"Living Life in the Moment": Chronic Stress and Coping Among Families of High-Functioning Adolescent Girls with Autism Spectrum Disorder

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“LIVING LIFE IN THE MOMENT”: CHRONIC STRESS AND COPING AMONG FAMILIES OF HIGH-FUNCTIONING ADOLESCENT GIRLS WITH AUTISM SPECTRUM DISORDER

A dissertation by

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Abstract

Autism spectrum disorder (ASD) prevalence rates have risen dramatically over the past decade and boys are five times more likely to be diagnosed than girls. Prior research on children with ASD includes samples that are overwhelmingly male, but does indicate that girls with high-functioning ASD may have distinct needs and profiles. This study begins to address this gap in the research through a qualitative study of eleven families with an adolescent daughter with high-functioning autism spectrum disorder. The family is the primary unit of analysis and the study focuses on the following: (a) families’ experience with the diagnostic process (b) families’ management of their daughter’s adjustment to adolescence, and (c) the impact of the ASD on family well-being. Family stress theory was the conceptual framework used to guide the study. Using grounded theory with a supplemental quantitative data strand, the study involved forty in-depth semi-structured interviews. Parents completed the Stress Index for Parents of Adolescents (SIPA) and a demographic questionnaire.
Findings indicate that parenting a daughter with ASD could be categorized as a chronic stressor. The majority of parents endorsed clinically significant levels of stress on the SIPA. The mean age of ASD diagnosis was 8.7 years, well above the most recent (2014) Centers for Disease Control findings (6.3 years). Delayed and misdiagnosis for girls with ASD resulted in significant stress for families and reduced access to appropriate intervention. A shift in perception of the ASD from an acute to a chronic stressor allowed families to move toward acceptance and adaptation. The study findings support the need for a family centered model of assessment and intervention. Social workers in schools and in early intervention programs can play a critical role in providing education and support for families.
DEDICATION

This dissertation is dedicated to the parents who participated in this study for their generosity in sharing their stories and caring so deeply for their daughters.
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Chapter I. Introduction

“Many girls and women [with ASD] are living their lives having been misdiagnosed and they are subsequently misunderstood, often leading to feelings of self-doubt, sadness, anxiety, and isolation. Whether or not we believe that labels are important in and of themselves, the understanding that can come from an appropriate diagnostic evaluation can be the turning point in a female’s life and that of their family – it can create an Aha moment, and it can lift the weight of feeling inadequate or feeling that you’re not trying hard enough.” (Nichols, 2012, p. 9)

How autism has been conceptualized and operationalized in research and practice has changed considerably since its first introduction in the 1980 Diagnostic and Statistical Manual of Mental Disorders, DSM-3. The DSM is the primary tool utilized by educational and clinical practitioners to diagnose a child with a specific disability or mental health disorder. A diagnosis is the lens through which parents, teachers, and clinicians understand a child’s behavior and the vehicle to provide intervention. Without a diagnosis, a child is unable to receive critical intervention, specifically within the public school system, and the child’s behavior is perceived inaccurately. Long considered by parents, educators, and clinical practitioners as a boy’s disorder, attaining a diagnosis of autism is more complicated for girls and a significant diagnostic gender gap exists with boys five times more likely to receive a diagnosis (Centers for Disease Control [CDC], 2014). The most recent changes to the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) place autism, Asperger’s syndrome (AS), Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS), and High Functioning Autism (HFA) under the classification of Autism Spectrum Disorders (ASD) as of May 2013 (American Psychiatric Association [APA], 2012).
Having a child diagnosed with autism spectrum disorder places enormous responsibility on the parents to understand, adapt to, and manage complicated symptoms (Attwood, 2007; Riley-Hall, 2012). The diagnostic process is likely to be even more daunting for parents of girls with ASD, due to their “minority status in the autism community” and the pervasive perception of autism as a “boy’s disorder” (Riley-Hall, 2012, p.37). A further complication is that girls with ASD are described as “research orphans”, with the majority of research on ASD including samples that are overwhelmingly male (Bazelon, 2007). This has resulted in diagnostic tools, clinical interventions, and educational programming developed exclusively through the lens of boys with ASD. There is limited empirical evidence on families managing a daughter’s ASD diagnosis and adapting to her specific needs. This dissertation study aims to address this gap in the research through an inductive exploration of families as they encounter the diagnostic process and manage their daughters’ needs. The underlying assumption is families are a critical unit of analysis, as they are coping with and managing the stress of the ASD diagnosis.

Autism spectrum disorder (ASD) is a neurodevelopmental disability characterized by significant deficits in social interaction, communication skills, and restricted behavioral patterns (American Psychiatric Association [APA], 2012; Centers for Disease Control [CDC], 2012). The CDC monitors ASD prevalence rates in the United States through the Autism and Developmental Disabilities Monitoring Network (ADDM), an eleven site surveillance system that assesses children eight years of age identified with ASD by a qualified professional as indicated by the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision (DSM-IV-TR). The most recent data
from 2010 indicates that overall ASD prevalence is one in 68 children, one in 42 boys and one in 189 girls, a 28% increase from 2008 (CDC, 2014, p.1 & 6). These data indicate that the ASD prevalence trajectory continues to increase markedly each reporting period (CDC, 2014). In 2008 the overall prevalence rate was 1 in 88, among boys it was 1 in 54 and among girls 1 in 252 (CDC, 2012, p. 2). There was a 123% increase in ASD prevalence rates between 2002 and 2012 (CDC, 2014, p. 9). Although the CDC’s data has garnered widespread media attention and driven strong public health initiatives, there continues to be a significant diagnostic “gender gap” between boys and girls (Attwood, 2007; CDC, 2012, 2014). It remains unclear as to why this gender gap continues to occur, warranting further investigation, specifically regarding how ASD manifests with girls.

Girls functioning on the high end of the autism spectrum disorder have received limited attention within research, despite a decade of significant increases in prevalence rates (CDC, 2014). This dissertation uses grounded theory methods to address this gap in the research, through an in-depth analysis of eleven families living with an adolescent daughter with average to above average intelligence and currently diagnosed with an ASD. Due to these recent DSM changes, autism spectrum disorder (ASD) is used as the primary diagnostic reference in the study. All of the girls in the study were diagnosed prior to the DSM-5 changes with either Asperger’s Syndrome (AS) or pervasive developmental disorder – not otherwise specified (PDD-NOS) and these diagnoses are referenced within the study when appropriate. Therefore, the three diagnoses are used interchangeably and should be understood as the same diagnosis. The family is the primary unit of analysis and the study focuses on three primary areas for analysis with a
particular emphasis on the constructs of stress and coping within the family: (a) an exploration of families’ experience with the diagnostic process (b) families management of their daughter’s adjustment to adolescence, particularly within the public school environment and neuro-typical peers (c) the impact of the ASD on family well-being. Family Stress Theory (Boss, 2002) provides a framework for the analysis. The first chapter provides an introduction to autism spectrum disorder in the United States, including prevalence rates. Chapter two provides a review of the current research literature on ASD and an overview of Family Stress Theory, concluding with specific research aims and research questions. Chapter three reviews the specific methods utilized in the study. Chapter four presents the findings and chapter five concludes with the discussion and implications for social work practice, policy, and areas for future research.

**ASD Classifications, Prevalence Rates and Sex Ratios**

This section will outline and review the history and recent changes to the way in which Asperger’s Syndrome (AS), Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS), and high functioning autism (HFA) have been defined and labeled. This study focuses on girls with average to above average IQ with a diagnosis of Asperger’s, PDD-NOS, or high functioning ASD. These are the girls that are most at risk for misdiagnosis, and delayed diagnosis; the reasons for which remain unanswered. There is general agreement among researchers and experts in the field that the experiences and needs of those with Asperger’s or high functioning autism are quite distinct from those with more typical autism (Attwood, 2007).
**Asperger’s (AS) and High Functioning Autism (HFA).** Asperger’s Syndrome (AS) and high functioning autism (HFA), are considered by most researchers to be interchangeable (Wing, 2005; Attwood, 2007) neurodevelopmental disorders that fall now within the mild category of autism spectrum disorders (ASD). The disorders are characterized by significant social impairments with average to high levels of intelligence that frequently mask the child’s deficits (Wing, 1997; Attwood, 2007; Toth & King, 2008). A relatively new diagnosis, Asperger’s Syndrome was first defined by the American Psychiatric Association and introduced in the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) in 1994 based upon Lorna Wing’s description and publication of Hans Asperger’s work in the 1940s (APA, 1994; Wing, 2005; Mattila, et al, 2007; Attwood, 2007; Toth & King, 2008).

As of May 2013, with the advent of the American Psychiatric Association’s (APA) publication of the new DSM-5, the diagnoses of Asperger’s and high functioning autism merged and are now referred to as a mild form of autism spectrum disorder (American Psychiatric Association, 2012). Controversy among both researchers and clinicians continues as to whether Asperger’s is a distinct diagnosis from autism (Attwood, 2003, 2007; Wing, 2005; Toth & King, 2008). According to the DSM-IV-TR, the primary distinction between AS and HFA is those with AS have no early childhood language or cognitive delay (APA, 2000). Most research finds that children diagnosed with HFA in early childhood are by early adolescence clinically no different than children diagnosed with Asperger’s syndrome (Attwood, 2003; Wing, 2005; Toth & King, 2008). For the purposes of this study, the two diagnoses are considered interchangeable, given the overall research findings and the APA’s diagnostic changes.
Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS).

Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS) was first introduced in the 1987 DSM-3-R as a diagnosis within the new spectrum of Pervasive Developmental Disorders. Clinicians have frequently used the diagnosis of PDD-NOS when symptoms of autism were present but did not reach the diagnostic threshold (APA, 1994). The Pervasive Developmental Disorder spectrum was again altered in the 1994 DSM-4, to include a spectrum that included Autistic Disorder, Childhood Disintegrative Disorder, Rett Syndrome, Asperger’s Syndrome, and PDD-NOS (APA, 1994). PDD-NOS has been considered a catch-all disorder used when symptoms were present but atypical or not as severe (APA, 2000). PDD-NOS, Asperger’s Syndrome, and high functioning autism were frequently used interchangeably, without clear distinctions among children diagnosed with each. The recent alterations to the DSM were guided by a desire to increase the validity and consistency of the diagnoses within the PDD spectrum (APA, 2012).

Autism Spectrum Disorder (ASD) as a New Classification. The American Psychiatric Association in 2012 established two new diagnoses, autism spectrum disorder and social communication disorder, as part of their revision of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) released in May of 2013 (APA, 2012). Autism Spectrum Disorder is a new category, which subsumes the diagnoses of autistic disorder (autism), Asperger’s disorder (AS), childhood disintegrative disorder, and pervasive developmental disorder not otherwise specified (PDD-NOS). ASD diagnostic criteria, includes two primary areas of significant and ongoing impairment in daily functioning. The first is comprised of deficits within both social communication and
social interaction as evidenced by limitations in social-emotional reciprocity, non-verbal communication behavior, and inability to develop and maintain relationships appropriate for one’s developmental level (APA, 2012). The second area involves evidence of restricted and repetitive patterns of behavior, interests, and activities, which manifests through repetitive speech, motor activity, or use of objects, rigid adherence to routines, patterns of verbal or non-verbal behavior with extreme resistance to change; restricted and fixated interests with abnormal levels of intensity and focus; highly reactive or non-reactive and/or interested in sensory input within one’s environment (APA, 2012). These symptoms present significant challenges in a number of contexts for both the child diagnosed with ASD and the family caring for and supporting the identified child.

Extensive controversy exists regarding the new classifications of these neurological disorders along a continuum from mild to severe rather than distinct disorders (APA, 2012). There are significant concerns among professionals and parents regarding how those with high functioning autism (HFA), Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS), and Asperger’s (AS) may be excluded from the new criteria and without a diagnosis, risk losing access to critical services within schools, medical insurance, community based service providers, and government based support such as Social Security and Disability (Attwood, 2007). Autistic disorder or severe ASD is more readily recognized and diagnosed among parents and professionals, due to more pronounced symptoms and lower functioning across most domains (Attwood, 2007). Children with symptoms of higher functioning autism frequently experience delays in both diagnosis and treatment (Attwood, 2007). This is a particular concern for girls with high-functioning ASD, whose symptoms frequently go
Social Communication Disorder. Social communication disorder, a new disorder in the DSM-5, comprises deficits in two primary areas: (1) verbal and non-verbal communication resulting in deficits within social reciprocity and social relationships not otherwise explained by language or cognitive deficits and (2) deficits in the area of the development and use of spoken and written language (APA, 2012). Social communication disorder’s primary distinction from ASD is the non-inclusion of restricted, repetitive behavior and interests (APA, 2012). This new disorder may be particularly applicable to girls formerly diagnosed with Asperger’s Syndrome or high functioning autism, given some of the current research on sex differences indicating that girls are less likely to engage in restricted and repetitive behavior and interests (Hartley & Sikora, 2009; Sipes, Matson, Worley, & Kozlowski, 2011; Solomon, Miller, Taylor, Hinshaw, & Carter, 2012; Frazier, Georgiades, Bishop, & Hardan, 2014).

Prominent Features of ASD. Children with ASD experience a great deal of difficulty initiating and maintaining effective social interactions with both peers and adults, which frequently results in frustration, shame, and isolation (Wing, 1997; Attwood, 2007). The social skills that come naturally for most young people must be taught and practiced repeatedly for children with ASD. Reciprocity (responding to and actively listening to others, perspective taking, theory of mind), accurate interpretation of non-verbal communication (body language, facial expressions, maintaining eye contact), and unstructured communication (natural give and take in a conversation) are all critical
social skills but very difficult skills to develop for young people with ASD (Wing, 1997; Attwood, 2007).

Children with ASD are frequently described as withdrawn, socially awkward, and cognitively rigid. The communication skills of children with AS are characterized by a tendency to talk exclusively about themselves and their narrow interests. Children with ASD may speak in an odd tone of voice with limited inflection and without understanding the perceptions of others around them. Those with ASD may also develop repetitive movements, rigid adherence to a specific routine, and sensory sensitivities with food, clothing, noise, lights, and smells (Wing, 1997; Attwood, 2007).

**Sex Differences in Manifestation of ASD Symptoms.** Tony Attwood (2006 & 2007), one of the leading experts on Asperger’s disorder, finds in his clinical practice that girls are referred far less frequently than boys for diagnostic assessment, skewing the male – female high-functioning ASD ratio. Attwood supports the thinking that girls’ expression of ASD symptoms are more “subtle”, and they may present with what Wing (1997) describes as the more passive personality type among those with ASD. The passive personality type may present with fewer behavioral issues, less rigidity with routine, and may accept peers approaching but will not initiate social interactions (Wing, 1997). Wing also found that children with a passive personality type managed the early school years more effectively, presented with higher IQ, and did not present with deficits until middle school when social and academic demands become more complex (Wing, 1997). Wing (1997) further surmises that higher-functioning adolescents with autism might be misdiagnosed with a psychiatric condition such as anxiety rather than Asperger’s. Attwood further theorizes that girls with AS may be “mothered” by other
girls early on and may present with much fewer externalizing behaviors. Attwood has found in his clinical work that girls with AS are more motivated to learn social skills and therefore, their prognosis in adulthood are much better and they might be “less conspicuous” than their male peers.

Tony Attwood (2006 & 2007) also provides a sense of the more “subtle” behavioral differences between girls and boys with AS. He finds that many girls are more adept at “camouflaging” their social deficits through what he calls “mirroring” the social behavior of others. Girls may use their observation skills to mimic the social skills and adopt a superficial competence in this area. He also finds girls with AS to be drawn to drama, theater, classic literature, animals, and imaginary play, which are interests quite different from their male peers. A rich imaginary life and solitary play has at times been confused with schizophrenia for some girls with AS, with their behavior interpreted as hallucinations and delusions (Attwood, 2006 & 2007). He has also found that when interacting with female peers, girls with AS can become “controlling” and lack true reciprocity in their play. As they enter adolescence, Attwood finds girls with AS prefer to present in a more childlike manner, especially in tone of voice and, similar to their male peers, lack any interest in fashionable clothing. Clothing and hygiene can become a significant stressor for both girls with AS and their parents. Sensory issues impact hair brushing, use of deodorant, and type of clothing, with girls opting for loose cotton clothing such as sweat pants and shirts. These issues can impact acceptance from peers and result in social marginalization as girls enter adolescence. Attwood emphasizes the need for research on girls with AS to further delineate how they manifest ASD symptoms and to target their specific treatment needs.
**Prevalence Rates of ASD.** Although ASD prevalence rates have continued to rise markedly since the early 1990s, there is widespread concern over the accuracy of the data (Fombonne, 2011; Elsabbagh et al., 2012; CDC, 2014). These prevalence rates do not necessarily reflect a rise in incidence but rather increased awareness and diagnostic clarification (Fombonne, 2011; Elsabbagh, 2012). Theories related to the rise in prevalence include a broadening of the concept of autism as reflected in the terms PDD and ASD, increased public awareness, changes within the U.S. Special Education policies and services to include ASDs, and the possible transitioning from one developmental disability diagnosis to ASD (Fombonne, 2011; Elsabbagh, 2012; CDC, 2014).

There is very little specific epidemiological prevalence data on high functioning autism and Asperger’s Syndrome, however current estimates on the ratio of autism to Asperger’s is 3:1 to 4:1 (Fombonne & Tidmarsh, 2003; Fombonne, 2003; Fombonne, 2011). Researchers conducting recent reviews of world wide epidemiological surveys found estimated prevalence rates of ASDs to be 1 in 150 children (Fombonne, 2011; Elsabbagh et al., 2012).

The latest estimates from the Centers for Disease Control and Prevention (CDC) in the United States indicate that the total ASD prevalence in 2010 was one in 68 children, for boys the rate was one in 42 and girls one in 189 (CDC, 2014, p). These rates reflect a 30% increase in prevalence from just two years prior in 2008 (one in 88) and a 60% increase in prevalence from the data reported in 2006 (one in 110) and a 120% increase from 2002 and 2000 (one in 150) (CDC 2010; CDC, 2012; CDC, 2014).

The CDC draws its data from the Autism and Developmental Disabilities Monitoring Network, collecting data from eleven states in the U.S. but is not a
representative sample, given significant variability in findings by geographic areas, sex, race/ethnicity, and level of intellectual ability (CDC, 2014). The CDC is unable to definitively account for the factors resulting in the continued rise in prevalence and unable to attribute the rise to an increase in risk. The CDC also recognizes that the variability in findings could be attributed to a limitation in diagnostic practices in recognizing ASD symptoms in some racial/ethnic groups, within certain geographic areas, and among different socioeconomic groups (CDC, 2014). Asperger’s Syndrome and high functioning autism are included in the ASD rates with 46% of the children in the sample having an average to above average intellectual ability. It can be quite difficult to accurately estimate prevalence for AS and HFA, particularly among girls (Attwood, 2007). Attwood (2007) attributes the range in prevalence to the different use of diagnostic criteria, misdiagnosis by clinicians, and a lack of referral for assessment among those with AS that present with more nuanced symptoms.

**ASD Sex Ratios and Age of Diagnosis.** Worldwide estimates on male to female ratios for ASD diagnosis are 4.2 boys to 1 girl (Fombonne, 2011) and recent CDC data put the ratio at 5 boys to 1 girl (CDC, 2014). It is more difficult to ascertain an accurate estimate for sex ratio within high-functioning autism due to limited data but the median sex ratio of 5.7 boys to 1 girl is cited from an epidemiological survey with a comparison sex ratio of 1.9 boys to 1 girl for autism with low cognitive functioning (Fombonne, 2003).

Although ASD is often perceived to be a “boys’ disorder”, both girls and boys on the more severe end of the spectrum with more typical autism symptoms, are diagnosed quickly during early childhood (CDC, 2012). It is the more high functioning girls on the
autism spectrum, with average to above average intelligence, that are most frequently misdiagnosed and may not be identified as having ASD until middle or high school when their symptoms become more pronounced (Attwood, 2006; Nichols, 2009; Simone, 2010). Age of first diagnosis continues to be later than necessary for all sub-groups within the CDC data, given that children can be diagnosed as young as two years of age. Most of the children, according to the CDC, were diagnosed after the age of four. The average age of an Asperger’s diagnosis in 2010 was 6 years and 2 months, compared to autism at 4 years of age, and PDD-NOS at 4 years and 2 months (CDC, 2014). Recent data from the Netherlands on age of diagnosis for girls with Asperger’s found a statistically significant difference from their male peers, with almost a two years difference (boys at 7 years, 9 months and girls at 9 years, 7 months) (Begeer, et, al, 2013). Delayed and misdiagnosis among those with high functioning autism may result in decreased access to intervention specific to ASD: early intervention, special education services within the public school system, and appropriate psychiatric intervention.

Although our knowledge base on autism spectrum disorders has increased dramatically in the last decade, there has been very little research focused specifically on girls with an ASD. In a 2007 New York Times article, Ami Klin director of Yale’s Autism Program, described girls with ASD as “research orphans”. Klin reports that girls with ASD are often excluded from studies, because it is too difficult to recruit sufficient numbers of participants to provide accurate sex distinctions (Bazelon, 2007). The research on children and adolescents with ASD includes samples that are overwhelmingly male. When study samples do include females with ASD, their numbers
are often too small to draw any gender specific conclusions. There are very few single-sex studies looking at the specific experiences and symptoms of girls with ASD.

Preliminary quantitative research on sex differences within ASD does indicate that girls may not exhibit the same level of repetitive behaviors, restricted interests, and disruptive behavior in the school setting (Attwood, 2006; Hartley & Sikora, 2009; Sipes, Matson, Worley, & Kozlowski, 2011; Frazier, Georgiades, Bishop, & Hardan, 2014). Girls also appear to present with more significant attentional and mental health symptoms than boys (Holtman, Bolte, & Poustka, 2007; Hartley & Sikora, 2009). There is some indication that girls with ASD are more symptomatic within the home environment, particularly with sleep problems, mental health symptoms of anxiety and depression, and behavioral disorders (Holtman, Bolte, & Poustka, 2007; Nichols, 2009; Hartley & Sikora, 2009).

There is a significant amount of qualitative and quantitative research on parenting a child with ASD, although the samples do focus predominantly on male children and mothers. There is very limited data on the experiences of the entire family, constraining our understanding of how the stress of raising a child with ASD impacts overall family functioning, including fathers/second parents and siblings. Evidence suggests that parents can encounter a diagnostic process that is both lengthy and frustrating (Howlin & Asgharian, 1999), frequently involves misdiagnoses, and involves high levels of stigma and shame during interactions with professionals and other parents (Gill & Liamputtong, 2011). A consistent theme within the research is that parents experience much higher levels of stress than other parents and stress that is related to the characteristics of their child with ASD (Gray, 2003; Rao & Beidel, 2009). Understanding how to effectively
support families is a critical component in developing interventions for girls with ASD. Parents are the primary supports and advocates for girls with ASD, and their involvement in all facets of intervention, academic, social, behavioral, and emotional, are critical to successful functioning.

Parents of girls with an ASD are uniquely capable of providing a more comprehensive understanding of the process of recognizing a child’s development as different and attempting to attain both an accurate diagnosis and effective treatment. Based upon research with parents of male children and a small number of female children, we know that these families experience very high levels of stress during the diagnostic process, as they attempt to understand the diagnosis and maintain family well being (Howlin & Asgharian, 1999; Gray, 2003; Rao & Beidel, 2009; Gill, 2011). ASD is a social disorder that may also create specific challenges for girls and their families as gendered norms regarding social behavior in adolescence become more difficult to negotiate (Attwood, 2006; Nichols, 2009). ASD girls may not respond to these gendered norms in a typical manner, creating increased stress on families that may become concerned about their daughter becoming isolated and socially marginalized. Further research is needed on how these families experience these potential stressors and mitigate the impact on their daughters and families.

**Study Rationale**

For the purposes of this research study, an emphasis on girls with average to above average intelligence with mild to moderate symptoms of ASD will be emphasized, rather than girls with severe autism symptoms. These are the girls that would be diagnosed, prior to the recent DSM 5 changes, with either Asperger’s Syndrome (AS) or
PDD-NOS and are more typically involved in the public school system, community based activities, and social interaction with neuro-typical peers. They are the ASD population most at risk for not being diagnosed in a timely and accurate manner and the population for whom we have the least amount of empirical data. Parents of girls with ASD are uniquely capable of providing data on how initial symptoms of ASD manifest and identifying the particular challenges in addressing their daughters’ needs.

Families experiencing the diagnosis and subsequent treatment of a female child with ASD are likely to encounter significant stressors related to the complexity of the diagnosis. Unfortunately, we have very little empirical data to develop an accurate understanding of this process. Outcomes associated with a diagnosis of high functioning autism or Asperger’s Syndrome include high rates of psychiatric comorbidity such as anxiety (Kim, et al, 2000; Russell & Sofronoff, 2005; Lugnegard, Hallerback, & Gillberg, 2011), depression (Kim, et al, 2000; Lugnegard, Hallerback, & Gillberg, 2011), Attention Deficit Hyperactivity Disorder, aggression and self-injurious behavior (Gillberg & Billstedt, 2000), exposure to high rates of bullying from peers in a school environment (Interactive Autism Network [IAN], 2012), and higher rates of being “ridiculed” by peers and significant fear of being laughed at for ASD type behaviors (Samson, Huber, & Ruch, 2011). These outcomes are likely to place enormous responsibility and stress upon family members who directly experience these symptoms and are in the best position to buffer the impact on the identified child. The ability for parents to access effective supports within their communities is critical in managing both the needs of their daughter and overall family well-being.
Social workers encounter young people with ASD and their families within a wide array of settings, particularly in schools, early intervention programs, and mental health clinics. The dramatic rise in prevalence has resulted in growing public awareness and policies aimed at increasing services to children and families with ASD over the last decade. The new requirements regarding autism spectrum disorders within the federal special education law, Individuals with Disabilities Education Improvement Act (IDEA) of 2004, identify specific training and intervention criteria required by professionals (Raines, 2006; Massachusetts Department of Education, 2006). The remarkably high comorbidity with mental health disorders such as depression, anxiety and attention deficit hyperactivity disorder and ASD, also requires social workers to develop assessment skills effective in understanding the complex nature of ASD symptomology and differential diagnosis.

There are also enormous economic costs associated with autism spectrum disorders. The CDC estimates that medical expenditures for a child with ASD were 4.1-6.2 times greater than for a child without an ASD (CDC, 2012). The Government Accounting Office (USGAO, 2005) report on special education services for children with autism in 2005 indicates that there has been a 500 percent increase in the number of children being serviced through Individuals with Disabilities Educational Improvement Act (IDEA) over the past decade (USGAO, 2005). The GAO report estimates that in 1999-2000, the average per pupil expenditure for a child with autism was over $18,000, which is three times the expenditure for a regular education student and among the highest for special education students (USGAO, 2005). Given these costs, it is imperative that research is conducted to clarify the specific experiences and needs of the
families with girls with ASD. The purpose of this study was to provide data on the characteristics of girls with high functioning autism spectrum disorder and their families and assess the applicability of family stress theory (Boss, 2002) as a framework for intervention, with the goal of moving toward the development and utilization of evidence based practices for intervention with girls with ASD and their families.

Study Aims

The purpose of this dissertation research study was to develop an understanding of the process of families managing and adapting to the diagnostic process and academic, emotional, behavioral, and social adjustment of daughters ages 12 to 17, who are identified as meeting the diagnostic criteria of a mild autism spectrum disorder. A mixed methods design was utilized in which quantitative data are embedded within a primary grounded theory qualitative design. In-depth semi-structured interviews with eleven families and three directors of programs servicing girls with ASD were conducted with the goal of developing a model outlining the process of families adapting to and managing the distinct needs of female children diagnosed with an autism spectrum disorder. A supplemental quantitative data strand was collected from all parents within the recruited families, during the qualitative data collection. Parents completed the Stress Index for Parents of Adolescents (SIPA) and a demographic questionnaire, both of which provided descriptive data on the sample and further enhanced the exploration of stress within the coping process (Sheras, Abidin, & Konold, 1998).

Parents, siblings, and girls with ASD are uniquely capable of providing building blocks in our understanding of how this diagnosis manifests, impacts social and academic adjustment, family well being, and the accessibility of appropriate resources. Family
stress theory (Boss, 2002) was utilized to frame the exploration of the parents’ appraisal of their daughter’s early developmental trajectory and subsequent diagnosis, use of specific coping strategies in managing their daughter’s adjustment during early adolescence, academic, social, emotional, and behavioral, perceptions of the impact of the ASD diagnosis on the family’s well-being, and challenges encountered as they negotiate the public school system, community based services, and relationships with caregivers. The following chapter will provide an overview of the current research on ASD.
Chapter II: Literature Review

Introduction

This chapter consists of an analytic literature review that explores the constructs within the ASD research most applicable to high-functioning adolescent girls with ASD and their families, an overview of family stress theory (Boss, 2002, 2006), the guiding theoretical framework, an outline of the conceptual framework developed by the researcher, and identifies the study’s research questions. Although the research on children and adolescents with ASD continues to include samples that are overwhelmingly male, research specifically on girls with ASD is beginning to gain momentum, and this review incorporates the most current findings.

A focus was directed on the following areas for critical review: (a) sex differences in manifestation of ASD symptoms, (b) significant variables related to adolescent functioning for youth with ASD, particularly public school challenges, bullying, and mental health, and (c) family stress and coping in parenting youth with ASD. A review of the current literature on sex differences in manifestations of ASD provides the context, history, and implications for how girls with ASD are diagnosed and their symptoms of ASD understood. Significant constructs from the research related to adolescent functioning for ASD youth provides a context for understanding their specific challenges and areas of need during the transition to the developmental stage of adolescence. Finally, the family stress and coping research on families, provides an initial framework for understanding the specific stressors encountered by families and the adaptive strategies employed to manage the stressors.
The samples included in most studies on children and adolescents with ASD are overwhelmingly male and often times do not differentiate based upon functional level as determined by cognitive ability and use wide age ranges, making it difficult to ascertain the specific manifestations of ASD among sub-groups. High-functioning is a term used to refer to youth with average to above average cognitive ability. Research studies were chosen for review if the following sample criteria was met: (1) differentiation according to cognitive ability, (2) differentiation according to age, (3) sufficient numbers of girls with high-functioning ASD to compare across groups. Given the current sex ratios within the ASD population, research studies with non-equivalent groups according to sex were not excluded if the sample size was large, due to the difficulties in identifying and recruiting girls with ASD. Most studies compare across sex but the groups are not equivalent in size.

Gender is an important construct to explore within the ASD research as emerging data indicates that lower-functioning girls with ASD are more severely impaired and higher functioning girls present with subtler and possibly distinct manifestations of ASD compared to their male counterparts (Kirkovski, Entocott, & Fitzgerald, 2013). This study is focused on girls with an average to above average cognitive ability. When study samples do include high-functioning females the numbers are frequently too small, making it difficult to draw any gender and cognitive specific conclusions. There is a recent surge in studies aiming to address this gap in the research and draw out factors specifically related to girls with high-functioning ASD. Emerging data suggests that high-functioning girls with ASD present with distinct differences from their male counterparts that may explain the gender gap in ASD diagnosis. Although
preliminary, the new data from the recent research studies provides a direction to explore new factors related specifically to girls with high-functioning ASD, specifically repetitive and restricted behavior (Hartley & Sikora, 2009; Sipes, Matson, Worley, & Kozlowski, 2011; Solomon, et al, 2012; Frazier, Georgiades, Bishop, & Hardan, 2014).

**Diagnostic Sex Differences**

The research on sex differences within ASD is characterized by small sample size, too few females to adequately compare across gender, limited differentiation according to cognitive ability and age, and inconsistent findings (Kirkovski, Enticott, & Fitzgerald, 2013). The findings were variable, often times contradictory, and may also not be applicable to those on the higher functioning end of the autism spectrum (Nyden, Hjelmquist & Gillberg, 2000; Hartley & Sikora, 2009). Controlling for cognitive ability has become increasingly important as there are a number of studies indicating that girls with ASD and lower cognitive ability present with higher levels of impairment than their male counterparts (Kirkovski, Entocott, & Fitzgerald, 2013). This explains the more equivalent sex ratios for those on the lower functioning end of the spectrum. Whereas, research on girls with ASD and average to above average cognitive ability indicate lower levels of impairment in restricted and repetitive behavior than males but higher levels of psychopathology (Kirkovski, Entocott, & Fitzgerald, 2013).

The research studies on sex differences are predominantly quantitative and exploratory in nature. The focus has been on comparing symptoms directly related to ASD across sex, which may not fully capture the more nuanced differences. Very recently, there are a number of quasi-experimental design studies that include larger sample sizes, use of comparison groups with boys with ASD and typically developed
control groups, and attempts to match across groups according to age and cognitive ability. The May (2013) study included a sample of 32 females (aged 7-12 years) with high-functioning ASD compared to 32 boys (aged 7-12 years) with high-functioning ASD, and a control group of 44 typically developed children matched by age and gender. In a similar research design, the Head (2014) study included 25 females (ages 10-16 years) with high-functioning ASD compared to 25 boys with high-functioning ASD and two control groups with a sample size of 25 girls and 26 boys of typically developed children matched on age. Emerging data from these studies indicates some differences between girls and boys on the high-functioning end of the autism spectrum (Solomon, et al, 2012; May, Cornish, & Rinehart, 2013; Frazier, Georgiades, Bishop, & Hardan, 2014; Head, McGillivray, & Stokes, 2014).

One of the more recent findings from the quantitative research studies indicates that girls with ASD and average intelligence, present with fewer symptoms of restricted and repetitive behaviors compared to their male counterparts (Hartley & Sikora, 2009; Sipes, Matson, Worley, & Kozlowski, 2011; Solomon, et al, 2012; Frazier, Georgiades, Bishop, & Hardan, 2014). The diagnostic gender gap may occur because high-functioning girls do not present with the same type of restricted behaviors most commonly seen in boys, which some researchers surmise could be due to measures that are normed on boys and their gendered interests (Solomon, et al, 2012; Frazier, Georgiades, Bishop, & Hardan, 2014). This finding has important diagnostic implications for girls, who may not meet the second diagnostic criteria for ASD. The Frazier (2014) study suggests that practitioners consider social communication disorder when evaluating girls if they do not meet the diagnostic threshold for an ASD diagnosis.
due to not endorsing restricted and repetitive behavior within current scales. Based upon their findings, researchers encourage practitioners to look for more gender specific restricted interests when evaluating girls (Solomon, et al, 2012; Frazier, Georgiades, Bishop, & Hardan 2014). Researchers emphasize the need for more extensive replication of the studies controlling for both age and IQ, as well as the need for more qualitative research, to illuminate more subtle sex differences that are difficult to distinguish in quantitative research.

Further evidence of sex differences among high-functioning youth with ASD is evident in the study comparing girls to both their male counterparts with ASD and neurotypical peers (Head, McGillivray, & Stokes, 2014). A sample of 25 high functioning girls with ASD, ages 10 to 16 years of age, presented with more highly developed social skills compared to 25 high-functioning boys with ASD, but lower scores on a test of friendship and social function than typically developing girls (Head, McGillivray, & Stokes, 2014). Although researchers cannot account for the cause of the difference, it warrants more careful consideration in both ASD assessment and intervention. This finding is consistent with Attwood’s clinical understanding of girls with ASD and their ability to mimic the social skills of peers. This finding also has diagnostic implications and could help explain the gender gap. If high-functioning girls with ASD are able to more effectively adapt socially within a school environment in comparison to their male counterparts, it is possible that they will be overlooked diagnostically.

In looking at autistic symptoms across high-functioning girls and boys many studies find no differences in manifestation of autistic symptoms but do find differences in co-occurring diagnoses (Holtmann, Bolte, & Poustka, 2007; Solomon, et al, 2012;
May, Cornish, & Rinehart, 2013). May (2013) found in a longitudinal study of children ages 7-12 years, no gender differences in autistic symptoms but boys with high-functioning ASD presented with higher levels of hyperactivity and received more school based services than their female counterparts who presented with higher levels of social anxiety. Solomon (2012) found higher rates of internalizing symptoms among girls with ASD compared to both boys with ASD and typically developing girls without a disability. Holtmann (2007) found much higher rates of psychopathology among high functioning females with ASD, particularly in social, attentional, and thought problems. These findings support prior research on females with high functioning ASD exhibiting more significant social deficits during adolescence (McLennan, Lord, & Schopler, 1993). In a small study, girls with ASD were found to have more impairment within one realm of executive functioning, response inhibition, than both males with ASD and typically developing youth, which could impact their planning and organizing abilities as well as impulsivity (Lemon, Gargaro, Entocott, & Rinehart, 2011). Although no definitive evidence exists to explain these differences, researchers posit that adolescent girls with ASD may encounter more significant social challenges with neuro-typical female peers than boys with ASD encounter. Adolescent girls may engage in more complicated social interactions with more tacit social norms that could be potentially challenging for a girl with ASD, despite their potential adaptive abilities. Parents and school staff may also have higher gender based social expectations for girls with ASD, and may overlook their needs within a school environment. Both theories point toward gender socialization differences as potential mediating factors for adolescent girls with ASD.
In further exploring sex differences, it will be important to look within group more extensively rather than across groups to understand the specific ways in which ASD manifests in high functioning girls. Given the possible gender bias within current scales and measures, qualitative research may be more effective in drawing out the specific ASD symptoms such as restricted interests and behaviors. The research on ASD sex differences has also focused on latency age children (6 – 12 years) and wide age ranges, which may not fully capture high functioning girls with ASD who may not exhibit symptoms within school environments until adolescence.

**Adolescent Functioning Among ASD Youth**

**Female adolescent development.** Early adolescence (11 to 14) for girls is a time of rapid growth both physically and psychologically. They reach puberty 2 years earlier than boys, on average by age 11, undergoing a marked increase in hormones and physical changes (Kaplan & Sadock, 1991; Reimer, 2002; Nichols, Moravcik, & Tetenbaum, 2009). This developmental stage presents significant challenges for girls, as they begin to internalize complex messages from parents, peers, and society as they struggle to develop a sense of self (Brown & Gilligan, 1992; Nichols, Moravcik, & Tentenbaum, 2009). The school experience becomes the primary arena for early adolescents, with the primary relationship focus on peers with similar interests (Kaplan & Sadock, 1991; Reimer, 2002; Nichols, Moravcik, & Tetenbaum, 2009). As social interactions with peers become a more prominent focus and the relational skills required become more complex, girls with ASD can experience isolation, confusion, and social marginalization (Nichols, Moravcik, & Tetenbaum 2009; Simone, 2010). Findings from a recent qualitative study on a very small sample of girls with ASD and their mothers provides
preliminary evidence to suggest that high-functioning adolescent girls with ASD may have particular difficulties negotiating neuro-typical female peers and may feel more comfortable with male ASD peers who may share some similar interests (Cridland, Jones, Caputi, & Magee, 2013).

Parents of girls with ASD may also play a more pivotal role during this developmental stage, as the need to assess for potential risk factors such as mental health issues, social isolation, and bullying becomes more critical. It is also important to understand how developmental expectations for early adolescents with ASD may be quite different, depending upon the girls’ skill deficits and need for specific supports within the home and school environment. There is some indication in the research that parents are more actively involved in their ASD adolescent’s life than parents of more typically developed peers, particularly in terms of homework, hygiene, and managing social interactions (Nichols, Moravcik, & Tentenbaum, 2009; Cridland, Jones, Caputi, & Magee, 2013). This would likely impact the parent-child relationship and could potentially create stress for families, as adolescents with ASD may still desire some independence and autonomy (Nichols, Moravcik, & Tentenbaum, 2009).

Gender socialization becomes a more prominent variable during early adolescence, as social, behavioral, and emotional expectations for girls become very distinct from those of boys (Brown & Gilligan, 1992; O’Reilly, 2001; Reimer, 2002). Highly prescriptive behavior for early adolescent girls regarding appearance, communication, and social interactions with peers creates high levels of stress and may result in losing one’s voice and internalization of mental health symptoms such as anxiety, depression, and eating disorders (Brown & Gilligan, 1992; O’Reilly, 2001;
Typically developing adolescent girls are at higher risk for depression and utilizing a ruminative coping style than typically developing male adolescents (Papadakis, Prince, Jones, & Strauman, 2006). However, research indicates that girls with high-functioning ASD present with higher internalizing and depressive symptoms than typically developed girls (Solomon, et al, 2012). Girls with ASD are therefore at higher risk during adolescence than both their male counterparts with ASD and typically developing adolescent girls for manifesting significant symptoms of depression and anxiety (Solomon, et al, 2012). Girls with ASD are more compromised socially than their neuro-typical peers and may have a harder time communicating their needs to adults.

Different gendered expectations for girls and boys regarding behavior, appearance, and social interactions become much more pronounced during early adolescence (Nichols, Moravcik, & Tetenbaum, 2009; Simone, 2010). Understanding these gendered norms can be difficult for young people with ASD, as these norms are often times communicated in subtle, non-verbal ways. How girls internalize these norms varies considerably, but girls with ASD may have particular difficulties with gendered expectations regarding appearance due to sensory sensitivities and behavior, particularly female peer interactions, due to social skill deficits (Nichols, Moravcik, & Tetenbaum, 2009; Simone, 2010). Girls with ASD tend to prefer a more androgynous physical appearance, short hair, no make-up, loose/comfortable clothing, which may impact the level of social acceptance from both female and male peers (Nichols, Moravcik, & Tetenbaum, 2009; Simone, 2010; Cridland, Jones, Caputi, & Magee, 2013). Adolescent female peer interactions become much more complicated, communication based, and
nuanced, which may create high levels of stress for girls with ASD (Nichols, Moravcik, & Tetenbaum, 2009; Simone, 2010; Cridland, Jones, Caputi, & Magee, 2013). Parents may also feel pressure to encourage their daughters to respond to gender norms in order to facilitate greater social acceptance. Gender socialization and early adolescent development are important areas to explore with parents and girls with ASD. There are a number of potential risk factors during the transition to early adolescence indicating a need to develop a clearer understanding of how girls with ASD and their parents experience these factors.

**Mental health.** Research findings indicate that there are significantly high rates of comorbid psychiatric disorders, particularly depression and anxiety among adolescents with ASD (Russell & Sofronoff, 2004; Kim, et al., 2000; Whitehouse, Durkin, Jaquet, & Ziatas, 2009) and young adults (Lugnegard, Hallerback, & Gillberg, 2011). Researchers have also recently found that high-functioning children and adolescents with ASD present with higher levels of anxiety than lower-functioning youth with ASD, with parents of high-functioning children with ASD reporting behavior such as physical agitation, sleep difficulties, and inability to relax (Hallett et al., 2013). Even in a study on high-functioning children and adolescents without a co-morbid diagnosis, ASD youth presented with extensive subclinical symptoms of depression, anxiety, obsessive-compulsive disorder, and attention deficit hyperactivity disorder compared to neurotypical controls (Caamano, 2013). Adolescents diagnosed with ASD also experience higher levels of loneliness than their peers (Whitehouse, Durkin, Jaquet, & Ziatas, 2009). There is also preliminary data suggesting that ASD youth with comorbid anxiety and
depression may be at increased risk for suicidal thoughts and behavior (Storch et al., 2013).

Preliminary evidence suggests that adolescent girls with ASD present with more significant psychopathology than males with ASD (May, Cornish, & Rinehart, 2013; Solomon, et al, 2013; Frazier, Georgiades, Bishop, & Hardan, 2014). Mothers of girls, ages 6-12 with ASD were also more likely to endorse symptoms of schizophrenia among their daughters than mothers of boys with ASD (Gadow & DeVincent, 2012). These findings suggest the possibility of additional burden for parents of girls with ASD, as they are likely to encounter increased stress related to managing comorbid psychiatric symptoms, as well as challenges accessing appropriate mental health services within the school and community.

**Public school experiences.** Public schools are the primary context for both socialization and intervention for high-functioning ASD youth and warrant careful consideration. High functioning girls with ASD are more likely to be educated within the public schools due to their high IQ and more subtle manifestations of ASD symptoms. It is important to understand how both girls with ASD and their families experience the middle and high school environment. This context is of particular concern for girls with ASD who may be less visible than their male counterparts with more internalized depressive and anxiety based symptoms and less overt behavior within the school environment (Solomon, et al, 2012; May, Cornish, & Rinehart, 2013). School staff may underestimate their need for support and intervention based upon their high IQ and more internalized symptoms, putting them at great risk for “falling through the cracks”. To date, there are no studies looking specifically at girls with ASD within the school
environment, but there is some research on the experiences of youth and parents with Asperger’s and autism that provides direction in identifying the constructs most critical to the experience.

**Educational policies.** Over the last decade, there have been a number of educational policies enacted at both the federal and state level in response to the dramatic rise in ASD prevalence rates. The Individuals with Disabilities Education Act (IDEA) was revised by the U.S. Congress in 2004 and included important changes to special education practices within public schools, impacting ASD youth and families in many ways (Raines, 2006). The principles of IDEA most likely to affect ASD youth include the construct of free appropriate public education (FAPE) requiring schools to meet the specific needs of each student, an emphasis on educating disabled students within the least restrictive environment (LRE), the inclusion of disabled students within mainstream classrooms, and increased involvement of parents in every step of the IEP process with consistent updates on student progress toward measurable goals (Raines, 2006). Given these mandates, there is increased emphasis on retaining youth with disabilities within their public school rather than placement in out of district private school settings specifically designed for students with special needs.

Furthermore, Massachusetts Law enacted Chapter 57 in 2006, *An Act to Address the Special Education Needs of Children with Autism Spectrum Disorders*, which requires IEP teams to consider and incorporate into ASD students’ IEPs a number of specific areas related to the disability (Massachusetts Department of Elementary & Secondary Education, 2006). The Massachusetts DOE has outlined these “best practices” for public schools to use as a guideline for IEP meetings. Areas to be specifically addressed in the
IEP process include verbal and non-verbal communication skills, social interaction skills, sensory sensitivities, transitions during the school day, repetitive activities and movements, positive behavioral interventions, executive functioning, and social-emotional development (MA DOE, 2006). The Massachusetts Department of Education explicitly outlines best practices for each of these areas. It is unclear if public schools share these guidelines with parents during the IEP process.

The IEP process is the primary avenue for youth with ASD to access intervention and supports within the school environment. A 504 Plan is another means for accessing modifications, accommodations, and supports for students not meeting the disability threshold for an IEP. Parents are considered part of the IEP team and with the new IDEA mandates, are expected to be more active participants. Participation includes decision making regarding goals, objectives, and determining necessary accommodations. We have very little data on how parents of girls with ASD experience the IEP or 504 process and understand their role on the IEP team. Although small in scale, we have some preliminary research on how parents of children with ASD perceive both the IEP process and the public school’s responsiveness to their children’s needs. Themes generated from qualitative research with parents include a desire for a more collaborative versus combative experience with school staff during IEP meetings (Fish, 2006), and in developing strategies with teachers to meet the students’ needs (Zeman, Swanke, & Doktor, 2011), concerns regarding how ASD students are disciplined (Fish, 2006), inadequate IEP services (Fish, 2006), and teacher flexibility and creativity in addressing student frustration within the classroom (Zeman, Swanke, & Doktor, 2011).
There is general agreement among ASD experts that altering the school environment to be more responsive to ASD youth is a critical component to their success (Wing, 1997; Attwood, 2007; Nichols, Moravcik, & Tetenbaum, 2009). Sensory sensitivities to noise, physical space, lights, and smells present unique challenges for youth who need to navigate crowded and noisy hallways, cafeterias, banging locker doors, and transitions from classroom to classroom. Difficulties reading social cues, particularly more nuanced social interactions, and negotiating more complex class discussions could potentially create high levels of stress for youth with compromised communication and social skills. There is very little research on how young people with ASD perceive the school environment, and understand their difference from neurotypical peers.

The transition to middle school or junior high school marks a period of significant change in academic, social, and behavioral expectations. The school size often increases dramatically, students are required to negotiate a much larger number of teachers and adults all with different teaching styles and expectations, and academic expectations become much more demanding both within the classroom and in regard to homework (Adreon & Stella, 2001; Cridland, Jones, Caputi, & Magee, 2013). In addition, youth are experiencing the onset of puberty, physical changes, and are encountering increased emphasis on social connections with peers (Adreon & Stella, 2001; Nichols, Moravcik, & Tetenbaum, 2009). Tolerance for differences may decrease during the middle school years as conformity and peer acceptance becomes more desirable, placing youth with ASD at higher risk for marginalization (Adreon & Stella, 2001; Nichols, Moravcik, & Tetenbaum, 2009). Youth with ASD will likely experience increased anxiety as they
anticipate the transition and its inherent challenges, particularly the number of transitions during the school day, organizing academic materials, lockers, and managing interactions with both teachers and peers (Adreon & Stella, 2001; Cridland, Jones, Caputi, & Magee, 2013).

Predicting and planning for the supports necessary for ASD youth to successfully manage the transition to middle school is a necessary step (Adreon & Stella, 2001). It is also well understood that this transition is a process that will likely involve a number of supports and interventions over a period of time rather than one discrete activity (Adreon & Stella, 2001). It will involve changes to the students Individual Educational Program (IEP) or 504 Plan, to carefully identify the supports required within the school environment. Providing too few supports would likely result in significant de-compensation and require even more intervention to re-stabilize the student (Adreon & Stella, 2001).

Training for school staff on ASD and best practices in successfully engaging and working effectively with ASD youth, is both a required and necessary component (Adreon & Stella, 2001). We have very little empirical data on how consistently and effectively training is implemented and how well school staffs integrate current research on ASD youth. School staffs are likely to be the most significant factor in an ASD students’ school success, as they implement all interventions and are the adults assisting the young person in negotiating these significant challenges. Teachers report that ASD youth struggle with work completion in the classroom, homework, and organization of academic materials (Adreon & Stella, 2001).
The areas considered to be most problematic for ASD youth during the school day are transitions, changes in daily routine, auditory instructions, unstructured times such as the school bus, hallways during change of classes, lunch in the cafeteria and physical education class (Adreon & Stella, 2001; Zeman, Swanke, & Doktor, 2011). These aspects of the school day are more challenging for ASD youth because they are less predictable, involve more complex social interactions, and evoke higher levels of sensory stimuli, and ASD youth tend to have limited gross motor skills (Adreon & Stella, 2001). When overwhelmed, frustrated, and anxious, ASD youth often times exhibit more inappropriate behavior, increasing the risk of ridicule by peers and negative interactions with school staff (Adreon & Stella, 2001; Zeman, Swanke, & Doktor, 2011).

**Bullying.** Bullying within schools has recently received national attention and resulted in policy changes impacting how schools intervene and prevent bullying for all students. The Interactive Autism Network (IAN) in early 2012 released preliminary data from their survey of over 1,000 parents with an ASD child regarding bullying. The statistics reflect a significant problem with close to two-thirds of the children with ASD reporting being bullied. Researchers from IAN found that children with ASD are three times more likely than typical students to report being bullied within the past month. It is important to explore how having high functioning autism may put adolescents at increased risk for bullying and subsequent mental health issues (IAN, 2012). These risk factors are likely to impact overall well-being as well as level of functioning in both the school and home environment. We know very little about how these risk factors are experienced and managed by families.
We have very little empirical data on how ASD students manage the experience of bullying and if they access support within the school environment. Qualitative data suggests that youth with ASD experience bullying, social rejection, and exclusion from their neuro-typical peers, and are at risk for being targeted specifically for their ASD symptoms and presentation (Gray, 2002; Nichols, Moravcik, & Tetenbaum, 2009; Cridland, Jones, Caputi, & Magee, 2013). There is some suggestion that disclosure of the ASD diagnosis may facilitate more acceptance and tolerance for ASD youth, however, further research is necessary. Given their communication skill deficits and tendency to isolate and withdraw, it is also likely that many incidents are not reported. Bullying within the school environment may present unique challenges for girls with ASD, who are more likely to internalize symptoms and the potential for bullying to exacerbate existing depression and anxiety is quite high.

**Family Stress and Coping**

Research findings on families with a high-functioning ASD child indicate significant stress as they negotiate the complicated process of meeting the needs of a child with ASD. To date, there was only one small qualitative study that explored the specific experiences of mothers with daughters diagnosed with ASD (Cridland, Jones, Caputi, & Magee, 2013). Given the potential for misdiagnosis or delayed diagnosis for high-functioning girls with ASD, differences in manifestations of ASD than their male counterparts, and complicating factors related to higher rates of comorbid mental health issues it is important to more fully conceptualize the experiences of these families. We have very limited data on how these families experience the period of time prior to a diagnosis, appraise and adapt to the initial diagnosis, and manage the overall impact on
the family system. Data does exist on the parenting experiences of males with high-
functioning ASD and autism with females often times a very small minority in the
sample. The primary constructs from these data provide some direction to explore in the
analysis.

**Diagnostic Process.** There is evidence to suggest that the diagnostic process for
both male and female children with ASD is lengthy (Howlin & Asgharian, 1999; 
Attwood, 2007; Cridland, Jones, Caputi, & Magee, 2013), frustrating (Howlin & 
Asgharian, 1999; Cridland, Jones, Caputi, & Magee, 2013), and confusing (Schall, 2000)
creating increased stress on the family (Cridland, Jones, Caputi, & Magee, 2013), the
couple (Gray, 2003), sibling relationships (Gray, 2003) and a delay in adequate services
for the identified child (Attwood, 2007; Toth & King, 2008; Cridland, Jones, Caputi, & 
Magee, 2013). Research indicates that parents of ASD children experience a number of
misdiagnoses and high levels of stigma (Gill & Liamputtong, 2011) and shame as they
attempt to identify and understand their child’s needs and access resources (Attwood,
2007; Nichols, 2009; Cridland, Jones, Caputi, & Magee, 2013). Whitaker’s research
(2002) with families parenting a preschool child with autism, found parents experience
fear, shock, isolation, and uncertainty during the diagnostic process and are eager for
professional information specific to their child.

Although no direct evidence exists, Fattigh-Smith (2010) finds that among
professionals working with the ASD population, there is a belief that girls are not referred
for evaluation at the same rates as boys, which results in delayed diagnosis and an
inaccurate ratio of boys to girls with ASD. In the only study to date on adolescent girls
with high functioning ASD, the majority of mothers report that the diagnostic process
was more challenging in comparison to their male counterparts (Cridland, Jones, Caputi, & Magee, 2013). There is also preliminary evidence to suggest that health professionals such as pediatricians, psychologists and psychiatrists may be hesitant to diagnose girls with ASD (Cridland, Jones, Caputi, & Magee, 2013). Theories regarding why girls are not referred and diagnosed at the same rate as boys, appear to focus primarily on a difference in the expression of ASD symptoms among girls, who may exhibit more subtle ASD symptoms and present as more passive and internalized than boys, particularly within the school environment (Attwood, 2006; Nichols, 2009; Fattigh-Smith, 2010; May, Cornish, & Rinehart, 2013). Girls may exhibit less aggression, anger, and behavioral difficulties than boys resulting in less intervention and attention within the school environment (Attwood, 2006; May, Cornish, & Rinehart, 2013). Girls may exhibit more behavioral issues within the home environment (Attwood, 2006; Nichols, 2009). Understanding how parents experience the process of finding an accurate diagnosis for their daughter, access appropriate services, and address the subsequent needs of the entire family is critical both in regard to informing family theories and developing appropriate interventions (Attwood, 2006, 2007; Nichols, 2009).

**The parenting experience.** Families “living with autism” was a term identified and conceptualized in Neely-Barnes (2011) and an apt descriptor of the experience of parenting a child with ASD. Findings from qualitative research with parents of high-functioning children with ASD illuminate a number of constructs related to the parenting experience, including blame, stigma, embarrassment, and isolation. Parents report experiencing blame and stigma from extended family, schools, and in public places, particularly related to their child appearing “normal” until exhibiting behavioral issues in
the presence of people outside the immediate family (Gray, 2002; Neely-Barnes, Hall, Roberts, & Graff, 2011; Gill & Liamputtong, 2011). The stigma was related to feeling isolated, as families either avoided social activities to prevent feeling stigmatized or were excluded from social events, with many parents acknowledging the negative impact on typically developed siblings’ social opportunities (Gray, 2002; Lasser & Corley, 2008; Gill & Liamputtong, 2011).

Children with high-functioning ASD often pass as “typically developed” in comparison to children with more severe autism or children with physical disabilities, resulting in higher expectations from adults and less empathic reactions when behavioral issues occur (Gray, 2002; Lasser & Corley, 2008; Neely-Barnes, Hall, Roberts, & Graff, 2011; Gill & Liamputtong, 2011). This appears to lead to increased stress for parents, who may feel judged and stigmatized as “bad” parents (Gray, 2002; Lasser & Corley, 2008; Neely-Barnes, Hall, Roberts, & Graff, 2011). In one study, mothers of children with Asperger’s, felt the most stigma within the public school environment where they felt their children were perceived to be “naughty” and found school staff to lack empathy for their child (Gill & Liamputtong, 2011). Mothers were more likely to endorse experiencing stigma than fathers in one study, possibly due to their role as primary caretaker and the parent most likely to interface with school and community outings (Gray, 2002).

Coping strategies associated with stigma included adaptation, avoidance, explanation, and a sense of humor (Gray, 2002; Gill & Liamputtong, 2011). These constructs are similar to those experienced by parents of more severe autism, who describe “living in a world of their own” and feeling both stigmatized and invisible with
both other parents and within the public school system (Woodgate, Ateah, & Secco, 2008).

The nature of a child’s behavior had an impact on the level of stigma and stress reported by parents. In cases where the child’s behavior was aggressive and volatile, particularly in school settings, parents encountered significant stress as they managed encounters with educational administrators and dealt with their child’s suspension and expulsion from the public school (Gray, 2002; Gill & Liamputtong, 2011). If the behavior of a student was more passive in nature, parents reported lower levels of stress and stigma (Gray, 2002; Gill & Liamputtong, 2011). In a recent multi-state study with a large sample size, ASD children and adolescents exhibited significantly more challenging behavior both internalizing and externalizing, than typically developing children (Kozlowski, Matson, & Rieske, 2012).

The qualitative research on the parenting experience also indicates that receiving a diagnosis decreased feelings of stigma and validated parents’ concerns, but also increased feelings of grief when contemplating long-term outcomes for their child (Lasser & Corley, 2008; Gill & Liamputtong, 2011). Educating others about their children’s ASD diagnosis was perceived to be important but also involved a great deal of effort and time (Gill & Liamputtong, 2011). Some families limited the disclosure of the diagnosis with anyone outside the immediate family in order to avoid stigma or only to those who would be sensitive and empathetic (Gill & Liamputtong, 2011).

The research has been conducted primarily with mothers. However, when fathers are included, the research indicates that there are important gender distinctions in the way couples negotiate the demands of a child with ASD and differences in coping style (Gray,
2003). Fathers report that parenting a child with ASD had less of an impact on them personally than mothers but did report that the stress experienced by their wives from their child’s ASD did impact them and in some cases threatened the marriage (Gray, 2002). Gender roles related to employment and parenting appeared to be associated with the difference in experienced stress, with the majority of the parenting responsibility falling on the mothers (Gray, 2002). Mothers reported a significant impact on both their emotional and physical well-being that often times necessitated medical intervention (Gray 2002). Mothers also reported experiencing significant career limitations related to parenting a child with ASD and endorsed feeling resentment toward their husbands for limited support and responsibility with the extensive care required for a child with ASD (Gray, 2002). Disconnection between spouses also occurred when perceptions of the autism were different (Woodgate, Ateah, & Secco, 2008).

Qualitative research on coping strategies employed by parents is limited, but Gray (2002) did explore and compare the strategies used by mothers and fathers in managing their child’s symptoms. Both mothers and fathers employed some similar strategies including anticipating the child’s potential difficulties and planning how to address their child’s behavior, and secondly taking “one day at a time” and addressing problems in the present as the unexpected is likely to occur (Gray, 2002). Fathers employed the strategies of keeping their child busy while at home and going to work (Gray, 2002). Mothers, on the other hand, used the strategies of active engagement in their child’s therapies and separating their child with ASD from his siblings (Gray, 2002). Further gender differences were reported in the emotional coping realm with fathers actively suppressing emotions, primarily anger and mothers opting to express their emotions, primarily grief
and sadness (Gray, 2002). Mothers were also more likely to access friends and family to seek out emotional support and endorse spousal support as important in managing stress (Gray, 2002).

**Reframing the parenting experience.** The qualitative research on parenting provides data on the family adaptation process. Themes include parental acceptance, meaning making, and reframing of the family experience. Parents reported that their other children developed both empathy and compassion through having a sibling with ASD (Neely-Barnes, Hall, Roberts, & Graff, 2011). Many of the studies found parents reframing the construct of “normal” and developing a new and positive sense of normalcy for their family (Lasser & Corley, 2008; Neely-Barnes, Hall, Roberts, & Graff, 2011). Focusing on the strengths rather than the deficits of their child with ASD and recognizing how their child enriched the parents’ lives was evident in parent narratives (Nelly-Barnes, Hall, Roberts, & Graff, 2011). Perceiving parenting as a team effort and spouses working together as a team in meeting their families’ needs was identified as a coping strategy (Woodgate, Ateah, & Secco, 2008). Parents also indicated that becoming a vocal and informed advocate for their child was critical when working with systems such as public schools and professionals (Woodgate, Ateah, & Secco, 2008).

There is some evidence to suggest that there is a developmental process in “living with autism”, as parents of younger children talk about a desire to work toward a “cure” for the ASD, whereas parents of older children have come to accept the diagnosis and focus energies on developing coping strategies for the long-term (Neely-Barnes, Hall, Roberts, & Graff, 2011). Other families reported learning over time to adapt to the stigma experienced as the parent of a child with a disability and coping more effectively
with feelings associated with the stigma (Gill & Liamputtong, 2011). Framing the ASD parenting experience as a developmental process with specific areas of growth and adaptation warrants further exploration as it may lead to more helpful family based interventions and supports.

**ASD and parenting stress.** The experience of high levels of stress is empirically well established among parents of children with high-functioning ASD (Sivberg, 2002; Lee et al., 2009; Rao & Beidel, 2009). Limitations in the research include samples that are predominantly parents of male children and control groups that are comprised of parents of children with no identifiable disability. These limitations reduce generalizability and strength of the findings. There is also frequently no differentiation based upon gender (inclusion of small numbers of girls with ASD in the sample), and co-morbid diagnoses limiting the ability to generalize to families with daughters diagnosed with high-functioning ASD.

Although the sample size was small (12 mothers and 3 fathers) of male children with high functioning autism and a control group of 14 parents with a son with no disability, Rao and Beidel (2009) found significantly high levels of parenting stress among parents of children with high functioning autism (HFA) in comparison to parents of children with no psychological disorder. The parenting stress was found to be directly related to characteristics of the child with HFA. In a similar study with a larger sample size of parents (n = 89) of 57 male and 5 female children (mean age of 9.5) with high functioning ASD, Lee (2009) found parents of children with high-functioning ASD reported significantly higher levels of stress and significantly lower levels of adaptive coping than a control group of parents with neuro-typical children (n = 46). In a study
with 101 mother-father dyads parenting at least one child with ASD (118 children, 42 females, 76 males), findings indicate an association between raising a child with ASD and marital distress, an association between hours of respite care and increased positive marital quality and lower levels of stress, and an association between greater numbers of children in families of children with ASD and higher level of stress and lower levels of marital quality for both mothers and fathers (Harper, Dyches, Harper, Roper, & South, 2013).

In a Swedish study, Sivberg (2002) used a quasi-experimental research design to compare the level of strain among 66 parents with children diagnosed with ASD with a control group of 66 parents of typically developing children matched on demographic variables. The sample included parents of 16 female children with ASD and 21 male children with ASD, and did include both low and high functioning children with ASD. The study did find significantly higher levels of strain within the families of ASD children (Sivberg, 2002). The study also found among the ASD families, a negative relationship between the level of strain on the family and the level of coping, indicating that among the ASD families, healthy coping strategies were negatively correlated with significant levels of strain, findings similar to Lee (2009) (Sivberg, 2002). Parents of children with ASD also employed the coping behaviors of escape and distancing, which were positively correlated with high levels of strain, as well as endorsing lower levels of social support (Sivberg, 2002). The strength of this study was its inclusion of fathers, although the control group was comprised of parents with a typically developed child, rather than parents of children with another type of disability or mental health disorder, which limits the strength of the findings.
In the United States, data were analyzed from the 2003 National Survey of Children’s Health (NSCH) comparing responses regarding parenting stress and aggravation from parents of a child with autism (n = 459) to (1) the responses of parents of children without special health care needs (N = 61826), (2) the parents of children with other developmental disorders (N = 4545), and lastly to (3) the parents with a child with special health care needs but no developmental problems (N = 11475) (Schieve, et al, 2007). Researchers found significantly higher levels on the Aggravation in Parenting scale among the parents of children with autism, particularly those parents that reported their child needed special services within the last year than all three comparison groups (Schieve, et al, 2007). The scale included four questions for parents to rate: feeling their child was harder to care for than same-age peers, feeling “bothered” a lot by their child’s behavior, sacrificing aspects of their life to care for their child, and feeling angry at their child (Schieve, et al, 2007). The NSCH is a large nationally representative sample of US children. The researchers only asked about a diagnosis of autism, which may have resulted in under-reporting of children diagnosed with high-functioning ASD (Schieve, et al, 2007).

**Research Implications.** The primary limitation in the ASD research is the absence of a specific focus on girls with ASD and their voices. To date, there is only one qualitative research study with a very small sample size that addresses girls with ASD (Cridland, Jones, Caputi, & Magee, 2013). This research study aimed to accurately conceptualize how girls and their families experience an ASD, through inductive research grounded in their specific experiences. The prior research provided constructs and variables, such as stigma, shame, bullying, comorbid diagnoses, and coping behavior, to
explore within the qualitative interviews and demographic questionnaire. Findings were also compared to prior research to identify similarities and differences.

**Conceptual Framework**

A theoretical lens is frequently utilized in qualitative research to frame the study and to provide a guide in forming research questions and identifying the important constructs to explore (Miles and Huberman, 1994; Padgett, 2008; Creswell, 2009). Boss’s (2002, 2006) “contextual family stress model” is a cyclical, flexible model that reflects the way in which a family responds individually and collectively to an identified stressor that has upset the balance within the family system. Boss advocates for the use of theoretical constructs that are broad, inclusive, and culturally sensitive. This allows researchers flexibility in identifying differences and similarities among families toward the goal of understanding the strengths and barriers that impact family growth.

Boss’s (2002) framework builds upon Rueben Hill’s (1958) ABC-X model. Boss uses Hill’s model in which A – is the stressor, B – is the family’s resources at the time of the event, and C – is the meaning attached to the stressor by the family, both on an individual and collective level, and X – is the degree of stress. Boss modifies the model to a cyclical process and emphasizes C – the perception of the event/stressor as the most critical influence on how the stressor is managed. Boss also assesses both the internal and external context of the family. Her model provides a framework for assessing how families perceive a specific stressor and adapt to and manage the stressor both as individuals and as a family unit.

Boss identifies Hill’s model as too linear and advocates for reconstructing his model to a cyclical framework that includes a stronger emphasis on a dialectical view of
the family system and understanding the family’s perceptions and meaning making through symbolic interaction. Symbolic interaction can be understood as the way in which a stressed family constructs a symbolic reality, through language and rituals, based upon shared meanings and role expectations within the family, which are influenced by the larger societal context (Boss, 2002). Dialectical thinking refers to an understanding of forces within the family that are in opposition to one another (individual versus family, independence versus dependence) and result in adaptation and change within the system (Boss, 2002). Boss advocates for a dialectical perspective “because such a perspective avoids blaming and scapegoating and instead helps the family to change and live with the tension from opposing forces that remain” (Boss, p. 77, 2002).

In this study, the family is the unit of analysis, with a specific focus on the constructs of stress and coping. Grounded theory methodology was chosen as the primary method for its ability to inductively, from the narrative data, develop a theoretical model of the coping process of families. Models of a specific process provide a practical and user-friendly means for disseminating information regarding a complicated human experience. Although, there is usually one primary caretaker of an ASD child, stress within a family system is experienced by all members and contributes to overall family functioning (Boss, 2002). Incorporating all voices when researching family stress allows opportunity for a more comprehensive and valid understanding of how the family perceives and manages the stressor.

The analytic review of the current research on ASD and family stress theory were utilized to develop a conceptual framework for the project. Boss’s family stress model was used as the primary guide in understanding the family’s coping process. The
constructs in Boss’s model were incorporated into the research questions and interview guides. These constructs were also used during data collection and analysis, as a reference point in understanding and interpreting the data. Miles and Huberman (1994) state the following regarding the utility of frameworks; “As qualitative researchers collect data, they revise their frameworks – make them more precise, replace empirically feeble bins with more meaningful ones, and reconstrue relationships (p.20).”

The conceptual framework for this study incorporates the constructs chosen from Boss’s (2002) family stress model and prior research identified as most important in orienting the researcher during data collection and analysis (Miles & Huberman, 1994). The conceptual framework is a graphic depiction of the key constructs selected and their relationship to one another (Miles & Huberman, 1994). The conceptual framework was revised following data collection and analysis to reflect new meanings and emergent data (Miles & Huberman, 1994). During the final stages of data analysis, new models were conceptualized and are displayed in the findings chapter.

Table 1 below outlines the major constructs within the conceptual framework developed for this study. They constructs reflect the potential process families may follow as they adapt to the ASD diagnosis. The interview guide questions follow the progression of the process beginning with the time period prior to the ASD diagnosis and then the families’ initial appraisal of the diagnosis.

Appraisal of the diagnosis refers to the internal context of the family system and how parents perceived the initial diagnosis and understood ASDs. The sensitizing constructs of ambiguity, stress and crisis were explored with parents as they described
this time period. Specific questions regarding how parents attained an ASD diagnosis and possible barriers to a diagnosis were explored.

Emotional response addresses the way in which each member of the family expressed affect regarding both the initial appraisal of the ASD diagnosis and the subsequent stress of managing the ASD within the family system. Interview questions were directed at how family members both expressed their own feelings and whether they were able to validate the feelings of other family members. There was a specific focus on exploring how parents responded to siblings of the identified daughter with ASD and how couples responded to one another’s affective expressions. The girls with ASD were asked both how they perceived their ASD diagnosis and any feelings they had regarding the diagnosis.

Boss emphasizes focusing attention on the unique ways families creatively adapt to stress within their specific context, rather than focusing on problematic coping behavior (Boss, 2006). Therefore, the construct of coping behavior was used more generally to identify the behavior family members engaged in as they managed stressors and how they perceived the specific behavior. Boss defines family coping as “the process of managing a stressful event or situation by the family as a unit with no detrimental effects on any individual in that family. Family coping is a cognitive, affective, and behavioral process by which individuals and their family system as a whole, manage, rather than eradicate, stressful events or situations” (Boss, 2002, p.79). Boss builds upon Lazarus’ (1984) individual theory on stress and coping, which outlines the coping process as beginning with the “initial appraisal” of the stressor, followed by coping strategies which include both affective and behavioral responses to the appraisal
Lazarus identifies emotion-focused coping as strategies used when there is very little possibility of changing the stressor but both actions and defense mechanisms such as denial may be employed to reduce the “emotional arousal” caused by the stressor (Boss, 2002, p.73). Whereas problem-focused coping strategies are specific actions employed in response to a stressor where change is possible (Boss, 2002).

Research and interview questions were developed to identify the primary stressors encountered by family members and the different ways they cognitively appraised and responded to the stressors, both affectively and behaviorally. Potential barriers to coping were also explored, specifically within the families’ external context, such as access to support services and responsiveness of systems of care (public schools, health care system). Problem-focused and emotion-focused coping strategies were explored with all members of each family.

Environmental response refers to the external context within which the families engage and the way in which the external context may impact families’ stress levels and coping process. There is evidence from prior research indicating that the external context, such as the public school system, peers, and community resources are an important area of inquiry in assessing family stress and coping. This research study focused on both the families’ perceptions of their external context and their experiences within specific systems, including public schools, health care, and ASD support services.

Relational growth, the final overarching construct in the conceptual framework, provides an opportunity to look for ways in which families grew and changed within the process of adapting to and managing ASD within their families. Within Boss’ (2002,
understanding of family stress, coping and resilience are not understood as always
being positive and in the best interest of families. Persevering may come at too high a
cost for families and change in the family system may trigger more healthy functioning
(Boss, 2002). Turning point refers to ways in which family members may have altered
their perception of the stressor and subsequently changed their coping behavior (Boss,
2002). Specific questions were asked of family members to illicit ways in which their
perceptions of the ASD diagnosis changed over time and triggered changes in how they
responded to stressors related to the ASD.

Table 1. Conceptual Framework

<table>
<thead>
<tr>
<th>Appraisal of Diagnosis</th>
<th>Emotional Response</th>
<th>Coping Behavior</th>
<th>Environmental Response</th>
<th>Relational Growth</th>
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<tbody>
<tr>
<td>Cognitive Appraisal</td>
<td>Individual</td>
<td>Individual &amp; Family</td>
<td>External Context</td>
<td>Turning Point</td>
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<td>- Public Schools</td>
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<td>- Pediatricians</td>
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<tr>
<td>Perception: Individual &amp; Family</td>
<td>Family</td>
<td>Emotion-Focused</td>
<td>Social Roles/gender socialization</td>
<td>Change in Perception of Diagnosis</td>
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<td></td>
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<td>- Primary Caretaker</td>
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<tr>
<td>Meaning Ascribed to Diagnosis</td>
<td>Couple</td>
<td>Problem-Focused</td>
<td>Culture -Stigma -Perceptions of Autism</td>
<td>Resilience - Transcend Diagnosis</td>
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<td>Ambiguity Stress Crisis</td>
<td>Validation of stress</td>
<td>-Level of Flexibility -Pile-Up of Stressors</td>
<td>Resources - Financial - Support - Extended Family</td>
<td>Family Managing as Outcome</td>
</tr>
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</table>
Three overarching research questions with sub-questions are outlined below, consistent with mixed method and qualitative design recommendations from Creswell (2009), Creswell and Plano Clark (2011), and Miles and Huberman (1994). The research questions reflect the conceptual framework and family stress theory (Boss, 2002, 2006). As Miles and Huberman (1994) state: “The research questions begin to operationalize the conceptual framework (p. 22).” Constructs from both prior research and the conceptual framework are used within the research questions to direct the inductive inquiry both during data collection and analyses. Interview questions were developed to answer each research question.

1. How do families describe the process of arriving at their daughter’s autism spectrum disorder diagnosis? Do families encounter similar experiences in how they
initially understood and experienced their daughter’s developmental trajectory (age of first symptoms, pediatrician referral for ASD, misdiagnoses, co-morbid diagnoses, early childhood school difficulties, stress within the family)? (Appraisal of Diagnosis and Emotional Response to the Stressor)

a. Do parents describe significant levels of stress prior to reaching a diagnosis? How do parents describe their level of stress post diagnosis? Do parents endorse significant levels of stress related to parenting a daughter with ASD (SIPA scores)? What factors do parents ascribe to their level of stress?

b. Do parents describe experiencing stigma or shame during the diagnostic process?

c. How do family members describe their emotional response to the diagnostic process (similar/different)? Are family members able to validate one another’s emotional experience during the diagnostic process?

d. Do family members (parents, daughter, siblings) describe similar/different initial perceptions of the ASD diagnosis? (Individual and Family Perceptions of Stressor)

e. Do family members ascribe similar/different meaning to the diagnosis?

2. How do families describe their experience negotiating the demands of early adolescence on their daughter as she adjusts to increased academic, social, and behavioral expectations within the middle or high school environment, manages social interactions with neuro-typical peers (particularly female peers), and experiences gendered expectations (appearance, behavior, relationships)? Do they describe particular risks (bullying, isolation from female peers, mental health issues) and areas of resilience
(academic strengths, building adaptive social strategies) during this developmental stage?

(Environmenal Response)

a. How do community based providers describe the specific experiences and needs of adolescent girls with ASD and their families as they negotiate academic and social demands?
b. Do professional providers describe similar/different areas of risk and resilience during the early adolescent developmental stage compared to parents and girls with ASD?
c. How do girls with ASD experience the school environment, particularly relationships with neuro-typical female peers, male peers (both ASD and neuro-typical), and helping professionals (teachers, counselors)?

3. How do families describe their experience in adapting to and managing the impact of the ASD diagnosis on family well-being? Are there common experiences among families in regard to impact on the family’s daily functioning, impact on the relationship between parents, impact on siblings? Are there specific coping strategies that families employ in managing stressors associated with the ASD diagnosis? (Family Coping Behavior)

a. Do parents describe a turning point in their perception of the ASD diagnosis that alters their emotional and behavioral response to the diagnosis?
b. Do parents describe specific resources that are critical to family well-being (family counseling, summer camp for ASD children)?
c. How do siblings describe their perception of their sister’s ASD diagnosis and impact on the family? Are there specific needs of siblings?
Chapter Summary

The literature review provides an overview of the research findings in three areas, (a) gender differences in manifestation of ASD symptoms, (b) adolescent functioning for youth with ASD, and (c) family stress and coping in parenting youth with ASD. A focus on the specific experiences and voices of girls with ASD and their families is missing from the research. This research study addresses this gap in the research through an inductive exploration of how adolescent girls with ASD and their families have perceived the diagnosis and its impact on the family system. The prominent constructs from the literature review and family stress theory were used as the foundation for the conceptual framework and research questions. The following chapter three provides an outline of the specific methods used to answer the research questions.
Chapter III: Method

Study Design

This dissertation study employed grounded theory (Charmaz, 2006) as the primary research method with embedded quantitative data (Creswell & Clark, 2011) supplementing the qualitative data. As Charmaz states, “grounded theory methods consist of systematic, yet flexible guidelines for collecting and analyzing qualitative data to construct theories ‘grounded’ in the data themselves. (Charmaz, p.2, 2006).” The goal of this study was to provide a theoretical understanding of how families with a daughter with ASD experience the process of attaining an accurate diagnosis, adapt to and manage the specific needs of their daughter as she encounters early adolescence, and manage family well-being. Grounded theory was an appropriate fit for this study because it provided a framework for developing theory inductively from the emerging data (Charmaz, 2006).

Grounded theory methodology is uniquely capable of integrating various perspectives, parents, siblings, girls with ASD, and program directors, on a complex human process and developing a visual model, through conceptual mapping, of how families understand, adapt to, and make meaning out of this experience (Miles & Huberman, 1994). The utility in developing a conceptual model is the provision of a clearer understanding of how families experience this process, so that social workers within schools, mental health agencies, and early intervention programs can better meet the needs of these vulnerable families. It is the goal of this project to provide information that will lead to better-informed direct practice and further research on girls with ASD.
In an embedded mixed methods grounded theory study, as described by Creswell and Clark (2011), quantitative data is embedded within a qualitative study for the purpose of enhancing the interpretation of the primary data source. The quantitative data strand includes the use of the Stress Index for Parents of Adolescents (SIPA) and a parent survey that collected data on family demographics and variables indicated as worthy of further exploration within the prior research such as psychiatric comorbidity, psychopharmacological treatment, sleep patterns, age of diagnosis, and school and community services. The primary purpose of the quantitative data was to provide descriptive data on girls with ASD, such as age of first diagnosis and comorbid diagnoses, as well as triangulate the data on the construct of stress as reported by the parents through both qualitative interview questions and the SIPA (Padgett, 2008). Using both qualitative and quantitative data provides opportunities to strengthen the validity of the findings (Padgett, 2008).

There are core elements within grounded theory methods that set it apart from other qualitative methods. Grounded theory involves the simultaneous process of both collecting and analyzing data (Charmaz, 2006). This provided opportunities to analyze narratives during the data collection phase and begin to develop analytic memos, which facilitated the identification of emerging data (Charmaz, 2006). The emerging data then lead to theoretical sampling, which created opportunities to refine the interview guide and pursue participants with the goal of further developing emerging data (Charmaz, 2006). Second interviews and follow-up contact with participants were initiated to complete missing data and further explore themes from the first interview. This process allowed
for prolonged engagement with the data, which increased confidence in the validity of the findings.

Although qualitative methods are flexible, they are also “systematic, transparent, and rigorous” (Padgett, 2008). The methodological guidelines stipulated within grounded theory were followed, transparency was established regarding all decisions made throughout the research process through the use of written records and analytic memos, and specific qualitative strategies for increasing the validity of the data were utilized.

Social constructivism was identified as the guiding epistemology. Social constructivist research is directed by the participants’ meaning of the experience and meaning is understood as contextually based (Creswell, 2009). The meaning a participant assigns to an experience is developed largely through their social interactions with others within the specific context and culture (Cresswell, 2009). Social constructivist research aligns with both Boss’s (2002) emphasis on participants’ perceptions of an experience as the critical factor in the coping process and with inductive qualitative research which emphasizes researchers building knowledge through a comprehensive interpretation of the participants’ lived experience (Cresswell, 2009; Padgett, 2008).

**Human Subjects Protection**

The Institutional Review Board at Boston College reviewed and approved the research protocol in April 2013. An amendment to the IRB was submitted and approved in January 2014 to expand the age range of the girls with ASD from ages twelve to fourteen to twelve to seventeen. Informed consent was carefully negotiated with participants. There were six different informed consent documents developed for the
The informed consent document outlined the purpose and goals of the study with complete transparency. After initial contact was made with a parent, informed consent was conducted in person and reviewed verbally. Each participant received a copy of the informed consent document. Each participant consented to the digital voice recording of every interview.

After the first interview and data collection was completed with the parents, the researcher discussed with the parents the appropriateness of interviewing their daughter with ASD and any siblings. If the parent was comfortable, the researcher completed informed consent with both the parent and child. Careful attention was made to fully explain the project to the child and the voluntary nature of participation. Confidentiality was ensured and specific measures reviewed with all participants.

Given the sensitive nature of the content, the researcher paid very close attention to emotional responses and the need for breaks during the interviews. All interviews conducted in participants’ homes were done in private but open areas of the home such as the kitchen, family room, dining room, or living room. Parents either participated in their child’s interview or were in close vicinity. This was done purposefully to avoid any discomfort for participants. Referrals to appropriate services were made to five families if the researcher identified a need or families requested further support.

**Sampling Strategy and Recruitment**

Grounded theory methods involve larger sample sizes than other qualitative designs. On average, most grounded theory studies have at least 30 participants (Padgett, 2008). The total sample recruited for this dissertation study was forty participants \((n=40)\). The sampling strategy for this study was purposive and consistent with
theoretical sampling utilized within grounded theory methodology. Active and ongoing recruitment of participants and data collection occurred from April of 2013 through February of 2014.

In qualitative research, “gaining entry” to specific sites to recruit the purposive sample involves the use of “gatekeepers” who have access to the specified sample (Padgett, 2008). Specific gatekeepers were identified prior to the IRB submission and were chosen for their access to the sample. Recruitment of sufficient numbers of girls with ASD is the primary limitation of prior research and was assumed to be a challenge (Bazelon, 2007). As a “minority within a minority”, girls with high-functioning ASD are difficult to locate and recruit, therefore a wide net was cast within the community of services available to families with a child diagnosed with ASD. The specific gatekeepers were both site and role specific. Sites were located in the northeast area of Massachusetts and included public schools, private special education schools educating students with ASD, mental health clinics, and agencies providing after-school programming to adolescent girls with ASD. Roles of the gatekeepers included program directors, clinical directors, educational directors, teachers, school social workers and counselors.

Three of the gatekeepers were asked to participate in the study, based upon their expertise in ASD. The purpose of their inclusion was to broaden the understanding of programming for girls with ASD over the last ten years. They were asked for their perception on the involvement of girls with ASD in programming for ASD, changes witnessed in ASD prevalence rates, differences witnessed between boys and girls with ASD, and any service needs for girls and their families.
Information on the research study was also posted on the website of Asperger’s Association of New England (AANE) in the spring of 2013. AANE is the leading Massachusetts provider of information, advocacy, and support for families of children with Asperger’s syndrome. The Coordinator of Child and Teen Services at AANE was contacted to discuss recruitment at appropriate conferences and venues. AANE approved the display of flyers, sign-up sheets, and business cards at AANE sponsored conferences and activities directed at parents and families. Direct contact was then made with families who expressed interest in participating in the research project and had provided contact information on the sign-up sheets.

The researcher contacted the directors and clinical directors of private special education schools licensed by Massachusetts Department of Education, and providing programming to girls with ASD and their families. For the schools that expressed interest in participating, visits were made to the school staff to describe the project and provided flyers for families that fit the inclusion criteria. School social workers then contacted families directly and disseminated project information and research study flyers.

Direct contact was made with a number of community-based programs providing specialized services specifically for youth with ASD and their families. Services provided at these sites include summer camps, after-school social pragmatic groups, neuropsychological evaluation, and family support groups. Meetings were conducted with the directors of three different programs. The research study was explained in detail and flyers, sign-up sheets, and contact information were given to program staff to disseminate to appropriate families. There were a very limited number of girls with ASD
participating in these programs, but in the fall of 2013 a group for early adolescent girls with ASD was established and direct recruitment within this group was conducted.

**Sample inclusion criteria.**

Inclusion criteria for families were as follows: (a) a two-parent family with an adolescent daughter between the ages of 12-17 currently diagnosed with ASD and average to above average IQ as evidenced by either an IEP classification and/or medical diagnosis, (b) one or more siblings, and (c) participating siblings between the ages of 10 and 17 years of age. This purposive sample was identified as most capable of reflecting a comprehensive understanding of families’ experiences. Including siblings and fathers/second parents in the study was a specific focus. This has been a limitation in prior research, which has focused primarily on mothers. Although mothers, are frequently the primary caretakers for a child with a disability, there is a need to understand how the family as a unit is impacted by and coping with a female child with ASD. Participants within the families included both parents, girls with ASD identified as appropriate by both the researcher and parents, and siblings older than age 10 willing to participate in the interviews.

**Sample**

The goal was to recruit ten families and reach at least thirty participants. Eleven families participated in the study and three program directors for a total of forty participants \(n = 40\). In-depth semi-structured interviews were conducted with eleven mothers, nine fathers, twelve adolescent girls with ASD, five siblings, and three professional providers. The eleven families recruited for the study reside in eight suburban communities in commuting distance to Boston, Massachusetts. Participants
were recruited primarily from the northeastern area of Massachusetts. All of the child participants were biological children, and included four sets of twins. Sample demographics are described in more detail in Chapter Four. All interested participants completed the study and no one dropped out during data collection and analysis.

The inclusion criteria were met by ten of the families. In one family, the parents had recently separated and divorced after 19 years of marriage, but were actively co-parenting their children. In one other family the parents shared during their interviews that they had separated for half a year but recently reconciled. These two families identified parenting stress and conflict related to parenting as a contributing factor in their marital difficulties. The decision to include these two families was related to their ability to broaden the perspective on parental stress.

Only one family opted to not have the researcher interview their daughter and this decision was made based upon the daughter’s discomfort with her diagnosis. Two fathers were unable to participate in interviews due to the time constraints of their work schedules and the research study’s timeline.

As data analysis from initial interview narratives occurred and emerging data developed, theoretical sampling was utilized to recruit or re-interview specific cases to facilitate further development of the data. Emerging data indicated a high level of socioeconomic status among the initial families. Efforts were then made to recruit a more diverse sample in regard to class. Three families were recruited in more working class communities. The interview guide was also refined to include more emphasis on emerging themes including suicidal ideation, mental health, transition from the public school, and dyadic coping.
Initially the project was focused on early adolescent girls and the transition to middle school, however, the younger girls had some difficulty talking in-depth about their experience. Their parents were excellent reporters, but the daughters were hesitant to talk about the difficulties they encountered. The researcher made the decision to expand the age range from ages 11 to 14 to ages 12 through 17. An IRB amendment was initiated and approved from the Boston College IRB. Girls ages 14 to 17 were excellent reporters and were able to talk more extensively about their experiences.

Data Collection Procedures

Participants that had expressed interest in the research study were contacted through either phone or e-mail to discuss the goals of the study, answer any questions, and set-up the first in-person meeting. The first contact was with the mother for all eleven families. During the first meeting, the participants were provided an introduction letter, which provided a brief description of the study and interview process, a demographic survey, and an informed consent specifically designed for parents.

Interview Setting. The majority of interviews with family members (25) were conducted in participants’ homes and nine were conducted in an office setting, based upon participant comfort and convenience. All three professional provider interviews were conducted in their office and place of employment. The researcher conducted data collection in nine of the eleven families’ homes. This provided an opportunity to put participants at ease in their home environment and allowed the researcher to spend considerable time with the entire family, even those not directly interviewed.
Interviews.

Intensive interviewing is the primary data-gathering method employed within grounded theory (Charmaz, 2006). The goal was to gather “rich data” through “thick description” of the families’ process (Charmaz, 2006). Interviews were “directed conversations” that followed a specific outline and focused on thoughts, feelings, and actions related to the question (Charmaz, 2006). All of the qualitative interviews were audiotaped using a digital voice recorder, and consent was included within the informed consent documents.

Building rapport with participants prior to beginning the interview is a critical element of qualitative research and is understood as “the sense of respect, trust, and positive regard between researcher and study participants that enhances openness in information sharing” (Padgett, p.84, 2008). All of the interviews were conducted by the researcher, who has twenty years experience as a family therapist and clinical social worker. Specific rapport building strategies included clear and timely communication with participants, respect and appreciation for their time and willingness to share their families’ story, flexibility in scheduling interviews, and active relationship building with all family members including those not participating in the study. Strategies employed within interviews included active listening, allowing time for reflection and expression of emotion, and validation of their process. Prior to interviews with the girls with ASD and siblings, information was gathered from parents on activities and interests to facilitate informal conversation prior to data collection.

Interviews began with the researcher clearly outlining the process for the interview and answering any questions. The interviews began with easier, more
strengths-based questions and lead into more difficult content. All interviews concluded with time to debrief and ease out of difficult content. There was a commitment to not ending interviews abruptly or without adequately addressing intense affect (sadness, crying, anger, frustration).

Interviews were conducted to allow for an in-depth focus on understanding the participants’ experience. Interview questions were formulated as open-ended and non-judgmental, with an emphasis on exploring participants’ meaning and experience. Strategies to increase depth of data included actively listening, encouraging elaboration on content, frequent follow-up probes such as asking for an example, and clarifying meaning (Padgett, 2008).

Interview length for parents was on average between two and 2.5 hours. Interviews with girls with ASD were one hour. Interviews with siblings ranged from 25 to 45 minutes. Data were collected from April of 2013 through February of 2014. Triangulation of data was achieved through the use of documents such as Individual Educational Plan’s (IEP), neuropsychological evaluations, functional behavioral assessments (FBA’s), and other types of written documentation on the girls with ASD. Follow-up questions and member checking was conducted with all participants both in-person and through e-mail. Prolonged engagement with the families and data was emphasized to increase the validity of the findings.

**Measures**

**Interview Protocol.** The primary data collection instruments were five semi-structured interview protocols. The protocols are distinct for each type of interview; one for the individual interview with the primary caretaker/parent, one for the dyad interview
with each couple, one for the interview with the girls with ASD, and one interview protocol for siblings, and one brief protocol for professional providers. The parent interview protocols were pilot tested by two parents recruited by the researcher from prior professional contact who mirror the projected sample. These parents were chosen for their familiarity with both the researcher and the research purpose. Their comfort level with the researcher facilitated honest feedback on both the protocol and research questions. The protocols were revised by the researcher based upon the feedback provided through the pilot testing and as interviews are conducted. Consistent with grounded theory methods, interview guides are refined during the data collection as data emerges and the researcher attempts to ask more directed questions aimed at discovering variation, elaborating on meaning within categories that have been developed within the data, and filling in gaps among categories (Charmaz, 2006). During data collection, certain sensitizing concepts were found to be less relevant among participants and emerging concepts were explored further.

After each interview, the researcher wrote up analytical memos that reflected on the researcher’s thoughts and questions regarding the interview. Memos included detailed descriptions of the context (home, neighborhood, location of each interview, contextual factors impacting interview), affect of participants during the home visit, and any problems encountered. This was an exercise that facilitated the researcher’s reflexivity and made transparent initial thoughts about the participants and data. Often times, the memos were directed at areas for further exploration in the next interviews or missing data to be addressed through e-mail or phone. Memos were reviewed regularly.
and were integrated into the each family's transcriptions and the family case summary completed at the end of within case analysis.

**Demographic Questionnaire.** Demographic data on family members and specific history regarding the daughter with ASD was collected on each family during the initial interview with the mother. The parent survey was developed (see appendix) by the researcher to include all the variables identified in prior research. Data on age of first ASD diagnosis, co-morbid diagnosis, family history of ASD, and other relevant variables from prior research are included in the survey. The survey data was organized and entered into the SPSS in order to compute frequencies and descriptive statistics.

**Stress Index for Parents of Adolescents.** (Sheras, Abidin, & Konold, 1998) The Stress Index for Parents of Adolescents (SIPA) is a 112-item self-report inventory, appropriate for parents of 11-19 year olds, that takes approximately 30 minutes to complete. It includes three domains, the adolescent domain (AD), the parent domain (PD), the adolescent-parent relationship domain (APRD) and a life stressor scale. The SIPA has been normed on a sample representative of the US census data in 1997. Reliability and Validity measures have been well established, with Cronbach alpha reliability coefficients exceeding .80 (see Sheras, Abidin, & Konold, 1998).

The adolescent domain (49-items) assesses the level of stress experienced by the parent based upon adolescent characteristics, with the four subscales including moodiness/emotional lability, social isolation/withdrawal, delinquency/antisocial, and failure to achieve/perseverance. The parent domain measures (34-items) level of stress related to balancing parenting with other roles, with the four subscales assessing life restrictions, relationship with spouse/partner, social alienation, and incompetence/guilt.
The adolescent-parent relationship (16-items) assesses the parent’s perception of the relationship, looking specifically at communication and affection. The life stressors scale identifies stressful life events within the last year that allows for interpreting the total parenting stress within the context of recent external life stressors.

The (SIPA) was completed by each parent participating in the study during their initial interview. The index allowed the researcher to quickly collect specific data on levels of parenting stress within the sample, focus the sample on the idea of stress, and descriptively describe the parent sample’s level of stress. SPSS was used to analyze group means and standard deviations. It was possible to compare mothers and fathers on total parenting stress. The SIPA or the Parenting Stress Inventory–Short Form (Abidin, 1995) has been used in a number of recent quantitative study exploring parenting stress among parents of children with high functioning autism (Rao & Beidel, 2009; Lee et al., 2009; Pakenham, Samios, & Sofronoff, 2005).

Written Documentation on the ASD Diagnosis. Parents willingly provided and offered written documentation on their daughter with ASD. This included IEPs, neuropsychological evaluations, psychological evaluations, functional behavioral assessments (FBAs), parent notes on daughter’s behavior, e-mails to teachers and school administrators. This documentation provided verification of the daughter’s current and prior ASD diagnosis, comorbid diagnoses, school progress, school services and interventions, and behavioral difficulties. Some parents had more documentation available than others but all parents were able to provide a history of their daughter’s diagnoses, psychopharmacological treatment, IEP history, services and interventions, and family history. The written documentation was used to triangulate the data. The
researcher referred to the written documentation when verifying, compiling and organizing quantitative data on each family. The documentation facilitated a more comprehensive understanding of the daughter’s history and presenting strengths and challenges. It was also instrumental in understanding the family’s history with helping professionals.

Data Management

Transcription. All of the qualitative interviews were audiotaped using a digital voice recorder. Once an interview was completed, the researcher checked the voice recording and downloaded the file to a password-protected folder on a laptop. The researcher transcribed all of the interviews. Analysis began during the transcription process, as the researcher listened to each voice recording at least three times for accuracy. During the transcription process, codes, themes and analytic memos were written (Bernard & Ryan, 2010). The researcher used a process of listening for repetition, categories, similarities, differences, language, and missing data (Bernard & Ryan, 2010). Glaser and Strauss’ (1998) “constant comparative” method was used throughout the transcription process, and notes taken on similarities and differences. Notes were taken on participants’ affect (laughing, crying) and delays in response. Notes were made on missing data within a transcription to facilitate follow-up contact. A codebook was developed during the transcription process that was used during the line-by-line coding stage.

File Management. Once the semi-structured interviews were transcribed by the researcher, the word documents were entered into HyperRESEARCH 3.5 (ResearchWare, 2014) qualitative data analysis software for data organization and
coding. Each family’s transcriptions were placed in their own file and were coded together in HyperRESEARCH.

**Quantitative Data.** Once data collection was complete on each family, the researcher organized the quantitative data and began to compile quantitative findings. The Statistical Package for the Social Sciences (SPSS) version 21 was the statistical software program used to organize and analyze the quantitative data. The researcher scored the SIPA scales, and the total score as well as each sub-scale score was entered into an SPSS data file. The data within the surveys completed by each family was reviewed and compiled by the researcher. SPSS data files were created to organize and display the survey data. Frequencies and descriptive statistics were completed on the quantitative data and used throughout the data analysis stage. An overall demographic matrix was developed on each family, which displayed the primary quantitative findings on each family member (Bernard & Ryan, 2010). This was a useful tool in writing up a case summary on each family that integrated both the qualitative and quantitative findings. Further cross case analysis was then completed across the eleven families. The study’s sample demographic matrix is displayed below.

**Table 2. Case Summary Matrix**

<table>
<thead>
<tr>
<th>Demographics</th>
<th>Town/City: ######, Level One School</th>
<th>Family Income: &gt;350,000</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Mom</th>
<th>Dad</th>
<th>Daughter 1</th>
<th>Daughter 2</th>
<th>Brother</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age 52</td>
<td>Age 54</td>
<td>Age 15</td>
<td>Age 15</td>
<td>Age 18</td>
</tr>
<tr>
<td>Two Masters</td>
<td>JD</td>
<td>Twin</td>
<td>Twin</td>
<td>Mood Disorder</td>
</tr>
<tr>
<td>Full-Time</td>
<td>Full-Time Lawyer</td>
<td>Age 11 DX with PDD-NOS</td>
<td>Age 11 DX with PDD-NOS</td>
<td>E#####</td>
</tr>
<tr>
<td>Engineer</td>
<td>Married 20 years</td>
<td>Age 14 DX with ASD</td>
<td>Age 14 DX with Asperger’s</td>
<td>Academy</td>
</tr>
<tr>
<td>Married 20 years</td>
<td>Total SIPA: 96% clinically severe</td>
<td>First DX: ADHD Age 10</td>
<td>First DX: ADHD Age 10</td>
<td>High IQ</td>
</tr>
<tr>
<td>Total SIPA: 96% clinically severe</td>
<td>SIPA AD: 95%, MEL 99% (highest)</td>
<td>Mood Disorder Age 11</td>
<td>Mood Disorder Age 11</td>
<td>IEP in PS</td>
</tr>
<tr>
<td>SIPA PD: 94%</td>
<td>SIPA AD: 96%, MEL 99% (highest)</td>
<td>Psychopharm since Age 10</td>
<td>Psychopharm since Age 10</td>
<td></td>
</tr>
<tr>
<td>SIPA</td>
<td>SIPA AD: 96%, MEL 99% (highest)</td>
<td>No developmental</td>
<td>No developmental</td>
<td></td>
</tr>
<tr>
<td>APRD: 95%</td>
<td>APRD: 95%</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Data Analysis

Analytic Memoing. The use of informal analytic notes occurred through all stages of data collection, transcription, and the coding process. Memo-writing is a strategy to develop ideas about the codes, and facilitate the conceptualization process (Charmaz, 2006; Strauss & Corbin, 1998). Early memos recorded what was happening within the data, with a focus on processes. Advanced memos described how categories/concepts were emerging and changing and involve comparisons within the data. They also served as a means for reflecting on the gaps in the data and indicated where theoretical sampling needed to focus. They assisted the researcher in identifying statements, events, and/or cases that needed further clarification and development.

Two notebooks were used and carried with the researcher to all interviews to record the researcher’s reflections on the interview, takes notes on topics to be explored further, and document any data not included in the demographic questionnaire, for example money spent by a family on private school tuition or on an educational advocate. The memos were written by hand and then organized by family and placed within each family’s file to incorporate during the family case summary. Memos were reviewed again during the final stages of data analysis to look at linkages among emerging concepts.
Coding Process

Once transcription of the interviews was complete, the researcher had a solid code-book to begin the coding process. The initial codes were reviewed and revised during the line-by-line coding phase.

**Initial Coding (Charmaz, 2006).** The first step in coding process entailed identifying and naming each action within each line of the written data, referred to as line-by-line coding. Sensitizing concepts were not used at this stage. The focus was on telling the story from the participants’ perspective with an emphasis on actions. “In-vivo” codes were used when participants’ verbatim words best expressed the action. These initial codes were more basic and simple, reflecting the specific actions, meanings, or experiences of the participants.

**Focused Coding (Charmaz, 2006).** During a second reading of the narrative, codes were synthesized. Codes that were similar in meaning were condensed, with an emphasis on codes that occurred more frequently and were more significant to the participants’ experience. A more conceptual analysis occurred in which the researcher began to use sensitizing concepts to ask questions of the data and to look for themes consistent with the sensitizing concepts and family stress theory. Codes were also compared within the specific narrative and across cases within a family. There was more of a focus on analyzing the process experienced within families and then across families. Decisions were made, regarding which codes were more reflective of the participants’ experiences. Questions were directed at the data, and missing data were identified for further exploration during subsequent interviews.
Axial Coding (Charmaz, 2006). The third step was focused on concept development from the text. Codes were further synthesized and selected to emerge as categories or themes within the data. Linkages were made among codes to reflect actions. Questions were asked of the data related to context: when, where, why, who, how, and with what consequences. Integrative diagrams were used to visualize emerging theories. Data was directly compared to Boss’ family stress theory process to look for both similarities and differences.

Theoretical Coding (Charmaz, 2006). The last stage in the coding process involved mapping out how the substantive categories were related to one another and the researcher began to develop emerging theories and/or hypotheses. Visual representation of the data, conceptual mapping, was used to explore potential theories and/or processes emerging from the data. Preliminary theoretical models were explored.

During the development of the overall analysis, the researcher returned to the literature review and explored current and prior research related to girls with ASD and family coping in order to further the analysis. As the data emerged, the researcher revisited family stress theory to facilitate a better understanding of the data. The researcher also identified ways in which the findings were consistent or divergent from prior research findings. The sensitizing concepts, identified prior to data collection and used to develop the interview guides and conceptual framework, were utilized during axial and theoretical coding (Padgett, 2004; Charmaz, 2006; Bowen, 2006).

Sensitizing Concepts

Sensitizing concepts are frequently used in qualitative research, particularly Grounded Theory studies, as a “tool” for orienting the researcher, developing both
research questions and interview guides, and analyzing the data (Padgett, 2004; Charmaz, 2006; Bowen, 2006). Charmaz (2006) describes the purpose of sensitizing concepts in the following quote, “These concepts give you initial ideas to pursue and sensitize you to ask particular kinds of questions about your topic. Grounded theorists often begin their studies with certain guiding empirical interests to study and, consistent with Blumer, general concepts that give a loose frame to these interests” (Charmaz, 2006, p. 16). Sensitizing concepts are used during analysis but may not ultimately prove to be applicable within the data. As Padgett states, “Sensitizing concepts are interpretive devices and a starting point. Their ultimate survival depends on where the data take us; emergent concepts may supplement or displace them altogether (Padgett, 2004, p. 301”).

In the interest of transparency, the sensitizing concepts that were utilized in this research study are defined in detail below:

*Family Stress:* a pressure or tension in the family system, a disturbance in the steady state of the family (Boss, 2002)

*Family Coping:* “the process of managing a stressful event or situation by the family as a unit with no detrimental effects on any individual in that family. Family coping is a cognitive, affective, and behavioral process by which individuals and their family system as a whole manage, rather than eradicate, stressful events or situations.” (Boss, 2002, p. 79)

*Meaning Making:* the meaning an individual/family attributes to the disability/stressor and influences how the family functions (Boss, 2002)
Ambiguity Loss: a risk factor or barrier to coping and grieving when an exact ASD diagnosis or prognosis is unclear, the lack of clarity may create high levels of stress (Boss, 2002, 2006)

Resilience: Contextual factors outside of family’s control (access to resources) mediates resilience; process & growth through adversity (Boss, 2002)

Internal Context: structural (form and function of the family boundaries, roles, and rules), psychological (family’s perception, appraisal, definition, or assessment of the stress), and philosophical (family’s values and beliefs) (Boss, 2002)

External Context: the family’s ecosystem: culture, community, resources, economy, heredity (Boss, 2002)

Family Crisis: a change that is so acute, overwhelming, severe, that the family system is blocked, immobilized, and incapacitated. Family functioning is limited, boundaries are not maintained, roles and tasks not performed, family members are not functioning at optimal levels. (Boss, 2002)

Turning Point: Is a change in the stressor event (diagnosis), a change in the availability of resources for coping, or a change in the family’s perception of the stressor (a reframing of the diagnosis) (Boss, 2002)

Family Strain: refers to a mismatch between a stressor and family strengths, between pressures within the family system and available supports, between rigidity and resilience within a family system (Boss, 2002)

Gender Socialization: “The socialization of gender results from an interaction between social influences from parents, media, peers, and books, and the simultaneous
development of a mental self-schema through which children organize their representations of the world” (Basow, 2008, p.81-82).

During data analysis the sensitizing concepts were used to ask questions of the emerging data. The family coping process was examined, and the narratives of the families were analyzed to assess whether there was evidence of a similar process. For example, do families experience a “turning point” in their understanding and perception of the ASD diagnosis that allows for changes in behavior/parenting? Evidence within the specific narratives of the families was used to support the analysis. Cross case analysis allowed opportunities for the researcher to look at similar and different experiences among the families in regard to specific sensitizing constructs. There were some families that did not yet experience a “turning point” and their experience was compared to those families that did experience a “turning point”. There was no direct evidence of some specific sensitizing constructs within the data, and instead new constructs emerged. The sensitizing constructs provided a starting point in the development of research questions, interview questions, and data analysis, but did not necessarily prove useful during later stages of the data analysis process.

**Final Stages of Data Analysis**

Once the interview narratives were entered into Hyperresearch and data analysis was conducted using the four-step coding process within the grounded theory approach: initial coding, focused coding, axial coding, and theoretical coding; the researcher began to integrate the quantitative data and compiled frequencies and matrices on all the data. Although the researcher conducted the primary analysis, consultation on emerging themes occurred with the dissertation committee members to increase validity of the
analysis. Feedback was actively solicited on emerging data and development of codes with dissertation committee members, experts in the field, and participants. Confidentiality of participants’ identity was maintained during consultation and feedback sessions.

**Integration of Quantitative Data.** The quantitative data was organized and analyzed following the completion of qualitative data collection. It was utilized in the final stages of the coding process, as the stories of the families evolve and a picture of the coping process began to emerge. The level of stress experienced by parents as indicated on the SIPA was analyzed in conjunction with the parents’ qualitative descriptions of stress and the various factors parents qualitatively attribute to family stress. Descriptive statistics and frequencies were used when indicated to further support qualitative findings. For instance, psychiatric comorbidity as a stressor was identified qualitatively, descriptive statistics on the number of girls experiencing psychiatric comorbidity was then provided within the analysis. The demographic variables were also used to describe the sample quantitatively.

**Cross-Case Analysis.** The researcher organized and completed the initial analysis on each family as a unit, integrating both quantitative and qualitative data with a written case summary. Once all of the initial analysis was completed on each of the eleven families, initial codes were condensed and using analytic memos, emerging themes and subthemes were developed based upon the three research questions and sensitizing concepts. Constant comparative methods were used to explore similarities and differences across cases (Strauss & Corbin, 1998). Data summary charts and matrices were used to outline each research question with accompanying themes and indicators
(Bertrand & Ryan, 2010; Bloomberg & Volpe, 2012). The researcher then carefully reviewed the data to identify which families and participants endorsed each indicator. Whenever possible, frequencies were used to describe the findings.

**Matrices.** Matrices were a useful tool in validating emerging themes. The visual display reflected the researcher’s more focused and comprehensive understanding of a specific emergent category/theme (Strauss & Corbin, 1998; Bernard & Ryan, 2010). The matrix below in Table 3 is an example of how a matrix was used during data analyses with an emerging category. Table 3 is the matrix that was used for the category of comorbid mental health, which emerged as a significant stressor for the study sample. Data from each family case is compiled under each indicator. Matrices facilitated a more accurate understanding of the range of data within the sample, assisting in ruling in or ruling out emerging categories.

**Table 3. Comorbid Mental Health Matrix**

<table>
<thead>
<tr>
<th>Case #</th>
<th>Diagnoses</th>
<th>Psychopharm</th>
<th>Stressors</th>
<th>Parent Quotes</th>
<th>Daughter Quotes</th>
</tr>
</thead>
<tbody>
<tr>
<td>101</td>
<td>ADHD Depression Anxiety Dysgraphia</td>
<td>Yes – 2 Stimulant Antidepressant</td>
<td>Sleep Issues Mood</td>
<td>“stress” of middle school “set off” mood &amp; anxiety</td>
<td>“my medication makes it hard to sleep”</td>
</tr>
<tr>
<td>102</td>
<td>Depression Anxiety</td>
<td>Yes – 2 Mood Stabilizer Antidepressant</td>
<td>Mood Dysregulation, Suicidal Ideation</td>
<td>“moody, withdrawn, explosive”</td>
<td>Medication “sort of” helps</td>
</tr>
<tr>
<td>103</td>
<td>Mood Disorder Anxiety Eating Disorder</td>
<td>Yes - Multiple for sleep &amp; mood</td>
<td>Significant sleep issues Eating issues – major weight loss</td>
<td>“Constant suicidal ideation last summer”, “eating disorder clinic”</td>
<td>doesn’t like “how it makes me feel” but it does “help me sleep”</td>
</tr>
<tr>
<td>104</td>
<td>Bipolar ADHD</td>
<td>Yes – multiple for mood &amp; sleep</td>
<td>Sleep issues, mood dysregulation</td>
<td>“refusing to take meds”, “not being safe”</td>
<td>“hate meds”, wants to be “normal”</td>
</tr>
<tr>
<td>105-A</td>
<td>ADHD</td>
<td>Yes - stimulant</td>
<td>Mood issues, irritability,</td>
<td>“side effects complicated”</td>
<td>“overwhelmed” with school –</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td></td>
</tr>
<tr>
<td>105-B</td>
<td>Anxiety</td>
<td>No</td>
<td>Monitored clinically, anxiety exhibited at home – related to “perfectionism” with homework</td>
<td>“people don’t see their anxiety and vulnerability”</td>
<td></td>
</tr>
<tr>
<td>106</td>
<td>Bipolar ADHD Anxiety</td>
<td>Yes – multiple for mood, sleep, &amp; anxiety</td>
<td>Mood dysregulation</td>
<td>“she gets herself so anxious”, “escaping”</td>
<td></td>
</tr>
<tr>
<td>107</td>
<td>ADHD Anxiety</td>
<td>Yes – SSRI – considering antipsychotic</td>
<td>Not present – psychiatrist recommended anti-psychotic</td>
<td>“in her own world”, “immobilized”</td>
<td></td>
</tr>
<tr>
<td>108-A</td>
<td>ADHD Mood Disorder- NOS</td>
<td>Yes – mood stabilizer, non-stimulant for ADHD</td>
<td>Mood dysregulation – oppositional</td>
<td>Meds “constantly changing” to get the right dose</td>
<td></td>
</tr>
<tr>
<td>108-B</td>
<td>ADHD Mood Disorder Trichotillomania</td>
<td>Yes – mood stabilizer, non-stimulant for ADHD</td>
<td>Mood dysregulation – oppositional</td>
<td>“worried” about her “mood issues”</td>
<td></td>
</tr>
<tr>
<td>109</td>
<td>Depression ADHD Anxiety Trichotillomania</td>
<td>Yes - multiple</td>
<td>Mood dysregulation – suicidal ideation – school refusal</td>
<td>“suicidal talk in second grade”, “heavy depression”</td>
<td></td>
</tr>
<tr>
<td>110</td>
<td>ADHD Anxiety OCD Trichotillomania</td>
<td>Yes -</td>
<td>regulation issues – primarily at home,</td>
<td>“frustrated with herself”, “meltdowns at home not at school”, recent self-injury/cutting</td>
<td></td>
</tr>
<tr>
<td>111</td>
<td>ADHD Depression Anxiety</td>
<td>Yes</td>
<td>Mood dysregulation,</td>
<td>“out of control” at home more than school – mood is “all over the place”</td>
<td></td>
</tr>
</tbody>
</table>

No Monitored clinically, anxiety exhibited at home – related to “perfectionism” with homework

“people don’t see their anxiety and vulnerability”

“stressed” about “homework” and “teachers”

“awkward”, “talk to Sophia my American girl doll”

“I like my psychiatrist – she’s funny”

“I’m always being judged by other people”

people “overwhelm me”, “need to be alone”

(no data) not interviewed

“Asperger’s is a sickness”, “I take medicine for AS”, “talk to my AG dolls”
**Conceptual Model.** Conceptual models facilitate a better understanding of complex processes (Strauss & Corbin, 1998; Bernard & Ryan, 2010). Building a model requires the researcher to further refine and reduce the data to the key constructs that have inductively emerged from the narrative data and build off the conceptual framework developed prior to data collection (Bernard & Ryan, 2010). Once the key constructs were identified, linkages among the constructs were explored. The conceptual models developed during axial coding as the most salient categories during the families’ processes are identified and linked (Bernard & Ryan, 2010). The model was an opportunity to visually map out the patterns within the data and test out how each case fits within the model. Conceptual models representing each of the research questions are provided in the findings chapter.

**Strategies for Rigor and Authenticity**

In qualitative research, rather than reliability and validity, specific strategies are employed to ensure rigor and authenticity. This study employed a number of strategies as outlined in Padgett (2008) and Miles and Huberman (1994) to mitigate researcher bias and increase the authenticity of the findings.

**Prolonged Engagement.** This strategy involved the researcher engaging with both participants and the data over a longer period of time. Multiple interviews with different family members over time, increased trust and comfort level with the researcher and provided opportunities to clarify data. Conducting research within the families’ homes allowed for more extensive data collection, as the researcher was able to observe the family system and interact with multiple members in an unstructured manner.
**Triangulation.** Data triangulation involves using multiple sources to provide a more comprehensive view of the phenomenon. In this study triangulation occurred through the use of multiple interviews within each family, written documentation on the daughters with ASD such as IEPs and neuropsychological assessments, quantitative data collected through both the SIPA scale and the survey, and with program directors to develop a comprehensive perspective on the families’ experiences.

**Member Checking.** Member checking was used extensively throughout both data collection and analysis. It entailed re-contacting participants during data analysis to collect any missing data or to re-interview participants if the data were incomplete in critical areas. Member checking was also used to communicate initial findings and interpretation with participants for the purpose of clarification and reducing researcher bias. Member checking was conducted with all eleven families as themes emerged from the data analysis. Follow-up questions were conducted in-person, over the telephone, or through e-mail depending upon availability of participants. Member checking was conducted more extensively with families interviewed earlier on in the data collection process as themes evolved considerably over time and interviews conducted later in the data collection process were more directed toward emergent themes as data saturation was occurring.

**Audit Trail.** All decisions during the research process were documented through written notes and analytic memos to provide transparency regarding the data collection and analysis. Two notebooks were used as audit trail tools. Memos were reviewed carefully and provided evidence of the researcher’s research process.
Chapter Summary

This chapter describes the grounded theory methods combined with a quantitative data strand used in this study. An extensive review of the researcher’s process was provided, including specific strategies to recruit the sample, collect in-depth data through semi-structured interviews, a quantitative scale on parenting stress, a demographic questionnaire on important variables identified in prior research, and strategies employed to increase the validity of the findings. In the next chapter, the sample characteristics and the qualitative and quantitative findings are presented.
Chapter IV: Findings

This chapter presents the findings of 40 semi-structured qualitative interviews with 40 participants from eleven families currently parenting a daughter diagnosed with an ASD, and directors of programs and schools servicing girls with ASD. In addition, supporting quantitative data will be provided throughout the analysis. The overarching research questions frame the chapter; (a) “How do families describe the process of arriving at their daughter’s autism spectrum disorder?” (b) “How do families describe their experience negotiating the demands of adolescence on their daughter as she adjusts to increased academic, social, and behavioral expectations within the middle or high school environment, manages social interactions with neuro-typical female peers, and experiences gendered expectations?”, (c) “How do families describe their experience in adapting to and managing the impact of the ASD diagnosis on family well-being?”

Demographic and survey data on participants are provided first followed by the qualitative data, and then the quantitative findings from Stress Index for Parents of Adolescents (SIPA) are presented. The chapter concludes with a summary and conceptual map of the family coping process.

Demographic Data on Participants

Demographic and quantitative data from the 11 families were collected through the use of a survey at the time of the first parent interview. The following tables display the data separately for parents, girls with ASD, and siblings. Pseudonyms have been assigned to all participants.

Parent Demographics. All of the parents are Caucasian and heterosexual. There is a significant range in socioeconomic status; 3 families, (27%) reported an annual
income of $30,000 to $100,000, 6 families (55%) reported an annual income of between $100,000 to $250,000, and 2 families (18%) reported annual incomes between $300,000 and $1,000,000. The 11 families reside in 8 different suburban communities in commuting distance to Boston, Massachusetts. The workforce in Massachusetts is the most highly educated in the nation with 43% holding a bachelor’s degree or higher (DEMO, 2014, p. 2). Median household income in Massachusetts from 2008-2012 was $66,685 compared to the U.S. average of $53,046 (U.S. Census, 2014). Median earnings for Massachusetts workers “were $43,509 in 2010, 22 percent higher than the U.S. median of $35,700” (DEMO, 2014, p. 4). These statistics indicate that this area of the country is unique in regard to both educational level and household income.

The demographics of the 11 families reflect high levels of education and income, with 73% of mothers and 36% of fathers having earned a graduate level degree and 73% of the families reporting a household income over $100,000. In regard to employment, 91% of fathers and 46% of mothers are employed full-time, 27% of mothers are employed part-time, and 27% of mothers are unemployed by choice. The couples in the study have established marriages with a mean of 19 years married and a range of 14 to 31 years married. Fathers are slightly older than mothers with a mean age of 51 and a range of 41 to 62, mothers have a mean age of 48 with a range of 44 to 52. All 11 families have 2 or more children with a mean of 3 and range of 2 to 4. The mean age of the siblings is 16 years with a range of 8 to 30 years of age. Developmentally, the sample demographics reflect middle-aged families with established careers, marriages, and families. Parent demographic characteristics are reflected below in table 4.
Table 4  Parent Characteristics (n = 22)

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Mean</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mothers’ Age</td>
<td>48</td>
<td>44 - 52</td>
</tr>
<tr>
<td>(n = 11)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fathers’ Age</td>
<td>51</td>
<td>41 - 62</td>
</tr>
<tr>
<td>(n = 11)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Years Married</td>
<td>19</td>
<td>14 - 31</td>
</tr>
<tr>
<td>Number of Children</td>
<td>3</td>
<td>2 - 4</td>
</tr>
<tr>
<td>Age of Children</td>
<td>16</td>
<td>8 – 30</td>
</tr>
</tbody>
</table>

Table 5 outlines the education and employment data for mothers and fathers. Mothers reported higher levels of education, 73% with a graduate degree and lower levels of employment, only 46% employed full-time. This data supports qualitative findings, which indicate that mothers are the primary caretakers for their daughters with ASD and fathers are the primary financial providers for their families.

Table 5  Parent Education and Employment

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Mothers (n=11)</th>
<th>Fathers (n=11)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Frequency</td>
<td>Percentage</td>
</tr>
<tr>
<td>Highest Level of Education</td>
<td></td>
<td></td>
</tr>
<tr>
<td>High School</td>
<td>1</td>
<td>9%</td>
</tr>
<tr>
<td>College</td>
<td>2</td>
<td>18%</td>
</tr>
</tbody>
</table>
Graduate School | 8 | 73% | 4 | 36%

**Employment**

<table>
<thead>
<tr>
<th></th>
<th>3</th>
<th>27%</th>
<th>1</th>
<th>9%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unemployed</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>3</th>
<th>27%</th>
<th>0</th>
<th>0%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Part-Time</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>5</th>
<th>46%</th>
<th>10</th>
<th>91%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Full-Time</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Girls with ASD Characteristics.** Table 6 displays the prominent demographic features of the 13 adolescent girls with ASD. There were 4 sets of twins in the study; 2 sets of twins are both girls with ASD. The mean age of the girls with ASD is 14 years with a range of 12 to 17 years. The current ASD diagnosis for the girls participating in the study is 77% Asperger’s and 23% Pervasive Development Disorder – Not Otherwise Specified (PDD-NOS). All of the girls were diagnosed prior to the changes within the DSM-5 released in May of 2013, which now categorizes Asperger’s and PDD-NOS as autism spectrum disorder. Parents reported the diagnoses, and the data were triangulated through a review of Individual Educational Plans (IEP) and psychological evaluations.

The mean age of the first ASD diagnosis among the 13 girls participating in the study is 8.7 years of age, standard deviation of 3.1 and with a range of 9 years (ages 4 to 13). This mean age of first diagnosis is well above the most recent data from the Centers for Disease Control (CDC), which identified children with typical autism diagnosed by age 4, autism spectrum disorder by 4.5 years, and Asperger’s by 6.3 (CDC, 2014).

The girls’ current school placement is listed, although all of the girls completed elementary school in their public school district, eight (62%) of the girls have since transitioned to a special education school/program out of their school district and approved by the Massachusetts Department of Education. The transition out of district
(OOD) occurred between seventh and tenth grade, with 46% of the girls transitioning out of district during middle school. One girl was placed by her parents in a private residential boarding school for ASD. Public inclusion refers to public school special education services implemented within regular education classrooms. Public sheltered refers to public school special education services implemented within a program separate from regular education students. All of the girls (100%) currently receive special education services outlined in an Individual Educational Plan (IEP).

**Table 6**    **Girls with ASD Characteristics (n = 13)**

<table>
<thead>
<tr>
<th>Daughter*</th>
<th>Age</th>
<th>ASD Diagnosis</th>
<th>Age of ASD Dx</th>
<th>Co-occurring Diagnosis(es)</th>
<th>School Placement</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sophie</td>
<td>13</td>
<td>Asperger’s</td>
<td>9</td>
<td>ADHD, Depression, Anxiety, Dysgraphia</td>
<td>Private Day</td>
</tr>
<tr>
<td>Annie</td>
<td>14</td>
<td>Asperger’s</td>
<td>8</td>
<td>Depression, Anxiety</td>
<td>Private Residential</td>
</tr>
<tr>
<td>Leslie</td>
<td>16</td>
<td>Asperger’s</td>
<td>12</td>
<td>Anxiety, Depression, Eating Disorder</td>
<td>Private Day</td>
</tr>
<tr>
<td>Kayla</td>
<td>15</td>
<td>Asperger’s</td>
<td>6</td>
<td>ADHD, Bipolar</td>
<td>Public-OOD**</td>
</tr>
<tr>
<td>Abby</td>
<td>14</td>
<td>PDD-NOS</td>
<td>4</td>
<td>ADHD</td>
<td>Public Sheltered</td>
</tr>
<tr>
<td>Alexa</td>
<td>14</td>
<td>PDD-NOS</td>
<td>4</td>
<td>Anxiety</td>
<td>Public Inclusion</td>
</tr>
<tr>
<td>Julie</td>
<td>17</td>
<td>Asperger’s</td>
<td>12</td>
<td>ADHD, Bipolar, Anxiety</td>
<td>Private Day</td>
</tr>
<tr>
<td>Phoebe</td>
<td>14</td>
<td>Asperger’s</td>
<td>11</td>
<td>ADHD, Anxiety</td>
<td>Private Day</td>
</tr>
<tr>
<td>Karen</td>
<td>15</td>
<td>Asperger’s</td>
<td>11</td>
<td>ADHD, Mood Disorder-NOS</td>
<td>Public Inclusion</td>
</tr>
<tr>
<td>Kim</td>
<td>15</td>
<td>Asperger’s</td>
<td>11</td>
<td>ADHD, Mood Disorder-NOS,</td>
<td>Private Day</td>
</tr>
</tbody>
</table>
Table 7 outlines the type and frequency of mental health diagnoses among the thirteen girls with ASD. The majority of the girls (77%), were first diagnosed with another mental health diagnosis, prior to an ASD diagnosis. Attention deficit hyperactivity disorder (ADHD) was the first diagnosis for the majority (54%) of the girls. The DSM fourth edition, text revision symptoms are listed for the diagnoses, as all of the girls were diagnosed prior to the release of the DSM five.

Table 7  Co-Morbid Mental Health Diagnoses

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>Frequency</th>
<th>Percentage</th>
<th>DSM-IV-TR Symptoms (APA, 2000)</th>
</tr>
</thead>
<tbody>
<tr>
<td>ADHD</td>
<td>10</td>
<td>77%</td>
<td>Consistent pattern of inattention and/or hyperactivity-impulsivity atypical for level of development, executive functioning deficits</td>
</tr>
<tr>
<td>Anxiety</td>
<td>10</td>
<td>77%</td>
<td>“Persistent and excessive anxiety and worry” (p.429)</td>
</tr>
<tr>
<td>Mood Disorder</td>
<td>10</td>
<td>77%</td>
<td>Depressed mood, irritability and/or sadness, withdrawal, inattention, hopelessness, decreased self-worth, lethargy, suicidal ideation, changes in sleep and appetite</td>
</tr>
</tbody>
</table>
Trichotillomania 3 23% "recurrent pulling out of one's own hair that results in noticeable hair loss" (p.674), tension precedes the act and relief post act

Bipolar 2 15% Features of both a mood disorder and manic behavior atypical for age and developmental level, such as temper outbursts, physical and verbal aggression, perseverative/irrational thinking. See Disruptive Mood Dysregulation Disorder (296.99) in DSM-5

Table 8, displays descriptive data on variables included in the demographic questionnaire completed by the mothers in the sample and within the qualitative interviews. Variables included: psychopharmacological treatment, bullying, suicidal ideation, sleep difficulties, medical issues at birth, school refusal, and school suspensions. Medical issues at birth are correlated with ASD in the research literature (NIMH,2014) and were reported for eight girls (62%) and all of the twins in the study. Medical issues included premature birth, placement in a Neo Intensive Care Unit (NICU), low birth weight, and low physical tone. Psychopharmacological treatment was reported for twelve of the girls (92%), and included at least one medication to address mental health symptoms. Suicidal ideation was a theme that emerged early on during interviews with parents, and subsequently added to the interview guide. Nine of the thirteen girls, (69%) regularly made statements such as “I want to die” and “you would be better off without me”. Sleep difficulties were reported by parents for eight of the girls (62%). Sleep difficulties included trouble falling asleep, interrupted sleep, and resistance to waking in the morning.

School refusal or avoidance became a significant issue for families beginning in middle school for eight of the girls (62%). School refusal occurred in the morning and included crying, yelling, and refusing to move. Bullying within the public school environment was reported by ten of the girls (77%), and not one of the parents (0%).
were aware of the Massachusetts Autism IEP Act of 2010 (MGL Ch.71B Sec 3) that requires public schools to address bullying within the IEP of students with autism spectrum disorders. Suspension from public school for behavioral issues related to ASD symptoms, particularly cognitive rigidity and mood regulation difficulties occurred for six of the girls (46%). School suspension only occurred within a public school, no suspensions were reported in private school settings.

Table 8  Descriptive Data on Girls with ASD

<table>
<thead>
<tr>
<th>Factors</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical Issues at Birth</td>
<td>8</td>
<td>62%</td>
</tr>
<tr>
<td>Psychopharmacological Treatment</td>
<td>12</td>
<td>92%</td>
</tr>
<tr>
<td>Suicidal Ideation</td>
<td>9</td>
<td>69%</td>
</tr>
<tr>
<td>Sleep Difficulties</td>
<td>8</td>
<td>62%</td>
</tr>
<tr>
<td>Bullying</td>
<td>10</td>
<td>77%</td>
</tr>
<tr>
<td>School Avoidance/Refusal</td>
<td>8</td>
<td>62%</td>
</tr>
<tr>
<td>Public School Suspensions</td>
<td>6</td>
<td>46%</td>
</tr>
</tbody>
</table>

Sibling Characteristics. The sibling characteristics are identified in Table 9 below. The DSM-Fourth Edition, Text Revision diagnoses are listed for the siblings, with 7 of the siblings (41%) from 6 of the families (55%), have at least one major mental health diagnosis, other than a learning disability or ADHD. The sister with ASD is listed by pseudonym and age to display birth order.
<table>
<thead>
<tr>
<th>Family</th>
<th>Gender</th>
<th>Age</th>
<th>Diagnosis(es)</th>
</tr>
</thead>
<tbody>
<tr>
<td>One</td>
<td>Female</td>
<td>8</td>
<td>Learning Disability</td>
</tr>
<tr>
<td></td>
<td>Male</td>
<td>10</td>
<td>Learning Disability</td>
</tr>
<tr>
<td>Sophie*</td>
<td></td>
<td>13</td>
<td></td>
</tr>
<tr>
<td>Two</td>
<td>Male</td>
<td>11</td>
<td>None</td>
</tr>
<tr>
<td></td>
<td>Male</td>
<td>14</td>
<td>ADHD</td>
</tr>
<tr>
<td>Annie*</td>
<td></td>
<td>14</td>
<td></td>
</tr>
<tr>
<td>Three</td>
<td>Leslie*</td>
<td>16</td>
<td>Anxiety, Mood Disorder-NOS</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>28</td>
<td>Bipolar</td>
</tr>
<tr>
<td></td>
<td>Male</td>
<td>30</td>
<td></td>
</tr>
<tr>
<td>Four</td>
<td>Male</td>
<td>10</td>
<td>High Functioning Autism, Anxiety</td>
</tr>
<tr>
<td>Kayla*</td>
<td></td>
<td>15</td>
<td></td>
</tr>
<tr>
<td>Five</td>
<td>Abby*/Alexa*</td>
<td>14</td>
<td>ADHD</td>
</tr>
<tr>
<td></td>
<td>Male</td>
<td>22</td>
<td></td>
</tr>
<tr>
<td>Six</td>
<td>Julie*</td>
<td>17</td>
<td>Anxiety, Depression</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>30</td>
<td></td>
</tr>
<tr>
<td>Seven</td>
<td>Phoebe*</td>
<td>14</td>
<td>Depression</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>17</td>
<td>Learning Disability</td>
</tr>
<tr>
<td></td>
<td>Male</td>
<td>19</td>
<td></td>
</tr>
<tr>
<td>Eight</td>
<td>Karen*/Kim*</td>
<td>15</td>
<td>Bipolar Disorder</td>
</tr>
<tr>
<td></td>
<td>Male</td>
<td>18</td>
<td></td>
</tr>
<tr>
<td>Nine</td>
<td>Male</td>
<td>9</td>
<td>Learning Disability</td>
</tr>
<tr>
<td></td>
<td>Male</td>
<td>12</td>
<td>None</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>14</td>
<td>None</td>
</tr>
<tr>
<td></td>
<td>Madison*</td>
<td>14</td>
<td></td>
</tr>
<tr>
<td>Ten</td>
<td>Jane*</td>
<td>13</td>
<td>Learning Disability</td>
</tr>
<tr>
<td></td>
<td>Male</td>
<td>15</td>
<td></td>
</tr>
<tr>
<td>Eleven</td>
<td>Male</td>
<td>9</td>
<td>Major Depression, Anxiety, Sensory Integration Disorder</td>
</tr>
<tr>
<td></td>
<td>Kelly*</td>
<td>12</td>
<td></td>
</tr>
</tbody>
</table>

*Daughter with ASD
Qualitative Data

The following section presents the qualitative findings for the first overarching research question; how parents described the process of reaching an ASD diagnosis. An overview of the most salient findings is provided, followed by a chronological progression of the themes related to the developmental trajectory of the girls with ASD. Data are first presented on the parents’ experiences prior to a diagnosis, as they first encounter their daughters’ “difference” and attempt to put the pieces of the “puzzle” together. Their initial appraisal of the diagnosis is then explored, along with their emotional appraisal of the diagnosis, and lastly, post diagnosis, their initial adaptation in meeting their daughters’ specific needs.

Research Question One: “How do families describe the process of arriving at their daughters’ autism spectrum disorder diagnosis? Do families encounter similar experiences in how they initially understood and experienced their daughters’ developmental trajectory, such as age of first symptoms, pediatrician referral for ASD, misdiagnoses, co-occurring diagnoses, early childhood school difficulties, and stress within the family?

as a parent you have these ups and downs and I would believe that I could figure it out – it became a mission to figure out my child – the puzzle that is Jane – you know because I care about her and you want the best [starts to cry].

Jen - Mom of Jane

All of the 20 parents interviewed in the study were first asked to describe the process of reaching an ASD diagnosis for their daughter and how they adapted to and managed their daughter’s needs once a diagnosis was attained. During data analysis, particular attention was focused on each parent’s personal experience, feelings, and perception of both the diagnostic process and their daughter’s ASD. None of the families described a clear, linear pathway to a diagnosis. For each of the families it was a multi-year odyssey in which they encountered numerous professionals including pediatric
neurologists, occupational therapists, physical therapists, speech therapists, psychologists, psychiatrists, social workers, school administrators, and teachers, all with varied opinions regarding their daughters before they reached an ASD diagnosis. Pediatricians were noticeably absent from the list of professionals who first identified atypical development and made a referral for evaluation.

A significant finding that emerged from the families’ diagnostic experiences was that each of the 13 girls (100%) also carried at least one co-morbid mental health diagnosis with the ASD diagnosis. Although ASD symptoms are frequently confused with other emotional and behavioral disorders, the mental health symptoms were identified as a significant stressor for all of the eleven families. The mean age of the ASD diagnosis was 8.7 years with a range of four to thirteen years. ASD was not the first diagnosis for 10 of the girls (77%), the majority (54%) were first diagnosed with attention deficit hyperactivity disorder (ADHD). All of the parents perceived the delay in ASD diagnosis as detrimental to their daughters’ development, largely because it prevented earlier interventions and services within the public schools. A delay in diagnosis also contributed to the parents’ stress level as the period of time prior to a diagnosis was very difficult, primarily in regard to managing their daughters’ behavior and the stress of “not knowing” what might be atypical behavior. Although all of the parents had difficulties accepting the diagnosis, an actual ASD diagnosis did allow for parents to begin the process of understanding how their daughter may need to be parented differently.
**Indicators Prior to an ASD diagnosis**

All of the parents described a gradual process of recognizing that their daughters’ development was in some ways atypical. Parents first recognized ASD type symptoms in early childhood, prior to kindergarten, for 12 of the girls (77%). Symptoms prior to the age of 5 included, echolalia, which is the automatic verbal repetition/mimicking of others’ words, (5 girls/38%), inflexible/repetitive routines (12 girls/92%), difficulties with transitions/change in routine (11 girls/85%), sensory sensitivities (11 girls/85%), poor eye contact (4 girls/31%), self-stimulating behavior such as pacing, rocking, twirling hands (9 girls/69%), parallel play/limited initiation with peers (12 girls/92%), atypical temper tantrums (11 girls/85%), and difficulties with physical touch/affection (11 girls, 85%). Two girls (15%) were described by their parents as more passive, affectionate, and compliant during early childhood with less overt (behavioral) symptoms until they entered public school.

Behavioral symptoms were the primary indicator in early childhood for 11 girls (85%), and over time became most apparent within elementary school and social settings, such as soccer games, birthday parties, and family activities. An elementary school teacher was the first professional to address the ASD and behavioral indicators with parents in 8 of the families (73%), and suggested an evaluation. In hindsight, all parents describe experiencing some denial regarding their daughters’ early symptoms but also feeling some confusion and anxiety regarding their daughters’ early development.

“Melt-Downs”. The primary behavior that parents describe as problematic in early childhood was a more extreme temper tantrum that was atypical for the age. This was indicated for 10 of the girls (77%). In hindsight, the parents identify sensory issues
and environmental stressors as precipitators to emotional dysregulation. Sensory issues were described as difficulties with any change in routine, large groups of people, noise, and lights that lead to an inability to regulate their reactions. Prior to a diagnosis, 10 families (91%) described a period of intense stress and desperation to find effective strategies to address their daughters’ behavior. These parents others described feeling embarrassment and shame, particularly when these behaviors occurred in public places and in front of extended family:

she had lot of what we call “meltdowns” – which of course I didn’t know what that meant at the time – she was having a lot of tantrums – you know we would go into a store and I didn’t know what would set her off – she would just start wailing and crying and then she had this thing where she would practically pass out – she would lay back on the floor – scream her lungs off and would just go limp and I couldn’t even pick her up........ That was certainly a big indication that something was not okay.  

- Mary – mom of Kayla age 15

Turning three – she was transitioning from early intervention to the pre-school in town ....she would have a tantrum that would last an hour – it would last forever. Over something that was seemingly so minor – I remember calling the OT at the pre-school – “what do I do? Who do I call about this?” I’m sure it was sensory, being rigid - you know – I can look back on them now and can understand but not at the time.  

- Jen - Mom of Jane age 13

She had the worst tantrums of any three year old I ever saw. And it was constant – several times a day to the point praise, punishment, rewards – nothing helped – she was off her rocker – she became so inconsolable she would make herself sick. And any little change would throw her off – even eating 15 minutes late – she was so particular about food, and clothing and bathing, noises, crowds I couldn’t take her anywhere. If you tried to take her somewhere that wasn’t her own space with all her own stuff she would freak out. She had all these rituals even at the age of 3 and 4. She had all these stuffed animal cats and beanie babies – she would have to have them with her at all times and she would line them up in a certain order and she couldn’t sleep in her bed unless all her cats were lined up perfectly straight and ten blankets on her bed. She was seeking out the sensory – that’s why she had all those blankets – I didn’t realize it at the time but she was weighing herself down – sensory input.... Everything was a routine, a ritual and a certain number.  

- Kim – mom of Kelly age 12
Social Indicators. Atypical social interactions with peers became a significant indicator for all 13 (100%) of the girls, particularly once they began public school and community-based activities. The following quotes reflect a couple’s growing sense that something was atypical in their daughter’s behavior within a typical social setting with peers, a birthday party and youth sports. The mother and father both struggled to understand her behavior and how to effectively address her “regulation” issues:

“It gradually became more and more concerning. You sort of go through denial and try to come up with reasons to explain it – oh her grandparents were here or she didn’t sleep but I never really thought it was any sort of mental issue. But social situations became more and more stressful for everyone. We went to this birthday party, these were new friends, and I’ll never forget I was just becoming close to this group of people. The twins were invited to the party and there was this birthday cake with Ariel on the top and when Annie figured out she wasn’t going to get the Ariel piece she completely flipped out. She was seven years old, too old for this and I remember the dad looking at her like “what’s wrong with you”, it triggered - this is something more than just being stubborn..... And to this day, she’d probably tell you that she should have had that piece of cake. It was really – there were lots and lots of incidents like that but that one got my attention.” - Kate - Mom of Annie age 14

thinking about how things have evolved. We tried to get her involved in typical things, like softball and skiing and soccer....though she couldn’t handle it if a teammate didn’t do what they were suppose to do. She didn’t have the self-regulation at that time and that was part of our recognition that something was wrong. - Alex – Dad of Annie age 14

Autism Spectrum Disorder Myths. For all of the parents in the study, there was very limited knowledge on Autism Spectrum Disorders prior to their daughter’s diagnosis. Most parents had some sense of the symptoms of more severe autism but were less aware of the “autism spectrum” and the more nuanced manifestations of the disorder. All of the mothers, (11), in the study took on the role of “figuring out” what was different about their daughter and, after the diagnosis, embarked on a long process of self-education on autism spectrum disorders. A frequent complication for all parents in
identifying their daughter’s difference through the lens of Autism were the “stereotypes” about the various diagnoses within the autism spectrum and a sense that their daughters did not fit the profile. They perceived autism and Asperger’s to be a “boy’s disorder”. Frequently, there were delays in picking up on the ASD symptoms because the girls expressed a desire for friendships, exhibited empathy for others, were very verbal and intelligent, and were able to maintain some eye contact.

*It wasn’t denial in the psychological sense. One of the big things was boys with Asperger’s were seen as loners and not having empathy. Sophie was never like that. She always wanted friends. In soccer if someone fell down, she was the one that would go over. She always had a group of 5 to 8 friends and that was a steady part of elementary school. Until she went to middle school and none of her friends were with her.*

- Frank - Dad of Sophie

*It was so difficult! It was so difficult! You know she started to talk a lot more – she was delayed in all her development but didn’t have language and lose it like more typical autism and her delays weren’t so severe that she got a PDD diagnosis but I think eight or nine years ago when she was diagnosed, people didn’t know what PDD was- everyone knew with typical autism, kids would have speech and then lose it but with Jane – she never had that so I didn’t think she had autism and I didn’t know there was this bigger spectrum – I remember I did read about PDD & some article I found online a reputable source – and it described my child – her obsessions.*

- Jen – mom of Jane

**Limited Professional Help.** During the process of figuring out the difference, parents were frequently confused and frustrated by the responses of professionals, particularly in pre-school settings and with pediatricians. The parents had a sense their daughters’ behavior and/or development was atypical, but they were not receiving information from professionals that validated their concerns. In the following quote, this mother perceived the early intervention and pre-school staff as withholding information and felt that their non-verbal communication relayed concerns:

*I would drive them (to preschool) and Anna would smash her head on the floor and would scream and cry. Anna had all echolalia – she would repeat everything*
you said to her at 3 years old before that she was non-verbal. You know how at the pre-school they can’t diagnose or say anything. But she wasn’t making any progress and I kept talking to them about it and they would give me a look.

- Kim - Mom of 14 year-old Twin Girls Abby & Alexa

Frequently, parents heard from both pre-school teachers and pediatricians that their daughters needed time to develop, particularly if there were medical issues at birth or they were twins. There were 4 sets of twins in this study, and medical issues at birth occurred for 6 of the girls (46%). These professionals did not encourage parents to pursue further evaluation, delaying an early diagnosis. Not one pediatrician for the girls in the study identified ASD symptoms or made a referral for further evaluation. For parents, this was a source of frustration and confusion:

*When you have a young child, your pediatrician is who you go to. If they can’t support you, you are left to your own devices, you know. Our pediatrician, I like her but I’ve been the one to educate her. I tell her, we need an OT eval and this is what the letter needs to say. She’s happy to write it but I wish pediatricians had a lot more knowledge about developmental issues, don’t say “give them time”, “everyone develops differently”. There needs to be better screening and more education for parents.*

- Jen – Mom of Jane age 13

In the case of another set of twin girls – Karen and Kim, both currently diagnosed with Asperger’s, their parents recognized that their early childhood behavior was problematic but their pre-school teachers did not communicate concerns: “*they kept saying they were developing normally – the pre-school kept saying they were on track developmentally*”. These twin girls were first diagnosed with ADHD in elementary school, a mood disorder in 5th grade, and finally an evaluation completed out of the public schools in 6th grade resulted in a PDD-NOS diagnosis. The PDD-NOS diagnosis was then changed to Asperger’s in 8th grade. Mom and dad clearly felt a high level of frustration with the process: “*I thought it was a late diagnosis. I knew it for awhile – it
“didn’t surprise me” – (Mom), and “’It didn’t really change anything. Because you know there was a lot of stuff we were already dealing with – the behavioral issues” – (Dad).

**Confusion Over Public School Concerns.** As the girls entered public school, all parents received feedback from schoolteachers that their daughters were struggling, but found school staff were not clear about the specific concerns. Leslie’s mom recalls crying after every parent-teacher conference in elementary school but never fully understanding her daughter’s behavioral issues. Leslie was “kicked out” of her elementary school in first grade for “throwing her shoes against the wall”, and placed in a “special program” for “behavioral” issues in another elementary school within the public school district. In the case of Sophie, her parents were shocked to hear from her second grade teacher that their daughter was struggling. Although there had been a few social indicators beginning in kindergarten, she was a very sweet, affectionate, and compliant child within the home environment. Mom describes her as “an easy kid” and “content” in a small home daycare situation but did begin to see small indicators when she began kindergarten in the public school. Looking back, her mother can assess her social interactions in kindergarten as atypical: “in reality it was Sophie not knowing how to interact with the other kids to have friends, so she was focused on having the one friend”. Sophie had difficulties in kindergarten “sharing” her friend with other children, a common indicator for all of the girls in early childhood.

In first grade Sophie was referred to a social skills group with the school social worker but her mother picked-up on some hesitancy to be straightforward from both the teacher and social worker in explaining “why” she had been referred:

*I went in and met with the social worker, and I think this was the beginning of my relationship with the school, being a “difficult parent”. I think I had very*
accurate questions, I hadn’t signed a release, what’s the group about? who else is going to be part of the group?, how long is it going for?, I had no previous children in the schools, I didn’t know what a social skills group is...so I met with the teacher too and they bounced around, dodged my questions, and couldn’t tell me what their concerns were, I asked “do you see any difficulties”, I had no knowledge that anything was going on in first grade.

- Anne – mom of Sophie

Sophie’s mother, Anne, continued to describe the first difficult conversation with her second grade teacher in which concerns are communicated but are not clarified. These types of conversations became very common for all parents. Communication with public school staff became a source of stress rather than an opportunity to learn about their daughter. This mother perceived the school staff as categorizing her as a “difficult parent” for asking questions:

So I went in and met with the second grade teacher and immediately the teacher said “I have never had a child like this in my life”, this teacher had 25 years of experience, “I don’t know what’s going on with her”. This is when the tantrums began. “She loses it if we don’t do reading - she’s rigid”. I told her that we don’t see tantrums in the household, so I tried to get a grasp on exactly what it was.

- Anne – mom of Sophie age 13

Anne began the process of breaking down her daughter’s school day and attempted to figure out what was setting Sophie off. Sophie was an early and very strong reader and was becoming very frustrated when the teacher altered the schedule and reading time would not occur when Sophie expected. Sophie would then pull out her book when she had expected reading to occur and a conflict would erupt with her teacher, resulting in Sophie being “ostracized to a table” for not following teacher direction. The public school’s hesitancy to be straightforward regarding concerns about Sophie continued even after the school psychologist completed an evaluation. The parents described attending a meeting after the evaluations were complete in which they were
reading the results in the meeting because the public school had not provided the results forty-eight hours prior to the meeting, as required by federal special education law. Mom reports “I wasn’t aware of the law at this point”. Both parents had difficulties sorting through the testing results and found the communication from the school psychologist unhelpful:

*I think she knew what the test results pointed to and they were not able to articulate it to us, and I am still really angry and distrustful of the school that they withheld this knowledge. I was dying for knowledge about my kid and they didn’t give it to me.*

- Anne – mom of Sophie

After the meeting Sophie’s Dad said, “that’s it.. we’re getting her tested somewhere else”. Sophie’s parents hired a private psychologist to complete further testing and interpret the school’s evaluation. This psychologist attended IEP meetings in the third grade and was the first professional to put Asperger’s “on the table” as a “rule out”. This was the beginning of both the school and the parents understanding Sophie through the lens of Asperger’s.

**Autism Spectrum Disorder “Rule Outs” and “Tendencies”**. Seven of the girls (54%) received a “rule out” or “tendencies” of Asperger’s rather than a full diagnosis, which impacted the way in which a special education Individual Educational Plan (IEP) was written and the type of services provided in the public school. In Madison’s case, when she was 8 years old, her parents consulted with a psychiatrist who quickly came to the conclusion that she had Asperger’s. However, when the psychologist he referred the parents to identified depression as her primary diagnosis and “tendencies” of Asperger’s, the IEP in her public school identified her disability as emotional and did not provide
interventions targeting the Asperger’s. The same psychologist gave her the primary diagnosis of Asperger’s when she was 13.

Madison you can’t go near her. So with Madison you can’t show any affection it makes her feel really uncomfortable. She doesn’t want to hear “I love you”, she doesn’t want me to rub her back. So he (psychiatrist) told us to go and get her evaluated and he recommended Dr S. We went to see Dr. S and it came back that she had depression with tendencies of Asperger’s. For instance she was totally obsessed with Pokemon and could recite every Pokemon figure – she would memorize the whole Pokemon book and would just walk up to you and start spouting off all these Pokemon facts and then just walk away. There was no conversation with her – no give and take. She didn’t have any friends. There were so many things that were clear that she had Asperger’s but she had the depression diagnosis and she wasn’t being treated for the Asperger’s.

- Tess, mom of Madison age 14

“Distrust” of Public Schools. In Madison’s case, similar to the other families, the parents, over time, began to distrust the public schools and felt “betrayed”.

Madison’s IEP identified a depression diagnosis as her primary area of disability therefore, she was seen by a local therapist, paid for by the public school. In working with the therapist, the parents became increasingly concerned about Madison’s behavior, but in hindsight feel very betrayed by the therapist’s lack of diagnostic transparency:

So I would go into these meetings [with therapists] crying and saying “there’s something wrong with her”, she doesn’t care about anyone besides herself, she’s so rude, I would tell them there’s something wrong with her and she [therapist] knew she had Asperger’s. But so here’s the thing, I’ve heard that if you’re hired by the school district you’re not allowed to talk about a diagnosis, not even hint about a diagnosis, you’re only allowed to treat the symptoms of what you think is going on….. I’m frustrated and you know I don’t think many people know about that. Because if we hadn’t had her privately evaluated, we wouldn’t have a diagnosis. If we were just going along with the public school, with all their evaluations because they do a million, and they never, ever diagnosed her with Asperger’s. And I guess that’s more of a legal thing. But I didn’t know that, Jake and I didn’t know that but we were going along with these professionals treating her, trusting them, not knowing what was going on.

- Tess, mom of Madison age 14
“High Functioning” as a Liability. Being on the “high functioning” end of the autism spectrum was perceived by all of the parents as a liability in terms of accessing both a diagnosis and services in the public schools. Parents perceived public school staff as “underserving” and not recognizing their daughters’ needs within the school environment. All of the girls in the study are of average to above average in full scale IQ and some parents (9 families) reported that their daughters’ frequently tested quite high in standardized tests, but their functional skills, executive functioning skills, and emotional regulation issues impacted their ability to effectively manage a public school setting.

*I think if we had gone for [private] testing earlier and had a diagnosis earlier it might have made it easier with the school system. But I don’t allow myself to dwell on it. Maybe if Chris [husband] had been on board earlier... Early childhood, when you are high functioning it was easy for them to say “give her time”, teachers need more education. Nobody can know everything.*

- Jen, mom of Alex age 13

*The problem we’ve always had is that in standardized testing she always does phenomenal, so why does she need help? Why do we need to give her help if she tests so high? ...She can’t turn in homework, she loses the test prep, she’s always losing papers, she doesn’t know where anything is. And in addition to that kids at school are calling her “freak” and “retard”.*

- Tess, mom of Madison

Initial Appraisal of the Diagnosis

For many families, the first ASD diagnosis was a beginning point in the process of both understanding and adapting to their daughters’ needs. As parents gradually recognized that their daughter’s development was atypical, it did not surprise most parents when elementary school teachers began to discuss their concerns and recommended further evaluation. All 11 families (100%) had their daughters privately evaluated by a psychologist. Once the evaluation was complete, however, it took time to accept and adapt to the diagnosis. All of the parents initially had a very limited
understanding of autism spectrum disorders and described an initial period of shock and denial before acceptance of the diagnosis as a “fit”:

So I went back to the pediatric neurologist at [hospital] and he told me to go to this place called [clinic] ... We waited four months to see Dr. D – she was 4 years old when we went to see her. We filled out all of this paperwork. Right is front of Adam (father) – she said you don’t need to come back next week (for the eval results). She said she (Abby) is classic PDD-NOS. I had a lump in my throat, I couldn’t cry because Anna was right there and if I cried she would get upset. I didn’t know anything about PDD-NOS. At the pre-school early intervention - they use to tell me that she definitely wasn’t PDD – and I didn’t know what that meant but I didn’t want her to have it. As a parent you don’t want to believe your child has it. I didn’t really understand this autism umbrella.

- Kim – Mom of Abby & Alexa

In the case of Annie, her second grade teacher was the first professional to talk with her parents about Annie’s “lack of progress” and recommended a psychological evaluation. Although the parents were open and welcoming of an evaluation: “I thought, great, they’ll tell me what’s wrong and what to do and then we’ll get on with our lives”, they, extended family and their pediatrician all experienced shock and denial with the actual diagnosis:

I remember the psychologist telling me in a long circuitous way – breaking something to me that I was not ready to hear and I was listening to her for 10 or 15 minutes before I thought to myself, I think she’s trying to tell me that Annie has Asperger’s. I was like “NO”, didn’t compute, and Alex and I both said we didn’t agree and then you go well if she has it it’s really mild, and then I got home & my mom was visiting and she said “no, definitely not”, and I told our pediatrician who said “you have to be careful with diagnoses like that”. Everyone was in denial. When you think of Asperger’s you think of boys, I honestly think that’s why.

- Kate – Mom of Annie Age 14

A limited understanding of what the diagnosis actually meant was a common theme among all the parents. There was a steep learning curve in regard to cognitively processing the diagnosis and integrating the amount of information that was provided by professionals:
I wasn’t quite sure what PDD-NOS was – which was their original diagnoses and I didn’t think they had a developmental disorder – I did think they had social skills issues and executive functioning problems – I thought they should have been diagnosed with Asperger’s and umm – the women at Tufts said “If I don’t really know then I put down PDD-NOS” – the other women that diagnosed – Kim in 8th grade said it was definitely Asperger’s because they didn’t have any developmental delays so I think they both have Asperger’s – it fits better.

- Rachel – Mom of Karen & Kim

Her teacher asked us to and when we got the diagnosis I was in denial. I thought that maybe she had some behavioral quirks that any kid that age might have – I didn’t see the social challenges that she had at that age. And that clearly manifested itself later on…. What I had trouble reconciling was the description of my child by the doctor and my perception of her and that was some mental block that was going on. But over the subsequent years, and even as she developed from there it was clear that the diagnosis was right.

- Alex – Dad to Annie age 14

Despite an initial period of shock, some parents described some “relief” at finally acquiring a diagnosis that made sense. As a psychologist was describing what Asperger’s was to a few of the parents there was an “aha” moment, where parents said to themselves “that’s my daughter”.

Well, it kind of shocked me because I wasn’t expecting it – but when Janice [psychologist] explained what Asperger’s actually was – I was like “yes, that’s Kayla”, “yes, that’s Kayla” – I mean all the pieces just fit together pretty well…. For me it was an aha moment - this is my kid – it was like oh this is my kid. There is a name for my kid.

- Mary – Mom of Kayla age 15

It was a doctor Madison had been seeing – a psychiatrist – who said one day to us “your daughter has Asperger’s”. Read it right out of a text book. He went over to a shelf, grabbed a book and read it. And my husband and I looked at each other and said “Oh my gosh, finally we know what’s wrong with her”. It was a huge relief.

- Tess – mom of Madison age 14

**Emotional Response to the Diagnosis: Shock and Denial**

All of the parents responded emotionally to the ASD diagnosis in a similar manner with an initial period of shock or denial, followed by feelings of sadness and grief, and then, over time, acceptance and adaptation. For all of the parents, this process
of acceptance and adaptation took years. The emotional response to the diagnosis evolved over the years as their daughters experienced significant developmental challenges, particularly socially. In some cases, particularly where there were complications during birth (6 girls/46%) or when there was a family history of autism spectrum disorders (7 families/73%), parents initially blamed themselves for their daughters’ ASD diagnosis. Feeling overwhelmed after receiving the diagnosis was a consistent theme among the mothers as they attempted to understand what the diagnosis actually meant and began to figure out next steps:

I felt so lost when I received the girls’ diagnoses. Jack has always supported me, but he leaves a lot of the research and advocacy to me. I was home with the girls. I got over that hump of okay here’s the diagnoses now what do we do. There’s some denial.

- Kim - Mom of 14 year-old twin girls Abby and Alexa

a little overwhelmed at first, especially the part that she would never outgrow it. The permanency of it, and that I would be her mother forever. Am I ever going to be able to let her leave home? Will she ever take a shower without being told? Being independent? How much is she going to mature? - Margaret – mom of Julie age 17

**Initial Adaptation**

As couples began to initially adjust to the ASD diagnosis, there were a number of similar stressors identified: finding resources and a community, developing a behavioral approach that was effective, working with the public schools in developing an Individual Educational Plan (IEP), educating extended family, addressing social skill deficits and managing mental health care. Ten of the girls (77%) were in elementary school when first diagnosed, and all of the girls were attending public school in their home community when first diagnosed.

The most significant challenge for couples after the initial diagnosis was “getting on the same page” regarding their perception of ASD and identifying realistic behavioral
expectations within the home. Most couples struggled to agree on and implement an effective behavioral approach. In 5 of the families (45%), this issue continues to be a challenge and a source of stress and conflict with the couples. For the other 6 families (55%), there were much lower levels of conflict within the couple relationship. In the families with lower-levels of conflict, the couples did not necessarily always agree on behavioral expectations but there was agreement on being a united front and deferring to one approach. Typically, the mother became the “expert” within the family unit and took the lead in developing a consistent approach.

**Different perceptions of daughters’ behavioral expectations.** In responding to difficult behavior, most parents found that typical behavioral approaches, such as time outs, rewards, incentives, punishment did not work; they tended to either escalate the behavior or their daughter did not respond. Parents relied on psychologists, books on Asperger’s, and blogs through Asperger’s Association of New England (AANE) to discover through trial and error how to manage the behavior and how to set realistic expectations of their daughters with ASD. All of the couples encountered differences in their expectations and found it challenging to “figure out” how best to help their daughters regulate their behavior.

*Dr. J [psychologist] told us…with the Aspies, no matter how hard she tried, she wasn’t going to be able to control her behavior. It was out of her control…So even now that continues to be the biggest challenge? Do I need to manage this because it is out of her control or can she control it?*

* - Mary mom of Kayla age 15

In the following quote, Mary describes the challenge she and her husband Ken encountered in attempting to develop both expectations and an approach that would work for their daughter, Kayla. Mary describes the importance of flexibility and collaboration
with her daughter whereas, Ken ascribed to a more traditional behavioral approach where the parent sets the expectation and the child is expected to respond:

I felt that I blamed him because I felt like he needed to be more flexible and he needed to understand more of where she was coming from. And he felt that I just basically let her get away with everything. Which, I didn’t let her get away with everything. I tried to work with her and he said “don’t just talk to her” – you know – I wanted as much as possible to get her input if I could, working together to figure out some of these things..because she’s so verbal and so expressive of her feelings. Me trying to work with her to make sense of things that were happening. Not all of the time but some of the time trying to work together to figure things out. She’s not stupid – she’s very smart. And you can’t pull things over on her so I felt that we needed to work together (mom and daughter)…whereas Ken wanted to just say, “this is the way you’re going to do it and this is it”.

Jen, in the following quote, describes a similar conflict between herself and her husband. Jen had taken on the role of “figuring out” their daughter, but her husband perceived this to be an “obsession” that created some disconnection in the couple’s relationship:

We were both on the same page when she was young – with the brushing and the sensory diet – he was right on board with all that but when behaviors started – the temper tantrums, he was of the mind that “she needs to learn to listen, she needs to learn that she’s not going to get her way”, so that was harder for him, we were not on the same page in terms of how to parent her – so we had gone to this therapist – which was not very helpful but one thing that came to light was that Chris thought I was obsessed with trying to figure out what was wrong with our daughter when he just figured she needed time and maybe a firmer hand. So that – I felt that expectations should be different – she couldn’t really do it – and I thought other things were going on

- Jen - Mom of 13 year-old girl Alex

All of the families developed behavioral strategies that were described as more flexible and alternative to the way in which they addressed the behavior of their other children. This approach was described as necessary and specific to the ASD. Using strategies to either prevent or de-escalate behavior was perceived to be critical in avoiding extremely volatile incidents. All of the parents described being more vigilant
with their daughters, particularly in situations that could result in anxiety or volatility, such as a change in routine, unmet expectations, family outings, and group interactions. Parents found this vigilance exhausting but necessary in managing family interactions.

**Couples supporting one another as a coping strategy.** Supporting one another, during this initial process of adapting to the diagnosis, was perceived to be a very important aspect of coping. Most couples were struggling to “get on the same page” but the couples that were able to coordinate their coping together described much lower levels of conflict.

_That has been the saving grace of my sanity, that Alex & I have a very strong relationship. And we see things the same way when it comes to our kids and I rely on that heavily. If he had been fighting me I would have been a mess._

- Kate – mom of Annie age 14

There were 4 couples that did “fight” each other, and reported feeling more isolated and “depressed” than the other parents in the study. Three mothers reported experiencing depression and one mother reported anxiety that was attributed to conflict with her spouse over parenting their daughter(s) with ASD. One couple divorced, one couple separated for 6 months and reunited, the third couple lives together, but the father has limited involvement in his daughter’s parenting, and the fourth couple continues to try “to get on the same page”. All 4 couples receive ongoing individual and family therapy.

**Coping through social support: Finding a community and resources.** During the initial adaptation to the ASD diagnosis, information gathering was a key coping strategy to reducing anxiety and stress. For the mothers in particular, finding other parents going through the same or similar experience was validating and an important element to their initial adaptation. Fathers were less likely to endorse social support as a
necessary coping strategy. Fathers were more likely to use work and activities (biking, skiing) as a strategy for managing stress within the family system. Mothers frequently perceived fathers as “avoiding” family stress through “going to work” and engaging in physical activity. Many mothers relied heavily on Asperger’s Association of New England (AANE) and their website, blogs, articles and referrals to community based resources:

*I used AANE in the early days it’s a great resource, I still read all the discussion boards but they are less relevant now but they were very reassuring when I was going through stuff with Annie and I’d read others having the same or worse experience. And their conferences are really great – I’ve been to three of them. I heard Tony Attwood twice – never have to hear him again – it was on creating a life of value with Asperger’s.*  

- Kate, mom of Annie

Finding a community of support was not always easy for parents. They reported feeling “different” from other special needs parents whose children had more obvious disabilities such as downs syndrome or cerebral palsy. “Passing” as typically developed was mentioned by all parents.

*I think with Jake and I we say “do we have a child with special needs?” , “Are we parents of a special needs child?”, I would say I do but then when people don’t understand, because Madison can pass, I think with a lot of these girls they do but then it’s like you always get a moment when you’re with people when she does something way off the wall it’s like “what just happened” and you can see it on their faces – its really hard... I feel like Asperger’s is a tough diagnosis because the kids can pass. A really good friend of mine has quads, one is blind, one has seizures, one is deaf. I really don’t ever feel like I’m part of the special needs community. It’s hard to figure out where I fit in all of that. There’s not a lot of support for it. My dentist of all people has an Asperger’s son and an autistic son. He told me to go to AANE.*  

- Tess, mom of Madison

**Psychopharmacological treatment.** Twelve of the girls (92%) are currently prescribed at least one psychotropic medication to address mental health symptoms. For all of the girls, it has been a long process of trial and error in finding a medication that both effectively addresses the symptoms and does not result in major side effects. All of
the parents identified psychopharmacological treatment as a necessary but stressful aspect of their daughter’s treatment. Finding a psychiatrist to treat their daughter in some cases was difficult, managing the stress of trying different medications many with unpleasant side effects such as weight gain or loss, lethargy, and irritability, and the financial cost of treatment. Many child psychiatrists do not take medical insurance.

they started to take a small dose [of the stimulant] in the afternoon to help with homework and routine...But we still noticed irritability in the afternoon and the temper tantrums – just got unmanageable – so their psychiatrist Dr. L put them on Risperidone – the Risperidone seemed to calm them down – but side effects were a lot of weight gain – they did not particularly like that
-Jake and Tess – parents of Madison and Laura age 14

Extended family. All of the families described difficulties with extended family members understanding and accepting the ASD diagnosis. Mothers experienced particular difficulties and felt their parenting was “judged” as too lenient and often times “blamed” for the cause of their daughter’s behavior. Most families spent considerable effort trying to educate family members and structuring extended family activities to be more successful for their daughters.

It [reading books on Asperger’s] helps take away some of the frustration I feel with people who don’t understand what its like to live with someone with Asperger’s. Because most people don’t have a clue, especially my family. They say, yeah, yeah, yeah “you just have to do this”. They dismiss it. So many dismiss it like it’s a cold, they’re going to get over it and it will go away. - Margaret – Mom of Julie age 17

In summary, the diagnostic process was arduous for all 11 families. The time period prior to a diagnosis involved high levels of stress for parents as they struggled to understand their daughters’ “difference”, often times in isolation. Most parents employed denial as an adaptive coping strategy to buffer the pain of recognizing that their daughter
did have a disability. Barriers to accepting the ASD diagnosis included delayed or misdiagnosis, a lack of diagnostic transparency from professionals and public school staff, myths regarding ASD, tendency among evaluators to give a “rule out” or tendencies” of ASD rather than a full diagnosis, and a limited understanding of autism. All 11 families followed a similar process as they adapted to the diagnosis, which is outlined in figure 2 below. Figure 2 displays each step in the adaptation process with the emergent categories experienced by the families. This was not a linear process for families and often times parents continued to experience denial or struggle with isolation later on in the adaptation process.

**Figure 2.** Families’ Diagnostic Process
Research Question Two. “How do families describe their experience negotiating the demands of early adolescence on their daughters as they adjust to increased academic, social, and behavioral expectations within the middle and high school environment, manage social interactions with neuro-typical female peers, and experience gendered expectations such as appearance, behavior, and friendships? Do they describe particular risks such as bullying, isolation and mental health issues? Do they describe areas of resilience such as academic strengths, building adaptive social strategies during this developmental stage?

All of the parents described the transition to adolescence and particularly the middle school environment as incredibly stressful and difficult both for their daughters and families. All of the families spent considerable time working with elementary school staff in planning the transition to middle school. The families described experiencing high levels of frustration regarding all of the planning and discussions resulting in very little follow through by middle school staff and very limited success for their daughters.

“She left 5th grade on a high note. In 6th grade, they transitioned to the middle school and everything fell apart from there.” Tess

Adolescence was particularly difficult for the three girls that were not diagnosed until middle school; Madison diagnosed at age 13, Julie, at age 12, and Leslie at age 12. All 3 girls were first diagnosed with ADHD and depression in elementary school and their transition to middle school was very problematic, resulting in school suspensions, suicidal ideation, and bullying for all 3, and psychiatric hospitalization for 2 of the girls. These girls also did not ever attain stability and success in public school and all 3 were eventually placed in out-of-district placements. Julie was not diagnosed with Asperger’s until her 6th grade year in public school, by a psychiatrist, which resulted in a significant delay in appropriate intervention in the public school. She had been first diagnosed with ADHD and a mood disorder in elementary school. She was perceived as “oppositional” by school staff and treated behaviorally with very limited success. She did not receive
specially designed social pragmatic instruction in the public school until her seventh grade year.

In comparison, the 4 girls diagnosed the earliest, Abby and Alexa at age 4, Jane at age 5, and Kayla at age 6, transitioned to adolescence with less difficulty and are currently still in a public school setting. All 4 have at least one co-morbid mental health diagnosis, but received the ASD diagnosis either first or at the same time as the co-occurring diagnoses. One other factor common to all 4 was the presence of medical issues at birth and early intervention services.

**Surviving but not thriving.** A consistent theme of surviving but not thriving was present in all of the family narratives in describing the middle school years. The majority of families (9/82%) felt that the elementary school years were positive and successful; especially the level of services provided after the ASD diagnosis, but there was a significant change during the middle school transition. As the academic and social demands of middle school increased, their daughters became more and more isolated socially and stigmatized by their behavior. Managing a public middle school setting was difficult for all of the girls in the study.

The majority of the girls (11/85%) developed maladaptive coping strategies to manage the sensory overload they experienced in a public middle school setting. One of the more prominent strategies was to hide or escape within the school, usually during lunch, recess and other more stressful and unstructured settings. Popular places to hide were the bathroom, nurse’s office, and offices (guidance, social worker). The following quotes reflects mothers’ perceptions on their daughters’ transition to sixth grade and middle school:
That was the biggest transition. That was her hardest year. She was overwhelmed. She had a lot of changes: rooms for classes; not the same teachers, not the same kids. Way too many changes and transitions. And I think the whole size of the building. That’s when she started her hiding and her escaping. She would escape at (elementary school) too, she would leave (class) to go to the bathroom and go hang out with the janitor, but it really escalated in middle school. 

-Margaret – mom of Julie age 17

there is a lot of change, a lot of teachers, it takes her a long time to warm up to one person. So every school year starting is tough for her because she has to figure out the teacher, and the rules. But this was 6 or 7 teachers, it’s quick, you’re going from one class to the next, a lot of sensory problems, the hallways were nearly impossible to navigate, she would huddle and run from one class to the next. She couldn’t eat in the cafeteria because it was too loud. She would either not eat, which is a whole other thing because she doesn’t respond to hunger.... And she had a guidance counselor who saw her huddled on the floor in the cafeteria by herself and walked by and said to herself “hmm, that’s unusual” and did nothing. 

- Tess, mom of Madison age 14

All of the parents perceived public school staff as inadequately understanding and addressing sensory issues within the middle school setting “I think they just didn’t get it”. When not addressed, the sensory issues resulted in significant behavioral issues within the school. Parents described chronic frustration with the schools’ resistance to altering the school environment. When done well, parents describe having a “safe space” within the school environment that was quiet and flexible for their daughters. One mother is very happy with a high school program in another public school district. They provide a safe and therapeutic classroom for her daughter to access whenever she becomes overwhelmed or encounters a problem in the mainstream setting.

All of the girls describe significant social anxiety in managing the middle school setting, particularly more unstructured settings that involved interacting with neurotypical peers. The majority of girls (11/85%) identified lunch and the cafeteria as the most stressful part of the day. Not knowing “what to say” and who to sit with, along with the noise, resulted in feeling “overwhelmed”. Phoebe’s feelings of extreme awkwardness
when walking into a classroom or cafeteria resulted in being late to class/lunch and requiring the school social worker to escort her. She describes herself as a “freak”, and being “terrified” at lunch if her one friend is not there to sit with her. Kelly had “no one” to sit with at lunch until her mother contacted the school and requested help for her daughter. The school social worker then identified a girl for Kelly to sit with.

**Limited Gender-Based Programming.** All parents commented on the dearth of programming for girls with ASD. Often times, their daughter was the only girl in the social skills group and available programming was heavily geared toward the interests of boys. Kim, mom of twin girls Abby and Alexa, pulled her daughters out of their public school IEP stipulated social pragmatic group in eighth grade, because they were the only girls in the group and the boys were “lower functioning”. Being a “minority within a minority” was a source of frustration and isolation. Professionals working in agencies and schools with children and adolescents with ASD, report that there are frequently “never enough” girls with ASD to develop specific gender based programming. One professional provider worked for over a year to put together a girl-only social skills group, which meant a delay in providing the intervention to interested families.

The following quote is from the youngest girl participant. She is describing the students in her public school program specifically for ASD. It is clear that she feels quite different from the boys and does not share similar interests. Her mother described the importance of having another girl her age in the program to increase her social connections.

*Six kids - all boys – kind of a pain – they are who I spend my time with – one other girl but she’s in 8th grade – we are all there because we need a little more help than the other kids socially. I like making friendship bracelets & the boys like to talk about video games – not my cup of tea – lately all they do is play*
Pokemon, and I don’t even really know what that it is – I’m there by myself which is okay because I like my own space but they are really obsessed with it (Pokemon) – I wish there was another girl but it’s okay.

- Kelly, Age 12

Punitive Discipline within Schools. Many of the families described frustration with the behavioral approach utilized within the public schools. Parents felt strongly that their daughter’s behavior was a manifestation of her ASD and not “willful” or “intentional”. Many of the girls were suspended and put on behavioral contracts within the middle school and even elementary school years.

She was famous that year for making the principal run after her, he’s kind of a portly guy, she bolted from school running toward the police station right after recess and the kids thought it was hilarious. This was my first disagreement with the school because he [principal] brought her in and asked her to sign a contract saying that running away was dangerous, and that if she ever ran away again that she would have detention the first time and would go home the second time. And he didn’t understand that this is what she was trying to do so if that’s the punishment, you are rewarding the behavior because then she will get to go home. But they never got to that but there were three incidents when she bolted or ran away.

- Kate, mom of Annie age 14

Negotiating Neuro-Typical Peers. All of the parents reported that one of the most painful aspects of raising a daughter with ASD is watching the way in which neurotypical peers perceived and treated their daughters. Most of the girls reported having a hard time connecting and relating to their female peers in middle school. The following quote is from Annie talking about where she chooses to sit at lunch and finding it uncomfortable to sit with female peers. She instead opted to eat lunch with the boys from her special education program within the public school.

Yeah – I was really different – I didn’t feel comfortable around the other girls – they talked about weird things and so I just sat with the boys and they just ignored me – it felt easier with the boys than the girls I don’t know why.. – it was hard for me to connect and relate to the things they [girls] are interested in.
Parents had a very hard time figuring out how to help their daughters negotiate neuro-typical female peers, especially during the middle school years. All of the girls experienced a “distancing” from female peers in middle school as social relationships changed and became more focused on “clothing”, “boys”, and “popularity”.

It’s when she watches neuro-typical girls interact, or when I see neuro-typical girls hanging out that’s the hardest thing for me. I’ll cry now. She’s never had that - being one of the gang and not being the only girl or sitting at a lunch table with a bunch of boys that tolerate her. - Kate – mom of Annie

Negotiating the IEP. Working with the public schools in meeting their daughters’ educational needs was identified as a significant stressor in all of the families. The following quote describes Margaret’s experience within IEP meetings: “I feel a lot of anxiety, fear. That Julie won’t get what she needs. How am I going to be judged as a parent? You feel like you’re under a microscope. There’s seven people and then there’s you.”

Every parent expressed high levels of stress regarding negotiating with the public school on their daughter’s IEP. Parents perceived the IEP as critical to their daughter’s success and emotional well-being in the school environment but found the process overwhelming. Parents consistently identified social-emotional services as a limitation within the public schools. The parents felt strongly that this realm was a critical aspect of the ASD and found public schools to be resistant to providing social-emotional supports.

I wish there was more people to do what a sped PAC person does. To help you navigate the system. But a school system can’t help you navigate itself – you feel like it’s an us-versus-them. A lot of families feel on edge – school systems are under servicing students, the ones who are high functioning don’t really get what they need. If Alice really needs more social emotional services but she’s not really acting out emotionally at school she doesn’t get it – they don’t really see it. Middle schools need to understand what’s going on for them, the pressures, depression, anxiety. They need a lot more education. The really lame IEP we have now, she has one goal, an academic goal.
Girls’ Perceptions of the Middle School Transition. The primary themes that emerged from interviews with girls when discussing middle school, included feeling isolated, overwhelmed, and not successful. Annie described middle school as a “shock to the system”:

the hardest thing was probably really the huge change from when you are in elementary to middle school— you are hoping for good things in middle school and then you kind of realize it isn’t what you thought it would be and it’s difficult to cope...It’s more – difficult to handle stuff...I felt frustrated - and kind of upset and then your just glad to get out of there [laughs]

Sophie talked extensively about her experience as an “outcast” in middle school and her isolation from peers. She had friends in elementary school, “we were all a group of outcasts” but despite her parent’s efforts to place her with friends in middle school, she transitioned to a separate middle school from elementary school friends. Sophie describes her middle school experience: “It wasn’t exactly easy [sighs]. At lunch I sat alone by myself. I’m introverted in the classroom. I didn’t participate much. It was all pretty daunting to me.” She describes “making friends” as the most challenging aspect and felt that some girls would initiate with her but “I felt like it was a pity thing.” In describing herself and how peers perceived her, she states: “I was the girl who was so insecure and didn’t like to talk and picked her nose and couldn’t run, that was me…the nerdy, ugly girl that everyone hated.”

Leslie also describes herself as introverted and isolated from peers during middle school: “I remember I almost never talked. I would say a few words, like yes, or no. I just didn’t find anyone I could connect to and I like to do my own thing.” Leslie then talked about her psychiatric hospitalization in 7th grade after an incident at school and
goes on to say: “I would rather be dead than go to school there again.” Leslie was placed in an out-of-district special educational placement after her second psychiatric hospitalization in seventh grade. She is now very happy and connected in her private day school.

**Loss of Identity as “Smart”**. This was a significant area of concern for both parents and the girls. All 13 girls had executive functioning weaknesses, consistent with an ADHD diagnosis, and struggled to manage the demands of organizing and planning for all the different academic subjects. As all of the girls were evaluated as being of average to above average intelligence, they were perceived by others and perceived themselves as “smart”. It was an identified strength for all of the girls, but as the girls became “overwhelmed” in middle school, their work completion both at home and school suffered. Homework became an area of significant stress and created much conflict within the home environment. All of the girls began to internalize the fact that their grades and feedback from teachers became more negative.

*I think in elementary school, she always felt like she was smart, because she is very bright. But when she got into middle school, she began to feel stupid because she was getting bad grades on homework, bad grades on tests and she couldn’t figure out why. I think that was a crushing blow to her self-esteem because that’s how she identifies herself – as being smart. Now her sister (twin) is getting better grades that she is and that was never Laura’s identity. But Laura gets straight A’s, will study for hours, very driven. But Madison won’t pick up a book, won’t study for a test, nothing. She has no work ethic if it doesn’t come easy she’s not interested.*

- Tess, mom of Madison age 14

Perseverance and working through challenge was identified as a concern among all the parents. Parents were unsure as to how to help their daughters manage challenges within the school environment, because frequently, when pushed, the girls would become dysregulated. Avoiding situations and activities that would involve challenge was a
coping strategy all parents utilized but with mixed emotions. All of the parents discussed their anxiety over their daughters’ limited ability to manage typical life stressors such as homework, hygiene, and getting up for school in the morning. Future success such as college and employment was perceived to be directly associated with learning to be more “independent” and manage daily responsibilities and self-care without parent supervision and support.

**Need for responsive school communities.** All of the parents described frustration with the public school environment and its inability to respond to the specific needs of young people with ASD. For many parents becoming an advocate for their child was a role that was required, but frequently out of their comfort zone. Tim, father to 14 year-old Phoebe, a successful lawyer described his discomfort within IEP meetings. He understood the importance of the IEP services for his daughter, but felt he did not have the expertise necessary to negotiate the meeting successfully. This was a theme throughout the parents’ narratives; although successful in the professional realm, many of the parents felt at a loss within the IEP process.

Not understanding special education law and policies was a consistent source of frustration that led to resentment and distrust with the public schools. Many parents felt they were labeled as “difficult” by public school staff, and often times found themselves in direct conflict with school staff over their daughter’s needs. There were two styles employed by parents when advocating; about half of the parents (6 families) strategically employed a collaborative style that emphasized relationship building with school staff, and the other half began with a collaborative style but evolved to using a more aggressive, combative style out of perceived necessity. All of the parents from lower
socioeconomic status were less inclined to take on a combative style with school staff and were more hesitant to advocate despite feeling that their daughters’ needs were not being met.

A director of a special education private school that services adolescents with ASD, describes new parents to his school as “traumatized” by their experience “fighting” for their children’s needs in the public school. A former public school administrator, he now emphasizes, “partnering with parents” as a value and expectation of his staff. He believes that youth with ASD can “absolutely” be served in public schools, but there must be willingness among school staff to create “an inclusive school community”. He finds that the majority of the high-functioning ASD youth attending his school come from wealthy, high achieving school districts, where they do not feel “wanted” or “included” in the community. He theorizes that more diverse school systems may do a better job creating inclusive school communities.

**Restricted and Repetitive Behaviors and Interests (RRBI).** Although not a direct focus in this study, there is increasing evidence to suggest that high functioning girls with ASD exhibit less RRBI than their male counterparts (Frazier, Georgiades, Bishop & Hardan, 2014). Directors of programs and schools were asked about differences between girls and boys in manifestation of ASD, and they all reflected on witnessing less “hand flapping”, “rocking” and behavioral issues among girls. Similarities included exhibiting the same level of cognitive rigidity and social skill deficits with peers. Many parents and directors reported very gender specific types of behavior with an overlay of ASD type traits, for example, Phoebe reading “steps to get a
boyfriend” in a magazine and understanding those steps in a very literal manner, or Leslie using the American Girl books to learn specific hygiene rituals such as shaving her legs.

Many of the girls expressed very typical gendered interests in the American Girl Dolls, crafts, art, drawing, horses, cats, music, and reading. Many of the interests could be considered “young” for their age and the girls were at times described as developmentally “immature”. Some of the manifestations of restricted and repetitive behaviors included specific routines/rituals that had to be followed, such as sitting at the same seat at the dinner table and only using a blue plastic cup to drink from; self-stimulating type behaviors such as pacing back and forth and twirling; and “obsessions” or restricted interests such as female anime characters, and cats/warrior cats. All of the girls in the study did exhibit some level of RRBI but it was manifested in more gender specific interests, than is typically seen with their male counterparts.

Acceptance and Management of Social Quirks and RRBI. Most of the girls in the study presented with significant “quirks” or RRBI type behavior that impacted their relationships with neuro-typical female peers. The more obvious quirks represented their special interests or “obsessions” such as wearing to school a Pokemon Hat and t-shirt or dressing like a warrior cat. Other quirks include their self-soothing activities, which varied from reading books in social settings (school, family get-togethers) that create a rich internal fantasy world (Anime, Cat Warriors, Harry Potter, Emergence, Zelda), “gaming”, self-stimulating behaviors such pacing back and forth during recess and thinking about stories, and twirling in the hallway at school. Parents had varied responses to these quirks. Many discouraged or limited their use/expression and other parents accepted and accommodated. Given the importance of these activities and
expressions in the girls’ ability to manage stressful environments, it is an area that requires some careful consideration. The following quote is written documentation provided to the public school by Jen, mom of Alice for the purpose of giving teachers a sense of Alice and how she might present:

*Alice’s love for cats is so strong, that we consider it to be an obsession, which warrants monitoring. She will actually tell you that she is “part cat.” At home, she likes to act like a cat (meows, hisses, arches her back); she wears cat collars on her wrist and around her neck. She collects cat figurines; she wears t-shirts with cats on them; and she searches for cat pictures on the internet every single day.*

Alice is a middle school student who has experienced her female friends withdraw and move toward other female peers with more typical interests in fashion, clothing, and boys. Alice is now more connected to the boys in her special education program that are also diagnosed with ASD. Many of the girls in the study expressed frustration with the way parents and school staff responded to their RRBIs and “quirks”. They perceive these activities as a very important aspect of their identity and ability to cope with certain environments. Sophie talked with fervor about her need to read as a strategy for coping with school and larger family gatherings.

*I can’t stand being around too many people – it’s suffocating to me. Like I need my book and I need a quiet spot to go—which is why I hate the big social things my mom will sometimes make me go to. Like friend’s parties and stuff and she (mom) won’t let me bring my book and my book its kind of like a security blanket and even if she does let me (bring my book) – she won’t let me go off to read. I feel suffocated in big places with lots of people – with all the people around. I don’t know what to say when they are talking and its scary.*

The majority of the girls did not engage in gendered dress and behavior during the middle and high school years, which created some stress for parents who were concerned about their daughters being marginalized by their peers.
She’s quirky. She likes to wear loud clothes still. She’ll wear one pink shoe and one blue shoe. She’ll wear orange pants and a yellow top (laughs). And that’s Kayla. And I’ll say “Kayla don’t you think you could tone this down a bit?” and she’ll say “No! This is how I dress”. “But Kayla you have to think about how other people view you” – and the school (staff) will say the same thing. I ask her to watch what the other kids wear. And she’ll say, “I don’t want to wear what the other kids wear. I won’t be comfortable in what the other kids wear!” You know so she does make it difficult for herself.

Well there are lots of clothes that I don’t want but my mom will hear another girls’ mom saying at one of (brother’s) games (baseball) that their daughter my age wants – and my mom says you have to have one to be popular and she’ll make me get one – and I don’t want it (emphatic)! I don’t even look good in it. I look ridiculous. It’s like putting lipstick on a pig (both laugh). I have my own style! I just wish she would let me wear it.

Among the girls’ narratives, there are strong themes of desiring acceptance from parents and school staff for who they are and respect for their needs and interests.

Overall many expressed “just let me be me” in reference to conflicts with adults over their interests, behavior, and presentation.

Safety Issues

**Increase in Mental Health Symptoms.** All of the parents described an increase in mental health symptoms during the middle school years. Parents did attribute the increase to the stress of managing the school environment. Three of the girls developed Trichotillomania in middle school, which became particularly difficult to manage.

I would say – the most challenging piece – is that Kim was having a lot of mood and anxiety symptoms and she didn’t how to deal with it – the changing social milieu – it was upsetting her a lot – Karen [twin sister] has much thicker skin – so Kim – someone would tease her on the bus and she would tease them back (laughs) – but Karen would get upset & was getting nervous about the demands of middle school – she actually noticed when people wouldn’t sit with her in school & she started doing things like pulling hair out of her eye brows & lashes – she had major mood issues & irritability…… and at the school they felt it was behavioral – under her control – and they started using ABA with her – with the mood disorder, the ABA techniques - consequence, consequence, reinforce, reinforce – just escalated her & the situation. - Rachel, mom of Kim and Karen
we realized she had trichotillomania... So Madison has pulled out all her hair, it started with a circle this big but now the top of her scalp through the back is gone. So she wears a baseball cap, which is suppose to help but for Madison it’s the reverse, she does it more and hides it with the cap. - Tess, mom of Madison age 14

the hair cutting .. I think was in 6th grade that started. I noticed one day, she came down and it looked like she had a buzz cut on the top of her head. I think she was trying to cut her hair like Warrior Cats because these cats that she draws from this book series have these mops of hair that fall into their faces. So it’s her way of personifying these warrior cats. - Jen, mom of Alice age 13

**Bullying.** Ten of the girls (77%) reported experiencing bullying by peers and in some cases teachers in the middle school environment. Most parents felt that their daughter’s atypical presentation and social quirks put them at increased risk for harassment and bullying by peers. This finding is consistent with recent research by the Interactive Autism Network, which found that youth with ASD are three times more likely than neuro-typical students to report experiencing bullying behavior from peers (IAN, 2012). In speaking with parents, they expressed both anger and sadness regarding the bullying. Not one of the parents were aware that bullying must be addressed within the IEP meetings of students with ASD, and none of the girls had specific measures within their IEP’s to address bullying within the school setting.

Margaret expressed her frustration with the school’s perception of her daughter’s behavior as an “annoyance” and in turn felt that they did not adequately address the teasing and ridicule she experienced with peers, “Too much bullying and teasing and no one taking it seriously. It was allowed to be rampant.” Many parents expressed concerns about their daughters’ readiness to learn in an environment where she is ridiculed and bullied.

*But you can see it all over her face when those things happen and for her to go from one class to another dashing through the hallway, trying to avoid everyone,*
and all the noise, and hearing “freak” and “retard”, and going into the classroom, I don’t think she’s available to learn. - Tess, mom of Madison

**Suicidal Ideation/Talk.** Along with bullying, all of the parents described concerns regarding their daughter’s safety within the school environment. Most of the parents attributed their daughters’ depression and anxiety to school related stress within the middle school environment. They described their daughter feeling “overwhelmed” by both social and academic pressures. Nine of the girls (69%) engaged regularly in suicidal ideation/talk or as one mom called it “negative self-talk”. The suicidal talk was expressed both at school and home. One mother shared her shock at how quickly her daughter fell apart in eighth grade after transitioning to all mainstream classes, “It came so fast. From being in the mentoring program and attending all her classes to “you all would be better off if I was dead””. The hardest part for this mother was not feeling confident that the school’s staff was equipped to deal with the suicidal statements. The following quote comes from a mother that has been coping with her daughter’s suicidal statements for many years.

> She started talking about suicide in second grade. She didn’t have the terminology for it but she would say “I want to die right now”, “I want to hurt myself and go away”, “I’m going to make myself die” and she would leave us notes by our bed and in second grade would tell her teachers “I want to die”, she would tell people because she has no filter.

- Tess, mom of Madison age 14

**Psychiatric Hospitalizations.** Two of the girls, Leslie and Julie, attending public middle, were psychiatrically hospitalized from their school on two separate occasions for exhibiting suicidal talk and emotionally dysregulated behavior. For Leslie, age 16, the second hospitalization during her 7th grade year resulted in an out-of-district placement. Leslie’s parents, Libby and Dan described feeling both “scared” and “overwhelmed”
during this time and worried that the hospital clinical staff were misconstruing her words. Dan describes a nurse telling him that his daughter had schizophrenia because she was “talking to herself” and “hearing voices”. Dan had to explain to the nurse that Leslie is very introverted and used a lot of “self-talk” when overwhelmed. Leslie had been diagnosed with Asperger’s the previous year at the age of 12.

Many of the girls in the study continue to present as highly dysregulated and at times make suicidal statements such as “I would rather be dead”. As parents adapt to the chronicity of the behavior, they find that the most important piece is that their daughters have access to highly skilled mental health professionals within their school setting who are equipped to address the behavior. Hospitalization was not perceived to be an adequate response and all parents described a desire to avoid reaching that point.

**Online activity.** Most of the girls described computers and online activities as a significant part of their recreational time. As the girls entered adolescence, parents began to see a marked increase in online activity and felt it important to monitor the activity. Monitoring the activity was complicated and many parents described feeling uncomfortable invading their daughter’s privacy. The following quote is from Jen, mom to Jane, age 13, as she describes her struggle to both respect her daughter’s privacy and need for independence while also maintaining her safety online.

*She tries to write her own warrior stories..., she likes to role-play a few warrior cats on Instagram and it makes me very nervous. The people she role-plays with and there is some intimacy with cats. She has a role play account and these kids can do these things on their own... She mentioned to me right before Christmas that she started role-playing again and I need to go check her account and I found her account online and I follow her role-play account. She was acting weird around me in the house and I asked her what was wrong and she said, “I wish you weren’t following me on my role-play account”, and I said “I just wanted to check out your role play, its great”, and here I am thinking that I need to be able to figure you out more – you’re so complicated.*
Identity Development

Most of the girls began to develop an awareness and understanding of their diagnosis during middle school. Three of the girls were resistant to the label/diagnosis and do not feel it is accurate. None of the girls perceive their diagnosis in a positive way. They perceive the ASD to be a deterrent to being “normal” and a source of chronic frustration. The following quote is from the youngest participant, currently in 6th grade in her local public school.

_I always wondered if I had a sickness. I have to take medicine. I thought Asperger’s was a sickness. Asperger’s make you different from everyone else, it makes you worry more and it makes some things harder for you than other people. You need to take breaks, you get stressed._
- Kelly, age 12

Many of the girls incorporated messages from their parents and counselors into their perceptions of the ASD. One girl referred to desiring a “brain transplant” because she had been told that her brain was “wired differently” than other kids. Other girls, as they became older, began to outright reject the ASD label and any services directed at ASD, as reflected in the following quote from a mom, Mary:

_It’s been very bumpy. She doesn’t want to take meds (psychopharm medication). She says “I don’t want to be Aspie anymore! I want to be normal!” She’s Kayla – she’s really clear that she wants to be who she is, you know._

Many of the girls had a limited understanding of ASD and what it actually meant, particularly the younger girls. The oldest girl in the study had a stronger sense of how ASD impacted her life and a higher level of acceptance. Julie, age 17, currently has a boyfriend with Asperger’s and a female best friend also diagnosed with Asperger’s. She
has developed a community of friends with similar interests, primarily anime, and enjoys these relationships.

**Transition from the Public School**

All 13 girls began their middle school years in their public school, however, the majority of girls (8/62%) ended up leaving to attend a private special education setting that specifically addressed ASD. Six transitioned to a private school setting within the middle school years, 5 in eighth grade and 1 in seventh grade, and 2 girls transitioned to a private school in early high school, 1 in ninth and the second in tenth. The 5 girls that remain in their public school continue on an IEP.

*that environment – in middle school they just didn’t know how to deal with her mood disorder. They knew how to deal with – nice happy kids with Asperger’s but they didn’t know how to deal with this combination with the mood disorder. So she is better off in the private school she is in now.*

- Rachel – mom of Kim and Karen

Parents frequently (6 families/55%) initiated this decision to leave the public schools after numerous attempts to increase their daughter’s functioning in the public schools failed. The process was stressful and entailed an abrupt departure for 4 of the girls; 1 due to a psychiatric hospitalization from school and in 3 cases parents decided to homeschool their daughters until a private placement was found. Parents perceived the public school’s IEP process as a series of “road blocks” meant to “wear parents down” in order to “avoid paying” for an out of district placement. There was a great deal of frustration regarding the number of team meetings initiated by the school and numerous attempts to alter services with little positive outcome. Parents felt that their daughters were “losing time”.

*I never sent in the homeschool form because my advocate told me they could wash their hands of us. I had letters from her doctors saying not to send her back to*
school. From her psychiatrist, from her pediatrician, and Dr. T. That’s how this came about. - Tess, mom of Madison

Private special education day programs are licensed and tuition costs determined by the Massachusetts Department of Elementary and Secondary Education (DESE) with tuition anywhere between $50,000 to $80,000 per school year (Mass.gov/doe). Transportation costs are also quite high with most programs far from the girls’ home communities. Public schools contract with private cab companies to transport students to their out-of-district placements. Leslie travels over an hour each way to her school. She has had many conflicts with both peers and staff during the transportation to school, which has created stress for her mother, Libby.

Residential special education school placements are also licensed and approved by Massachusetts DOE and tuition can be as high as $179,000 per school year. These costs are typically assumed by the public school system but at times families are required to share the tuition costs with the public school. One family is paying the total cost for a residential placement for their daughter in order to avoid a long drawn out legal battle with the public school system. They report feeling “fortunate” to have the resources necessary to provide this option for their daughter. Another family is sharing the cost of both tuition and transportation with the their public school system and it is an enormous financial burden for the family. One family estimated their legal fees for one school year to be approximately $20,000.

Summary. For all 11 families, their daughters’ transition to middle school was marked by significant strain as academic and social demands increased dramatically. Barriers to success included inadequate responses to sensory challenges in a loud, chaotic public middle school environment, including more appropriate accommodations within
the cafeteria, recess, and hallways; more gender and cognitively responsive social pragmatic support to manage the increased social demands, particularly with neurotypical female peers; and a higher level of therapeutic support to manage significant mental health symptoms that impacted their ability to successfully engage in the school community. Themes of isolation and decreased self-worth permeate the girls’ narratives regarding their middle school years. The adversarial nature of parents’ relationships with public school staff resulted in diminished opportunities to collaborate in the girls’ best interests, with the majority of girls transitioning to an out-of-district school placement at significant cost.

Figure 3 below displays the four categories that emerged as most significant during the transition to adolescence for girls with ASD in the study sample. The subcategories listed under each category further delineate the risk factors present for the girls in the study sample.
Research Question Three. “How do families describe their experience in adapting to and managing the impact of the ASD diagnosis on family well-being? Are there common experiences among families in regard to the impact on the families’ daily functioning, and relationships among family members? Are there specific coping strategies that families employ in managing stressors associated with the ASD diagnosis?

Having a daughter with ASD has a significant impact on family well-being. All of the parents described high levels of stress in adapting to and managing the needs of their daughter, which took an enormous toll on the entire family. Parents identified the following stressors: financial strain, employment/professional limitations, unmet sibling needs, disruption in family interactions/outings, and conflict between parents. Parents acknowledged that their daughter’s needs were primary in the family unit, and other members adapted largely through accommodating and adjusting their own needs.
The following quote is a description of how Annie presented at home during the middle school years and how it impacted other family members:

Moody, withdrawn, explosive, rigid, bossy – and this is the hardest part for me but there’s not a lot of kindness – she would be happy at times and we would be relieved to see her capable of laughing at jokes and having a good time at various things but it was stressful because every family activity would have to be filtered through “how is Annie going to cope with this?” will she go along with it? And how do we get through it? You can never relax and look forward to anything….We have not let her completely dictate everything. There’s plenty of times she re-directs what we do and where we go to eat on a day-to-day basis. As she’s gotten older, this is really sad but she can be left behind safely. She’s left behind and we go and do our hikes and things. So you can’t do it when they’re 8 but you can when they are 12.

- Kate, mom of Annie age 14

The following quote provides a sense of how aspects of ASD can impact relationships with family members. The cognitive rigidity and need for predictability requires family members to “give way” and accept behavior that might be considered inappropriate in a typically developed child. Many parents expressed frustration with the need to “always accommodate”.

So the impact that she has on the whole family is tremendous. If I were to tell her that she was going to sit here tonight (points to a dining room seat), it would be a total melt down, if I were to not give her the red cup, she’d have a total melt down, she has a color preference….Everything has to be her way or the highway. You know, there is no flexibility, she’s extremely argumentative, always picking at people. If Jeff [brother] says he found a diamond on mindcraft, she’ll argue with him about it, it’s not a conversation it’s an argument. Laura [twin sister] avoids Madison like the plague – there’s no twin relationship at all. It’s not even a sibling relationship.

-Tess, mom of Madison

The needs of girls with ASD can create significant disruption in family life. Parenting can be very time consuming; the need to predict ahead of time how she will respond to certain activities and the challenge in constantly establishing structure and predictability was reported to be exhausting for all of the parents. Most mothers reported
that parenting required always being “vigilant” to their daughter’s needs and thinking about how to buffer her potential reactions to situations that created stress. Managing how others reacted to their daughters was also a stressor, particularly siblings and extended family members. One mother, described her daughter as less behavioral and more emotionally vulnerable. This mother was particularly concerned about the younger sister who was quite socially astute and beginning to demean her older sister with ASD. In another family, the mom, Meg, spoke positively about Phoebe’s older sister Leslie, a popular and socially skilled teenager, who took a very protective and motherly role with Phoebe. Leslie would work with Phoebe on how to manage her social anxiety at school and was very supportive emotionally.

Girls’ perceptions of family. The girls with ASD in the study were acutely aware that their families had difficulties with their difference. All of the girls talked about their need to be “alone” and not participate in family activities that made them feel uncomfortable. The need to be alone created conflict with their parents, who expected them to participate in family gatherings.

_The fact I’m different or want to be alone – being different – they want me to do things – it’s kinda hard for them to understand why I don’t want to do certain things – they leave me alone (family) – I’m not exactly part of the family all the time – on my own- not exactly – not wanting to do all the family activities – watching movies – playing board games – more of just I want to be left alone._

-Annie

_That’s actually a hard one because I don’t really do anything with them. I like to be by myself. Like I’ll watch a movie with them. I’m trying to do more with them. Art is my sanctuary – it’s my life._

-Leslie

Financial Strain and Employment Limitations. Although the majority of families in the study were solidly in the middle to upper middle class, financial strain was
encountered by all families due to the high cost of lawyers, educational advocates, and eventually private and residential school placement costs. In early childhood, 3 families paid for occupational therapy, physical therapy and speech and language services that were not covered by medical insurance. As the girls became older, parents found themselves making different professional decisions because their daughters needed a higher level of parental involvement and supervision. One father, a lawyer, estimates that the family has lost about a million dollars in income, because he downsized his practice in order to assume “mother’s hours” to be available to his twin daughters in the morning and afternoon. Two mothers, each with an MBA, have found themselves full-time moms in order to be available to their daughters. Each talked about the number of school absences, 21 for Madison last year, and phone calls from the school due to behavioral issues and suspensions, weekly for Annie during eighth grade.

_It’s tough to navigate financially. It’s much more expensive to have Madison in our family so I would like to be working but last year Madison was home from school 21 days, then I’m homeschooling her, so I can’t do that professionally. I can now leave her home alone sometimes not for a long time and I do feel like right now she’s in a more fragile state. She’s hiding in the house now, which is something new. She was hiding the other night in the family room behind the chair with a blanket and we didn’t know where she was._

_Tess, mom of Madison_

Nine families in the study had hired an educational advocate or lawyer at some point to assist in developing an appropriate IEP or negotiating services for their daughter with the public school. This was more difficult in families with limited financial resources. Kim, mom to Kelly, although a seasoned public school teacher, finds it very difficult to effectively negotiate an IEP for her daughter, but she is putting off hiring an advocate due to the financial cost.
Pile-up (Boss, 2002) of Stressors and “living life in the moment”. Parents reported feeling overwhelmed with the number of stressors involved in raising a daughter with ASD and the chronic impact on family well-being. One mother described it as “intense” parenting. It requires parents to move from one stressor to the next without fully resolving each stressor. Pile-up refers to a number of stressors accumulating without time and resources to effectively address each stressor (Boss, 2002). Coping with pile-up in this sample involved learning to “live life in the moment”.

The most difficult thing is that there is so much involved. It’s not just – when you have to deal with the school and make sure they are following through on the IEP and that she’s getting what she needs and she gets the support she needs. They all kind of blend in together. It’s overwhelming. The hardest thing with parenting her is the way she reacts to us. Cause she can be very harsh and negative. I know it’s because she’s so frustrated and she can’t regulate herself. It’s losing that sense of self – you want to have time to figure out what you’re going to do professionally. - Jen, mom of Jane

Pile-up (Boss, 2002) occurred for all of the 11 families and financial resources did not buffer parental stress. Pile-up (Boss, 2002) occurred at different times for families but most consistently in families with a sibling struggling with major mental health diagnoses (6 families/46%). Two families had recently encountered a major crisis with a sibling, one was hospitalized for depression and the other has Bipolar disorder and was struggling with early adulthood. A parent with a major mental health disorder was identified in 3 families and was also described as a significant stressor that compounded the stress related to a daughter with ASD. In one family, the couple separated for 6 months in the prior year, due to the father’s difficulties managing his own Bipolar disorder along with parenting one child with major depression and a daughter with ASD. This family had encountered a crisis period but was in the process of re-stabilizing.
**Parental Coping Behavior.** In talking with parents and couples together about how they managed the stressors in raising a daughter with ASD, it became clear that once parents began to accept the diagnosis, there were coping behaviors that parents adopted. Some of these coping behaviors were coordinated by both members of the dyad, and others were adopted individually. The primary coping strategies in individual stress theory include both emotion and problem-focused strategies, and were employed by each parent in the sample (Lazarus & Folkman, 1984). Emotion focused coping employs strategies to address stressors that cannot be changed, whereas problem-focused coping employs actions to address stressors that can be changed (Lazarus & Folkman, 1984; Boss, 2002). In all of the families, the mom took the lead in researching ASD, managing the daily care, and accessing services within the school and community, all problem-focused strategies.

*I’ve learned a lot – you know that pang when you hear something about your kids. I had this tendency to want to fix things right away. I’ve learned to not respond right away. Wait until the next day. She’s not going to fall apart. I’ve been doing this a long time. You become a little numb. I don’t cry as easy as I used to.*

- Kim - Mom of Twin Girls Abby & Alexa

Many couples developed problem-focused strategies together to cope with the stress of negotiating IEP meetings and managing conflicts with public school staff. They described taking on specific roles within the meeting in order to both support one another and to ensure their daughter’s needs are met in the IEP.

*I’m going to tell you that [public school district] is not respectful to parents. I’ve been in IEP meetings where you’re not treated well. The chairperson was rolling her eyes while I was talking. At that point I would be so mad. I stopped the meeting and said, “I need you to stop rolling your eyes”. I think what’s hard – if there were no money issues – teachers want to help kids – but administrators. Not being treated respectfully is the hardest thing. I would be talking and two other staff people would be talking together. At one meeting I was talking. Jack is the note taker & I talk. That’s how we work. He trusts me. I’ve done the research*
and I know how it works. And he will talk when things get difficult. He says “Kim you were really good in there – you really sounded like you knew what you were talking about”. - Kim & Jack - Parents

Coping and Gender Roles. Although all 11 families included couples that were actively co-parenting their children, they generally followed traditional gender roles within the family system. The mother was the primary caretaker and interfaced most consistently with the schools and service providers (psychiatrists, social workers, pediatricians, neuropsychologists). Mothers were carrying the increased burden of managing the majority of their daughters’ needs. This role was acknowledged by most of the fathers. Three mothers reported that their husbands used “work” as a coping strategy and resented their ability to “leave” when they wanted.

as moms – at least for me – I can't speak for all moms - I have ownership of so many things – Chris [husband] can leave when he needs to leave – if he feels like going for a beer with Joe, he just goes. Maybe someday, I’m just going to not come home for two hours and let him pick the kids up and cook dinner and worry about getting them to their activities. I don’t know what it is as moms (crying) our expectations of ourselves maybe but carving that time out for ourselves – go for a walk, exercise, do something creative just doesn’t happen.

Most of the moms had difficulties carving out time for self-care; this was particularly true for mothers who were balancing full-time work and lower socioeconomic status. These mothers reported higher levels of isolation and employment constraints than mothers from higher socioeconomic status. Libby, mom of Leslie, works full-time and is the primary caretaker for Leslie. She reports feeling “resentful” toward her husband who can “choose” when he participates in Leslie’s care and at times does not attend IEP meetings. Leslie has significant sleep issues and a recent eating disorder, creating increased stress on the family but it was mom who found the eating disorder clinic and scheduled treatment appointments.
**Siblings and Coping: “Man Up”**. Siblings clearly describe problem-focused coping behaviors that were necessary in regard to family well-being. Siblings were acutely aware of their need to “*man up*”, as one brother called it, which involves siblings putting their needs aside and prioritizing their sister’s needs. The most significant stressor for siblings was managing their sister’s “*melt downs*”, which often times derailed family outings and created feelings of embarrassment and resentment. Many of the siblings interviewed described some level of awareness that their sister is “*different*” and “*she can’t help it*”, which lead to acceptance for who their sister is and “that’s just” her. Many of the siblings recognized the impact on their mother and felt the need to help out when stress is high.

*Sometimes I just say she was born different than other kids, she’s different but everyone is different. And she has more challenges than other kids. These kids [siblings] have been dragged to every doctor’s appointment Madison has ever had over the years. So a lot of their sports have been sacrificed over the years because I needed to take her to all these appointments, and I’ve been unavailable to them because I’m so focused on Madison. I have to be here and there, so they’ve become accustomed to the life with Madison and meeting all her needs.*

- Tess, mom of Madison

**Building Family Connections**. All of the parents described the difficulties in building a strong connection with their daughter. For many of the girls sensory issues preclude any physical affection and the desire to withdraw and isolate make it difficult to connect with family members. In most cases, there was one parent that had an easier time connecting and forging an authentic relationship.

*He (Dad) and Madison are very much alike. I think he might have some Asperger tendencies as well (laughs). He and Madison are like two peas in a pod, they can talk about engineering and science, they have a connection in that way where Madison and I don’t have a connection in that way... It’s great, I think he identifies with her more so he can empathize with her in a way I can’t – I just get frustrated.*

- Tess, mom of Madison age 14
The following quote is from a father reflecting on how he has evolved in his relationship with his daughter, and recognized the need to use different relational strategies to connect.

*I think Kate obviously took the lead on how to do this and forming that empathic bond with Annie. And I think that what evolved for me was this evolution from trying to get her to adapt to us - to us adapting to her. Kate was fantastic – has really coached me about how to interact with Annie and I would say over the last two years that Annie and I have developed a pretty good relationship especially compared to where we were three years ago. Where before there was a lot of conflict – the classic male thing – trying to apply logic or solve the problem for her so I’ve learned to walk away especially when she’s really emotionally heated or trying to not push her buttons as much.*

**Creating a new normal.** As parents came to a place of accepting the diagnosis and their daughter’s needs, there also is an acknowledgement that a healthy family life entails accepting that people are “doing the best they can”. The following quote reflects a mother’s acceptance of her daughter and letting go of expectations.

*I gave up on having expectations, because you don’t know what to expect. You can always hope that things will change and evolve but I accept her for who she is and what she can offer... if I have expectations they’re false – it would be unfair. She’s grown so much.... I’ve always been there for her and I always will.*

- Jen, mom of Jane

Most parents describe a movement toward a new understanding of their family and in particular their daughter. As one mom described, “I thought I was going to Italy but ended up in Holland, Holland is fine but I needed to accept that I wasn’t going to Italy.” Some of this acceptance involved letting go of the “idealized” child and family, and developing new ideas about “normal” within the family.

*You constantly have to remind yourself that this is a real disability. That she’s not trying to drive you crazy. So anything that reminds you that this is a condition and its real. And it leads to all these great things along with the challenges, you come back thinking “I’m not alone” and what I went through which was so bizarre and weird and stressful is actually normal in this world.*

- Kate, mom of Annie
This ability to create a new conceptualization of “normal” could be framed as resiliency. Resiliency could be understood as the ability to adapt to adversity/stress over time (Boss, 2002). All of the parents in the study, despite feeling resentful and frustrated at times, were able to recognize their daughter’s strengths and place within the family system. One mother relayed such pride in her daughter’s ability to recite the Torah and travel to Israel with a group from their synagogue, despite a very difficult year both at home and in her public middle school. Although parenting a daughter with ASD did involve coping with chronic stress, it did not diminish parents’ loyalty and commitment to their daughters.

The ability to adapt to chronic stress or be resilient among the families in the study also had some limitations, as it involved many family members negating their own needs, particularly siblings and mothers. The following quote comes from a father reflecting on his mixed emotions regarding his daughter going to a residential special education school and how her absence re-created some “normalcy” in the family. He reported feeling guilty, elated, and sad. “The thing that’s been a dramatic change is on the selfish side, when she’s away we are much more like a normal family.”

**Reaching A Place of Hope.** Although only a few families had reached a place of hope, all of the families had begun to see a more positive future for their daughter. Families that were further along in finding a school placement that was effective in facilitating progress and growth for their daughters were more able to articulate a vision for their daughters’ future. Building their daughter’s independent living skills was perceived to be both a major challenge and critical component to achieving success in the future.
My lofty goal is that there will be a community for her that we’ll be a part of but she’ll have friends, find work that is satisfying – I think she’s capable of pretty advanced work if she finds something interesting – but she’s loath to work hard – so something she feels passionate about that she’d be willing to work hard at – have a great professional career. No guarantee that anyone finds it, so a lofty goal. That she has a relationship with someone – someone to put up with her. But I think, as she gets older, she’ll regulate better, that’s hard to believe when they’re in middle school. There were a lot of kids on the panel at her school [private residential] who were at college and doing well and I would hope for that for her. I don’t want to spend my life looking after her. My goal is for her not to be living in my basement the rest of her life. I would like to be a part of her life if she wants that but I don’t want to be her caregiver. And if we don’t address the things she’s struggling with now, I definitely will be. That’s why she’s at [residential school] – to learn how to be independent. - Kate – mom of Annie

Having hope for their daughters’ future was a consistent theme but perceived to be unattainable without further work on being independent. All of the parents expressed a strong desire for their daughter(s) to successfully graduate from high school, attend college, and build a “meaningful” life with successful relationships. The fear that their daughter would remain dependent on them was present with all parents and all had difficulties finding effective ways to build their independence.

**Summary.** Family well-being was a struggle to manage for all 11 families, with siblings needs frequently going unmet. Parents expressed feelings of guilt, resentment, and remorse over the sacrifices needed to manage a child with ASD. Over time, families developed strategies to adapt and cope more effectively. Pile-up of stressors occurred more frequently in families with a sibling and/or parent diagnosed with a major mental health disorder. All of the parents expressed a strong commitment to meeting their daughters’ needs and recognized their strengths. Hope for their daughters’ future was strong and involved a vision for success in college and relationships.

**Figure 4. Conceptual Model of the Family Coping Process**
External Context

Prior to Diagnosis

Initial Appraisal of ASD Diagnosis

Emotional Response

Family Management

Coping Behaviors

Chronic Stress

Internal Context

Acceptance

Adaptation
SIPA DATA

The construct of parental stress was assessed quantitatively through the Stress Index for Parents of Adolescents (SIPA) (Sheras, Abidin, & Konold, 1998). The SIPA is a scale that integrates research findings related to the most salient factors related to stress in parenting an adolescent, including both adolescent and parent attributes. The SIPA reflects norms from the 1997 U.S. census and has high reliability (.93) and validity (Sheras, Abidin, Konold, 1998). It is not a scale developed and normed on families with an adolescent with ASD, and is therefore imperfect in capturing the unique experiences of parents of a child with ASD, but it does provide an overall sense of how parents perceive their current level of stress related to parenting.

The SIPA is comprised of four domains that contribute to the overall parenting stress score: Adolescent Domain (AD), Parenting Domain (PD), Adolescent-Parent Relationship Domain (APRD), and Life Stressors (LS). Within the Adolescent and Parent domains, there are four subscales each. The Adolescent Domain measures the parents perceived stress attributable to the adolescent’s characteristics such as mood and behavior. The AD subscales include Moodiness/Emotional Lability (MEL), Social Isolation/Withdrawal (ISO), Delinquency/Antisocial (DEL), and Failure to Achieve or Persevere (ACH). The Parent Domain measures the parents’ perception of the impact of parenting related stress on other relationships (e.g. spouse, social connections). The PD subscales include Life Restrictions (LFR), Relationship with Spouse/Partner (REL), Social Alienation (SOC), and Incompetence/Guilt (INC). The Life Stressors domain is an indicator of any life events (e.g. death of a family member, job change) within the last year that may have contributed to the parent’s overall level of stress. The Adolescent-
Parent Relationship domain measures how the parent perceives the quality of his/her relationship with the adolescent. (Sheras, Abidin, Konold, 1998)

The SIPA scores in the following three tables reflect current parenting stress post ASD diagnosis. The majority (65%) of parents in the study endorsed borderline to clinically severe parenting stress as reflected in Table ten. Mothers endorsed more parenting stress within the borderline to clinically severe range (72%) than fathers (55%). The parent domain was more strongly endorsed by fathers in the clinically severe range (44%) than mothers (11%). The adolescent-parent relationship was a more significant contributor to parenting stress for mothers, 33% in the clinically severe range, than fathers with only 10% in the clinically severe range. These scores are consistent with the qualitative data, indicating that mothers play a more active and instrumental role in the parenting of a daughter with ASD and are therefore more likely to experience higher rates of stress related to parenting. Scores in the clinically severe range are considered quite high, and indicate a need for clinical intervention. All of the families were receiving some type of therapeutic support at the time of the study.
### Table 10
Stress Index for Parents of Adolescents (SIPA)

<table>
<thead>
<tr>
<th>Percentile Score Range</th>
<th>Total Parenting Stress</th>
<th>Adolescent Domain</th>
<th>Parent Domain</th>
<th>Adolescent-Parent Relationship</th>
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<tbody>
<tr>
<td></td>
<td>M</td>
<td>F</td>
<td>M</td>
<td>F</td>
</tr>
<tr>
<td><strong>Parent</strong>*</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Clinically Severe</td>
<td>36%</td>
<td>44%</td>
<td>36%</td>
<td>44%</td>
</tr>
<tr>
<td>95-100</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Clinically Significant</td>
<td>18%</td>
<td>11%</td>
<td>18%</td>
<td>22%</td>
</tr>
<tr>
<td>90-94</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Borderline</td>
<td>18%</td>
<td>0%</td>
<td>27%</td>
<td>0%</td>
</tr>
<tr>
<td>85-89</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Within Normal Limits</td>
<td>28%</td>
<td>45%</td>
<td>19%</td>
<td>34%</td>
</tr>
<tr>
<td>&gt; 85</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

* M=Mother; F=Father

**Adolescent Domain.** The Adolescent Domain is elevated in comparison to the two other domains, Parent Domain and Adolescent-Parent Relationship Domain. This indicates that the parents in the study perceive their stress to be related primarily to the adolescent child’s characteristics versus parental characteristics (Sheras, Abidin, & Konold, 1998). In Table eleven, there are two subscales in the Adolescent Domain that reflect data consistent with the qualitative data. The results of the Moodiness/Emotional Liability subscale and the Social Isolation/Withdrawal subscale indicate that the majority
of parents find their daughters with ASD to present with significant challenges in mood, behavior, and social skill deficits (Sheras, Abidin, & Konold, 1998).

Table 11
SIPA: Adolescent Domain Subscales

<table>
<thead>
<tr>
<th>Percentile Score Range</th>
<th>Moodiness/Emotional Liability</th>
<th>Social Isolation/Withdrawal</th>
<th>Failure to Achieve or Persevere</th>
<th>Delinquency/Anti-social</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parent*</td>
<td>M    F</td>
<td>M  F</td>
<td>M  F</td>
<td>M  F</td>
</tr>
<tr>
<td>Clinically Severe 95-100</td>
<td>64% 56%</td>
<td>55% 67%</td>
<td>27% 33%</td>
<td>9% 11%</td>
</tr>
<tr>
<td>Clinically Significant 90-94</td>
<td>9% 0%</td>
<td>18% 33%</td>
<td>18% 11%</td>
<td>18% 22%</td>
</tr>
<tr>
<td>Borderline 85-89</td>
<td>9% 11%</td>
<td>18% 0%</td>
<td>0% 11%</td>
<td>18% 11%</td>
</tr>
<tr>
<td>Within Normal Limits &gt;85</td>
<td>18% 33%</td>
<td>9% 0%</td>
<td>55% 44%</td>
<td>55% 56%</td>
</tr>
</tbody>
</table>

*M=Mother; F=Father

Parent Domain. The Parent Domain subscales are outlined below in Table twelve. The Parent Domain subscales indicate the majority of parents did not perceive their parenting role as impacting their relationship with their spouse and with social connections. The Life Restriction subscale is elevated, indicating the majority of the parents (65%) find their role as parent restricting or limiting their ability to make choices for themselves in life (Sheras, Abidin, & Konold, 1998). Life restrictions did emerge as a theme in the
qualitative data, particularly for mothers in their professional roles. Mothers (36%) also endorsed very high levels of guilt and incompetence related to their parenting role, as compared to fathers (11%).

Table 12
SIPA: Parent Domain Subscales

<table>
<thead>
<tr>
<th>Percentile Score Range</th>
<th>Life Restrictions</th>
<th>Relationship with Spouse</th>
<th>Social Alienation</th>
<th>Incompetence/Guilt</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M</td>
<td>F</td>
<td>M</td>
<td>F</td>
</tr>
<tr>
<td>Parent*</td>
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</tr>
<tr>
<td>Clinically Severe 95-100</td>
<td>55%</td>
<td>33%</td>
<td>18%</td>
<td>22%</td>
</tr>
<tr>
<td>Clinically Significant 90-94</td>
<td>0%</td>
<td>11%</td>
<td>9%</td>
<td>0%</td>
</tr>
<tr>
<td>Borderline 85-89</td>
<td>18%</td>
<td>11%</td>
<td>9%</td>
<td>0%</td>
</tr>
<tr>
<td>Within Normal Limits &gt;85</td>
<td>27%</td>
<td>45%</td>
<td>64%</td>
<td>78%</td>
</tr>
</tbody>
</table>

*M=Mother; F=Father

Summary of Findings

Based upon the experiences of the 11 families in this study, having a daughter with an ASD could be categorized as a *chronic and cumulative stressor* (Boss, 2002). In
listening to the stories of the families, one is struck by the number of ongoing challenges encountered by the families and the lack of predictability in the stressors. Families are forced to continually adapt as their daughters encounter developmental challenges that have a significant impact on family functioning. The high number of stressors involved, particularly when first diagnosed, can result in “pileup”, where families have limited time and energy to cope effectively.

Prior to a diagnosis and during the diagnostic process, families experience high levels of ambiguity in “figuring out” what is different about their daughters’ development and perceive professionals as “withholding” important diagnostic information, consistent with the construct ambiguous loss (Boss, 1999, 2002). Ambiguous loss is also evident post diagnosis, in the girls’ narratives as they describe being “not really part of the family” and parents finding “normalcy” difficult to establish. Manifestation of ASD symptoms can be more nuanced in girls and many families experienced both isolation and judgment from others because their daughters “passed” as typically developed, making the disability less visible. The families experienced very limited understanding and support from their external context, such as public schools, community based activities, extended families and professionals, increasing levels of stress.

A shift in perception of the ASD from an acute to a chronic stressor allowed families to move toward acceptance and management of the stressor. Acceptance of the chronic nature of the stressor contributed to families letting go of a “cure” and managing the chronicity of their daughters’ needs more effectively. Pileup of stressors occurred for all families at different stages, but particularly in families with a sibling diagnosed with a
major mental illness. Adaptation as family resiliency presented both benefits and costs. Re-conceptualizing a “normal” family facilitated coping behavior among both parents and siblings, but also resulted in the acceptance of unmet needs among family members.

The SIPA data on parental levels of stress supported the qualitative findings. The majority of parents endorse on the SIPA scale clinical levels of stress despite strong evidence of family resiliency as evidenced by adaptation to the stressor through coping behavior. The sample is overwhelmingly resource rich as evidenced by high levels of education, employment, and socioeconomic status, yet struggling to manage individual levels of stress. The findings indicate the need for more preventative and supportive intervention for these families, which will be discussed in chapter five.
Chapter V: Discussion and Implications

This chapter will discuss the qualitative and quantitative findings from a study of 11 families currently parenting an adolescent daughter with high functioning autism spectrum disorder. Study findings were compared to the current research literature where applicable for the purpose of illuminating consistencies and variations in the knowledge base on girls with ASD and their families. The three overarching research questions that guided this study are addressed sequentially: (1) How do families describe the process of attaining their adolescent daughters’ autism spectrum disorder diagnosis? (2) How do families describe their experience negotiating the demands of early adolescence on their daughter as she adjusts to increased academic, social and behavioral expectations within the middle and high school environment, manages social interactions with neuro-typical peers (particularly female peers), and experienced gendered expectations? (3) How do families describe their experience in adapting to and managing the impact of the ASD diagnosis on family well-being?

The analysis utilized family stress theory as the theoretical lens, with the family system as the primary unit of analysis. The sensitizing concepts from family stress theory guided the final stage of analysis, and were identified within case, each family as one case, and analyzed across case. The sensitizing concepts that emerged as central constructs to the family coping process were incorporated with new constructs that emerged from the final stages of analysis into a theoretical model. This goal of this study is to build from inductive data, a family systems theoretical lens that describes the coping process of families with an adolescent daughter with ASD.
The Diagnostic Process

All of the parents described the process of attaining an ASD diagnosis for their daughter and initially adapting to her specific needs as arduous, lengthy, and stressful. The time period prior to diagnosis could be characterized as a period of family strain, which can be understood as a time when the stress encountered by the family outweighs the family strengths and resources (Boss, 2002). The “not knowing” how to understand and adapt to their daughter’s “difference” prior to a diagnosis created immense pressure on the family system. Barriers to adapting to the strain within the family context, or internal context, included misperceptions of autism, denial, stigma, shame, and ambiguity related to the ASD symptoms. Barriers to families effectively adapting in the external context, included professionals “withholding” information on their daughters’ difficulties or denying/minimizing ASD symptoms, limited access to information on autism and its “umbrella” of diagnoses, contentious relationships with the public school system, and misperceptions of “high functioning” autism in the public schools leading to girls being “underserved”. These findings on the diagnostic process are consistent with prior research on parents of children with ASD (Howlin & Asgharian, 1999; Schall, 2000; Gray, 2003; Toth & King, 2008; Lasser & Corley, 2008; Gill & Liamputtong, 2011; Cridland, Jones, Caputi, & Magee, 2013).

Entering elementary school and encountering challenges negotiating peers and group interactions was the primary ASD indicator for 9 (69%) of the girls in the study. Although behavioral indicators occurred earlier for ten of the girls (77%), it did not lead to a direct referral for testing. Elementary school teachers were the first professionals to address ASD indicators and encouraged a referral for evaluation for eight of the families
These findings have significant implications for girls with ASD, and are not evident in prior research. Their ASD symptoms may not become visible and prominent enough to warrant evaluation until they are challenged by interactions with neuro-typical peers. Public school teachers and school social workers could play a significant role in earlier detection and understanding girls with ASD.

**Impact of delayed and misdiagnosis.** Delayed and misdiagnosis operated as obstacles for study families attempting to manage the needs of their daughter. Consistent with prior research, the timing and type of the diagnosis impacted access to preventative interventions and appropriate framing of behavior (Cridland, Jones, Caputi, & Magee, 2013). The mean age of ASD diagnosis among study participants was 8.7 years, standard deviation of 3.1 years, and a range of 9 years (ages 4 to 13). The mode was 8 years, consistent with the qualitative findings indicating that girls with ASD began to manifest symptoms more significantly once they entered elementary school and began to encounter challenges with peer group interactions. This mean age of first ASD diagnosis is well above the most recent CDC data with Asperger’s diagnosed by 6.3 years (CDC, 2014).

Although the CDC data did not find significant differences in age of diagnosis between boys and girls with Asperger’s, the sample was not representative and there was wide variation geographically in regard to age of diagnosis (CDC, 2014). A recent study from the Netherlands did find a statistically significant difference in timing of diagnosis between boys and girls with Asperger’s, with girls (9.7 years) diagnosed close to 2 years later than boys (7.9) (Begeer, et al, 2013). The later diagnosis in girls with Asperger’s has been attributed to later onset of symptoms, parents’ gendered expectations or
“interpreting bias” for girls to be more socially appropriate than boys, and girls masking their ASD through higher cognitive ability and more subtle manifestations (Holtman, Bolte, Poustka, 2007; Attwood, 2007; Begeer, et al, 2013).

An “interpreting bias” was evident in the study sample among all parents as they had difficulty perceiving their daughter as autistic, which was perceived to be a boy’s disorder (Holtmann, Bolte, & Poustka, 2007, p. 364). This bias was closely associated with parents’ limited understanding of autism and perceiving boys with Asperger’s as “loners” and “lacking empathy”, which did not “fit” with their perception of their daughters. These misperceptions of ASD symptoms delayed parents’ acceptance of the diagnosis. The “interpreting bias” was also evident among medical, school, and mental health professionals within the current study, who were hesitant to give the girls in the study a full ASD diagnosis, instead opting for “rule outs”, “tendencies”, and other diagnoses (Holtmann, Bolte, & Poustka, 2007, p. 364). This finding is consistent with the one other study on girls with ASD, which found “health professionals” to be “reluctant” to give girls with ASD a “formal diagnosis” (Cridland, Jones, Caputi, & Magee, 2013, p. 4).

**Initial Adaptation to the ASD Diagnosis**

**Denial as an adaptive strategy.** The construct of denial served as an adaptive strategy for parents prior to and during the initial adaptation to the ASD diagnosis. All of the parents reported being in some level of “denial” during the diagnostic process, and denial was evident in the way parents’ initially minimized their daughters’ behavior, minimized teacher concerns, and attempted to avoid the stigma associated with autism. Denial appeared to assist parents who needed time to adapt to and accept their daughters’
diagnosis, and was supported by the lack of visibility of the diagnosis, as most of the girls “passed” as typically developed in public.

Acceptance of the diagnosis took a long period of time for all of the parents in the study sample. Letting go of denial was closely associated with acknowledging the chronic nature of the ASD symptoms and witnessing their daughters’ repeated difficulties within the public school environment. Denial may be a particularly important construct in families adapting to a chronic stressor and one that involves some ambiguity (Boss, 2002, 2006). High functioning ASD is not as visible as more severe autistic symptoms, and high levels of intelligence and “adult like” verbal skills make it particularly easy for parents and teachers to minimize the extent of the disability. The ambiguity regarding whether or not high functioning ASD is a “true disability” was evident in the narratives. As one mother said “are we the parents of a special needs child?”. 

**Ambiguous loss.** All of the parents in the study expressed levels of grief and loss related to their daughters’ ASD diagnosis. The loss of their “ideas” about their child and in particular her future featured prominently; “will she be independent?”, “will I always care for her?”, “will she go to college and have a job?”, “will she be accepted by her peers?”. Fear and anxiety about what an ASD diagnosis meant for their daughter and her chances in life were feelings closely related to the construct of ambiguous loss. Most parents became visibly upset and tearful when considering the impact of the ASD diagnosis on their daughters’ future. The theme of physically present but in some ways disconnected from the family system was prominent in most of the families. The family role of a daughter with ASD was distinct; she is present but in many ways absent from aspects of family dynamics. As Annie said, “I’m not really part of the family”. The
perception of some members is that she is physically present but at times chooses to withdraw and isolate from family functions. When she is present for family interactions, significant accommodations are made, expectations modified, and possible derailment expected by family members.

The feelings of loss and altered expectations were closely associated with core ASD symptoms that include limited reciprocity in relationship, difficulties with emotional relatedness, and aversion to physical affection. Parents frequently experienced extreme sadness regarding the lack of physical affection in their relationships with their daughter, wanting to hug or physically comfort her but knowing that it would cause her distress. Letting go of expectations regarding the character of their daughters’ relationships with family members was linked with acceptance of their daughter for “who she is”. There were two girls with ASD in the study that did not present with some core features and were more comfortable with physical affection, indicating the need to look carefully for exceptions.

Acceptance of the diagnosis was closely associated to couples “getting on the same page” in regard to how they perceived the ASD and working together to modify their behavioral expectations. As one mother stated, “I don’t have expectations, that would be unfair. She is doing the best she can”. Letting go of prior expectations regarding both their daughter and family life, allowed parents to adapt to a new conceptualization of their family and their new “normal”. As one mother stated, “I thought I was going to Italy but I went to Holland. Holland is perfectly fine, but I needed to let go of Italy”. The construct of “normalcy” was central in a similar study with mothers of children with Asperger’s, the sample was predominantly male children (18
boys, 3 girls), but the findings were very similar in regard to parents constructing new ideas about “normal” for their child (Lasser & Corley, 2008).

**Implications for Working with Denial and Ambiguous Loss.** In working with families managing a child with ASD, it would be important to understand how both denial and ambiguous loss may operate within the family system. Parents were keenly aware of being “judged” and “misunderstood” by professionals. As one mother reported, a school social worker in her daughter’s public middle school once gave her a booklet on Asperger’s syndrome and told her she “should,” read it. The mother found this interchange demeaning and patronizing. What was clear in meeting with parents, is that they have a strong desire to have helping professionals validate the chronic nature of the stress and loss they are encountering and to respect them as collaborative members of their daughters’ treatment team. Part of what was helpful in accepting and managing their daughters’ diagnosis was time to adjust and process their changing perceptions of their daughters. For all the parents it was a paradigm shift that required time and authentic support for family members and professionals.

Parents employed a number of adaptive coping strategies to mediate the stress of raising a daughter with ASD, including denial. Frequently assumed to be a maladaptive coping strategy, within the context of chronic stress and when there is ambiguity regarding the ASD diagnosis, denial was the norm within this study’s sample. Intervention efforts with families managing ASD may be more effective if all coping strategies are understood and assessed within the unique family context.

Understanding an ASD diagnosis through the lens of ambiguous loss as defined by Boss (2006) may prove useful with many families. When there is a lack of clarity
regarding a diagnosis and what it means for the future of a child, parents may encounter ambiguous loss, a construct that may impede the coping process. Providing opportunities for parents to explore their feelings and thoughts related to the ASD diagnosis may facilitate more healthy adaptation to the stressors encountered.

Need for early ASD diagnosis. Later diagnosis in the study sample was associated with poorer outcomes in the public school environment, higher risk for safety issues such as suicidal ideation, and psychiatric hospitalization, and higher rates of reported parenting stress. Protective factors associated with an earlier diagnosis include more prominent autism symptoms such as hand flapping, delayed language, and gross motor deficits in early childhood; higher levels of education among mothers; and higher levels of socioeconomic status. The range in age of first ASD diagnosis among the sample of girls with ASD is quite extensive at 9 years (ages 4 to 13). There are important variables that are associated with the outlying groups in the sample. Those diagnosed earlier; Abby and Alexa twins, diagnosed at age 4, Jane (age 5), and Kayla (age 6) compared to those diagnosed later; Madison (age 13), Julie (age 12), and Leslie (age 12).

The early diagnosis group received more preventative services in early childhood, including applied behavioral analysis (ABA), physical therapy, speech therapy, occupational therapy, and brushing protocols for sensory integration. All four girls had medical issues at birth that required early intervention services. The early childhood ASD symptoms in the early diagnosis group were closely associated with more typical autism; language delays, repetitive behaviors (lining up toys), echolalia, hand flapping, and gross motor delays. In the later diagnosis group, only one (Madison) received early intervention for medical issues at birth, and all three exhibited ASD type symptoms in
early childhood but they were described as more subtle. It is likely that parent and school staff’s perception of these early symptoms played a role in how the girls’ behavior was understood.

One potential explanation could be that the mental health symptoms of the girls in the later diagnosis group were more prominent than ASD symptoms. All three girls in the late diagnosis group were first diagnosed with both ADHD and depression in elementary school. The girls in the early diagnosis group received their ASD diagnosis first or at the same time as their co-occurring diagnoses. However, the girls in the early diagnosis group also had significant co-occurring mental health diagnoses, particularly Kayla (ADHD and Bipolar) and Jane (OCD and Trichotillomania).

The adolescent outcomes for the two groups are markedly different. The girls in the early diagnosis group had a more successful transition to middle school with no school suspensions or psychiatric hospitalization, and all four are still progressing in a public school environment. These findings indicate that earlier diagnosis and treatment may lead to better outcomes and this finding is consistent with prior research (Lord, 1995; Begeer, et al, 2013). The three girls in the late diagnosis group had a much more difficult transition to middle school including school suspensions, suicidal ideation, and bullying for all three and psychiatric hospitalization for two of the girls. Public school stability and success was not achieved in the late diagnosis group with all three having transitioned out of the public schools and currently placed in private day schools for students with ASD and behavioral issues.

Differences in parent demographics between the two groups are striking. The three mothers (Abby and Alexa are twins) in the early diagnosis group are more highly
educated, all three have a graduate degree, and two are teachers. In the late diagnosis
group, the mothers have lower levels of education and none of the parents have a degree
or employment in a related field, such as education or social work. The other prominent
difference is that two of the families in the late diagnosis group have the lowest
household income in the sample.

In comparing the total parent stress index from the SIPA data for the two groups,
the early diagnosis group had an average parenting stress index score of 81, which is
within normal limits compared to the average score among the parents of the late
diagnosis group, which was 96, which is in the clinically severe range. Although the
sample size is too small to draw any definitive conclusions, the data offers general trends
to explore in future research.

**Social Work Practice Implications.** Study findings indicate the need for
psycho-education with parents in early childhood on social and behavioral indicators
associated with ASD, particularly in peer group interactions, breaking down the
perception of autism as a “boy’s disorder”, and closer attention to differential diagnosis
with girls diagnosed with ADHD and depression in elementary school. School social
workers are in a unique position to observe, assess, and intervene within peer groups,
which may lead to earlier and more effective intervention for girls with ASD.
Increased training for school social workers on neuro-developmental disabilities is
necessary to provide the assessment skills necessary to identify and intervene with young
girls who present with social skill deficits.

**Role of Pediatricians in Diagnosis During Early Childhood Development.** As
one mother stated, pediatricians are “who parents go to” when they have developmental
concerns and are parents’ primary resource during their child’s early development.

Pediatricians were not a significant source of support or education on ASD for study participants. The girls’ ASD symptoms were not detected by their pediatricians and in some cases were minimized or dismissed. The study findings indicate that the “interpreting bias” may be evident among medical professionals as well as parents. All parents reported early childhood professionals, other than elementary school teachers, as minimizing or dismissing parental concerns regarding their daughter, encouraging parents to “give them time” to develop and assessing their development as “typical”. This finding is consistent with the Cridland (2013) study which found “health professionals” hesitant to provide a diagnosis to girls with ASD.

Pediatricians could play a more pivotal role, particularly for families with limited financial resources, in providing education on early childhood development and understanding the broader autism spectrum disorder symptoms. Although some pediatricians may administer developmental checklists, public health initiatives to increase consistency and uniformity in early assessment and detection are warranted. The different ASD diagnoses and symptoms have been confusing for parents in this study’s sample and resulted in a lack of access to appropriate diagnoses and resources. Parents would benefit from more clarity on the different diagnoses and the use of simple check lists, to identify key symptoms. For overburdened families working full-time and managing multiple children, pediatricians are the one guaranteed point of contact in early childhood.

**ADHD as first diagnosis.** The majority of the study sample (ten girls/77%) was first diagnosed with another mental health disorder other than ASD, and for 54% that first
diagnosis was ADHD. This is consistent with parents reporting that the first primary symptom in early childhood was extreme behavioral issues that included low frustration tolerance, atypical temper tantrums, and mood regulation issues. Prior research also indicates that girls with ASD present with more attentional and executive functioning deficits (Holtman, Bolte, & Poustka, 2007; Lemon, Gargaro, Entocott, & Rinehart, 2011). This finding is important for early childhood professionals who may need to look closer at these “behavioral” symptoms to assess their etiology and rule out other diagnoses such as ASD. It is also probable that receiving a diagnosis of ADHD first, prevented further assessment from school staff that understood the girls’ behavior through an ADHD lens.

**Manifestation of core ASD symptoms: RRBI.** All of the girls in the study did present with the core symptoms of autism spectrum disorder, including restricted and repetitive behaviors and interests (RRBI). This finding counters recent research findings indicating that girls endorse lower levels of RRBI than boys (Frazier, Georgiades, Bishop, & Hardan, 2014). The girls in the study often times were more covert about their RRBI, self-stimulating in private, and withdrawing to private spaces to engage in their specific interests. Consistent with Frazier’s (2014) hypotheses about girls endorsing lower levels of RRBI, girls in the study may have manifested RRBI in more subtle and gender specific ways. Some of the girls exhibited similar interests to their male peers with ASD such as anime, Pokemon, and gaming, but all of the girls exhibited some gender specific interests such as friendship bracelets, American Girl dolls, theater, and art. Frazier hypothesizes that current diagnostic tools may not pick up on the gendered interests of girls. The study findings support Frazier’s recommendation for closer
assessment of RRBI in girls and looking closely for more gendered manifestations of RRBI.

A gender specific approach to assessment could include a more in-depth clinical interview to draw out the specific interests and activities that girls with ASD may engage. Observation within a peer group interaction may be a key piece, as girls with ASD within this study exhibited social skill deficits within peer group interaction in the public schools. This is an area of assessment that is best determined by school social workers that are engaged in both classroom observation and small group peer interactions.

**Psychiatric co-morbidity among girls with ASD.** Psychiatric co-morbidity was very high in the study sample with all of the girls diagnosed with at least one co-occurring mental health disorder, consistent with prior research findings on girls with ASD (Holtman, Bolte, & Poustka, 2007; Solomon, et al, 2012; May, Cornish, & Rinehart, 2013). Mental health symptoms, particularly anxiety and depression, became more prominent as the girls in the study entered adolescence, a finding consistent with recent research on adolescent girls with ASD exhibiting higher rates of internalizing symptoms than both boys with ASD and neuro-typical female peers (Solomon, et al, 2012). The parents in the study endorsed very high levels on the SIPA sub-scale moodiness/emotional lability, which refers to a parent’s perception of their daughter’s unpredictability in mood, irritability and behavior as well as the level of energy required by parents to adapt and cope with the affective symptoms.

Psychiatric symptoms were a significant area of risk for girls in the study as they were associated with suicidal ideation, feelings of isolation and marginalization from peers, and bullying. The mental health symptoms also placed additional strain on parents
in the study as they reported feeling “overwhelmed” with the chronic nature of the suicidal ideation and unpredictability in mood. These chronic mental health symptoms required mothers, as primary caretakers, to develop strategies for managing mood regulation issues and keeping their daughters’ safe when suicidal ideation and severe depression occurred. All of the parents reported that the mental health symptoms increased their daughters’ “vulnerability” in the public schools, and they did not “trust” public school staff to handle the symptoms appropriately. Three girls were removed from their public middle schools by their parents due to what they perceived as inadequate responses to suicidal ideation and depression by public school staff. All three were homeschooled by parents or tutored for three months to a year before being placed in a private school.

Coordination of care is essential in meeting the needs of girls with ASD and comorbid psychiatric diagnoses. Parents did not feel equipped to cope with the severity of these psychiatric and behavioral symptoms in the home. Access to home-based clinical social workers with expertise in both ASD and mental health disorders could be beneficial in supporting parents when their daughters become dysregulated. There is a need within the mental health field to develop proficiency in assessing and treating the unique clinical presentation of girls with ASD and comorbid psychiatric symptoms. Parents had difficulties finding mental health care providers that were competent in treating their daughters. Coordination among treatment providers (psychiatrists, psychologists, social workers, and school staff) is equally critical in order to effectively assist stabilization of symptoms in both the home and school environment. Conflicting
messages and approaches from treatment providers created increased stress and confusion for parents.

**Transition to Adolescence**

Adolescence for the study sample could be characterized as a period of significant risk for girls with ASD as evidenced by high rates of psychiatric co-morbidity (100%), suicidal ideation (69%), isolation and marginalization from peers (100%), withdrawal (100%), academic difficulties/failure (100%), bullying (77%), and limited access to gender based ASD programming (100%). The primary theme from the qualitative narratives was, surviving but not thriving, within the public school environment, which resulted in significant levels of stress for families. There is very little empirical data on this time period for girls with ASD, however recent studies confirm the finding that adolescence is a period of increased risk for internalizing psychopathology (Solomon, et al, 2012) and marginalization from neurotypical female peers (Cridland, Jones, Caputi, & Magee, 2013).

Implications for this finding include increased responsiveness within the public school environment to providing support to girls with ASD as they transition to middle school. Support services may include access to a school social worker, provision of social pragmatic groups, and accommodations within unstructured settings such as the cafeteria, hallways, and classes that involve group interactions such as gym. Case management of mental health care could be coordinated by the school social worker to ensure effective communication among professional providers and adequate response to psycho-pharm needs. The skill and responsiveness of school social workers on this front could prove potentially critical in avoiding unnecessary out-of-district school placements.
Gender socialization and losing identity and voice. All of the girls in the study were acutely aware of their “difference” in middle school and recognized their difficulties interacting with neurotypical female peers. The girls struggled to find a place where they “fit” in middle school as one girl reflected, “I was really different – I didn’t feel comfortable around the other girls – they talked about weird things – so I just sat with the boys and they just ignored me”, similarly, another girl said “I could never find anyone to connect to”. Girls reported that they “almost never talked” or “didn’t participate much” and described themselves as “introverted” and preferred to escape into their books and art.

Adolescence also coincided with acknowledgement of their ASD diagnosis, which was not perceived to be positive for any of the girls. One girl described Asperger’s as a “sickness” and girls either wished they could be “normal” or refused to accept their diagnosis. Intelligence was an area of identified strength for the girls but in middle school all of the girls began to struggle academically, which challenged their prior sense of self as “smart”. All of the girls presented with executive functioning weaknesses that resulted in difficulties managing the organizational demands of middle school.

Interestingly, only two girls attempted to conform to gendered norms regarding dress, interests, and behavior. The majority of girls were adamant about being themselves, displaying a strong commitment to a more authentic self. A desire for acceptance and respect for their autonomy permeates their narratives. Girls reported conflict with parents and school staff centered on the expression of their own interests, dress, and behavior. This was particularly evident when the girls discussed their special interests such as reading, anime, art, and self-stimulating activities (pacing and twirling).
These activities and interests were described as an essential aspect of their well-being and quality of life. Frequently, these activities were used to cope with feeling overwhelmed and anxious, particularly in peer group or family interactions.

These findings illustrate an important need to focus research and intervention efforts toward building a more positive identity for girls with ASD. They also call into question the efforts made by parents and school staff to alter and minimize the girls’ restricted and repetitive interests and behavior. These interests and behavior appear to serve an adaptive and positive function in the girls’ lives. Research is needed to further illuminate the utility in focusing on reducing these behaviors so that girls with ASD appear more “typical”, “age appropriate”, and “fit in”.

**The need for responsive and inclusive school communities.** All 13 of the girls from the study sample began middle school in their local public school, but 6 (46%) of the girls transitioned to a private school for ASD youth by eighth grade and 2 more girls in early high school (total of 62%). These private school placements come at an enormous cost to both parents and public school budgets. The primary reasons for leaving the public schools included: inadequate response to mental health symptomology, particularly depression and anxiety and inadequate supports to manage the increased academic and social demands.

All of the parents in the study sample perceived their daughters’ increased mental health issues in middle school to be triggered by the stress of managing a public school environment. Parents identified inadequate implementation of IEP supports and services as a critical factor. Parents perceived their daughters’ designation as “high functioning” on their IEP, particularly high IQ scores as a liability and resulted in their daughters being
“underserved” by teachers and school staff. A recent study did find that girls with ASD received fewer school-based supports than their male counterparts possibly due to their higher levels of internalizing symptoms such as social anxiety, versus boys with ASD exhibiting higher levels of hyperactivity (May, Cornish, & Rinehart, 2013). Concerns regarding their daughters’ safety within the public school permeated parents’ narratives. They perceived their daughters with ASD as “vulnerable” and public school staff “resistant” to modifying the school environment to meet their needs more effectively.

Parents overwhelmingly expressed a strong desire for their daughters to be successful in the public schools and did not want their daughters to leave the public school community. The decision to move to an out of district placement came at a time of crisis for the 6 girls that transitioned in middle school. In the case of 3 of the girls, parents removed their daughters from the public school due to significant depression and suicidal ideation with the support of community based mental health professionals. The 4th girl was psychiatrically hospitalized for a second time and never returned to her public middle school. The last 2 girls transitioned out of public middle school through the IEP team process after repeated interventions proved ineffective. The process of leaving the public schools was described as very stressful for families. As one father stated, it was “so hard to know when it was time to acknowledge that she wasn’t going to make it [in the public school]”. A director of a private school for adolescents with ASD, describes parents as “traumatized” by the process of “fighting” with public schools for an out of district placement.

This same director, formerly a public school administrator, feels strongly that youth with ASD can “absolutely” be successful in the pubic school environment. Parents
and girls with ASD from the study sample were asked to describe important elements for building a responsive and inclusive public school community. The components identified included collaborative and respectful relationships with school staff, regular communication between parents and school staff, creating quiet and “safe spaces” within the larger school community for youth with ASD to take breaks and connect with therapeutic staff as needed, opportunities for girls with ASD to recognize and build on their strengths, and access to gender-specific ASD programming with other girls with ASD.

The girls from the study currently attending private schools reported experiencing positive programming, and improved success academically, emotionally, and socially. Despite experiencing significant “relief” when their daughters were placed in a private school, it was not a panacea. All of the girls experienced more success in a private school setting, and although mental health symptoms continued to be stressful, parents felt they were managed more effectively in a private school setting. The most significant “gain” in a private school setting reported by both parents and the girls was a “peer group” that facilitated a sense of belonging and acceptance.

**Managing Family Well-Being**

Although the families in the study sample were overwhelmingly resource rich, as evidenced by high rates of parent education, employment, and household income, the level of stress reported qualitatively and within the SIPA scale indicate that the families have experienced chronic stress in parenting a daughter with ASD. Chronic Stress is a construct that refers to a stressor of “long duration” that requires continual adaptation and management (Boss, 2002). The families in the study displayed high levels of resilience
in adapting to the chronic stress as evidenced by their ability to persevere and manage the unpredictable, but resilience came at a cost for other family members whose needs did go unmet at times. Siblings became accustomed to deferring to their sister’s needs, and mothers reported frequently feeling “overwhelmed” and experiencing isolation and depression.

_Pile-up_ of stressors occurred in families with a sibling diagnosed with a major mental health issue (6 families) and in families with at least one parent diagnosed with a mental health disorder (3 families). Stressor _Pile-up_ can be understood as families experiencing an accumulation of stressors that impact the overall level of stress within the family (Boss, 2002). Pile-up within families in the study resulted in less time to effectively cope and manage the stressors, often times leading to periods of family crisis. In one family the hospitalization of a sibling for depression and suicidal ideation resulted in a family crisis as the father was unable to cope effectively and the parents separated for 6 months. This family has since stabilized and is coping more effectively with a number of ongoing stressors. Socioeconomic status did not buffer pile-up within the family system.

Family well-being was impacted by how parents perceived the ASD and couples’ abilities to align their perceptions to coordinate effective parenting of their daughter with ASD. Five families continue to struggle in aligning their perceptions of the ASD, particularly in regard to behavioral expectations. Couples disagreed over the level of accommodation and flexibility necessary for their daughter. Six families have managed to align their perceptions and experience much lower levels of stress and conflict.
All of families had reached a turning point in their acceptance of the ASD diagnosis and a reconceptualization of their family. A turning point in a family system refers to a change in perception of the stressor (Boss, 2002). Accepting the chronic nature of their daughters’ ASD provided opportunity to reframe perceptions of both the ASD and what the family understood as “normal” expectations within the family system. A new “normal” was established within the family systems that integrated new ideas regarding family relationships and expectations. A turning point did not necessarily result in reduced conflict and stress in all families but it did mobilize family members to adapt and cope within the new “normal”. One common example for families was to accept the daughter with ASD’s absence from family activities and outings, such as allowing her to remain in the car while the rest of the family had dinner out in a restaurant. Another coping strategy, involved mobilizing the efforts of both parents and extended family members to assist in the homeschooling of their daughter with ASD for a full school year. Receiving “permission” from mental health professionals and AANE blogs to adapt family interactions that in typical families would be considered atypical, alleviated feelings of guilt.

**Strengths and Limitations of the Study**

This is the first study to date that examines the specific experiences of families adapting to and managing a daughter diagnosed with a high functioning autism spectrum disorder. Study samples on youth with ASD are overwhelmingly male and this exploratory study aimed to begin to address this gap in the research. The study provides a descriptive understanding of adolescent girls with ASD that has been missing from prior research. The inclusion of sibling and fathers strengthened the study as the family
was the unit of analysis and prior research has focused predominantly on mothers and excluded siblings.

These data provide a foundation for understanding families managing ASD, through a family systems lens. A number of constructs from family stress theory were applicable to the experiences of families coping with a child with ASD, and may inform both educational and social work practice.

The most significant limitation of the study is the lack of diversity within the sample. Although the goal of qualitative research is not the generalizability of the findings, the applicability of the study sample is limited to the study demographics. The study sample is Caucasian, heterosexual, predominantly highly educated, and of high socioeconomic status. Participation in the study involved a large time commitment from participants and may have precluded the participation of families with fewer resources and less time to participate. Families were recruited from a number of agencies and schools but may have inadvertently targeted families accessing ASD supports and resources. All of the study families were engaged in supportive services. It is likely that more isolated families with fewer resources were not accessed through the purposeful sampling strategies.

In qualitative research, the “researcher-as-instrument” involves significant threats to the validity of the findings (Padgett, p.185, 2008). The researcher of the current study was the sole interviewer and coder of the data. This increases the possibility that researcher bias occurred within both data collection and analysis (Padgett, 2008). Grounded theory methods are not strictly descriptive and do involve a high level of researcher interpretation. The recommended strategies to mitigate researcher bias during
data analysis were employed, particularly member checking, matrix displays, and conceptual models (Padgett, 2008; Miles & Huberman, 1994; Bernard & Ryan, 2010). The participant interview transcriptions and emerging themes were also shared and discussed with all members of the dissertation committee.

It is also possible that *respondent bias* occurred during data collection (Padgett, 2008). The focus of the research study was on parenting and coping with stressors related to the family system. Data collection involved the self-report of participants and it is likely that some respondents withheld information to avoid perceived judgment. Furthermore, it is possible that *reactivity* occurred, as the researcher spent considerable time with families in their homes (Padgett, 2008). The researcher’s presence in the home may have altered participants’ behavior.

In an effort to mitigate potential biases, strict adherence to grounded theory methods and strategies to increase rigor and authenticity of the findings were employed. Grounded theory methods do provide a structured format for implementing a qualitative research study.

**Implications for Utilizing a Family Systems Lens in ASD Research and Practice**

There is a strong tendency within mental health and education to focus intervention efforts on the child identified with a disability. The findings from this study indicate that stress is present within the entire family system. The health of the family system impacts a child’s functional level, particularly in a school setting. There is recent interest in developing a family systems theoretical framework in ASD research and practice (Cridland, Jones, Magee, & Caputi, 2014). This study contributes to the development of a family systems (FS) framework through the identification of FS
constructs that are applicable to families with a daughter with ASD. The constructs of denial and ambiguous loss figured prominently in the period prior to the ASD diagnoses and during the initial adaptation. Conceptualizing parenting of a daughter with ASD as a chronic stressor will facilitate a more accurate understanding of the process and could formulate more effective interventions. In social work practice, theoretical constructs such as ambiguous loss and chronic stressor provide a common language and understanding of a complicated process. There is utility in building practice-based theories that could potentially become the basis for evidence-based practices.

Parenting a daughter with ASD is a unique and at times isolating experience for family members. The findings from this study support prior findings regarding the potential “special needs” of high-functioning girls with ASD, specifically the significant level of comorbid mental health symptoms (Holtman, Bolte, & Poustka, 2007, p. 365). Each of the girls with ASD in this study’s sample presented with a complex constellation of symptoms and needs that required family members to continuously and creatively adapt. There is no “one size fits all” approach in building interventions for families parenting girls with ASD, however, utilizing a family systems lens in assessment, treatment, and research is more likely to identify the strengths and specific needs for this vulnerable population.

**Implications for Social Work and Educational Practice**

**Role of School Social Worker.** School social workers are in a potentially pivotal role in facilitating the success of girls with ASD at all levels (k-12) within the public school environment. Partnering with parents and teachers in early elementary school to assess potential social skill deficits could provide important opportunities to prevent
delayed ASD diagnosis. At the middle school level, identification and intervention with internalizing mental health symptoms and facilitating positive connections with the school community could lead to more positive outcomes for girls with ASD. Consistent with the NASW code of ethics, the role of social worker in school settings may include advocacy, educator, assessment, referrals, clinician, and collaborator.

A critical finding from the study involved parents not “trusting” public school staff and feeling “betrayed”, this included interactions with school social workers. Further research is needed on how school social workers perceive their roles and alliances with parents. There was some indication from the findings that social workers felt obligated to follow the lead of special education administrators and were not “straightforward” or “transparent” with parents regarding an ASD diagnosis and intervention needs. Parents perceived potential financial costs for services as the primary reason for school professionals not being more honest regarding their daughters’ needs.

**Building public school and family partnerships.** Shifting the adversarial relationship between public school staff and special education parents may facilitate better outcomes for girls with ASD and lower special education costs. Federal special education law, the Individuals with Disabilities Education Act (IDEA) of 2004, stipulates that parents are active members of the IEP team and should be involved in all stages of decision making. Parents in this study did not feel “respected” or “included” in the IEP process, consistent with prior research (Fish, 2006; Zeman, Swanke, & Doktor, 2011). Further research is needed on how to build collaborative and effective partnerships between public schools and special education parents. When communication broke down
in the current study between parents and school staff, collaboration regarding interventions and services for the girls with ASD also lapsed.

**Building Social Work Expertise in Neurodevelopmental Disorders.** There is limited instruction and curriculum within schools of social work focused on childhood neurodevelopmental disorders. Given the dramatic rise in prevalence rates, social workers will encounter families, children, adolescents and adults struggling to manage ASD within an array of settings. The Council on Social Work Education and accredited social work programs could develop avenues for increasing social work expertise in neurodevelopmental disorders, through a Certificate of Graduate Studies (CAGS) program and an Early Childhood Specialization within the Masters in Social Work Program. Social workers are the professionals most likely to be providing services within early intervention programs, pre-schools, and home-based services and would benefit from increased training in assessing symptoms of developmental disorders and working with families to access the appropriate interventions.

**Family therapists.** Family therapists with expertise in families managing ASD, could play a pivotal role in facilitating the acceptance of the diagnosis and assisting parents in aligning their perceptions of the ASD. Couples in the study who were unable to “get on the same page”, reported much higher levels of stress and conflict in the couple relationship. Giving families opportunities to share their fears, frustrations, and challenges together may facilitate more adaptive coping strategies. Assessing families through a family systems lens and working with constructs such as denial and ambiguous loss may reduce parents’ feelings of stigma, shame, and judgment.
Identifying Best Practices in Public School Programming for Girls with ASD.

There is currently no evidence-based public school programming for youth with ASD, but there is the potential for identifying best practices in current programming both public and private through program evaluation initiatives. The Massachusetts Department of Elementary and Secondary Education is likely to be in the most opportune position to identify current programming in the state that has been successful in intervening with girls with ASD. Public schools are currently implementing programming for girls with ASD without a clear model and direction toward outcomes. As empirical evidence continues to provide information on the needs of girls with ASD, it is critical that those needs are translated into programming. The current study identifies middle school as a time of increased risk of school failure for girls with ASD. Findings indicate that beneficial interventions during the middle school years would include increased attention to social and emotional needs. If social-emotional services are more directed during this developmental period, they may reduce expensive out-of-district school placements and reduce potentially negative outcomes for girls with ASD.

Implications for Policy

The Massachusetts Autism Commission Report released in March 2013 and initiated by Governor Deval Patrick, outlines a number of recommendations that could prove beneficial to the specific needs of girls with ASD and their families. The three primary areas that may be potentially beneficial include increased access to early intervention services, mental health services tailored for ASD, and a primary state agency to coordinate services for ASD.
**Early Intervention Programs.** Currently, early intervention services terminate at the age of three, and the Autism Commission recommends extending services through the age of five. This change could be instrumental in facilitating earlier detection of ASD and access to preventative services such as occupational and physical therapy, applied behavioral analysis (ABA), and parenting education and support. Four of the girls in the study were enrolled in EI following medical issues at birth but none were referred for further evaluation for ASD, despite evidence of classic autism symptoms such as echolalia, RRBI, and gross motor deficits. Social workers are instrumental in EI programs and have the opportunity to provide assessment, support, education, and referrals to families. Further training within both EI programs and MSW programs on early childhood developmental disorders, particularly ASD, is warranted given the dramatic growth in ASD prevalence rates.

**Recommendations for the Department of Developmental Services (DDS) and the Department of Mental Health.** When parents of girls with ASD pursue support through state agencies they are found ineligible. The Department of Developmental Services (DDS) would find the girls ineligible because their full scale IQs are well over the cutoff of 70, despite significant functional limitations. The Department of Mental Health (DMH) would also deny eligibility and access to services because Autism is a developmental disability. All of the girls in this study presented with co-occurring mental health disorders that had a significant impact on their functional level. The Commission recommends that the DDS expand its eligibility criteria to more of a functional skills assessment rather than a cutoff at a full scale 70 IQ. The Commission also recommends that those with autism and a co-occurring mental health disorder
receive access to DMH services. Identification of one state agency to coordinate services for ASD is recommended by the Autism Commission. This model would prevent further frustration and delay in services for families pursuing support.

**Implications for Educational Policy.** A major finding and source of significant stress for all of the families in the study was interfacing with the public school system and not understanding the policies and legal requirements within the IEP process. Not one parent was aware of the Massachusetts Autism IEP Act (MGL Ch. 71B Sec. 3), which requires IEP teams of children with ASD to consider and specifically address all aspects of their development in relation to the ASD. This includes social-emotional, social pragmatics, and in a recent update in 2010, addressing any bullying, harassment, or teasing from peers. This finding indicates a major gap in communication with parents regarding IEP policies and procedures. The majority of families in the study (9/82%) spent enormous amounts of time and money on educational advocates to develop an appropriate IEP, which often times created a contentious relationship between parents and school staff. In one family of lower socioeconomic status, the Department of Mental Health paid for an educational advocate to facilitate a more effective IEP. More effective communication of special education policies and procedures with parents, particularly parents with fewer resources, is necessary. IDEA could further stipulate a process for effectively disseminating information to parents. To be active members of the IEP team and strong advocates for their children, parents must have easily accessible and clear information on special education policies and procedures.

**Public health initiatives to address the misperception of ASDs.** Increased awareness of the symptoms associated with high-functioning ASD is needed to
counteract the misperception of ASD as a “boys’ disorder”. Delayed and misdiagnosis of girls with ASD appears to be associated with stereotypes regarding ASD and the tendency for both parents and health professionals to misperceive the social and communication deficits of girls. Girls with ASD may first be diagnosed with ADHD and/or a mental health diagnosis rather than ASD, which may limit access to appropriate assessment of needs and more effective intervention. Public health efforts to inform medical practitioners and parents on the potential for girls to be misdiagnosed or underdiagnosed may facilitate more consistent and accurate diagnostic practices.

**Recommendations for Future Research**

The dramatic rise in ASD prevalence rates over the last decade warrants further research to draw out the complicated manifestations and comorbidity among girls with high-functioning ASD. Although the new classification of ASD in the DSM-5 will likely bring more clarity and reliability in diagnostic practices, efforts to recruit representative and equivalent samples by sex, race/ethnicity, and socioeconomic status in research on ASD is needed. The CDC’s data is limited in its ability to generalize findings, because of the sample’s representative limitations. Research studies that target more urban and diverse public school systems may provide a new window into the experiences of young people with ASD. Race and socioeconomic status are two demographic variables that have not been adequately addressed within the ASD research. The samples are overwhelmingly Caucasian and middle to upper middle class. Further research is also warranted on the siblings of youth with ASD, as this study indicates that they encounter significant stress within the family system. Research focused specifically on siblings
may provide a more comprehensive understanding of their experiences and intervention needs.

Evidence-based gender specific programming for girls with ASD is needed both within public schools and community-based organizations. Although tentative, research findings indicate that girls with high-functioning ASD have different mental health needs than their male counterparts. Interventions are needed to more effectively address these mental health needs within public schools to support healthy identity development among these young women, and avoid school failure and costly out-of-district school placements. Next steps might include identifying current best practices within public and private school programs for youth with ASD and developing models to be pilot tested.

Research on the development of more effective behavioral interventions targeted specifically for high functioning ASD is needed to support the success of young people with ASD in school and home. Pilot testing models such as Dr. Ross Greene’s Collaborative Problem Solving Model (2008) within the public schools might prove useful in determining if a more flexible, collaborative and cognitively oriented approach would be effective. Traditional behavioral approaches, including applied behavioral analysis, utilized with these study participants escalated behavior within both the home and school environment. Behavior was one of the more significant stressors for parents and finding appropriate strategies and resources was very limited. Behavioral strategies that are effective and would facilitate increased mood regulation for girls with ASD would have a significant impact on their ability to successfully manage environments that trigger stress and sensory issues.
Grounded theory studies frequently provide opportunities to build hypotheses from the findings for future research (Strauss & Corbin, 1998). In this study, hypotheses could be generated in three areas: risk factors (bullying, increased psychiatric symptoms, suicidal ideation) associated with the transition to middle school and early adolescence for girls with ASD; outcomes (removal from public school, behavioral symptoms, psychiatric hospitalization, parental stress levels) related to early versus late ASD diagnoses; and variables (behavioral symptoms, late ASD diagnosis, psychiatric comorbidity) that may predict higher levels of parental stress. Although preliminary, the data provides a number of constructs and variables to test quantitatively in further research.

**Research Summary**

In summary, this study provides descriptive data on the lived experiences of 13 adolescent girls with ASD and their families. The study’s findings support the need for further research on girls with ASD, specifically the way in which girls may manifest ASD symptoms differently from boys and the way in which parents and professionals perceive these symptoms. Continued research and public health initiatives to dispel the perception of autism as a “boys’ disorder” are necessary to ensure early detection of ASD among girls and access to appropriate interventions.

Furthermore, the study findings support the need for a family centered model of ASD assessment and intervention. Families encountered a significant number of challenges in meeting the needs of their daughters with ASD at each developmental stage, creating high levels of stress within the family system. Utilizing a family systems lens within the development of interventions, holds promise for more positive outcomes.
for both girls with ASD and their families. Specific efforts by professionals to be responsive to the families’ unique contexts and to understand their process of adapting to the chronic stress are warranted.

Listening to the voices of girls with ASD is an important aspect of accurately understanding their specific needs. This study’s sample of girls with ASD was comprised of highly unique, creative, and intelligent young women with many strengths to offer their communities. They are hopeful that people will see their potential and provide opportunities for them to build on their strengths and share their unique talents.
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Appendix A: Qualitative Data Collection Instruments

Individual Primary Caretaker/Parent Semi-Structured Interview Guide

Script: Thank you for taking the time to talk with me today. Everything you share today will be confidential. Your identity will be disguised in the study’s write-up. Today we will be discussing your daughter’s early childhood development and diagnosis of ASD/HFA/AS. This interview will take approximately 1.5 - 2 hours. If at any time you need a break, please let me know. If any of my questions or the discussion becomes uncomfortable or confusing, please let me know and we can slow down and spend time answering any questions you may have. I will be audiotaping our interview today to make sure I understand your experience clearly. This audiotape will be destroyed by the researcher one-year after the completion of the study.

Warm-up Question:
1. In beginning today, I would like to ask you to share what you enjoy most about your daughter?

Appraisal of AS/HFA symptoms & Diagnosis (cognitive):

2. Could you describe your daughter during her first year of life? (prompts: birth, developmental milestones, eating, sleeping, & response to soothing?)
3. Could you describe your daughter during very early childhood - her pre-school years? (follow-up) Did she attend pre-school? Home? Primary caretaker? Interests? Play behavior? Did you notice anything different in her development compared to other children her age/siblings?
4. How would you describe her transition to elementary school? Did she like elementary school? How did teachers describe her K-2 & 2-4? Were there any behavioral difficulties during elementary school? Learning difficulties? Did teachers describe any difficulties with language or communication (verbal & nonverbal)? How well did she express herself?
6. How would you describe your daughter at home during elementary school (prompt – behaviors, sleeping patterns, relationships with family members)?
7. Did any helping professionals (teachers, counselors, doctors/pediatricians) ever discuss any concerns regarding your daughter’s development during elementary school?
8. When did you first discuss your concerns regarding your daughter and with whom (prompt - school staff, family member, pediatrician)?
9. Did you ever receive other diagnoses before receiving the AS/HFA diagnosis?
10. When did you first receive your daughter’s AS/HFA diagnosis? Could you describe the experience for me (prompt for specific experiences – where, how, with whom, responsiveness of helping professional)?

Emotional Appraisal of Diagnosis:

11. Could you describe your thoughts and feelings when you first heard about your daughter’s diagnosis (prompt to compare before dx)?
12. Were there differences in the way you and your (wife, husband, partner) first responded to the diagnosis?
13. At the time of her diagnosis, what, if anything, did you know about AS/HFA?

Individual Coping Strategies:

14. Were there any supports/services that you used after receiving the diagnosis (prompt for specifics & perceived helpfulness – online info/blog, support groups, books, AANE, counselor)?
15. Did you share the diagnosis with anyone (family members, school, etc.)? Why or why not?
16. Have there been changes in the way you think & feel about the AS/HFA diagnosis since first receiving the dx?
17. Could you describe what you find most challenging about your daughter’s behavior currently?
18. What specific actions do you take to cope with this behavior (problem-focused)?
19. How do you cope with this behavior emotionally (emotion-focused)?

Family Coping:

20. Do any of your daughter’s behaviors and needs impact your family? If yes, could you give me a recent example?
21. As a family, are there specific strategies that are used in response to your daughter’s needs and behavior?
22. How would you describe your daughter’s relationships with her siblings?
23. How would you describe her relationship with you? Her father/other parent? Extended family members?

External Supports:

24. Who has been most helpful to you in understanding your daughter’s diagnosis and needs?
25. Who has been most supportive to your family?
26. If you were to look back on the time period before you knew your daughter had AS, what stands out for you?

Meaning Making/Turning Point:
27. Are there any positive changes that have occurred in your family’s life since your daughter’s diagnosis (reconfiguring/making meaning)?
28. After having experienced the diagnostic process with your own daughter, what advice would you give other families just learning about their daughter’s diagnosis (transcend experience)?
29. Could you describe a recent situation or event that has made you proud of your daughter?
30. Is there anything else you think I should know to better to understand your family’s experience?
31. Is there anything you would like to ask me?

Ending script: Thank you again for talking with me. I appreciate your willingness to share your family’s experience. Once I listen to the interview, I may have some follow-up questions to make sure that I have an accurate understanding of your experience. I look forward to meeting with you & your (wife/husband/partner) on _______. Please do not hesitate to contact me if you have any further thoughts &/or questions.

**Dyad - Parent Semi-Structured Interview Guide**

Script: Thank you both for coming today. We will be talking today about how together you have managed your daughter’s needs since her diagnosis and her adjustment to middle school. Everything you say is confidential and if anything you share is used in the write-up of the study, your identity will be disguised. I will be audiotaping our interview so that I can be clear about the information you share today. If you have any questions or need a break, please let me know.

Dyadic Coping:

1. As a couple, how often are you able to talk together about your daughter?
2. In managing your daughter’s needs, what are the biggest challenges you encounter as a couple?
3. Could you describe what has been most helpful as a couple in managing these challenges?
4. Are there differences in the way each of you parent your daughter?
5. Have you made changes in the way you parent your daughter? Could you give an example?
6. Could you give me an example of a recent family activity that was difficult for your daughter? During this family outing, what was most difficult for you as parents?
7. Have either of you made changes to your professional life in order to accommodate the needs of your daughter?
8. Have there been changes in your relationship as a couple as you have worked together to manage the needs of your daughter?

School Based Questions:
9. Could you describe your daughter’s transition to middle school from elementary school? (prompt – what was most different for your daughter during the transition? What stands out for you in looking back on that time period?)

10. How does your daughter manage the academic expectations of middle school (prompt – homework, organization, transitioning in hallways/different classrooms, locker, academic materials – books, notebooks, writing, reading)?

11. How would you describe her social adjustment to middle school? (prompt – could you give me an example of a “typical/everyday” interaction with a peer, lunch room, recess, hallways, friends)

12. Has your daughter experienced any bullying type behavior from peers (prompt - define bullying, verbal harassment for ASD/HFA/AS)?

13. Could you describe a typical “morning routine” before school (prompt – getting up, dressing/hygiene, eating, organizing materials)?

14. Has your daughter ever refused to attend school? If yes, could you walk me through what happened?

15. Does your daughter participate in any extracurricular activities at school? School dances? How have these experiences been for her? Do you think they are positive experiences for her?

16. How would you describe the support your daughter receives in school (teachers, school counselors, principal, etc.)? Are there more supports you would like her to receive?

17. How much do school staff know about your daughter’s diagnosis of ASD/HFA/AS? Have you ever chosen to not disclose her diagnosis to school staff? Why or why not?

18. How would you describe your relationship with school staff (teachers, social workers)?

19. How would you describe your meetings with (school staff, psychiatrists, counselors) when discussing your daughter? Do you feel supported and listened to? Do you attend these meetings together, separately, shared responsibility?

20. Does she participate in community based activities not geared specifically for children with Asperger’s (sports, YMCA, dance, camps)?

21. Does your daughter participate in community based supports (counseling, psychiatrist, social groups) to address her AS/HFA? If so, what has been your experience with these supports?

22. How did you find out about these community supports for Asperger’s? Are there any supports you have been unable to access for your daughter?

23. Have either of you connected with the parents of your daughter’s peers?

24. How do other parents and friends of the family respond to your daughter? Are they aware of her diagnosis?

Hopes/Fears - Wrap-Up Questions:

25. As a couple could you describe your hopes for your daughter’s life ten-years from now?

26. Is there anything further that I should know about your and your family?
Ending script: Thank you for sharing your family’s story with me today. Once I listen to the interview, I may have some follow-up questions to make sure that I have an accurate understanding of your experience. Please do not hesitate to contact me if you have any further thoughts &/or questions.

Interview Guide – Girls with ASD

Beginning Script: Hi __________, thank you for talking with me today. As you know, I’ve been meeting with your parents to learn more about you & your family. Everything you share today is confidential, which means that no one will be able to identify you as the source of the information you share. If I write-up what you share, your identity will be disguised. Today I would like to focus on your experiences at school, with other kids your age, and your family. As you know, this study is learning about girls with (specify participant’s exact diagnosis – Asperger’s, high functioning autism, PDD, ASD) and your input is very important. I will be audiotaping our interview in order to make sure I get all of your thoughts. If at any time you need a break or feel uncomfortable, please let me know and we can stop and take a break. Do you have any questions before we get started?

Beginning Questions – close ended to ease into content & build rapport:

1. Your parents told me that you are very interested in (special interest, hobby, skill/strength) – could you tell me more about _____?
2. Where are you currently going to school?
3. How long have you been there?
4. How would you describe your school to someone your age who may start at your school?
5. What do you like most about school?
6. What is your least favorite thing about school?
7. How would you describe the teachers and staff?
8. Do you have a favorite adult at school? What do like most about he/she?
9. How would describe the other students?
10. Which students do you hang out with? What do you like about them?
11. Do you hang out with these kids outside of school? (If yes) What do you do together?
12. Have you ever had any problems with other kids at school? Could you describe a specific conflict you’ve had?
13. Has anyone ever made fun of you for being (diagnosis)?

Script: I’m now going to ask you some questions about being a girl with (diagnosis).

1. What does it mean to have (diagnosis)?
2. What are the best parts of being (Asperger’s, high functioning autism)?
3. What are the hardest things about being (diagnosis)?
4. Do you have friends with (diagnosis)? Girls &/or boys?
5. What should people who don’t have (AS, HFA, ASD) know about you and being AS,HFA, ASD?
Family/Home Functioning

1. After a day at school, what do your afternoons & evenings at home look like? (prompt – could you walk me through a typical afternoon/evening? Homework, relaxation/self-stimming activities, sibling interactions, parent interactions)
2. Who do you go to at home if you need help with something (homework, peer conflict, sibling conflict)?
3. Where do you feel most relaxed and calm (least amount of stress)?
4. What helps you relax after a stressful day?
5. Could you give me an example of a family activity that you enjoy the most? An activity you enjoy the least?
6. What would you change about your family if you could?
7. What is the best thing about your family?

Thank you for talking with me today – this was very helpful and important information. Do you have any questions for me before we end today? After I listen to our interview, I may have some follow-up questions for you – would it be okay to talk again?

Interview Guide – Sibling

Script: Hi __________, thank you for agreeing to talk with me about your family and your sister. Everything you share today is confidential, which means that no one will know what you have said, and I will disguise your identity when I write-up your thoughts. The purpose of this study is to better understand girls with ASD and their families. Your input is very important. I am going to audiotape our interview to make sure I get all of your thoughts. If you need a break or feel uncomfortable at any time, please let me know and we will stop and take a break. Do you have any questions before we get started?

(The following questions will be adapted according to the age and developmental level of the sibling.)

Beginning – close-ended questions to build rapport & comfort:
  1. How old are you _______?
  2. Where are you currently going to school?
  3. How do you like school?
  4. Your parents told me that you are really interested in (skill, hobby, sport, specific strength), could you tell me more about _______?

I am now going to ask you some questions about your sister.
  1. What do you think is your sister’s biggest strength?
  2. How would you describe your relationship with your sister?
  3. Most brothers (sisters) & sisters get into conflict with one another, could you describe the last time you & your sister had a problem?
  4. What do you know about your sister’s diagnosis of (AS, HFA, ASD)?
  5. When did you first find out about your sister having (AS, HFA, ASD)?
  6. What kind of support does your sister need from your family?
  7. What is most difficult about your sister having (AS, HFA, ASD)?
Thank you for talking with me today – this was very helpful. Do you have any questions for me before we end the interview?

Professional Providers - Interview Guide

Script: Thank you for taking time today to share your thoughts on girls with Asperger’s syndrome. This interview is confidential, and I will disguise your identity in the written study. As outlined in the informed consent, I am audiotaping this interview. If you have any questions or need a break, please let me know and I would be happy to stop. Do you have any questions before we begin?

Background:
1. Could you describe your professional background and how long have you been in your current position?
2. Could you describe your training and employment experience with AS/HFA?
3. In your program, what is the current ratio of boys to girls with AS/HFA?

Perceived Changes:
4. In your professional experience, could you describe any changes you’ve seen among the AS/HFA population?

Comparison of Males – Females:
5. In your recent experience here at …, do females with AS or HFA present differently than their male peers with AS/HFA? If so, could you give examples?

Challenges:
6. In working with AS/HFA girls, what behavioral symptoms do families find most challenging? Schools? Program staff?
7. Do you find a high rate of psychiatric comorbidity among the AS/HFA girls you see professionally? Do you notice differences in type of comorbidity between girls and boys?
8. Among AS/HFA peers, what are the primary social challenges for AS/HFA girls?
9. What do you perceive to be the most important supports for AS/HFA girls?
10. Do you provide supports/interventions (academic, clinical, social skills group) that are specific to girls? Which supports are most effective for girls?

Families:
11. In your opinion, what are the biggest challenges facing families with a female child diagnosed with AS or HFA?
12. Do you provide family based supports?
13. What types of supports would be most helpful for families?

Thank you for talking with me today, this was very helpful. Do you have any questions before we end the interview?
Appendix B: Family Contact Sheet and Family Demographic Questionnaire

Case # __________
This form to be completed by researcher & used for contact & scheduling purposes

Parent (1)
Name (first, middle, last): ________________________________
Age: __________ Date of Birth: ________________________________
Address: __________________________________________________________________

Phone number: __________ Cell Phone: __________
Marital Status:  
   __Married, __Single, __Divorced, __Separated, __Widow/widower, __Living with Partner

Parent (2)
Name (first, middle, last): ________________________________
Age: __________ Date of Birth: ________________________________
Address: __________________________________________________________________

Phone number: __________ Cell Phone: __________

Children:

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Parent Demographic Questionnaire
Case # __________

1. Highest Level of Education:
   Parent 1: ____________________________________________
   Parent 2: ____________________________________________

2. Job Title/Employment:
   Parent 1: ____________________________________________
   Full-Time: ___    Part-Time: ___
   Parent 2: ____________________________________________
   Full-Time: ___    Part-Time: ___
3. Race/Ethnicity (select one or more):

Parent 1:

__American Indian, __Asian, __Black/African American __Hispanic/Latino, __White
__Native Hawaiian/Pacific Islander, __Mixed Race, __Other

Parent 2:

__American Indian, __Asian, __Black/African American __Hispanic/Latino, __White
__Native Hawaiian/Pacific Islander, __Mixed Race, __Other

4. Total Household Income: __30,000-60,000, __60,000-80,000, __80,000-100,000,

__100,000 – 250,000, __250,000 – 350,000, __350,000+

The following questions are on your daughter with an ASD diagnosis

5. Daughter’s Age: ____ Date of Birth: ____________

6. Biological Child? Yes No

7. If Adopted, age of placement in home ____

8. Daughter’s Diagnosis (please check all that apply):

__Autism spectrum disorder (ASD)
__Pervasive Developmental Disorder (PDD-NOS)
__High Functioning Autism (HFA)
__Asperger’s Syndrome (AS)
__Social Communication Disorder

9. Age of First Diagnosis: ________________

10. Date of first Diagnosis: ________________

11. Please identify the professional that first diagnosed your daughter with an autism spectrum disorder:

Name: __________________________________________________________

Professional Affiliation (Pediatrician, Neurologist, Psychologist): _____________

Office name & address: ________________________________________________

12. Is there a family history of diagnosed &/or suspected autism spectrum disorder

(please specify family member & diagnosis)? ____________________________

_______________________________________________________________

13. Does your daughter have any sleep difficulties (please check all that apply)?
Difficulties falling asleep ___  Difficulties staying asleep ___
Difficulty waking-up in the morning ___  Other________________________
Approximate bedtime: _______  Approximate wake-up time: _______

14. Has your daughter ever been diagnosed with the following – please check yes/no & specify approximate age of diagnosis?

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>Yes</th>
<th>No</th>
<th>Age of Diagnosis</th>
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</thead>
<tbody>
<tr>
<td>Attention Deficit Hyperactivity Disorder (ADHD)</td>
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<tr>
<td>Depression (Dysthymia, Mood Disorder, Major Depression)</td>
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<tr>
<td>Bipolar Disorder</td>
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<tr>
<td>Anxiety (social anxiety, generalized anxiety disorder, panic attacks)</td>
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<tr>
<td>Oppositional-Defiant Disorder</td>
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<tr>
<td>Schizophrenia</td>
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<td></td>
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<tr>
<td>Other:</td>
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</tbody>
</table>

15. Is there a family history of any of the mental health diagnoses listed above (please specify family member & diagnoses)?

<table>
<thead>
<tr>
<th>Relationship to Daughter with ASD (i.e. father, brother, aunt)</th>
<th>Age</th>
<th>Diagnoses</th>
<th>Medication for Diagnoses Yes/No</th>
</tr>
</thead>
<tbody>
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</tbody>
</table>
16. Daughter’s Current School: __________________________________________
    Grade: __________________________
17. Private Special Education Placement (public school paying tuition): __ Yes __ No
18. Private School (public school not paying tuition): __ Yes __ No
19. Public School Regular Education Placement: __ Yes __ No
20. Public School Special Education Placement: __ Yes __ No
21. Current Individual Educational Plan (IEP): __ Yes __ No
22. Current 504 Accommodation Plan: __ Yes __ No
23. School/District Accommodation Plan: __ Yes __ No
24. Do you transport your daughter to school? __ Yes __ No
25. Please check all of the following services your daughter has received (either currently (C) or in the past (P)) within a school setting:
    ___ Individual Counseling ___ Group Counseling ___ Social Pragmatics
    ___ Social Skills Training ___ Behavior Plan ___ Functional Behavioral Assessment
    ___ Mentoring/Buddy ___ Occupational Therapy ___ Speech/Language
    ___ Physical Therapy
    ___ Other (please specify) __________________________________________
26. Please check all of the following services your daughter has received (either currently (C) or in the past (P)) within the community setting:
    ___ Individual Counseling ___ Group Counseling ___ Social Skills Group
    ___ Psychiatrist ___ Clinical Nurse Specialist ___ Neurologist ___ Psychologist
    ___ Mentor ___ Summer Program for ASD ___ Occupational Therapy ___ Speech
    ___ Physical Therapy ___ Other (please specify) ________________________
27. Daughter’s Medications Please specify Current (C) or Past (P):

<table>
<thead>
<tr>
<th>Medication</th>
<th>Purpose</th>
<th>Dosage</th>
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28. Daughter’s Current (C) and Past (P) Medical Diagnoses (Asthma, Gastrointestinal Disorders, etc.):

<table>
<thead>
<tr>
<th>Medical Diagnosis</th>
<th>Treatment</th>
<th>Current Treatment</th>
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29. Please complete the following table on the children (other than your daughter with ASD) you are parenting:

<table>
<thead>
<tr>
<th>Child #</th>
<th>Current Age</th>
<th>Sex (M/F)</th>
<th>Adopted (A) or Birth Child (B)</th>
<th>Medical/Learning Disability</th>
<th>Mental/Emotional Disability</th>
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