting in fatigue, occasional sickness, and sometimes distress. These states have sometimes had a negative effect on relationships with others and professional careers. Professionally, I have worked with children with special needs and have witnessed the heightened struggle that parents often experience with their children's problems and maladaptive behaviors. I have sat across from parents in professional meetings and recognized the distress that is sometimes projected as anger and hostility toward service providers. I have wondered what the experience is of those who have a child with special needs and how the parental stressors they experience may differ or be similar to my own. As a mental health counselor, I also wonder how many of these parents are having success caring for themselves in the midst of caring for their children.

As I have progressed in my career, I have become more aware of the power of working with children with special needs and the families that support them. It is my professional understanding that by neglecting to acknowledge the parent and nuclear families emotional and support needs, we as providers are missing a very important piece of treating the child with special needs. Research on families with developmentally disabled members has been poorly represented in terms of looking at the dynamics from a systems perspective. It has been my experience that working with parents of special needs children is often most meaningful when the practitioner has an understanding of what their experience truly is and can see it from a systemic lens. This study is dedicated to coming closer to understanding the experience as expressed by those who live it. The information gathered is intended to expand and add depth to the current literature and serve to inform practitioners who work with this population by providing insight into the experience of parenting a child diagnosed with and autism spectrum disorder.

Review of Literature

A literature review is a way to investigate what has previously been studied in relation to your research questions and determine this information’s relationship to the study. Qualitative research is intended to build and refine theory and knowledge in a particular area—not to replicate findings or test the veracity of extant grand theories. The literature review serves as a frame for the study. A literature review relevant to emergent findings may be conducted throughout the process of data collection and analysis and is also revisited at the end of the study to embed the findings of your study into the current literature that is discovered to be relevant to the phenomenon (Glesne, 2011; Rossman & Rallis, 2017).

A literature review answers the question: “What do we already know?” It is important to review literature prior to beginning a qualitative study to not only establish what is known and not known already, but to establish the need for the inquiry. When reviewing the extant literature, it is important to determine areas that may be missing from the existing body of knowledge and determine how it might be a moral and ethical responsibility of the researcher to contribute to understanding in these areas. The researcher may attempt to explore areas and perspectives of the phenomenon that are poorly represented or lack richness. By thoroughly reviewing the existing literature, the researcher can enhance the moral praxis of their impending study. A review of literature is also used to provide an overview of what has already been established or investigated through other closely related inquiries. It is possible that something has already been studied but there is still a poor understanding of the phenomenon or topic so further research is warranted (Rossman & Rallis, 2017). Theoretical sensitivity is also enhanced by a thorough review of the extant literature. The review of literature can determine the questions to ask participants in the study, the ability of the researcher to evoke a true emic experience that stays close to their reality (Rossman & Rallis, 2017).

Caregiver and Family Stress and Distress

Caregivers and immediate family members of an individual with an autism spectrum disorder (ASD) can experience a tremendous amount of stress and distress. The experience can be personally overwhelming and put strain on many aspects of the family and parental unit. The effects of ASD span across not only the individual diagnosed but the families that love and care for them. Research by Van Hecke and Karst (2012) suggest that the pervasive and severe deficits often present in children with ASD are associated with a plethora of challenges to caregivers, including a sense of decreased parenting efficacy, increased parenting stress, and an increase in mental and physical health problems compared with parents of both typically developing children and children with other developmental disorders.

"Parents of children diagnosed with ASD often report concerns regarding social behavior, communication, play, and motor skills within the first 6 months of a child's life yet formal diagnoses are most commonly given at approximately 3.1 years of age and sometimes as much as 5 years later for those diagnosed with Asperger's Syndrome" (Mandell, Novak, & Zubritsky, 2005). Sometimes caregiver and family distress can begin before a formal diagnosis is given and remain present for the duration of the caregivers lives as many individuals with ASD require care into adulthood (Mandell et al., 2005). Nevertheless, caregiver and family distress is often overlooked as the focus is placed on the child with the disability and his or her treatment. These factors support a lifetime of untreated caregiver distress and emotional instability leading to persistent poor mental health status.

In a study by Abbeduto, Seltzer, Shattuck, Krauss, Orsmond, and Murphy (2004) that compared parenting stress among mothers of children with Fragile X syndrome, Down syndrome, and ASD, the researchers found that mothers of children with ASD showed the lowest levels of psychological well-being and coping. It has been hypothesized by a number of researchers that the diagnosis of a child with ASD could in fact be more stressful than the diagnosis of other disorders because of the range of functioning that comes with a diagnosis, the lack of clarity in diagnostic criteria, as well as the multitude of symptoms that may or may not present with the diagnosis (Saini et al., 2015).

Parenting efficacy. There are many areas of impact ASD has on the caregivers, parents, and families. One of the areas that is impacted is the parental view of their parenting efficacy (Van Hecke & Karst, 2012). The perception of their own parenting efficacy may be impacted by their lack of confidence in helping their child address difficulties which they also share. The genetic component associated with the diagnosis of ASD makes it likely that parents could share some social, communication, or functional skill deficits that their children experience. The caregivers perception that they lack efficacy and confidence of parenting skill can serve to increase the stress among them and lead to inconsistent follow through of intervention techniques and parenting responsibilities. Essentially, if parents see themselves as lacking the skills or efficacy to parent their children with autism, they are more likely to lack follow through with learned intervention techniques. This lack of follow through further diminishes their confidence in parenting and serves to increase their stress about it.

Parental wellbeing. Along with the effects raising a child with ASD has on parenting perceptions of self-efficacy and stress, there seems to be a general decrease in parental well-being and an increase of mental health concerns (Ekas, Lickenbrock, & Whitman, 2010). Researchers Karst and Van Hecke (2012) have identified elevated levels of caregiver mental health problems, particularly depression and anxiety, in comparison to parents of typically developing children and parents of children with other developmental disabilities.

Similar to a study conducted by Ross (1996) using a large national sample of U.S. adults, Benson and Karlof (2009) found that parents of children with ASD reported significantly higher levels of both anger and depressed mood. There was also evidence that the mental health effects were not limited to depression, anxiety, and anger as discovered in a study by Gau et al. (2011). Gau et al.’s study indicated that when compared with parents of children without developmental concerns, parents of children with ASD in Taiwan demonstrated increased obsession-compulsions, interpersonal sensitivity, hostility, schizoid traits, paranoia, and schizophrenia. Many of the caregivers also reported a general distress and lower quality of life than the parents assessed with children diagnosed with an intellectual disorder but not ASD.

A review of the extant literature conducted by Karst and Van Hecke (2012) further suggested that parents and caregivers of children with ASD experience higher levels of fatigue and greater physical health impairment than parents of typically developing children and children with other intellectual disabilities. Families of children with an ASD are faced with a disorder for which etiology is unclear and optimal treatment is contested (Karst & Van Hecke, 2012). This may play a major role in the unique stress along with the high level of demands placed on parents of children with ASD. The above factors can take a toll on the caregivers in the form of physiological and mental fatigue. This fatigue may make it unlikely that the caregiver engages in self-care activities. It may be true that the lack of time for themselves in combination with limited financial resources due to costly therapy for their child and taking leave from work to care for the child, make it likely that individual psychotherapy will not be sought out to address their poor mental health status.

In addition to significant financial strain and time pressures, high rates of divorce and lower overall family wellbeing highlight the burden of having a child diagnosed with an ASD (Van Hecke & Karst, 2012). Most interventions for ASD are evaluated only in terms of child outcomes, ignoring parent and family factors that may have an influence on both the immediate and long-term effects of therapy (Van Hecke & Karst, 2012). This parental and family stress may be related to less than optimal treatment outcomes for the child with an autism spectrum disorder.

Partner relationships. The research suggests that parents of children with autism spectrum disorders are at risk for having higher stress and lower marital quality than other parents (Harper, Dyches, Harper, Roper, & South, 2013). An emerging line of research reveals important differences in marital functioning of couples parenting children with ASD compared with couples parenting typically developing children (Papp & Hartley, 2019). Hartley, DaWalt, and Schultz (2017) examined the daily experiences of couples and found that parents of children with ASD generally spent less time with their partners, reported lower partner closeness, and exhibited fewer positive couple interactions than parents of typically developing children. Additionally, they found that parents of children diagnosed with an autism spectrum disorder self-reported having more intense and unresolved marital conflicts than parents of children without the diagnosis.

Research by Hartley, Barker, Seltzer, Floyd, Greenberg, Orsmond, and Bolt (2010) took a look at the risk of divorce of parents with a child/children diagnosed with an ASD compared to parents of children without the diagnosis. Their results suggest the risk of divorce for parents of children with an ASD is high through the son/daughter's childhood, adolescence, and early adulthood. In fact, the risk could be as high as 80% and does not decline until the target child has reached 30 years of age. This may be due to the prolonged care needs and behavioral stressors associated with some individuals on the Autism Spectrum.

Sibling effects. Due to the overall increase in marital conflict and high levels of stress among parents of children diagnosed with ASD, this population of children and their siblings may be more prone to parental discord than children who live in homes without and individual diagnosed with ASD (Papp & Hartley, 2019). This stress within the family unit can have negative effects on siblings of individuals on the spectrum. It may be true that the needs of the typically developing child could be neglected at times because of the tremendous amount of time the parent takes caring for the child with special needs. In recent years "sibling support groups" for siblings of children diagnosed with an autism spectrum disorder have been developed and carried out in schools and clinics to address the need.

Educator relationships. Educational services and therapies often begin for many children diagnosed with ASD before they formally enter kindergarten. Early intervention programs are often the first educational experience the parents and child navigate followed by pre-kindergarten programs either offered by the department of education or privately funded. Parent involvement is typically highly encouraged during these early education years and the parent is often present for all services due to the child's age and sometimes the requirement of the program. The early intervention services are commonly provided in the home or a clinic setting.

Once the child begins kindergarten, the parent involvement often decreases due to the location of services within a school. The interfacing between parents and educators/ therapists can vary greatly depending on parent or teacher preferences and tendencies. As children with ASD begin elementary school, two relational dynamics come into play, family educational involvement and parent-teacher relationships which may have an important impact on outcomes for students with ASD (Garbacz, McIntyre, & Santiago, 2016). The educators and therapists now share the role of supporting growth and development for the child. Garbacz et al. suggest that there are many factors that influence the family's educational involvement and parent-teacher involvement. These include child characteristics, maternal education, sources of support, and satisfaction with services. Child characteristics could include the level of behavioral disturbances or maladaptive behaviors the child displays. The degree of behavioral disturbance in addition to satisfaction with services then determines the likelihood that the parent will attempt to partner with the school or ask for their help. Additionally, Garbacz et al. found that family histories accessing services emerged as a significant predictor of family involvement and parent-teacher relationships moving forward in their educational experience.

Parental coping. Martin and Cole (1993) identified two factors that contribute to the well-being of families who have an individual diagnosed with a developmental disability among them. These two factors are cohesion and adaptability. *Cohesion* is explained as the emotional bonding that exists between members and adaptability is described as the family's ability to change its roles, structure, routine, and expectations in response to situational factors or stress (Martin & Cole, 1993). These two factors likely develop over time as the family learns of their value or suffers because of poor functioning of the factors. There seems to be a balance that is ideal to the functioning of these factors. Lack of adaptability can cause rigid functioning within the family structure while too much adaptability can lead to chaotic, unstructured functioning.

Hastings, Beck, and Hill (2005) suggest that positive outcomes and improvement in marital relations are more likely to occur when parents are encouraged to consider the positive aspects of having a child with special needs. It could be important to encourage parents to view their children's differences less from a deficit model, which largely ignores their cognitive strengths and unique ways of being, and more from a neurodiversity model which highlights their unique abilities and talents. In contrast to the deficit model, the neurodiversity model highlights the neurology and personhood of autistic individuals through the lens of human diversity (Robertson, 2010). Parents and professionals who adopt the neurodiversity perspective in reference to autism often specifically emphasize the strengths, gifts, and talents of autistic individuals in an effort to establish a balance of focus from what is typically looked at from a deficit model (Robertson, 2010).

Diagnosis

Delays in diagnosis and treatment. It has been my experience when speaking with parents that some report a fear of diagnosis or a denial of the symptoms their child is displaying that leads to delays in diagnosis or treatment seeking. Clearly, parental stress is extremely high around the time of diagnosis, and its level depends, in part, on the parental experiences during the period between first noticing a problem with their child and the diagnosis itself (Reed & Osborne, 2012). As outlined in research by Reed and Osborne (2012), there is evidence that there may be a substantial contribution to parental stress if their diagnostic experience lacks good communication and unsatisfactory overall.

Alternatively, it may be true that their experience navigating the public education system of services as well as poor access to community resources could be contributing to their degree of stress. Accessing special education services and behavior analytic services could pose as a stressful barrier to parents who would be new to the systems.

The experience of receiving a diagnosis. The experience of being presented with a diagnosis itself likely contributes to the way in which parents make sense of their child's disability. Shyu et al. (as cited in Van Hecke & Karst, 2012) found that the way parents explained their child's deficits to others was correlated with their personal well-being, their child's functioning, and the treatment methods chosen by the family.

Van Hecke and Karst (2012) suggested that a parent's understanding and subsequent explanations of their child's deficits is also highly correlated with the way ASD is explained to them by treatment professionals (e.g., Pediatricians or Psychologists). While early interventions designed specifically for children diagnosed with ASD have been demonstrated to be the most effective in producing quantifiable gains, a diagnosis must first be made (Sallows & Graupner, 2005). The nature of this experience, however, can be highly variable for parents (Reed & Osborne, 2012). The experience of receiving a diagnosis can leave parents with many worries and unanswered questions. Parents experiences during the diagnosis of their children can be stressful, and such stress can impact parental health, the development of child-behavior problems, and child outcomes following treatment (Reed & Osborne, 2012).

Treatment Experiences

Once diagnosis is established, a treatment plan needs to be developed by professionals who have training in determining skill deficits to target with intervention. There is limited evidence that interventions and treatment actually impact ASD and its prognosis (Reed et al., 2012). The prognosis or effectiveness of treatment rely on the early and consistent implementation of intervention strategies. Often, consistency of intervention is the best predictor of positive treatment outcomes, but this is difficult to achieve (Reed et al., 2012).

Factors such as a lack of trained therapists, high costs, and family schedules can get in the way of consistent implementation of therapy. Because of this, there has been a great deal of emphasis in the field to train caregivers and family members of the individual to be able to implement behavioral interventions and strategies in order to improve consistency and access to specialized treatment across time. Many of the treatment programs include “parent training” to assist in this effort. However, little consideration is made regarding the readiness of parents to absorb the “training” and implement the strategies. It is likely that parents are still struggling emotionally with the diagnosis given and may not be ready to absorb intervention strategies and behavioral modification techniques. The mental health status of the parents and their ability to implement behavioral intervention is an important consideration in future research.

Summary

The body of research reviewed suggests that in general the mental health status of the caregivers of individuals with ASD is significantly poorer than that of those caring for an individual who does not have an ASD diagnosis. There are a number of child factors linked to caregiver burden for parents of individuals with ASD, including medical problems, ASD severity, mental health issues, and intellectual disability (Lake, Lunsky, Robinson, Tint, Vogan, & Weiss, 2014). Research by Lake et al. (2014) suggests that the burden may persist for very long periods of time as the stress of caring for a child with an ASD may extend beyond childhood and adolescence and into adulthood. Many individuals with ASD require care into adulthood and sometimes up until the caregiver is unable to serve in this role because of old age or health decline.

Research by Saini et al. (2015) found that a number of positive outcomes, in terms of family relationship stress, can occur when families have found a way to adapt to the various stressors that are associated with parenting a child with ASD. Utilizing resources available and learning to cope with the stressors associated with parenting a child with an ASD can improve relationship among these family members and reduce the friction or distance between them.

Statement of the Problem

The statement of the problem in a qualitative proposal identifies the rationale for doing the study. After an initial literature review is completed and the researcher has a better understanding of what has already been studied with respect to the phenomenon of interest, a statement of the problem noted in the extant literature is developed. It may be that the current literature is not comprehensive enough to answer questions you have or is missing details, warranting future studies. The rationale for future research may also reflect concerns about omissions in the current literature and the social costs for those whose story is not included in the current knowledge base. The more you know about the existing research, the easier it is to see the gaps and, thus, the better able you are to narrow and focus the questions guiding your research (Glesne, 2011; Rossman & Rallis, 2017). By developing the statement of the problem, researchers can explain why their continued research is necessary and useful. It sets a frame for the study and substantiates its purpose.

With respect to this study, research by Karst and Van Hecke (2012) suggest that parents of individuals with an autism spectrum disorder spend an enormous amount of time caring for their children and coordinating services for them. It is not uncommon for parents in general to neglect their own mental health and self-care needs, but it may be more common for parents whose children have special needs to do so. It may also be true that other children within the family system are unintentionally neglected if they are doing alright functionally, academically, and socially. Research by Van Hecke and Karst (2012) also shows that the pervasive and severe deficits often present in children with ASD are associated with a plethora of challenges for caregivers, including perceived decreases in parenting efficacy, increased parenting stress, and an increase in mental and physical health problems compared with parents of both typically developing children and children with other developmental disorders. Despite the substantial evidence that parents experience these difficulties, little is documented regarding the experiences of parenting from parents' perspectives using a qualitative design for research.

Statement of Purpose

A statement of purpose captures, in a sentence or paragraph, the essence of the study (Rossman & Rallis, 2017). It should convey the emergent nature of qualitative inquiry. The statement of purpose is important as it establishes the "why" of the study. It explains the way in which you are thinking about your topic, your perspective and its link to the study's utility (Rossman & Rallis, 2017). The purpose of any qualitative study should be to explore, capture, and articulate the emic experience of its participants. The purpose should include a way of describing or comparing the central concept of the phenomenon being studied while outlining the unit of analysis and the method of inquiry. The topic should be generally defined and should explain the way in which it will be discussed (Creswell, as cited in Rossman & Rallis, 2017).

The purpose of this study is to describe the experiences and needs of the parent of an individual with an autism spectrum disorder using a transcendental phenomenological approach. The result will be a discussion of themes and patterns. At this stage in the research, *autism spectrum disorder* will be provisionally defined as a pervasive neurodevelopmental disorder characterized by difficulty in communicating, repetitive behaviors, and social deficits with evidence of cognitive dysfunction (American Psychiatric Association [APA], 2013).

Research by Van Hecke and Karst (2012) shows that the pervasive and severe deficits often present in children with ASD are associated with a plethora of challenges for caregivers, including the perception among these parents of decreased parenting efficacy, increased parenting stress, and an increase in mental and physical health problems compared with parents of both typically developing children and children with other developmental disorders (Van Hecke & Karst 2012). Despite the substantial evidence that parents experience these difficulties, little is documented regarding the experiences of parenting from parents' perspectives.

The intent of this study is to begin exploring a need that is often overlooked—the mental health needs of parents and families of children with pervasive physical and mental health conditions. Qualitative inquiries are typically utilized to inductively generate and refine extant theories through the collection of data that can help broaden and deepen understanding of a phenomenon. In this study, qualitative methodology will be used to begin investigating the experiences of parents of children diagnosed with ASD and the identification of critical periods or phases in their parenting experience where mental health support or services could have been crucial in enhancing or establishing resilience. This study is intended to be replicated by other researchers and participants, then tested over time. Over time, it could serve to benefit training faculty and clinical supervisors by informing their approach to training or supervision of direct care staff through a better understanding of the hidden or unexamined needs of parents. This may be especially important information for clinicians or supervisors who have not personally experienced having a child diagnosed with an autism spectrum disorder.

Research Questions

Research questions are born from queries or curiosities one might have about a particular phenomenon. It outlines the overall intent of the study and what you hope to answer as a result of your work (Glesne, 2016). It can emerge from a need for a study or a problem that exists (Rossman & Rallis 2017). The purpose of a research question is to help identify the overall intent of the study which helps establish boundaries or parameters of the study (Rossman & Rallis 2017). They help to focus and narrow the study.

Phenomenological studies are guided by the following categories of questions: descriptive, experiential, process, and meaning (Moustakas, 1994). Descriptive questions explore the participants' perceptions of what the phenomenon is, while experiential questions explore their experiences when engaged in the phenomenon. Process questions seek to explore how the phenomenon unfolds and changes over time as well as how meanings evolve or are constructed/reconstructed over time. Finally, meaning questions explore the significance and meaning ascribed to the phenomenon (Moustakas, 1994).

The questions used to guide this methodological pilot include the following:

1. (Descriptive Question) What is involved in being the parent of a child diagnosed with an autism spectrum disorder and what is not?
2. (Experiential Question) What is the experience of being the parent of a child diagnosed with an Autism Spectrum Disorder?
3. (Process Question) How does the experience of having a child diagnosed with an autism spectrum disorder change over time? How does the meaning of this experience change over time?
4. (Meaning Question) What is the meaning of having a child diagnosed with an autism spectrum disorder for parents?

Grand Tour Questions

Grand tour questions are the questions asked in a qualitative interview. Grand tour questions are designed to elicit the sharing of experiences. The term *grand tour question* is credited to James P. Spradley (1979), who was an ethnographer and developed the term to capture the nature of the questions used to facilitate focused conversations with participants in the field. Since the introduction of this approach in the field of ethnography, these types of questions have been adopted as a standard approach to qualitative inquiries. The questions tend to be open ended to facilitate conversation and invite participants to bring the researcher along as they navigate through the participants' phenomenological field. Ultimately, the researcher strives to elicit participants' life narratives. Embedded in these narratives are the participants' feelings, beliefs, intentions, and prior behaviors. The intent is to have the participants take the researcher on a verbal "grand tour" of their experience rather than the researcher guide the direction of the interview (Spradley, 1979).

The rationale for using grand tour questions instead of research questions during interviews is that they evoke thick and rich life stories and freedom of direction for the participant. This freedom of direction allows the researcher to document, in the greatest breadth and depth, what the participants believe to be most relevant to their phenomenological experiences. The process of conducting a qualitative research often raises more questions than it answers; the road you take has many intersections, each more intriguing with possibility than the last (Rossman & Rallis, 2017). The intent of the grand tour questions is to begin exploring emic experiences of a phenomenon as well as identifying future directions for future study.

The initial grand tour questions for the first interview are as follows:

1. (Experiential Question) How did you find out that your child had autism? Where were you when you got the news?
2. (Experiential Question) What were some of the experiences you had as a parent before the diagnosis was given?
3. (Process Question) What has it been like since the diagnosis?
4. (Meaning Question) What does autism mean to you personally? That's what the clinicians say but what do you think? How do you understand it?
5. (Descriptive Question) What do you wish the team working with you and your child understood about your experiences?
6. (Descriptive Question) What do you wish the team working with you and your child understood about your child?
7. (Experiential Question) What are some critical events that have happened along the way that would be important in understanding your experience (positive/negative)?

Significance of the Study

The significance of a study is often presented in a study's write-up as a general statement that expresses the aspirations of the researcher—what he or she hopes the study will accomplish. What is unique to postmodern qualitative studies is its emphasis on moral praxis (ethical responsibility) and utility; the importance of insuring that a study will uncover something useful and beneficial not only to the participants, but to other relevant stakeholders. The statement of significance, therefore, includes identification of some of the principal stakeholders of the study and a discussion of how they might benefit from the study (Rossman & Rallis, 2017).

This study can potentially impact or deepen our understanding of the experience of parenting a child with an autism spectrum disorder. By identifying critical events in the lives of those who are parenting children diagnosed with autism spectrum disorder, we may deepen our understanding of how to better support these families. Though this study would mark a beginning of inquiry into the deeper experiences of ASD, it may provide new insights to mental health professionals, especially ways to begin working from a more strength-based approach with ASD families.

Another stakeholder group that could potentially benefit from the outcome of this study are the parents of children with an autism spectrum disorder. They may find the results of this study to be cathartic. They may recognize elements of their own stories and feel validated. If the participants believe that their reality is captured and portrayed in the study's final write-up with fidelity, they may find their participation empowering. This would support the trustworthiness of the study and authentic sharing of participants, providing others with a more nuanced understanding of participants' experiences.

Additionally this study could serve to establish a need that is often overlooked. It could validate the assumption that often the parent and family mental health needs are overlooked or pushed aside throughout the experience of parenting a child with an ASD. The study may contribute to recognizing critical periods or phases in the parenting experience where mental health support or services could be crucial in enhancing or establishing resilience. This study could serve to benefit training faculty and clinical supervisors by informing their trainings or supervision of direct care staff through a better understanding of need. This may be especially important information gathered from the research for clinicians or supervisors who have not personally experienced having a child diagnosed with an autism spectrum disorder.

CHAPTER II. APPROACH

[This chapter appears in its original form so is scripted in future tense. This is the field methodology as proposed. Chapter II focuses on methodological learning in the field.]

Rationale for Use of Qualitative Inquiry

Qualitative inquiry is a form of inquiry that analyzes information conveyed through language and behavior in natural settings. It is used to gather information not readily accessible through quantitative methodology about beliefs, values, feelings and motivations that underlie behavior (Glesne, 2011). Qualitative inquiry is used to learn directly from participants what is important to them, to provide the context necessary to understand their personal stories, and to identify emergent themes important for future clinical studies. Its ultimate purpose is learning and theory building as well as exploring the phenomenon of study (Glesne, 2011).

While quantitative inquiries focus on testing theory, qualitative inquiries focus on theory building. A quantitative study focuses on testing the veracity of extant master theories that attempt to hypothesize the average experience of a phenomenon. A qualitative study attempts to broaden and deepen these theories or to construct provisional grounded theories that explore the range of human experiences associated with the phenomenon, making master theories more robust (Rossman & Rallis, 2017). Thus, while outliers are typically attributed to measurement error in quantitative studies, the outliers in a qualitative study are collected and studied to see whether they represent an important exception or variant of the phenomenon, or an error in classification. Since dispersion of the experiences to assess what is average or common is not the objective of a qualitative inquiry, the number of participants typically do not exceed 10 and qualitative inquiries investigate the lived phenomenon from individuals' perspectives (Rossman & Rallis, 2017).

Utility is another cornerstone of qualitative research and ensures the research will benefit the lives of those we research as well as decision makers who institute change (Rossman & Rallis, 2017). The researchers place focus on why they did the research and how it will be important and applicable to their practice. Qualitative researchers recognize that an individual enters a context with a personal perspective that shapes and is shaped by the perspective of those he or she encounters in the field

(Rossman & Rallis, 2017). Qualitative research emphasizes moral and ethical practice throughout all stages of the research and addresses biases that evolve or are uncovered as the researcher progresses (Rossman & Rallis, 2017).

The four main uses of qualitative methodology are: instrumental, enlightened, symbolic, and transformative/emancipatory (Rossman & Rallis, 2017). Instrumental use of qualitative research utilizes knowledge gained from the research in a way that it can be applied to specific problems. Once knowledge is acquired, solutions or recommendations are provided. Enlightenment as an intent for conducting a qualitative inquiry involves seeking information that may contribute to more informed, future decision making. Symbolic use of qualitative methodology reinforces values or beliefs based in knowledge gained (e.g., knowledge fosters social acceptance of children with disabilities). Transformative/emancipatory use ensure the results alter some aspect of society not just the academic community.

Instrumental use is likely the use that fits most accurately the intent of this study. For Instrumental use, knowledge gained from the research is applied to specific problems. Once knowledge is acquired, solutions or recommendations are provided. It would make sense that once knowledge is gained about the experience of parenting and individual with an autism spectrum disorder, the mental health community of providers can develop greater empathy through understanding and tailor support systems and therapeutic opportunities to the unique needs of these parents.

Specific Methodology

The goal of qualitative research is to describe the lived experience of a phenomenon from the perspective of those who have an intimate knowledge of the phenomenon. The aim is to determine what an experience means for the persons who have had the experience and are able to provide a comprehensive description of it (Moustakas, 1994). From participants' descriptions, "the essence" or structures of the experience is examined (Moustakas, 1994).

Transcendental phenomenological method is a postmodern version of the traditional phenomenological approach. It uses a semi-structured rather than structured interview protocol and focuses on capturing the participant's emic meaning constructions (Moustakas, 1994). Important to this process is the concept of epoché, which involves the identification and management of suppositions or biases (Moustakas, 1994). Any phenomenon represents a suitable starting point for investigation (Moustakas, 1994).

It may be best to use a semi-structured interview for my phenomenon of study rather than a strictly structured one as it may capture the essence of my research better. It is likely that I may be able to capture more of the parental experience by giving them more freedom to share what they feel is relevant. It may be true that potential participants for this study may not have had opportunities in the past to share and express meaning of their experience. Because of this, it is likely that a semi-structured interview protocol would support optimal sharing and engagement.

Role of the Researcher

Intersubjectivity

Qualitative inquiries are assumed to be *intersubjective*; they are conditioned by the subjectivities of both the researcher and participants (Glesne, 2011). Despite this mutual influence, it is the responsibility of a qualitative researcher to capture the experiences of the other while minimizing his or her own etic interpretations. The researcher must also try to minimize his or her impact on the participant by using reflexive strategies and active examination and challenges of the researcher's assumptions and biases throughout the process. In order to accomplish this, qualitative researchers typically adopt the role of a participant-observer role (Glesne, 2016).

Participant-observer Role

The term *participant-observer* is credited to James P. Spradley (1979) who first identified the ideal positioning of the researcher relative to the phenomenon of interest. Essentially the role of the researcher is that of a learner. The participant-observer attempts to position himself or herself somewhere on the continuum between pure participant and pure observer, allowing him or her to both actively engage and detach from the phenomenon. This can allow the researcher to truly immerse himself or herself into the entirety of what the participant is sharing while monitoring how his or her filter impacts data collection and analysis (Spradley, 1979).

A participant-observer role is utilized in qualitative research because it helps the researcher capture more of the participants’ experiences. If one became a full participant, one would need to function as a member of the community being studied and although fully immersed, would risk losing sight of the fact that the researcher is still an outsider, albeit one with some in-group privileges. The researcher must be careful not to assume that he or she knows and experiences what in-group members experience, despite having more direct access to the phenomenon of interest. If the researcher assumed a position at the opposite end of the continuum and became a full observer, he or she might risk distancing himself or herself from the phenomenon and social field of participants. He/she would be limited in their access to the participants, their moment-by-moment experiences, and their construction of meaning over time (Glesne, 2016).

Ethical Considerations

Five basic principles of specific responsibilities should be included in all qualitative research. The first should be that participants must have sufficient information to make informed decisions about their participation in the study. This allows them to provide informed consent in their participation through voluntary participation. They must also be allowed the right to withdraw from the study if they wish and waive questions that they prefer not to answer. The researcher must provide confidentiality in what is disclosed and anonymity to the participant. The researcher is expected to maintain a respectful and trusting relationship with the participant as the participant is often sharing intimate details about their personal experience (Glesne, 2011).

There are four general categories of ethical theory that inform qualitative inquiries. These theories are informed by ethical theories of consequences, rights and responsibilities, social justice, and care (Rossman & Rallis, 2017). The first category, theories of consequence, falls under the broad category of ethical theories called consequentialist theories. The understanding is that no action is particularly good or bad, however, it becomes good or bad as a result of its consequences (Rossman & Rallis, 2017). Conversely, non-consequentialist theories recognize that a standard or rule about the right or wrongness of something should guide all behavior, regardless of the consequences or particular circumstances surrounding the behavior (Rossman & Rallis, 2017).

Theories of rights and responsibilities fall under the general category of non-consequentialist theories which uphold the unconditional and equal respect to which all human beings are entitled.

Additionally, the responsibilities portion upholds the responsibility individuals have to protect those rights that are given unconditionally (Rossman & Rallis, 2017). Another non-consequentialist theory is the ethic of social justice encouraging researchers to pay extra attention to previously silenced voices ensuring that everyone is better off as a result of research conducted. An example from this category is critical ethics. Lastly, ethical theories of care emphasize concrete circumstances over abstract principles (Rossman & Rallis, 2017). As researchers, we are as dependent on our participants as they are on us. Just as they depend on us, our growth and understanding are dependent on their contributions (Rossman & Rallis, 2017). Therefore, it is with great care that we must treat our participants and highlight the relationships within the study in a careful way. Reciprocity is important in achieving the standard of care offering mutual respect and striving to meet the needs of your participant, so they can strive to meet the needs of the researcher (Rossman & Rallis, 2017).

Researchers have many ethical responsibilities, many of which involve fidelity to participants or treating participants as they would like to be treated if participating in another researcher’s study. Most importantly, researchers should never exploit another person for his own advantage (Rossman & Rallis, 2017). It is the responsibility of the researcher to consider consequences of their research, the rights and responsibilities of both the researcher and participant, the aspect of social justice, as well as the level of care given to participants during the experience.

There are some basic ethical responsibilities of a researcher to their participant such as informed consent and allowing them certain rights (Rossman & Rallis, 2017). During this study, I will use a two-part consent protocol. During the initial informed consent protocol, I will ask for initial consent based on the participants’ understanding of what is being asked of them and their rights as participants. During the second consent protocol, I will first ensure that the data analysis was accurate. During this process, I will allow the participants the right to redact, add, or remove any information in the final write-up they believe do not accurately represent their experiences.

Throughout the process, participants will maintain the right to waive questions, defer and answer questions later, and withdraw at any time from the study without being required to provide a reason and without the fear of negative consequences from the principal investigator.

The consent protocols also seek to inform the participant about ownership. In qualitative research, it is assumed that participants remain the owners of their own life stories. The analysis and interpretation of these stories are co-owned by the researcher and participant (Glesne, 2011). Participants are empowered to exercise interpretive authority or the right to full control over the process of adding, removing, or modifying the what will be presented to the public. It is also imperative that the researcher assure the participant that the stories told and the data collected will be kept confidential and secure until he or she can check the researcher's write-up and can make an informed decision about releasing the information in that write-up for dissemination.

Purposive Sampling and Bounding of the Study

Purposive sampling is a sampling logic intended to include participants who can help capture the complexity of a phenomenon. This is in contrast to the sampling logic used in quantitative studies, which selects participants who would represent the distribution of people's experiences relative to a particular phenomenon. In qualitative studies, the researcher selects participants who most directly experience and understand the breadth and depth of a phenomenon.

Choosing an information-rich case, involves finding a participant whose experiences are in line with your research question, an individual who can help uncover aspects of a phenomenon that are not well understood. It is important to choose these types of participants in order to inform the development of new theories rather than test the veracity of extant theory and research. It is also important to choose participants who can articulate their experiences in a reflective and expressive manner (Rossman & Rallis, 2017).

The intent of conducting qualitative research is to develop grounded theories or refine extant grand theories about a phenomenon. There is a specific interest in developing a better understanding of process and meaning construction. The intent is to gain a stronger and deeper understanding of the nuances of a phenomenon so they can help us understand the varied human experience of the particular phenomenon rather than just the average experience. Qualitative researchers seek to understand a phenomenon from an individual or a few individual's perspectives based on their adherence to inclusion criteria and their lack of qualities or criteria that would exclude them (Glesne, 2016).

For the purposes of the impending research, I intend to explore aspects of the experience of those parents who have, despite all odds, remained resilient and persistent in their exploration of parenting a child diagnosed with an autism spectrum disorder. The hope is that through the research, what will emerge are some factors, events, or supports that have contributed to their resilience. My intent is to choose one information rich participant for this research study. Snowball or network sampling followed by atypical case selection will be used in this study. By networking with gatekeepers to identify potential participants, then selecting an atypical case will allow me to locate a parent who has experienced “better than normal” resiliency and coping beyond what is described in the existing research. The researcher may be able to derive elements from their story that may then help build a theory and intervention strategy that could benefit other parents.

This study will be based on interviews with one participant between the ages of 30-60. The participant will be a parent who raised and is continuing to raise a child diagnosed with an autism spectrum disorder. For the purposes of this research study, *ASD* is to include all severity levels and specification categories. The diagnosis of social (pragmatic) communication disorder will not be an eligible diagnosis for this research study.

This study will not include any institutionalized participants or members of protected groups. Participants will not be part of a psychologically or developmentally protected group. In order to participate in the study, the participant will need to be psychologically stable per his or her self-report.

Data Collection and Analysis

Pre-entry

Preparation is imperative prior to entering into the field of study. The pre-entry period involves preparation for access to the field. The researcher must prepare by reading, choosing an appropriate approach, begin identifying and meeting gatekeepers, anticipate potential obstacles, and negotiate some reciprocity or benefits to all involved (Jorgensen, 1989).

Gatekeepers. It is also important to identify and build a relationship with potential gatekeepers who can help you to enter and stay in the field. One must try to know as much as they can about the site or population they instead to study before entering into the field (Glesne, 2011). Despite extensive experience in behavioral analysis prior to conducting this study, I plan to use gatekeepers to help me identify potential participants for the study with experiences and perspectives not yet a mainstay of the extant literature.

Review of biases. Prior to entering the field, researchers must further prepare by reviewing biases that may have an impact on the study. Biases are factors that exist within the researcher that could affect his or her relationship with the participant and possibly cloud their understanding of the stories told. By documenting theoretical, methodological, and personal biases as a researcher, one can control for them as much as possible and improve the rigor of their study (Shenton, 2004).

Theoretical/professional biases. Theoretical or professional biases are related to one's socialization in a field of study. Clinicians in training may experience bias challenges in role relationships and those that may stem from their theoretical orientation(s). Therapists who utilize a non-directive non-expert approach to therapy are particularly prone to these biases as their theoretical approach to therapy is that of a learner.

A bias that I might encounter is related to my position as a clinician. I typically work with parents from a person-centered or humanistic non-expert theoretical orientation early on in therapy. This can be a bias as the relationship of participant-observer could be easily confused with that of a therapist. I tend to work from this frame early in the therapeutic relationship while building rapport and trust before moving into a more cognitive behavioral frame. Sometimes this person-centered approach can be instrumental in creating an environment of unbiased compassion and healing during which the process of change can begin to occur for the client. I will attempt to maintain clarity with respect to my role by remaining present to the participants and their experiences while limiting my empathic conjectures or evocative responses to their stories. I will attempt to focus on clarifying the participants’ content and making a conscious effort not to interpret the content and reflect it in a very different way as I might in a therapeutic relationship. Between interviews I will utilize peer debriefing to keep me honest about my interactions with the participant and by listening to recording or reading through transcripts.

Additionally, I sometimes think of people’s social experiences as being heavily influenced by reinforcement and the behaviors elicited. I must carefully monitor a tendency to listen for behavioral patterns and how they are being reinforced, especially if this is not how the participants understand their experiences. This could get in the way of hearing their emic portrayal of their experiences. I will attempt to address this bias by utilizing a peer debriefer in-between interviews to ensure I am hearing the stories without a tendency to conceptualize behaviorally. During interviews, I will restrict questions to those which are intended to evoke stories and not necessarily "antecedents, behaviors, and consequents."

Methodological biases. Methodological biases encountered by the researcher are impacted by the researcher's previous training in research or familiarity with other research paradigms. Quantitative studies, with which I have a greater familiarity, tend to test the veracity of grand theories as opposed to qualitative research that tries to understand a phenomenon as a whole and not necessarily relationships of discrete constructs or dimensions of the phenomenon. Qualitative inquiries are also conducted in order to build or refine extant theories.

Biases that I may be prone to from a role management standpoint, could be that my training in behavior analysis may have an effect on my ability to see the phenomenon in a holistic manner as opposed to reducing it to its parts. In behavior analysis, we reduce behaviors into discrete, definable, and measurable parts. When conducting qualitative research, however, the researcher should try to understand the experience as a whole instead of breaking it down into parts. I will attempt to address this bias by structuring my grand tour questions in a way that illicit whole stories and critical events as opposed to definable behaviors. Between interviews I would utilize a peer examiner from a different theoretical orientation to ensure my coding of stories fits the stories told. By consulting with my peer debriefer and peer examiner, I can develop ways to elicit narrative responses from my participants.

Additionally, I think I am at risk for methodological drift as my tendency is to ask questions that explore cause and effect relationships. This is again related to my training as a behavior analyst. I tend to look at experiences and conceptualize them in terms of antecedents, behaviors, and consequents, or cause and effect relationships. While cause and effect relationships may emerge from narratives in a qualitative inquiry, a focus on this aspect of participants' stories might keep me from eliciting thick, rich data that tells a robust story of the participant's experiences as a parent that go beyond cause and effect. It might instead give me information about specific behaviors and their potential cause and effect. To counteract this, I will use questions to elicit stories and not quantitative type data or enumerations. I will also utilize methodological consultants to ensure that I do not ask meaningless questions or those that do not elicit stories. During interviews, I would ask questions that encourage storytelling and be prepared with follow-up questions if the participant answers the question with a culturally rehearsed response.

Personal biases. Personal biases are ones that stem from the researcher's understanding of the world based on his or her own life experiences and socialization. These biases can cloud the researcher's understanding of others' stories and draw him or her away from the role as a learner toward that of expert and interpreter, eliciting confirmatory biases.

I may hold a personal bias because I myself am a parent, and it may be true that I think I understand others' experiences as parents as being similar to my own. This may affect my ability to hear their stories as different from my own. For example, my experience of having my child tantrum in a grocery store brought feelings of shame, but I would have to be careful not to assume others also feel the same thing in others who find themselves in similar circumstances. These types of assumptions could hinder my understanding of their experiences if I made these assumptions about their personal experience. I will monitor this bias by making sure I ask follow-up questions or make reflections that verify their experience as I am hearing it so that I do not make assumptions. I will also utilize a peer debriefer to back up my own personal reflexive process by asking me about other plausible hypothesis.

The second bias I may be at risk for is thinking that having a child with an autism spectrum disorder is more difficult, challenging, and stressful than having a typically developing child. This could lead to an overdramatized perception of their struggles on my part. This can be addressed by asking participants to explain the severity of a difficulty, challenge, or stressor. I could use a peer debriefer to allow me to candidly discuss my reactions to the interviewing experience and challenge my understanding of the participant's experience.

Entry

As qualitative researchers enter the field, their objective is to ensure trustworthiness of their findings (Shenton, 2004). This requires that researchers begin building rapport and respect within the relationship between researcher and participant. The researcher enters the field by making contact with gatekeepers, informants, and participants. The researcher enters the scene with consideration of relationships as emergent processes, deep versus surface culture, role management, participant recruitment, and informed consent. Some issues that may arise at this stage might be with role management if a dual relationship exists between the researcher and the participant. It is important to acknowledge and understand the new complex relationship emerging with the participant. It is also important to make the distinction that this research is not done through experiment, the intent to learn about the phenomenon. During initial entry into this study, the most important entry issue will be the informed consent process.

Two-part informed consent protocol. A two-part consent protocol will be used in this qualitative project to ensure consent is informed and data is accurately represented in the final product. It is governed by covenantal ethics and is used to ensure the emic experience of the participant is captured in the final analysis and coding. The assumption is that at the outset of the study, the participant will not know what he plans to share in the study. Thus, the participant can only make an informed decision about certain aspects of his or her participation. A truly informed consent will ensure the participant knows the potential risks and benefits of participation as well as how much input they will have in the final product. Every attempt should be made to make the language readable and understandable by the participant. In a two-part consent, the initial consent provides participants with an overview of the study—what is being asked of the, the rights they have throughout the process, and the potential benefits and minimal risks of participation.

The final consent protocol allows the participant to check the researchers work, add, retract, and modify what was gathered before it is put in the final write up. This gives them a chance to ensure the researcher has captured their story with accuracy and strengthens the validity of what is used. The participants are asked to review transcripts of interviews, exemplar quotes, analyses of data, and personal narratives.

Immersion. Because data is collected in repeated cycles during this process, it is important for the researcher to remain in the field for prolonged periods of time. Immersion in the field allows the researcher deeper entry in order to gather and test the veracity of more data. In order to achieve saturation of the data gathered in the study, I hope to interview each participant three times.

Constant Comparative Method

Constant comparative method involves repeated cycles of data collection and analysis that allow for deepening immersion into the world of participants, relationship building, and the opportunity to explore the participants' experiences more broadly and deeply (Strauss & Corbin, 1998). It allows the researcher to test emerging descriptive hypothesis against confirming and disconfirming evidence helping to refine the overall accuracy of emic portrayal over time (Strauss & Corbin, 1998). This simultaneous data collection and analysis also allows the researcher to assess their own impact on the participant and behave in ways to minimize this impact. Simultaneous data collection and analysis also enables the researcher to revisit expected and unexpected issues over the course of their interviews, seek elaboration or clarification, and to probe more deeply with the participant (Rossman & Rallis, 2017). By using this method, the researcher has the opportunity to arrive at a more accurate portrayal of the participants' lived experiences over time (Strauss & Corbin, 1998).

This phenomenological research pilot will utilize constant comparative method and incorporate the following steps:

Semi-structured interview. The researcher will interview the participant using a semi-structured interview style. Questions intended to evoke stories describing their experience will be utilized. The interview will be flexible allowing the participant to drive the direction it takes when discussing the main research question. The interview will be audio taped and transcribed. The intent is to engage the participant in three semi-structured interviews with the addition of an exit interview.

Data management. Since the urban qualitative researcher typically is juggling multiple roles and responsibilities, the researcher may opt to use a strategy of data management to facilitate a less rigorous constant comparative analysis process that allows him or her to continue conducting interviews informed by emergent data, prior to completing full transcription, auditing, and coding. Following each interview, I would code the interview using macro-level codes. This process of coding-by-document would involve jotting down major themes heard during the interview. These themes could then be used to generate questions for the following interview.

This strategy is especially helpful given my limited resources as a graduate student. Since time is in short supply, microanalysis would be used during and just after interviews. These themes could then be discussed during peer debriefing to brainstorm the generation of grand tour questions that might elicit further depth and breadth with respect to emergent categories and subcategories.

In cases where interview data appears nuanced or detailed, I will supplement coding-by-document with the generation of running codes. This is a more structured and systematic approach to macroanalysis in which the researcher listens to the interview on audiotape and jots down phrases that capture themes and subthemes. This offers a more detailed, preliminary understanding of what is emerging in the study (Glesne, 2011).

Peer debriefing. A peer debriefer is someone on the research team that provides methodological consultation to the researcher. This is done before, during, and after data is collected in the field (Glesne, 2016; Shenton, 2004). The debriefer and researcher should remain in close contact and meet weekly to discuss the researchers emerging observations, conceptualizations, and methodological challenges (Shenton, 2004). The peer debriefer should prompt the researcher to look at their reflexive process of questioning inferences, exploring alternative hypotheses, and brainstorming.

Transcription and auditing. Qualitative researchers generate transcripts of the interviews they conduct and of specific focused conversation or story. Currently, I am planning to transcribe the interviews myself. However, if I begin to fall behind and this begins to negatively impact the immediacy and depth of interviews, I will seek the assistance of a transcriptionist. The transcriptionist will be trained to honor the same ethical guidelines as the peer debriefer, peer examiner, and myself, following protocols that secure the data and protect the confidentiality of the participants. If a participant knows the individual I plan to have transcribe the interview tapes, I will seek the assistance of someone else. Whether I personally transcribe the interview tapes or seek the assistance of another, I will audit the transcripts for accuracy to ensure the participants words were captured correctly.

Coding. Data coding in the transcendental phenomenological method is conducted in three different ways according to Moustakas (1994). The process of data analysis begins with breaking the interview up into smaller chunks such as stories and themes (phenomenological reduction). These themes are then clustered and subclustered (imaginative variation), until the researcher arrives at an integrated coding list that captures both the essence of the phenomenon as experienced by the participants, and the major aspects or themes relevant to that experience (synthesis).

Peer examination. During the study, researchers often consult with other researchers or peers who have worked within the field or with the phenomenon before. Peer examiners examine discrepancies between current data and older data in support of reinterpretation, elaboration, and refinement of the coding (LeCompte & Preissle, 1993). They also help to manage potential biases in the emergent coding system.

Generating a narrative. While engaging in continuous data collection, the researcher begins to generate a narrative of the participants' stories. The codes are back-translated into a narrative outlining the most essential aspects of the participants story, illustrated by exemplar quotes from the interviews.

Member checking. Participants have the opportunity to verify the accuracy of the narrative developed and the transcript it was derived from during the member check. This member check gives the participant ownership and conveys the researchers efforts to give them interpretive authority. During this time, the participant can discuss things they would like to add, retract, or restate (Glesne, 2016; Shenton, 2004). Members are co-owners of any written material and invited to participate in its final construction.

Methods of Verification

Qualitative researchers strive for trustworthiness in their studies. *Trustworthiness* refers to rigor in terms of validity and reliability. Rigor is enhanced through the use of *methods of verification*, strategies that enhance the researcher's reflexivity and support fidelity in the portrayal of participants' emic accounts of their lived experiences (Shenton, 2004).

Validity

Validity in qualitative research refers to the credibility of one's findings. The most important goal of qualitative research is to capture a phenomenon from the participants' perspective while managing or minimizing the influence of the researcher. The findings should boast emic accuracy if the validity of the study is strong. *Emic accuracy* refers to how well the participants' lived experiences are reflected in the study's findings, which ensures the credibility of the study (Shenton, 2004).

Validity is enhanced by using methods that enhance credibility of the findings, that manage the researcher's subjectivity. It will be very important for me to check in with the participants to ensure I am capturing their experience as opposed to my own interpretation of their experience. It will be particularly useful for me to use exact wording that my participants use rather than using my own language after making "meaning" of their response to prompts or questions.

Validity is strengthened using strategies that enhance the quality of the relationship between the researcher and participant, and manage the researcher's biases throughout the process of data collection and analysis (Glesne, 2016). Among the methods of verification that can enhance a study's credibility are: entry, relational ethics, role management, epoché (review of biases), debriefing, peer examination, and member checking.

Entry in qualitative inquiry refers to the ongoing development of rapport, and maintenance of the trusting relationship. This is developed over time and across contexts. It enhances the extent to which the participant will voluntarily share their private authentic experiences to an outsider (Rossman & Rallis, 2017).

Epoché includes the researcher's ongoing review of biases and use of reflecting opportunities such as field journaling. This helps researchers continually assess how their personal filters may bias what they are able to hear and see, as well as how they may impact the authenticity of the participant's narrative (Moustakas, 1994).

Peer debriefing is often used to enhance validity as it allows someone else to serve as a methodological consultant before, during, and after the data is collected. The debriefer serves as a sounding board and sometimes a "devil's advocate" regarding the researcher's methods, biases, and interpretations. You may also use a debriefer to assess confirmability or the objectiveness of your study (Rossman & Rallis, 2017). Peer examination is often used to provide further reflexive oversight. The peer examiner reviews the fit of the researcher's coding with the transcripted data. The focus of the peer examiner's feedback is on whether the researcher has used low inference coding or codes that stay close to the language and lived experiences of the participants as portrayed in their conversations with the researcher (LeCompte & Preissle, 1993).

It is important to assess the credibility of one's study by determining how congruent the findings are with the participant's reality. This could be done by utilizing a member check. A *member check* involves asking participants whether one is understanding their story correctly (Glesne, 2016; Shenton, 2004).

Reliability

Reliability in qualitative inquiries is achieved when the findings of one's study can be generalized to inform understanding of other people's experiences in similar contexts. The standard of reproducibility with regard to findings is not typically used in the qualitative research vocabulary in the same way that it is in quantitative studies (Rallis & Rossman, 2017). Instead, it is understood that there should be some transferability but not complete transferability to a similar study due to the nature of the research. Qualitative research is employed in the hopes of obtaining transferability and dependability of the findings. This is to say that it is likely that what is captured can inform similar phenomenon (transferability) and if replicated using comparable methodology, comparable findings will emerge (dependability) (Shenton, 2004). Methodological transparency can also serve to enhance the reliability of one's findings as the researcher tries to document emergent field method in descriptive detail which helps in the replication of studies. The inclusion of the researchers reflexive appraisal of the research can also contribute to its methodological transparency and reliability of findings (LeCompte & Preissle, 1993; Shenton, 2004).

Reliability is assessed by examining particular dimensions such as purposive sampling, data collection (triangulation) and analysis methods (constant comparative method), immersion, and replication over time. The researcher's documentation of emergent field method as well as peer examination can be important strategies employed in order to enhance reliability of one's findings. It is the intent of research to learn something new about a phenomenon and have this new information inform similar phenomena studied in the future. This idea is called transferability and can enhance the reliability of a study. Transferability is enhanced by obtaining thick, rich data over time through the use of techniques such as immersion and replication.

Purposive sampling is a method for selecting participants based on the experiences and perspectives of the phenomenon of interest. The researcher chooses participants with a purpose and intent for their contribution to what is already known. It also outlines the number and diversity of the participants chosen. These participants are suspected of being able to offer thick and rich information about the phenomenon of interest.

The data collection and analysis method are important to examine when assessing reliability because it is important to make sure that this process contributes to a rich, complex understanding of the emic experience rather than replication of what is already known or theorized. Rigorous qualitative studies utilize constant comparative analysis, a process of simultaneous data collection and analysis. Constant comparative analysis involves repeated cycles of data collection, hypothesizing emergent themes, and refining these hypotheses through additional cycles of data collection and analyses (Strauss & Corbin, 1998).

Peer examiners are also utilized to enhance reliability as they support clarification, exploration, and strategy from an outsider perspective. Although the peer examiner is likely to have knowledge about the phenomenon and possibly by studying something similar, he/she may be able to provide a cross-theoretical validation of the researcher's coding structure (Glesne, 2016).

Documentation of emergent field method is a process that requires the researcher to disclose discoveries and problems encountered throughout their study. With whom and how they were encountered are detailed as well as how they were addressed through methodological refinements or other changes. These are recorded in the field journal and often included in the final write up of the study. This documentation helps to enhance a studies analytical generalizability by keeping the researcher present with attention to the details of the emergent method and findings of the study (Glesne, 2016). Documentation of emergent field method can also enhance comparability across studies in the future (Shenton, 2004).

Utility

Utility in a qualitative inquiry is considered an additional criterion used to assess the rigor of an inquiry. In particular, it examines the study's ability to address issues of covenantal ethics (LeCompte & Preissle, 1993). If the study has adequate utility, that would mean that it would enhance the current knowledge base, add to our understanding, be readily accessible to multiple stakeholders, and/or address the statement of a problem (LeCompte & Preissle, 1993). Utility can be targeted to achieve five different outcomes. The first is *fairness* or the study's ability to provide a balanced presentation of multiple realities of one situation or group, whether or not multiple stakeholders were interviewed. The second is *ontological authenticity* which refers to the idea that the study provides a new or fresh understanding of the phenomenon. The third is *educative authenticity* or the study's ability to provide a new appreciation for current understandings of the phenomenon by deepening the knowledge already available. The fourth criteria is *catalytic authenticity*, which involves assessing whether the study's results support new courses of action that intervene constructively in current practices. Lastly, the results could be used to enhance *tactical authenticity* or the study's ability to offer potential benefits to those who are directly concerned with the phenomenon and its potential to help many more (LeCompte & Preissle, 1993).

For my study, it is likely that the results would be utilized for educative authenticity and used as a learning tool for working therapists and therapists in training who may have a client parenting a child on the autism spectrum. It is the intent of this study to grasp a better understanding of the experience of this phenomenon to inform mental health professionals. It appears that the current research reviewed does not capture the richness or deepness of the experience. Individuals working with parents of children diagnosed with an autism spectrum disorder would be well served to recognize some of the process code clusters that may come up across participants.

CHAPTER III. EMERGENT FIELD METHOD

[While the methodological design of this project as proposed in Chapter II did not change, my deeper understanding of qualitative method did. The following discussion documents the methodological lessons learned in the field.]

Pre-entry

Pre-entry preparation is imperative prior to entering into the field. It involves preparation for access to the field. The researcher must prepare by reading related literature, choosing the specific qualitative approach to the study, identifying potential obstacles, and negotiating some reciprocity (Jorgensen, 1989).

One must try to know as much as they can about the site or population they intend to study before entering into the field. Identification of potential gatekeepers and informants may help one to address potential challenges before entering the field and may help the researcher maintain entry as the study continues.

An initial review of biases is also essential. The researcher must do a thorough review of initial theoretical, methodological, and personal biases and consider how they may negatively impact or compromise the rigor of the study (Glesne, 2011).

In preparation for entering the field, I thoroughly assessed my connections to those professionals and parents who have direct lived experiences with autism spectrum disorders (ASD) and those that it affects. I familiarized myself with different approaches to contacting them and weighed the pros and cons of their different positions and perspectives. I considered how they might benefit from participation, and tried to determine which parties might offer the richest accounts of what is still poorly understood about ASD.

Review of Biases

Prior to entering the field, researchers must further prepare by reviewing biases that may have an impact on the study. Biases are factors that exist within the researcher that could affect his or her relationship with the participant and possibly cloud their understanding of the stories told. By documenting theoretical, methodological, and personal biases as a researcher, one can control for them as much as possible and improve the rigor of their study (Shenton, 2004).

Theoretical biases. I began the process by contemplating the biases I might encounter due to my greater familiarity with the role of a clinician. Early on in the therapeutic process, I typically work with parents from a person-centered or humanistic non-expert theoretical orientation—especially during the early development of the therapeutic relationship. This can be a bias as the interactional style of the participant-observer in qualitative research can be easily confused with that of a humanistic therapist. I focus on building rapport and trust before moving into a more cognitive behavioral frame. Sometimes this person-centered approach can be instrumental in creating an environment of compassion and healing during which the process of change can begin to occur for the client in therapy.

As this study began, I attempted to maintain clarity with respect to my new role as a researcher, in counterpoint to my more familiar role as a therapist. I tried to remain present with the participant, listening to their personal accounts of her experiences, expressing empathy but limiting my empathic conjectures or evocative responses to her stories. I attempted to focus on clarifying the participant’s content and facilitating the participant’s elaboration of her experiences while making a conscious effort not to interpret the content and reflect on it in ways I might have in a therapeutic relationship. Between interviews, I utilized a peer debriefer to keep me honest about my interactions with the participant and by listening to the recordings of the interviews or reading through transcripts. These strategies appeared to be sufficient in managing my role-related biases during these interviews as verified by a review of my transcriptions which reflected few instances of interpretation.

In addition to this potential role management issue, I carefully monitored my behavioral assumptions. I sometimes think of people’s social experiences as being heavily influenced by reinforcement and the behaviors elicited. I carefully monitored my tendency to listen primarily for behavioral patterns and how they might be reinforced, especially if this was not how the participant understood her experiences. I knew that this could get in the way of hearing what was most meaningful to her about her experiences. I attempted to address this bias by utilizing a peer debriefer in-between interviews to ensure I was hearing the stories without a tendency to conceptualize behaviorally. During the interviews, I successfully restricted questions to those that were intended to evoke stories and not necessarily “antecedent, behavior, consequence” responses.

Methodological biases. Methodological biases encountered by a researcher conducting a qualitative inquiry may reflect the researcher’s previous training in the positivist research paradigm. I have greater familiarity with quantitative studies that tend to test the veracity of grand theories as opposed to qualitative research that tries to understand a phenomenon as a whole and not necessarily relationships of discrete constructs or dimensions of the phenomenon. Qualitative inquiries are also conducted in order to build or refine extant theories (Rossman & Rallis, 2017).

Entering the field, I knew that one of my biggest challenges would be managing role-related behaviors linked to my training in behavior analysis. My concern was that it might affect my ability to see the phenomenon in a more holistic manner as opposed to reducing it to its parts. In behavior analysis, we reduce behaviors into discrete, definable, and measurable parts. When conducting this qualitative study, though, I tried to understand the experiences of my participant as a whole. I attempted to address this bias by structuring my grand tour questions in a way that elicited whole stories and critical events as opposed to lists of definable behaviors. Between interviews, I utilized a peer examiner from a different theoretical orientation to ensure my coding of the participant’s stories remained experience near. By consulting with my peer debriefer and peer examiner, I was able to develop ways to elicit narrative responses from my participant. I believe that these strategies were enough to manage this methodological bias.

Additionally, I was concerned about the risk of methodological drift as my tendency is to ask questions that explore cause and effect relationships. This is again related to my training as a behavior analyst. I tend to look at experiences in terms of antecedents, behaviors, and consequents; to generate hypotheses about the causes of behaviors or actions. While cause and effect relationships may emerge from narratives in a qualitative inquiry, I was concerned that an exclusive focus on this aspect of the participant’s stories might keep me from eliciting thick, rich data that could provide more robust understandings of her experiences. To counteract this, I took special care to generate questions that would elicit stories rather than enumerations or listings. Participants often report more than they consciously know in the context of their narratives, so I diligently consulted with my methodological support team throughout the study. I also utilized methodological consultants to ensure that I did not ask questions that were limited to my theoretical biases and training. During interviews, I would ask questions that encouraged storytelling and was prepared with follow-up questions if the participant answered the question with a culturally rehearsed response.

Personal biases. Personal biases are ones that stem from the researcher's understanding of the world based on his or her own life experiences and socialization. These biases can cloud the researcher's understanding of others' stories and draw the researcher away from his or her role as a learner toward that of an expert and interpreter, eliciting confirmatory biases (Shenton, 2004).

As a parent, I wanted to take special care in attuning myself to the similarities and nuances of difference in my participant's experiences as a parent, to hear her stories as different from my own. I was concerned that it could hinder my understanding of the participant's experiences if I made these assumptions. For example, the experience of my child having a tantrum in a grocery store often elicited feelings of shame, but I wanted to be careful about assuming that my participant's experiences of similar behaviors would be the same. I made an effort to monitor this bias by making sure to ask follow-up questions or make reflections that verified her experiences—especially those that seemed more unique to her constructions of her experiences as a mother. I was diligent in my efforts to reflect what I was hearing the participant say in interviews and ask for clarification or expansion of an account when I was not clear about what she was saying. I also utilized a peer debriefer to back up my own personal reflexive process, to help me brainstorm alternative plausible hypotheses.

The second personal bias I monitored while in the field was the assumption that having a child with an autism spectrum disorder would be more difficult, challenging, and stressful than having a typically developing child. Unchecked, this bias could have contributed to an overdramatized perception of my participant's struggles. This was addressed by asking the participant to explain the severity of the difficulty, challenge, or stressor in her own words. I used phrases in my responses that encouraged the participant to expand on experiences she labeled as "difficult" or "hard" to make sure I understood the magnitude of these challenges from her perspective. I also used a peer debriefer to allow me to candidly discuss my reactions to the interviewing experience and challenge my understanding of the participant’s experience.

Role Management

Role management needs to be closely monitored not only in the field, but during the pre-entry and entry stages of a qualitative inquiry. In the case of my study, I anticipated that because of my years of experience working in the field, I might know the gatekeeper or participant in other capacities besides the researcher-participant role. If a dual relationship existed between the participant and me, I knew it would be especially important to acknowledge and understand this new complex relationship. It was also important to make the distinction that this was not an experimental study; the intent of this study was to learn about the participant’s phenomenological experiences as a parent of a child diagnosed with ASD. Both of the gatekeepers I contacted, knew me professionally. I never had any authority over either of them, but had worked collaboratively with them. My previous “colleague to colleague” relationship with both gatekeepers did not seem to interfere with, conflict with, or confuse them in terms of understanding my new role as researcher.

Entry

As I entered the field, my focus was on ensuring freedom and integrity in the process that would unfold between the participant and me. This is an ongoing process that is built through good rapport and respect within the relationship between researcher and participant (Rossman & Rallis, 2017). The researcher enters the field by making contact with gatekeepers, informant, and participants. The researcher enters the scene with consideration of relationships as emergent processes, deep versus surface culture, role management, participant recruitment, and informed consent.

As a researcher, I found myself anxiously awaiting entry into the field albeit excitement about the process. In anticipation that gatekeepers and participants would not be quite as anxious and excited about starting the research as I was, I reached out to them with the request that they respond to my invitation to participate within one to two weeks of receiving it. I used this time to review my interview questions and refresh my understanding of what my initial exploration of the existing literature had revealed about my topic. In reality, the time line was protracted given the busy schedules and commitments of the gatekeepers and potential participants referred to the study.

Gatekeepers

As I moved forward with contacting individuals who I had selected as potential gatekeepers for this study, I came across two individuals who had an interest in the nature of my study and who seemed to be able to offer contacts of potential participants. One of them was a parent of a child diagnosed with an autism spectrum disorder, who I had interviewed previously for a class project and who had expressed an interest in helping me find other participants. The other was a care provider who had access to and knowledge of parents of children diagnosed with an autism spectrum disorder through her work. The experience of contacting these individuals and receiving responses was fairly seamless. They responded quickly via email and text message to my request for assistance in acquiring participants for my study.

Both gatekeepers had the potential to make an important contribution to my recruitment efforts, however, in the end, only one potential gatekeeper had the time to dedicate to assisting in the study. This gatekeeper was able to put me in contact with a potential participant who had done some groundbreaking advocacy work that had led to the development of laws and regulations aimed at helping children on the autism spectrum and their families. With the permission of a potential participant, the gatekeeper offered me the email of this potential participant.

Purposive Sampling

Finding a participant who could commit the time and effort to participating in this study took longer than expected and I became discouraged when my initial invitations did not result in timely responses. Despite my easy communication and prompt response from potential gatekeepers, my experience with potential participants was not as seamless. It is, however, the responsibility and duty of the researcher to be flexible and adapt to potential participants' routines and schedules. My persistence paid off. By remaining flexible despite my urge to promptly schedule interviews and get consent forms signed, I was able to finally make contact with a very knowledgeable participant. This was a good exercise in patience and understanding for me. It was also important for me to consider that I was asking parents to participate in something extra with the understanding, from my experience and literature review, that these same parents were ones who were typically overwhelmed with their children's special needs and services. The reality of asking individuals parenting a child diagnosed with an autism spectrum disorder to commit to multiple time-consuming interviews was a lot to ask. I believe I found a good balance of persistence and patience when pursuing potential participants for this study and eventually found one that I believed would be ideal for the study.

As soon as I received the invitation from the gatekeeper to email the potential participant, I promptly emailed him the following day. That was March 29, 2019. I emailed the potential participant with an inquiry about participation and offered my phone number and email for correspondence to discuss the study further. It was my intent to engage the potential participant through more than one method of introduction to ease the process. I had hoped to have both email correspondence and a short telephone conversation to hopefully increase the potential participant's comfort. On April 2, 2019, I received an email reply stating that both parents were interested in being involved in the study but that they were soon leaving for vacation and would contact me when they returned in about one week. Thus, on April 22, 2019, I sent a follow-up email to see if the couple was still interested in participating. A response was sent on May 9, 2019 acknowledging the delay and asking about a way to become involved. On May 15, 2019, it was decided that the wife of the couple was interested in participating and a formal invitation was sent to her as well as a copy of all the informed consent documents. A brief phone call was made to clarify the purpose of the study, the rights of the participant, and other formalities. Because the end of the school year was occurring at the same time as the projected dates for interviews and she found herself very busy, the participant asked to utilize phone interviewing instead of face-to-face interviews.

Role Management

As the interviews progressed, I noticed that it was taking considerable effort to stay grounded in my role as researcher. I found myself pulled to respond as I might in therapy with empathic conjectures but made every effort to stay in my role and stick to reflections to clarify stories instead. I found it helpful to focus on clarifying the participant's content rather than interpreting it. Additionally, during the interview process, I found I was able to circle back to themes that I had heard in earlier interviews and ask the participant to expand on them again. I found this useful in expanding on important concepts and staying in my role as researcher by focusing on expanding the data set from previous interviews that I had already begun to code.

Informed Consent Protocol

A two-part consent protocol was used in this qualitative project to ensure consent is informed and data is accurately represented in the final product. This protocol was governed by covenantal ethics and was used to ensure the emic experience of the participant would be captured in the final analysis and coding. The assumption was that at the outset of the study, the participant would not know what she planned to share in the study. Thus, the participant could only make an informed decision about certain aspects of her participation. A truly informed consent would ensure the participant knows the potential risk and benefit of participation as well as how much input she would have in the final product. Every attempt was made to make the language readable and understandable by the participant. In an effort to make sure the participant was aware of what she was consenting to on the paper forms, I discussed the key points of consent with the participant over the phone during our first conversation. She did not indicate any reservations or concerns when asked if she understood the agreement she was signing.

In this two-part consent procedure, the initial consent provided the participant with an overview of the study—what was being asked of her, her rights throughout the process, and the potential benefits and minimal risks of participation. After we reviewed the document, she signed the initial consent form. At that time, she asked to be referred to as “the participant” in the final write up of the study. Although the participant reported having no objections to using her real name in the final write up of the study, it was brought to her attention that this could indirectly expose her family to potential recognition to which they had not consented. The participant ultimately agreed that the pseudonym “the participant” would be used for the final write up.

The final consent protocol in this two-part informed consent protocol allowed the participant to member check my work, to add, retract, and modify what was gathered before it was put in the final write up. This gave her a chance to ensure that I had captured her story with accuracy, strengthening the validity of the final presentation of her story. The participant was asked to review transcripts of interviews, exemplar quotes I wanted to incorporate in the final write-up, and analysis of data.

Constant Comparative Method

Interview Process

Prior to the interviews, I spoke with the participant over the phone, reviewing the consent form highlights and reiterating the purpose of the study. I made sure to mention she could request to stop the recording at any time throughout the interviews and that, in the end, she would have authority to inform me of things she wanted included in the data and things that she would want left out of the final narrative presentation of her story.

I had originally proposed that we hold the interviews at my private practice office in Kailua. However, during the phone conversation, the participant had requested phone interviews for convenience as her schedule was very busy and she lived on the other side of the island. I had suggested we meet in person and assured her that I would drive to meet her at a convenient, confidential location if that would help. Despite efforts to accommodate, the participant seemed more comfortable scheduling phone interviews, so we agreed on using that modality. I was initially worried about the possibility that phone interviews would be less personal than face-to-face interviews and contribute to me missing elements of her story that were important. However, I felt it was important to be flexible and accommodate the participant, so we scheduled phone interviews.

A series of three interviews were completed via telephone with the participant. The interviews took place two to three days apart and lasted 30-46 minutes each. The first interview on May 22, 2019 covered the first three grand tour questions on my list and lasted a total of 37 minutes and 44 seconds. The first interview was important as its flow and content set the stage for further interviewing. I wanted the participant to feel comfortable and able to express herself without fear of judgment. Due to the fact that I was asking her to talk about her parenting experiences, and with her knowledge of my career as a behavior analyst in the field, I wanted to make sure that she did not feel like I would be assessing her or judging her for the parenting choices she made. I focused on reflections and encouraging remarks during this first interview in an effort to show an unbiased position and encouragement.

The second interview took place on May 25, 2019 and covered the next three grand tour questions on my list. It lasted a total of 46 minutes and 8 seconds. The third and final interview took place on May 27, 2019. It covered the last experiential grand tour question on my list and lasted 30 minutes and 45 seconds. The participant seemed candid and unrestrained with her descriptions about her experience across all interviews. I let her know that I would be compiling and analyzing the data over the next few weeks before getting back with her for a member check.

Weekly meetings with my research chair as well as my debriefer were extremely helpful in the analysis of the interview process and checking in on potential biases. I was able to clarify questions I had about the method of research and the considerations that emerged. I began to notice emergent themes across the interviews that seemed important in the expression of my participant's experiences. The development of my coding was inspired and spurred by the discussion and processing that occurred during my meetings with my research chair. It was helpful to check in with my chair who examined the transcripts and reinforced my finds or mentioned ones that I may have overlooked.

Coding Process

Although reoccurring themes naturally registered with me while interviewing, I often found it difficult to categorize them once the interview was over. It seemed there was so much important content and insights offered by the participant that it seemed overwhelming to boil down during the coding process. One thing I found helpful was throughout the interviewing, I made an effort to systematically record my impressions, insights, and thoughts about emergent themes. This helped me to pinpoint just exactly what I found important during the actual interview. Some of this was conveyed through her inflection, intonation, and the occasional emotionality I heard in her voice. This documentation made up the field notes that were essential in recording my perceptions and internal commentary throughout the process. As I reviewed the field notes in combination with the transcriptions, I was able to augment and interpret the exact words of the transcription which helped in the analysis.

Although time intensive, it felt natural for me to write up emergent themes and tie them to topics from the interviews. I listened to the recordings of the interviews multiple times while generating running codes and highlighting potential quotes to be used as evidence. The tedious process of reviewing transcripts and listening to recordings multiple times allowed me to become intimately familiar with the data. The questions I asked during interviews, specifically the experiential questions, led to some very thick and rich descriptions from the participant allowing the coding process to run smoothly.

Phenomenological reduction. As I reviewed transcripts alongside my field notes, I developed categories that began to suggest codes. These codes were often in the form of a word or a short phrase that symbolically captured the essence of the participants emic experience. I spent time each week talking about these codes and categories with my research chair, clarifying their meaning and significance.

Imaginative variation. Thematic analysis typically requires the deep familiarity with the data that comes from categorizing (Rossman & Rallis, 2017). Declarative phrases were drawn out in many of the categories identified through coding. These phrases really described a particular process, connection, or insight. Finding these enduring themes throughout the interviews seemed like a natural way to interpret the data from the interviews as the themes were often used word-for-word throughout them. The generation of themes takes the analysis to a deeper, more integrative level (Rossman & Rallis, 2017). While I used the themes to help me make sense of the data and categories developed through coding, it seemed like the participant used themes to make sense of her experience too. She naturally circled back to them and used key topics, such as “grief,” to express and expand on them. The goal of developing an emic view of the data requires the researcher to ensure that the themes developed were not based on the researcher’s meaning making process but based on the participant’s meanings. Checking back with the participant to see if the themes rang true for her was an important part of this process.

Synthesis. After reviewing all thematic and topic codes with my research chair and examiner, I was able to begin the process of synthesizing the data. I developed an outline with headings to organize my findings. Additionally, I used specific language in the form of quotes in my synthesis to reinforce the concepts I found meaningful. To reduce the likelihood that an etic portrayal of the data was being used and to ensure my biases were not getting in the way of interpretation, I checked in with my research team regularly through this process.

Methodological Consultation

During the study, I would often consult with my research chair who has worked with this form of inquiry before. She helped me examine discrepancies between data from my most recent interviews with older data from previous interviews in support of reinterpretation, elaboration, and refinement of the coding. She also helped me to manage potential biases in the emergent coding system I was developing. The experience of debriefing with my research chair after interviews was invaluable. I found that throughout this process, my awareness that I was an inexperienced researcher had an impact on my confidence as a competent analyst of the data I was collecting. Through the process of debriefing, I was able to reflect on the connections I was making and questions I had. My debriefer engaged me with patience and curiosity, helping to strengthen my confidence and move forward.

Construction of the Narrative

While engaging in continuous data collection, the researcher begins to generate a narrative of the participants' stories. The codes are back-translated into a narrative outlining the most essential aspects of the participants story, illustrated by exemplar quotes from the interviews. The construction of the narrative was time consuming but with the aid of concept mapping flowed easily.

The participant this study provided many salient quotations which were inserted as evidence of the theme being discussed in each section. The final narrative felt like a comprehensive account of her experiences, highlighting important topics and themes.

Member Checking

Participants have the opportunity to verify the accuracy of the narrative developed and the transcript it was derived from during the member check. This member check gives the participant ownership and conveys the researcher's efforts to give them interpretive authority. During this time, the participant can discuss things they would like to add, retract, or restate (Glesne, 2016; Shenton, 2004). Members are co-owners of any written material and invited to participate in its final construction.

The participant read through the narrative and made comments throughout. While constructing the participant's narrative, I found it difficult to know if I was hearing the participant's story the way she intend to convey it without confirmation from the participant herself. Therefore, it was a relief to hear her say she felt like I had captured her experience well and with great detail. She mentioned that she was concerned with how many times she said “like” during her interviews, which she noticed in the exemplar quotes, but we both agreed that it did not get in the way of her message. Her teaching background came in handy as she was able to correct a few grammatical errors I had left in the document.

When asked if there was anything she felt I missed or interpreted incorrectly, she said no. I asked if there was anything that she wished to add to the narrative and she said she wanted to mention that she found herself increasingly in the role of “the middle man” between the therapist and her son. The role was often stressful for her and their family and she wished that this was considered by his care providers, so it was important to the narrative findings. This was added to the narrative and sent to the participant for review before being added to the final narrative write-up.

CHAPTER IV. NARRATIVE FINDINGS

Becoming a parent can be stressful and bring about anxiety when things do not go as you might hope or prove to be more difficult than anticipated. The literature shows that parenting a child diagnosed with an autism spectrum disorder can bring about amplified stress and distress while often putting a strain on many aspects of the family and parental unit. The purpose of this research study was to come closer to understanding what the experience might be like for a parent of a child diagnosed with an autism spectrum disorder. I had the unique pleasure of interviewing a participant who was both eloquent and candid in her expression of her experience up until this point and her anticipation of the future with her son. She provided a rich account of her experiences as a mother, beginning in the early years of learning to navigate a journey she was not expecting to her development as a strong parent advocate instrumental in developing a bill that came into law, offering hope to countless families in Hawaiʻi. The following is a presentation of her narrative categorized by common themes and concepts that offer the essence of her emic experience.

Things Were Not as I Had Expected

The participant’s experience of parenting her first-born son was marked with the intuitive sense that “things were different.” From an early age, she noted that he showed signs of delay and was not meeting his developmental milestones as expected. The new parents, living in a rural area on the Big Island of Hawaiʻi at the time, took advantage of a 0-3 program through their state’s early intervention initiative and enrolled him in special education preschool at the age of three.

> There were a lot of things that he was getting help with the 0-3 program, vestibular, and so on—with PT. [There were] people coming to the house, and you could see how he would lay on the ground on his stomach without his hands and his feet touching the ground. So there was like obvious signs that things weren't going right.

As a preschooler, he had difficulty transitioning between home and preschool and would often refuse to get dressed or separate from her at drop off.

> There [were] behaviors...I remember him being in the tub, and just doing like yelling, or whatever it was. And it was just like, "Wow, this is very different."

The participant recounted having the understanding that things were not as they were "supposed to be" and a fear that he might have autism. Her understanding of autism at the time was based on the minimal training her teacher education program had assigned to the diagnosis. She had also met a friend's older child who had been diagnosed on the spectrum.

> Back then when you're getting your teaching degree, you have a chapter in the book about autism, and that chapter was about the spinning plates. And so that was my depth of understanding of autism, so this is like a whole new thing. A whole new journey.

She noted that her son was often repetitive in his language and song singing when he latched onto a particular tune. She recounted a video a friend had taken when her son was very young during which he was walking around in a pull up at home repeating a tune he had heard on the television. She remembered comparing these observations to those of her daughter at the same age and noting how different they were. His sister was born about 20 months after him but soon became an exemplar to him, teaching him how to say "mom," "dad," and other first words.

Help Isn't Here

It was difficult to know what kind of help their son needed and it always seemed as if there were not many options or much direction from the professionals in the rural community in which the participant and her family lived. Eventually, she and her husband made the decision to travel to Rochester, Minnesota for a diagnostic assessment to be completed at the Mayo Clinic. The participant found it comforting to be surrounded by experts in the field at the Mayo Clinic who worked as a team to assess her son.

> I was really lucky to get to go to the Mayo and to have a whole group of people work with him. The Mayo is huge. It's like a city. And so we stayed a couple [of] days.

After a few days of evaluation, the team at the Mayo Clinic diagnosed the participant's son with Autism Spectrum Disorder. At times, she recalls he was difficult to test even taking apart one of the pediatrician's glasses during the testing. In addition to the Mayo Clinic's diagnosis, the team gave her some information about what the family should expect from him developmentally, and recommended services and educational accommodations he might need going forward. Many of the things they shared with her affirmed many of her intuitions about where he should have been in his developmental progress and what he needed to help him further develop. For example, the school in her rural area was telling her son that he could not leave the classroom without tying his shoes, but the Mayo Clinic staff was saying that he was not developmentally ready to perform the shoe tying task independently. She desired an inclusive preschool setting for her son so he could learn by observing neurotypical peers. Her background in education as well as her observance of her son learning from her daughter strengthened her conviction that this is what would be best for him.

A major challenge going forward was that the Department of Education (DOE) did not have such a program in Hawai‘i, so she proposed that they allow her son to attend a preschool off campus for part of the day. She and her husband were even willing to pay all costs associated with this blended approach. Her hope was that his skills trainer could accompany him to the preschool in order to promote social interaction and learning opportunities through peer-to-peer interaction. The DOE denied this accommodation which led to a due process hearing.

These critical events early on further deepened her concerns that the educators in her small rural town were not educated with the specific knowledge she felt was necessary to be effective in teaching her son. The help she was seeking just did not seem to be where they were. Across all ages and communities in which they lived, the family was chronically frustrated about the eligibility requirements for service. Because they were not living at the poverty level, they were not eligible for certain services and therapies available to those who were.

> And for us, I feel like we're like gap people…because it just seemed like, if you're Quest [a medical insurance plan available to those who are economically disadvantaged], or whatever it is, your kids get the therapies but yet with my teacher salary, however much it is, or whatever you're doing, you're in that middle place and you don't make enough to be affording ABA because it’s like five thousand dollars a month or more than that. So if you don't have that disposable income then you're just out of luck.

At the same time, the couple was also struggling to figure out how to manage his behaviors at home. Unable to find any guidance from professionals in their rural area, they needed to become more resourceful.

> So I knew that this was different. I knew his behaviors. I didn't know how to help him with the behaviors when we got home. I still—I couldn't—I just, I didn't know how to…I didn't know what to do, and I was like searching for things as like a parent, and as an educator. So, I'd go to the library, and I'd get the 1-2-3 Magic, and whatever discipline guru thing was at the time, to try to find something that would help him. Because I didn't know what we were doing, and what we

> were seeing. But I just knew there was better. And coming from the East Coast too, I started doing research, and there was Yale, and I wanted to take him back home. I wanted to take him to Yale, so that...that I was thinking that they would help.

Should they move in order to access resources available in other states? The participant noted that she was originally from the east coast of the United States while her husband was born and raised in Hawaiʻi. She also noted that their son's connection to Hawaiʻi was so strong, though, that they ultimately decided that although their desire to find effective services and providers for him was becoming more urgent to them, his love for the ocean, the freedom of swimming, and proximity to her husband's family took precedence.

> Like I said, he's part Hawaiian, and if he wants to go to the ocean. He should have that ability. He shouldn't have to like run away. And my husband's family is here too. But I just—I felt that we should get help here. This shouldn't have to be a choice.

The minimal speech and Occupational Therapy (OT) services that they were able to get through their insurance were offered a few towns over which meant traveling a far distance. Eventually the family moved to a larger town a few hours away from their rural community and eventually to another island in order to have access to the services they needed.

> Then we ended up moving to…We just...We couldn't get any more help. It was just like it wasn't happening. So we moved to Hilo because Easter Seals was there. And so he got help at Easter Seals….When we left Hilo, it was because a psychologist had said to us, "You better get to Oʻahu. The faster you do it, the better because he's going to max out at 16."

Meanwhile, it seemed developments in educating children on the spectrum were popping up in other areas of the islands and more rapidly on the mainland, but her son was missing out on them.

The participant described how many people imagined that because she was an educator herself, working in the same school her son was attending, her child must be receiving all the services available through the department and they must be treating her very well. However, she believed the opposite to be true and described a lack of acceptance among the educational staff. In fact, she felt like she was often given a hard time. She wanted to be an equal voice in his Individualized Education Program (IEP) meetings and in educational decision making but felt like an outsider. She noted that her knowledge of her son's idiosyncrasies or behavioral tendencies were not inquired about and her insights about what might work for him were often ignored. She described researching new ways of addressing behaviors or managing rage cycles but found his teachers unwilling to adopt any of these strategies.

> I found this really cool information [educational strategies], and I think that was actually [a] day that really inspired me, I had tears when I left I had walked out of that office doors [where I had researched the information] and I brought it to his teacher and I was so happy. I was like, "Oh my gosh, check this out. This is great." And she said, "Oh, don't tell me how to teach." And I was like, "Whoa, okay. That's not where I was coming from. That was not about it at all. I thought this is Pre-K! [Can't I have some input?] I thought we were on the same page and let's find something that works!"

Beyond her impression that her son's educators were unwilling to accept her participation in her son's educational planning and support, she again shared her feeling that the specific knowledge base about autism was lacking.

> It was a lot of people not knowing—just a lot of not being educated."

There Is a Lot of Grief as a Parent

What Can't Be or What Isn't

The participant talked about the grief she experiences as a parent. The grief began early in her experience of parenting her first born son. When he did not develop in the way she had expected, she reached out, but the support she needed, personally and educationally, were not in place.

> This was not the path I had envisioned at all….Being my first child, I had a sort of like some set of expectations and so on, that weren't happening. So I remember just being in tears. Absolute tears because some of the—Like I said, and the preschool things weren't going well. And one of the teachers had made this comment to me, and so I walked out of the office, and I was just crying. And I was like, "This is my first born. I've waited years. I'm an older parent. I've waited years for this to happen. I pictured him to be—you know, after school like coming to my classroom, and doing all these different things, and it was not that."

During our first interview, she spoke about the day her son was diagnosed at the Mayo Clinic. She still remembers trying to listen to the doctors as she also attended to her son. She recalled trying not to cry as they explained the label.

> I remember that day…when they gave that. Like, it was the diagnosis. My initial thought was, "He'll never drive."...I'm like, "He'll never drive."—which to me is like freedom. It's the whole thing. You know, coming of age. It's freedom.

She described the joy of freedom as something she valued and was fearful her son would not experience that in a typical way. In later interviews, she went on to talk about her grief as he aged. The grief she experienced as a parent often related to the things she saw other children do but hers could not. She described this as a very painful, recurrent experience that was often difficult to cope with.

> I remember when the kids started driving, and I would see one of the neighbor boys get in his car, and off he went. Or like my daughter, she had her first boyfriend now, and [he would get] to watch. And…he would love to have a girlfriend. And just a lot of the social aspects I guess of autism, he's hindered with. I mean like he can ride a bike, but just a lot of the other things. The whole freedom thing. Just going off to the movies or having a friend. Somebody that they can say different things to, or call each other, whatever it is. Or be in a gang of boys who are learning these social skills. You know, all those things are closed doors.
>
> You're grieving what can't be—or what isn't.

Grief was also present in her reflections on her own mortality and the impact that it could have on her son if it were ever to happen prematurely.

> So I've always been like, "Oh my gosh. I hope I don't die." I don't want to die when he's like four years old, and he needs me because I was very much his interpreter. I could tell...like moms do, they can tell when their kids need something, or whatever. But for my son it was especially...I could understand either how we was speaking, with what words he was using, or what kind of emotions he was displaying, whether he was in a fit of rage, like to leave him alone. And I had learned a lot of these things, so I was like...You know, I just...I wanted to see him grow up and be there for him.

Additionally, the participant discussed how her grief was also tied to the reality that she would not be there to care for her son for the rest of his life and the thought of preparing for his future without her was difficult.

> And as a special needs parent, it's—I've heard other people say, but for me especially it's bothered me for a long time of like how do you prepare? How do you...I mean we're not wealthy. I'm a teacher. My husband, he's an [educator], or whatever. So, how do you? I mean, how do you prepare financially? How do you prepare to have people around him? Where do you end up? Like I said, "Do I take him back to the mainland? Is my daughter going to end up on the mainland? And then do I—" It's not her job, or she shouldn't be taxed with him. She has things she needs to do in life. So then and like I'm always trying to figure out, do I...Like, now he's got his first job. Do I cement everything with the area, so he knows how to do everything? And is this where we're going to...I don't have family here, so is this where he's going to end up in life? Without anybody? Is this the safe place for him? Is this where he'll thrive?
> One of my biggest fears is that he would go homeless.

His Grief is My Grief

The grief took on a new meaning as the participant discussed how her son had grown to become aware of his differences and grieved himself over the things he could not do or misses out on now and would miss doing in the future.

> He has the wherewithal to know that he's missing out on something, something is not right. And so but he can't put his finger on it. You know, he'll ask my daughter. He'll be like insecure.
>
> I knew [he] would love to join the National Guard, but he can't, and he knows he can't, so he hates the whole autism thing because he can't join [the] National Guard.

> You know, some people...There's a lot of like...In the autism community, like, "Oh, if there was a cure, would you want your kid to be cured?" And some people are like, "No." Some parents are like, "No, that's who they are." And I'm like, "You know I would because he really wants to go in the National Guard…."

I Want Them to Understand Where I'm Coming From

Educators/Providers

As a part of our interview, I had asked the participant what she wished her team had known about her child or about their experiences as a family. Her response to this question was that she never really felt like she was part of the team. Her understanding of her position was often as one who was separate from the care providers and educators that worked with her son. She was an outsider.

> I didn't feel I had a team.
>
> I did not feel like they have my kid's interest at heart.

Her early experience with the department of education denying accommodations that the family believed to be necessary likely perpetuated this notion. She desired providers and educators who were willing to listen to her and come in with the mentality of "whatever this kid needs," we will try to do to help.

> It's not a point of like I'm looking for the loopholes, so I can sue you. I'm looking for some compassion. So I'm looking for some understanding, and I'm looking for people who are looking out for my kid.

In "looking out for her kid," she hoped for strong educators with training in how to address behaviors associated with autism. She hoped for some flexibility in sometimes rigid rules and standards associated with public schooling.

> I just wish that they were be open to new knowledge and open to understanding and I think to understand just to have a little empathy and maybe understand the parent and maybe what the parent is going through and we'll support each other, maybe it would be really conducive for both supporting each other.

A discussion during the participants member check revealed a desire for educators and therapists to consider the impact many of the interventions, programing variables, and plan changes would have on the family. Despite the understanding that the educators and therapists may implement these strategies because they have either been based on research or found to be effective in the past, the disruption to the family along the way may be substantial. For instance, she described a recent event when her sons behavior technician was not available to attend work at a local grocery store with her son as his car broke down. The behavior analyst supervising the case could not find a replacement but explained to the participant that this was a "good opportunity" to help him see that he was not independent yet. On the surface this change may have seemed to be an "opportunity" to help him learn that he still needs assistance but with a deeper look, the provider may see the potentially negative impact this may have on the family.

> In saying that, she didn't have to live it.

The participant's son became very anxious and angry at the change in plans and disruption to his support schedule. The participant had to become "the middle man" and try to calm him and direct his anger away from the behavior technician and analyst who he saw as the source of the problem. The incredible effort it took to calm him and explain the concept that he still needed support in the community was a tremendous burden that the participant had to absorb.

Other Advocates and Parents

Today, in her advocacy work, she describes the feeling of being among other advocates and care providers for kids on the autism spectrum as being "wonderful." The unconditional acceptance of her child who sometimes displayed behaviors in public that would not be considered "socially acceptable" felt comforting to her. It seemed like the understanding and compassion she sought previously had begun developing in among this community.

> I felt like I was in Disneyland because I didn't need to say anything about [my son], because a lot of times when those social miscues and things would happen in public, I just saw the cycle like, "Oh, he has autism." And so for people to understand and stuff like that, it [was] just like, wow, okay, cool or this is wonderful.

In recent years, she has met people who have shown her compassion and understanding. Many of these people were professionals in the field and parents of children or adults on the spectrum.

> Getting to know those people,…it brought me into contact with a lot of people who are extremely positive, who wanted to help [my son], who I could relate to, who were teaching me. It was just like a deep breath of, "Wow. I'm not alone." That was really good.

Close Friends

She also desired compassion and understanding from friends and family. Multiple times throughout the interviews, she talked about a woman who she described as “a close teacher friend” who taught at the same school she did. This friend’s support and acceptance along with a curiosity about her son’s differences seemed to make her presence memorable.

> I had a friend, a close teacher friend, who used to come over, and she'd videotape his—the things that he would do. He'd sing and kind of dance around the couch. And he loved Barney… and he'd eat Cheerios, and all that kind of stuff. And so she videotaped a lot of that, and she interacted with him a lot, and kind of had a really good relationship with him.

She described the process of keeping friends difficult because of her often unreliability due to her son’s special needs. His care was time consuming and often his needs were unpredictable. It would not have been uncommon for the participant to have to change plans quickly and without warning.

> You definitely find out who your friends are who can handle different things and who are supportive and those are the kinds of people that you care really hard to (keep) with whatever energy you have left to maintain those relationships.
>
> Just understanding that you can't do certain things or that your child's going to act a certain way and they're not fazed by it or that you can go or you can't go depending upon the circumstances or if you're going to be doing something, you know that you're no longer that reliable because you never know what's going come up….It’s not that you set out to find them, it’s kind of like they find you.

The advice of those with whom she maintained relationships seemed to be instrumental in the installation of hope that things were going to be okay despite the often-discouraging path she was traveling.

> [A friend] who worked at the same school I did, she kind of told me it was a kind of a carousel and there were people that were getting on and were going to be helpful and there’s people that need to get off.

She described her early experience of learning her son’s diagnosis at the Mayo Clinic and feeling urged to reach out to a good friend as she began to digest the gravity of it.

> And I remember telling my good friend from Connecticut. I texted her, and I was just like, "Oh my gosh. He's never going to drive." And she said, " By the time he reaches that age, they're going to have self-driving cars!"

As she struggled through difficult and critical events related to her son’s diagnosis, she was able to find hope and comfort from good friends who showed her compassion. In recent years, through her advocacy she said she had met people who had shown her compassion and understanding. Many of these people were professionals in the field and parents of children or adults on the spectrum.

> Getting to know those people—It brought me into contact with a lot of people who are extremely positive, who wanted to help [my son], who I could relate to, who were teaching me. It was just like a deep breath of "Wow. I'm not alone." That was really good.

Spouse

The relationship between the participant and her husband has had to weather some changes in perspective throughout this experience, too. She describes how there would be times that it seemed her husband would find it difficult to tolerate some of her sons' behaviors, specifically related to his expression of anger, and would become angry himself.

> I had to learn like when [my son]...would get violent, and when he would get angry or mad, there was a portion of time where he just wouldn't....If things weren't correct, and meaning like rigid thinking, like things weren't in alignment, like his phone. If like his phone had a little crack in it, it was all wrong, and he needed a [new] phone. Whatever it was. So then he would get very upset. Like, he threw the remote one time, and then my husband got upset. And then I'm like trying to run in between the middle of them, as far as...."He's in this cycle, and I understand this, you know, read this book, [husband]!"

She found herself becoming angry with her husband for not knowing about the "rage cycle" process because he had not done the reading as she had. However, she came to understand that his position with their son had some utility and she had a shift in perspective on his role.

> Someone needed to point out to me that [my husband] needed to be the authority figure, in that he needed to...[my son] needed to know that when (my husband) said no, like that was the end, and that was it. He was the alpha. Put it that way. So, that's been really helpful. And [my son] hasn't been...he hasn't been mad in like I think two years.

It seems she was able to recognize and celebrate some of the special ways in which her husband did interact with their son, in ways that were different than the way she did.

> My husband is really good. [He] is the one who shaves him, and he jokes with him. And they joke back and forth, like they'll say certain things, like they'll take the dog's leg, and point it at him, and go like, "Here." And then the other one takes the other dog, and goes, "Here." And they're just laughing with each other. They have this thing going. And so that's really cool.

She talked about the stress and pressure the experience of parenting a child diagnosed with an autism spectrum disorder has had on her marriage. The chronic stress has often left one or both of them feeling irritable and distant from their partner.

> I'm going to knock on the wood because we've had our moments, and there have been times where I'm like, "It's been nice. Let's get divorced." Then the other one's like, "Yeah. It's been really nice. Let's get divorced." It's like a pressure cooker, so I think we're very lucky to still be married.

Despite these moments, there have been times where they have desired to lean on one another for support and compassion.

> On the converse side, it also can bring you closer because you have shared experiences, kind of a shared outlook, and something like a goal that you share. I think that's important.

Sibling

The participant felt it poignant to talk about some advice she had received from another parent regarding the care of her typically developing younger daughter who travels on this journey with her parents and brother.

> ...but things that I think are important, like the siblings. I think that, for me, another person who had a child with autism kind of said to me, "Make sure you take care of your daughter," because that was something that was important. That was something that I always kept in the back of my mind, even though I kind of relied on her a lot. She had a very different upbringing because of her brother. I think, for other people to understand that the siblings have a very different familial type of family. Also, I think they grow up and they have empathy for others, and they see the world with a different perspective than others do. They grow up, I don't know if I want to say quicker, but they can tend to be more mature.

She said she has recognized that her daughter's experience of having an older brother was likely different than most other children's experience of growing up with a neurotypical sibling. She previously discussed how her daughter taught him his first words as a young child and often reassured him as a young adult when he showed signs of insecurity.

Despite their different sibling relationship, she noted their closeness as one of the similarities other sibling relationship might have.

> And then [his sister] just treats him normally, like a regular sibling. And she gets mad at him.

Sister

Another important family member that was able to offer the participant compassion, guidance, and knowledge was her sister.

> I'm fortunate in that the other thing too is I have a sister whose a doctor, and so that was helpful because a lot of the times—And she's in another state. And so I was able to talk to her, or consult with her. And she was really good right at the beginning, and has been along on the journey, and really helped me a lot. And she makes me tow the line. Like, even in the beginning she was like, "You better get his behavior under control because he's going to get bigger."

She recognized that her sister understood the difficulty in raising a child with special needs but was armed with the knowledge to see how things might turn out if she did not “tow the line.” Beyond that, it seemed her commitment to helping them went as far as offering to take her son in if something were ever to happen to his parents.

> And so little things that are big things that I didn't have the wherewithal…she was there kicking me in the butt and telling me get going on certain things. And so that was super helpful. And she always said that she would take him, but she's older than me.

Understanding Comes in Increments and by Looking Back

The journey for this participant had roots that extended back before her son was born, ones that she believed may have helped prepare her for her parenting journey.

> I look back at things that I did in college. I had a friend who had CP.…She needed access to the professors and stuff like that and they didn't have the accommodations and all that kind of stuff back then and everything. So we got together to write something up and so on.

It seemed natural for her to help this person who needed assistance with doing something that other people could do on their own. In college, as she began studying to become a teacher, she discovered that many of these helping qualities and creative tendencies were innate. Additionally, as a teacher she believed in the power of education and its ability to change your, and your students, circumstances. She described how she had always been a “stand up for people” kind of person and believed this may have helped her persist when it came to her son’s education.

> I was an inclusion teacher before I had my children. All these different experiences, I just wonder ....All those things kind of prepped me a little bit, I think.

She can describe all of the insights she has had about her experiences and their purpose as she looks back, but noted that it is difficult to see their purpose while they are happening. She said she had been able to make sense of or see clearly the lessons and purpose in her journey by looking back and reflecting upon it.

> So every little step of the way, you look back and go, wow, okay, so now we're doing this, or oh I get that now.

Looking back at her journey up until this point, she noticed a need she had that was as yet unmet. She described the chronic experience of stress throughout her journey and described it as a “post traumatic stress" that lingered with her and likely other parents who have experienced raising a child diagnosed with ASD. She wished there had been opportunities for respite care. That opportunity never really presented itself to her despite her inquires with the social security department at the state office.

> You are constantly 24/7 in this situation, and so a minute of respite would be golden to regulate yourself and be able to get back in with batteries charged, we got this…but when you don't have that, it's like I said. It's 24/7.

There is Healing in Forgiveness

Laced throughout the interviews were stories and critical events involving her son's educational experience that the participant described as intense, disappointing, and hurtful. She harbored feelings of hurt and betrayal from one incident to another. In recounting her experience when the public school her son was attending refused to allow her son to attend an inclusive preschool program for part of the day so that he could socialize with and learn from his interactions with children who were not in special education. Inclusion was very important to the family but the teacher did not deem it to be appropriate for his program. After engaging in a lengthy due process hearing and eventually pulling him from public school, the participant described seeing the teacher who had determined mainstreaming as non-essential to his program. When she saw her, the teacher said to her:

> "I'm really good at what I do, so if you need anything or you need me to do stuff for [my son], just let me know."

The participant remembers being "blown away" by this offer after all the contentious interactions they had had previously and after what she had denied her son.

> I found it hard to forgive….I'm Catholic, so that's where I drew my strength from….Somehow, I had to find this forgiveness piece because I knew it was hurting me. That was like, "Oh, my gosh. This is intense."

After reading a report from the hearing officer post due process with the school district, the participant discovered many of the staff members were led to lie about what was provided to them by the parent. One of these staff members called their family home to ask for forgiveness and said "her job was on the line."

> She said she was really very sorry. For me, I feel bad in both ways. I saw her later….I gave her a hug and stuff like that. She ended up resigning. But the point is, I gave her a hug and stuff like that. I felt bad because I would never want someone to be in that position where they have to lie. What an awful position to be in. At the same time, it's just really difficult to know that.

When asked, the participant said she was able to forgive this woman because she called and felt bad about the position she was put in.

> I don’t think it was her intention to hurt (my son)… it just really bothered me for a long time.

She said she came to understand that by forgiving others, she was able to come to terms with the incidents herself.

> So I do want to say that after, in 2016...I went and I got therapy...and so it was wonderful and I did sandplay. And like that's a good thing.

Advocacy

The Early Years

There were things that the participant wanted for her child that she hoped could be provided educationally through programing, support plans, and service delivery. Advocacy came naturally to her and she practiced it with others before her son was even born. Some of those things proved to be easier to acquire than others. As a teacher, she had special insight into what might be helpful for her son in the classroom but often felt like she had to sensor her suggestions or assertions to other teachers and administration for fear of their reaction to it.

> It’s very interesting how things are done [within the education system]. When you know better, it’s really hard.

In the early years, her focus was on advocating for inclusive services in education. Finding opportunities to be with other children who were typically developing was a priority for her. She knew the benefit of having neuro-typical exemplars to model behavior was imperative instead of only children who had multiple handicaps and delays as the only exemplars.

> I’m a teacher so I knew how important that was, and so…I began advocating already for [my son] and kids like him when he was in pre-school because I felt like he should be included.

In her advocacy, she took it upon herself to do much of the research that she felt was necessary in developing the most effective program for her son and his education. She had a desire to teach others who may not have the knowledge she thought would be helpful.

> I passed out folders to everybody at the IEP team with all his information that I had gleaned from somebody from one of the universities, from all these different places. I printed everything out, and I made it a nice thing and gave it to people. I was trying to teach them and help them understand that he [was] having trouble.

In conceptualizing her experience during those early years, she described the important qualities and actions that she worked to achieve.

> To be your child's advocate, is to ask lots of questions, don't take no for an answer, be involved, be at the teacher's door, find out what's happening with your child....I think that's super important.

Installation of Hope for Others

As her son aged and changed in his needs, her advocacy work changed too. It seemed she began looking at affecting change for others and trying to give them many of the experiences and support that she did not have.

> It was definitely for the greater good. Again, you look back, and you say...I would tell people, too, "I would have never done this if it hadn't happened to me. I would have never stepped forward."

She recognized that because she had gone through what she did and had experienced what she did, she was destined to try and change the experience for others struggling through the system.

> I've explained to others too, that the roads we drive on, it's not because I built them and now we're driving on them. It's because somebody before us did that, and we're lucky. Now we can drive on the roads. That's what I felt like. Because of the experiences that I had, I could be a part of this change and that other people wouldn't have to go through it.

Finding strength in her teaching tendencies, the participant was able to see her advocacy work as an opportunity to share her knowledge through experience with others.

> So I think as each of these, I'm just call them little things, but they were big things as they happened. I think that it was like, okay, now I can help others with that. And of course, like we know, right. When you help others you actually help yourself…and so then when other parents are going like, what do I do or whatever, you know, that it can point them in that direction because now I've learned something.

The participant described a recent critical event where she felt the opportunity to instill hope in another parent during a presentation she attended. A parent was discussing her frustration over her child’s behaviors. There seemed like little hope that things would get better.

> They asked if anyone wanted to speak to [her concern], and I stood, [my son] with me, and I'm like, ”You know, I felt the same way that you did,”... like “this is never happening for me or my kid.” And I said (to her), “He's right there!” I'm like, “Look at him now!” And so after you learn these things, for me, it's important to help other parents to understand that labels are not a dead end.

Finding knowledge and understanding in her experience and research over the years gave her the confidence to share what she knew with others.

> I think having the knowledge is the number one way to know stuff, so to understand how things should be, and I think that is super helpful… and so then when other parents are going like, what do I do or whatever, you know, that it can point them in that direction because now I've learned something.

He Has Strengths in His Differences

Across all interviews with the participant, I recognized a hopeful pride she expressed in her account of raising her son. She often spoke of his “atypical” presentation socially which she learned to recognize as an incredible strength.

> …because again this is atypical… He would talk to people sometimes and I get to know like the most interesting type of people, like in the grocery store, some of those social filters they leave. He allows himself to just “be present” and interact with people without holding back.

She described an experience during which her son was able to connect with a random man in a wheelchair on the city bus by candidly asking him if he was a veteran. After the man responded that he was in fact a veteran, her son was able to share that his grandfather was also a veteran and had been hurt. Through their candid talk, her son was able to learn of how his grandfather could seek services and assistance through the VA helping him to acquire a specialized wheelchair which he desperately needed after his injury. Through his candid, unrestrained connection with a stranger, he was able to help someone he loved.

Her recognition of his differences and perception of strengths has developed as he has aged. When asked how she has come to see things this way she hesitated and said:

> Like I said, it’s a learning journey, so it’s taken the understanding and so on, it just comes for me in increments.

Summary

The participant described her journey of parenting a child diagnosed with an ASD as one of learning and adapting. The stress and grief associated with her experience has been both pervasive and intense at times. In looking back, a wholistic view has emerged with periods of struggle and those of joy flowing into each other. Her perspective on relationships and support systems has been heavily shaped by those she held tight to during her periods of stress and grief. As her son grows into adulthood, she desires to share her experiences and advocate for others while instilling a hope for parents new to the experience. She advocates for the supports, services, and team approaches that she did not experience much of during her son’s school age years. She recognizes that the road ahead will be marked with new stressors and new grief but she has found room to celebrate many of her sons successes as he becomes a young man.

CHAPTER V: DISCUSSION

The intent of this study was to explore the experience of a parent's journey raising a child diagnosed with an autism spectrum disorder. This experience varies from parent to parent, but it seems based on the extant literature and the participant's account that there are some common elements. These elements of the participant's story can serve to inform care providers, educators and therapists who see the value of considering the family as a whole when treating or educating the child on the spectrum. The information gathered is intended to expand and add depth to the current literature and serve to inform practitioners who work with this population to perhaps consider some of the insights uncovered during this exploration of a parent's experiences of parenting a child diagnosed with an autism spectrum disorder.

A Discussion of the Findings in Relation to the Literature

The Experience of Being the Parent of a Child Diagnosed with an Autism Spectrum Disorder

The experience of parenting a child diagnosed with an autism spectrum disorder varies for each parent it affects. It seems that the degree of developmental deficit the child displays can play a role in the experience as do parental strengths and coping ability. There are a number of child factors linked to the experienced burden of caregiving for parents of individuals with ASD. These include medical problems, ASD severity, mental health issues, and intellectual disability (Lake et al., 2014). How the parent experiences these child factors can also change over time as can their ability to cope with them.

Diagnosis and availability of treatment. "Parents of children diagnosed with ASD often report concerns regarding social behavior, communication, play, and motor skills within the first 6 months of a child's life, yet formal diagnoses are most commonly given at approximately 3.1 years of age and sometimes as much as 5 years later for those diagnosed with Asperger's Syndrome" (Mandell, Novak, & Zubritsky, 2005)

For the participant, the early years were plagued with "obvious signs that things weren't going right." The participant's educational background in early childhood development armed her with the understanding of what developmental milestones and typical behaviors were to be expected by young children. Her son's needs were more exaggerated and "different" than his typical peers or neurotypical sister who was about 20 months younger than him. His behavioral presentation was atypical, and his speech development delayed. When asked what the experience was like for her in those early years before formal diagnosis, the participant expressed a sense of helplessness as she recognized that early intervention was essential to his progress, but the help may not be available for him where they lived.

> For me, it was difficult, especially being here in Hawaiʻi because I felt like his needs weren't being met already….I knew how important that was.

The research backs up her notion that early interventions designed specifically for children diagnosed with ASD has been demonstrated to be the most effective in producing quantifiable gains (Sallows & Graupner, 2005). The family was able to access zero-to-three services such as occupational therapy (OT) and physical therapy (PT) but the demand for these therapies in their small rural community far outweighed the availability of them.

> It was so hard in [rural island town] to even get speech services. And so we sat down at a meeting and they were like "Oh, we are really sorry, but we don't have anybody [therapists]" and I was like "Lady! This is a federal thing. You have got to have somebody!" But they didn't…"Oh my gosh, it's so unfair."

The family chose to travel off island to the Mayo Clinic for a diagnostic evaluation because of its reputation and team approach. A number of researchers have suggested that the diagnosis of a child with ASD could in fact be more stressful than the diagnosis of other disorders because of the range of functioning that comes with a diagnosis, the lack of clarity in diagnostic criteria, as well as the multitude of symptoms that may or may not present with the diagnosis (Saini et al., 2015). The participant's stress was compounded by poor access to care in her rural community and the burden of having to travel for quality care.

As outlined in research by Reed and Osborne (2012), there is evidence that there may be a substantial contribution to parental stress if their diagnostic experience lacks good communication and is unsatisfactory overall. For the participant the experience of receiving the diagnosis for her son at age three was recalled as a supportive team approach with good communication. The Mayo Clinic employs developmental pediatricians as well as specialists from other disciplines to form a comprehensive team of evaluators. Although this experience was validating, it made it difficult to return to Hawaiʻi where access to treatment was poor and inclusive educational settings for children in special education were not available.

Public education. The participant spoke extensively about her experience within the public education system in the state of Hawai‘i. It was clear that her experience was not one of support or encouragement. Despite her own employment by the same department of the state, in looking back, she describes her experience as disappointing and stressful. It may be true that the parent and child’s experience navigating the public education system of services as well as poor access to community resources could be a contributing factor in their degree of stress. Accessing special education services and behavior analytic services could pose as a stressful barrier to parents who would be new to the systems.

In a study by Garbacz et al., the researchers found that one of the strongest predictive factors of positive teacher-parent relationships was a family history of successfully accessing educational services. For the participant, her access to care was met with very limited resources from as early as zero-to-three early intervention services. Her access to what she believed was essential programming tailored towards her son’s deficits was even more restricted when he entered pre-k (pre-school) and was denied an inclusive setting. The participant described her experience of these “closed doors” to her son as discouraging. The support she was seeking was not available.

The participant also spoke about what seemed to be a lack of knowledge on the part of her son’s educational staff. Many of her notions that the staff was not properly trained in how to navigate the special needs of an individual on the spectrum were “cemented” when staff at the Mayo Clinic shared some consultative educational information to the participant. For instance, the staff in the public schools were trying to teach some skills that the Mayo Clinic reported her son was not developmentally ready for like toilet training and tying his shoelaces. Another incident she described was one in which her sons “transition item,” a toy he had brought to school, was taken away from him. Only after the participant met with the educators did they decide her son could keep it with him. The forced removal of the item resulted in some disruptive behaviors from her son and he was sent to administration.

These stories describe the participant’s dissatisfaction with the services her son was receiving at the school and support Garbacz et al.’s findings that parental satisfaction of services plays a predictive role in the existence of a positive relationship between teacher and parent. The strained, untrusting relationship between the educators and parent may have contributed to the lack of openness the teacher felt towards the participant’s offer of educational tools and programming ideas. The participant spoke about the first time she felt rejected by an educator during her sons pre-school years. She said the educator told her, “Don’t tell me how to teach,” after she offered the teacher some educational materials that she really thought would help her son. During the participant’s description of this event, it was easy to hear the drop in her tone and defeated sighs between her words.

The participant verified that although she tried different techniques in trying to work with her son’s educators over the years, nothing ever really worked. She shared that at times she would record meetings and follow through with litigation, sometimes she would come in strong with what she wanted, and other times she says she would just stay quiet and not express her thoughts. She still feels, up until now as he graduates high school, nothing really worked in terms of developing a good working relationship with the school and the educators.

The participant in this study had training as a teacher and had worked in the public schools for many years before having her son. This made the experience of disappointment and disagreement with her son’s educators within the public schools particularly difficult. The experience was explained as “different” than she had expected and harder to access quality education than she would have hoped. She described a desire to have educators and therapists who would allow her to sit at the table as an equal team member developing an educational program with the mentality of “whatever this kid needs.” Her experience, however, was quite the opposite. Her requests for specific programming and support were frequently denied, her input discarded, and her expertise in her son ignored. Throughout her experience with the public education system, she never felt there was an inclusive team called “us” but rather two groups, “them” and “me.” This was discouraging and often difficult to cope with.

The Meaning of Having a Child Diagnosed with an Autism Spectrum Disorder

Autism is defined in clinical terms as a pervasive neurodevelopmental disorder characterized by difficulty in communicating, repetitive behaviors, and social deficits with evidence of cognitive dysfunction (American Psychiatric Association [APA], 2013). This description is scientifically based and describes deficit and dysfunction that characterize the disability. The definition is useful for diagnosticians and other professionals who are either interested in diagnosing a child or determining ways to address their deficits. This definition does not, however, give us any indication of what the meaning of the disorder is in the lives of those who love and care for the individual. As care providers seek to understand a child's deficits and plan for addressing them educationally, they rarely seek to include information or analysis of how the family understands the disorder and is consequently affected by it. The meaning of this diagnosis is not clinical to family, the diagnosis represents something else, something more dynamic.

The participant describes autism as a neurological disorder that means "a different journey" for the family. The experience of parenting her first born was "not the path [she] had envisioned at all." The diagnosis meant "learning, constant learning, its adjustment, a ton of patience" for the family. The research points to two factors that contribute to the well-being (or distress) of families who have an individual diagnosed with a developmental disability among them; adaptability and cohesion (Martin & Cole, 1993). The participant alluded to both of these familial elements in her recount of critical events during which the family had to be flexible (adaptable) and lean on each other for support (cohesion). She also discussed instances where the amount of adaptability and cohesion were not optimal causing distress and rift in the family unit.

The effects on family. ASD is "a lifelong neurodevelopmental disorder marked by restricted or repetitive interests and behaviors, impairments in social communication, and often clinically significant co-occurring behavior problems such as inattention and anxiety" (American Psychiatric Association, 2013). The challenging and pervasive behaviors associated with this profile often make living with, caring for, or associating with someone on the spectrum difficult. Those closest to individuals on the spectrum often have to adjust to the needs of that person despite the difficulty or disruption it might cause to their own lives. The participant shared her perspective on the importance of understanding the effects on the family unit. Parenting a child diagnosed with an autism spectrum disorder has meant unique challenges for the participants family.

> I think understanding the family, the demands, the pressures, and just everything that comes at a family is hard on a marriage.

Partner relationships. The research suggests that parents of children with autism spectrum disorders are at risk for having higher stress and lower marital quality than other parents (Harper, Dyches, Harper, Roper, & South, 2013). Some research suggests that the divorce rate could be as high as 80% (Hartley et al., 2010). When discussing the meaning of autism and its effects on relationships, the participant shared the struggles she has experienced in her marriage due to the stress associated with raising their son. She reported that on many occasions, the couple had considered divorce because of their compiled stress and sometimes ineffective coping.

> …we have had our moments, and there have been times where I'm like, "It's been nice. Let's get a divorce." And then the other one [husband] is like, "Yeah, it's been really nice. Let's get divorced." This is like a pressure cooker, so I think we are very lucky to still be married….

Hartley, DaWalt, and Schultz (2017) took a look at daily experiences of couples and found that the parents of children with ASD in their study spent less time with their partners, reported lower partner closeness, and exhibited fewer positive couple interactions than parents in their comparison group made up of parents of typically developing children. This was likely true of the participant's experience as she talked about the time-consuming nature of her son's treatment and needs. This left her less time to physically spend with her husband, leaving room for emotional distance.

Often, during a couple's relationship, when they have small children, their time together decreases significantly. However, this phase of the relationship passes as typically developing children age and become more independent and less needy of their parents' time and attention. Unlike typically developing children, often times children on the spectrum continue to require parental attention and assistance even into adulthood. Research by Hartley et al. (2010) found that the risk of divorce for those parenting a child on the spectrum remains high through the son/daughter's childhood, adolescence, and early adulthood. This may be due to the prolonged care needs and behavioral stressors associated with some individuals on the autism spectrum. The participant talked about the continued care needs of her son, even as he nears his 20s. He is not able to be independent with many of the things his typically developing peers are. During the first interview, she talked about her fear of not being able to care for him forever as she herself aged. It is likely that while other parents of children in their late teens are preparing for more free time as their children "leave the nest," the participant is trying to keep things consistent for her son and "cement things in place"—like his assisted job in the community—for fear that she will not be able to facilitate change for him forever.

The participant was also able to share how she and her spouse were able to work through the strain and find comfort and strength in each other during times of stress and grief.

> It also can bring you closer because you have shared experiences, kind of a shared outlook, and something like a goal you share. I think that's important.

It was noted in the interviews that the couple assumed different roles in relation to their son and it had taken her some time to appreciate her husband's role in their son's life. During one particular portion of the interview, she spoke about her sons "rage cycle," when he became angry and had difficulty calming down. She found that reading a book on the subject of "rage cycles" was helpful in understanding the process of the cycle and therefore found it easier to cope with the incidents. Conversely, these episodes of rage would often upset her husband and she would find herself trying to mediate between them. She initially felt frustrated with her husband. She thought maybe his lack of understanding was rooted in his lack of knowledge that she had taken the time to read. However, as time went on, and when a friend brought it to her attention, she recognized the purpose and utility of her husband's disciplinarian role in her son's life and allowed him space to provide consequences to their son.

Siblings. Siblings can be affected in many different ways by the experience of having a member of their family diagnosed with an autism spectrum disorder. The effects could come in relation to familial stress or in terms of heightened responsibility within their family unit. Young children can sometimes even mimic the behaviors of a sibling on the spectrum such as hand flapping or toe walking.

The participant shared that she relied on her daughter a lot as she grew up. She also recounted that her daughter had matured quicker than other kids her age because of the increase in responsibilities and awareness of the family's needs.

> Other people [need] to understand that the siblings have a very different familial type of family….I think they grow up and they have empathy for others, and they see the world in a different perspective than others do….

Although the participant reported that the siblings fought “just like any sibling would do,” she also saw her take on the role of teacher and exemplar for him despite their chronological age. A friend who had an older child on the spectrum was able to give her salient advice early on.

> …the other person [I knew] who had a child with autism kind of said to me, “Make sure you take care of your daughter.”…That was always something I kept in the back of my mind, even though I kinda relied on her a lot….I know, for my daughter it was hard on her when she’d see other people making jokes about special needs kids….

The literature about the effects of heightened familial stress and its impact on siblings of children with ASD was consistent with the participant’s account, however, her perspective on the positive effects of the experience was novel. As the participant spoke about the negative effects, she took pause and then added the positive effects that she understood now by looking back. It seemed that while the participant talked about the grief her daughter felt when she heard others making fun of her brother or making comments about children with special needs, she was able to see now how the experience helped her daughter to develop an empathy for others that came from her “different” experience growing up with her brother.

Friendships. Additionally, the participant discussed how having a child on the spectrum meant “a new set of friends.” She spoke about her inability to maintain her regular group of friends because at the time, she “never found any respite.” She felt like she was “on” 24 hours a day, 7 days a week caring for her young son and daughter (who were just 20 months apart). So instead, she found friendship in the people she came across doing the things she was already doing like working or taking her children to school. She described friendships as a “kind of carousel, and there were people getting on who were going to be helpful and there [were] people that need[ed] to get off.” It seemed in her descriptions that it was essential that those who “stayed on her carousel” were those who were willing to help her, who were supportive, and who were understanding when she would put her sons needs above her own desire to do something with them.

> I think understanding is a huge one. Just understanding that you can’t do certain things or that your child is going to act a certain way and they are not fazed by it.

She described herself as “unreliable” because she never knew what was going to come up. The element of unreliability and unpredictability seemed to define a critical stressor for the participant. She described needing friends who could withstand this and offer her comfort instead of criticism.

This comfort was exactly what was offered to her by a dear friend who she texted just after learning of her son’s diagnosis. Her friend was able to instill some hope by reassuring her that her son could still some day have the independence the participant was mourning the loss of. This friend recognized the grief of the participant as she expressed that the diagnosis would mean her son would “never drive a car…be independent.” Her friend instilled hope by offering the notion that we would have “self-driving cars by then.” The installation of hope was comforting for it allowed her to cope with the grief she was feeling at the time of diagnosis.

Lifelong learner. Having a child on the spectrum also means becoming a lifelong learner. The participant reported that 90% of what she has learned about caring for her son has been learned through doing and experience. There is a certain basic knowledge you can learn through formal education, reading books, et cetera, but the bulk of the learning lessons happened in real life. This insight was meaningful to me as a therapist because it substantiated the need to engage parents in conversations about their experiences with their child because the majority of their answers cannot be discovered by reading a book.

What Being the Parent of a Child Diagnosed with an Autism Spectrum Disorder Entails

Grief. The participant said, “There is a lot of grief as a parent” of a child diagnosed with an autism spectrum disorder. The grief involved comes in many forms and occurs in every stage of the experience. In the early years, her grief encompassed the developmental deficits present in her son’s development. The lack of resources and services available to her son at the time and the dissatisfaction she had in her son’s educators were contributing factors in her grief. Help did not seem to be there for her son or for their family. She expressed that the grief persists as her son missed out on many of the things his typically developing peers were experiencing. She discussed his sadness and anger about not being able to join the National Guard because of his autism and her grief over watching his peers learn to drive and gain independence. Her son had the wherewithal to recognize that he was missing out on many of these things, these rites of passage, and his grief about missing out also became hers.

Fatigue. In addition to grief, there was fatigue and exhaustion both physically and mentally. She spoke about the lack of respite care and chronic exhaustion she suffered all the time. Karst and Van Hecke (2012) conducted a review of literature that identified similar emotional factors and greater physical health impairment among parents and caregivers of children with ASD as compared to parents of children with other developmental disabilities. Their review of literature also suggested that the fatigue experienced by these parents and caregivers might exacerbate the grief and contribute to the development of depressed moods and anxiety. When compared to a large national sample of U.S. adults utilized in a study by Ross (1996), Benson and Karlof (2009) found that parents of children with ASD reported significantly higher levels of both anger and depressed mood.

The participant shared that she had read some literature that hypothesized that parents might experience a kind of stress during the early years of parenting that could morph into a post traumatic kind of stress later in life. The participant reported that she could relate to this hypothesis and in looking back could see how the stress of her experience could develop into something similar to Post-traumatic Stress Disorder (PTSD). She did not seek therapy for herself during these difficult years, though. It is likely that the unique stress along with the high level of demands placed on parents of children with ASD during their early developmental years make it difficult for them to take time for therapeutic intervention for themselves. The fatigue may make it unlikely that the caregiver engages in any self-care activities at all, including therapy. Lack of time for themselves in combination with limited financial resources due to costly therapy for their child and taking leave from work to care for the child, make it likely that individual psychotherapy will not be sought out to address their poor mental health status during the early years. The participant shared that in 2016 (when her son was in his mid-teens) she had made the decision to seek help through sandplay therapy. She found the experience to be very helpful in processing her experience and finding meaning in it.

Worry. For the participant, another significant factor involved in being a parent of a child diagnosed with an Autism Spectrum Disorder was constant worry. Worry is present in the lives of most parents and seems to persist as children age and gain more independence. Parents of children on the autism spectrum, though, may have an amplified sense of worry as their child's developmental deficits can impair decision making and independence. The participant spoke at length about her present worry that she could die and leave her son without the care she has provided him his whole life. The literature reflects the participant's experience that worry and distress can persist beyond the early years of care. Sometimes caregiver and family distress can begin before a formal diagnosis is given and remain present for the duration of the caregivers' lives as many individuals with ASD require care into adulthood (Mandell et al., 2005). The participant's notion that her son would need continued support into adulthood was a source of worry for her as she recognized that he would outlive her and her support. The participant described trying to prepare by identifying people around him who might check on him and take care of him if something should happen to her.

The experience of the participant seemed to be characterized by involving herself in constant action. Throughout her interviews and stories, it seemed like there was always something that came up that required action, work, or adjustment on her part. She described the lack of respite care despite the 24/7 intensity of her experience of parenting a child on the spectrum.

> You are constantly 24/7 in this situation, and so a minute of respite would be golden to regulate yourself and be able to get back in with batteries charged, we got this…but when you don't have that, it's like I said, it's 24/7.

It seemed difficult for the participant to find time to reflect and "catch her breath" before another wave of issues, grief, or advocacy work came along.

Joy. There is a substantial body of new evidence that suggests that looking at autism through a neurodiversity lens can instill hope and positivity in those who are either diagnosed with it or care for someone who is. The neurodiversity model highlights the neurology and personhood of autistic individuals through the lens of human diversity (Robertson, 2010). Parents and professionals who adopt this perspective emphasize the strengths, gifts, and talents of autistic individuals in an effort to establish a balance of focus from what is typically looked at from a deficit model (Robertson, 2010).

The participant in this study highlighted some of her son's strengths in his differences. As she spoke I got a sense of her pride and joy in his "atypicality" when compared to others on the spectrum.

When asked about how she came to see these strengths in her son, she described a process of reflection that allowed for this perspective. She described stories of when his outgoing, “unfiltered,” and genuine conversations with strangers had positive impacts on the whole family. She spoke proudly of how he would “get to know the most interesting people even in the grocery store” because of his natural ability to be “present” and not hold back by the social stigma that might hold a neurotypical individual back from engaging with a stranger.

Advocacy. Additionally, a great deal of advocacy has been a part of the experience for this parent. Her involvement at the school level and advocacy for an inclusion program for her son began in pre-school. She considers herself a “stand up and fight” kind of person and described helping and advocating for others even before she knew what it was. Although she spent a great deal of time advocating for her son and his needs, she did not begin advocating for the larger community of children with autism and their families until after her son aged out of many of the services she was advocating for. In recent years, her advocacy work has become focused on acquiring services and therapies for children on the spectrum that her son was not provided. She has found strength in her instillation of hope for others and has taken all of the lessons that she has learned through experience and taught them to others.

Advocacy work is hard, especially when you are trying to pass a bill through the legislature and many people including one’s spouse questions why you are being so persistent and adamant about the work. To many, it seemed like the participant was putting so much time and effort into something that had been denied passage for many years and was not even applicable to her son anymore. To the participant, however, it seemed as though this was breathing new life into her advocacy and her purpose. She saw herself in the parents who were new to the experience of parenting a child on the spectrum and felt a desire to share her story and fight for them. She came to realize that this might be a part of her own healing from years of grief and disappointment and recognizing that “when you help others, you actually help yourself.” This gave her the strength to persevere.

Need for respite care. While the parents for whom the participant advocated expressed a desire for respite care, the participant noted that this was something she never received. She noted that as a "gap family," making just enough money not to qualify for state services and not enough money to pay for them out of pocket, they had missed out on respite services for themselves and therapies for her son. Her frustration over what seemed an unfair appropriation of funds at the state level left her without a break.

In a survey study of 101 mother-father couples raising at least one child with ASD together, Harper, Dyches, Harper, Roper, and South (2013) found that the number of hours of respite care was positively correlated with improved marital quality and reduced stress for the couples. "Increased uplifts were [further] associated with improved marital quality; and more stress was associated with reduced marital quality. The number of children in the family was associated with greater stress, and reduced relational quality and daily uplifts. Results suggest policymakers and practitioners should develop supports for providing respite for families raising children with ASD" (Harper et al., 2013, p. 2604).

How the Experience Changes Over Time

The participant's experiences have changed significantly over time. During the early years, it was difficult to reflect and cope as she moved from one critical issue to another. Whether it was advocating for her son's educational needs, coordinating whatever therapies they could access, or strategizing ways to manage his behaviors at home, she was always engaged in something that required lots of effort. Over time, her perspective on relationships in her life have changed. She was able to appreciate her husband's role in her son's life and discovered ways to lean on him in times of stress because of their shared experiences. She learned to recognize that the experience of having a brother on the spectrum helped her daughter to develop an empathy and maturity that others her age may not have had.

Over time, her perspective on the things that had happened in her parenting journey also changed. She described her experiences as a "learning journey." It has become clear to her that "90% of the learning happens by doing" which leads to understanding. It takes time, happens in increments, and only by looking back can you really see it. She believes every experience had meaning and she can now understand or grasp the lessons in looking back at each step. She attributes her insights and drive as an advocate to these experiences.

Research by Saini et al. (2015) suggests that a number of positive outcomes, in terms of family relationship stress, can occur when families find ways to adapt to the various stressors associated with parenting a child with ASD. Adaptation takes time and is a learning process in itself. The participant identified “looking back” as a critical element of this learning journey. Looking back helped her learn from her mistakes and triumphs and become more effective in affecting change for all children diagnosed with ASD. Her learning journey has become the platform on which she stands. Her story instills hope in others and the lessons she learned along the way inspire perseverance and generativity, standing up for others as she has stood for her son.

Implications for Clinical Work

The support needs of parents raising a child diagnosed with an ASD is poorly represented in the extant literature, yet it has important implications for understanding how to support the family. A dynamic family approach to working with children on the autism spectrum may be a more comprehensive and effective treatment than therapeutic services aimed at treating the child alone. It has been suggested by Garbacz et al. (2016) that parents and early childhood service providers should discuss a family’s interests and needs at the outset of their work together. They should tailor their approach in a manner that both addresses the family’s needs as well as the child’s individual educational and therapeutic needs to increase overall satisfaction of both child and family. In the participant’s case, this would have provided inclusive opportunities to work with other stakeholders in the interest of her son in pre-school and beyond. It is suggested by the research findings of Garbacz et al. that if this early experience of accessing services in the public school is positive and collaborative, it may set the child and his family on a different trajectory for the journey ahead with public education services. The same strategy may be beneficial for therapeutic services as well including applied behavior analysis services, occupational therapies, and physical therapies. When developing a team to work with the child, it is important for the parent to take an equal “seat at the table” in designing treatment plans.

Significant financial strain and time pressures, high rates of divorce, and lower overall family wellbeing highlight the burden having a child with an ASD can place on families (Van Hecke & Karst, 2012). Because caregiver and family distress is often overlooked at the onset of therapies where the focus is placed on the child with the disability and his or her treatment, the therapists or treatment team may be missing the boat. Most interventions for ASD are evaluated only in terms of child outcomes, ignoring parent and family factors that may have an influence on both the immediate and long-term effects of therapy (Van Hecke & Karst, 2012). It may be true that without addressing or assisting families with resolving sources of distress, therapies aimed at addressing the child's deficits will not be as effective. This parental and family stress may be related to less than optimal treatment outcomes for the child with an autism spectrum disorder. It is hypothesized that children who live in a household with parents and family members who report good emotional and physical well-being and low distress achieve therapeutic goals more efficiently than those who live in households where there are high levels of distress and poor wellbeing among family members. This hypothesis could support a more comprehensive and dynamic treatment approach for children diagnosed with ASD utilizing a family systems approach to their care. This is an area for future research and discussion.

It is possible that service providers, therapists, and special educators have tried to take such an approach by offering what is called "parent training" for parents of children on the spectrum. Although this is a service offered in the direction of family systems care, the language used and measurable goals required imply that a parent is ready and willing to be "trained." In my experience, this places the therapist in the "expert role" and requires them to measure the parents progress on their observable and measurable goal. In creating this dynamic, the parents' expert knowledge of their own child's behavioral tendencies and idiosyncrasies is largely regarded as unimportant and the focus is placed on the therapist's expert plan. It may be more useful and beneficial to the parents, child, and family to offer a "parent support" service as opposed to a "parent training" service in conjunction with the child's therapy program. This service could be used to address the parents' sources of distress in relation to the intense demands of parenting a child on the spectrum depending on their needs at the time. This service could vary and include such things as respite care, couples' therapy, parent-child interaction therapy, financial planning, parent support groups, navigating public education psychoeducational seminars, and self-care seminars.

There are many important implications identified throughout this study for public educators and therapists who work with children on the spectrum and their families. The participant shared many insights that she had identified by looking back on her experience. The first was the importance of being offered an equal seat at the table with educators and therapists during IEPs and treatment planning for her son. She reported never feeling like she had a team of providers available to her son, looking out for him and including her in the education process. It is important for parents to have input, offer their expert knowledge on their child, and have it held in high regard. The participant said that she wished educators were willing to do “whatever this kid needs” to give the child the best education possible within reason. She wished to feel as though the educators and therapists her son interacted with were “looking out for him” as she had.

Secondly, the participant wished that providers would strive to “understand where [she] was coming from.” She was looking for “compassion” and not defensiveness. It is important for educators and care providers to understand the parent’s perspective, whatever it might be, and have some compassion for them. Also, if the provider does not know where the parents are coming from or their stance on something, they should ask. Keeping the dialogue open can promote collaborative work between parents and providers.

Promoting educational systems and therapy agencies that utilize family support and train educators and therapists to uphold the family dynamics takes particular leadership with open minded and creative thinking. Often, large state departments such as the Department of Education rely on authoritarian leadership styles that dictate policies and procedures while directing and maintaining control over all activities taking place under its leadership. For parents, it may be difficult to see that the educators or therapists are willing to “do whatever this kid needs” when there are policies driving services and not always need. The educators and therapists are often plagued with strict guidelines and procedures that might not be conducive to open minded and creative solutions. The participant acknowledged that in recent years, a new and innovative team of therapists and educators had evolved within the Department of Education, but it was on the other side of the island and inaccessible to her son at the time. She described this team as well educated and willing to go above and beyond to educate the children with autism in their district and involve families. It may be true that the leadership style at the helm of this team had a creative vision and the quality of open mindedness. The qualities of leadership that are able to minister to both families and team members while supporting creative and flexible programming and support for families of children with ASD is a topic for future research and inquiry.

Additionally, it is important for parents to recognize a curiosity about their experience in educators and therapists. Educators and therapists who consider themselves expert with nothing left to learn can be a major turn off for parents. The participant shared her experience with a pre-school teacher who rejected curriculum for a behavior management program the participant had discovered, and thought would be effective for her son. The response the participant received from the educator was: “Don’t tell me how to teach.” This teacher had lost her curiosity and openness to learn new things. By asking questions and accepting ideas and feedback, educators and therapists can develop a deeper understanding of those they work with and ultimately a better, trusting relationship.

Lastly, parents and professionals who adopt the neurodiversity perspective in reference to autism often specifically emphasize the strengths, gifts, and talents of autistic individuals in an effort to establish a balance of focus from what's typically looked at from a deficit model (Robertson, 2010). This perspective has been shown to increase coping thoughts of caregivers and possibly lead to improved self-image of those diagnosed with and autism spectrum disorder. Providers and educators may find it useful to consider introducing this concept when parents or caregivers are finding it difficult to see the child’s strengths in their differences.

Limitations of the Study

One of the most salient limitations of this study was the number of participants involved. This study was intended to find an exemplar participant and focus on her story as it relates to the experience of parenting a child diagnosed with an autism spectrum disorder. To develop a more robust understanding of the experience, it would be beneficial to engage more participants and develop a more comprehensive thematic analysis over time.

Another limitation of this study was the amount of time spent in the field. This study was designed to incorporate three 30-60 minute interviews and one member check. This may not have been sufficient for full immersion in the field. In order to gain a deeper understanding of this participant’s experience and the experience of others, it is ideal to spend more time in the field as well as increasing the number of participants.

It may be true that I did not spend enough time during our interviews developing rapport with the participant and promoting candid conversation. Although Rossman and Rallis (2017) suggest that the focus of the researcher should be to engage the participant in dialogue that evokes creative conversations, I admittedly always felt rushed to dive into my grand tour questions. In an effort to obtain answers to my questions, I may have inadvertently discouraged open and comfortable discussion that uncovered what the participant may have thought was more important for me to know. It is my hope that the participant felt comfortable enough to share her experiences as candidly as possible without being rushed or subject to judgment.

Lastly, because of the participant's knowledge of my professional career as both a licensed behavior analyst and employee of the Department of Education, it may be true that she held back in her expression of experience for fear of offending me. It may also have been risky for her to share details of her experiences as the island we both reside on is small and the Department of Education community is even smaller. She may have had concerns that I would either know someone who she was speaking about or that I might share her confidential information with someone in the community despite my assurance of the confidentiality of our discussions.

Recommendations for Future Research

The participant's experience of parenting a child diagnosed with an autism spectrum disorder was thoughtfully explored during her interviews and candid conversations. Although the findings were salient and easily applied to clinical work, a deeper understanding of the phenomenon would be best explained through multiple individual accounts of it. Despite the understanding that each person's parenting experience is different with unique themes, it is likely that there are some common elements that ring true for most parents caring for a child on the spectrum. It would be a great service to the goal of understanding the experience to replicate this study over time, across a greater number of participants spanning different demographics. It would be informative to interview parents new to the experience, parenting young children, as well as parents who have adult children whom they still care for. It would also be interesting to explore the experience of parenting a child with autism across the entire spectrum, ranging from non-vocal individuals with multiple handicaps to those who can function independently in the community. The experience of parenting across the spectrum could offer us insights into the unique needs of each demographic.

Additionally, testing the anecdotal observation that children who live in households with parents and family members who report good emotional and physical well-being and low distress achieve therapeutic goals more efficiently than those who experience high levels of distress and poor well-being among family members is implicated. This topic is poorly examined in the extant literature and if there is evidence to support this hypothesis through research, a more comprehensive and dynamic treatment approach for children diagnosed with ASD could be developed. Utilizing a family systems approach to their care could change the way agencies deliver services.

In addition to the above recommendation for future research, it would also be recommended that leadership roles supporting this structure be considered. As discussed earlier, it is not likely that the leadership styles that currently govern many of the service delivery agencies (Department of Education, major therapy agencies) would be effective in supporting a service delivery system that is rooted in flexibility and creative solutions. Exploration of the types of leadership best suited for this model would be imperative to its success, too. It may be important to interview leadership and employees of systems such as the creative one the participant was mentioning at the Department of Education which has been able to achieve creativity despite the rigid system under which it works.

Conclusion

The participant’s story captured the essence of her journey through parenting a child diagnosed with an autism spectrum disorder from the beginning stages of her son’s life to the developing stages of her advocacy work beyond her son. The benefit of interviewing a parent who has trudged through the often discouraging and stressful journey and come out on the other side was an unintended benefit of this study. It really allowed for the participant to retrospectively share what the experience was like and how she has come to understand it now. These two expressions of meaning added a depth to the findings that may not have been available if the participant was in the midst of trudging through the process.

It seems, for parents, that finding time to care for themselves and their relationships is difficult when caring for a child with special needs. The participant's recount of the effects having a child diagnosed with autism have had on her family was consistent with much of the findings in the extant literature. Physical and emotional exhaustion washes over the journey, often leaving grief in its wake. The mental health and personal wellbeing of the parents often suffer and in turn put strain on their relationships with each other and their families. The time and energy consuming nature of caring for a child on the spectrum can also have professional consequences for parents and sometimes lead them to take leave or quit their job to manage their child's care. The stress of behavioral disturbances with their child, developmental challenges, exhaustion, and grief work together to chip away at a once healthy psyche.

The stress of this change in a person's life can be seen by others close to them or by individuals who work with their child. The stress and grief can manifest itself in anger or hostility. Sometimes these intense emotions are projected toward individuals who the parent sees as compromising or even denying their access to therapies and services for their child. In turn, those affected (care providers and educators) can either become defensive in their response or show compassion for the parent's position. Compassion does not require agreement, but it does require an effort to understand "where they (the parents) are coming from." It requires a concerted effort and willingness, on the providers/educators part, to adapt to the needs of the family whenever possible. The participant shared that she wished for someone to assure them that although they may not achieve all the parent is asking, they will do their best to meet all of the child's needs.

The participant's contribution to the recognition of ideal qualities of service providers and educators—empathic, hopeful, and committed–was substantial. It is difficult to know the experiences one might have as a parent of a child diagnosed with an ASD unless one encounters the journey personally. Therefore, whatever knowledge the parent can impart on the experience is often the closest providers and educators can come to understanding it.

Much of a parent's experience is difficult to capture with words on a paper. The lived experience is complex and fueled with emotions and thoughts that are often difficult to convey through speaking. A parent holds a certain knowledge of and love for his or her child that is non-transferrable and indescribable. This element of the parent-child bond is what often drives the instinct to protect and defend their child against any individual who may be perceived as not "looking out" for them. For service providers and educators, understanding this instinctual desire can help them develop compassion. Compassion and understanding came across as qualities that the participant felt were essential in those people who she did feel were "looking out" for her child and her family. Additionally, a curiosity about her child would have been comforting to the participant. Having a solid educational knowledge base about best practices in treating a child on the spectrum is key but also having the curiosity to learn about each individual child and family a provider works with is just as important.

Understanding the meaning of an experience takes time. It "comes in increments…and by looking back." This concept represents an important element of the participant's story and message for parents who are just beginning the journey. The participant sees her advocacy work as an opportunity to instill hope and provide access to needed services for children and their families on this learning journey of parenting a child on the spectrum. Only because of her ability to look back and reflect on all she has experienced and learned is she able to sit comfortably in a position of advocacy, leadership, teaching others, and working hard for change.

> Hopefully we're at the cracks of change. So, I'm really excited that we're going to support these children *and* their families.

References

Abbeduto, L., Seltzer, M. M., Shattuck, P., Krauss, M. W., Orsmond, G., & Murphy, M. M. (2004). Psychological well-being and coping in mothers of youths with autism, down syndrome, or fragile T syndrome. *American Journal on Mental Retardation, 109*(3), 237-254.

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed). Arlington, VA: American Psychiatric Publishing.

Benson, P. R., & Karlof, K. L. (2009). Anger, stress proliferation, and depressed mood among parents of children with autism spectrum disorders: A longitudinal replication. *Journal of Autism and Developmental Disorders, 39*(2), 350-362.

Ekas, N. V., Lickenbrock, D. M., & Whitman, T. L. (2010). Optimism, social support, and well-being in mothers of children with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 40,* 1274-1284.

Garbacz, S. A., McIntyre, L. L., & Santiago, R. T. (2016). Family involvement and parent-teacher relationships for students with autism spectrum disorders. *School Psychology Quarterly, 31*(4), 478-490.

Gau, S. S., Chou, M., Chiang, H., Lee, J., Wong, C., Chou, W., & Wu, Y. (2011). Parental adjustment, marital relationship, and family function in families of children with autism. *Research in Autism Spectrum Disorders,* 1-8.

Glesne, C. (2011). *Becoming qualitative researchers: An introduction* (4th edition). New York: Longman.

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

Hartley, S. L., Barker, E. T., Seltzer, M. M., Floyd, F., Greenberg, J., Orsmond, G., & Bolt, D. (2010). The relative risk and timing of divorce in families of children with an autism spectrum disorder. *Journal of Family Psychology*, *24*(4), 449-457.

Hastings, R. P., Beck, A., & Hill, C. (2005). Positive contributions made by children with an intellectual disability in the family: Mothers' and fathers' perceptions. *Journal of Intellectual Disabilities*, *9*(2), 155-165.

Karst, J. S., & Van Hecke, A. V. (2012). Parent and family impact of autism spectrum disorders: A review and proposed model for intervention evaluation. *Clinical Child and Family Psychology Review, 15*(3), 247-277.

LeCompte, M.D. , & Preissle, J. (1993). Ethnography and qualitative design in educational research (2nd ed.). New York : Academic Press.

Mandell, D. S., Novak M. M., & Zubritsky, C. D. (2005). Factors associated with age of diagnosis among children with autism spectrum disorders. *Pediatrics, 116*(6), 1480-1486.

Martin, J. M., & Cole, D. A. (1993). Adaptability and cohesion of dyadic relationships in families with developmentally disabled children. *Journal of Family Psychology, 7*(2), 186-196.

Moustakas, C. (1994). *Phenomenological research methods.* Thousand Oaks, CA: SAGE Productions, Inc.

Papp, L. M., & Hartley, S. L. (2019). Child-present and child-themed marital conflict in daily life of parents of children with and without autism spectrum disorder. *Developmental Psychology, 55*(1), 148-156.

Reed, P., & Osborne, L. A. (2012). Diagnostic practice and its impacts on parental health and child behavior problems in autism spectrum disorders. *Archives of Disease in Childhood, 97*(10)*, 927.*

Robertson, S. M. (2010). Neurodiversity, quality of life, and autistic adults: Shifting research and professional focuses on to real-life challenges. *Disabilities Quarterly, 30*(1).

Ross, C. E. (1996)*. Work, family, and well-being in the United States,* 1990. Champaign, IL: Survey Research Laboratory, University of Illinois [producer]. Ann Arbor, MI: Inter-university Consortium for Political and Social Research (distributor), ICPSRNO# 6666.

Rossman, G. B., & Rallis, S. F. (2017). *An introduction to qualitative research: Learning in the field* (4th ed.). Los Angeles: SAGE Publications, Inc.

Saini, M., Stoddert., Gibson, M., Morris, R., Barrett, D., Muskat, B., Nicholas,D., Rampton, G., & Zwaigenbaum, L. (2015). Couple relationships among parents of children and adolescents with autism spectrum disorder: Findings from a scoping review of the literature. *Research in Autism Spectrum Disorders*, *17*, 142-157.

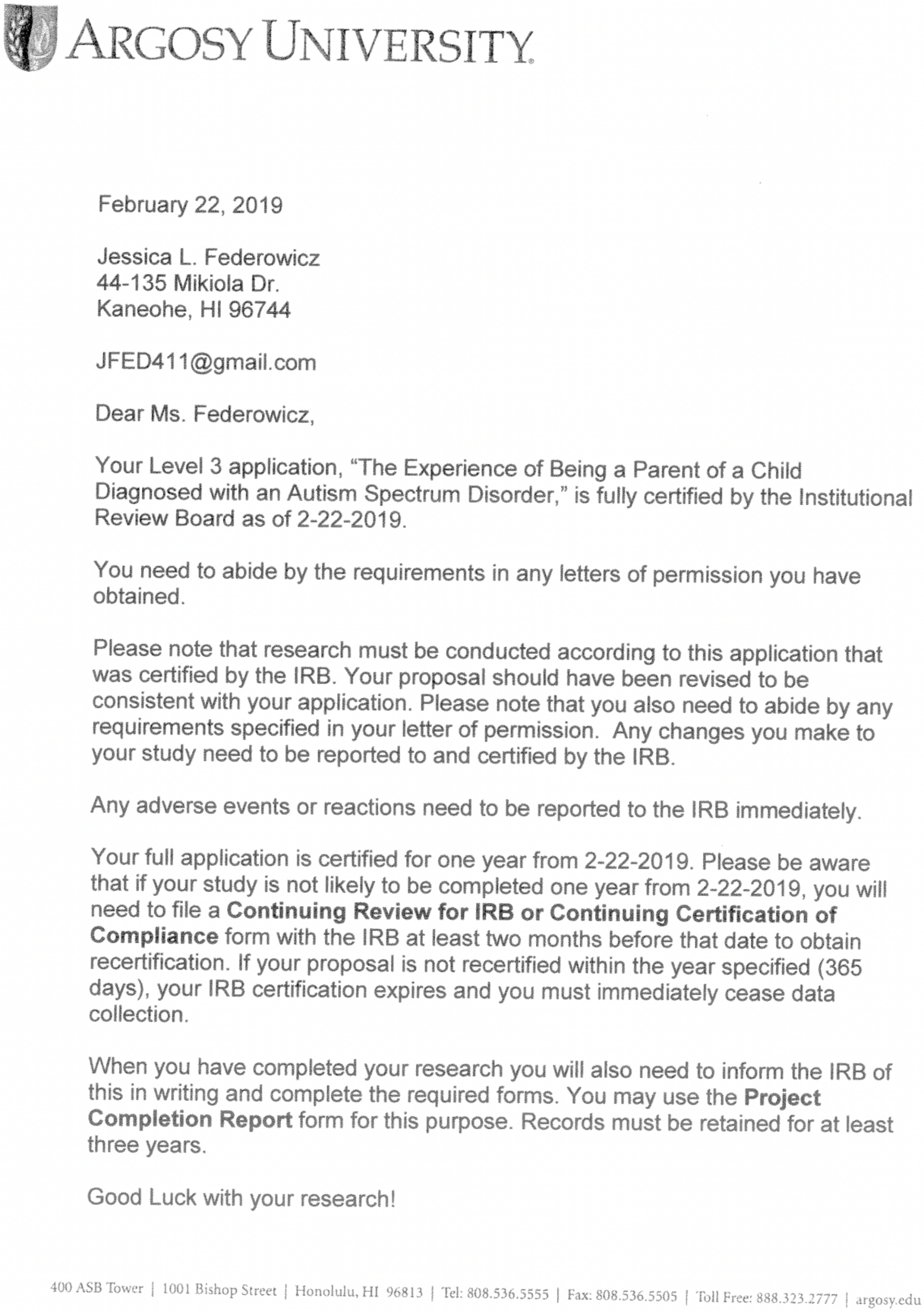
Shenton, A. K. (2004). Strategies for ensuring trustworthiness in qualitative research projects. *Education for Information, 22*, 63-75.

Spradley, J. P. (1979). *The ethnographic interview*. New York: Holt, Rinehart and Winston.

Strauss, A., & Corbin, J. (1998). *Basics of qualitative research: Grounded theory procedures and techniques (2nd ed.).* Newbury Park, CA: SAGE Publications Inc.

Vogan, V., Lake, J. K., Weiss, J. A., Robinson, S., Tint, A., & Lunsky, Y. (2014). Factors associated with caregiver burden among parents of individuals with ASD: Differences across intellectual functioning. *Family Relationships, 63*, 554-567.

Appendix A: Argosy University, Hawaii IRB Letter of Certification



ARGOSY UNIVERSITY

February 22, 2019

Jessica L. Federowicz
44-135 Mikiola Dr.
Kaneohe, HI 96744

JFED411@gmail.com

Dear Ms. Federowicz,

Your Level 3 application, "The Experience of Being a Parent of a Child Diagnosed with an Autism Spectrum Disorder," is fully certified by the Institutional Review Board as of 2-22-2019.

You need to abide by the requirements in any letters of permission you have obtained.

Please note that research must be conducted according to this application that was certified by the IRB. Your proposal should have been revised to be consistent with your application. Please note that you also need to abide by any requirements specified in your letter of permission. Any changes you make to your study need to be reported to and certified by the IRB.

Any adverse events or reactions need to be reported to the IRB immediately.

Your full application is certified for one year from 2-22-2019. Please be aware that if your study is not likely to be completed one year from 2-22-2019, you will need to file a **Continuing Review for IRB or Continuing Certification of Compliance** form with the IRB at least two months before that date to obtain recertification. If your proposal is not recertified within the year specified (365 days), your IRB certification expires and you must immediately cease data collection.

When you have completed your research you will also need to inform the IRB of this in writing and complete the required forms. You may use the **Project Completion Report** form for this purpose. Records must be retained for at least three years.

Good Luck with your research!

400 ASB Tower | 1001 Bishop Street | Honolulu, HI 96813 | Tel: 808.536.5555 | Fax: 808.536.5505 | Toll Free: 888.323.2777 | argosy.edu

Please be careful not to lose this letter.

If you have questions, please feel free to contact me.

Sincerely,

Robert M. Anderson Jr., Ph.D., Co-Chair
Institutional Review Board

cc: Dr. Joy Tanji

Chaminade
University

Institutional Review Board.
Chair: Helen Turner, Ph.D.
Vice-Chair: Claire Wright, Ph.D.
Vice Chair: Darren Iwamoto, Ph.D.
irb@chaminade.edu

April 25, 2019

Ms. Jessica L. Federowicz 44-135 Mikiola Drive Kaneohe, Hawaii 96744

Dear Ms. Federowicz:

This letter is to confirm receipt of your Argosy University Institutional Review Board (IRB) approval for "The Experience of Being a Parent of a Child diagnosed with an Autism Spectrum Disorder".

The CUH IRB IRB00007927 reviewed the above IRB external approval.

The Chaminade University IRB will accept your current number and will not require reapproval at this time. Your Chaminade IRB protocol number is CUH 088-2019. You will now be entered into our annual report cycle (due date below). Please use the attached Form VI to complete your annual reporting.

The final date for your Argosy approval is February 22nd 2019. Continuation of research after this date will require:

1. Submission of Form IV Final Report; and
2. Request for an extension letter to be submitted to irb@chaminade.edu 30-days prior to the expiration date of your Argosy approval. The Board may require a new protocol submission, so please do this as early as possible.

Effective proposal approval date: February 22nd 2019

Date of annual or final report due to Chaminade IRB: February 22nd 2020

Please submit a copy of your current CITI training certifiable by email to irb@chaminade.edu. Please be advised that if you submit future protocols to our IRB we will require updated CITI certification aligned with Chaminade’s requirements.

Please feel free to contact the IRB above with any questions or concerns.

Kind Regards,

Helen Turner, PhD
Chair, Chaminade IRB Committee

Appendix C

Gatekeeper Agreement Form

The Experience of Being the Parent of a Child Diagnosed with and Autism Spectrum Disorder

Hawai‘i School of Professional Psychology at Chaminade University of Honolulu

Script for Working with Gatekeepers

I plan to use the following script for approaching gatekeepers if participants are unable to be found through purposive sampling within the community.

Contacting A Gatekeeper

Researcher: “Hi ___________. My name is Jessica Federowicz and I am a Clinical Psychology doctoral candidate at the Hawai‘i School of Professional Psychology at Chaminade University of Honolulu. I appreciate you taking the time to talk with me today. I am hoping that you might be able to help me find a willing participant for a qualitative research study I am conducting as part of my doctoral requirements. The topic of the study is entitled “**The Experience of Being the Parent of a Child Diagnosed with and Autism Spectrum Disorder**.” I am hoping to explore the experiences of parents who have a child diagnosed with an autism spectrum disorder. In particular, I am interested in identifying potential participants who have remained resilient and persistent in their exploration of parenting a child diagnosed with autism spectrum disorder. My hope is that by learning more about the journey of a parent who has remained active and engaged in this process, I might begin to identify themes that could contribute to the development of future interventions that support the resilience of other parents. Are you able to help me find potential participants?

Wait for verbal understanding and approval of gatekeeper.

Researcher: “Okay, great. Thanks again for your assistance. Before you contact any potential participants, I would like to assert the importance of the confidentiality of their identity in relation to this study. Your role will be to identify people who are interested in learning more about this study and may be interested in participating in it. Are you willing to give those who are interested a letter that I will provide you?

Wait for verbal understanding and approval of gatekeeper.

Ok, thank you. This letter will provide a general overview of the study and provide my contact information. As the gatekeeper, in the interest of anonymity, you are not to ask and the researcher will not disclose who ultimately ends up participating in the study. Can you agree to maintain the confidentiality of the potential participant’s identity in connection with this qualitative research study?”

Wait for verbal agreement of gatekeeper.

Researcher: “Okay, thank you very much. I greatly appreciate your assistance in this matter. Please contact me on my cell phone if you find a potential participant. My phone number is: (716) 430-6999.

Appendix D

Invitation to Participate in the Study

The Experience of Being the Parent of a Child Diagnosed with and Autism Spectrum Disorder

Hawaiʻi School of Professional Psychology at Chaminade University of Honolulu

Aloha, my name is Jessica Federowicz and I am a Clinical Psychology doctoral student at the Hawaiʻi School of Professional Psychology at Chaminade University of Honolulu. I am in the process of conducting a Clinical Research Project in order to fulfill my requirements for the degree of Doctor of Psychology. This project represents a topic I feel passionate about and find meaningful to study. The information gathered is intended to expand and add depth to the current literature and serve to inform practitioners who work with this population by providing insight into the experience of parenting a child diagnosed with and autism spectrum disorder. This study is dedicated to coming closer to understanding the experience as expressed by those who live it.

I would like to invite you to participate in three interviews and one member check in which you will be given an opportunity to review my analysis and write-up of your story. During the interviews, I would like to explore your experiences of parenting a child diagnosed with an autism spectrum disorder and express what it has meant to you. Your personal experiences may help provide insight to mental health providers who have not experienced this parenting journey but desire to assist parents who are on it.

If you are interested in participating in this study or would like to know more before making a decision about participating, please contact me, Jessica Federowicz, at (716) 430-6999.

Thank you for your time and consideration,

Jessica L. Federowicz BCBA LBA LMHC

Appendix E

Participant Information File Form

The Experience of Being the Parent of a Child Diagnosed with and Autism Spectrum Disorder

Hawai‘i School of Professional Psychology at Chaminade University of Honolulu

Participant Information File Form

Participant’s Name: ____

Address: ____

____

Phone Number: ____

Email Address: ____

Please indicate your preferred method of contact with the researcher, Jessica Federowicz:

○ Phone
○ E-mail

Appendix F

Scripts for Audio Recordings

The Experience of Being the Parent of a Child Diagnosed with and Autism Spectrum Disorder

Hawaiʻi School of Professional Psychology at Chaminade University of Honolulu

The following scripts are what I will use when the recorder is turned on (begin the session) and off (end the session) to give the participant clear notification each time.

Turning Recorder On

Researcher: “Hi ___________. Thank you so much for taking the time to talk with me today. Our interview today will be about one to one-and-a-half hours long with breaks as needed. Let’s go ahead and get started. Are you ready for me to begin recording our conversation today?”

Wait for verbal approval of participant.

Researcher: “Okay, great. Just as a reminder, I want you to know that if you feel the need to speak off the record or take a break, you may do so at any time and without negative consequences. Please ask me to stop the recorder whenever you’d like to speak off the record. At that time, I will stop the recorder and only begin recording again once you are ready to do so. I will now press record and we can begin. Each time we begin a conversation I will ask you if its ok to begin recording, if you verbally agree, then and only then will I begin recording.”

Press record.

Researcher: “I have turned the recorder on.”

Turning Recorder Off

Researcher: “Okay ___________. Thank you so much for sharing your story with me today, and for being part of my study. I think I’ve gathered some great information today and this seems like a good place to stop for the day. Are you ready for me to stop recording?”

Wait for verbal approval of participant.

Press stop.

Researcher: “Ok, I have stopped the recorder for the day. Thank you again.”

Off-the-Record Discussions

Participant states that he or she would like to speak off the record:

Researcher: “Okay, that’s no problem at all. I’m going to turn off the recorder now, and I want to remind you that whatever you share with me off record will not be part of the study unless you share the same information with me later on the record.”

Turn off the recorder.

Researcher: “I have turned off the recorder.”

Attend to off record discussion and ensure safety and wellbeing of participant. Utilize the Community Resource List should the participant be experiencing feelings of distress beyond the scope of processing through conversation with the researcher and consider taking a break or discontinuing for the day, depending on issues that have come up.

If the Participant shares that he or she is ready to begin recording again:

Researcher: “Okay, so it sounds like you are ready to begin recording again?”

Wait for verbal approval from participant.

Press record.

Researcher: “The recorder is now on again. We can begin again.”

Participant Requests Break/Stop for the Day

Participant states that he or she would like to take a break from interviewing:

Researcher: “Okay, that’s no problem at all. I’m going to turn off the recorder now, and whenever you are ready to begin again, just let me know. You can take a break for as long as you need to.”

Turn off the recorder.

Researcher: “I have turned the recorder off.”

Attend to the safety and wellbeing of participant. Offer assistance as needed as well as water and/or directions to refreshments. Utilize the Community Resource List should the participant be experiencing feelings of distress and/or process their feelings through conversation with the researcher. Consider discontinuing the interview for the day depending on the issues that have come up.

If the Participant shares that he or she is ready to begin recording again:

Researcher: “Okay, so it sounds like you are ready to begin recording again?”

Wait for verbal approval from participant.

Press record.

Researcher: “I have turned the recorder on again. We can begin.”

Participant states that he or she would like to stop for the day:

Researcher: “Okay, that’s no problem at all.”

Press stop.

Researcher: “I have turned off the recorder. Thank you so much for your contributions today.”

Appendix G

Initial Consent for Participation in Research

The Experience of Being the Parent of a Child Diagnosed with and Autism Spectrum Disorder

Hawaiʻi School of Professional Psychology at Chaminade University of Honolulu

1. *Who is the researcher?* Hello, my name is Jessica Federowicz and I am a student at the Hawaiʻi School of Professional Psychology at Chaminade University of Honolulu. I am conducting this study in partial fulfillment of my requirements for the Degree of Doctor of Psychology, in Clinical Psychology.

2. *What is the aim of the study?* The aim of this qualitative study is to explore the experiences of a being the parent of a child diagnosed with an autism spectrum disorder. The information gathered is intended to expand and add depth to the current literature and serve to inform practitioners who work with this population by providing insight into the experience of parenting a child diagnosed with and autism spectrum disorder. This study is dedicated to coming closer to understanding the experience as expressed by those who live it.

3. *How was I chosen?* I will be interviewing parents of children diagnosed with an autism spectrum disorder for this study. I have chosen you because of your dedication to your child and because you have shown interest in sharing your experience. This study will continue my work with families of children diagnosed with an autism spectrum disorder and deepen my understanding of the experience and needs of the parents.

4. *What will be involved in participating?* I would like to schedule three (3), one hour interviews with you and one (1) meeting at the end to see whether I have captured your experience accurately. During our meetings, I would like to reflect on your experience of participating in this project as well so that as the process unfolds, I can structure it in a way that is most beneficial to you.

5. *Audio recording.* With your permission, I would like to tape our conversations, take notes during the interviews, and make transcriptions from the tapes, so that I may attempt to accurately represent your perspectives in the narrative write-up I will generate of your story over time. Each time we begin a conversation, I will ask you if it is okay to begin recording. If you verbally agree, then and only then will I begin recording. I will also inform you when I have begun recording.

   I, ________________________________ (printed name) agree to be audio recorded for the purpose of this study. I also agree to allow you to take notes during our interviews and make transcriptions from the tapes.

   ____ ______________________

   Signature **Date**

The interviews will take place in my personal private practice office that is both quiet and private. I will utilize a sound machine to reduce the likelihood that our conversations can be heard outside of my office. It should also be a place that is easy for you to reach.

Prior to our last meeting, I would like to give you the opportunity to review your transcripts and the narrative I have written about your experiences so you have time to review it carefully before we meet. During our last meeting, I will begin by reviewing this consent agreement. You will then have the opportunity to discuss where you might want to add, remove, or adjust the write-up I sent to you in order to make it more accurate. You will also have the opportunity to review the quotes from our conversations that I would like to use to illustrate the themes that emerged during the study. I will take notes again, to ensure my understanding of what you have shared with me and then let you review the edited the draft before signing off on the final consent and release of information form. You will also have an opportunity to revisit your decision to remain anonymous in the final document or select a final pseudonym that will be used in the document.

6. *Who will know what I say?* Currently, I plan to transcribe the audiotapes of our conversations and audit or check them for accuracy. In the event that I am unable to transcribe the interview tapes in a timely way, I will utilize a transcriptionist. If I chose to use a transcriptionist, I want to reassure you that this individual will be educated about the importance of confidentiality and security of the data will sign an agreement to maintain these ethical standards. Additionally, if a transcriptionist is used, you will be made aware of the identity of the individual. If, for any reason, you do not feel comfortable with the transcriptionist I have selected (i.e., there is a conflict of interest where confidentiality is concerned), I will then obtain another transcriptionist and ask for your consent again. I also will be personally auditing or checking the accuracy of the transcriptions against the audiotapes even if I use a transcriptionist.

   The following individuals, who are members of my research team, will also know what you share with me: Dr. Joy Tanji, my research committee chair, will serve as my primary methodological consultant and debriefer. Her job will be to review the rigor of my work and help me to tell your story with as much accuracy as possible. Dr. Lianne Philhower, my research committee member, will serve as my peer examiner. Her job will be to look at my analysis to make sure that it remains faithful to what you have shared with me. Drs. Tanji and Philhower will have only limited access to the password-protected transcripts/audio recordings in order to check my work and provide further support.

   All notes, audio taped recordings, transcripts, and drafts for the study’s final write-up will be stored using a double-locked system. I will place these documents in a locked box that will be secured in a locked filing cabinet to which only I have access. Whenever members of my research support team (the debriefer, peer examiner, and transcriptionist) are in possession of the interview transcripts, or in the case of the transcriptionist who will have access to the audio recordings of our conversations, these documents will be secured using password-protected files or password-protected data storage devices (USBs) that will be further secured in a locked filing cabinet. Passwords will be sent to members of my research team through a separate email. Team members will not be permitted to save these files onto their own personal computers.

7. *What potential risks may be associated with participation?* I will work closely with you throughout the process to minimize any major risks to you. This process privileges you in terms of direction and pace of the study. What this means is that while I may offer some questions to start us off, I would like you to help me in understanding what is meaningful to look at in your experience. I would also like to work closely with you to determine the pace of our exploration—deciding what is meaningful to explore first, what you feel ready to disclose, and how much time passes between each interview.

   Your participation is also completely voluntary. Thus, throughout the study, you may decline answering questions you do not wish to answer. You also may table questions you do not wish to answer in the moment but would like the option of returning to in the future. You also may decide to withdraw from the study and withdraw what you have shared during your participation, without having to provide a reason and without being concerned that such a decision might result in negative consequences.

   Despite my efforts to minimize major risks, I am aware that talking about your experiences may sometimes bring up unexpected memories and insights that could be disturbing. The remembrance and experience of intense feelings associated with traumatic experiences may be painful and possibly unresolved. If at any point in the process, you find that the recollection and processing of your experiences contribute to feelings of distress, I would like to end the interview, stop recording, process what may be coming up for you, and explore what may be the most helpful way to address these concerns. Anything we discuss when the tape recorder is turned off, would not be included as part of the study unless you choose to share it with me again at a later date while we are taping. Whenever I turn the audio recording device on and off, I will let you know that I have done so.

   Since my role during the study will be that of a researcher and interviewer rather than a therapist, you are encouraged to continue mental health treatment with your treatment team (e.g., therapist or psychologist) during this time to discuss your thoughts and feelings about the process during your participation in this study. Today, I will be providing you with a Community Resource List to supplement the services you receive from your regular mental health service provider. Should there be a time when you feel distressed during an interview, I would like to revisit this list of resources with you.

   Should you begin to feel distressed during an interview, there are a number of options. You may decide to end the interview for the day and reconvene at a later date, allowing you to process what came up and to engage in self-care. You may decline answering questions you do not wish to answer. You also may table questions you do not wish to answer in the moment but would like the option of returning to in the future. You also may decide to withdraw from the study without having to provide a reason and without being concerned that such a decision might result in negative consequences. You may further decide to withdraw the data you have provided without having to provide a reason and without being concerned that such a decision might result in negative consequences.

In these instances, I would encourage you to contact your mental health provider. You might also wish to utilize some of the resources included on the Community Resource List I am providing you today. Please be assured that your welfare, above all else, is most important to me.

Following the conclusion of an interview, in which the circumstances described above occur, I also would contact my research committee members to consult, explaining what has happened. A follow-up call later that day or the following day would be made to you from me, and then over the course of the following few days to check in with you for your safety and well-being. If you experience severe emotional distress at all during the study, even if unrelated to the interview content, I would suspend the interview(s) and resume only when you feel that you have recovered sufficiently enough to make an informed decision about continuing your participation.

During the study, I will attempt to protect not only your confidentiality but your anonymity too. However**,** because this is a small community, there is the possible risk that despite my best efforts, someone who reads the study may be able to figure out who you are. To minimize this risk, your real name will not appear on any transcripts or in my write-up. In addition, when not in use, I will store your audio recordings and transcripts in a locked box in a locked filing cabinet to which only I have the keys. The computer I will be using is password protected and I am the only person who is aware of the password. The documents I will keep will be stored on a USB drive only and secured in the locked box when not in use. My peer debriefer (CRP chair; Dr. Joy Tanji) and peer examiner (CRP committee member; Dr. Lianne Philhower) will have only limited access to these materials when performing their duties as described above. In my journal entries and discussions with them, I will not refer to you by name. Instead, I will refer to you by a pseudonym of your choosing. This will be the name used in all transcriptions and write-ups.

The pseudonym I would like to use is: ______________________________

While there are no anticipated physical, economic, or legal risks associated with this study, there could be social ramifications for you if you choose to inform others of your participation. For example, if informed of your participation in the study, others may make assumptions and express biases based on their interpretations of the findings.

Every attempt to protect your confidentiality will be made, as the law requires, with the following exceptions: Any reports of suicidal or homicidal intent that appear to be imminent, or any reports of abuse of children, elders, and/or individuals with mental or physical disabilities will be reported to the proper civil or legal authorities. My research supervisor, Dr. Joy Tanji, will also be notified in such instances. Confidentiality also may have to be broken if the materials from this study are subpoenaed by a court of law. The limits of confidentiality are in place to protect your safety and the safety of others.

8. *What are the potential benefits of participating?* Sometimes people find participating in focused conversations about critical life experiences to be beneficial insofar as it gives them a chance to talk about things that deeply matter to them. I hope the same will be true for you. I also hope that your participation will help you gain a better understanding of your own story. I also hope that

your participation in this study, and the subsequent data gathered, will contribute to a better understanding of the experience of parenting a child with an autism spectrum disorder for those who do not have the actual experience.

The hope is that professionals with gain insight and empathy and parents will find their services meaningful and therapeutic.

9. *What are my rights as a participant?* As a participant in this study, you are considered a co-owner of the outcomes of the study. The study attempts to document important themes from your personal story that may be of benefit to you, others with similar stories, service providers, researchers, and program development specialists. To best benefit these many stakeholders, I want to tell your story with fidelity. As such, I want to work closely with you throughout the interviewing, analysis, and write-up process.

As a participant in the study, you have the right to ask any questions regarding the study at any time, and I will attempt to answer them fully. You will also have the right to withdraw from the study at any time without negative consequences. Your participation is completely voluntary.

If at any time, you would like to speak to me off the record, you may turn off the tape recorder, then turn the tape recorder back on only when you feel that you are ready to proceed. Each time we begin a conversation I will ask you if it is okay to begin recording, if you verbally agree, then and only then will I begin recording. As stated above, anything you discuss while the tape recorder is turned off will not be included as part of the study unless you choose to share this information later while we are taping. I will let you know when I have turned the tape recorder off and will only turn it back on with your permission.

You also may take breaks as needed during the interview. You may pass on any question you do not wish to answer, and you may choose to think about a question and answer it at a later time.

At the conclusion of the study, you also will have the right to add, remove, or change anything in the final write-up so that it best represents your experiences.

On June 28, 2019 or sooner, at the conclusion of this study, I would like to give you a copy of the transcripts and recordings of our conversations.

Please verify which of the following you would like me to do at that time (please check all that apply):

___ Please return my audio recordings to me.
___ Please provide me with electronic transcripts (e.g., on an electronic storage device).
___ Please provide me with a copy of your clinical research project.

I am required by the Chaminade University Institutional Review Board to keep the audiotapes and transcriptions of the study for three (3) years following completion of the study.

Alternately, I can do one of the following (please check all that apply):

___ Please destroy my audio recordings.
___ Please destroy the transcripts of the audio recordings.

This is so that I will be able to respond to any queries by other researchers regarding the findings and approach used. On June 30, 2022, I will shred the paper documents I have that are associated with the study and erase the audio recordings of our conversations.

10. *What will be published?* Prior to our last meeting, I will send you a draft of my findings. During our last meeting, I would like to review this draft with you. At that time, I will ask you for permission to use certain quotes from our conversations to illustrate your experiences more clearly to others. You have the right to review these materials and decide which quotes you will allow me to include. You may also reword, add to, or decline my use of others. The final write up of this study, including the materials you have reviewed and given your consent to use, will be published as part of the Chaminade University e-library. The study may also be presented at a conference. Prior to any presentation of information, you will be contacted and consulted regarding what will specifically be presented in the conference presentation. At that time you will have the opportunity to either agree or not agree to what will be presented.

11. *If I want more information, who can I contact about this study?* If at any point in the course of our work together, you have questions about anything regarding this study, you may contact me at: (716) 430-6999.

    This study has been approved by the Institutional Review Board of Chaminade University of Honolulu, Hawaiʻi. Thus, if you have questions about your rights as a participant, you can contact Dr. Helen Turner, IRB Chair, Chaminade University of Honolulu, 3140 Waialae Ave., Honolulu, HI 96816, or by phone at (808) 791-5207. If at any time in the process, you have any concerns about my study or our interactions with each other, you may contact my clinical research committee chair/supervisor, Dr. Joy Tanji, with your feedback, via her direct line at: (808)791-5206.

By written notification to Jessica Federowicz, below, I indicate that the information presented in this document has been reviewed and explained to me to my satisfaction. This procedure does not preclude me from seeking further clarification of any items in the future. I understand the nature and intent of this study. I also understand my rights and what is being asked of me as a participant. I understand all of the above and provisionally agree to the terms and conditions specified. I understand that I will be given an opportunity to complete this informed consent procedure at the completion of my participation—after I have had a chance to review the materials I have been provided for this study. This will allow me to make any corrections or changes I feel necessary. I understand that I still maintain the right to revoke this consent at any time during the study.

By signing this form I am also affirming that I am at least 18 years of age or older and am not considered a minor.

____

Participant’s Signature Please Print Name Date

____

Interviewer’s Signature Please Print Name Date

Appendix H

Final Informed Consent and Release of Information Form

The Experience of Being the Parent of a Child Diagnosed with and Autism Spectrum Disorder

Hawaiʻi School of Professional Psychology at Chaminade University of Honolulu

I, ____________________________, hereby authorize Jessica Federowicz to submit the following information, collected in the course of my participation in the study indicated above, in partial fulfillment of her requirements for the Doctor of Psychology degree in Clinical Psychology, through the Hawaiʻi School of Professional Psychology at Chaminade University of Honolulu. I hereby indicate that the initial informed consent agreement has been reviewed with me, and that I have had the opportunity to review the transcripts of our conversations together and the narrative generated on the basis of what I have shared about my experiences. I have had the opportunity to make the necessary corrections, additions, and retractions to my interview transcripts and the narrative so that they best represent my experiences and what they have meant to me.

I hereby authorize the use of these materials as part of Jessica Federowicz's Clinical Research Project. I also authorize the use of the highlighted quotes in the final write-up to better capture and illustrate the perspectives they represent. Because Hawaiʻi is a small community, I recognize that there is the possibility that individuals may still be able to identify me despite the use of a pseudonym. Having this knowledge and deciding to complete the study (please check all that apply):

____ I would like to remain anonymous and use the pseudonym agreed upon earlier in the study
____ I would like to use my real name for this study
____ I would like copies of the study data, including the audio recordings, transcripts, and study write-up.

My signature, below, indicates that the nature and intent of the study, as well as my rights as a participant, have been reviewed, again, so that I may refresh my memory of the issues reviewed in the original informed consent procedure. I am aware that I may still withdraw from the study at any time and withdraw the information I have shared as a participant without negative consequences. I understand the material reviewed and agree to the conditions specified now that I am aware of what I am specifically contributing to the study. I understand that the final write up of this study, including the materials I have reviewed and given my consent to use, will be published as part of the Hawaiʻi School of Professional Psychology e-library. I also am aware that the study may be presented at a conference. Finally, by signing this form I confirm that I am 18 years of age or older.

Participant's Signature	Please Print Name	Date
Interviewer's Signature	Please Print Name	Date

Appendix I

Confidentiality Agreement for Debriefer/Peer Examiner

The Experience of Being the Parent
of a Child Diagnosed with and Autism Spectrum Disorder

Hawai‘i School of Professional Psychology at Chaminade University of Honolulu

As a researcher, one of my priorities is to uphold and protect the confidentiality of the participant in my study. The information contained in the audio recordings and transcripts of interviews conducted in this study may be sensitive in nature and personal, therefore must be kept confidential in order to protect the privacy of the participant. By signing this agreement, the Debriefer/Peer Examiner acknowledges the importance of protecting the participant's confidentiality and agrees to protect the information contained in the conversations, audiotapes and transcripts, including the identity of the participant. The limits of confidentiality extend throughout the duration of the study and even after the study has been completed.

I, _______________________________, have accepted the responsibilities of
(*Debriefer/Peer Examiner*)
reviewing and discussing transcriptions and audiotapes as a part of the research support team for Jessica Federowicz's clinical research project. I understand that these tapes and transcripts, and the discussions I will have with the principal investigator will contain personal and confidential information. I understand that during the course of the study, I will be provided limited access to research materials in order to help me provide appropriate feedback and support to the principal investigator. While in my possession, I accept responsibility for keeping the password-protected documents provided by the principal investigator, Jessica Federowicz, protected and secure. When in my possession, I agree that when not in use, I will keep the password-protected audiotapes and transcripts being reviewed stored in a locked filing cabinet to which only I have the key. I will not release these research materials to, and will not discuss their contents with, anyone other than the researcher, Jessica Federowicz. No copies of the audiotapes, transcripts, or notes will be retained by me during or after the study. I understand the importance of keeping all discussions, audio recordings, and transcripts secure and confidential.

I have read the terms and conditions of confidentiality listed in this document. By signing this agreement, I agree to protect the identity of the participant(s) in the study. I also agree to keep all documents, audiotapes, and transcripts secure, and agree to protect the personal and sensitive information contained in these materials.

____
Debriefer's/Peer Examiner's Signature   Please Print Name   Date

____
Researcher's Signature   Please Print Name   Date

Appendix J

Community Resource List for Oahu, Hawaiʻi

The Experience of Being the Parent of a Child Diagnosed with and Autism Spectrum Disorder

Hawaiʻi School of Professional Psychology at Chaminade University of Honolulu

As a researcher, one of my top priorities is your welfare and the welfare of others. I encourage you to maintain communication with your own mental health provider or treatment team and contact them should the need arise. Below, I also have compiled a list of mental health centers with multiple providers and services, as well as a 24-hour crisis line should you experience any feelings of distress, whether due to your participation in this study or not.

Local Mental Health Centers:

Oahu Community Mental Health Windward
45-691 Keaʻahala Rd.
Kaneohe, HI 96744
(808)233-3775

Waimanalo Health Center
41-1347 Kalanianaole Hwy.
Waimanalo, HI 96795
(808) 259-6449

Mental Health Kokua
1221 Kapiʻolani Blvd.
Honolulu, HI 96814
(808) 737-2523

Kalihi-Palama Community Mental Health Center
1700 Lanakila Ave.
Honolulu, HI 96817
808-832-5770

Crisis Line:

You may call the 24-hour Access line at ***(808) 832-3100*** on Oahu or toll free at ***1-(800) 753-6879*** for support. They are open 24 hours a day, seven days a week.

National Mental Health Care Resources:

The Suicide Prevention Hotline
Connects callers to trained crisis counselors 24/7
1-800-273-8255

Anxiety and Depression Association of America (ADAA)
Provides information on prevention, treatment and symptoms of anxiety, depression, and related conditions.
1-240-485-1001

Sidran Institute
Helps people understand, manage and treat trauma and disassociation; maintains a helpline for information and referrals.
1-410-825-8888

Autism Society
Provides information and support.
www.autism-society.org
1-800-328-8476

Appendix K

Emergency Contact Information

The Experience of Being the Parent
of a Child Diagnosed with and Autism Spectrum Disorder

Hawai‘i School of Professional Psychology at Chaminade University of Honolulu

As a researcher, one of my top priorities is your welfare. I would like to obtain the phone number of an emergency contact person who might be reached in case of an emergency. I will only contact this individual in the event that you are sick, or unable to contact them yourself. The nature of our relationship and your participation in this study will be kept confidential.

I, _________________________________, will allow Jessica Federowicz to contact the named emergency contact person at the phone number provided, written below, in case of emergency.

Emergency Contact Name: ____

Relationship: ________________________________Phone Number: (____)_____-_______

____
Participant’s Signature Please Print Name Date

____
Researcher’s Signature Please Print Name Date

Appendix L: Integrated Coding List

Phenomenological studies are primarily open ended. Researchers search for themes that express meaning in participants' lives as expressed through interview data. Broad categories are sought inductively building subthemes that elaborate the meaning expressed by the participant. Focused questions were used to draw out descriptions of the experience of parenting a child diagnosed with an autism spectrum disorder. The meaning associated with these descriptions and themes were documented across interviews and integrated into this coding list.

Interview #1 coding

- Different: Things were not right
- Grief: "There is a lot of grief as a parent"
- Hope/ joy: There is strength in his differences
- Future (grief): How do I prepare for his future without me?
- I want them to understand: Caregivers miss the boat

1. **Things were not right/ different**
    a. Developmentally- led up to diagnosis

    b. Educationally-
        i. wished for inclusive experience
        ii. Poor access to care/ limitations of living in a rural area
        iii. Searching for something different (1-2-3 magic) as a parent and an educator
        iv. Wanted to find better services/ wanted to leave the islands (Yale) but it wasn't fair to take him away from the ocean
    c. Behaviorally-
        i. Didn't want to get dressed for preschool – struggle
        ii. Wouldn't separate
        iii. Yelling in tub (mom thinking "wow, this is different")
        iv. Repeating songs or phrases

2. **Grief** ("There is a lot of grief as a parent")
    a. Expected parenting experiences not occurring "this is my first born. I've waited years. I'm an older parent. I've waited years for this to happen. I pictured him to be… you know, after school like coming to my classroom, and doing all these different things, and it was not that."
    b. After diagnosis, initial thoughts was "He'll never drive." That was…. I'm like "He'll never drive"- loss of hope for independence, freedom. "Coming of age, **freedom**"
    c. Watching other children do things that your child is not doing (driving, dating, having a friend) (14:50) "You know all those things are closed doors for [son]"
    d. Sister Emma went to Kamehameha preschool in Waikaloa but this wasn't an option for [son] because they don't take special ed students "a lot of her opportunities were not opportunities for him"
    e. "Yeah, you're always… you're… not always, but you're grieving what can't be, or what isn't… and what you would like for your child."

      i. **Sadness** – “[[son]] has the wherewithal to know he's missing out on something, something is not right. And so but he can't put his finger on it…. He’ll be insecure…”
      ii. **Fear**- “oh my gosh, I hope I don’t die” – when he was 4 because I was his interpreter, now because he is a young adult and starting a job…
      -Fear of him becoming homeless
      -Fear he will be taken advantage of

3. **Hope/ joy (pride?)**
   a. He’s a-typical in a “social” sense. He says hello to strangers
   b. He was happy as a young child
   c. Mother and child had an affectionate routine “we sang songs. Like I kissed him every time I put him in the car seat and I took him out. That was like our thing”
   d. Close teacher friend who had a good relationship with [son], videotaped him and celebrated him
   e. A friend from Connecticut offers hopeful thinking in a time of despair after learning of the diagnosis and thinking “he will never drive a car”. Friend offers the notion “[participant], by the time he reaches that age, they’re going to have self-driving cars” – powered a sense of belief, installation of hope. Memorable moment.

4. How do I prepare for his future without me
   a. Financially
   b. Prepare to have people around him to check on him and take care (like I have)
   c. Pulling in people to help- “I have a sister, whose a doctor, and that was helpful a lot of times… I was able to talk to her, consult with her… really helped me a lot”
   d. How do you train a caregiver to care for your loved one the way you do?

5. Care providers miss the boat
   a. Mayo clinic “cemented” my thoughts that some of the educational things happening were not what was best for [son].
      i. Forcing him to cut
      ii. Couldn’t leave class without tying his shoe (outside of his developmental readiness)
      iii. Speech teacher taking [son] without skills trainer
   b. Inclusion
   c. How do you train a caregiver to care for your loved one the way you do? Experience that goes beyond training…. What can you share with someone that might help?

<u>Coding Interview #2</u>

Topic: Thematic code

- Different: This journey is different than I expected
- Grief: There is a lot of grief as a parent
- Relationships: Having and keeping relationships requires understanding
- Hope/ joy/ pride in his “atypicality”: He has strengths in his differences
- Learning Journey: the understanding comes in increments and by looking back
- Advocacy: Installation of hope for others
- Need for compassion (understanding and Knowledge): “I want them to understand where I’m coming from”
- Respite: “a minute of respite would be golden”

1. Different: This journey is different than I expected
   a. [autism means] “right now just means a different journey”

   b. [autism means] “its constant learning, its adjustment, a ton of patience, its educating others” 1:59 -because the experience was different than what I had thought things were going to be like
   c. [autism means]
   “I see it as a neurological disorder, or whatever's going on in the brain is, you know not helping him to function..”

2. Grief: “There is a lot of grief as a parent” 1st interview

   a. “because he was my first born I was….” “this was not the path I had envisioned at all”

3. Relationships: Having and keeping relationships requires understanding
   a. [autism means] “a new set of friends”
   b. “you don’t have a chance to like maintain your regular friendships”
   c. “it’s the people you come across… that one friend I was telling you about who taught at the same school I did, she kind of told me it was a kind of carousel and there were people that were getting on and were going to be helpful and there’s people that need to get off.”
   d. “you definitely find out who your friends are who can handle different things and who are supportive and those are the kinds of people that you care really hard to (keep) with whatever energy you have left to maintain those relationships”
   e. Just understanding that you can't do certain things or that your child's going to act a certain way and they're not fazed by it or that you can go or you can't go depending upon the circumstances or if you're going to be doing something, you know that you're no longer that reliable because you never know what's going come up.
   f. “(friends) it's not that you set out to find them, it’s kind of like they find you”

4. Hope/ Joy / Pride in his “atypicality”: He has strengths in his differences
   a. “because again this is typical. He would talk to people sometimes and I get to know like the most interesting type of people, like in the grocery store, some of those social filters they leave.’
   b. He allows himself to just “be present”, interact with people without holding back.
   c. Helping grandpa get connected with the VA by asking a veteran he met on the bus about it
   d. He can tell you what year you were born automatically when you tell him your age

5. Learning Journey: the understanding comes in increments and by looking back
   a. “So every little step of the way, you look back and go, wow, okay, so now we're doing this, or oh I get that now.”
   b. “90%” is learning by doing

6. Advocacy: Installation of hope for others
   a. “I felt the same way that you did”
   b. “(I felt like) this is never happening for me or my kid. I felt the same way that you did. I'm like look at him now. And so after you learn these things, for me it's important to help other parents to understand that labels not a dead end.”
   c. Teacher tendency
   “whatever I learned that I want to teach somebody else or give back or stand up for them or...
   So I think as each of these, I'm just call them little things, but they were big things as they happen. I think that it was like, okay, now I can help others with that. And of course, like we know, right. When you help others you actually help yourself.”

  d. and so then when other parents are going like, what do I do or whatever, you know, that it can point them in that direction because now I've learned something.
  e. I think having the knowledge is the number one way to know stuff, so to understand how things should be, and I think that is super helpful.

7. Need for compassion (understanding and Knowledge): "I want them to understand where I'm coming from"
   a. "It's not a point of like I'm looking for the loopholes, so I can sue you. I'm looking for some compassion. So I'm looking for some understanding, and I'm looking for people who are looking out for my kid."
   b. "whatever this kid needs"
   c. I didn't feel I had a team…
      I did not feel like they have my kids' interest at heart.
   d. We're trying to figure out like, are they coming from a bad please or are they just not educated?
      I really think like for me the education part is, huge
   e. Wanted to be an equal part of his educational team.
   f. Experienced a pre-K teacher respond with "don't tell me how to teach" after she shared a new programing idea with her.
      "I thought we were on the same page and let's find something that works."
   g. Story of the toy he brought to school and the attachment he had to it. The teacher took it away and he had behaviors- they didn't seem to have an understanding of the significance of this toy to an autistic child-
      "it was a lot of people not knowing…
      just a lot of not being educated"

8. Respite: "a minute of respite would be golden"
   a. PTSD for parents -24/7 in this situation (high alert all the time)
   b. Need respite so you could "regulate yourself and be able to go back in with batteries charged and we got this and when I can make sense of this, but when you don't have that, it's like I said, it's 24/7.

<u>Coding Interview #3</u>

Topic: Thematic code

- Relationships: Taking care of loved ones
- Hope: Hope in the future
- Learning Journey: the understanding comes in increments and by looking back
- Forgiveness: to deny forgiveness to others is to hurt yourself/ there is healing in forgiveness
- Powerless: They won't listen to me
- Advocacy: "be your child's advocate"
- Need for compassion (understanding and Knowledge): "I want them to understand where we are coming from"

1. Relationships: Taking care of loved ones
   a. ...but things that I think are important, like the siblings. I think that, for me, the other person who had a child with autism kind of said to me, "Make sure you take care of your daughter," because that was something that was important. That was something that I always kept in the back of my mind, even though I kind of relied on her a lot. She had a very different upbringing because of her brother. I think, for other people to understand that the siblings have a very different familial type of family. Also, I think they grow up and they have empathy for others, and they see the world with a different perspective than

    others do. They grow up, I don't know if I want to say quicker, but they can tend to be more mature.
    b. I'm going to knock on the wood because we've had our moments, and there have been times where I'm like, "It's been nice. Let's get divorced." Then the other one's like, "Yeah. It's been really nice. Let's get divorced." It's like a pressure cooker, so I think we're very lucky to still be married. On the converse side, it also can bring you closer because you have shared experiences, kind of a shared outlook, and something like a goal that you share. I think that's important.

2. Need for compassion (understanding and Knowledge): “I want them to understand where we are coming from”
    a. I know, for my daughter, it was hard on her when she'd see other people making jokes about special needs kids that either passed by the classroom, or someone that didn't have that wherewithal that she has. I think understanding a sibling is really important. I think understanding the family, the demands, the pressures, and just everything that's coming at a family is hard on a marriage.
    b. Testifying – “telling some of my stories of the things that happened and how I felt things could be different for [son] and kids like him… I would prepare and just start crying as I’m writing because of what we have been through.”

3. Advocacy: “be your child’s advocate”
    a. ….be your child's advocate, to ask lots of questions, don't take no for an answer, be involved, be at the teacher's door, finding out what's happening with your child....I think that's super important.
    b. I passed out folders to everybody at the IEP team with all his information that I had gleaned from somebody from one of the universities, from all these different places. I printed everything out, and I made it a nice thing and gave it to people. I was trying to teach them, and help them understand that he's having trouble.
    c. Doing advocacy work can be time consuming, family would ask, why are you doing this? It's not even going to directly help your child?. I would tell myself “I have to do it”
    d. “I've explained to others too, that the roads we drive on, it's not because I built them and now we're driving on them. It's because somebody before us did that, and we're lucky. Now we can drive on the roads. That's what I felt like. Because of the experiences that I had, I could be a part of this change and that other people wouldn't have to go through it.” – glimmers of hope.
    e. It was definitely for the greater good. Again, you look back, and you say ... I would tell people too, "I would have never done this if it hadn't happened to me. I would have never stepped forward." I'd have been all happy.

4. Forgiveness: to deny forgiveness to others is to hurt yourself/ there is healing in forgiveness
    a. School refused to allow [son] to attend a preschool program that was inclusive of children who were not in special education. Inclusion was very important to the family but the teacher did not deem it to be appropriate for his program. [participant] saw the teacher a few months later after she had already pulled [son] from that school. The teacher had said to her
    "I'm really good at what I do, so if you need anything or you need me to do stuff for [son], just let me know." [participant] reports being “blown away” by this offer after all the contentious interactions they had had previously and after what she had denied her son.
    I found it hard to forgive
    I'm Catholic, so that's where I drew my strength from
    Somehow I had to find this forgiveness peace because I knew it was hurting me. That was like, "Oh, my gosh. This is intense."

   b. After reading a report from the hearing officer post due process with the school district, [participant] discovered many of the staff members were led to lie about what was provided to them. One of these staff members called their family home to ask for forgiveness and said "her job was on the line".
      "She said she was really very sorry."
      "For me, I feel bad in both ways. I saw her later… I gave her a hug and stuff like that."
      "She ended up resigning. But the point is, I gave her a hug and stuff like that. I felt bad because I would never want someone to be in that position where they have to lie. What an awful position to be in. At the same time, it's just really difficult to know that."
      She said she was able to forgive this woman because she called and she didn't "think it was her intention to hurt [son]"… "it just really bothered me for a long time".

5. Learning Journey: the understanding comes in increments and by looking back
   a. I look back at things that I did in college. I had a friend who had CP…she needed access to the professors and stuff like that, and they didn't have the accommodations and all that kind of stuff back then and everything. So we got together to write something up and so on.
   b. I was an inclusion teacher before I had my children. All these different experiences, I just wonder ... All those things kind of prepped me a little bit, I think.
   c. Its only by looking back that you can understand why things were happening and what you learned.

6. Powerless:
   a. "To me, this is my child. You're hurting somebody who can't defend themselves."
   b. "I wanted to tell her a few things and so on, but ... I always felt, too, and I do feel that I always have to be careful, because I'm a teacher. That's my livelihood, so very hard to go against the very institution that is doing these things."
   c. There are so many things, but ... Sorry. It's just totally frustrating, and it's hard not being able to really speak.
   d. It's very interesting how things are done. When you know better, it's really hard.

7. Hope
   a. it brought me into contact with a lot of people who are extremely positive, who wanted to help [son], who I could relate to, who were teaching me. It was just like a deep breath of, "Wow. I'm not alone." That was really good.
   b. I met people from Autism Speaks, and now all the LBAs, the BCBAs, the RBTs, and so on. So it's been super exciting to have that piece of hope and to know that they're actually helping your child.