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The Experiences of Mothers of Children with Autism in Jamaica: An Exploratory Study of Their Journey

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The Experiences of Mothers of Children with Autism in Jamaica:
An Exploratory Study of Their Journey

by

Angela Mann

A dissertation submitted in partial fulfillment
of the requirements for the degree of
Doctor of Philosophy
Department of Psychological and Social Foundations
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DEDICATION

Throughout graduate school, the dissertation process, and all life prior to being consumed by such my mother, Carol Evanson, stood by my side supporting and encouraging me along the way. She is truly a mother who loves with all of her heart and sets an example for her daughters through living a life of compassion and giving to others. It is in part her experience as a mother of a child with an Autism Spectrum Disorder as well as the values she has instilled in me that inspired this journey and I'd like to dedicate this dissertation to her.

I also dedicate this work to the mothers I met in Jamaica who work every day to advocate for their children and trusted me enough to tell their stories and to the mothers I have met throughout the years that in many ways echo their tale. Hearing their daily battles and striving for better, especially from those mothers going it alone, is what inspired this work. I hope that in some small way this work, sharing your voices, brings you comfort and support.

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ABSTRACT

Autism Spectrum Disorders (ASDs), also referred to as Pervasive Developmental Disorders (PDDs), are characterized by deficits in verbal and nonverbal communication, social interaction, and repetitive or restricted interests and behaviors. To date, much of the literature on ASDs has been conducted from a western perspective, although interest in ASDs from a global perspective has dramatically increased in recent years. Over the last decade, there have been numerous conceptual papers attempting to explain how autism might be experienced in other parts of the world. However, in actuality, little research has been conducted in this area, and further exploration of the experiences of individuals diagnosed with ASDs and the families raising them across the globe is needed. The nature of qualitative methodology makes it best-suited for capturing the nuances and complexity of the psychological phenomenon underlying the experiences being studied. These experiences help to capture and reflect the ways in which culture impacts these experiences.

The purpose of this study was to examine the lived experiences of mothers raising children diagnosed with an ASD in Jamaica using a qualitative, exploratory methodological approach. Jamaica is in its infancy in terms of creating a standardized diagnostic process for ASDs and is early in development of government programs designed to provide services to newly diagnosed children on the spectrum. Many children diagnosed with ASDs living in Jamaica have very limited access to educational settings, and an abundance of barriers to treatment exist. As such, there is much to be gained from studying mothers' experiences with their child's early development and their initial concerns for their child's development, their

experiences with the diagnostic process, the perceived impact of raising a child on the spectrum for themselves and their family, their daily living experiences, their experiences accessing supports and services, their vision for the future, as well as any advice they would give to mothers of children who were recently diagnosed. To this end, the experiences of 13 mothers raising a child diagnosed with an ASD and living in Jamaica were captured through open-ended interviews in this study.

The results of this study found a number of notable themes to emerge from interviews with mothers raising a child on the spectrum and living in Jamaica. In particular, a number of mothers reported a typical pregnancy, with a slightly higher Cesarean-section rate than would be expected, and fairly typical early development noted in the child. Mothers reported first noticing a number of different developmental concerns, most especially language delays, lack of eye contact, and unusual social interactions, although a number of mothers were not the first to notice these issues. All but one mother reported first seeking out the counsel of their child's pediatrician, many to have their concerns dismissed, with all but one mother going on for evaluation at a clinic specializing in ASD assessment where their child was later diagnosed. Most mothers reported a number of stressors, in particular difficulties finding respite care, appropriate educational settings for their child, as well as coping with the tremendous financial burden they had in raising their child. They reported their lives to be busy, especially because they were dealing with their child's challenging behaviors on a daily basis. The mothers' vision of the future for their child varied greatly including hope for independence, for them to learn a skill, for better communication, or that they be able to live a "normal" life. The mothers all varied greatly as far as the advice mothers would give to mothers of children recently diagnosed

on the spectrum, with some saying to have hope or keep their faith and others noting the importance of being the advocate and “structuring” the child early.

This study not only provides a better understanding of the experiences of mothers raising a child on the spectrum in Jamaica but also provides empirical support for their advocacy efforts and the need for increased supports and services for these families. It also serves to inform a number of ecological, systemic factors impacting families raising a child on the spectrum in Jamaica and a framework for other studies who seek to also understand the various types of experiences that families of children on the spectrum have.

CHAPTER I

Background

Autism Spectrum Disorders (ASDs), also referred to as Pervasive Developmental Disorders (PDDs), currently encompass several disorders, most notably Autistic Disorder, Asperger's Syndrome, and Pervasive Developmental Disorder-Not Otherwise Specified. ASDs are characterized by deficits in verbal and nonverbal communication, social interaction, and repetitive or restricted interests and behaviors (National Institute of Mental Health, 2008). The needs of individuals with ASDs are extensive and include behavior therapies, respite care, special education, and supported employment. Given these needs, it is estimated that the average cost to society for supporting a person with ASD throughout his/her lifetime is approximately \$3.2 million U.S. dollars (Ganz, 2007). In addition to the overwhelming economic impact of ASD to society, researchers have found the emotional stress of caring for a child with ASD to rival that experienced by combat soldiers and Holocaust survivors (Mailick Seltzer et al., 2010).

To date, much of the literature on ASDs has been conducted from a western perspective. Importantly, Grinker (2008) noted that the Western classification and diagnostic system sometime conflict with the more localized cultural conceptualizations of ASDs, creating tensions for families trying to understand and assist a family member with an ASD. For example, although a doctor may diagnose the child and recommend behavioral therapy to remediate symptoms of challenging behavior, a parent may have members of the community encouraging them to seek the advice of a witch doctor to remove the child's "curse." As such, there is much to be gained in studying not only the epidemiology of ASDs from an international perspective

but also the experiences of families who are impacted by these diagnoses in different cultures. More specifically, much remains to be learned about the help-seeking behaviors of families who suspect their child is not developing typically; what the diagnostic process looks like in different parts of the world; what treatment options are available to children diagnosed with an ASD in different countries; how the family functions after the diagnosis is received; the relevant community and legal issues surrounding ASDs in other countries; and how children on the spectrum are socialized in other parts of the world. When compared to other disabilities, ASDs in other countries have received very little attention from researchers across fields (Daley, 2002a). Therefore, further study in various cultures and countries from around the world is needed in order to better understand the experiences of families raising a child diagnosed with an ASD and the impact of their culture on those experiences.

Statement of the Problem

Although much of the research on ASDs has been conducted in the U.S., interest in ASDs from a global perspective has dramatically increased in recent years. Initial calls for cross-cultural research in this area date back as far as the early 1980's, not long after autism first began to be widely diagnosed in the U.S. Over the last decade, there have been numerous conceptual papers attempting to explain how autism might be understood in other parts of the world. However, little research has been conducted in this area, and further exploration of cultural conceptualizations of ASDs is needed.

The current study focuses specifically on Jamaica. Jamaica is in its infancy in terms of creating a standardized diagnostic process as well as government programs designed to provide services to newly diagnosed children. As such, there is much to be gained from studying the current process and families' experiences with the process in order to better inform efforts

toward improvement. Given the population and current estimates of prevalence, it would be expected that approximately 500 children born in Jamaica would be diagnosed on the spectrum each year (Flemming, 2012, p.2). Preliminary results from an epidemiological survey conducted in Jamaica, however, indicated that only about 168 children were identified as having an ASD within a nine year period. Of these, 86% were diagnosed with Autism, 6% with PDD, 5% with PDD-NOS, and 3% with Asperger's. The average age of diagnosis was 4.7 years (Rahbar, Samms-Vaughan, & Brooks, 2009). This data suggests that there may be significant underidentification of children on the spectrum living in Jamaica.

Despite the growing number of identified children with ASDs living in Jamaica, few schools exist in Jamaica to serve children with ASDs and the schools where staff have been trained in meeting the needs of this population are overcrowded (Wilson, 2011). There currently are no fully state-funded schools or therapy centers on the island designed to support students on the spectrum. Recently, an initiative was started by the Minister of Labour and Social Security to create a registry of the number of children requiring assistance from the ministry's Early Stimulation Programme (Patterson, 2012). This program began in 1975 and currently serves 105 children with special needs such as Down Syndrome, cerebral palsy, learning disabilities, behavior problems, and intellectual disability (deemed mental retardation in Jamaica). The program was developed to provide assessment and early intervention for children from birth to six-years-old, although anecdotal reports suggest that this program is very difficult to access and most families requiring such services are not currently receiving them.

In terms of research on ASDs in Jamaica, a collaboration between a research team from the United States and the University of the West Indies where the only specialty clinic for ASD evaluation and assessment is housed has recently begun work to investigate the potential link

between genes and toxic metals as etiological factors involved in the development of ASDs in Jamaica (Lake, 2009). Most recently, the team released a study examining maternal and paternal factors related to the development of ASDs in a Jamaican sample (Rahbar et al., 2012). This study, examining 68 age- and sex-matched case control pairs, found that there were significant associations between paternal and maternal age and symptoms, meaning that the older the parent, the stronger the likelihood having a child with an ASD. To date, this is the only research conducted on ASDs on the island. There are, however, a number of reports from parents with children with ASD from around the island in local papers such as the Jamaica Gleaner (see Drummond, 2006; Flemming, 2012; Ustanny, 2002) and the Jamaica Observer (see Wilson, 2011). A parent support organization, Jamaica Autism Support Association (JASA), was created in 2006 for parents of children with ASD with the help of the Kingston Rotary, the Kingston YMCA, and collaboration with the Florida Association for Volunteer Action in the Caribbean and the Americas (FAVACA). The group (JASA) continues to meet monthly at the Kingston YMCA to give parents a forum for sharing tips and resources for supporting their children.

Although progress has been made over the past several years, primarily through the work of parent advocates, awareness of ASDs and access to proper treatment for related symptomology is still very young within the country. Little is understood about the diagnostic process experienced by parents seeking diagnosis for their children in Jamaica. Even less is understood about the impact of the diagnosis on the lived experiences of families.

Purpose of the Study

The purpose of this study is to examine the experiences of mothers with the diagnostic journey for their child, as well as their experiences raising their child after receiving a diagnosis. More specifically, this research will focus on how mothers were first alerted to their child's

symptomology; the help-seeking behaviors leading to the diagnosis; and then experiences with accessing treatment and educational opportunities for their child. Also of interest are the reactions of family, friends, and coworkers to learning of the child's diagnosis; the impact of the child's diagnosis on the lives of the mothers; and the perceptions of Jamaican society with regard to ASD as told from the perspective of the mothers. The nature of this study calls for an exploratory, qualitative approach in order to better capture the nuances and complexity of the experiences being studied.

Conceptual Underpinnings of the Current Study

The primary theory central to this study is offered by Berry, Poortinga, Segall, and Dasen (1992). In their framework for cross-cultural psychopathology classification, they suggest that disabilities or psychiatric conditions can be viewed in three ways: Culturally relative (unique and only understood by certain cultures), universal (the disorder is present in some way in all cultures, but the origin, expression, etc. seem to vary across cultures), or absolute (indicating that the symptoms of a disorder do not vary in their origin, expression, etc. across cultures). For the purposes of this paper, the author will take the position that ASDs are universal in that there now exists a fairly expansive body of literature suggesting that ASDs have been identified in various countries around the world. However, what the review of the available literature also seems to suggest is that the perception of ASDs is largely culturally-defined and perceived quite differently in different parts of the world (See Anthony, 2009; Riccio, 2011). More specifically, the literature suggests that although symptom presentation is similar in that all three diagnostic categories of impairments are evidenced, families may perceive these symptoms differently (e.g., as more behavioral or social-emotional than medical in origin) or may place different values on symptoms differently as a result of their culture (e.g., greater value placed on the child's ability

to socialize in collectivist cultures where community is essential or less emphasis on communication in cultures where communication with elders may actually be considered rude or disrespectful) leading to biases in the symptoms they report to doctors or the ways in which doctors from these cultures view symptoms (Mandell & Novak, 2005; Tincani, Travers, & Boutot, 2009)

The author operated from an “Advocacy/Participatory” worldview (Creswell, 2007, p.21) within an ecological theory framework (Bronfenbrenner, 1979). More specifically, from an Advocacy/Participatory worldview perspective research should ultimately create a platform for reform that may lead to improvements in quality of life and well-being as a result of participation. Typically, this type of research seeks to give a voice to those who have experienced oppression, domination, suppression, or alienation. Ecological theory (Bronfenbrenner, 1979) posits that an individual operates within multiple systems impacting the individual’s experiences. These systems include the macrosystem, or the larger socio-cultural context in which the individual operates (e.g., the language or dominant religion of the larger culture); the exosystem, or the external environments indirectly influencing development (e.g., parental career factors); the mesosystem, or the interaction of two systems that directly affect the person (e.g., the family and the school); the microsystem, or the immediate environment that directly impacts the individual (e.g., the classroom); and finally, the chronosystem, or the way environmental impacts over time impact the individual (e.g., generational influences). Typically, this type of research considers the experiences of the individual from these multiple perspectives.

With regard to methodology, an exploratory approach to qualitative study will best allow the author to describe the experiences of mothers raising children on the spectrum living in Jamaica. These experiences are generally captured best through either single or multiple

interviews with a recommended three to ten individuals (Dukes, 1984 as cited in Creswell, 2007).

Research Questions

The following research questions were proposed for this study:

1. How do Jamaican mothers describe their journey from the birth of their child to diagnosis of their child with an ASD?
2. How do Jamaican mothers describe the experience of having their child diagnosed with an ASD?
3. How do Jamaican mothers describe how they and their family have been affected by having a child diagnosed with an ASD?
4. How do Jamaican mothers of a child diagnosed with an ASD describe what day-to-day life is like for them?
5. How do Jamaican mothers of a child diagnosed with an ASD describe supports and services that their child and family receive?
6. How do Jamaican mothers of a child diagnosed with an ASD describe their vision of the future for their child?
7. What advice would Jamaican mothers of a child diagnosed with an ASD give to other mothers who have a child who has just been diagnosed with an ASD?

Definition of Key Terms

Autism Spectrum Disorders

Autism Spectrum Disorders (ASDs), also referred to as Pervasive Developmental Disorders (PDDs), is described as encompassing several disorders most notably Autistic Disorder, Asperger's Syndrome, and Pervasive Developmental Disorder-Not Otherwise

Specified. ASDs are characterized by deficits in verbal and nonverbal communication, social interaction, and repetitive or restricted interests and behaviors (National Institute of Mental Health, 2008).

Jamaican Mothers

Jamaican mothers are, for the purposes of this study, defined as women living in Jamaica and having a child diagnosed with an Autism Spectrum Disorder.

Youth

For the purposes of this study, youth are defined as children and adolescents between the ages of 0 years to 18 years of age.

CHAPTER II

Gillian Whyte, a 36-year-old unemployed single mother of three living in Montego Bay, Jamaica, first noticed something was different with her daughter around the age of two. Alicia was only making sounds and had not started talking yet. At times, she would violently flop to the ground. After receiving a referral for evaluation at the University Hospital of the West Indies, the only center available for assessing children suspected of having an Autism Spectrum Disorder (ASD), Gillian finally had her answer. “The doctor said she has a severe case of autism. That news was devastating. My little girl is able to hear you, but she does not respond as a normal child would” (Flemming, 2012). So began Gillian’s struggle for services for her daughter. Living in tenements in Montego Bay where pit latrines are still utilized and the area is open with no fencing, there are concerns for Alicia’s safety and difficulties with potty training. She sought help from the Child Development Agency of Jamaica (which provides early intervention services on the island) but did not hear back from them for months. Gillian would like to work to provide a better life for her children, but given the intensity of Alicia’s needs and refusal for admittance to a school for children with special needs, she finds it impossible (Flemming, 2012). Gillian’s story of struggle as a mother of a child with autism is one of many present throughout the world, although many of these voices have yet to be heard.

ASDs, also referred to as Pervasive Developmental Disorders (PDDs), are described as being characterized by deficits in verbal and nonverbal communication, social interaction, and repetitive or restricted interests and behaviors (National Institute of Mental Health, 2008). At the time of this study, the Worldwide Health Organization (WHO), the publishers of the

International Statistical Classification of Diseases and Health Problems (ICD-10; WHO, 1993), described PDDs or ASDs in a similar fashion. Classifications of Childhood Autism, Atypical Autism, and Asperger's Syndrome all related closely to the American Psychiatric Association's (APA) classifications as outlined in the *Diagnostic and Statistical Manual-IV-Text Revision (DSM-IV-TR; APA, 1994)*. According to ICD-10 criteria for autistic disorder, symptoms begin early in childhood (before the age of three years old) including a total of at least six symptoms from three categories (WHO, 1993). The first category of symptoms involved a qualitative impairment in social interaction and can be manifested in the following ways: failure to adequately use eye gaze, facial expression, body postures and gestures to regulate social interaction; failure to develop peer relationships (relative to developmental age) that involve a mutual sharing of interests, activities, and emotions; lack of social-emotional reciprocity as demonstrated by a lack of responses to others' emotions, or a lack of modulation of behavior related to the social context, or a weak integration of social, emotional, and communicative responses; and finally, lack of spontaneous seeking to share enjoyment. The second category of symptoms related to qualitative abnormalities in communication and can be manifested in the following ways: a delay in or total lack of spoken language; relative failure to initiate or sustain conversational exchange; stereotyped and/or repetitive use of language or idiosyncratic use of words or phrases; and finally, a lack of spontaneous make-believe play or, when young, social imitative play. The final category of symptoms focus on restricted, repetitive, and stereotyped behaviors, interests, and/or activities as manifested by one of the following: an encompassing preoccupation with one or more restricted patterns of interest that are abnormal in content or focus; apparent compulsive adherence to nonfunctional routines or rituals; stereotyped and repetitive motor mannerisms; and/or preoccupations with parts of objects of non-functional parts

of play materials (e.g., the wheels of a car). Finally, these symptoms must not be better attributed to a different disorder. It should be noted that the newest version of the *Diagnostic and Statistical Manual-V* (DSM-V; APA, 2013) was recently at the finalization of this study. This new diagnostic criteria both collapses the criteria for the separate diagnoses previously listed under PDDs into one Autism Spectrum Disorder Diagnosis and narrows the criteria for being diagnosed with such. Similar changes have been reflected in the new *International Statistical Classification of Diseases and Health Problems* (ICD-10-CM; WHO, 2013) criteria. It is unclear at this time how this new diagnostic criteria will change the identification, evaluation, and intervention for ASDs.

Current point-prevalence estimates indicate that approximately 1 in 88 children are diagnosed with an ASD in the United States (Centers for Disease Control and Prevention, 2012). This population requires a number of services including behavior therapies, respite care, special education, supported employment, and more. Coordinating care for a child with ASD also takes a heavy emotional toll on families (Mailick Seltzer et al., 2010). As such, it becomes important for communities to understand how to better serve and support these children and their families.

Cultural Conceptualizations of Disability

Berry, Poortinga, Segall, and Dasen (1992) provide one of the most widely-recognized frameworks for cross-cultural psychopathology classification. Although they note that all cultures recognize a separation between body and mind, there are differences in the expression of the symptoms of psychopathology, termed “culture-bound syndromes.” The authors suggest that disabilities or psychiatric conditions can be viewed in three ways as mentioned previously in this paper: *culturally relative*, *universal*, or *absolute*. For the purposes of this paper, the author will take the position that ASDs are universal in that there is now a fairly expansive body of literature

suggesting that ASDs have been identified around the world. However it also seems, as will be shown in this literature review, that the perception of ASDs is largely culturally defined.

Although many cultures may view diversity and, in particular ASDs, through different lenses than others, there is nothing to say that one conceptualization of the disorder is of greater import than another. Anthropologist Richard Roy Grinker (2008) has studied autism from a cross-cultural perspective extensively. He speaks of science as being largely contextually defined in that knowledge is made up of the prevailing cultural beliefs at the time. In Western culture, and especially within American psychiatry, the past several decades have brought a zeitgeist of classification and diagnosis leading to our current conceptualization of ASD.

Within Western culture in the United States, documented discrepancies in diagnosis, help-seeking behaviors, and treatment decisions among culturally and linguistically diverse (CLD) groups exist. Although this is a fairly new area of research, a number of studies have suggested that CLD groups within the U.S. have a far different experience having a child with an ASD when compared to European Americans (EA). Through the calculation of odds ratios, preliminary research suggests that children identified as Black or Latino are less likely to get a diagnosis of ASD compared to what would be expected (Bernier, Mao, & Yen, 2010; Mandell et al., 2009; Tincani, Travers, & Boutot, 2009; Travers, Krezmien, Mulcahy, & Tincani, 2012) and are generally identified later than their EA counterparts (Mandell et al., 2009). There also is research to suggest that the lower the socioeconomic status of the family, the more severe the diagnosis given to the child with Blacks and Latinos tending to receive more severe diagnoses overall for their child (Liptak et al., 2008). Although most researchers attribute these disparities in diagnoses to biases on the part of diagnosing professionals (Mandell et al., 2009; Travers, Krezmien, Mulcahy, & Tincani, 2012), there also is research to suggest that non-Western

cultures may have different definitions of ASD that do not conform to the strict clinical definitions put forth by those belonging to Western cultures, thus leading to differences in the reporting of symptoms (Tincani, Travers, & Boutot, 2009). There also is research suggesting that CLD groups may appraise ASD symptomology differently, leading to differences in the reporting of symptoms that are considered when differentiating a diagnosis (Mandell & Novak, 2005). Mandell and Novak (2005) reviewed literature focused on the role of culture in help-seeking behaviors and treatment decisions for families of children with health conditions. In their work, they pointed out that certain cultures may place greater value on particular developmental milestones and, as such, may be more concerned with delayed development in these areas. For example, in India social development is highly valued and parents of children with ASD in this country are found to focus more on delayed development in this area when compared to American parents who tend to focus more on delays in language. Since delays in social development may be more noticeable later than delays in language development, parents in India may tend to seek help from professionals later when compared to American parents. The authors also noted the tendency of ethnic minorities in the U.S. to view their child's symptoms as more behavioral than related to a medical condition and, therefore, they may be less likely to seek out traditional medical attention to address their child's symptoms. Additionally, they pointed out that culture also may impact help-seeking behaviors and/or treatment decisions in that culture is often highly correlated with certain socioeconomic or geographical characteristics that are related to barriers in accessing appropriate care. Other individuals conducting research in this area point to the impact of stigmatization of ASDs in certain cultures as being a barrier to accessing treatment (Bernier, Mao & Ye, 2010). More specifically, many CLD families who are able to access treatment may often encounter service professionals lacking cultural competency

in supporting these families. This may lead to a general mistrust of a the system related to institutionalized discrimination, making these families more likely to rely on extended family members and friends for support and less likely to utilize the services of professionals (Bernier, Mao, & Ye, 2010). These bodies of research, while in their infancy, support the notion that culture impacts the identification and treatment of ASDs and, therefore, continued research in this area is warranted.

Cross Cultural Research and ASD

Much of the research on ASDs has been conceptualized and conducted in the U.S., although in the past several years the interest in understanding autism from a global perspective has dramatically increased. Initial calls for cross-cultural research in this area date back as far as the early 1980's, not long after autism first began to be widely diagnosed in the U.S. Over the last decade, there have been numerous conceptual papers attempting to explain how autism might be viewed in other parts of the world.

Among the first to recognize a need for studies of autism in other cultures was Lotter (1980), who traveled to several countries in Africa in search of children meeting Western criteria for autism (described later in this chapter). Lotter (1980) noted the need for further study of the deficits in social development seen in children given that “local expectations of what ‘normal’ social behavior is may be very different from expectations based on American or European norms” (p.132).

Grinker (2008) noted that although Westernized classification and diagnostic systems may be available in communities, it does not always mean that a child will be correctly diagnosed or that their symptoms will be conceptualized according to diagnostic criteria. He referenced observations in India where most children who would meet the criteria for ASD using

the Western classification (ICD-10; available and widely used in India) continue to be labeled as mentally retarded or “mad.” He also noted that regardless of the diagnosis (e.g., ASD, intellectually disabled or otherwise), diversity of this kind is highly stigmatized in India. As such, Grinker (2008) has noted the importance of studying not only epidemiology in order to gain a better understanding of cultural perceptions of ASDs but also the experiences of families who are impacted by these diagnoses in different cultures.

When compared to other disabilities, autism in other countries has received very little attention from researchers across fields (Daley, 2002a). This is true despite the fact that with the development of the World Autism Organization of 1998, diagnostic information traveled around the globe. Today, thousands of national parent organizations for families of youth with ASD exist around the world and yet little is understood about autism in other cultural contexts and possibly even less is understood about the experiences of families raising youth on the spectrum. Daley (2002a) highlighted a number of important reasons that studying autism in a variety of cultural contexts could be beneficial. First, if we are to assume that there is little variation in the presentation of symptoms of ASD, then it would follow that studying autism may actually help us to understand culture by better understanding “differentness” as it is conceptualized in other cultures. She also noted that this research would better help us to understand what is considered to be normative in terms of development in a variety of different cultural contexts. Finally, she suggested that studying autism from a cross-cultural perspective increases our understanding of the meaning that is attributed to this diagnosis around the world. Daley (2002a) also proposed several areas within cross-cultural research that warrant further examination including (a) the help-seeking behaviors of families who suspect their child is not developing typically, (b) what the process of diagnosis entails for families around the world, (c) what treatment options are

available, (d) how the family functions after the diagnosis is received, (e) the relevant community and legal issues surrounding autism in other countries, and (f) how children on the spectrum are socialized in other parts of the world.

Review of Prevalence Rates and Issues Surrounding Diagnosis Worldwide

Given the convergence of diagnostic criteria between the DSM-IV-TR (APA, 1994) and the ICD-10 (WHO, 1993), one would expect similar prevalence rates across countries utilizing such criteria. However, epidemiological studies do not yield similar rates across countries. As such, it is hypothesized that differing cultural conceptualizations may account for the differences in prevalence rates seen internationally (Grinker, 2008).

There are a number of benefits to studying prevalence cross-culturally including informing governments of the needs for services or educational programming in keeping with their population requirements, providing information regarding the suitability of assessment tools across cultures, and, finally, allowing for international comparisons that may serve to inform how the identification of ASDs is impacted by both culture and etiological factors (Samadi & McConkey, 2011).

Several reviews of prevalence or the number of individuals affected by a diagnosis at a particular point in time, in recent years illustrate the universality of ASDs. One study examining prevalence rates for ASDs across countries including Japan, China, Indonesia, Israel, and Iran found a range from .32/10,000 cases in Nanjing City, China to 250/10,000 cases in Tongling, China (Sun & Allison, 2010). Although the study showed increases in prevalence over time across all countries and a greater proportion of diagnosed males to females, other factors including the geographical region the sample was taken from and whether it was a rural or urban area seemed to impact the prevalence estimates reviewed. Similarly, Matson and Kozlowski

(2011) reviewed prevalence rates across several countries including the United Arab Emirates, the United States, Norway, Canada, Germany, Sweden, France, Iran, Iceland, Finland, Israel, and Britain and also found variability in prevalence rates ranging from 8.6 per 10,000 cases in Iceland to 250 per 10,000 cases in Iran. They noted that prevalence rates differed depending on the age group studied and the year in which prevalence was measured. When looking cumulatively across many of these countries, researchers have found an incidence rate of 27.2 per 10,000 cases (Honda, Shimizu, Imai, & Nitto, 2005). More recently, in the most comprehensive look at global prevalence to date, prevalence of ASDs were examined across a number of countries including the United Kingdom, Denmark, Sweden, Ireland, Germany, France, Norway, Finland, Israel, Portugal, Iceland, Japan, China, South Korea, Australia, Indonesia, Sri Lanka, United Arab Emirates, Oman, Iran, Canada, the United States, Argentina, Aruba, and Brazil (Elsabbagh et al., 2012). Prevalence estimates were combined and examined across regions. For example, recent European prevalence estimates varied from 1.9/10,000 to 72.6/10,000 with a median value of 10/10,000. In the Western Pacific, South East Asia, and the Eastern Mediterranean, prevalence estimates range from 2.8/10,000 to 94/10,000 with a median value of 11.6/10,000. In the United States, prevalence estimates range from 34 to 90/10,000 with a median of 65.5/10,000. Finally, prevalence studies have yet to be conducted in Africa, although it was noted that there appears to be a higher male-to-female ratio consistent with other regions around the world. Much of the variability in these findings was attributed to methodological issues meaning that the approaches to measuring prevalence varied greatly from country to country.

Elsabbagh and colleagues (2012) noted that there are significant costs associated with prevalence studies and many have wondered if conducting these types of studies in regions

where resources are already limited would be worth potentially forgoing in order to focus on the study of other illnesses including preventable life-threatening conditions. However, this must be weighed against the potential benefits epidemiological research can yield. These benefits include providing information regarding the availability, quality, and accessibility of services; greater information about the socioeconomic and geographical factors influencing prevalence rates; and finally, information regarding certain region-specific factors, environmental or otherwise, that play a role in the disproportionate levels of prevalence we see when controlling for differences in measurement across studies.

What appears consistent across these findings is that prevalence seems to be increasing worldwide and a number of contributing factors are cited including methodological issues, environmental components such as increased survival rates of premature infants due to improved perinatal and neonatal care, and increased awareness (Matson & Koslowski, 2011). Additionally, researchers cite cultural factors as contributing to increased prevalence worldwide. More specifically, rates of ASD in Westernized countries have risen dramatically over the last several decades, although the conceptualization of ASD in the West is very new to the Eastern world leading to greater variability in prevalence rates throughout Asia (Matson & Koslowski, 2011).

Researchers have asked what impact the views of those professionals diagnosing in countries across the world has on reported prevalence rates as one means of examining the impact of culture upon diagnostic conceptualization. Findings across several countries including Nigeria (Bakare et al., 2009), Japan (Koyama et al., 2009), India (Daley & Sigman, 2002), and Pakistan (Rahbar, Ibrahim, & Assassi, 2011) suggest great variability in providers and lay people in their awareness of ASDs and their ability to correctly identify an ASD. In Pakistan, for example, only 44% of general practitioners had heard of autism (Rahbar, Ibrahim, & Assassi,

2011) and in Japan, only around 46% of the general population sampled could correctly identify a child as having ASD (Koyama et al., 2009). In Nigeria, 27% of healthcare workers surveyed believed that ASDs were caused by natural, preternatural, and supernatural causes (Bakare et al., 2009), and in Japan very few professionals were able to identify all of the various symptoms required for being able to correctly identify a child (Koyama et al., 2009). This variability in perceptions of the providers who are typically charged with making a diagnosis suggest the importance of examining these types of cultural factors in order to improve the diagnostic process for families of children with ASDs.

Overall, further examination of prevalence estimates worldwide using consistent methodology is desperately needed in order to extend the current literature and to better inform the cultural variations in prevalence rates. This research also serves to inform potential intervention or treatment strategies and how culture is impacting the conceptualization of the diagnosis. More specifically, if ASDs are assumed to be a universal diagnosis with biological underpinnings, one could assume that prevalence rates (when measured using similar standards) would be relatively similar across cultures. However, if this were found to not be the case, it would suggest that in fact something related to the environment or cultural beliefs surrounding the diagnosis are impacting the ways in which symptoms are viewed and identified.

The Experiences of Families Affected by ASD Internationally

Although much of the literature exploring cross cultural issues related to ASDs has focused primarily on prevalence rates and issues surrounding diagnosing children on the spectrum, some researchers have begun to focus on the experiences of families of children with ASD in different countries. Studying families' experiences internationally can tell us many things. First, by examining the diagnostic process that parents encountered such as when they

first became aware of symptoms and also by examining how they came to receive their child's diagnosis provides important information to government organizations and non-government organizations working with these families, in particular any barriers that parents encountered preventing them from getting a timely diagnosis for their child (see Riccio, 2011 for an example). More specifically, stakeholders interested in improving awareness and catching children earlier when they are more amenable to intervention will have a better sense of how to tailor awareness efforts towards this end in these communities. Another important piece of information to be gained from studying the experiences of families who have a child diagnosed on the spectrum is the etiology they are ascribing to their child's symptoms. Families will most likely seek treatment based on what symptoms they perceive as being amenable to treatment and this may frequently be linked to what they perceive is causing their child's symptoms. For example, families who believe a specific environmental cause such as immunizations to be the source of their child's symptoms may be more likely to pursue complementary and alternative medical interventions such as chelation (see Harrington, Patrick, Edwards, & Brand, 2006). On the other hand, families who are living in cultures that believe a child's symptoms to be a result of a curse placed upon the family may be more likely to pursue spiritual means of intervention for their child (see Anthony, 2009; Riccio, 2011; Shyu, Tsai, & Tsai, 2010). It is also important to understand how families have reacted to or coped with the diagnosis, in addition to gaining a greater awareness of the difficulties they may be experiencing on a daily basis in order to better inform efforts toward services and supports. For example, while practitioners may have experience with evidence-based interventions many of which depend on family involvement and implementation, and may prioritize this as the primary need for a family whose child has recently been diagnosed, it is possible that the family may have other needs that must first be met before

such interventions can be implemented (see Jagatheesan, Miller, & Fowler, 2010). Finally, it is important to understand what these families hope for their child and how they have envisioned the future for their child. In understanding what these families dream for their children in the future, we as professionals can better tailor our treatment goals with those end goals in mind. These are just a few of the many things we can learn from families.

Although both mothers and fathers may be impacted by raising a child with significant needs, there exist a number of reasons why research in this area has traditionally focused on the experiences of mothers in particular. First, even in our changing society where more mothers than ever are employed and taking on numerous roles outside of parenting, they continue to provide the majority of childcare and therefore may be most impacted by raising a child who presents with special needs (Pew Research, 2013). Mothers of children diagnosed with an ASD tend to do more caregiving, engage in less leisure activities, and experience significantly more stressful events than mothers of typically developing children among other things (Smith, Hong, Mailick Seltzer, Greenberg, Almeida, & Bishop, 2010). There is preliminary evidence to suggest that mothers tend to experience significantly greater levels of overall parental stress possibly due in part to greater caregiving responsibilities (Malaysia: Kamel-AlHorany, Aishah-Hassan, & Zaid-Bataineh, 2013; U.S.: Montes & Halterman, 2007; Iran: Samadi & McConkey, submitted for publication). There is further reason to believe that caregiving tends to fall most heavily mothers of children diagnosed with ASD in that their careers tend to be most impacted by the demands of raising a child on the spectrum when compared to fathers (Baker & Drapela, 2010; Thyen, Kuhlthau, & Perrin, 1999).

The following section will review what many families, in particular what many mothers, raising a child on the spectrum from around the world have told the field about their experiences.

In particular this research looks at parent experiences related to the diagnostic process, the impact of raising a child diagnosed on the spectrum upon the family, and family experiences related to accessing supports and services.

Parent Experiences Related to the Diagnostic Process

Literature from across the globe examining the experiences of parents raising a child diagnosed with an ASD related to the diagnostic process focus on three primary areas: experiences specific to the diagnostic process, parent beliefs about the etiology of their child's symptoms after receiving a diagnosis, and finally the parent's evolving feelings about their child's diagnosis on the spectrum.

Experiences Specific to the Diagnostic Process

A number of studies have been conducted across the United Kingdom examining the experiences of families of children with ASD specific to their experiences in attaining a diagnosis for their child. An early study focused on family access to information and use of services (Mansell & Morris, 2004). Ninety-nine parents of children ranging in age from two to three years of age to older than ten years of age were given a questionnaire with a mixture of Likert scale questions and open-ended areas for comments. Parents reported a range of ages ranging from two years to ten years old for first receiving a diagnosis with the most common age of diagnosis around four to five years of age. More than half of parents reported that information related to resources, treatment, coping strategies, and prognosis were either not at all explained or explained only slightly well, although these reports seemed to improve with the recency of diagnosis suggesting that this has improved over time. In terms of what information was the most useful to them, parents reported information from family services workers, information from local support groups, as well as workshops and early years courses offered by the support groups

were the most helpful sources of information. With regard to how they felt about receiving the diagnosis, about 90% reported relief, 87% reported understanding their child better and another 83% reported being able to accept their child's behavior better. About 74% of parents reported being able to better adapt their lives to their child, and another 71% reported being able to get practical help for their child as a result of the diagnosis. About half of the sample reported feeling that other people have a better understanding of the child as a result of the diagnosis, that it helped them to stop blaming themselves, and that they were able to get support for themselves. About 40% reported being shocked by the diagnosis and a small minority of parents (14%) reported that their child was treated more poorly as a result of the diagnosis. This preliminary information suggests a number of improvements to the diagnostic process for families living in the U.K. including greater information and resources provided and the time of diagnosis, including connecting parents with local support groups and agencies that are able to provide continued access to resources and support.

Similarly, Osborne and Reed (2008) conducted 15 focus groups across the U.K. to examine parents' perceptions of the communication with professionals during the diagnostic process. Seventy parents of children ranging from preschool-age to secondary-age participated in the study. When asked who made the diagnosis, most parents received the diagnosis from a medical practitioner, but others reported receiving the diagnosis from a speech and language therapist or from a psychologist. Most parents felt that it was their child's behavior problems, developmental differences, language, or perseveration that led to the diagnosis. Most parents also report receiving not very little support, advice, and information, although some parents were able to obtain either professional advice or advice from leaflets and books. In terms of when information should be given to parents, the vast majority felt that information should be provided

immediately after the diagnosis. In terms of the diagnostic process, many parents recommended improving the standardization and speed as well as the information provided about organizations and services as well as what to expect. They also recommended that practical information on how to deal with the child be provided as well as support and help (counseling and services). With regard to how helpful they found the diagnostic process overall, most parents reported nothing helpful or that they felt relief/confirmation. A number of parents reported that the diagnostic process provided understanding and found support from it, but few mentioned that the diagnosis altered their expectations. A majority of parents would have liked greater communication through support groups and meetings and ultimately would like more information in general.

More recently, several researchers out of Belfast continued the journey in understanding parents' experiences with the diagnostic process in Ireland (Braiden, Bothwell, & Duffy, 2010). Researchers interviewed 11 mothers with children ranging in age from 5 to 11 years old, who had received a diagnosis within 18 months of the interview. In contrast to many of the other studies interested in when parents first noticed signs at an early age, some parents felt that their children were different from birth. Other parents reported having no concerns while still others felt that there might be something different about their child, chalking it up to temperament or personality until another person noticed something different as well. Parents noted the delivery of the diagnosis to be the most difficult part of the journey in that they were both being informed of their child's diagnosis and at the same time hearing verbal information about the diagnosis that they felt they had trouble focusing on. Parents commented that although this was a difficult time, they actually wished more professionals would have provided greater information in written format regarding what happens after diagnosis. Interestingly, parents still reported being

satisfied with the communication between themselves and professionals and reported understanding the process. Many parents commented on the length of time that it took to be evaluated with one mother commenting, “I felt my sons’ notes had been lost or they had been forgotten about” (p. 385). Among the mothers interviewed, the level of support they received after the diagnosis varied greatly. Although initial reports seemed to suggest that parents were fairly satisfied with the diagnostic process, later accounts seemed to suggest otherwise. Even within this culture, it seems there is a great deal of variability across the country in how Irish parents experience the diagnostic process.

Researchers have recently begun to explore the journeys of families in obtaining a diagnosis for their child in France (Chamak, Bonniau, Oudaya, & Ehrenberg, 2011). In Chamak and colleagues’ study, parents were recruited through parent associations (51%) as well as psychiatrists and “care units” dedicated to children with ASD from around the country (37%), and from the Internet (12%), and data were compiled from questionnaires ($N=248$) as well as in-depth interviews ($N=43$). The ages of the children of these parents ranged from 4 to 45 years of age, representing families who experienced receiving a diagnosis at various points in France’s history over the years. Parents were asked around what age they first became concerned that their child was not developing typically; worries typically began around the age of 18 months (44%). When parents were asked about the first symptoms they remember being of concern, many parents noted that they first noted their child’s social skill deficits (68%), communication deficits (64%), behavior disturbances (54%), sensorimotor disturbances (29%), restricted interests and stereotypy (26%), sleep disorders (13%), regression of skills (10%), hyper- or hypo-sensitivity (9%), feeding difficulties (7%), and finally somatic diseases (6%) and late toilet training (2%). Parents whose children were adults at the time of this study were asked about the age their child

first received a diagnosis. Parents' responses varied greatly with an average age of first diagnosis being around ten years, eight months. Several parents who were not initially given a diagnosis of autism reported that instead doctors told them things such as the child having "severe psychosis, he's beyond redemption" or "Your son is an imbecile, from Latin 'imbecilus', which means idiot. We will do as a tailor who has to make a suit with a bad material." Others remember hearing "If the mother gets better, the child will be cured" or "It's a severe disease: autism. It would be better to abandon your child." Interestingly, when asked about the delay between when the parents first sought consultation to when they first received the child's diagnosis, parents reported delays between zero and thirty years. Perhaps not surprisingly, 93% of parents were dissatisfied with the diagnostic process. Parents who went through the diagnostic process more recently (between 1995 and 2005), reported an average age at diagnosis as five years and three months, although diagnosis came earlier and earlier through the years. For parents who did not receive a diagnosis, their child was labeled as being in child psychosis, psychotic disharmony, being disabled or developmentally retarded, or as having a communication or language problem. Despite apparent improvements in the diagnostic process for this cohort, 63% of these parents still reported being dissatisfied with the experience.

A study of Chinese parents of children with ASD utilizing survey and interview methods looked specifically at the steps parents took immediately following receiving their child's diagnosis which they directly link to the kinds of information provided to parents in the diagnostic process. The strategies taken by parents upon learning of their child's diagnosis varied greatly, although McCabe (2008a) notes that many sought out multiple treatments and doctors possibly as a reflection of the lack of a systematic referral process. Many of the parents noted seeking training (39%; although it should be noted that families in this study were

recruited through a parent training center), while others (34%) noted they sought medical treatment or help from doctors. Others (28%) felt helpless and did not know what to do or did nothing. A number of other parents sought more information, either online (12%) or from books or other such resources (18%). This information may suggest that the kinds of information provided to parents or the lack thereof immediately following the diagnosis may influence the trajectory they later take in later help-seeking or decision-making surrounding treatment, depending upon the sources of information they are relying upon for make such decisions.

A study conducted by Daley (2004) further examined the journey from symptom recognition to diagnosis for families of children with ASD living in urban India. In-depth, semi-structured interviews were conducted with 95 families living in four major metropolitan areas across India: Kolkata, Bangalore, Chennai, and New Delhi. These data were supplemented with data collected through a survey of 165 psychiatrists, 95 psychologists, and 677 pediatricians from around the country. In terms of when parents report first noticing symptoms, responses ranged from three months to six years, five months of age with an average age of around 26 months of age. Of the behaviors that were first noticed, responses ranged from social difficulties, speech and language, typical autistic behaviors, behaviors not specific to autism, and medical or developmental difficulties with around 50% of parents noticing just one behavior. With regard to how they responded to their suspicion, parents waited as long as two years and eight months with an average waiting time of around seven months before seeking help from a medical professional. Boys were taken for evaluation significantly later than were girls and the age of first diagnosis was four years and eleven months of age. In terms of who finally diagnosed their child, around 29% were given diagnoses by a psychiatrist, around 26% by a psychologist, 21% from pediatricians or neurologists, and finally around 23% by a team of professionals. Daley

(2004) does note that when looking specifically at the more recently diagnosed children in this sample, it seems that there are improvements in the length of time between first suspicions to diagnosis. She concludes by re-emphasizing the importance of understanding these help-seeking behaviors among parents of kids on the spectrum that directly impact diagnosis and treatment.

In a similar study conducted by Samadi, McConkey, and Kelly (2012) with 43 parents of children with an ASD diagnosis between the ages of 3- and 7-years-old (average age of 8.2 years) living in Tehran, researchers hoped to better explore the information and support needs of parents of children on the spectrum. Structured interviews were conducted primarily in family homes and were later transcribed verbatim, translated to English, and analyzed by a team for codes. The findings of their qualitative study indicated that all of the parents (100%) were sure that their child had a problem; almost 40% endorsing communication and social relationship problems as their child's primary area of difficulty, 37% indicating behavioral problems were most problematic, 33% indicating that language and speech impairments were their child's most important problem, and 23% of parents reporting that learning disabilities, "mental problems," and/or their child's inability to understand as being the child's most important problem. In terms of the terminology parents used to describe their child, parents used a number of different terms including 42% of parents using "Autism" or "Asperger's" to describe their child's problem, 16% of parents saying "mentally disabled or disturbed" described their child, 5% reporting their child had a "behavioral problem," and 2% saying their child had a "genetic deficit." Interestingly, 16% of parents reported using no label for their child. One parent said "I call it a disaster! The most difficult problem and tragedy that ever could happen to someone! These are the names I used to describe it" and another stating "My daughter has a cloudy brain something like a fog which makes understanding the world difficult for her. I call her problem having a cloudy brain."

These findings have important implications for researchers in that developing a sample of families through identification of having a child with ASD may prove difficult given the number of parents who do not use diagnostic labels to identify their children. In this study, parents were also asked to discuss their hypotheses for the causes of their child's ASD and how they responded to learning that their child was on the spectrum. Most parents (33%) had concerns for their child prior to the age of one-year-old, 21% identifying a problem prior to the age of 2-years-old, 42% reporting becoming concerned prior to the age of 3-years-old, and 28% of parents reporting worry for their child after the age of 3-years-old. There were four children who were not diagnosed until they first registered for school, around the age of 5-years-old. Parents received diagnoses from a variety of specialists (21% from a neurologist, 21% by a psychiatrist, 19% by a pediatrician, 16% by rehabilitation specialists such as a speech or occupational therapist, 12% by special education specialists, and 12% by psychologists). About 67% of parents were told that ASD was the main diagnosis for their child, while 23% were told that it could or might be ASD. In terms of their awareness of ASD prior to the diagnosis, 79% of parents reported having never heard of ASD, 16% having limited knowledge, and 5% saying they were relatively well-informed. Most parents found out about ASD from other parents of children on the spectrum (23%), from books or brochures (21%), from professional and experts visited (16%), from friends and family (14%), from their spouse (9%), from the Internet (12%), television (2%), and another parent (2%) from undescribed personal experience. In general, parents reported a desire for greater information regarding their child's diagnosis and the steps to take following receiving the diagnosis.

Although there are many new parent-directed organizations for families of children with ASD cropping up around Africa every day, little research surrounding the experiences of

families with such diagnoses in Africa exist to date. Early descriptions of the perceptions of children with ASD on the continent are offered by Lotter (1980) who took an extended visit between 1975 to 1976 traveling to nine major cities in six English-speaking countries in central and Southern Africa. Lotter (1980) notes several important themes in his anecdotal observations: (a) symptoms of ASD could also be seen in children throughout Africa, (b) it appeared there were fewer children on the spectrum than expected, (c) the characteristics of children on the spectrum were similar to those seen in other parts of the world including a greater number of presenting boys than girls and these characteristics were evident in both verbal and non-verbal children, and (d) that children with ASD in Africa appeared to exhibit much less stereotyped movements when compared to children with ASD in the U.S. and the U.K. Lotter (1980) notes the importance of looking cross-culturally at the related social deficits associated with ASD as “local expectations of what ‘normal’ social behavior is may be very different from expectations based on American or European norms” (p. 132).

Continued research in Africa seems to suggest that the diagnostic process for parents presents many barriers. In Ghana, nine caregivers of children with ASD participated in focus groups, semi-structured interviews, and text analyses. The primary themes in their experiences was a reported lack of information surrounding the symptoms and causes of ASDs, as well as a lack of diagnosing professionals trained in the evaluation of ASD symptomology (Anthony, 2009). Similarly, research conducted through informal interviews with five families of children with autism in Kenya found many parents reporting that, although they suspected something was not typical in their child’s development, they did not know where they could go to get help suggesting disconnects in the diagnostic process within this country (Riccio, 2011).

Krauss-Mars and Lachman (1994) conducted a cross-sectional retrospective descriptive, structured questionnaire study to take a more in-depth look at how parents in Cape Town, South Africa responded to receiving a diagnosis that their child had some type of intellectual disability. A stratified sample was developed to reflect the racial distribution of children seen in the assessment clinic from which participant families were taken including English and Afrikaans speaking individuals of either white or mixed race, as well as Xhosa speaking individuals who are described as black. Of the 65 participating families, children ranged from 2- to 85-months of age, with an average age of 51-months of age, with the majority of respondents (90%) being the mother of the child with a diagnosis. Approximately 91% of parents received their child's diagnosis from a doctor at an assessment clinic, although several (8%) of parents reported receiving the news from a psychologist and one family reported receiving the news from a joint interview with a doctor and a psychologist. Approximately 29% of families reported their doctor labeling the diagnosis, while another 51% reported that their doctor did not provide them with a labeled diagnosis and around 20% stated that they could not remember. In terms of explaining to families how their child came to develop their symptoms, only 40% of families remembered their doctor explaining etiology, as opposed to nearly 50% reporting receiving no explanation and 11% reported they were unable to recall whether they received an explanation of etiology or not. A large majority of parents surveyed reported having an opportunity to ask questions (62%) or having a limited opportunity to ask questions (3%), while others reported receiving no opportunity or being unable to answer (25%). Three parents were unable to understand the question. When asked whether parents were able to understand explanations provided to them, 51% reported understanding completely, 25% reported understanding to some extent, and 5% did not understand. One parent was unable to understand the question. The researchers also asked

families whether the doctor checked for understanding of the diagnosis. Around 49% of families reported that their doctor asked, when compared to 23% who reported their doctor not asking, 8% reported not being able to remember, and 5% answering that the question was not applicable to them. Finally, when researchers asked for feedback from parents regarding how the diagnostic process could be improved, parents made comments such as: “The doctor must first have some introductory small talk before he breaks the news,” “She must explain it in a simple and nice way,” “He must be honest,” “She must give hope,” and that advice on resources available to families must be given.

A study conducted by Shaked and Bilu (2006) was interested in the experiences of families affected by ASD in an ultraorthodox community in Israel. Members of this community, called Haredi, make up approximately 10% of Israel’s population and are best recognized for the strictest of adherence to Halacha, or Jewish religious law. This manifests in modesty and strict separation of the sexes with very different socialization experiences for boys and girls, early indoctrination especially for boys, and early (late teens) arranged marriages. Although the ultraorthodox attempt to remain as separated as possible from the outside communities, including the provision of their own educational programming for children with special needs, they are still largely dependent on healthcare practitioners outside of the community. Interviews were conducted with members of 30 families (27 mothers, two couples, and one father) of children with an ASD diagnosis living in the ultraorthodox community. When asked about their quest for a diagnosis and later for treatment, many families noted that, while seeking counsel from their rabbis is important, families typically first sought out information for their child from the medical community. They described their journey for a diagnosis as an arduous process, initially filled with hope, but upon receiving a diagnosis resulting in indifference as described by one

mother who states “It no longer mattered to us whether he was retarded or autistic...let me tell you, this is just word play” (p. 7).

In general, parents from around the world often describe long waits for evaluation or a lack of information surrounding how to address their concerns for their child’s development. Upon receiving the diagnosis, many parents reported that they wished they had received greater information surrounding resources, treatment, and prognosis for their child.

Beliefs about Etiology

Early accounts of parent experiences of having a child on the spectrum in the U.S. focused on parent beliefs surrounding the etiology of autism as well as what the diagnostic process was like for them (Harrington, Patrick, Edwards, & Brand, 2006). In surveys completed by 71 parents attending a conference for teaching behavioral strategies to parents, educators, and professionals in New York and surrounding areas, a variety of beliefs surfaced regarding etiology. These beliefs included 26% of parents who thought that something specific (most frequently immunizations) had definitely caused or contributed to their symptoms and another 45% saying there maybe was a specific cause. When probed further, parents stated that immunizations, genetic predispositions, and environmental exposure of the mother or child of some kind were among some of the many specific events they believe may have been implicated. The reported median age of diagnosis was two years, three months, and parents reported attempting a number of treatments following their child’s diagnosis. Many parents reported being not at all (40%) or only somewhat confident (32%) in their physician’s ability to recognize autism, while only one parent chose very confident (19%) or extremely confident (8%). Interestingly, parents who reported trying a greater number of therapies also were much less

confident with their physicians. It is unclear how the relationship between parents and their physician's may relate to parent beliefs surrounding etiology.

In a Canadian survey-based study aimed at better understanding parents' perspectives on the causes of ASD in their children ranging in age from one to 25 years of age with a median age of 8.9 years, researchers found a range of beliefs about the causes of their child's autism (Mercer, Creighton, Holden, & Lewis, 2006). The majority of participating families were living in Canada, although some families (8%) were recruited through the Autism Spectrum Disorders-Canadian-American Research Consortium (ASD-CARC). Of the families surveyed, approximately 54% had a child diagnosed with Autistic Disorder, 15% with Asperger Disorder, 10% "High functioning autism," 10% PDD-NOS, and 12% an "otherwise undefined ASD." When asked about the perceived cause of ASD in their child, most parents (approximately 90%) believed that genetics played some role in the development of their child's ASD with approximately 26% believing that a single gene would eventually be found to cause ASD. When asked about the family dynamics related to diagnosis, approximately 32% of families reported being affected by genetic issues. More specifically, 39% of these families reported feeling that future reproductive planning (e.g., "The child's father had a vasectomy") had been impacted by their child receiving the diagnosis; another 39% of these families reported believing that their child's symptoms had been transferred down through the generations (e.g., "After my son's diagnosis, I realized my father's condition"); 31% suggested feeling guilt (e.g., "...everyone is upset that they could have contributed to my son's problem"); and around 8% reported blaming one side of the family for their child's diagnosis related to genetic reasons. Similarly, 61% of parents felt that they had a family member (44% of which suspected first degree relatives) who either displayed symptoms similar to ASD or had a confirmed ASD diagnosis. When asked

about prenatal or perinatal factors that parents perceived to have contributed to their child's diagnosis, approximately 44% of parents reported believing that prenatal maternal risk factors were at play pointing to either advanced maternal age (15%), smoking (10%), influenza (10%), prescription medications (7%), maternal vaccination (7%), uterine bleeding (5%), toxemia (5%), street drugs (2%), upper respiratory infections (2%), and genital herpes (2%). Similarly, 68% felt that specific perinatal events contributed to their child's diagnosis naming injury during birth (20%), fetal distress or anoxia (20%), premature labor or premature rupture of the membrane (15%), low birth weight/premature birth (15%), induced labor (12%), hyperbilirubinemia (12%), requirement for oxygen after birth (7%), emergency C-section (7%), blood group incompatibility (7%), resuscitation/ventilation (5%), respiratory distress syndrome (5%), anemia (5%), and infection after birth (2%). Additional data gathered from parents suggest that approximately 40% believed that vaccinations contributed to their child's ASD, with approximately 33% of these parents specifically identifying the MMR vaccine as the contributing vaccine. Researchers also asked questions related to the perceived contribution of dietary factors to their child's diagnosis of ASD and found that approximately 51% of parents felt that dietary factors such as gluten and casein intolerance contributed to their child's diagnosis. In summary, almost all parents but one indicated that their child's diagnosis most likely were the result of multiple contributing factors.

In the United Kingdom, semi-structured interview research was conducted with 17 parents of children with ASD ranging in age from seven to sixteen-years-old to better assess parent attributions to the causes of their child's ASD symptoms (Russell & Norwich, 2011). Most parents believed their child's symptoms were the result of biological factors as opposed to bad parenting. Later, parents reported reconstructing their ideas about ASD – that symptoms were due to neurological differences in the brain, that these differences provided both strengths

and even benefits, and that they are now “traveling a different road” (p. 10). Suggesting that parent views surrounding etiology and symptoms may actually evolve with time.

Several studies have been conducted now examining the experiences of families of children with ASD in Taiwan. The first, conducted by Shyu, Tsai, and Tsai (2010) was interested in exploring the impact of parental explanations of the development of their child’s symptoms on the kinds of treatments they sought out for their children. Semi-structured, face-to-face interviews were conducted with 13 parents (twelve mothers and one father) of children with a diagnosis of autism between the ages of 3- and 7-year-olds. Most mothers reported an average age of symptom onset around 18 to 24 months and most frequently reported symptoms including speech delay, lack of eye contact, lack of interest/responses to the environment, poor social interactions, and “self-centered, obsessive, and fixed behaviors” (p. 1325). In terms of the perceived reason for symptom development, 100% of parents pointed to biological reasons (e.g., genetic factors, brain damage during pregnancy, etc.) and around 85% believing their child’s symptoms were caused by supernatural reasons as exemplified by the following quote: “The fortune-teller... told us that in his prior life he [the child] was a very lazy and wealthy man. When he wanted to eat, he did not need to ask for it – just opened his mouth. That’s why he does not want to talk now” (p. 1327). In terms of symptoms parents found most salient in their child’s diagnosis, parents described their child being impacted in that they have delayed speech, poor self-care ability, social difficulties and isolation, poor adjustment to new environments, and poor eating habits and tantrums.

Persian parents of children diagnosed on the autism spectrum in Iran, spoke in interviews about their beliefs related to the etiology of their child’s symptoms leading to the diagnosis (Samadi, McConkey, & Kelly, 2012). Approximately 37% of parents indicated they believed

maternal factors during the pregnancy were the cause of their child's ASD, 23% attributed the diagnosis to environmental factors such as air pollution, chemicals, etc., 16% believed the child's brain or body had a defect, 12% felt that their child's symptoms were related to religious factors most notably that they were being punished for sins they had committed, 7% mentioned heredity or genetics as potentially playing a role in their child's diagnosis, and finally 2% talked about their lack of social relationships as a family causing their child's ASD. On the other hand, 12% of parents reported having no idea or no concern for what caused their child's ASD. It is unclear how these perceptions impacted their help-seeking or treatment decision-making behaviors.

In a very comprehensive and well-researched dissertation conducted by Anthony (2009), a variety of aspects of experiences of families of youth with ASD living in Ghana were explored. In particular, Anthony (2009) provides a comprehensive look at the understanding of autism in Ghana. In terms of the overall view of autism held by many Ghanaians there appears to be a range of very complex views. One perspective that appeared particularly salient across respondents was the idea that parents, most especially the mother, were to blame for their child's symptoms either by not providing quality prenatal care or that they must have experienced some illness or accident during the course of their pregnancy causing the ASD. Several community members interviewed reported believing the child's autism was due to a failed abortion attempt, especially abortions involving ingestion of tonics, saying "Sometimes the mother tries to abort the baby, we have all different types of medicines, afterwards they affect the baby." Another belief illustrated by the quote "And I remember when my wife gave birth...she was pushing it got to a time she didn't even want to push again and so...you know those things so I was thinking ah, could it have been due to that small delay in pushing," is the idea that autism was resulted from a lack of maternal effort during childbirth. Others find other maternal errors that

they believe could be related to the child's symptoms such as "The mother was not faithful to the husband during the pregnancy. Or she didn't do as she was supposed to, there are taboos."

Another very salient view of the etiology of ASD in Ghana is that symptoms are a result of magic or spell cast upon the child in retribution by a hired spiritual practitioner. There are a number of specific transgressions mentioned including punishment for greed or failure for "Juju money" or "blood money" in the form of wealth, advancement and prosperity or for fertility from the spirits. Others believe that divine retribution manifests in the form of the child becoming a witch or wicked appearing similar to the symptoms of autism. As will be discussed later in this paper reviewing access to supports and service experiences of families, these beliefs greatly influenced the kinds of treatments sought by parents of children diagnosed with ASD and living in Ghana.

Similarly, a study comprised of 16 informal interviews with five families of children with autism and professionals from in and around the urban regions of Nairobi, Kenya, was conducted to inform the social, educational, and political perspectives of autism in Kenya (Riccio, 2011). These interviews focused on the participants' perspectives on the etiology behind autism. Although it appears that Kenya is making many efforts toward better awareness of ASDs, primarily through the Autism Society of Kenya and Autism Awareness Kenya organizations, the knowledge of ASD in the country is still somewhat in its infancy. As both accurate and inaccurate information floods the country, diagnosis remains largely unattainable to a majority of affected youth in the country. Barriers for accessing evaluation and treatment for families of children on the spectrum in Kenya include the widespread stigmatization of the diagnosis and related symptoms with a large number of Kenyans still attributing the development of the disorder to witchcraft and sorcery brought on the family, typically because of suspected negative

actions on the part of the mother and similar to conceptualizations reported in Ghana (see Anthony, 2009). Professionals in the area stress the importance of dispelling myths surrounding the development of autism and providing greater information across the country regarding the facts about ASDs in an effort to increase the likelihood parents will seek out identification and evidence-based interventions for their child.

When examining cultural differences across countries, one could also consider examining cultural differences across religious beliefs. Two studies in particular focused on the perspectives of families in the context of their religious affiliation.

A series of open-ended interviews conducted with 27 mothers and several couples raising a child with an ASD in an ultraorthodox Jewish community in Israel focused specifically on beliefs surrounding etiology of ASD symptoms (Shaked & Bilu, 2006). When questioned regarding their conceptualization of what caused their child's symptomology, the majority of parents reported physiological causes including, in descending order, labor complications, problematic infant immunization, genetic inheritance (although this appeared to often be rejected), viral infection during pregnancy, serious disease in the first year of life, head trauma, organic defect in the brain, and complications in liver functioning. As far as psychological conceptualizations of etiology, which were salient in approximately half of interviews, suggested that the following factors were perceived as contributing factors to their child's diagnosis (listed in descending order): parental negligence or inappropriate care taking, frightening events, teasing from other children, emotional distress of the mother during pregnancy, and envy in a younger brother. Of these psychological explanations, researchers found around one-third to be of a self-deprecating nature on the part of the parents. Nearly all of the mothers conveyed their belief that their child's diagnosis was God's will reflected in such statements as "It is from God," "It is

from above,” or “It was intended,” with many indicating that their child was intended to make amends for the sins of others in a previous life. Similarly, many families reported believing that their child’s illness was a form of suffering that the family had been chosen for, providing them an opportunity for “moral rectification and... spiritual growth” (p.17). Accounts from parents also suggested that many of the parents also felt naturalistic factors (e.g., physiological pathology such as brain damage) and metaphysical factors (e.g., God created the bodily mechanisms resulting in ASD) were at play in their child’s symptomology. However, it should be noted that, although these parents conceded their child’s body may be “damaged,” around two-thirds of parents also believed that their soul was intact with many more suggesting that their children may actually be of higher spiritual status.

In contrast, researchers conducted a similar study looking at the parental beliefs of South Asian Muslim immigrants living in the United States (Jagatheesan, Miller, & Fowler, 2010). Three families who had immigrated to the U.S. for approximately 10 to 15 years and, at the time of the study, were living in a large, Midwestern state were recruited based on their having a child between the ages of 2- to 8-years-old old diagnosed with autism. This study was longitudinal and ethnographic in approach and involved 17 months of fieldwork, including more than 700 hours of observation of families in their home and in community environments. Two of the families identified as Sunni Muslim and one family as Shiite. With regards to these parents’ beliefs surrounding having a child with autism, similar to the ultraorthodox Jewish families studied by Shaked and Bilu (2006), all of the parents felt strongly that they were blessed and chosen by Allah to raise “His special child” (p. 101). More specifically, families felt that Allah granted their family with love, hard work, piousness, resilience, and an ability to nurture their sons. They also believed that their child was pure and innocent and, as such, they believed that Allah had chosen

their family because he knew that they would protect their child from neglect or harm. Interestingly, differences between the Sunni and Shiite families reported differences in the way they viewed their fated or karmic connection to their child. More specifically, Sunni families believed that their child was fated to them and, therefore, they accepted this and never questioned this. On the other hand, the Shiite family believed they were connected to their child through karma “because in our past life we had some relationship together. I don’t know what, but we owed each other” (p.103).

A study looking at the beliefs of parents across cultures, specifically Germany, Brazil, Greece, and Italy in the early 1990’s, found a mixed group of beliefs or attributions related to etiology (Probst, 1998). When asked about the cause of their child’s symptoms all countries with the exception of Greece pointed to biological reasons for their child’s symptomology. In Greece, most parents reported psychosocial-external reasons for their child’s symptoms including that they were “Given by God” or “Fate, Destiny” with one parent believing her child’s symptoms were due to “bad mental conditions during pregnancy” (p. 471).

Feelings about the Diagnosis

Several studies have focused specifically on how parents react to initially hearing the news that their child has an ASD and how those feelings may evolve over time. In a survey based study conducted in the United States by Bayat (2007), 175 parents and primary caregivers of children with ASD reported initially experiencing depression that eventually turned to love and adjustment. Similarly, when Myers, Mackintosh, and Goin-Kochel (2009) surveyed 493 American parents of children with ASD they found parents to report initially feeling emotions ranging from grief, depression, guilt, and blame but eventually feeling increased levels of compassion, tolerance, patience, and joy.

Mansell and Morris (2004) asked nearly 100 parents of children diagnosed with ASD and living in the United Kingdom to describe their reactions to receiving a diagnosis on the spectrum for their child via structured and open-ended questionnaire. Most parents reported that they were shocked, devastated, or upset by the diagnosis and that their view or attitude about the child's diagnosis has not changed over time. Most parents also reported that they wished their child had been diagnosed earlier. The findings of this study seem to highlight the mixed feelings and reactions many families around the world seem to have to the diagnosis.

Following this seminal work, Russell and Norwich (2011) took an in-depth look at the reactions of parents in the United Kingdom to receiving a diagnosis of ASD for their child through semi-structured interviews with 17 parents of children with ASD. Parents reported that before the diagnosis, they often wanted professionals to note their child's differences to confirm their own suspicions. They reported an inner tension between wanting to continue believing they had a "normal" child but also recognizing that something was different about their child. At the "tipping point" or the place of diagnosis, parents who previously resisted seeking a diagnosis for fear of stigma began to change their mind because of the pressure of professionals, pushing them to begin to look for greater information and resolution. After obtaining the diagnosis, all of the mothers reported being eager to partake in the benefits of the diagnosis, namely coming to terms with their child's behavior, as well as allowing them to better understand it.

French parents of children diagnosed on the spectrum and ranging in age from 4 to 45 years of age were surveyed regarding their feelings about having a child diagnosed on the spectrum (Chamak, Bonniau, Oudaya, & Ehrenberg, 2011). These parents had experienced receiving a diagnosis at various points with some raising a child who had been diagnosed over 30 years earlier. Parents' reactions to the diagnosis were categorized in five ways: negative effects

(e.g., distress, helplessness, despair, guilty, depression, dejection), positive effects (e.g., relief, understanding, confirmation of what I already knew, put a name on the difficulties of my child at last), positive/negative effects (e.g., mixed emotions), perplexity (e.g., incredulity or indescribable), and finally parents who described being unaffected because they already knew their child would be diagnosed prior to receiving the official diagnosis. A great many parents (75%) had difficulties accepting the diagnosis when their child was younger than four years of age. However, for parents whose children were older than four years of age, about 43% report feeling relieved for finally receiving the diagnosis. It is unclear how these feelings may have differed based upon the point in history in which children had received their diagnosis and how feelings surrounding diagnosis may have changed with increases in the availability of services and supports.

In China, McCabe (2008a) utilized open-ended questionnaires given to the parents of 74 children with autism to better ascertain their feelings related to having a child diagnosed on the spectrum. Of the parents completing these questionnaires, thirteen were interviewed as a follow-up on questionnaire data provided. Parents were recruited from a short-term, 11-week, parenting training program aimed at teaching parents how to teach their children. The data yielded an important theme in the area of diagnosis: “Response to Diagnosis: Shock, Devastation, and Lack of Information.” More specifically, parents talked about their experiences and reactions to learning of the actual diagnosis of their child as either being shocked and devastated (82%), not understanding (39%), and/or being in state of denial (14%). One mother described her feelings as “at the time I felt as if the sky was about to fall down... We did not take any measures, we felt really confused and helpless!” China’s family planning policy that limits couples to one child provides a unique stressor to families who are first learning of their child’s diagnosis. These

parents commented that the stress was often extreme because this child was, in most cases, their first and only child. It is unclear how these feelings about their child's diagnosis evolved over time raising them.

In Iran, 43 parents were asked in structured interviews about their reactions to receiving a diagnosis for their child on the autism spectrum (Samadi, McConkey, & Kelly, 2012). In terms of how they responded to receiving their child's diagnosis, 63% of parents reported feeling shocked and depressed, while others (12%) felt shocked and rejected the diagnosis. Approximately 21% of parents reported feeling uncertainty about the diagnosis due to lack of information and 5% of parents reported feeling relief given that they were expecting what they considered to be a worse prognosis (i.e., intellectually disabled).

A recent study conducted by Bilgin and Kucuk (2010) involved informal interviews with mothers in Turkey surrounding their experiences raising a child on the spectrum found similar reactions to the diagnosis. The 43 mothers were recruited from the Education Center for Autistic Children where their children, ranging in age from 6 to 17 years old (average age 9 years), attended daily. When asked specifically about their experience raising a child on the spectrum, answers ranged from grief (19%), shock, pessimism, denial when diagnosed, then acceptance with devotion (14%), emotional breakdown (12%), worry (9%), and hopelessness (9%). One mother commented "Sometimes I think that my child is not mine. But then I say to myself that she must have a mother. She is always my child."

When 65 parents of children diagnosed with an ASD in South Africa were given retrospective questionnaires to better inform how parents processed the diagnostic information they received and their reaction, responses varied greatly (Krauss-Mars & Lachman, 1994). In terms of parents reporting their reaction to the diagnosis, about 23% of parents reported being

able to name their child's diagnosis, another 48% could describe their child's symptoms, around 25% denied their child's diagnosis (e.g., 'Nothing wrong, just lazy'), approximately 2% parents' responses were vague, and finally approximately 5% discussed their child's diagnosis in the context of the cause of their symptoms. Much of parents processing of information surrounding their child's diagnosis varied greatly by what culture within South Africa they belonged to. More specifically, the researchers examined patterns by racial categories (i.e., White, Black, and Mixed) and found that the majority of Black parents reported that they were not asked about their understanding of the diagnosis, suggesting their reactions to the diagnosis may be based in large part to their understanding of the diagnosis. Interestingly, a large percentage of White parents denied their child's diagnosis when compared to the other racial categories.

An early study comparing the reactions of parents to learning of their child's ASD diagnosis in various parts of the world, compared parent reports from across Germany, Brazil, Greece, and Italy between the years 1990 and 1992. Around 163 families were given questionnaires and later interviewed about their feelings about the prognosis for their child upon receiving a diagnosis. In general between 6% and 23% said they felt hope for their child, and between 46% and 25% of parents report being either hopeless or afraid for their child. In total, around 70% of parents expressed fears for their child's future. The thoughts or reasons leading to these beliefs, however, is less clear. Similar to other research reviewed within this body of literature, it is unclear if parents feeling about their child's diagnosis may have changed as they continued raising their child over the years.

Parent Experiences Related to the Effects of Having a Child Diagnosed with an ASD

The research examining parents experiences related to the effects of having a child diagnosed on the spectrum in various corners of the world focus on three broad categories: the

overall emotional impact experienced by parents of youth with ASD including life enhancement that may come with raising a child on the spectrum, as well as the specific impact upon the careers of parents of children with ASD.

Overall Emotional Impact

Following this study, a researcher in Chicago conducted a survey with 175 parents and primary caregivers of children with autism ranging in age from two to eighteen years of age to examine the evidence of resilience in families of children with autism (Bayat, 2007). In this survey, parents were asked about the positive and/or negative effects of autism on their family life, as well as their perceptions of ASD and their family functioning. From this data, several themes emerged. Most notably, parents reporting becoming an advocate for their child; and worrying about their child's future. Parents noted that although their children did not have many friends, they were a source of pride, hard-working, and an honor. Families also noted that they had developed stronger relationships and tended to meet daily goals and events. They also reported experiencing behavior problems, financial stressors, and fights with the system, out of which eventually came acceptance and adjustment over time with a great deal of lessons learned. Interestingly, evidence of family resilience emerged in the families' pulling together of resources, being connected, making meaning out of adversity, experiencing a change in their world view, feeling affirmed in their strength and becoming more compassionate, and finally feeling a spiritual experience and strengthening of their belief system.

Similar mixed feelings were reported in a related study conducted by Myers, Mackintosh, and Goin-Kochel (2009). In this study, 493 parents of children on the spectrum were surveyed online regarding how having a child on the spectrum has affected their lives and their families' lives. From this, fifteen negative themes emerged as well as nine positive themes. When asked

about their stress, over 70% of parents reported feeling stressed, noting difficulties related to marital strain, school struggles, challenging behaviors, not being able to go anywhere, and disrupted family life. On the other hand, about 29% of parents relayed that they are “no different than any other household with three kids. They all need to figure out a little something different” (p. 674). With regard to their child’s behavior as well as their needs for care and therapy, parents reported difficulty dealing with the child’s behavior problems, time demands for care and therapies, sleep problems, exhaustion, and struggles with schools and services. They also reported that through these experiences, they were able to develop a new understanding regarding the world of disabilities and that they were glad about their child’s uniqueness. Parents also reported feeling difficult emotions including grief, depression, guilt, and blame and also reported careers being impacted and/or marital or couple strain. They also noted that their child’s diagnosis also had enriched their lives, leading to enhanced positive emotions including compassion, tolerance, patience, and joy. Similarly, families noted that they had learned to appreciate life and slow down as well as have a more enriched marriage and spiritual life. In terms of the impact on the family as a whole, parents reported autism becoming the center of their lives, having negative impacts on siblings including embarrassment, hurt, or neglect, as well as negative impacts on relations with extended family members. Additionally, parents reported experiencing financial strain as a result of their child’s diagnosis. They did, however mention that their family did feel stronger in many ways and that their other children had become more sensitive, compassionate, and humble as a result of having a sibling on the spectrum. Finally, parents discussed the negative way their lives as families had become isolated and restricted, however a few parents did said they had enjoyed meeting other parents with children on the spectrum.

Most recently, a combination of survey, interview, and daily journal data were collected from 96 mothers of adolescents and adults with ASD ranging in age from seventeen to 53 years, (Smith, Hong, Mailick Seltzer, Greenberg, Almeida, & Bishop, 2010). This study was designed to assess mothers' positive and negative emotions, fatigue and work, time use, daily stressors, positive events, and giving and receiving of emotional support. The results taken from mothers of children on the spectrum were compared to a community sample. Overall, mothers of adolescents and adults with ASD had significantly lower levels of positive affect, significantly higher levels of negative affect, and greater fatigue with more work intrusions. In terms of time use, mothers of children with ASD reported significantly more time spent caring for their child and completing household chores and significantly less time in leisure activities. Not surprisingly, mothers of children with ASD also reported significantly greater stressful events including more frequent arguments or chances for arguments, work stress, home stress, or stressors from extended family and friends. On a more encouraging note, mothers of children with ASD did not differ from peers in the amount of positive interactions reported and they also were more likely to give and receive social support from others. These findings seem to highlight the importance of respite for parents of children on the spectrum.

Kayfitz, Gragg, and Orr (2010) took a refreshingly different approach to much of the research in the field examining the experiences of parents on the spectrum. Their study of Canadian parents employed questionnaires asking about positive experiences raising a child on the spectrum in addition to the levels of parenting stress felt in the home. Questionnaires were administered to 23 mother/father married pairs. When comparing mothers and fathers, mothers reported significantly more learning through experience of special problems ($d = .74$), finding the diagnosis as a source of strength and family closeness ($d = .61$), better understanding life's

purpose ($d = .68$), as well as enjoying an expanded social network ($d = .96$). Interestingly, and in contrast with a great many other countries as mentioned in later summaries throughout this paper, there was no significant difference in the amount of stress experienced by parents across mothers and fathers.

In Belgium, an in-depth, mixed methods designed study was conducted to better understand parenting experiences of families with a child diagnosed with an ASD when compared to raising a typically developing children (Meirsschaut, Roeyers, & Warreyn, 2010). Seventeen mothers of children with autism ranging in age from 46 to 84 months (mean age 69 months) who were also raising typically developing children ranging in age from 29 to 83 months (mean age fifty months) were recruited from local rehabilitation centers to participate in this study. Information gathered through in-depth interviews and questionnaires asking about maternal efficacy and agency, as well as maternal guilt and stress were compiled in an effort to develop a more comprehensive picture of lived experience for these mothers. When examining cognitions surrounding parenting a child on the spectrum when compared to parenting their typically developing (TD) child, not surprisingly, mothers felt a lower sense of self-efficacy about parenting their child on the spectrum, $F(1,16) = 11.2, p < .01$, as well as more stress related to parenting their child on the spectrum, $F(1,15) = 4.58, p < .05$, and depression, $F(1, 16) = 10.38, p < .01$. However, mothers reported a greater sense of guilt surrounding their parenting of their TD child than their child with ASD, $\chi^2(1) = 3.11, p < .01$. Several meaningful themes emerged from qualitative data suggesting that, first, “it affects our whole lives” in that everything must be structured and planned, making it difficult to do normal family activities or to be spontaneous or flexible and also decreasing the amount of leisure time families are able to enjoy. A few mothers did, however, note a positive impact saying “We definitely do not want to change Loic for a Loic

without autism. Having a child like him is also enriching for our family. This way, we realize that everyone is different. We are happy that our children, this way, learn to be considerate of each other.” Many mothers also reported marital strain and isolation from their relatives, citing an overall lack of understanding from others. They shared concerns about the future for their children, including the impact of the child’s diagnosis on siblings, and noted that there were long waiting lists for care, limiting their support. They found the ability to cope by doing everything they can for their child and striving to maintain balance as stated by one mother “It’s so hard to keep things balanced. Sometimes I really become a maniac in planning. We are constantly seeking for the right balance between “being normal” and doing something which is also nice for Robin.”

To the knowledge of this author, only one study has been conducted to date examining the experiences of parents of children with ASD in Sweden. In this study, conducted by Allik, Larsson, and Smedje (2006), 61 parents (31 mothers and 30 fathers) of children diagnosed with Asperger Syndrome (AS), High-Functioning Autism (HFA), or other PDD diagnoses in children of average intellect were surveyed regarding their health-related quality of life. These results were compared to the results of the survey when administered to 59 parents (30 mothers and 29 fathers) of age – and gender-matched children with typical development. The findings of their study indicated that mothers of children with ASD tended to report poorer physical health when compared to both fathers of children with ASD and mothers of typically developing children. Additionally, the results suggest that the better teacher and parent-rated prosocial behaviors of the child, the better the reported physical health of the mother. However, no association was found between impairment in terms of ASD symptoms and poorer health outcomes for mothers. No differences were noted in reported mental well-being amongst the groups. The authors

concluded that it is mother's health-related quality of life that is most impacted by having a child diagnosed with ASD and that this impact is both unique and strong, especially when their child exhibits higher levels of behavior problems but not necessarily an overall greater degree of impairment related to ASD.

Recent research from Australia explores the stigmatization experienced by families of children with ASD as well as their level of awareness surrounding issues related to ASDs. Farrugia (2009) recruited 16 parents (11 mothers, five fathers) through a support group to participate in semi-structured interviews in their home. All of the parents told examiners that they knew that 'something was wrong' even prior to their child getting their diagnosis and most parents believed their child's symptoms were the product of biological factors. In terms of changes in their family life as a result of their child's diagnosis, the families primarily spoke of the need to have their lives and households very structured around the needs of their child. Parents reported experiencing a narrowed social circle after their child was diagnosed, especially those whose children were described as being more socially inappropriate, believing that others blamed their parenting for the child's behaviors. Overall, the author concludes that conceptualizing their child's diagnosis as a medical condition helps the families to fight stigma and, perhaps even the guilt or shame experienced by others in cultures where etiology is much less understood.

More recently, a research team from Australia examined the self-efficacy, well-being and fatigue of mothers of children with ASDs (Giallo, Wood, Jellett, & Porter, 2011). Although parents in the Farrugia (2009) study reported having fairly positive cognitions surrounding their experience raising a child on the spectrum, the findings from this study suggest that there may still be great difficulties for these families. More specifically, after surveying 59 parents of

children with ASD on their level of fatigue, depression, anxiety, stress, and sense of competence and comparing them to a community sample, mothers typically reported moderate levels of fatigue significantly greater fatigue than parents of typically developing children. It follows that mothers who reported being fatigued also reported greater levels of depression, anxiety, and stress. Fatigue appeared to be the result of a combination of a number of factors including quality of maternal sleep, perceived need for social support, more problematic child behavior, poorer quality diet, with little exercise, as well as lower educational attainment, which when combined accounted for approximately 63% of the variance. The strongest predictors of fatigue were quality of sleep, perceived need for social support, and quality of physical activity. The mothers who reported the highest level of fatigues felt themselves to be less efficacious and less satisfied with their parenting role. These findings combined seem to highlight the need for greater support of many forms for mothers of children with ASD.

Another of the more well-studied countries within this focus is the People's Republic of China. McCabe (2007), one of the most prominent researchers in the experiences of families of children with autism in China, began her early research exploring parent advocacy. McCabe notes that children first began to be diagnosed with autism in 1982 by Dr. Tao Kuo-Tai and since that time more and more doctors in China have become more familiar with the diagnosis leading to increases in identified children. Although there is greater awareness, there continues to be a lack of services and a lack of understanding of autism on the part of educational professionals and schools. Families often face stigmas and feel a sense of shame or embarrassment for having a child with a disability. Qualitative interviews and open-ended questionnaires conducted in the native Mandarin language were administered to 43 parents of children with autism who were attending a 3-month parent training program at either a nongovernmental organization or a state-

run children's mental health center. All of the parents were married and reported having a strong support system through their extended family, although they were of varied educational and vocational backgrounds. All but one of the families reported that their child with autism was an only child. From these data several themes emerged related to the impact of raising a child with ASD in China: "Discrimination, fear, and being alone" and "Dedication of parents." With regards to the theme including discrimination, many parents reported being blamed for their child's autism or being discriminated against for their child's difficulties, resulting in a reluctance to tell others of their child's diagnosis. This is reportedly improving with a slow increase in acceptance of disability and difference. One parent reported that, in Chinese tradition, "If you see the son has no future prospects [i.e., is good for nothing], then there's no need to respect the father." Others commented that, because of the translation of autism in Chinese to "lonely disease," many felt their child would be misunderstood or stigmatized if they told of the diagnosis. An especially salient theme was the "Dedication of parents." Despite these obvious challenges, families are persistent. One father commented that in China, "children are considered 'a piece of a mother's heart and body,' that is, a piece of the mother's body has fallen off." These parents would go to any length including changing their work habits and their lives to devote their lives instead to full-time advocacy and educating their child. Many parents reported spending all their money, even borrowing from others, in order to be able to attain the services necessary for their child.

In China, McCabe (2008a) utilized a combined open-ended questionnaire and interview method to better understand the impact of the diagnosis on 78 parents of children diagnosed with an ASD. In terms of the impact of the diagnosis on the parents, a number of differences were noted between the effects on mothers when compared to fathers (as reported by mothers). Most

notably, 51% of mothers expressed feeling like they have limited or no social interaction or activities, 43% saying their life revolves around their child or that they have no life of their own, and 44% reporting feelings of stress, worry, or depression. On the other hand, they reported that although about 43% of their husbands also feel stress, worry, or depression, about 33% of fathers were reported to, in general, have not had much of an impact on their life because of the diagnosis. When speaking of the impact of the diagnosis on their relationship, 36% of mothers reported that they argue more about either their child or interventions to help their child, or that their relationship is more distant (11%). On the other hand, another grouping of mothers felt that their relationship with their spouse had either not changed (21%), or that their relationship has improved (13%) or that it is actually more positive and collaborative (23%) as a result of their child's diagnosis. Many noted that immediately after the diagnosis, their relationships involved more conflict but gradually evolved into a more collaborative and positive relationship.

Thirteen parents of young children with autism living in Taiwan were interviewed about the impact of having a child diagnosed on the spectrum (Shyu, Tsai, & Tsai, 2010). They reported their child's symptoms causing a financial strain and making them feel depressed, tired, and exhausted, frequently worrying about their child's future. Their parent-child relationship was impacted in that they felt they had lost confidence in their ability to parent their child, with one parent saying "I feel that there is a distance between us. It seems like there is a membrane between us that you cannot penetrate. I really want to help him, but he excludes me. He seems to refuse my help. I get really anxious and angry sometimes" (p. 1327). When asked about the impact of the child's symptoms on other siblings in the home, many parents reported feeling guilt for having such little time to spend with their other children. They also expressed their concern over the sibling potentially being burdened later with the child on the spectrum as the

parents age. In terms of the impact on the family and marital relationship, parents reported increased tension among both the immediate and extended family. One mother described her experience, saying “My in-laws had wanted a grandson very badly. When they found out that I was pregnant with a boy, they were very excited, but they did not expect to have this kind of child... They seldom come to visit me. They just keep asking my husband when he [the child with autism] will recover. They think it [autism] is like the flu or something.” (p.1328).

Adding to this study, Lin (2011) asks what factors influence caregiving burden and pessimism among mothers of children with ASD in Taiwan. A sample of 50 mothers of children with ASD was selected from various parts around the country. Their children ranged in age from ten to eighteen years of age with an average age of 13.8 years. Mothers were administered surveys asking them about their caregiving burden, maternal pessimism, the behavior problems of their son or daughter with an ASD, and the functional independence of the son or daughter with an ASD. Results revealed that only 4% of youth were able to complete daily living skills such as bathing, grooming, or personal care independently. They were often described as withdrawn or inattentive (80%), unusual or demonstrating repetitive behaviors (66%), demonstrating uncooperative behavior (44%), socially offensive behavior (38%), destructive property (34%), disruptive behavior (34%), self-harm or self-injury (28%), and aggression toward others (20%). Given the intensity of behaviors reported, it’s perhaps not unexpected that many mothers indicated that they felt a moderate (44%) to moderate to heavy (26%) caregiving burden. Only 22% of mothers reported feeling a mild caregiver burden. In terms of how they viewed the future for their children, 90% of mothers felt their child would always be a problem to the family, 82% worrying about what will happen when they can no longer care for their child and 74% worrying that their child can’t do as much as they feel they should be able to do.

Mori, Ujiie, Smith, and Howling (2009) studied parental stress associated with caring for children with a diagnosis of Asperger's Syndrome or Autism among a sample of 238 families living in Japan. The authors found extremely high levels of parent stress in the parents of children diagnosed with Asperger's Syndrome (between the 95th and 99th percentiles), as well as among the parents on children diagnosed with Autism (around the 90th percentile). Upon further examination, it appears that parents whose children were reported to have greater behavior or developmental problems at an earlier age, as well as those reported less involvement from the child's father experienced higher levels of stress. Overall, these findings again underscore the high levels of stress parents of kids with ASD report and the need for greater supports, especially supports focused specifically on reducing the intensity of challenging behaviors or developmental concerns.

Samadi and McConkey (submitted for publication) have since followed up on their initial qualitative study by conducting more formal, rating scale-based study to further elucidate the impact of having a child with ASD on Iranian families. The authors asked 103 parents from 74 families of a child with ASD (29 couples, 29 mothers only, and 16 fathers only) of children ranging in age from 3- to 19-years-old (average age of 7.4-years-old) to provide information regarding their general health, their parenting stress, and their family functioning. Additionally, researchers collected data regarding the child's level of symptomology using parent-reports on the Gilliam Autism Rating Scale – Second edition (GARS-2; Gilliam, 2006). All rating scales were administered via interview conducted primarily in the family's homes. This format allowed families to provide greater qualitative information as relevant, further enhancing the data collected. Findings from parent-report on the GARS-2 indicated that the mean Autism Index for the children in this sample was 100 (ranging from 68 to 130) with a mean score of 21.4 (range 5

to 41) for stereotyped behaviors. In terms of the impact of the diagnosis and related symptoms on families, mothers rated themselves as having significantly poorer health than fathers, with 80% of mothers and more than 50% of fathers reporting scores about the cutoff for optimal health. Mothers also indicated significantly higher levels of parenting stress than fathers. Of note, the authors found no significant differences between mothers and fathers in terms of their ratings of family functioning, with both reporting positive and negative aspects of how the family functions. After further analysis, it appears that parents whose children had fewer ASD symptoms actually reported poorer health. On the other hand, parents who had obtained higher levels of education appeared to be buffered by negative health outcomes. The authors hypothesize that this additional stress and resulting negative health outcomes could potentially be protected by greater levels of social support as this has previously been found to be lacking in Iran. This is supported by a finding from this study indicating that parents who took care of the child together and also who lived with extended families that were able to assist with care for the child, reported lower levels of stress. This, however, did not appear to effect health outcomes in this study. These preliminary outcomes yield a great amount of information about the impact of the diagnosis on families of a child with ASD living in Iran.

To the knowledge of the author, only one study has been conducted to date examining the experiences of families of children with ASD in Pakistan (Sabih & Sajid, 2008). Researchers administered the Parental Stress Scale (PSS; Berry & Jones, 1995) and a demographic information sheet to collect data from 60 parents (30 fathers and 30 mothers) of children diagnosed with ASD ranging in age from 4- to 18-years-old. The results of this study found that Pakistani mothers reported significantly greater stress when compared to fathers, $t(60)=2.194$, $p<.01$. Researchers hypothesized that given cultural expectations for men to suppress their

emotions and for mothers to be the primary care giver for children, mothers are more susceptible to stress and fathers less likely to openly report being impacted by stress. The results also suggest that, the younger the age of the child diagnosed, the greater the levels of parental stress reported ($t(60)=2.281, p<.01$). These findings appear to be inconsistent with other literature suggesting that as the child ages so do the demands for care, increasing the level of stress for caregivers. Interestingly, parents whose diagnosed child was a boy reported significantly lower levels of stress when compared to those whose diagnosed child was a girl ($t(60)=2.053, p<.01$). Again, the authors hypothesize that, in general, Pakistani parents are more concerned for the future of their daughters. Therefore, the impact of having a daughter diagnosed on the spectrum may have greater impact on the parents. This study further highlights the importance of examining cultural beliefs and values when considering the impact on families and the area best targeted for intervention and supports.

Mothers in Turkey were interviewed regarding their experiences raising a youth with an ASD and the impact these experiences have had on them emotionally (Bilgin & Kucuk, 2010). Many mothers (30%) reported experiencing a lack of acceptance of their children among the community with one mother saying “We are still trying to make people understand our child’s situation. There are still people who ask me if my child has an auditory problem. We are easily offended and become angry.” When asked about stressors, many mothers reported difficulties related to a lack of knowledge about what caused their child’s symptoms or how to care for them (47%), as well as financial difficulties (49%). Mothers were also asked to share how they coped with the difficulties they face, many reporting solidarity within their family and having mutual support with their husbands (23%), being able to talk out their worries with family (19%) and with friends (9%), or resignation (12%). Other reported strategies include brisk walking (9%),

crying (7%), and smoking or using alcohol or coffee (7%). Researchers asked mothers to describe who the burden of caregiving for the child fell on primarily and most responded that either the burden fell on them as mothers (44%) or that they shared the role equally with the child's father (35%).

In Ghana, parents were interviewed regarding their experiences related to raising a child on the spectrum to understand the broad impact on the family (Anthony, 2009). As mentioned previously, many mothers are blamed in some way for causing their child's autism resulting in significant stress and isolation. Additionally, Ghanaian culture places a heavy emphasis on appropriate sociability for children and believe that anti-sociality is a result of powerful wickedness. Rites of passages are held in the highest esteem and typically require a demonstration of social savvy in some form. Given the social impairments associated with ASDs, the expected rites of passages would be difficult for most kids on the spectrum to perform and their overall difficulties with social skills often result in stigmatization, further isolating them from society. Anthony (2009) also reports a general view that, because youth with autism have difficulties meeting these societal norms they are often viewed as "useless" and unable to learn or contribute to society. In addition to the isolation of individuals on the spectrum, families report feeling isolated and stigmatized, unable to attend church, celebrations or community events with their child because of their child's behaviors and the way these behaviors are perceived in Ghanaian society. Siblings often have difficulty marrying for fear of the family being cursed. These siblings often become advocates and caregivers for their brother or sister with autism.

Similarly, mothers in Kenya are frequently the source of blame for their child's ASD symptomology (Riccio, 2011). Not surprisingly, these mothers report emotional stress, guilt, financial hardships, and disrupted family relationships. As a result of this stigmatization, many fathers are encouraged to abandon the family in an effort to save himself and his future children from the curse. As such, many mothers are tasked with raising the child alone, many of whom hide their children away or choose painful and unethical medical practices and often the care of witchdoctors to rid themselves of the evil curse.

Although it was not the primary focus of the study, researchers in Israel did briefly touch upon the impact upon mothers raising a child with ASD and living in an ultraorthodox Jewish community in Israel (Shaked & Bilu, 2006). Given the separatist nature of the ultraorthodox community, many families reported feeling as if they had journeyed into a foreign land, leading to a great deal of emotional conflict especially in terms of whether or not to leave their community in order to better access appropriate interventions to support their child. Many of these families sought to alleviate their conflicted emotions through the endorsement of their actions by authorities or rabbis within their community.

Kediye, Valeo, and Berman (2009) conducted focus group interviews with 10 Somali-Canadian mothers living in Toronto aimed at better understanding the experiences of these mothers in raising a child with autism. The mothers, whose children ranged in age from 6- to 12-years of age, were part of the Somali Parent Support Group and most (90%) had had their children in Canada. Several notable themes emerged from the mothers' reported experiences. In addition to the barriers created by having limited understanding of the English language, mothers also reported encountering difficulties due to inflexible immigration policies that prevented them from bringing family members to Canada to provide assistance with raising their child. Many of

these mothers reported that their greatest concern and stress for their child was their lack of ability to communicate and contribute meaningfully to the family, something very important in Somali culture. However, they noted difficulties with getting the assistance of professionals who could help to improve their child's symptomology, one mother saying "I swear, there is no doctor that I trust. They treat you like you are a child because you come from different part of the world and don't speak English the way English speakers do, they think that we are not worthy to be informed what they are giving to our children..." and another commenting of the school system which many reported to be problematic, "For me what depresses me is, the teachers always tell[ing] me bad things that my child did. I respect them, they are the teacher of my child, how can I say to them tell me what he learned. I am afraid they may take in a wrong way, so I don't do anything. And every day I am worried what else they say to me, it is not good feeling but there is not much I can do. Sometimes I want to go somewhere else but that's what the teachers want and I am not going to do it." In addition to the reported discrimination from professionals, mother also reported being unfairly judged by strangers with one mother stating "When we are outside and my child screams and other people stare at us is the biggest thing that worries me. The worse thing is when we are in the mall and my child starts picking up things such as potato chips. People just look at you and they don't understand. The only thing they see is an older child that looks healthy that has behavior problems... people don't have knowledge about autism... Going outside is what worries me the most and because of it I don't go out." These findings suggest that immigrants or displaced persons raising a child with an ASD are an especially vulnerable population and may require even greater support than most.

Researchers revisited cross-cultural comparison studies of parents starting again recently when Kim (2012) examined family experiences across Nicaragua and South Korea. Through in-

depth interviews with families in each of the regions, it appears that ASDs are conceptualized quite differently. More specifically, in South Korea Kim met with a mother whose child was suspected of being on the spectrum and most likely was, however, the mother denied her child being on the spectrum, remarking that she was told by her pastor to read a book on Reactive Attachment Disorder in order to better help her child, seeming to suggest that the child was not appropriately bonding with the mother. In general, the people of South Korea seemed to be either indifferent, or neglectful and hostile towards children with disabilities with the general perception that they are stubborn, irresponsible, unsophisticated, and incapable. Kim's accounts from Nicaragua are very different; with the general attitude amongst Nicaraguans that "everyone is the same" and that difference should be embraced (p. 8).

The Impact upon Career

In the United States, a numbers of studies have found parents to report a negative impact upon their career after having a child diagnosed on the autism spectrum (Bayat, 2007; Myers, Mackintosh, & Goin-Kochel, 2009). More specifically, parents reported having to put their careers on hold or switching to a career in special needs (Bayat, 2007) or simply experiencing greater levels of work stress when compared to other parents (Smith, Hong, Mailick Seltzer, Greenberg, Almeida, & Bishop, 2010).

Parents in Belgium noted similar impacts to their careers via in-depth interviews and questionnaires (Meirsschaut, Roeyers, & Warreyen, 2010). Many mothers also spoke of having to make job or career adjustments as exemplified by this quote "My work life has changed completely since Lisa's diagnosis. I used to work full-time, now I am full-time at home for the children."

Preliminary qualitative research conducted in China suggests that many families and mothers in particular, found themselves changing their work habits in order to better meet their child's needs in many cases quitting their jobs and shifting to full-time advocacy (McCabe, 2007). In perhaps the most extensive study focusing solely on the impact upon the career of mothers of children with ASD, McCabe (2010), utilized qualitative methodology aimed at better understanding the employment experiences of mothers within China. Open-ended questionnaires written in Mandarin were distributed to 70 mothers of children with an ASD diagnosis who were a part of a 3-month parent training program in Beijing. Of the women completing the questionnaire, 57 mothers volunteered to be a part of follow-up interviews conducted in Mandarin as well. Given time constraints, the author chose 12 of these 57 women to interview based upon a desire to include a range of ages of children and employment experiences. Of the participating women in this study, 36 reported working full-time and seven were working part-time. For decades now in China, women have worked full-time alongside men. However, 27 of the women participating in this study were unemployed. From these surveys and interviews two themes emerged: satisfaction of work and being responsible and making sacrifices. Mothers noted that they consider work to be very satisfactory both for practical reasons (including money for autism expenses as available services in China are limited and typically paid for by the family) and also for increasing mood, providing feelings of accomplishment, and also for giving them a sense of identity. One mother noted "Currently I am quite satisfied with working. First, I can have some income, second I am not separated from society." Within this theme, several undercurrents emerged. Most notably, job satisfaction depended on the mother's ability to balance her work with caring for the needs of her child. This requires flexibility in their job and positive interactions with coworkers. These mothers also felt that having their own identity or

sense of accomplishment through their careers allowed them to better care for their child. In relation to this idea, one mother said work, for her, was “a place to relax a bit, a place of confidence, to make up for [challenges at home].” Finally, mothers reported that they drew satisfaction from work because it allowed them to be like “normal” people and to not feel so isolated. Within the second theme, “being responsible and making sacrifices,” mothers who were unemployed stated that there were really only two benefits: because of lack of access to services or education for their children, not working gave them more time to teach and work with their children. Finances were involved in the decision either to work or not work in that mothers who decided to stay home frequently did so because child care and intervention services were not affordable. Mothers who were employed stayed employed in an effort to provide for these services for their children. The authors found that the mothers’ responsibility and sacrifice for their child with autism was a recurring theme.

In summary, a great deal of research has looked at the impact of raising a child on the spectrum upon the family and found increased levels of stress and, at times, isolation often associated with the child’s challenging behaviors or the significance of their developmental concerns. There is preliminary research to suggest that raising a child on the spectrum not only impacts parent well-being, but also may impact their livelihoods and work. This caregiving burden tended to most often lie with the mother and, as mentioned at various points throughout this literature review, mothers often also seem to be the most impacted by the challenges associated with raising a child on the spectrum. In addition to the numerous stressors associated with raising a child on the spectrum, parents do also note that caregiving for a child on the spectrum may be life enhancing in other ways. Namely, raising a child on the spectrum may at times make the family unit stronger, teach parents and siblings greater acceptance of diversity and patience.

Parent Experiences Related to Supports and Services

The two primary areas of interest to researchers from around the world regarding the experiences of families of children with diagnoses on the autism spectrum include treatment decision-making on the part of parents as well as their experiences related to accessing services and supports.

Treatment Decision-Making

Preliminary research conducted by the Interactive Autism Network (2011) yielded over 380 different treatments or interventions available to parents in the United States. In this study parents reported using five interventions or treatments simultaneously on average, although some parents reported utilizing as many as 56 treatments simultaneously, with the most frequently utilized interventions being speech and language therapy, occupational therapy, applied behavior analysis, and social skills group interventions. Much less is understood about how parents go about making treatment decisions, how accessible these treatments are to families, and how available these different supports and services are in the countries.

Harrington and colleagues (2006) utilized a cross-sectional questionnaire method administered to 75 parents of youth diagnosed with an ASD in the United States in order to better ascertain the types of treatments parents were most frequently utilizing. In this study, many parents had identified specific causes such as immunizations or other environmental toxins as contributing to their child's symptomology. Not surprisingly, families also reported trying a number of different interventions to address their child's symptomology including complementary and alternative medical (CAM) treatments or drug treatments (87%), with a median of six attempted treatments. More specifically, parents reported trying at least one dietary restriction (69%), at least one dietary supplement (60%), at least one other CAM treatment

(63%), and at least one medication (53%). Overall, parents reported trying six treatments on average.

In Taiwan, 43 parents of children ranging in age from three-years-old to 11-years-old were interviewed regarding their treatment decision-making process (Shyu, Tsai, & Tsai, 2010). Parents sought a number of strategies for supporting their child including vitamin supplements (38%), occupational or speech therapy (92%), acupuncture (39%), treatments for food allergies (46%), or detoxification therapy (8%). They reported deciding which treatment to pursue based on either what they believed caused their child's symptoms, what the child preferred or resisted, and/or the fit of the child and parent with the therapist. One parent reported believing of treatments, "All treatments have their own theories and have worked for some children. We do not know which one will work for him [the child with autism]. As parents, we can only keep trying. It is like fishing in the ocean. Perhaps one day, I will catch the fish." (p.1328). Like previous studies discussed, this study also seems to suggest that the information provided at the time of diagnosis surrounding the etiology of the child's symptomology could strongly influence later treatment decision-making on the part of parents.

As mentioned previously, the limited research available out of Africa suggests a pervasive belief that mothers in some way, in most cases through drawing a curse to the family, have caused their child's symptomology. As such both Ghanaians (Anthony, 2009) and a great many Kenyan parents (Riccio, 2011) seek out the services of local witch doctors or spiritual leaders for assistance in removing their child's "curse." Additionally, Kenyan parents report attempting expensive drug therapies over other recommended treatments such as behavioral therapy believing that a pill or injection will alleviate symptoms, allowing their child to speak.

Although the cultures are very different, reports from parents of children with ASD living in an ultraorthodox Jewish community in Israel found that although a majority of parents believed there were some physiological factors at play in their child's symptom development, a great many also held similar beliefs surrounding supernatural causes being related to the development of their child's ASD symptomology to those mothers in Africa (Shaked & Bilu, 2006). More specifically, the belief that they were chosen by God to have a child with autism in order to teach them suffering providing them an opportunity for moral rectification to God or that in some way through their own perceived negligence or distress during their pregnancy they had caused their child's symptoms. Parents reported seeking out a number of medical (e.g., analysis of liver metals), educational (e.g., auditory training), and alternative interventions (e.g., homeopathic methods, reflexology, biofeedback, electrical treatment, energy transmission through laying-on of hands, chiropractics, and dolphin therapy), most of which required the family to leave the confines of their community in an effort to obtain these treatments for their children. Parents also reported seeking spiritual and mystical treatments for their children including prayers and blessings from rabbis, lead treatment, traditional dream analysis, amulets, recitations of religious texts, holy water (drunk by the child), changing the child's name, exorcism, and prayer on the graves of revered rabbis in Israel or abroad.

Experiences related to Accessing Services & Supports

A British questionnaire-based study conducted with nearly 100 parents of youth diagnosed with an ASD sought to better understand the experiences of parents related to accessing supports and services for their children (Mansell & Morris, 2004). In terms of what treatments they found to be the most helpful, 87% reported that speech and language therapy was the most helpful, and about 69% reported special schools or units were also useful. Occupational

therapy and behavior management were rated as being moderately useful. Parents noted the lack of resources and long waiting lists for behavior therapy as being problematic.

Following this study, researchers conducted interviews with 68 mothers of children on the spectrum to better understand their social support, mental health status, and their satisfaction with services (Bromley, Hare, Davison, & Emerson, 2004). In this study, about 40% of mothers reported feeling that their current housing situation was unsuitable for raising their child, and less than half of mothers reported support from family or friends. Parents did report having support from coworkers (70%), parents' groups (85%), social groups/clubs (99%), religious organizations (78%), and early intervention programs (85%). Only 6% of parents reported finding their child's school as a source of support. While almost all parents reported being aware of the various services surveyed and asked about, very few parents were able to obtain services. About 75% said that they were able to access speech therapy, 47% could access a pediatrician or doctor, and about 31% said that they could access a social worker. Less than 20% of parents surveyed said that they could access a psychiatrist, clinical psychologist, disabled child's team, alternative therapy, respite, support workers, or educational psychologists. About 96% of children were attending schools, but only 74% of parents said it was their preferred school. The most commonly reported unmet needs included help with care during the holidays (93%), to do things parents enjoy (91%), advice on the best way to help their child (87%), someone to talk to (85%), help with making plans for the child's future (81%), and managing the child's behavior (80%). The parents mentioned a number of other unmet needs including advice on services, meeting other parents, and respite care. A later study utilizing data from 15 focus groups conducted with 70 parents in the United Kingdom found similar results with very few parents reported being offered in the form of respite care, reviews with professionals, community worker

visits, or medical help with only a small minority of parents were able to access intervention packages and educational help (Osborne & Reed, 2008).

A fairly recent report to the 6th Annual National Disability Authority Disability Research Conference examined parents' experiences of the ASD diagnostic process in County Mayo, Ireland (Langford et al., 2007). At the time in Ireland, the diagnostic process varied greatly throughout the country with no specific designated provider. Focus groups and individual interviews were conducted with 10 parents in total. Parents mentioned the length of the diagnostic process ranging from four months to two and a half years and being in a number of settings including over the telephone to in a clinic room and by either one professional and one parent there all the way to multiple professionals with both parents present. Overall, a majority of parents reported being satisfied with the process. Despite general positive feelings about the process, the report went on to recommend that a number of strategies be implemented for increasing knowledge of ASDs among professionals; better involving parents in the process; earlier access to early intervention services; and greater provision of support services immediately following the diagnosis including counseling.

Semi-structured interviews were conducted with 16 parents of youth diagnosed with an ASD and living in Australia in order to better understand their experiences accessing supports and services for their child (Farrugia, 2009). Parents spoke of transitioning into the 'world of autism' and finding new sources of interpersonal connectedness through support group meetings which helped them to redefine 'normal' (p. 1019). Very few parents reported feeling stigma and, of those who did report feeling stigmatized they said that it was rare they felt that way. Parents did, however, consistently report feeling somewhat stigmatized in schools, especially in the school's response to challenging behaviors which often contradicted treatment recommendations

from professionals in the field of autism. Parents reported doing things to battle this stigma such as bringing psychologists with them to meetings at the school.

McCabe (2007) utilized a mixed approach to data collection comprised of open-ended questionnaires and semi-structured interviews to better understand the experiences of families of children diagnosed with an ASD living in China in accessing services and supports for their child. One of the primary themes to emerge was “Lack of schooling opportunities and rejection.” Parents spoke of a desire to have their children go to school, but being required to prepare their children with a variety of basic learning skills (e.g., being able to sit for instruction, being able to understand the teacher’s verbal commands, being potty trained, etc.) lest face rejection from general education schools. It was also noted that special education schools in most areas are limited, one mother saying “It seems where we are from there are no schools like this [offering special education for autism].” If such schools do exist or the child is able to go to school, it is typically as a result of utilizing connections parents have in the community.

McCabe (2008b) has also researched the impact of parent-to-parent support in the People’s Republic of China finding that support from other families of children with autism was of huge importance to other parents of children on the spectrum. Her study involved open-ended questionnaires and interviews of parents attending the same training program as those sampled in her other works. The qualitative study was conducted with the caregivers of 43 children on the spectrum ranging in age from three years, two months to eleven years old, with a mean age of five years and two months. Parents expressed two important benefits of parent-to-parent support provided to them through the training centers they were attending: sharing and learning from one another and support and accepting each other. With regard to sharing and learning from one another, some mothers even remarked that, after completing the program, they would still

contact one another, “Often calling, chat a bit, we can exchange understanding of teaching (from experience) and methods.” They also noted that during their time at the center, they also benefited by learning from other parents mistakes in teaching their children that they would like to avoid in the future. Parents also noted that they felt bonded to the other parents in the program and that the emotional support and encouragement of the other parents were essential, one mother saying “This environment is definitely different. To be frank, everyone is equal here. First is this. There is no discrimination, discriminatory looks toward other people. There is absolutely none,” and another commenting, “this type of parents, what they need most is mutual encouragement, mutual support, and help.” McCabe (2008b) concludes that, because of the overwhelming benefits discussed by parents participating in this study, parent-to-parent support should be considered for inclusion in all interventions programs for children on the spectrum whenever possible.

In the last several years, a number of publications examining the experiences of families of children with ASD in Iran have been published. In Iran, the services and supports available for families of children with ASD vary greatly starting with the diagnostic process. Children are typically diagnosed by medical doctors either through clinics provided by volunteer organizations or privately. Although most parents opt for private schooling, children diagnosed with ASD may either attend state-funded schools through the Iranian Special Education Organization or, for children with greater impairments, may be placed in a day program available through the Iranian State Welfare Organization (Samadi & McConkey, 2011). It should be noted that these services are most likely not available in more rural areas and are described to serve primarily affluent families. Researchers in Tehran (Ahmadi, Sharifi, Azizi Zalani, Bolouk, & Amrai, 2011) conducted a study of 62 parents whose children attended a school for children with

special needs regarding their needs as a family. By providing a modified Family Needs Questionnaire (FNQ; Kreutzer, Serio, & Bergquist, 1988) asking parents to rate a variety of suspected needs based on their importance, researchers were able to identify the top ten rated needs of families including: “I need to be shown what to do when my child is acting unusually or displaying difficult behaviors” (100%), “I need weekend and after-school activities for my developmentally delayed child” (100%), “I need to spend time with my friends” (98%), “I need to have other family members understand my child’s problems” (98%), “I need to be told why my child acts in ways that are different, difficult, or unusual” (98%), “I need help dealing with my fear about my child’s future” (98%), “I need to be encouraged to ask for help” (98%), “I need services continuously rather than only in times of crisis” (98%), “I need to work with professionals who have expertise working with children who have the same developmental disorder as my child” (98%), and finally “I need for the professionals working with my child to understand the needs of my child and my family” (98%). This study did not look, however, at whether or not these needs were being met.

Also in Iran, 43 parents of youth diagnosed with ASD were interviewed regarding their experiences with attaining services for their child with autism (Samadi, McConkey, & Kelly, 2012). With relation to services received after diagnosis, 98% of families reported receiving some types of services (occupational therapy, speech therapy, and education), but only 40% of these parents reported that part or all of their services were covered by the government. Approximately 75% of parents reported being unsatisfied with the intensity or range of services they received. In terms of social support, 16% of families reported having no informal support, while 70% reported having support from immediate family and 14% reporting receiving support from a more removed group of relatives or friends. In general, almost all parents interviewed in

this study reported a desire for both greater services, as well as informal support, similar to findings from elsewhere in the world.

A Turkish study utilizing interviews with 43 mothers of children with autism ranging in age from six to 17-years-old looked specifically at their experiences related to accessing services and supports (Bilgin & Kucuk, 2010). In terms of the perceived resources for support in raising their child, mothers reported budgeting (33%), receiving financial aid from family (23%), as well as relying on the cohesiveness of their family for support (14%). Only a small number reported being supported by close relatives (9%) and approximately 21% reporting having no financial or emotional support. Mothers were asked to describe what they expected for their children to receive when attending school and many (72%) reported wanting their child to learn to be independent and to be able to communicate their needs to others (47%). A handful of mothers (14%) wanted their child to be able to speak fluently or to improve their maladaptive behaviors (7%), with around 7% wanting for their child to be able to develop at least a little speech. Few (14%) expected their child to have good opportunities for the best education or to be literate (9%). In terms of what they saw in the future for their children, many parents (59%) again mentioned wanting their child to have made major improvement in their ability to self-care, with many (47%) believing their future would always involve caring for their child with autism. A handful of other mothers (14%) stated they hoped for their child to be able to speak, or to be social (7%), or that they were concerned for the future of their child (7%). One mother said that what she wanted was “A day when I call to him, and he can reply to me, or come to me and ask me, ‘What do you want?’” and another “The big concern of our family is who will protect him after we pass away.” Many of the feelings of mothers in Turkey as reported here echo the voices of mothers of children on the spectrum heard around the world.

Anthony (2009) briefly touched upon the experiences of families in Ghana with accessing supports and services. Her study clearly outlines pervasive stigmatization and isolation surrounding having a child on the spectrum within this culture. With regard to how this stigmatized impacts treatment, many families report difficulty with accessing inclusive education for their child despite national mandates for such services. Interestingly, despite what seems to be overwhelming stigmatization and difficulty living with a child on the spectrum in Ghana, many of the families participating report living abroad and returning to Ghana after their child was diagnosed. When probed further, it appears that some find it easier to retire in Ghana to care for their child or return to have the support of relatives. Parents interviewed in Kenya report very similar experiences in that, although inclusive education is currently being advocated in the country, many still report denied access to educational services for children with ASD and also mentioned having limited resources for accessing treatments that are available (Riccio, 2011).

South Asian Muslim immigrants living in the United States discussed an interesting barrier to accessing appropriate services and supports for the child they were raising diagnosed with an ASD (Jagatheesan, Miller, & Fowler, 2010). In particular, parents reported several goals for their child's future, namely to be fully included in everyday life and to be fully included in a multilingual world. Parents reported being guided by the Qur'an which emphasizes participation in ordinary social life including religious activities in the home, community, and in the mosque, in order to develop and overcome limitations. They also reported wanting their child to learn to pray in Arabic because this is a defining characteristic of Muslims. They noted that most professionals were generally concerned with their child's difficulties, where they generally refused to participate in negative conversations with professionals regarding their child, and that

in many cases the prioritized areas targeted for treatment did not always align with the goals they had for their child.

Probst (1998) briefly examined the experiences of families across various corners of the world including Germany, Brazil, Greece, and Italy in their beliefs about various treatments and their access to supports and services. The parents in all countries believed educational and psychological treatments were of great importance. In terms of the coping resources relied upon, most parents reported finding strength in the child itself, finding comfort in their religious beliefs, receiving social support from professionals, and receiving social support from parent organizations.

Finally, McCabe (2008b) has also researched the impact of parent-to-parent support in the People's Republic of China finding that support from other families of children with autism was of huge importance to other parents of children on the spectrum. Her study involved open-ended questionnaires and interviews of parents attending the same training program as those sampled in her other works. The qualitative study was conducted with the caregivers of 43 children on the spectrum ranging in age from three years, two months to eleven years old, with a mean age of five years and two months. Parents expressed two important benefits of parent-to-parent support provided to them through the training centers they were attending: sharing and learning from one another and support and accepting each other. With regard to sharing and learning from one another, some mothers even remarked that, after completing the program, they would still contact one another, "Often calling, chat a bit, we can exchange understanding of teaching (from experience) and methods." They also noted that during their time at the center, they also benefited by learning from other parents mistakes in teaching their children that they would like to avoid in the future. Parents also noted that they felt bonded to the other parents in

the program and that the emotional support and encouragement of the other parents were essential, one mother saying “This environment is definitely different. To be frank, everyone is equal here. First is this. There is no discrimination, discriminatory looks toward other people. There is absolutely none,” and another commenting, “this type of parents, what they need most is mutual encouragement, mutual support, and help.” McCabe (2008b) concludes that, because of the overwhelming benefits discussed by parents participating in this study, parent-to-parent support should be considered for inclusion in all interventions programs for children on the spectrum whenever possible.

As mentioned previously, another country that is gaining attention from the research community for its views and treatment of families of children with ASD is India. Autism was not legally recognized as a disorder in India until 1999 and, until that time, schools for children with autism and families did not receive government funding or assistance (Vaidya, 2009). Not only were there far more families needing service providers than were available, but the services can be quite costly and were, therefore, even further inaccessible for many families (Aluri & Karanth, 2002; Krishnamurthy, 2008). As of a review of the literature conducted in 2005 (Gupta & Singhal, 2005), both public and special education schools refused to serve children with autism, reporting that they are unequipped to handle the needs of these children. Daley (2004) notes that India also possesses several unique systems of care including Allopathic, Ayurvedic, homeopathic, and Unani leading to multiple options for treatment to parents. Indian parents report trying pharmaceutical intervention, megavitamin therapy, pranic healing, reflexology, astrologists, acupressure, speech therapy, vitamin therapy, tutoring, Siddha, behavior therapy, and yoga, with over half the sample using either or both Ayurvedic and homeopathic treatment (Daley, 2004).

Global Patterns in Experiences and Culture-Specific Experiences

As reviewed, the literature from around the world studying the experiences of families of children diagnosed with ASDs falls into three broad categories: parent experiences related to the process of having their child diagnosed with an ASD, parent experiences related to the effects of having a child diagnosed with an ASD, and finally parent experiences related to accessing services and supports for their child who has been diagnosed with an ASD.

Literature looking specifically at the journey leading to diagnosis and immediately following centers upon examining parent experiences with the diagnostic process itself, their beliefs surrounding etiology, and their evolving feelings surrounding their child's diagnosis. Although the diagnostic process differed across countries, with some parents finding it difficult to even find a professional to properly evaluate and diagnose their child (Ghana; Anthony, 2009) and others reporting that they were delivered the news via phone sometime after evaluation (Braiden, Bothwell, & Duffy, 2010), many parents reported similar feelings regarding improvements in the process of evaluation and diagnosis. More specifically, a great many parents report experiencing long waits for evaluations and also a desire for greater information and resources given at the time of diagnosis including parents in the U.K. (Mansell & Morris, 2004; Osborne & Reed, 2008), in Ireland (Braiden, Bothwell, & Duffy, 2010), in China (McCabe, 2008a), in India (Daley, 2004), in Iran (Ahmadi, Sharifi, Azizi, Zalani, Bolouk, & Amrai, 2011), in Ghana (Anthony, 2009), and in Kenya (Ricchio, 2011). In their views of the etiology of their child's symptoms, we see that many families attributed their child's symptoms to biological or genetic factors including the U.S. (Harrington, Patrick, Edwards, & Brand, 2006), Canada (Mercer, Creighton, Holden, & Lewis, 2006), the United Kingdom (Russell &

Norwich, 2011), and Australia (Farrugia, 2009). Some blamed factors during the mother's pregnancy such as was the case of Iran (Ahmadi, Sharifi, Azizi Zalani, Bolouk, & Amrai, 2011), Kenya (Riccio, 2011), and Ghana (Anthony, 2009). A number of other families believed that there were environmental factors that could be related to their child's symptomology. African countries (Anthony, 2009; Riccio, 2011), and to a certain extent, Muslim (Jagathessan, Miller, & Fowler, 2010) and Jewish families (Shaked & Bilu, 2006), as well as the participants in Taiwan (Shyu, Tsai, and Tsai, 2010) report supernatural or religious reasons were considered to be the cause of their child's ASD symptoms. When interviewing Muslims, it appeared that having a child on the spectrum was a gift from Allah who knew the family would be strong enough to care for the child (Jagathessan, Miller, & Fowler, 2010), whereas in the interviews conducted with Ultraorthodox Jewish mothers in Israel feeling that they were given a child with special needs to make up for the sins of previous lives (Shaked & Bilu, 2006). More specifically, in Ghana, Kenya, and also according to Lotter's (1980) observations across Africa, the mother is typically believed to have brought about the child's symptoms through some type of behavior (e.g., fertility greed) that warranted a curse or attracted sorcery. China (McCabe, 2007) and Iran (Samadi, McConkey, & Kelly, 2012), also had a significant number of parents reporting frequently be blamed for their child's autism in China. Reported reactions to receiving the child's diagnosis also differed across parents in various cultures. Although a great deal reported feeling shock including those in the United Kingdom (Mansell & Morris, 2004), France (Chamak, Bonniau, Oudaya, & Ehrenberg, 2011), China (McCabe, 2008a) and Turkey (Bilgin & Kucuk, 2010), a number also reported positive emotions following the diagnosis such as relief including the U.S. (Bayat, 2007; Myers, Mackintosh, & Goin-Kochel, 2009), Canada (Kayfitz, Gragg, and Orr, 2010), United Kingdom (Mansell & Morris, 2004; Russell & Norwich, 2011),

and France (Chamak, Bonniau, Oudaya, & Ehrenberg, 2011). Other parents in countries including Canada (Mercer, Creighton, Holden, & Lewis, 2006), Taiwan (Shyu, Tsai, and Tsai, 2010), and Kenya (Riccio, 2011) reported feeling guilt and many still report feeling stress or depression including those in the U.S. (Bayat, 2007; Myers, Mackintosh, & Goin-Kochel, 2009; Smith, Hong, Mailick Seltzer, Greenberg, Almeida, & Bishop, 2010), Canada (Kayfitz, Gragg, and Orr, 2010), Australia (Giallo, Wood, Jellett, & Porter, 2011), Taiwan (Shyu, Tsai, and Tsai, 2010), Japan (Mori, Ujiie, Smith, & Howling, 2009), Pakistan (Sabih & Sajid, 2008), Iran (Samadi & McConkey, In press; Samadi, McConkey, & Kelly, 2012), and Kenya (Riccio, 2011). Finally, a great deal of families reported feeling isolated including those in the United States (Myers, Mackintosh, & Goin-Kochel, 2009), France (Chamak, Bonniau, Oudaya, & Ehrenberg, 2011), Belgium (Meirsschaut, Roeyers, & Warreyn, 2010), and China (McCabe, 2007; McCabe, 2008a).

The impact of raising a child on the spectrum is very well studied worldwide and can be found in some ways to vary greatly, and yet there remain a great many of shared experiences among families despite coming from very different cultures and regions of the world. For example, many parents reported experiencing significant stressors including dealing with their child's challenging behaviors, financial stressors, fights for services, feelings of isolation, concerns about the impact on siblings, and stressors in their marital relationships among many other stressors in a number of countries including the U.S. (Bayat, 2007; Myers, Mackintosh, & Goin-Kochel, 2009; Smith et al, 2010), in Canada (Kayfitz, Gragg, & Orr, 2010), in Belgium (Meirsschaut, Roeyers, & Warreyn, 2010), in Sweden (Allik, Larsson, & Smedje, 2006), in Australia (Farrugia, 2009; Giallo, Wood, Jellett, & Porter, 2011), in China (McCabe, 2007; McCabe, 2008a), in Taiwan (Lin, 2010; Shyu, Tsai, & Tsai, 2010), in Japan (Mori, Ujiie, Smith,

& Howling, 2009), in Iran (Samadi & McConkey, Submitted for publication), in Pakistan (Sabih & Sajid, 2008), in Turkey (Bilgin & Kucuk, 2010), in Ghana (Anthony, 2009), in Kenya (Riccio), and many more. Some researchers have looked specifically at the impact of raising a child with an ASD on the career or work life of parents and found mostly negative impacts including increased work stress or having to put their careers on hold or quitting altogether in order to better care for their child (US: Bayat, 2007; Myers, Mackintosh, & Goin-Kochel, 2009; Belgium: Meirsschaut, Roeyers, & Warreyn, 2010; China: McCabe, 2010). Interestingly, mothers in China actually cited their careers as a source of support providing a sense of “normalcy” and giving them an outlet for feeling success and independence (McCabe, 2010). A great many other parents report that, although they may experience increased levels of stress, they also have experienced life enhancement as a result of raising a child with autism including becoming stronger and more tolerant (US: Bayat, 2007; Myers, Mackintosh, & Goin-Kochel, 2009; Canada: Kayfitz, Gragg, & Orr, 2010) or accepted by the community in the case of Nicaraguan mothers who report their community embraces diversity with an attitude of “everyone is the same” (Kim, 2012).

With regard to parent experiences with supports and services, parents from around the world reported relying on support networks and/or groups for coping or as a need in terms of resources including countries such as the U.S. (Smith, Hong, Mailick Seltzer, Greenberg, Almeida, & Bishop, 2010), Canada (Mercer, Creighton, Holden, & Lewis, 2006), the United Kingdom (Bromley, Hare, Davison, & Emerson, 2004; Mansell & Morris, 2004; Ryan & Cole, 2009), Belgium (Meirsschaut, Roeyers, & Warreyn, 2010), Australia (Giallo, Wood, Jellett, & Porter, 2011), China (McCabe, 2008b), Taiwan (Lin, 2011), Japan (Mori, Ujiie, Smith, and Howling, 2009), Iran (Amadi, Sharifi, Azizi Zalani, Bolouk, & Amrai, 2011; Samadi,

McConkey, & Kelly, 2012), and Turkey (Bilgin & Kucuk, 2010). Parents also reported desiring better therapeutic services or better access to therapeutic services including parents in countries such as the United Kingdom (Bromley, Hare, Davison, & Emerson, 2004), Ireland (Langford et al., 2007), Belgium (Meirsschaut, Roeyers, & Warreyn, 2010), China (McCabe, 2007), Iran (Amadi, Sharifi, Azizi Zalani, Bolouk, & Amrai, 2011; Samadi, McConkey, & Kelly, 2012), Ghana (Anthony, 2009), Kenya (Riccio, 2011), and Somali-Canadians (Kediye, Valeo, & Berman, 2009).

Please see Table 1 for an overview of the literature reviewed as well as the themes identified across the literature.

The Current Study

As mentioned at many points throughout this paper, conceptualization of disability and, in this case, ASDs vary greatly around the world. The diagnostic experience as well as the attributions given to factors related to etiology can have a significant impact on the experiences of families after the diagnosis including the treatments they seek out and the levels of stress, fatigue, positive emotions, and more that they continue to experience. As such, it remains critical that research continue to tease out cultural factors influencing their experiences and perhaps the protective factors that appear to help ease the difficulties experienced by a great many of these families.

The Characteristics and Culture of Jamaica

The United States State Department (2012) reports that Jamaica is a country of around 2.8 million with just a little over half (52%) of the population living in urban areas; approximately 670,000 in the capital of Kingston alone. Jamaica is a constitutional parliamentary democracy and only recently (1962) gained its independence from colonization from Britain.

Approximately 91% of the island identifies as being African, with smaller numbers of those reporting to be East Indian (1.3%), Chinese (0.2%), White (0.2%), Mixed (7.3%) or Other (0.1%). English is primarily spoken throughout its tropical and mountainous terrain, although a great many continue to speak Jamaican Patois or Creole. There is great diversity in reported religious beliefs including Church of God (21%), Seventh Day Adventist (9%), Pentecostal (7.6%), Baptist (9%), Anglican (5.5%), Roman Catholic (4%), United Church (2%), Methodist (2%), Jehovah's Witnesses (2%), Moravian (1%), Bretheren (1%), unstated (3%), or Other (10%), comprised of 24,020 Rastafarian, 5,000 Muslims, 1,453 Hindu, 350 Jews and 279 Bahai.

When examining the culture of Jamaica and Kingston in particular, Wardle (2000) says in his book, *An Ethnography of Cosmopolitanism in Kingston, Jamaica*, that “while civic institutions have failed to deliver the frameworks for social justice promised by independence, ordinary people continue to discover spontaneously generated forms of consensuality – very often as a direct result of the disintegration of wider levels of social control” (p.xix). He notes that their communicative ambiguity is often laden with negotiations of cosmopolitan culture. Wardle (2000) also notes that the essence of a Kingstonian, Jamaican's both a desire for connectedness and satisfying interactions with others in their community as well as freedom in movement.

The Story of ASDs in Jamaica

Preliminary results from an epidemiological survey conducted in Jamaica, indicated that around 168 children were identified in a 9 year period, 86% with Autism, 6% with PDD, 5% with PDD-NOS, and 3% with Asperger's with an average age of 4.7 years for diagnosis (Rahbar, Samms-Vaughan, & Brooks, 2009). Dr. Samms-Vaughan, a researcher on the study, was later interviewed by a local newspaper and suggested that “We are having approximately 500 children

born in Jamaica with this condition each year and it affects boys four to five times more commonly than girls (Flemming, 2012). The discrepancies between these data (168 identified each year versus the approximation of 500 children born each year on the spectrum) seem to indicate that either preliminary prevalence estimates are grossly underestimated or that dramatic underidentification is currently occurring.

There is a research team out of Houston, Texas, that has been collaborating for several years with Dr. Samms-Vaughan at the University of the West Indies to better understand ASDs on the island. This same research group has recently begun work to investigate the potential link between genes and toxic metals as etiological factors involved in the development of ASD (Lake, 2009). Most recently, the team released a study examining maternal and paternal factors related to the development of ASD in a Jamaican sample (Rahbar et al., 2012). This study, examining 68 age- and sex-matched case control pairs found that there were significant associations between paternal and maternal age and symptoms and in both cases, the older the parent, the stronger the association with having a child with ASD. To date, this is the only research conducted on ASDs in the island.

Anecdotally, there are a number of studies of parents with children with ASD from around the island in local papers such as the Jamaica Gleaner (see Drummond, 2006; Fleming, 2012; Ustanny, 2002) and the Jamaica Observer (see Wilson, 2011). Currently, two parent organizations exist on the island. The first to develop, the Jamaica Autism Support Association, was founded by a group of five parents of children with ASD on the Island close to who meet every month at the Young Men's Christian Association (YMCA) to encourage and support each other.

There currently are no fully state-funded schools or therapy centers on the island. Recently, an initiative was started by the Minister of Labour and Social Security to create a registry of the number of children requiring assistance from the ministry's Early Stimulation Programme (Patterson, 2012). This program began in 1975 and provides assessment and early intervention for children from birth to six years old, although it is unclear if this is a free program to parents. The program currently serves 105 children with special needs such as Down Syndrome, cerebral palsy, learning disabilities, behavior problems, and intellectual disability (termed mental retardation in Jamaica).

Few schools exist to serve children with ASD and the ones that do exist are overcrowded (Wilson, 2011). In particular, children with ASDs are rarely served by their local schools due to lack of training by staff to address associated behaviors and symptomology. Rather, many families are tasked with "shopping" for schools willing to take their children and who have the necessary resources to provide instruction specific to these students' needs. In most cases, families must provide a "shadow" or "auntie" to monitor the child's behavior and provide additional assistance as necessary. Costs for a shadow can be around \$288,000 JD (\$3,118 USD at the time of this study), with tuition costs around \$296,800 JD (\$3,212 USD at the time of this study), and therapy costs similar to those in the U.S. although therapy in Jamaica is not covered by insurance. When considering approximately 17.5% of the population lives below the poverty line (The World Bank, 2012), a relatively high inflation rate (7.5% compared to 3.1% in the U.S.; CIA World Factbook, 2011), and the gross national income per capita (GNI per capita) in purchasing power parity (PPP) for a family in Jamaica is around \$6,660 USD (by comparison GNI per capita in PPP is \$48,820 USD in the United States at the time of this study; The World Bank, 2012), the costs of supporting and educating a child on the spectrum are extremely

prohibitive for most families. While the first six years of primary education is compulsory in most of Jamaica, there was only an 81% net enrollment between the years 2007-2009 according to UNICEF (2012) with similar rates of attendance in both rural and urban areas and, according to the Jamaica Education Ministry, education is not compulsory for the close to 3,400 students labeled as having “special needs” (i.e., visual impairment, hearing impairment, physical impairment, mental retardation, giftedness, and/or learning disabilities) (Jamaica Education Ministry, 2012). Given that most educators and schools in Jamaica are extremely under-prepared for supporting the needs of children with ASD and the relatively high costs of educating a child on the spectrum for families, it seems likely that many children with ASD may go without access to education or at the very least without access to appropriate education.

Although progress has been made over the past few years, primarily through the work of parent advocates like Kathy Chang, president of the Jamaica Autism Support Association, awareness of ASDs and proper treatment for related symptomology is still in its infancy within the country. Little is understood about the diagnostic process experienced by parents seeking diagnosis for their children in Jamaica and even less is understood about the impact of the diagnosis on family’s daily lived experiences. It is one of the goals of this study to better understand how the perseverance of this culture manifested in relation to social justice for children with ASD in Jamaica.

CHAPTER III

Methodology

Purpose

The purpose of this study was to explore the perceptions of mothers in Jamaica with regard to (a) how their child came to be diagnosed as having an ASD, (b) what types of supports and services the child and family have received, and (c) how having a child with an ASD has impacted family life. The following research questions guided the study:

1. How do Jamaican mothers describe their journey from the birth of their child to diagnosis of their child with an ASD?
2. How do Jamaican mothers describe the experience of having their child diagnosed with an ASD?
3. How do Jamaican mothers describe how they and their family have been affected by having a child diagnosed with an ASD?
4. How do Jamaican mothers of children diagnosed with an ASD describe what day-to-day life is like for them?
5. How do Jamaican mothers of children diagnosed with an ASD describe supports and services that their child and family receive?
6. How do Jamaican mothers of children diagnosed with an ASD describe their vision of the future for their child?
7. What advice would Jamaican mothers give to other mothers who have a child who has just been diagnosed with an ASD?

Theoretical Framework

The author used an *ecological systems theoretical framework* (Bronfenbrenner, 1979) to guide data collection, analysis, and interpretation. This framework posits that children's development is heavily influenced by the contexts or environments they develop within. More specifically, Bronfenbrenner (1979) noted that there are five important environmental systems that influence an individual's development: the *microsystem*, *mesosystem*, *exosystem*, *macrosystem*, and the *chronosystem*. The macrosystem is best described as the larger socio-cultural context in which the individual operates (e.g., the language or dominant religion of the larger culture). The exosystem can be defined as the external environments indirectly influencing development (e.g., parental career factors). The mesosystem, on the other hand, is where the interaction of two systems that directly affect the person (e.g., the family and the school) exist. The microsystem is the immediate environment that directly impacts the individual (e.g., the classroom). Finally, Bronfenbrenner (1979) defines the chronosystem as the way environmental impacts over time affect the individual (e.g., generational influences). This framework considers the experiences of the individual from these multiple perspectives and research based in this framework considers these multiple systems when explaining phenomena.

An exploratory, qualitative approach was used to describe these mothers' lived experiences before, during, and after the diagnostic process. In keeping with this approach (Dukes, 1994), experiences or perspectives were captured through single interviews with 13 participants. These perspectives relate to the current study in that the author is completely blind as to what the experiences of these families living in Jamaica may be. It is the belief of this author that, whatever the findings may be, they are the result of these individual's reality, which is shaped by their perceptions. The broadly developed semi-structured interview was intended to

capture these perceptions without the constraints of discrete categorical units of analysis for participants to choose from, however, still using an interview guide in order to draw the participants' attention toward these experiences.

Participants

A participant sample was obtained using the purposeful sampling, snowballing procedures, and inclusion/exclusion criteria described later in this chapter. Using these procedures, a sample of 13 mothers was attained with the intention of capturing a diversity of voices from around the greater Kingston area within Jamaica. Parents volunteering to participate in this study differed within themselves in the areas from within Jamaica where they were located at the time of interview, their occupations, their child's gender and age at the time of interview, as well as their diagnosis and the age at which they received the diagnosis. All of the mothers' children had been diagnosed by the same doctor at a university clinic on the island but were diagnosed at various points within the last decade reflecting some of the changes that have occurred in the diagnostic process within the last 10 years.

Of the 13 mothers who participated in this study, six of the 13 (46%) reported their marital status as "single," another five reported their status as "married" (38%), with one (8%) mother describing herself as living with her partner (her child's father), and the final mother (8%) describing herself as "divorced." While all of the mothers reported living in Jamaica year-round, most of the mothers (9/13; 69%) reported living in the greater Kingston area, two mothers (15%) living in the St. Catherine/Portmore area, one mother (8%) living in the St. Anne area, and the last mother (8%) living in the Spanish Town area outside of Kingston. Of the 13 mothers, 11 of the mothers (84%) described themselves as Jamaican, one mother (8%) described herself as Trinidadian, and another (8%) as Jamaican-Chinese. The mothers reported holding a variety of

occupations in a variety of fields, including professional and clerical work, with all but one mother (8%) working (92%).

With regards to the characteristics of the child diagnosed with ASD whom mothers were raising and discussing in interviews, 11 of the 13 children (85%) were male and 2 were female (15%). Children ranged in age from four years old to 17 years old at the time of the interview with the average age at the time of diagnosis 34 months or almost three years old (ranging from two years old to six years old). Of the 13 children whose mothers participated in the study, their diagnoses (as reported by mothers) were as follows: four with moderate autism (31%), three with autism (23%), three with mild autism (23%), two with severe autism and Attention-Deficit/Hyperactivity Disorder (15%), and one with mild to moderate autism (8%). It should be noted that physicians and psychologists on the island were using ICD-10 (WHO, 1993) criteria for diagnosing at the time of this interview.

Participant Descriptions

Breona. The researcher first met Breona and her friend Taneisha when visiting the Jamaica Autism Support Association (JASA) monthly meeting at the Kingston YMCA. They both appeared reluctant to participate when the researcher first described the study, but after explaining my motive to share their stories with others from around the world in an effort to gain more attention for improving services in Jamaica for their children, both were very eager to participate. Early on the day of the JASA workshop the following weekend, both Breona and Taneisha approached me and asked to be interviewed during breaks later in the day. When meeting with Breona for the interview, she was open and appeared eager to share the story of her family. Breona was raising her children with her partner.

Cantrice. When this researcher first met Cantrice it was apparent that she was very guarded. While the researcher explained consent for the study, Cantrice stopped her to ask why the experiences of fathers or grandparents were not being explored. When the researcher explained that she considered these experiences to also be important to understanding how to support families of children with ASD, but that it was beyond the scope of what could be accomplished in her first trip to Kingston, Cantrice encouraged her to return to look into this further. Cantrice was raising her children with her husband.

Carsandra. Carsandra was one of the first participants to respond to the announcement of the study through the JASA listserv. Upon first meeting Carsandra at the researcher's hotel to interview her, she appeared to be reserved and asked that the interview be conducted outside of the café away from other hotel guests. She had just gotten off work and said she wanted to meet with the researcher to share her story in the hopes of improving awareness of autism in Jamaica. Carsandra was raising her child alone.

Dondrea. Dondrea was one of the first mothers who volunteered to be interviewed when the study was announced by JASA. She met the researcher at her hotel after she left her job for the day to talk about her experiences raising Brian. Brian was nine-years and six-months old at the time of this interview, but around two-years and six-months when he was diagnosed with autism. Dondrea was raising Brian alone.

Elesha. Elesha was living outside of Kingston in a more rural area and so the best meeting place for her to interview with the examiner was at the workshops being offered by JASA. She was raising her daughter with her husband at the time of this interview.

Ella. When the president of JASA first told the researcher about Ella, she made sure to let me know that, although Ella was interested in participating in the study, she was very suspicious

of the researcher's motives for travelling to Jamaica to interview mothers about their experiences. Ella asked to meet with the researcher at the café at the researcher's hotel after she left her job. There she discussed the study further with the researcher and what the researcher was hoping to achieve by sharing the stories being compiled. Ella told the researcher that it was hard to share her story but that she felt like it was important for bringing greater understanding and attention to autism on the island. Ella was raising her child alone at the time of this interview.

Ernestine. Ernestine was living in a rural area outside of Kingston at the time of this interview and elected to interview with the researcher at the JASA workshops. Ernestine was working professional field and was raising her son alone at the time of this interview.

Libby. Libby was bubbly and vivacious from early interactions with the examiner. Throughout her interview, although she spoke of a number of difficulties she has encountered in her journey, Libby used humor frequently and spoke of her no-nonsense, just-do-it approach to her journey having a child on the spectrum. Libby was raising her children with her husband at the time of this interview.

Louella. Before the researcher met Louella, she had been introduced to Louella's husband Wesley. Wesley was very active in JASA and escorted the researcher and her traveling companion, Dr. Keating, to dinner one evening where he expressed a great deal of interest in this study. While he talked with the researcher about his own experiences raising a child on the spectrum, he mentioned on several occasions how eager he was for his wife to participate in interviews. Louella appeared somewhat reluctant to interview, although she verbalized on a number of occasions that she was eager to participate. The interview seemed somewhat difficult for Louella, who became emotional on a number of occasions throughout the interview.

Rebecca. Rebecca met with the researcher at the JASA workshop to tell her story about raising her nearly four-year-old son who was diagnosed with moderate autism a little over a year earlier at the age of three-and-a-half-years-old. Rebecca seemed eager to speak with the examiner when the interview began. She was raising her children with her husband at the time of this interview.

Rosie. Rosie and the researcher first met at the JASA fundraiser. Rosie was not especially talkative, but her interview was compelling in its optimism. Rosie appeared to take everything in stride despite raising Astrid and an 18-year-old son on her own on a modest salary and expressing hints of frustration over not being able to provide Astrid with what she considered more appropriate education. Rosie was raising her children alone at the time of this interview.

Taneisha. As described earlier, the researcher first met Taneisha when she attended the JASA monthly meeting at the Kingston YMCA with her friend Breona. Taneisha appeared guarded when first describing the study to her, but similar to Breona, after hearing that the goal of the study was to share their stories with others from around the world in an effort to gain more attention for improving services in Jamaica for their children, she was very eager to participate. Taneisha and Breona approached the researcher early on the day of the JASA workshop the following weekend, asking to be interviewed during breaks later in the day. Although the researcher had been interviewing mothers in a classroom away from the workshop meeting rooms, Taneisha asked that her interview could be conducted in an office space far-removed from the rest of building. She was raising her son alone at the time of this interview.

Wyndolyn. At the time of the interview, Wyndolyn was living in a rural area outside of Kingston and as such elected to interview with the researcher when she came to Kingston for the

JASA workshops. Wyndolyn was raising her five-year-old son with diagnoses of severe autism and Attention-Deficit/Hyperactivity Disorder alone.

Procedure

Figure 1 presents the flowchart of how data collection and analysis were conducted.

Step 1: Pilot Study

Pilot interviews were first conducted with two mothers of youth (ages 2-years-old and 4-years-old) with a diagnosis of ASD living in a community within a large urban area in the Southeastern U.S. Mothers participating in pilot interviews were given a brief introduction to the pilot interview process and a reminder of the approximate time necessary for completing the interview (approximately 60 to 90 minutes). See Appendix A for the “Explanation of Pilot” sheet provided to mothers participating in the pilot study. Pilot interview questions are provided in Appendix B. The results of the pilot study yielded adequate data necessary for theme identification and also showed the researcher that the interview would take approximately 45 to 60 minutes. The transcripts from the pilot and sample themes pulled from pilot interviews are included in Appendix C. It should be noted, however, that pilot data seemed to be too constricted by the nature of the structure of the questions and, as such, final interview questions in Appendix G reflect more broadly posed open-ended questions. A letter indicating final approval to conduct this study given by the Institutional Review Board at the University of South Florida is included in Appendix H.

Step 2: Bracketing Interview

An initial bracketing interview was conducted as is common in qualitative research (Gearing, 2004). Bracketing involves the researcher deeply examining his or her own experiences as much as possible to take a fresh look at what is being studied (Creswell, 2007).

The process consists of “unpeeling” the many layers of various levels of consciousness surrounding the researchers own preconceived notions, presuppositions, emotions and biases in an effort toward greater self-awareness for the researcher (Tufford & Newman, 2010). It is recommended that the bracketing process begin prior to interviewing and continue throughout the entire course of study. Later, the researcher engages in unbracketing or reintegration involving folding the bracketing back into the larger study. For the purposes of this study, the researcher engaged in a bracketing process immediately following study conceptualization and immediately prior to traveling to Jamaica. The researcher continued to engage in the bracketing process throughout the course of her trip in Jamaica through an online blog. Finally, the researcher engaged in an unbracketing process at the end of data analysis, which involved integrating earlier bracketing and reflections upon results. The bracketing interview for this study and screenshots of posts from the author’s blog are included in Appendix D. The unbracketing interview for this study is included in Appendix J.

Step 3: Participant Recruitment and Sampling

Purposeful sampling (Creswell, 2007) was used with the intention of finding approximately six to 10 mothers, the recommended sample size for research of this kind (Dukes, 1994). The final sample included interviews from 13 mothers. Mothers were required to meet study standards including the criteria of living in Jamaica and having a child diagnosed with an Autism Spectrum Disorder. Participants were recruited through the Jamaica Autism Support Association (JASA) and all participants that had been recruited were included in the final sample. Initial contact was made at a fundraising event for JASA held in Kingston, Jamaica, at the Spanish Court Hotel and by the officers of the JASA organization who were informed of the study’s purpose, inclusion criteria, and informed consent materials. The author engaged in

extensive dialogue with the officers of this organization via the Internet (email and Facebook). These officers consulted with the researcher regarding culturally sensitive research practices in Jamaica including offering food and/or drink at interviews rather than financial incentives which may be perceived as offensive, the preference for interviews to be conducted at a location of the participant's choosing such as the hotel of the investigator as opposed to in the family's home where they might feel uncomfortable. The researcher also worked with the officers of JASA in an attempt to recruit mothers who may potentially vary in their experiences raising a child on the spectrum including and in particular living in both urban Kingston and surrounding rural areas, having a child who had been diagnosed many years ago on the island as well as mothers raising a child who had very recently been diagnosed, and mothers who were raising their child alone as well as those mothers raising their child with a partner.

A "snowballing" method was used in an attempt to reach more potential participants. Snowballing is a method of sampling that asks other participants or community members to identify more individuals that could also be information-rich for the purposes of the study (Creswell, 2007). Researchers suggest that using this type of approach to sampling not only better enables researchers to identify a greater number of individuals affected by the phenomenon but also yields rich information about the social networks, grassroots organization, and social dynamics of the individuals involved in sampling (Noy, 2007). For the purposes of this study, interested participants and officers identified at the fundraiser were read the informed consent and asked to voluntarily contact other members of the community who they believe may be interested in participating. If participants felt they knew of interested parties, they were asked to provide the researcher's contact information in Jamaica to said parties. At this point, the researcher explained the study's consent including, confidentiality,

as well as the data collection procedures (e.g., the interview will take approximately 60 minutes, the use of audiotaping and transcription, the use of pseudonyms). See Appendix E for the Informed Consent Form. At this time the researcher also confirmed that the family met inclusion criteria. More specifically, that English is their primary language spoken, that they live in Jamaica for more than 75% of the year, and that their child has received a diagnosis on the Autism Spectrum by a medical doctor or professional with similar training in assessing and diagnosing Autism Spectrum Disorders. Mothers were also required to live with their child at least 50% of the time. The researcher utilized a checklist (see Appendix F for inclusion checklist) to ensure mothers met criteria for inclusion in the study. The researcher intentionally selected families who varied as much as possible in their cultural, racial, ethnic, and demographic factors (as listed in the Inclusion Criteria Checklist) but who share the culture of families of children and adults with Autism Spectrum Disorders. Participants were read the informed consent form (as the investigator was not sure of the literacy level of participants) and were asked to provide verbal consent. At this time, participants were asked about their preference for where the interview would take place and a time for the interview to be conducted was set up.

Step 4: Interview Data Collection

Consent. In addition to the reading of the informed consent form at the initial phase of recruitment when verbal consent was obtained, the researcher read the informed consent form immediately prior to conducting the interview. At this time, the researcher took a second opportunity to explain the study's purpose, the use of a digital voice recorder, confidentiality, and the use of pseudonyms to the participant. Participants were then given an opportunity to also read the informed consent form, ask any remaining questions they may have about the study, and provide their signature indicating their consent on the form.

Interviews. Interviews and interview techniques were formulated according to the standards for interviewing put forth by Kvale and Brinkman (2009). More specifically, the type of interview utilized in this studied best meets the definition of narrative interviewing which focuses on the stories, plots and structures as told by interviewees. Typically, this interview structure is temporal and asks the interviewees to describe the beginning of their story and progress through to present day. An interview begin with briefing, which involves description of the situation under which interviews came about to participants, purpose of the interview, and the use of a sound recorder; the researcher asked participants if they had any questions prior to the start of the interview. Upon completion of the interview, the interviewer engaged the interviewee in a debriefing process which involved asking the participants if they had anything more to say and mentioning a few summarizing points of what the interviewer had learned through the interview. The interview used a script and, for the purposes of this interview, a semi-structured interviewing technique composed of open-ended questions was used to provide opportunity for mothers to share their experiences, starting with reflection upon when they first suspected that something was different about their child's experience and ending with their expectations for the future. The interview guide was composed of introductory questions, potential follow-up, probing, and specifying questions. Kvale and Brinkmann (2009) suggest that, when preparing to interview participants across cultures, the interview guide should be developed with a solid understanding of the new culture and any verbal and non-verbal factors that should be considered when interviewing participants from another culture. As such, the researcher consulted with contacts at the Jamaica Autism Support Association (JASA) to ensure cultural-sensitivity in the interview guide. Additionally, JASA consultants discussed potential cultural barriers to the interview including the importance of first establishing trust and credibility with participants

prior to the interview. This was done through the introduction of the researcher to participants in a number of social settings including visits to therapeutic settings, participation in a local support group meeting, and attendance at a JASA fundraising function.

Confidentiality. All written information and interview transcripts contained no identifiers and were assigned pseudonyms. Written information was stored in a locked filing cabinet and digital recordings were encrypted and stored on an encrypted laptop. Participants and their children were referred to using pseudonyms in all subsequent analyses and sharing of results.

Step 5: Data Analysis

Dialogue with the mothers from the pilot study was analyzed using the approach outlined by Creswell (2007, p. 159) in order to assess whether the interview questions developed could adequately produce themes related to the author's research questions.

More specifically, the researcher followed these steps in analysis:

1. Describe the researcher's personal experiences with the phenomenon through bracketing.
2. Transcribe conversations with participants verbatim and develop a list of statements appearing significant to the interviewer in relation to other salient information provided throughout the course of the interview.
3. Take the statements seen as significant in that they were mentioned by a number of participants or mentioned frequently for one participant and begin grouping them together into larger units of information called themes.

Regarding transcription, Oliver, Serovich, and Mason (2005) describe two trends in transcribing conversations with individuals who may have accents or speak in different dialects. In the "naturalistic" approach, the researcher transcribes by trying to capture the dialect and

accent used by participants and includes nonverbal nuances, whereas in the “denaturalized” approach the researcher transcribes data using Standard English attempting to best represent what participants have said. The researcher used blended “naturalistic” and “denaturalized” approach to transcription (Oliver, Serovich, & Mason, 2005). More specifically, after reading several articles in Jamaican newspapers, the researcher noticed that accents and Patois were represented in quotes. As such, the researcher took a similar approach to transcription of her conversation with participants, leaving out nonverbal communications (e.g., smiles, tears up, etc.) made during the course of transcription for fear that she may overinterpret the nuances related to these nonverbals as pointed out by Oliver and colleagues (2005). After transcribing the interviews with mothers, the researcher contacted mothers and asked them to review the transcripts in order to ensure that transcripts accurately reflected the participants’ responses and also to allow them the opportunity to decide whether or not the transcripts best represented them. Unfortunately, the timing of transcript reviews coincided with a major hurricane hitting the island causing weeks of recovery work. As such, only five mothers (39%) responded with reviews of their transcripts. Participants responded with only minor edits targeting grammar errors with one mother preferring to translate several instances of Patois from her transcript to Standard English.

Following these guidelines, the researcher then pulled significant statements from transcripts and organized them according to research questions. Themes were then analyzed according to the three levels of analysis adapted from LeCompte and Schensul (1999). The model of analysis was as follows: (1) *pattern-level* describing trends across participants as they relate to each research question; (2) *structural-level*, which addresses patterns across participants that were not related to the research question but still important to the study, and finally; (3)

interpretation which is describing the ways in which themes relate back to the ecological framework within which this study was developed. Additionally, any information in the mothers' stories that deviated from categories and themes pulled was also noted where appropriate. The final codebook developed for theme analysis is included in Appendix I.

At this point, the researcher engaged in a number of validation strategies as described by Creswell (2007). The researcher began by conducting triangulation of data through multiple analysts. The first step in triangulation involved reliability checks of the identified themes. Both the researcher's major professor as well as the faculty member who assisted with coordinating the study in Jamaica, and thus was more familiar with the culture of ASD in Jamaica, reviewed a random selection of a little more than half of the available transcripts and coded themes independently of one another and independent of the researcher. The researcher then calculated interrater reliability among the two faculty members and the researcher. Interrater reliability was calculated using a method outlined by Marques and McCall (2005) whereby the number of independently agreed upon themes (as measured by the matching presence of a code) between the researcher and each reviewer was divided by the totally number of researcher-identified themes to give an overall percentage of agreement. Agreement between the researcher and the researcher's major professor was found to be 61% and the agreement between the researcher and the faculty member who accompanied the researcher on the trip for data collection was 65%. These levels of agreement fall within the suggested acceptable range across a review of several studies, which suggest between 50% and 90% agreement as the standard (Marques & McCall, 2005). The team of raters then met and discussed disagreements until a consensus was reached on the most appropriate theme for the text chunk in question. The next step in triangulating data involved conducting member checks. More specifically, the themes and deviations were checked

with participants through the emailing of transcripts and/or discussion of transcripts and themes via telephone or Skype, depending on the participant's preference. Five mothers were reached and engaged in the member check process. There were no suggested changes to the themes pulled from each mother's story and all of the mothers engaging in member checks reported themes represented their story well.

CHAPTER IV

Results

The results of this study have been examined both as they relate to the initial research questions the examiner sought to explore as well as the theoretical framework or ecological theory the author chose as a lens for examining these findings.

Analysis of Themes

Pattern-Level Analysis

Pattern-level analysis describing trends across participants as they relate to each research question was conducted and a number of notable themes emerged.

Question One: How do Jamaican mothers describe their journey from the birth of their child to diagnosis of their child with an ASD? The responses from mothers to this initial question first yielded some general information regarding their pregnancies, the child's birth, and their early development. Themes began to emerge regarding what age they began to have concerns for their child's development and what behaviors they could recall to be the first signs of developmental concerns.

In response to this question, most mothers (62%) report having an unremarkable pregnancy and typical vaginal delivery without complications (46%). There was a smaller number of mothers (31%) who noted complications with pregnancy including prematurity or suspicion of infection prior to birth and a relatively high number of mothers (46%) reporting delivery via C-section. Interestingly, most mothers (67%) report that their child experienced typical early development, although several mothers (33%) did recollect seeing behaviors early

on such as the child crying inconsolably or being very picky about breastfeeding or eating that led them to suspect their child may not be developing typically. In reflecting, Elesha said:

...I think bit of an issue on the day she was born, I got torn so I couldn't breastfeed her so I hear that girl crying for the whole night and it was heartbreaking for me because I knew it was her. Hear her crying and the next morning when they finally brought her to me the nurse said, "I don't want to hear her crying no more! Take her home!" and so another morning the other nurse said "Do not take her back into the nursery!" and she said "Do you want to keep her?" and of course I said, "yes." So she just cried a lot... Ya know old people are able to hold your baby and you couldn't hold my baby because she would go kind of like, we just thought that she was maybe a little bit of a selfish person and I remember I had to give her to my mother and her other grandmother and when I came back she was still crying. She was still bawling. They were outside pacing the backyard with her and she was bawling and those were her grandmothers. Ya have to push around her all the time.

When asked about when they first noticed signs of developmental concerns, there was an equal distribution of answers ranging from 6 months (25%), to 12 months (25%), to 18 months (25%) to as late as two-years-old or 24 months (25%). Additionally, several mothers (23%) reported that they had no idea their child wasn't following expected development until a neighbor or teacher, or in some cases their pediatrician, pointed it out to them. Cantrice mentioned:

We thought he was great until he was 18 months old. I mean, I had no clue. The first suspicion was from his pediatrician. Up until then, he was perfectly fine. When she said that he was not speaking as he should and that might be an early sign of autism that I was

like, “Huh?” So there was no concern until she said that. And then other things came to my mind.

Louella had a similar experience and shared, “Parents want to think that it’s just a phase, but it’s not. The teacher noticed the difference in behavior and she suggested that I should have him assessed.” For parents who did notice signs and symptoms they believed to later be associated with their child’s ASD, the primary concerns that piqued their attention included a language delay or that the child wasn’t speaking (39%), hyperactivity (31%), picky eating (31%), not responding to their name or acting as if they weren’t hearing (23%), a regression in skills that they had previously demonstrated (23%), lack of socializing (21%), repetitive behaviors such as flapping, spinning or rocking (21%), as well as less frequently noticed behaviors including self-injury (8%), echolalia (8%), and toe walking (8%). Elesha thinks back to her daughter’s early development and remarks:

I can’t remember at which point I was thinking “She is not responding when I call her,” and I really don’t remember when it was. I remember feeling like “She’s not looking at me and she’s just staring past me and she was looking past me.” People always coming and saying “Why is she not calm?” I go to church and people would say, “Oh look at that little baby!” and she would scream and I remember she would knock herself in the wall or the bed. Like if things don’t go her like she wanted attention and would knock into the wall and you hold her in your hand and you pick up her and she bend back and hit her head on the wall. She used to do that when she was very little. I didn’t know what that was. I did not think that was anything. I just thought the child was I don’t know just stubborn or whatever or defensive or whatever.

Similarly, Breona remembers that, “when he was about 18 months we realized that he’s not saying anything...But his side of the family say when daddy was late to talk. So we really didn’t think there was anything wrong.” Rosie noticed similar delays in her daughter:

She didn’t have language so that was a problem. She got language of like one word. She wanted something she would pull ya to it. She didn’t get language until she was about 5-years-old. Not full sentences. Like two or three words or whatever ya understand?

As is demonstrated by the relatively large amount of variability in mothers’ descriptions of their journey from pregnancy to early development and early signs of ASD, there is no clear profile of pregnancy, delivery or development that stands out as being unique to children on the spectrum, other than that the most prominent signs alerting parents to atypical development is in most cases delays in language, although a variety of other behavioral symptoms can also be of concern to parents.

Question Two: How do Jamaican mothers describe the experience of having their child diagnosed with an ASD? Themes in this area emerged in several categories: the help-seeking behaviors mothers engaged in after first noticing signs of developmental concerns (if they were the first to notice), the reactions from the child’s pediatricians if mothers had brought their concerns to the pediatricians, and their experience with the process of having their child diagnosed and the changes they would suggest for improving the process. Mothers also spoke with the researcher about their initial reactions to diagnosis and the reactions of other important people in the child’s life when first learning of the diagnosis. Finally, several mothers also spoke of their hypotheses regarding the etiology behind their child’s symptoms.

When mothers were asked to describe their help-seeking behaviors after growing concerned about their child’s development (for those who had concerns prior to their child’s

diagnosis), a number of parents (39%) began researching the Internet or reading in books and magazines (23%) in search of answers. A small number of mothers (15%) began talking to other parents they felt might be able to help them better understand their child's behavior and a few (15%) went ahead and began to get treatment for their child's behaviors before they even pursued an evaluation to look at possible diagnoses for their child knowing that there may be an extended wait for evaluation. Libby especially spoke of her proactive approach to addressing her son's symptoms before he had even been evaluated:

Before he was diagnosed I said "there is something wrong with him" and no one is taking me on, but I'm on the Internet and researching this is what it looks like to me and I told Nursey, "If you see him in a corner or anything like that doing anything repetitive you stop him" and she said "sure" so she was structured from when he was very young. She did stuff that probably as a parent I could not do at the time but anything I asked when I came to her she was quite willing to do, plus she has a nephew who was autistic but she didn't say it so anything he got into like rituals, etc. anything like wheel spinning things or rocking or sitting in the corner, I said "no." I didn't care. This was before he was diagnosed.

A majority of parents (62%) reported seeking out further assessment from their pediatrician. Of parents who pursued assessment from their pediatricians, half reported that their pediatrician acknowledged their concerns and gave them a referral for further evaluation at the specialty clinic at the University of the West Indies (UWI) that, at the time, was the only place where there were professionals trained in ASD evaluation and assessment, or in the case of one mother, the pediatrician went ahead and diagnosed the child as having autism. However, another half reported that their pediatrician was dismissive of their concerns. Breona remembers, "We

brought him to the doctor and drew his attention and the doctor said, ‘No man. Boys take a while to talk’ and he was saying the baby talk and alla dat,” at which point she sought a second opinion from another pediatrician on the island who later provided her a referral for further evaluation at UWI. Ella remembers:

The teacher say to me, “he’s not responding to me when I call him” and he was doing that at home, but at the time his pediatrician told me “Oh he’s a boy... my son does that when he’s older he look alright...” but I think something is wrong with him because when you call a child he look to ya, even if they don’t look for long periods, they turn their head. Something is happening and he wasn’t doing that.

Similarly, Taneisha remembered that her pediatrician wasn’t altogether dismissive, but was also reluctant to pursue further assessment saying:

So then I take him to the doctor and the doctor said, “Well let’s wait til two years to see what is happening because at different stages you do different things.” But he walked early. He walked at 10 months but he wasn’t actually saying anything up til then.

Finally, one mother, Carsandra, did not wait for a referral and instead immediately scheduled an appointment for an evaluation at UWI and simultaneously began seeking treatment for her child. She remembered:

It was like from out of nowhere people came who either had autistic children and so where we used to live, there was this next door neighbor. She was an Indian and her child was mildly autistic and she goes to Lisa. So I was talking to her about what I was experiencing with Alan and she said “Why don’t you see Lisa and try and find out?” Because I had already booked with [the University of the West Indies specialty clinic] but it would take like a year before I could find out. So I said “Ok, I’m going to go to Lisa”

and she said it may not be as good in your little boy but there are signs that he has autism. But I started treatment at Lisa before I even got the diagnosis from Dr. Samms-Vaughan.

All but two of the participants, went on to later receive their diagnosis from a physician at UWI. With regards to that specific evaluation process, two mothers made mention of an extremely long wait for evaluation. Three mothers reported that after the initial assessment appointment when they returned to review the results of the evaluation with the physician, they were handed a report to read in the waiting room. One mother stated:

First and foremost, [the physician] came to the interview one hour late. The interview was done in a very across the desk situation and you wait for the results. She again was another hour late. Then she handed me the report and said I am to read and she'll soon be with me. So my girlfriend who came with me for the report, she did the reading while I sat there and wept.

Another mother recollected:

So the whole assessment process was very traumatic for everybody. They're doing things that, ya know, the child is not capable of doing to assess where they reach, so it's traumatic. I don't know if it was a time thing issue or if that is the culture because she knew I would understand, but she just gave me the report to read and that is how I found out, but as a parent it was very strange to me. I don't know why, but ya know... you start to think about it and you're like "What am I going to do? What is he going to do? What is he going to become? What is he not going to become?" That was my process and it was without the doctor and it was not good at all.

One mother commented specifically on the fact that, until very recently, there was really only one doctor on the island available for diagnosing noting, "Jamaica seems to have a monopoly

where a lot of things are concerned including telephone, cable, it's just a way of life. So one person has a monopoly on us and she's not necessarily right. Ya know?"

Most parents (62%) reported receiving information including referrals for services and therapies, although some parents did not necessarily find this helpful. Dondrea remembered being told: "Occupational therapy recommended. Speech recommended – a couple of names. ABA recommended, but not available in Jamaica. That kind of thing." One mother remembered the doctor recommending medicine to address her child's challenging behaviors, although a great many more went on to later receive similar recommendations at later points in their child's development. Additionally, three mothers (23%) reported receiving limited information about course or prognosis in terms of what to expect as their child continues to develop and age.

Finally the researcher asked mothers to describe any changes they would recommend for improving the diagnostic process for parents and families. A little less than half of mothers (39%) said they would recommend improvements to the evaluation process currently in place in Kingston including two mothers recommending a shorter wait for an evaluation, one mother recommending more time, care, or sensitivity taken in delivering the diagnosis, one more recommending that there be more doctors to diagnose as illustrated by the previous quote, and one mother suggesting that more time be taken in the evaluation process and that the evaluation take place in multiple settings where the child's performance may look different depending on their comfort level.

The researcher was also interested in learning more about the mothers' initial reactions to learning their child was diagnosed on the autism spectrum. Although mothers demonstrated a range of emotions immediately following the diagnosis, the most salient feeling experienced by 10 of the 13 mothers (77%) was one of despair, sadness, or being overwhelmed at the news.

Breona remembers receiving the diagnosis and says, “After that I cry and I say “Lord Jesus” because based on what I see and hear on the Internet I’m like “Lord Jesus”... I stayed home the whole day and cried.” Ella had similar sentiments saying:

At first, I mean, it’s overwhelming because you now know that your child is falling into a category of special needs section of society. Therefore, I cried a lot, I didn’t leave the house... I was just in tears literally for the first weeks.

Ernestine recalled, “I couldn’t stop crying. I just couldn’t stop crying. I cried and cried about that. That’s how you couldn’t get me to talk at that time until maybe 3 months, I don’t know. Too long.” Wyndolyn remembers when the doctor said “autism” and says:

Ya know that sometimes you know the truth, but when you hear it from somebody else it’s a little more real and you really don’t like it. So that’s how he was diagnosed. I’m crying and most of the time I’m wondering, “How am I going to get through this?” because I am a person that I have a problem and I am not going to stop until I can figure it out. That’s just my nature. That’s how I am.

Other mothers (31%) report initially reacting by dismissing the diagnosis or remaining in denial for some time. Dondrea talks about her mixed feelings:

Oh man, my world crumbled. Devastated. Personally, I never knew the extent of the condition. I knew it was not something good, but as to the extent of it, I never knew. I just wasn’t prepared to accept it. I was in denial for a while. Not very long because I’m very proactive so that is why I sought a second opinion. So yeah it was devastating.

Other mothers remember immediately worrying about the future for their child as illustrated by Louella’s experience saying, “Well, I mean, it was kind of hard. Sometimes you think that... you

worry about the future. And sometimes you feel like a lot of pressure. [Tears up.]" Cantrice had similar thoughts saying:

When we got home I thought "What is going to happen to him? What is going to happen when I can no longer control him when I'm 90 years old with a 6'3" doing 5-year-old kind of things. What is going to happen to him when he's 30, 40, 50?" You don't plan to have a child with a disability. You plan to have a healthy child.

Several mothers (15%) reported feeling relief at having an answer or feeling acceptance.

Carsandra, who had done research prior to having her child assessed prompting her to begin treatment while she waited for the evaluation, remarked:

I already had an idea that something was wrong. So when she called us... she said "Yeah, he has autism but it's mild ya know" and so I said I have to do something about this and we catch it early so I wasn't crying. I have heard stories whereby you are expecting that your child has autism, but when the doctor actually says "Yes" you are crying. But I wasn't really like that. I was like, ok sorta a thing, I kinda expected it.

Libby talks about "redefining the dream" she had for her son after receiving his diagnosis saying:

I come from a strong academic background and you have expectations for these children and you have to learn to let that go. You learn to let that go, but you learn to appreciate what they're doing. What they're actually getting done

One mother spoke of feeling guilt after learning of her son's diagnosis. His conception was unplanned and very close to the birth of her older daughter. She had been depressed throughout the pregnancy at the thought of having two very young infants at the same time and wondered if this had in some way impacted his development in the womb. She recounts:

I worried because during the pregnancy, I really feel guilty because when I found out he was diagnosed with autism, I was really sad and really shaken up and I feel so guilty. Because now when I look back on it I realize that I shouldn't be different and thinking about, I should be there and nurturing him inside because I have him when it was over. I had my first child and I was - the first one came out in a different way. This is one of the things which I think he has the autism, so I have this guilt. I was happier... ya know sometimes people say, ya know "You shouldn't be like that" and it's still not bad. You have never heard of that causing autism?

In summary, although mothers had a range of reactions including denial, guilt, worry over the future for their children, and engaging in a process of redefining their vision of the future for their children upon learning of their diagnosis, most mothers experienced a period of sadness, despair, or feelings of being overwhelmed.

The researcher was also interested to learn of the reactions of their partners, close friends and extended family upon learning about the child's diagnosis. All of the mothers reported sharing the news of their child's diagnosis with another important individual in their life, in many cases the child's father if he was not already present when the diagnosis was delivered. Mothers described the child's father's reactions as either one of denial or dismissal or of despair and sadness, similar to their own reactions. Carsandra said that, although her former husband later came to be much more accepting of their son's diagnosis, he initially he said, "the boy's alright. There's nothing wrong with the boy. Typical woman worrying about this." Libby also felt like her husband was initially in denial upon learning of their child's diagnosis, saying:

Well, [his father] didn't react at all. I think it's a typical man thing. Deny, deny, deny. It will go away. And the other thing is, he had met through his training autistic kids and the

autistic kids that he met he's like "This isn't Kevin." And he really wasn't, ya know, the typical autistic kid, but I had enough to do with the structure early rather than to let him develop into the autism. Ya understand what I am saying?

Cantrice reported her husband reacting similarly:

It didn't go well for his father. It didn't go well for grandparents. I don't think for his father that he grasped the full meaning of the diagnosis initially it was such, but for me I understood what it meant from the start

Two mothers reported that their husbands reacted with acceptance or relief at learning of the child's diagnosis. Elesha, whose reaction was also one of relief and acceptance upon learning of their child's diagnosis, remarked:

My husband umm.. I think he was a little bit...I think he was hoping it would come back negative and say "No, she's not," but he did see the signs. He did understand that something was definitely wrong ya know? So he knew that.

On the other hand, the same mother who had initially reacted with both guilt and despair, described her husband as moving forward and taking action after learning of their child's diagnosing saying, "I think his faddah accept it... I think sometimes I think in two or one days he will be better... but the time just... even if you have your downs ya just pick up."

When asked about the reactions of extended family and friends, mothers described fairly different reactions to what they themselves or their child's fathers had experienced. In particular, they described many (46%) of their extended families being supportive or accepting of the diagnosis, with only one mother reporting her extended family reacted with despair or sadness. There were significantly more family members (46%) reacting with denial than mothers reported they or their husbands had experienced. Breona remembers when they first spoke with her

husband's side of the family about their son's diagnosis and she says, "The family say when daddy was late to talk." When Carsandra first brought her concerns to her mother who was helping her to raise her son, she remembers:

"How come you don't notice anything about Alan like..." She said, "What are you talking about?!? Leave him alone! He's ok." So I said "Ok," and I was getting worried at that time and umm... he had started talking very well but had kind of fallen off. He was like talking and he was mumbling now. I said, "Mummy, you don't notice that Alan is not speaking the way he used to speak." She said "No, not really. Maybe because he doesn't have other little kids around him, maybe he has fallen off somehow?"

Sadly, two mothers reported their extended family reacting by blaming the parents or mother for the child's symptoms. Breona describes folklore that the researcher later found through anecdotal reports from around the island to be pervasive:

So from when he was 8 months we had to trim him because he had ya black people hair – curly, ya know? So daddy trimmed it. So we have a case in Jamaica when you trim kids early, they won't talk. My family think that, what they're saying it's from is because he got the da trim and alla dat. It's a Jamaican ting ya know? Ya don't trim kids early even if da hair is long. But my family always say its cause we trim him early because he wasn't talking and alla dat, but ya know he was talking and saying "dada" and "mama" and alla dat

Wyndolyn remembers her mother's reaction to the news:

My mother thought that because I was a Christian and was not married when I had him that this was why. My brother was totally like ya know there are lots of people out there without husbands like this without autism.

Finally, several mothers spoke on their thoughts related to the etiology behind their child's symptoms and eventual diagnosis on the spectrum. Although Carsandra believed there was most likely a genetic cause behind her son's autism, she had also wondered if vaccines weren't somehow also implicated in his development of autism saying:

I told my mother before that that she shouldn't be, because of the immunizations and alla dat. Don't give him none of that mumps, rubella, and measles – not to give him the immunizations. However, when I got back I heard there were two types – one that causes a fever and the one that they can tolerate as children. She went and she gave him, cause her friend was on her, so she got him the one that gave him this awful fever. It was after dat that I was noticing... I'm not linking anything, but I am just telling you the developmental as to what I observed right?

Ernestine spoke of her thoughts about how her son's symptoms came about and said:

I think there might not have been a genetic thing for autism. My problem is the environment was what brought it outta late manifestation of autism because I did not see anything until that time. Sometimes, because I am a dental nurse and I work with mercury, sometimes I wonder if...because I was around alla dat when I was pregnant. Maybe it was the mercury? So we are to mix up the mercury and amalgam and all of that. Sometimes I think that that was it. I don't know. What more do we got to do to learn about what and all of the mercury was going on in school. I would have to get home and clean it off. I don't have a clue. I don't know, maybe if I was pregnant, come here after pregnancy or what. I just don't know what to say.

Finally, as mentioned previously, another mother had wondered if her regret over being pregnant so quickly after having her first child and the resulting depression that she felt during her

pregnancy with her son hadn't in some way impacted his development leading to his diagnosis on the spectrum.

Question Three: How do Jamaican mothers describe how they and their family have been affected by having a child diagnosed with an ASD? In contrast to some of the information gathered in question two regarding the mother and families' initial reactions to the diagnosis, the researcher was especially interested in learning more about how the families' feelings had evolved since learning of the diagnosis and while continuing to raise their child on the spectrum. Themes emerging in this area fell into several categories: post-diagnosis or current emotional impact for mothers, stressors specific to accessing resources such as supports and services, the specific impact of raising a child on the spectrum on the mothers' careers, and finally, the current emotional impact of other important individuals in the child' life including their father, the extended family, and close friends of the family.

Mothers reported a number of ways their lives had been impacted after learning of their child's diagnosis, sometimes in positive ways. Several mothers (23%) reiterated for the researcher that raising a child on the spectrum can often be stressful. Rebecca says of the stress:

I think sometimes I get very impatient with him and I wish that sometimes I would be at home because I work and, with his education, I don't think he gets - because of work and you're so tired I think that my patience with him. Sometimes it's really stressful.

Sometimes you go home and you say "Hi Damien" and he - it's like he can't recognize that you're calling him. It's hard.

Many mothers (46%) mentioned needing to take on the role of "Parent-as-Advocate" or "Parent-as-Therapist" in order to better meet the needs of their child. Elesha said of her new interest and studies in childhood education, "That's kind of also why I wanted to learn to do therapy because

I want to be able to be there for her.” Taneisha spoke frequently in her interview about how she was gathering as many resources as possible to learn how to teach her son due to some of the barriers she was encountering in finding the appropriate school setting for him. In particular, she said:

I bought a book, *Teaching a Child with Autism*, so this summer I am going to do it step-by-step with him each evening until he masters it. So if I took him right now [to school] it’s a challenge because if I took him - they keep trying to get him to focus and they keep moving, the school keeps moving. So it was like a disruption.

Perhaps one of the most notable themes to emerge in this category was that many of the mothers felt isolated either due to a lack of community or public awareness (62%) or because of their child’s challenging behaviors or intense needs (31%). Cantrice said:

I have been told that - when he has some behaviors, I’ll say, “It’s because he has autism” and they’ll say “Oh! And they’ll back off”... In terms of the general public in the country, anything that is not typical whether it be autism or mental retardation or a mental disorder, they can’t well understand.

Louella spoke with the examiner about one situation that stuck out in her mind illustrating the idea that going out with her son can often be a challenge saying:

Once I went to the store he tried to take something away from a girl and I told him to apologize or he will have to go home. He did apologize, but because of the symptoms echolalia, he kept repeating himself saying, “Don’t do that again. Don’t do that again.” and then the girl’s father was saying, “You better not do that again.”

Specific to how both a lack of awareness coupled with the child’s challenging behaviors can often lead to isolation, Carsandra told the researcher that:

His godmother I stopped going to her totally and we were friends like 20 or more years from high school because the funny thing about it she was trained in child psychology and she just didn't get it either. So I stopped going there and there were some relatives which I knew I couldn't go to because he would rearrange their place and I knew they wouldn't like it sorta a thing so it was like our social life, it kinda was situated around Alan.

Another source of stress for many mothers (39%) was worry over the future. Wyndolyn describes planning now for his future, saying, "I am thinking of what kind of business can I do that he can actually have 20, 30, 40 years from now? What am I going to do to make it more fruitful? Or how can I change this?" Louella talks about having her moments, "Well I think that it has some ups and downs for me. Sometimes I feel like everything's going to be OK and other moments I feel like I don't know what is going to happen in the future." Cantrice reported being especially concerned about how her son's challenging behaviors would progress saying, "If there is an issue, I take it on, but I think about when I get older, physically, how am I going to manage him? Ya understand?" On the other hand, several mothers (23%) mentioned specifically that they try not to worry as much about the future and that, instead, they coping by taking life one day at a time. Ella says, "And now you don't want to take things for granted anymore. He might be fine today. He might be fine tomorrow. We just work with what we can."

Many mothers had lots of positive things to say about the impact of raising a child on the spectrum. Some of the mothers spoke of gaining acceptance of their child's diagnosis or "redefining the dream" (31%). Taneisha says that over the years she's realized, "When I look at da situation, I tank God because I am blessed because people out dere is in a worse situation than

I am so I have to give God tanks and praise.” Ella spoke specifically about “redefining the dream”:

I mean you get pregnant and you think I know everything in and you hope everything is ok and you give birth and birth is fine and they’re doing normal things like everybody else, but you recognize that something is a little bit off and then it changes your whole world. But the key is to make the best of the situation.

Nearly all (92%) of mothers mentioned some type of positive self-change as a result of raising a child on the spectrum. Elesha said:

I have changed in so many ways. Having children and having Tara, before I was so not directed. Since I have Tara, I think more about what do I want to do, what are we going to do, where are we headed.

Taneisha said:

I’ve become more tolerant and I mean more sympathetic to people and not that I wasn’t sympathetic because I have a neighbor from outside of my that has a sister or something, but if I can help, I will, ya understand? So I am more sympathetic with other persons in my field. And any other persons with disabilities, I now know what they’re going through because if you have gone through this you know what they are going through. You can’t know a journey that someone is going through if you’re not wearing the same size shoes. Right. So I’ve become more sympathetic of people and more sympathetic in general for people with disabilities.

Ella echoed these sentiments saying:

I’m now more tolerant of certain situations. I mean I was thrown into this thing I never thought I’d be able to be thrown into. After I have become a different person and

therefore my heart goes out to anybody, anybody with a special needs child. Not necessarily autism, but Downs Syndrome or Cerebral Palsy or whatever because it is just a whole new life.

Ernestine emphatically said of the ways in which she felt she had changed as a person since her son's diagnosis:

Wow! I never... how have I changed as a person? Oh God! Tolerance. Tolerance.

Because of Jerrod I am a tolerant person. I learned to listen! I learned to listen, believe you me! Faith. Believe you me! Oh my God! That is all, believe you me. I have learned not to be judgmental, never.

A number of mothers (39%) also mentioned that they believe they were fated or chosen by God to be the mother of a child on the spectrum. Elesha said, "I think she's actually slowed me down, made me be more patient. However, I'm not very patient so now I'm learning. I'm thinking it's God's way of teaching me patience."

Breona said:

Well, this is what I believe. God provided me with this child... maybe it is because of my own personality because maybe if I wasn't supposed to be with this child maybe I wouldn't have patience, courage... didn't have it before that child with any disability especially autism.

Rosie, who had begun working as a shadow for another child with autism after her own daughter had been diagnosed on the spectrum said:

I would say God makes no mistakes because in terms of she being autistic, I've been out there meeting so many people and everything. Just her whole program... she brings a

new perspective to my life. Being out there. Meeting other people. Knowing so much that I hadn't known before. Trust me

An equal number of mothers (39%) talked about how raising a child on the spectrum has really made them redefine their priorities in life. Dondrea said:

I find that I am not so up on material things anymore because he has broken off anything I have ever bought in my lifetime. So all my chinases and crystals and jars and everything that I so cherished as a single parent, they're all broken. So it says to me that, ok, you don't have to live with these things.

Libby remarked:

So that's a change, umm... that and the calmness has changed. I find myself less able to deal with bullshit. If you feed me the bullshit - I don't have time for the bullshit. If you are going to be in my life, I don't really have time for it. I used to, but I don't really have time for it. My friends are all pretty upfront and honest. I don't need anyone to bring anymore drama into my life. So that is a big change! I do not deal with drama stress very well. I don't let people give me stories.

Finally, a few (23%) mothers spoke of how raising a child on the spectrum has taught them to celebrate the little victories in life. Carsandra remembers delighting in potty training perhaps more than your typical parent, saying, "He was not potty trained until he was about 4. It was hell getting him potty trained. He wasn't potty trained until he was 4 years old and when he got potty trained it was like Whoa! Celebration!" Ella remembers when her son first called her "mommy":

He didn't call me mommy until he got to like three. The first time I heard the word "mommy" coming from his mouth I mean that just really shook my heart. I mean I

bawled for like days because I couldn't believe it actually came out. Now he might say "mama" depending on the mood, but he knows that I'm his mommy. So now it's different. We're very close and he's very affectionate towards me now like touching my hair, wants to lie with me when he goes to sleep, some part of his body has to be touching mine. He knows that I am his mommy so he gets accustomed to seeing me. He doesn't go too far if he can't eyeball me.

There were several stressors that mothers mentioned specific stressors they had encountered in trying to access supports and services for their child on the spectrum. Namely, many mothers (39%) mentioned the financial burden or strain related to accessing appropriate supports and services for their child. Cantrice talked about the impact that the financial burden of caring for her son on the spectrum has had on her family saying, talking specifically about the cost of supplying an aide or "shadow" for her child at school:

I mean shadows are not cheap and again, my daughter, but she is 6-years-old by herself and I mean there are things she wants and I can't afford it and I think about how she could have had the whole world to herself. I mean the biggest thing is not so much emotional, it is financial.

Dondrea was considering a new life in a country such as Canada that provides greater services through the government saying, "My money has run out. My money has run out because these services are not cheap, so my money has certainly run out. I can't afford ABA anymore. I can't afford OT anymore. I can't afford anything here anymore." Another frequent stressor noted by mothers (31%) was difficulty finding appropriate respite or childcare for their child. When speaking of respite, several mothers mentioned that they worried about their child being a burden

(23%). Breona simply stated, “I really don’t want to inconvenience anyone and I would prefer my child is with me.” Ernestine said:

I worry about leaving him home because sometimes I think my mommy gets tired. She is tired but not like one time when he was just diagnosed she was ready to do this, do that, whatever. I don’t ask her to do much anymore because I know it’s a lot for her and I don’t know how much time she’ll have.

Other mothers (31%) said that they often worried whether they could entrust caregiving to others due to their child’s lack of ability to communicate and the fear they may be victimized or abused. Ernestine said, “I am not afraid to say I am afraid of him being touched in an unkind manner because I wouldn’t know if he was being touched in an unkind manner.” Breona says of her childcare situation:

Yeah because I’m not working. If I could find someone to keep him during the day. But he’s not able to say “Mom, she slapped me upside the head.” Ya understand? I’ve heard so many stories. But I think “Dear God, let me try.”

Many mothers also mentioned stress related to finding the appropriate school for their child (23%), accessing therapies prior to the behavior analyst coming to the island (15%), or stress related to the fact that there is a lack of government programs or supports (15%). Rosie talked about wanting for her daughter to continue in the private school she has been attending, but due to the additional cost, she is no longer able:

I’m not sure about the situation [at the neighborhood school] compared to the private schools because when I went to the other school that she is supposed to be at now it’s all broken and whatever and I really don’t want her to go there but what can I do? I’ve been trying so hard to get sponsorship for her but I’m not there yet.

Taneisha talked about her experiences trying to get services through the country's Early Stimulation Programme and said:

So even if you're trying, ya say, alright I don't have the money and you're rocking back on da government, but there's no rock to rock. It's one person to do a total of thousands of children with disabilities and dat one person just cannot stretch so sometimes they have - I know they have tried to count and ya can't really know the permanent number. Ok, so we have 7 people in Jamaica with autism or we have 10,000 people with autism. And no place to assist them for them to get help with speech therapy. Cause dem said in 2007 I went to get Peter da one term and dat's it. She said you need to come back and, up to dis point, I went over dere and dey're supposed to call me and den don't call me

Several mothers also spoke specifically about the impact of raising a child on the spectrum on their career. Of the six mothers who spoke about the impact on their career, most (83%) reported negative impacts such as work intrusions or having to leave early all the way to having to quit their job in order to better meet their child's needs. Carsandra spoke of needing to have flexibility from her workplace, a sentiment echoed by several other mothers regarding the impact on their careers:

I have to be careful where I work because if I don't reach there by 2 o'clock he will go and drive everybody nuts and he's going to go to every teacher and say "Can I get a call to my mother please?" [Laughing] So I have to know what I am doing in terms of the way I work and all that. They have to be understanding that I have to go sometimes.

One mother, Cantrice, spoke of how having a career was actually helpful in coping with some of the difficulties that are often encountered as a parent of a child with autism. She said:

If you can hold down a job that helps. The idea that he could be institutionalized, that's not an option. Ya understand me? So that's my focus is on all of that. I try to deal with it and try to get some sense of normalcy. Yeah, basically that's my coping.

Mothers also often spoke of the feelings of other important people in the child's life as they relate to being a part of raising a child on the spectrum. Four mothers (31%) had attributed strain or separation in their relationship with their partners to raising a child diagnosed with an ASD. Carsandra especially felt that her marriage to her son's father ended in large part due to his needs needing to be prioritized:

Daddy wasn't dealing very well with that because I was like in a cocoon ya know? All focused on Alan, nothing else mattered and he, ya know how men are? They're not very understanding so they can get like that so we had regular arguments and stuff and my mother said to me, "ya know this isn't healthy for Alan. You have to choose. You have to choose whether you guys are going to stay together or you're going to be apart and have separate lives with Alan as the main center." He wasn't up for the separation. He wanted to try, but I kinda had enough. He was a cheat, ya know? He was a good provider, but I just wasn't able to be with that aspect of it and I think after a while men are turned off by that and he said that my focus was always too much on Alan and, I mean it was his son, but I guess he wanted a little attention, but I wasn't really too involved. We parted and so it was me and Alan.

One mother, Louella, actually spoke of how she felt her marriage and her husband's role as a co-parent had been enhanced as a result of raising a child on the spectrum. She noted that:

I think there's some good to it in the sense that, Wesley, I don't think that Wesley would have taken such a great interest in him. It used to be just me and him but when he realized

that Kevin had a problem, he stepped up to the plate and he's more attentive to him. So that's one good thing about it. That Wesley had to step up to the plate to be more attentive to him.

In speaking of how the child's father's feelings had evolved since receiving the diagnosis (if the father was involved in the child's life) with two mothers reporting that the child's father had gained increased acceptance. Libby spoke of her husband who works as a doctor:

Now he tells everyone that Kevin is autistic. The only thing that he will tell you is that, you know how now we're exposed to more kids, he will say he's not like them and I'm like "I know! It's a spectrum disorder! Are you a psychologist? No!" especially when they are exposed to other children on the spectrum and what they do, we compare and I don't think deep down he has accepted it, but he says to people, he uses the word in connection with Kevin so yeah. He's my son. He's my first born. We waited so long to have him and it was hard for him to deal with, but he's very open with it now. He actually failed his first exam period when he was in med school because it was when we took Kevin for the evaluation. It was his final exam to specialize. So I just let him deal with it the way he wanted to deal with it, but he was always supportive.

Cantrice also felt that her husband's feelings about the diagnosis and recognition of their son's challenges had evolved saying:

He realizes with school that he might have to repeat and, yes, he didn't speak but maybe by age 5 he will speak. I think he thought he would be delayed but would follow the normal development. But now that he is standing out more than before. I think he's starting to understand it's not just going to be slow, it's going to be different.

One mother, Ernestine, also noted that, although it was still hard for her, her mother had gained acceptance of her son's diagnosis. On the other hand, she said of her brothers:

My brothers, they have never accepted that that is so, not that they treated him anywhere worse but he like, he couldn't touch them, didn't have enough patience to sit there and listen to it and see that he was on the computer and so there was not always...it affected them, it affected them and so forth and if you asked them, they don't understand was is expected of him. They want him to be like this and therefore he tries to do what the uncles wanted, you know, because this is what they want and he could not. So I guess it's hard for them.

Almost half of mothers (46%) reported continued difficulty or denial or resentment on the part of either the child's father or their extended family similar to Ernestine's experience with her brothers. Several mothers (23%) talked about how they viewed their extended family had been very supportive and involved in raising their child. Breona told the examiner that her mother will often watch her son for her and Ella said, "I mean my family has really been my backbone wit all a dis." Finally, a number of mothers spoke of the impact of growing up as a sibling of a child on the spectrum for their other children. Five mothers (39%) mentioned that they felt like the child on the spectrum and their sibling had a difficult relationship or they worried that the child was a burden on the sibling in some way. Cantrice noticed that having a sibling on the spectrum was especially difficult for her daughter saying:

You have other children, but do you really want that child to have that responsibility?

And unfortunately my daughter, you may not realize that she is pretty observant. And I think the gravity of it that he in the future, it might be her responsibility and I think about her having children and they being autistic and I think she thinks about it as well. And

that's sad because a nine, 10-year-old - unfortunately unless something happens and there is a miracle cure – [She] shouldn't be having those thoughts and responsibilities. My daughter, she's the only one that, she'll try to talk with me. She understands what it is, but she'll get angry so we try to talk with her. I will try to comfort her when nothing else can be done.

Several mothers (23%) reported that the child's sibling had taken on the role of a Sibling-as-Advocate or Sibling-as-Therapist role. Rebecca talks about how it can be difficult for her other son, but that he also has taken his brother under his wing saying, "His big brother will come and help and so they are very close. So I have to concentrate on both of them because I can't ignore his brother because Damien needs a lot of things and it's hard."

Question Four: How do Jamaican mothers of children diagnosed with an ASD describe what day-to-day life is like for them? When asked about their daily lived experiences raising a child on the spectrum, the mothers' responses tended in the direction of discussing the challenges that they encounter daily.

Most mothers (46%) reported stressful daily living and experiencing very busy days either taking the child from school to therapy to childcare or as a result of raising the child alone. Rebecca relives the stress saying, "Sometimes you go home and you're so tired and then with the behaviors and trying to get them to bed. Because he has these challenges, I mean, it's really difficult." Elesha talks about her busy days and how it impacts her ability to support her child saying:

I work full time and then I have school and I study everyday so I do the pick-ups and the drop-offs sometimes but you have to get early the children in the morning - I still have to do my picture schedule. I haven't done it yet. I don't have the time. So ya know we kind

of organize mornings. Then at the end of the day I pick them up, I come home and take them food.

A great deal of mothers (39%) report much of their day being spent in their Parent-as-Therapist or Parent-as-Teacher role. Breona has used resources on the computer for instructional activities daily, saying:

He might not be able to read and write but he knows how to use the computer and find the cartoons. So we sacrificed and bought one. He'll say "Mummy, come here!" and I'll say "What do you want? You want the computer?" He'll say "uh huh, yep." So sometimes he'll go on YouTube and do what he wants to but sometimes he'll wake up and go "Ed!" [an educational website]. So I'm trying to get him to learn it the right way.

Libby had gone so far as to homeschool her son for two days a week due to concerns over whether or not the school was really adequately meeting his needs. She tells the researcher of her days by saying:

So we go to homeschool two days a week so if it's not catching, ya know? So that is his schedule now. Therapy once a week. Speech once a week. Two or three times a week mainstream and two days a week homeschool.

Many mothers (54%) spoke of day-to-day life consisting of management of the child's challenging behaviors such as running or elopement from the area, aggression, or picky eating.

Cantrice talked about her son's behaviors saying:

I mean he is now able to open things. He now tries to run. He's done it twice. He runs up and down the street. The first time running, it was unexpected. He went outside, opened the gate, and went straight to the street. So now I try to check for that. But the second ~~one~~ time, the gate was locked but the key was left in the lock. He never opened locks before

so when he developed at that age he opened the lock so he opened the lock and he bolted. So my keys have a bunch of keys on it and he'll take the keys and try to figure out which one opens it so it's now become a challenge. And now he's bulking up. He's getting bigger. Physical problems now become the issue.

Similar to their responses about the impact of raising a child on the spectrum, many mothers again highlighted the fact that their daily lives were affected by the lack of public awareness, leading to feelings of isolation. Finally, when asked about their daily lived experience raising a child on the spectrum, many mothers (39%) also spoke of how their day-to-day lives had improved over the years as their child's ability to communicate and do things independently had increased. Wyndolyn talked about her son's increased independence and says, "He'll start getting up and making it for himself... The hyperactivity is down... He used to be afraid of large people but I don't think he is anymore." Taneisha talked about how her son's increased skill level has made her life a little easier saying:

He might not be where I want him but at least he's at a point where I can take him around anywhere. He can tell me if he's hungry or he's not feeling well. The other day I take him to the supermarket and ya say "Mummy don't have the money to buy dis today," him will understand. Even if it will upset him, but ya know, I can say that he is a good-behaving child and I really don't have a lot of behavioral problems wit him as such.

Louella said:

The good thing is he is communicating. So he will communicate with other kids or if I take him to the supermarket and I say "leave it in the cart" he will do it. He doesn't eat everything. He'll choose one food and he'll eat it for breakfast, lunch and dinner when he is tired of it he will move on to another food type . He doesn't eat so well and sometimes

he won't eat much. He'll just want a snack. So I give him what he likes to eat. He likes chocolate milk so that fills the gap and that's how I cope with the eating.

In thinking about the overall experiences share by mothers with regards to daily living, Dondrea captured the overall sense that daily life is almost like a marathon saying, "My journey is long. I have faith. I am climbing my mountain and I am expecting to reach the top."

Question Five: How do Jamaican mothers of children diagnosed with an ASD describe supports and services that their child and family receive? In response to the kinds of supports mothers report receiving, a number of themes regarding their experiences emerged. The greatest source of support mentioned by nearly half of mothers (39%) was the Jamaica Autism Support Association (JASA). Elesha talked about the impact JASA and Kathy (the co-founder of JASA) have had in her life saying:

I have JASA. JASA has been completely awesome. Kathy is awesome. She doesn't even know this. I really look forward to her. We have a little Blackberry and a little text or a picture. I just, everyone just, we share. I just "Oh you have a child with autism? My child does this!" and "My child does that too!" It's really, really interesting and I take support from that. And that's it. I don't have a lot of emotional support.

Ella talks about what a support Kathy and JASA were to her right after her son had been diagnosed. She remembers:

So I went to the meetings, the first JASA meeting, a couple of days after I got the diagnosis and I went again and Kathy said to me, "We are all here. Now you can get therapy started and do what you need to do." And she also told me that, "Reading sometimes, there's so much literature to go to your head - ease up on the reading. Just

relax. Just absorb it for what it is and enjoy.” So I do that and just try and work it out.

And that’s what I’m doing.

The next most frequently mentioned source of support was the support of extended family and/or friends (31%). As mentioned previously, Breona frequently cited her brother as a source of support saying, “I think that right now my brother is, he’s basically the only one I can rely on... If my brother is available, he is there with him.” Cantrice remarked that she also finds support in friends and extended family:

I have good family supports with my mother-in-law and I have a very good friend who is capable of keeping him, but I don’t know as it becomes more physically challenging if she will be able to, but for the time being the real issue is whether or not the shadow is there. If she is there, I have that support. Family support is more emotional support.

One mother, Cantrice, mentioned having the support of either her religious community or faith. Cantrice said, “My church I think is excellent. So they understand his behavior, but what it means I don’t know. Every day is a struggle, but that spiritual connection helps.” Libby spoke of her youngest child as being a source of support to his brother by providing a good language model for him. She says, “His brother has made a huge difference with his speech as well.”

Finally, one mother spoke of having to go it alone without supports. Dondrea talks about having to go it alone and explains:

Well it’s me really. I don’t have that much extended family here and he has really been my challenge. Any assistance I get with Brian I have to pay. I have to pay everything from having a housekeeper. I really don’t get any help with him. I don’t know how I’m still alive. My parents, well, my father has never been a part of my life, but my mother is

not here. But even if she were, she wouldn't be able to manage him because he comes with a lot of work, ya know? So that's my work.

With regards to the kinds of services, many mothers spoke of their child's education as being a primary focus within this category. Eight mothers spoke of trying their child's neighborhood school at one point in the child's life, if they were not still enrolled in their neighborhood school. Six mothers spoke of enrolling their child in a private school or "center" specializing in teaching children with special needs. More than half of mothers (54%) mentioned having trouble finding an appropriate or accepting school setting where they felt staff were adequately trained in supporting the needs of a child on the spectrum. Given that corporal punishment is still widely used in schools in Jamaica, Wyndolyn spoke of being especially concerned about appropriate training for staff after an experience with her son:

Last year at school he came home with a mark and the teacher said he fell down but there was no scratch or anything like that. There was nothing on the chin or arm to show he had actually fallen so I don't know. I planned on not sending him back. Period.

Breona echoed some of Wyndolyn's concerns saying:

So then we moved him and the primary education starts. I just didn't like the whole education and I'm not saying that they don't have any idea about autism, but to me they are not - nobody wanted to accept him. Ya understand? Because it is a lot that the teacher faces working with the child, but based on what - I have an idea of what you working in the field is supposed to know.

Dondrea had similar problems in finding the right match for her son for school. She says of her experience:

It's been rough. Trying to get him into an integrated school where there were behavior problems. I took him out of school. I took him to the U.S. for 6 months. Took him back again for trying to get him into a school. Found a little daycare for him now. He's getting into little incidents, but it's not enough. It's just not enough. Right now, I don't what is going to happen come September.

One mother, Carsandra, was worried specifically about what kind of secondary setting her son would be able to fit into. She says, looking to the future:

He will go to a technical or secondary school which is not where you really want your child to go sorta a thing. How people look at these schools if you're here, your child is going to the Champion College or Kingston College, your child is doing well, but if they hear the name of a secondary or, what's the other name, ya know? So there are challenges too. I don't look at what other people say, but you still want to your child to go to a [good school]

Due both in part to the lack of training amongst school staff in Jamaica for supporting the needs of children on the spectrum and also as a result of some of the significant needs of many of the children on the spectrum being served by these schools, many parents are required to send a "shadow" or "auntie" with their child to the school. Five mothers report the involvement of a "shadow" in their child's life at the time of this interview. Many of the mothers spoke of the shadow serving several roles with the first being to support their child by redirecting them in the classroom and managing their behaviors, but also, in the case of many of the children who were nonverbal, to report back to the mothers about what was happening in the classroom or if their child was being treated unkindly.

Although there exist very few service providers in Jamaica for providing therapy (e.g., there is only one behavior analyst on the island and she is required to receive supervision from a senior level behavior analyst, or BCBA, via Skype with an individual in Florida), a number of mothers did report accessing such services at some point in the child's life. More specifically, seven (54%) mothers report obtaining speech therapy services for their child, one mother reported taking her child for occupational therapy at one point, four mothers (31%) report enrolling their child in behavior therapy or applied behavior analysis services in conjunction with occupational therapy (the behavior analyst is also trained as an occupational therapist), as well as another two mothers who reported trying pharmacological intervention to support their child. Although the Early Stimulation Programme offered through the Ministry of Labour and Social Security in Jamaica is supposed to be accessible to all families of children from birth to six years old with a disability, many families report that it is extremely difficult to access such services. This is evidenced by the fact that only two mothers report being able to access these services.

It should be noted that all services were paid for out of the pockets of the family, including tuition for school as is customary in Jamaica. Due to the significant costs associated with all of these services, it is not surprising that nearly half of the mothers participating in interviews (46%), mentioned the high cost or expenses of services as being prohibitive. Additionally, three mothers spoke of the need for more services. Perhaps as a result of these barriers, three mothers reported that they were essentially their own service providers, taking care of their child's educational or therapeutic needs by reading in books and teaching the skills themselves.

Question Six: How do Jamaican mothers of children diagnosed with an ASD describe their vision of the future for their child? Parents were also asked about their vision for the future for their child. The most common themes in this category were either for their child to be independent or to not be a burden on others (54%). Taneisha's sentiments illustrate this concept well:

I'm not gonna be for the rest of his life so I want him to be functional so dat if I'm not dere he is not a burden to anybody, he can help himself. I pray one day he can make a sandwich and den he eat the food.

Mothers also said that they worried about who would care for their child (23%). Cantrice said, when thinking about the future and who would care for her son, "It's not like a disease. This child is not going to die. He's going to outlive you. Physically he is fine in every way possible. Who's going to care for him?" Other mothers said that they hoped for their child to grow to be a "normal" child or have a "normal" life such as getting married, having kids, or getting a regular education (54%). Louella talks about this idea:

Importantly though, I want him to have a good sound education and go as far as his abilities can take him. Although, I admit, one day it made me a bit sad to think that he might not be able to go to college. Well, I want him to have a good education, do the [GSAT] exams [for secondary school entrance] like everybody does, hold a job. I want him to have an education. I want him to have a good chance... I don't want anybody to take advantage of him because of his disability.

Rebecca says:

I hope he can grow up to be a normal child like his brother because I don't want to put him dependent on his brother because it's like his brother is always taking care of

Damien and I'm hoping that God will give me a long life and I pray to God that he can be normal-like.

Cantrice talked about wanting Alan to someday have a family:

I was worried about girls. Like, I want grandchildren. His father says he has his genes so I shouldn't worry because da boy look like him. Girls are dumb in that way so they won't mind and I'm like, "please!" Ya know?

Four mothers mentioned the importance of their child having a skill or work. Rosie says:

Everything that is good and she is good at recording. She will go into a classroom. She would walk around and she would look at the nametags on the desk and she would go home and she would write grade three and she would record every child's name in grade three. Yeah but ya know I have been trying to find a guitar because I know she can listen and right...

Libby says:

So I don't care what it is but you have to do something constructive with your life. I don't care if you're a gardener... whoever is handing you money... as long as you have something to contribute. At this point, I don't see any reason why that shouldn't happen.

Several others (15%) mentioned that they hope for their child to have greater literacy in the future. Wyndolyn talks about how she hopes a good education, and in particular, increased literacy, will lead to greater independence for her son:

What do I hope for him? I hope that he is a totally different person. That he knows how to get around. He likes books. He looks at everything. He reads the signs and directions. What I want, I will push him. Whatever it is. I hope that, the words are not there yet, but whatever it is he likes I will make sure that he gets everything that he wants out of it. I

hope that he will be a person that, I try to teach him to be a person to do things for himself. I hope that one day it will actually register and he will understand it. Because I want him to be independent. I want him to have a good education and make sure that he is happy.

Breona had similar sentiments:

Right now, just to learn the alphabet, to be able to communicate better, and to read instead of climbing up here and alla dat, ya know? To read “That is dangerous. Don’t go in there.” Ya understand? I take it day-by-day.

A couple of other mothers (two) mentioned that they hoped their child would be able to communicate more fluently in the future. Mothers had several other ideas about what they hoped for their child in the future that did not necessarily fall into these categories. One mother, Elesha, said that she hoped for her child to have love and support.

I know she’s going to be good with her academics so I am hoping that she’s going to excel in that area as well. I just want her to have people around her who love her and support her even when I’m not there.

Several other important ideas were mentioned by mothers as they looked toward the future.

Carsandra actually said that her son Alan had reminded her to take it a day at a time:

The other day I said, “Alan, what do you want to be when you grow up?” “I want to be like Sponge Bob mummy. I want to flip burgers.” And I was like taken in fear and I was like “What!?! Burgers boy?!?” And he said, “Mummy I’m just kidding. Ok mummy, what do you want me to be? A lawyer?” Ya know? Just to get me off his case. But he says that he hasn’t yet decided what he wants to be and he doesn’t think he’s of the age to decide that yet.

Dondrea said that she was hoping for a miracle:

I'm hoping for functionality. I have hope, yeah. And I pray. There's a god that I pray to and I know he doesn't give hand-outs. He has to see you, your interest and that you're working towards it and he knows I have done all I can. I'm still doing all I can within my capacity so I'm really hoping for a miracle.

Question Seven: What advice would Jamaican mothers of children diagnosed with an ASD give to other mothers who have a child who has just been diagnosed with an ASD? Many of the mothers (six) told the researcher that it would be important to convey to the mother that she should be the advocate and find supports and services for her child. Wyndolyn simply says, "Pray and stop crying. Just think about how you're going to help your child." Related to advocacy, Elesha says, "Advocate for your child. Be the advocate. Don't expect somebody to do it. You have to do it." Cantrice says about finding supports:

Well I hope that she has support. Support is absolutely... you can choose family and friends who can try to support you, not try to tell you what to do even though they don't know because they make the job harder. Find one person who you can break down with, who you can talk to.

Five mothers (39%) said they would tell her to have hope. Taneisha really focused on the idea of imparting hope in the mother of a newly diagnosed child saying:

I would tell her one, there is hope. There is hope in Jesus. There is hope in da Lord and she must be, she at all times must depend on her... no therapy, no doctor. She must know what she put in is as much she get and just remember that you are living your life for your child. Don't get caught in doing what you used to do. Life has changed. You're a

mom of a special needs child now. Not that ya can't do it, but ya have to know ya focus and ya have to have a strong head because if ya don't have a strong head, you'll get mad and you'll go into a depression. Ya understand? Ya'll go into a depression and dat is what ya don't want because when ya go into depression what will happen to your child? Ya understand? So she must remember dere is hope and she just have to tell herself dat she is the first speaker for her child and she can't depend on no one but herself. And what she put in, she will get. She just have to be stronger and every time she must be strong. It's not an easy road. Really not an easy road.

Similarly, three mothers (23%) said that they would tell her to keep her faith and to have religion or God in her life. Breona says of how faith can get you through:

Make sure she is a child of God, the creator, and make sure you have faith and tolerance because if you don't have tolerance. Pray to god. But the tolerance piece... he's not a typical child, ya understand? You have to have tolerance. You have to have God in your life.

Another four mothers said that they would tell her to have tolerance or patience and to know that it's a long journey. In response to what she would advise a mother, Dondrea says, "It's a long journey. It's a very, very steep, winding hill. I have no idea when I'll get to the top." Breona says to, "Be patient, because if you don't have that you'll either kill yourself or get crazy or something. Understand that while the child is young, the hyperactivity... ha! I mean I've been there with the child. I've been there." Somewhat similar to these sentiments, two mothers said they would tell her to give herself time or to take it a day at a time. Louella says, "What I'd like to tell a mother who has a child with a disability is just take one day at a time."

Mothers had other ideas that were only mentioned by them, but were also significant. One mother, Libby, would tell mothers to “trust their gut” and to “structure” the child saying:

A lot of mothers know what’s going on ya know? They have an inkling even before they’ve accepted it. Yes you’re blindsided by the assessment because on paper it’s a totally different thing. When you see that written on paper it’s raw. So the first I would tell her is go through it and that is easier said than done because a lot of them they learn something and it’s not acceptable. I would say take the time and if you don’t accept it, go to another person. Don’t let anyone try to influence your decisions. I cannot tell you I would have done any differently for Kevin because when my husband asked for us to give it a year and I knew what he was doing before we went to Samms-Vaughn I don’t think I would have done any differently. If I had pushed it at that time, I don’t think it would have done any good. It’s still a balancing issue. So go with your gut. Don’t let anybody unduly influence you and what you’re doing. Find something. You need to find somebody or something. I think the biggest problem in Jamaica is that most people can’t afford it. That is the bottom line and me telling me you that, they can’t support it.

But even me telling you that, I would tell a mother who is newly diagnosed there is no guarantee she can do that so I don’t know what I would tell her. The child needs help and it costs money. In Jamaica when they are diagnosed, that is the situation, but if you have any kind of resources at all and what you can do at home is structure the child immediately. That is free. Structure the child IMMEDIATELY and that is hard as hell! [Laughing] But that is free. If that is the only thing that you can do then that is what you can do. If they are not sleeping, I mean I don’t know what you are going to do because you are dog tired, but I mean if it’s a free thing you are looking for and you cannot afford

the therapy structure the child. So I guess that's it. Follow your gut. Get what help you can, but you need to structure the child immediately.

In addition to talking about getting supports and services through advocacy for your child, Ernestine talks specifically about how the mother may initially be reacting to the diagnosis:

Do not stay in denial. Get out of denial immediately. Of course she is going to have her bouts of crying and she is going to be sad and all of that. But quick, quick, quick... get over this immediately. Comes to our support group meeting. Get therapy immediately and when the money is a problem do as much as possible to get therapy immediately. One more, love the child and love yourself. You didn't do anything wrong. Give him more love back ever.

Finally, Rosie seems to want mothers to understand that it not only gets better, but that having a light-hearted spirit and taking things in stride also helps:

Don't sweat it. It may be hard, but sometimes it fun and when ya get out of denial it will be much funnier because things they do may seem bad to other people but sometimes it's funny... some little things they do, but when you look back on your children you think "Oh" and ya laugh because it seems funny. Trust me.

Structural-Level Analysis

Since the majority of identified themes across participants fit under the "pattern-level of analysis" only those themes that were not directly related to research questions posed by the author will be reported in this section. Three themes surfaced that were not necessarily related to the research questions posed, but that seems relevant to the experience of mothers raising a child with an ASD and living in Jamaica. The first theme to emerge that was mentioned by three mothers in the course of interviews was the mention that some children with autism are "locked

away” in their homes due to a lack of understanding of what autism is in many parts of the country. Mothers suggested that because families did not understand their child’s symptoms or recognize these symptoms as belonging within the autism spectrum, many families did not know how to seek an evaluation for their child. Rebecca spoke of how some mothers, even despite receiving the diagnosis, just don’t understand their child’s behaviors:

The parents, after they find out the child has autism, ya put them in a bathroom because sometimes they think they’re mad. They just don’t know anything about it. They don’t know about speech therapy so they just lock them up in the house because they have the behavior. It’s just that we need the awareness. It’s just sometimes when you ask someone... it’s just the awareness... I don’t think it’s really... ya know.

Interviews with mothers also suggested that kids on the spectrum may be locked away due to difficulties accessing services on the island. When Taneisha was asked about services on the island she said:

Trust me. Trust me. Because we care more than the teachers actually do and we understand. But we need help. We need help. We need help. It is so depressing especially for the children who are never, never get the occupational therapy or the speech children. These children are home. People beat them. People abuse them. Them mothers lock them inside. It is very frustrating, because sometimes you think you have a problem but somebody has a bigger problem. So you have to give god thanks, ya understand?

Rosie spoke with the examiner about how many times it is both a lack of understanding of the child’s symptoms, but also difficulties with accessing services leading to children being locked away:

They need a lot of things because there are a lot of children in Jamaica who are autistic but parents do not know where to go, but unlike me, I have been in a situation where I am familiar with everything, but there are people out there who don't know where to go. That there's nothing is paid for them. They can't afford it. So they need to put something in place so when children are diagnosed they can say to the parent right there and then, "Go here. Go there." Whatever. Because it's too costly. That's why there are many autistic children locked away at home, not because they want to but because they have no other options. If I wasn't fighting hard ya know, my child would be locked away at home too. Yes.

Another difficulty raised by two mothers interviewed was related to the lack of government-subsidized services and the exponential financial cost of obtaining services for their child in Jamaica. Several mothers, because of these barriers, had left the country at several points to obtain what they perceived to be better services in other countries, in particular the United States. These mothers stated that they had considering permanently moving from the island to other countries where they believed they could more easily access government subsidized services for their child (Canada was specifically mentioned). Carsandra mentioned the educational system in particular as being an area of concern for her. She was especially concerned about her son passing the GSAT exams which determine placement in secondary schools in Jamaica. She said, "The problem that I have though is that people don't understand how - I don't think I'm going to stay here long because the educational system isn't developed for these children." Dondrea had previously gone to Florida to obtain what she deemed better services for her son, but after dealing with a number of financial difficulties in Jamaica, was

thinking about moving to Canada where she might receive government-subsidized services for her son saying:

No, between diagnosis and age 6, I got – ya know, you deal with speech therapy, occupational therapy, ABA things. Went to Florida – tangible difference. Shaped up behavior. I went to a couple of places in Florida where, ya know, you try to get a one week or a two week intervention. Umm.. but my money has run out. My money has run out because these services are not cheap, so my money has certainly run out. I can't afford ABA anymore. I can't afford OT anymore. I can't afford anything here anymore.

Although it was only mentioned by one mother, the researcher also thought that a conversation she had with one participant, Carsandra, related to pervasive homophobia on the island was important to understanding how this cultural phenomena might present another barrier to many families of children diagnosed with autism living on the island. As reviewed previously, one of the core areas of impairments for youth with ASDs is in their social skills. In particular, many children on the spectrum have a poor sense of personal space and can often violate the unspoken personal space boundaries of those they are interacting with. Carsandra's son Alan had a great deal of difficulty judging the appropriate boundaries of personal space, most especially with those individuals he felt comfortable with. Although Alan's father seemed to handle this well, when Alan interacted with his grandfather, Carsandra's father, and his uncles, Carsandra's brothers, he would many times come too close for their personal comfort. This was not only uncomfortable for them, but because of the tremendous stigma surrounding homosexuality on the island, it was visibly upsetting to them and had begun to significantly impact their relationship with Alan. She says:

With other persons he has a problem with is his father and his grandfather. Even his father is incidentally ok with it, but his grandpa (my father), is not. So you have to understand that... and he'll get really mad and he'll say "Grandpa, what's wrong?!" And he'll demand an explanation and *alla dat*. His father is ok with all the closeness.

Interpretation

As mentioned previously, the "interpretation" level of analysis of themes involves relating themes back to the ecological framework within which this study was developed, which in this case is Bronfenbrenner's Ecological Theory (1979) comprised on the following levels of ecological influences on the individual: the *microsystem*, *mesosystem*, *exosystem*, *macrosystem*, and the *chronosystem*.

A number of themes illustrate the impact of the microsystem, or the immediate environments within which the child and family operate in, upon the mothers raising a child diagnosed with an ASD in Jamaica. For the participants who were raising a child with a partner or the involvement of the child's father, mothers reported that almost half of the children's fathers continued to have difficulty with accepting their child's diagnosis, while a couple of mothers did report that the child's father had grown to accept the child's diagnosis. Several mothers (four) actually cited their child's diagnosis as being the source of strain or separation from their partner, while one mother, Louella, reported that her relationship with her partner as a co-parent was strengthened by their child's challenging behaviors necessitating that they work together to meet his needs. More than half of the participants reported raising their child without the involvement of a partner, with greater reliance and involvement of their extended families so in many ways their extended family can be counted as part of these families' microsystem.

Almost half of mothers reported their extended families were a source of support assisting with

childcare and the raising of their children. Other mothers described more tenuous relationships with their extended families as a result of the extended families' reaction to the diagnosis. For example, several mothers reported that their families blamed them for their child's diagnosis either because they trimmed the child's hair too early or because they had the child out of wedlock, while others found their extended families to either be in denial or dismissive of their child's symptoms citing other members of the family who were late in developing language or saying that the child was fine and that the mothers were overreacting to the child's symptoms. Several mothers also spoke of the impact of having siblings in the home to provide support while others focused more on their concern for how the child's diagnosis impacted other siblings in the home. More specifically, they were concerned about how their child diagnosed with ASD often took a significant amount of their time and resources for care leaving them feeling that they were not always able to adequately address the needs of their other children. They also worried about siblings having to most likely eventually take over caregiving for their child diagnosed with autism. Although several mothers reported that they would recommend a mother of a newly diagnosed child keep the faith and have God or their religion to rely upon, only one mother mentioned her religious community as a source of support. Another mother described her experience of attempting to attend church services, but deciding she could no longer attend due to her child's challenging behaviors.

Many of the mothers' responses inform the influence of the *mesosystem* level of the environment on the family, in other words the impact of the interactions between individual factors within the microsystem such as the interaction between the local community and the school, for example. One interesting interaction that appeared to be impacting the experiences of mothers raising a child diagnosed with ASD living in Jamaica was the mothers' perceptions of

teachers and the educational system. These perceptions tended to reveal a general attitude of mistrust of both the teachers abilities to understand their child's needs and to provide adequate instruction for their child, but also mistrust of the teacher's treatment of their child with several mothers specifically saying that they believed their child had been mistreated or abused by the teacher or that they preferred their child's shadow attend with the child in order to report back to the mothers what was occurring in the school setting. One could also argue that the difficult interactions between mothers and the Early Stimulation Programme offered by the Jamaica Ministry of Labour and Social Security are interactions at a mesosystem level impacting the mother and her child diagnosed with ASD. More specifically, several mothers mentioned that although they had attempted to reach the Early Stimulation Programme, some even receiving an assessment from the program or briefly receiving services, the program was difficult to access and most families were never able to reach anyone from the program to obtain services.

At the *exosystem* level, or the level of influence of more global factors such as the educational system, government programs, etc. we see a number of impacts in the mothers' reflections. Perhaps the most notable exosystem impact mentioned was the mothers reported difficulty finding the appropriate school for their child or their feelings that the schools their child had attended were not adequately trained in supporting the needs of children with ASD. This is demonstrated in the fact that families of children diagnosed with ASD are required to provide a shadow or auntie to support their child in the classroom. Additionally, many families discussed the lack of government subsidized services and the corresponding financial burden or strain resulting from the lack of government subsidized services as having a source of stress. Additionally, mothers mentioned that there is currently a monopoly on the services that do exist on the island including doctors able to provide an appropriate assessment or evaluation related to

ASD symptoms leading to a diagnosis, only one individual able to provide applied behavior analytic services and only a handful of speech and language pathologists and occupational therapists trained in providing interventions to individuals diagnosed on the spectrum. This means that families are forced to not only utilize the services that are available regardless of the quality of the services they feel is provided, but also that service providers are able to charge more than might be expected for their services given the demand. Another exosystemic issue mentioned by mothers was their difficulties in accessing appropriate respite care for their child, reported by at least four mothers. This is most likely both symptomatic of the fact that so many of these mothers were raising their child alone and without the support of a partner, but also could point to the fact that respite care services are not currently provided through the Jamaican government or other community agencies. Five mothers spoke of how their careers had been negatively impacted by having a child on the spectrum in that they were either forced to discontinue their employment to meet their child's significant needs or that they had frequent work intrusions as a result of their child's diagnosis. It could be argued that the lack of programs on the part of employers for supporting families who may need additional flexibility or more when caregiving a child with significant needs was impacting mothers. Another perspective is that if greater government-subsidized or community agency programs or services were available to mothers, they would be more enabled to be gainfully employed or to suffer from less intrusions in the workplace. Finally, eight mothers spoke of feeling isolated or impacted by the lack of awareness within the community concerning autism. While visiting Jamaica this researcher was able to view a documentary that had recently been made by a young, aspiring filmmaker interviewing people from around the greater Kingston area about their views regarding autism. Many interviewed in the documentary, when asked what they knew about

autism, replied with answers such as, “Autism? Who’s Autism?” Many mothers said that because of this lack of understanding, they felt that they would be judged or criticized if their child exhibited symptoms while in public. As such, many preferred to simply not go out in the community with their child to avoid said situations.

The *macrosystem* level of influence of the environment on individuals consists primarily of a culture’s overarching beliefs or values. Macrosystem level influences were mentioned on several occasions by mothers again include a lack of understanding regarding what autism is and what symptoms are associated with a diagnosis of autism. This may speak to a larger cultural attitude toward people with disabilities. While visiting Jamaica, the researcher had an opportunity to see a good number of individuals with physical impairments who were living on the streets. Many of the families who escorted the researcher around Kingston would make mention of the fact that so many people with disabilities struggle with employment or are rejected by their families, eventually leading to life on the streets. They also pointed out the lack of wheelchair ramps or handicap accessible buildings around the town. The examiner had the opportunity to meet one of the influential members of the disability community within Kingston, Sarah Newland-Martin. Just prior to the examiner arriving in Kingston, Ms. Newland-Martin was involved in a situation in which she felt discriminated against for being a person with a physical disability that gained national attention and had begun the wheels of change toward reform. Ms. Newland-Martin, who is paraplegic and is the National General Secretary of the National Council of YMCA’s based in Kingston, is a former athlete and has won numerous medals and broken a number of records in her sport of swimming. Ms. Newland-Martin was at the Manley International Airport outside of Kingston attempting to travel to attend a World Council of Churches summit in Manila in the Philippines, when officials stopped her, asking her

to remove her prosthetic limbs and strip-searching her in a room within the airport. Sarah was not traveling with the tool she required for reattaching the prosthetics and, as such, faced a 21-hour journey which she was forced to remain without her prosthetics correctly attached (Budd, 2012). Several days later and after outcry from the public, the Transport Minister, Dr. Omar Davies, ordered an investigation into Sarah's treatment and issued a public apology (Hunter, 2012). This led to a dialogue with public officials about the treatment of individuals with physical disabilities on the island resulting in dialogue surrounding adding "sensitization programs" for transportation officials. After leaving the island, one of the most read newspapers in Jamaica, the Jamaica Observer ran a story about a mother who was forced on the streets with her child diagnosed with autism (Hussey-Whyte, 2013). Rosa-Lee told the reporter from the Observer that she first became concerned with his development at the age of two-years-old, but despite taking him for tests at that time, he was not diagnosed with autism until the age of seven-years-old after taking him to a local psychiatric hospital. Even after receiving his diagnosis, she had no idea what autism was or what it meant for her and her family until a neighbor looked it up in her "doctor dictionary." Rosa-Lee and her son's father were taking turns working and watching her son in order to provide for his tuition to attend school until the age of nine-years-old when the child's father left. She continued to provide for his tuition until the age of 15-years-old when she was forced to remove him from school due to financial difficulties. She was forced to quit her job in order to care for her son and it wasn't long before Rosa-Lee, her son with autism, and another young son were forced out into the streets. Rosa-Lee told the reporter that there was many occasions where she thought of either killing her son diagnosed with autism or killing herself due not only to the stress of living homeless, but also due to the stress of trying to contain her son's aggression to passerby's or property, as well as stealing of food. Rosa-Lee

reports that on these occasions, people have hit her son in response to his behaviors. These are just a few instances illustrating the cultural beliefs and values surrounding disability in Jamaica impacting the mothers' experiences. As mentioned previously another potential source of difficulty related to the cultural norms within Jamaica is the pervasive homophobia that persists within Jamaican culture. Saddique Elliott speaks with the Huffington Post about his experiences living in Jamaica, or what he calls "homophobic hell," as a man who identifies as gay saying he preferred living homeless on the streets in the United States than living as a gay man in Jamaica (Elliott, 2013). This is mentioned as a source of difficulty due to the fact that many individuals on the spectrum struggle with understanding the unspoken rules of personal space so when a boy on the spectrum violates the personal space of a man, the reaction can often be severe.

Finally, the influences at the *chronosystem* level, in other words generational impacts, on the mothers interviewed include differences between the time periods within Jamaican history within which mothers received the diagnosis for their child. For example, Taneisha mentioned that at the time of her son's diagnosis the physician recommended behavior therapy or applied behavior analysis, however, at the time these services were non-existent on the island. On the other hand, mothers like Ella or Libby whose sons had been diagnosed fairly close to the time of the interview noted that they were able to begin therapy prior to even getting a diagnosis for their child. This reflects the improvements in access to services over the course of time on the island. Mothers whose children had been diagnosed more than six or seven years prior to the time of interview also spoke of how the creation of JASA changed their experience of having a child on the spectrum in that they finally had a means of connecting with others who understood their child's diagnosis and that, with the creation of JASA came the increase in awareness efforts on

the island, although many mothers still noted that they believed Jamaica to have a long way to go in this area.

CHAPTER V

Discussion

The purpose of this study was to expand the knowledge base regarding the experiences of Jamaican mothers raising children with autism. Seven research questions were posed. These questions focused on pregnancy and early development; experiences with the diagnostic process; the impact of raising a child with an ASD; what day-to-day life is like; experiences accessing supports and services; mothers' vision of the future for their child; and advice these mothers would give to other mothers raising a child who was just diagnosed with an ASD. Throughout the researchers visit she had a number of opportunities to engage with participants and build relationships with them and the autism community prior to interviewing. Beginning with a fundraiser on the researchers first day in Jamaica and attending a support group meeting a day later, all the way to providing childcare and parent training on language building during a workshop for parents, participants had several opportunities to engage with the researcher in informal settings. It was felt that this rapport building prior to interviewing led to greater openness and willingness to engage with the researcher during the interview process. These experiences also allowed the researcher the opportunity to engage with mothers and their children, to observe their interactions as well as community perceptions and reactions to their children providing the researcher with greater context for information gathered through interview data. It should be noted that since leaving the island at the end of this trip, the researcher has maintained contact with many participants who continue to send pictures of their children as they

progress through different developmental milestones or to ask questions or for advice in continuing to develop their child's skills.

Journey from Birth of Child to Diagnosis of ASD

The first research question focused on the journey from birth of the child to the diagnosis of ASD. The purpose of this research question was to better understand mothers' experiences from conception to the early developmental concerns leading them to seek an evaluation for a diagnosis. In response to this question, there were not necessarily any noticeable trends in pregnancy or birth patterns with most mothers saying that their pregnancy was fairly typical with no major complications. However, half of the mothers did give birth via a C-section while the other half described having a vaginal delivery. The age range when concerns were first noted among mothers was 6 to 24 months, although there was a lot of variability in this range, with no one developmental period or age emerging as most common in terms of onset of concerns among mothers. Also of note, there were several mothers who reported that they did not even notice developmental concerns in their child but rather someone else such as their child's pediatrician or teacher was the first to notice and bring the mother's attention to these concerns. When mothers did have concerns about their child's development, the behaviors that caused those concerns again varied greatly, with language delays (the most common); hyperactivity; picky eating; not responding to their own name or acting as if they did not hear; a lack of socializing; or repetitive behaviors being amongst those mentioned most frequently. The average age of diagnosis for children in this sample was around 34 months of age, which is actually quite young compared to the U.S. where the average age of diagnosis is 44 months of age for children with more significant symptoms (Maenner et al., 2013). Given the severity of symptoms present in the children in this study, one might hypothesize that the children who are being identified in

Jamaica fall toward the more severely impaired end of the spectrum. This could be attributed in part to the limited autism awareness in Jamaica discussed at several points throughout this paper.

The Experience of Raising a Child Diagnosed with an ASD

The second question posed in this study examined the process of having a child diagnosed with an ASD in Jamaica. Similar to other research in this area, this study also investigated the help-seeking behaviors mothers engaged in at the outset of noticing their child was not meeting developmental milestones or when someone pointed out to them that their child was not meeting developmental milestones. Additionally, the researcher was interested in learning what the journey to and through the evaluation process was like for mothers as well as better understanding their perceptions regarding etiology.

With regard to the help-seeking behaviors mothers engaged in after first becoming concerned with their child's development or alerted to potential developmental delays, the majority of mothers had first brought their concerns to their child's pediatrician. Others simultaneously began to research their child's symptoms on the Internet or by reading books and magazines. This is similar to other research conducted in the U.S. that suggests that the primary way in which parents gather information to inform decision-making surrounding treatment is often through the Internet (Interactive Autism Network, 2008). Of the parents who sought the council of their child's pediatrician, half of mothers reported their pediatrician taking their concerns seriously and providing them with a referral for further evaluation by a specialty clinic. However, another half of mothers reported their pediatrician initially being dismissive of their concerns for their child's development. From the literature it seems that it is not necessarily uncommon for professionals to delay giving the diagnosis for a variety of reasons including beliefs that the family is unable to cope with the diagnosis, that parents may simply be neurotic,

or believing that the child's prospects or responses to treatment would most likely not be good and therefore not seeing a need for diagnosing (Seligman & Darling, 2007). Additionally, the researcher has received a number of anecdotal reports over the years to suggest that parents in the U.S. have had similar experiences when they have first brought their child's behaviors to their pediatricians. Interestingly, two mothers, knowing that the wait for evaluation can be a long one, went ahead and began Applied Behavior Analysis and occupational therapy for their child prior to even receiving a diagnosis.

Relative to the diagnostic or evaluation process, many mothers reported a long wait to receive an evaluation from the specialty clinic doing assessments specific to ASD. Many mothers noted that until several weeks prior to the time of these interviews, there was only one doctor on the island trained in evaluation for ASD. This is not unlike the experiences of mothers in other countries such as Ghana (Anthony, 2009) and Kenya (Riccio, 2011) where there are very few doctors available for diagnosing. The long wait for evaluations was noted in other countries as well, including the United Kingdom (Mansell & Morris, 2004) and India (Daley, 2004). Similar to the experiences of mothers in Ireland who reported being called to be told of their child's diagnosis, several mothers told the examiner of being handed a report to read in the waiting room of the clinic informing them of their child's diagnosis. Unlike many of the other mothers' experiences reviewed from around the world, however, most mothers in Jamaica reported receiving a list of referrals and resources, as well as information regarding the child's prognosis, leaving them mostly satisfied with the amount of information provided to them following their child's diagnosis. That being said, one mother who reported receiving a great deal of information and recommendations, noted that there were no professionals on the island to provide the services recommended and so she did not necessarily find this information to be helpful. When

asked about what they would like to improve in terms of the diagnostic process, recommended changes included a shorter wait for evaluation and greater time and sensitivity taken when delivering the diagnosis.

In terms of how Jamaican mothers reacted to first learning of their child's diagnosis, the majority of mothers reported feeling despair, sadness, or feelings of being overwhelmed, with several also reporting feelings of denial. This is very similar to reports from mothers living in the U.S. (Bayat, 2007; Myers, Mackinstosh, & Goin-Kochel, 2009), France (Chamack, Bonniau, Oudaya, & Ehrenberg, 2011), China (McCabe, 2008a), Iran (Samadi, McConkey, & Kelly, 2012), Turkey (Bilgin & Kucuk, 2010), and South Africa (Krauss-Mars & Lachman, 1994). A couple of mothers reported feeling more along the lines of acceptance or relief upon learning of their child's diagnosis, which is similar to mothers in the United Kingdom (Russell & Norwich, 2011) and France (Chamak, Bonniau, Oudaya, & Ehrenberg, 2011), perhaps in part due to mothers already feeling quite strongly that their child was most likely experiencing symptoms of autism. One mother who believed she may have somehow caused her child's symptoms due to having feelings of regret about the pregnancy prior to him being born did report feeling guilt upon learning of his diagnosis. This reaction also was reported in countries where mothers lived in cultures that believed something the mother had done had brought a curse of some sort upon the family causing their child's symptoms including Taiwan (Shyu, Tsai, & Tsai, 2010), Ghana (Anthony, 2009), Kenya (Ricchio, 2011), and Greece (Probst, 1998).

Finally, this study explored mothers' ideas regarding the perceived etiology of their child's symptoms. Several mothers believed that there was a genetic risk that had led to their child's symptoms. Two mothers also made mention of exposure to environmental toxins as possibly being implicated in their child's development of autism, with one mother in particular

mentioning vaccines as a possible cause. Although the mothers themselves did not believe this to be the cause, they did report that several of their extended family members had blamed them for their child's symptoms due to Jamaican folklore beliefs that dictate that when a child's hair is trimmed before they are speaking fluently their development in this area is often stunted.

Similarly, another mother reported being told by the child's grandmother upon learning of his diagnosis that perhaps his symptoms were caused by her having the child out of wedlock. These somewhat supernatural beliefs about the child's symptomology are similar to the prevailing ideas held in Ghana (Anthony, 2009), Kenya (Riccio, 2011), Taiwan (Shyu, Tsai, & Tsai, 2010), and South Korea (Kim, 2012) that suggest that the mother must have brought a curse upon the family in some way leading to the child's symptom development.

How Mothers Perceive Themselves and Their Families to be Affected by Having a Child

Diagnosed with an ASD

The third question examined in this study focused on mothers' perceptions of how raising a child with an ASD has impacted them and their families. Interestingly, when asked this question, most mothers' responses focused on how they were personally impacted, with less discussion focused on how other family members were impacted. The researcher was also interested in learning about how mothers of children diagnosed on the spectrum and living in Jamaica describe their experiences raising a child diagnosed with an ASD. The ideas or feelings shared in this area ranged from the mothers' emotions surrounding the diagnosis at the time of the interview, the stressors they noted specific to accessing supports and services, and the impact of raising a child on the spectrum on their careers.

The majority of mothers reported that raising a child on the spectrum in Jamaica was a stressful experience, with almost half of mothers reporting having to take on a parent-as-

advocate or parent-as-therapist role and many reporting stressors related to accessing services and supports, most especially adequate respite care. Many mothers also cited the financial burden associated with accessing supports and services, for their child, including appropriate educational opportunities, as being a source of stress, with a couple of mothers even mentioning planning to leave the country in order to obtain government-subsidized services for their child abroad. Nearly all of the mothers reported feeling isolation as a result of a lack of public awareness surrounding ASDs and/or because their child's challenging behaviors were likely to draw unwanted attention or trouble. Several other mothers mentioned worrying over the future including how they would continue to manage the child's challenging behaviors as they grow, who would care for the child after they are unable, etc. These experiences are again very similar to multiple reports from other parents around the world including mothers in the U.S. (Bayat, 2007; Myers, Mackintosh, & Goin-Kochel, 2009, Smith et al., 2010), Belgium (Meirsschaut, Roeyers, & Warreyn, 2010), Sweden (Allik, Larsson, & Smedje, 2006), Australia (Farrugia, 2009; Giallo, Wood, Jellett, & Porter, 2011), China (McCabe, 2007, 2008a), Taiwan (Shyu, Tsai, & Tsai, 2010; Lin, 2011), Japan (Mori, Ujiie, Smith, & Howling, 2009), Iran (Samadi & McConkey, submitted for publication), Pakistan (Sabih & Sajid, 2008), Turkey (Bilgin & Kucuk, 2010), Ghana (Anthony, 2009), Kenya (Riccio, 2011), Ultraorthodox Jews living in Israel (Shaked & Bilu, 2006), and South Korea (Kim, 2012). Specific to how this stress or the challenges associated with raising a child on the spectrum had impacted their career, most mothers said that raising a child on the spectrum had made it significantly more difficult to work with some mothers finding it necessary to quit their jobs. Of the scarce literature specific to the impact on the career of the mothers, the experiences of mothers in Jamaica seems similar to mothers in the U.S. (Myers, Mackintosh, & Goin-Kochel, 2009) and Belgium (Meirsschaut,

Roeyers, & Warreyn, 2010). Similar to the reports of mothers in China (McCabe, 2010), one mother in Jamaica did report that her career provided her with a means of coping with life's challenges by providing a sense of normalcy for her.

Nearly all of the mothers interviewed said that their life had changed since their child's diagnosis in positive ways, some either gaining acceptance of the child's diagnosis or being able to "redefine the dream," but also many mentioning increased tolerance, patience, improved assertiveness and self-advocacy skills, redefining their priorities in life, or taking joy in the small victories of everyday life. Mothers in the U.S. (Bayat, 2007; Myers, Mackintosh, & Goin-Kochel, 2009) and Canada (Kayfitz, Gragg, & Orr, 2010) reported very similar sentiments.

Mothers' Descriptions of Day-to-Day Life Raising a Child Diagnosed with an ASD

The fourth research question focused on mothers' perceptions of day-to-day life. The researcher posed this question to mothers in an effort to better understand the kinds of daily hassles or challenges they may face raising a child on the spectrum in Jamaica. There has been little examination of what day-to-day life is like in previous qualitative studies of mothers raising children on the spectrum. In the current study, most mothers reported that their lives were very busy, but they did not go into great detail about daily routines or specific types of daily stressors. Most reported stressful daily living that included managing their child's challenging behaviors; acting as their child's therapist or teacher; and being isolated as a result of the limited public awareness or the child's challenging behaviors. Several mothers also mentioned that as their child had acquired more skills and attained greater independence, the stress of day-to-day life was reduced. Overall, these findings are consistent with previous research showing that mothers raising children with autism have higher levels of stress than are typical among mothers (Mailick Seltzer et al., 2010). It is perhaps not surprising, given these mothers' reports of what day-to-day life is like for them, that

researchers have found that mothers of children diagnosed with ASD to experience significant levels of fatigue (Seymour, Wood, Giallo, & Jellett, 2012).

Accessing Supports and Services

The fifth research question asked about supports and services that the children in this study and their families received. One of the primary contributions the researcher hoped to make not only to the literature but also to the Jamaican community of professionals hoping to support children diagnosed with ASDs and their families was to document the experiences mothers had with accessing supports and services. Many mothers reported obtaining behavior therapy or applied behavior analysis services; speech and language therapy; occupational therapy; and pharmacological intervention for the child, and these are believed to be the primary means of intervention available for remediating the symptoms of ASD on the island. While nearly all children were enrolled in school at the time of interviews, many mothers mentioned having significant difficulty locating a school where staff was appropriately trained for supporting the needs of children on the spectrum. Most mothers also mentioned that all of these services, including the cost of a “shadow” or “auntie” (thought to be unique to Jamaica), were often cost-prohibitive or caused a significant financial burden. They also reported that they wished more government-subsidized programs were available to families of youth diagnosed on the spectrum in Jamaica. These sentiments again echo the thoughts of mothers from around the world including parents in the United Kingdom (Bromley, Hare, Davison, & Emerson, 2004), Iran (Ahmadi et al., 2011; Samadi, McConkey, & Kelly, 2012), Ghana (Anthony, 2009), and Kenya (Riccio, 2011) who also cited difficulty accessing services and supports for their child as a stressor.

In addition to the support of their extended families, many mothers reported finding the Jamaica Autism Support Association (JASA) to be a significant source of support to them in raising their child. Again, many mothers from around the world reported that the opportunity to connect with other parents raising a child on the spectrum through a support group or parent connection network to be invaluable or that it was one of their primary needs. These findings have been reported among mothers in the United States (Osborne & Reed, 2008), the United Kingdom (Bromley, Hare, Davison, & Emerson, 2004), Ireland (Langford et al., 2007), Australia (Farrugia, 2009), China (McCabe, 2008b), and Iran (Samadi, McConkey, & Kelly, 2012).

Mothers' Vision of the Future for Their Child

The sixth research question asked about mothers' visions of the future for their child. It was hoped that in asking the mothers interviewed to describe their vision of the future for their children, several pieces of information would follow. First, the researcher hoped to learn more about their goals for their child in order to better inform professionals regarding possible treatment priorities for their children in the present. The second idea that the researcher was hoping to understand is how their vision of the future might be connected to other information collected through other research questions. For example, how are mothers' visions of the future for their child related to their day-to-day lives?

Although responses to this question varied, more than half of mothers worried about their child being a burden later in life or worried that they did not really know what the future would bring for their child. This could be at least in part due to the fact that there are no established residential settings or agencies to provide support for individuals on the spectrum past a certain age in Jamaica (see Morris, 2013). Many mothers said they hoped their child could have a "normal" life or could acquire a skill or have increased independence, including increased

literacy. Several mentioned that they had already begun to think about the kinds of skills their child would need to be independent and had begun planning for their child's care in the future. Several mothers, however, stated that they tried to not think too much about the future and coped by taking life a day at a time.

Advice Mothers Would Give to Other Mothers of a Newly-Diagnosed Child

Finally, the last research question posed to mothers asked what advice they would give to another mother whose child had been recently diagnosed with an ASD. The researcher thought that in asking mothers to describe what they might tell another mother, much would be revealed in terms of what they themselves would have hoped to have heard upon first learning of their child's diagnosis. To the knowledge of the researcher, no other studies have asked mothers for their insight in this way. What was learned from asking this question differed from mother to mother and was, in many ways, inspiring.

Many mothers said that they would tell the mother that they will have to be their child's advocate and would stress the importance of obtaining services for their child right away, perhaps reflecting on their own experiences with being their child's advocate and their own desire for their child to gain independence and skills. A number of other mothers felt it would be important to tell the mother to have hope and that although it is a long journey and life is now different, things will improve. Similarly, many mothers said they would stress the importance of faith or believing in God, and nearly half of mothers said that they would tell her to have tolerance and patience as she embarks upon her journey. This is again is interesting considering how many mothers reported initially feeling despair upon learning of their child's diagnosis, perhaps reflecting that they had to eventually find hope that things would improve. One mother, Libby, would tell mothers to structure the child immediately and to trust her gut. This seems

directly related to her own experience beginning her own form of behavior therapy in the home prior to her son even receiving his diagnosis and the long journey that ensued thereafter. One mother said she would tell a mother of a child who was newly diagnosed that although the journey may be difficult, there are high points as well and, at times, humor, perhaps communicating that things will not always look as bleak as they did for her when she first learned of her child's diagnosis.

When considering all of these experiences through an ecological lens, a number of systems are impacting the mothers' experiences in both helpful and unhelpful ways. Mothers noted that support systems including the JASA support group, assistance from their extended families and friends, and the support of their faith or religious community as having a positive impact on their raising of children on the spectrum. Although many mothers had been able to access services for their child, they did note that the educational system and offering of government subsidized programs was lacking. Additionally, several mothers mentioned the lack of options in these systems of care given the lack of professionals on the island available for service delivery. Another salient theme from these interviews was the feeling of lack of acceptance within their communities due to a reported limited awareness of Autism Spectrum Disorders on the island. These systemic impacts resulted in many mothers reporting isolation, several cases mothers considering leaving the country to seek better opportunities for their child, and reports that other mothers on the island were forced to "lock their child away" for lack of better options.

Limitations

There are a number of limitations inherent to this study that should be noted. The first is that the majority of mothers in this study lived within the greater Kingston area and therefore

closer to the few services that are available on the island. It is possible that mothers living in more rural areas where access to services such as schools that have staff with limited training in supporting the needs of children with special needs or where speech or behavior therapy is limited may have a very different experience when compared to the mothers interviewed.

A second limitation in this study is that the researcher was only in Jamaica for a period of two weeks. Although she was able to interview 13 mothers during that time, the member checks had to be conducted via e-mail. Although it is not uncommon for member checks to be completed via e-mail as opposed to in-person, in this study, only half of the participants could be reached. As such, not all participants completed member checks, leaving open the possibility that those participants who did not complete a member check might have made some alterations to the transcripts or identified themes. Given that there no changes suggested by participants who did engage in member checks, which may indicate that other members most likely would have only offered minimal changes.

A related limitation is that the researcher only had a brief opportunity to engage with participants while in Jamaica and even more limited contact after leaving the country. It is possible that with more time immersed in the community and, through further interviews and communications, more or perhaps different information might have been revealed. Additionally, this was the researcher's first time conducting qualitative research and, therefore, she felt more comfortable having several guiding questions (as opposed to a more general, open-ended "Tell me your story"). Although many mothers did answer all of the researcher's questions without them having to be asking, resulting in an even more general, open-ended discussion of their experiences, it is possible that limiting the discussion to the seven research questions used may

have been restrictive. As such, it is important that this research be considered preliminary and exploratory in nature.

Additionally, it should be noted that the researcher is not Jamaican and from the United States and, therefore, is possibly operating from a different cultural background and lens. In preparing for her trip, the researcher took great care to attempt to understand the culture prior to meeting mothers through consulting with the founder of JASA as well as her trip companion who had been working with these families for many years in addition to reading ethnographies and newspaper articles on Jamaica. Additionally, she attended several events including a support group meeting, a fundraiser, and several meals with families to begin to get to know potential participants and families. This kind of transcultural research is done quite frequently and the recommendations from the field are that the researcher engaged in this type of research take measures to understand the cultural context and to establish trust with participants. Also, it is recommended that the researcher reflect on his or her personal culture, which was done in this case through the bracketing process (Eide & Allen, 2005). That being said, the very fact that the researcher looked different and spoke differently from the participants, in addition to potentially having a different worldview given her personal cultural background, could potentially have influenced the results.

Finally, as mentioned in the methodology section of this paper, many mothers spoke with thick Jamaican accents and alternated between Standard English and Patois, or Jamaican Creole, which is essentially a nonstandard form of English specific to Jamaica and considered a type of slang dialect. For this reason, the researcher chose to present transcripts as true to the participants' accents and with the Patois used in an effort to accurately represent what was said. Although the researcher obtained a Patois "translation" sheet for reference when needed and was

able to engage nearly half the mothers in checks of their final transcripts for accuracy, it is possible that these factors (i.e., some participants speaking with thick accents or occasionally using Patois) culminated in a language barrier of sorts which may have influenced the results of this study.

Implications for Future Research and Practice

Despite the limitations of this study, this research also makes a number of contributions to the understanding of the experiences of mothers raising a child diagnosed on the spectrum to the field. First, although research examining the experiences of families, and in particular mothers, raising youth on the spectrum has begun to take shape from various regions of the globe, no literature exists to describe the experiences of mothers living in Latin America or the Caribbean. This study provides a glimpse into how some members of this culture may experience raising a child on the spectrum. To the knowledge of the researcher, Jamaica has yet to conduct informal or formal research of this kind. It is hoped that once this research is shared with those on the island, it may serve to better inform the need for services and supports for families raising a child diagnosed with ASD living on the island. Further, it is hoped that this research may encourage other professionals in Jamaica to continue to explore the experiences of families of youth diagnosed on the spectrum in order to better understand how to approach service delivery, especially evaluation, on the island.

Additionally, this researcher hopes that by synthesizing the literature conducted looking at the experiences of youth on the spectrum, a more holistic view of the kinds of researcher questions asked that inform this type of research may be provided. More specifically, it is felt that the kinds of research questions asked in this study were taken from various other studies conducted around the world and represent a comprehensive approach to the study of the

experiences of families of children diagnosed with an ASD. Researchers may want to consider using a number of other qualitative methods in addition to interviewing to capture even more information regarding family experiences. Several considerations for future research include using photoelicitation as part of the interview process (Harper, 2002) or considering the use of experience sampling (Scollon, Kim-Prieto, & Diener, 2003) either using the computer (Feldman-Barrett & Barrett, 2001) or pencil and paper methods.

This study was seminal in examining several unique experiences of mothers including their experience from conception to first noticing developmental delays and the help-seeking behaviors that ensued following these concerns developing. Further research in this area may help professionals to better understand the kinds of behaviors that stand out most to parents when watching their child grow and also the kinds of feelings and experiences they initially have that set the process of evaluation and diagnosis in motion. Additionally, this study was among the first to ask mothers to not only describe their vision of the future for their child, but also to ask mothers what advice they would give to another mother whose child had just received a diagnosis. Further research in this area would help us to better understand the priorities parents have for their children's development which is essential to treatment planning, but also what kinds of information or words of comfort mothers felt it was important for mothers of newly diagnosed children to hear, perhaps better informing professionals own practice in delivering the diagnosis.

Conclusions

This research provides a preliminary look at what the experience of raising a child on the spectrum in Jamaica may be like for mothers including the process of evaluation and diagnosis; the experience of accessing supports and services; and the impact on mothers and other family

members. Although mothers clearly identified areas where systemic improvements would be helpful to their families, including greater awareness of ASDs in the community and especially on the part of school staff, as well as greater government-subsidized supports and services among many things, the mothers also reported a number of positive impacts of raising a child on the spectrum. These life-enhancements include redefining priorities in life, increased tolerance, patience, and self-advocacy or assertiveness. Although raising a child on the spectrum appears to be a long and possibly stressful journey for many mothers, they felt that they would share with mothers who had a child who was recently diagnosed that it is important that they be their child's advocate and, perhaps most importantly, that there is hope. This research serves to inform existing literature in this area from around the world, but also provides greater insight into the needs of children on the spectrum and their mothers living in Jamaica.

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APPENDIX A

Explanation of Pilot Study

Hello, my name is Angela Mann and I am a graduate student at the University of South Florida where I study School Psychology. I have been working with the families of children diagnosed with an Autism Spectrum Disorder for several years now and am a sibling of a wonderful sister who is diagnosed with Asperger's Syndrome. In working with a great many families, I realize that there are many tiny threads that connect us but we have also all had very many different experiences. I am interested in learning more whether or not the interview that I have created will adequately capture your experiences as a mother of a youth on the spectrum.

I would greatly appreciate you taking the time to speak with me. I expect interviews to take approximately one hour and greatly value your knowledge and opinions. There are no right or wrong answers; I am simply interested in hearing your experiences. You are encouraged to stop the interview at any time if you are uncomfortable or wish to end your participation. You may also decline to answer any questions you chose and we will simply move on to the next question.

All information you share with me in the interview will be kept confidential. In any writing or reporting of your experiences, no names will be used and it will be impossible to tell what your specific comments are when I write up my report. Please note that this interview serves as practice for the actual research interview and, therefore, the results of your interview will not be published or disseminated.

If you have any further questions, please do not hesitate to contact me at 1.813.270.9210
or at angelamann@gmail.com.

Thank you very much for your consideration!

Angela Mann, M.A., BCBA
School Psychology Program
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APPENDIX B

Pilot Semi-Structured Interview Guide

Journey before Diagnosis

- What did you first notice in your child that made you concerned about his/her development?
- Were you the first person to be concerned or did another person bring their concerns to your attention?
 - What did this other person notice in your child?
- Why did you think your child was displaying these concerns or behaviors?
- When you became worried about your child's development what did you do?
 - What happened?
- How long did it take for diagnosis from your first suspicions?

Receiving a Diagnosis

- When was the first time the term autism was used?
 - How did that make you feel?
- Tell me more about your experiences with receiving a diagnosis for your child
 - Tell me how your child came to be diagnosed?
 - Who made the diagnosis?
 - What factors led them to make the diagnosis?
 - What support, advice, and information were you given at the time of diagnosis?
- On the day of the diagnosis, how did you feel about how you were told?

- How do you feel now about how you got the diagnosis?
- Did you tell others about the diagnosis at the time? How did you tell them?
 - How do you explain it now?
- What suggestions would you make to improve the diagnostic service?

Following the Diagnosis

- Tell me more about how your child's diagnosis has affected you and your family, both positively and negatively if applicable.
 - What impact does having a child on the spectrum have on your other children?
 - What impact does having a child on the spectrum have on your relationship with your spouse/significant other? Other adult family members (parents, siblings)?
 - What impact does having a child on the spectrum have on your work life?
 - On your own sense of self? Self-esteem? View of the world? View of other people?

Moving Forward

- What is day-to-day life like for you since your child received their diagnosis?
- What kinds of support are available to your family?
- What kinds of services are available to your child and your family?
- How would you describe the roles in your family in raising your child?
 - Who is responsible for what types of activities in child-rearing?
- What kinds of stressors do you experience related to have a child on the spectrum that may be different from the challenges experienced by others in the community?
 - How do you cope?

- Tell me more about the services, supports, and education that are available for supporting your child
- Tell me more about how you found information about these services and supports
- Tell me more about your opportunities to go out in the community with and without your child.
- Tell me more about your opportunities to spend time with your neighbors, extended family, or friends
- Tell me about the kind of supports that you have for yourself (if necessary)

Future

- What are your hopes and dreams for (child's name)?
- How do you describe your expectations for your child for the future?

Reflection

- How have you grown from raising (child's name)?
- Are there good things about raising a child on the spectrum?

APPENDIX C

Pilot Transcripts and Themes

Holly

Angela: So basically what I am doing is a practice interview for my interviews in Jamaica.

It will give me a good sense of how the questions work, if they capture the right amount of information, if the time works... all of that kind of stuff. So I really appreciate you helping me. The other thing to mention is that if there's anything that you are uncomfortable with, that you just don't want to answer, if you want to stop at any time you can let me know too. Everything we talk about will be confidential, so if you happen to mention your child's name I will change the name. So I just wanted to make sure you knew all that. I'll let you keep [information sheet about pilot]. So are you ready to get started?

Holly: Yes

Angela: So the first questions I have are kind of about prior to the diagnosis. So when did you first notice or become concerned about Jason's development?

Holly: A little before he turned two he wasn't talking. He didn't have any language. My oldest son at two only had like ten words, but then by like 2 years, 2 months he had like this language explosion so I really didn't get too terribly concerned that he wasn't talking at 2 years. But then he was two in March and then Memorial Day (so two months later by which my older son was talking) a friend of mine said "Well you should just take him

and have him screened at this place called Early Steps.” And so that’s when we had him screened. Initially it was just a speech delay.

Angela: And was this just recently?

Holly: He’s five now, so this was 3 years ago.

Angela: So were you the first person to become concerned or were...?

Holly: ...my husband and I. There was no one else really, but my husband and I.

Angela: Ok,...

Holly: You know what I take that back, his caregiver at the time, um, she had two other children at the same time and would say little things about Jason not having any language, so..

Angela: And how did you react to that? What were you thinking when she said those things?

Holly: Again, my oldest did everything late, but then when he did it he just took off and went so I think that was all I had him to compare to so I wasn’t too worried until he got to be about 2 years, 2 months when he wasn’t doing those things, so no....

Angela: Ok. And so it was really the lack of talking that first got you concerned?

Holly: Mmm hmm.

Angela: And why did you think? Just typical development and he’d catch up or was there something else you were thinking?

Holly: I didn’t think autism. I though speech language delay. I had no clue that...

Angela: So from the time that you first started to become concerned and the time this friend said something to you about Early Steps... What did you do from there?

Holly: So we signed up for Early Steps. They came out. They evaluated Jason. They said that he qualified for speech therapy, but that first they wanted to do some behavioral therapy to get him ready for speech; to get him ready to be able to sit down and pay attention. I mean he was two, ya know... a two year old. And we had behavioral therapy over the summer and then in late summer was when we transitioned from the behaviorist to the speech. However, the behavioral therapist was the one who first used the word Autism. But I actually did take him to Dr. Alexander that September at USF, but Dr. Alexander said no and so then we didn't give it anymore thought. So we went to speech therapy all the way up until almost his third birthday when we had to transition into Child Find and they told us the same thing and so at that point we went to a pediatric neurologist.

Angela: So they told you they're concerned there might be...

Holly: So it was at the Child Find... the transition from Early Steps to Child Find when they evaluated him there for his eligibility to go into the EELP program. They're the ones who said, "We think it's more than just a speech and language delay."

Angela: So from the time that the behaviorist told you "Autism" until the time when he was finally diagnosed by the pediatric neurologist, how long was that time period?

Holly: Um well it was summer of 2009... late summer and then he was diagnosed the February of the next year so about 6 months. But like I said, between then she said no so we had just kind of put that aside until February and we went immediately to Child Find and immediately we saw our pediatrician after the referral to see the pediatric neurologist. I mean it all happened very quickly.

Angela: And so that pediatric neurologist, that was in Tampa?

Holly: Mmm. Hmm.

Angela: Ok so that's when they finally made the diagnosis.

Holly: Yes and it was PDD-NOS – so not Autism but on the spectrum as Pervasive Developmental Disorder – Not Otherwise Specified.

Angela: So is that his current diagnosis now?

Holly: Um, well they don't keep PDD-NOS. PDD is usually just sort of for toddlers so on his IEP eligibility on Friday they said ASD and Language Impaired are his two eligibilities.

Angela: Got it. So are you expecting his label to continue?

Holly: Honestly, I think he'll wind up maybe being Asperger's but that gets diagnosed a little later is kind of what I'm thinking. He doesn't present like a typical autistic child but he has a lot of the features.

Angela: Got it. So when the behaviorist first said Autism what was your reaction?

Holly: Um, I didn't think she was right because I just couldn't see it. You know she was like "He doesn't make eye contact" but he does. I mean he'll hold your face and look right at you but he wouldn't look at her and she's like "The running around and the flapping..." And I'm like yeah but "Don't all two year olds run around and act crazy?" I just, I mean, I just didn't see it.

Angela: And when the pediatric neurologist diagnosed him? How did you feel about that?

Holly: Um, now by that point because we were looking for eligibility for Child Find, I wanted the label. My pediatrician was like, "Are you sure?" and I'm like, you don't get help without a label. She said, "You know a lot of people don't want their kids to get labeled. Are you sure?" and I'm like I want it on the chart. I want it on the blue and yellow forms that go to school. I want it everywhere. Because by that time I had done my research and

I'm like, you're not going to get speech, you're not going to get OT, without the label. I need the label. I was grateful to have it at that point.

Angela: So it was kind of you advocating for...

Holly: Yes.

Angela: Ok. Got it. Um, in terms of the factors that led to the diagnosis, it sounds like some of it... a lot of it was language with some behavior types of stuff. Is that still kind of the case? Are those still the concerns?

Holly: Um, the social is more relevant now. I mean two year olds don't really socialize with each other. He didn't really have as much of an issue with adults as he did with other children. He doesn't have obviously the language skills to socialize with other five year olds. When they were two they don't really talk well so it's not a big deal. It's more evident now and then he just, yeah, he just doesn't socialize the right way. Not only with the language, but he gets too close or just yeah, ya know, I just know other kids look at him and think "Yeah he's weird. I don't want to play with him." And, which he gravitates to younger children and I'm like, I know why he wants to play with the younger children. I mean the younger kids are not judging him. The other five year olds are like why do you so funny? Why are you this? The babies, like he calls him, wanna play.

Angela: How do you feel now about having him diagnosed? You said you were relieved and almost grateful at first... how do you feel now about it?

Holly: About the diagnosis itself? I'm happy to have it because you know, even two years ago I knew about McKay Scholarship and I had already looked at the criteria and I'm like if I have an Autism diagnosis I know he can get McKay and it will open up my options for

education. You know that's what I'm looking for. What are my options? What is the best way that I can do for him.

Angela: Got it. Um, ok. When you found out his diagnosis did you tell family, friends?

Holly: [nods yes}

Angela: How did it go?

Holly: Um, I mean it was... I mean one of my closest girlfriends that, I mean, we all have kids. I called my parents because I wanted my parents to, you know, be able to do a little research on their own, especially because they live here so that you know when they come for a visit, they have to adjust their expectations because he is on the younger end of the grandkids so their expectations are different because of the older and, you know, Jason is different. He's not going to do what they did or whatever. So, no, I'm very open about it.

Angela: Are there any suggestions you'd make in terms of improving the process that you had to go through to get the diagnosis?

Holly: I don't know. I mean... I think the pediatricians, I mean it took forever to get on board. She never thought. Even after we got that diagnosis from the neurologist she was saying "I think he's fine," but I'm like you're just not seeing in it. You're just not seeing it in that time with him. She's like "He's doing fine for me. You know, yeah a little language delay but other than that." I do wish there were better ways to pick up on it faster. I wish I had gotten him into Early Steps sooner. I mean with a speech delay you're not going to find maybe but in 18 months, but still, this was 7 months. It could have made a big difference.

Angela: So do you feel like better awareness efforts? Do you feel like more information out there?

Holly: I mean more awareness. I mean I don't know if there's more.... I don't know if there's more questions that the pediatrician could have asked me. I mean she asked me development questions at all of those appointments, but I guess it didn't throw up any red flags so I don't know if different or more specific questions that they could ask at maybe those developmental milestone appointments that would maybe raise a red flag at those developmental milestone appointments that would raise a red flag for parents. You just aren't aware. My husband and I... it's a second marriage for both of us. We each have one son. We have two kids between us. We were pretty sure we knew what we were doing [laughing]. You know... we raised two boys already, but you know we weren't prepared.

Angela: But I mean, how *do* you know? So I think that's like...

Holly: And for me it's like, every kid is different. Now my husband would be like, my son was potty-trained by the time he was... but I feel like they're all different. Everybody's different. So we've just kind of cut Jason some slack and, you know, they're all different. But we didn't know.

Angela: So how has Jason's diagnosis affected you and your family in their day to day life?

Holly: Honestly, he's really an easy kid so it doesn't impact our day-to-day life too much. He's not a rigidly scheduled child. He doesn't, you know, get upset if you do things differently. I know a lot of kids do but day-to-day it's just maybe like little reminders. You know my husband's like "Stop jumping! Stop running around!" and I'm like remember, he needs to do that. And it's funny because Jason has figured out... Jason has

called it 'dancing' and he knows that he cannot dance everywhere. So he will go, "I want to dance. Is it ok to dance here?" But really just running and flapping. I mean when he was younger, it was that vocalizing. Now he's, because he has some language, he'll actually sing or something, but I mean I look at my husband and, I mean, he is driving him crazy and I'm like, but he's held it together at school all day long. I don't know why he needs to do this, but he needs to do this and home needs to be a safe place for him to do it. I mean it's conversations like that that come up during the day or, with my older son, he gets annoyed with him and I'm like, you know, remember that Jason has issues or whatever and you need to cut him a little slack.

Angela: So everyone just getting to be a little more flexible? But it sounds like he's not too extreme?

Holly: No, not at all.

Angela: Um, how about the impact on your other kids? And I mean how both negative and positive things... just any changes.

Holly: Well you know the other boys were 10 and 12 so and they both had been only children, so it's hard to say, when my husband and I first got married and they both had been raised by single parents so you know, we got married and had Jason pretty quickly, so it's hard to know how much of it is Jason's Autism and how much of it is just like getting a sibling and a parent and a step-sibling - all of that together.

Angela: And how about your relationship with your spouse or other family members like parents? That kind of thing?

Holly: No, my husband and I, we try to balance each other out. When one's frustrated with him, the other one sort of tries to... ok, let me give you a break. We try not to be annoyed

at the same time. Um, I mean it's a constant battle with the grandparents just reminding them that Jason is not Gerald. Um this is on my family's side. They just can't expect the same things. My mom has this husband that is military and I mean, he just wants to run a tight ship and, you know what, it's not happening that way! [Laughing.] We're doing it Jason's way, alright? Sometimes you can't make everybody happy, you know. Alright?

Angela: Got it. Um, how about how having a child on the spectrum may have impacted your work life at all?

Holly: Work life... no. I mean, I was out of work when I had Jason. I left my previous job and was out of work for 16 months during the time that Jason was diagnosed. During the whole Early Steps, Child Find, all those transitions I was not working. Um, that probably would have affected my work because it was a lot of therapies. By the time I went back to work, he was in an EELP class so he was in school all day, but I lost my job right when he turned two. We called Early Steps two months later and so, while we were having OTs and everything come to the house, I mean I wasn't working. So it's hard to say. And then, by the time I started working again, he was in EELP and he's been in EELP ever since.

Angela: So for you specifically, has his diagnosis impacted kind of how you view yourself, the way you view the world or even like how you view other people at all?

Holly: I mean, I know I used to be judgmental when I saw other parents out with their kids because I... like I see how people judge when they see how Jason behaves out in public and I'm like, oh that was probably me at some point in time just not being aware, because an autistic child looks just like a regular child. I mean if you see a child with Down's syndrome or something like that there is a physical manifestation that you recognize there

is some kind of disability. Autistic children look just like regular children and so then when they start talking with serious language impairment or whatever. Other people are like, “Well he’s awfully big to be talking like a baby.” I mean you can just tell by the looks in their faces. And I’m like, I’m sure I judged like that too so I am a little more careful and open.

Angela: So now, moving forward, past the diagnosis, what is day-to-day life like for you?

And you’ve kind of already answered this a little, but um, are you busy? Are you running around to therapies? What happens for you during the week?

Holly: Well, during the week, I mean normally he’s at the bus stop at 7:10a. I’m off to work. I don’t get home until 6:00p. And his bedtime is 7:30p so it’s a very harried hour and a half of dinner, bath, story, bed. Sadly, I don’t get as much therapy for him, but I would like to do some one-on-one during the week. There just isn’t time. It takes me an hour to get to and from work. My husband is home with him after school though so they’ll work on some school stuff and on the weekends are all about whatever Jason wants to do. The older boys are 15 and 17. They don’t want anything to do with us. They wanna go be with their friends and girlfriends. It’s really just all about Jason. So he’s like getting the benefits of being an only child, even though he has two brothers. So when we wake up on a Saturday and Jason says “I want to go to Disney today,” we go to Disney today. Go to the children’s museum. I mean whatever he wants to do. He loves characters. He likes to take pictures. He would go to Disney and take pictures with characters every day. He would watch Disney Channel about 20 hours a day if you would let him. We just kind of indulge whatever his obsession is at the time. We just indulge that and let him be happy. And when my husband gets annoyed and then, I’m like, you know what, he’s only going

to be little once. It makes him happy and I'll remind him, you know, we don't know what his future life holds. I'm sure there is going to be crummy parts and really difficult parts.

While we have the ability to make his life happy and not difficult, why not?

Angela: That's a great attitude. I really like that. Um, what kinds of supports are available to you and your family.

Holly: Well, we talked about the educational. I don't really feel a need for respite though.

Honestly, I mean I would take Jason if he likes to go, but I don't need a break from him.

He's in school all week so it's not like I have him at home with me all week long. So you, know I don't really need respite like that. I would like more private therapy on top of what he gets at EELP, but we had an insurance change and they have one OT for all of Hillsborough County.

Angela: Oh, wow!

Holly: So I wish we had the therapy. What I've been looking for, this is what I've decided is a huge need in our community is based on what the school psychologist said about putting him in a typical youth sport. Well there aren't any team sports for kids like Jason on a regular soccer team, because he's just not... he doesn't have any of those skills. I mean he's delayed in everything. You know, adaptive, social, cognitive... I mean, he is behind everywhere. I mean you can't be on a soccer team or t-ball team with 5 year olds. I've been looking for some kind of youth sport team for kids with disabilities where I mean, he could at least, I mean they're not going to all be kids with you know; they'll have physical disabilities so it still would be a good environment. So you know, it would still be a good exposure for him. That has been my mission for the past week. There's one Buddy Baseball program at the Y but you have to be 8 and there is nothing else, so I told

my girlfriend, I'm like, do you know somebody with some time and some money that has a heart for philanthropy? Tell them this is where the need in the community is. Special needs athletics.

Angela: That is true and, I mean, in terms of interacting with the kids and getting social skills, I mean I don't think people realize how huge that is.

Holly: Yeah, and you know, my older son, when he was Jason's age he was already playing soccer every week. He did the U4 league, the U5 league. Jason would be in an U6 league right now so... Gerald I mean, I think that relationship that kids have with their coach, it's almost like another teacher, another beneficial relationship in their life. I think it's good for kids to learn to respect someone else and do what someone else says. So I mean, Jason has a teacher, and his mom and dad, but I think that's another individual that is a good person to have in your life. I mean my older son he had coaches and his 3rd grade soccer coach, he formed a really strong bond to him and when that gentleman started a lacrosse team a couple years later and invite Gerald to come and play lacrosse, he changed sports so he's now a 3-letters, you know, 3-time, varsity lacrosse just from someone that he liked in the 3rd grade.

Angela: That's definitely too bad that experience isn't here. Um, how would you describe the roles in your family? Like between you and your husband, what kind of roles do you guys pick up...

Holly: OH, I'm the nice one, the give them whatever they want nice one and my husband is the disciplinarian. That's pretty standard.

Angela: [Laughing] so good cop, bad cop?

Holly: Yes! I mean, he's my baby. You know, you know you're not having anymore. You know he's the baby. Give the baby whatever he wants! I can't... I mean I literally am incapable of telling him no.

Angela: So you have kind of complementary roles? [Laughing]

Holly: *He* would probably say that I undermine him, but ya know...

Angela: Well, I'm interviewing moms today, so, ya know... [Laughing]. Um, ok, what kinds of stressors do you experience from kind of like, or challenges that might be different from other parents in the community? I mean like the athletic league.

Holly: A place to teach him to swim. I mean I'm having a hard time even finding swim lessons. I mean I was looking at the Y and they have an adaptive swim coach, but ya know just the simplest things are not simple for me. Um, a birthday party. Someone having a typically developing child having a birthday party and it's at taekwondo. I mean that's not something that he's going to do too well at taekwondo. I don't think that's going to work out for us! [Laughing]

Angela: Anything else you can think of?

Holly: I don't know that there's stressors, we just really do have to cater our lives to him. Well I guess we don't have to, but we do. He is the squeaky wheel in the family that gets the oil. And luckily nobody really seems to mind because the older boys are so much older and don't really want to... I can't imagine if we had three children and they were all close in age and like why are we always doing what Jason wants and why is everything centered around Jason? I mean, families in that situation probably have a whole lot more stress than we do, but our other kids aren't complaining. And our other kids kind of already had their time and they're done with us [laughing].

Angela: Yes, they're off with girlfriends! [Laughing] So in terms of the like a birthday party comes up or you're struggling to find swimming lessons, how do you cope with those situations?

Holly: Um, other than just finding resources, I just keep plugging away until I find that everybody that I've asked... I'll give you an example since you said this was private...

Removed to protect confidentiality [27:06.3]

Recording begins [27:32.9]

Angela: Ok and you said right now that he is getting services from school, but that's kind of it. You're not really getting speech or OT or anything like that. Ok...

Holly: Well, also with speech, they're only available during the school day. And then you can't get services on nights and weekends, and that's really all we have since he's in school full time.

Angela: And how about like McKay and all of that? How did you find out about those kinds of resources?

Holly: Someone told me a couple of years ago, right before he was diagnosed, it was a mutual friend, I have so many friends who are teachers. A lot of my friends are teachers, so I think it was a friend who was a teacher who mentioned it. If I hadn't heard about it from her I think I have a cousin with four children and one of her boys is two years older than Jason and he's on a McKay Scholarship so I mean they were playing in the play area and I mean she had just told me that she had gotten a McKay Scholarship for Jonathan so I mean I've known about it practically since the diagnosis. I had always said that would be an option.

Angela: That's great to know that you knew about that so long. We've kind of hit on this one a little already, how about opportunities to go out in the community, with or without Jason?

Holly: Oh, all the time, anywhere. He's really good about that. I mean Jason wakes up every day and on school days he goes "What day is it? What are we having for centers today? What are we having for lunch today?" This morning he's like "We're having pizza for lunch today!" and on Saturdays, he's up before 6:00a and goes, "There's no school today! I get to eat a Pop Tart" because I won't let him eat Pop Tarts during the week, so I open one packet and one on Saturday and one on Sunday. He says "I can have a Pop Tart and watch TV!" and then when the sun comes up and other people wake up, "What do you want to do today?" "Where are we going to go today?" So yeah, we take him everywhere.

Angela: Do you get time for alone time ever?

Holly: We're lucky that, with the older one, he babysits and we just put Jason to bed early and by the time, he wakes up so early that we'll put him to bed at 7:30p and we'll go out around 8:00p so...

Angela: How about opportunities to hang out with neighbors or extended family, friends?

Holly: Um, we do. Like for Memorial Day, like all of the girls that I grew up with and their husbands and their kids, we get together the day after Thanksgiving, New Year's Day, 4th of July, Labor Day, but you know, I've known them for almost 40 years now and we get together. Some of my friends have kids the age of my oldest, but you know, my friends whose kids are 17 or 18 don't hang out as much because they don't have five year old, so it's a much smaller group that I had than when, when I already had Gerald, I had a lot of people to hang out with because we all had kids the same age but then I started basically

a second family and we do, my other two sisters have a seven year old and an almost two year old so we have family time and go out to grandma and grandpa's and play.

Angela: And how about the supports that you had for yourself? Can't you rely on friends? Is it your cousin?

Holly: My sister and I were close and she died about a year and a half ago. Since then it's been a couple of girlfriends and then two of my girlfriends both have seven year olds and one that has been diagnosed with Asperger's and entered the school system so no significant delays but no social and things like that so they're both probably the two that I talk to the most about Jason-related stuff.

Angela: In terms of the future, what are your hopes and dreams for Jason?

Holly: Am I going to have to live with him forever? The big question my husband asked the neurologist, he was like "So is he like... going to get a job and go to college instead of living with us forever?" I mean he wasn't being mean. He just really wanted to know. And the neurologist said, "That's dependent upon his IQ. IQ is completely separate from Autism. I cannot tell you that right now." The school psychologist just gave him his first IQ test and it was an 80. An 80 is below average. Its 10 points above mentally-handicapped, but she even said, he answered 'elephant' for the first seven questions. He was just playing around on purpose so I can't take that score seriously because he's five. He's autistic and he isn't going to take that test seriously so even that, we still don't really know enough. Our hope is that, um, when we were choosing the school before us deciding to go the private school route, I was told that he can't go to regular Kindergarten because he's not quite ready, but he doesn't belong in an ASD class. They have a developmental support class, but within that you have either a 'hard track' or a 'soft

track.' Soft track means that they're going to be on academic supports and they're going to get a special ed diploma. Hard track means they're going to take the FCAT and get a regular diploma. At Kindergarten! I have to decide, what kind of diploma is he going to get? And I'm like, how am I supposed to know?! And it was all supposed to be based off all of the school psychologist, all the testing... but the testing, everybody agreed Jason has to go hard track. He has the capability you know, if he can't do it, he can't do it. We'll move him, but at least let's give him a shot at it so he's not behind. You know, he can't start out behind because, you know, you chose the soft track and in kindergarten, they're doing preschool work. I would like for him to be mainstreamed. That he go to college. That he get a job. Grows up to be happy and successful and all of that. If he's still living with us when he's forty and watching his characters, so be it! And I told my husband, "Do you think it will still be fun in 30 years?!" [Laughing].

Angela: Hopefully it will be something else at that point! I'm sure! I have a sister on the spectrum and it was Little Mermaid but now it's Jane Austen so you know, it'll get better! And so, kind of a similar question, what are your expectations for the future for him?

Holly: No just that he'll grow up and be happy and do what he wants to do. That's what we want for all of our kids. Be happy at whatever they choose. And not have to live with us forever!

Angela: Every parent's dream!

Holly: Even though my oldest, it came up in conversation one day and he just said, "I just want you to know, when I grow up, Jason is the only one that's ever allowed to live with me. I'm serious. If you get old and you can't live by yourself, I'm sorry but you can't live

with me.” [Laughing]. So I asked what about my dad? And he said, “Oh gosh no! He’ll still be lecturing when he’s 103, you know he’s no moving in with me. I said, what about granny, my mom, and I’m like, you love granny! And he said “Dude, she waits on me hand and foot and she’s drive me batty after that! She can’t live with me either.” He goes, “You can’t live with me when you get old, but if Jason needs to live with anyone, he can live with me!” And I said, well that’s good to know.

Angela: Aww, that’s sweet. There’s a place for him. The next couple of questions are just reflecting back to how you’ve grown since Jason’s diagnosis. Have you, do you feel like there have been changes in you, positive or negative since finding out about his diagnosis?

Holly: No, you know, I really just...it’s redirecting my energy. My other child is very gifted and, honestly, if you have a child anywhere outside of average, it’s hard work. It was trying to keep him challenged, trying to keep him motivated, choosing books that suited him. I mean he’s in elementary school and I have the librarian telling me there is no books at Gerald’s level because he reads at a 12th grade level, but he’s 9 and I’m going introduce him to, so you know she basically made him his own little private club, but you know finding ways that you can help your child, for Gerald, I may have had to redirect that energy in another way, but it’s really not any different. Like I said, if you’re anything outside of average, the world is not created for you and you have to try a little harder.

Angela: Last question is, are there good things about raising a child on the spectrum?

Holly: Oh, I mean, I wouldn't trade Jason for anything! I can't even imagine. I can't imagine him being any different than, I mean, he's wonderful the way he is so, I think that's about it.

Angela: Thank you so much! That's it!

Recording ends. [38.05]

Betty

Angela: Alright so I know I sent you the information sheet, but I have another copy here and so what you're helping me do is kind of like test out like timing and how the questions work. So that's basically it. If you mention anything confidential, I will change all that and it's not really going to be published or anything like that. It's just to help me practice. I'll kind of start out by asking questions prior to Elissa's diagnosis. If there's anything that you're not comfortable answering, skip it, and we can stop at any time too if you're not comfortable with the interview. The first question I had for you is what did you first notice about your child that made you wonder about her development?

Betty: Um, speech. Wasn't speaking and I had a neighbor who had a son the same age and like 6 months younger and he was already talking and she was not talking.

Angela: Were you the first to be concerned or did someone else bring it to your attention?

Betty: No, I was the first.

Angela: What age was that at that you started to kind of notice?

Betty: Around two.

Angela: And why did you think, when you heard, when you thought about her speech problems, what did you think was going on?

Betty: I had actually no clue so. I don't know. I really didn't have any clue at the time. I just knew that, wow, he's talking so much and he's younger than mine. And even my neighbor was like oh, well, sometimes boys do first and that kind of thing. And I was ok. Then she had her next doctor's appointment and I brought it up to him and I might be getting ahead of myself...

Angela: No you're fine.

Betty: And so her pediatrician was old and about to retire from the Navy and he said oh, she'll be fine. She'll catch up. She was born in Italy, but by then we were in Rhode Island.

Angela: So he said, "She'll catch up" and what happens from there.

Betty: Um, he retired and we got a new pediatrician within probably about 6 months of me bringing that up to him and she was very, um, I brought it up to her who at this point, she was still not saying anything. So she started doing a lot of developmental tests and screenings on her and she said, yeah, there is definitely something wrong here.

Angela: So did she give you the actual diagnosis or did she send you out?

Betty: She sent us out to the Child Development Center at Brown University, Rhode Island. It's like a developmental center where they diagnosis developmental delays.

Angela: Who gave the final diagnosis?

Betty: She got diagnosed then and she was still at the age where she was diagnosed with global developmental delays and Apraxia and so that was that. Then we went to Georgia and we started early intervention, all that. Speech therapy. Occupational therapy. Um, so she went to school and same thing with even the school. They just said developmental delay. Her speech therapist who I would still recommend, around age 3 or 4... she was 4... she started telling me, "You know I don't think she has Apraxia because she's picking up speech too quickly and kids with Apraxia don't do that. I was reading this book about PDD and, you know, it sounds an awful lot like Elissa!" So then I got on the computer and started looking up what's PDD and found out that... same thing as Autism basically and so everything refers back to Autism so I brought her in to her pediatrician then, so she sent us to Atlanta to the Marcus Institute and so it was there that she was diagnosed.

Angela: Wow, so how old was she then?

Betty: It was like a two year span so that initial was two with Apraxia and then at 4 the Autism.

Angela: And was it a doctor that diagnosed her?

Betty: It was a pediatrician and a neuropsychologist and kind of a team like an educational person. Just like a couple of people that she saw. Same thing in Rhode Island. It was like a two day appointment. At the one in Rhode Island we saw like six individuals like speech, the developmental pediatrician, and educational person, an OT and a neuropsychologist I guess. And at Marcus I think there was a social work also.

Angela: Wow, so you like saw the whole gamut. Ok, so would that, that kind of conversation with the speech therapist, that was the first time that you were hearing Autism?

Betty: She didn't say Autism. She said PDD because she didn't want to say Autism.

Angela: How did you react or how did you feel when you were like looking up the info on PDD and kind of things were connecting?

Betty: Kind of like, in a way I was ok with it because we'd already been through so much at that point and I was kind of already on that mode of let's fix it, ya know what I mean? So Apraxia is very much similar as far as maybe even a little harsher as far as language because kids with Apraxia don't ever really speak well and, in my mind I guess, I knew that she would already kind of get there so I was ok with it. And I had already gone through that phase of she will never be what I thought she was going to be a few years earlier.

Angela: Got it. How did you react to that first diagnosis?

Betty: So she had numerous medical issues when she was a baby. She almost died a couple of times so... um, what they think is like glycolic storage problems. I think it's something different now, but at that point, I was just glad that she was ok so I was out of that "Oh my gosh!" stage, ya know? Because I had already almost lost her a couple of times so I was just like we're going to deal with it.

Angela: I didn't realize that all of that had happened. That's insane.

Betty: So that's why we saw a geneticist and stuff like that to see what, the genetic doctor said the glycogen storage disease and another said "No it's not that. I see kids all the time come in here with low blood sugar problems and I don't know what it is, but it's very common in kids with ADHD and also with Autism. And um, so I think there are studies being done and I just read the mitochondrial thing so I'm thinking it's maybe that, but to know they have to do a liver biopsy to find out if it is for sure that and, because she had tubes in her ears and she had a reaction to the anesthesia, they wouldn't put her under just to get the liver biopsy.

Angela: My god! That's crazy. You went through a big journey there!

Betty: Yeah, so by then it was just like, this is wonderful!

Angela: Yeah, that makes sense. Um, ok, so what was the big thing that kind of led, like what was when they finally diagnosed her...

Betty: Um, ok, so by that time she was talking a little bit and her voice was very monotone and very deep for a child that was four years old, a really extremely deep voice so it was that and then also like they spent a half day with her and during that time she never interacted with them. She would only address me or my friend that was with me and, um, just very behaviors of course during that four year period.

Angela: Got it. Ok, so it was the full range of symptoms. So in terms of her getting the diagnosis, look back now, how do you feel about knowing that she's on the spectrum.

Betty: I'm totally ok with it now. I still have like concerns like things about what she's going to do in the long term like when she becomes an adult. Will she get a job? Employment? That kind of thing. I have no clue. I have no clue whether she's going to be able to do any of that stuff. So those are my only concerns, but then my main concern now is she's in school now, but what happens when she's not.

Angela: That make sense but it sounds like , from where she's come from, incredible what's she's doing now so... Ok, so when you first found out, after the Marcus Institute, did you tell other people?

Betty: Family? A lot of my family were just like "She's spoiled. She's a brat. She needs a spanking." That kind of thing so this kind of helped for them I think more than anything. For me to validate, why she does what she does and it wasn't because of bad parenting.

Angela: How did they react to that?

Betty: Um, you know I don't really recall. I think they were just so used to some of the behaviors and some of that stuff and everything that was going on that was like ok, but maybe a little more accepting of her. That kind of thing.

Angela: In terms of the process and going through it, do you have suggestions for how to improve that process that you went through? Just kind of like from the time you had suspicions to the time that you got the diagnosis, is there anything you wish had been different?

Betty: No because just looking at families here now and what they go through, I know that I got the best of the best so-to-speak for where I was. You know Brown University and then the Marcus Institute in Atlanta, so you know, I have the best of the best, so I wouldn't change it, but I know here that families don't have experiences like that.

Angela: Ok, so now I have some questions for after the diagnosis. So can you tell me how Elissa's diagnosis has affected your family? I mean it can be both positives and negatives.

Betty: I mean, kind of like I was saying earlier, at first it was difficult. It was work. It's like having another job, so it wasn't easy, but I think, given the work you put into it, it's what you'll get out of it. So like I can take a breather now and sort of do things but I had to sacrifice early to get here.

Angela: Has there been anything about her diagnosis that's affected your work life?

Betty: So when she was first diagnosed, at this time she had so many medical problems prior to the diagnosis, so I had to get out of the Navy which I had spent 13 years in so I gave up a retirement to take care of her basically. I ended up going back to school, getting my degree in special education and then I got my job teaching kids with Autism and now I work at [removed for confidentiality].

Angela: How has it affected your own views of yourself or your view of the world or your feelings about yourself or other people?

Betty: Um, basically I think it like it definitely allowed me to find my purpose, so to speak, so my career and so as far as world views, I think people are more aware of it and more accepting so to speak.

Angela: Ok, so what is day-to-day life like for you with Elissa?

Betty: [Laughing.] Very routine. I think having a child on the spectrum it kind of makes your life become routine. So day-in and day-out we get up at the same time and get her ready for school and I get ready for work, but on the weekends we're flexible so... but no surprises though. You can't surprise her with anything! Everything has to be planned and...

Angela: Got it. What kinds of support have been available to you and your family?

Betty: One of the benefits of working in the military for so I had that luxury of having the best of the best, so we were very fortunate in the early years that she has that. Here I see the same thing, we have great support system in the school and I wish they all could go to that school, but because of my job I think people are more willing to work with me, so you know that helps. As far as global stuff, APD, she got accepted, but we'll probably never see services before ya know... who knows. I'm fortunate to have a good job with good insurance, but she doesn't need therapy or anything because frankly I am not sure if I could afford even that. I would like to get her into cognitive-behavioral therapy, but who can afford that today? So...

Angela: How would you describe the roles in your family, and even your extended family, in raising Elissa?

Beverly: That's probably more just... being a single parent, my family was somewhat supportive but probably not as supportive as they could have been and I think it was mainly because they just didn't know how to deal with her. They just wanted to, you know, my mom is in her 70's so she can do very little for my daughter. And my sister has a lot of medical issues so she can barely take care of herself so um, as far as that, I don't have a lot of a whole lot of family support so I mean when she was younger I mean, in

the most extreme cases, they would help me out, but most of the time I had to do it for myself.

Angela: Wow. That's incredible. You're Navy training probably came in handy huh?

What kinds of stressors were related to kind of her diagnosis that might be unique to what most parents experience?

Betty: I think early on is the hardest again, because when they're younger small things just like going to the grocery store is difficult. Being able to go to family events it's difficult. So those kinds of things, I mean even family events can be stressors, but I have learned to let her, you know. Ok she doesn't have to stay in the crowd of everybody so if she wants to go to the back bedroom let her go.

Angela: Got it. So are there any specific things that you like do to cope with the stress yourself?

Betty: It wasn't until the last couple of years that I was really able to... she's kind of self-sufficient now so I mean it would be great if you could do that, but again, single parents – that's not going to happen.

Angela: Um, you've already told me a little about the services and supports available to you. Is there anything more to add to that?

Betty: Just that there's not much in Florida! [Laughing.] No...there's plenty of programs for kids. There's a lot more here than there was in Georgia, but again you have to have the money to do them.

Angela: And how did you find out about them?

Betty: We do ACT which she gets a scholarship for that so you know, that's one way, we do that. The services... how did I find out about that? Pretty much just you know, at work we have a resource center that kind of thing.

Angela: Tell me more about your opportunities to go out into the community with and without Elissa.

Betty: I know what her triggers are so I know what she can do. I still try to push her, but you know, I kind of make her go and I know her limit so I allow her to go sit in the car when she's done. I go and do things that she may not want to, again, I can't do it without preparing her like oh we're going to go here before. That sort of thing. Like last year, I made her do Surfer's for Autism. She would never want to do that, but it worked out nice!

Angela: Are there certain places that are harder for her to go than others?

Betty: Yes, going to a place where there are a lot of people or a lot of noise. That's the main thing. Like going to a sporting event, because of the heights... she's scared of the heights, so she doesn't climb the stairs, so she doesn't go to games with me but that's ok. Because I know what her triggers are...

Angela: And how often are you able to get out on your own without Elissa?

Betty: On the weekends, I can go out.

Angela: When did that kind of start?

Betty: I would say maybe last October so...

Angela: Ok, how about opportunities to spend time with your neighbors, extended family?

Betty: I mean basically we have one particular neighbor that will ya know come over and play a game with us or with Erica so we did that. My friends that I work with... we hang out with them all the time too. Family not so much.

Angela: Ok, um, tell me about any sorts of support that you have for yourself right now.

Betty: Um, probably just the people I work with. I think they are it

Angela: Ok, now I'm going to ask you questions about Elissa's future. So what are your hopes and dreams for Elissa?

Betty: Um, again, I just I have it set up for her to go to the Learning Academy at CARD and probably we'll start there, but with school, when she graduates which is soon and I'm kind of leaving that up to her. At this point, she's saying she wants to graduate next year, but she knows that we're not just going to sit at home. We're either going to school or we're going to work. She knows that's not an option.

Angela: How would you describe your expectations for Erica for the future?

Betty: Um, again, I expect her to do something whether it be work or school or...she's not going to just sit at home alone. Sorry!

Angela: Ok, so the next part is just kind of reflecting back, so how would you say you've grown from raising a child with Autism?

Betty: It's calmed me down and settled me down you could say. [Laughing.] and I've grown too just, ya know, knowing about Autism.

Angela: Would you say, are there good things about raising a child on the spectrum?

Betty: I mean I tell everybody, I'm so fortunate because they're the most honest children and I guess in a way, it could be a sad thing, but for me, having a 16-year-old daughter who is

not having to worry she's going to go party and do drugs or date... I feel very lucky. But I think I just accept them and accept other people for whatever, whoever.

Recording ends. [35:00.28]

APPENDIX D

Bracketing Interview

Bracketing begins on June 9, 2012.

My Personal Story with Autism Spectrum Disorders

I knew very little about autism other than what I had learned in undergraduate psychology classes when I became a teacher. After college, I knew that I wanted a career working with kids and, while I was still trying to figure out what exactly that would be, I was fortunate enough to get a position teaching at a private school for kids with a variety of exceptionalities and learning needs. My class was comprised of 3rd through 5th graders whose parents felt the public school systems were not meeting their unique needs ranging from significant anxiety to dyscalculia to giftedness to hearing impairment. Two of my students were in the process of also being evaluated for placement on the Autism Spectrum and this was my first introduction to children with these characteristics. Despite their common diagnoses, their strengths, areas of need, personalities and behaviors were drastically different. On the one hand, I had a student who was highly verbal, picked up on concepts extremely quickly, had unusual and intense interests not at all common for a child his age who desired spending recess with me more than his peers. On the other hand, the other student could best be described as nonverbal, although I was able to understand the means by which he did communicate to me quite well, who clearly desired a relationship with his peers but seemed almost “trapped” in his body or in his own world at moments throughout the day. He needed concepts illustrated to him using

manipulatives and benefitted from repeated, direct instruction. While I loved all of my students as if they were my own, these two students in particular intrigued me.

At this same time in my life, I had moved home and my contact with my family which was fairly significantly limited while I was away in college increased dramatically. My family was always quirky and I had spent plenty of time reflecting on their differences when compared to others while I was away at college, but coming home really drove the point home. My parents were long divorced at this point, my mother had remarried and the relationship between my stepfather and my sisters and I was tense. This tension was especially great between my sister, “Astrid” (name changed), and my stepfather. Astrid had grown up a beautiful and incredibly intelligent girl. She could lock herself in her room for hours on end reading Jane Austen novels, seemingly disinterested in family interaction. Astrid had been diagnosed with ADHD at a very young age and was immediately placed on the highest doses of Ritalin or Adderall that could safely be given to a child her age. She struggled in school, many teachers discounted her struggles with comments to my parents that “she was cute and she knew it” and the like. Astrid never really made friends and mainly tagged along with my youngest sister and her friends, four years her junior. As she entered her middle and high school years, life was rife with social conflict. My parents were faced with a number of difficult situations including teachers reporting that Astrid would “explode” on peers in her theater group if others weren’t taking the script as seriously as she was or performing in a way she expecting, these same kids all leaving for lunch breaks from practice and intentionally leaving Astrid at the school, and finally, a dissected fetal pig being put in her locker which my parents only found out about when Astrid reported back the day’s events in her usual routinized way. Although none of these difficulties were especially new, they were certainly growing. Astrid was now in college when I had moved home. She

didn't drive, primarily due to what I perceive to be my parents' significant overprotection, and my parents were commuting her to school 45 minutes each way. My dad was writing her papers for her because she found writing to be overwhelming and sincerely seemed unable to sort out main ideas and supporting ideas let alone organize them into a structure and flow expected of a college student. These battles over papers would literally go on for days. Perhaps of greater concern was the deterioration in Astrid's ability to make it through her days. She was increasingly socially anxious to the point where she struggled running into the grocery store alone and she was having episodes of explosive aggression when things didn't go according to her plan. I could no longer show my face in a Blockbuster Movie location without feeling like my family's picture was posted somewhere behind the counter warning the clerks of the girl who would explode if "Pride and Prejudice" was out that night. Despite Astrid's many strengths; her smarts, her ability to remember every single fact from hearing one lecture in class about Egyptian history, her intense interests in subjects to the point of expertise in these areas; it was pretty clear that something had to give.

With everything I had been researching to better understand my students, the pieces of my sister's picture slowly started coming together. When I approached my parents with the idea of getting a second opinion or reevaluation of some type for my sister they were initially reluctant. My sister had been seeing the same developmental pediatrician for the majority of her life and with as many medication changes and such as they'd gone through, I'm sure adding a new twist to consider wasn't exactly welcome, but eventually they did and the answer came – Asperger's Syndrome. Certainly that wasn't where the struggle ended but it sure helped us all to better understand.

Career in Supporting Individuals with Autism Spectrum Disorders

After almost two years of teaching and living with my family while they sorted out how to navigate these new waters, it was time for me to move on to that next step. For me, I knew I enjoyed research and I knew I enjoyed psychology, so when I learned of a Master's program in north Florida that offered greater experience in both, I jumped at the chance. Fairly soon after moving to Jacksonville, I found out about an opportunity to help with a Family Fun Day for families of kids with ASDs offered by the local chapter of the Autism Society of America. I signed up to assist throughout the day and enjoyed getting to know the families, feeling like I was a part of something really great for them that day. As I was helping clean-up, a young woman I'd seen floating around and doing what appeared to be behavioral therapy with kids approached me. Her name was Dr. Mae Barker and she was a behavior analyst and the Executive Director of the University of Florida-Jacksonville Center for Autism & Related Disabilities (CARD). When I said I was a former teacher and interested in learning more about autism, she kind of whimsically asked me if I would interview for a position as an educational consultant at CARD. I did (which was an interesting experience in and of itself) and somehow got the position. My first day on the job Mae introduced me to my first family. The little boy proceeded to strip down naked and pee on Mae as he protested her attempts at getting him to vocalize his requests. I felt completely in over my head. Fortunately for me and for that little boy, I was surrounded by people who loved these kids and had dedicated their lives to receiving the highest levels of training to support them. We both made it through pretty well in the end.

Over the next couple of years my colleagues at CARD taught me everything they knew, enough to get my certification as a Board Certified Behavior Analyst. As my family and I's understanding of my sister's diagnosis grew, so did my interest in supporting individuals with

ASD, especially those with Asperger's. As a teacher I saw so many of these kids included in general education settings with teachers who were less than thrilled to have them there and definitely underprepared to support them. So this became my niche – I learned as much as I could about successfully including kids with ASDs in general education settings and the community. I became a fierce advocate for these kids and schooled myself on the neurodiversity movement which aims to reconceptualize ASDs as being one part of a continuum of neurological differences as opposed to a disability. Several colleagues and I developed a social skills curriculum to support kids with ASDs with navigating social interactions in inclusive settings that became increasingly popular in the community. These social skill group sessions served not only as an opportunity for these kids to learn new skills and experience some social successes, but it also became a time for parents to band together and support one another. To date that program has supported over 100 families.

As I developed as a professional, my personal connections with these families and the community grew. I seemed to particularly gravitate to the many single mothers who were going it alone, many without much social support at all. The significant stress and struggle these mothers endured battling the schools, battling for appropriate treatment, working within limited financial means, and more was completely overwhelming to me. Towards the end of my tenure at CARD in Jacksonville, a mother I had grown quite close to through our social skills group accidentally overdosed on what was suspected to be her son's medication right around the time that several private schools had rejected her son because of behaviors related to his ASD. Her kids found her and fairly soon after their grandparents contacted us for information on how to help her son with understanding and coping with the loss. Attending her funeral and watching her son face this immense tragedy knowing all of the other struggles the family had already been

dealing with made me feel helpless. Sadly, I have known several single mothers of children on the spectrum who have since committed suicide and every time that same sense of helplessness has crept back in.

I think it was these tragedies more than anything that motivated me to shift my attention away from simply supporting the child to trying to better understand how I can support the whole family.

My Present Day World View and Theoretical Framework

As mentioned previously, I approach my work with families and my research in this area with an “Advocacy/Participatory” worldview (Creswell, 2007, p.21) meaning that I subscribe to an idea that research and therapeutic work with families should create greater social justice and improved quality of life for the individuals participating in such research or therapy. More specifically, it is my hope that the work I do helps individuals on the spectrum come into greater contact with the community in positive ways, that their families feel supported and welcomed into the community, and that the community itself grows to better understand ASDs and the families of individuals with ASDs and all of the incredible things that being neurodiverse has to offer.

I operate from an ecological theory framework (Bronfenbrenner, 1979) meaning that I think that multiple systems operate on an individual and influence their experiences including those at a macrolevel such as the greater culture the family and child live in all the way to the microlevel meaning the school, religious community, or neighborhood for example that the family and child interact with on a regular basis.

It is my goal to better understand the experiences of these families on all of these levels in an effort to give voice to those experiences and inform reform efforts to support them.

Why I Chose to Study Jamaica

After reading Roy Richard Grinker's *Unstrange Minds* (2008) which details not only the author's personal experiences having a daughter with autism, but also chronicles the history of the culture of autism here in the U.S. My favorite part of the book is where Grinker highlights the experiences of families of children with autism in several different parts of the world. The idea that autism could be viewed so drastically differently in different cultures was fascinating to me and his descriptions of even greater struggles for families than I had ever witness here in the states was shocking. When I entered my Ph.D. program in School Psychology at USF, I knew I wanted to give voice in some way to the experiences of families of children with ASD abroad, but I was quickly met with a number of obstacles to overcome. When I shared this goal with colleagues and mentors the answer was typically that doing this kind of work was well beyond the scope of what could be accomplished in the course of my program. Right when I abandoned the idea, opportunity knocked. After accepting a position assisting several professors with their international research my interest was renewed. That position showed me how to accomplish international research and opened my eyes not only to the potential obstacles in doing this kind of work, but also the plausibility with careful planning. I realized that realizing my dream of conducting a dissertation abroad with families was within reach, but that it would be essential to pick a location where I could easily establish connections with the autism community, where language barriers were not an issue, and it would be financially possible to visit on a number of locations. As I began my search for the perfect country of study meeting these criteria, I was introduced to Dr. Amanda Keating who had been visiting Jamaica for a number of years providing consultation to families of children with ASDs as part of the Florida Volunteer Corps Program. Jamaica was perfect for so many reasons – autism aware efforts were in their infancy

on the island, resources were scarce and the need for greater community and educational inclusion was great. Certainly these families' stories needed sharing. I was also inspired to hear about how parents had banded together there to begin initial reform efforts. I knew I could communicate with families and had at least a cursory understanding of the culture living in an area heavily populated with immigrants from the Caribbean, plus it was close and relatively inexpensive to fly to from Tampa.

When I approached Dr. Keating with my idea, she initially seemed skeptical (which at this point I was pretty used to), but said that she would be willing to hear more about my study when it was better flushed out at which time she would consider sharing the idea with her contacts in Jamaica. As I began to work on a proposal, Dr. Keating contacted me and said she was planning a trip within a month and could I get a proposal together and approved in time? Working best under fire, I obliged, and with the most supportive and encouraging advisor ever was able to piece together the study you are reading about today.

Preconceived Notions of Jamaica

With limited information about Jamaica and the Jamaican culture available on the Internet or in the stacks at the library, most of my information about Jamaica comes from Dr. Keating's descriptions, Bob Marley and Peter Tosh songs, and CIA World Factbook and UNICEF statistics, although I have had the benefit of living in a community with a relatively large Jamaican-American population and have had the opportunity to learn a little about this culture through my interactions with those Jamaicans living in my local community. I picture Jamaica and Kingston in particular to be relatively economically disadvantaged and afflicted with corruption. From reading several newspaper articles from Jamaican papers about autism, it seems that families not only struggle to provide appropriate care and education for their children

on the spectrum, but that they also battle pretty significant stigma from the community. Despite some of these preconceived notions of Jamaica with more negative connotations, I think of the Jamaican people as resilient, hard-working, with a persevering spirit and deep sense of connection to their Jamaican identity. I sense that perhaps connectedness carries through in family structures and that Jamaicans may actually enjoy more support from extended family than those of Western cultures. I'm definitely eager to learn more for myself.

Bracketing online while in Jamaica during the period of June 27, 2012 through July 5, 2012.



The screenshot shows a blog post on a wooden-textured background. At the top right is a small 'About' button. The main content area has a title 'The Story of Autism in Jamaica' and a subtitle 'My Journey in Kingston' above a photograph of a tropical beach with palm trees and turquoise water. Below the image is the post title 'Preparing for lift-off – Holy Smokes! It's early!' followed by the author 'angelamannboba' and the date 'June 27, 2012'. The post text describes the author's experience at an airport and their work with autism.

The Story of Autism in Jamaica
My Journey in Kingston

Preparing for lift-off – Holy Smokes! It's early!
Posted on [June 27, 2012](#) by [angelamannboba](#) [Edit](#)

So here I sit... 5:53a at Gate 79 awaiting departure to Miami. After being interrogated about my transcription foot pedal and what causes autism (is it the shots? of course) by the Homeland Security guy, I am in!

It's been quite a journey getting here. I reminisced with my boyfriend on the ride here about how quickly it's all happened. From a very far-fetched dream of going to India, then Ghana, then any number of 30 different countries just around 6 months ago to meeting the fabulous Amanda Keating who guided me to Kingston to writing my dissertation proposal in under 2 weeks, defending, getting IRB approval and now sitting at the airport waiting to take-off. Would have never thought I would be here today!

Perhaps I could have thought back even earlier to when I first got into this field working at the UF-Jacksonville Center for Autism & Related Disabilities way back when. I certainly wouldn't have thought that when I interviewed with Dr. Schwarz (which he'd fallen asleep in the middle of and I questioned if he still had a pulse) that I would be where I'm at in my career today. At that time, I had barely read the diagnostic criteria for Autism, let alone really understood what it was all about. Through the years, I've had the time to meet and work with some truly amazing families. I was awestruck by their struggles, but also lived with them in those moments that would be tiny, pleasant events for most, but huge victories for these kids like attempting to say their first word. I've had the good fortune to assist families in their journeys and hopefully lighten the burden, but it has always been evident to me that there is so much more help to be had. I've been profoundly affected by these children, but especially the story of their mothers, many of whom who've had to go it alone. Devastatingly, I have lost several of these mothers to suicide or overdose from substances meant to ease the pain. It's these mothers that I constantly carry

the torch of struggle for.

As my friend Sarah and I talk about frequently, the universe provides in intentional, serendipitous ways and as it would have it, I had the privilege of volunteering for an event last week called "Deliver the Dream." This was a retreat for families of children with ASD and my job was to be acting "parent" for my assigned family's 3 kids – a 22 month old, 2yo little girl with Autism who currently has a limited ability to communicate her needs, and a very protective 6yo brother – for the weekend. I am still exhausted! Through kicks, pinches, screams, diaper changes, and some fun (yes – we squeezed it in!), I really got to experience what this family lives on a daily basis while the parents enjoyed some much needed rest & relaxation with the other parents. It was a very emotional experience and I am feeling incredibly appreciative now of the little things I used to think were big challenges. There's no way it was a coincidence that I was able to experience this immediately before flying out to interview mothers about their lives.

We have to make it better for these families and that's what brought me here to wanting to learn more about the struggles and advocacy work of the mothers living in and around Kingston, in a country with only one licensed psychologist, one behavior analyst, and where the vast majority of children with special needs receive little if any services including education at all.

Again, the universe provides. I noticed this in a post by a group called "Single Mothers who Have Children with Autism" last night. For those of you who seek a better understanding of what life can be like having a child with Autism, I think this is a beautifully written introduction.

"WHAT THEY DIDN'T TELL ME ABOUT MY CHILDS AUTISM..."

Here are some things you will not find in your research on autism:

You will not learn how this diagnosis will affect your marriage or other members of your family. You will not be told how it may fundamentally alter your perceptions of what is "normal," how it may change your view of human beings, how it can force you to question small talk and why we behave the way we do, how it will transform your outlook on life, how it will change you, how your life and everything you assumed to be true, is no longer what you thought.

Having a child with autism may cause you to feel things you never dreamed possible. You may know moments of joy and moments of despair you could not have imagined. You may find yourself going to untold lengths in the hope of helping your child. You may feel distracted, unable to concentrate. Your work and career may suffer. You may learn what it is to be sleep deprived. You will come to know what it means to feel desperation. You will know sorrow in a way no one can prepare you for. You will know happiness in a way no one can prepare you for. Sometimes you may feel both sorrow and happiness within the same day, within the same hour, within the same minute.

You may spend money you do not have on yet another treatment, yet another doctor, yet another specialist, yet another therapy, yet another intervention, all the while rationalizing that if it helps, it will all be worth it. You may contemplate doing things you would have scoffed at before your child was diagnosed. You may find yourself trying things that defy logic and have no medical basis. You may listen to implausible, anecdotal stories and think — we will try that next. You may dream your child is speaking to you in full, complex,

beautifully self aware and revealing sentences. You may wake from those dreams believing for a few seconds they were real and not a dream. You will pray that you might dream again. You will welcome sleep, as you never believed possible. You may ache with sadness because your child is crying and in pain and your presence brings them no solace. That ache may become unbearable when your child hits themselves in the face, bites their own arm or hand, punches their own legs or stomach. You may question every maternal instinct you have.

You may feel ecstasy from being hugged, unprompted. You may feel the exquisite joy from having your child reach for you, ask for you or look at you. You may know the joy that comes from seeing your child work so hard at something that does not come easily to them. You may celebrate when they use the bathroom unaided, drink from a cup, sleep for more than a few hours without waking you, try a new food or simply acknowledge your presence. You may feel a gratitude you would not have believed possible. You may cry from happiness when they say a word, any word, even if you are the only person who can understand what the word is. You will know what it is to appreciate commonplace things — eye contact, the correct use of the word "me," "you" and "I," physical contact initiated by your child, a word, any word spoken or a smile.

You will feel a fierce love for your child that seems to come from a place that is not of this world. You will know what it is to love unconditionally and you will understand what that really means."

- Ariane Zurcher

Off to board... catch you in Kingston!

Boarding my flight and arrival!

Posted on June 28, 2012 by [angelamannboba](#) [Edit](#)

Boarding my flight from Tampa to Miami I meet a man named Devon who runs the Carnival Caribbean Festival in Tampa. When I told him of my work, he offered to connect me in with the local community and we exchanged numbers. (I later called my mother and we both laughed at how my naivety had most likely already gotten me into trouble before even getting to Jamaica. Turns out he was legit mom! Universe wins again and naivety pays off!)

Arriving at my layover in Miami and awaiting my flight to Kingston continued to be interesting. As passengers began to fill the gate, I gazed around at who I would be arriving with. I was excited to see what appeared to be a great many deaf individuals at first glance. I thought to myself that it was quite a coincidence a large deaf population was traveling on my same flight to Kingston. Turns out they were just very expressive and communicated a great deal using their hands! (ha! probably could have used some more coffee.) In any case, it was a good first introduction to the culture. As I'm preparing to board, 3 policeman circle a beautiful woman with her child and ask her to come with them to pay for an item she had allegedly shoplifted at a store down the terminal.



Maybe over Ocho Rios?

I am seated next to a Jamaican-American couple in their late 70's on the flight and, as the customs forms for Jamaica are passed out, I quickly realize that they are struggling with the forms and appear to be barely literate. I struggled with whether or not to offer help, risking offending them, or letting them continue struggling through the forms (which are confusing to someone who has the skills to read them!). In the end, I offered help and they seemed very grateful. I fell asleep unfortunately for most of the flight so as much as I'd love to tell you how it was, I have no idea. The husband joked with his wife about the plane catching fire as we waited for everyone to deplane and she teased back in her lovely Jamaican accent. How I would have loved to pick their brain and ask them all they've seen in Jamaica through the years, but I wasn't that brave

just yet! I turned to look out the window and there was the directing guy with the orange-glowy sticks giving me a friendly wave. What a nice welcome!

As I leave the airport to catch my JUTA taxi to the hotel, smells of curry and who knows what else permeate the exit from the Manley airport. Turns out there are jerk and curry stands and a Red Stripe bar (hollah!) directly outside the airport! I didn't stop for fear of getting a little too tipsy to adequately find my way to my new home, but there are already plans to hit it up on my way out.



Over Kingston Harbor
Preparing to Land

My cabbie is Lionel, a young and sweet former fisherman. The first thing I notice is the Bob Marley being pumped out of the CD player thinking to myself that this was quite the pandering to tourists. The first thing Lionel asked me is if I was going to the Bob Marley Museum and then explained his significance to the country. Turns out it wasn't just pandering – he loved the Bob! He also noted how much former Prime Minister Manley was loved and why so many areas within Kingston and New Kingston were named after him. Jamaica has a new PM, Portia Simpson-Miller, who is also much loved. GO Jamaica for having their first female PM!!! Let's hope the US can catch up to you here soon! We pass building after building with barbed wire and bars on the windows and doors and I think to myself how grateful I am that Amanda warned me they would be everywhere. Apparently this isn't so much a sign of poverty, but more of a declaration of ownership.

wire and bars on the windows and doors and I think to myself how grateful I am that Amanda warned me they would be everywhere. Apparently this isn't so much a sign of poverty, but more of a declaration of ownership. Either way it would have most likely been jarring without her heads up.

On that note... So this may not be the forum for political issues (or it may be the perfect one), but one of the first things I wanted to find out when logging onto my computer at the hotel was what the Supreme Court decided today about Obamacare. As Lionel passed a fisherman friend from Shantytown who had just been injured on his motorcycle, we spoke of healthcare for Jamaicans. Here I am passing shantys (literally 4 foot by 4 foot concrete block "houses" with tin roofs) as Lionel tells me of public hospitals where anyone can be treated at no cost – most likely where King, his friend, was headed. We then passed a maximum security prison "where the big names go" and a rehabilitation prison where Lionel tells me of a program to take prisoners, most of whom are in their current situation due to poverty and "sitting idle thinking bad things," and teaches them new trades. Lionel said the most beautiful scallions he'd ever seen had come from the prison's farm program. Really puts it into perspective doesn't it? All the warnings I received that Kingston was "worse than Calcutta;" filled with extreme danger and poverty and it would appear they have better access to healthcare and treatment of prisoners than we do in our country which is held in such high esteem. Just something to think about I suppose. What a momentous day and how great to experience it being here in Jamaica.

I'm off to grab some Jamaican delights recommended by Lionel! Keep an eye out for pics! I will try to post them periodically 😊



The lovely Spanish Court Hotel where they are graciously hosting the fundraiser



Check out gas prices!
Somewhere around \$1.24
USD



Sunset from the Balcony
of my Hotel



Rum with a splash
of punch at the
hotel

My First Day in Kingston

Posted on [June 29, 2012](#) by [angelamannboba](#) [Edit](#)

I have now spent the greater part of the day here in Kingston, albeit primarily in my hotel room. I've had the opportunity to meet our "host per se, Kathy, who is one of the leads (if not the lead?) of the Jamaica Autism Support Association (JASA). She has been absolutely fabulous and greeted me warmly with a hug. I will be spending part of the day with her tomorrow and hopefully, she will let me assist her with wrapping up the finishing touches of the JASA cocktail party fundraiser that will be held on Saturday night. She has also graciously invited me to come along to a visit with Amanda to a school for children with special needs. I am SO eager to see the school here (it actually sounds fairly familiar based on her description so far)!

Kathy has introduced me to my very first potential participant who, again, I am so grateful for her openness and willingness given I am a brand new person and will be asking about her personal life. I can't quite get a gauge yet on how I am perceived just yet, but I'm hoping that as the time goes on, I can be of some assistance!

On a lighter note... I've learned my first not-so-serious lesson of Jamaica...

- (1.) When they say rum punch, they mean RUM with a splash of punch! Yowzas! Looks like, fortunately for me, I will be a cheap date here.
- (2.) Also, I gotta say, life should be set to the soundtrack of reggae with palm fronds swaying in the breeze. It's kind of like Jamaica's natural benzo gift to the world!
- (3.) This isn't actually a lesson learned but a point of interest; there are some amazing dreadlocks around here! My interest in shagging up some blond dreads of my own has been renewed! That would sure be an interesting start to my internship in the schools eh?

Day 2 in Kingston

Posted on [June 30, 2012](#) by [angelamannboba](#) [Edit](#)



First breakfast and first johnnycake! Yum!

Ok, so this wordpress is really ticking me off! I had a post and this darn thing apparently deleted it when I tried uploading images. I will try to replicate here.

Spent the day running errands with Kathy. I was able to see her partner's family bakery, a Kingston supercenter where Kathy was asked by a worker about which school would be best for her children, got to meet Kathy's f

amily and see her aunt's home, had lunch at Island Grill (think Pollo Tropical) with her partner, see a therapy center briefly where they were doing some cool exposures with a blender (love it!), and saw some goats being herded around town!

I can't blog too much because Kathy repeatedly joked that I couldn't post all of her work, but I will say this -she has super powers! And since I know she's reading this - Kathy, you didn't tell me not to post that! Kathy is almost singlehandedly running the show on the



Inside the Azan Supercenter. It's Jamaica's 50th anniversary of independence so there are flags everywhere!



island.

On that note, I have neglected to mention that you can support the Jamaica Autism Support Association (JASA) that Kathy runs! This organization holds monthly support group meetings, brings in international speakers to train teachers and parents in interventions for children on the spectrum, and so much more. Kathy is basically the point person for families of children with Autism on the island (and apparently, because these types of organizations don't really exist on the island, she's the point person for families of kids with other disabilities as well). You can check out a little of their work here: <http://www.jamaicaautism.org/>

Will attempt to post some pics from my day of arrival and second day with Kathy soon!

Off to my very first interview for now though. I'm a little nervous! Wish me luck, man!



Jamaican backyard AKA I'm a tourist



Beautiful old mango tree in the backyard of Kathy's aunt's house



Goats being herded down the road!



View from a neighborhood in Kingston



Rolling through Kingston



Lunch from Island Grill - Jerk Chicken, Festival, Rice and Peas (red kidney beans) and some veg

Olympic Trials in Jamaica

Posted on [June 30, 2012](#) by [angelamannboba](#) [Edit](#)

So did I mention the Olympic Trials are here in Jamaica this weekend? There are all kinds of track bigwigs staying at my hotel and there is currently a police escort in the lobby. Let me tell you – Jamaican police look badass! Ooo and there's a guy in a suit with an earpiece! Holy crap it's awesome! I sat close to the earpiece guy and his posse at breakfast.

There's also the Jamaica Military Tattoo being held this weekend so there are all kinds of high-ranking military officials walking around from all about. Since they are celebrating Jamaica's 50th year of independence from Britain it is a big deal! I believe tickets are totally sold-out and most people I've spoken with are going.

If I get brave enough (or drink enough) I will try to snap some pics!

My New Friend Sarah

Posted on [July 1, 2012](#) by [angelamannboba](#) [Edit](#)



Sarah Newland-Martin is an incredible woman! I know I've used inspiring a whole lot in this blog, but hey mon, what else is there to say? I came to be aware of Sarah through her support of JASA. She not only runs the Kingston YMCA where she basically serves as a place for children in Kingston to go and stay out of trouble (see Gleaner Article dated 10/14/08: <http://jamaica-gleaner.com/gleaner/20081014/news/news1.html>), but she also provides JASA with meeting space, supports their events, and connects parents in with the organization. Aside from being an incredible "social worker," as the article points out, she is also an incredible person. (Lots of incredibles, I know, but she's worth it!)

Despite being paraplegic since birth, Sarah has set world records for swimming including a record for crossing the Kingston Harbor (!). She has won over 40 medals and was named Sportswoman of the Year at one time. She has shown Jamaica what people with disabilities can do and one could argue that she is the definitive face of disabilities for the island. (See more about her sports career in same article as above.)

Despite the gains she has made in raising awareness of disabilities in Jamaica, there continue to be difficulties and stigma as mentioned in an earlier post. Sarah was just recently treated pretty horribly at the Kingston airport, being asked to remove her prosthetics which she could not reattach because the tools were in her checked luggage. (See Observer article dated 4/17/12: <http://www.stabroeknews.com/2012/archives/04/17/disabled-ymca-head-traumatized-by-jamaica-airport-incident/>) Sarah had to maneuver her entire 21-hour flight without her prosthetics. Fortunately, there has been some public outcry (See Observer Letter to the Editor dated 4/20/12: http://www.jamaicaobserver.com/letters/Give-Sarah-Newland-Martin-special-airport-pass_11288093) and a public defender was assigned to review the situation further (See Go-Jamaica article dated : http://go-jamaica.com/news/read_article.php?id=36722). This recent incident has led some to call for the passage of the National Disability Act (See Observer Letter to the Editor dated 4/22/12: <http://m.jamaicaobserver.com/mobile/letters/Time-to-pass-the-National-Disability-Act>). You can read more about the National Disability Act in this Jamaica Gleaner article. (See Gleaner article dated 2/11/12 here: <http://jamaica-gleaner.com/gleaner/20110202/news/news6.html>). From the sounds of it, the passage of this act or at least something similar would mean huge things for people on the island.

If you're interested in helping the cause, it's recommended that you write in to the Ministry of Labour and Social Security here: http://www.mlss.gov.jm/pub/index.php?artid=34&par_id=34

The best way to contact the Prime Minister appears to be by becoming friends with her on FB. Maybe some wallposts will draw attention? 😊 Her name is Portia Simpson-Miller and she definitely seems cool enough to listen!

I'll leave you with Sarah's "Prayer for Autism" from Autism Awareness Month.

Prayer for Autism by Sarah Newland-Martin

Dear God, Psalm 139:14 says 'I will praise you for I am fearfully and wonderfully made,
marvelous are your works, And that my soul knows very well.'

Lord, this a reminder that You created your children in a very special way.

As we celebrate Autism Awareness Month,

We pray for all children especially those with Autism

because we know that they are wonderfully made.

Give strength to the parents who may sometimes ask

'Why Me Lord?' and yet depend on you

To find ways and means to handle the uncertainty that

Prevails as the child develops at his own pace.

We thank you for drying up the tears,

When there is sign of hope,

Joy when a little progress is made,

Laughter when we see a positive response.

We thank you for the opportunity of being able to share

And provide support to each other and we thank you

That despite the challenges as parents, you enable us to cope.

We pray for the teachers who sometimes lack understanding of

What Autism is about, but who in their own way try to help our children;

For the Therapists, for being extremely patient and tolerant as

They help our children realize that they too have the ability to achieve,

No matter how small the progress may be;

And for the doctors who have to share their findings with anxious

Parents who at times find it difficult to accept.

Most of all Father, we thank you for the fact that You

Have enabled individuals to carry out research

That will one day lead us closer to the answers

For our many questions we have had.

Lord, empower us with greater awareness

And tolerance of people with special needs in our communities,

And help us to embrace the differences that make

Us all unique and wonderfully made.

Please continue Lord, to surround us with your love and comfort us

In our weakest moments. We depend on you.

In Jesus' name we pray.

Amen

The JASA Fundraiser

Posted on July 1, 2012 by [angelamannboba](#) [Edit](#)



The fundraiser was a smash and, the best part, Kathy finally let me take a picture of her! :) Kathy and her friends, especially co-founder Gayle and mother, Sian, did a great job on the event and I have my fingers crossed that they were able to raise some good funds for the organization. It was also a wonderful opportunity to meet some of the key players in Autism in the community, including the only behavior analyst on the island, Lisa Stoddart-Milligen. Lisa had a really interesting perspective on Autism on the island and has agreed to meet with me tomorrow for an impromptu interview about her experiences doing therapy on the island.

I also got to meet a pretty cool woman named Halthea Latty who has produced a documentary on Autism in Jamaica. What I loved most about her work was the portion of the documentary where she went around town asking those in the community what they thought Autism was. One man replied with something like, "I don't know who he is!" I am trying to get my hands on a copy now. She did a great job!

Here are some pics from the event!



JASA



Sponsors



Kathy, Amanda,
Gayle (co-
founder)



Sian



Spanish Court



The Crowd

Dinner with Wesley

Posted on July 3, 2012 by [angelamannboba](#) Edit

(Name has been changed to protect confidentiality.)

Kathy set up a "taxi" ride from a man named "Wesley" tonight for dinner. We end up at a sushi place in a little center called the Market Place. Apparently a chef was shot here last night, but Amanda commented that it was ok because it was by a co-worker. We kind of laughed about what a strange comment this was, but how comforting it actually was.

In any case, Wesley is a total trip and I'm pretty sure this was an intentional set-up by Kathy knowing my penchant for conversation. I've kind of decided to just record every conversation I have now given that each one has been incredibly informative for it's own reason and Wesley agreed.

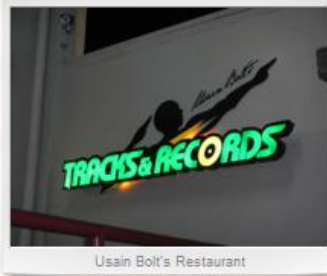
My dinner with Wesley was so interesting for many reasons! Not only is he a character with a larger than life personality, but he had a lot of great insights into the culture and into some of his own struggles with his child. He talked with us about something I've noticed, but not formally asked about. Depending on where you look, you will find different numbers, but the CIA World Factbook describes Jamaica's population as being comprised of 91% black, 6% mixed, and around 3% other or unknown reported ethnicities (according to a 2001 census). I can tell you that a large number of the "mixed" population is most likely Jamaicans of Chinese descent. In the 19th century, the British brought a fairly large number of Chinese over to work on the island. There was apparently another wave of immigration in the 1980's and 90's. Wesley, who is mixed and of Chinese descent, describes some of the prejudice he feels for being of this ethnicity here on the island. He says that, because he is of lighter skin, he and his son are immediately presumed to be of a wealthier status. Not only does his son draw stares because of his behavior, but he is looked upon even more disparagingly because of his skin color – the typical thought is that he wasn't raised right and is a spoiled child. (I've heard this from quite a few parents now.) Wesley says one of the biggest things he would like to see changed is better "sensitization" for people on the island.

He went on to describe several stories he'd either heard or experienced where individuals on the street were asking for handouts and he believed them to be autistic or something similar. Wesley said he thinks there are probably a great many older individuals with autism on the streets because members of the community couldn't relate to them. From my own observations, when we've driven around in the evenings, I have seen a disproportionate number of people walking the streets with physical impairments, primarily missing or deformed limbs, so I am not terribly surprised to hear his confirmation of my suspicions.

It is disheartening, but it also makes me (and Wesley – he went on for a while about it!) so grateful for people like Kathy who push and push for awareness and fair treatment for people on the spectrum and those with other disabilities. I'm very much looking forward to the parent support group meeting tonight and will fill you in on my observations there ASAP!

Cool Runnings Mon

Posted on July 3, 2012 by [angelamannboba](#) [Edit](#)



Usain Bolt's Restaurant

As we're leaving dinner, I am taking pictures of Usain Bolt's, famous Jamaican track athlete, restaurant when "Wesley" tells me that the woman standing near his car is Sherone Simpson! Sherone came in 2nd this year at the Olympic Trials for the 200m. It was a bit of an upset! (See <http://theislandjournal.wordpress.com/2012/07/02/jamaica-national-trials-2012-sherone-simpson-upset-veronica-campbell-brown-in-200m-finals/>)

Wesley of course has no problem asking her for me if she wouldn't mind a picture with me!!! It totally made my lifetime and I will forever be a fan. Check it out!

Dear Ms. Simpson, I promise to return to running when I get back to Tampa in your honor. If it looks as though I've gained 25 pounds since I've been here it's possible that it was my choice in Stevie Nicks-wear for the evening (really regretting that choice with this awesome photo op), or it could be entirely possible that I have! Nearly everything I've eaten here involves some kind of frying. Even more reason to get back on the running wagon!

In any case, what an awesome end to an awesome evening. I will totally be cheering her on in London and the 200m is now my favorite event.



With Sherone Simpson

Visit to the Bob Marley Museum

Posted on July 3, 2012 by [angelamannboba](#) [Edit](#)



Me and Bob – One!

What an awesome experience! I got to visit the Bob Marley Museum today (and we passed the PM's house on the way back). Kathy and Amanda made fun of me a little (1.) For crying during the video about his life and beliefs and (2.) For thinking he's the sexiest man that ever lived and that I would totally have been one of his little birds (yeah, maybe not the best partner considering he impregnated a whole lotta women! Not as bad as his bandmate though who apparently has over 40 children!).

It was an emotional experience though. When you think about all that Bob Marley stood for... everyone coming together, everyone loving one another, attempting to bring together two political parties, spreading the message of love and acceptance for all... it's fitting that I would visit where he is memorialized today to honor his life. Bob was the voice of oppressed peoples in Jamaica and, although there are still plenty living in Trench Town in poverty who still need his message to be heard, in my book his message speaks loudest to this community moving toward better acceptance of all

– including those with disabilities.

In the words of Bob: "So don't you forget (no way) your youth, Who you are and where you stand in the struggle." Let's stand up for our fellow brothers and sisters. One Love.

JASA Support Group Meeting

Posted on [July 5, 2012](#) by [angelamannoba](#) [Edit](#)



Support Group Meeting at the YMCA
- Shipping Containers

I have a lot to catch you guys up on! I had the privilege of attending the JASA support group meeting at the Kingston YMCA. Around 13 parents attended (3 fathers and 10 mothers) along with two children of attendees. Parents were given a free question and answer time with Amanda (and I jumped in here and there) and had tons of great questions!

Topics varied from needing assistance with bullying (more specifically, how the child with ASD should address it and how they can make friends to have a better support system), how to decrease jumping on the furniture, how to get their child to sit at the table to eat, how to address feeding issues and a number of self-stimulatory behaviors, and the favorite amongst parents worldwide – how to finally get their child to use the potty independently!

Every parent was given a chance to speak, some being more reluctant to speak in front of the group than others, but everyone got a chance. It was a nice mix of parents and questions, although most of the "answers" surrounded using positive behavior supports/preventing, teaching, and reinforcing versus using more punitive or punishing strategies. This has overall been a common theme in what I've heard from parents and of schools around here. I am actually taking a page from the paper here of an article that ran yesterday trying to encourage parents to use other means rather than beating their kids. The headline reads "Discipline them... yes, but don't

beat them." This one definitely be one of my wishes for the island... to not only better understand Autism Spectrum Disorders or just people in general who are different, but also to take a more proactive, supportive, teaching approach to behavior. The good news is that it does seem like the tide is starting to turn though!

On a lighter note... it seems that every culture has its own quirky superstitions related to child development and, more specifically autism. Got to learn a few of Jamaica's...

- (1.) Don't cut the child's hair until they start speaking
- (2.) If they're not talking, feed them their meals from a calabash bowl and they will begin to



Strawberry Hill Adventure

Posted on [July 5, 2012](#) by [angelamannboba](#) [Edit](#)



Amanda and I at Strawberry Hill

Had the chance last night to have a ladies night out with Kathy and Amanda! It was quite the adventure! Although they took the wind out of my sails by saying anytime something cool happened that I would blog about it 😊, I gotta say that it was an experience! Strawberry Hill is located in Blue Mountain in the Irish Town area of Kingston. As we wove through the mountains on windy, old narrow paved roads, we searched the tiny little advertising signs for any kind of direction to the restaurant. There aren't really street signs or lights in Kingston so it made the drive interesting.

We got a little lost and came upon a bad accident. It appeared a man on a motorcycle was hit and I think we all honestly suspected he was dead as he wasn't moving and people began to circle him and simply look. Eventually, what felt like forever later, he began to move and appeared ok aside from a bloody

arm.

As we kept winding up, we saw so many cute colorful little stops and mini grocery stores along the way, dogs roaming all over, huge bamboo... wish I could have taken pictures but it was so dark nothing turned out.

It took us forever to get up there, but when we did what we found were beautiful villas! Strawberry Hill is a beautiful spa resort type of place owned by Chris Blackwell, former owner of Island Records who produced all the Bob Marley records. The food was amazing, but the music was even better!

Kathy was a little apprehensive to begin the ride back down dealing with the windy roads again and I nearly killed her and Amanda when I excitedly shouted "Goats! Goats on a trash mountain!" It was just sooo exciting to see! This herd of goats were just pigging out on trash night. Who wouldn't get excited right? Luckily Kathy didn't drive us off the road and we made it home safe.

The whole evening is going to be quite the memory!

Supporting JASA

Posted on [July 5, 2012](#) by [angelamannbcba](#) [Edit](#)



Since I have gotten here, I've been trying to think of ways that I can help these parents beyond my study after I leave. When I speak to the parents here, there are a few things that have really been salient especially "sensitization" of the community and better awareness, more places to turn for support (given that it's an island, there is typically only really "1" of everything and a monopoly of sorts on services), and for more support from the government.

When you speak with good therapists here they too speak of a need for more service providers, but also emphasize the need for people with quality training. In Jamaica, there is nothing to prevent someone from coming and saying that they are a psychologist even though the only thing they've ever studied is a crystal ball. With limited resources to go around, it's important that when resources are invested it's in good people. Wesley, for example, mentioned to us that even though his son receives speech therapy at the school he has no idea what that looks like, how much he actually receives, and if improvement has been made. When he asked to see the therapist's notes, she said it would cost him extra. He said he'd be willing to pay, but still hasn't seen a note all year. Any therapist that is good, would not only be providing notes, but also be having parents sit-in on therapy so that they may work on similar skills at home to promote generalization of skills (an area that is notoriously difficult for kids on the spectrum).

At dinner in Strawberry Hill, I asked Kathy what her top wish would be for JASA. Her response was money. She said that she hated to sound materialistic but that everything requires money – things like scholarships for parents (all education in Jamaica come at a cost for parents, but schools for kids with special needs are especially costly), printing awareness materials to disseminate, etc.

For those of you wondering what you can do, I have a few suggestions:

- (1.) Buy Amazon Gift Cards to send to JASA (jasa.jm2k9@gmail.com) – They would really like to start a library of books and this would be a great start, plus therapy materials and more can be found here so the money can be used flexibly as needs arise.
- (2.) Spread awareness in your own community! Educate people. Don't use the "r"-word or use autism as a slur like 50 cent did the other day. Educate people when they do.
- (3.) Interested in working as a behavior analyst in Jamaica? Interested in supervising individuals from Jamaica who are interested in becoming BCBA's from a distance/via Skype? Let me know!

My mental to-do list – For myself, what I'd like to do (and you can help me!) is:

- (1.) Finish up with getting a support group off the ground in Tampa when I return.
- (2.) Talk with Kathy about having JASA be our "sister" support group – think the "Sister City" program. When we do trainings, we can record and send them over. When we do make-and-takes of visual supports, first-then boards, token strips, task analyses for teeth brushing, getting dressed, etc. we make extra for JASA to distribute to parents in need.
- (3.) Work on collaborating with Dr. Samms-Vaughan and Amanda to apply for the NIH R21 Grant to establish a parent training program on the island so that the reliance on/need for professionals is not so dire. <http://grants.nih.gov/grants/guide/pa-files/PAR-11-031.html>
- (4.) Assist Kathy with connecting with Autism Speaks for the Global Autism Public Health Initiative <http://www.autismspeaks.org/science/initiatives/global-autism-public-health>
- (5.) Find a "National Hero" to be the face of autism awareness in Jamaica. Jamaica is all about its national heroes. I would love to contact some of these famous track stars and see if one of them wouldn't be willing to take up the cause and start spreading awareness. Anyone happen to be friends with Usain Bolt?
- (6.) Start a toy bank of used toys and therapy items donated by parents in the states that could be sent to families here or even disadvantaged youth in Tampa

Does anyone have other ideas? I know that I have some very creative and well-connected friends. Any support you can lend to the cause is much appreciated!

APPENDIX E

Informed Consent



Informed Consent to Participate in Research Information to Consider Before Taking Part in this Research Study

IRB Study # 8631

You are being asked to take part in a research study. Research studies include only people who choose to take part. This document is called an informed consent form. Please read this information carefully and take your time making your decision. Ask the researcher or study staff to discuss this consent form with you, please ask him/her to explain any words or information you do not clearly understand. We encourage you to talk with your family and friends before you decide to take part in this research study. No risk, inconveniences, discomforts, and are anticipated to result from this study.

We are asking you to take part in a research study called:

*Global Perceptions of Autism Spectrum Disorders (ASDs):
The Story of Autism in Jamaica*

The person who is in charge of this research study is Angela Mann, M.A., BCBA. This person is called the Principal Investigator. However, other research staff may be involved and can act on behalf of the person in charge. She is being guided in this research by Dr. Linda Raffaele Mendez.

The research will be conducted at multiple sites throughout Jamaica.

Purpose of the study

The purpose of this study is to:

- Provide greater information about the experiences of mothers of children with Autism Spectrum Disorders living in Jamaica.
- This research is being conducted by a student as part of their dissertation.

Study Procedures

If you take part in this study, you will be asked to:

- Participate in a one-time, approximately 60 minute, semi-structured, audio-recorded interview asking about your experiences raising a child on the Autism Spectrum.
 - Interviews are expected to take place either in your home or at the Jamaica Autism Support Association conference hotel.
-
-

IRB Number: 8631 IRB Consent Rev. Date: _____
IC Adult Minimal Risk - SB Rev:9-3-2010

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Total Number of Participants

Approximately 10 individuals will take part in this study at all sites.

Eligibility Criteria

In order to participate in this research study, English must be your primary language spoken and you must live in Jamaica for more than 75% of the year. Additionally, you must be caring for a child that has received a diagnosis on the Autism Spectrum by a medical doctor or professional with similar training in assessing and diagnosing Autism Spectrum Disorders

Alternatives

You do not have to participate in this research study.

Benefits

The potential benefits of participating in this research study include:

- A chance for reflection about your journey with your child
- Comfort in being heard
- Providing the field with a better understanding of the needs of these families
- Informing key stakeholders will take notice, beginning the winds of change in changing current stigmatizations, lack of resources, lack of support, and more.

Risks or Discomfort

This research is considered to be minimal risk. That means that the risks associated with this study are the same as what you face every day. There are no known additional risks to those who take part in this study.

Compensation

No compensation will be provided for your participation.

Privacy and Confidentiality

We will keep your study records private and confidential. Certain people may need to see your study records. By law, anyone who looks at your records must keep them completely confidential. The only people who will be allowed to see these records are:

- The research team, including the Principal Investigator and Co-Principal Investigator.
- Certain government and university people who need to know more about the study. For example, individuals who provide oversight on this study may need to look at your records. This is done to make sure that we are doing the study in the right way. They also need to make sure that we are protecting your rights and your safety.
- Any agency of the federal, state, or local government that regulates this research. This includes the Department of Health and Human Services (DHHS) and the Office for Human Research Protection (OHRP).
- The USF Institutional Review Board (IRB) and its related staff who have oversight responsibilities for this study, staff in the USF Office of Research and Innovation, USF

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Division of Research Integrity and Compliance, and other USF offices who oversee this research.

We may publish what we learn from this study. If we do, we will not include your name. We will not publish anything that would let people know who you are.

Voluntary Participation / Withdrawal

You should only take part in this study if you want to volunteer. You should not feel that there is any pressure to take part in the study. You are free to participate in this research or withdraw at any time. There will be no penalty or loss of benefits you are entitled to receive if you stop taking part in this study.

New information about the study

During the course of this study, we may find more information that could be important to you. This includes information that, once learned, might cause you to change your mind about being in the study. We will notify you as soon as possible if such information becomes available.

You can get the answers to your questions, concerns, or complaints

If you have any questions, concerns or complaints about this study, or experience an adverse event or unanticipated problem, call Angela Mann at +1-813-270-9210.

If you have questions about your rights as a participant in this study, general questions, or have complaints, concerns or issues you want to discuss with someone outside the research, call the USF IRB at +1-813-974-5638.

Consent to Take Part in this Research Study

It is up to you to decide whether you want to take part in this study. If you want to take part, please sign the form, if the following statements are true.

I freely give my consent to take part in this study. I understand that by signing this form I am agreeing to take part in research. I have received a copy of this form to take with me.

Signature of Person Taking Part in Study

Date

Printed Name of Person Taking Part in Study

Statement of Person Obtaining Informed Consent

I have carefully explained to the person taking part in the study what he or she can expect from their participation. I hereby certify that when this person signs this form, to the best of my knowledge, he/she understands:

- What the study is about;
- What procedures will be used;
- What the potential benefits might be; and
- What the known risks might be.

I can confirm that this research subject speaks the language that was used to explain this research and is receiving an informed consent form in the appropriate language. Additionally, this subject reads well enough to understand this document or, if not, this person is able to hear and understand when the form is read to him or her. This subject does not have a medical/psychological problem that would compromise comprehension and therefore makes it hard to understand what is being explained and can, therefore, give legally effective informed consent. This subject is not under any type of anesthesia or analgesic that may cloud their judgment or make it hard to understand what is being explained and, therefore, can be considered competent to give informed consent.

Signature of Person Obtaining Informed Consent / Research Authorization

Date

Printed Name of Person Obtaining Informed Consent / Research Authorization

IRB Number: 8631 IRB Consent Rev. Date: _____
IC Adult Minimal Risk - SB Rev:9-3-2010

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APPENDIX F

Inclusion Criteria Checklist

Name: _____ Age: _____

Child's Name: _____ Age: _____

City Where Currently Living: _____

Ethnic Identity: _____

- English is their primary language spoken
- Live in Jamaica for more than 75% of the year
- Child has received a diagnosis on the Autism Spectrum by a medical doctor or professional with similar training in assessing and diagnosing Autism Spectrum Disorders

Child's Diagnosis: _____

Diagnosed by: _____

Where: _____

At what age: _____

- Live with their child at least 50% of the time

APPENDIX G

Final Semi-Structured Interview Guide

Opening Statement to Mothers:

“Many people view having a child as going on a journey. You become pregnant, you give birth, you watch your child grow. For my dissertation, I am interesting in learning more about the journeys of Jamaican mothers who are raising a child with an Autism Spectrum Disorder. I would like to ask you about your journey from the time you conceived your child (NAME) to the present day.”

Topic Domain	Example of Question
<p>The Early Part of the Journey—Child’s Early Development <i>Lead off Question:</i> Please tell me about your child’s early development.</p>	
Pregnancy	Tell me about your pregnancy with NAME.
Birth	Tell me about the birth of NAME.
What child was like as an infant (first year of life)	How would you describe NAME as an infant?
Developmental milestones	How would you describe NAME’s development after the first year? Probe about motor development, language development, social development, adaptive skills, and cognitive development.
First perceptions of atypical development	Who was the first person to perceive that NAME was not developing typically? What did that person notice? (If not the mother), how did you respond to that person’s perception?
Maternal perceptions of child’s development	When did you as a mother first begin to become concerned about your child’s development? What did you notice? How did you explain (to yourself) what you were seeing?
Maternal actions after perceiving that child was not developing typically	When you thought that your child was not developing typically (i.e., saw X and Y behaviors that mother noted above), what did you do?
Results of maternal actions	What was the result of what you did (question directly above)?
First mention of autism to the mother	When did you first hear the word autism as a way of describing your child’s behaviors? How old was your

	child at this time?
Mother's reaction to first mention of autism	How did you react when you first heard the term autism to describe your child's behaviors?
<p>Receiving a Diagnosis</p> <p><i>Lead off Question:</i> Please tell me about when your child was diagnosed with autism.</p>	
Details of the diagnosis	Tell me how NAME came to be diagnosed with autism. How old was NAME when he/she was diagnosed? Who made the diagnosis? What were you told about how your child qualified for a diagnosis of autism? How was the diagnosis communicated to you (e.g., face-to-face, phone call, letter, etc.)? How did you feel about how the information about diagnosis was communicated to you?
Information given at time of diagnosis	What support, advice, and/or information were you given by the diagnosing professional at the time of diagnosis?
Mother's reaction to diagnosis	How did you feel when you were told NAME was being diagnosed with autism? What went through your head at that time?
Sharing the diagnosis with others	At the time that you received the diagnosis, did you tell others? What/how did you tell them?
Mothers' suggestions for improvement in the diagnostic process	What suggestions would you make to improve the diagnosis of children with autism in Jamaica?
<p>Adjustment Following Diagnosis</p> <p><i>Lead off Question:</i> Please tell me how you and your family have been affected by having a child with autism.</p>	
Impact on family	Tell me how NAME'S diagnosis has affected you and your family. (Probe for both positive and negative if not spontaneously mentioned.)
Impact on siblings	How has having a brother or sister with autism impacted your other children?
Impact on marital (significant other) relationship	What impact has having a child with autism had on your marital (significant other) relationship?
Impact on other adult family members (extended family, grandparents)	What impact has having a child with autism had on other adult family members (e.g., such as your parents or siblings)?
Impact on work life/career	What impact has having a child with autism had on your work life?
Impact on mother's self	What impact has having a child with autism had on your sense of self? Your self-esteem? Your view of the

	world? Your view of other people?
<p>Raising a Child with Autism Following Diagnosis</p> <p><i>Lead off Question:</i> Please tell me about what day-to-day life is like for you now and about the supports and services that your family receives.</p>	
Day-to-day life	What is day-to-day life like for you since NAME received a diagnosis of autism?
Support	What kinds of emotional support are available to you and your family?
Services	What kinds of services are available to you and your family?
Caregiving roles	How would you describe the roles in your family in raising your child? Who is responsible for what types of activities in child rearing?
Stressors and coping	What kinds of stressors do you experience related to having a child with autism that may be different from challenges experienced by others in your community? How do you cope with those stressors?
Child's education	Tell me about your child's education.
Help seeking	Tell me more about how you found information about the services and supports that you are currently using.
Inclusion opportunities	Tell me about your opportunities to go out in the community with or without your child. Tell me about your opportunities to spend time with your neighbors, extended family, or friends with or without your child.
Parent self-care	Tell me about the kinds of supports that you have for yourself. Tell me about getting your own needs met.
<p>Looking to the Future</p> <p><i>Lead off Question:</i> When you look towards the future, what do you see for your child?</p>	
Hope and dreams for child	What are your hopes and dreams for NAME?
Expectations for child	How do you describe your expectations for the child for the future?
<p>Reflections</p> <p><i>Lead off Question:</i> Reflecting back on your entire journey, how have you changed as a person? If you had the opportunity to share 3 things with a mother of a newly diagnosed child, what would those be?</p>	
Personal growth	How have you grown from raising NAME?
Benefits	Are there good things about raising a child with

autism?

APPENDIX H

University of South Florida Institutional Review Board Approval



DIVISION OF RESEARCH INTEGRITY AND COMPLIANCE
Institutional Review Boards, FWA No. 00001669
13901 Bruce B. Downs Blvd., MDC035 • Tampa, FL 33612-4799
(813) 974-5638 • FAX (813) 974-5618

June 19, 2012

Angela Mann, M.A., BCBA
Psychological and Social Foundations
1810 E. Palm Ave., Unit 1314
Tampa, FL 33605

RE: **Expedited Approval** for Initial Review
IRB#: Pro00008631
Title: Global Perceptions of Autism Spectrum Disorders (ASDs):
The Story of Autism in Jamaica

Dear Mrs. Mann:

On 6/16/2012 the Institutional Review Board (IRB) reviewed and **APPROVED** the above referenced protocol. Please note that your approval for this study will expire on 6/16/2013.

Approved Items:

Protocol Document:

[Protocol.doc](#)

Consent Document:

[Adult Informed Consent.docx.pdf](#)

Please use only the official, IRB- stamped consent document found under the "Attachment Tab" in the recruitment of participants. Please note that these documents (the consent documents to be signed by participants) are only valid during the approval period indicated on the stamped document.

It was the determination of the IRB that your study qualified for expedited review which includes activities that (1) present no more than minimal risk to human subjects, and (2) involve only procedures listed in one or more of the categories outlined below. The IRB may review research through the expedited review procedure authorized by 45CFR.46.110 and 21 CFR 56.110. The research proposed in this study is categorized under the following expedited review categories:

(6) Collection of data from voice, video, digital, or image recordings made for research purposes.

(7) Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.

As the principal investigator of this study, it is your responsibility to conduct this study in accordance with IRB policies and procedures and as approved by the IRB. Any changes to the approved research must be submitted to the IRB for review and approval by an amendment.

We appreciate your dedication to the ethical conduct of human subject research at the University of South Florida and your continued commitment to human research protections. If you have any questions regarding this matter, please call 813-974-5638.

Sincerely,



John A. Schinka, Ph.D., Chairperson
USF Institutional Review Board

APPENDIX I

Final Codebook of Themes

Pattern Level Themes

One statement can have multiple codes

(1.) How do Jamaican mothers describe their journey from the birth of their child to diagnosis of their child with an ASD?

1. Pregnancy
 - 1a. Normal pregnancy
 - 1b. At-risk pregnancy/Pregnancy with complications (e.g., gestational diabetes)
 - 1c. Bed rest at end of pregnancy

2. Delivery
 - 2a. Normal Delivery
 - 2b. C-section
 - 2c. Delivery with complications – specify: (e.g., extended delivery before moving to C-section)

3. Birth Status
 - 3a. Healthy Baby without Complications
 - 3b. Premature
 - 3c. Other health problems – specify: (e.g., wouldn't breastfeed, etc.)

4. Development
 - 4a. Typical Early Development
 - 4b. Very early (<6 mos old) concern

5. Age at First Signs
 - 5a. 6 mos
 - 5b. 12 mos
 - 5c. 18 mos
 - 5d. 24 mos
 - 5e. 20 mos.

- First Signs of Developmental Concerns
 - 6a. Echolalia
 - 6b. Hyperactivity
 - 6c. Picky eating

- 6d. Language Delay/Not speaking
- 6e. Lack of eye contact
- 6f. Not responding to name/"Not hearing"
- 6g. Regression of skills
- 6h. Toe walking
- 6i. Self-injury
- 6j. Lack of socializing
- 6k. Repetitive behaviors (e.g, rocking, spinning, flapping, etc.)
- 6l. Other – specify: (e.g., putting everything in his mouth, etc.)
- 6m. No signs; Someone else noticed – specify: (e.g., Pediatrician first to notice)

(2.) How do Jamaican mothers describe the experience of having their child diagnosed with an ASD?

- 7. Help-seeking Behaviors after First Signs
 - 7a. Sought out pediatrician
 - 7b. Went straight to University of West Indies/Dr.Samms-Vaughan (bypassed pediatrician)
 - 7c. Began Internet research
 - 7d. Began reading in books and magazines
 - 7e. Began treatment prior to diagnosis
 - 7f. No help-seeking behaviors – someone else noticed and referred
 - 7g. Talked to other parents
 - 7h. Talked to teacher
- 8. Pediatrician Reactions (code for all Pediatricians)
 - 8a. Initial Dismissal
 - 8b. First to Notice
 - 8c. Not applicable; Went straight to Dr. Samms-Vaughan or did not see pediatrician
- 9. Receiving the Diagnosis
 - 9a. Long wait for evaluation – specify: (e.g., year, 6 months, etc.)
 - 9b. Handed report to read
 - 9c. Physician-Delivered and/or Dr. Samms-Vaughan Diagnosed
 - 9d. Information and/or referrals given
 - 9e. Prognosis for future given
 - 9f. Medication recommended/prescribed
 - 9g. Sought out second opinion
 - 9h. Called to be given diagnosis
- 10. Recommendations for Improving Diagnostic Process
 - 10a. Shorter wait to be evaluated
 - 10b. More time, care or sensitivity taken in delivering the diagnosis
 - 10c. More information provided
 - 10d. More doctors to diagnose
 - 10e. More time taken in evaluation; more testing across multiple settings
 - 10f. No change recommended

11. Initial Mother Reactions
 - 11a. Initial Dismissal
 - 11b. Redefining the “dream” or the future
 - 11c. Despair/Sadness/Overwhelmed
 - 11d. Relief or Acceptance
 - 11e. Concern for future
 - 11f. Guilt

12. Initial Family Reactions
 - 12a. Father Denial
 - 12b. Extended Family Denial/Dismissal
 - 12c. Father Supportive/Accepting
 - 12d. Extended Family Supportive/Accepting
 - 12e. Extended Family or Friends Folklore – specify: (e.g., trimmed hair too early)
 - 12f. Extended Family Despair/Sadness/Overwhelmed
 - 12g. Father Despair/Sadness/Overwhelmed

13. Thoughts about Etiology
 - 13a. Vaccine-related
 - 13b. Self-blame
 - 13c. Related to genetics/family origin
 - 13d. Some unknown environmental component
 - 13e. Other – specify: (e.g., traumatic birth, etc.)

(3.) How do Jamaican mothers describe how they and their family have been affected by having a child with an ASD?

14. Stress Specific to Accessing Supports and Services
 - 14a. Difficulty finding appropriate school
 - 14b. Difficulty finding appropriate respite/childcare
 - 14c. Difficulty accessing therapies
 - 14d. Financial burden/strain
 - 14e. Lack of government programs/supports

15. Career Impact
 - 15a. Negative impact (e.g, had to quit work/school, has to leave work early, had to change jobs)
 - 15b. Help with coping; provides sense of normalcy

16. Post-diagnosis/Current Emotional Impact
 - 16a. Positive self-change
 - 16b. Believe chosen by God to be the mother/Increased faith
 - 16c. Celebration of the little victories

- 16d. Taken on Parent-as-Advocate or Parent-as-Therapist role
- 16e. Redefine priorities in life
- 16f. Acceptance and/or “dream” redefined
- 16g. Lack of community and/or public awareness/Isolation
- 16h. Isolation due to challenging behaviors/intense needs
- 16i. Stress
- 16j. Worry over future
- 16k. Worry over possible child victimization/abuse
- 16l. Worry about child being a burden
- 16m. Coping by taking it one day at a time

17. Other Family Member Impact

- 17a. Father gains acceptance
- 17b. Extended family gains acceptance
- 17c. Extended family support/involvement
- 17d. Difficult sibling relationships and/or burden on sibling
- 17e. Strengthened parental relationship; complementary roles
- 17f. Parental relationship strain/separation
- 17g. Continued difficulty for father or extended family
- 17h. Sibling as advocate or sibling as therapist

(4.)How do Jamaican mothers describe what day-to-day life is like for them?

18. Challenges of Daily Life

- 18a. Dealing with child’s challenging behaviors or lack of communication
(running/elopement, aggression, picky eating, etc.)
- 18b. Busy daily living (e.g., taking kids from school to therapy to childcare, etc.)
- 18c. Lack of public awareness and/or Isolation due to
- 18d. Parent as therapist/teacher
- 18e. Increased communication over the years, increased skills for independence
- 18f. Stressful
- 18g. Other (e.g., behaves better with father)

(5.)How do Jamaican mothers describe supports and services that their child and family receive?

19. Supports

- 19a. Support from religious community
- 19b. Support from faith
- 19c. Support from child’s siblings
- 19d. Support from extended family and/or friends
- 19e. Support from Jamaica Autism Support Association (JASA) support group
- 19f. No support/going it alone

- 20. Services
 - 20a. Need for more services
 - 20b. High cost and/or expenses of services prohibitive
 - 20c. Support of shadow
 - 20d. Speech therapy
 - 20e. Occupational therapy
 - 20f. Behavior therapy/ABA
 - 20g. Psychiatric/medical intervention
 - 20h. School for kids with special needs/private school
 - 20i. Traditional school/neighborhood school
 - 20j. Early intervention services
 - 20k. Parent as a therapist
 - 20l. Trouble finding appropriate/accepting school setting/need for better trained schools and/or staff
 - 20m. Worry about appropriate/accepting secondary setting

(6.) How do Jamaican mothers describe their vision of the future for their child?

- 21. Thoughts about the Future
 - 21a. Hope for independence and/or not to be a “burden”
 - 21b. Worry about who will care for them
 - 21c. Better communication for the child
 - 21d. “Normal” life (e.g, have regular education, to get married, have kids, etc.)/”Normal” child
 - 21e. Hope for them to have love and support
 - 21f. Hope to have a skill/work
 - 21g. Increased literacy
 - 21h. Take it day-by-day/future unknown

(7.) What advice would Jamaican mothers give to other mothers who have a child who has just been diagnosed with an ASD?

- 22. Advice for Other Mothers
 - 22a. Have hope
 - 22b. Keep faith/have your religion
 - 22c. Find supports and services/Be the advocate
 - 22d. Have tolerance/patience
 - 22e. Know that it’s a long journey
 - 22f. Give yourself time/Take one day at a time
 - 22g. Follow your gut
 - 22h. Other

OTHER NOTABLE THEMES (Can be under any research question)

- 23a. Mention of children with autism being locked away
- 23b. Considering leaving the country to find better supports and services
- 23c. Issues related to homophobia in Jamaica

APPENDIX J

Unbracketing Interview

Upon returning from Jamaica, I really needed to take a break to process all of the information I gathered there. I left feeling overwhelmed both because I was surprised to learn of how difficult the journey of being a mother of children diagnosed on the spectrum can be living in Jamaica, especially hearing that some mothers left with no good options must “lock away” their children, but also because the perseverance and connectedness of the mothers I met was inspiring. Based on their descriptions, some of my own observations driving through the streets of Kingston, and some of what I have read in papers, these mothers live in a culture or a community that appears to be in the early stages of embracing individuals with diverse backgrounds and needs even beyond those presented by autism. They are pioneering efforts for helping their neighbors and families to better understand their children, but still face stigma and, as a result, isolation due to a lack of understanding in the community of their child’s behaviors. Interviewing mothers who had traveled by bus (some for several hours) to attend a workshop where they might learn more about how to support their child in a classroom with bars on the window, no air conditioning, and what appeared to be limited resources compared to the schools I am in everyday, was humbling but also in many ways inspiring. Against these odds, these mothers found each other and, through their connection with one another, formed a bond. Some of these mothers had been through the diagnostic process many years ago and had seen the slowly evolving changes including several more service providers popping up around Kingston,

the development of a parent support group, and through the efforts of that parent support group more training and awareness of teachers or schools. Despite these changes, there is still struggle. Their optimism, however, came through in a great many cases.

Doing this study, taking this trip, has affected me profoundly. I feel guilt for having learned and taken so much more from this experience than the mothers who interviewed with me could have ever gained from participating in these interviews. I want to share their stories with as many people as I can and hope that, maybe at some point in my career, I can give back to them.

Table 1. Review of Literature and Themes

Study & Country	Methods	Participant Information	Findings	Themes	Topics
<i>Parent Experiences Related to the Diagnostic Process</i>					
Harrington, Patrick, Edwards, & Brand (2006); United States	Cross-sectional questionnaire	75 parents representing 71 families of children with the avg age of 8 yo	26% reported there was definitely a specific cause of their child's ASD and 45% reported a specific cause was possible. Specific causes include immunizations, genetic predispositions, and/or environmental exposure of the mother or child.	Specific Cause Etiology	Beliefs about Etiology
Bayat (2007); United States	Survey comprised of Likert-rated questions and open-ended questions	175 parents and primary caregivers of children with autism	Parents reported initially experiencing depression which eventually turned to love, adjustment, and advocacy.	Conflict to Acceptance	Feelings about Diagnosis
Myers, Mackintosh, & Goin-Kochel (2009); United States	Online survey of close-ended, short answer and open-ended questions	493 parents of children with ASDs	Parents reported initially feeling grief, depression, guilt, and blame which later turned to compassion, tolerance, patience, and joy.	Conflict to Acceptance	Feelings about Diagnosis
Mercer, Creighton, Holden, & Lewis (2006); Canada	Survey	41 parents of children with ASD ranging in age from 1 to 25 yo with a median age of 8.9 yo	Most parents (~90%) believed genetics to be the cause of their child's ASD. Approximately 44% reported believing prenatal maternal risk factors played a role. 68% of parents believed specific prenatal events played a role. Almost all parents believed multiple contributors played a role.	Multiple Factors	Beliefs about Etiology

Russell & Norwich (2011); United Kingdom	Semi-structured interviews	17 parents of children with ASD ranging in age from 7 to 16 yo	Parents reported being excited about the benefits of the diagnosis including coming to terms with their child's behavior and allowing them to better understand it. Most parents believed their child's symptomology resulted from biological factors.	Relief Specific Cause Etiology	Feelings about Diagnosis Beliefs about Etiology
Mansell & Morris (2004); United Kingdom	Questionnaire comprised of Likert scale questions and open-ended areas	99 parents of children with ASD ranging in age from 2 to >10 yo	Parents reported stressors including a lack of resources and information provided as well as long waiting lists.	Long Diagnostic Process Lack of Information	Diagnostic Process
Osborne & Reed (2008); United Kingdom	15 Focus groups	70 parents of children ranging from around 3 to 18 yo	Most parents report receiving very little support, advice, or information following the diagnosis.	Lack of Information	Diagnostic Process
Braiden, Bothwell, & Duffy (2010); Ireland	Interviews	11 mothers of children ranging in age from 10 to 11 yo who had received a diagnosis within 18 mos of interview	Parents reported desiring more information, especially in written format following the diagnosis.	Lack of Information	Diagnostic Process
Chamak, Bonniau, Oudaya, & Ehrenberg (2011); France	Questionnaires and in-depth interviews	248 surveyed, 43 interviewed. Child diagnoses of ASD, ranging in age from 4 to 45 yo	Parents reported negative reactions to receiving the diagnosis including distress, helplessness, despair, guilt, depression, dejection. Other parents reported feeling relief, understanding, confirmation of what they already knew, finally understanding child's difficulties	Unpleasant Emotions Relief	Feelings about Diagnosis Feelings about Diagnosis

McCabe (2008a); China	Open-ended questionnaires and semi-structured interviews	78 parents of children with autism ranging in age from 3 to 12 yo	<p>Parents reported feeling shock and devastation after their child's diagnosis.</p> <p>Parents also reported being provided with a lack of information.</p> <p>Most parents reported that although their relationships involved more conflict at first, it evolved into a more collaborative and positive relationship.</p>	<p>Unpleasant Emotions</p> <p>Lack of Information</p> <p>Conflict to Acceptance</p>	<p>Feelings about Diagnosis</p> <p>Diagnostic Process</p> <p>Feelings about Diagnosis</p>
Shyu, Tsai, and Tsai (2010); Taiwan	Semi-structured interviews	13 parents of children with autism ranging in age from 3 to 7 yo	<p>100% of parents pointed to biological reasons for their child's symptomology.</p> <p>85% also believed that their child's symptoms were at least in part due to supernatural reasons</p>	<p>Specific Cause Etiology</p> <p>Supernatural Reasons</p>	<p>Beliefs about Etiology</p> <p>Beliefs about Etiology</p>
Daley (2004); India	In-depth semi-structured interviews	95 families of children with autism ranging in age from 2 to 27yo (avg age of 10 yo)	Parents reported significant delays between when they first noticed symptoms and when their child was actually given a diagnosis. They also reported desiring greater information.	Long diagnostic process, Lack of information	Diagnostic Process
Ahmadi, Sharifi, Azizi Zalani, Bolouk, & Amrai (2011); Iran	Questionnaire	62 parents of children with autism	Parents also reported needing as much information as possible in addressing their child's behaviors or planning for their future.	Lack of Information	Diagnostic Process

Samadi, McConkey, & Kelly (2012); Iran	Structured interviews	43 parents of children with ASD ranging in age from 3 to 7 yo with an avg age of 8.2 years	Parents reported maternal factors (37%), environmental factors (23%), body or brain defect (16%), supernatural reasons (12%), and genetics (7%) were to blame for their child's symptoms. Most parents reported experiencing shock, rejection, depression, uncertainty after receiving their child's diagnosis.	Multiple Factors Unpleasant Emotions	Beliefs about Etiology Feelings about Diagnosis
Bilgin & Kucuk (2010); Turkey	Informal interviews	43 mothers of children with autism ranging in age from 6 to 17 yo (avg age of 9 yo)	Most parents reported grief, shock, pessimism, denial, and breakdown.	Unpleasant Emotions	Reactions to Diagnosis
Krauss-Mars & Lachman (1994); South Africa	Cross-sectional retrospective descriptive, structured questionnaires	65 families of children with ASD ranging in age from 2 to 85 mo with an avg age of 51 mo	Only around a quarter of parents were able to name their child's diagnosis after receiving it from their doctor, with around half being able to describe the symptoms, and approximately another quarter denying their child's diagnosis (e.g., 'Nothing wrong, just lazy').	Lack of understanding and Denial	Reactions to Diagnosis
Anthony (2009); Ghana	Focus groups, semi-structured interviews, text analysis	9 caregivers of children with autism of unknown ages	Very salient view that symptoms are a result of magic or spell cast upon the child in retribution by a hired spiritual practitioner for transgressions typically blamed on the mother. Difficulty accessing information or professionals able to diagnose.	Supernatural Reasons Lack of Doctors to Diagnose	Etiology Diagnostic Process

Riccio (2011); Kenya	Informal interviews	5 families of children with autism of unknown ages	Parents report not knowing where they could go to get help for diagnosis; widespread stigmatization of the diagnosis; widespread attribution of the disorder to witchcraft and sorcery brought on the family, typically on the part of the mother	Lack of information/ Culture-specific Stressor	Diagnostic Process/ Etiology
Shaked & Bilu (2006); Ultraorthodox Jews, Israel	Open-ended interviews	Thirty families (27 mothers, 2 couples, 1 father) of children with ASD of varying ages	Diagnostic journey an arduous process, initially filled with hope, but upon receiving a diagnosis resulting in indifference Most report medical causes, with around half pointing to psychological conceptualizations of etiology primarily centering on parental self-deprecation. Nearly all of the mothers conveyed their belief that their child's diagnosis was God's will and a form of suffering that the family had been chosen for.	Conflict to Indifference Multiple Factors Supernatural Reasons	Reaction to Diagnosis Etiology Etiology
Jagatheesan, Miller, & Fowler (2010); South Asian Muslim Immigrants	Longitudinal and ethnographic	Three families of children with autism between the ages of 2 and 8 yo	Parents felt strongly that they were blessed and chosen by Allah to raise "His special child."	Supernatural Reasons	Etiology
Probst (1998); Cross Cultural Comparisons Germany,	Questionnaires and interviews	163 families of primarily school-aged children with autism	All countries with the exception of Greece pointed to biological reasons for their child's symptomology.	Specific-Cause Etiology	Etiology

Brazil, Greece, and Italy			<p>In Greece, most parents reported psychosocial-external reason for their child's symptoms including that they were "Given by God" or "Fate, Destiny" one parent believing her child's symptoms were due to "bad mental conditions during pregnancy."</p> <p>Mixed feelings of either hope or hopelessness/fear for the child with most expressing fear for the future.</p>	<p>Supernatural Reasons</p> <p>Unpleasant Emotions/ Relief</p>	<p>Etiology</p> <p>Feelings about Diagnosis</p>
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Study & Country	Methods	Participant Information	Findings	Themes	Topics
<i>Parent Experiences Related to the Effects of Having a Child Diagnosed with an ASD</i>					
Bayat (2007); United States	Survey comprised of Likert-rated questions and open-ended questions	175 parents and primary caregivers of children with autism	<p>Parents reported having to put their careers on hold or switching to a career in special needs.</p> <p>Parents reported significant challenges including behavior problems, financial stressors, and fights with the system.</p> <p>Parents also reported stronger relationships and greater likelihood to meet daily goals and events. They also report feeling reaffirmed in their strength, becoming more compassionate, and a strengthening of their belief system.</p>	<p>Career Interference</p> <p>Significant Stressors</p> <p>Becoming stronger and more tolerant</p>	<p>Career Impact</p> <p>Emotional Impact</p> <p>Life Enhancing</p>

Myers, Mackintosh, & Goin-Kochel (2009); United States	Online survey comprised of closed-ended, short-answer questions and open-ended questions	493 parents of children with ASDs	<p>70% of parents reported feeling stressed, noting difficulties related to marital strain, school struggles, challenging behaviors, isolation, and disrupted family life.</p> <p>They also reported developing a new understanding of the world of disabilities and appreciation of their child's uniqueness.</p> <p>Parents also reported negative impacts on their career.</p>	<p>Significant Stressors</p> <p>Becoming stronger and more tolerant</p> <p>Career Interference</p>	<p>Emotional Impact</p> <p>Life Enhancing</p> <p>Career Impact</p>
Smith et al (2010); United States	Survey, interview, and daily journal data	96 mothers of adolescents and adults with ASD ranging in age from 17 to 53 yo	Mothers spent significantly more time caring for their child and completing household chores and less time in leisure. They also reported greater stressors including frequent arguments, home stress, or stress from extended family and friends.	Significant Stressors	Emotional Impact
Kayfitz, Gragg, & Orr (2010); Canada	Questionnaire	23 married mother/father pairs of children with autism ranging in age from 5 to 11 yo with a avg age of 7.39 yo	Mothers reported significantly more learning through experiences of special problems, finding the diagnosis as a source of strength and family closeness, better understanding of life's purpose, as well as enjoying an expanded social network.	Becoming stronger and more tolerant	Life Enhancing
Meirsschaut, Roeyers, & Warreyn (2010); Belgium	In-depth interviews and questionnaires	17 mothers of children with autism ranging in age from 46 to 84 mo	Parents reported significant stressors including lower sense of self-efficacy, greater stress, depression, marital strain, lack of understanding from others, long waiting lists, limited support, and isolation.	Significant Stressors	Emotional Impact

			Many parents spoke of having to make career adjustments.	Career Interference	Career Impact
Allik, Larsson, & Smedje (2006); Sweden	Survey	61 parents of children diagnosed with ASD	Mothers of children with ASD tended to report poorer health and greater stress related to their child's challenging behaviors	Significant Stressors	Emotional Impact
Farrugia (2009); Australia	Semi-structured interviews	16 parents of youth diagnosed with ASD ranging in age from 5 to 23 yo	Parents reported stressors including isolation, having to have their lives very structured, difficulties with school understanding the child's behaviors, and contradicting recommendations.	Significant Stressors	Emotional Impact
Giallo, Wood, Jellett, & Porter (2011); Australia	Survey	59 parents of children with ASD age 2 to 5 yo	Parents reported greater levels of fatigue, depression, anxiety, stress, sleep deprivation, poorer diet, problematic challenging behaviors when compared to those raising typical children.	Significant Stressors	Emotional Impact
McCabe (2007); China	Open-ended questionnaires and semi-structured interviews	43 parents of children with autism ranging in age from 3 to 11 yo	Parents reported discrimination and blame for their child's diagnosis as well as lack of schooling and isolation, financial strain, and lack of access to services.	Significant Stressors	Emotional Impact
McCabe (2008a); China	Open-ended questionnaires and semi-structured interviews	78 parents of children with autism ranging in age from 3 to 12 yo	Parents also reported isolation, having no life, marital strain, feelings of stress, worry, and depression.	Significant Stressors	Emotional Impact

McCabe (2010); China	Open-ended questionnaires and semi-structured interviews	70 parents of children with autism ranging in age from 3 to 12 yo	Mothers who were continuing to work reported enjoying time away to be themselves, socialize, feel accomplished, and have a sense of identity. Other mothers reported conflicts with work or having to give up their career entirely for their child.	Source of Support Career Interference	Career Impact Career Impact
Shyu, Tsai, and Tsai (2010); Taiwan	Semi-structured interview	13 parents of children with autism ranging in age from 3 to 7 yo	Parents reported significant stressors including financial strain, depression, exhaustion, worry, loss of confidence in their parenting abilities, or guilt	Significant Stressors	Emotional Impact
Lin (2011); Taiwan	Surveys	50 mothers of children with ASD ranging in age from 10 to 18 yo (avg age 13.8 yo)	Parents reported significant stressors including uncooperative, socially offensive, self-injurious, destructive or repetitive behaviors from their child leading to a heavy caregiving burden	Significant Stressors	Emotional Impact
Mori, Ujiie, Smith, and Howling (2009); Japan	Questionnaire	193 families of children with ASD aged up to 12 yo	Parents reported high levels of stress including greater behavioral challenges and less involvement of the child's father.	Significant Stressors	Emotional Impact
Samadi & McConkey (submitted for publication); Iran	Rating scale	103 parents of 73 families of children with ASD ranging in age from 3 to 19 yo (avg age 7.4 yo)	Surveying health-related impacts, mothers were significantly more impacted than fathers and also demonstrated greater levels of stress. Children with fewer symptoms were actually associated with poorer health outcomes.	Significant Stressors	Emotional Impact

Sabih & Sajid (2008); Pakistan	Questionnaire	60 parents of children with ASD ranging in age from 4 to 18 yo	Parents reported greater levels of parenting stress when the child diagnosed was a girl compared to a boy.	Culture-Specific Stressor	Emotional Impact
Bilgin & Kucuk (2010); Turkey	Informal interviews	43 mothers of children with autism ranging in age from 6 to 17 yo with an avg age of 9 yo	Mothers also reported a lack of acceptance into the community, lack of knowledge, and financial strain.	Significant Stressors	Emotional Impact
Anthony (2009); Ghana	Focus groups, semi-structured interviews, text analysis	9 caregivers of children with autism of unknown ages	Families report feeling isolated and stigmatized, unable to attend church, celebrations or community events with their child.	Culture-Specific Stressor	Emotional Impact
Riccio (2011); Kenya	Informal interviews	5 families of children with autism of unknown ages	Mothers report emotional stress, guilt, financial hardships, and disrupted family relationships. Many fathers are encouraged to abandon the family in an effort to save himself and his future children from the curse.	Significant Stressors Culture-specific stressor	Emotional Impact Emotional Impact
Shaked & Bilu (2006); Ultraorthodox Jews, Israel	Open-ended interviews	Thirty families (27 mothers, 2 couples, 1 father) of children with ASD of varying ages	Families were typically forced outside of the community in an effort to obtain these treatments for their children with many families reporting feeling a great deal of emotional conflict.	Culture-Specific Stressor	Emotional Impact

Jagatheesan, Miller, & Fowler (2010); South Asian Muslim Immigrants	Longitudinal and ethnographic	Three families of children with autism between the ages of 2 and 8 yo	Parents noted how most professionals were generally concerned with their child's difficulties, whereas parents refused to participate in negative conversations regarding their child.	Culture-Specific Stressor	Emotional Impact
Kediye, Valeo, and Berman (2009); Somali Refugees living in Canada	Focus group interviews	10 mothers of children with autism ranging in age from 6 to 12 yo	Barriers related to limited English proficiency, mothers also reported encountering difficulties due to inflexible immigration policies that prevented them from bringing family members to Canada to provide assistance with raising their child.	Culture-Specific Stressors	Emotional Impact
Kim (2012); Cross Cultural Comparisons South Korea and Nicaragua	In-depth interviews	Unidentified number of mothers of child on the spectrum	In South Korea, many mothers report lack of support and pervasive stigmatization and lack of community awareness. In Nicaragua, mothers report acceptance from their community which believes "everyone is the same" and that diversity should be embraced.	Significant Stressors Embraced by Community	Emotional Impact Life Enhancing

Study & Country	Methods	Participant Information	Findings	Themes	Topics
<i>Parent Experiences Related to Supports and Services</i>					
Harrington, Patrick, Edwards, & Brand (2006); United States	Cross-sectional questionnaire	75 parents representing 71 families of children (avg age of 8 yo)	Parents reported trying a median of 6 attempted treatments including complementary and alternative (CAM) treatments or drug treatments (87%)	Various Treatment Attempts	Treatment Decision-Making

Mansell & Morris (2004); United Kingdom	Questionnaire with Likert questions and open-ended areas	99 parents of children with ASD ranging in age from 2 to older than 10 yo	Parents reported information from family service workers, from local support groups, workshops, and early year's courses offered by the support group were the most helpful sources of info. 87% reported speech and language therapy to be most helpful and about 69% reported special schools to be helpful.	Information Sources Evidence-based Treatments	Sources of Support Services
Bromley, Hare, Davison, & Emerson (2004); United Kingdom	Interviews	68 mothers of children with ASD ranging in age from younger than 5 to 18 yo	Parents reported a number of unmet needs including advice on services, meeting other parents, respite care, managing their child's behavior, unsuitable housing conditions, worry about the future, access to leisure activities, and someone to talk to. Parents reported having support from coworkers, parents' groups, social groups/clubs, religious organizations, and early intervention programs.	Lack of Services Support Outlets	Services Sources of Support
Osborne & Reed (2008); United States	15 Focus groups	70 parents of children ranging from around 3 to 18 yo	Parents reported desiring greater connection with support groups and more frequent meetings.	Support Outlets	Sources of Support
Langford et al. (2007); Ireland	Focus groups and individual interviews	10 parents of children ranging in age from 3 to 10 yo	Most parents reported desiring greater support services and counseling following the diagnosis.	Support Outlets	Sources of Support
Farrugia (2009); Australia	Semi-structured interviews	16 parents of youth with ASD ranging in age from 5 to 23 yo	Parents reported feeling new sources of interpersonal connection through support group meetings.	Support Outlets	Sources of Support

McCabe (2008b); China	Open-ended questionnaires and semi-structured interviews	43 parents of children with autism ranging in age from 3 to 11 yo	Parents expressed important benefits of parent-to-parent support including sharing and learning from one another, support, and feeling acceptance.	Support Outlets	Sources of Support
Shyu, Tsai, and Tsai (2010); Taiwan	Semi-structured interviews	13 parents of children with autism ranging in age from 3 to 7 yo	Parents sought a number of treatments including acupuncture, occupational or speech therapy, treatment for food allergies, detoxification therapy, and vitamin supplements.	Various Treatment Attempts/ Metaphysical	Treatment Decision-Making
Daley (2004); India	In-depth interviews	95 families of children with autism ranging in age from almost 3 to 27 yo (avg age of 10 yo)	Parents report trying a number of different treatments including pharmaceutical intervention, megavitamin therapy, pranic healing, reflexology, astrologists, acupressure, speech therapy, vitamin therapy, tutoring, Siddha, behavior therapy, and yoga, with over half of the sample using either or both Ayurvedic and homeopathic treatment.	Mix of Evidence-Based Treatments and more	Services
Ahmadi et al (2011); Iran	Questionnaire	62 parents of children with autism	Parents reported extended family being sources of support. Parents reported significant stressors including lack of respite and lack of ongoing services.	Support Outlets Lack of Services	Sources of Support Services
Samadi, McConkey, & Kelly (2012); Iran	Structured interviews	43 parents of children with ASD ranging in age from 3 to 7 yo (avg 8.2 yo)	Parents reported lack of services and lack of social support as being stressors.	Lack of Services Lack of Support	Services Sources of Support

Bilgin & Kucuk (2010); Turkey	Informal interviews	43 mothers of children with autism ranging in age from 6 to 17 yo (avg age 9 yo)	Mothers reported their husbands, extended family and friends as sources of support.	Support Outlets	Sources of Support
Anthony (2009); Ghana	Focus groups, semi-structured interviews, text analysis	9 caregivers of children with autism of unknown ages	Lack of access to inclusive education leaving many to attempt treatments from witch doctors or spiritual leaders.	Lack of Services Metaphysical	Services Treatment Decision-Making
Riccio (2011); Kenya	Informal interviews	5 families of children with autism of unknown ages	The resources for families who have the means to be able to attain treatment are few and limited; many report denied access to educational services leaving many to seek treatment from witch doctors or spiritual leaders.	Lack of available services Metaphysical	Services Treatment Decision-Making
Shaked & Bilu (2006); Ultraorthodox Jews, Israel	Open-ended interviews	Thirty families (27 mothers, 2 couples, 1 father) of children with ASD of varying ages	Parents reported seeking out a number of medical, educational, and alternative interventions. Parents also reported seeking spiritual and mystical treatments for their children.	Various Treatment Attempts Metaphysical	Treatment Decision-Making
Probst (1998); Cross Cultural Comparisons Germany, Brazil, Greece, & Italy	Questionnaire and interviews	163 families of primarily school-aged children with autism	All cultures believed educational and psychological treatments were of great importance.	Various Treatment Attempts	Treatment Decision-Making

Figure 1. Data Collection and Analysis Flow Chart

