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# A phenomenological study of the lived experiences of adolescent females with Asperger Syndrome

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Walden University  
2008

ABSTRACT

A Phenomenological Study of the Lived Experiences  
of Adolescent Females with Asperger Syndrome

by

Lisa Marie Beteta

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Dissertation Submitted in Partial Fulfillment  
of the Requirements for the Degree of  
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Special Education

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## ABSTRACT

Minimal research focuses on females with Asperger Syndrome (AS). Without understanding the experiences of this population, the knowledge and understanding necessary for the development of appropriate diagnosis and supports is unavailable. The purpose of this phenomenological study was to gain insights into the challenges faced by females with AS by describing the central phenomena of their lived experiences from a critical feminist theoretical framework. Four participants were included in the study that explored their lived experiences pertaining to academic, home, personal, and social experiences including their recollections pertaining to these social contexts during elementary, middle, and high school. Data was collected through semi-structured, in-depth interviews, observations, and artifacts. Data were examined for significant statements that aligned to the research focus, and these were then coded into four significant thematic units to inform textual description and synthesis of shared experience. Four significant units emerged including victimization, anxiety, social issues, and age-appropriate interests. The essential conclusion was that female adolescents with AS share common interests, though qualitatively different, with neurotypical peers while continuing to battle internal and external circumstances. Analysis of nonconforming information pointed to the utility of other theoretical models in understanding the AS experience of young females. This research contributes to positive social change by providing a voice to females with AS, lessening their invisibility as a minority within a minority. Contributing such knowledge of the lived experiences of female adolescents with AS can lead to the development of better diagnostic criteria and appropriate supports.



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## DEDICATION

This dissertation is dedicated to my family. Justin Michael (1993-1999), you taught me so much in such little time. I love you, miss you, and will be with you again. Darcy, without you, I may not have ever known about Asperger Syndrome. You have taught me about the world and about myself as we journey through this adventure. Michael, without your tremendous support, everyone would have suffered. Thank you for cooking dinners, doing the grocery shopping, running the house, putting up with my quirks, and telling me, “you can do it!” You will now have your wife back. To Cyanna and Greyland, and my parents, Joe and Virginia Beteta, thank you for your patience and enduring the time it has taken me away from you.



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CHAPTER 1:  
INTRODUCTION TO THE STUDY

Introduction

Autism spectrum disorders (ASDs) has been used in the literature to refer to the various developmental conditions that include autistic type characteristics (Jordan, 2005). ASDs include autism, Asperger Syndrome, Rhett Syndrome, Pervasive Developmental Disorder, and Pervasive Developmental Disorder Not otherwise Specified. One of the conditions included in the autism spectrum disorders includes “classic” autism, which refers most often to the Kanner type autism (Kanner, 1943). “Classic” autism is also referred to as low functioning autism, where IQ is less than 70 (Tsatsianis, 2004). Individuals with high functioning autism, in comparison to low functioning autism demonstrate higher intellectual functioning, where IQ is greater than 70 (Leekham, Libby, Wing, Gould & Gillberg, 2000). Asperger Syndrome is considered by some researchers to be the mildest expression of the autism spectrum (Dillon, 2007). However, many researchers interchange the terms high functioning autism and Asperger Syndrome in the literature (Attwood et al., 2006; Baron-Cohen & Wheeler, 2003; Baron-Cohen & Wheeler, 2004; Beaumont & Newcombe, 2006; Bellini, Peters, Benner & Hopf, 2007; Crooke, Hendrix & Rachman, 2008; Halvorson, 2006; Losh & Capps, 2006; Müller, Schuler & Yates, 2008; Rajendran & Mitchell, 2006; Rubin & Lennon, 2004; Solomon, Goodlin-Jones & Anders, 2004). Another condition included in the autism spectrum includes pervasive developmental disorder not otherwise specified (Jordan, 2005). Researchers suggested that of the individuals on the autism spectrum, approximately 75%

are expressions of Asperger Syndrome, while 25% are expressions of classic autism (Baron-Cohen, 2005b).

Autism spectrum disorders have increased in recent years, in part to better diagnostic measures (Gillberg, Cederlund, Lamberg & Zeijlon, 2006; Iovannone, Dunlap, Huber & Kincaid, 2003; Jennings, 2005; Palmer, Blanchard, Jean & Mandell, 2005; Wilkinson, 2005; Yell, Katsiyannis, Drasgow & Herbst, 2003). According to the Centers for Disease Control, “1 in 150 eight-year-old children in multiple areas of the United States had an ASD [autism spectrum disorder]” (Centers for Disease Control, 2007). Currently, Minnesota has the highest rate of autism, with Maine coming in second, and Oregon third (Autism Society of Oregon, 2006). It should be noted that states use differing criteria to determine educational services, which might account for differing figures reported by states (Newman, 2007).

As states are reporting varying diagnostic rates, expressions in males and females are also different. The ratio of males to females affected with Asperger Syndrome is cited as 10:1 (Baron-Cohen, 2004, p. 137). While identification of autism spectrum disorders may occur during the first few years of life, the educational system seems to be recognizing the condition first (Howlin, 2003; Palmer, Blanchard, Jean & Mandell, 2005). However, referrals for autism spectrum disorder evaluations are primarily for males (Wilkinson, 2008). Attwood (2006) stated that the “ratio of males to females is around 10:1, yet the epidemiological research for Autistic Spectrum Disorders suggests that the ratio should be 4:1.”

## Background of the Problem

### *Pioneer Autism Spectrum Researchers*

Leo Kanner (1943), an Austrian American psychiatrist, described eleven children in the United States that shared similar characteristics. Kanner (1943) believed these children exhibited a unique syndrome. The foremost unifying trait of the children was their inability to “relate themselves” to other people (Kanner, 1943, p. 242). Kanner (1943) claimed the children demonstrated “extreme autistic aloneness.” Kanner’s work received international attention (Wing, 1981). In a different part of the world, another Austrian born psychiatrist made similar observations.

Less recognized than Kanner, Hans Asperger (1944/1992) observed childhood cases demonstrating behavior that he described as “autistic psychopathy” referring to the demeanor difference this population presented. Rather than continue using negative terminology, Asperger Syndrome has replaced the name of the condition described by Hans Asperger (Wing, 1981). Asperger (1944/1992) claimed that the condition he observed occurred more often in males than females. Asperger also believed that the condition could not be observed prior to 3 years of age (Wing, 1981). Unfortunately, knowledge of Asperger’s research remained virtually unknown until Lorna Wing brought attention to Asperger’s findings (Lee & Park, 2007).



### *Definition of Asperger Syndrome*

Since Hans Asperger (1944/1992) first identified certain characteristics of individuals with Asperger Syndrome, other researchers have contributed to the understanding of Asperger Syndrome (AS). In 1981, Wing identified seven characteristic areas of AS including lack of empathy, naïve or inappropriate interaction, little or no ability to form friendships, repetitive speech, poor nonverbal communication, intense absorption in certain subjects, and clumsy or ill coordinated movements and odd postures. Following Wing (1981), many other researchers have contributed to the characteristics displayed by the population with AS (Lee & Park, 2007).

In 1994, the *Diagnostic and Statistical Manual of Mental Disorders*, 4<sup>th</sup> edition (*DSM-IV*; American Psychiatric Association), first included AS (Attwood et al., 2006). Diagnostic criteria for AS include six areas (see Appendix B). The areas are as the follows (APA, 1994, p. 77):

1. Impairments in social interaction
2. Restricted repetitive and stereotyped patterns of behaviors, interests, or activities
3. Disturbance causes clinically significant impairments in social, occupational, or other areas of functioning
4. No clinically significant general delay in language
5. No clinically significant delay in cognitive development or in the development of age-appropriate self-help skills, adaptive behavior

6. Criteria are not met for another specific Pervasive Developmental Disorder or Schizophrenia.

### *Characteristics of Asperger Syndrome*

AS is a developmental condition (Asperger, 1944/1992; Wing, 1981). A prominent issue for individuals with AS is comprehension of societal norms. Myles and Simpson (2001) addressed this issue as the understanding of the “hidden curriculum.” Neurotypical individuals learn societal expectations without direct instruction (Myles & Simpson, 2001). Although individuals within a society are expected to learn society’s norms, individuals with AS cannot seem to learn these societal norms without direct instruction. Comprehension of societal rules is often assumed and therefore, expected of individuals who have no understanding of the importance of such expectations (Myles & Simpson, 2001).

Debate continues about the diagnostic differences between high functioning autism (HFA) and AS (Atwood, 2006; Hully & Larmar, 2006). Many researchers use the terms HFA and AS interchangeably (Attwood et al., 2006; Baron-Cohen & Wheeler, 2003; Baron-Cohen & Wheeler, 2004; Beaumont & Newcombe, 2006; Bellini, Peters, Benner & Hopf, 2007; Crooke, Hendrix & Rachman, 2008; Halvorson, 2006; Losh & Capps, 2006; Müller, Schuler & Yates, 2008; Rajendran & Mitchell, 2006; Rubin & Lennon, 2004; Solomon, Goodlin-Jones & Anders, 2004). For the purposes of this research, the term AS will be used, but may also refer to HFA.

### *Autism Spectrum Disorders and Females*

Since Kanner (1943) and Asperger (1944/1992) first described the characteristics of people with autism, the belief that males were impacted more often than females has been widely accepted (Howlin, 2003; Gillberg, Cederlund, Lamberg & Zeijlon, 2006; Wing, 1981). While males with autism outnumber females four fold, males with AS outnumber females ten fold. However, more recently researchers have stated that females with AS are most likely underdiagnosed (Attwood et al., 2006; Hully & Lamar, 2006; Kopp & Gillberg, 1992; Nydén, Hjelmquist & Gillberg, 2000).

Where are the females with AS? Are females with AS underdiagnosed? Are females being supported sufficiently? What is known about females with AS, and in particular, what are the lived experiences of adolescent females with AS? Without sufficient research into the experiences of this population, an understanding of the needs of females with AS cannot be achieved.

#### Problem Statement

Currently, much of the research on AS focuses on male participants (Hedley & Young, 2006; Klin, Pauls, Schultz & Volkmar, 2005; Winter-Messiers, 2007). Minimal research focuses on females with AS, and in particular, adolescent females with AS. The problem is there is a lack of understanding of this population. As a result, knowledge necessary for the development of appropriate diagnosis and supports is unavailable.

There are many possible factors contributing to the lack of research, including the ratio of males to females diagnosed with AS, which favors males 4:1 (Attwood, 1999, 2006). In addition, several factors make diagnosing females difficult, as there may be

differing behavioral characteristics displayed (Attwood et al., 2006; Baron-Cohen & Wheelwright, 2004; Hully & Larmar, 2006). There is more societal pressure for females with AS to exhibit appropriate social behavior (Hully & Larmar, 2006; Willey, 1999). As a result, females with AS may be provided more instruction in appropriate behaviors than males. Inappropriate behaviors often lead to diagnostic referrals. Another factor leading to a possible underdiagnosis of females with AS may include surrounding females, such as familial members or peers, who take the female with AS under their wings and provide needed support. For example, neurotypical female classmates may assist a female classmate with AS to shield her from being bullied or help her organize her materials. As a result, behavioral characteristics of females with AS are not as evident. Discussions that are more detailed will be included in chapter 3.

#### Statement of Purpose

The purpose of this phenomenological research study was to describe the central phenomena of the lived experiences of adolescent females with AS. Experiences pertaining to academic, home, personal, and social were examined. AS is defined as a neurologically based developmental disability demonstrating impairments in social communication and difficulty with appropriate social responsiveness.

#### Research Questions

##### *Main Question*

What are the lived experiences of adolescent females with AS pertaining to academic, home, personal, and social experiences?

### *Subquestions*

1. What were the experiences in elementary school?
2. What are the experiences in middle school?
3. What are the experiences in high school?
4. What are the academic experiences?
5. What are the social experiences?
6. What are the home experiences?

### Phenomenology

This research focused on a phenomenological approach that attempts to understand the lived experiences of adolescent females with AS. The researcher attempted to describe the essence of the social lives of female adolescent with AS as they navigate their world. Descriptions provided by participants provided understanding of their experiences. Information was gathered through interviews with participants, field notes, observations, and artifacts. Data collected through additional methods other than interviewing was of particular significance, since AS is associated with social difficulties. Data was analyzed and coded for thematic significance, and textural descriptions to determine the essence of participants' experiences. As research on AS has focused primarily on male participants, a phenomenological approach provided a voice to females with AS.

### Conceptual Framework

The conceptual framework chosen for this study channeled the direction of the research. A phenomenological approach provided an opportunity to examine the shared

experiences of adolescent females with AS. Society often socializes females to a more intense degree than males (Attwood et al., 2006). Through the theoretical framework of the critical feminist phenomenological approach, the perspectives of adolescent females with AS was examined. The critical feminist framework is established when people are being unheard. Critical feminist perspective subscribes to the notion that the lives of females will be improved because of conducted research (Barclay-McLaughlin & Hatch, 2005). As criteria developed to identify individuals with AS may be primarily based on the male population, females with AS may not be identified. As a result, appropriate supports and interventions may be developed and implemented.

This study focused on the phenomena of adolescent females with AS. Phenomenology is the examination of experience. Phenomenology condenses study participants' perceptions of their experiences and applies the experiences to the broader phenomena (Creswell, 2007). The individual experiences examined helped determine the similarities and attempted to understand the fundamental nature of the phenomena. This was understood through attempting to comprehend what and how adolescent females with AS experience various situations (Moustakas, 1994).

#### Definition of Terms

A list of definitions to terminology used in this study is included. Terms are listed in alphabetical order. Information pertaining to sources will also be included.

*Adolescent.* An individual between the ages of 13 and 19 years old.

*Asperger Syndrome.* A developmental disability on the high end of the autism spectrum that includes characteristics of lack of empathy, naïve or inappropriate

interaction, little or no ability to form friendships, repetitive speech, poor nonverbal communication, intense absorption in certain subjects, and clumsy or ill coordinated movements and odd postures (Wing, 1981).

*Aspie.* An individual with AS (Willey, 1999).

*Autism.* Sometimes referred to as “classic autism.” Classic autism is often associated with Kanner’s (1943) description of the syndrome. Classic or low functioning autism is typically is displayed with intellectual functioning below normal levels (IQ < 70) (Tsatsanis, 2004).

*Autism Spectrum Disorder (ASD).* A phrase used to describe pervasive developmental disorders the demonstrate impairment in communication skills, social interaction, and restricted, repetitive and stereotyped patterns of behavior” (National Institute of Mental Health, 2008). The disorders covered by the spectrum include autism, Asperger Syndrome, Rhett Syndrome, Pervasive Developmental Disorder, and Pervasive Developmental Disorder Not otherwise Specified.

*Critical Theory.* A theoretical framework implemented in qualitative studies that analyzes issues of estrangement or social conflict, while pursuing favorable results. (Creswell, 2007).

*Empathizing.* The tendency to relate to another individual’s emotions and ideas, and to react with an appropriate mental state. See Extreme Male Brain Theory (Baron-Cohen, 2005a).

*Extreme Male Brain Theory (EMB Theory).* Theory that claims that the majority of female brains are biologically predisposed towards empathic leanings and that the

male brain is mostly biologically predisposed for comprehending and creating systems (Baron-Cohen, 2005a).

*Feminist Theory.* A theoretical framework implemented in qualitative studies where the examiner is a part of the study to prevent “objectification” of participants and hopes to allow for positive changes to occur as a result of the research for the participants (Creswell, 2007).

*High functioning autism (HFA).* Used synonymously with AS by many researchers and is on the high end of the autism spectrum (Attwood, 2007; Baron-Cohen & Wheeler, 2003; Baron-Cohen & Wheeler, 2004; Beaumont & Newcombe, 2006; Bellini, Peters, Benner & Hopf, 2007; Crooke, Hendrix & Rachman, 2008; Halvorson, 2006; Losh & Capps, 2006; Müller, Schuler & Yates, 2008; Rajendran & Mitchell, 2006; Rubin & Lennon, 2004; Solomon, Goodlin-Jones & Anders, 2004). Individuals with HFA are often indicated as possessing cognitive abilities above standard score of 70. (Tsatsanis, 2004)

*Lived experiences.* Used in phenomenological research to communicate the experiences of the participants as authentic individuals (Moustakas, 1994).

*Mind-blindness.* The term ‘mind-blindness’ was first coined by Baron-Cohen to provide a description of how individuals on the autism spectrum perceive others (1990, 1997). See mindreading.

*Mindreading.* The ability to think about mental states including both the state of self or of another, and contemplate actions in terms of the mental states of the self or



others. Mental states include a variety of states such as beliefs, longings, and ambitions (Baron-Cohen, 1997; Baron-Cohen & Hammer, 1997).

*Neurotypical.* Term used to describe individuals that are neurologically typical. These individuals are not on the autism spectrum. This term is often used among individuals on the spectrum to describe normally functioning people Larson (2007).

*Nonverbal Learning Disability (NLD).* A set of neurodevelopmental deficits caused by white matter damage in the right hemisphere of the brain and is demonstrated by significant problems in social competencies, academic performance, visual spatial abilities, and motor coordination. Individuals with NLD demonstrate difficulties reading nonverbal communication (Little, 2003). Individuals with AS might display the learning profile of NLD (Little, 2003; Tsatsanis, 2004).

*Social Echolalia.* The observation of others who are socially skilled with the intent of mimicking their mannerisms, voice, and persona. A form of social mirroring leading to the acquisition of superficial social competence (Attwood et al., 2006).

*Systemizing.* The drive to analyze and explore a system, to extract underlying rules that govern the behavior of a system, and to construct systems. (Baron-Cohen, 2005a)

*Teenager.* See adolescent.

*Theory of Mind (ToM).* The ability to assign mental states to the self and others (Beaumont & Newcombe, 2006; Dahlgren, Sandberg & Hjelmquist, 2003; Premack & Woodruff, 1978). The existence of ToM precedes pretend play (Baron-Cohen, Leslie & Frith, 1985).

### Assumptions

1. Study participants honestly answer interview questions and effectively communicate their lived experiences.
2. Participants' diagnoses of AS were accurate.
3. Participants attend all scheduled in-depth interviews.

### Scope

The focus of this study included 4 adolescent females with a medical diagnosis of AS. All participants were between the ages of 13 and 19. This research included participants residing in the Pacific Northwest.

### Limitations

1. This research was limited by the number of participants included in the study. Nine potential participants were contacts. However, only four were able to participate in the study due to various factors.
2. This study may not be used to predict, as it is a snapshot of the experiences of the participants at a given moment in time.
3. The geographic location of this study was limited to Southern Oregon. The quality of this study would have been enhanced by a larger geographic area used to solicit participants.

### Delimitations

Neurotypical adolescent females, males with AS or HFA, and females with AS under 13 years of age and older than 19 years of age were excluded from this study.

Female adolescents that fit the criteria of the study living outside of the geographic location of the Southern Oregon were excluded from this study.

### Significance of the Study

According to researchers the number of diagnosed cases of autism spectrum disorders has risen in recent years (Iovannone, Dunlap, Huber & Kincaid, 2003; Jennings, 2005; Palmer, Blanchard, Jean & Mandell, 2005; Wilkinson, 2005; Yell, Katsiyannis, Drasgow & Herbst, 2003). As the rates of cases increase for autism spectrum disorders (ASDs), so does the need for knowledge pertaining to ASDs. Existing studies have primarily included male participants. This has left a gap in the literature pertaining to females with AS. Research is needed pertaining specifically to the female population with AS.

The significance of this research is the augmentation of literature pertaining to the knowledge of females with AS. Minimal research exists pertaining to the perspectives of this segment of the population with AS. Researchers have noted in the literature a need for additional knowledge pertaining to females with AS, and qualitative studies that provide a glimpse into the essence of the lived experiences and perspectives of individuals with AS (Carrington, Templeton & Papinczak, 2003; Klin, Pauls, Schultz & Volkmar, 2005; Winter-Messiers, 2007).

### Implications for Social Change

This study included information that enriched the foundation pertaining to what experiences female adolescents with AS have experienced, and may lead to future research validating theories in a quantitative format. Female adolescents with AS have

been assumed to have the same expression of AS as males. This study shed light on the experiences of this population, possibly leading to the development of better diagnostic criteria and development of appropriate supports for females with AS.

### Summary

The number of individuals with AS has increased over the past several years. According to some researchers, AS is now believed to comprise 75% of the population on the autism spectrum (Baron-Cohen, 2005b). However, researchers believe that females with AS are under-diagnosed (Attwood et al., 2006; Hully & Lamar, 2006; Kopp & Gillberg, 1992; Nydén, Hjelmqvist & Gillberg, 2000; Thompson, Caruso & Ellerbeck, 2003). As a result of underdiagnosis, appropriate supports may not be implemented for females with AS who need additional support. Males may engage in aggressive behaviors leading to immediate attention and diagnostic referrals. Females often display less aggressive behaviors. Behaviors that are easier to overlook or ignore may lead to parental oversight. As a result, pursuing professional opinions of behaviors or struggles of females with AS may not occur.

Currently, research studies are heavily weighted with male participants with AS, or do not include any female participants with AS (Bock, 2007; Crooke, Hendrix & Rachman, 2008; Klin, Pauls, Schultz & Volkmar, 2005; Winter-Messiers, 2007). As a result, current research exhibits a gap in the literature pertaining to any distinct needs of the female population with AS. In particular, little information exists pertaining to female adolescents with AS. While many studies exist that include female participants,

the ratio of females to males is minimal, and rarely focuses on the female portion of the population with AS.

This phenomenological study included an examination through the lens of a critical feminist perspective of the central phenomenon of the lived experiences of adolescent females with AS. Through the understanding of the experiences of this purposeful sampling, the intent is to derive an understanding of similarities and differences among adolescent females with AS. Through the acquisition of knowledge pertaining to this unique subpopulation, an understanding of specific needs will be understood that can lead to the development of appropriate supports specific to adolescent females with AS.

Chapter 1 included an introduction to the phenomenological study of female adolescents with AS, including background of the problem, research purpose and questions, conceptual framework, and significance of study. Chapter 2 will include a literature review of research pertaining to female adolescents with AS and surrounding phenomena. Chapter 3 includes a summary of methodology to be used in this study. Chapter 4 includes findings from this phenomenological study. Finally, a discussion of findings is contained in chapter 5

## CHAPTER 2: LITERATURE REVIEW

### Introduction

Chapter 2 includes a literature review relating to pertinent information surrounding this research. The areas examined in the literature review will include AS, sex differences, the Extreme Male Brain Theory, and females with AS. Chapter 2 is organized to provide an understanding of the phenomena of AS and how and why gender affects females with AS. Chapter 2 also includes information pertaining to the lived experiences of diagnosed females with AS who are known in various areas such as the media, popular culture, or academia. Chapter 2 closes with a brief discussion of the phenomenological method that will be implemented in this study.

### Research Strategy

As minimal research exists dedicated to females with AS, information gathered from peer-reviewed sources, biographies, books, and online sources are also included. Several databases were used in locating research articles. Databases included (a) Academic Search Premier, (b) Proquest, (c) SAGE, (d) Education Research Complete, (f) Educational Resource Information Center, (g) PsycARTICLES, (h) MEDLINE, and (i) PsychINFO. A search of keywords included *Asperger*, *Aspergers*, *Asperger Syndrome*, *Asperger disorder*, *autism*, *autism spectrum*, *female*, *girl*, *women*, *sex differences*, and *gender differences*. These keywords were used either singularly or grouped.

## Asperger Syndrome

Hans Asperger (1944/1992) first reported on a syndrome he termed *autistic psychopathy*. Approximately forty years later, Lorna Wing (1981) brought life to Asperger's forgotten work, and combined it with her research that brought international attention to the syndrome that now bears Hans Asperger's name. Asperger Syndrome, or Asperger's disorder, is included in the autism spectrum of disorders (Attwood et al., 2006).

Recent studies suggested an increase in the number of cases of AS (Gillberg, Cederlund, Lamberg & Zeijlon, 2006; Iovannone, Dunlap, Huber & Kincaid, 2003; Jennings, 2005; Palmer, Blanchard, Jean & Mandell, 2005; Wilkinson, 2005; Yell, Katsiyannis, Drasgow & Herbst, 2003). In light of a population with AS growing, additional knowledge is needed.

Debate exists as to whether AS is a unique syndrome by itself (Macintosh & Dissanayake, 2004). However, many researchers interchange the term AS and HFA in the literature (Attwood et al., 2006; Baron-Cohen & Wheeler, 2003; Baron-Cohen & Wheeler, 2004; Beaumont & Newcombe, 2006; Bellini, Peters, Benner & Hopf, 2007; Crooke, Hendrix & Rachman, 2008; Halvorson, 2006; Losh & Capps, 2006; Müller, Schuler & Yates, 2008; Rajendran & Mitchell, 2006; Rubin & Lennon, 2004; Solomon, Goodlin-Jones & Anders, 2004). The following section includes a discussion of the characteristics of AS.

### *Characteristics*

Several criteria exist for diagnosis of AS (American Psychiatric Association, 1994; Wing, 1981; Leekham, Libby, Wing, Gould & Gillberg, 2000; World Health Organization, 1993). Each of the diagnostic criteria exhibits similarities. According to Lee and Park (2007), the sets of diagnostic criteria most used for clinically diagnosing AS are that of the *Diagnostic and Statistical Manual of Mental Disorder*, 4th edition (*DSM-IV*; American Psychiatric Association, 1994), and the *International Classification of Diseases*, 10<sup>th</sup> revision (*ICD 10*; World Health Organization, 1993). Both the DSM-IV and ICD 10 contain comparable diagnostic criteria for AS. The literature review revealed additional characteristic areas.

*Gullibility and lessened empathy.* Individuals with AS might exhibit gullibility and demonstrate impairment in showing empathy towards others. Individuals with AS may be susceptible to bullying, as a result of their gullibility (Williams, 2001). Some researchers suggested that individuals with AS exhibit difficulty with theory of mind (Beaumont & Newcombe, 2006; Dahlgren, Sandberg & Hjelmquist, 2003; Fisher & Happé, 2005; Hinds, 2007; Kaland et al., 2002). Difficulty with theory of mind may make it difficult for individuals with AS to place themselves in the perspective of another. Feeling emotional reactions to others' circumstances may lessen the ability of individuals with AS to feel empathy towards others. Other researchers claimed that empathy expression might be linked to a biological basis (Baron-Cohen, 2005a).

*One sided interactions.* The individual with AS might appear to dominate conversations with others. Interactions with other individuals might appear one sided, or



appear self-centered in nature (Adams, Green, Gilchrist & Cox, 2002; Bellini, Peters, Benner & Hopf, 2007). The understanding of the conversational dance, where each partner takes a corresponding turn, may not be understood by the individual with AS.

*Difficulties with friendships.* Individuals with AS may demonstrate minimal social skills leading to difficulties in developing relationships with peers (Howard, Cohn & Orsmond, 2006). Reliance on cognitive skills for learning social rules, rather than intuitive abilities may be necessary (Attwood et al., 2006; Carrington, Templeton & Papinczak, 2003; Crooke, Hendrix & Rachman, 2008). Individuals with AS may exhibit difficulties with initiation, which may affect engagement with peers (Howard, Cohn & Orsmond, 2006). For example, initiating conversations, or asking to join a social session already in progress, may challenge the individual with AS.

*Language issues.* Conversations of some individuals with AS may sound scholastic in nature, or focus on a particular topic. However, language acquisition appears to be normal in development for individuals with AS (Macintosh & Dissanayake, 2006). Other individuals with AS may demonstrate elegant use of language in brief conversations. The appearance of sophisticated language use hides the difficulties encountered when faced with other authentic day-to-day situations requiring communication skills, such as difficulties when required to question others (Palmen, Didden & Arts, 2008; Rubin & Lennon, 2004). Social language involving the back and forth nature of conversation and the social niceties that many individuals learn unconsciously provide challenges for individuals with AS (Crooke, Hendrix & Rachman,

2008). Along with repetitive or pedantic speech, individuals with AS often demonstrate literal understanding of language (Berney, 2004).

*Difficulty with nonverbal communication.* Difficulties in understanding nonverbal communication and processing surrounding information provide issues for individuals with AS (Safran, Safran & Ellis, 2003). Difficulties may include interpreting facial expressions, deciphering voice intonations, and reading body language (Rubin & Lennon, 2004). Understanding the “hidden curriculum,” or norms and rules that are understood without direct teaching, presents a challenge to the individual with AS (Myles & Simpson, 2001).

*Unusual interests.* Individuals with AS may possess interests in topics that may appear unusual, and not held by others, such as electric fans or telephone books. The interest area of the individual with AS might appear “all consuming” (Winter-Messiers, 2007). In a recent study, individuals with AS claimed that positive emotional experiences existed during conversation pertaining to their special interests (Winter-Messiers, 2007).

*Issues with motor skills.* Motor skills may be impaired, and an awkward appearance of movement may be demonstrated by individuals with AS. Individuals may shy away from physical activity such as team sports. Individuals with AS may perceive depth inaccurately, affecting balance (Harrison & Hare, 2004). In addition to the motor aspects, sensory issues may plague the individual with AS.

*Sensory issues.* Along with difficulties associated with depth perception, individuals with AS may be overly or under sensitive to stimulation. Individuals with AS

may exhibit difficulty simultaneously processing multiple sensory channels. An abundance of sensory information may overload the individual with AS (Harrison & Hare, 2004).

*Disorganization.* Organization appears to be a challenge for many individuals with AS (Hurlbutt & Chalmers, 2004). Development of cognitive strategies and compensatory skills designed to overcome organizational issues may assist the individual with AS. Organizational issues may affect academic and employment situations.

*Learning style.* Research suggests that individuals with AS demonstrate specific learning style profiles (Little, 2003; Tsatsanis, 2004). Receptive language difficulties have been noted for individuals on the autism spectrum (Conti-Ramsden, Simkin & Botting, 2006; Singer & Bashir, 1999). Although receptive language was shown to be challenging, expressive language is a strength for individuals with AS. As a result, vocabulary and verbal problem solving strategies may work well for individuals with AS. For example, transitions from one concept to another can be simplified for individuals with AS using verbal cues (Tsatsanis, 2004).

Difficulties might include visual spatial processing. For example, a document that is cluttered with visual text may be over stimulating to the individual with AS. Challenges with maintaining attention, especially to visual information may present difficulties for individuals with AS (Tsatsanis, 2004). Additional research on learning styles of students with AS needs further exploration.

### Educational Services and Placement

The intention of legislation, such as No Child Left Behind Act (NCLBA) and the Individuals with Disabilities Educational Improvement Act (IDEIA), is to provide an education to students with a disability that need special education (Handler, 2006). NCLB requires that instructors be highly knowledgeable in the areas they instruct (Handler, 2006). Services provided to students are to be individualized (Ratcliffe & Willard, 2006). Least restrictive environment should be sought when offering services to students with special needs to allow for integration with typical peers (Ratcliffe & Willard, 2006).

School systems are encountering more and more students with autism spectrum disorders each year. Researchers claim that educational systems appear to first recognize the symptoms of autism spectrum disorders in students (Howlin, 2003; Palmer, Blanchard, Jean & Mandell, 2005). As a result, more and more students are being identified and entering special education.

Research suggests that effective programs designed for students with autism spectrum disorders consist of key components (Iovannone, Dunlap, Huber & Kincaid, 2003). The components include the following (Iovannone, Dunlap, Huber & Kincaid, 2003, p. 153):

1. Individualized student programs
2. Organized and systematic teaching
3. Structured and organized learning areas
4. Curriculum targeting deficits

5. Functional behavior interventions

6. Family cooperation

To be effective, educational staff should collaborate with parents to determine the direction desired for students. Through collaboration, appropriate programs can be designed to progress families' desires for their child (Iovannone et al., 2003). Special interest areas should be taken into account as possible avenues to introduce and teach concepts. Educational service quantity and intensity should be determined by the individual student's abilities (Iovannone et al., 2003). For example, if a student is capable of longer periods of instruction, such instruction should be granted. Similarly, if a student is only able to maintain attention for short periods of time, consideration of attention should be given when developing the student plan.

As more students are diagnosed with autism spectrum disorders, such as AS, educational systems should adapt to the needs students bring. A great deal of instruction in today's classrooms is conveyed through the verbal modality (Jordan, 2005). Classroom assessment of student work is often conducted through methods requiring abstract thinking such as essays, or group projects requiring social interaction (Crooke, Hendrix & Rachman, 2008; Jordan, 2005; Safran, Safran & Ellis, 2003). Both of these assessment techniques provide challenges for the student with AS. Social difficulties may be addressed through direct instruction of social skills (Bernard-Ripoll, 2007; Bock, 2007; Denning, 2007; Solomon, Goodlin-Jones & Anders, 2004). Collaboration between specialists, teachers, and parents is essential for the success of the student with AS (Wilkinson, 2005).

## Legal Implications

### *Educational Systems*

Educational systems may encounter legal implications in servicing students with autism spectrum disorders if services are not provided according to legal mandates.

Research conducted by Yell, Drasgow, and Lowrey (2005), suggested that Educational leaders should be well versed with the requirements of NCLBA. Educational leaders should require all associates engaged in the educational process of students covered under IDEIA and NCLBA to be familiar with the legal (Yell, Drasgow & Lowrey, 2005).

Knowledge and responsibility associated with the laws should be required of all educational associates that engage in the education of students with disabilities. Failure to follow the requirements of the laws may lead educational systems to possible litigation.

Educational systems should pay attention to three areas surrounding the services provided to students with autism spectrum disorders, including AS (Yell, Katsiyannis, Drasgow & Herbst, 2003).

1. Familiarization with and strict adherence to procedural guidelines
2. Use of scientifically based research in implementation of individualized student programs
3. Use of data collection and analysis to determine student progress and effectiveness of interventions

*Adult Issues*

Jennings (2005) claimed that courts proceedings are increasingly encountering divorce cases with either a child or parent on the autism spectrum, or both. Jennings (2005) suggested that legal professionals design parental plans that take into account the specific needs of children with autism spectrum disorders. For example, if the child exhibits a special interest area (SIA), parents may be required to maintain items specific to the SIA at both residences.

Jennings (2005) warns court professionals that parents with AS may appear highly intelligent, and mask their disability. Jennings (2005) suggested that women and girls with AS may present themselves differently than men and boys with AS. Assessment of parental capacity was recommended in determining custodial rights of parents (Jennings, 2005). Rather than view AS as a disability, could it be viewed as a difference?

#### Difference or Disability

Olfman (2002) offered that AS resulted from today's cultural values. According to Olfman, more time is devoted to "screens" that entertain such as computer monitors, videogames, and television, instead of human contact. Olfman (2002) claimed that while a genetic component may be called into play, environmental factors leading to AS might be involved.

In contrast to Olfman, Corsey (2005) suggested that society would benefit from more members having AS. Corsey (2005) claimed that honesty would become more

common, and fewer laws would be broken. Corsey (2005) viewed similar information to Olfman, but perceived the information differently.

Berney (2004) offered the possibility that AS might be a variation of typical behavior. Baron-Cohen (2002) questioned whether AS is a difference or a disability. While the term 'difference' is more socially acceptable, 'disability' enables the recipient of the label to receive governmental support. The main challenge exhibited by individuals with AS surrounds social interaction. If society lessened the demand for social interaction, would the individual with AS be considered disabled? As Berney (2004) offered the notion of the behavioral variations, Baron-Cohen (2004, 2005a, 2005b) looked further into the possibility. Examination of behavioral variation will be reviewed in a later section.

#### Sex Differences

While differences among genders exist overall, it is important to understand that individuals cannot be judged similarly. Individuals reflect the biological and environmental uniqueness experienced by that individual. When examining information pertaining to averages of males or females, differences emerge (Baron-Cohen, 2005b; Byrd-Craven & Geary, 2007; Thompson, Caruso & Ellerbeck, 2003).

Overall, at 12 months of age, females respond more empathetically to others' anguish, and exhibit behaviors that might be described as comforting (Baron-Cohen, 2005a). Women are believed to exhibit higher skills in the areas of interpreting nonverbal communication, comprehending meanings of tonality and expression, and determining character (Baron-Cohen, 2005a; Hall & Mast, 2008; Lawson, Baron-Cohen



& Wheelwright, 2004; Von Hellens, Nielsen & Beekhuizen, 2004). While aggression may be associated with males, females tend to exhibit less obvious belligerence, such as gossip, cliques, or harsh comments (Baron-Cohen, 2005a).

In contrast to females, at 12 months old, males prefer to view a car instead of a human face when provided an option (Baron-Cohen, 2004; Baron-Cohen, 2005a; Lawson, Baron-Cohen & Wheelwright, 2004). Males exhibit overtly combative behaviors more often than females, such as hitting and pushing (Baron-Cohen, 2005a). Males are believed to exhibit competitiveness and concern over hierarchical rank, focus on task accomplishment, and prefer communication as a means rather than an end (Baron-Cohen & Wheelwright, 2003). Males demonstrate advance skills in comparison to females in visual spatial abilities and math reasoning (Thompson, Caruso & Ellerbeck, 2003).

Typical males and females demonstrate differences in recreational activities even during the childhood ages (Thompson, Caruso & Ellerbeck, 2003). Males gravitate towards play that involves action, such as cars, wrestling, or building. Females gravitate towards recreational activities that are social such as playing with dolls or having tea parties. These preferences are also expressed through childhood drawings, as males tend to illustrate vehicles more often than females who often illustrate people and nature (Iijima, Arisaka, Minamoto & Aria, 2001). Male drawings also incorporate dimensionality more often than female drawings. Drawings made by males are more often masculine while, drawings made by females are feminine. Similar to childhood

experiences, typical males engage in more aggressive activities while typical females are more sensitive to social activities (Baron-Cohen, 2005a; Hall & Mast, 2008).

#### Lived Experiences of Individuals with Asperger Syndrome

Additional research is needed pertaining to the lived experiences of individuals with AS (Carlson, 2007; Carrington, Templeton & Papinczak, 2003). Some females with AS have stated that they identify more with males with AS than typical females (Miller, 2003). Understanding the social rules and nonverbal cues of many typical females, such as latest fashions or social hierarchy, proves extremely challenging (Attwood et al., 2006). Although challenges associated with AS characteristics appear to be less impacting in females, challenges continue to exist.

Individuals with AS have expressed difficulty with establishing friendships. Establishing and maintaining relationships was noted by both males and females with AS at various age levels (Carlson, 2007; Carrington, Templeton & Papinczak, 2003). Relational issues were noted in geriatric males with AS at the other end of the life continuum (James, Mukaetova-Ladinska, Reichelt, Briel & Scully, 2006). Anxiety, similar to friendships, has been noted as an area of difficulty for individuals with AS.

Anxiety has been reported as being experienced by both males and females with AS as they enter middle (Adreon & Stella, 2001; Carrington, Templeton & Papinczak, 2003). Middle school offers a significant routine change, as well as higher social expectations. For example, academic projects requiring group work are significantly increased. Similar challenges present themselves for students with AS in high school. Unlike males with AS, females with AS may be taken under the wing of nurturing typical

female students, lessening the challenges (Attwood et al., 2006). In addition, females with AS often attempt to mimic others socially, allowing them to appear to fit in the crowd (Attwood et al., 2006).

### EMB Theory

The extreme male brain (EMB) theory is also known as the empathizing-systemizing (E-S) model (Baron-Cohen, 2002; 2005a; 2005b). EMB theory claims biological and environmental factors lead to brain variances (Baron-Cohen, 2002; 2004; 2005a; 2005b). EMB theory provides a theory for generalizations, rather than for individuals. EMB theory suggests existence of three “brain types.”

#### *Empathizer (Female Brain)*

Females are typically associated with possessing heightened social abilities in comparison to males, as exhibited when playing with dolls (Baron-Cohen, 2005a). Females, rather than males, exhibit the empathizing brain type more often. Female brain types are “hard-wired” for empathy (Baron-Cohen, 2004, p. 1). Empathizers experience an appropriate emotional response to the feeling of others. The experience occurs to understand, predict, and connect with another (Baron-Cohen, 2004). While the average female exhibits strength in the skill of empathy, not all females possess the skill to the same degree. Some males may also exhibit skills similar to the female brain type.

#### *Systemizer (Male Brain)*

Similar to the empathizing brain, the systemizing brain type appears more often in males, yet also appears in females (Baron-Cohen, 2004, 2005a; 2005b). The systemizing brain is also called the “male brain” type. Male brains are “hard-wired” for both

“understanding and building systems” (Baron-Cohen, 2004, p. 1). Systemizing includes the desire to “analyze, explore, and construct” a system (Baron-Cohen, 2004). Some females may exhibit the male brain type.

### *Balanced Brain*

While empathizers may be connecting with others, and systemizers may be analyzing systems, a third brain type is encountered. The third type is the balanced brain. Balanced brains appear to be equal in ability to both empathize and systemize. Is there a developmental cause for brain types?

### *Prenatal Hormonal Exposure*

During development, testosterone is secreted in substantial amounts during three periods (Baron-Cohen, 2004; Knickmeyer & Baron-Cohen, 2006). The first surge occurs in the womb, between 8 and 24 weeks of gestation. The second surge occurs around 5 months of age. The final surge takes place during puberty. During these times, the brain is hypersensitive to hormonal changes (Baron-Cohen, 2004; Knickmeyer & Baron-Cohen, 2006). The amount of fetal testosterone influences the growth rate of the brain hemispheres (Baron-Cohen, 2004; Knickmeyer & Baron-Cohen, 2006). According to EMB theory, brain sensitivity to testosterone levels may influence the developing brain and behavior, including empathizing and systemizing traits. What is the link to autism?

### *Extreme Male Brain Theory of Autism*

The EMB theory echoes Hans Asperger (1944/1992) belief that the “autistic personality” is an “extreme male variant of the male intelligence” (Baron-Cohen, 2004, p. 149). EMB theory suggests that individuals with AS demonstrate heightened systemizing

and lower empathizing abilities. Rather than viewing AS as a disability, EMB theory provides a dimensional approach to the ability levels of individuals on the autism spectrum in variation to neurotypical individuals (Baron-Cohen, 2002). According to Baron-Cohen (2004, 2005b), autism might be viewed as an extreme expression of the systemizing brain type.

Researchers claim the connection of autism and “maleness” exists (Baron-Cohen, Lutchmaya & Knickmeyer, 2004; Knickmeyer & Baron-Cohen, 2006). The ratio of male to females with autism spectrum disorders favors males. Baron-Cohen (2004) also suggests that research on brain types provides support towards autism being an expression of the extreme male brain. Researchers suggest that prenatal exposure to testosterone may be connected to autism (Baron-Cohen, Lutchmaya & Knickmeyer, 2004; Knickmeyer & Baron-Cohen, 2006). In addition, evidence exists that support the inheritability of the “extreme male brain cognitive style” (Baron-Cohen, 2004, p.154).

### *Measures*

*Autism Spectrum Quotient – Adolescent Version.* Can the dimensions of empathizing and systemizing be used to differentiate between adolescents with AS and neurotypical adolescents? Researchers developed an instrument to quantify the autism spectrum quotient (AQ) for adolescents (Baron-Cohen, Hoekstra, Knickmeyer & Wheelwright, 2006). Researchers conducted a study comprised of three groups of adolescents that demonstrated normal cognitive functioning (Baron-Cohen, Hoekstra, Knickmeyer & Wheelwright, 2006). One group consisted of 52 individuals with AS or

HFA. Another group comprised 79 individuals with classic autism. The last group was a control group, consisting of 50 neurotypical participants.

When administered the AQ adolescent version, adolescents with an autism spectrum disorder demonstrated higher scores than the neurotypical control group (Baron-Cohen, Hoekstra, Knickmeyer & Wheelwright, 2006). The facets assessed on the AQ adolescent version did not change with age (Baron-Cohen, Hoekstra, Knickmeyer & Wheelwright, 2006). The AQ adolescent version is claimed to support the EMB theory of autism (Baron-Cohen, 2004; Baron-Cohen, Hoekstra, Knickmeyer & Wheelwright, 2006).

*Empathy Quotient.* Researchers engaged in a project to determine if quantifying one's "empathy quotient" could demonstrate divergence of neurotypical adults and adults with AS (Baron-Cohen & Wheelwright, 2004). In a qualitative study on the Empathy Quotient (EQ), individuals with AS scored below neurotypical participants on the EQ (Baron-Cohen & Wheelwright, 2004). The EQ supported the EMB theory, as the EQ was inversely correlated to the AQ and positively correlated to the Friendship Questionnaire (Baron-Cohen & Wheelwright, 2004).

*Friendship Questionnaire.* The Friendship Questionnaire (FQ) was developed to measure the dimensionality of one's ability to engage in supportive relationships (Baron-Cohen & Wheelwright, 2003). Researchers claimed that both male and female individuals with AS scored "significantly" below neurotypical male participants who took the FQ in a qualitative study. According to researchers, study results provided support for the EMB theory (Baron-Cohen & Wheelwright, 2003).

The EMB theory claims autism is an extreme version of the male brain (Baron-Cohen, 2004; Baron-Cohen, 2005b). Are females with AS examples of predominantly male trait brains? Are these male traits at times disguised in females with AS?

#### Sex Differences in Asperger Syndrome

Existing research studies primarily include male participants with AS, or do not include any female participants with AS (Baron-Cohen, 2004; Bock, 2007; Crooke, Hendrix & Rachman, 2008; Klin, Pauls, Schultz & Volkmar, 2005; Winter-Messiers, 2007). Differences exhibited by males and females have been shadowed by the quest of knowing incidence rates (Thompson, Caruso & Ellerbeck, 2003). While the ratio of males to females diagnosed with AS more highly favors males than at the lower end of the autism spectrum (Attwood et al., 2006; Thompson, Caruso & Ellerbeck, 2003).

Neurotypical males demonstrate certain strengths such as visual spatial and mathematical abilities, assertiveness, and creating structures. Males with AS demonstrate similar expressions to neurotypical males, but the expressions are more exaggerated (Baron-Cohen, 2004; Baron-Cohen, 2005b). As neurotypical males demonstrate lower social skills than females in general, males with AS demonstrate significantly lower social abilities. Males with AS typically fit the diagnostic criteria established with qualitative impairment in designated categories (Kopp & Gillberg, 1992).

While males with AS fit the existing diagnostic criteria necessary for AS, researchers suggest that females with AS may not (Attwood et al., 2006; Baron-Cohen, 2004; Jennings, 2005; Kopp & Gillberg, 1992; Thompson, Caruso & Ellerbeck, 2003). Some researchers suggest that as females may be “hard-wired” for specific brain

hemispheric skills such as verbal abilities and social skills, expression of AS may appear differently than in males (Attwood et al., 2006; Cohen, 2003; Hully & Larmar, 2006; Jennings, 2005; Kopp & Gillberg, 1992; Thompson, Caruso & Ellerbeck, 2003).

If females with AS present in a different manner, existing criteria used for diagnosis might be inadequate, particularly if the criteria was based on a large male population (Nydén, Hjelmquist & Gillberg, 2000). Do existing criteria enable correct diagnosis for females with AS? Do females experience similar degrees of difficulty in areas used to diagnose AS? How do the lived experiences of females differ from the experiences of males with AS?

#### Females and Asperger Syndrome

The ratio of males to females affected with AS is cited as 10:1 (Attwood et al., 2006, p. 2; Baron-Cohen, 2004, p. 137). However, Attwood (2006) suggests that the ratio should be closer to the 4:1 ratio that exists for the remainder of autism spectrum disorders. If this is the case, where are the females with AS? Minimal focus has occurred with relation to gender differences related to developmental disabilities (Nydén, Hjelmquist & Gillberg, 2000; Thompson, Caruso & Ellerbeck, 2003). According to Myles, the female population is “underdiagnosed” (Donovan, 2008). Other researchers concur with Myles (Attwood et al., 2006, p.2; Hully & Larmar, 2006; Thompson, Caruso & Ellerbeck, 2003).

Bottomer (2007) has suggested that the author Jane Austen might have been on the autism spectrum, as well as several of the characters created by Austen. According to



Bottomer, Austen might have met diagnostic criteria for an autism spectrum disorder.

Who are some of the women of today that are diagnosed with AS?

Women are the largest group of individuals that have a disability in the United States (Noonan, Gallor, Hensler-McGinnis, Fassinger, Wang & Goodman, 2004).

Several prominent women today have diagnoses of AS or HFA including Liane Holliday Willey, Donna Williams, Erika Hammerschmidt, and more recently, Heather Kuzmich.

Some individuals offer a substantial amount of personal information pertaining to their lived experiences, while other offer less information. The most widely known is probably Dr. Temple Grandin.

### *Temple Grandin*

Temple Grandin, PhD stated that her family provided needed interventions as a child (Grandin & Duffy, 2004). Grandin received speech therapy and social skill interventions. She was expected to participate in activities that would prepare her for situations encountered in adulthood. Grandin earned a doctorate degree and pursued a career in designing of facilities to handle livestock. Grandin publishes articles pertaining to her career, as well as books on autism. Grandin also engages in speaking engagements internationally (Grandin & Duffy, 2004).

Grandin shares a significant amount of her lived experiences through books and DVDs (Grandin, 1996; 2003; 2004; 2006). Highlights of her lived experiences pertain to how she experiences the world and the descriptions she provides for her audience. Grandin (2003; 2006) stated that she “thinks in pictures.” Grandin also offers insight into her journey from childhood into adulthood.

Grandin (n.d.) stated that she began to experience anxiety attacks during at puberty upon beginning of her menstrual cycle. Medication alleviated the attacks. Grandin was expelled from high school before attending a boarding school for gifted students with behavioral issues. While Grandin's (n.d.) mother served as her mentor during her earlier years, Grandin's aunt served in a similar capacity during her adolescent years.

*Liane Holliday Willey*

Liane Holiday Willey, EdD is a writer, consultant, and speaker on AS. Undiagnosed as a child, Willey was diagnosed after a family member received a diagnosis of AS. Willey coined the term "aspie" to describe individuals with AS. Willey (1999) claimed that she would be associated with the term "aspie" than a man's namesake.

Willey (n.d.) stated an awareness for her differences and believed herself to be "odd." Willey claimed she was "prone to reclusiveness and eccentric behavior" and suffered from issues surrounding poor self-esteem. Willey acknowledged her differences as her daughter began to display similar characteristics, and both were eventually diagnosed with AS. Willey indicated that prior to her recognition of having AS, she felt ashamed of her differences. Following her diagnosis, Willey felt "free" to be who she was.

*Donna Williams*

Donna Williams is an Australian writer that has published several books regarding her lived experiences. Williams also engages in other artistic endeavors

including painting, music composition, and screen writing (Williams, n.d.). Williams was not diagnosed as being on the autism spectrum until she was in her 20s (Williams, 1994).

In describing her lived experiences, Williams (n.d.) described herself as “an alienated out of control feral child.” Williams claimed her disposition allowed her to learn about “assumptions, integrity, resilience, passion, adaptability, war, humility, empathy, and it made me a natural anthropologist.” Williams (n.d.) claimed she lived in an “emotional and perceptual chaos” which helped her to understand that “normality” is relative. While Grandin’s (2003; 2006) thought processes were based upon visual imagery, Williams (n.d.) cognitive processes involve sound, pattern, and texture.

*Erika Hammerschmidt*

Erika Hammerschmidt was diagnosed with AS and Tourette Syndrome as a child. Hammerschmidt (2008) captured the essence of her lived experiences vividly and with humor in *Born on the Wrong Planet*. Hammerschmidt writes on issues she faced pertaining to school, peers, employment, and the opposite sex, among other topics.

Some highlights from Hammerschmidt's book on her lived experiences include her childhood, adolescence, and young adulthood. Hammerschmidt (2008) shared her vivid recollections indicating that she was bullied by others:

I never once got sexually molested by an adult. Just emotionally molested by other children, nonstop through grade school! It's amazing how important gender is to people who haven't even gotten to puberty yet. They couldn't stop teasing me, and I couldn't stop being hurt by it. By the time I realized the entertainment potential of being able to pass for male, I was already starting to look too female for it to work. (Hammerschmidt, 2008, p. 26)

Hammerschmidt (2008) stated that during her adolescent years, she lacked the understanding of typical female rules pertaining to attire. Hammerschmidt claimed she was unaware of the need to wear a bra under tight shirts. This led to male attention for which she was not cognizant of the reasons.

Boyfriends were also experienced during Hammerschmidt's teen years. However, she claimed that her ability to navigate the relationships were underdeveloped, leading to hurt feelings of her suitors. Hammerschmidt (2008) stated that her social abilities have improved since childhood. However, she still has difficulty deciphering comment appropriateness until observing facial expressions.

*Heather Kuzmich*

Heather Kuzmich recently emerged as a female with AS in the popular media. Kuzmich was featured on a popular television show that was searching for fashion models. However, Kuzmich's appearance has opened up the eyes of millions of viewers to AS. Kuzmich was voted one of the "most popular contestants" in the show's history (Parker-Pope, 2007). Kuzmich's exposure in the popular media might provide opportunities as a role model figure for young girls with AS (Parker-Pope, 2007).

Kuzmich stated in an interview with a national newspaper that she was accustomed to being ignored by others and was concerned that others "would laugh at me because I was so very awkward" (Parker-Pope, 2007). Kuzmich reported in the interview that friendships were nonexistent during her childhood. According to the interview, Kuzmich recognizes the positive impact her attention has had on her mother.

In a separate interview, Kuzmich indicated that maintaining eye contact was not an issue for her as she had attempted to increase her ability in that area (ShrinkingViolet, 2007). Kuzmich stated that talking in social situation continues to be a struggle for her. Kuzmich claimed that other females on the reality show were nurturing and protective when others attempted to bully her. Kuzmich indicated that her ability to engage in conversation with others was greatly improved through repeated practice while involved in the show.

#### Adolescent Females

Neurotypical adolescents have increased responsibility placed upon them, such as additional household chores, caring for younger siblings, and obtaining employment (San

Antonio, 2006). Neurotypical adolescent females are often portrayed as engaging in vast amounts of socializing with other neurotypical peers in the popular media. In current society, the character of *Hannah Montana* might be viewed as exhibiting neurotypical female behaviors and demonstrating the multiple roles and responsibilities young girls engage in today (Disney Channel, 2006).

Neurotypical females focus on four areas including the following (Attwood et al., 2006):

1. Physical appearance and appeal
2. Understanding place in social hierarchies
3. Satisfying social requirements and norms
4. Maneuvering aggressive females

Many of the neurotypical adolescent female characters shown on television can be observed as engaging in maneuvering situations involving the previously mentioned four situations. Neurotypical females appear to exhibit more sensitivity in social interactions than males (Hall & Mast, 2008). Females with AS encounter difficulty when attempting to navigate these situations, as their social awareness is less developed than neurotypical females. Are the lived experiences of adolescent females with AS similar to the experiences of neurotypical adolescent females? How similar? What are the experiences of adolescent females with AS?

#### Diagnosis and Gender

Existing diagnostic criteria for AS are the same for both genders and includes impairments in the following areas (Wing, 1981):

1. Social impairments
2. Communication impairments
3. Restricted range of interests or thought rigidity
4. Normal language and cognitive development

Researchers have suggested that existing criteria may be based on male expressions of the disorder (Kopp & Gillberg, 1992). Researchers suggest that for females to be diagnosed using existing criteria, their observable characteristics must be exaggerated in order to score sufficiently to warrant a diagnosis (Hully & Larmar, 2006; Kopp & Gillberg, 1992).

Attwood (1999; 2006; 2007) suggested several possible scenarios as to the reason leading to fewer female diagnosis of AS. One reason might include a reluctance to pursue evaluations as the female might present with issues, yet familial members may be unsure as to the degree the issues need intervention. This “hesitancy” may lead to the delay or negligence of seeking an evaluation, as the female may be coping sufficiently (Attwood et al., 2006).

Another potential reason leading to the delay or negligent recognition of females with AS may involve stereotypical behaviors of genders. Males tend to be more aggressive and assertive than females (Baron-Cohen, 2005a, p. 24). When there is an expression of AS, the Extreme Male Brain (EMB) theory suggests that the behaviors may be exaggerated (Baron-Cohen, 2005b). The demonstration of aggressive behaviors typically is noted by teachers and parents. Such behaviors may quickly lead to an

evaluation by a professional, who may also recognize the characteristics of AS (Attwood et al., 2006).

Females with AS may demonstrate characteristics less obviously than males, including aggression. Some characteristics, such as atypical visual reactions and inappropriate stereotypic recreational activities were less common in females than males when intellectual ability was controlled (Lord, Schopler & Revicki, 1982). Social skill difficulties in females might be viewed as being a personality trait, such as shy or passive, rather than a developmental disability (Attwood et al., 2006; Ernsperger & Wendel, 2007). Attwood et al. (2006) finally offers that females with AS tend to be more “motivated” and “quicker” to grasp social concepts. As a result, parents may hesitate to pursue a professional opinion regarding difficulties the female might encounter.

#### Characteristics of Girls with Asperger Syndrome

Researchers have stated that the phenotype of females with AS might appear differently than in males (Kopp & Gillberg, 1992). The different phenotype might have resulted in the lack of recognition of AS in females. Researchers have suggested that characteristics are less intense than characteristics expressed in males with AS (Attwood, 1999; Cohen, 2003; Kopp & Gillberg, 1992; Hully & Larmar, 2006). What characteristics appear in females that are different from males with AS?

Girls with AS often demonstrate artistic interests such as poetry, creative writing, drawing, and drama (Cohen, 2003; Miller, 2003; Winter-Messiers, 2007). For example, girls with AS often demonstrate an interest in Japanese cartooning, or anim .



Researchers suggest that girls with AS demonstrate more passive personalities (Attwood, 1999; Cohen, 2003).

Passive personalities may result in girls with AS. Engagement in “social play” with toys such as dolls or stuffed animals may occur (Attwood, 1999; Cohen, 2003). Lack of natural social ability, apprehension towards socialization, and passivity might be reasons social expression occurs with items or through their imagination, rather than with peers. Developing friendships with others may be difficult (Howard, Cohn & Orsmond, 2006).

Kopp and Gillberg (1992) suggested that girls with social impairments demonstrated “clinging” behaviors and imitated behaviors involving “speech and movement” of those around them. Researchers refer to the mirroring of behavior as a social echolalia (Attwood et al., 2006). The behavioral imitation often hides social ineptness of females with AS (Attwood, 1999; Cohen, 2003). Social echolalia is less evident in males with social deficits (Kopp & Gillberg, 1992).

More evident in girls than boys with social deficits were “repetitive questioning” (Ehlers & Gillberg, 1993; Kopp & Gillberg, 1992). According to Kopp and Gillberg (1992), some girls with social deficits demonstrated less visuospatial abilities than males with social deficits. This decreases a female’s ability with social deficits to engage in self-stimulation activities that are visual. This characteristic is commonly associated with autism spectrum disorders.

Researchers suggested that the number diagnosed females with AS might increase if the cases currently diagnosed with other conditions were evaluated, and thorough

developmental histories were analyzed (Kopp & Gillberg, 1992; Hully & Larmar, 2006).

According to researchers, other conditions divert diagnosticians' focus away from suspecting and diagnosing for AS (Kopp & Gillberg, 1992).

#### *Females and Comorbid Conditions*

Researchers have suggested that females with AS are often diagnosed or misdiagnosed with comorbid conditions, rather than diagnosed with AS (Gillberg, I., Rastam, Wentz & Gillberg, 2007; Kopp & Gillberg, 1992). Some of the other conditions females with AS may be misdiagnosed or diagnosed with include the following conditions (Cohen, 2003; Gillberg, I., Rastam, Wentz & Gillberg, 2007; Kopp & Gillberg, 1992; Zucker, Losh, Bulik, LaBar, Piven & Pelphrey, 2007)

1. Anorexia nervosa
2. Obsessive compulsive disorder
3. Mild paranoia
4. Unusual voice patterns
5. Learning disability
6. Sensory integration
7. Attention deficit hyperactivity disorder
8. Anxiety
9. Depression

Are comorbid conditions diverting appropriate diagnoses of girls with AS? The milder expression of typically acknowledged characteristics of AS might lead clinicians to overlook considering a diagnosis of AS. Diagnosticians might be attempting to control

the presenting condition and not engage in sufficient developmental histories of female patients.

### Summary

Chapter 2 included a literature review relating to pertinent information surrounding this research. An exhaustive review of existing research indicated that minimal research exists on females with AS. The areas examined in the literature review included AS, sex differences, the Extreme Male Brain Theory, and females with AS. Brief descriptions were also included on diagnosed women and their lived experiences.

Autism spectrum disorders are occurring with greater prevalence. Given current ratios with males diagnosed more often than females, the phenotype of autism and diagnostic criteria for autism spectrum disorders has been based primarily on males. Attwood (1999, 2006) claimed that the “ratio of males to females is around 10:1, yet the epidemiological research for Autistic Spectrum Disorders suggests that the ratio should be 4:1.” The extreme male brain theory suggests that autism spectrum disorders may be the result of an extreme dominance of the male type brain (Baron-Cohen, 2004). The cause of the male type brain may be the level of prenatal testosterone exposure (Baron-Cohen, Lutchmaya & Knickmeyer, 2004). Females with AS may have been exposed to higher levels of testosterone, according the extreme male brain theory. As neurotypical females typically have different characteristics and strengths, the female with AS may be reflecting the condition of AS in different ways than males with AS, such as milder expression of characteristics typically associated with AS. Chapter 2 closed with a brief discussion of the phenomenological method that will be implemented in this study.

Chapter 3 includes a discussion on the methodology used in this study. Specific information pertaining to the study population and the data collection and analysis will be discussed. Information pertaining to a pilot study is also included in chapter 3.

## CHAPTER 3: METHODOLOGY

### Introduction

Chapter 3 includes an examination of the theoretical framework of phenomenological research and the suitability for addressing the purpose of this study. Research design will be discussed in this chapter. Chapter 3 also includes information pertaining to participant selection, ethical issues, data collection, management, and analysis, and a previously conducted pilot study related to the protected population of female adolescent with AS.

Qualitative research utilizes various methods to ensure validity and reliability. A discussion of the various tools used in this study to ensure validity and reliability of research is incorporated in this section. Among the tools used, epoche played a significant role in this study. Self-reflection on and understanding of the fundamental nature of a phenomenon allow researchers to chronicle the “qualities, meanings, and essences” of the distinctive experiences of participants (Moustakas, 1990, p. 13). A critical feminist framework was implemented which was supported by the notion that females with AS are thought to be a “minority within a minority” (Attwood et al., 2006).

### Research Questions

#### *Main Question*

What are the lived experiences of adolescent females with AS pertaining to academic, home, personal, and social experiences?

### *Subquestions*

1. What were the school age experiences in elementary school?
2. What are the school age experiences in middle school?
3. What are the school age experiences in high school?
4. What are the academic issues?
5. What are the social issues?

These questions assisted in focusing the exploration of the study. The intent of the study was to gain a deeper understanding of the lived experiences of adolescent females with AS. Thorough answers to each research question were not anticipated. A glimpse into the lives of research participants in reflected areas was desired.

### Research Design

Several research methodologies were evaluated in selecting a design for the study. In conducting the literature review, it was noted that while a significant number of studies focused on AS, few focused on or included equal number of female participants. A deeper understanding of females with AS appeared necessary (Attwood et al., 2006; Hully & Larmar, 2006). This gap in the literature led to the dismissal of a quantitative design, in favor of a qualitative study.

Each of the qualitative approaches was examined for appropriateness to the purpose of the study. A grounded theory approach was considered, and then rejected, as the purpose of the study was to develop deeper understanding of a particular population of society, rather than to develop theory. While a case study may have suited this study, an examination of several participants was desired that focused on a shared phenomenon,

so the case study approach was dismissed. An ethnographical approach was then contemplated. Ethnography focuses on the significance of actions, communication, and relations among a “culture-sharing group” (Creswell, 2007, p. 68). The researcher rejected the ethnographical approach, as the intent was not to examine the actions or culture of females with AS, but to obtain a deeper understanding of the lived experiences of the phenomenon. Following the ethnography, the narrative approach was evaluated. Thematic significance was desired, rather than individual theorization that accompanies the narrative approach. While narrative passages were included, the narrative approach was rejected. The phenomenological approach was selected as it best fit the purpose of this study. The phenomenological approach explores for significance and nature in “significant human experience” (Douglass & Moustakas, 1985, p. 40).

Reliability and validity are discussed in research studies. Phenomenological research is subjective in nature. Reliability in qualitative studies is pursued in different methods than in quantitative research (Creswell, 2007). In addition, methods used to assure reliability and validity often overlap. As explained below, researcher reflexivity, audit trails, member checks, and triangulation become the tools of the qualitative researcher in evaluating reliability.

Researcher reflexivity involved the reflection of the researcher in recognizing the thoughts and feelings experienced during the research journey. The audit trail consisted of notes documenting the various steps along the study. Participants reviewed their words in member check to verify the accuracy of their meaning. Triangulation was used

through the combination of the various techniques to ensure the study demonstrated both reliability and validity.

Rich thick description that provides vivid details offered insight into lived experiences of participants. The subjective nature of qualitative research provided data in the form of a snapshot in time that pertained to a given moment. The intent of phenomenological research is to gain deeper understanding.

#### Ethical Issues

Some individuals with AS may demonstrate difficulties with executive processes, as well as understanding social situations. In addition, the population that was studied consists of minors. As a result, special consideration was taken to ensure that participant privacy and safety are protected (Belmont Report, 1979). Half of the participants of the current study were under 18-years of age. Institutional Review Board (IRB) approval was obtained for the current study and documented in approval number 08-18-08-0148954.

AS is marked by impairments in communication. However, interviews were based on the communication between participant and researcher, which could be a concern. It was important to balance the discomfort with communication and the requesting of information so that participants remained comfortable and the information exchange remained smooth. Only through mutual ease of conversational partners were the experiences of the participants learned.



### Confidentiality

Once data was collected, all identifiable information was eliminated. This included information disclosed through interviews, observations, or artifacts. All signed forms and information pertaining to the study were maintained in locked files or password protected if digitally maintained. Signed information will be destroyed after 5 years. Within the discussion of study results, a number was assigned to each individual study participant.

### Study Population and Sample

This study was conducted within two large counties within the in the Northwest. The population of these counties combined is approximately 300,000 residents. Setting selection was determined based on accessibility for data collection purposes and proximity to researcher. All participants came from the same state. One of the participants lived half the year in one state, and the other half in another.

### *Recruitment*

Within the Northwest counties, communication with autism specialists, school districts, and community groups were made in order to locate study participants. Community research partners received a letter explaining the nature of the study and requesting their assistance in locating possible participants (see Appendix D).

An invitation letter was prepared for parents explaining the purpose of the study. The letter stated interviews were to occur with parents and their daughters pertaining to questions surrounding their daily lives. The letter indicated that precautions were being taken to ensure the privacy of their daughters. The researcher's telephone number and

email address were also provided for parents to ask any questions prior to accepting the invitation (see Appendix E).

Along with the invitation letter was an assent form. The assent form included information about the researcher and the study for participant to read (see Appendix F). A paragraph was included that indicated to participants that involvement in the study was their choice. Information pertaining to the researcher's supervisor and the university were also provided. A space was provided on the assent form for the signatures of the parent, minor, and researcher.

### *Sample Selection*

A purposeful sampling methodology was used in order to access the particular selection of participants needed to study the phenomenon of female adolescents with AS. Nine potential study participants were contacted. Two potential participants did not meet age criteria. Two potential participants were not interested in participating. One potential participant had relocated. Four participants met criteria and were willing to participate. Four participants were included in the current study. The rationale for maintaining a relatively small sample size was to allow for in-depth interviews with each participant. Criteria to participate in the study included the following:

1. Female
2. Medical diagnosis of an autism spectrum disorder including AS or HFA
3. Between the ages of 13 and 19
4. Parental permission for participation if under 18 years of age

### Pilot Study

A pilot study was conducted in May of 2008. Institutional Review Board approval number was 05-21-08-0148954. Three key areas were determined as needing further development for the research to be conducted for the dissertation on the lived experiences of female adolescents with AS. These three areas surrounded the interview, data collection, and data analysis. This essay will explain each of these areas and needed improvements in each area.

#### *Interview*

The researcher anticipated the participant population to be challenging to gather information from in an interview. Difficulty was anticipated in that conversational communication might be a relative weakness for this population. Although approximately 10 minutes was used initially to build a rapport with the study participant, once the interview questions began, the responses were often minimal. Interview techniques focused on gathering additional information through participant prompting, such as “tell me more” or “what else.” Asking the question in different words also appeared to help the participant understand and answer more fully. Although the participant stated she was not nervous, she engaged in a variety of behaviors to assist in self-regulation such as twirling hair, leg tapping, or avoiding eye contact.

The questions the researcher developed did not seem to grasp the essence of the purpose of the study. As a result, the researcher asked different questions, in addition to the previously designed questions in an attempt to understand the participant’s lived experiences. It almost appeared that responses obtained from the spur of the moment

questions were more insightful and valuable in shedding light into the participant's experiences than the questions prepared in advance.

The interview lasted 40 to 50 minutes. A session may be divided into two sessions depending upon the needs of the participants. The participant seemed to be more relaxed towards the end of the interview, but appeared tired of engaging in the interview. The participant began to get distracted and verbally indicated such. The participant was possibly unaware of or did not accurately recall some of her experiences.

#### *Data Collection*

Along with the interview, areas of data collection appeared to require further development. The question list that the researcher had printed out consisted of a straight list of questions. This list proved to be cumbersome during the actual interview process. No specific location had been prepared for notes during the interview.

The researcher observed behaviors exhibited by the participant during the interview process. However, the question list did not have an indicated area to collect such data, or a key to quickly code observed behaviors. During the transcription process, the researcher created a revised form to use during upcoming interviews. In the pilot study, the researcher was able to include some of the behavioral observations that were not apparent in the audio recording. For example, hair twirling, and foot and leg tapping were noted.

#### *Data Analysis*

Upon beginning the transcription portion of the data analysis of the pilot study, the researcher noticed the participant engaged in cluttering behavior. However, rather

than transcribe the cluttering, the researcher transcribed the participant's final thought. This was typically the ending sentence. Cluttering data might be useful to collect for a separate study in the future.

Originally, the researcher intended to use Dragon Naturally Speaking 9 to transcribe the data. However, the software did not work as originally intended. Punctuation was not captured, and the final transcription performed by the software package resulted in several nonsense sentences. As a result, the researcher went back and manually transcribed the interview. Fourteen typed pages resulted. While initially the interview questions were transcribed verbatim, after the fourth page, the researcher began to transcribe the interview questions by topic. For example, rather than type, "Did you have any sleepovers?" the researcher typed, "Sleepovers?" The participant responses were transcribed verbatim. This included strategies to gain processing time by the participant such as the use of "hmmm," "uh," etc.

The researcher did not have a specific direction for thematic units to pursue. At first, the researcher questioned whether this was accurate, but realized themes would surface, particularly when interviewing several participants. Upon reviewing the transcription several times, thematic units began to emerge. Upon restructuring of interview questions, anticipated thematic units were targeted.

Transcriptions were color-coded using Word. Eight thematic units were revealed in the interview. The thematic units were as follows:

1. Feelings of anxiety resulting in behaviors; might be judged as "brat"
2. Bullied or taken advantage of by peers – male or female

3. Unimportance of name remembering
4. Personal likes
5. Quirks
6. Supports
7. Perceptions
8. Social activities

The pilot study conducted provided an opportunity to examine the intended methodology for a larger study focusing on the lived experiences of female adolescents with AS. Three key areas were determined to require further development for the dissertation. These three areas included the interview, data collection, and data analysis. Following the pilot study, interview questions were slightly modified including format of question list.

### Data Collection

#### *Semistructured Interviews*

The purpose of this study was to understand the lived experiences of adolescent females with AS. In order to understand what this population believes, feels, and experiences, questions were asked to target that information. As conversational flow is necessary to build rapport and ease among partners, a lengthy list of questions was developed by the researcher in an attempt to minimize anticipated periods of silence. It was not the researcher's intent to ask every question developed, but to have a list of questions available to maintain "conversational partnership" and flow (Rubin & Rubin, 2005).

Interview questions consisted of both closed and open-ended questions. Questions were designed specifically in this format to collect information regarding the language abilities of the participants. Language appears to be stronger in females with AS than males (Kopp & Gillberg, 1992).

Interview questions were developed by age categories including early childhood, childhood, preadolescent years, and adolescent years. Within each section, questions pertaining to academic experiences and social experiences both at school and away from school were addressed. Depending on the age of the participant, specific categories of questions were asked. For example, if a participant was a sophomore in high school, she was not asked the questions designed for an older student.

While some participants demonstrated difficulty with conversational skills, other participants did not. In addition to having questions available for participants, it was equally important to listen to the participants in terms of the direction each participant took the conversation. The researcher allowed conversations to develop spontaneously, as qualitative research is focused on revealing distinctions and complexity of experiential significance (Rubin & Rubin, 2005, p.202).

One interview was conducted per participant. Interviews were scheduled based upon a convenient time and location for the participant or participant's parent. Interviews lasted approximately 45 to 90 minutes. During this time, parental comments were also noted. As the focus of this study was the understanding of experiences from the perspective of female adolescents with AS, parental comments were considered secondary. All interviews with individuals other than participants were considered

informal in nature, as the intent of the information gathered was to gather information for triangulation purposes (Hatch, 2002, p. 93)

#### *Field notes*

During the interviews, notes and observations pertaining to participant and researcher interactions were made. For example, body language, eye contact, proximity, and conversational flow were all noted to gain insight into participants' comfort with social exchanges. Another aspect of the observation included the researcher's impressions to various exchanges.

#### *Artifacts*

Participants were asked to share artifacts that may demonstrate an expression of self. Participants were informed that sharing such artifacts was voluntary. For example, during an interview a participant disclosed that she enjoyed writing stories. The researcher asked the participant if she could read a story the participant had written. The researcher believed that such data provided additional understanding of the cultural experiences of adolescent females with AS. Hatch (2002) suggested the benefit to unobtrusive data is the collection of information without disturbing the natural occurrence of events (p. 119). Collection of participant artifacts, such as a short story or an origami design, allowed the researcher to glimpse into the interest areas of participants without disturbing the interview or interfering in natural circumstances. Data collected through artifacts was utilized in the triangulation process.



## Data Analysis

Creswell (2007) suggests a six step approach to analyzing phenomenological data (p. 159). First, the researcher must bracket personal experiences related to the phenomena so that emphasis is placed on the experiences of study participants. Secondly, the researcher searches the interviews and other data for meaningful statements related to how participants experience the phenomena. In this study, the research questions related to the experience of female adolescents in relation to academic, home, personal, and social experiences during their school years. Thirdly, Creswell (2007) suggests that statements be grouped into thematic units. The fourth step involves describing what participants experienced in relation to the phenomena being described. Next, a description of how participants experience the phenomena is provided. A description of how females with AS describe their social experiences during high school is an example of the fifth step. The final step is the composition of a description of the “essence” of participant experiences (Creswell, 2007, p. 159).

The researcher attempted to bracket all personal experiences related to the phenomena of female adolescents with AS. The researcher’s daughter is medically diagnosed with AS. In addition, the researcher is employed as an autism specialist.

Interviews in this dissertation were audiorecorded. Recordings were transcribed by the researcher. Field notes were added to transcriptions near the time where impressions were formed or observations occurred. The researcher read each transcription several times. Many qualitative researchers recommend multiple readings of transcriptions in order to become fully familiarized with the interviews. Interview

familiarization assists in understanding the nature of the interviews (Creswell, 2007). While reading transcriptions, additional questions and comments were added by the researcher. During transcription readings, researcher searched interviews for thematic units and created initial codes in relation to the research questions.

Thematic units were highlighted and color-coded to represent various themes within a transcription. Codes were written out to form a color-coded key. Initially, participants' exact wordage was coded as the phrases pertained to themes. Creswell (2007) referred to using participants' exact words as "in vivo" coding (p. 153). Phrases or statements reflecting the themes were used to develop thematic units. The researcher's personal experiences were noted in relation to emerging thematic units and as the essence of female teenagers with AS was investigated.

Thematic units were analyzed in respect to existing knowledge of females with AS in the literature. A descriptive understanding of participants' experiences was developed. The essence was captured through the words of participants as they related to the thematic units that were revealed.

Upon conclusion of the data analysis, data was presented through the rich, thick description of participant dialogue. Data was also presented using tables for clarity. Artifact description was included to provide examples of participant experience. Finally, a discussion on the essence of participants' experiences was included.

### Summary

The purpose of this phenomenological research study was to describe the central phenomenon of the lived experiences of adolescent females with AS. Chapter 3

examined phenomenological research and the suitability for addressing the purpose of this study. The methodology section included information pertaining to participants' selection, ethical issues, data collection, management, and analysis, and a prior pilot study conducted surrounding the protected population of female teenagers with AS. Chapter 3 included a presentation of research methodology. Research questions were offered and design was reviewed. Information related to study findings, a discussion related to the description of research participants, procedures used in the qualitative study, and data analysis will be included in the following chapter.

## CHAPTER 4:

### FINDINGS

#### Introduction

Chapter 4 includes information related to study findings. A discussion related to the description of research participants, procedures used in the qualitative study, and data analysis will be included in this chapter. Information will be summarized at the conclusion of the chapter.

#### Data Collection Processes

##### *Locating Research Participants*

The researcher contacted the regional education services district for autism and explained the proposed research. Regional education service districts act in partnership with local school districts to offer services and leadership to increase learning opportunities for students, schools, and communities who subscribe to their services. Autism services are one of the areas provided by the regional education services. Autism specialists employed by the regional educational district work in partnership with school psychologists, speech and language pathologists, and special education teachers in to offer autism evaluations for children age 0 to 21. Regional autism specialists serve as consultants, providing training and recommendations for parents and professionals related to students with autism spectrum disorders. Regional services provide services to 5 counties, giving the researcher access to over 77 schools, and multiple school districts. The researcher contacted autism specialists at regional services to obtain contact information or ask for dissemination of parent invitation letter for the research project.

In addition to the regional services, the researcher asked the Three Rivers School District, the district in which the researcher is employed as a special education teacher, to assist in locating potential research participants within the district. The researcher had not had prior contact with any of the research participants. The school district provided a listing of all students with autism and allowed the researcher to engage in a file review for students that met the criteria necessary for the study. Both the school district and the regional services provided signed letters of community partnership to the researcher, which were submitted to the Institutional Review Board for approval.

The researcher documented all potential participant names and contact information in the research journal. The researcher contacted potential parents and participants through email and telephone calls. During these contacts, the researcher explained the purpose and significance of the study. The interview process was also explained. Results of the phone calls and emails were documented in the research journal. Letters of consent, assessment, and the parent invitation letters were provided to participants and parents who agreed to participate in the study. Any questions by participants or parents were handled at this time. Interview times and locations were arranged, per the discretion of each parent and participant. Interview locations included a community college student center, a McDonald's restaurant, a high school library, and a participant's home. Interviews held in public places were more difficult to engage in than the interview that took place at the participant's home. The researcher paused on several occasions to allow participants to observe distractions during the interviews, then redirected participants back to the conversation topic. Parents were particularly excited

during these initial contacts, indicating that they were unaware of other females in the age parameter indicated with AS. All participants were medically diagnosed with AS and resided in rural areas.

### *Semistructured Interviews*

Semistructured interviews were used to several reasons. The semistructured format provided organization to the interview in order to ensure that four areas were covered including home, academic, personal, and social experiences. The semistructured format also provided participants the opportunity to provide information related to different experiences not asked by the researcher. Engaging participants in discussion gave a voice to the views of participants. The researcher devised several open-ended questions based on a previous pilot study that encompassed designated areas. Open-ended questions are questions that require an individual to explain an answer in more than one or two words. Open-ended questions were utilized in order to encourage participants to share their opinions and experiences. As communication is often a deficit area for individuals with AS, prepared questions were believed to be necessary in order to maintain a consistent conversational flow.

Interviews ranged from 45 to 90 minutes. Approximately 10 minutes was utilized in an attempt to establish connection between researcher and participants. During this 10-minute period, conversations were not audiorecorded. Information gained during this time was later recorded in the researcher's journal. The researcher conducted all interviews. Interview locations were arranged with the participants and their families. Participants and families were told prior to meeting, and at the beginning of the

interview, that the interview could be stopped at any time if they chose. Any question that was thought too personal or uncomfortable did not need to be answered by simply stating “skip” to the researcher. The researcher also instructed participants to notify the researcher if a break was needed during the interview. All interviews were audiorecorded and transcribed by the researcher. While the researcher’s questions were shortened to capture the essence of the questions, participant responses were transcribed verbatim to capture the rich, thick descriptions of participant experiences and capture the phenomenon of adolescent female adolescents with AS. In vivo coding Transcripts were printed out and analyzed. Thematic units were color-coded using colored markers for essential themes.

As the focus of this study was on the experiences of the selected population, information derived from other sources, such as parents and teachers, was considered secondary. Interviews with parents or teachers were not originally planned as a part of this study. However, when parent or teacher contacts were accomplished in context of natural conversation, they were added to the analysis.

The researcher received calls and emails concerning potential participants and study participants. These communications occurred primarily following the interviews. Notes were taken during these conversations in the researcher’s journal. All four parents of study participants indicated concerns related to the lack of socialization opportunities their daughters had. Two parents claimed that the friends their daughters had were not particularly good role models. One participant emailed the researcher following the interview as though they were friends, requesting the researcher’s assistance in obtaining

employment and in joining her for social activities. The email stated, “Can you help me find a job?” and “I found a movie I’d like to see. Can we go to the movies?” Additional information is discussed further in this chapter. Information gathered from these conversations was used to supplement findings and added to the triangulation process.

### *Artifacts*

In addition to semistructured interviews, participants were asked to share artifacts demonstrating hobbies or creative interests, if desired. Participants were not required to share artifacts with the researcher. Artifacts offered the researcher a different perspective of participants one that is not accessible through interviews alone. The researcher observed various artifacts including quilts, origami, and a short story.

### *Observations*

The researcher attempted to engage in participant observations in unstructured activities. Three of the four participants were observed at a time other than the interview. Observations were arranged to determine how participants engaged with others in unstructured environments. Observation occurred for approximately 20 minutes in addition to the interviews. The researcher also made observational notes pertaining to participant behaviors during interviews. These observations appear in brackets ([ ]) in the transcriptions, and are evidenced in the dialogue used in chapters 4 and 5.

### *Researcher’s Journal*

The researcher maintained a journal throughout the research process. Examples of information maintained in the journal include a script used in initial contacts, contact log of all possible participants, reflections during interviews and observations, and notes



and procedures used for coding and data analysis. The journal served as a reflective constant, assisting the researcher in remaining focused, as well as a location to include tangent thoughts related to the research experience.

Bracketing is a term used in phenomenology to indicate the deferment of one's own experiences and beliefs pertaining to a specific phenomenon while attempting to study the phenomenon (Hatch, 2002, p. 86). Through bracketing, researchers attempt to understand their own prejudgments and opinions pertaining to the context of study. While the researcher attempted to become aware of judgments and previous experiences, the question of the necessity to do so arose. The researcher believed knowledge and experience of adolescent female with AS might assist in gaining a repertoire with study participants and share an understanding in participants' experiences. According to Hatch (2002), certain phenomenological approaches, including feminist and critical, do not require researchers' lived experiences to be put aside (p. 86). Instead, an awareness of views is essential. While feminist approaches focus on the issues faced by females, critical approaches attempt to "empower" individuals, regardless of gender (Creswell, 2007, p. 27

#### Information Management and Record Keeping

Data collected prior to interviews, including community research partner letters, parent invitation letters, and assent forms were maintained in a locked box at the researcher's home. A research log that included information such as initial contacts and dates were maintained in a research journal. The journal was divided into multiple sections including a research log, observational notes, field notes, and researcher

reflections, and a visual matrix. All computer files were backed up to a separate thumb drive and maintained in a locked box at researcher's home. In order to maintain integrity of information, backup occurred each time files were updated. All computer files were locked with a password. A computer folder was designed specifically for each participant. Participants' files were maintained in their respective folders.

Data collected from interviews consisted of recordings and field notes. Digital recordings were maintained and stored in the participant's respective computer folder. Transcriptions were maintained in the participants' respective computer folder. Field notes were added to transcription, located near to where in the interview the impression occurred. Field notes that occurred outside the interview process were maintained in the research log.

#### Research Participant Characteristics

All participants involved in this study included females that had medical diagnoses of AS. An age limitation included females who were 13 to 19 years of age. Participant names were obtained from several community partners including the Three Rivers School District and referrals from the regional education services district autism services area. All participants lived in rural areas. Prior to interviews, the researcher had not met any of the study participants. Table 1 indicates the attributes of study participants.

Table 1

*Participant Attributes*

	Age	Special Ed	Age Diagnosed	Educational Level
P1	19	Yes	15	College
P2	17	Yes	13	High school
P3	15	Yes	5	High school
P4	18	Yes	12	High School

In portraying the words of the lived experiences of study participants, the researcher coded the dialogue. Dialogue used by the participant was symbolized by the letter P followed by a number to indicate the study participant. For example, Participant 4 was abbreviated as P4. Dialogue spoken by the researcher was coded by the letter R.

*P1*

The researcher obtained information pertaining to P1 through a regional autism specialist. A regional autism specialist called P1's mother to ask permission for the researcher to contact her. The researcher called P1's mother and asked to interview her daughter. P1's mother asked P1 while the researcher was on the phone if it would be ok if the researcher interviewed her. P1 suggested a time and location. P1's mother continued the conversation. P1's mother indicated she had concerns for P1, particularly her lack of current friendships. In comparison to P1's female adolescent siblings, P1 had not maintained similar social relationships.

P1's interview was arranged and a meeting was scheduled at the community college library where P1 attends. The meeting was scheduled for a Friday afternoon,

following P1's classes. Prior to meeting P1, the researcher located an appropriate location in the student center to interview the participant and sought permission to use. When the researcher approached the participant, she was sitting down playing with her cell phone. P1 greeted the researcher with a smile and a light handshake. P1 made eye contact with the researcher while the researcher introduced herself. P1 oriented her body with the researcher and immediately indicated that she was not contagious, as she had marks on her arms. She indicated that the marks were from poison oak and she was currently using a medication to lessen the appearance. Participant was wearing bell-bottomed jeans, a pink short sleeve blouse with a v-neck, and white sneakers. She carried a light blue shoulder sling pack, and a black backpack decorated with blue dolphins. P1 had long wavy dark hair and wore glasses.

The researcher indicated that the interview would be held in the student center. P1 stated that the student center was closed at that time. The researcher assured her that permission had been obtained to conduct the interview at the student center. P1 changed the subject to her current courses, reading and writing. Light conversation continued surrounding her "boring summer," as the participant felt she had not engaged in any interesting activities thus far. The researcher and P1 reached the student union. Both the researcher and P1 purchased canned sodas from a vending machine. P1 selected a Mountain Dew. The researcher chose a round table in the corner of a room in the student center. The room was empty when the researcher and P1 sat down. As P1 was sitting down, she exclaimed, "I hate this shirt! A guy was staring at me in one of my classes. I

look at him and said, ‘What are you staring at?’” P2 began adjusting her blouse while laughing at her story.

P1 spoke with a clear voice in a moderate tone. During the interview, P1 used her tone of voice to express emotion in her words. An example of this was evidenced in her declaration of a desire for a boyfriend.

R: “Do you want to go out on dates?”

P1: “YES [vehemently, then chuckles]. Right now, I’m working my career area. Once I get up on higher level college and more settled down. I DO want to have a boyfriend, but I have so much work. You know, with the college, I’m so busy and once I start my work, I don’t stop until I’m done.”

P1 enjoyed creative writing. P1’s tone of voice became animated as she described her story to the researcher. Following the interview, P1 emailed her story to the researcher. Additional information pertaining to Participant’s story is found later in chapter 4.

During P1’s interview, the researcher did not observe self-stimulating behavior. However, when the interview concluded, P1 was observed engaging in a conversation with another female student. P1 was observed rocking back and forth, as she sat with the other girl.

## *P2*

P2 was located by the researcher from a list of students on the autism spectrum that was provided by the Three Rivers School District. The researcher called P2’s mother to ask permission to interview her daughter. At that time, both the participant and her

family were living out of state, but would be returning within a few weeks. The family resided in two states during different parts of the year. P2's mother indicated the laws were different regarding the services for which P2 was eligible, including supplemental security income.

During the time before P2 returned, her mother emailed the researcher twice, indicating that she needed assistance locating a psychologist. P2's mother was attempting to gain supplemental security income for P2 in the state in which the researcher resided. The state would not recognize existing assessments, and a psychologist needed to reassess P2 in her adaptive living skills. Assessment needed to be completed prior to P2's 18<sup>th</sup> birthday, which was in the near future.

When the family returned, the researcher called and spoke to P2's mother to arrange an interview. A nearby McDonald's was selected as an interview location on the following weekend. The researcher asked P2's mother if that location might make her daughter uncomfortable. P2's mother indicated it would not. During this conversation, P2's mother indicated her daughter did not like to be touched, did not like using the telephone, and was a very picky eater. Participant enjoyed Digimon and Pokémon animé. P2 enjoyed movies made about Marvel comic characters, such as Spiderman and X-Men, but did not like movies made about DC comic characters, such as Batman and Superman. Socially, P2's mother felt her daughter was socially isolated and needed to engage in new social experiences.

The day of the interview, the researcher was seated in McDonald's waiting for P2. One other male approximately 55 years old was in the restaurant. The interview was

scheduled for 11:30 pm. The researcher sat by a window facing the direction from which customers would approach the building. A car pulled up and three people exited the car, a woman, a young male with Down's Syndrome, and a young woman. The young woman exited the car and lagged behind her mother and brother. Her brother came in and immediately went to the counter. P2's mother looked over at the researcher, smiled, and approached the table where the researcher sat. P2 followed behind her.

The researcher extended her hand and said, "It's nice to meet you." P2 took the researcher's hand and lightly shook it. P2 appeared to use her body as a shield to hide from the world. She wore a simple tee shirt and jeans during the interview, and her shoulders were hunched over, with her elbows pointed inward. The researcher attempted to engage P2 with conversation and questioned the participant as to whether the location needed to be changed. The research project was explained to the participant and the interview began. Her conversational responses began brief and to the point, as demonstrated in the excerpt below:

R: "Do you remember your first day of school?"

P2: "No."

R: "Do you remember lunch time?"

P2: "No."

R: "What was the name of your preschool?"

P2: "I went to [provided name] Elementary School."

R: "Did you like it?"

P2: "I don't know."

P2 appeared to become more at ease with the researcher as the interview continued. The participant appeared to relax, as her posture straightened and eye contact was held for longer periods. Participant smiled and chuckled. Her length of sentences grew in length.

R: "What do you like to buy besides Digimon stuff?"

P2: "Basically, video games. I had to pay \$300 for Magic [participant's horse]. She got kicked in the knees a couple of days ago. She's a little bossy. She's in a stall with a gelding who also wants to be boss. Her knee was open. We don't know if it's going to get better...I rode a Fjord that had a little man's syndrome [participant smiles and chuckles]."

While P2 completed a college math and English course when she was 16 years of age, her difficulty with sensory issues prompted her to be home schooled at times. P2 currently is enrolled in a special program with other students with special needs. The program is not located on a school campus, but at the district office. The majority of students in this program display more severe cognitive deficits and academics are not emphasized. P2 is minimally mainstreamed at the nearest high school for one period a day in a nonacademic class.

R: "Are you going to take any other classes at the high school?"

P2: "I was going to take math, but precalculus is going on at the same time as Band. I think I got all the credits necessary for math right now."

Throughout a significant portion of the interview, P2 engaged in the origami creation of a dragon. The dragon consisted of 75 steps and took approximately one hour



to fold, as indicated by P2 who claimed she timed herself repeatedly. Cognitive testing indicated P2's intelligence was in the superior range.

### *P3*

Similar to P2, P3 was located through the list of students with autism spectrum disorders provided by the Three Rivers School District. Upon gaining the participant's phone number, the researcher called and left a message on the family answering machine. P3's mother returned the researcher's telephone call. During that time, P3's mother disclosed that she had an older son who was also diagnosed with AS. He was unable to maintain employment and was often depressed, as he recognized he was different from others. P3's mother indicated that her daughter was much more social than her son. However, she wished she had more friends.

The researcher contacted P3's special education teacher to arrange a date and time for an interview at school. The interview was scheduled for that afternoon. P3's interview was conducted in the high school library during what would have been the time for her physical education. The researcher would later find out from one of the special education teachers that physical education was P3's least liked class.

R: "Why don't you like PE?"

P3: "I don't like PE because it's so confused. I'm like...you idiot, you're supposed to go that way!"

Upon observing P3 walk through the halls at school, she appeared to avoid eye contact and maintained her hands near her face. In science class, she was hunched over her desk with her head low. Her body was slightly hunched over with her head near the

desk, giving the appearance of sheltering herself from others. She did not engage in any conversation during this time with her peers, although many other students were talking.

P3 was called to the office where the researcher was waiting for her. She initially appeared confused and was hesitant. The researcher introduced herself but did not offer her hand. The researcher told her that she was going to interview her, if she consented. The researcher asked P3 if she could show her where the library was. As P3 and the researcher walked to the library, the researcher engaged in light conversation to develop a rapport with P3. The researcher asked P3 about her summer. P3 indicated that it was “boring.” She stayed home and did not engage in any “fun” activities. The researcher went over the letter of assent with P3. P3 asked how long the interview would last. The researcher said 30 to 45 minutes. P3 asked if she could retrieve her items from the classroom.

Upon P3’s return from retrieving her items, she was animated in voice and body language. P3 demonstrated conversational skills during the interview in the area of social communication. P3 engaged the researcher in questions, made good eye contact, and used age-appropriate phrases. Her responses to questions were very lengthy.

R: “Have you been around horses?”

P3: “Yeah. I got to ride at my elementary school. There was a horse in the back field. I rode on the girl horse. So we got turns to ride on the horses. I went on trail and hay rides. We had a field trip and went to this farm. We went around and went on a hayride. There was this one field trip with a garden We were like walking through it, going this is cool! Yeah we were going to a garden and it was pretty cool. We got to go

to my 5<sup>th</sup> grade teacher's house. She had 3 dogs. A couple of German Shepherds and a Delilah dog from Homeward Bound. Do you have those DVDs?"

R: "Yes."

P3: "Do you have a DVD burner?"

R: "No."

P3: "You should download DVD Decryptor and DVD Shrink and make me copies. I want that one movie in DVD. I want Lady and the Tramp in DVD and 101 Dalmatians. I have it in VHS and it's horrible. It's old, like very old back when my parents were little. And when I get it now, it skips. And I'm like, 'what the heck?' I was watching Benji the original; you know where he found a girlfriend. Well, I was watching that and it was like blah blah blah throughout the entire movie. I rewounded and, and I was like, this movie is messed up. So I have to get that movie again."

P3 demonstrated difficulties transitioning from one topic to another, often continuing the conversation from the previous question. However, her responses were vivid in detail and her word choice included numerous age-appropriate phrases and words, although she often went off on a tangent.

R: "Are you anxious to move out?"

P3: "Uh huh. I want to have horses, dogs, cats, and rabbits. All the things my mom and dad wouldn't let me have. You know, I tried to get a rabbit, I asked her for another kitten, because my other one died 'cause she got killed by a coyote or cougar. I heard her scream in the mountain, but I also saw a cougar in the yard...yeah. The night she disappeared, we went to collect all the animals. We

got them except my cat. There was a cougar in the yard. It had like a 4-foot long tail. I could have sworn we have foxes, too. We tried sneaking a cat over. My mom found it after 5 days. The cat was so smart she'd hide from my mom (participant chuckles). My parents gave her away. They thought that K and M gave it to me, but they didn't. Aunt S snuck her to me. Everyone got mad at Aunt S, and she's like, 'geez I didn't rob a bank!' I want a rabbit and I want a Beagle, my favorite dog in the world."

In comparison to the other participants, P3 demonstrated a tendency for verbosity. However, she is noted in reports as failing to clarify information or ask questions in class. The majority of experiences P3 discussed surrounded highly social activities with other females. Eye contact remained constant throughout the interview and she appeared to be thoroughly engaged. P3 has a brother 8 years older who was diagnosed with AS.

As the researcher was walking out with P3, another special education teacher approached the researcher. P3 continued walking to her locker, which was through a set of double doors. The special education teacher remained and spoke with the researcher. She indicated that P3 demonstrated "willful behavior." P3 was seen as telling "untruths and misrepresented the truth." The special education teacher gave the example of an occasion when a Teacher A had given P3 permission to go to her locker. This permission was granted during the early part of the day. P3 was seen at her locker at the end of the day. When questioned, P3 indicated that Teacher A had given her permission. The special education teacher indicated that Participant used that information in an attempt to avoid a reprimand for being at her locker at an inappropriate time.

The special education provided the researcher a copy of her grades from the previous year. P3 had a D in three classes, including English, pre algebra, and physical education. The special education teacher indicated that the D in the pre algebra was due to P3 not turning in her assignments on time. The special education teacher also indicated that P3 demonstrated sensory issues that were often exhibited in physical education. The special education teacher gave the example of catching and throwing a ball.

Following the interview, P3's mother called the researcher and wanted to know how the interview went. The researcher indicated that the interview had gone well and that her daughter was very conversational. P3's mother was surprised. P3's mother indicated that her daughter's friends resulted from activities that her daughter was exposed to because of her parents' social activities, such as the bowling league to which they belonged. P3's mother indicated that her friend, C, was in fact not her cousin, but that they claimed they were close like cousins. According to P3's mother, her daughter would "cling" to people. However, none of the people her daughter was clinging to went to the same high school as P3. P3's mother stated that she had wanted her daughter to become involved in choir at school. P3 sang constantly at home and had an excellent voice, according to her mother. P3 had previously attended a singing camp and had performed in front of others in the past. P3's mother did not understand why she would not join choir at school.

P3's mother stated that when her daughter was younger, she did not speak to very many people, even after being around them for many years. However, as her daughter

has matured, her social skills had improved. For example, P3 is better at greeting people now, but occasionally still needs to be reminded to greet her grandmother.

P3's mother indicated that her daughter would "hand twitch around her eyes" often at a young age. However, her daughter did this less frequently now. P3's mother stated that she catches her daughter engaging in the "hand twitching" when her daughter is alone and thinks nobody is watching her. P3 had also improved in terms of anxiety. P3's mother indicated that the morning of the conversation, P3's water bottle fell to the floor and broke. P3's mother scurried to find another water bottle but could not find a lid that fit. Participant had to leave to catch the bus. P3's mother stated that she was worried that that incident would "throw her off all day." P3 had another water bottle at school, but claimed the water at school did not taste right. P3's mother considered calling the school to let P3's special education teacher know that an incident had occurred that morning that might "throw off" her daughter's day.

P3's mother indicated that her daughter misplaces items quite often. She stated that she bought several calculators for her daughter, giving her only one. P3's mother "hid" the other calculators so that one would be available each time her daughter lost her calculator.

P3's mother indicated that last year P3 failed her physical education class. P3 had a physical issue with her knee was afraid to participate in coeducational football. P3's mother had requested accommodations in her daughter's IEP for physical education to accommodate her daughter's fear. She stated a different activity could have been

substituted. This had been done for her son previously. However, according to P3's mother, the special education teacher refused.

#### *P4*

P4 was located through a regional autism services autism specialist. The autism specialist contacted P4's mother and asked permission to give the researcher her name and phone number. P4's mother agreed. The autism specialist contacted the researcher who then called P4's mother and arranged an interview for the following evening. The interview took place in P4's home.

The researcher was greeted at P4's home by a large dog, cat, and a brother. P4's brother directed the researcher where to park, and then escorted her into their home. P4's mother was in the kitchen cooking. P4's mother directed me into the living room, where P4 was folding laundry. Throughout the interview, P4's mother drifted from the living room to the kitchen.

P4's mother invited the researcher into her home and directed the researcher to the living room. P4 greeted me with a firm handshake and a smile while holding my gaze. P4 recently graduated from high school and is currently not enrolled in postsecondary education or employed. P4 explained that she was about 3 years behind her chronological age, so she was actually a 15-year-old teenager mentally.

P4 appeared to experience similar situations as neurotypical peers.

R: "What was your favorite part of middle school?"

P4: “Having a crush on a guy. That was my 8<sup>th</sup> grade year. Every science class my 8<sup>th</sup> grade year, I’d go in and look at him and look away when he’d catch me. I dated him before, and I just broke up with him. It was pain during my 8<sup>th</sup> grade year.”

P4 Mother: “She [P4] came home with this nice ring...it was nicer than my wedding ring! The next day she said she’d lied to me that, the guy hadn’t given it to her for friendship, that they were engaged. All I could do was yell, “Oh no you’re not!” I’d heard about this guy twice, and had never even met him. How do you explain to your Asperger daughter that she can’t marry him without alienating her? It’s like dealing with two different girls. It has to be done so carefully. It needs to seem natural. We’ve taken stands on a few things, and let her work it out on others. If the guy won’t even come and talk to the parents, he’s sneakin’ behind your back. That’s when she started really thinking that if I have to sneak, it must be wrong. We took her to a counselor that did neurofeedback with her. She started believing she could do it on her own. It’s helped tremendously.”

P4 appeared to be comfortable with having AS. She was clear in her descriptions of the grief she has endured as a result of being victimized by others and how other people were her largest barrier to overcome. Each of these aspects will be discussed in further detail later in the chapter. P4 discussed her 7 First Place and 2 Best of Show awards for her quilting projects. P4 discussed similar experiences and desires of neurotypical female adolescents.

R: “Did you enjoy high school?”



P4: “High school was a blast. I had a cool Ag science class. Went to dances, prom, homecoming, Valentines dance. I went to Prom twice. That was fun. My favorite part is that they would bring out a DJ, and me and my friends would dance, and people would look at us like we were crazy!”

P4 claimed she was now focusing on learning to become independent. Hands-on training was not sufficiently provided during her formal education, according to P4 and her mother.

P4 Mother: “She needed more but they didn’t offer it, so I did a lot of it at home. I’d take her to the grocery store, we’d pick out the food, she’d make dinner. She could keep a house, make dinner, do the shopping, but she would have trouble with the stress of keeping down a job. I don’t know that she could do that, and that’s what worries me. Unless you have a really understanding boss...where do you go from here? She’s about 3 years behind, so she’s like a 15-year-old right now. So, could she live completely on her own right now...I doubt it. Not without some huge difficulties. Do I think she’s the one who could overcome them? Absolutely, but it would not be easy.”

P4 claimed she could maintain a household, and is hoping to learn the skills necessary for maintaining employment.

Both P4 and her mother expressed concern for other girls with AS. P4 and her mother gave permission to use their real names and to provide their names and numbers to other families with girls with AS. P4’s mother indicated that sufficient support is lacking for families with daughters that have AS.

### Thematic Units and Essence of Central Phenomenon

This study included an analysis of the central phenomenon of female adolescents with AS. The main research question sought to explore the lived experiences of adolescent females with AS pertaining to academic, home, personal, and social experiences. Four areas were addressed in the participant interviews including academic, home, personal, and social experiences. Four thematic units emerged. Each area was explored from the perspective of each participant, using their own words to express their lived experiences. Together, the thematic units generate the essence of the central phenomenon (Moustakas, 1994). Each thematic unit, derived from participant interviews, will be addressed followed by a discussion of the essence of the central phenomenon.

#### *First thematic Unit: Victimization*

Two of the research subquestions focused on examining the social experiences participants experienced with others and their personal feelings about the interactions. In this examination, a theme of victimization emerged from participants. Victimization appeared to occur during the elementary, middle, and high school years. These findings also addressed the research subquestions regarding experiences during elementary, middle, and high school. Individuals with AS are often targeted as potential victims for bullies (Attwood et al., 2006; Willey, 2003). While bullying may occur anywhere, study participants indicated that bullying typically occurred in the school setting during unstructured settings, such as recess time. Each of the participants mentioned incidents that would qualify as being bullied at some point in their lives. Experiences described by

the participants touched on the research questions seeking to understand experiences pertaining to academic, home, personal, and social settings.

*P1.* P1 indicated bullying in the academic setting occurred primarily in the elementary school years.

R: “Did you ever get picked on at all when you were in elementary school?”

P1: “Oh yes, a lot.”

R: “Tell me a little about that.”

P1: “Oh, you know, I’d get teased, I get called a freak, weirdo, dork, uh, you know, made fun of because I had elf ears (participant moved her long hair and pushed both ears forward).”

R: “When you were in elementary school and you got teased, what did you do?”

P1: “Well, I’m not the kind of person who likes to hit and punch like my sisters. You know, they fight with each other. You know they’re brats! Trust me; you know they are more spoiled than I am. Oh, I just ignore it. Like sometimes, I might take it hard, or tell the teacher, you know, like what’s up.”

R: “Well that’s good.”

P1: “Well, one time, I had my best friend HC (always gave first and last names) she was nice and all, then she turned into a you know what, I don’t want to say it (participant laughs). And, uh, she used to pull my pants down, so...yeah, I told Mrs. W, she was my 5<sup>th</sup> grade teacher, and she got in trouble, and so forth, so...yeah.”

P1 mentioned another occasion of victimization. However, the incident did not involve the academic setting, but a home setting. P1’s response addressed the research

questions related to both academic and home experiences. While the researcher struggled with including this information in the study, the researcher believed that the importance of understanding experiences outweighed the researcher's personal dilemma. P1 disclosed this information when asked whether the students who teased her in elementary school ever hurt her. The researcher had not addressed the topic of sexual harassment.

P1: "Well, actually, I didn't get sexual harassment until my dad's 40<sup>th</sup> birthday. And there was no supervision at all. And the creepiest thing of all is that it was my cousins. It was the very worst experience I had."

R: "If you're comfortable, tell me about what happened when you were sexually harassed."

P1: "I was watching TV and my cousins were 12 and 14 in my aunt's room in her old house. My aunt and uncle are no longer together. My grandma and grandpa are helping her, you know, because of her SSI and stuff. My cousin, N just farts all of a sudden and I'm like, N, what are you doing? We're playing games, then they were calling cuss words. I don't want to go that far. Then suddenly, N was poking me in the boobs. I was like, what the hell? Then that's when it starts. Next cousin comes in. I asked if they had been watching rated R movies. They said yes cause pretty much they'd been alone at the time. They got grounded for 6 months which should have been a year."

R: "When did you tell your mom what happened?"

P1: "I had to tell her the next day because I was tired. My grandpa took care of that. He spanked them and stuff. It was creepy when I was telling her the entire story."

An additional situation described by P1 when asked about recollections of teachers included information pertaining to a home situation she was experiencing. The researcher assumed P1 was referring to a situation with teachers, which proved to be incorrect, as the participant changed topics within the conversation.

R: "Do you remember your teachers?"

P1: "Uh, I remember one teacher, uh Mr. N. He was fun and active teacher. He was a dance teacher. Mr. M was ok, but was not impassioned to help me, and stuff like that. My math teacher, I forgot his name, but he was a pain in the neck! That's how I am, you know, I'm just sincere! Yeah, I show my sincerity if people let me, you know, I don't need to be yelled at."

R: "Did you get yelled at?"

P1: "No, I get yelled at a lot by my dad though."

R: "So does he yell at you because he thinks you're not listening or doing something right?"

P1: "Yeah. Sometimes he says, 'you're not paying attention' or...I think my dad is still in denial about the Aspergers."

P1 conversed comfortably throughout the interview. P2 demonstrated concise communication. Yet, also indicated lived experiences with victimization.

P2. Although P2's answers were short and concise, she brought up a lived experience of victimization that occurred during middle school. This addressed the research subquestion pertaining to experiences during middle school.

P2: "I went to [provided name] Middle School."

R: "Is that a 6-7-8 grade?"

P2: "Yes."

R: "Did you like that school?"

P2: "No."

R: "How come?"

P2: "There was a mean girl when I was in 6<sup>th</sup> grade. She choked me."

R: "She choked you?"

P2: "Uh huh. Then she almost pulled my shirt off."

R: "What did you do?"

P2: "Sat on the middle of the floor and cried."

R: "Did anyone see?"

P2: "Other students saw and told the teacher."

R: "Did you come home and tell your mom?"

P2: "Well, I cried on the whole bus ride, and then I went to a friend's house because my mom was at work, but then I told her when she got home."

R: "What did your mom say?"

P2: "She called the principal."

R: "What did the principal tell your mom?"

P2: "I don't remember."

R: "Did you have a lot of friends when you were at middle school?"

P2: "I was all by myself. I'm normally picked on by bullies."

P3. P3 did not indicate an issue with bullying. She mentioned a single incident, but did not label it as bullying. P3 was noted as appearing to have a processing delay, often answering questions after another question had been asked. P3 also demonstrated difficulty in completing a full thought, as some of her words and sentences appeared jumbled.

R: Have you ever been bullied at school?

P3: No.

R: Do you ever get depressed?

R2: There was this one girl...She didn't really bully us, but she chased us. She got mad at us.

Victimization may take several forms. While being bullied at school is often noted, it is not necessarily the only realm. As a research question was asked pertaining to social experiences, the Internet was commonly mentioned by participants as a form used for social engagement. The Internet has been suggested as a new area for adolescents to engage in social diversion (Bradley, 2005). Female teenagers with AS may particularly be susceptible to predatory individuals. On the other hand, misunderstanding social rules may cause individuals with social cognitive deficits to inaccurately perceive they are being victimized.

R: "What does your MySpace page look like?"

P3: "Uh...I just have this picture of a girl, 'cause I don't like people to know who I really am. 'Cause I don't really give out my personal information. There's already this guy stalking me. So..."

R: "Through MySpace?"

P: "Oh, MySpace and Yahoo. I know he met me on Belazer(?). On my MySpace, there's a blonde girl. She's pretty, though. Yeah. And then this guy is like stalking me. He found my Yahoo. He's like you met me in Belazer because he's like a captain. He's one of the leaders of Belazer. He sends out newsletters. Somehow, he got my MySpace. I don't know how but he's 18.

R: "Does your mom know?"

P3: "He's starting to scare me. He's like, 'Hey, Hottie.' It's like, ok, I'm telling Tom because I know the guy in charge of MySpace. Because he made it to where I can't delete him."

*P4.* In searching for answers to the research questions pertaining to P4's social and personal experiences through her school years, P4 offered insight into lived experiences encountered with victimization.

R: "Did you ever get bullied?"

P4: "Yes...all the way through. And by teachers, too. I had a group of girls in high school. They told me to go back to special ed. In middle school, a friend's parent called my schizophrenic. In elementary, a bunch of girls said I had cooties. If I accidentally brushed them, they'd yell they needed to take a shower. I learned in my senior year that some people are going to have a problem with me and I need to just ignore it."

R: "Bullied physically?"



P4: “Mostly verbal. Actually, in elementary I had a girl shove me down and she told another girl to get a ball so she could throw it at my face. I got up and ran. Teachers even told me I was going to be pregnant by 15. The funny thing is...I’m still a virgin!”

P4’s mother was also questioned about the other student that bullied her and the pregnancy issue. P4’s mother indicated that there were several other instances during elementary school her daughter was bullied. In addition, the participant’s mother indicated that students were not the only individuals that bullied her daughter.

P4 Mother: “This girl pushed her around quite a bit. P4 had a teacher in 2<sup>nd</sup> grade...kids could get an ice cream after lunch. We’d given her \$0.50 to buy an ice cream. A field trip was also going to be coming up. My husband didn’t get paid until after the field trip so I asked if I could pay later and they said, ‘oh sure...no big deal.’ The teacher saw the 2 quarters and asked, ‘What’s that for?’ P4 said for her ice cream after lunch. He said, “Oh no it’s not, you owe me \$5.00. I went to the school to confront him and took her because I thought she needed to hear this. He said, ‘Well, she owes me money.’ I said, ‘Oh no she doesn’t, I do.’ And I said, ‘I don’t owe you, I owe the school. You have no right to take the money.’ He took two quarters out of his pocket and threw them at my daughter. I told him, ‘I think you owe my daughter an apology.’ He said, ‘Oh no I don’t!’ I cleaned out her desk and she never went back to that room. She’s had teachers like that. She’s had teachers in junior high call me up and cuss me out because she has a meltdown. You’re throwing 40 to 50 kids in a classroom with no extra help, she’s special needs, you won’t believe she’s special needs, and now you’re telling me you

don't know she's melting down. We had incidents all through school. Junior high was just hell. I had Special Ed coordinators telling me she wasn't going to qualify. I spent years getting her on an IEP...there's no way they were going to take it away!"

P4's mother was asked about the pregnancy issue.

P4 Mother: "The special ed coordinator said it in front of her and in front of me. Said she's going to get pregnant before she's 15 because she doesn't have a social clue. That wasn't appropriate to say in front of my daughter, even if you're thinking about it."

#### *Second Thematic Unit: Anxiety and Frustration*

Females with AS have been reported to experience anxiety (Cohen, 2003).

Expression of anxiety may be revealed in various ways. Anxiety and frustration appeared to address participants' experiences addressed in the research questions pertaining to personal, social, home, academic experiences and settings. Each of the participants lived experiences pertaining to anxiety or frustration are provided below.

*P1.* P1 indicated that she used to rock and flap when she was younger. However, she stated that she believed she controlled the behavior in public while continuing to engage in such behaviors at home. While P1 did not engage in any rocking or flapping activities during the interview, she was observed rocking when she was seated with other adolescent females on two separate occasions.

In addition to demonstrating anxiety through rocking, P1 indicated frustration concerning feeling misunderstood, primarily by her family.

R: "Do you ever feel pressured to act a different way?"

P1: “Yeah, from my mom and dad a lot. You know, every time she opens her mouth, ‘Oh that’s ridiculous, honey,’ ‘Oh, that’s the wrong way,’ ‘Oh you shouldn’t do that.’ And my dad doesn’t understand either. He yells so much, I don’t open up to him much either.”

R: “What are you usually doing when he starts yelling at you?”

P1: “Well, yeah, I usually cry in my room, or whatever.”

A file review indicated that when P1 was in high school her mother reported that she was overly anxious. P1 was also reported as picking at herself. Deviation from routine was reported as eliciting anxiety from P1. P1’s feelings of frustration and anxiety relate to the research questions pertaining to personal, home, and social experiences.

P2. P2’s mother indicated that the participant was sensitive to sound. The interview location at times became rather loud. P2’s eyes would scan the room, while continually answering the researcher’s questions. P2’s response to one of the questions confirmed her dislike of excessive sound.

R: “How about parties...do you like them?”

P2: “Too many people, too much noise.”

P2 indicated a physical response to anxiety as a result of a previous experience that she had associated with a specific food item. P2 also recognized feeling anxiety due to proximity of others. P2 appeared to develop compensatory skills to deal with her anxiety, as indicated below.

R: “Do you like salads?”

P2: “Yes.”

R: "Pizza?"

P2: "No. I used to throw up all the time in elementary school and for some reason it was always Friday. And my body thinks it was the pizza, but it was stress."

R: "Do you get stressed a lot?"

P2: *[Participant nods.]*

R: "What stresses you?"

P2: "People."

R: "When you get anxious what are some of the things you do to relieve it?"

P2: "I go for walks always by myself or sometimes I play my videogames."

Anxiety may result from sensory issues. P2 indicated that excessive sound elicited anxiety. Similar to P2, was P3.

P3. P3's mother indicated that her daughter demonstrated sound sensitivity. Both P3 and her mother indicated fireworks and balloons as items causing stress. According to P3's mother, walking into a room with balloons elicited a screaming tantrum when her daughter was much younger. This past 4<sup>th</sup> of July, the family left P3 several miles away from a fireworks show at a relative's home. The participant hid in the bedroom and indicated that the sound was still too loud.

R: "How does Asperger's affect you?"

P3: "Nothing."

R: "When you were little?"

P3: "My ears are really sensitive...even now."

P3 appeared to exhibit anxiety over social situations that drew others' attention to her. P3's experiences added to the information related to the research questions related to social and personal experiences. P3's mother indicated that her daughter had participated in several performances that required her to perform in front of others including both a dance and cheerleading camp. While she continually expressed anxiety over such performances, P3's mother stated her daughter was capable of performing in front of others.

R: "Do you like your English class?"

P3: "All right I guess, except I don't want to do speeches. I have stage fright. I can't. I'll faint, though. I can't. Half of sophomore year, though, is speeches."

R: "Have you ever fainted before due to nerves?"

P3: "No. I gave one presentation in middle school. I was trying to, I was giving it on kittens, but I had [names kittens]. I was doing the presentation on them. I had little pictures of the...I did a tiny speech and I was done."

R: "What else gets you nervous?"

P3: "Anything in front of crowds. My mom says I should be an actress or singer. Um...let's see, I have stage fright...that would be really dumb."

R: "When you were in middle school did you go to any dances?"

P3: "Uh...no."

R: "Why?"

P3: "I don't like dancing. I have stage fright. I don't do anything in front of people. I don't dance, sing, or anything. I do at home, alone."

P4. P4 shared with the researcher behaviors she engaged in during feelings of anxiety.

R: “When you would get anxious, what would you do?”

P4: “Scream, cry, throw a fit, smack myself.”

R: “Where would you smack yourself?”

P4: [Participant indicates palm to head]

R: “Do you still do that?”

P4: “It’s gotten better, but I still cry a lot.”

R: “Why did you stop hitting your head?”

P4: “I think I outgrew it.”

P4’s mother indicated her daughter continued to engage in head banging. The behavior had subsided in frequency. P4’s mother stated that P4 also engaged in other behavior to alleviate stress, as well.

P4 Mother: “She’d tear her clothes. It took her three months on a brand new coat...she bit holes in the arms. She’d just start shredding it. She’d pick the desk apart....pants, shoes. Everything... she’d pick apart.”

P4 Mother: “I think a lot of it is also the parenting has changed so much. It went from my first daughter...my first child...I expected her to fit in the mold of a first child. She didn’t do that so I wasn’t a good mother figure for the first 12 years of life. She is who she is...I need to learn to live with her. A lot of her stress is caused by others who don’t understand, so we’ve been teaching her advocational skills. When they do this, you do that. Worry about them getting in trouble. Come call me and I’ll take care of it. A lot

of it is education for teachers or others. Many don't want to know. She's not a problem child."

P4 provided insight into the research question related to academic experiences. Issues in the academic setting may also lead to frustration and anxiety, as demonstrated by P4's comment.

P4: "Most of the times in 2<sup>nd</sup> grade I got so many of these blue slips that represent punishment. I had teachers telling my mom that I stood up on top of the desk. Get 3 of these blue slips and you get a referral. I got them so many times and I didn't know why I was getting in trouble."

P4's mother indicated concern over the impact her daughter's anxiety holds over potential employment.

P4 Mother: "She could keep a house, make dinner, do the shopping, but she would have trouble with the stress of keeping down a job. I don't know that she could do that, and that's what worries me. Unless you have a really understanding boss...where do you go from here? She's about 3 years behind, so she's like a 15-year-old right now. So, could she live completely on her own right now...I doubt it. Not without some huge difficulties. Do I think she's the one who could overcome them? Absolutely, but it would not be easy."

### *Third Thematic Unit: Social Issues*

Social issues are a hallmark experience of individuals with AS (Chamberlain, Kasari & Rotheram-Fuller, 2007; Humphrey & Lewis, 2008; Kopp & Gillberg, 1992; Nydén, Hjelmquist & Gillberg, 2000). Social issues appeared to be a common

experience shared by the participants. Attwood et al. (2006) stated that females with AS engaged in a social echolalia, enabling them to appear more advanced in social ability than actuality. Social echolalia is the ability to mimic another's behavior leading to superficial social competence (Attwood et al., 2006)

*P1.* P1 appeared to engage in examples of social echolalia. P1 was noted observing her cell phone on several occasions during an observation. However, when asked who calls her, she indicated few friends.

R: "Who calls you besides your parents on your cell phone?"

P1: "My sisters, my pick-ups, not really my friends that much."

The behavior of fidgeting with a cell phone may be an example of social echolalia exhibited by P1. Social echolalia might also be exhibited in outer appearance. P1 also stated that while her mother selected some clothing, the participant observed what was popular.

R: "Who picks your clothes when you go shopping?"

P1: "Sometimes my mom finds my stuff, but I look around and stuff to see what's in fashion."

P1 provided a wealth of experiential information related to the research questions pertaining to social experiences experienced during middle and high school. P1 was asked about attending dances during high school. She indicated she had a guest and they danced, but when asked if she had a date, she said she did not. P1 then started a conversation about males being interested in her. It appeared that P1 recognized the significance of a date while attending the prom.



R: "When you were in high school did you go to any of the dances?"

P1: "Except for my senior prom...that was it."

R: "Tell me about that."

P1: "It was exciting. It was pretty loud...the music. It was 1920s...the jazz sort of stuff. And it kinda sucked because, you know, there's not a lot of 1920s stuff. There's pictures, and a couple of cars. There needs to be more details, you know, that catches the eye. The music was not really 1920s. It was mostly hip hop, pop...the music from today. It kinda blowed...after a couple of hours, you know...I had a guest, and my left foot started killing me....so ok, we're done. But, it was really nice. We danced for a while. We saw friends, and so..."

R: "So you had a date?"

P1: "No... I didn't have a date. Boys didn't like me until...oh, about last year, I guess. You know, oceanography class, and this sophomore, CW, thought I was a junior. 'Are you taking zoology? No, I'm a senior!' You know, it's like...oookaayy! He was like a nerd, but that's ok. Well, he didn't have glasses, but he had those assets."

Social opportunities are often awarded to females with AS (Attwood et al., 2006). Social opportunities provide added practice of social situations, such as participation in 4H. While the researcher questioned P1 about sleepovers, the participant appeared to show an understanding of the researcher's intent to develop an understanding of the participant's social experiences during high school. As a result, the participant offered her 4H memories and thoughts. This exchange was of particular importance in relation to

the research question related to social experiences, as it demonstrated a shared perspective.

R: "How about sleepovers. Have you ever had any?"

P1: "Um...not that I know of...I've done 4H."

R: "How did you like that?"

P1: "It was great. I liked it. I went to the meetings. It was fun. I earned ribbons and stuff. The thing is...the hard thing is that in the show arena, even though I seen it many times gone by, it's just getting used to it. The things I hate so much is that if you have to look at the judges constantly, you know...."

While P1 appeared to engage in conversation or behavior that was age-appropriate, P1 appeared to recognize her areas of delay. Parental involvement evidenced, as well.

R: "Do you feel confident that you could move out right now and support yourself?"

P1: "No...my mom's suggesting I should have assistance. And yeah, assistance because I'm not great at it...I don't know how to cook or any of the above yet, because I haven't gotten that far."

R: "What 3 skills would you like to work on to help you become independent?"

P1: "Would say geographic mapping (yawn)."

R: "How about dealing with money?"

P1: "If it's too difficult, I can't handle that much."

R: “If you need a hair cut or need to make a doctor’s appointment, do you do that?”

P1: “My mom does that.”

Another social experience described by P1 included eating alone when she attended school.

R: “When you were in elementary school, what did you do for lunch?”

P1: “Oh...(pause)”

R: “Did you eat with other kids?”

R1: “Well...I usually eat my own lunch. I usually eat yogurt pudding, a little snack, and a sandwich.”

R: “Did you eat with anybody?”

P1: “No, not really. I usually stay out of the group, or don’t have the courage to go over to a group.”

P1 expressed social discomfort and isolation. A slight hesitation was noted towards the question. The researcher asked the question twice.

*P2.* P2 experienced success in completing distance learning college courses. However, other areas of delayed development caused P2 to rely on her mother. This may be observed in the following dialogue.

R: You’re taking college courses aren’t you?

P2: I did last year.

R: Do you like living at home or are you anxious to be on your own?

P2: I want to be with my mom.

Socially, P2 appeared comfortable with children who were approximately 5 years younger than her chronological age. Unfortunately, when the below mentioned children moved out of the country, P2 claimed she hid in a corner and cried.

R: What was your best friend's name?

P2: [name] and [name]

R: Oh, two friends.

P2: Yeah. They are in Okinawa right now.

R: What grade are they in.

P2: [name] is eleven now...she just turned 12.

R: What are some things you did with your friends?

P2: We liked to pretend we were Peter Pan.

P2 stated she had previously been employed working with adults with "special needs." She enjoyed the experience as she shared common interests with the adults at the facility. P2 referred to the adults with special needs as clients.

R: Have you ever had a job?

P2: Yes, I worked at a day camp facility for adults with special needs, helping my mom out.

R: How many hours a day did you work?

P2: They varied. Some days were long. I think Friday's were the long day.

P2: Mondays everyone was dropped off at 4. Fridays we left at 5.

R: That's a long day.

P2: Yeah, but the clients we worked with had a lot of similar interests. That helps out.

R: Tell me some of the similar interests you have.

P2: We both like Power Rangers [*participant smiles*].

P3. P3's mother claimed that a benefit of running a day care allowed children to grow up knowing P3 and accepting her differences. P3's mother noted that the individuals her daughter maintained as friends were not appropriate role models. P3's mother stated it as a decision between friendships or no friendships for her daughter. P3 expressed concern over her daughter's inability to develop friendships at school. However, according to P3, friendships did not appear to be an issue.

R: "It sounds like you have a ton of friends."

P3: "Yeah, if you're friends with C and E. Yeah...yeah, and then K and M are my other friends. But they haven't come over for a while because their mom, like, always says no."

Some of P3's friends are chronologically younger. P3's reason for creating a MySpace suggested an observance of behaviors in which peers engage. However, P3's focus did not appear to be on collection of cyber friends, but on having a page.

R: "So, how many friends do you have in your MySpace?"

P3: "I just have A for now, 'cause nobody...my friend doesn't have a MySpace. My friend is 9. My other friend is 11. Yeah, she's going to turn 11. C, yeah, she has a MySpace, but I haven't told her mine because she doesn't have a computer. Every teenage person has one, so that's why I made one."

Listening to P3's use of word choice, select phrases, and voice intonation suggested social echolalia. P3 appeared to recognize her older sister's ability to choose clothing that was age-appropriate. The sister's selection of items allowed P3 to blend in with her peers.

R: "Do you like to go shopping?"

P3: "Me and my sister...my sister has good taste. I never go school shopping with my dad cause he doesn't have good taste. She wears pretty clothes."

*P4.* P4's mother indicated her daughter did not have significant friendships until middle school. P4's mother stated that she was concern regarding her daughter's choice in friends. This is indicated below.

P4 Mother: "She played by herself quite a bit when she was real young. By the time she got into middle school, she started getting friends, but they were real...special needs friends, too...really had some mental problems. Not just Aspergers. Social problems. They're not necessarily upstairs, but family related, so outbursts. It was hard because she tries to emulate the people she's around. It made it real difficult, because you couldn't say you can't have that friend when she only has one friend. It was hard."

When P4 was asked to describe her early recesses and lunches, she did not mention peers. This omission informed offered insight into the research question related to academic and social experiences during elementary school.

R: "Tell me about elementary school, recess, and lunch."

P4: "I went outside and played and then I ate."

Researcher asked P4 about her ability to be independent. P4 indicated she knew how to cook, sew, shop, and clean as a result of her mother's training. According to P4's mother

P4 Mother: "She needed more but they didn't offer it, so I did a lot of it at home. I'd take her to the grocery store, we'd pick out the food, she'd make dinner."

#### *Fourth Thematic Unit: Interests*

The fourth thematic unit included interest areas. Each of the participants will be discussed below. Portions of the interviews pertaining to interest areas have been included.

*P1.* P1 experienced similar interests and desires of many other individuals her age. This was evidenced in her desire for a boyfriend, to go out on dates, and to have a career. P1 offered significant insight into the research question related to her personal experiences.

P1: "...I like other movies like Lord of the Rings, Harry Potter, Eragon. I like the fantasy fictional. Yeah I'm trying to create a story right now that that going to be for children. The twist is it's going to be for all ages. I haven't worked on it this term because I've been so busy."

R: "It sounds like you enjoy creative writing."

P1: "Uh, huh."

R: "I bet you're good at that."

P1: "Yeah. I didn't notice until I got in college. My first writing course...uh...it was very rocky. You know, I had to rewrite every single paper. You know, in high

school, I had As, etcetera. I'm like what the heck is going on here! I'm like...it's a whole different level, but as I grew, I changed my prewriting techniques, did different aspects, added more supportive details, and became stronger. Actually, writing is going pretty well. It's improved."

P1 emailed the researcher a copy of her fantasy fiction story. It was an interesting 10-page typed story that led the reader through an adventurous journey. P1 claimed she was only half way through the story and had plenty more to write. Her interest in writing appeared to demonstrate a qualitative difference in intensity. P1 displayed a talent that could potentially lead to a future career. Upon P1's file review, the autism specialist noted that P1 demonstrated difficulty in creative writing when the topic did not interest the participant.

R: "Where do you see yourself in 10 years?"

P1: "A novelist, a veterinary assistant, maybe have some kids (chuckles). I want at least 6...maybe 4. We're a big family. We're a big family."

*P2.* P2 offered a unique glimpse into the varied interests of an adolescent female with AS. Similar to P1, P2's contribution provided insight into the research question related to personal experiences. In addition to discussing and owning several items related to animé (Japanese animation), P2 pretended to interact with the animé characters. P2 demonstrated an intense interest in animé. P2's interests varied from animé to state and federal politics. Her creativity was apparent in her origami skills. Yet, P2's demeanor and presence is acutely humble and unassuming.

R: "Do you watch the news?"



P2: “My mom does, but I stay in the room. Sometimes I watch. [Discusses the politics of the state, including who is running for senate by name.]”

The researcher considered including P2’s discussion on politics. However, the researcher decided elimination of the discussion was necessary to protect the participant’s identity. P2’s discussion offered a glimpse into her home experiences and addressed the related research question.

R: What do you like to buy besides Digimon stuff?

P2: “Basically, video games. I had to pay \$300 for Magic [her horse]. She got kicked in the knees a couple of days ago. She’s a little bossy. She’s in a stall with a gelding who also wants to be boss. Her knee was open. We don’t know if it’s going to get better. I rode a Fjord that had a little man’s syndrome.”

During the interview, P2 asked the researcher if she liked origami.

P2: “Do you like origami?”

R: “Yes I do. Do you?”

P2: “I think I’m very good at it. I like to fold dragons. I’m waiting for a book to come from Japan so I can fold a really complicated one.”

R: “How long have you done origami?”

P2: “I don’t know, but I know someone came to my class in 2<sup>nd</sup> grade.”

R: “Have you ever made your own [origami] design?”

P2: “A dragon head.”

R: “Where did you learn to do this dragon?”

P2: “On the Internet. It has 75 steps and takes an hour to fold. I have a different type of dragon I make. I can also make a beetle. I also folded Yoda. I get almost all my diagrams off the Internet.”

P2 claimed the instructions for the dragon she folded for the researcher was 14 pages long when she printed it. The dragon was impeccably folded with a head and open jams, large wingspan, body, and tail. In addition to showing her creativity through origami, P2 was a musician. P2 indicated to the researcher that she had a good ear for music.

R: “How long have you been playing the flute?”

P2: “Since 4<sup>th</sup> grade. When I was in 4<sup>th</sup> grade, I played with the 5th graders.”

P2 indicated several interest areas that were similar to others in her age range. Several were noted from country music, to her iPod, and favorite television programs. Below are excerpts from P2’s interview that reflect some of her common interests.

R: “Do you ever listen to music?”

P2: “Yes.”

R: “What kind of music do you listen to?”

P2: “Country.”

R: “Who’s your favorite?”

P2: “I like a lot of singers. I like Reba McEntire a lot.”

R: “Do you have an iPod?”

P2: “Yes.”

R: “How many tracks do you have on your iPod?”

P2: "A hundred something [*chuckle*]."

R: "What are some of your favorite shows?"

P2: "Digimon, Power Rangers, House, NCIS"

P3. P3 indicated several interests that were typical of adolescent females.

Interests included boys, technology, and website surfing. P3 was also very familiar with current popular television stars targeted at teenagers. P3 provided substantial experiential information related to the research questions pertaining to social experiences.

P3: "I had a crush on a guy last year...J...but he moved away. He was just like me...He didn't dance. He got suspended the last day. J...he lives in Washington now."

R: "Do you have a cell phone?"

P3: "No...I want one though...Can you convince my mom to get me one (laughing)? My mom's not buying me one."

R: "Do you own an iPod?"

P3: "It's so unfair though. My sister got her first cell phone when she was 16."

R: "Do you have an iPod?"

P3: "She's got a bunch of them now. I don't have an iPod...no. I don't have a laptop or any electronics. It's really boring. I had a CD player, but like I got it for Christmas, but obviously, it was a cheap CD player 'cause it broke half way through the year."

R: "What are your favorite internet sites?"

P3: "NeoPets, MySpace, Google, YouTube, and lots of game sties. I like MyroPets and Zano Pets."

P3 appeared to have a particular interest in popular culture. Current movies such as High School Musical and Hairspray were mentioned, as were numerous television shows geared for teens on the Disney Channel. Of particular interest were the actors and singers in these forums. P3 claimed she wrote down popular song lyrics over and over.

R: "Who are your favorites?"

P3: "My favorite celebrities?" [Participant clarifies understanding.]

R: "Yeah."

P3: "I like Hillary Duff, Justin McCartney, all the High School Musical stars...and...Danna, Vanessa Hutchins, [participants names 3 others]. Not Monique, I swear to God, I don't like her much. And then I like Kelly Clarkson...Ashley Simpson...who else? I like Josh Hutchers, but he doesn't sing. He's just on a lot of movies. Like have you seen Bridge to Terabithia? Or Firehouse Dog? Yeah, I hate that little kid. Let's see... Leanna Sophia is pretty cool. She's the one in Bridge to Terabithia that dies. Dies in Bridge to Terabithia (unusual voice quality). Uh...let's see...let me think...um...I don't really remember...I like a lot of stars."

P4. P4 claimed to have many interests that were typical for her age. In elementary and middle school, her hobbies and interests remained the same.

R: "What were your hobbies in elementary?"

P4: "Coloring, Barbies, animals"

R: "Hobbies in middle school?"

P4: "Stayed the same."

R: "Did you want to go, or were you "encouraged" to go (to school dances)?"

P4: "I wanted to go. I didn't have a date for any of the dances except for that [name]. That was like junior year prom."

P4 has an MP3 player loaded with current songs that elicit raised eyebrows from her parents, has a cell phone that she claimed is careful of its usage, and has a MySpace page that sports a black stallion, with a picture of herself in a very attractive pose.

R: "What are some of your favorite sites?"

P4: "MySpace, Players, Howrse, I think that's about it."

R: "How many friends do you have on MySpace?"

P4: "13"

P4 appeared to display interests in horses, as indicated by the picture on her MySpace page and her mention of the Howrse website. However, her reading interests lie in different areas. P4 mentioned a particular fascination with vampires.

P4: "I have a lot of different things I like. I like the Twilight series, a vampire romance novel. I also read a lot of smut. They're romance novels. The first smut book I read was in the teenage section and it was written by Judy Blume. This guy is all about wanting to have sex. The scenes in there are very explicit. It wasn't the best thing to be reading."

P4: "My cousin tries to get me into horse stories...but it doesn't work. Although, there are certain comedies that I like...Achmed, Jeff Dunham, Larry the Cable Guy, Bill Engvahl, Jeff Foxworthy, kinda Ron White, kinda not. He's like my least favorite. Larry the Cable guy is my favorite."

R: "Do you like to go shopping?"

P4: [Laughs heartily.] “I like to shop. I like to shop for prom dresses, fabrics, because I do quilting, crocheting, knitting, make clothes. If there’s fabric and thread, I’ll use it.”

*Essence: Female Teenagers with Asperger Syndrome Share Similar Interests with Neurotypical Peers While Continuing to Battle Internal Issues and External Circumstances*

Study participants appeared to share similar interests with their neurotypical peer group. This supports Attwood’s (2006) claim that interests of girls with AS demonstrate age-appropriate interests. Examples of age-appropriate interests included the ownership or desire of ownership of items such as an MP3 player, cell phone, or laptop computer. See Table 2.

Table 2

*Participant Interests*

	P1	P2	P3	P4
Animé		✓		
Artistic Interests	✓	✓	✓	✓
Cell Phones	✓		✓	✓
Horses	✓	✓	✓	✓
Imaginary Play		✓	✓	✓
Internet	✓	✓	✓	✓
MP3/CD Player	✓	✓	✓	✓
Reading	✓	✓		✓
Social Activity	✓		✓	✓
Video Games	✓	✓	✓	✓

Three participants provided the researcher with samples or the opportunity to examine artifacts pertaining to their interest areas. This included a dragon origami creation, a fantasy fiction story, and samples of quilts. The first participant engaged in creative writing and emailed the researcher a ten page typed story in the fantasy fiction genre. According to the participant, she still had not completed the story. According to P2, the dragon consisted of 75 steps and took approximately one hour to fold. P2 timed herself on many occasions to determine the length of time it took her to create the dragon. P4 discussed her 7 First Place and 2 Best of Show awards for her quilting projects. P4's quilts were displayed in the family living room.

One participant sounded typical for her age, as she demonstrated a slightly rebellious nature, often seen during the adolescent years.

R: "If you won the \$10k, what would you do?"

P3: "Buy a horse, I'd be like, forget you mom and dad...who cares what you say. It's not staying at their house anyway. I would be staying at my grandmother's. I already asked my grandmother. She said it was fine."

Another participant recognized her strengths and perceived her social challenges.

P4: "I'm a refreshing person."

R: "Would the biggest obstacle be to independence at this point?"

P4: "People would think I'm retarded."

However, study participants appeared to continue to battle both internal and external circumstances. Examples of internal circumstances affecting the participants included anxiety, frustration, and social issues. All participants experienced anxiety, and two participants were observed during such situations. Each of the two participants displayed their anxiety differently, one rocking and the other using physical distance. In addition to the internal circumstances, external circumstances offered additional challenges.

All study participants experienced victimization. In addition to physical and verbal victimization, perceived victimization was also experienced. Perceived victimization is used to describe the participant's perception to being harassed when in actuality, the participant is misperceiving social situations. A study participant perceived



herself being stalked by an individual over the internet, when it was a mass communication presented in a personal format. See Table 3.

Table 3

*Participant Victimization*

	P1	P2	P3	P4
Physical	Yes	Yes	No	Yes
Verbal	Yes	Yes	No	Yes
Perceived	No	No	Yes	No

Discrepant and Nonconforming Information

All interviews except for P4 occurred in public locations. No family members were present during these interviews. P4 requested to be interviewed at her home. During P4's interview, her mother came and went throughout the interview. This had the potential of influencing the interview, although P4 appeared to be relaxed and talkative.

*First Thematic Unit: Victimization*

All but one of the participants indicated an experience with victimization at some point in their lives. P3 indicated she did not have experience with victimization.

R: Have you ever been bullied at school?

P3: No.

P3: There was this one girl...she didn't really bully us, but she chased us. She got mad at us.

P3 later indicated that she was being stalked on two websites.

P3: “There’s already this guy stalking me. So…”

R: “Through MySpace?”

P3: “Oh, MySpace and Yahoo”

P3: “He’s starting to scare me.”

#### *Fourth Thematic Unit: Interests*

P2 displayed interest differences from the other study. P2 was the only participant interested in animé, such as Digimon and Pokémon, and Power Rangers. P2 was not interested in having a cell phone, as talking on telephones was indicated as something that produced anxiety. P2 had also not been involved in social activities arranged through either parental involvement or her own desire.

#### Evidence of Quality

##### *Trustworthiness*

Trustworthiness was established with a variety of information collection tools. Researcher engaged in in-depth interviews, observations, file reviews, observed participant artifacts, and engaged in incidental discussions with parents. Field notes and researcher reflections were also captured. Researcher documented an audit trail in the research journal, as well. Participant interviews were digitally audiorecorded. Participant responses were transcribed by the researcher and checked for accuracy. Researcher reviewed transcriptions repeatedly until thematic units emerged.

### *Member Checks*

Member checks were conducted during in-depth interviews to ensure the interviewee's voice was accurately captured. Misunderstandings or information that needed clarification was handled through telephone conversations. Member checks were performed with both study participants and parents.

### *Triangulation*

Information was gathered from a variety of sources including the following:

1. In-depth interviews with participants
2. Observations and field notes
3. Participant artifacts
4. Incidental information provided by parents and teachers

### Summary

Chapter 4 included information related to study findings pertaining to the lived experiences of adolescent females with AS. Experiences pertaining to academic, home, personal, and social life were explored. A discussion related to the description of research participants, procedures used in the qualitative study, and data analysis was included in this chapter. In asking research questions related to academic, home, personal, and social experiences, four thematic units emerged from the findings. The thematic units were as follows: (a) victimization, (b) anxiety and frustration, (c) social issues, and (d) interests.

The thematic units offered an essence to the central phenomenon. While the study participants shared common interests with neurotypical peers, the continued to

encounter internal and external circumstances. Interest areas showed qualitative differences than neurotypical peers. Some interests appeared to be reflective of social echolalia, where the behavior was mimicked without possessing a deeper understanding, while other interest areas were more intense. For instance, an interest in horses may be expressed through owning a real horse, virtual horse, horse bedspread, towels, and clothing depicting horses. A pattern of parental involvement emerged that flowed through the themes. Parents were protectors and attempted to ease and compensate for anxiety, frustration, and social issues.

Chapter 5 includes an overview of the study, an interpretation of findings, and implications for social change. Recommendations for further action and study will be provided. The researcher also will include a reflection of the research experience.

## CHAPTER 5: SUMMARY, CONCLUSION, AND RECOMMENDATIONS

### Introduction

This phenomenological study is an exploration of the central phenomenon of the lived experiences of adolescent females with AS. A qualitative study was conducted to provide a voice for the participants while attempting to capture a glimpse into their lives. Chapter 5 includes a brief overview of the study including the research question, purpose, method, and findings. Implications for social change will be addressed in addition to recommendations for action and further study. The chapter will conclude with the researcher's reflection on the research experience.

### Study Overview

Minimal research currently exists that targets females with AS. Less research exists pertaining to the select age range offered by the adolescent years. Appropriate diagnosis and support is unavailable for affected adolescents without an understanding of the lived experiences of adolescent females with AS. The purpose of this study was to provide insight into the central phenomenon of the lived experiences of adolescent females with AS. Interview questions targeted four areas of life including academic, home, personal, and social experiences.

Four participants were selected for in-depth interviews. File reviews, observations, and artifact examination, offered contextual information in gaining a clear understanding into the lived experiences of the participants. Participant in-depth interviews were transcribed, and whenever possible, participant dialogue was used to

provide a voice through their own rich thick descriptions. Four thematic units emerged. Thematic units included the following: (a) victimization, (b) anxiety and frustration, (c) social issues, and (d) interests.

The essence of the central phenomenon suggested that adolescent females with AS share many interests with their neurotypical peers while battling both internal issues and external circumstances. Participants appeared to rely heavily on parental involvement. Parental involvement appeared to weave through the various thematic units as teacher and assistant, offering additional training and added support that was often compensatory in nature. For example, one mother attempted to prevent situations that might cause her daughter anxiety.

### Interpretation of Findings

#### *Victimization*

The first thematic unit involved victimization. Individuals with AS are often targets of violence (Donovan, 2008). Each of the participants indicated an experience with being victimized by another, often during unstructured times, except for P3. P3 initially stated that she had not been bullied, then indicated that a girl used to get mad and chase after her, but she did not think it was bullying.

P3 had indicated prior to the questioning of whether she had ever been bullied that she was being stalked. P3 perceived she was being harassed over the Internet, and claimed, "He's starting to scare me." However, P3 did not understand the nature of the communication she received over the Internet is from a figurehead and is actually a mass communication that is generated to all who have an account with the particular website.

P3's situation indicated that instruction was needed on the use of social communication websites, such as MySpace and FaceBook.

P3 also believed she was a personal friend of "Tom," the "leader" of MySpace. This is another example of P3's lack of knowledge pertaining to the social norms of the website. Users of MySpace receive messages from Tom that indicate general information pertaining to the website. She did not appear to understand Tom was a figurehead. Instead, she appeared to believe she engaged in a personal relationship with him. P3's comment pertaining to Tom reinforces the need for direct instruction on the use of the social aspects related to the Internet.

While most of the participants mentioned being bullied by peers, two other situations stood out. P1 indicated that her father often yelled at her and she would flee to her room and cry. P1 indicated that she believed her father was "still in denial about the Aspergers." P1 indicated that he father says, "You're not paying attention." Individuals with AS may not hear an external stimulus if attention is intently focused on something due to neurological differences (Attwood, 2006). Behaviors and social blunders made by individuals with AS may increase stress levels of parents. As a result, parent frustration may be expressed towards children.

P4's mom indicated that prior to understanding her daughter's needs, her parenting style was inappropriate for her daughter. Parental understanding of the social and perceptual difficulties faced by their children's needs as a result of AS is tantamount to the child's success. This underscores the need for appropriate diagnosis for girls with AS as it provides answers for parents as well.

Other adults might also engage in behavior that is considered bullying towards individuals with AS. For example, P4 indicated that a peer's parent had called her "schizophrenic." P4 and her mother involving educational staff indicate additional training is needed to understand issues female teenagers with AS. As many female teenagers with AS appear to handle social situations appropriately, it leaves some people questioning whether an actual condition exists. However, when a female teenager with AS experiences a melt down, staff may misconstrue the behavior as a deliberate tantrum.

Victimization towards female teenagers with AS occurs from many settings. These settings may include school, home, and even the Internet. Female teenagers with AS require strategies to avoid both actual and perceived victimization. In addition to victimization, female teenagers with AS also experience anxiety.

#### *Anxiety and Frustration*

The second thematic unit to emerge was anxiety and frustration. Anxiety is a prevalent condition among individuals with AS (Attwood, 2007). Participants in this study were no different, as they expressed feelings of anxiety as well. Participants in the study each appeared to express their anxiety in different ways.

Participants expressed anxiety in several ways. Some of the expressions were as follows:

1. Rocking or flapping
2. Establishing physical distance
3. Removing eye contact
4. Hands to mouth



5. Head banging
6. Yelling or screaming

Anxiety appeared to result from a variety of situations. Each of the participants reacted to different triggers. Some of the triggers are listed below:

1. Balloons, fireworks, or loud noises
2. People and crowds
3. Break in routine
4. Being late
5. Performing in front of others
6. Needles

One of the participants experienced such great levels of anxiety over fireworks that her parents removed her by several miles to diminish her anxiety. However, the participant claimed she could still hear the fireworks and hid in a room. Had she actually heard fireworks or had she psychologically convinced herself of hearing them? The anticipation of the anxiety producing event may produce an effect on the individual that is as potent as the actual event.

Another participant indicated that she needed to remove herself from others in order to calm down when she felt anxious. She recognized specific activities allowed her to calm down. During times of stress, she engaged in these behaviors.

Yet, another indicated that cognitively, she could control her fears in order to maintain her behavior. However, this required a tremendous amount of energy to do so. Even though she remained fearful, she focused on maintaining her behavior.

Females with AS could benefit from cognitively dissecting fears and establishing strategies to combat the reaction the fear has on them. This should take place during a time when there is no possibility of the trigger occurring. Ideas could be brainstormed as to what can be done to remove oneself from the situation and what strategies can be implemented if removal is impossible. Recognition of changes to physical state should also be brought to attention so that the girl will recognize what is occurring and take steps to overcome the anxiety. Along with anxiety, adolescent females with AS also experienced social issues.

### *Social Issues*

The third thematic unit experienced by female teenagers with AS was social issues. Individuals with AS are often bullied or nurtured (Attwood, 1999). One of the participants has been around a group of peers for many years because her mother ran a day care. These peers have grown up with the participant, and according to her mother, continue to nurture her daughter. The nurturing nature of females may protect and support some girls with AS. This may offer the appearance to adults that the affected girl is surviving fine in the world. What is not realized is that the survival is a supported one.

The ability to mimic others social behavior offers a useful compensatory skill to females with social cognitive deficits as they experience their surroundings. Attwood (2006) stated that females with AS engage in social echolalia. Social echolalia offers the ability to camouflage oneself from the difficulties encountered in attempting to navigate unwritten social rules. Social echolalia may also encourage social development.

Neurotypical individuals often use peer observation to determine socially acceptable behavior and apply meaning based upon the experience. Females with AS may be engaging in a similar manner. However, without a deeper understanding of what the behavior meant. The participant who created a MySpace page because others were doing so lacked the understanding that the purpose was to collect cyber “friends.”

Social echolalia may be one of the main reasons why females have been both misdiagnosed and underdiagnosed. Social behaviors may appear appropriate unless the behaviors are closely examined. The advantage of social echolalia is that it offers girls with AS to fit in more with their peer group than if they did not demonstrate such behaviors.

Two of the parents indicated that both of their daughters attempted to act like their friends. The parents expressed concerns over the behaviors exhibited by their daughters’ friends. Without the ability to understand the deeper meanings behind social behaviors, it becomes imperative to monitor girls with AS to ensure that the behaviors that are being mimicked are appropriate. As social echolalia may be a factor in the misdiagnosis and underdiagnosis of girls with AS, so might their interests.

### *Interests*

The fourth thematic unit focused on interests. Participant experiences with hobbies and activities during leisure time indicated that participants shared common interests that were also typical of unaffected adolescent females. For example, music, reading, websites, horses, and videogames were reported as favorite pastimes by most of the participants. Animals were mentioned by all participants. Two of the participants

visited websites where they maintained virtual horses as pets. All participants were frequent users of technology, including the Internet. Just as social echolalia may be a factor in the misdiagnosis and underdiagnosis of girls with AS, the common interests girls with AS may also be interfering.

Interest areas need to be reviewed for qualitative difference. Are the interests superficial, demonstrating social echolalia or does the interest area appear more intense? For example, does the girl with AS like to ride horses, or is her room decorated with horses, does she have horse towels, horse pajamas, stuffed horses. The point to consider is to what degree the interest consumes the girl. Is the degree of interest similar to the interest level of other girls of the same age?

In the present study, one participant (P2) demonstrated superior cognitive ability. She was interested in animé and Power Rangers. This participant stood out in comparison to the other participants in that her interests would not be considered age-appropriate for a high school senior. This particular participant demonstrated the least amount of social skills in comparison to the other participants. These particular interests are commonly observed in males with autism spectrum disorders. P2 did not use voice intonation or body language to communicate emotion, as she displayed a flat affect. The other participants were animated and appeared to engage in social echolalia more than P2. Based on EMB theory, could P2 be more affected than the other participants, giving rise to interests that are more typical of male interests? Could interest areas be used to discriminate between HFA and AS?

### *EMB Theory*

EMB theory suggests the existence of three brain types including the male, female and balanced brain types (Baron-Cohen, 2005a). Females are often associated with demonstrating heightened social abilities in comparison to males. While females with AS may be prenatally exposed to testosterone may result in a male brain type, the resulting adolescent may exhibit traits more often associated with males, yet maintain some of the strengths associated with females. Participants in this study demonstrated the use of social echolalia. Social echolalia enables females with AS to fit into social situations without truly understanding contextual meanings. While this may beneficially serve females with AS by allowing them to blend with their peers, it may also hinder recognition and appropriate diagnosis. Participants demonstrated qualitative differences in age-appropriate gender-typical interests, such as boys and popular culture. A more intensive interest, although not unusual in nature, may result from a tendency towards the male brain type of females with AS. Participant victimization may also result from a diminished ability to empathize with others, particularly in not being able to perceive what others may be thinking.

### Discussion of Parental Involvement

During this study, a pattern appeared to emerge, particularly in the area of social issues, where parental involvement became apparent. Parental involvement appeared to play a significant role in the lives of all study participants. Participants appeared to realize the significance of the role their parents, primarily mothers, played in their lives.

The parental role appeared to be twofold. In many cases, parents compensated for deficit social or developmental skills displayed by their adolescent daughter with AS. For example, arranging social activities such as dance camp or social dates with others.

The other role parents assumed included active teaching of necessary skills needed for independence such as cooking, cleaning, and shopping. While these skills are not necessarily directly taught, females with AS appeared to need direct instruction in the skills necessary for daily life. While these skills were touched upon in school, sufficient hands-on learning or repetition did not occur. As a result, parents were left to fill the gap.

#### Theoretical Framework

This study is viewed through the lens of a critical feminist perspective. Critical feminist researchers attempt to improve the state of lives for people who are in some way deprived (Barclay-McLaughlin & Hatch, 2005). Many females with AS have not been adequately perceived as a group of people affected by AS. Females with AS have been judged from the perspective of males with AS. The notion that the phenotype of affected females may be different has not been thoroughly evaluated by researchers or taken into account when making a diagnosis. As a result, many females have gone misdiagnosed or undiagnosed (Attwood et al., 2006; Wilkinson, 2008). Existing supports and interventions are based on research developed using males as study participants. What may be applicable to males may not be applicable for females in terms of supports.

## Findings in Relation to Literature Review

### *Later Diagnosis*

Current research suggests that females with AS receive later diagnoses than males with AS (Goin-Kochel, Mackintosh & Meyers, 2006). In reviewing the participants and age of initial diagnosis, all were diagnosed in their adolescent years except for one participant. That participant's brother was 8 years her senior and was also diagnosed with AS. According to this participant's mother, her son is more affected than her daughter is. The fact that this family previously had a child diagnosed with AS most likely helped this girl get a proper diagnosis prior to entering kindergarten.

### *Comorbid Conditions*

Comorbid conditions occurring with AS are mentioned in the literature, such as depression, learning disabilities, and eating disorders (Attwood, 2007; Kopp & Gillberg, 1992). Depression is reported as being the most common comorbid condition associated with AS (Hully & Larmar, 2006). However, in this study, anxiety appeared to be more prevalent, based on participant interviews and parental reports.

### *Friendships*

Most of the participants in this study indicated that they had friends. Parental reports indicated that participants displayed difficulty making and maintaining friendships. Chamberlain, Kasari, and Rotheram-Fuller (2007) conducted a study to investigate the social network of children with AS and HFA. The study was conducted primarily with male participants only. Researchers concluded that children with autism perceive their social situation differently than those around them. Participants viewed

their social position more favorably than others did. Researchers also found that study participants varied in their social abilities. This is similar to the findings of this study. Participants' mothers voiced concern over their daughters' lack of sufficient friendships or social activities. However, participants voiced no concern regarding current social situations. Perhaps participants' definition of a 'friend' varies from what their mothers' perceptions are. Perception and reality, however, are two distinct areas. Other research suggests that females with AS encounter difficulties in developing friendships (Nydén, Hjelmquist & Gillberg, 2000).

#### *Social Abilities*

Researchers have suggested that females with AS are better able to grasp social concepts (Attwood et al., 2006; Wilkinson, 2008). Females with AS have been said to demonstrate social echolalia (Attwood et al., 2006). This study supported this claim, as many of the participants engaged in social behaviors that were being imitated.

Participants did not necessarily assign deeper meaning to the behaviors.

#### *Creative Interests*

This study supported previous research that females with AS exhibit artistic and creative interests (Cohen, 2003; Miller, 2003; Winter-Messiers, 2007). All participants in this study demonstrated artistic and creative abilities. One participant proudly discussed her numerous quilts that had won multiple awards. In addition, this participant engaged in sewing, crocheting, and knitting.

The second participant was "musically talented" according to a note found during a file review. She played the flute for over 8 years. This participant also engaged in the



art of origami. She was meticulous in her folding and created ingenious designs. She also created original designs.

The third participant enjoyed singing. According to both the participant and her mother, she sang and danced often. Although the participant's mother encouraged her daughter to further her creative endeavors, the participant refused because of her anxiety to perform in front of others.

The first participant engaged in creative writing. She enjoyed writing stories that were fantasy fiction. The story the participant shared with the researcher was ten-typed pages, and still not finished. The story took the reader on an adventure with a mermaid.

#### *Age-appropriate Interests*

Research suggests that females with AS often engage in similar interests as neurotypical peers (Attwood, 1999; Wilkinson, 2008). This study supported this claim. Each of the participants exhibited age-appropriate interests. Some of those interests included dating, current movies, books, horses, and websites. Researchers have suggested that a qualitative difference may exist in the interests of girls with AS (Attwood, 1999). Participants in this study also demonstrated qualitative differences in interests.

P2 demonstrated a qualitative difference in her interest areas of animé and origami. P2's interests in these areas was much more intense than what would be expected from a neurotypical peer. For example, P2 folded complicated origami designs by memory and timed herself to determine how fast she could create the design each time. P2 owned items related to animé. P2 enjoyed animé to the extent that in her free

time, she would pretend to live in a world with animé characters. In addition to the qualitative difference, the researcher questions the age-appropriateness of the interest area. P2 was almost 18 years of age, but was highly focused on Digimon, Pokémon, and Power Rangers. Similar to P2, P3 showed the qualitative differences in her love of popular music, as she would repeatedly write down lyrics to a song. Several of the participants were interested in horses. Horses are commonly seen as a female interest area, however, the qualitative difference was evident. Horse websites were visited, virtual horses pets were owned in addition to having real horses, and rooms were decorated with horses, such the bedspread, sheets, and wall decorations.

#### Implications for Social Change

Females with AS have been noted as being a minority within a minority (Faherty, n.d.). Current criteria for diagnosing AS are based on the male population. As a result, many females with AS are undiagnosed. Gender-linked behavior needs to be identified. Identification will remove the confusion in diagnosis so that appropriate diagnosis and supports are developed. Males with AS have typically been the recipients of supports and interventions.

Uncovering the lived experiences of females with AS lifts the veil off the hidden world in which they live and provides a voice for their experiences. Females with AS experience gender related difficulties. In addition to offering thematic information pertaining to what they experience, such as anxiety, victimization, and social deficits, this study offers recognition of a community of females who have a place in this world.

Females with AS are aware of their differences. The higher functioning females with AS are, the more able they are to blend into society. Yet, the acknowledgement of difference exists. ‘Why am I like this?’ and ‘Is something wrong with me?’ are questions asked. Enlightenment of the characteristics of females with AS may provide comfort to the women not formally diagnosed. Understanding of self and of one’s past is what most people seek, and in particular, females with AS.

The researcher hopes that this study will impact social change for females affected by AS. Additional information provided through this study may be added to the informational base when reviewing criteria used in examining eligibility for females with AS, both medically and educationally. Qualitative differences in interest areas may be exhibited by females with AS, as demonstrated by participants in this study. This study included a glimpse into the importance of parental involvement to provide support that was not provided through the educational setting. This study included perspectives of female teenagers with AS and highlights the need for understanding and development of proper supports. Further research is needed to continue understanding females with AS.

#### Recommendation for Action

As more information is gained regarding the profile of females with AS, it becomes essential to disseminate the information to professionals diagnosing individuals. Sixteen years ago, Kopp and Gillberg (1992) suggested that the autism profile exhibited by females might differ than that exhibited by males. Unfortunately, lack of communication between researchers and diagnosticians has led to many misdiagnosed or undiagnosed females. Recommendations for further action are as follows:

1. Individuals responsible for diagnosing AS need to become aware of the qualitative differences in females as compared to males with AS. This is of particular importance for medical doctors and nurse practitioners that often provide a medical diagnosis. In addition, individuals that offer educational diagnoses such as autism specialists and psychologists need to become aware of the subtle nuances exhibited by females with AS. Research articles that appear in journals frequently read by these professionals or speakers at professional conferences are needed to assist in educating these professionals.
2. Special education departments in school systems, including special education teachers, speech and language pathologists, and school psychologists, need to be educated in the differences between male and female expression of AS so that recognition of female students with AS occurs promptly.  
  
Accomplishment of staff education may occur through a brief presentation at staff meetings, in service training, informational email, or a compiled informational packet that is distributed to all relevant special education associates.
3. Regular education teachers should also be educated on the qualitative differences between males and females with AS. Many regular education teachers tend to be hesitant to refer a student for special education testing if unsure whether the student will meet eligibility requirements. Similar to the suggestions for special education staff, regular teachers could be educated. In

addition, special education teachers at each site could act as trainer for the regular education teachers at their respective schools.

4. Regular education assistants are often the individuals that handle unstructured time at school, such as playground, cafeteria, and library time. Unstructured time tends to be difficult for both males and females with AS. Characteristics of the disorder are often most evident during unstructured times. Recognition of social difficulties by regular education assistants would bring attention to students that are being overlooked.
5. Recognize social echolalia. Evaluate whether girls with AS understand the deeper meaning behind the social behavior in which they are engaging. Teach the deeper meaning behind the social exchanges that are not understood. Develop social skills groups and curriculums designed specifically for girls with AS that takes advantage of social echolalia to assist in the appropriate skill development. Include older girls for appropriate modeling and interactions. Use current television shows or movies designed for the appropriate age level, such as a Hannah Montana episode, to explain the behaviors and deeper meanings. Include social rules of Internet behavior and norms, such as typing in all capital letters is screaming, and reviewing social networking sites, such as MySpace and FaceBook.
6. Teach girls with AS what victimization means. Provide a variety of scenarios of potential situations to determine understanding. Include Internet stalking. Role-play situations where the instructor uses appropriate tone of voice and

body language to simulate situations to assist girls in developing appropriate understanding, behaviors, and self-protection skills.

7. Teach girls with AS methods of coping with anxiety. Instruct on self-recognition of physical changes to body when anxiety begins to develop to eliminate cause or self from situation immediately when possible.
8. Assist girls with AS in locating specific social groups who share common interests, such as book clubs that read science fiction, create virtual worlds, or animé chat rooms. Chat room conversation, however, should be monitored as a safety precaution. Provide opportunities to express creative interests while interacting with others who share in that interest.
9. Assist parents in managing their involvement with their daughters' lives by offering suggestions on how to increase skill levels in daily life to maximize future independence.

#### *Who Needs to Pay Attention?*

This study supported findings that indicate girls may demonstrate qualitative differences in social abilities (Attwood, 2006). Information pertaining to characteristics of females with AS should be heard by students in teacher preparatory programs, teachers, special educators, diagnosticians, health professionals, autism specialists, parents, and females with AS.

Teachers, special educators, and students in teacher preparatory programs should be made familiar with the digression of females with AS from stereotypical characteristics of autism spectrum disorders. While girls with AS may appear more

social and show interest in others, the needs for supports may be more critical for this population.

### *Information Dissemination*

The researcher plans to do training for the district she is employed. In addition, packets have been prepared with information pertaining to the profile of females with AS to be provided to parents for their personal use. Creation of a website devoted to females with AS may also serve as method of information dissemination.

Referring individuals to the published dissertation may disseminate results of this study. In addition, at least one article will be written and sent for publication to various journals reporting the results of this dissertation. While journals attract an academic following, popular reading material such as parent magazines and teacher publications may be an avenue to direct information to the public.

### Recommendation for Further Study

Qualitative studies provide the opportunity for discovery, exploration, and understanding. Quantitative studies offer measurable and definitive information. Both additional qualitative and quantitative studies are needed pertaining to females with AS, as well as the differences between females and males with AS. Below are some areas where further research would be beneficial.

Females with AS appear to demonstrate a qualitative difference in social abilities and exchanges (Attwood, 2007; Kopp & Gillberg, 1992). Additional studies into the social thinking abilities of females with AS would be beneficial. If social echolalia appears to be a commonly used by females with AS, would appropriately designed

interventions be more successful than with males with AS? Are the communicative abilities different in females with AS than males? Could diagnostic tools be developed based on gender to diagnose AS?

Müller, Schuler, and Yates (2008) indicated that some individuals with AS often used self-initiated strategies to cope with social anxiety. What specific self-initiated strategies do females use? Some participants appeared to feel more at ease with the researcher than with other female adolescents as observed during observations. Do young females with AS experience more social anxiety engaging with peers than with older adults?

What impact does social echolalia play a role in the underdiagnosis of females with AS? Many females with AS display more stereotypical behaviors associated with autism spectrum disorders at a young age, but appear to outgrow them. Is this a result of social echolalia? Neurotypical individuals often use peer observation to determine socially acceptable behavior and apply meaning based upon the experience. Females with AS may be engaging in a similar manner, without the application of deeper meaning. For example, one of the participants created a MySpace page because it is a common behavior among her peers. The concept of making social connections through cyber friends appeared to elude her.

Participant interests appeared to be similar to neurotypical females. One participant in the study deviated in interests in comparison to the others. Is there a difference between the interests of females with AS and females with HFA?



Participants appeared to have less definitive responses to question related to their experiences than provided by their mothers. This may be a result of developmental delay. Although each of the participants were in their mid to late adolescent years, perhaps a study using older females who reflect back on their adolescent experiences may yield more insight.

One of the participants offered an interesting glimpse into perceived victimization because of misinterpreting a form of mass communication disguised in a personal format. Is perceived victimization by individuals with autism spectrum disorders common? Is perceived victimization more common in females than males with AS?

Finally, this study was carried out in one state with a small number of participants. Replication of findings is needed in varying geographic areas, and with more participants. This section included an examination of potential future research areas related to this dissertation. The following section will include a reflection of the research experience by the researcher.

### Reflection

The researcher of this study embarked on an interesting journey during this project. It was essential for the researcher to bracket personal feelings of the context of females with AS, as the researcher's daughter is diagnosed with AS. In addition, experience and opinions needed to be isolated in order to be open to new ideas. The researcher works with students with autism spectrum disorders, and is an autism specialist for the school district where she is employed. In addition, the researcher

became aware of the politics and potential ramification involved in seeking information in territories that are not one's typical assignation.

The researcher hopes this research disseminated will both enlighten and comfort participants and parents. Owning an awareness of others similar to self offers a level of comfort. After closing each email, hanging up the telephone after each call, and after walking back to the car following each in-depth interview, the researcher felt that she was leaving the situation in a more positive light than when she first entered it.

The most fascinating aspect to the journey for the researcher was that of self-discovery. Delving into the research on females with AS, the researcher met herself for the first time. Pouring through the literature, the researcher often found herself peering around her shoulder to see if anyone was reading what she had read, to see if anyone had realized what she had realized, almost feeling embarrassed. While the researcher had suspicions, following the in-depth interviews, she saw herself in some of the girls she had interviewed. The researcher continues to ponder whether the participants recognized parts of themselves in her.

### Conclusion

This chapter contained a overview of this research study and findings. While participants shared with similar internal issues, participants expressed their issues differently. A discussion pertaining to parental involvement in the lives of adolescent females and the impact of a critical feminist perspective played in the study was contained in this chapter. Parental involvement appeared to be important in the lives of participants. Research findings supported the literature in relation to females with AS an

age of diagnosis, comorbid conditions, friendships, social abilities, and creative interests. While most participants discussed age-appropriate interests that were qualitatively different than neurotypical peers, one participant demonstrated interests that were not age-appropriate. In relation to EMB theory, the possibility exists that this participant may be more impacted, and as a result demonstrate interests more similar to an affected male.

The purpose of this phenomenological research study was to explore the central phenomenon of the lived experiences of adolescent females with AS pertaining to academic, home, personal, and social experiences. In addition to a literature review surrounding females with AS, this study included an examination of the lived experiences of 4 adolescent females with AS. Thematic units were analyzed and an essence was revealed. Female teenagers with AS share common interests with neurotypical peers while continuing to battle internal issues and external circumstances.

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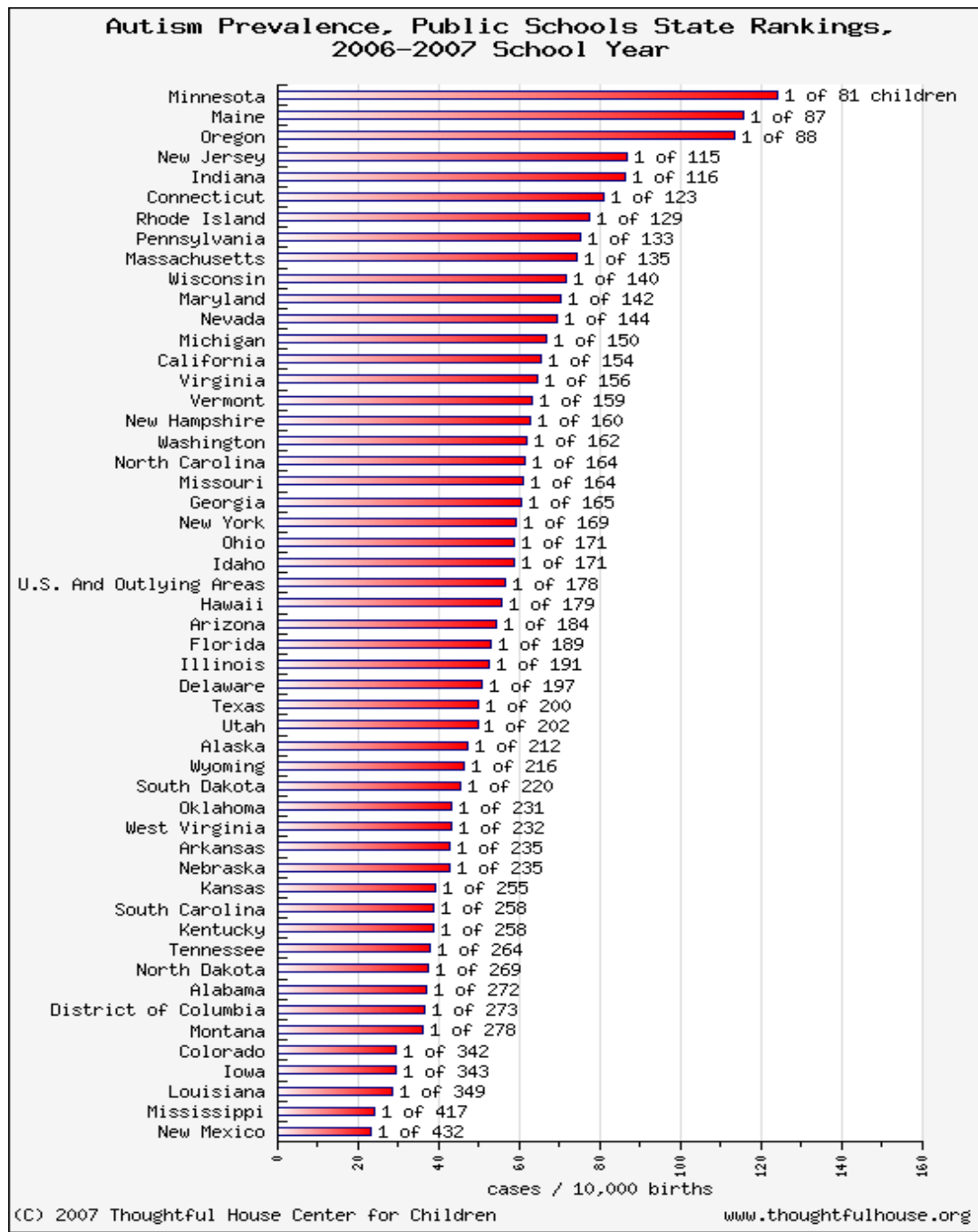
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## APPENDIX A:

### AUTISM PREVALENCE



Fighting Autism. (n.d.). Retrieved from <http://www.fightingautism.org/idea/autism-state-rankings.php>

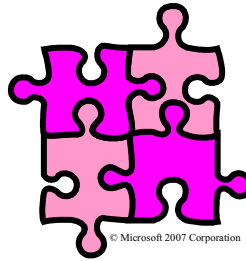
## APPENDIX B:

### DSM-IV CRITERIA FOR ASPERGER SYNDROME

Criteria for 299.80 Asperger Syndrome  
Diagnostic and Statistical Manual of Mental Disorders (DSM-IV, 1994, p. 77)

- A. Impairment in social interaction, including at least two of the following:
  - 1. marked impairments in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction
  - 2. failure to develop peer relationships appropriate to developmental level
  - 3. a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g. by a lack of showing, bringing, or pointing out objects of interest to other people)
  - 4. lack of social or emotional reciprocity
  
- B. Restricted repetitive and stereotyped patterns of behavior, interests, and activities, as manifested by at least one of the following:
  - 1. encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus
  - 2. apparently inflexible adherence to specific, nonfunctional routines or rituals
  - 3. stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements)
  - 4. persistent preoccupation with parts of objects
  
- C. The disturbance causes clinically significant impairment in social, occupational, or other important areas of functioning
  
- D. There is no clinically significant general delay in language (e.g., single words used by age 2 years, communicative phrases used by age 3 years)
  
- E. There is no clinically significant delay in cognitive development or in the development of age-appropriate self-help skills, adaptive behavior (other than social interaction), and curiosity about the environment in childhood
  
- F. Criteria are not met for another specific Pervasive Developmental Disorder or Schizophrenia

APPENDIX C:  
GRAPHIC

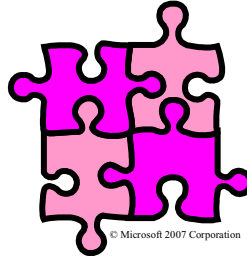


Permission is granted at the following website address.

<http://office.microsoft.com/en-us/help/HP030900871033.aspx>



APPENDIX D:  
COMMUNITY RESEARCH PARTNER LETTERS



Three Rivers School District  
PO Box 160  
Murphy, OR 97533  
Attn: Midge Vaudreuil

Date

Dear Ms. Beteta,

Based on my review of your research proposal, I give permission for you to conduct the study entitled "A Phenomenological Study of Female Teenagers with Asperger Syndrome" within the Three Rivers School District. As part of this study, I authorize you to invite members of my organization, whose names and contact information I will provide, to participate in the study as interview subjects. Their participation will be voluntary and at their own discretion. We reserve the right to withdraw from the study at any time if our circumstances change.

I understand that the data collected will remain entirely confidential and may not be provided to anyone outside of the research team without permission from the Walden University IRB.

Sincerely,

Asperger Support Group of Southern Oregon  
Attn: Janal Salazar  
janel@mighty.net

Date

Dear Ms. Beteta,

Based on my review of your research proposal, I give permission for you to conduct the study entitled "A Phenomenological Study of Female Teenagers with Asperger Syndrome" within the Asperger Support Group of Southern Oregon. As part of this study, I authorize you to invite members of my organization, whose names and contact information I will provide, to participate in the study as interview subjects. Their participation will be voluntary and at their own discretion. We reserve the right to withdraw from the study at any time if our circumstances change.

I understand that the data collected will remain entirely confidential and may not be provided to anyone outside of the research team without permission from the Walden University IRB.

Sincerely,

Southern Oregon Regional Educational Service District  
101 N Grape  
Medford, OR 97501  
Attn: Regional Autism Services

Date

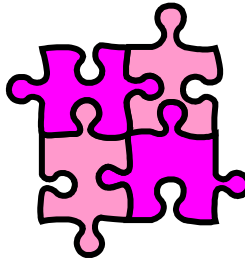
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I understand that the data collected will remain entirely confidential and may not be provided to anyone outside of the research team without permission from the Walden University IRB.

Sincerely,

APPENDIX E:  
PARENT INVITATION LETTER



© Microsoft 2007 Corporation

August 21, 2008

Dear Parents,

My name is Lisa Marie Beteta. I'm in the process of working on my PhD and am doing a pilot study to learn about teenage females with Asperger Syndrome. I am inviting you and your daughter to join my project.

Little research exists on females with Asperger Syndrome, as much of the information out there focuses on males. Because information is limited, information needs to be collected on the experiences and needs of girls with AS. That way, individual needs of girls with AS can be identified, proper supports can be provided, and in addition, appropriate intervention skills can be developed and taught.

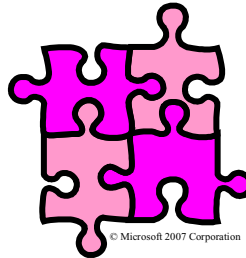
I am looking to interview your daughter and yourself, in a location and time of your choice, on questions that relate to her daily life and what she experiences. For example, I would ask her about her days at school, what she does on weekends, and what hobbies she has. I will be taping the interview to look for similarities and variation among interviews. However, all identifiable information pertaining to your daughter will be removed. If you are interested, I will provide a full list of possible questions that might be asked.

Please feel free to call me any time. I look forward to hearing from you, and the opportunity to meet your daughter! Your daughter's name will not be used. The information shared will be used, taking every precaution not to identify her in any way.

Sincerely,

Lisa Marie Beteta, MS Ed. And Autism Specialist  
Lisa\_Beteta@yahoo.com  
(541) 659-6837

APPENDIX F:  
ASSENT FORM



Hello, my name is Lisa Marie Beteta and I am doing a project to learn about Teenage females with Asperger Syndrome. I am inviting you to join my project. I picked you for this project because you are a female teenager and have Asperger Syndrome or high functioning autism (HFA). Some people might call it AS, others might call it HFA. I am going to read this form with/to you. You can ask any questions you have before you decide if you want to do this project.

**WHO I AM:**

I am a student at Walden University. I am working on my doctoral degree. I am interested in the experiences of teenage girls with Asperger Syndrome . There is not much information out there on teenage girls who have AS.

**ABOUT THE PROJECT:**

If you agree to join this project, you will be asked to:

- Participate in an interview with me. I will ask you some questions about school, people you like to hang out with, things you like to do. It will take around an hour. I will record our conversation, because I won't remember everything if I don't! I will also be doing observations and jotting down notes while we're talking. I might also talk with your autism consultant.
- I'll ask you if you'd like to share anything that you like to do, such as a poem you've written or a picture you've drawn.
- I'll also talk with your parents, and your teachers, too.

**IT'S YOUR CHOICE:**

You don't have to join this project if you don't want to. You won't get into trouble with your parents, family, or me if you say no. If you decide now that you want to join the project, you can still change your mind later just by telling me. If you want to skip some parts of the interview, just let me know.

It's possible that being in this project might make you uncomfortable since you will be talking with me and I'm a stranger. However, I'll try not to be too boring! This project might help others by understanding what it's like to experience Asperger Syndrome when you are a teenage girl!

**PRIVACY:**

Everything you tell me during this project will be kept private. That means that no one else will know your name, but the world will have answers to questions about girls with AS. The only time I have to tell someone any information you have shared is if I learn about something that could hurt you or someone else.

**ASKING QUESTIONS:**

You can ask me any questions you want now. If you think of a question later, you or your parents can reach me at (541) 659-6837 or my professor at Walden University. She is real nice, and her name is Peggy Locke, PhD. You can email her at [peglocke@hotmail.com](mailto:peglocke@hotmail.com). If you or your parents would like to ask my university a question, you can call Dr. Leilani Endicott. Her phone number is 1-800-925-3368, extension 1210.

I will give you a copy of this form. Thank you!

Please sign your name below if you want to join this project.

Name of Child

Child Signature

Parent/Guardian

Signature

Researcher Signature

## APPENDIX G:

### PARTICIPANT INTERVIEWS

P1 – Participant, 19 years old

R - Researcher

Interview location: Community College library

R: My research project is on Asperger Syndrome

P1: Just because some girls are successful, people think they don't have Aspergers.

{Researcher opened a can of soda. Made loud pop. Participant laughed and said , “That was louder than mine!”}

R: Tell me about your memory ability.

P1: I remember things early...I also wrote papers too. I wrote about my bicycle accident. My mom was surprised...she laughs. “How do you remember all this?” you know. She was surprised I remembered how...She was a hard worker, you know. My dad hasn't been around, so I haven't wrote a paper for him but...My English class. My last college English paper I had to write 3 thank you letters. Um...in the future...This young soldier who I read about was in WWII was a cook and he decided one day to thank his family teachers, and friends, so, it was a nice paper.

R: How old were you when you had your bicycle accident?

P1: I was about 8.

R: Did you go to Preschool?

P1: Yes...I had some people come over and work with me for hormones and all that stuff because of my [other condition], as well.

R: Do you remember all that?

P1: Not very often. I was a couple years old so I don't remember a lot of things. My mom tells me stories, you know, like how I created shapes at a young age when I got glasses. I managed to shove my sisters...one under a chair and another under a couch! {both participant and researcher giggle over this incident}

R: When's your birthday?

P1: Uh, Jan 27<sup>th</sup>.

R: What year where you born?

P1: 89



R: Do you have any brothers or sisters?

P1: Just sisters. Me, my mom, and my sisters. My dad is outnumbered! He's the only guy in the family...she's pretty dominant though.

R: Are your sisters older or younger than you?

P1: Younger.

R: Do you remember when you went to kinder?

P1: Not that I know of...it was really a big school. A lot of people I think I did some Braille. I don't know much about Braille except there's a lot of dots.

R: How about 3,4, or 5<sup>th</sup> grade? What school did you go to?

P1: I went to W Elementary, which is actually a hillbilly place now. It used to be a nice place with ranchers and farmers when I was growing up (chuckles). It was a nice school I had some friends. I got out of touch, though.

R: Tell me about your friends.

P1: I had a friend named BK (male). You know, I'd speak my language and he'd manage to keep track. He was a nice guy. He'd play tricks on me. There was JR. He liked me a couple of times. There's MD and during [middle school], which was a nightmare, he gave me a rose after valentines day.

R: That's not a nightmare!

P1: No, no the process, you know, the special education stuff. There was no special ed.

R: Oh.

P1: Yeah, all that. I didn't like the teachers, you know, it was not a great school.

R: Do you remember your teachers?

P1: Uh, I remember one teacher, uh, Mr. N. He was fun and active teacher. He was a dance teacher. Mr. M was ok, but was not impassioned to help me, and stuff like that. My math teacher, I forgot his name, but he was a pain in the neck! That's how I am, you know, I'm just sincere! Yeah, I show my sincerity if people let me, you know, I don't need to be yelled at.

R: Did you get yelled at?

P1: No, I get yelled at a lot by my dad though.

R: Did you ever get picked on at all when you were in elementary school?

P1: Oh yes, a lot.

R: Tell me a little about that.

P1: Oh, you know, I'd get teased, I get called a freak, weirdo, dork, uh, you know, made fun of because I had elf ears (participant moves her long hair and pushed both ears forward).

R: Oh my gosh, they don't look like elf ears to me!

P1: Well, I got them from my grandpa's side of the family. Well, actually, my cousin James had elf ears when he was very young.

R: Did they ever hurt you?

P1: Oh no. It was just a lot of teasing and name calling. Not very much harassment. Well, actually, I didn't get sexual harassment until my dad's 40<sup>th</sup> birthday. And there was no supervision at all. And the creepiest thing of all is that it was my cousins. It was the very worst experience I had.

R: How long ago was that?

P1: About 3 years ago.

R: When you were in elementary school and you got teased, what did you do?

P1: Well, I'm not the kind of person who likes to hit and punch like my sisters. You know, they fight with each other. (researcher laughs). You know they're brats! Trust me, you know they are more spoiled than I am. Oh, I just ignore it. Like sometimes, I might take it hard, or tell the teacher, you know, like what's up.

R: Well that's good.

P1: Well, one time, I had my best friend HC (always gives first and last names) she was nice and all then she turned into a you know what, I don't want to say it (participant laughs). And, uh, she used to pull my pants down, so...yeah, I told Mrs. W, she was my 5<sup>th</sup> grade teacher and she got in trouble, and so forth, so yeah.

R: Before H was a you know what...

P1: Yeah, my parents think I might say stuff like that, but I know better (chuckles)...I was raised better, too! My sisters need their mouths washed or restrained!

R: But when she was nice, did she used to come over your house?

P1: Oh yeah, I'd come over her house. I swam with her in her pool. We had a good time. We'd chat, and etcetera, and once we got into high school, it's like, we haven't seen much of each other. I've seen her brother, CC, which he was a jerk face.

R: Did you guys ever call each other on the phone?

P1: Uh, we used to. I don't know her number anymore. She lived on K Rd, which was next door to us, we weren't that far away, we could move around all over [city], sort of.

R: When you were in elementary school, what did you do for lunch?

P1: Oh....(pause)

R: Did you eat with other kids?

R1: Well...I usually eat my own lunch. I usually eat yogurt pudding, a little snack, and a sandwich. (*Did she understand and avoid?*)

R: Did you eat with anybody?

P1: No, not really. I usually stay out of the group, or don't have the courage to go over to a group.

R: When you were in elementary school, what were some of your favorite things to do?

P1: Oh I loved math. My math was strong. It still is. It's a little shaky from my last math class. Uh...I still passed, but I think I should retake algebra 'cause I don't feel I have enough information to go on (*yawns*). The teacher was nice, though. I don't know if it was just me, or if I wasn't concentrating or I didn't ask for help. Yeah, because I usually don't ask for help. I kinda' wing it out.

R: What did you do for fun in 5<sup>th</sup> grade?

P1: When I was younger I used to play on computers, do games, strategy puzzles, games,...like that. Uh...I used to...ummm...it's been awhile (*chuckles*). I used to have bottles of bubbles, I used to blow bubbles a lot. I still have a couple...I like to do that.

R: How about when you were in 5<sup>th</sup> grade...did you have a favorite movie or video?

P1: Um...it's been a while, but for example I like other movies like Lord of the Rings, Harry Potter, Eragon. I like the fantasy-fictional. Yeah I'm trying to create a story right now that that going to be for children. The twist is its going to be for all ages. I haven't worked on it this term because I've been so busy. I've learned my lesson though. Take one class and a part time job!

R: So do you have a job right now?

P1: I'm close to...at the OST, I'm like, come on cuz we have to do certain stuff. We have to do job shadowing and etcetera.

R: So do you know what your job is going to be there?

P1: I was going to work with children. I'm kinda' torn. I want to work with children 3-5-year-olds 'cause I used to babysit 3-5 yr old kids. They're adorable children. You know ED is going to be 6 yrs old and she's a nice little girl. And HD, 4. Actually, there is a new baby in the house, A...a boy.

R: When did you baby sit?

P1: When I was in high school...sophomore or junior.

R: It sounds like you enjoy creative writing.

P1: Uh, huh.

R: I bet you're good at that.

P1: Yeah. I didn't notice until I got in college. My first writing course...uh...it was very rocky. You know, I had to rewrite every single paper. You know, in high school, I had As, etcetera. I'm like what the heck is going on here! I'm like...it's a whole different level, but as I grew, I changed my prewriting techniques, did different aspects, added more supportive details, and became stronger. Actually writing is going pretty well. It's improved.

R: Do you do any drawing?

P1: No...I can't draw. I draw like a child....stick figures. My sister is the artist.

R: When you were in high school did you go to any of the dances?

P1: Except for my senior prom...that was it.

R: Tell me about that.

P1: It was exciting. It was pretty loud...the music. It was 1920s...the jazz sort of stuff. And it kinda' sucked because, you know, there's not a lot of 1920s stuff. There's pictures, and a couple of cars. There needs to be more details, you know, that catches the eye. The music was not really 1920s. it was mostly hip hop, pop...the music from today. It kinda' blowed...after a couple of hours, you know...I had a guest, and my left foot started killing me....so ok, we're done. But it was really nice. We danced for a while. We saw friends, and so...

R: So you had a date?

P1: No I didn't have a date (*misleading me?*). Boys didn't like me until...oh, about last year, I guess. You know, oceanography class, and this sophomore, CW, thought I was a junior. "Are you taking zoology? No, I'm a senior!" You know, it's like...oookaayy! He was like a nerd, but that's ok. Well, he didn't have glasses, but he had those assets.

R: Have you ever gone on a date? (*No response, but chuckles*)

R: Do you want to go out on dates?

P1: YES (*vehemently, then chuckles*) Right now I'm working my career area. Once I get up on higher level college and more settled down. I DO want to have a boyfriend, but I have so much work. You know, with the college, I'm so busy and once I start my work, I don't stop until I'm done. You know, I take breaks, and stuff to keep me going.

R: Well, you've got a lot going on.

P1: Yeah, plus we have animals that we have to deal with, too.

R: Animals?

P1: We have swine. We just had a litter, um, a couple of weeks ago that turned out to be nice. And we're about to sell a litter that's about to be thoroughly weaned. So they're going to be ready to be gone.

R: Have you ever had any parties at your house that you've done on your own?

P1: Not that I know. My mom usually makes the arrangements for the parties. But you know, my 16<sup>th</sup> birthday was great, but I was sick. I had a sore throat at the time. I couldn't talk or anything and I was tired. So that really sucked. I really liked it. When I opened my presents...when my dad sees money, he jumps for joy (*laughs*).

R: How about sleepovers. Have you ever had any?

P1: Um...not that I know of...I've done 4H.

R: How did you like that?

P1: It was great. I liked it. I went to the meetings. It was fun. I earned ribbons and stuff. The thing is...the hard thing is that in the show arena, even though I seen it many times gone by, it's just getting used to it. The things I hate so much is that if you have to look at the judges constantly, you know...it's hard for me to trust the pig. And when I was a senior, you know, the last year I was in 4H, I had a little more trust in my pig. I spent time with her and, you know, my sisters didn't. So she turned out to be good. You know, she didn't make weight, and so we had to get a private buyer.

R: It sounds like it was fun.

P1: It's really fun. You see all the other animals, steer, sheep, poultry, rabbits, horses. We just been through a fair for my sisters. It was so hot...jeez. It was so humid...jeez. After the fair, they showed fire dancers. I was like, cool! While my mom and dad went to monster trucks...I heard monster trucks all the way from the staging area!

R: How about high school, did you enjoy it?

P1: I liked the environment, but I didn't feel a welcome presence, you know, from the students. I didn't get that at all.

R: Socialize with other kids during breaks/lunch in HS?

P1: After I'd eat my lunch, I'd work on homework.

R: Where did you work on your homework?

P1: Where I just ate, cause I had big round tables like these. (19:35)

R: What does your normal afternoon look like now?

P1: Oh, about an hour, I take a break. Watch TV or do whatever I want. Then about an hour later, I start homework. That gets tedious sometimes. (*yawns*)

R: Do you have any chores?

P1: Uh, yeah, but I do that in the morning.

R: What chores do you have?

P1: I have the kitchen. I do the dishes, sweeping, mopping, etcetera.

R: If you could do anything in the world right now, what would you do?

P1: I'd want to go on a trail horse ride, so bad. I've seen my mom do it, but there wasn't enough horses, at the time.

R: Do you have horses?

P1: We used to, but we had to sell them. I've done some competitions

R: Did you used to ride them?

P1: Oh yes. It was really fun. And actually, the thing is, horses are like healers. Because they make you feel happy when you spend a lot of time with them. It helps.

*Some unfamiliar people come into room. Participant is distracted.*

R: Do you have your own computer?

P1: Uh...yeah. It's in my room.

R: What are some of your favorite sites?

P1: Oh boy...chuckles...I...I don't chat on the internet. I usually just play games on there.

R: Do you ever go to MySpace?

P1: No I HATE MySpace because we had some confusions with some family relatives because, you know, some pictures Tiff sent to us, and you know, that didn't look like Tiffany. So we had some conflicts about that sight.

*Noisy in background*

R: Do you like to read?

P1: Uh...(pause)..yeah, as long as I'm in the mood for it.

R: iPod?

P1: Chuckles...No not really.

R: Do you like music?

P1: Yeah, I have a little stereo.

R: Who calls you besides your parents on your cell phone?

P1: My sisters, my pick ups, not really my friends that much.

R: Tell me about when you went from high school to college.

P1: It was kinda' exciting, but I hesitated a little bit. The college seems more quieter, you know. The high school, you know, was huge...more crowded, you know. Not a lot of help from anybody. You know, I had to carry huge books, and no one helped.

R: Did you use a locker?

P1: Yeah, I put some stuff in there.

R: Is it easier here in college?

P1: Yeah.

R: How long have you been coming here (to this college)?

P1: It's been about a year.

R: Help with assignments/accommodations?

P1: I usually do my projects on my own. It depends on the assignment and the class.

R: You live at home right now. Are you anxious to move out?

P1: I'm pretty excited. I want to do my own thing. My mom is pretty over protective. I don't know, when she's out of the equation, I seem to do things just fine, even though I don't have a great map mind, I seem to move alright and function adequately.

*(Yawns twice)*

R: How do you do in class?

P1: I have good auditory skills. My mind wanders, but I seem to recall good.

R: Do you feel confident that you could move out right now and support yourself?

P1: No...my mom's suggesting I should have assistance. And yeah, assistance because I'm not great at it...I don't know how to cook or any of the above yet, because I haven't gotten that far.

R: What 3 skills would you like to work on to help you become independent?

P1: would say geographic mapping (yawn).

R: How about dealing with money?

P1: If it's too difficult I can't handle that much.

R: If you need a hair cut or need to make a doctor's appointment, do you do that?

P1: My mom does that.

R: If you could tell a little girl with As anything, what would you tell her?

P1: Well it takes me a little slow...when there are normal people around it takes me a while...then I talk or interact.

R: Would you have advice for her?

P1: (*Yawns 2x*)

R: Is there anything?

P1: Well its been a while, pretty good experiences. I'd suggest to keep dreams and inner child alive. If you have a bad experience, I'd suggest a defense course. I used to take karate, but then we couldn't afford it.

R: How long did you take it?

P1: A couple of months.

R: Where did you take it?

P1: I don't remember. My mom would remember.

R: Where do you see yourself in 10 years?

P1: A novelist, a veterinary assistant, maybe have some kids (chuckles). I want at least 6...maybe 4. We're a big family. We're a big family.

R: How many kids are in your family?

P1: My whole family? About 50. Mostly from my dad's side.

R: Do you like to go shopping?

P1: Yeah. Sometimes me and my mom go to the mall. I hate to go grocery shopping. Sometimes my feet hurt so I don't want to go to the mall. Sometimes my sisters are looking for something, and I think, why bother.

R: Who picks your clothes when you go shopping?

P1: Sometimes my mom finds my stuff, but I look around and stuff to see what's in fashion.

R: If you're comfortable, tell me about what happened when you were sexually harassed.

P1: I was watching TV and my cousins were 12 and 14 in my aunt's room in her old house. My aunt and uncle are no longer together. My grandma and grandpa are helping her, you know because of her SSI and stuff. My cousin, N just farts all of a sudden and I'm like, N, what are you doing? We're playing games, then they were calling cuss words. I don't want to go that far. Then suddenly, N was poking me in the boobs. I was like, what the hell? Then that's when it starts. Next cousin comes in. I asked if they had been watching rated R movies. They said yes cause pretty much they'd been alone at the time. They got grounded for 6 months which should have been a year.

R: When did you tell your mom what happened?

P1: I had to tell her the next day because I was tired. My grandpa took care of that. He spanked them and stuff. It was creepy when I was telling her the entire story.

R: Do you ever feel pressured to act a different way?



P1: Yeah, from my mom and dad a lot. You know (cluttering), every time she opens her mouth, “Oh that’s ridiculous, honey,” “Oh, that’s the wrong way,” “Oh you shouldn’t do that.” And my dad doesn’t understand either. He yells so much, I don’t open up to him much either. So...

R: What are you usually doing when he starts yelling at you?

P1: Well, yeah, I usually cry in my room, or whatever. He doesn’t understand or know how to stop and listen to other people, or speak in a nice tone.

R: So does he yell at you because he thinks your not listening or doing something right?

P1: Yeah. Sometimes he says, “you’re not paying attention” or...I think my dad is still in denial about the Aspergers. My mom and I usually get along well. See needs to stop that limit crap. My dad...I trust a little more than my sisters. My sisters I don’t feel I get any respect or helpfulness because they are rude all the time.

R: Hobbies?

P1: Swimming, reading, medieval times/monk music.

R: Do you like history?

P1: NO...it’s dull! (*laughs, yawns*) I’m so tired. (*Burp*) Sorry...I don’t usually burp, I got it from my dad’s side. They say, I burp like a man.

R: Favorite food?

P1: Spinach soufflé, enchiladas, eggplant parmigian, I used to be a picky eater, but as I grew...I love sea food

R: Self stimulating behavior?

P1: When I was little did rocking/flapping. Now I do privately.

P2 - Participant, 17 years old

R – researcher

Interview Location: McDonalds

R: What's your horse’s name?

P2: My Little Magic

Researcher asks participant if environment is too loud, and to let researcher know if it becomes uncomfortable (McDonalds during the lunch hour on a Saturday)

R: Did you go to preschool?

P2: Yes

R: What was the name of your preschool?

P2: I went to [provided name] Elementary School.

R: Did you like it?

P2: I don't know

R: Do you remember your first day of school?

P2: No.

R: Do you remember lunchtime?

P2: No.

R: What did you do during recess?

P2: I don't know.

R: Did you go to middle school?

P2: I went to [provided name] Middle School.

R: Is that a 6-7-8 grade?

P2: Yes.

R: Did you like that school?

P2: No.

R: How come?

P2: There was a mean girl when I was in 6<sup>th</sup> grade. She choked me.

R: She choked you?

P2: Uh huh. Then she almost pulled my shirt off.

R: What did you do?

P2: Sat on the middle of the floor and cried.

R: Did anyone see?

P2: Other students saw and told the teacher.

R: Did you come home and tell your mom?

P2: Well, I cried on the whole bus ride, and then I went to a friend's house because my mom was at work, but then I told her when she got home.

R: What did your mom say?

P2: She called the principal.

R: What did the principal tell your mom?

P2: I don't remember.

R: Did you have a lot of friends when you were at middle school?

P2: I was all by myself. I'm normally picked on by bullies.

R: Have you ever taken kung fu or karate?

P2: No.

R: Did you ever go to the library in middle school?

P2: Yeah.

R: What kind of books did you like to read?

P2: Well at the middle school, I was reading all the animal books.

R: Did you go to any dances in middle school?

P2: No, I went home on Friday.

R: How about high school?

P2: Home schooled for 3 years and now I'm back at school in the [program]. I went for a few months last year, too.

R: Do you like it?

P2: Yes.

R: Is there anything in [current program] that you wish could be different?

P2: That they didn't swap teachers. *[New teacher serving program this year.]* Mrs. X is not there.

R: Yes, she was a good teacher; I worked with her for many years.

R: What do you like to eat?

P2: I like chicken.

R: What else. Do you like hamburgers?

P2: I don't like ground beef.

R: Do you like salads?

P2: Yes.

R: Pizza?

P2: No. I used to throw up all the time in elementary school and for some reason it was always Friday. And my body thinks it was the pizza, but it was stress.

R: Do you get stressed a lot?

P2: *[Participant nods.]*

R: What stresses you?

P2: People.

R: Do you like being with animals?

P2: Yes, with dogs.

R: What kind of dog do you have?

P2: A lab and a mini Australian Shepard.

R: Do you ever work on computers?

P2: All the time.

R: Do you have your own computer?

P2: We have a laptop that I use.

R: Do you get on the Internet?

P2: Yes.

R: What are some of your favorite sites?

P2: I like to go on Digimon sites.

R: What else?

P2: That's mainly it. Sometimes Power Rangers.

R: Do you ever use email?

P2: Very rarely.

R: Do you collect Digimon cards?

P2: Yes. Mine are in my room.

R: Do you have other kind of cards?

P2: I have Pokémon and a little bit of Yugioh.

R: Do you ever listen to music?

P2: Yes.

R: What kind of music do you listen to?

P2: Country.

R: Who's your favorite?

P2: I like a lot of singers. I like Reba McIntire a lot.

R: Do you have an iPod?

P2: Yes.

R: How many tracks do you have on your iPod?

P2: A hundred something [*chuckle*].

R: Cell phone?

R: No. [*Participant's mom had mentioned that the participant dislikes talking on phones*]

R: Have you ever had a job?

P2: Yes, I worked at a day camp facility for adults with special needs, helping my mom out.

R: were you getting your own paycheck?

P2: Yes.

R: What did you do with your paycheck? Cash it or put it in the bank?

P2: My mom deposits into her account.

R: Do you ever do any of your own banking?

P2: No. I don't have any of my own accounts.

R: How many hours a day did you work?

P2: They varied. Some days were long. I think Friday's were the long day.

R: What time did you start?

P2: Time of the day?

R: Yeah, what time of the day did you start work?

P2: Ten.

R: What time did you finish?

P2: Mondays everyone was dropped off at 4. Friday's we left at 5.

R: That's a long day.

P2: Yeah, but the clients we worked with had a lot of similar interests. That helps out.

R: Tell me some of the similar interests you have.

P2: We both like Power Rangers [*participant smiles*]

R: Do you ever watch TV?

P2: Yes.

R: What are some of your favorite shows?

P2: Digimon, Power Rangers, House, NCIS

R: Video games?

P2: Digimon video games for PlayStation.

R: GameBoy?

P2: A DS

R: Do you like to read?

P2: Yes

R: What are some of the books you like to read?

P2: Eragon.

R: Did you see Lord of the Rings.

P2: No.

R: Comic books?

P2: I read one Spiderman comic book. Xmen, I don't care for DC that much.

R: When you come home from school, what do you do?

P2: Go in my own little world.

R: Describe your own little world for me.

P2: I like to pretend I'm with the characters in Digimon.

R: Do you get a snack?

P2: No

R: Do you go straight to your bedroom?

P2: Sometimes I go for a walk.

R: Do you have any chores at home?

P2: Well...I have to put dishes away, help with laundry, clean my room.

R: How often do you read?

P2: Only will read if I have a book that I'm interested in. Then I won't put the book down.

R: Do you have any friends that come over your house?

P2: I used to.

R: Have you ever had a sleepover?

P2: Very few times.

R: When was the last time?

P2: Just before my friends left, because they are in the military.

R: How old were the friends who slept over...your age?

P2: I don't remember how old they were.

R: Are they older than you or younger?

P2: Younger.

R: How about parties...do you like them?

P2: Too many people, too much noise.

R: Do you like to go shopping?

P2: Not really. If it's electronics I'm ok, but grocery I don't like.

R: How about clothes?

P2: *[Participant makes a face]*

R: Who picks out your clothes?

P2: I pick out the basics.

R: Who buys them [clothes]?

P2: She [mom] buys them.

R: Have you ever gotten in trouble at school?

P2: I don't think so. I think I got threatened to go to the principal's office for sucking my fingers, though...in preschool. *[participant chuckles]*

R: What do you want to do when you are all finished with school?

P2: I want to be a horse vet.

R: You're taking college courses aren't you?

P2: I did last year.

R: What did you take?

P2: Algebra and English.

R: What school did you take these?

P2: University of [state].

R: Are you going to take any college classes this year?

P2: No.

R: Have you ever worked in a vet's office?

P2: No.

R: Any boyfriends?

P2: No.

R: Do you want one?

P2: No. *[participant smiles]*

R: Have you ever gone to a dance?

P2: No.

R: Would you consider going to your prom this year?

P2: I doubt if I'd ever go.

R: Do you like living at home or are you anxious to be on your own?

P2: I want to be with my mom.

R: Do you think you'd be ready to move out on your own at 18?

P2: No...I don't like being alone.

R: Do you know how to cook?

P2: Yes.

R: What are some of your favorite things to cook?

P2: I like to bake. I like to bake cakes, but I only do them from scratch.

R: What's your favorite type of cake?

P2: I make this red cake.

R: If you have a doctor's appointment...who makes it?

P2: Mom

R: How's your memory?

P2: Not very good.

R: How's your bedroom...clean or messy?

P2: VERY MESSY!

R: Do you ever feel pressure to act or behave in a certain way?

P2: No.

R: When the phone rings at home, do you ever answer it?



P2: Only if no one is around.

R: Do you feel uncomfortable answering it?

P2: No not really...as long as it's someone I know.

R: Do you like scary movies?

P2: I saw Ghost Rider.

R: Did you like it?

P2: Too scary.

P2: Do you like origami?

R: Yes I do. Do you?

P2: I think I'm very good at it. I like to fold dragons. I'm waiting for a book to come from Japan so I can fold a really complicated one.

R: Do you like writing stories or poetry?

P2: I'm not very good at it.

R: Do you like to draw?

P2: I like drawing...Digimon or Power Ranger characters.

R: Did you ever watch Sailor Moon?

P2: No

R: When you get sad, do you hold it in or let it out?

P2: The last time I got sad, I hid in a corner and cried.

R: What made you cry?

P2: When my friends moved to Japan.

R: What was your best friend's name?

P2: [name] and [name]

R: Oh, two friends.

P2: Yeah. They are in Okanawa right now.

R: Are those the friends that are in the military?

P2: Yeah.

R: Are they in the military or their parents.

P2: It's their dad.

R: What grade are they in.

P2: [name] is eleven now...she just turned 12.

R: What are some things you did with your friends?

P2: We liked to pretend we were Peter Pan.

R: Did they ever call you on the phone?

P2: We're allowed to use the phone now, so we can still talk to each other. And my mom will be on the phone for hours.

R: Where did you learn to do this dragon?

P2: On the Internet. It has 75 steps and takes an hour to fold. I have a different type of dragon I make. I can also make a beetle. I also folded Yoda. I get almost all my diagrams off the Internet.

R: Have you made a Picachu?

P2: Yes, but it's very basic.

R: Did you play with dolls when you were little?

P2: A little bit, but then I decided that I didn't like them.

R: Did you play with other kids or by yourself?

P2: No...by myself.

R: How long are you allowed on the Internet?

P2: One hour a day, because we don't have a phone while I'm on the Internet.

R: What do you think of Ms. [name – new teacher]?

P2: She's nice. I'm also going over to the high school for band.

R: What do you play?

P2: Flute.

R: How long have you been playing the flute?

P2: Since 4<sup>th</sup> grade. When I was in 4<sup>th</sup> grade, I played with the 5th graders.

R: Are you going to take any other classes at the high school?

P2: I was going to take math but precalculus is going on at the same time as Band. I think I got all the credits necessary for math right now.

R: After this year, what are you going to do?

P2: I don't know. Maybe enroll in more college courses?

R: Are you planning on taking most of your classes online or do plan on attending any courses in a college building?

P2: I think I'm going to do distance learning.

R: How many times have you made this dragon?

P2: A couple of hundred. I fold this all the time.

R: When you get anxious what are some of the things you do to relieve it?

P2: I go for walks always by myself or sometimes I play my videogames.

R: When you buy your video games, do you buy them or your mom?

P2: I buy them.

R: How are you with money?

P2: Not very good. I spend it all.

R: What do you like to buy besides Digimon stuff?

P2: Basically, video games. I had to pay \$300 for Magic [*her horse*]. She got kicked in the knees a couple of days ago. She's a little bossy. She's in a stall with a gelding who also wants to be boss. Her knee was open. We don't now if it's going to get better. I rode a Fjord that had a little man's syndrome. [participant smiles and chuckles].

R: When did you start riding horses?

P2: When I was in 3<sup>rd</sup> grade.

R: What's your room decorated with?

P2: I have a fig Japanese fan with horses on it on the wall. The bottom half of the wall is yellow and green like grass. The roof is blue with white clouds on it.

R: Do you like history?

P2: That's my worse subject, I think.

R: Math?

P2: That's my best subject. I don't know anyone who's at my math level. Algebra is easy, except for story problems.

R: Have you ever made your own [origami] design?

P2: A dragon head.

R: How long have you done origami?

P2: I don't know, but I know someone came to my class in 2<sup>nd</sup> grade.

R: Do you watch the news?

P2: My mom does, but I stay in the room. Sometimes I watch. [Discusses the politics of the state, including who is running for senate by name.]

R: How many pages were the instructions for this dragon?

P2: 14...75 steps.

P3 – Participant, 15 years old  
R – researcher  
Interview location: School Library

R: Science?  
P3: So so.

R: How about algebra?  
P3: No!

R: English?  
P3: All right I guess, except I don't want to do speeches. I have stage fright. I can't. I'll faint, though. I can't. Half of sophomore year, though, is speeches.

R: What's your favorite subject?  
P3: I don't have it yet, but it's going to be jewelry making. Yeah, we just got it this year.

R: What elementary school did you go to?  
P3: I went to [name] school for kindergarten through 2<sup>nd</sup>. Then we moved and I went to [name] school for the rest.

R: Did you like elementary school?  
P3: Well, it was more funner than high school, cause you get to celebrate holidays and stuff. You don't get to do that here or at middle school.

R: What was your favorite part of the day in elementary school?  
P3: Lunch.

R: What did you do during lunch?  
P3: I hung out with my friends C, A, and R.. Two of them moved away. One of them is now an alcoholic, and the other one is pregnant.

R: Do you stay in touch with them.  
P3: No not any more. One of them hangs out with some weirdoes. She threatens her brother because he wasn't treating his girlfriend right.

R: How many brothers and sisters do you have?  
P3: One brother and one sister. I'm the youngest.

R: Is your sister older than you?  
P3: A lot...she's 20 and my brother is 23, but hers turning 24 soon.

R: When you were in middle school did you go to any dances?

P3: Uh...no.

R: Why?

P3: I don't like dancing. I have stage fright. I don't do anything in front of people. I don't dance, sing, or anything. I do at home, alone, but...I write songs. I just wrote my first song. I write down songs so I can remember them.

R: Do you use a compute?

P3: A lot. Computer, TV or I go outside and play volleyball. I hang out with my friends A, C, E, T, and a whole lot of other people cause if you're in C's family, and you're a part of their friendship, you're going to have a lot of friends. They know a lot of people. They live up that street where they don't get any privacy. They have people around them all the time.

R: It sounds like you have a ton of friends.

P3: Yeah, if you're friends with C and E. Yeah...yeah, and then K and M are my other friends. But they haven't come over for a while because their mom, like, always says no.

R: Do your friends hang out at your house a lot?

P: Um...Yeah...and A just me over this summer. And P and S are back. Their 2 of my best friends. They just moved back. I got to see them at 4<sup>th</sup> of July and I was so happy. They bought my grandma's dog, and I got to see her and I was like, so happy. Uh, right now they could sell her for \$500 but they'd never give her away because they love her. But, yeah, still...I wouldn't care how much money...I wouldn't sell my dog. The other dog is really beautiful. Yeah...I had that dog at grandma's house. C had another dog.

R: How many times did your friends come over your house last year?

P3: Last...no...in 7<sup>th</sup> grade I had this friend named A and R but they moved away. They lived like down the street from me. They moved away 'cause their mom had married a guy who was abusive. So, yeah, one day they were screaming and their whole family spent the night at our house...yeah, R, A, and their mom. Their dad died before of cancer or something...their real dad. And their step dad, which is John, killed himself. He committed suicide. He locked N out of his own house and killed himself [names several names as if I know who these people are]. We were like, "are you mad that john killed himself?" He was like, "yeah, he got blood all over my floor!" Yeah, N could care less. And R used to come over all the time. Mostly every single day in the 7<sup>th</sup> day. I was in 8<sup>th</sup> and she was in 7<sup>th</sup>. She was supposed to be in 8<sup>th</sup> but she got held back in kindergarten because her teacher liked her so much. And she's the same age as me. She used to come over everyday after school. She's stop at my bus stop a lot.

R: Did you have a lot of friends over this summer?

P3: My sister had a lot of friends over. Like every time she was here...every single day she was here she had a person come off the bus with her. She was a cheerleader.

R: How about you, though?

P3: What do you mean?

R: During the summer, did any of your friends come over?

P3: Yeah...No.

R: Yeah...no?

P3: No, actually. I went to Jill's house. But she's not really my friend. I went to her. I knew her for years. She tried stealing a movie from me.

R: When did that happen?

P3: It was the real movie. She did that since when I first met her. I've known her for years. I went over her house this summer because I'm friends with her sister. I went and spent time with [4 girls] at the beginning of this summer. We went to the beach with 2 dogs. We went to McDonalds and the dogs got into it. I know, cause this guy in a truck...he's weird looking and he's like, "who gave that dog McDonalds?" And C's like, "what?"

R: So what did you have at your house?

P3: A daycare carnival day. It was for daycare. C couldn't make it because she had an appointment for her hair. So she couldn't make it. She went to that appointment and Andréa came instead and she helped with face painting.

R: Are they all in your grade...sophomores?

P3: No...A is a little girl. C is a junior, but she got kicked out and she won't go back to school. She's supposed to go but she's not going.

R: Sounds like you have fun.

P3: Hmm...sometimes. The funnest part this summer was at the beach when the dogs sat on us. It was a 2 hour drive there and a 3 hr drive back. The dogs were like...ugh! They got some air, but still. They kept laying on us. We were just laying and were so cramped. My friend C is really fat and she was telling the dog that it was pushing her fat all to one side. It was really funny! I was like, ok.

R: Who was driving?

P3: My uncle. We go everywhere with him. He's sometimes a jerk though. He used to be really nice but now he's a jerk. Me and C are like cousins so we go everywhere together.

R: What did you do during breaks at middle school?

P3: Let's see... uh...I don't really know...I hung out with R during lunch and we stayed after for this stupid thing, is was really dumb, I can't believe we stayed. I just stayed because A came because she was going to another school. And then R came.

R: What was it?

P3: Because A is a year older than me and R is the same age but she goes to a different grade. We were going to this one thing where there was a bunch of owls and pencils and sharpeners and everything. Her sharpener, R got a sharpener, and then it broke. It was really dumb, though. It's like...oh God. And then, we like got to design bags and stuff. And A's like, "I fell like I'm back at preschool. This is boring"

R: You like to write songs? Do you write lyrics or music?

P3: I write lyrics.

R: How many?

P3: I've only done one so far. Because I'm still like trying to learn. And then there's some that I'm writing down. Just like my favorite songs. Like all my favorite celebrities. I just write them down because I like them. And then all the lyrics, my dad was about to kill me because I used all the lyrics. But...

R: Who are your favorites?

P3: My favorite celebrities? [*Participant clarifies understanding*]

R: Yeah.

P3: I like Hillary Duff, Justin McCartney, all the High School Musical stars...and...Danna, Vanessa Hutchins, [participants names 3 others]. Not Monique, I swear to God, I don't like her much. And then I like Kelly Clarkson...Ashley Simpson...who else? I like Josh Hutchers, but he doesn't sing. He's just ion a lot of movies. Like have you seen Bridge to Terabithia? Or Firehouse Dog? Yeah, I hate that little kid. Let's see... Leanna Sophia is pretty cool. She's the one in Bridge to Terabithia that dies. Dies in Bridge to Terabithia (*unusual voice quality*). Uh...let's see...let me think...um...I don't really remember...I like a lot of stars.

R: Do you use email?

P3: Well my favorites is Justin and Zack. Out of the girls it's Hillary.

R: What are your favorite internet sites?

P3: NeoPets, MySpace, Google, YouTube, and lots of game sties. I like MyroPets and Zano Pets. [Told me password and user name for MySpace...discretion]

I don it that way so that so that no one has the same password as me. There's so many people who use the name, like soccer and stuff. I tried to use the name soccer...big mistake. I even tried putting numbers where there was supposed to be...like look like letters. And I did like 10 digits of numbers. I'm like...this is a nightmare. It was a nightmare trying to get an account... I was trying to get this one name...I was trying to get BabyDoll. I did all caps, a period in between, a dash, I'm like Oh! This is a nightmare! I'm like, oh my God; this is a nightmare it's going to take forever.

R: What does your MySpace page look like?

P3: Uh...I just have this picture of a girl, cause I don't like people to know who I really am. Cause I don't really give out my personal information. There's already this guy stalking me. So...

R: Through MySpace?

P3: Oh, MySpace and Yahoo. I know he met me on Belasare(?). That's another account I have. It's about horses. And I go on Horseland II. I go on Howrse...I don't know why they call it that...don't ask me, but it's spelled H-O-W-R-S-E. And I tried to go on that but if you to feed your horse, it says your horse has been fed. And then they complain to me, like you haven't been on this account in 3 months. Like this is really dumb. Like...we're going to take away your account if you don't get on... I'm like, hell, I don't really care! There's a reason why I quit that account. It's boring. So I'm like...oh I found belazer(?). Its so much better. But Belazer is so pretty the colors are blue and purple. I like the color blue. I don't really care about purple, but it's like lavender. On my MySpace, there's a blonde girl, she's really pretty, though. Yeah. And then this guy is like stalking me. He found my Yahoo. He's like 'you met me in Belazer,' because he's like a captain. He's one of the leaders of Belazer. He sends out newsletters. Somehow he got my MySpace. I don't know how but he's 18.

R: Does your mom know?

P3: He's starting to scare me. He's like, 'Hey, Hottie.' It's like, ok I'm telling Tom because I know the guy in charge of MySpace (does she realize the figurehead of the company as a personal relationship?). Because he made it to where I can't delete him.

R: So how many friends do you have in your MySpace?

P3: I just have A for now, cause nobody ...my friend doesn't have a MySpace. My friend is 9. My other friend is 11. Yeah she's going to turn 11. C, yeah, she has a MySpace, but I haven't told her mine because she doesn't have a computer. Every teenage person has one, so that's why I made one.

R: How many hours are you on the computer a day?

P3: Probably 2 at the most. On Saturday it's probably 2-3. I watch TV about 5 hours a day. My favorite shows are on Disney. I like the sweet life of Zack and Cody. It's really funny. I like certain episodes of Life with Derek...certain ones. But I he's too much of a clean freak....I don't really like that show. I also like Discovery Kids.

R: Videogames?

P3: PS2. I like Kingdom Hearts.

R: Read?

P3: I like the Movie Channel.

R: Movies?

P3: High School Musical. There's a new movie of number 3. It's going to be out in October. High School Musical came out like 2 summers ago, and then the first one came



out 4 summers ago. Actually, because they made the second one a year later but it came out 2 years to come out with the extras and everything. I like all the Harry Potters. I like Lost. And the best thing is that everyone has that channel. I liked Little Mermaid, but not the series. That ruins the story.

R: Why do you like Lost?

P3: It's very romantic. I like the adventure. It's really cool, but I was so mad when Charlie died. Season 5 will come out soon [DVD].

R: Lost website?

P3: Yes, I went to the magazine thing. I bought one at Blockbuster so I knew about the whole 4<sup>th</sup> season before it came out.

Extremely loud in the background as interview is in open library and students are transitioning between classes.

R: PE?

P3: I don't like PE because its so confused. I'm like...you idiot, you're supposed to go that way!

R: Reading vs. books?

P3: I don't like reading the books because they give the secret away.

R: Drawing?

P3: Sometimes when I'm bored but I don't like art at all because I'm not good at it. The only drawing I do is on my hands and arms.

R: Best thing you do?

P3: I went to the bowling alley and let everyone draw all over my arms. I don't care. My brother is like and I don't care attitude. He can wear mismatching socks, and he doesn't care.

R: Shopping?

P3: Me and my sister...my sister has good taste. I never go school shopping with my dad cause he doesn't have good taste. She wears pretty clothes. She tells me not to wear booty shorts, and she wears them all around the house, like all the time. I have short shorts, but not that short. I wear them during summer, and she's like, 'do you want to be a slut or something?' No, you wear booty shorts all the time so looks who's talking. She's moved away now. She lives with her boyfriend. She and her boyfriend used to live with us. People are like, your parents let your sister's boyfriend live with you guys? Me, C and Annie were trying to get some sleep and we're hearing some screeching noises.

R: Trouble in school?

P3: Last year I had a teacher, I swear, she hated me. I don't know, but Wednesday was my bad luck day. Every single Wednesday, I'm like, what the heck? I got detention from her. She made me so mad. I'd be like working in my word search and she's like you're supposed to be doing your homework. I told her I finished my homework, and she's like, you're supposed to be working on something else then. She took away my word search and I told her she owed me a dollar because that was how much I'd paid for it. Yeah, she finally gave it back to me at the end of the year. She took it away near the end. It's so dumb...she hated me.

R: Is that the only problem?

P3: I got in trouble in math class. It was the stupid aid. When she left, I never got in trouble again.

R: What did the assistant do?

P3: She just always yelled at me.

R: Sleepover?

P3: I don't know...not that much.

R: More than one?

P3: If it's C, A and E, its a lot. Yeah, once T and E came over and we were like in the pool and her boyfriend he lived down the street and he kept texting her with like, "Are you still at your cousin's house cause I think I hear you!" We were like, all screamin' havin' a great time.

R: Last Birthday Party?

P3: Not a very good memory...uh...let me think...I had a lot of friends over last year, and I think the year before that, but the year before that they didn't get invited. Before that they didn't get invited or I didn't call them. When I don't want to invite someone, I tell them that my mom said I have too many people coming. [*Realizes use of white lie*]. Last year I think I...last year I also invited K and M. S and page came, and spent the night with me. I asked my mom if they could spend the night this weekend and she said no, so maybe I'll ask if they can spend the night this weekend. I had a lot of friends at the bowling alley. One birthday wasn't so great though, because a bunch of my friends were spending the night because one of my friends lit a paper on fire...jeez like, almost burn our house down! The birthday party was insane though. J tried to steal \$5 from C's wallet.

R: How old is C?

P3: We told C that J tried to steal money from her wallet. She also got kicked out of church. She comes over the house sometimes, not very often. Cause we don't really trust her that much. We had to go to the bowling alley and apologize for all the stuff she did. All the girls at the party told my mom about what happened. Once it looked like there was a ghost at my house. I ran into a table and it hurt so bad! C had black hair

then, she has brown hair now. We were like, there's nothing out there. She's like, I saw a man walking right outside the door. Our house is haunted. I hear a lot of sounds and noises. We played Midnight with flashlights. My parents were out getting pizza. They came back with pizza and nobody told them anything. A few years later we told them. We probably thought it would be safer if we told them years later. *[Never addressed question]*

R: How old is C?

P3: Seeing the side door...we were looking on the side door. C? She's Sweet 16. I'm going to be sweet 16 this year.

R: When's your birthday?

P3: My birthday is [provided] and my brother's is [2 days following participants]. My brother's is 2 days between so like, what happens is I have my birthday like the first weekend and the next weekend he has his. So, yeah...I have my party, so like, if I have any sleepovers, 'cause I like having sleepovers...all my friends spend the night.

R: Sleepovers/Parties...who invites?

P3: I call them and get invitation. My mom does the invitations. I send them to the bowling alley cause that's my hangout. I have bad handwriting so my mom writes them out. So like, they can read it.

R: Cell phone?

P3: No...I want one though...Can you convince my mom to get me one? My mom's not buying me one.

R: iPod?

P3: It's so unfair though. My sister got her first cell phone when she was 16.

R: iPod?

P3: She's got a bunch of them now. I don't have an iPod...no. I don't have a laptop or any electronics. Its really boring. I had a CD player, but like I got it for Christmas, but obviously, it was a cheap CD player 'cause it broke half way through the year. It kept skipping. It's gotta be something in the cord or something cause it just keeps skipping. That's so weird. I had a CD player, but the headphones are broken 'cause I stepped on them by accident.

R: Room messy or clean?

P3: In between. If my room clean, because I don't use my room any more. I use my sister's old room. It would be kinda messy because all my blankets and pillows. I don't like my room because its so small. I just sleep on the floor, because obviously her bed is wood and there's no mattress. We need to get a king size or queen size mattress.

R: Prefer to sleep on the floor than your room because of the room size?

P3: Yeah. I have like a lot of toys and my room is going to explode if I don't put them somewhere! [Brother] thinks he should have this room. I'm like, at least you have enough room to put your stuff. I need that room more than you. I have a lot of electronics.

Yeah when I was a little kid, the funniest thing was that J vacuumed the stairs and picked it, picked up some toys...pieces to my dollhouse.

R: Job?

P3: No but I did daycare in the summer because I wanted to earn money...I earned \$40. 'cause I was working in the daycare helping my mom. A lot of my old friends they go to school or go to the Boys and Girls Club during summer so I don't see them anymore. The Boys and Girls club though, is really dumb. I've been there. I had to go there during Girl Scouts and I was like, 'how can people survive here?'

R: Are you still in Girl Scouts?

P3: It was so loud, it's like people were screaming and stuff across the room like AAHHHH!! Like it was literally like screaming the whole time. I couldn't stand it. I was there with my Girl Scout leader. I wanted to leave. We were going to make arts and crafts

R: How long were you in girl Scouts?

P3: The first 6 years. No, I was actually in girl scouts...in 4<sup>th</sup> grade and the 5<sup>th</sup> grade.

R: So for 2 years?

P3: Maybe.

R: Were you still in Girl Scouts in middle school?

P3 No. Girl Scouts is in the elementary grades only. At least in this school district, anyway.

R: What do you want to do when you grow up?

P3: Uh...I want to work with horses I think. Horses are my thing.

R: Do you have any horses?

P3: No. I would get horses though. We have this big huge field out there. The grass is like to here on your legs. There's a funny story my 8<sup>th</sup> grade teacher told me. I had pre-algebra. I had Pre-algebra last year again, and this year I have algebra. She had really tall grass and she would duck and hide. Her parents called the police, and she finally came out from the tall grass and got in trouble. She was in the grass for 3 days. I wonder what she was eating.

R: Have you been around horses?

P3: Yeah. I got to ride at my elementary school. There was a horse in the back field. I rode on the girl horse. So we got turns to ride on the horses. I went on trail and hay rides. We had a field trip and went to this farm. We went around and went on a hay ride. There was this one field trip with a garden. We were like walking through it, going this is cool! Yeah we were going to a garden and it was pretty cool. We got to go to my 5<sup>th</sup> grade teacher's house. She had 3 dogs. A couple of German Shepherds and a Delilah dog from Homeward Bound. Do you have those DVDs?

R: Yes.

P3: Do you have a DVD burner?

R: No.

P3: You should download DVD Decryptor and DVD Shrink and make me copies. I want that one movie in DVD. I want Lady and the Tramp in DVD and 101 Dalmatians. I have it in VHS and it's horrible. It's old, like very old back when my parents were little. And when I get it now, it skips. And I'm like, 'what the heck?' I was watching Benji the original, you know where he found a girlfriend. Well, I was watching that and it was like blah blah blah throughout the entire movie. I rewound and, and I was like, this movie is messed up. So I have to get that movie again.

R: When you graduate, what are you going to do?

P3: I don't know. I'm not going to go to school. I'm going to go to college online. It's easier...you know like that one commercial where lady is going in her cute little pink slippers and it's like, guys cover up please. I like that commercial, it's funny. But you can go to college online. You can wear your pajamas. If I ever went to a real college I'd probably go to [local community college]. I don't want to have to live at the college.

R: Anxious to move out?

P3: Uh huh. I want to have horses, dogs, cats and rabbits. All the things my mom and dad wouldn't let me have. You know, I tried to get a rabbit, I asked her for another kitten, because my other one died cause she got killed by a coyote or cougar. I heard her scream in the mountain, but I also saw a cougar in the yard...yeah. The night she disappeared we went to collect all the animals. We got them except my cat. There was a cougar in the yard. It had like a 4ft long tail. I could have sworn we have foxes, too. We tried sneaking a cat over. My mom found it after 5 days. The cat was so smart she'd hide from my mom. My parents gave her away. They thought that K and M gave it to me, but they didn't. Aunt S snuck her to me. Everyone got mad at aunt S, and she's like, geez I didn't rob a bank! I want a rabbit and I want a Beagle my favorite dog in the world.

R: How often do you go to the movies?

P3: Not that much. The last movie I saw...first summer I saw three. Nancy Drew, the other one with Ann Roberts, and ...some other movie. If you guys ever get Hairspray

save it for me, I like What a Girl Wants. It has Amanda Bynes. This one guy told her to leave because she was like pregnant. She sang at the beginning of the movie, the middle, and the guy showed up at the end. The mom looked really pretty in it. They met because she rolled down a hill and he saved her.

R: Have you ever fainted before due to nerves?

P3: No. I gave one presentation in middle school. I was trying to, I was giving it on kittens, but I had S, S, A, and M. S had red eyes that glowed at night. When I first saw her with red eyes I was laying in bed and I screamed. She would do sneaky tricks with her red eyes. She had red eyes and she would do that on purpose. She's ;jump on your back. You little brat. I was doing the presentation on them. I had little pictures of the. I did a tiny speech and I was done.

R: What else gets you nervous?

P3: Anything in front of crowds. My mom says I should be an actress or singer. Um...lets see I have stage fright...that would be really dumb. There has to be something else that you can get a job and don't have to go to school. I practice singing all the time. You know the song Shake It? Its Tracy Cyrus. I love that song. My brother got mad because I kept playing that song over and over.

R: Have you ever been bullied at school?

P3: No.

R: Do you ever get depressed?

P3: There was this one girl...she didn't really bully us, but she chased us. She got mad at us.

R: Depression?

P3: I get depressed over animals dying. Did you hear about what happened at the animal shelter? They came here. The other one was a graduate. The girl went to jail and the others went to juvy. They said they're going to stay there until senior year. It's ridiculous. It's really stupid though. My uncle and dad were bad when they were kids because they went to the animal shelter and feed all the cats and let them go. Yeah, but...

R: Did you tell your mom about the Yahoo guy?

P3: Yeah I told her.

R: How did you do last year in your classes?

P3: PE was horrible. Who would play football? We always played indoor soccer. PE is going to be really boring next semester. People always get hurt in PE.

R: This year some cute guy asked you to the prom...would you go?

P3: I don't go to proms.

R: Do you want a boyfriend this year?

P3: Uh uh. I had a crush on a guy last year...J...but he moved away. He was just like me...He didn't dance. He got suspended the last day. J...he lives in Washington now.

R: When you grow up do you want to stay single or get married?

P3: Stay single.

R: Sounds?

P3: I hate fireworks, balloons used to bother me.

R: Eating?

P3 I'm very picky. Vegetables...none. Fruit...I eat one...apples only. I wont eat yellow apples because they're disgusting. I will not eat certain meat like beef. I like chicken. If I eat dinner I have chicken, Cheetos, and mashed potatoes, and a Trix yogurt. I'm trying to collect Trix yogurts because you can win \$10k dollars.

R: If you won the \$10k, what would you do?

P3: Buy a horse, I'd be like, forget you mom and dad...who cares what you say. It's not staying at their house anyway. It would be staying at my grandmother's. I already asked my grandmother, she said it was fine. She said she doesn't care. We were going to buy these horses...2 horses for \$60. We just needed a trailer, but they'd already sold.

R: How Asperger's affect you?

P3: Nothing.

R: When you were little?

P3: My ears are really sensitive...even now.

R: Touch...bother you if people touch you?

P3: No

R: Smells?

P3: No.

P4 – Participant, 18 years old

R – researcher

M - Mother

Interview location: Home

M: Diagnosed in 3<sup>rd</sup> grade. Took 3 years to get diagnosed. Started noticing something when she went to school. Took a pencil and had a very hard grip. Would press as hard

as she could. Draw letter very dark. Would erase multiple times. Huge holes in paper. Teachers brought stress up. Many people thought she was ADHD. I didn't think so, my son has ADHD.

R: When you would get anxious, what would you do?

P4: Scream, cry, throw a fit.

M: She'd smack or bite herself.

R: Where would you smack yourself?

P4: *Participant indicates palm to head*

M: She'd tear her clothes. It took her 3 months on a brand new coat...she bit holes in the arms. She's just start shredding it. She'd pick the desk apart...pants, shoes. Everything she'd pick apart.

R: Do you still do that?

P4: It's gotten better, but I still cry a lot.

M: You don't smack your head as often. Still do that, but not as often.

R: Why not?

P4: I think I outgrew it.

M: I think a lot of it is also the parenting has changed so much. It went from my first daughter...my first child...I expected her to fit in the mold of a first child. She didn't do that so I wasn't a good mother figure for the first 12 years of life. She is who she is...I need to learn to live with her. A lot of her stress is caused by others who don't understand, so we've been teaching her advocational skills. When they do this, you do that. Worry about them getting in trouble. Come call me and I'll take care of it. A lot of it is education for teachers or others. Many don't want to know. She s not a problem child.

P4: I'm a refreshing person.

M: Those who really like her understand it's a meltdown. She doesn't hold a grudge why should they.

R: Tell me about elementary school-recess and lunch.

P4: I went out side and played and then I ate. Most of the times in 2<sup>nd</sup> grade I got so many of these blue slips that represent punishment. I had teachers telling my mom that I stood up on top of the desk. Get 3 of these blue slips and you get a referral. I got them so many times and I didn't know why I was getting in trouble.

R: Where you in special education yet?

P4: [*Nods no*]

R: Did you have friends?

P4: I had one friend and then she moved on. After that I had another friend. I didn't have friends until about 7<sup>th</sup> or 8<sup>th</sup> grade.



M: she played by herself quite a bit when she was real young. By the time she got into middle school, she started getting friends, but they were real...special needs friends, too...really had some mental problems. Not just Aspergers. Social problems. They not necessarily upstairs, but family related, so outbursts. It was hard because she tries to emulate the people she's around. It made it real difficult, because you couldn't say you can't have that friend when she only has one friend. It was hard.

P4: But now I have a friend, her name is C and she works with people with special needs.

M: She's not exactly my role model friend either.

R: How old is C?

P4: My age.

R: Why isn't she a good friend, mom?

M: She does things I don't approve of. She's a little more risqué than I am, listens to things I wouldn't allow in my home and is not supervised. P4 downloaded some of C's song on her MP3 player and I didn't approve of the lyrics.

R: Middle school...Dances?

P4: I went to at least 2.

R: Did you want to go or were you "encouraged" to go [to school dances]?

P4: I wanted to go. I didn't have a date for any of the dances except for that [name]. That was like junior year prom. That wasn't really even fun.

M: That wasn't even really a date. You just gave him your extra ticket.

P4: And then he didn't even want to do anything.

R: Did you dance?

P4: I danced a lot.

R: Hobbies in elementary?

P4: Color, Barbies, animals....

M: She would shred Barbie doll clothes. She never really understood what the issue was...they were just Barbie clothes. She's make up stories in her head...always talk about Indians and wolves and things like that. That was her thing...Indians and wolves.

R: Hobbies in middle school?

P4: Stayed the same.

M: freshman year she started getting a lot of friends. So other stuff went to the wayside so she could pay attention to the friends.

R: Favorite part of middle school?

P4: Having a crush on a guy. That was my 8<sup>th</sup> grade year. Every science class my 8<sup>th</sup> grade year, I'd go in and look at him and look away when he'd catch me. I dated him before, and I just broke up with him. It was pain during my 8<sup>th</sup> grade year.

R: What were some of the dates?

P4: Winter Dance.

M: You went to the Valentine Dance.

P4: I did?

M: Yeah, I remember.

P4: I had a really cool science teacher. It was my favorite.

R: High School?

P4: High school was a blast. I had a cool AG science class. Went to dances, prom, home coming, Valentines dance. I went to Prom twice. That was fun. My favorite part is that they would bring out a DJ and me and my friends would dance, and people would look at us like we were crazy.

R: Did you ever get bullied?

P4: Yes...all the way through. And by teachers, too. I had a group of girls in high school. They told me to go back to special ed. In Middle school, a friend's parent called my schizophrenic. In elementary, a bunch of girls said I had cooties. If I accidentally brushed them they'd yell they needed to take a shower. I learned in my senior year that some people are going to have a problem with me and I need to just ignore it.

R: Bullied physically?

P4: Mostly verbal. Actually, in elementary I had a girl shove me down and she told another girl to get a ball so she could throw it at my face. I got up and ran.

M: This girl pushed her around quite a bit. P4 had a teacher in 2<sup>nd</sup> grade....kids could get an ice cream after lunch. We'd given her \$0.50 to buy an ice cream. A field trip was also going to be coming up. My husband didn't get paid until after the field trip so I asked if I could pay later and they said, 'oh sure...no big deal.' The teacher saw the 2 quarters and asked, "what's that for?" P4 said for her ice cream after lunch. He said, oh no it's not, you owe me \$5.00. I went to the school to confront him and took her because I thought she needed to hear this. He said, 'well, she owes me money.' I said oh no she doesn't, I do. And I said I don't owe you, I owe the school. You have no right to take the money. He took two quarters out of his pocket and threw them at my daughter. I told him, 'I think you owe my daughter an apology.' He said, "oh no I don't!" I cleaned out her desk and she never went back to that room. She's had teachers like that. She's had teachers in jr high call me up and cuss me out because she has a melt down. You're throwing 40-50 kids in a classroom with no extra help, she's special needs, you won't believe she's special needs, and now your telling me you don't know she's melting down. We had incidents all through school. Junior high was just hell. I had Special Ed coordinators telling me she wasn't going to qualify. I spent years getting her on an IEP...there's no way they were going to take it away!

P4: They even told me I was going to be pregnant by 15.

M: The special ed coordinator said it front of her and in front of me. Said she's going to get pregnant before she's 15 because she doesn't have a social clue. That wasn't appropriate to say in front of my daughter, even if you're thinking about it.

P4: the funny thing is...I'm still a virgin!

M: by her choice, too. Not for lack of the guys trying. She's made those choices and has come to us for advice. She's had bad boyfriends...some who were REALLY Bad. These guys are in jail bad! P4 is mature than some adults as she has made the decision to let those relationships go.

R: How many relationships with guys have you had?

P4: 3

R: When did you get on an IEP?

P4: 6<sup>th</sup> grade

R: What areas where you served in?

P4: Language arts, speech, math.

M: I pulled her out of school her 7<sup>th</sup> grade year. I was getting called into school so much. It was a mess. She had a 3<sup>rd</sup> grade education in 7<sup>th</sup> grade. She wasn't expected to succeed,, but I did. She graduated with a general education with a regular diploma. She passed state standards for graduation. In 3 months after I pulled her, she went from 3<sup>rd</sup> grade level to 7<sup>th</sup> grade level. The gray areas are the hardest. Sometimes you have to do something this way, sometimes it's this way. We play with her sarcastically, and she has to think about it before she understands its sarcasm.

R: By senior year in high school, what special ed services did you still get?

M: She only had 5 hours a year. It was in speech and it was to allow for a go to person if she needed help. She was getting the help she needed on an as needed basis.

R: Did you have any life skills training?

P4: I had cooking, sewing, check book class, etc.

M: She needed more but they didn't offer it, so I did a lot of it at home. I'd take her to the grocery store, we'd pick out the food, she'd make dinner. She could keep a house, make dinner, do the shopping, but she would have trouble with the stress of keeping down a job. I don't know that she could do that, and that's what worries me. Unless you have a really understanding boss...where do you go from here? She's about 3 years behind, so she's like a 15-year-old right now. So, could she live completely on her own right now...I doubt it. Not without some huge difficulties. Do I think she's the one who could overcome them? Absolutely, but it would not be easy.

R: Would the biggest obstacle be to independence at this point?

P4: People would think I'm retarded.

M: It's more immature than retarded because of fits she throws when she gets stressed. That's the meltdown and unless you understand autism and Aspergers, you don't see it for what it is. What adults yells, and throws a fit in the work place? What boss and group of employees is going to understand and put up with that? That's where we are right now. That's what we have to deal with. Because she's a hard worker.

R: Do you like to go shopping?

P4: *[laughs heartily]* I like to shop. I like to shop for prom dresses, fabrics, because I do quilting, crocheting, knitting, make clothes. If there's fabric and thread I'll use it.

M: She got 7 First Places and 2 Best of Shows at the county fair this year. And she had a teacher in her senior year who told her she did everything wrong.

R: Do you use a computer?

P4: When I was in school I used it for typing and when I was home schooled for research.

M: She also used an AlphaSmart in school because her handwriting was such a huge stress so I pulled for some device that she could type or speak into. P4 weaned herself off of it. Now she's writing in a journal everyday. She outgrew it and it became unnecessary.

P4: Now I use the computer for the Internet.

R: What are some of your favorite sites?

P4: MySpace, Players, Howrse, I think that's about it.

R: How many friends do you have on MySpace?

P4: 13

M: She doesn't do much searching, I'm not sure if she completely grasps the concept. She's very focused so It's like she doesn't know where else to go. [creativity, concreteness]

R: What does your MySpace look like?

P4: [Picture of P4, a black horse running in the background

R: Do you have a lot of friends who come to your house?

P4: I sometimes go to their house.

R: Sleepovers?

P4: Not very much

M: You did a few.

P4: A few but not much.

M: It's hard because we live out in the country and they don't want to come this far. So really, it's just a matter of space.

R: In high school did you develop any job skills?

M: Sped class in freshman and sophomore year, but mostly bookwork. Not hands-on. She was in a student store.

P4: Have you seen Just Friends? It's a funny movie!

R: Did you build this site all by yourself?

P4: Yes.

R: Reading?

P4: I have a lot of different things I like. I like the Twilight series, a vampire romance novel. I also read a lot of smut. They're romance novels. The first smut book I read was in the adolescent section and it was written by Judy Blume. This guy is all about wanting to have sex. The scenes in there are very explicit. It wasn't the best thing to be reading.

M: Daughter is 18, she can read what she wants. It's kind of a new genre for her.

R: Fantasy?

P4: I tried to get into the Harry Potter books, Wrinkle in time, Eragon...they're just not me. Bridge to Terabithia was not me either. But that's about it. My cousin tries to get me into horse stories...but it doesn't work. Although there are certain comedies that I like...Achmed, Jeff Dunham, Larry the Cable Guy, Bill Engdvahl, Jeff Foxworthy, kinda' Ron white, kinda' not. He's like my least favorite. Larry the Cable guy is my favorite.

R: In 5 years, what would you like to accomplish?

P4: I would like to be a veterinarian assistant, be married and have kids.

M: the first time I saw her hold hands with a guy, I cried.

R: If you could talk with a female child who just got diagnosed with AS, what would you tell her?

P4: Ignore half the people who treat you like trash, do what you've been taught, and stay away from dating for a while! Wait until your parents approve! I wrote these people a note and said I just broke up, but that never really happened...

M: It doesn't matter.

P4: ...and they sent me this book!!! I'm like, cool!

M: She thought because other people had a boyfriend, she needed a boyfriend.

P4: I thought if you kissed a guy and it felt right, you had to marry him, and he'd be your husband later in life. I got engaged at 15. It didn't work out very well!

M: She came home with this nice ring...it was nicer than my wedding ring! The next day she said she'd lied to me that, the guy hadn't given it to her for friendship, that they were engaged. All I could do was yell, "Oh no you're not!" I'd heard about this guy twice, and had never even met her. How do you explain to your AS daughter that she

can't marry him without alienating her. It's like dealing with two different girls. It has to be done so carefully. It needs to seem natural. We've taken stands on a few things, and let her work it out on others. If the guy won't even come and talk to the parents, he's sneakin' behind your back. That's when she started really thinking that if I have to sneak, it must be wrong. We took her to a counselor that did neurofeedback with her. She started believing she could do it on her own. It's helped tremendously.

R: How long did you do the neurofeedback?

M: A couple of months

P4: No...wasn't it about a year?

M: No, it was for a couple of months.

R: Do you use the phone much?

P4: Only to call my grandmother.

M: I keep telling you to get off the phone!

P4: I have my own cell phone and mom pays the bill. I don't use it that much.

R: Mom, what would you tell a mom whose daughter just was diagnosed?

M: You didn't do this, and don't let anyone tell you different. Be an advocate first. If you feel someone is treating your daughter bad, they probably are. The thing I did wrong most, was not say enough. I eventually did say more...I just wish I'd done it before she'd been treated badly. I just didn't know...I just didn't know. We each get our own cross to bear...but look at what a prize I got!

Anxiety?

P4: I hate needles...

M: She had knee surgery. We told her that if she ever wanted to run again, she'd need to control her fear because she was going to get poked. We told the nurses she was terrified. Most nurses understand fear...especially if you tell them she's autistic. But teachers who deal with autistic kids, don't. In second grade she used to wear a hood, and long sleeve shirts because she was so afraid of bugs.

P4: I was so afraid of bugs, I didn't want to garden, so I'd throw seeds in the ground and kick the dirt because there must have been bugs in the dirt! I went to

Sensory?

P4: I'm sensitive to sounds, I'm not picky with food, but I'm lactose intolerant.

M: We needed to lock the cupboards when she was younger. Last week her grandmother told her about a news story about a brand of cereal we buy. I came home to find her throwing out all our cereal. She was afraid it was going to kill us all. Whoever gets to her first, gets the clean slate and gets to write on it. Discernment is not her strong suit.

## CURRICULUM VITAE

Lisa Marie Beteta

### **Education:**

Ph.D., Education, Walden University, 2008

Emphasis: Special Education, Asperger Syndrome

Dissertation: A Phenomenological Study on the Lived Experiences of Teenage Females with Asperger Syndrome

### **Research Interests:**

Asperger Syndrome, autism spectrum, social thinking, executive functioning and relation to life success, brain-based learning, phonological awareness and relationship to reading

MS. Ed., Education, Southern Oregon University, 2002

Emphasis: Special Education, Autism Specialist Certificate

Council for Exceptional Children, previous Vice President, SOU chapter

GPA: 3.97

B.A., Psychology, California State University, Fullerton, CA, 1988

Member, Psi Chi

Deans List: 6 out of 8 semesters

GPA: 3.66

### **Research Skills:**

Knowledge of SPSS, NVivo, and Excel as statistical programs

### **Presentations:**

Modifying and Accommodating Instruction: Looking at the Neurology and Brain of the Child, Evergreen Elementary Staff Development, February 2007

Developed presentation for approximately 40 teachers and staff surrounding the understanding of students with differing neurological needs. Collaborated with speech and occupational therapist. Created handouts and Power Point Presentation.

Data Collection to Support IEP progress, Three Rivers School District Special Education Teachers, June 2005

Instructed on data collection and tracking using Excel that provided visual demonstration of student progress. Procedure could be implemented with IEP goals including reading, math, writing, and social thinking. Created handouts with detailed instructions of

### **Experience:**

Autism Specialist, Three Rivers School District, 2002 to present

Conduct autism spectrum evaluations for referred students. Provide training to district employees. Implement social thinking groups within the district. Provide consultation to district teachers. Serve as Autism Committee member for the district.

Oregon Traumatic Brain Injury Educational Consulting Team Member, 2008 to present  
Provide support and consultation within the state of Oregon in the educational community on students with traumatic brain injury.

Special Education Instructor, Evergreen Elementary School, 2005 to present  
Design and implement curriculum and instruction in largest elementary school in district in a resource room setting. Manage five special education paraprofessionals. Offer programs in social thinking, self-regulation, and visual spatial difficulties. Caseload consists of wide range of eligibility categories including autism spectrum, orthopedically impaired, and traumatic brain injury, mental retardation, and learning disability. Incorporate sensory integration training into academic activities. Conduct approximately 80 IEP meetings annually. Participate as Positive Behavior Support (PBS) Committee member for Evergreen and Student Study Team. Provide consultation for district in executive functioning and organizational skill development for high school students.

Special Education Instructor, Fruitdale Elementary School, 2004 to 2005  
Implemented Linda Mood Phonetic Sequencing Program in resource room. Developed data tracking system on Excel to determine baseline and demonstrate growth comparison through data analysis for reading, math and writing programs. Began social thinking group. Managed three special education paraprofessionals. Managed caseload of approximately 22 students. Participated as district committee member for behavioral classroom (Camp Sunrise).

Multi-handicapped Special Education Instructor, Manzanita Elementary School, 2002 to 2004  
Developed program in self-contained environment for high needs students including augmented communication utilizing picture symbols. Attended Picture Exchange Communication (PECs) training and TEACCH training on autism. Closely worked with regional services involving occupational therapist, physical therapist, and teacher for the deaf.

Special Education Instructor, Hacienda-La Puente School District, Valinda Elementary School, 1998-1999  
Provided instruction for special education students in a special day class environment. Managed caseload of approximately ten students consisting of behaviorally challenged and cognitive deficit disabilities. Managed one special education paraprofessional.

**Skills and Qualifications:**

- Computer software and research skills
- Excellent communication skills



- Collaboration skills – committee memberships for Three Rivers School District include principal and staff interviews, development of behavioral classroom (Camp Sunrise); Autism Task Force; consultation for high school on development of study and organizational skills curriculum; consultation for district on social thinking program.